

A qualitative study of Samoan cancer patients' experiences

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Abstract

Abstract: To investigate the palliative care experiences of Samoan patients with cancer and the impact these experiences have on their quality of life. **Methods:** This qualitative interview study was part of a larger study that interviewed 19 participants recruited among patients with cancer registered with Samoa Cancer Society, or patients recently discharged from the main tertiary hospital in Samoa. Interview transcripts were reviewed, and the research team identified the key palliative-care-related themes. **Results:** Analysis led to the generation of the following key themes: living with pain; resource constraints; support from family and faith; and interactions with healthcare professionals. Most participants were experiencing unresolved pain as a result of poor health knowledge, lack of access to medications and practical issues, such as financial limitations and lack of transport. Participants also reported a lack of resources, including financial constraints, as a significant barrier to effective healthcare. Sources of support for patients with cancer were most commonly strong family relationships and religious faith. Although it was difficult for the participants to access care from healthcare professionals, they found that honest communication about their condition was comforting. However, they were frustrated if they felt communication was unsatisfactory. **Conclusion:** This study provides much needed evidence on the issues that affect the quality of life patients with cancer receiving palliative care and their families in Samoa. It also highlights the intersectionality of these issues and how this compounds the patient experience. Practical recommendations for improving palliative care lie in a few key areas, including a need for improved access to opioids and support for family caregivers. However, from a systemic perspective, the way forward should lie in harnessing the strengths of Samoan culture, including the strong sense of family and the role of religion, to provide support and care for palliative patients.

Key words: ● cancer ● palliative care ● quality of life ● qualitative study ● Samoa

Cancer is the leading cause of morbidity and mortality worldwide. It is estimated that there will be 22 million cases and 13 million cancer-related deaths occurring annually by 2030 (Fidler et al, 2018). Pacific Island nations are increasingly adopting unhealthy lifestyles which have been linked to rising incidences of cancer (Tervonen et al, 2017). In Samoa, it is estimated that 374 people were diagnosed with cancer in 2020, with 218 cancer-related deaths the same year (WHO, 2020).

Early detection and intervention increases the likelihood of successful cancer treatment (World Health Organization, 2022). However, for low-income Pacific Island nations such as Samoa, access to healthcare is limited and diagnostic services are poor (Anderson and Irava, 2017). As a result, treatment is often limited to

surgical options and palliative care (Abu-Odah et al, 2020).

The limited available data specific to Samoa indicates that many patients present late and experience diagnostic delays (Samoa Cancer Society, 2019), which along with a lack of awareness of the available resources for people with cancer, cultural modesty and lack of trust in the healthcare system all contribute to impeding the provision of quality healthcare (Naidu et al, 2021).

The Global Atlas of Palliative Care (Worldwide Hospice Palliative Care Alliance, 2020) revealed that only 12% of the worldwide demand for palliative care is being met. In Pacific Island nations, healthcare systems focus on combating communicable diseases and promoting maternal and child health (Anderson and Irava, 2017).

The ageing population in Samoa will have

Box 1. Independent state of Samoa

- Samoa is a country located in the South Pacific Ocean. It is comprised of two main islands, Upolu and Savai'i and several smaller ones. The capital city is Apia. The population of Samoa is approximately 200 000, its official languages are Samoan and English
- Samoans aged 19 years or younger comprise 46% of the population of Samoa (World Health Organization, 2017)
- The country has a rich cultural heritage, villages, the extended family (or 'aiga') and God, are central to the Samoan social structure and are the foundation of Fa'a Samoa (the traditional way of life in Samoa) (Scroope, 2017)
- Samoa gained independence from New Zealand in 1962, and is a member of the Commonwealth of Nations. Samoa has a stable political environment and is a lower-middle income country. However, its small population, limited natural resources, isolation and susceptibility to natural disasters render its economy vulnerable (Juswanto, 2016)
- Many Samoans live outside of Samoa and send financial remittances to their extended families. The economy of Samoa is primarily based on these remittances, as well as agriculture, tourism and foreign aid (AusAID, 2012).

