

Palliative Care in the Pacific: initial research

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Abstract

This report presents an initial examination of palliative care across the Pacific region. There is scarce literature on palliative care in Pacific island countries and territories, but the documented disease profile shows a need for expanded palliative care. Through a small number of individual interviews, this initial research builds an overview of what is occurring at the regional level and in some Pacific island countries. There is scant attention to palliative care at the regional level. Multilateral and regional agencies, and key donors, do not have focused programs of support for palliative care. The main drivers of action to date have been local champions, supported through collegial, cross-border clinical engagement and networks. Some civil society organisations are active, such as the Fiji and Samoa Cancer Societies. Country snapshots of action are included in Appendix 2. This report draws out some common themes related to palliative care, alongside selected lessons from elsewhere. Suggestions for regional agencies and donors are offered, based on key principles for action. These suggestions include the need to: provide funding; foster leadership; support training, coaching and mentoring; nurture networks; and conduct further research.

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How do the poorest of the poor die? Do we really want to know? That knowledge could be very disturbing, loaded as it might well be with imperatives for action. (Roy 1999, pp. 3-5)

Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity. (Knaul et al. 2017, p. 1)

1. Introduction

Recently, a Lancet Commission explored access to global palliative care and pain relief, and released the seminal report *Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage* (Knaul et al. 2017). This Lancet Commission report provides a comprehensive and contemporary analysis of palliative care across the world, and should be read by any individual working to improve palliative care.

The Commission concluded that despite pockets of progress across the world, there is an “access abyss in palliative care and pain relief” that “is a medical, public health, and moral failing and a travesty of justice” (Knaul et al. 2017, p. 1). In countries that are poor only two per cent of palliative care needs and an even smaller percent of analgesic needs are being met (Knaul et al. 2017, p. 7). An estimated 61 million people are affected by serious health-related suffering, with more than 80 per cent of these people living in low- and middle-income countries (Knaul et al. 2017, p. 2). Every year approximately 2.5 million children die with serious health-related suffering, and over 98 per cent of these children are from developing countries (Knaul et al. 2017, p. 2).

The Lancet Commission highlights “the imperative of implementing a rigorous, vigorous, and substantive research agenda” (Knaul et al. 2017, p. 53) to provide the required knowledge for expanding palliative care. This report aims to serve as a starting point for a palliative care research agenda across the Pacific region and outlines the findings of initial research into palliative care across the Pacific. The aim of the study is to add impetus to the evolving conversation about palliative care needs in the Pacific.

Before continuing, acknowledgements are due. I wish to thank the people who gave their time to be interviewed for this research, particularly Dr. Linda Huggins, who generously shared her substantial knowledge of, and experience in, palliative care work in various PICTs.¹ I also wish to acknowledge people working in health care across the Pacific. The health challenges in various countries place significant demands on health workers, policymakers, communities, churches and families. The commitment and resilience of all these people must be acknowledged, as must that of people experiencing serious health-related suffering, and the family and friends who care for them. This report aims to stimulate thought and action about how to best support these people.

The literature review brought forth no publications focusing on palliative care in PICTs, although there is a handful of grey literature available, such as conference presentations and unpublished reports. Given the limited state of documented knowledge about palliative care in the region, this research was deliberately broad and descriptive. The aim was to gain an initial understanding of what action was underway, and what needs and gaps existed for future action and research.

The report is structured as follows. Section 2 details the research design, while section 3 defines palliative care. Section 4 outlines the palliative care need across the Pacific, including a review of existing assessments and a rationale for investing in palliative care in PICTs. An overview of palliative care action already occurring is the subject of section 5, while section 6 highlights emerging common themes. Section 7 introduces selected lessons from other parts of the world, before section 8 concludes with ideas for future regional action and research. Appendix 1 provides a list of interviewees. Appendix 2 includes country snapshots of relevant action in several Pacific island countries. As useful reference, Appendices 3, 4 and 5 bring key ideas from the Lancet Commission (Knaul et al. 2017) into this report, covering the palliative care Essential Package, a health systems framework for assessing palliative care, and an overview of lessons from elsewhere.

¹ Dr. Huggins has conducted and facilitated a great deal of work in pain management and palliative care in specific PICTs, as have others, including Dr. Amanda Landers, Dr. Jane Skeen, Dr. Sue Marsten, Dr. Odette Spruyt, Dr. Ann Davis, Dr Jane Greville, Dr. Michael Sullivan and Dr. Kees Lodder. The countries involved include the Cook Islands, Fiji, Kiribati, Niue, Samoa, Tonga and Vanuatu. In several cases, there are long-standing relationships between New Zealand/Australian and PICT colleagues. Clinicians have often used their professional development funding, searched for small amounts of funds, and self-funded this work. In some instances, they provide ongoing clinical support and advice through phone calls and emails.

2. Research design and justification

This initial research took a broad regional perspective, and explored the questions: what is already happening across the Pacific region, and what are the opportunities for future action and research? Data collection involved a literature review and a limited number of phone/skype interviews. The approach is qualitative and exploratory, given so little is known about palliative care across the Pacific region. This broad, regional overview is complemented by a more in-depth country analysis of Solomon Islands, detailed in a companion Discussion Paper (Spratt and Spencer 2018).

Snowball sampling was used to identify interviewees. In total, 32 interviews were requested. Of the 25 responders, 21 were interviewed, three provided information via email, and one forwarded the interview request on (with no further response). Interviewees are listed in Appendix 1. There were seven non-responders. Those who were interviewed are champions of palliative care, which has the benefit that they will have a more detailed knowledge of what is actually occurring in palliative care. It also brings a limitation, in that views will not be representative of the broader health and community situation.

This initial research was limited by design. It was not possible or necessary to interview everybody who is working on palliative care, particularly at the country level. The decision was made to not actively pursue interviews with policymakers and health professionals at the country level: their time is limited and country-specific case analyses are required to fully understand each unique country context. Nevertheless, a small number of interviews were conducted with people in Fiji and Samoa. Country-specific case analyses are the appropriate opportunity to speak with people working in each country. This is why one country case study was conducted alongside this initial regional research (see Spratt and Spencer 2018). Therefore, this research is as stated – initial research to start to understand the regional landscape of palliative care policy and provision.

3. Definition of palliative care

The World Health Organization (WHO) defines palliative care as: “an approach that improves the quality of life of patients and their families facing the problem associated

with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (World Health Organization).

“Palliative Care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiotherapy;
- includes the investigations needed to better understand and manage distressing clinical complications” (World Health Organization 2007, p. 3); and
- “avoids futile interventions” (Palliative Care Expert Group 2010, p. 2).

Palliative care should focus on relieving serious health-related suffering (Knaul et al. 2017). “Suffering is health-related when it is associated with illness or injury of any kind. Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, or emotional functioning. Palliative care should be focused on relieving the serious health-related suffering that is associated with life-limiting or life-threatening health conditions or the end of life” (Knaul et al. 2017, p. 15).

Many people think of cancer when they hear the term ‘palliative care’. Yet, there are many more reasons why an individual and their family might need palliative care. In some PICTs, end-stage kidney failure or non-ischaemic heart disease are significant causes of the serious health-related suffering requiring palliative care. Globally, 20 health conditions cause the heaviest serious health-related suffering burden: atherosclerosis; cerebrovascular disease; chronic ischaemic heart diseases; congenital malformations; degeneration of the central nervous system; dementia; diseases of the liver; haemorrhagic fevers; HIV disease; inflammatory disease of the central nervous system;

injury, poisoning and external causes; leukaemia; lung diseases; malignant neoplasms (cancers); musculoskeletal disorders; non-ischaemic heart diseases; premature birth and birth trauma; protein energy malnutrition; renal failure; and tuberculosis (Knaul et al. 2017). Serious health-related suffering is experienced across the lifespan – from birth to aging.

Chronic and mild, and moderate to severe, pain is the most common symptom associated with serious health-related suffering (Knaul et al. 2017, pp. 19-20). Fatigue and weakness, dyspnoea (difficulty breathing), anxiety or worry, depressed mood, confusion and delirium, nausea and vomiting are also prevalent serious health-related suffering symptoms. For some people, constipation can be more of an issue, or not being able to eat, or the existential questions associated with coming to the end of one's life. At its best, palliative care is an open engagement with a person and their loved ones, focused on alleviating suffering in whatever form that might take for those people. Palliative care requires community workers and health care professionals to have high-quality patient assessment and problem-analysis skills, underpinned by the ability to communicate therapeutically and build therapeutic relationships.

Palliative care is often medicalised and thought of in the context of the formal health system. Yet, the site of palliative care is often not a hospital or medical clinic. In PICTs (as in many places), most palliative care is provided in the home. Serious health-related suffering, dying and death are societal phenomena and involve the community. While the formal health system may be the 'hub' for palliative care, holistic palliative care requires a network that cuts across other government departments, such as social protection and education, and is embedded in communities. People with chronic and life-limiting conditions require long-term care inputs, while the health system in most developing countries is focused on acute care (Kumar & Palmed 2007). A broad public health strategy for palliative care needs to be owned by the community (Stjernsward, Foley & Ferris 2007), including churches, non-government organisations, the private sector, village committees and neighbours.

