SPIRITUAL CARE IN HOSPICE PALLIATIVE CARE SETTINGS IN SOUTH AFRICA: NATIONAL CURRICULUM NEEDS, DESCRIPTION OF PROVINCIAL SERVICES, AND A LOCAL CASE STUDY

by

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Dissertation presented for the degree of Doctor of Philosophy in the Faculty of Arts and Social Sciences at Stellenbosch University

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December 2021

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Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights (save to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

This dissertation includes five original articles published in peer-reviewed journals. The development and writing of the papers were the principal responsibility of myself and, for each of the cases where this is not the case, a declaration is included in the dissertation indicating the nature and extent of the contributions of co-authors.

Ronita Mahilall
December 2021

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Dedication

I dedicate this dissertation to my Mom, SHAMAWATHI GOKUL and my late Dad, SAMLALL GOKUL.

My Mom, like most moms, holds our family together, as she nurtured our emotional and cognitive growth and encouraged my sisters and I to succeed and exceed as individuals and academically. My Dad was a storyteller of note, a charismatic entertainer and a humble man who loved his family fiercely and who would stop at nothing to give us the best life he could.

My parents were progressive thinkers who chose to embrace apartheid and made apartheid work for them! I owe my parents a deep bow of gratitude for all the sacrifices they made just so that my sisters and I could experience and achieve what they were denied.

I hope that I have made you proud Mommy and Daddy and I hope that I could have shared this achievement with you in person, Daddy.

To the best parents and role models I could ever have asked for, I dedicate this dissertation to you, Mom and Dad.

I love you, always and forever.

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Acknowledgements

I owe this dissertation to my dearest loved ones who live both in “that other world” and “this other world”! During my journey undertaking this project I drew strength from their collective wisdom, and I drew inspiration from their own stories.

Deep love and gratitude go to my late Dad, my late husband, and my late son:

- My Dad, SAMLALL GOKUL, whose laughing eyes showed me that everything is possible and who insisted that my sisters and I leave home with a degree and driver’s licence in hand! What an enigma you are Dad, love you!
- My husband, RAJENDRA (REX) MAHILALL, who loved and supported me in everything I did and plunged in, boots and all, in all of my craziness. How I love and miss you, Rex!
- My beautiful baby, PEREZ MAHILALL, my *Guru* who taught me that verbal communication is nothing compared to talking with our eyes, talking by touch, and understanding with our hearts. I love you my baby, always and forever!

Deep love and gratitude go to my Mom and daughters:

- My Mom, SHAMAWATHI GOKUL, who always strived to give us an education so sadly denied to her and who never stopped believing that her kids are the best. Love you Mom!
- My daughters, CHIARA MAHILALL and UREESA MAHILALL, who are my reason to live, love and laugh again. From your earliest days as curious babies to inquisitive toddlers, through all the tragedies you have endured in your young lives, to now being fiercely independent, successful, beautiful young professionals you make my soul sing with love, pride, and joy! My heart bursts with love for you, my baby girls!

Deep love and gratitude go to the following invaluable people:

- Professor Leslie Swartz; my mentor, my supervisor, and a true legend! I am so glad that I picked YOU Leslie! This tribute is not just to your brilliance as an academic and mentor, but it’s to your wisdom to understand me and the trust you had that I could do this. Your witty humour is unparalleled and your capacity to get excited by research every time we met has certainly rubbed off! Even if I imagined a supervisor, it would be nowhere close to how incredibly inspirational you are Leslie; you are simply the best!

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- My crazy, ghoulishly supportive, and incredibly insane sisters – Innera, Rita and Shubby – for cheering me along and simultaneously suggesting that I get my head read! Thank you, girls, love you!
- Varkey George, an accidental and incidental meeting some four years ago that led to such an incredible relationship of so many common and shared interests. Thank you Varkey so much for all your support, co-facilitation, and cheering. A gem of a friend!
- Grateful thanks to Christine Dempers for your gracious assistance. A remarkable friend!
- Jacqueline Gamble, editor extraordinaire and a deeply treasured genius. Thank you!
- Ian Robertson, my deeply valued friend, and statistician. Thank you, Ian.
- Prof JP van Niekerk, another legend! Thank you deeply for your support and wonderful conversations.
- All the truly amazing participants of this research study without whom this would certainly not be possible. Your passion for spiritual care, hospice care and palliative care is palpable. Salutations and blessings.
- My colleagues at St Luke's Combined Hospices, and especially our Spiritual Care Team; you are modern day heroes/sheroes. Bless you! Deep gratitude to Patrick Paulsen, Michelle Peterson-Damon, Dr Mary Hlalele, Michelle Lehmann-Shantall, and Feerouza Kruger for your support and being my sounding board.
- No job is ever complete unless the paperwork is done! Huge thanks to Prof Dianna Yach and the Mauerberger Foundation for the part funding of this study. So grateful to you Dianna!
- Huge thanks also to Arm-in-Arm-in-Africa (AIAIA)'s Dr John Song Memorial Fund for the part-funding of this study facilitated by Eileen Jacobs and Jen Song. So grateful and appreciative to have this opportunity to be a part of making the late Dr John Song's palliative care passion live on.

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Abstract

Palliative care is gaining momentum in South Africa. Spiritual care is slowly being recognised as an important component of palliative care and hospice work. However, how spiritual care services are offered and prioritised depends largely on the hospices' ability to fund this service and to have the necessary skilled spiritual care staff in place to offer this specialised service.

The aim of this study was to explore whether hospices in palliative care settings in South Africa offered spiritual care services, how spiritual care services were offered, what the spiritual care training needs are and, more critically, to explore if there was a need to develop a national spiritual care training curriculum.

To answer these questions, I conducted a three-tiered study. In Sub-Study One, I conducted an online survey of all hospices registered as member organisations of the Hospice Palliative Care Association of South Africa. The aim of Sub-Study One was to explore what spiritual care services were currently being offered at hospices nationally, what spiritual care training needs existed, and how hospices suggested filling the training gap. In Sub-Study Two, I conducted focus group discussions with hospices in the Western Cape province of South Africa. These focus groups explored the above questions but with a focused view on issues of multi-layered contextual diversities and inequalities which, largely, are by-products of the South African Apartheid era. Sub-Study Three took the form of one-on-one interviews and focus group discussions with participants who are practising spiritual care workers registered with St Luke's Combined Hospices in Cape Town, to explore how they offer spiritual care services and navigate issues of diversity. Further, I explored this cohort's spiritual care training needs and their ideas of developing a national spiritual care curriculum for South Africa.

The findings of this three-part study suggest that hospices in South Africa offer spiritual care services to varying levels, and where such a service is not on offer, arrangements are made to link patients and families to external resources. Common to the three sub-studies was the expressed need to develop a national spiritual care training curriculum that comprised both an academic and practical component. However, the realities of limited funding and limited expertise in spiritual care was a significant consideration towards developing a spiritual care curriculum. Added to that was the consideration of the multi-layered diversities that are part of South Africa and its troubled history.

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These findings present further perspectives on the fluid, dynamic and often multi-faceted nature of an aspect of health care provision in South Africa. The study concluded by outlining some potential next steps for developing further dialogues on spiritual care services in South Africa.

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Opsomming

Palliatiewe sorg tel momentum in Suid-Afrika op. Geloofsorg word stadigaan as ‘n belangrike deel van palliatiewe sorg en hospieswerk erken. Hoe geloofsorg egter aangebied en geprioritiseer word, hang grotendeels af van die vermoë van hospiese om hierdie diens self te befonds en om die nodige bekwame geloofsorgpersoneel in plek te hê om hierdie gespesialiseerde diens aan te bied.

Die doel van hierdie studie was om ondersoek in te stel na of hospiese in palliatiewe sorgomgewings in Suid-Afrika geloofsorgdienste aanbied, hoe geloofsorgdienste aangebied is, wat die geloofsorgopleidingsbehoeftes is en, van meer kritieke belang, om ondersoek na die behoefte aan die ontwikkeling van ‘n nasionale geloofsorgopleidingskurrikulum in te stel.

Om hierdie vrae te beantwoord, het ek ‘n drie-vlakkige studie uitgevoer. In Substudie Een het ek ‘n aanlynopname van alle hospiese, wat as lidorganisasies van Hospies Palliatiewe Sorg Vereniging van Suid-Afrika (Hospice Palliative Care Association of South Africa) geregistreer is, uitgevoer. Die doel van hierdie substudie een was om ondersoek in te stel na welke geloofsorgdienste huidiglik aangebied word by hospiese landswyd, welke geloofsorgopleidingsbehoeftes bestaan en hoe hospiese meen die opleidingsgaping gevul moet word. In Substudie Twee het ek twee gefokusde groepbesprekings met hospiese in die Wes-Kaapprovinsie van Suid-Afrika gevoer. Hierdie fokusgroepe het die bostaande vrae ondersoek, maar met ‘n gefokusde lens op die veellagige, kontekstuele diversiteite en ongelykhede wat, grotendeels, neweprodukte van die Suid-Afrikaanse Apartheidsera is. Substudie Drie was in die vorm van een-tot-een onderhoude en gefokusde groepbesprekings met deelnemers wat praktiserende geloofsorgwerkers is, en as sulks geregistreer by St Luke se gekombineerde hospiese in Kaapstad, om ondersoek in te stel na hoe hulle geloofsorgdienste aanbied en kwessies van diversiteit bestuur. Verder, het ek die kohort se geloofsorgopleidingsbehoeftes en hulle idees rondom die ontwikkeling van ‘n nasionale geloofsorgkurrikulum vir Suid-Afrika, ondersoek.

Die bevindinge van hierdie driedelige studie dui aan dat hospiese in Suid-Afrika geloofsorgdienste in wisselende vlakke aanbied en, waar sulke dienste nie aangebied word nie, word reëlings getref om pasiënte en families aan eksterne hulpbronne te koppel. Die uitdruklike behoefte aan ‘n nasionale geloofsorgopleidingskurrikulum, met beide ‘n akademiese en praktiese komponent, was gemeenskaplik aan die drie substudies. Die werklikhede van

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beperkte befondsing en beperkte deskundigheid in geloofsorg was egter ‘n beduidende oorweging in die ontwikkeling van ‘n geloofsorgkurrikulum. Daarby is die veellagige diversiteite, wat deel vorm van Suid-Afrika en sy problematiese verlede, oorweeg.

Hierdie bevindinge verteenwoordig verdere perspektiewe op die vloeibare, dinamiese en dikwels veelkantige aard van ‘n aspek van gesondheidsorgverskaffing in Suid-Afrika. Die studie sluit af deur ‘n paar potensiële volgende stappe, vir die ontwikkeling van verdere dialoë oor geloofsorgdienste in Suid-Afrika, uiteen te sit.

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List of Abbreviations

ANC	African National Congress
APCA	African Palliative Care Association
CEO	Chief Executive Officer
CPL	Centre for Palliative Learning
EPCA	European Palliative Care Association
FBO	Faith-Based Organisation
HIC	High-income countries
HPCA	Hospice Palliative Care Association
IAHPC	International Association for Hospice and Palliative Care
ICT	Information Communication Technology
IDT	Inter-disciplinary Team
IHI	International Hospice Institute
IOELC	International Observatory on End-of-life Care
ISPEC	Interprofessional Spiritual Care Education Curriculum
LMIC	Low- to middle-income countries
MDT	Multi-Disciplinary Team
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NHI	National Health Insurance
NHPCO	National Hospice and Palliative Care Organization
NPC	Non-Profit Company
NPFSPC	National Policy Framework and Strategy on Palliative Care (2017–2022)

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OR	Operations Research
PBO	Public Benefit Organisation
PEPFAR	President's Emergency Plan for AIDS Relief
SA	South Africa
SCA	Spiritual Care Australia
SLCH	St Luke's Combined Hospices
UCT	University of Cape Town
USA	United States of America
USAID	United States Agency for International Development
WC-HPCA	Western Cape - Hospice Palliative Care Association
WHO	World Health Organization
WHPCA	World Hospice Palliative Care Alliance

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PART 1: INTRODUCTION AND BACKGROUND

Preamble

I am the Chief Executive Officer (CEO) of St Luke's Combined Hospices (SLCH), an established hospice offering palliative care services in the larger precinct of Cape Town, South Africa (SA) for over 40 years. I have been in this post as CEO since September 2016. SLCH is a Non-Profit Company (NPC) with its core business being palliative care. I came to this work with an established and personal interest in spirituality. My fascination with spirituality was heightened after the loss of my beloved husband and son in 2007; five months apart from each other. While they did not suffer from any longstanding terminal illness, having experienced such deep losses left me questioning life, and death, and the after-death phenomenon. Being a devout Hindu, I am also a believer in reincarnation; yet I found that religion alone did not provide me with the broader existential answers I was seeking. With that as a backdrop, and having joined SLCH, I was introduced more meaningfully to palliative care work, and more in-depth to the spiritual care services offered. I was struck by the scale and scope of the spiritual care services on offer. I was somewhat saddened that, as I and others saw it, spiritual care was not recognised and prioritised as it deserved to be. I was impressed by the work of the spiritual care team at SLCH, and by the spiritual care services provided by other hospices in the Western Cape, and hospices throughout SA. I became interested in questions of why spiritual care services were not given the prominence and recognition that spiritual carers and others in my organisation believed they deserved, as part of the overall palliative care service package.

Reviewing literature on spiritual care, both from local and international scholars, I found that there is a paucity of relevant and current literature which addresses the role of spiritual care, spiritual care education, and models of spiritual care within hospice palliative care settings in SA.

Reviewing the palliative care programmes and interventions that are offered by the Inter-Disciplinary Team (IDT) at SLCH, I have noted a significant absence of formal guidelines that shape spiritual care interventions. For a significant length of time in my organisation there was a felt need to develop a national spiritual care curriculum, which I learned from many discussions with members of the IDT, and with hospice management. Germane to that, the spiritual care workers themselves lamented about not being heard as key role-players in the development of such a curriculum. Further, they felt excluded as key role-players of the IDT

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and somewhat marginalised from the holistic palliative patient care experience. Conclusions drawn by some spiritual care workers about their exclusion from the IDT centred on spiritual care not being a recognised profession.

