

**A MINISTRY FOR PALLIATIVE CARE PATIENTS
(PCPs) AND THEIR FAMILIES IN THE CONTEXT OF
THE CONGREGATIONAL CHRISTIAN CHURCH
SAMOA (CCCS)**

A Thesis Presented to the
Faculty of
Malua Theological College
Samoa

In Partial Fulfilment of the
Requirements for the Degree
Bachelor of Divinity with Honours

Lancealotte Alaimoana

November 2021

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ABSTRACT

Palliative care improves the quality of life of patients and their families facing a life limiting illness, through the relief of suffering from pain and other associated problems physically, psychologically, socially, and spiritually, making it possible for people to die with dignity (Temel et al, 2010).¹ This thesis describes a model of service delivery for Palliative Care within Samoa, and to explore how pastoral care is provided to support palliative care patients (PCPs) and their families. Such a service becomes part of the integrated palliative care service team, to comfort and support PCPs during the end of life stage they are faced with. The thesis will also explore how the Congregational Christian Church Samoa (CCCS) cares for PCPs at present, to ensure PCPs in Samoa receive the holistic care they need to improve their quality of life. The study conducted interviews using the Qualitative methodology to seek data from selected target groups of patients diagnosed with terminal illnesses, as well as their families. The study also collected completed questionnaires from the focus group of church ministers from the Sub-district of the CCCS that I belong to—Pulega West Brisbane, Queensland. The scope of this research originally aimed to obtain data from Pindara Private Hospital in Gold Coast, Queensland where I previously worked as a Registered Anaesthetic Nurse before entering Malua. Yet due to the Covid-19 lockdown that restricted travel between Samoa and Australia I needed to obtain data to inform my study elsewhere. I therefore used palliative care patients and their relatives in Samoa instead. Interestingly, the palliative care service guidelines proposed in Samoa, works collaboratively with models used in Western countries such as New Zealand and Australia. These include models that deliver optimum care

¹ Temel, J., Greer, J., Muzikansky, A., Gallagher, E., Admane, S., Jackson, V., Dahlin, C., Blinderman, C., Jacobsen, J., Pirl, W., Billings, J., & Lynch, T. (2010). *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*. New England Journal of Medicine, 363 (8), pp733-742.

physically, psychologically, socially, and spiritually, to support PCPs and their families. In Samoa at present, Palliative Care Services (PCS) uses a home-based care model; however, the focus of the Palliative Care Team (PCT) cares for the PCPs on their treatment and medical problems only. That leaves a gap to the holistic care of the PCPs because the spiritual aspect of the palliative care is not provided by the PCT. Findings depict that the ministers (faifeaus) have limited knowledge about the PCPs terminal illnesses and their medical diagnosis. Yet they are fully aware of the spiritual aid of these patients and as a Minister in the community or respective congregations, they feel responsible as part of their role is to provide pastoral care support for the PCPs. The ministers aimed to provide spiritual care by reflecting on the bible quotes and prayers, to comfort and give them hope of life, through faith to the Lord and His power of healing. The minister's regular visits and their words of encouragement helped uplift the PCPs spiritual escape and allowed them to accept the dying stage of life they faced.

So even though the spirituality perspective is currently not integrated in the PCS team, on implementing the palliative care to the PCPs. The ministers in the congregations provide the spiritual moral support to the PCPs and their families, helping them to appease their grief. The PCPs and their families appreciated the work done by the Ministers, acknowledging the good effects of their involvement in their journey. Every time the Minister, sometimes his Faletua (wife) is present, they bring peace and joyful moments to ease a bad day. The PCPs praise the service provided by the PCS team on their medical treatments as well as their respective ministers who healed their souls spiritually, gave them hope to cope with their sufferings and the shocking news of dying due to an incurable disease.

DEDICATION

This work is dedicated to my wife, Naomi Alaimoana and my four beautiful children, Geraldine Tapai-Marie Alaimoana, Damien Lima Alaimoana, Gardenia Lealofi-Melaina Alaimoana and Geraldaisy Sandra Alaimoana. Thank you very much for all the sacrifices you have all made allowing me to pursue my study and to complete this task. I understand with all the struggles we went through but you overcome those hurdles and put all the trust in me to serve our purpose here in Malua. Every little thing you have done, from cooking a delicious meal or offering a marvellous coffee, I do appreciate it and nothing goes unnoticed before the Lord. *Faafetai le lagolago ma le alolofa i le tou tamā.*

Not forgetting the *tapuaiga* and the support of my parents Pastor Misa Alaimoana and Siliana, Lealofi Faifua and Tapai Tanielu. Thank you so much for your support financially. My spiritual parents late Rev Dr Faafouina and Margret Tui Iofi, and my MTC *tamā-faaleagaga* Rev Dr Seumaninoa Puaina. You were my inspiration and my guardian to this journey. You may all rest in paradise.

To all the Palliative Care Patients in Samoa, this work is just the start of my dream to explore a suitable way spiritual care is integrated into the Palliative Care Service provided in Samoa. Special dedication goes to three (3) of my patient participants who were rest in peace during the time schedule for this research. Especially to our fellow MTC colleague, *Susuga ile Aoao ia Periti Tauapai*, words cannot express the feeling of sorrow and mourn to your loss. I personally escorted you to the hospital on 16th April 2020, when you were in severe abdominal pain without knowing that was our last time together in Malua. You did not come back since and yet our Heavenly Father called you on 18th May 2021. *Le Auauna lelei e male faamaoni, ulufale maia ile fiafia o lou Alii.* You may rest in love and peace brother.

ACKNOWLEDGEMENTS

First and foremost I want to give all Glory, Honour and Praise to God the Creator, the Sustainer and the Provider of life and love, who through tender loving care and guidance, had made the undertaking, the struggles and the completion of this thesis all possible.

A big *faafetai and faamalo* to my supervisor, Rev Dr Alesana Pala'amo for his comprehensive support and guidance enabled me to complete this paper. Thank you for all your patience, encouragement, dedication and love that you have poured out to me. I appreciate all the energy, hard work and your precious time spent mentoring me on this work and the critical conversations that have inspired me to continue to stretch my perspectives beyond my own insecurities and fears. Not forgetting the help from Rev Filemoni Crawley and Rev Kara Ipinui, Department of Practical Theology for their educational support and ideas that motivates me throughout this thesis.

A special *faafetai* to Rev Elder Lance Tautiepa and the entire ordained ministers of my *Pulega Purisipeni i Sisifo* Queensland, Australia who took the time to respond to my questionnaires, thank you so much. Thanks to Afioa Su'a John Ryan and Rn Fuamatala Tofilua of Samoa Cancer Society, who helped me conducting the interviews, especially the questionnaires to PCPs, *faafetai tele lava*.

To my spiritual parents, Rev. Petaia and Sarai Tuifao, Rev. Ruperake and Mary Petaia as well as Rev. Maluelue Lima and Melaina Pone, *faafetai tele* for your endless prayers and moral support. Special *faafetai* to Tinā Filemū Tauialo *mo lau tapuaiga ma tatalo mo ma'ua ma le fanau ao aumau ai i Malua*. May God bless you all, and may God continue to bless Malua Theological College.

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LIST OF ABBREVIATIONS

CARC	Cancer Awareness Ribbon Colours
CCCS	Congregational Christian Church of Samoa
CEO	Chief Executive Officer
Dr	Doctorate (usually refer to as Doctor)
GC	Gold Coast
MOH	Ministry of Health (in Samoa)
MTC	Malua Theological College
NRSV	New Revised Standard Version Bible
PCPs	Palliative Care Patients
PCS	Palliative Care Service
PCT	Palliative Care Team
PPH	Pindara Private Hospital
QLD	Queensland
Rev	Reverend
Rn	Registered Nurse
RSLP	Religion, Spirituality, Life support, and Philosophy
SCS	Samoa Cancer Society
WBD	West Brisbane Sub-District (Pulega Purisipeni Sisifo)
WHO	World Health Organisation

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CHAPTER ONE

INTRODUCTION

1.1 An Introduction

Palliative care can be defined as specialised care and support provided for people living with a terminal illness, where medical professionals have exhausted all possible interventions to restore health.² PCPs are thus diagnosed with nothing more medically that can be done for their conditions, as they await the inevitable end of life stage. This type of care focuses upon providing relief from pain, discomfort, and stresses of the terminal illness at this end of life stage, and often is implemented by medical practitioners such as nurses and doctors. The goal here is no longer to bring life and restore health, but more so, to improve the quality of life and to be as comfortable as possible for both the palliative care patient and their families, as they await inevitable death.³

In my past profession as a Registered Nurse in Samoa and Australia working within our CCCS communities, I have observed Palliative Care Patients (“PCPs”) when discharged from the hospital with the diagnosis that there is no further treatment available — *‘ua lē toe aogā i ai se togafitiga’*,—both the patient and the family are saddened and feel hopeless. In such situations, PCPs and their families have difficulties accepting the end of life stage. Yet, the suffering palliative care patient and family carers still have faith in God believing that our Lord will heal the sick. However, when the inevitable death occurs as originally and correctly diagnosed by the medical professionals, often the families of PCPs question the supremacy of

² Twycross, Robert. *Introducing Palliative Care*. (Radcliffe Publishing, British. 2003). 9 –19.