implications for the provision of palliative care (Government of Samoa (GOS), 2019). Consequently, the healthcare sector will work towards strengthening the healthcare system through the improved provision of palliative care and training for healthcare professionals (GOS, 2019). Despite the need, palliative care in Samoa is, for the most part, left to family, support networks, traditional healers, non-government organisations and faith-based services (Foliaki et al, 2017). To understand the healthcare and palliative care context in Samoa, it is crucial to consider the cultural viewpoint of Samoans regarding health and wellbeing. Samoa has a strong focus on the importance of family and faith, while health and wellbeing is strongly associated with cultural identity (Capstick, 2009).

The aim of this study was to investigate the palliative care experiences of patients with cancer in Samoa, and the impact these experiences have on their quality of life from their own perspectives in a lower-middle income country, such as Samoa.

Methods

This study was part of a larger qualitative study underpinned by Bronfenbrenner's socioecological theory and within a social constructivist epistemology (Bronfenbrenner, 1989). The larger study aimed to explore the broad experiences of cancer patients in Samoa, undertaken by the Samoa Cancer Society, in collaboration with the National University of Samoa (Cuesta-Briand et al, 2021). The present study applied Bronfenbrenner's sociological theory (Bronfenbrenner, 1989) through the lens of the World Health Organization's palliative care framework and palliative care as a human right.

Srivastava and Hopwood's (2009) framework for qualitative data analysis is comprised of three iterative questions to analyse data and engage with the process of continuous meaning making.

Recruitment

Participants were Samoans aged 18 years and above with a cancer diagnosis. Participants were recruited among patients with cancer registered with Samoa Cancer Society or patients recently discharged from Tupua Tamasese Meaole Hospital, the main tertiary hospital in Apia. Samoa Cancer Society patients received a telephone call from Samoa Cancer Society staff explaining the purpose of the research and inviting them to participate. Discharged hospital patients were contacted by a research assistant who explained the purpose of the research and provided potential participants with information and the opportunity to ask questions. Following a 2-week period, the research assistant contacted the person to determine if they wished to participate in the study.

Data collection

Data were collected through a face-to-face interview, which had a semi-structured format, and explored the following topics:

- Factors influencing patients' decisions to access medical services
- Services initially accessed and experience of that contact
- Patients' journeys from the initial detection of symptoms until diagnosis.

Interviews were conducted by trained research assistants fluent in English and Samoan.

Consent was obtained in writing before the interview. Interviews took place at participants' convenience in the language of their choice. Demographic and medical history data were collected prior to the qualitative interview.

Data analysis

The lead author of the larger study (BCB) led the preliminary analysis of the data set, along with Samoan colleagues. As part of this initial analysis, the research team identified palliative care related themes within the interview transcripts by using Srivastava and Hopwood's (2009) framework to focus on specific variables and define specific viewpoints. The lead author (AE), a volunteer palliative care nurse advisor at the time of data collection, led this analysis.

BCB and AE read the individual interview transcripts a minimum of five times, with AE performing line-by-line coding focusing on data related to palliative care. Following this initial

coding, the research team met weekly for 4 weeks to discuss overarching impressions. This led to iterative refinement of themes.

Results

A total of 19 participants were interviewed between December 2017 and May 2019. The interviews had an average duration of 20 minutes. As shown in *Table 2*, there were more females (n=11, 57.9%) than males (n=8, 42.1%). Participants had an average age of 55 years (range 25-71), with the majority aged 50 or older (n=15, 79%) and 68% (n=13) had some form of treatment, the majority of which occurred in Samoa (n=11, 58%).

As shown in *Table 3*, most participants (n=13, 68.4%) reported seeing a doctor regularly, and most (n=16, 84.2%) were taking Western medicines. More than half the sample (n=10, 52.6%) reported visiting ‘taulasea’ (traditional healers) regularly, and among those taking traditional medicines (n=7, 36.8%), the most commonly reported were herbal remedies, mainly teas made of pawpaw, seasea or sasalapa leaves and turmeric juice.