International scholars, mostly from the Global North, point out that spiritual care education has a positive impact on participants' perceptions of spirituality and spiritual care and suggest that a higher education level, and more spiritual care lessons or training courses can increase perception levels (Cipriano-Steffens et al., 2021; Javanmardifard et al., 2020; Wu & Lin, 2011). Swinton and Pattison (2010) affirm that an education in the field of spirituality encompasses a variety of human needs and thus enables spiritual care workers to identify and respond effectively to any particular need they may encounter within whatever situation they find themselves in. Wasner et al. (2005) suggest that spiritual training can generate significant improvements in one's compassion for the dying, but also in compassion for oneself and can help increase job satisfaction while reducing work-related stress. Research work along similar lines in the Global South is significantly limited and is only just emerging in SA (Chandramohan & Bhagwan, 2016; Mthembu et al., 2016).

Given the context in which the spiritual care workers find themselves in hospice palliative care settings, and the dearth of literature on hospice spiritual care within a South African framework, an important starting point, for me, was to draw on the experiences and the wisdom of the hospice personnel and spiritual care workers themselves. Further, I got a sense from some of the spiritual care workers that there was a need to develop such a spiritual care curriculum because the current practise portrays spiritual care as individualistic and even idiosyncratic in nature. In other words, there is a view that the spiritual care workers approach their work with their patients from their own spiritual framework and experience of spirituality, and that there are no, or few, common factors at play across the practices of different spiritual care workers, and no common sets of skills and attributes that coordinate their work as a collective. In addition, because the spiritual care workers are volunteers, they may be utilising varied, and a wide range, of care practices.

The question arises whether there may be common skills and knowledge which will assist spiritual care workers, even if they retain their individuality, to do their work in the best way it can be done. I was struck by the fact, as shown in the literature, that spiritual care workers in some countries in the Global North, such as the United States of America (USA) and Europe, are often professional social workers (Callahan, 2012; Hodge & Bushfield, 2006), professional

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nurses (Balboni et al., 2013; Cockell & McSherry, 2012), and chaplains (Cadge, Calle, & Dillinger, 2011; Derrickson, 2012). In some settings in the Global North, such as Australia, both professionals and volunteers work as spiritual care workers, but even volunteers in many contexts are required to undergo formal training in spiritual care (Spiritual Care Association, 2020). The Global South (including SA) is significantly more reliant on volunteers to provide spiritual care interventions, with professionally qualified spiritual carers being a rarity and often non-existent. There are also resource constraints in terms of providing and paying for trainings. Consequently, formal curricula, largely developed by and within the Global North contexts, may not be readily applicable for volunteers in a country like SA (something I discuss in detail in Chapter Four). The hospice where I work, SLCH, I know to be relatively well-resourced for SA, but even in this context, while significant work around spirituality has been documented at SLCH, it has fallen short of developing a formal spiritual care curriculum and consequently, a formal model of spiritual care intervention.

Despite having a large body of anecdotal data suggesting their work is valuable (Hickman, 2009; Swartz et al., 2015), the spiritual care workers at SLCH have repeatedly called for assistance in developing a formal curriculum to frame spiritual care within the IDT and within a hospice palliative care setting. This led me to ask the questions: What are the current spiritual care practices within hospice palliative care settings in SA? What are the spiritual care training needs of hospices in SA? Is there a need to develop a national curriculum for spiritual care intervention? To ask those questions, I needed to establish if there is in fact an appetite, wider than expressed at SLCH, for such a curriculum.

Through this dissertation, I set out to understand how spiritual care is practised in hospices in SA and, crucially, if there is a need for a national spiritual care training curriculum. This was accomplished through a three-tiered study, which I describe below.

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CHAPTER ONE

INTRODUCTION

1.1 Background

With the launch of the Republic of South Africa National Policy Framework and Strategy on Palliative Care 2017-2022 (Republic of South Africa, 2017) by the National Department of Health's (NDoH) National Health Council in October 2017, palliative care has finally found its rightful place on the continuum of health care platform in South Africa (SA) (Republic of South Africa, 2017).

The shift in thinking from the old concept that palliative care is "end-of-life care" to the new thinking of palliative care as being care "from the time of a terminal diagnosis to death" has led government and service providers to position palliative care within the context of this policy (Republic of South Africa, 2017). The new concept of palliative care now sees palliative care as a bridging programme that benefits patients and families while potentially reducing the utilisation of medical services and costs of medical care at the end of life (Gwyther et al., 2019).

An illness trajectory, as commonly written about, is from diagnosis, to treatment, to a curative outcome (Steinhauser et al., 2017), but some illnesses are not cured, and may end in death. Increasingly, the shift now is for the attending health care professionals to refer patients for palliative care interventions at the point of the terminal diagnosis (Mason et al., 2020). Typically, the trajectory of the palliative care phase is characterised by medical interventions, psychosocial services (Callahan, 2018; Elk, 2017), and spiritual care services (Puchalski et al., 2020), until death occurs (Baur et al., 2019; Gwyther, 2018; O'Callaghan et al., 2019). Bereavement then follows for the families and loved ones (Githaiga & Swartz, 2017a). Growing evidence suggests that referral at the early stage of the terminal diagnosis allows for the patient and family members to explore different palliative care services more meaningfully and in-depth, and to explore resources and facilities available as the patient progresses on the palliative care path to end-of-life (De la Porte, 2016; Drenth et al., 2018).

Spiritual care is an essential element of the holistic palliative care experience (Best et al., 2019; Mthembu et al., 2016; Paal et al., 2019; Puchalski et al., 2009; Selman et al., 2014; Snapp & Hare, 2021). Unlike pain management protocols that have clear indicators, spiritual care

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interventions appear to be loose and organic (Steinhauser et al., 2017). Consequently, impact is challenging to track, as is the effectiveness of the varied formal and informal approaches utilised in spiritual care interventions. Historically, chaplains offered spiritual care services and it is partly because of this that spiritual care has a religious connotation attached to it (Cohen et al., 2012). It is therefore important to differentiate spirituality from religion. According to many authors, religion is a set of texts, practices, and beliefs about the transcendent shared by a community, and involves a relationship with God (see, for example, Hall, 2014). Spirituality, on the other hand, is about a *"person's relationship with the transcendent questions that confront one as a human being, and this may or may not involve a relationship with a god or gods"* (Puchalski et al., 2014, pp. 645–646). Defining spirituality is highly contentious, as spirituality takes on different meanings for different people, an issue I discuss in greater detail in Chapter Three. These meanings may be based on several factors, including culture, religion, gender, geographic location, and belief systems. The scholarly field of spiritual care is further troubled by being dominated by research from countries in the Global North[1]. Clearly, wealth is the criterion used to make the distinction between the Global North and Global South. The ramification of such a distinction creates multi-faceted levels of diversity. Global North countries generally have better resources, health care, education, employment opportunities and infrastructure, and consequently advance and progress more rapidly. By contrast, in the Global South, many countries are beset by abject poverty, failing health care systems, and fading economies. Issues of diversity, conflict and poverty are global issues, but they are particularly prevalent in the Global South. It can be further argued that within diversity there is diversity and while this may be the case, diversity takes on a different valence in the Global North as compared to the Global South, as I describe in Chapters Five, Six and Seven.

Some of the general spiritual care issues discussed in the Global North include credentialed spiritual care training curricula for spiritual care workers (Brennan, 2007; Carrasco et al., 2015; Mason et al., 2020), providing psychosocial support for spiritual care workers (Callahan, 2017a; Ferraz et al., 2020), measuring the impact spiritual care services have on patients' palliative care experiences (Bone et al., 2018; Horsfall, 2018), and developing and testing

[1]There are many debates about how to classify countries. The 'Global North' generally corresponds to countries categorised by the World Bank (World Bank Blog 2021/2022 Atlas) as high-income countries (HICs) – so, for example, Australia, which is a high-income country is commonly viewed as part of the Global North, despite its being in the southern hemisphere. Countries in the 'Global South' generally correspond to the World Bank low and middle-income countries (LMICs) (World Bank Blog 2021/2022 Atlas). South Africa is a middle-income country. The distinction here is based largely on financial resources, though of course other factors are associated with relative wealth.

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spiritual care tools kits for improved spiritual care patient outcomes (Best et al., 2020; Paal et al., 2019). While this is needed and is necessary, and must be applauded, it needs to be considered whether spiritual care, a service which is strongly influenced by local contexts, may need adaptations or different approaches in diverse settings in the Global South (a discussion I come back to in Chapter Four). Adaptations, improvements, new approaches and reimagined models of spiritual care bespoke to the needs of countries and their contexts may need to be explored. This study aims to explore and understand how spiritual care is practised, prioritised, and provided by hospices in SA and what the spiritual care training needs are of spiritual care workers in SA, which, like others, is diverse, but which also has a particular political and social history.

1.2 Problem statement and research questions

Given the gap in the literature on spiritual care in hospice palliative care settings in SA, I sought to explore and understand what the national and provincial views, practices and training curriculum needs related to spiritual care work in hospice palliative care settings in SA are, with particular reference to a group of localised hospices in the Western Cape, and with a focus on spiritual care workers in a local hospice in Cape Town. The following questions underpin the study:

a) What are the current spiritual care practices within hospice palliative care settings in SA?
b) What are the spiritual care training needs and is there a need to develop a national curriculum for spiritual care intervention?
c) What could the barriers be to developing such a spiritual care curriculum?

1.3 Research design and methods

I used a largely qualitative research design but within a broader mixed methods approach. The study incorporated a range of data gathering techniques to explore and understand what spiritual care services are currently offered, how hospices view and use spiritual care, and the experiences of spiritual care workers within a hospice palliative care setting, including understanding their expressed and nuanced spiritual care training needs. The research comprised three Sub-Studies, namely:

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1. A national online study targeting all hospices in SA to get an understanding of their current spiritual care services and, more crucially, to establish if they felt a need for training in, and the development of, a spiritual care curriculum.
2. Within the Western Cape Province, SA, establishing what the spiritual care practices are at these hospices and to explore what their training needs in spiritual care are. This study applied the focus group discussion design. This province was chosen because I live and work in the Western Cape, SA, I have strong networks with these hospices, and am familiar with their services.
3. Interviews and focus group discussions at SLCH, the hospice I lead as CEO, provided the data for this Sub-Study. SLCH was chosen to undertake this tier of the study partly for reasons of convenience, but also because SLCH has one of the most established spiritual care services in the Western Cape, SA, and has a large cohort of spiritual care workers undertaking spiritual care work. Therefore, I felt it was relevant and important to reach spiritual care workers offering the service to explore and understand from their perspectives their work as spiritual care workers and explore what their training needs in spiritual care are.

These Sub-Studies are now discussed in more detail:

1. Sub-Study One: This was a largely quantitative national online survey (See: Addendum 1) of all registered hospices in SA. This study was undertaken to establish what spiritual care practices were in place, if any, what their spiritual care training needs are, and if they saw a need for the development of a national curriculum in spiritual care. There were significantly quantitative and, to a lesser extent, qualitative components to this Sub-Study. The survey was undertaken with all Hospice Palliative Care Association of SA's (HPCA[2]) registered hospices (or member organisations[3], as HPCA refers to them). The survey was directed at either the CEO or the Health Services Manager of each of the 104 hospices in SA. Figure 1 shows where the hospices are situated in SA and which hospices participated, which hospices did not participate, and which hospices agreed to participate in this study, but did not.

   Figure 1

[2] HPCA is a national association operating in all nine provinces in SA and 51 health districts. Some of its voluntary member organisations offer hospice palliative care, some home-based care, and others both services.
[3] I use the term "member organisations" and "hospices" interchangeably. HPCA calls its members "member organisations" because all organisations offer palliative care, but not all call themselves hospices.

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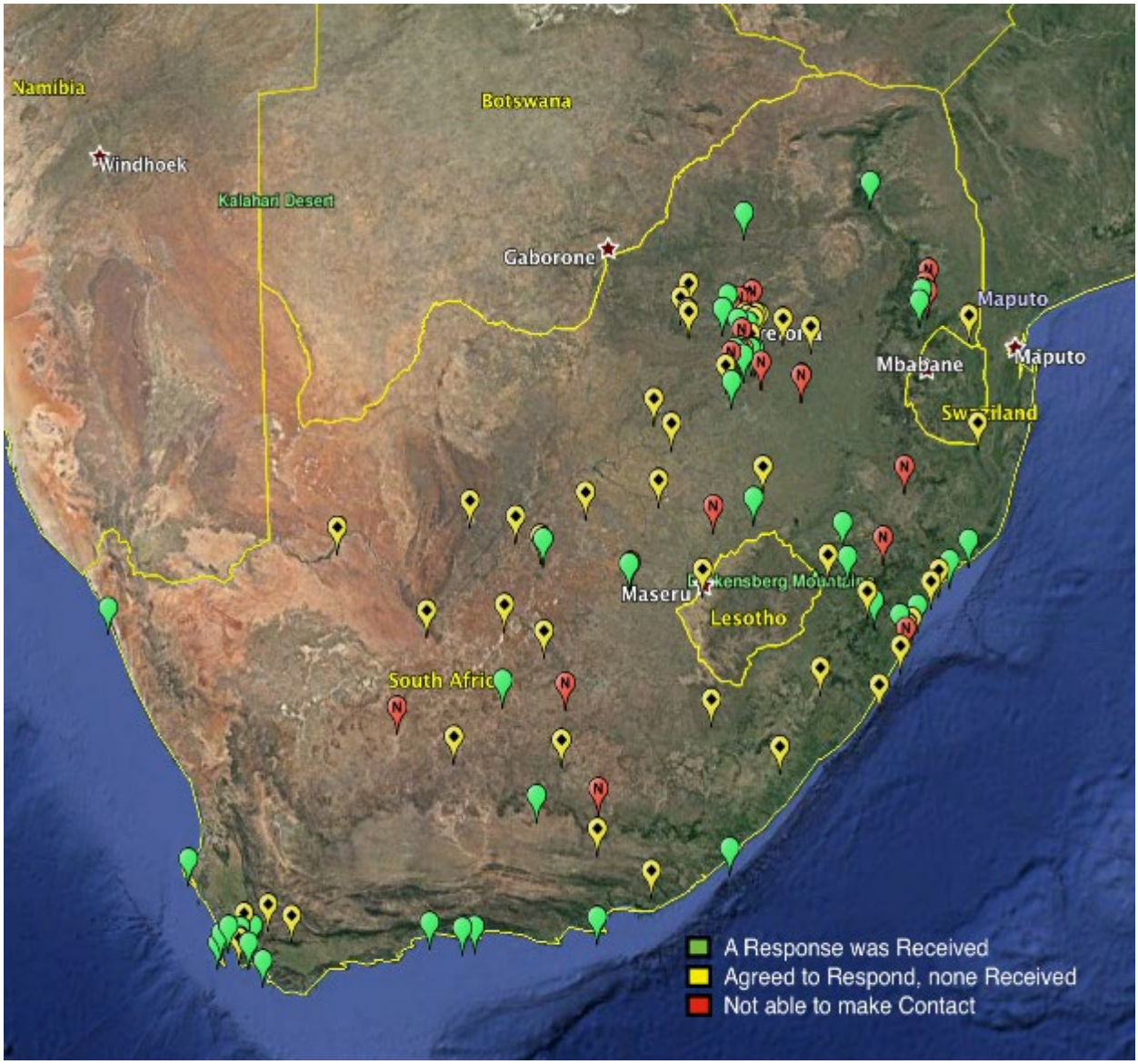
Sub-Study One – National Online Survey Participants