³ Lawton, Julia. *The Dying Process: Patients' Experiences of Palliative Care*. (Psychology Press, 2000). 81-122

God for not healing and restoring the life of their loved one. PCPs and their families commonly experience denial that the patient has become terminally ill, and has begun the end of life stage. Often at this end of life stage, the PCP's church minister frequently visits them during this period.

This issue has interested me through my biblical and theological studies here at Malua, which has become the drive to research this important topic and propose some practical and pastoral insights to understand palliative care support in the CCCS at present. I believe that pastoral care support assists patients at the very end of their lives, that despite all their ailments and agonies, they are still children of God created in the image and the likeness of God. PCPs are precious, although they suffer from old age or a terminal illness. Findings from this work may motivate and inform church ministers how to provide effective spiritual support and pastoral care support to PCPs, as an opportunity to manifest God's unfailing love for the terminally ill and the dying.

1.2 Aim of the Study

The aim of this study is to discover effective ways to provide pastoral care support for palliative care patients and their families, to comfort and support PCPs during the end of life stage they are faced with. Furthermore, this study also aims to explore how the CCCS cares for PCPs at present.

1.3 Research Question

The research question that drives this study is as follows: What is the Role of the CCCS regarding palliative care patients (PCPs) and how can the church meet the needs of PCPs and their families?

1.4 Methodology

The study will be conducted using the Qualitative methodology to answer my above-mentioned research question. This qualitative methodology includes a focus group of PCPs who have been diagnosed by medical professionals as being at the end of life stage from their terminal illness. The study will also include a focus group of family members who either care for PCPs, or have experienced the loss of a loved one due to a terminal illness. Furthermore, interviews and questionnaires will seek data from a selected group of church ministers from the Sub-district of the CCCS that I belong to—Pulega West Brisbane, Queensland. All the data collected were analysed and findings discussed, to stimulate proposed action about how to best support PCPs and their families in the CCCS ministry today.

CHAPTER TWO

LITERATURE REVIEW

2.1 Defining Palliative Care

Palliative care is the active total care of patients with life-limiting disease, and their families, by a multi-professional team, when the disease is no longer responsive to curative or life-prolonging treatments. 'Palliative' is derived from the Latin word *pallium*, meaning 'a cloak'. In palliative care, symptoms are 'cloaked' with treatments that have its primary aim to promote comfort. However, palliative care extends far beyond physical symptom relief; it seeks to integrate physical, psychological, social, and spiritual aspects of care so that patients may come to terms with their impending and inevitable death as fully and constructively as they can. Palliative care therefore includes the following:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients' illness and in their own bereavement;
- 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; and,
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those

investigations needed to better understand and manage distressing clinical complications (World Health Organisation, 2018).

2.2 The Effective Palliative Care Model

A highly used model of Palliative care by medical practitioners and professional carers of terminally ill patients is *The Effective Palliative Care Model* as displayed in Figure 1:

Figure 1 Effective Palliative Care Model – TEAM⁴



The different components of the **Effective Palliative Care Model – TEAM** can be explained as given below:

⁴ Robinson, Jackie, Merryn Gott, Clare Gardiner, and Christine Ingleton. "The 'Problematisation' of Palliative Care in Hospital: An Exploratory Review of International Palliative Care Policy in Five Countries." *BMC palliative care* 15, no. 1 (2016): 1-8.

(i) **Physicians:** these are the professionals who focus upon the illness prognosis, and medical treatments, making patient visits or providing supervision in collaboration with advanced practice registered nurses or physician assistants.

(ii) **Advanced Practice Providers:** also known as physician assistants and advanced practice registered nurses, who expand the capacity to deliver complex care and provide direct care.

(iii) **Spiritual Care:** these are spiritual care specialists who assess and address spiritual issues and help to facilitate continuity with the patient's faith community as requested. These professional care workers may include church ministers and their wives, pastors, chaplains, and the clergy.

(iv) **Social Work:** these are professional care workers who attend to the family dynamics, assess, and support coping mechanisms and social determinants of health, identify and facilitate access to resources, and mediate conflicts.

All of the four components of the *Effective Palliative Care Model-TEAM* surround and oversee the holistic care for the Patient (PCP) and the Family (of the PCP) at the end of life stage they have begun. **TEAM-work**, as its root acronym 'TEAM' can be explained as 'Together Everyone Achieves More.' Robert Twycross,⁵ his model as given here believed that to deliver an effective care to palliative care patients, is best administered by a group of people working together as a team. As noticed in this model, the team consists of physicians, advanced practice providers, social workers and spiritual care professionals. They all work collectively and collaboratively concerned with the total wellbeing of the patient and their family.

⁵ Twycross, Robert G. *Introducing Palliative Care*. (Radcliffe Publishing, 2003).11-20

2.3 A Review of Literature

There is a vast array of literature available about palliative care from different regions around the world. For this review I have focused largely upon literatures that include the Pacific region, leading towards a review of literature that covers palliative care in Samoa. From such a review I can begin to develop a foundation to propose a pastoral approach to support PCPs and their families from a CCCS perspective.

In a study by Robinson⁶ about palliative care, the focus is largely upon Government policies concerning palliative care of five major countries: Switzerland, England, Singapore, Australia and Ireland. These policies are fundamental in initiating change to improve the provision of palliative care at a national level. The World Health Organisation's recognition of palliative care as a basic human right has seen many countries worldwide develop national policy in palliative and end of life care. There is increasing debate about what form comprehensive palliative care services should take, particularly in relation to the balance between acute and community based services. It is therefore timely to review how national policy positions the current and future role of the acute hospital in palliative care provision.

The aim of the exploratory review was to identify the role envisaged for the acute hospital in palliative and end of life care provision in five countries with an 'advanced' level of integration. Countries were identified using the Global Atlas of Palliative Care. Policies were accessed through internet searching of government websites between October and December 2014. Using a process of thematic analysis key themes related to palliative care in hospitals was identified. Policies from Switzerland, England, Singapore, Australia and Ireland were

⁶ Robinson, Jackie, Merryn Gott, Clare Gardiner, and Christine Ingleton. "The 'Problematisation' of Palliative Care in Hospital: An Exploratory Review of International Palliative Care Policy in Five Countries." *BMC palliative care* 15, no. 1 (2016): 1-8.

analysed for recurring themes. Three themes were identified: preferences for place of care and place of death outside the hospital setting, unnecessary or avoidable hospital admissions, and quality of care in hospital. No policy focused upon exploring how palliative care could be improved in the hospital setting or indeed what role the hospital may have in the provision of palliative care. Palliative care policy in five countries with ‘advanced’ levels of palliative care integration focuses on solving the ‘problems’ associated with hospitals as places of palliative care and death. No positive role for hospitals in palliative care provision is envisaged. Given the rapidly increasing population of people requiring palliative care, and emerging evidence that patients themselves report benefits of hospital admissions, this area requires further investigation. In particular, a co-design approach to policy development is needed to ensure that services match the needs and wants of patients and families. The updates in researching the area of palliative care in the leading countries shows us a glimpse here in Samoa of how important palliative care is as an issue that affects families if left uncared for or without any pastoral guidance.