4. The situation across the Pacific region

The 22 countries and territories across the Pacific region are diverse in culture, history and geography. To illustrate, Papua New Guinea has a population of approximately eight million people speaking over 800 languages, and geography that encompasses offshore islands and high mountain ranges; while Kiribati has a population of approximately 120,000 people, living on 33 atolls spread over 3.5 million square kilometres of ocean. Within the total Pacific population of approximately ten million people, communities in PICTs are resilient and often have high social capital. Systems of family support can be strong, and the robust rituals surrounding death have anecdotally been reported to assist people in their bereavement processes. Yet, PICTs face significant challenges in providing for their people. This is partially due to their large ocean territories, often with small populations living across significant distances. In many countries, “poverty (hardship), vulnerability, inequality and exclusion are on the rise” (Moustafa & Abbott 2014, p. iv). No group of people are immune to this.

Government expenditure is the dominant source of funding for PICT health systems (with support from donors), with low out-of-pocket expenditure.

“Governments in the Pacific face the challenge of financing the response to a double burden: an unfinished agenda of communicable and reproductive needs while also addressing rising costs for NCDs as populations age. But there are limited prospects for significantly increasing government expenditure to health... Nor is there large scope (“fiscal space”) to increase the share of general government expenditure going to health.” (Anderson 2013a, p. xiii)

For example, across Samoa, Tonga and Vanuatu, the share of government expenditure to health ranges from ten to 24 percent, at least twice what other lower middle-income countries expend (Anderson 2013a, p. xiii). Yet, once the remoteness of small populations is accounted for, this expenditure is generally relatively efficient (Edwards 2016).

This initial research did not investigate the potential costs and savings of providing palliative care in PICTs. This requires a specific analysis of what is already provided in the palliative care Essential Package in each country and what the current costs are (both government and out-of-pocket), including analysis of potential savings through

decreasing hospital admissions and using the diagonal approach (i.e. improving the entire health system through focusing on palliative care). Given that most PICTs will require Official Development Assistance (ODA) for decades to come (Edwards 2016, p. iv), and that they already spend significant amounts on health, there is an important role here for donors.

Social protection mechanisms are an important part of broader palliative care, as they provide some form of support for people who need to leave work to care for a loved one or who may have relied upon the sick person for household income. It is beyond the scope of this study to analyse in-depth the social protection mechanisms in place for people who need and provide palliative care. However, in general, across PICTs, social protection measures remain weak and fail to reach those who are most likely to need them (Asian Development Bank 2016).

4.1 Need for palliative care in PICTs

Given the low prevalence of palliative care in the developing world, and the high prevalence of serious health-related suffering-causing diseases across the Pacific, it is likely there is a significant unmet need for palliative care in the region. PICTs experience small populations spread across wide land and ocean areas, and the heavy burden of non-communicable diseases (NCDs), maternal and child health, injury and trauma, communicable diseases, and the growing health impacts of climate change” (Tervonen et al. 2017, p. 184). This disease profile indicates a high need for palliative care. For example, the WHO estimates that 80 per cent of people who die from cancer alone would have needed palliative care, and 50 to 80 per cent of people with HIV, or HIV and AIDS, will benefit from palliative care services, with additional requirements for those who provide care (World Health Organization 2007, p. 9).

While not the only cause of serious health-related suffering, NCDs will cause a significant proportion of serious health-related suffering across PICTs. In twelve Pacific island countries where data is available, NCDs are the leading cause of death, accounting for approximately 70 per cent of all deaths in nine of these countries (Anderson 2013a, p. 2). Key NCD risk factors are common: obesity, physical inactivity, poor diet, and tobacco and alcohol consumption (Tervonen et al. 2017). The presence of these risk factors amongst PICT populations indicate that NCDs will be a “major health challenge for the Pacific in

coming years” (Anderson 2013a, p. xi) along with high and unsustainable health costs (Anderson 2013a, p. 3). Further, while most Pacific country populations are currently youthful, where data is available, the population share for people aged over 60 years is projected to increase between 2015 and 2050, more or less doubling in Fiji, Kiribati, Papua New Guinea, Solomon Islands and Vanuatu (Anderson & Irava 2017, p. 194).

Although poor-quality cancer registration and mortality data limit the availability of information (Foliaki et al. 2017; Tervonen et al. 2017), cancer is increasing across the Pacific.² Cancer registration systems are still under development in most Pacific island countries, although those associated with the United States of America have been supported through the Pacific Regional Cancer Registry since 2003 (Varghese, Clem Carlos & Shin 2014, p. 361) Weak diagnostic systems and tools also hinder accurate diagnoses (Tervonen et al. 2017). It is estimated that across the WHO Western Pacific region, from 2012 levels cancer will increase by 45 per cent in men and 35 per cent in women by 2025 (Varghese, Clem Carlos & Shin 2014, p. 361). While cancer incidence is recorded to be low in PICTs, cancer has been “among the leading causes of death in most PICTs” (Tervonen et al. 2017, p. 189). Cancer is often diagnosed at a late stage, when treatment options are reduced and more intensive care is required, including more complex palliative care. Infectious diseases that cause cancer are also present in several Pacific island countries, and the high rates of liver and cervical cancer attest to this (Foliaki et al. 2017, p. 193).³

Diabetes is a significant issue in all PICTs, with countries having limited capacity to provide diabetes prevention and care, and a low proportion of people who practice self-care (Thu Win Tin et al. 2014). Complications associated with diabetes were found to be high in Nauru, Solomon Islands and Vanuatu, and people with diabetes struggled to achieve the blood pressure, blood glucose and cholesterol management (Thu Win Tin et al. 2014) that would assist in avoiding health complications. While this highlights the need to do more to prevent, treat and manage diabetes (Thu Win Tin et al. 2014), it also

² A Lancet oncology series on cancer in small island developing states is currently in production, due out in 2019. The Pacific is included in this, and there is a section on palliative care.

³ Communicable infections, such as from *Helicobacter pylori*, the Human Papilloma Virus (HPV), Hepatitis B and C viruses, and the Human Immunodeficiency Virus (HIV), are all associated with cancer.

indicates that significant numbers of people will experience severe complications of diabetes, leading to the need for palliative care.

There is little data on injuries and their contribution to serious health-related suffering in PICTs. A systematic review of the literature on road traffic injury (Herman, Ameratunga & Jackson 2012) found limited literature on this topic, but studies from Papua New Guinea indicated that road traffic injuries were more frequent amongst young men, and head injuries were the most common cause of death or hospital admission. A more recent study in Solomon Islands highlighted the disproportionate involvement of young men in road traffic accidents (Stewart et al. 2012). Injury is a cause of serious health-related suffering, requiring palliative care.

The palliative care needs for children must not be overlooked. There is little PICT-related data available in the literature regarding congenital malformations, preterm birth and birth trauma, lung and heart diseases, and protein energy malnutrition – all of which cause serious health-related suffering. One study estimated that preterm births comprised 6.4 per cent of births across all PICTs in 2005 (Beck et al. 2010, p. 35), but this is likely to be an underestimate. Cancer in children and adolescents accounts for one to four per cent of all cancers worldwide (Skeen 2017). As child health in some Pacific island countries improves, “childhood cancer is becoming a significant cause of morbidity and premature death” (Skeen 2017, p. 5). Estimates have been made regarding the prevalence of cancer in children in various PICTs, but there is no formal record available in the literature.

Anecdotal evidence indicates that health literacy is low across the PICTs and people often turn to traditional medicine and healers in the first instance. Due to these and other reasons, in general, people present late to health services, meaning that their chances for full recovery and survival are low. This places additional burdens on already stretched health services, and additional cost.

In most PICTs, treatment for advanced disease is not available or is extremely limited. In many PICTs chemotherapy and radiotherapy is not available at all, with surgery the main approach to cancer. Highly technical interventions, such as dialysis and intensive care treatment, are limited and expensive. The outcomes from some of these interventions, where they are offered, do not necessarily contribute to sustainable quality of life

outcomes. For example, in Samoa, one third of patients who receive dialysis treatment die in less than a year, “and almost half of all patients have died a year later” (Anderson 2013b, p. 25). Overseas treatment schemes have variable long-term outcomes, are expensive and carry potential opportunity costs, and it is not clear if they are allocated equitably in all PICTs (see, for example Anderson 2013b, pp. 23-25). The high prevalence of risk factors for non-communicable diseases (NCDs), as well as the ongoing presence of serious health-related suffering-causing communicable diseases and other conditions, combined with low health literacy, means that efforts to prevent serious health-related suffering-causing conditions will take time. In the meantime, people will continue to present with serious health-related suffering, which requires palliative care. The available evidence shows a need for heightened attention to palliative care across the Pacific region.

4.2 Morphine and opioids in PICTs

Access to opioids is essential for managing moderate to severe pain. At a minimum, all countries should make oral and injectable immediate release morphine universally accessible. Yet, opiates can also cause harm if they are misused. The Single Convention on Narcotic Drugs, 1961, classifies opioids as controlled substances and specifies that governments need to *both* control these drugs to prevent abuse, and ensure they are available for medical and scientific use (Bosnjak et al. 2011): the ‘principle of balance’. Governments report annually on opioid consumption (the amount distributed to clinics, hospitals etc.) to the International Narcotics Control Board (INCB).

Oral morphine for analgesia is available in 71 per cent of PICTs (15 countries) (Varghese, Clem Carlos & Shin 2014, p. 364). In the WHO Western Pacific Region, fentanyl and oxycodone have increased in use, while morphine has not (Hastie et al. 2014, p. 268). Yet, the Western Pacific Region includes wealthy countries, such as Singapore, Japan, New Zealand and Australia, so it is highly likely that these countries drive the increase in the use of these medications. As Table 1 below shows, there are very low rates of actual consumption of morphine-equivalent opioids in comparison to a calculated adequate consumption. The lack of data also hinders a good understanding of opiates’ availability across PICTs.