Participation was voluntary (See Addendum 2: Recruitment Material {Online Survey}; Addendum 3: Participant Information Leaflet {Online Survey}; Addendum 4: Electronic Consent Form {Online Survey}). Using an online survey for this tier of the study was useful as no other research method can provide this broad capability at a reasonable cost. I wanted to have a national sample to gather targeted results from which to draw conclusions and make important decisions. I analysed the quantitative data using simple statistical analysis according to categories, patterns, and themes. The three key purposes of this survey were to establish what spiritual care services were on offer by hospices nationally, what their spiritual care training needs are, and if, in their

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view, there was a need for a national curriculum in spiritual care to be developed or not. A limitation of this research method was that the survey could be ignored and consequently not responded to, or not fully completed by the target hospices.

2. Sub-Study Two: Focus group discussions were conducted with key role-players within the 12 hospices in the Western Cape, SA, registered with HPCA, to explore and understand how these hospices offered spiritual care services and to explore their views on whether there was a need for a curriculum in spiritual care to be developed. I engaged with my provincial peers of the Western Cape Province, SA, largely through focus group discussions, to discuss relevant questions regarding a national curriculum in spirituality, and to explore what practices were at play at their hospices, bearing in mind the complexities and diversities in this province from a socio-economic, demographic, and socio-political perspective (See: Addendum 5: Sub-Study Two – Guiding Questions for Semi-Structured Focus Group Discussions.). The regional HPCA body, the Western Cape - Hospice Palliative Care Association (WC-HPCA) – calls for these hospices to meet quarterly. Each hospice was represented by the CEO, and/or a senior member of the management team, usually the Health Services Manager. Table 1.1 gives an overview of the participants, their background, and the participating hospices in this Sub-Study.

Table 1.1

Sub-Study Two – Overview of Participants from Participating Hospices

District	**Represented hospice #**	**No of participants from represented hospices**	**Designation of participants at the represented hospices**	**Palliative care background of the hospice participants: Medical, psychosocial, spiritual, bereavement**
	Hospice #1	4	Psychosocial Counsellor (1) Social Worker (1) Manager (1)	Medical (1) Psychosocial (2) Spiritual (1)

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Eden District, Western Cape			Pastor (1)	
	Hospice #2	3	Professional Nurse (1)	Medical (2)
			Chief Executive Officer (1)	Psychosocial (1)
			Psychosocial Manager (1)	
	Hospice #3	1	Chief Executive Officer (1)	Psychosocial (1)
	Hospice #4	1	Nursing Manager (1)	Medical (1)
	Hospice #5	2	Social Worker (1)	Medical (1)
			Medical Doctor (1)	Psychosocial (1)
	Hospice #6	2	Professional Nurse (1)	Medical (1)
			Social Worker (1)	Psychosocial (1)
	Hospice #7	4	Spiritual Care Coordinator (1)	Medical (1)
Cape Town District, Western Cape			Training Facilitator:	Psychosocial (1)
			Professional Nurse (1)	Spiritual Care (2)
			Chief Executive Officer (1)	
			Spiritual Care Worker (1)	
	Hospice #8	1	In-Patient Unit Manager (1)	Medical (1)
	Hospice #9	3	General Manager (1)	Medical (1)
			Patient Care Manager (1)	Psychosocial (2)
			Social Worker (1)	
	Hospice #10	1	Nursing Manager (1)	Medical (1)
	Hospice #11	1	Chief Executive Officer (1)	Medical (1)

Participation in the study was voluntary (See Addendum 6: Recruitment Material {Focus Group Discussions}; Addendum 7: Participant Information Leaflet {Focus Group Discussions}; Addendum 8: Confidentiality and Non-Disclosure Agreement (Focus Group

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Discussion and One-on-One Interview). I appreciated that this phase of the project could pose researcher/participant relationship complexity, because I knew the participants as peers in the association as I, too, am the CEO of a hospice in the Western Cape, SA. I thought about the multiple roles and relationships to be borne in mind, but on balance I felt that being an insider, I was best placed to engage with the provincial and national participants. I used a neutral co-facilitator to work with me in running the groups, but I also played an active role in this Sub-Study. (See Addendum 9: Consent to Participate in Research (Focus Group Discussion)).

3. Sub-Study Three: This study explores spiritual care services in a hospice setting through the perspectives of a group of spiritual care workers from SLCH, the hospice where I work, in Cape Town. This took the form of interviews and focus group discussions (see Addendum 10: Sub-Study Three – Guiding Questions for Semi-Structured Interview). SLCH has a large cohort of spiritual care workers, largely volunteers, offering spiritual care services throughout the precinct of Cape Town. SLCH has one of the most established spiritual care services in SA with a significant body of anecdotal records of this practice. I chose SLCH partly for convenience, but it is also especially useful to look at a spiritual care programme that is very well established and has a good reputation. Furthermore, much has been written about the spiritual care work undertaken at SLCH, in the form of notes, pamphlets and books – there is an established tradition of the spiritual care team thinking reflexively about their work. This history positioned SLCH to be well placed for this phase of exploring in a nuanced way what has been learned about spiritual care practice in the South African context (Hickman, 2009; Swartz et al., 2015). SLCH has 26 active spiritual care workers, 23 of whom are volunteers and three are paid staff. Some spiritual care workers have been volunteering in this capacity for over 20 years.

   I also had complex relationships with the research participants of this Sub-Study. Though most of the spiritual carers are volunteers, as CEO I am technically their ultimate line manager. Though I would have preferred to interview the spiritual carers myself, I was concerned that they might feel constrained, especially from making negative comments about the organisation in my presence. For this reason, I employed a co-facilitator to conduct the one-to-one interviews, though all interviewees were informed that I would have access to all the data. However, I facilitated the focus groups and engaged with some participants individually, with their permission and where necessary, to seek clarity on issues they raised. In this process a stronger relationship

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of trust and understanding emerged. I also shared the papers I wrote (see Chapters Seven and Eight) as these focused largely on this Sub-Study, for discussion and comment before submitting them to journals. My supervisor, who is an expert researcher with an interest in palliative care but external to the organisation, attended all focus group discussions, which added another layer to this Sub-Study. I explored the experience of spiritual care workers, and asked them for their views on what, if anything, should be done at SLCH and nationally to strengthen spiritual care as one of the four key pillars of the holistic palliative care experience.

Table 1.2

Sub-Study Three – Demographic Characteristics of Participants

Participant #	**Gender**	**Qualifications**	**Years of practice and experience as a spiritual care worker**	**Years of practice and experience as a spiritual care worker at SLCH**	**Religion**	**Languages spoken**
#1	F	BCom Honours (Economics)	3 years	3 years	Christian by birth. Currently, none	English, Afrikaans
#2	F	Higher Dip. Education. Dip. Special Ed (Remedial); MPsych(clinical)	2 years	2 years	Islam by birth. Currently: none	English, Afrikaans
#3	F	Certified Lifeline Counsellor	30 years	28 years	Christian by birth	English

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					Currently: none	
#4	M	Grade 12 Lay councillor in Church	25 years	7 years	Christian	English, Afrikaans, Xhosa, Zulu
#5	F	BA (Social Work) Certificate: Family Constellation Certificate: Gender Reconciliation Capacitar (Energy healing)	35 years	10 years	Quaker (Historical Christian denomination)	English, Afrikaans
#6	M	BSc (Psychology) BA (Psychology)	25 years	15 years	Islam by birth but embrace all religions	English, Afrikaans
#7	M	MA (Practical Theology) MA (Missiology)	15 years	13 years	Christian	English, Afrikaans, Xhosa
#8	M	Dip in Theology BA (Hons)	35 years	3 years	Christian by birth but embrace all religions	English, Afrikaans

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#9	M	Dip. Interior Design Dip. Interior Architecture	6 years	6 years	Christian by birth. Currently: none	English, German, French

Participation in this study was voluntary (see Addendum 11: Recruitment Material {One-on-One Interview}; Addendum 12: Participant Information Leaflet {One-on-One Interview}; Addendum 13: Consent to Participate in Research {One-on-One Interview}). This study began with one-on-one interviews. Before coming to the interviews, I encouraged the spiritual care workers to bring along poems, stories, paintings, arts, and crafts that they had made and have used in their spiritual care work. As the CEO of SLCH, I am aware that some of the spiritual care workers are very artistic and creative and use visual effects in their spiritual care work at SLCH. With their permission, I photographed and catalogued these assets which formed the basis of subsequent focus group discussions. Nine spiritual care workers participated in this Sub-Study.

Interpretation is a means to amplify meaning, to explore and clarify the many strands of meaning which constitute the phenomenon of spiritual care practice at hospice palliative care settings (Daniele et al., 2020; Malterud, 2001). Interpretation implies gaining a better understanding of phenomena than those who manifest or enact them would normally have themselves (Ritchie et al., 2013). This includes paying attention to absences and their significance (Willig & Stainton-Rogers, 2008). Psychosocial studies facilitate interpretation on two levels: on the one level it integrates descriptions of "what is there" (ground up research), and on the other level it involves personal interpretations or making assumptions of what is there (Frosh & Saville-Young, 2008). In this study, I set out to understand what spiritual care interventions are already in existence at hospices in palliative care settings in SA. Because of the limited local literature on spiritual care within palliative care, and limited anecdotal local spiritual care training guidelines, my personal interpretation (or assumption) was that a training curriculum must be the main need, which could have been an attractive assumption to make. Although established theories provide powerful tools for analysis, they also can offer blind spots and projections that can cover up meanings as well as reveal them (Willig & Stainton-Rogers, 2008). To guard against this, I conducted follow-up focus group discussions to obtain

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clarity on certain points that were shared as effective learning tools in spiritual care intervention. Engaging with the question of interpretation raises issues of ownership and power and I had to often think about who has the last word (Frosh & Baraitser, 2008; Willig & Stainton-Rogers, 2008).

1.4 Chapter layout

This dissertation has been carried out in the "thesis-by-publication" format which has several advantages, including the rich experience of scholarly writing, external review, and publishing. This format was also chosen partly because of the underrepresentation of African authors in scholarly work in Africa. Perhaps the one drawback of this format is some repetition of information. To position this study, it is important to give the reader context such as the location of the study and who the participants are. Similarly, to position the articles and manuscript, I needed to give the reader context of the study's location and participants' data. Therefore, the reader will see repetition of certain information, for example, Figure 1, Tables 1.1, 1.2 and 1.3 are presented in this chapter and in Chapters Five to Nine.

Understanding the spiritual care training needs within hospice palliative care settings is necessary in contexts such as SA where literature (and therefore data) is scarce. Such data, when brought to the public domain, could potentially inform practice and policy (Callahan, 2017a; Clelland et al., 2020; Drenth et al., 2018; Hedt-Gauthier et al., 2019; Herzig van Wess & Holmer, 2020; Gwyther, 2018; Kirby et al., 2018). This dissertation contains four published articles and one manuscript which have been submitted to, and accepted by, international journals and one is currently under peer-review. Each article or manuscript is presented in this dissertation as a separate chapter, with a short discussion on how it is linked to the larger study presented at the beginning of the chapter. Consequently, the traditional Methods, Results and Discussion chapters of dissertations have been omitted in this case as each article and manuscript contain these components. As each chapter is a complete article or manuscript, there is, unavoidably, some overlap and repetition in the introductions, relevant literature reviewed and methods sections within each article and manuscript and chapter. There may also be some overlap in the cited references.

With the overarching aim of understanding how spiritual care is practised in a diverse SA and what the spiritual care workers' training needs are within hospice palliative care settings, the chapters are arranged to facilitate a scrutiny and discussion on spiritual care practices and

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spiritual care training needs within the SA hospice palliative care context. Therefore, this dissertation is divided into four broad parts:

a) **Part 1** comprises Chapters One through to Four and presents the introductory and background information for the study. I review literature on palliative care and spiritual care in the Global North and Global South with focused reviews on legislation and, more critically, on the different continents' palliative care associations, the role of spiritual care within hospice palliative care settings, and the training and workforce issues related to spiritual care service provision. In Chapter Three, I examine the above points but with specific relevance to SA and within the unique context of SA. I drill down further to give an overview of SLCH and, crucially, illuminate how spiritual care is offered and practised at this hospice. The chapter presents frequently cited definitions of spiritual care with a review of SLCH's bespoke spiritual care service within its own hospice context. In Chapter Four I undertake a conceptual analysis of three recently developed spiritual care curricula from the Global North and analyse them from a Global South perspective.

b) **Part 2** comprises Chapters Five through to Seven with each containing published articles which describe the impact of diversity on the provision of, and training in, spiritual care within the context of a middle- to low-income country like SA, as well as contextual opportunities regarding spiritual care within hospice palliative care settings in SA. In these papers, I examine spiritual care practices in SA as an answer to research questions one and two.

c) **Part 3** comprises Chapters Eight and Nine, with each containing a published article, which describe the training needs of spiritual care workers towards the development of a spiritual care curriculum and explores the barriers hindering the development of a spiritual care curriculum for SA. These chapters re-address and respond in greater depth to research question two and answer research question three. At the beginning of each chapter, a short discussion on how the paper fits into the bigger picture of the research is provided which, in this Part 3, focuses on the experiences and motivations of spiritual care workers undertaking spiritual care work with a focused view on their spiritual care training needs within the context of their work. Together, Chapters Five to Nine present the five papers which form the results of this dissertation.

d) **Part 4** comprises Chapters Ten and Eleven, which are the concluding chapters of this dissertation. Chapter Ten is a reflexivity chapter where I reflect on my experiences

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during the research process. Chapter Eleven is the concluding chapter where my concluding thoughts are presented. This chapter ends by connecting the findings of all the manuscripts and making recommendations for future research.