Lawton’s⁷ book aims to substantially revise concepts of the ‘Western’ self through an analysis of empirical research on the experiences of dying patients receiving palliative care in contemporary England. There is now a proliferation of sociological and cultural studies on the ‘Western’ self and its relationship to the body, yet few of these explore the process by which people negotiate and understand themselves in practice in their daily lives, let alone during traumatic moments such as the period of decline and deterioration leading towards death. Through closely detailed ethnographic research, this study both contextualises these intellectual debates and challenges some of their underlying presuppositions. In particular, it focuses on concepts of the person, and the importance of certain physical capacities and

⁷ Lawton, Julia. *The Dying Process: Patients' Experiences of Palliative Care*. Psychology Press, 2000. 81- 122

boundaries for the maintenance of the ‘Western’ self. As the research described in this book reveals, many characteristics central to the ‘Western’ self only become visible after they have been lost, as it were. It is for this reason that a study of dying patients has a unique and important contribution to make to these debates. Whilst particular attention is focused upon the ways in which patients’ experiences of self, body, space and time shift and change during the period between receiving a diagnosis of terminal disease and their eventual bed-ridden rarely analysed, is the question of the ‘intersubjectivity’ and ‘intercorporeality’ of the process of dying. This book has a western perspective which, unlike my thesis topic, is different and foreign to a Samoan context,

Twycross⁸ introduces in his book, a highly successful and well-established key introductory text for palliative care has been in use for so many years now. It has been fully revised and updated throughout with greatly expanded sections on ethics and communication and other aspects of psychological care. *Introducing Palliative Care* was developed from the author’s training programme now used in many countries around the world; this new edition is an essential introduction for all professionals working within palliative care. This book is important as it shows the psychological approach to palliative care, further adding more dimension to my thesis topic.

Lynch’s⁹ study categorised palliative care development, country by country, throughout the world, showing changes over time. This paper attempts to adopt a multi-method approach. Development is categorized using a six-part typology: Group 1 (no known hospice-palliative care activity) and Group 2 (capacity-building activity) are the same as developed during a

⁸ Twycross, Robert G. *Introducing Palliative Care*. Radcliffe Publishing, (2003). 11-20

⁹ Lynch, Thomas, Stephen Connor, and David Clark. "Mapping Levels of Palliative Care Development: A Global Update." *Journal of pain and symptom management* 45 (2013): 1094-1106.

previous study (2006), but Groups 3 and 4 have been subdivided to produce two additional levels of categorization: 3a) Isolated palliative care provision, 3b) Generalized palliative care provision, 4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision, and 4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. Although more than half of the world's countries have a palliative care service, many countries still have no provision, and major increases are needed before palliative care is generally accessible worldwide. This paper attempts to introduce palliative care that is happening around the world and how much is provided for. This paper helps my thesis in that it shows the global scale in the importance of palliative care. Samoan palliative care would be useful to see how it compares with the rest of the world and what the CCCS can do to address it in their pastoral ministry.

Spratt¹⁰ 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 report 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. 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

¹⁰ Joanna Spratt., "*Palliative Care in the Pacific: Initial Research.*" (2019). 1- 49

for action. These suggestions include the need to: provide funding; foster leadership; support training, coaching and mentoring; nurture networks; and conduct further research. This current study proposes to develop a palliative care perspective that includes theological insights and understandings concerning the challenges for PCPs and their family. I aim to provide a theological perspective alongside my nursing background, to help explain the issue a lot easier, and propose insights towards an effective ministry concerning palliative care for Samoans at present.

Hayley¹¹ resides and works at Kokua Kalihi Valley, one of the first federally qualified (from the United States) community health centres offering home based palliative care (HBPC). Kokua Kalihi Valley serves low-income, immigrant populations from Asia and the Pacific Islands, whose end-of-life needs are rarely addressed. Their team includes a palliative medicine physician, nurse, case manager, psychologist, interpreter, and volunteers. The purpose of this study was to measure symptom relief and quality of life, resource utilization, and satisfaction with HBPC. Data on outcomes and quality indicators of HBPC programs are scant, especially among immigrant Asian and Pacific Islanders patients. Their organisation's experience demonstrates the effectiveness of palliative care approaches in this population. It addresses Samoans overseas which can give context as a Samoan in how the CCCS ministry should also be addressing their pastoral ministry in this area.

Kaopua¹² focuses on development of the psychosocial-cultural components of a breast cancer patient navigation program (PNP) in the Territory of American Samoa. Efforts to reduce

¹¹ Kim, Hayley. "Using a Right to Health Framework to Assess Cancer Services in Samoa." Research Space Auckland, 2018. 1 - 32

¹² Ka'opua, Lana SI, Jennifer F Tofaeono, Soono H Park, Luana MY Scanlan, Margaret E Ward, Victor W Tofaeono, and Salilo J Foifua. "Developing Tautai Lavea 'I, a Breast Cancer Patient Nativation Program in American Samoa." Journal of Indigenous Social Development 1, no. 2A (2010).

cancer mortality in American Samoa must necessarily consider the territory's limited cancer resources and indigenous culture, as well as the individuals at risk for poor health outcomes and premature death. Within this complex set of challenges resides the prospect of health equity and opportunities for advancing service innovations that meaningfully plait native ways of knowing with Western evidence based practice. Increasing adherence to diagnostic and treatment procedures is of significant concern to the American Samoa Cancer Community Network who initiated this inquiry to assess patients lost to follow-up, describe treatment-seeking influences, and identify cultural preferences for inclusion in a PNP tailored on *fa'aSamoa* or the Samoan worldview. Tailoring towards the Samoan context adds an important contribution to my research especially with cultural preferences, which have an awareness of cultural sensitivities that may differ to other cultures too.

Ian¹³ states that Samoa currently faces two important public policy challenges in the health sector. One is to stem, and then reverse, the rapid rise of non-communicable diseases (NCDs). The second challenge is to put the country on a health-financing path that is effective, efficient, and financially affordable and sustainable. The two challenges are interconnected. This discussion paper examines eight options to address these challenges. The eight options are the following: (1) increasing government expenditure via higher general taxation; (2) increasing government expenditure via deficit financing; (3) increasing the share of government expenditure to health; (4) increasing external and donor financing; (5) increasing specific taxes; (6) mobilizing additional non-government resources via insurance (including social health insurance, and community and private insurance); (7) increasing cost-recovery measures; and (8) increasing efficiency. The paper concludes that the chief opportunity arises from more efficient use of resources already in the health system that are not presently used to

¹³ Anderson, Ian. "*Health Financing Options for Samoa: Challenges and Opportunities*." (2013).

maximum effect. Improving technical and allocative efficiency of the existing system has the potential to make a large difference especially in the area of palliative care where funding is badly needed.

Every¹⁴ in her research believed the lack of access to palliative care is one of the largest global inequalities in health care - worldwide only 14% of people who need palliative care currently receive it with 78% of those going without living in low- and middle-income countries (WHO, 2018). For children the situation is worse with even less access to palliative care and a much higher risk than adults to face inadequate pain relief. In addition to this, demand is continuing to grow due to the increasing population of elderly who also have end of life needs. Although Samoa is working hard towards a robust tertiary medical service, it will take time for these measures to take effect, in the meantime there needs to be consideration into how to support patients with life-limiting illnesses and their families. I used this document to describe a model of service delivery for Palliative Care within Samoa. It sets out guidelines for the Palliative Care Service in how to provide care and support for patients, and their families, who have been diagnosed with a life limiting illness in the context of Samoa.

2.4 Palliative Care and Spirituality

The manner in how parents of children with life threatening conditions draw upon religion, spirituality, or life philosophy, as not empirically well described, is the focus of a study by Hexem.¹⁵ The participants of Hexem's study were the parents of children receiving paediatric palliative care. Most parents of children receiving palliative care felt that RSLP

¹⁴ Every, Alice. *National Palliative Care Guidelines* Ministry of Health (2018).

¹⁵ Hexem, Kari R, Cynthia J Mollen, Karen Carroll, Dexter A Lanctot, and Chris Feudtner. "How Parents of Children Receiving Pediatric Palliative Care Use Religion, Spirituality, or Life Philosophy in Tough Times." *Journal of palliative medicine* 14, no. 1 (2011): 39-44.

(religion, spirituality, life support and philosophy) was important in helping them deal with tough times, and most parents reported either participation in formal religious communities, or a sense of personal spirituality. A minority of parents, however, did not wish to discuss the topic at all. For those who described their RSLP, their beliefs and practices were associated with qualities of their overall outlook on life, questions of goodness and human capacity, or that “everything happens for a reason”. RSLP was also important in defining the child’s value and beliefs about the child’s afterlife. Prayer and reading the bible were important spiritual practices in this population, and parents felt that these practices influenced their perspectives on the medical circumstance and decision-making, and their locus of control. From religious participation and practices, parents felt they received support from both their spiritual communities and from God, peace and comfort, and moral guidance. Some parents, however, also reported questioning their faith, feelings of anger and blame towards God, and rejecting religious beliefs or communities. RSLP plays a diverse and important role in the lives of most, but not all, parents whose children are receiving paediatric palliative care.