Analysis led to the following key themes: living with pain; resource constraints; support from family and faith; and interactions with healthcare professionals.

Living with pain

Most participants described unresolved pain, with barriers to resolving pain including poor health knowledge and access to medications. There were also significant practical barriers, such as financial limitations related to the cost of medications and a lack of transport to purchase medications. Pain was often described as all-consuming, unrelenting and disruptive to sleep and movement as the participant below expressed:

‘There are nights where I don’t sleep, daylight would come and I still haven’t caught a wink of sleep, moving my body around ...’ (Participant 19)

Participants’ narratives revealed that they often felt ill-equipped to manage pain and even when medication was available, it was often experienced as being ineffective, or there was limited assistance available to seek advice and support on its use. There was no sense that anything could be done to resolve situations where pain was unrelenting, compounded by a common expectation that medication should ‘cure’ pain. When a dose of medication began to lose its effect, participants often perceived this as an indication that it was not working and would cease taking it. As one participant explained:

‘So, when the strength of the painkiller has worn off, I could drink however many tablets, but still no change, and my condition would be severe ...’ (Participant 19)

The consequence of unresolved pain and poor understanding of medication management was that participants would often seek advice and treatment from traditional healers who were usually more accessible, affordable and culturally accepted than Western healthcare services. One participant described seeking the advice of a traditional healer when medication failed to ‘cure’ their pain:

‘... after being discharged with the word of no other treatment options, I then tried searching for a local Samoan healer... I arrived (at the traditional healer’s) in extreme pain ...’ (Participant 12)

Table 2. Personal characteristics and treatment

Characteristic	Participants (n)	Participants (%)
Gender	Female	11
	Male	8
	Total	19
Age group (in years)	35–49	3
	50–64	10
	65+	5
	Total	19
Treatment location	In Samoa	11
	Overseas	2
	No treatment	6
	Total	19

The convergence of resource constraints

Along with the expectation that Western medication was unlikely to be of benefit, participants reported a lack of resources, including financial constraints, as a significant barrier to effective symptom management. For instance, participants voiced an inability to afford transport and doctors' fees contributing to them waiting until pain was severe before seeking medical advice:

'There is a reason I did not go to the private doctor—due to funding, it is only ten Tala (Samoan currency) to attend the public hospital which is something that I could afford.' (Participant 5)

The inability to afford private transport often resulted in participants having to endure long bus trips on difficult roads, or undertake a significant walk to local health services. This further delayed access to treatment, or in some cases, made it completely unfeasible:

'Well, we do not have a car which is a challenge for us when we have to catch the bus. There was a day when we went to town, we travelled on the bus, it is so uncomfortable and difficult, but I hung in there, but once I almost stopped the bus ...' (Participant 7)

Sources of support: faith and family

Sources of support were strong family relationships and religious faith. These are the cornerstones of Samoan society. Participants described a strong faith in the 'will of God' and feelings of loneliness or isolation were virtually non-existent due to strong family connections. When responding to the question 'Who is your biggest support?' participants most commonly referred to family and God;

'... It's not just my family; it's the Pastor, my friends (she names a few friends) and it's my faith, my belief in God. When people ask me how are you? My response is usually, "I am walking with God, praise God." (Participant 1)

Family was broadly seen as being integral to the support and social structure in Samoa. The extended family is the central unit of society and provides invaluable social protection.