Table 1.3 provides more details about the chapter layout and the publication status of each article:

Table 1.3

The Layout of the Dissertation Chapters and their Publication Status

Part	Chapter	Topic	Publication status	Authors and title
	1	Introduction & Background		
1	2	Positioning palliative care and spiritual care within hospice palliative care settings in the Global North and Global South		
	3	Positioning spiritual care within hospice palliative care settings in SA		
	4	Contextual analysis of existing		

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		curricula in spiritual care		
	5	Article 1	Article published in *BMC Palliative Care*.	Mahilall, R., & Swartz, L. Spiritual care in palliative care in a middle-income country: Contextual challenges and opportunities. (2021). https://doi.org/10.1186/s12904-021-00756-9
2	6	Article 2	Article published in *BMC Palliative Care*.	Mahilall, R., & Swartz, L. Spiritual care practices in hospices in the Western Cape, South Africa: The challenge of diversity. *BMC Palliative Care,* 20(9). (2021). https://doi.org/10.1186/s12904-020-00704-z
	7	Article 3	Article published in *Culture, Medicine, and Psychiatry*.	Mahilall, R., Swartz, L. 'I am Dying a Slow Death of White Guilt': Spiritual Carers in a South African Hospice Navigate Issues of Race and Cultural Diversity. Cult Med Psychiatry (2021). https://doi.org/10.1007/s11013-021-09750-5
	8	Article 4	Article published in *Journal of Religion and Health*.	Mahilall, R., & Swartz, L. Spiritual care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa. *Journal of*

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3				*Religion & Health.* (2021). https://doi.org/10.1007/s10943-021-01232-7
	9	Article 5	Article published in *Journal of the Study of Spirituality*.	Mahilall, R., & Swartz, L. Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial, and local voices. *Journal of the Study of Spirituality, 11*(2). (2021). https://doi.org/10.1080/20440243.2021.1922257
4	10	Research experience and self-reflection		
	11	Concluding thoughts and directions for future research		

1.5 Funding

This study was part funded by the Mauerberger Foundation; a charitable foundation based in Cape Town as well as Arm-in-Arm-in-Africa's Late Dr John Song's Memorial Foundation. There was no requirement from both Foundations that I conduct the work in any specific way, and the Foundations had no say in the data interpretation and writing of the dissertation.

1.6 Ethical considerations

All research has the potential for negative consequences, for those directly involved in the research and the research population itself (Frosh, 2013). It is important not to let the researchers' assumptions or personal investment blind them to possible negative consequences.

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It is my ethical responsibility to explore the possible negative consequences and mitigate these as much as possible.

I used reflexivity as an ethical tool (Frosh, 2003; Guillemin & Gillam, 2004). By locating myself as the researcher in the research study, it improved my awareness of the ethics of the study by making explicit my investment in the topic and the various roles I play in the different hospice palliative care spaces. Considering the ethicality of this study allowed me to think about the impact that I might have on the way I research the topic, on the interactions with the study by the participants, and my possible bias in the interpretation of the texts generated in the interviews (Pearson & Piazza, 1997).

I was mindful that in-depth interviews about sensitive topics can sometimes develop into relationships that mimic psychotherapy in some ways (Duncombe & Jessop, 2005; Minikel-Lacocque, 2018). The spiritual care workers face emotional complexities surrounding terminal illness, death and dying daily which can be emotionally taxing on them. I was equally mindful that the interview process may shift the participants' perspective or bring to the surface aspects of their experience that are uncomfortable. Strong or unpleasant emotions may be elicited (Hollway & Jefferson, 2013).

Consequently, I made provision for all participants interviewed in Sub-Study Two and Sub-Study Three to have access to the services of a social worker and a psychologist to debrief and process these experiences if any distress was caused. Further, the offer I made to the participants was that the social worker or psychologist could be of their choice or colleagues unrelated to the study whose services I was able to recommend. Based on previous experience of sensitive research of this nature, I did not anticipate many such referrals, but nonetheless this offer was made and budgeted for.

Interpretation of the interview data also poses challenges (Hollway & Jefferson, 2013; Willig & Stainton-Rogers, 2008). We must be alert to this and incorporate ways to interrogate our interpretations. Having a different interviewer to the researcher improves the ability to see these blind spots (Hollway & Jefferson, 2013). Given these considerations, and given the fact that as CEO of SLCH, I have a management role in relation to the spiritual carers, I engaged the services of a well-trained and experienced co-facilitator to collect interview data. The participants were aware that I would have access to the data, but experience in similar research (Lyner-Cleophas, 2016) suggests that, especially where participants have negative issues to raise about their work and/or the organisation, they are more likely to discuss these with a co-

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facilitator. In line with Hollway and Jefferson's (2013) suggestions, having a co-facilitator also allows for debriefing discussions as part of the analytic process.

The method of triangulation was used to check and establish validity in the three sub-studies by analysing the research questions from multiple perspectives. Further, the method of triangulation seeks to map out the richness and complexity of human behaviour by studying it from multiple standpoints (Cohen et al., 2011) which was obtained by this three-tiered study.

Ethics approval was sought and obtained from the following bodies:

- Stellenbosch University (Project Number: 10237) – university through which I am undertaking this PhD programme. (See Addendum 14)
- HPCA (Ref.: 02/19) – the national body of hospices in SA. (See Addendum 15)
- SLCH – the Research and Ethics Committee approved the engagement of the spiritual care workers registered at the Hospice. (See Addendum 16)

1.7 Chapter summary

In this chapter, I present the background and rationale for the study, and the research questions which guided the process were discussed. I describe the structure of the thesis, the methods employed in carrying out the Sub-Studies, and the ethical considerations. In the next chapter, I discuss relevant literature, thereby positioning palliative care and, more specifically, spiritual care, within hospice palliative care settings in the Global North and the Global South.

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CHAPTER TWO

POSITIONING PALLIATIVE CARE AND SPIRITUAL CARE WITHIN HOSPICE PALLIATIVE CARE SETTINGS IN THE GLOBAL NORTH AND GLOBAL SOUTH

2.1 Introduction

Wherever they may be in the world, patients with advanced, irreversible disease need palliative care, whether formally or informally offered (Callahan, 2012; Centeno et al., 2018; Connor et al., 2020; De la Porte, 2016; Drenth et al., 2018; Elk et al., 2020; Fraser et al., 2018; O'Brien et al., 2019; Pastrana et al., 2010, Pesut et al., 2015; Puchalski et al., 2020; Robinson et al., 2014). A palliative care approach can be applied to both acute and chronic life-limiting illnesses as an added layer of support to patients and families, concurrently with disease-modifying treatment (Simon, 2018). It is estimated that over 40 million people globally will need palliative care each year, yet only an estimated 14% of this population are offered such care formally (WHO, 2018). There is a concerted global movement to include palliative care into primary health care systems (Rosenberg & Yates, 2010; Ryan et al., 2020); to credential palliative care (Best et al., 2020; Paal et al., 2019); to train health care professionals in palliative care (Adams et al., 2016; Connor et al., 2020); and to make palliative care services available to the global citizenry (Dempers & Gott; 2017; Hasson et al., 2020; Mills, 2019). Typically, palliative care is offered at health care institutions such as hospitals, hospices, and clinics. Palliative care is also offered at home-based and community-based levels.

There is consensus (Balboni et al., 2007; Best et al., 2020; Callahan, 2015; Chandramohan & Bhagwan, 2016; Mthembu et al., 2016; Paal et al., 2019; Puchalski et al., 2009; Selman et al., 2013) on the importance of the four components of palliative care – medical care, psychosocial care, bereavement care, and spiritual care services. Spiritual care is rapidly emerging as one of the key components of palliative care, with global recognition that patient health care should be holistic in nature and underpinned not only by medical and psychological interventions (Yildirim & Ertem; 2021). But the Global North and Global South have many differences, which impact how palliative care, and more specifically spiritual care services, are prioritised

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by governments and health care ministries; how, and the extent to which these services are made available, if at all; and how these services are received by patients. I discuss this at length in Chapter One.

Also, in Chapter One, the background and rationale and the research questions which guided this study are introduced. In this chapter, I review literature on the constructs of palliative care, with a focus on spiritual care services within palliative care settings globally, and with specific reference to hospices. The field of spiritual care within palliative care is a broad one with a myriad of differentiations. As such, and within the context of this dissertation, it is not possible to discuss all the global differentiations. Therefore, in this chapter, I focus on discussing and contrasting spiritual care within hospice palliative care settings in the Global North and Global South and on issues germane to my central concerns.

Additionally, I review health care frameworks that underpin palliative care in both the Global North and the Global South, focusing on organised hospice associations. Although they are commonly formed as voluntary bodies, they play an increasingly active advocacy role in bringing prominence to palliative care, and by extension to spiritual care services. The regulations that are discussed and compare are relevant to this dissertation and these research questions. A large body of legislation related to palliative care is available, for example, Global Atlas of Palliative Care at the End of Life (Worldwide Palliative Care Alliance, 2014); International Observatory on End-of-life Care (IOELC); and International Association for Hospice and Palliative Care (IAHPC). These will not be discussed in detail as my focus is on spiritual care specifically. I will therefore discuss the role spiritual care services play in palliative care interventions with a view to highlighting how spiritual care is practised and prioritised in the Global North and Global South. This chapter ends with a review of resource and workforce issues which assist in, or hamper, the delivery of spiritual care services in palliative care settings, and the implications thereof. In the next chapter I will discuss these very issues within a South African context (where this study was based) and compare, and contrast, how spiritual care is practised within a context of hospice palliative care settings in a diverse SA, thereby drawing similarities with and points of departure from the Global North and other low- to middle-income countries (LMIC).

2.2 Global palliative care practices

For this study, I feel it is useful and necessary to present the top three trending and widely subsumed definitions of palliative care. It is not necessary for me to adopt a specific definition

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of palliative care for this dissertation, but it is important to ground this study in a set of commonly established definitions. While there are several definitions proffered globally to define palliative care (Ryan et al., 2020), two established definitions of palliative care widely used are from the World Health Organization (WHO) and the IAHPC. The WHO (2018) defines palliative care as:

> An approach that improves the quality of life of patients and their families facing…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).

The IAHPC (2017) defines palliative care as:

> The active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.

The Lancet Commission on Global Access to Palliative Care and Pain Relief (the Lancet Commission) identified the need to review and revise the definition of palliative care for global relevance and use and as commissioned by the WHO, the IAHPC took on this task of recalibrating and redefining palliative care as part of its agreement of work as a non-governmental organisation (NGO) (Baur et al., 2019; Radbruch et al., 2020). Radbruch et al., (2020) reviewed how and when palliative care is introduced and integrated into patient care plans, with the "how" and "when" largely suggesting which definition of palliative care was being adopted. They developed a consensus-based definition of palliative care that accentuates the focus on relief of serious health-related suffering and the care of patients with a very limited remaining life span.

The new suggested definition of palliative care, arising out of that process, is:

> The active holistic care of individuals across all ages with serious health-related suffering…because of severe illness…and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers. (Radbruch et al., 2020, p. 761).

Though the concept of palliation and care at the end of life is probably universal, palliative care as a specific discipline is very much a Western concept that may not easily translate into indigenous languages nor non-Western cultural practices (Speck, 2016). Even in the Global

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North, there remains deep rooted contention about the constructs of palliative care with the emergence of a new nomenclature that conceals the end-of-life component of palliative care, which is at the heart of palliative care (Ryan et al., 2020). The IAHPC was commissioned by the WHO to develop a global consensus-based definition of palliative care, which it did in 2017. Criticism of this definition remains, with two well-respected palliative care bodies – the European Association of Palliative Care (EAPC) and World Hospice Palliative Care Alliance (WHPCA) – opting to endorse the WHO 2002 definition of palliative care (discussed above). If there can be no accord in the Global North on an accepted definition of palliative care, it cannot be expected that the two established definitions would be easily adopted in non-Western countries given that these countries have added complexities of diversity in the context, commonly, of histories of colonisation and conquest and deep rooted, traditional familial care practices. These two prominent definitions lack common language. Most of the palliative care tools have been developed in the English language, which has limited linguistic and cultural relevance in countries where English is not the official or main language. Many such countries, for example African countries, often have multiple languages and dialects, which makes the translation, adaptation, testing, and re-evaluating of these tools for their reliability and validity increasingly challenging (Powell et al., 2008).

Palliative care has made tremendous strides as a speciality area of professional health care practice (Baur et al., 2019). Evolving largely from a socially informed hospice movement, championed by Dame Cicely Saunders in 1967 when she founded St Christopher's Hospice in South London, and thereby giving rise to the modern-day hospice movement (Saunders, 2006), palliative care has made significant advances in many countries. This has been achieved by the development of palliative care quality frameworks, advance care planning, early referral for palliative care services, and capacity-building efforts to support the provision and integration of palliative care services into health care systems (Mills, 2019). Ryan et al. (2020) term this movement the *'upstream migration*' of palliative care. Despite these developments, many disparities remain in palliative care, especially when considering LMIC. Access to palliative care is a fundamental human right (United Nations, 2009). However, palliative care in LMIC is limited by the lack of ready availability of opioid analgesia for pain management (Lamas & Rosenbaum, 2012), the lack of integration of palliative care into health care systems (Court & Olivier, 2020), the lack of health care infrastructure (Downing & Hastings-Tolsma, 2016); the limited availability of health care professionals trained in palliative care (Krakauer et al., 2018),

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and a dearth of empirical research on palliative care in such countries (Hedt-Gauthier et al., 2019).