McDowell¹⁶ stresses in his study the need to include the spiritual dimension when assessing clients and planning their healthcare is evident from numerous studies conducted by various disciplines. Practitioners of holistic care agree that spiritual care must be included to fully address the needs of clients. The aim of this qualitative research was to explore and document the stories of clients regarding the role healthcare professionals provide in spiritual care. A hermeneutical phenomenological approach was used to interview, document, and analyse the stories of 15 participants regarding their perceptions of spiritual care received or given during times of illness. Initially, only one participant mentioned the role of doctors and

¹⁶ McDowell, Liz, and Robbie Madden South. "Christians' Perceptions of Receiving Spiritual Care in the Bible Belt of the United States: A Qualitative Study of Care Provided in the Healthcare Setting." *Religions* 8 (2017): 127.

nurses in providing spiritual care. After specifically asking about spiritual care, half of the participants shared that they had received spiritual care. Prayer as a mode of spiritual care merged as a prominent theme. Lack of spiritual care received was documented. The hesitancy to provide spiritual care was evident in participants who were also healthcare providers. More research is needed to further define spiritual care. Education regarding spiritual assessments and spiritual care strategies is needed for both patients and healthcare providers. This paper helps shape how the CCCS should also approach the patients in their pastoral care. It may also draw upon this paper as a way of understanding what not to do with patients, especially in the Samoan context.

Kurt¹⁷ in their study predicts the input of community pastor into the care of palliative patients. Health care professionals view the psychosocial support of patients and families and the collaboration amongst the different care providers as the main deficiencies. In this context little is known about the viewpoints of community pastors who might have an important role in providing psychosocial and spiritual care for patients at home. In order to study their perspectives we performed 76 standardized telephone interviews with Protestant and Catholic pastors and examined how much contact pastors had with palliative care patients; their views of the collaboration with health care professionals; and how the pastors assessed their own skills in palliative care. Forty-one percent of respondents had no contact with any palliative care patients. The majority perceived collaboration with family doctors to be insufficient. The pastors assessed their own skills concerning palliative care predominantly as “satisfactory”. Findings suggest that community pastors’ participation in the delivery of palliative care in Germany might be encouraged by specialized training and intensified contact with health care

¹⁷ Kurt Buser, Volker E. Amelung & Nils Schneider (2008) *German Community Pastors' Contact with Palliative Care Patients and Collaboration with Health Care Professionals*, *Journal of Social Work in End-Of-Life & Palliative Care*, 4:2, 85-100.

professionals. This study emphasizes how the community pastors participate in the delivery of palliative care and I think would be a good issue to look into on providing pastoral care for PCPs in Samoa.

Elizabeth Kubler-Ross¹⁸ was known for her theory of the stages of death and dying. She recognized five different stages known as denial, anger, bargaining, depression, and acceptance. The denial stage is generally when a patient is in a state of shock after hearing bad news. “Denial and shock help us to cope and make survival possible. Denial helps us to pace our feelings of grief. In the anger stage one may feel different types of anger. Some get angry toward the medical providers, some are angry and envious toward others, and many tend to be angry with God. The bargaining stage is exactly that. One will question different scenarios such as maybe if I were better or lived a better life, or even making countless promises in order to keep their loved one from dying. The depression stage is a stage of mourning. Many individuals lose interests once held before and could become more dependent on family. The acceptance stage is where one moves past the depressive stage toward accepting he or she is dying or the loss of his or her loved one. These five stages are stages one must go through when either the individual is dying or one is losing or has lost a loved one. Technically speaking this theory could help a wider variety of our society. People die on a daily basis. So whether you have lost a loved one to an illness or are facing death oneself then the five stages will help any individual come toward acceptance. This model helps me understand the feeling that the grief patients with terminally ill and their families went through once they received their shocking news about their disease.

¹⁸ Kubler-Ross, Elizabeth *The five stages of grief*. Retrieved from <http://grief.com/the-five-stages-of-grief> (14/06/21/)

Jayard¹⁹, in his book depicts that death is inevitable, but that does not mean it can be planned or imposed. It is an ethical imperative that we attend to the unbearable pain and suffering of patients with incurable and terminal illnesses. But this is where palliative care plays a vital role. Palliative care has been growing faster in the world of medicine since its emergence as a specialty in the last decade. Palliative care helps to reduce physical pain while affirming the aspect of human suffering and dying as a normal process. The goal of palliative care is to improve the quality of life of both the patient and the family. Palliative care resonates with the healing ministry of Christianity that affirms the sanctity and dignity of human life from the moment of conception to natural death. Christianity is convinced that patients at the very end of their lives, with all their ailments and agonies, are still people who have been created in the image and likeness of God. The human person is always precious, even when marked by age and sickness. This is one of the basic convictions that motivate Christians to take care of the sick and the dying. Palliative care is a great opportunity for Christians to manifest God's unfailing love for the terminally ill and the dying. This is one of the basic convictions that motivate Christians to take care of the sick and the dying. Palliative care is a great opportunity for Christians to manifest God's unfailing love for the terminally ill and the dying. It can relate to our Samoan context: when one member of the church is sick, the members of the congregation prayed for a speedy recovery. They also put them forward as one of the prayer subjects, to pray for God's healing power to heal the sickness and to comfort the carers.

2.5 Palliative Care Services in Samoa

The *Effective Palliative Care Model-TEAM* discussed at the beginning of this chapter may work effectively in Westernised contexts because all four teams as noted by the model

¹⁹ : Jayard SS, Irudayadason NA, Davis JC. *Healing ministry and palliative care in Christianity*. Indian J Med Ethics. 2017 Oct-Dec;2(4)NS:238-43. DOI: 10.20529/IJME.

work collectively alongside with each other, with the one goal of holistic wellbeing for the patient and their family. However, this collective approach to the care of PCPs most likely does not happen in the Samoan context, since spiritual care workers (*faiifeau* or ministers) are absent from such services; I have experienced and observed that ministers in Samoa are not included in the multi-professional team of carers for PCPs. However, ministers in Samoa undertake their own visitations and provide pastoral care for PCPs at their discretion, apart from being linked to any collective effort for the holistic wellbeing of PCPs and their family as suggested by the *Effective Palliative Care Model-TEAM* model. This largely becomes a purpose for this research, to propose ways how ministers in Samoa can participate in a collective effort for the holistic wellbeing of PCPs and their family, providing spiritual and emotional support to those who have been diagnosed by medical professionals as being at the end of their life stage.

According to the study by Alice Every²⁰ from the Samoa Cancer Society, on “National Palliative Care Guidelines” lays a platform as a Palliative Care Guidelines to guide the palliative care practise here in Samoa. This document describes a model of service delivery for Palliative Care within Samoa with the introduction of a dedicated Palliative Care Service integrated into the National Health Service (NHS) and Primary Health Care (PHC) Unit. It sets out guidelines for the Palliative Care Service Staff and other stakeholders in how to provide care and support for patients, and their families, who have been diagnosed with a life limiting illness. This document clearly stated that the Palliative Care Service aims to provide a high quality service for PCPs and their families, not only to improve their quality of life but to prevent and alleviate suffering problems, physically, mentally, socially and spiritually. However, the first three dimensions of the palliative patient are well looked after, supported and treated by the palliative medical team leaving their spiritual aspect unassigned.

²⁰ Every, Alice. *National Palliative Care Guidelines* Ministry of Health (Research 2018).

According to Su'a John Ryan,²¹ the spiritual aspect of the holistic care of palliative patients is lapsed from their service and they are looking on ways to incorporate the pastoral care service into their practice:

I am grateful and happy with your study because currently we don't have the pastoral care service into our Palliative Care Team. We were long wanted to provide this service to our patients but we just don't know how.

The above conversation with Ryan confirms that there is no spiritual care service in this integrated palliative care team looking after palliative patients in Samoa. For this reason, I interpret that the care PCPs received is not holistic because the palliative care service only treats and supports the patient physically, socially and mentally, but not spiritually.

The current level of palliative care in Samoa is still under developed. Samoa does not have specialised units or hospitals designated for palliative care patients like overseas and western countries. All diagnosed patients admitted and treated in the main hospital and then discharged to their own home for the continuing of care by the community practitioners using *their referral system*. They came up with the idea of a home-based *care model* as it is more convenient and effective for both the service and PCPs.

Home-based Care Model provides care in the home in which the patient lives. The benefits of this model are that:

- most patients feel more comfortable in their home than in a hospital setting;
- family members are integrated into the process, which in turn means that the patient has easy access to 24 hour care;
- it helps the patient and family maintain privacy and confidentiality;

²¹ Ryan, Su'a John. *CEO, Samoa Cancer Society* (personal interview with the author, 12/06/21)

- it helps to increase community awareness of palliative care;
- it is more cost efficient for the health system as it uses local resources and support networks.