'My ... number one support, yeah. If I didn't have that support, it would be difficult, very difficult.' (Participant 3)

Interactions with healthcare professionals

Where people were able to access healthcare professionals, participants often gained comfort from honest communication and support. One participant described a conversation which she perceived as the first time a doctor had been honest with her about her condition, and the impact this had had on her:

'... the doctor held my hand ... he said "... yes, of course you've got cancer cells"... and it was then that I believed in the love that God has for me ...' (Participant 1)

Despite the barriers to healthcare, the small acts of healthcare professionals making time for patients, kindness and friendliness were also valued, regardless of whether these clinicians were able to provide any other treatment or symptom relief:

'I am grateful ... for the extensive help they have provided, and the encouragement, as well as taking a heavy load off our shoulders. I am also grateful for (their) smiling faces as that is a big help for me ...' (Participant 18)

Although many reported having positive interactions with healthcare professionals, there were contrasting opinions, with some expressing feelings of dissatisfaction and frustration with communication. One participant described waiting 4 months to receive the results of a biopsy:

'So, with this situation, if the result was received then the patient should be alerted immediately. This was so disappointing to me,

Table 3. Western and traditional medicine

Characteristics	Regular visits to doctor		Regular visits to traditional healer		Western medication		Traditional medication	
	(n)	(%)	(n)	(%)	(n)	(%)	(n)	(%)
Yes	13	68.4	10	52.6	16	84.2	7	36.8
No	6	31.6	9	47.4	3	15.8	12	63.2
Total	19	100	19	100	19	100	19	100

and I was not very happy.’ (Participant 1)

Other participants described a lack of ‘clear talk’ (Participant 15) or feeling that doctors were ‘unhappy’ with them (Participant 18).

Discussion

This study provides much needed evidence on the issues that affect the quality of life of patients with cancer and their families in Samoa, including resource constraints, distress from pain, insight into the importance of positive interactions with healthcare professionals and family and spiritual faith. It also highlights the intersectionality of these issues, and how they can each compound the patient experience, both positively and negatively.

It was clear throughout the interviews that financial constraints impacted all aspects of health care. Social determinates, such as poverty, contribute to 30–55% of health outcomes, and in this study, a lack of financial resources was often linked directly to being unable to afford transport or adequate pain relief (WHO, 2023b).

Over 80% of the world’s population lacks adequate access to opioid medications for pain control (WHO, 2023a), and in Pacific countries, despite WHO listing oral morphine as an essential medicine, access is extremely poor, particularly in rural areas (WHO, 2023a; Sarfati et al, 2019). One paper has estimated that in Samoa, this is over 130 times less than what would be considered ‘adequate’ for the population (Spratt, 2019).

The reasons for low usage have not been adequately researched, however, globally low opioid usage in developing countries is attributed to opiophobia—or fear of use from medical professionals or patients, inadequate national policy on the use of controlled medications and inaccessibility of appropriate formulations of opioids (Roques et al, 2022). Without a reliable supply of adequate opioid medications, and an improvement in the confidence of healthcare providers to use these medicines, it will be exceedingly difficult to provide meaningful palliative care in low-income countries (Spruyt, 2018).

Over 50% of participants indicated that they regularly visited a traditional healer, attributing their symptoms to a ‘Samoan illness’, highlighting the importance traditional healers play in Samoan culture (Cuesta-Briand et al, 2021). This was in conjunction with over two thirds of participants also visiting traditional doctors, demonstrating how the two healthcare systems coexist with what Whistler (1996) described as:

‘Mutual tolerance and even some cooperation between the two systems.’

A second overarching impact on patient experience was the cultural overlay, in particular Samoan cultural norms which dictate that caring for family members is a fundamental family responsibility (Foliaki et al, 2020).

The burden of providing care is significantly reduced in a collectivist society, such as Samoa, where practical and moral support is abundant from their village, family and church (Yemoh et al, 2021). However, the financial burden of healthcare can be significant, and consideration needs to be given to ensuring adequate resources are available to support the families of palliative patients.

The final theme which underpinned the patient experience was participants’ accounts of interactions with healthcare professionals—it was clear in this study that the perception participants had of the performance of the healthcare system played an important role in their wellbeing. This is supported by similar findings that when healthcare professionals were perceived as rude or unfriendly, this created a barrier to Samoans seeking help (Bollars et al, 2019). This was in contrast to the comfort patients received from small acts of kindness—a healthcare professional being present and not being feeling abandoned has been described as more important than pain medication in some settings (McFarland and Markovina, 2021). As Coghlan (Coghlan, 2019) described:

‘Sometimes, doing something is found not in elaborate preparations, but in small things which reach out to the sick and lonely person and bring them back to us.’