Ddunga (2011) laments that despite the demonstrated need for palliative care in Africa, access to such care is at best limited and at worst non-existent. However, palliative care in many less wealthy countries is a relatively new concept and, while access to palliative care, according to WHO (2018), is universal, its newness may be a contributing factor for it not being widely available, easily accessible, and possibly easily taken up as a health care service (Court & Olivier, 2020). LMIC such as SA face significant resource constraints – financial and human capital are in the main – something not as acutely felt in high-income countries (sometimes abbreviated to HIC). Lynch et al. (2013) found only one country in Africa, namely Uganda, to have an advanced palliative care component offered from its limited bouquet of medical services, with generalised palliative care only offered by a handful of other African countries. Furthermore, what may be considered part of a formal service in the Global North may, in cases, be delivered informally through kin and other networks in the Global South (Ntizimira et al., 2014).

A lack of funding to undertake evidence-based research, for integrating palliative care into health care systems, and for improving infrastructure and upskilling health care workers in palliative care, gives urgency to the development and presence of sustainable partnerships between the Global North and Global South. Examples of such international donor partnerships between Africa and the United States of America (USA), for example, are with United States Agency for International Development (USAID), the United States President's Emergency Plan for AIDS Relief (PEPFAR), and The Open Society Foundation who have largely initiated the integration of palliative care into health care in the African continent. These partnerships led to other collaborations between government and NGOs (Whyle & Olivier, 2016) and between health care workers from Public Benefit Organisations (PBOs) and professionals from NGOs (Gwyther, 2018; O'Brien et al., 2019). The shortcoming of these well-meaning and well-placed partnerships appears to relate to the transfer of funds, knowledge and palliative care models into countries that are culturally, racially and linguistically different from wealthier counties, at times with limited exploration of how a largely Western palliative care model of integration will play itself out within such very different contexts, and at times without due regard for the possible existence of informal palliative care networks and systems which are operating but not named as such in largely Global South settings.

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Diversity, is, of course, a global issue. However, despite previous discussions about cultural issues and health care, only in recent years has there been a serious recognition of, and focussed research on, the role culture plays in the acceptance of palliative care in wealthier countries (Johnson et al., 2016; Taylor et al., 2013). For example, a research team in the USA immersed themselves in an aboriginal African American community to understand that community's needs before a bespoke palliative care intervention model was tailored specifically for their needs (Elk et al., 2020). It is important for researchers in the Global South to take due account of such initiatives, as what may be viewed as a specialist area of palliative care in the Global North may be a mainstream issue in the Global South.

2.3 The role of hospice palliative care associations, globally

According to the World Hospice Palliative Care Association (WHPCA) and WHO (2014), access to formal quality palliative care services is rare outside North America, Europe, and Australasia.

There are several hospices and palliative care bodies that have been formed over the decades to champion a specific course, or several courses, in palliative care advancement (Wright et al., 2008). The WHPCA is rooted in giving a voice to hospices and palliative care with over 350 member organisations in over 100 countries. The National Hospice and Palliative Care Organization (NHPCO) is the largest non-profit membership organisation representing hospices and palliative care programmes and professionals in the USA. The focus of this dissertation is on palliative care associations globally. The participants in my study are from hospices in a formal, albeit voluntary, association with the HPCA of SA. To this end, I felt it necessary to define an association within the health care context. According to the McGraw-Hill Concise Dictionary of Modern Medicine, an association is *"a professional organization for health professionals…often based on specialty and are usually national, often with subnational or regional affiliates…usually offer conferences and continuing education"*.

The IAHPC was born out of the International Hospice Institute (IHI) in the USA and evolved into the IAHPC. Both the (then) IHI and the current IAHPC remain focused on globally championing palliative care. The distinct difference between them is beginning to recognise that palliative care needs, models, implementation approaches, and how palliative care is prioritised, or not, is different for each country (IAHPC 2020–2024). Increasingly, the IAHPA (2020–2024) recognises that cultural globalisation is characterised by hybridity, and that palliative care may be adapted, modified and re-invented to suit the needs of each country.

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With that as a backdrop, IAHPC suggests a roadmap which it terms its *"thematic areas of work*" and which centres on advocacy, education, research, and information dissemination (IAHPC 2020–2024, 2019, pg. 7). While the IAHPA's five-year plan is to *"accelerate global access to palliative care for those who need it, in order to relieve serious health-related suffering"* (IAHPC 2020–2024, 2009, pg. 7), the opening lines to this chapter, supported by citing local and international scholars in palliative care, suggest that globally, terminally ill patients need palliative care. The *"palliative care for those who need it"* in the above citation gives the impression that to access palliative care, or not, is the patient's decision to make, when, conversely, such a decision is already made for the patient based on considerations such as: are palliative care services offered globally?, are all countries able to fund the provision of palliative care services?, culturally how is palliative care integrated into the different countries' health care systems?. Consequently, it can be argued that the suggested five-year roadmap may have easy uptake and relevance for well-resourced countries, typically in the Global North, who largely have well-developed health care systems (Nita, 2019; Shiffman, 2015; Walsh et al., 2006), but may not be readily embraced by LMIC who have added burdens of poverty, conflict, and deep rooted cultural and traditional practices (McIntosh et al., 2021; McIntyre & Klugman, 2003; Meessen et al., 2011).

Countries largely in the Global North drove the IAHPC movement. Other countries globally were encouraged to form their own country hospice palliative care associations, with the aim of each being a member of IAHPC while retaining their own autonomy. The affiliated countries saw the benefit of a global voice, especially regarding policy change and advocacy at different governmental levels (Baur et al., 2019). In some countries, policy change in palliative care had positive impact on health care systems by integrating palliative care as part of the continuum of health care to varying levels (Gwyther, 2018). This positively impacted education and training of professional health care workers in palliative care to varying degrees (Paal et al., 2019). As more was learned about palliative care, through case studies and other empirical research, information was shared with other countries, thereby creating an awareness of the importance and relevance of palliative care (Hedt-Gauthier et al., 2019). While this scorecard suggests that the work of IAHPC is done and it may be true for the countries in North America, Europe and Australasia, the picture is significantly different for other continents, such as Africa and South America, which have either only recently, or have not yet, formed their own country hospice palliative care associations.

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There are several established hospice palliative care associations globally, such as the Hospice Association of America, European Palliative Care Association (EPCA), Australian Palliative Care Association, Canadian Palliative Care Association, Latin American Association for Palliative Care, African Palliative Care Association (APCA) and more recently, in SA, the HPCA of SA. The common thread that unifies these associations, besides their palliative care mandate, is to advocate for the integration of palliative care services into national mainstream health care systems and national health strategies (IAHPC, 2019; Mpanga et al., 2003). Given the heterogeneous settings of the different country palliative care associations, the scope, progress, and impact are varied across many health care settings, with stronger associations lending support, such as care expertise, research expertise, financial aid, and palliative care toolkits, to up-and-coming associations largely in the Global South, and with the aim of supporting them with their palliative care services (Mpanga et al., 2006). Significant strides have been made in simulating a twinning relationship of an established palliative care association supporting a less established palliative care association, but several added barriers have emerged that need to be understood and addressed. These include recognising and understanding the needs of the people against the model of palliative care that is proposed; recognising and understanding how health care is legislated, prioritised and practised in different countries; recognising and understanding that offering support by a well-established palliative care association to a lesser established one should not be a "jug and mug" partnership (Haralambos, 1985) where typically the Global South is seen to be a passive recipients of aid, but rather a partnership of shared responsibilities with recognition of the many layers of diversities that exist in each country.

2.4 Global spiritual care practices in hospice and other palliative care settings

Before discussing anything related to spirituality and spiritual care, I feel it is important to discuss spirituality and religion (briefly touched on in the Preamble to Part 1). Especially important are the deeply debated and contentious issues around the definitions of these two concepts as both terms are sometimes used interchangeably, are conflated, or have different meanings in different contexts and settings. The difficulty with defining spirituality and religion does not lie so much in the many ways in which these concepts are expressed, but more so by spirituality and religion being vague and broad phenomena to describe (Koenig et al., 2012). Spirituality and religion take on different meanings depending on the context in which they are being viewed. For example, scholars in the disciplines of sociology, anthropology, psychology, and health debate this topic robustly (Horii, 2019). While there is no consensus-

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base for an accepted definition of religion, an established definition that is often referenced is that of Durkheim (1917/1995) who defined religion as:

> A unified system of beliefs and practices relative to sacred things - set apart and forbidden - beliefs and practices which unite into one single moral community called a church, all those who adhere to them. (p. 47)

In this definition, the reference to a church dichotomises and makes a distinction between places of worship with the church, traditionally having a strong Western world connotation, thereby giving authority to priests, bishops, and clergy (Beckford, 2003). Similarly, when encountered by African religions, one is again faced with the problem of definition and the issue of how African traditional religion is constructed, especially in the argument that *"religion does not become solidly incorporated into that system unless it is explicitly formed as one of the religions, recognised by outsiders and constructed by insiders"* (Beyer, 2006, pp. 266–267).

While the word spirituality made its entry into the English language from the year 1500 onwards, spirituality today attempts to reconcile *"spirit and body, sacredness and sexuality together in a redemptive experience of the totality and mystery of life"* (Tacey 2004, pp. 36–37). Like religion, spirituality takes on different meanings in different contexts with many definitions being proffered in different disciplines and settings. But unlike religion, spirituality has been lauded for recognising the unity of the sacred, human beings and nature, and breaking down barriers between the different religions, by allowing for choices between beliefs and practices that individuals can make themselves without the aid of a religious institution that autocratically dictates dogma to its adherents (Van Niekerk, 2018). The definition of spirituality is criticised for, amongst other issues, not having a "sacred canopy" (Berger, 1969) as a holding structure or community for like-minded people to meet, which raises the question of institutionalising spirituality – the same criticism levied against the religious domain. Clearly more empirical research is needed to clarify the definition of religion and spirituality, especially within the many contexts in which these concepts are used.

The term spirituality within the context of care for this dissertation is now considered. Leininger (1996) suggests that there are two types of caring: generic caring, which refers to kin or family providing care in a lay manner and often shaped by culture, religion, and tradition; and the other type of caring: professional care, which refers to learned and practised care. It is important to determine how caring is expressed among different cultures in the world and what

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these generic and professional elements of caring are (Buqa, 2015; Eliastam, 2015; Himonga, 2013; Nolte & Downing, 2019; Prinsloo, 2001). Africa, for example, is a continent deeply steeped and rooted in culture and beliefs, with strong faith in traditional methods of healing and the belief that ancestors hold the key to healing and respect for ancestors invokes curative outcomes (Gureje et al., 2015; Musyimi et al., 2016). Spirituality and spiritual care are considered a natural part of cultural practices in most countries in the Global South, such as those in Latin America (Schmidt, 2019), Africa (Metz & Gaie, 2010), Asia (Mok et al., 2010) and India (Rajagopal & Venkateswaran, 2003), and consequently the need to categorise spiritual care as an intervention or a formal service becomes superfluous. Through the process of socialisation and nurturing of children and the passing down of norms, mores, values and cultural practices, spirituality and spiritual care practices are similarly passed down as part of the socialisation process, with the expectation that at a time of illness or end-of-life, spiritual care will be provided by the family and the community (Hitlin, 2006; Parke & Buriel, 2006; Vidal, 1988; Wilson, 1992). In LMIC spiritual care is often not considered as a stand-alone service but is incorporated and entwined as part of a collective of skills for daily living, which I explore at length in Chapter Four. By the very nature of how spiritual care is practised in certain contexts, it supports one school of thought that suggests that formally researching how spiritual care is practised in LMIC is challenging precisely because this practice cannot be boxed into a finite service package and nor can it be extracted as a neat unit from the holistic care package.

Spiritual care is hard to define; it involves personal values that are difficult to base on empirical evidence and to put into general guidelines for health care practice (Nolan et al., 2011). The path of formalising spiritual care within palliative care and within the broader health care system gained traction in the Global North, largely spearheaded by the USA, Western Europe, and Australia, and thereby limiting its applicability in other Global North and Global South countries. However, through years of consultative processes, evidence-based practices[4], and practice-based evidence[5], a consensus-based definition of spiritual care was arrived at:

> *Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment,*

[4] Evidence-Based Practices seek to integrate best research evidence with clinical expertise and patient values (Titler, 2008).
[5] Practice-Based Evidence seeks to explore a range of treatment approaches that are supportive of the culture of the local society and traditions (Titler, 2008).

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> *to self, to others, to nature, and to the significant or sacred*. (Puchalski et al., 2014, p. 643)

Dame Cicely Saunders coined the term "spiritual pain" to describe the desolate sense of helplessness and hopelessness experienced by many people at the end of life (Saunders, 1988). Ratshikana-Moloko et al. (2020), in a South African study, used the terms religion and spirituality interchangeably and clustered religious and spiritual needs of patients as a collective. Uwland-Sikkema et al. (2018), in a study in the Netherlands, suggests that to understand spirituality one needs to look at it from a meaningful perspective of a person's beliefs, goals and sense of meaning. Tao et al. (2020) found the disjuncture between the understanding and practice of spirituality striking and, consequently, found it difficult to define spirituality. There were similar findings in a study conducted at a Taiwanese tertiary hospital where hospice physicians and nurses were burdened logistically with cultural diversity, afterlife considerations (van Laarhoven et al., 2011), the professional team's own training capabilities (Best et al., 2020; Paal et al., 2019), and broken family relationship dynamics (Callahan, 2013).