Home-based Palliative Care is delivered by a multidisciplinary team trained in palliative care, including doctors, nurses, social workers, community health workers and volunteers. The home based model also understands that the spiritual side of the patient is cared for by their Ministers (Faifeau) when they do their pastoral care work. This understanding is due to Samoa largely seen as a Christian country, and every family goes to church and believes in God.

There is presently The Palliative Care Service, which provides advice and support to family members to help them as caregivers, as well as facilitate referrals to additional services as required. The Palliative Care Service provides training to other nurses and community health workers in the local area to further support the patient and their family/caregivers (World Health Organization, 2016).

The Palliative Care Service also recognizes the importance of traditional healers (Taulasea) in giving health and spiritual care in Samoa and the important role they play in Samoan cultural, religious and family life.

The Palliative Care Service aims to:

- i. Provide a high quality service for palliative care patients and their families/carers;
- ii. Provide a seamless patient journey with smooth and timely transitions from one service to another;

- iii. Ensure that wherever possible, people are able to die in their place of choice;
- iv. Provide an integrated service which promotes a multidisciplinary approach and:
- v. Comprehensively assesses the needs of patients and their families;
- vi. Ensures relief from pain and other symptoms;
- vii. Addresses psychosocial and spiritual needs;
- viii. Supports families and caregivers.

Patients referred to the Palliative Care Service should expect to receive:

- Timely referral to the Palliative Care Service;
- Effective communication with the patient and family and other service providers;
- Timely and straightforward transfer from acute care to the palliative care service;
- Continuity of health care provision across the various care settings;
- Maximised living and minimised suffering, through comfort care and choice.

According to the Ministry of Health – National Palliative Care Guideline, once the patient is diagnosed with a terminal illness and classified as a palliative patient, they need to refer to the Palliative Care Team and Specialists for the continuation of the care. So the palliative care patient is discharged to their own home, and the Palliative Care Team will visit them for their treatment and other support required by the PCPs and their family. While the patient has been discharged, Medical Staffs in the hospital ensure they referred this PCP to the palliative care team for follow up and management of care. These are the main stakeholders for referrals:

Table 1

Patient	<ul style="list-style-type: none"> ● Patient ● Family/ Caregivers ● Village
	<ul style="list-style-type: none"> ● Clinical Manager

NHS Primary Health Care Unit	<ul style="list-style-type: none"> ● Principal Nurse ● PHC Clinical Staff
Palliative Care Team	<ul style="list-style-type: none"> ● PC Doctor ● PC Nurse Specialist ● PC Social Worker ● PC Volunteers
Referring Health Providers	<ul style="list-style-type: none"> ● NHS Medical Staff ● NHS Allied Health Staff ● General Practitioners

Table 1 Referral Stakeholders

As we can see on the above referral stakeholders for the continuation of the care of these PCPs, they only focus on the medical management and the treatment of the patient. However, an effective and holistic care for these patients, the palliative care service needs to provide support physically, mentally socially and spiritually. But there is nothing in this referral system that reflects the management of the spiritual aspects of the patient and their family. So from this research, I found that this is where it lapse and caused the incomplete managements of PCPs here in Samoa.

CHAPTER THREE

FINDINGS AND DISCUSSIONS

3.1 Introduction

This qualitative study explored views from the focus group of 10 patients that are dying from terminal illness and a focus group of 10 relatives who either care for the dying patient or have experienced the loss of a loved one due to a terminal illness. These Palliative Care Patients and their carers were randomly selected from patients cared by the Samoan Ministry of Health Palliative Care Team and the Samoan Cancer Society. The selected participants were invited to partake in this research, and all gave their consent to use their information provided in this study.

Furthermore, interviews and questionnaires sought the opinions of 7 church ministers from the West Brisbane District of the CCCS (*Pulega Purisipeni Sisifo*) to explore their pastoral care contributions on managing palliative care patients in their parishes. The letter of consent was also sent together with the questionnaire and they were happy to participate and use their input in this research. The interview consisted of open-ended questions and prompts designed to explore patients' journey from initial contact until diagnosis. In addition, basic demographic and health-related information was collected through a brief questionnaire administered prior to the interview. The breakdown of the qualitative sample group is given in Table 2:

Qualitative Target Group: Interview/ Questionnaire	Number of the Target Group	Number of Respondents
Palliative Care Patients	10	10
Family/Carer of the Palliative Care Patient	10	10
Ministers of West Brisbane District of the CCCS (Pulega Purisipeni Sisifo, Kuigiselani)	7	6

Table 2 Qualitative Sample of the Target Group

The face-to-face interviews were conducted by the researcher at the participant's place of convenience in the language of their choice and were audio-recorded. Written consent was obtained prior to the interview.

3.2 Participants' Understanding of Palliative Care

The research questions target the responses of the PCPs respondents on their personal views and understanding on their situation. Eight (8) out of 10 of the respondents believed that even though they have been told and diagnosed by the medical practitioners, they are terminally ill, incurable (*le toe aoga iai se togafitiga*) and they are at the end stage of their life, they never gave up with their hope. They always have faith to the Lord that He is the only healer (*ua na'o le Atua le fomai sili*). They strongly believed through the Lords healing power, they will be healed and regained their strength. The same question asked to their relatives, and all 10 participants agreed and supported their loved one. Always believe with God's healing power and have in Him. Two (2) of the PCPs respondents deny their diagnosis as terminally ill patient.

They believed they were misdiagnosed and investigations for their disease are still in process. However, they also trust in the Lord that they will be healed.

When asked to explain how they felt when they were first being told or diagnosed with a terminally ill disease, reluctantly all 10 of them said they didn't believe it. They were in the stage of denial and hope what they have been told is wrong. So many questions came into their mind that made ~~mad~~ makes them confused and sort of questioning the love of God. That question of "Why me" came into their minds. Why is it happening to me? Some said they pay regular visits to the doctors for medical check-ups but were shocked with the news they have been told. But this was the stage Kuber-Ross was talking about on her model of 5 Stages of Grief. Kuber-Ross spoke about the first reaction of a person when receiving shocking news is to deny it. Denial is the stage that can initially help you survive the loss. You start to deny the news and, in effect, go numb. It's common in this stage to wonder how life will go on in this different state – you are in a state of shock because life as you once knew it, has changed in an instant. When diagnosed with a deadly disease, you might believe the news is incorrect – a mistake must have occurred somewhere in the process of medical investigations. Interestingly, it is denial and shock that help you cope and survive the grief event. Once the denial and shock starts to fade, the start of the healing process begins. At this point, those feelings that you were once suppressing are coming to the surface. A summary of these findings is given in Table 3:

Response to palliative care and Terminal illness	PCPs (10)	Family/Carer (10)
Accept but believe in God's healing to regain their strength. Have Hope and Faith to God	10	10
Shocking and in Denial	2	10
Misdiagnosed	2	4
Satisfied with the medical palliative care service	8	6

Table 3 Participants' Understanding of Palliative Care

3.3 Participants' Perspectives about Pastoral Care at present

The interview questions also explored the existence of the pastoral care role and the importance to palliative care patients. Hence, one of the core questions asked during the interviews with the ten (10) PCPs was 'Does the Minister or the Faifeau visit her/him during this time of their sickness? And if Yes, How often? All of them, which is ten out of ten said 'Yes', their minister visited them while they were in the hospital, even now they have been discharged and cared for at home, he always came. He visited at least once a week. Now they have been in bedridden and unable to attend their normal Sunday service, some Sundays when it's communion he came to bring our communion. They said, it was refreshing when the minister came because not only did they have someone different to talk to, but he brought the light of faith and words of encouragement to lift their morale. I asked what the Minister does when he visited them. Eight (8) out of ten (10) stated that he normally do a prayer, read a quote from the bible and comment about relating it to their current situation. They always feel good after every visit because he is like bringing hope to them.