Table 1: Actual and adequate consumption of morphine equivalents in mg/capita, 2006 and 2010, and in kg, 2010.

Country	Consumption of morphine equivalents in mg/capita			Consumption of morphine equivalents in kg	
	Actual (2006)	Actual (2010)	Adequate (2010)	Actual (2010)	Adequate (2010)
Cook Islands	No data	11.07	96.75	0	1
Fiji	No data	No data	201.43	No data	178
Kiribati**	1.86	2.55	85.80	0	9
Marshall Islands **	3.08	No data	191.86	No data	13
Federated States of Micronesia**	3.45	No data	140.74	No data	15
Nauru	No data	No data	255.85	No data	2
Niue	No data	No data	133.44	No data	0
Palau**	No data	17.70	163.11	0	3
PNG	2.84	No data	237.75	No data	1471
Samoa**	0.67	No data	90.95	No data	18
Solomon Islands	Not in study	No data	143.08	No data	82
Tonga**	Not in study	2.73	134.00	0	14
Tuvalu	Not in study	1.40	217.39	0	2
Vanuatu**	Not in study	No data	157.20	No data	35

***Calculations based on cancer and injury mortality data only (Seya et al. 2011, p. 8). 2006 data from Seya et al. 2011 (p. 13). 2010 data from Duthey & Scholten 2014 (p. 289).*

There may be barriers to opiate use at the country level, such as opiophobia – the “prejudice and misinformation surrounding the appropriate medical use of opioids in the context of a balanced approach that reduces risks of non-medical use” (Knaul et al. 2017, p. 8). This includes the fear of addiction and side effects, amongst patients, families, regulators and health professionals. Opiophobia leads to low use and underestimates of the need for opiate pain relief, and therefore low production and importation. Weak health systems are also a constraint to opiate access, including supply management, and a lack of knowledge about opiates, not only amongst health professionals, but also the general public and policymakers (Bosnjak et al. 2011, p. 1242). Some argue that cost is a barrier, but there are mechanisms that can be instigated to lower cost, and it is unclear if cost is a barrier in PICTs.

4.3 What is known about palliative care in PICTs?

The most recent global mapping of palliative care (conducted in 2011) found most Pacific island countries and territories had no known palliative care activity (32 per cent of all countries mapped, n: 75) (Conner & Bermedo 2014, p. 36; Lynch, Connor & Clark 2013, p. 1099).⁴ In Fiji and Papua New Guinea, activity was recorded under the criteria of ‘capacity building’, which could include policy, workforce and organisational development for palliative services, but not yet any service provision.⁵ These PICT categorisations had not changed since the 2008 global mapping (Wright et al. 2008, p. 472).

In WHO’s 2015 global survey on national capacity for prevention and control of non-communicable disease, the Western Pacific region (WPRO)⁶, scored second-best globally for the provision of palliative care services in primary healthcare (48 per cent) or in

⁴ This includes: American Samoa, Cook Islands, French Polynesia, Guam, Kiribati, Marshall Islands, Micronesia, Nauru, New Caledonia/Kanaky, Northern Mariana Islands, Palau, Pitcairn, Samoa, Solomon Islands, Tokelau, Tonga, Tuvalu, Vanuatu, and Wallis and Futuna.

⁵ See Appendix 2 for updated information, including hospice construction in Port Moresby and Fiji Cancer Society activities in Fiji.

⁶ There are 37 countries in the WHO WPRO: Australia, Brunei Darussalam, Cambodia, China, Cook Islands, Fiji, French Polynesia (France), Guam (USA), Hong Kong SAR (China), Japan, Kiribati, Lao PDR, Macao SAR (China), Malaysia, Marshall Islands, Federated States of Micronesia, Mongolia, Nauru, Niue, Northern Mariana Islands (USA), New Zealand, Palau, Papua New Guinea, Philippines, Pitcairn Islands (UK), Republic of Korea, Samoa, Singapore, Solomon Islands, Tokelau, Tonga, Tuvalu, Vanuatu, Viet Nam, Wallis and Futuna (France).

community or home-based services (44 per cent) (World Health Organization 2015, p. 74)⁷. Yet the Western Pacific region includes countries such as Australia, New Zealand, Japan and Singapore. Australia and New Zealand lead the world in quality of death, according to the Economist Intelligence Unit's study in 2015 (The Economist Intelligence Unit 2015).⁸ Therefore, it is likely these wealthy countries significantly pull up the average for this region. Low-to-middle income countries in the WHO global survey saw only 20 per cent of their primary health care services providing palliative care, and 12 per cent of their community or home-based services (World Health Organization 2015, p. 74). In contrast, a separate study found that community or home care for people who required disability care or late-stage palliative care was present in 71 per cent (15) of PICTs (Varghese, Clem Carlos & Shin 2014, pp. 363-364). It also appears that PICTs reported to WHO in 2017 that palliative care was generally not available in primary health care, but generally available in community or home-based care (Suva World Health Organization 2018). Given the information shared in interviews for this initial research, it seems highly likely that the high ranking for community and home-based care simply refers to the fact that families are the main caregivers for people who need palliative care. This indicator does not provide any information about the support families receive or access to specialist palliative care interventions.

Overall, it is reasonable to infer that the provision of palliative care (as defined above) in Pacific island countries is likely to be low. Yet, without more regional and country-level analysis, it is difficult to make any useful conclusions about what action is underway in various Pacific island countries and where the gaps are in alleviating serious health-related suffering.

4.4 Why invest in palliative care in PICTs?

People across the Pacific are experiencing serious health-related suffering. Palliative care can alleviate this suffering. Fundamentally, this is why palliative care requires greater investment, particularly because we have the means and knowledge to do so.

⁷ The 2017 global progress report did not include any palliative care indicators (World Health Organization 2017a).

⁸ The Economist Intelligence Unit's 2015 Quality of Death Index did not include any Pacific island countries in the 80 countries it assessed (The Economist Intelligence Unit 2015).

Further, “well-designed and appropriately financed palliative care relieves pressures on other parts of the health system and reduces overall costs”, also “provid[ing] financial risk protection for patients and families” (Knaul et al. 2017, p. 42). Palliative care is highly conducive to the diagonal approach, whereby investing in palliative care will also assist in strengthening the wider health system. For example, investing in clinician pain management and communication skills will improve quality of care and health outcomes for all patients, not only those requiring palliative care. For health systems that are struggling under the weight of multiple demands with limited resources, investing in palliative care can have significant benefits, not the least of which is improving patients’ quality of life.

The Lancet Commission devised a palliative care Essential Package (Knaul et al. 2017, p. 3) (see Appendix 3), which is estimated to cost between US \$2.16 per capita per year in low-income countries (two to three per cent of the cost of the UHC Essential Package) and US \$0.78 per capita per year (0.6 per cent of the UHC) in lower middle-income countries (Knaul et al. 2017, p. 3). What degree of extra investment is required in individual PICTs will depend upon what aspects of the Essential Package are already available and whether cost-lowering mechanisms, particularly for opiate pain relief, can be implemented.

5. What is happening now?

Health professionals, communities, churches and families across PICTs are providing palliative care to the best of their abilities. This research found that there is some country-level action occurring, but there is little regional coordination or coherent support for this work. Appendix 2 contains country snapshots of information about what is occurring that were gathered through interviews. This section outlines action that has been undertaken across the region, and that continues today. The information documented here is not comprehensive.

What is clear, however, is that little action is occurring at the regional level, and palliative care is not well-integrated into regional frameworks. While the site of most action must be at the country level, there are specific actions that regional actors can undertake to support expanding palliative care in PICTs. These are detailed in section 8 below.

5.1 Pacific Regional Frameworks

The 1995 Pacific Ministers of Health Yanuca Island Declaration states a vision for a healthy Pacific region. Healthy islands are places where: “children are nurtured in body and mind; environments invite learning and leisure; people work and age with dignity; ecological balance is a source of pride; and the ocean which sustains us is protected” (World Health Organization & Secretariat of the Pacific Community 2015, p. 2). Elaborating in 1997, Pacific Ministers of Health stated that “the healthy islands concept involves continuously identifying and resolving priority issues related to health, development and well-being by advocating, facilitating and enabling these issues to be addressed in partnerships among communities, organisations and agencies at local, national and regional levels” (World Health Organization & Secretariat of the Pacific Community 2015, p. 2). Palliative care fits well within this overarching vision, because palliative care enables people of all ages to be nurtured, to learn, to experience dignity, and to live to their fullest until the moment they die. This has not yet been comprehensively acknowledged in regional action.

There is no regionally-led framework that explicitly addresses palliative care. With the exception of the 2008-2013 Pacific Framework for the Prevention and Control of Non-communicable Diseases (World Health Organization & Secretariat for the Pacific Community 2007, p. 5) (where it is situated once in a diagram), regional frameworks on NCDs do not incorporate palliative care (Pacific Island Forum Economic and Health Ministers 2014; Pacific Island Forum Secretariat & Secretariat of the Pacific Community 2014; Pacific NCD Partnership 2014). The focus is on NCD prevention, which is warranted because “without decisive action, NCDs can undo the development gains of the last 20 years” (Pacific Island Forum Economic and Health Ministers 2014, p. 1). Yet, as shown above, greater attention to palliative care is also needed.