Similarly, there appears to be different focus areas amongst the established palliative care associations around developing spiritual care services. The APCA considers religious beliefs, coping, and transcendence to be part of spirituality (Selman et al., 2011), while the EPCA strongly advocates for training and education in spiritual care for health care workers towards enhanced patient care outcomes (Best et al., 2020; Gamondi et al., 2013). This I discuss further in Chapter Four. The WHPCA has made a concerted effort to develop a palliative care toolkit, including spiritual care assessment tools, thereby further supporting palliative care professionals and spiritual care workers to offer an effective palliative care service (Connor, 2017). After conversations with *"more than 300 global health leaders, students, and practitioners from 2010-2014"*, Addiss (2018, p. 337) found that while spirituality is easily and readily recognised as an integral part of the palliative care framework, spirituality is rarely mentioned in practice, literature, or training programmes of global health. Yet, spiritual concerns are among the most pressing for palliating patients and their families (Fricchione, 2011).

Globally, spiritual care services, like palliative care services, are offered at hospitals, hospices, community levels and at patients' homes. In higher income regions such as USA, Australasia and Europe, spiritual care services are typically offered to chronically and terminally ill patients

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at hospitals and hospices (Holmes, 2018), and largely through chaplain services (Best et al., 2021; Liefbroer & Berghuijs, 2019). Such countries also offer home-based care services by trained groups of health care professionals supported by strong associations to churches and pastoral services (Liefbroer et al., 2021; Seymour & Cassel, 2017). In LMIC such as Africa, India, and countries in South America, where typically their health care facilities and infrastructure are limited and significantly overburdened, spiritual care takes on a different valence, with services largely being offered at home by family members or by community-based volunteers. A neighbourhood model of spiritual care is offered in India where local volunteers are trained in spiritual care and palliative care, with active support from a network of trained professionals, and where the care of the terminally ill and aged is the shared responsibility largely of the community, and of the state to a lesser extent (Gielen et al., 2016; McDermott et al., 2008; Rego et al., 2020; Shanmugasundaram et al., 2006). Similarly, in African countries with large rural populations, including SA, there is a significant thrust by their health departments and ministries to empower community-based health care workers to the care of the ill and infirm at the community and home levels (Drenth et al., 2018; Gwyther et al., 2019; Mwangi-Powell et al., 2013; O'Brien et al., 2019). The decanting of services back into communities and family homes, largely into the hands of family members, volunteers, and Faith-Based Organisations (FBOs) (Du Toit, 2019), is increasingly necessary due to the ever-increasing demand for health care services that conventional health care institutions such as hospitals, hospices and clinics are unable to adequately meet because of funding constraints, lack of trained professionals, and lack of adequate infrastructure (Rawlinson et al., 2014). Consequently, care services (including spiritual care services) are largely assigned to volunteers, family members, traditional leaders, traditional healers, and religious leaders (Akintola, 2011; Compion, 2016). An interesting observation is that spiritual care services in the Western world are significantly Christian-based, while in the more rural and LMIC, spiritual care is provided from a cultural-base of health care beliefs (Agom et al., 2019). This further lends support to the call for spiritual care services to be bespoke to the needs of each country and that a universal approach may not be the best solution in meeting individual country's spiritual care needs. I explore this in greater detail in Chapter Four.

Historically, spiritual care terminologies were largely underpinned by emotive words such as compassion, empathy, and sympathy. While these words share a common emotive lineage, the language also evolved and devolved to give contemporary meaning to patients' current situations termed as "spiritual pain" and "end-of-life" (Soto-Rubio & Sinclair, 2018). In a

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recent EPCA Blog, Radbruch and Richter (2020) added "resilience" to the spiritual care vocabulary which explores resilience in praying, and resilience in coping from the perspectives of the care givers and from the perspective of the patients. The spiritual care "buzz word" in the African context is *"Ubuntu"* – an isiZulu word in African philosophy that means "a quality that includes the essential human virtues; compassion and humanity" (Nweke, 2014). The *Ubuntu* concept refers to the fact that our humanity comes from our relatedness to other people (Mji et al., 2011). Spirituality and *Ubuntu* are difficult to define. While both concepts have relevance and meaning in multiple settings in health care, both concepts take on a common communal caring component towards improved patient care outcomes (Akinola & Uzodike, 2018). *Ubuntu*, like spirituality, focuses on relational personhood, the concepts are emotive, and largely both concepts are infused by people's ideas of identity. Some African scholars say that one cannot understand *Ubuntu* if one is not African (Idoniboye-Obu & Whetho, 2013; Mangaliso, 2001). Some global scholars suggest that one cannot understand spirituality unless one is religious, thereby suggesting that there is a perception that one must belong to a particular cultural or religious group to understand *Ubuntu* and spirituality (Ngubane-Mokiwa, 2018). Similarly, people believe that one does not have a right to talk about *Ubuntu* if one is not part of it (Gray & Vawda, 2019). While trying to make spirituality and *Ubuntu* into an object of intellectual scholarship, there is considerable emotion and emotional investments that go into practising these concepts.

I was struck by the similarity of the meaning and intent of these words – spirituality and *Ubuntu* – in the context of the Global North and South. Instead of having these words in competition and comparison with each other, there should be a pooling of terms, phrases and terminologies that resonate with spiritual care services globally, and which allows for flexibility of relevance and salience for individual country contexts. When reviewing the literature on spirituality and *Ubuntu,* they may appear to be irreconcilable concepts, based largely on how spirituality and *Ubuntu* are practised, yet they can coexist whether a person lights a candle, or another sits in meditation. The concept of *Ubuntu* will be considered in greater detail in Chapter Three when I discuss and position spiritual care within hospice palliative care settings in SA.

Spiritual care services are usually practised using a team approach in health care (Buljac-Samardzic et al., 2020), and within a palliative care setting spiritual care is practised within an Inter-Disciplinary Team (IDT)[6] (Callahan, 2017b; Sinclair et al., 2015) or Multi-Disciplinary

[6] An interdisciplinary team is a group of professionals from several disciplines working interdependently in the same setting, interacting both formally and informally towards improved patient care outcomes. Separate

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Team approach (MDT)[7] (Puchalski et al., 2009; Schultz et al., 2020). Rego and Nunes (2019) and Richardson (2014) suggest another approach – the individual approach – by the creation of a "spiritual advocate" who typically could be a health care professional who neutrally assesses the spiritual care needs of the patient. Lower income countries and rural communities are starkly different where spiritual care is largely provided by local volunteers (Barnard & Furtak, 2020), family members, FBOs (Bowers du Toit, 2019; De la Porte, 2016; Magezi, 2012) and traditional healers in seemingly loosely coordinated approaches (Harding et al., 2011). O'Connor et al. (2006) critically reflected on the IDT approach in palliative care and Hall et al. (2019) critically reflected on the MDT approach, with both citing barriers of inadequate communication, role confusion, and power struggles as significant stumbling blocks to optimal care.

2.5 Resources and workforce issues impacting spiritual care in hospice palliative care settings, globally

To respond to the global population growth, and an expanding aging population, it is increasingly necessary for palliative care organisations and hospices to maintain, sustain and grow a vibrant workforce (Lysaght Hurley et al., 2020). Hospice work, at its inception and until recently, has ostensibly been nurse-driven and nurse-led (Safrina et al., 2021; Schroeder & Lorenz, 2018). Therefore, it is not surprising that much of the counselling, breaking of bad news, psychological support, spiritual care services and bereavement work fell largely on the shoulders of nurses, who in addition had their core nursing care duties to fulfil (Brighton et al., 2017). As palliative care became more recognised and widely practised, especially in the Global North, the importance of including other disciplines and professionals, such as medical doctors, social workers, spiritual care workers, and bereavement counsellors (Elsner et al., 2017), became necessary. There is a steady move, as discussed earlier in this chapter, to grow palliative care globally with clear advancements made in pain control (Knaul et al., 2018), psychosocial support interventions (Lynch et al., 2013) and increasingly on formalising

assessments may be conducted, but team members work to achieve a common goal. Information is communicated and problems are solved in a systematic way among team members, typically during team meetings (Clark et al., 1986).

[7] A multidisciplinary team is composed of members from more than one discipline so that the team can offer a greater breadth of services to patients towards improved patient care plans. Team members work independently and interact formally. Appropriate experts from different professions handle different aspects of a patient's case independently. The patient's problems are subdivided and treated in parallel, with each provider responsible only for his or her own area. A project manager or team leader may mould these parallel efforts at the end of the process, however (Zeiss & Steffer, 1996).

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spiritual care services as part of the holistic palliative care experience for terminally ill patients and their families (Gwyther et al., 2019; Mason et al., 2020). There is also a concerted thrust, more so in the Global North, to grow the professional workforce in spiritual care and to develop spiritual care as a key component of palliative care (Abu-Odah et al., 2020). The approach is significantly different in many countries in the Global South where financial constraints largely determine and direct what health care services are offered and prioritised as essential services (Clark & Emerson, 2020).

Taghavi and Johnston (2020) explored workforce planning in palliative care using operations research (OR) methods. OR is widely valued by management in a wide range of industries, but its use to date in health care resource planning has been limited (Cameron & Johnson, 2015). Workforce planning in palliative care is essential (Etkind et al., 2017). Within the health care delivery system, variability can result in bottlenecks, reduced quality of care, increased staff workload and overcrowding, which could lead to patient and staff dissatisfaction (Helm et al., 2011; Tolu et al., 2016). OR methods have been applied to hospital operations to improve effectiveness and efficiency where the usual approach is to analyse the problem in economic terms and then execute the solution within the context of that institution (Kumar, 2019). Largely undertaken via surveys, OR outcomes for spiritual care and palliative care can assist with managing workers' caseloads, duty rostering, and timeous workforce recruitment which will, by extension, improved patient care service and experience (Taghavi et al., 2018; Tupla et al., 2020). This largely Global North model is gradually gaining traction and uptake in the Global South. This is not to say that health care in the Global South cannot benefit from such a model; the opposite may in fact be true. While the Global South may well be ripe and ready for this model, it can be argued that resource limitations, particularly poor infrastructure, financial, and human capital, may prevent the implementation of OR research findings to improve, upscale and increase workforce pools. Elements of the OR model can, however, be adopted and adapted by countries in the Global South, especially those utilising volunteers to offer spiritual care services and other health care services, to identify workforce (volunteer-force) gaps so that the volunteer recruitment process can be expediently undertaken long before that resource runs dry. In Chapter Three I explore spiritual care workforce issues in greater depth within a South African context. In Chapter Eight I also provide a more focused scrutiny of this issue.

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2.6 Chapter summary

In this chapter, I position palliative care in the Global North and Global South with some descriptions of hospices and palliative care practices in both settings. I also explore how spiritual care is viewed, incorporated, and prioritised in both settings. The relevant legislation, with a focus on the different palliative care associations that largely coordinate hospice palliative care work globally, is reviewed. I conclude the chapter with an exploration of resource and workforce issues in the Global North and South and their implications. In the next chapter, I give greater context to the spiritual care practises within hospice palliative care settings in SA.

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CHAPTER THREE

CONTEXTUALISING SPIRITUAL CARE WITHIN HOSPICE PALLIATIVE CARE SETTINGS IN SOUTH AFRICA

3.1 Introduction

In Chapters One and Two I gave a background to this study and positioned and contrasted spiritual care practice in hospice palliative care settings in the Global North and Global South. I start this chapter by briefly positioning palliative care and spiritual care in Africa (extensively covered in Chapter Two), with a focused view on SA. A background to the configuration of SA's health care system, pre- and post-Apartheid, is given. I discuss in greater depth the concept of *Ubuntu* as a social and health care issue within a South African context. I then take a closer look at how spiritual care is practised, how spiritual care is provided, who the workforce is who provides spiritual care services, where spiritual care is provided, and how spiritual care will be sustained into the future. The work SLCH is undertaking in spiritual care is explored. I conclude this chapter by exploring SLCH's sustainability model of spiritual care. The next chapter focuses on the training needs of spiritual care workers in diverse hospice palliative care settings in SA.

3.2 Positioning health care in Africa and South Africa

Africa comprises 53 independent countries. Of these, only four have integrated palliative care into health care policy (Ntizimira et al., 2014). These are Kenya, SA, Tanzania, and Uganda, with Rwanda and Eswatini having developed stand-alone national palliative care policies (Mwangi-Powell, 2011). As discussed in Chapter Two, spirituality in Africa is largely considered to be embodied and experienced through cultural practices that are passed down the family's lineage through home-socialisation and sharing of traditional beliefs and customs (Mahlangeni et al., 2014). Ben-Arye et al. (2011) suggest that spirituality in health care in Africa is a fundamental component of complementary and alternative medicine and is often discussed in the context of holistic care. Hoosen et al. (2020) add that spirituality and complementary and alternative medicine are interconnected in many ways, with an estimated 80% of African countries' people accessing complementary and alternate medicine for their holistic health care needs. Much work still needs to be done in understanding how spiritual care

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is practised in health care settings and contexts in Africa (Chaudhry & Aswal, 2013; Karsten & Illa, 2005; Omonzejele, 2008; Oni et al., 2016; Rhee et al., 2018).

SA, situated at the tip of Africa, has a population of just over 58 million, has nine provinces, see Figure 2, and eleven official languages (Stats SA, 2018). Sub-Study One was a national study of hospices in SA and Sub-Study Two was localised in the Western Cape, also shown in Figure 2.

Figure 2

Map of South Africa Highlighting Nine Provinces

(https://saspecialist.southafrica.net/za/es/modules/entry/an-introduction-to-south-africa – downloaded 10 April 2021)

The third Sub-Study was conducted at SLCH in Cape Town, SA. SLCH is a longstanding and well recognised hospice providing palliative care in the larger Cape Town Metropolitan district which has a population of 3 740 026 (StatsSA, 2011). SLCH has a catchment population of just under 450 000 inhabitants (StatsSA, 2011) and as shown in Figure 3 (SLCH's Centre for Palliative Learning, 2020).