Ten (10) out of ten (10) of the relatives I interviewed also agreed that the ministers visited their loved one at this stage of their life. They were also happy with the minister visitations because they experienced some bad days with their loved one when they are in pain and distress, the ministers visits soothe their sufferings and enlighten their days. The minister spoke about the word of God and the bible quotes he preached about relates to the healing process that they went through. They feel good spirits in mind and soul. They appreciated every visit because they witnessed the good effects the minister brought into their family while caring for their terminally ill loved one. When asked about the inclusiveness of the minister into the integrated palliative care service provided by the medical staff. They all support it however, preferably their own minister because they are Christians and they go to church, so they already have the congregational relationship and they felt the whole congregation is praying for their loved one and their family. The same thought expressed by the ten (10) PCPs interviewed. Normally the team from the health care providers treated them medically but none ever speaks about their spiritual side of the caring. Participants' perspectives about pastoral care at present are given in Table 4:

Pastoral Care to PCPs and their Family	PCPs (10)	Family/Carer (10)
Minister visit	Yes	Yes
Minister Pastoral Activity – Prayer & Biblical Encouragement	Yes	Yes
Does it help you spiritually	Yes	Yes
Minister as part of the integrated Palliative Care Team	Yes	Yes

Table 4 Participants' Perspectives about Pastoral Care at present

3.4 Pastoral Perspectives towards Palliative Care Patients

The questionnaires given to the ordained Ministers of the West Brisbane District (WBD) of the CCCS (*Pulega Purisipeni Sisifo*) asked them about their views and how they manage palliative care patients in their parishes. The WBD is made up of seven (7) parishes ('parish' and 'church' is hereafter used interchangeably where it is appropriate but both refer to the church/parish the community worships) each with a pastor looking after each parish under the guidance of the WBD Elder. With the seven minister target on this research, only six (6) responded to the questionnaire because one (1) minister is away on his 3 months break (*malologa*).

I am aware that these seven (7) ministers from WBD, do not represent the pastoral perspectives of the CCCS as a whole. However, given the time frame and limited resources for this research, the information obtained from the six (6) ordained minister respondents to the questionnaires, will be used as a case study to collate a qualitative sample for the research.

One of the focus questions asked to the ministers was to express their understanding of palliative care patients. Four (4) out of six (6) respondents that they do not have any knowledge about palliative care patients, however, if they are the members of the congregation, it was their responsibility as a minister of the church to visit and provide spiritual care for them:

Rev LT: E leai so'u malamalamaaga i le tausiga o lē ua gasegase, i lona tulaga i le tino, ae e iai lo'u malamalamaaga i le tulaga o lona moomia o le tausiga faaleagaga. Ua manino o le tagata o le tino, mafau fau ma le agaga. O mea ia e tolu e fausia mai ai o ia. O le galuega faafaifeau, o le galuega faaleagaga. O le vaega foi lea o le tagata e faasaga iai le galuega faafaifeau. E le mafai ona aveesea le moni ma le taua o lea talitonuga ma lea malamalamaaga. Ua iai tagata sa aumai i tua i o latou aiga e faatalitali ai o latou oti.

[Rev LT said, he doesn't have any understanding or knowledge about PCPs but he had the spiritual knowledge that he can share with them. The three aspects of the

being consist of the body, mind and soul. Therefore, as a minister, the soul of the patient is your priority to ensure they are well looked after spiritually. Especially with severely ill patients and are in the dying stage.]

They believed regular visits of the Faifeau and his wife to conduct family devotions is a great opportunity to talk about the word of God, which is not only to strengthen the patients and their families' faith in the Lord but also gave them hope because nothing is impossible to the Lord.

The question asked about the involvement and the support of the church on the caring of the PCPs, all six agreed and strongly supported the participation of the church community in the caring of the sick patient and their family. One minister quoted the sacrament of the baptism and its vow when baptising a child “...*ua ou folafola atu, ona o le fesoasoani o le Atua, o le a matou tatalo mo lenei tamaititi ma ona matua,*” He believed that the role and the responsibility of the church to its members, is from birth until died. The least the church can do to help this patient and their family is to pray for them. They prayed for comfort and healing upon them. Sometimes the minister announced in the church to keep those who were sick and their families in prayers.

RevPT - Ioe, e selau pasene le i ai o le lotu i le vaega lea o le tausiga o le tagata ua maua i ia gasegase tuga. O le lotu, o le Tala o le Faaolataga. O le tala o le alofa tunoa o le Atua i tagata. (Mareko 2:17). O le lagolago ma le fesoasoani tele a le faifeau, o le asiasi lea i ai i taimi uma e fai ai ana asiasiga. Ia logo le aulotu ina ia tatalo mo le ua maua i gasegase tuga o le ola. Ia i ai se taimi a asiasi i le ua maua I ia ma'i, ia faitau le tusi paia ma faamatala ai tala o loo I le tusi paia e faatatau i le ola ma le tagata ua maua I mafatiaga, aua e leai se mea faigata I le Atua. Ia malosi le lagolago a le faifeau I le itu faaleagaga, e fiafia ma mausali ai le faatuatua o le tagata mai, ma fiafia ma olioli ai lona mafaufau ma malamalama ai o le Atua lava le faapogai o le ola. Ona maua ai lea o le fiafia ma le malosi.

[Rev PT agreed with the involvement of the church to the caring of the PCPs. The church is the story about the salvation and the unconditional love of God. The

Church as the community will pray and fast to the Lord, to support and enlighten the patient faith to keep them happy.]

The majority of the respondents in regards to the main objectives of their visiting the PCPs are to ensure their (PCPs) spiritual well-being is active. Especially at the end stage of life, some patients were very distressed, and easily temper. They feel lonely with all other mixed feelings rushed in their brain and then prefer to be alone. But the presence of ministers and their pastoral care work delivered the message of hope, helps lift their self-esteem, make them feel important and have not been neglected. All the ministerial work, the minister has to be prepared together with the spirit of God, to comfort the patient and their family. They needed to be upfront if the PCP is dying, tell them we do not belong to this earth. God already prepared an everlasting new life for us after death, if we repent and believe in Him with faith, truth and honesty.

3.5 Summary

The summary of the interviews and the questionnaires collected, confirms the lapse of the spiritual care aspects in the service delivered by the Palliative Care Service. Of course they work tirelessly to provide treatment and support to PCPs, but they only focus on the medical treatments to promote the *patient's quality* of life physically, mentally and socially. However the spiritual side of the caring is done by ministers in the community. The findings from this research suggest that Ministers always make their visits to these patients even though they are unaware of PCPs. As a minister in the congregation having a palliative care patient, they are accountable on their spiritual side. The majority of the respondents are happy to support the importance of the involvement of Ministers/Faifeau into the Palliative Care Service.

CHAPTER FOUR

THEOLOGICAL REFLECTION AND RECOMMENDATION

Palliative care team includes physicians, nurses, social workers, ministers, and spiritual counsellors. In their own capacity as professionals all of them have to contribute to the total welfare of the patient being given palliative care. Physicians and nurses normally focus on treating the patient only from the medical perspective, but they must also take the patient's spiritual and existential dimensions seriously. Nurses here in Samoa are the main core members of this palliative team actively work tirelessly to deliver the care to palliative patients. But one of the titles Samoan Nurses address themselves is the *Ositaulaga*. They believed they are not only a "Pae male Auli" but they were also a *Ositaulaga*. So from this perspective, they believed they also can deliver the spiritual care aspects of caring to the PCPs. The holistic approach of palliative care emphasises physical, emotional, social and spiritual aspects. 'Palliative care does not serve only the dying. Instead, it focuses more broadly on improving life and providing comfort to people who may be of any age and have serious, chronic and life-threatening illnesses'²². The spiritual dimension of palliative care has specific goals: to comfort the grieving, break through their isolation, deliver them from fear, to help them deal with guilt, enhance their emotional stability, and encourage them to face the pain together.

Christianity is convinced that patients at the very fag end of their lives, with all their ailments and agonies, are still people who have been created in the image and likeness of God (Gen1: 26)²³. They cannot be dehumanised and reduced to bundles of corrupted and

²² Wilson, Michael. *The Church is Healing* Birmingham University, West Africa 1966. 55 – 75

²³ Genesis 1: 26 (Then God said, Let us make man in our image, in our likeness NRSV)

malfunctioning organs. This is one of the basic convictions that motivate Christians to take care of the sick and the dying. As Christians believe in life after death, the experience of death is not at all a frightening one. Since they believe in the resurrection of Jesus, everything does not end with death for them; death is not an end. God has miraculous powers to cure illness; they are also convinced that such cures are only temporary because we all have to die one day. Therefore, the care of patients at an advanced stage of illness involves preparing them for a peaceful death. It helps them to become reconciled to the facts of life and not to be frightened of death because death, after all, is not the ultimate disaster; it is not the end of everything, but the beginning of a new life. Galatian 2:20 ²⁴

Christianity firmly believes in the healing power of Jesus Christ. James 5:14-15 “Are any among you sick? They should call for the elders of the Church and have them pray over them, anointing them with oil in the name of the Lord. The prayer of faith will save the sick, and the Lord will raise them up; and anyone who has committed sins will be forgiven.” The other references supporting this aspect of the healing ministry of the Church are: “Cure the sick, raise the dead, cleanse the lepers, cast out demons. You received without payment; give without payment” (Mathew 10:8) “Whenever you enter a town and its people welcome you, eat what is set before you; cure the sick who are there, and say to them, ‘The kingdom of God has come near to you’ (Luke 10:8–9) and, “They cast out many devils, and anointed with oil many that were sick, and cured them” (Mark 6:13).