The WHO’s Western Pacific Regional Action Plan for the Prevention and Control of Non-communicable Diseases 2014-2020, (which was endorsed in October 2013) does include palliative care. Under the objective of strengthening and orienting the health system to address NCDs, it is recommended that states “improve access to palliative care and pain relief for patients with cancer and other life-threatening conditions” (World Health

Organization 2014, p. 18). Developing and implementing a palliative care policy is also a recommended option for states to enact (World Health Organization 2014, p. 31).

Globally, there is attention to palliative care in key policy documents. In 2014, the World Health Assembly passed Resolution 67.19, which urged governments to attend to palliative care needs in their legislative, policy, planning and service-provision activities, and to build partnerships with non-state actors to provide palliative care (World Health Assembly 2014). Palliative care is explicitly recognised in the 2013-2020 WHO Global Action Plan for the Prevention and Control of Non-communicable Diseases (World Health Organization 2018), and the Comprehensive Global Monitoring Framework includes an additional indicator assessing the access to morphine-equivalent consumption of strong opioid analgesics (except methadone) per death from cancer (World Health Organization 2011). Palliative care comprises part of Universal Health Coverage (UHC)⁹, and Sustainable Development Goal 3 – good health and well-being – has a target to achieve universal health coverage.

5.2 Australia and New Zealand Overseas Development Assistance

Australia and New Zealand were the only two donors contacted for this initial research. The Ministry of Foreign Affairs and Trade in New Zealand (MFAT) does not provide any specific funding for palliative care, nor does Australia’s Department of Foreign Affairs and Trade (DFAT). However, MFAT funds the Pacific Health Development program, through the Counties Manukau District Health Board, to provide support to various Pacific island Ministries of Health. The funding under this program has supported several palliative care and pain relief trainings, facilitated by joint requests from countries and New Zealand clinicians (Huggins 2018a). DFAT is funding construction of a hospice in Port Moresby. Beyond this small and piecemeal funding, these donors have no coordinated or coherent approach to palliative care in PICTs. While donors fund regional and country NCD responses, maternal and child health, and some communicable disease interventions, without a specific focus on palliative care, any funding for a response to

⁹ UHC “means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.” (World Health Organization 2018b).

serious health-related suffering – often associated with these health areas – will continue to be limited and lack coherence.

5.3 Multilateral and regional organisations

In terms of multilateral organisations in the Pacific, there is limited attention to palliative care. WHO has the Action Plan outlined above, but there is not yet action underway to assist countries to develop a palliative care policy or expand access to palliative care. This may be partially explained by the fact that WHO aims to respond to requests from governments, and there have reportedly been none made to WHO regarding palliative care.

The International Agency for Research on Cancer, which is part of WHO, established a Pacific islands regional hub in 2014 for cancer registries (part of the Global Initiative for Cancer Registry Development) (Tervonen et al. 2017, p. 185).¹⁰ Improved cancer data can assist with palliative care provision through identifying the need for palliative care. The International Atomic Energy Agency (IAEA) has a Program of Action for Cancer Therapy (PACT) (International Atomic Energy Agency 2017), due to the use of radioactive material in radiotherapy. While not part of an Essential Package for palliative care, radiotherapy can be used in palliation. The IAEA conducted an ‘imPACT’ assessment in Fiji in 2014, and supported clinicians from New Zealand and Australia (and associated with Australasia Palliative Link International) to run a workshop in Fiji in 2016. In the past they have also supported a radiotherapist from PNG to attend a course.

It is understood that the Specialised Clinical Services Heads of Health Sub-Committee is considering the potential to discuss palliative care at a workshop early in 2019. This is a promising initiative and could make a significant contribution to expanded action on palliative care.

5.4 Civil society and collegial action

The most significant regional action on palliative care has occurred through cross-border clinical training and support offered through various professional associations in New

¹⁰ Related, in some Northern Pacific states, the Cancer Council of the Pacific Islands initiated the Pacific Regional Central Cancer Registry, in collaboration with the USA Centre for Disease Control and Prevention (Foliaki et al. 2017, p. 196).

Zealand and Australia, and by individual clinicians. In some cases, the relationships involved have a long history and continue today. These relationships offer great potential for expanded action on palliative care, and shared learning and support could be boosted through regional action. In both Fiji and Samoa, the local cancer societies are also very active. Appendix 2 details country-specific information gathered through this initial research. Here, I outline the main groups or mechanisms through which palliative care training, action and collegial support have evolved.

There are several global civil society organisations that are the 'key' global agencies for palliative care: the International Association for Hospice and Palliative Care, International Children's Palliative Care Network, and Worldwide Hospice Palliative Care Alliance. These appear to have limited connections with the Pacific region. The Asia Pacific Hospice Palliative Care Network's (APHPN) recent paediatric palliative care directory listed no Pacific island countries (Asia Pacific Hospice Palliative Care Network 2018b), although there is at least some action in Fiji (see the Fiji country snapshot in Appendix 2). The APHPN did establish a special interest group for the Pacific region, but it is not clear if this group functions. The APHPN general services directory lists one individual member from Samoa and one from the Cook Islands (Asia Pacific Hospice Palliative Care Network 2018a). The APHPN has been very active in Asian countries, implementing a range of successful activities, some of which provide useful lessons and potential models for expanded action in PICTs. (See section 7 below for more details.)

An NGO more relevant to the Pacific region, with important future potential, is the Australasian Palliative Link International (APLI). APLI was established in Australia in 1996 to grow relationships between palliative care providers and organisations in Australia and New Zealand, and colleagues across Asia and the Pacific (Spruyt & Brennan 2011). APLI members have done some work with colleagues in Fiji (see the Fiji country snapshot in Appendix 2).

Another important group, with links to APLI, is the New Zealand branch of The Australia New Zealand Society of Palliative Medicine (ANZSPM) (The Australian & New Zealand Society of Palliative Medicine 2018), which established a Pacific Working Group in 2017. This Working Group is new and has six New Zealand and four Australian members, many of whom regularly train and connect with colleagues in various PICTs. This emerged from

ANZSPM previously sponsoring three doctors who approached ANZSPM for sponsorship to attend the ANZSPM biennial conference. The Working Group plans to continue to provide scholarships such as this, and potentially support sponsored individuals to stay after the conference for a short placement in a hospice or palliative care unit. The overarching aim of the Working Group is to be a mechanism for networking, knowledge-sharing and collegial support.

There is also the New Zealand National Child Cancer Network (NCCN), which established a Pacific Working Group in 2011. While not focused solely on palliative care, palliative care support is provided, particularly in countries where treatment is not an option. This Working Group evolved from New Zealand aid-funded work between 2006-2008 that supported scoping visits to Cook Islands, Fiji, Samoa, Tonga and Vanuatu (Skeen 2017). Twinning relationships were established between Christchurch Hospital and Fiji, and Starship Hospital and Cook Islands, Niue, Samoa, Tokelau, Tonga and Vanuatu (Skeen 2017). Triage criteria, treatment protocols, supportive care guidelines and cancer registration forms were established. Nurses from Fiji and Tonga were trained in New Zealand (Skeen 2017). Work continues although the funding has ended, including through teleconferences with colleagues in these countries to provide guidance on patient care and treatment protocols (Foliaki et al. 2017, p. 196). Through the relationships established, a clinician at the Melbourne Royal Children's Hospital now has a relationship with Papua New Guinea and Solomon Islands, and the Westmead Children's Hospital has links with New Caledonia/Kanaky (Skeen 2017, p. 47).

Another mechanism that has fostered ongoing collegial support and palliative care training is the Essential Pain Management program.¹¹ Essential Pain Management has been delivered in various PICTs since 2011. Piloted in 2010 in Papua New Guinea, the training involves an eight-hour course to expand health professionals' ability to recognise, assess and treat pain (Goucke et al. 2015). There is also a trainers' course, for five hours, after which participants are supervised in delivering an eight-hour Essential Pain Management course. Initially, Essential Pain Management delivery in PICTs was funded through the Faculty of Pain Medicine and Royal Australian College of Surgeons (RACS). This funding is no longer available. Dr. Linda Huggins undertook a great deal of

¹¹ The Essential Pain Management package was developed by Roger Goucke (pain specialist) and Wayne Morris (anaesthetist). The website is [here](#).

this work in PICTs, and continues to do so with other colleagues. Often, palliative care training has been run alongside Essential Pain Management courses. A truncated Essential Pain Management module (Essential Pain Management Lite) has been embedded in the Fiji National University's College of Medicine, Nursing and Health Sciences medical curricula, and Dr. Huggins provides ongoing technical support for this (Huggins 2018a). There have also been discussions with the College to embed Essential Pain Management Lite into nursing curricula, but this has not yet occurred.

Another group that may also implement palliative care support is the Royal Australasian College of Physicians (RACP), yet it is unclear at the time of writing what this may be.

6. Common themes and ideas

The data collected for this initial research highlighted some common themes, present to greater or lesser degrees in different countries, depending upon their resources and civil society action. Key themes stand out, in conjunction with the findings from the Solomon Islands' case study documented in Spratt and Spencer (2018). These themes are detailed below.

6.1 Recognition of the need

Everybody interviewed acknowledged the need for palliative care and a desire to improve on what is already occurring. The fact that many people present late with advanced NCDs mean that health professionals are working with patients and families with complex needs, many of whom need integrated palliative care. Health professionals are doing their best to respond, but are working in resource-scarce conditions and are often pulled in many different directions. There are opportunities to enhance primary health and community action in palliative care, which could relieve some pressure on tertiary health institutions.