Figure 3

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St Luke's Combined Hospices' Catchment Area of Service

(Source: SLCH's Centre for Palliative Learning, 2020)

Prior to 1994, SA's health care system was segregated and divided along racial lines, with one highly resourced system favouring a minority White[8] population and another grossly under-resourced system that serviced a majority Black population (Coovadia et al., 2009; Omotos & Koch, 2018). Post-1994 the ruling African National Congress (ANC) political party developed a National Health Plan (ANC, 1994) that was significantly more equitable and made primary health care the centrepiece of health policy, with the health system being divided into private and public health care sectors (Ross, 1999). SA's public health care system has five layers: primary health care (typically offered from clinics at the community level with hospices falling within this category), district hospitals, regional hospitals, tertiary/academic hospitals, and central/academic hospitals (Gwyther et al., 2019; Republic of South Africa, 2017). The aim of this structure is to provide, as far as possible, cost-effective health care for all citizens, at an

[8] In SA, as elsewhere, the use of "racial" terminology is complex and contested and remains a source of debate and great pain. We make no claim for the scientific validity of the different "racial" categories, but the labels used still have social significance (Swartz et al., 2020). In the South African context, the term "Coloured", which is the most contested, is an official term still used in government documents, and refers to a diverse group of people of mixed and diverse origin, with Afrikaans being the predominant language spoken (Swartz et al., 2020). By contrast, the term "Black African" commonly refers to people who speak indigenous languages such as isiXhosa, spoken in the Western Cape. Under Apartheid, the Western Cape was viewed as a preferential area in which "Coloured" people could live and work, whereas "Black Africans" were viewed as not being citizens of SA, but of racially defined "homelands".

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appropriate level, and to ensure better health for all (Ataguba et al., 2015). The public health services are divided into primary, secondary, and tertiary levels and are provided through health facilities that are in, and managed by, the provincial departments of health (Young, 2016). Hospices and health care institutions providing palliative care and spiritual care do so at all three health care levels. However, the extent to which palliative care services are offered varies depending on several variables, such as funding, human capital, infrastructure, and patient uptake of this service, which I discuss in more detail in Chapters Five to Nine.

SA has a problematic history to overcome, but also the potential to draw on its experiences of health care inequalities and on the lessons from the multi-faceted ills of apartheid to build good quality health care for all its citizens. One lesson that SA has learnt from the apartheid past, and has embarked upon addressing, is mapping a process towards establishing a National Health Insurance (NHI). This process was started in 2012 and is envisaged as a 14-year process aimed at providing universal health coverage for all South Africans (see National Health Care Act, 2003 (Republic of South Africa, 2004) and White Paper on National Health Insurance, 2015 (Republic of South Africa, 2015)). The NHI further seeks to ensure that every South African will be issued with a NHI Card which will secure them a right to access comprehensive health care services, free of charge, by accredited health facilities such as clinics, hospitals, and private health care practitioners and more so that the services will be delivered closest to where people live or work (Republic of South Africa, 2004, 2015).

The other lesson that resonates throughout Africa for all-inclusive health care, and increasingly more so globally, is based on the concept of *Ubuntu*, as mentioned in Chapter Two. *Ubuntu* is a Nguni, Bantu language term meaning "humanity" and is often glossed as "I am because we are", denoting humanity towards others (Mwipikeni, 2018). The *IsiXhosa* saying "*Umntu ngumntu ngabantu*" ("a person is a person because of other people") is often cited as central to the *Ubuntu* concept – the definition of humanity, or what constitutes a person residing not in individual qualities but in relationships with others (Dladla, 2017). Scholars often use the term *Ubuntu* to refer to a belief in a universal bond of sharing that connects all humanity (Brunsdon, 2019; Manda, 2016; Ogude, 2012). *Ubuntu* has its roots in humanist African philosophy, where the idea of community is almost ubiquitous. (Manda, 2016; Morgan & Okyere-Mann, 2020; Ward, 2015). *Ubuntu*, like spirituality, holds different meanings for different people, and it is difficult, if not impossible, to settle on a single, unidimensional understanding of the term.

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Archbishop Desmond Tutu (a South African Anglican theologian, a Nobel Peace Prize winner, and known for his work as an anti-apartheid and human rights fighter) leaned heavily on the concept of *Ubuntu* when he led South Africa's Truth and Reconciliation Commission, which was a restorative justice body put in place to help SA deal with events which occurred during its apartheid era (Battle, 2007). Another example of enacting *Ubuntu* in a different context is that of Nelson Mandela, an anti-apartheid revolutionary who became the first democratically elected President of SA, who likened *Ubuntu* to an innate understanding amongst humanity. Mandela poignantly captured the enactment of *Ubuntu* in the metaphor of a traveller being offered food and water by villagers without the traveller asking for it (Lewis & Louw, 1995). An example of *Ubuntu* being showcased to a global audience is that by the (then) US President Barak Obama, in his speech at Nelson Mandela's memorial, who likened *Ubuntu* to sharing and the oneness of humanity (Obama, 2013).

The concept of *Ubuntu* has been applied to many fields. Education scholars such as Takyi-Amoako and Assié-Lumumba (2018) have called for a consideration of an *"Ubuntu-inspired"* education for humanity. Health care advocates such as Mthembu (2019) call for greater emphasis to be placed on *"Ubuntu-inspired"* hospice palliative care and spiritual health care work. In the field of care more broadly, Watson and Smith (2002) suggest that caring looks different depending on the ethical and ontological context in which the caring is located, with the *Ubuntu* concept emphasising reciprocity in relationships of care. Nolte and Downing (2019), in a conceptual analysis of *Ubuntu*, sought to determine how the principles of *Ubuntu* can provide a useful framework to guide care practices in SA. *Ubuntu*, as a concept, can be widely used in multiple fields with its relevance and applicability for the health care profession being most dominant (Buqa, 2015; Downing & Hastings-Tolsma, 2016; Nolte & Downing, 2019).

The concepts of spirituality and *Ubuntu* are not the same – it is possible to subscribe to a reliance on spirituality without reference to *Ubuntu*. But the concepts, as applied to health care, arguably may have overlapping implications. Health care which takes *Ubuntu* and/or spirituality seriously may foreground a system focussed not only on cure and symptom amelioration but also on care and compassion for life, in the context of a broader vision aimed at ameliorating the quality of life for all and throughout all sectors of society (Barron & Padarath, 2017; Mamman & Zakaria, 2016). The strength of a spiritual care intervention, such as *Ubuntu,* may lie in its holistic approach between different components of health, welfare, and civic systems, thereby providing a more seamless service that supports whole-patient

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centredness, and when patients and those close to them may need it most – at the end of the patient's life (O' Brien et al., 2019; Puchalski et al., 2020; Swinton & Pattison, 2010).

3.3 Spiritual care practices within hospice palliative care settings in South Africa

As I have discussed in Chapter One, there is little literature focusing on spiritual care practice within hospices offering palliative care services in SA. This is not surprising given that palliative care has only recently been recognised as a health care service in SA (Republic of South Africa, 2017). The location of hospices in SA does not appear to bear any relation to population size or the need for hospice care services and so, as seen in Figure 1 in Chapter One, regarding the location of hospices in SA, there are more hospices in better-served areas, which mirrors in fact the historical maldistribution of health care services in general. Gwyther et al. (2019) explain that palliative care in SA started in the NGO sector in the 1980s. Gwyther et al. (2019) further explain that the first hospital-based palliative care team was established in Charlotte Maxeke Johannesburg Academic Hospital in SA in 2001. Being largely PBOs depending heavily on the generosity of public funds, hospices are generally established in communities that can afford to support them (White et al., 2019). This reinforces how and why hospices are found in more affluent communities and largely absent in poorer communities (Higginson, 1997; Weissman & Meier, 2010; White et al., 2017). The unequal distribution of hospices across and within the provinces in SA is of concern, as it may indicate a mismatch between need and availability of services. O'Brien et al. (2019) assert that while most patients in the urban districts and suburbs in the Western Cape have access to palliative care, access to palliative care services is significantly poorer in rural communities throughout SA.

The concepts of illness, healing, and dying are culture-sensitive concepts (Boyd, 2000; Dantas & Amazonos, 2016). From a worldview perspective, Ward (2015) suggests that the Global North has culture-texts which view diagnosis, cure, medicine, and surgery as the core of health care, with relatively little attention paid to spirituality. Many have argued that in the African context, the opposite is true, as illness is largely viewed and understood fundamentally from a spiritual and relational framework (Brunsdon, 2019). Therefore, sickness may be viewed as a need to restore relationships (Ward 2015; Zahan, 1979). This restoration (which may be considered as part of the work of *Ubuntu*) may be sought through the work of traditional and faith healers, herbalists, elders in the family, with collective rituals and rites being central to individual healing (Ngubane, 1992). An important component of traditional healing is the search for reconciliation within families and amongst antagonists. When people and the forces

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that shape them are brought together in a reconciliatory manner, forgiveness and healing is believed to take place, and when (especially) healing cannot be achieved then death becomes an inevitable and accepted outcome (Long, 2000). There are of course many understandings of death in Africa, as elsewhere, but death in Africa may be viewed as an important interface between the human and the spirit worlds and as a *"passage to a new level of existence…a transition to a new life…a return home*" (Ikwuagwu, 2007, p. 90). This view is not necessarily uniquely African, but in the African context it is often emphasised that an ailing individual is never an isolated or individual matter. The illness of one person affects the entire familial network. Consequently, while there is understanding that an individual must carry the illness, community help and support remains a deeply rooted belief and practice (Githaiga & Swartz, 2017b), in keeping with *Ubuntu* principles. Spiritual care services should ideally be culturally sensitive, with recognition and understanding that in some cultures spiritual care may not only be centred on the patient or the immediate family but extended further to the extended families and even to the community level.

3.4 An overview of the clinical palliative care services offered by St Luke's Combined Hospices (SLCH)

Sub-Study Three was localised within SLCH, of which I am the CEO. SLCH has one of the most established and longest functioning spiritual care services provincially, and in SA. While it was convenient for me to undertake this part of the study at SLCH, it was also helpful that, as insiders with a longstanding and recognised spiritual service in place, the SLCH spiritual care workers would be given a platform to share their experiences as spiritual care workers. They could also share their ideas and insights on the training needs of spiritual care workers undertaking hospice palliative care work in diverse South African settings. SLCH, as part of the third-tier study, is as an example of an actively functioning spiritual care hospice service, and the issues raised by spiritual carers in a long-established service may be of broader relevance. Founded in 1980 and registered as an NPC, SLCH transcends conventional in-patient palliative care by also offering decentralised satellite palliative care services in significantly marginalised communities and more affluent suburbs within the greater precinct of Cape Town, SA, as depicted in Figure 4. This level of outreach is achieved through the establishment of day hospices which are community-based hubs for medical, psychosocial, and spiritual interventions. While still offering in-patient care on a limited basis (capacity to hold 20 patients in the In-Patient Unit in Kenilworth, Cape Town, SA), SLCH's day hospices have

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an overarching aim of providing care and support to terminally ill patients within their own communities and home environments. The clinical teams at SLCH care for ±500 terminally ill patients daily (SLCH, 2020). A further ±300 chronically ill patients are cared for daily through a partnership with the national Department of Health's (NDoH) Home Based Care Programme, which is localised within Khayelitsha, a partially informal township on the Cape Flats in the City of Cape Town and is purported to be the largest and fastest-growing township in SA (SLCH, 2021). In addition, a Multi-Drug Resistant Tuberculosis In-Patient Unit called Lizo Nobanda, also located in Khayelitsha and in partnership with NDoH and the City of Cape Town, is managed by SLCH in which a 10-bed facility cares for multi-drug resistant patients suffering from Tuberculosis. The IDTs at all these care sites provide medical, psychosocial, spiritual and bereavement care services to patients and their families through the well positioned community-based hubs, and in the comfort of the patients' homes.

The patient referral pathway into SLCH's service is professionally managed, well documented, and closely supervised by a set of team leaders, coordinators, and the head of health services department. Typically, patients access palliative care largely for pain management and terminal care. Once triaged and settled it is usually the medical team that reaches out to the other IDT members for continued psychosocial care parallel to medical care. Spiritual care services are one pathway to which patients and families are referred. Figure 4 outlines the Patient Referral Pathway into SLCH.

Figure 4

Patient Referral Pathway

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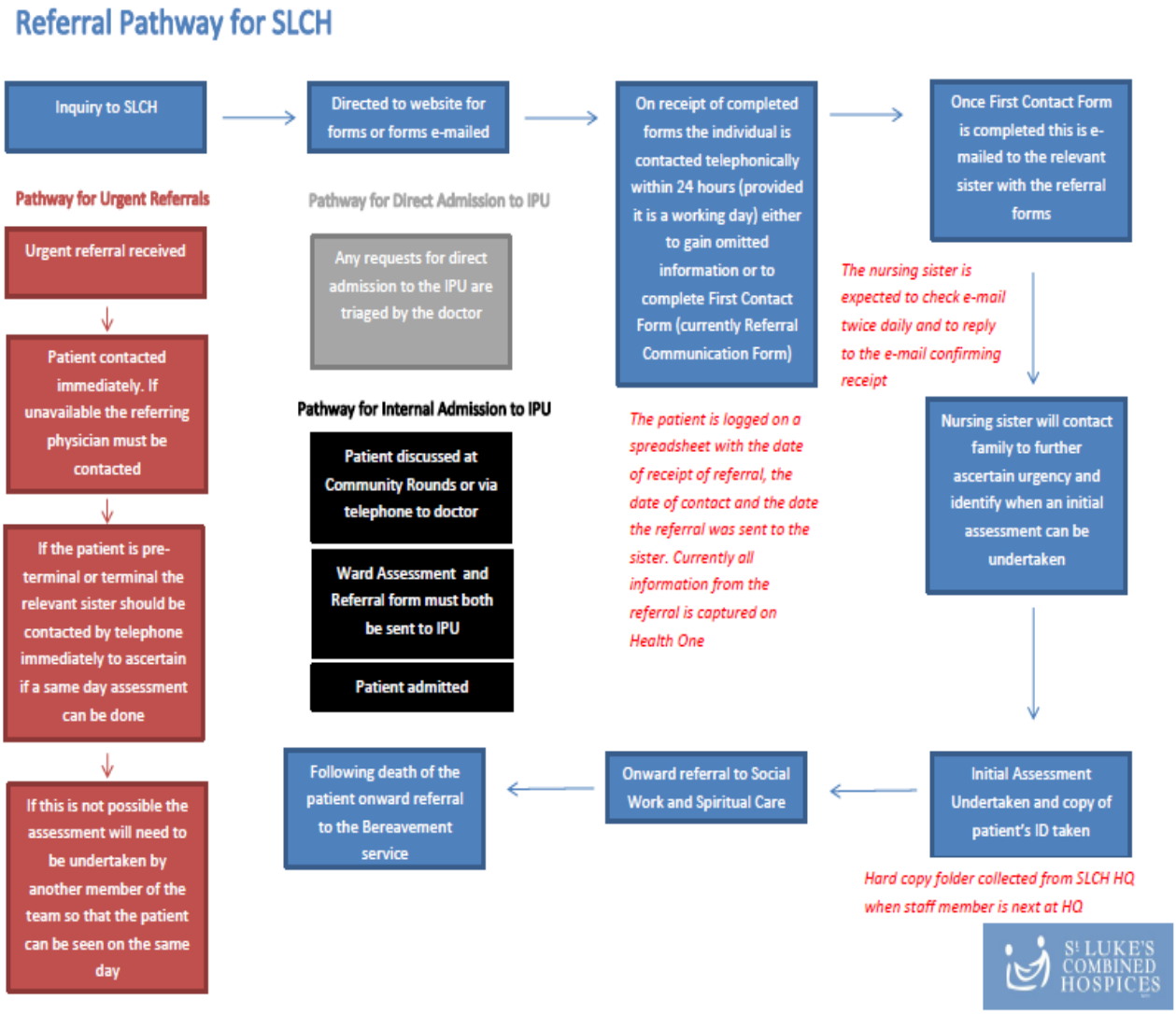