²⁴ Galatian 2:20 I have been crucified with Christ and I no longer live but Christ lives in me....NRSV

In order to enforce the spiritual aspects in the palliative care service, I would like to propose the recommendation of a Pastoral Care Model for Palliative Care as shown in Figure 2:

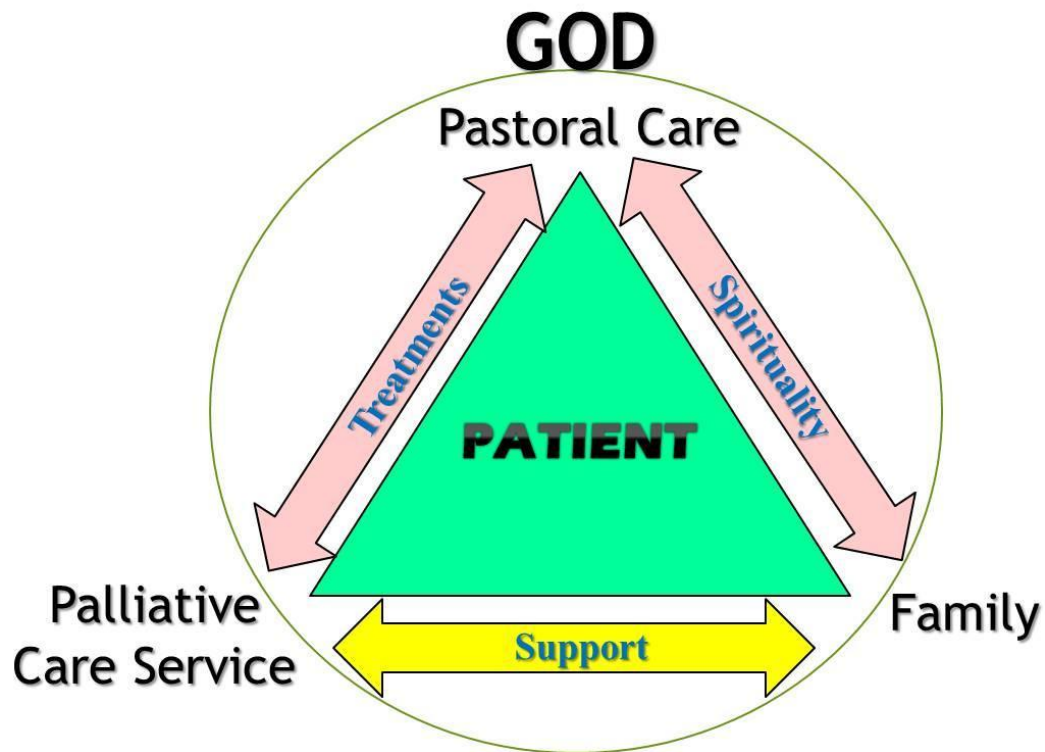


Figure 2 (Source: by the Author)
Pastoral Care Model for Palliative Care

4.1 Description of the model

4.1.1 The Triangle

Patient: is in the middle of the triangle because they are the main focus of the caring and people around them working collaboratively to give support, medically, socially, psychologically, physically and spiritually.

Pastoral Care: These are the Ministers, their wives and the congregation community provide the spiritual care for the patient. They united with prayers and

fasting to the Lord for His healing power to heal the PCPs and their families spiritually to give them hope of quality life.

Palliative Care Service: are the integrated team of medical professions including Physician, Nurse Specialist, Social Worker and other healthcare agents working tirelessly to implement their palliative care plan to comfort the PCPs medically, socially and psychologically.

Family: These are the relatives of the PCPs working 24/7 to support and provide for the patient. The home based care model used by the PCS team solely depends upon the relatives' co-operation to perform their duty of care to support the patient.

4.1.2 The Arrows

The three (3) arrows on the three sides of the triangle represent the characteristics of the holistic care for the PCPs. The Pastoral Care Model believes that the three (3) dimensions of family, the Palliative Care Service and the Ministers working together to provide holistic care to the terminally ill patient. The main objectives are to alleviate sufferings from pain and provide comfort to the PCPs through the support from the families, the medical treatments by the PCS team and the pastoral care essence by the Ministers to provide spiritual stability. The three arrows are not connected or linked together, meaning there is a space, a freedom or the patient rights to receive or reject the service or the treatment provided by PCS either medically or spiritually.

4.1.3 The Colours

The Green colour in the triangle represents the colour of life associated with meaning of renewal, growth and hope. In western countries when it is in the spring season, all the plants are coming back to life with fresh growth after winter. Such meaning, I believe all the palliative care and support of the PCS including the Pastoral Care gave the PCPs a bright light of life and hope.

The Pink colour in the arrows according to the Cancer Awareness Ribbon Colours (CARC), honours those who passed with Breast Cancers, which is one of the common cancer affected women in Samoa.

The Blue colour bolded the aspects of caring written in the arrows, honoured men who died from Prostate Cancer according to CARC which is also one of the common cancers in Samoan men.

The Yellow colour according to the CARC, represents all different types of Cancers affecting children and it is called Childhood Cancers.

4.1.4 The Circle

The circle around the model reflects the supremacy of God. Only God has the fullness of every good service. His perfection in our bodies, minds and souls is a gift of life. The integrated palliative care team working together to provide support to the PCPs, hope for God's miracle to comfort and heal the patient. They just did their job believing in God's mercy, His miracle can also be obtained through their work. So whether the PCPs are Christian or not, God's everlasting love is for all and He helped and blessed all those in need of help from all sorts of problems and difficulties.

CHAPTER FIVE

CONCLUSION

The discussion and analysis chapters presented about how PCS supported PCPs and their families, and the role of the CCCS at present in supporting these patients. As a way forward, the research question targets the effective ways to provide pastoral care support for PCPs and their families and to explore how the CCCS currently cared for them. From this research, the data collected and analysed proposes that dialogue and further consultations with key stakeholders of the Ministry of Health, Samoa Cancer Society, and the CCCS are needed, on how to integrate the Pastoral Care aspect by the CCCS into the holistic care of the PCPs.

First of all in relation to the Ministry of Health, in their palliative care patient guidelines, they have a list of stakeholders for referral (Table 1). I have noticed with this list of stakeholders, they are all medical agents and clinicians and have specific roles to play in the management of the patient. This is where I believe there is a lack of understanding, leading to a lapse in the spiritual care for the PCPs. From the findings of this study, I propose to involve the PCPs church Minister into the list of the stakeholders, so they too can also be involved in the referral system. When the PCPs discharge to the care of the PCS for the continuation of their treatment and management, a referral letter would be sent to all the stakeholders, which needs to include the Minister. This ensures that all aspects of the PCS delivered and the PCPs receive their holistic care physically, psychologically, socially, and spiritually.

Secondly, every patient who visits or is admitted to the hospital for medical treatments, patient information normally is collected such as the patient's name, date, and place of birth or

village, contact number, Next of Kin and so forth. This information is stored and used by the medical staff when the patient is hospitalised, or used to trace the patient if ever the patient is required for further investigations or follow-ups. However, one key piece of information that is useful to be collected for the hospital's database, is the patient's religion and the name of their church Minister or Pastor. Therefore if the patient is diagnosed with a terminal illness and discharged, the patient's Minister can be located from the patient information to become involved in the palliative care service referrals.

In regards to the Samoa Cancer Society, this research confirms the hard work this organisation does in Samoa to run cancer awareness programmes, outreach, workshops and symposiums to educate the people of Samoa and the community about cancer symptoms and the importance of regular health checks. I have noticed most of the awareness programmes run in schools, on radio air and some non-government organisations which I believe is an effective way of spreading their message. However I would also like to recommend a good partnership of the Samoa Cancer Society with church communities to run awareness programmes and to invite Ministers and/or their Wives to participate in workshops and symposiums. Furthermore, to allow Ministers and their wives to present on the spiritual care of dying patients and/or their role as a Minister dealing with a terminally ill patient in their congregation. This partnership can strengthen good relationships and the SCS team can also be invited by the church Minister to conduct an awareness programme to their church community. Having the knowledge means more understanding about PCPs conditions and how to support them.