6.2 Families, home and community

Families across PICTs are the main providers of care for people experiencing serious health-related suffering. This is a strength to be acknowledged and supported. This care may well be what policymakers are thinking of when they record palliative care as being available in the community. Yet this care should not be taken for granted, and can have

significant impacts on families, such as the need to leave employment or education to care for a loved one. In some countries, the requirement for family care can also extend to the hospital setting. In some cases, nurses no longer provide personal care in hospitals, meaning families provide important nursing cares for family members, such as providing food and water, skin care, mouth care, and assistance with toileting.

Whether at home or in the hospital, serious health-related suffering manifests itself in many different ways. Families do not always know what to expect or what care to provide. As much as they want to care for their loved one, people can feel alone and overwhelmed by the complexity of care required (wounds, pressure area care, manual handling, incontinence, pain relief). When providing this care over long periods of time, people can become fatigued, an issue exacerbated by the fact that they are watching somebody that they love suffer and come to the end of their life. Families and caregivers need training and support, and specialist palliative care input. There is an important role here for churches and NGOs, such as the Samoa and Fiji Cancer Societies, and opportunities for expansion of this work. The Nurse Maude caregiving training planned in Fiji for early 2019 holds great potential as a model for use elsewhere. (See the Fiji country snapshot in Appendix 2 for more detail). There is great need for more family and community support.

6.3 Collegial connections, relationships and champions

Interviewees noted the importance of on-the-ground champions who have the space to lead action. Local health systems are extremely challenged, and dedicated health professionals are pulled in many different directions. Often the desire exists to improve palliative care, but work demands mean there is little time or opportunity to do so. While health professional champions are essential, it is also important to have a political champion at the decision-making level, either in the political or professional executive. This person can help to ensure the space and resources necessary for health professionals or community groups to expand their work.

Any progress made in palliative care expansion in PICTs has predominantly been advanced through connections between health professionals and community groups who want to provide services for people who are experiencing serious health-related suffering and who are dying. These connections with colleagues in New Zealand and Australia, and in some cases other PICTs, are a great strength, offering local champions a source of

technical advice, as well as support from people who understand the situation. While these connections have often been made through trainings, they then develop into low-key mentoring and coaching-type relationships. There are opportunities to support and nurture these relationships further.

6.4 Health systems

As would be anticipated, opportunities to expand palliative care services are impacted by, and linked to, broader health systems strengthening efforts. Palliative care requires attention across the health system, including financing and public education. A comprehensive approach to palliative care in the five health system domains is detailed in Appendix 3. There are governance and stewardship issues to consider, such as legislation and regulation regarding health professionals' scope of care, prescribing rights, and management of medicines, such as opioids. Policies, guidelines and procedures are required to support and maintain basic standards of quality care. Yet, these need to be developed by people who are using them, taking an evolving, iterative approach. There are health workforce issues, such as supply, training and potential task-shifting. There are supplies issues, with opiates and other essential medicines, but also equipment, such as oxygen, incontinence pads, and pressure-relieving mattresses. Access issues also need to be considered, such as often-severe differences in access between rural and urban populations. However, it is important to note that while good palliative care relies on a functioning health system, improving palliative care can help to build a functioning health system – it is not an either/or scenario.

6.4.1 Access to medicine, particularly morphine

A full assessment of access to palliative care medicines, including morphine, was not possible in this initial research. One study analysed the Essential Medicines Lists for Cook Islands, Niue, Samoa and Tonga (Greville 2016). It appears that even when morphine is available, it is not always available in the most appropriate formulation, and due to prescription and distribution restrictions, it may not be available to the extent that people in pain require it. (See also Spratt and Spencer (2018), which presents a Solomon Islands case study.) As detailed earlier, there are multiple challenges with the provision of morphine (and other opioids), and health professionals, including nurses, are not always confident about how to use opioids. Access to other medicines in the palliative care

Essential Package is also inconsistent, and may differ in practice even when available on the country's Essential Medicines List. These issues warrant further in-depth investigation.

6.4.2 Specialist versus integrated?

Many interviewees commented on their desire to have a specialist palliative care team, although some recognised the challenges this might pose. As one interviewee commented, “if we had a palliative care team they would fall over with the volume of work.” There is also the risk that palliative care comes to be viewed as the palliative care specialist's work, yet given the needs in most PICTs, palliative care principles need to be integrated across the work of all health professionals. In practice, the best approach is likely to be a dual-track approach that is country-specific. This could include ensuring that all health professionals have basic palliative care skills, such as therapeutic communication skills, preventative care (for example, mouth care, skin care, bowel care), and symptom identification and knowledge of basic interventions, combined with upskilling palliative nurse specialists who could act as resource people for more complex cases. Ideally, a medical palliative care specialist would also be available, but this is unlikely to be realistic or viable given resource constraints, at least in the short term. There is the potential to draw on colleagues in other countries for support, through the existing networks outlined above.

These strengths and issues are not unique to PICTs. Other countries have, and do, experience similar challenges and have found ways to expand on their strengths. While all action needs to be context-specific, there are many lessons to be learned from other parts of the world where palliative care has been expanded successfully.

7. Lessons and ideas from elsewhere

Action to expand palliative care is possible in resource-poor environments with complex health needs, such as in many PICTs. In fact, there are opportunities unique to these contexts. Developing countries have opportunities to quickly and efficiently develop palliative care systems that learn from mistakes other countries have made, and are innovative and context-specific. Some developing countries and regional networks have

made great achievements in palliative care provision and provide useful ideas for further action in PICTs. A small selection of examples are detailed below.

An example often referred to is Uganda, which was the only developing country to achieve 'advanced integration' in the 2011 global mapping of palliative care (Lynch, Connor & Clark 2013, p. 1109). From its founding in 1992, the pioneering Hospice Africa Uganda has a centre in Kampala, with three satellite hospices that include a community volunteer program, and several home care services and day care clinics (Rhee et al. 2017). Uganda has a public-private partnership between Hospice Africa Uganda and the health ministry, which now sees the government supporting free oral morphine to anyone who needs it (The Economist Intelligence Unit 2015, p. 12). Uganda passed a law in 1994 that allowed trained nurses, medical assistants and clinical officers to prescribe oral morphine (The Economist Intelligence Unit 2015, p. 42). Hospice Uganda Africa imports morphine powder and from it produces oral morphine (liquid) for distribution. They have also worked with police, and with patients, to dispel fears about morphine. Now, Hospice Africa Uganda also has a Department of International Programs, which provides palliative care training to health professionals across Africa (Rhee et al. 2017; Hospice Africa Uganda).

Initially, an individual champion drove Hospice Africa Uganda – Dr. Anne Merriman. As in so many social change processes, across the world, palliative care expansion has relied a great deal on individual champions, or groups of champions, often working across borders (Bosnjak et al. 2011; Paudel et al. 2015; The Economist Intelligence Unit 2015, p. 16, 19, 34, 45). It is a shared passion for alleviating the suffering associated with life-threatening and life-limiting conditions that bring these people together. While champions are necessary, one individual cannot do it alone and while initially there might be one person, they quickly gather others to build “collaborative efforts by clinicians, advocates, governments, and communities” (Harding et al. 2010, p. 23).

A good example of this collaborative effort occurred in Nepal (Paudel et al. 2015). Since 1995, palliative care religious and non-government groups – the Pashupati Temple and Maiti Nepal and Hospice Nepal – began work in this area. In 2002, the Nepal Network for Cancer Treatment and Research, a branch of the International Network for Cancer Treatment and Research, started working with global palliative care experts and formed

a national palliative care group. At about the same time, key medical services opened palliative care wards, and Thankot Hospice for cancer patients opened in 2007. International conferences were held, and a multidisciplinary non-government organisation, called NAPCare, was established to advance palliative care through training, research and standard promotion.

Panama took a quintessential diagonal approach – integrating palliative care into the primary care system and therefore strengthening the entire health system – based on the decision that they could not afford specialist services (The Economist Intelligence Unit 2015, p. 34). They used a standardised national education program to train professional caregivers, and trained staff in basic palliative care. Palliative care program coordinators were placed in all 14 health regions to support caregivers and staff. This enabled Panama to triple the number of patients receiving palliative care between 2010 and 2014 (The Economist Intelligence Unit 2015, p. 34). Given the multiple health challenges PICTs face, integrating palliative care across the primary health network may be a worthwhile approach to consider.

Kerala in India took a community-based approach, developing the community-led ‘Neighbourhood Network in Palliative Care’ palliative care program (Kumar & Palmed 2007). Individuals who had at least two hours a week to spare were offered 16 hours of theory education and four supervised clinical days, and they were then able to work as a community volunteer. They are expected to form groups of 10-15 volunteers, and identify people with chronic illness and in need of palliative care in their villages. Doctors and nurses provide support, and the volunteers link-in with existing palliative care services in the health system. The volunteers regularly visit people at home, and address a variety of patient needs, as well as conducting community awareness and fundraising activities (Kumar & Palmed 2007). Within five years, the Neighbourhood Network has expanded palliative care coverage significantly, raised funds for palliative care locally, and also involved the local government in their activities (Kumar & Palmed 2007).