Coghlan described these as ‘small but potent’ compassionate acts of caring and comfort. These more human-centered healthcare skills can sometimes be critically referred to as ‘soft’ skills (McFarland and Markovina, 2021). However, in low-income countries with poor access to medication, limited specialist training and few resources, these ‘small but potent’ acts are sometimes all that is available and should not be underestimated.

Overall, this study highlights the interrelated issues faced by Samoans and starts to build a picture of the supports which may assist to overcome these issues. As a result of resource constraints, for palliative care to be effective, it needs to be radically different and innovative compared to that offered in countries with well-resourced healthcare systems (Sarfati et

al, 2019).

The World Health Organization recommends a public health approach to delivering palliative care in low-income countries, with most patients preferring to be in their own home and receiving care from family. Public health palliative care recognises that the health and wellbeing needs for palliative patients is beyond many healthcare systems, particularly those in developing countries (Quintiens et al, 2022) and employing a public health approach to palliative care can make a significant difference at a population level (Cohens and Deliens, 2011). Methodologies similar to this have previously been shown to be successful in Samoa, by developing critical human resources at a community level, which has improved access to care, as well as strengthening the existing health system (Baghirov et al, 2019).

As highlighted by Coghlan (2019), there is a widening gap between specialist and generalist palliative care. History has shown that globalising specialist palliative care has proven challenging (Cohens and Deliens, 2011), however generalist palliative care, which benefits from community and family support, is far more likely to be successful in a developing country such as Samoa. By connecting the generalist model with the 'small acts' of deep family and community collective conscientiousness which are commonplace in Samoan culture, lies the potential for a model of radically different palliative care.

This study has some limitations that should be considered. The participants were all sourced from a single organisation (Samoa Cancer Society), thus, not representing the experiences of individuals who may not have had access to this resource. Furthermore, the lack of prior research on cancer patients in the Pacific region means it is difficult to compare the findings of this study with others in similar settings.

This study provides an important overview of the quality-of-life issues faced by palliative cancer patients and their families in Samoa. Practical recommendations for improving palliative care lie in a few key areas including a need for improved access to opioids and support for family caregivers. However, from a systemic perspective, the way forward to improve palliative care in Samoa should lie in harnessing the strengths of Samoan culture, including the strong sense of family and the role of religion, in providing support and care for palliative patients. Future research is needed to ensure a thorough evaluation of the needs and preferences of palliative patients and their families to ensure any future model of care remains patient centered. But the reality is that providing care at the end of life can

sometimes be even simpler than that. In the words of Spruyt (Spruyt, 2018):

'When our hands are empty and our hearts heavy ... turn to the joy and the beauty to be found in the simplicity of a smile, or an act of kindness, a song or a sunrise, reconnect and persevere together.' *IJPN*

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CPD reflective questions

- In what ways do cultural beliefs and practices influence the healthcare decisions of patients with cancer in Samoa?
- What role do faith and family play in supporting cancer patients in Samoa, and how could these be harnessed to improve palliative care?
- How can a public health approach to palliative care be adapted to meet the unique needs of cancer patients in low-income countries such as Samoa?

Key points

- Issues that negatively affect the quality of life of patients with cancer and their families in Samoa, include resource constraints and pain
- Positive interactions with healthcare professionals are important to patients with cancer, alongside close relationships with family and spiritual faith
- For palliative care to be effective in Samoa, it needs to be radically different from palliative care that is offered in well-resourced countries and draw on the strength of strong family relationships and support

Short reports

International Journal of Palliative Nursing now publishes short reports, and invites submissions for consideration. Short reports are intended to provide the international palliative care community with the opportunity for concise communication of work that will be of interest to nurses working in palliative care. Short reports should be submitted via the usual channel: www.ijpn.co.uk/contribute.shtml The Editor will be happy to respond to any queries: ijpn@markallengroup.com