Credit needs to be given to the church Ministers for the work they are currently involved in. The research findings depicts 100% of the respondents visited PCPs in their congregations at least once a week. Even though they have little knowledge about their medical conditions,

they have the spiritual knowledge to share to ensure that the PCPs spiritual well-being is addressed. The limited knowledge of the Ministers towards their PCPs condition because of the breakdown of the PCS referral system, I have proposed a PCPs Pastoral Care Model (Figure 2) for the Ministers as a tool to use, to deliver pastoral care for the PCPs and their families within their congregations.

In conclusion, the findings and the data collected, confirm the lapse of the spiritual care aspects in the services delivered by the Palliative Care Service. This lapse I believe is due to the current referral system in place. At present when the PCPs are discharged from the hospital, the medical Physician refers them to the PCS stakeholders (refer to Table 1). These stakeholders are only medical professionals doing the community and the outreach work to cater for the home-based model used for PCPs in Samoa. Of course the PCS work tirelessly to provide treatment and support to PCPs, but they only focus on the medical treatments to promote the patient's quality of life physically, mentally and socially. However, the spiritual side of the care given is absent from this referral system. Nothing has been documented or addresses the need of the Ministers participation in their palliative care guidelines. Yet the Ministers are doing their pastoral care work in the communities. The findings from this research confirm that Ministers always make their visits to these patients even though they are unaware of PCPs. As a minister in the congregation with a palliative care patient, the Minister becomes accountable and responsible for the PCPs spiritual wellbeing. The Ministers felt obliged as part of their duty of care, to visit these patients and their families to comfort and preach the word of God about hope, and eternal life after death. This research has highlighted the importance of the involvement of Ministers/Faifeau into the Palliative Care Service. The proposed Pastoral Care Model developed from this research, is proposed as a relevant tool that guides the Ministers' pastoral care work, working collaboratively with the Medical Palliative Care Team

to deliver palliative care service that supports the PCPs and their families physically, socially, psychologically, as well as spiritually.

APPENDICES

Appendix A: PCP Interview Question Schedule

- 1) What is your understanding of palliative care?
O le a sou malamalama'aga ile gasegase ua maua ai oe? Ose ma'i, ete talitonu e toe faafoisia lou malosi pe leai?
- 2) Can you explain how you felt when you were diagnosed with a terminal illness and you are going to be a palliative care patient?
Faamatala mai o le a se lagona na tupu ane ia oe, ina ua faailoa atu ele fomai ia oe, ua aafia oe i ma'I tugā ole ola ma ua le toe iai se fofo o lou gasegase?
- 3) Does your Minister visit you at this stage of your sickness? If yes, how often?
E masani ona asia oe e lau faifeau I lenei taimi o lou gasegase? E faafia?
- 4) When the Minister/Pastor visits you, what does he do?
A asia oe ele Faifeau, o le a lana galuega e masani ona fai ia te oe?
- 5) Do the Minister's job/presents help you and your current situation? Explain?
O aoga, pe o fesoasoani le galuega ale faifeau ia te oe ma lou gasegase? I le a le itu?
- 6) With the Palliative care team of medical professionals looking after you, do you feel you also need pastoral care personnel in this team?

Appendix B: PCP's Family member Questionnaire

NAME: _____ RELATIONSHIP: _____

1) What is your understanding of palliative care?

O le a sou malamalama'aga ile gasegase ua maua ai lou _____?

2) How do you feel when your loved one is diagnosed as a palliative care patient?

O a ni lagona na tupu ae ia te oe ina ua faapea mai le fomai, o le gasegase o _____,
ua le toe aoga iai se togafiti?

3) Did your minister come to visit your _____ since he/she was diagnosed? If yes,
how often?

Ua asia lou _____ e le tou Faifeau? E faafia ona asia/sau?

4) When the Minister comes, does he only focus on your sick loved one, or you are also
included?

O le asiasi mai ole Faifeau, e na'o ole gasegase lava e faatino ai lana galuega, pe faasoa
atu foi ia te outou oloo tausia le ma'i?

5) Was the Church Minister's visit helpful in your situation? Please explain.

O aoga le asiasi mai ale Faifeau isi tou aiga? Faamatala mai.

6) Where do you feel that journey with the church minister ends?

(A) After your loved one passed. (B). Would you rather continue it until you feel
you do not need that support?

7) With the Palliative care team of medical professionals looking after you at present, do
you feel you also need pastoral care personnel in this team?

Appendix C: Consent Letter

Thesis Topic: A Ministry for Palliative Care Patients (PCPs) and their families in the context of the CCCS Congregation Christian Church Samoa (CCCS)

I, Lancealotte Alaimoana, am currently writing a thesis paper on the above mentioned topic in BD with Honors Level at the Malua Theological College, Samoa. It is with all due respect that this research ensures that all information from this interview questionnaire will be strictly confidential, and will not be used for any other purpose(s) rather than this task as requested. It is also your right to participate in this study and whether to mention or not to mention your name in this paper. The primary aim of this project is to explore how to provide pastoral care for palliative care patients and their families, to comfort and support them during the end of life stage for PCPs. Furthermore, to explore how the CCCS cares for palliative care patients at present.

I would like to acknowledge with utmost gratitude your time and valuable experience shared for this research. May God bless your good self, ma ia togo pea malama aua le feagai ai ma le soifua vala'auina.

Ma le faaaloalo,

Lancealotte Alaimoana: _____

Reverend: _____ Parish: _____

Are you agreeing to mention your name in this paper? Yes/No:

Appendix D: Questionnaire for Church Ministers (Faifeau)

Name: _____

Date: _____

Parish: _____

1) What is your understanding of palliative care for a terminally-ill patient?

O le a sou malamalama-aga/iloa ile tausiga o gasegase ua maua i ma'i to'atuga o le ola?

2) Do you think the church should be involved in palliative care? Please explain.

3) What support would you give to a palliative care patient?

4) What is/are your main objective/s in your role as a church minister (faifeau) visiting a palliative care patient?

5) How can the church meet the spiritual needs of the palliative care patient and his/her relatives?

6) If you have a palliative patient in your parish/congregation when do you think the support offered should cease?

7) What do you think the church can do better in supporting palliative care patients and their relatives?

8) Extra comments:

(Faafetai tele lava mole faaavanoaina o lou taimi taua e faatino ai lenei suesuega.)

Appendix E: Approval from the Health Research Committee

ANNEX A: APPROVAL FROM HEALTH RESEARCH COMMITTEE (attached)

Please address
all correspondence to the
Chief Executive Officer



Office of the Chief Executive Officer
Private Mail Bag, Apia
Tel: (685) 23330
or 68100 ext 102
Facsimile: (685) 26333

Lancelotte Alaimoana
Principal Researcher
Malua Theological College

23rd June 2021

Title of Research: "Ministry for Palliative Care Patient and their Families in the context of Congregation Christian Church of Samoa."

Dear Lance,

Thank you for your request for ethics approval to conduct your research, "Ministry for Palliative Care Patient and their Families in the context of Congregation Christian Church of Samoa". The Health Research Committee (HRC) has assessed and evaluated your research proposal and is pleased to inform you that your ethics application has been successful. The Health Research Committee (HRC) supports your undertaking as the results will provide insights of what sort of support palliative patients expect.

The Health Research Committee suggested if you could include a question that can provide information on how well/ gaps in our health system with treatment and care of people undergoing palliative care. So we can see where we can improve also as well.

Please note the following conditions apply to your research ethics approval. Failure to adhere to these conditions may result in suspension or termination of approval and/or disciplinary action.

- i. **Duration of Approval** – approval is granted till the duration of the research study as outlined in your research proposal. If for some reason you cannot complete the study in the time frame given, you will need to inform the Health Research Committee by submitting a progress report and stating the reasons for the delay.
- ii. **Variation to the Research Project** – any changes or modifications to your research study must be communicated to the Chair of the Health Research Committee for reassessment and approval.
- iii. **Monitoring** – your research project is subject to monitoring at any time by the HRC.
- iv. **Memorandum of Agreement** – a MOA needs to be signed between your good self and the Ministry of Health (MOH) before you undertake your research. Please liaise with Unaite Asi of the HRC Secretariat to organize matters prior to the signing of the MOA.
- v. **Final Report** – You must submit a final report at the conclusion of your research project.
- vi. **Publication of Findings** – Your final report should not be published without the prior consent of the MOH.

Should you require further information/clarification, please do not hesitate to contact Sina Faaluga or Unaite Asi on telephone 68106 or email: Sinaf@health.gov.ws or UnaiteA@health.gov.ws at the Strategic Policy, Planning and Research Division.

We wish you all the best with your research

Sincerely,

A handwritten signature in blue ink, appearing to read "Leausa Toleafoa".

Leausa Toleafoa Dr Take Naseri
Director General of Health / Chief Executive Officer
Chairman - Health Research Committee

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