A focus in many countries is training, particularly of the health workforce. This often involves cross-border collegial clinical training and support. For example, since 2006 the International Pain Policy Fellowship has supported and empowered emerging leaders from developing countries to improve the availability and accessibility of opioids to treat

pain (Bosnjak et al. 2011; Paudel et al. 2015). The Fellowship runs for two years and has a competitive selection process. Fellows receive education, a week-long training at the University of Wisconsin's Pain and Policy Studies Group (a WHO Collaborating Centre for Pain Policy in Palliative Care), and then ongoing support and assistance over the following two years. Fellows are required to develop action plans and then implement them. Significant gains were made by Fellows in several countries as diverse as Sierra Leone, Colombia, Serbia (Bosnjak et al. 2011) and Nepal (Paudel et al. 2015).

The Asia Pacific Hospice Palliative Care Network implemented a similar approach, engaging Flinders University to develop and implement a Graduate Certificate in Palliative Care, focusing on resource-poor contexts (Hegarty et al. 2014). The course was available from 2006 to 2012, based in Singapore with a distance-learning framework. Students (108) came from a variety of disciplines. Clinical placements took place across the region. Several of the students were leaders in palliative care in their own countries, and the course built on this, including expanding their teaching skills. Following the course, most participants remained in clinical work in palliative care and gained support from the peer networks they had formed through the course. There were no Pacific participants on the course.

Finally, there are multiple examples of how clinical research and cross-border research collaborations have helped to improve palliative care. One example is the development of the African Palliative Outcome Scale. This Africa-specific tool was developed through literature reviews, surveys and consultation. A simple tool was created that allows patients and their family to score their problems over five domains¹² covered in 12 indicators (Powell et al. 2007, pp. 229-230). The tool was tested and validated, with staff finding it useful for assisting them in their care provision, as well as for ongoing quality improvement (Powell et al. 2007).

These are just some examples of the action globally that has expanded palliative care, and which could inspire PICT-specific approaches. In their comprehensive literature review, Knaul et al. (2017) gathered lessons learned from global action, according to health system function. These are included below in Appendix 5.

¹² Pain and symptom relief; access to drugs; emotional/spiritual support and grief counselling; support for family carers; and family-based advanced care planning (Powell et al. 2007, pp. 229-230).

8. Ideas for future regional action and research

Ideas for future action and research at the regional level conclude this report. These ideas are provided to stimulate thought and start conversations. Overall, the ideas suggested here are incremental in their nature, based on the recognition that social and system changes require consistent action over time. Based on lessons from elsewhere and the existing strengths across the Pacific region, the key areas where regional action could support country-level palliative care expansion include funding, leadership, training, networking, and research.

8.1 Principles for action

Before offering more specific ideas for regional action and research, it is important to note several principles that to be effective, regional approaches should be based on. These are as follows.

- Support existing strengths. As outlined above, there is action underway across various PICTs to expand palliative care. Any future action needs to draw on what is already occurring and build on this. In particular, acknowledgement of, and support for, the care that families provide is crucial.
- Build on existing relationships. There are many cross-border collegial relationships in place, and these often have long histories. To be most effective, future action can expand on these, and perhaps most importantly, ensure that the people involved in these relationships are consulted about any future action.
- Promote a holistic perspective of palliative care. While it is necessary to start where people are 'at' in relation to how they view palliative care, it is also important to ensure that palliative care is provided early in the disease process – not only at the end of life, and for children and people who are older and/or who have conditions other than cancer that cause serious health-related suffering. Palliative care must not be viewed as confined to the formal health system – families, villages, churches, community organisations and NGOs do, and can, play important roles in palliative care provision.
- Carefully consider how best to open and protect space for local champions to act. There are several local champions in various PICTs, but particularly when they are health professionals with full-time jobs, there is little space for them to advance

palliative care action. There may be creative ways for regional and donor support to allow more space for these individuals to drive changes forward.

- There are several organisations already active in supporting palliative care provision in PICTs: the Pacific Health Development program at Counties-Manukau District Health Board in New Zealand, the Australian New Zealand Society of Palliative Medicine Pacific Working Group, the New Zealand National Child Cancer Network Pacific Working Group, and Australasian Palliative Link International. These organisations provide useful foundations for future action.

8.2 Funding

Funding is crucial to expand palliative care and alleviate serious health-related suffering across the Pacific region. Through providing funding, donors and regional agencies can play important roles in increasing action and ensuring it is sustained over the long-term. Large amounts of money are not necessarily required. For example, there is the potential to consider a small grants fund that clinicians could access to support their training, coaching and mentoring work.¹³ However, more significant funding packages will support greater action. Whatever the amount, it is important that the funding is sustained. Improvements will take several years and sustained funding support will allow strengths to be expanded over time.

8.3 Leadership

Regional actors can provide leadership on palliative care, particularly through acknowledging it is an important area for attention in PICTs. It can be difficult for country-level policymakers and health professionals to discuss palliative care, as there is a fear that communities may perceive this as an acknowledgement that health systems are failing. This is not the case, and by talking about palliative care, regional actors can provide space for country-level actors to consider and discuss palliative care as an important part of quality universal health care. Palliative care is already in WHO's Western Pacific Regional Action Plan for the Prevention and Control of Noncommunicable Diseases 2014-2020, and these provisions should begin to be

¹³ There is the potential for existing Australian organisations to apply to DFAT's new 'Friendship Grants', if they continue past their first round.

promoted. The potential for the Specialised Clinical Services Heads of Health Sub-Committee to consider palliative care is a promising initiative, and could establish a foundation for regional leadership on the issue. Ideally, a regional action plan would be developed and implemented.

8.4 Training, coaching and mentoring

Similar to what has occurred in other parts of the world, there is the potential for professional development programs to be developed for PICTs, as well as curricula for formal tertiary institutions, and training for families and communities.

In relation to tertiary health professional training, a potential regional action could be to develop nursing curricula for palliative care, and support nursing schools to then adapt and integrate it into their curricula. Similarly, palliative care could be integrated into the medical curricula at the Fiji National University, and Samoa and Papua New Guinea medical schools.

In terms of in-service training, there is the potential to support deeper and wider Essential Pain Management training, with a particular focus on the ‘training of trainers’ approach. Ordinarily, ‘training of trainers’ workshops are not optimal – to learn a skill requires more than attending a workshop, and learning technical skills does not mean a participant is a good teacher. Having said that, the Essential Pain Management does integrate adult learning principles into their ‘training of trainers’ course, and also enables trainers to conduct a supervised Essential Pain Management course. This is a more sophisticated approach than most ‘training of trainers’. Yet, any ‘training of trainers’ must be accompanied by some mechanism to ensure that trainers have the space, resources, ability, support and time to go on to teach others.

Blended approaches that integrate some formal training with ongoing coaching and mentoring, such as the International Pain Fellowship, and the Flinders University Graduate Certificate in Palliative Care, are existing programs that could be used. Donors or regional agencies could explore the potential to adapt and provide these in the Pacific.

In terms of community training, the Nurse Maude (Christchurch) family training package to be implemented in Fiji, may offer a useful approach that could be contextualised and

implemented in other PICTs. The work that the Samoa Cancer Foundation already do can also offer useful insights into what training families need. (See Appendix 2.)

8.5 Growing and nurturing networks, knowledge sharing, learning and support

There are significant opportunities for building a more formalised regional network for palliative care. There are enough similarities across PICTs, and developing countries in general, for benefit from knowledge-sharing, learning and support. Working in palliative care is challenging. Those who do it have a passion for it. While it can be satisfying and uplifting, there is great potential for burn-out. This is exacerbated when local champions are often working to advance improved care in multiple areas, in resource-scarce environments. Training will assist in preventing burnout¹⁴. But greater networking, knowledge-sharing and opportunities to debrief with colleagues will also contribute to sustaining local champions. A formalised network could become a hub for action across the region. This hub could provide a central contact point to share and store information, resources and learning, support the network, and coordinate regional training, mentoring and coaching activities. The point of this hub should not be to control or manage all activities across the region, but to provide a supportive coordination point.

8.6 Research

There is a real need for more research to build understanding and develop effective, efficient and evidence-based interventions. Given the needs for palliative care, the best focus for research at this point is to improve access to quality palliative care. Key priority areas that would make a significant contribution to expanding palliative care across PICTs are listed below.

- The situation regarding morphine, and other opioids, requires in-depth investigation. This should include: the cost (and ways to reduce cost, if high); the legal, regulatory and policy environment; attitudes and beliefs about morphine amongst health professionals and the community; prescription and administration practices; and morphine's availability in practice, from the hospital

¹⁴ In Australia, 80 per cent of health professionals with burnout believed they did not have the opportunity to train to develop appropriate skills (Palliative Care Expert Group 2010, p. 17).

to the home. This research could explore options for how to improve home access to morphine, (while also balancing the needs to prevent misuse). It may also be useful to consider, including alongside access to morphine, an examination of other Essential Package medicines and/or equipment.

- Given the extent to which palliative care is provided at home, research with families and villages is essential. This will assist in understanding how they manage and what support they would prioritise from the formal health system and from the broader community. This research can inform expanded efforts to provide appropriate support to families and communities.
- Related to this, it would be useful to consider development of a Pacific (or Polynesian/Micronesian/Melanesian) Palliative Outcome Scale. This research could be modelled on the approach taken in Africa, using literature reviews, surveys and consultation to develop a tool that patients and families can use to assess their problems, and staff can use to provide tailored and appropriate care. The African Palliative Outcome Scale offers a potential starting point. An outcome scale could significantly improve care, through facilitating patient input and giving regular feedback to staff for ongoing quality improvement.
- The costs of providing palliative care require further investigation, starting at country level to build an assessment across the region. The Essential Package should be used as a baseline for this assessment. This will necessarily also involve assessing how many people require palliative care.
- Finally, there are specific opportunities for research and development – innovation – to develop new products. In particular, there are few low-cost options available for adult incontinence pads (Knaul et al. 2017), but great potential “for design innovations that could reduce price, improve quality, and be environmentally friendly” (Knaul et al. 2017, p. 28). Similarly, research and development of portable, affordable pressure-relieving mattresses would also be useful, and patients and families may identify other products they would benefit from.

8.7 Conclusion

This initial research contributes to a growing conversation about palliative care across the Pacific region. Health professionals and policymakers see the need for palliative care,

but often do not have the resources (including time) to take the action they see necessary. Community organisations, such as in Fiji and Samoa, are providing useful support to families, and inspiring others to act. But it is families who are providing the vast bulk of palliative care in PICTs. This is not an easy task. There is work underway to improve palliative care in PICTs, and collegial networks and key organisations exist. Local champions, whether individuals or organisations, with support from peers in other countries, are the ones who will drive forward improved access to palliative care. Yet, donors and regional agencies have the opportunity to recognise and build on these existing strengths, through providing funding, leadership, coaching, training, networking, and research. Donors and regional agencies can help to support people to fully live life in comfort, with their loved ones, right until the moment they die, rather than enduring the extreme suffering that makes them wish death would come quickly.

Appendix 1: List of interviewees

There were seven interviewees who did not want to have their names listed here: five researchers, one program manager and one clinician. The WHO, Fiji Cancer Society and DFAT provided information via email. Others interviewed include:

- Ian Anderson, Independent Health Consultant, Research Associate, Development Policy Centre
- Shelley Burich, Chief Executive Officer, Samoa Cancer Foundation
- Rob Condon, Pacific Regional Health Specialist
- Ann Davis, General Practitioner and Palliative Care Specialist, New Zealand
- Alice Every, Palliative Care Nurse, AVI, Samoa Cancer Foundation
- Jane Greville, Palliative Care Specialist, New Zealand
- Linda Huggins, Palliative Care Specialist, Counties Health Manukau District Health Board, New Zealand
- Salina Iupati, Palliative Care Specialist, Te Omanga Hospice, New Zealand
- Susan Ivatts, Senior Health Specialist, Health, Nutrition and Population, World Bank
- Kees Lodder, Palliative Care Specialist, New Zealand
- Amanda Landers, Palliative Care Specialist, Nurse Maude, New Zealand
- Jane Skeen, Paediatric Oncologist, Starship Hospital, New Zealand
- Odette Spryut, Palliative Care Specialist, PeterMac Cancer Centre, Melbourne, Australia
- Sumi Subramaniam, Health Advisor, Ministry of Foreign Affairs and Trade, New Zealand.

As stated in the section on research design, there were few country-level interviewees. This was a deliberate approach, based on the view that country-specific case analyses are the most appropriate time to engage with people working at the country level.

Appendix 2: Country snapshots

Cook Islands

Recently, the Cook Islands drafted a palliative care model of care, with support from Dr. Linda Huggins (Huggins 2018a). They also plan to develop a local team, a palliative care patient register, an end-of-life pathway and a 'Do not resuscitate' protocol, symptom control guidelines, and various other protocols (Huggins 2018b). This work has emerged from the drive of local champions, and Dr Huggins' long association with colleagues in the Cook Islands. Dr. Huggins first delivered Essential Pain Management training in 2011, and follow-up trainings alongside palliative care support have been provided in 2012, 2013, and 2016 (Huggins 2018a). Some Cook Island staff had a short attachment with the Middlemore Hospital and Mercy Hospice in 2012, and three New Zealand palliative care nurses visited the Cook Islands subsequently to provide training (including the provision and use of syringe drivers) (Huggins 2018a). Dr. Huggins has also provided support via videoconference, and regularly offers advice on request. Analysis on the availability of adult palliative care medicines shows that several key medicines are unavailable and/or not available in useful formulations (Greville 2016, p. 14).

Fiji

There has been past work to establish overarching policy settings for palliative care in Fiji. In 2016, with funding from the International Atomic Energy Agency, New Zealand and Australian-based doctors and one nurse provided a week-long series of workshops on palliative care in Suva. Approximately 60 people attended from across a wide range of stakeholders. Work during the week included drafting a mission statement, values, and a potential model of care. A steering group was tentatively developed to take this work forward, but this does not appear to have progressed. The desire remains to create palliative care policies and guidelines, and one internal physician who has had one year's oncology training is a key champion for palliative care.

There are several organisations in Fiji that provide some support for people with life-threatening or limiting conditions, including the Kidney Foundation of Fiji, and Fiji Cancer Society. WOWS – Walk On Walk Strong/Tai Kami Foundation – is a specialist NGO for children with cancer and other life-threatening conditions. They provide support,

education and awareness, and assist with treatment in Fiji and overseas. The Colonial War Memorial (CWM) Hospital has several practitioners who provide an acute pain service, as well as providing chemotherapy.

The Fijian Cancer Society works closely with the team at the Oncology Unit at the Ministry of Health and Medical Services. The Ministry recently appointed a palliative care nurse in the Central Division on Viti Levu. The Fijian Cancer Society provides a car and driver to support this nurse to conduct home visits. This nurse can administer morphine in the home, as well as provide other care, such as wound care and changing of indwelling urinary catheters. The Fijian Cancer Society also supports patients and families through the provision of supplies, such as incontinence pads and dressings, and oxygen, in some areas. Outside of Central Division there is no facility for home-visitation for palliative care beyond the existing hospital and community services.

In January 2019, the Fijian Cancer Society plans to run a ‘train the trainers’ workshop on palliative care in the community, with support from a palliative team from Nurse Maude Hospice, based in Christchurch, New Zealand. This workshop will adapt a very successful program from New Zealand, which teaches family members and non-health professionals about how to provide basic palliative care in the home. The Fijian Cancer Society is also creating a palliative care booklet, utilising a Nurse Maude resource, which should be finalised by January 2019 for use in the training and subsequent provision of palliative care in the community.

Essential Pain Management has been taught regularly since 2011 (approximately annually), in Suva, Lautoka and Labasa. Instructors have come from New Zealand and Australia (Huggins 2018a). Often palliative care training has also been provided alongside the Essential Pain Management training.

‘Friends of Fiji Health’ is a New Zealand group of health professionals with connections with Fiji. They aim to provide training and support to improve health services in Fiji (Friends of Fiji Health 2013). They have received requests for more education in palliative care and pain management. They visited Lautoka, Suva and Labasa in September 2017 (Huggins 2018a), and returned in June 2018 (Huggins 2018b).

Kiribati

A palliative care workshop was conducted in July 2018, supported by Counties Manukau Health Pacific Health Development (Huggins 2018a). Essential Pain Management was taught in Kiribati in 2014 and 2016, and they recently received a follow-up training course, including in palliative care.

Papua New Guinea

Recently, Sister Tarcisia Hunhoff, a member of the Missionary Sisters, Servants of the Holy Spirit obtained government support and DFAT funding (AU \$3.5 million) to build a hospice in Port Moresby (Pettus 2017). It is called 'The Supportive Living Project'. Essential Pain Management was taught in Papua New Guinea in 2010, 2011, 2012, and 2014.

Republic of the Marshall Islands

Although cancer is the second leading cause of death in the Marshall Islands, there are no palliative care services and patients tend to present late (Fernandes et al. 2014, p. 275). A small project, training volunteers in Ebeye to support women, led to a 200 per cent increase in screening in one year, with the conclusion that trained navigators would offer benefits to people requiring access to palliative services (Fernandes 2014, p. 276). In response, a culturally appropriate palliative care navigation curriculum was developed and piloted.¹⁵ From this, a navigator program was to be implemented.

Samoa

Palliative care is recognised as an important need in Samoa, and there is a good deal of action underway to improve palliative care. The 2018-2022 Ministry of Health Plan includes an objective to provide palliative services in the hospital. Currently, there are a variety of services that provide some basic aspects of palliative care but there is no central coordinating point. Samoa benefits from the Samoa Cancer Society's concerted leadership. The Society has expanded from providing an advocacy service, to providing

¹⁵ Patient navigators provide individualised services to people experiencing cancer, and have been shown to improve screening, follow-up and treatment (Fernandes et al. 2014, p. 276).

home visits to people who require palliative care at home, help to facilitate access to medical services when needed, and navigation of these services. Through this work, the Society saw how challenging it was for people at home trying to manage various health issues while living with cancer. There was nothing available for them. The importance of palliative care evolved from this recognition of the need for support, and the Society began to focus on making palliative care a priority for the health sector. Currently there is an Australian Volunteers for International Development palliative nurse specialist working with the Society.

In May 2018, the Society hosted a two-day Palliative Care forum to stimulate a national discussion about palliative care. This forum was inclusive: participants included nurses, traditional healers, the National Kidney Foundation, medical practitioners, Ministry of Health personnel, and a small number of selected international participants. The Prime Minister attended parts of the Forum and expressed his support, as did the Minister of Health. The main decision emerging from the Forum was agreement to create National Palliative Care guidelines. These guidelines will be approved by Cabinet, and from them a policy will be developed. The Samoa Cancer Society will facilitate and coordinate the working group to devise the draft guidelines.

Overseas medical practitioners have visited Samoa since 2011, conducting training on palliative care and Essential Pain Management (Huggins 2018a) with interested individuals and community nurses. Two New Zealand palliative care specialists ran a five-day palliative care workshop in 2011, and returned in 2013. New Zealand doctors ran three Essential Pain Management courses in 2013, 2014 and 2015, for medical students. Through the Pacific Working Group of the New Zealand National Network on Child Cancer, Starship Hospital has supported paediatric oncology in Samoa for many years. Other New Zealand clinicians continue to provide ongoing support. An analysis of essential adult palliative care medicine availability shows reasonable availability, although at times not in useful formulations (Greville 2016, p. 11). There are some staff in the National Health Service (NHS) who have expressed an interest in developing palliative care further, and it is hoped they will work alongside the Samoa Cancer Society to make improvements for the National Health Service.

Tonga

Tonga has recently decided to develop its palliative care services, and Dr. Linda Huggins visited Tonga in May 2018 for a scoping trip and palliative care training (including Essential Pain Management, or EPM) (Huggins 2018b), with a colleague from Christchurch Hospital. EPM training was also run in Tonga in 2012, 2013 and 2015. Tongan Ministry of Health officials and clinicians have requested ongoing support and advice through the Counties Manukau District Health Board Pacific Health Development program, including for the development of palliative care policies and guidelines (Huggins 2018b). The availability of essential medicines for adult palliative care has been analysed in Tonga, showing patchy availability (Greville 2016, p. 10). Areas of particular interest for the Ministry of Health include end-stage kidney disease, community care, and paediatric palliative care (Huggins 2018b).

Vanuatu

The Butterfly Trust has been established in Vanuatu to support expanded palliative care work, and they have canvassed various stakeholders to ascertain their views on palliative care (Butterfly Trust 2017). A more detailed needs assessment and implementation plan have also been conducted. Three New Zealand medical practitioners have been working in Vanuatu, two for several years, predominantly with communities on Epi. They have recently expanded their efforts in palliative care, in liaison with the Butterfly Trust. They have provided some palliative care training in Port Villa and on Epi. The communities on Epi that they have worked in, including health professionals, are very engaged and keen to learn more. Clinicians in Vanuatu received Essential Pain Management training in 2012, over two separate trips (Huggins 2018a).

Appendix 3: The palliative care Essential Package

In response to the global need for palliative care, the Lancet Commission identified a low-cost palliative care Essential Package that, if implemented, will alleviate much of the serious health-related suffering burden (Knaul et al. 2017, p. 4). The Essential Package is the minimum package that a health system should make available to all, and is one of the lowest cost components of the essential Universal Health Coverage (UHC) package (Knaul et al. 2017). Alongside this palliative care Essential Package, social supports to alleviate spiritual, social and financial suffering also need to be implemented, including particular attention to the needs of families caring for a loved one (Knaul et al. 2017, p. 4).

Outlined in Table 2 below, the palliative care Essential Package can be safely prescribed and administered in primary care settings, and is based on WHO's essential medicines list.

Table 2: The Essential Package for palliative care

<p>Medicines</p> <ul style="list-style-type: none"> • Amitriptyline • Bisacodyl (Senna) • Dexamethasone • Diazepam • Diphenhydramine (chlorpheniramine, cyclizine or dimenhydrinate) • Fluconazole • Fluoxetine or other SSRI (sertraline and citalopram) • Frusemide • Hyoscine butylbromide • Haloperidol • Ibuprofen (naproxen, diclofenac, or meloxicam) • Lactulose (sorbitol or polyethylene glycol) • Loperamide • Metaclopramide • Metronidazole • Morphine (oral immediate release and injectable) • Naloxone parenteral 	<p>Medical equipment</p> <ul style="list-style-type: none"> • Pressure-reducing mattress • Nasogastric drainage or feeding tube • Urinary catheters • Opioid lock box • Flashlight with rechargeable batteries (if no electricity) • Adult diapers (or cotton and plastic) • Oxygen. <p>Human resources (varies by referral, provincial or district hospital, community health centre, or home). The Essential Package uses a staffing model based on competencies, not professions.</p> <ul style="list-style-type: none"> • Doctors (specialty and general, depending on level of care) • Nurses (specialty and general) • Social workers and counsellors • Psychiatrist, psychologist, or counsellor (depending on level of care) • Physical therapist
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<ul style="list-style-type: none"> • Omeprazole • Ondansetron • Paracetamol • Petroleum jelly 	<ul style="list-style-type: none"> • Pharmacist • Community health workers • Clinical support staff (diagnostic imaging, laboratory technician, nutritionist) • Non-clinical support staff (administration, cleaning). <p>(Knaul et al. 2017, p. 4)</p>
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While this Essential Package is low-cost by design, it will require additional investments in health expenditure (Knaul et al. 2017, p. 3). Across developing countries, the Essential Package is estimated to cost between US \$2.16 per capita per year in low-income countries (two to three per cent of the cost of the UHC Essential Package), and US \$0.78 per capita per year (0.6 percent of the UHC) in lower-middle income countries (Knaul et al. 2017, p. 3). Yet, there are also cost-savings to introducing the Essential Package, as “palliative care can reduce hospital overcrowding and costs for overburdened health systems and provide financial risk protection for patients and families” (Knaul et al. 2017, p. 42). Using the diagonal approach could also contribute to greater efficiency across the health budget.

Currently, medicine costs vary significantly across countries, particularly for injectable morphine. “[F]or example, the overall medicine cost of the Essential Package in Rwanda, using reported country prices, is nearly three times that using lowest reported international prices, whereas for injectable morphine, the difference in price is almost six fold” (Knaul et al. 2017, p. 3). Further work is required to make sure that all countries can purchase at the best international prices, and this would decrease the cost of the Essential Package, potentially up to about 25 per cent in some countries (Knaul et al. 2017, p. 3).

Appendix 4: Assessment against health system functions (Knaul et al. 2017)

Stewardship

- *Priority setting*
 - Implement public education and awareness-building campaigns on palliative care and pain relief (PCPR).
 - Incorporate PCPR into the national health agenda.
- *Planning*
 - Develop comprehensive PCPR guidelines, programs, and plans
 - Integrate palliative care into disease-specific national guidelines, programs and plans.
 - Include PCPR essential medicines in national essential medicines list.
- *Regulation*
 - Establish effective legal and regulatory guidelines for the safe management of opioid analgesics and other controlled medicines that do not generate unduly restrictive barriers for patients.
 - Design integrated guidelines for provision of PCPR that encompass all service providers.
- *Monitoring and evaluation of performance*
 - Monitor and evaluate PCPR interventions and programs using an explicit outcomes scale, measuring coverage as well as effect.
 - Promote civil society involvement in performance assessment.
- *Inter-sectoral advocacy*
 - Engage all relevant actors in the promotion and implementation of palliative care interventions through ministries of health.

Financing

- Explicitly include PCPR interventions in national insurance and social security health-care packages.
- Guarantee public or publicly-mandated funding through sufficient and specific budgetary allocations, starting with the Essential Package.
- Develop pooled purchasing schemes to ensure affordable, competitive prices for palliative care inputs and interventions.

Delivery

- Integrate PCPR at all levels of care and in disease-specific programs.
- Design guidelines to provide effective and responsive PCPR services.
- Integrate pain relief into platforms of care, especially surgery.
- Establish efficient and effective referral systems.
- Implement quality-improvement measures in palliative care initiatives.
- Develop and implement secure opioid supply chain and ensure adequate prescription practices.

Resource generation

- *Human resources*
 - Establish palliative care as a recognised medical and nursing speciality.
 - Make general PCPR competencies a mandatory component of all medicine, nursing, psychology, social work, and pharmacy undergraduate curricula.
 - Require that all health and other professionals involved in caring for patients with serious, complex, life-threatening health conditions receive basic training in PCPR.

Information and research

- Incorporate PCPR access, quality, and financing indicators into health information systems.
- Ensure that government-funded research programs include palliative care.

Appendix 5: Global lessons in expanding palliative care

The Lancet Commission report (Knaul et al. 2017) draws lessons from across the world that will assist in providing a comprehensive palliative care response to serious health-related suffering. These are listed below, arranged according to health-system functions.

“Stewardship

1. A legislative and normative framework is essential to guarantee the integration of palliative care and pain relief into health systems.
2. Public awareness of and support for palliative care that can drive systemic policies and integration into universal health coverage usually derive from professional groups and non-governmental organisations (NGOs), often in association with international and regional civil society organisations. Government institutions tend to be late adopters of palliative care initiatives.
3. Feedback between global and national policy making and evidence can drive policy change.
4. Monitoring and evaluation of palliative care interventions, programs, or policies is uncommon, yet essential for effective scale-up.

Financing

5. System-wide integration of palliative care is facilitated by the existence of a national universal health coverage platform and integration into the package of covered services.

Delivery

6. The initial adoption of palliative care interventions by governments is usually associated with cancer or HIV disease. Expansion of access to palliative care and pain relief to other health conditions and for children has been slow and is associated with a leap from a disease-specific model to a systemic approach.
7. Community involvement in the provision of palliative care is crucial given the limited capacity of health systems in LMICs [low- and middle-income countries] and the important role of home-based care.
8. Strong small-scale or state-wide programs can be a fulcrum for developing a national palliative care model and achieving systemic integration – especially in delivery.

Resource generation

9. Training and capacity building for primary care providers, complemented by specialised medical education and certification, is essential in the expansion of access to palliative care.
10. Health systems research and lessons learned from country experiences need to be published and disseminated.” (Knaul et al. 2017, pp. 38-39).

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