(SLCH/Everyone Drive/Health Services/Referral Pathway)

In accordance with the National Policy Framework and Strategy on Palliative Care 2017–2022 (NPFSPC), and with the aim towards strengthening palliative care services in SA, SLCH has positioned and up-scaled its services along the three fundamental tenets of effective palliative care service delivery: good management, a fully functional IDT, and excellent communication amongst all concerned parties in the value chain (Republic of South Africa, 2017). SLCH has a strong focus on developing the capacity of its personnel to ensure that palliating patients and their families have access to a full complement of competent practitioners. Through its Centre for Palliative Learning (CPL), SLCH aspires to offer quality education and training with a view to creating a critical workforce of palliatively trained practitioners aimed at ensuring equitable access to palliative care services to patients for both communicable and non-communicable diseases. SLCH believes that a good balance of interventions, through this approach, will

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facilitate the strengthening of primary health care services through local community clinics and in the homes of patients. The CPL is well positioned to offer on-going training, through which staff and volunteers, at all levels of service delivery, are supported and equipped with the requisite skills, knowledge, and competencies in the practical application of the palliative care approach (see Addendum 17 for SLCH's CPL's Palliative Care Course Outline).

To keep abreast with current literature and information on palliative care and hospice trends, SLCH has an in-house library fully equipped with relevant literature (books, journals, training manuals, and information pamphlets) that can help address the needs of a host of users from staff, volunteers, patients, family members, and other health care professionals. SLCH further aims to keep its staff abreast of latest trends and approaches in hospice care by making provision for them to attend and participate in local and international conferences, workshops, webinars, and seminars. This is largely also why SLCH encourages empirical studies to be undertaken by staff and external researchers at its many sites. These sites provide fertile grounds for such studies. SLCH has its own Research and Ethics Committee and has recently revived its Journal Club where staff, volunteers, and external professionals can learn and share on salient topical issues.

SLCH is also a teaching hospice where local and international students in medical fields (such as registrars and nurses), para-medical fields (such as dietetics, radiology, and physiotherapy), and allied fields (such as social work and psychology) undertake their practical student rotations at SLCH's different community-based day-hospice hubs, Home-Based Care Programme in Khayelitsha, and the In-Patient Units in Kenilworth and Khayelitsha. Students also accompany clinical team members on patient visits as part of their practical training. These partnerships are formalised by Memorandums of Understanding between SLCH and the universities or other institutions seeking such a partnership. The spiritual care team members are often called upon to present at seminars and workshops and are increasingly called upon to provide information to other hospices in the Western Cape, SA on spiritual care practices.

Spiritual care is a key service offered by SLCH at all its intervention sites. The spiritual care services provided by SLCH is ensconced in the Outreach Services Department which sees social services (social work), bereavement services and community-based day-hospice services as completing that department's scope of work. SLCH provides services across a wide range of cultural, racial, linguistic, and socio-economic sectors. The spiritual care services are offered by a large team of spiritual care workers across several cultural and religious faiths such as

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Christianity, Islam, Hinduism, the Baha'i faith, Judaism, agnostics, and Rastafarianism. Spiritual care services are offered by the team in several languages such as English, *Afrikaans*, *IsiZulu*, *IsiXhosa* and, to a lesser extent, in the other eight official South African languages, with most spiritual care workers being bilingual, usually in English and *Afrikaans*. Typically, spiritual care workers at SLCH are volunteers who have varied and diverse socio-economic, academic, and cultural backgrounds, as discussed in detail in Chapter Eight. Spiritual care services are valued and prioritised at SLCH to the extent that a dedicated facility, the "Oasis", was built, that allows for quiet time, prayer, and contemplation. Nestled within the garden expanse the "Oasis" offers staff, patients, and visitors a refuge and private space to reflect and be. The "Oasis" facility was named after the donor and takes the shape of a round hut which is symbolic of the circle of life metaphor. Photograph 1 depicts the "Oasis" in the exterior garden setting and Photograph 2 shows the interior of the "Oasis".

Photograph 1: *SLCH's "Oasis" Exterior*

Photograph 2: *SLCH's "Oasis" Interior*

Spiritual care workers are recruited through a formal volunteer recruitment process that leads to a formal one-day orientation workshop. At the end of the orientation workshop, volunteers who express interest in spiritual care work are registered for a more detailed introductory course called the Basic Hospice Course that essentially introduces them to SLCH, hospice

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work, palliative care, and spiritual care services. Thereafter, and after successful completion of the Basic Hospice Course, a careful interviewing and screening process follows, after which the volunteer is registered as a spiritual care worker. Orientation and training are facilitated largely through peer support and on-the-job training and mentoring by more experienced spiritual care workers and the formally employed spiritual care staff. Like most hospices in SA, SLCH had not prioritised spiritual care from a funding point of view and consequently this important component of palliative care has been underrepresented on the IDT and not fully integrated into the overall palliative care patient care plan. As discussed in Chapter One, the spiritual care workers at SLCH expressed the desire to develop an accredited and recognised spiritual care training curricula and toolkit so that all staff, and by extension, patients, would benefit from this. SLCH is currently prioritising the development of a spiritual care training curriculum and is also prioritising the sourcing of funds while it simultaneously draws upon past and present staff, volunteers, external experts, research such as this study, and others related to spiritual care, to develop a bespoke spiritual care training curriculum that caters for the training needs of spiritual care workers and other health care workers working in hospice palliative care settings in a diverse and complex SA. Figure 5 presents a three-phase flow pathway into spiritual care work with phase three being currently prioritised by SLCH.

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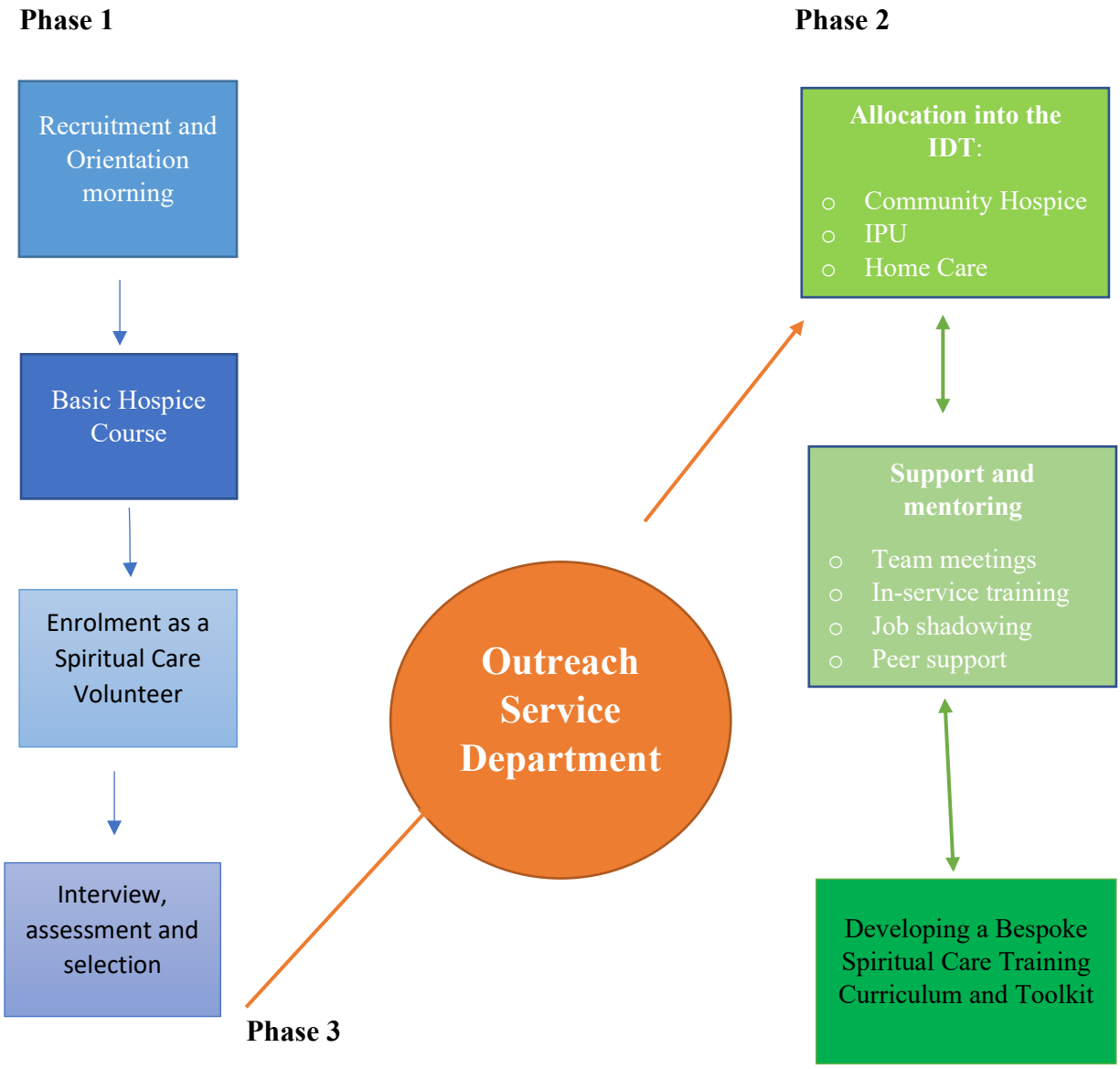
Figure 5

Flow Pathway of Spiritual Care Services into St Luke's Combined Hospices



3.5 Chapter summary

In this chapter I positioned spiritual care in SA and reviewed the makeup of SA's health care system, signalling the impact and consequences of the apartheid era on health care. The concept of *Ubuntu* as a social unifier was explored. I presented a more contextual review of how spiritual care is practised, prioritised, and managed at SLCH, with discussion on sustainability issues of spiritual care services in diverse hospice palliative care settings in SA. In Chapter Four, I discuss the spiritual care training needs in SA, and I analyse three recently developed

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Global North spiritual care curricula for relevance and applicability for SA, from a Global South perspective.

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CHAPTER FOUR

CONTEXTUAL ANALYSIS OF EXISTING CURRICULA IN SPIRITUAL CARE

4.1 Introduction

As I have shown in earlier chapters, curricula in spiritual care as part of palliative care are more common in the Global North than in the Global South. Paal et al. (2020), Rudbruch et al. (2020) and Bush et al. (2021) note that curriculum and training development has been prioritised for health professionals, and that there is also an interest in supporting NGOs in their palliative care work. As discussed in Chapter Three, most hospice spiritual care work in SA is undertaken by NGOs who have largely played a leading role in advocating for spiritual care in palliative care in SA. It is with these contextual issues in mind that, in this chapter, I explore the development of spiritual care curricula from the Global North, to consider the relevance and practical applicability of these curricula (and the ideas and values which underpin them) to the South African context.

4.2 Training trends and training needs in spiritual care in hospice palliative care settings in South Africa

Unarguably, there is a growing call for more focused and formal training in spiritual care for the health care workforce so that patients and families can benefit from the full palliative care experience, and health care workers can be better equipped to engage with patients on spiritual matters (Chandramohan & Bhagwan, 2016; Penman, 2012; Tjale & De Villiers, 2008). However, in SA and other less resourced contexts, there is recognition that very real barriers hinder the fulfilment of hospices' spiritual care training needs, with funding challenges and limited workforce capacity being key issues (Friedman, 2005; Moosa, 2006; Oppenheimer & Bayer, 2007). In SA there is no mandatory or statutory requirement in place for the accreditation and certification of spiritual and pastoral workers in health care (De La Porte, 2016; Ndaikile et al., 2018; Van Ginneken et al., 2010)[9]. Bross and DeAngelo (2012)

[9] There are graduate trainings in pastoral care, such as the MTh in Practical Theology (Specialiation: Clinical Pastorate) at Stellenbosch University (http://www.sun.ac.za/english/pgstudies/Documents/THEOLOGY%20Faculty/Programmes%202020/Master%2

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emphasise that key to the strategic planning and functioning of spiritual, pastoral and chaplaincy services should be the inclusion of funding and infrastructure development as well as a concerted thrust for accredited, formal spiritual care training programmes to train and up-skill care workers.

There is by now a well-established interest in the role community health workers can play as part of task-sharing within human resources for health in SA (Mhlongo et al., 2020; Van Ginneken, 2010). MacRae et al. (2020) undertook the first systematic evidence review across LMIC regarding the role community health workers play in the provision of palliative care services and found that their role is central to raising awareness about palliative care and identifying patients in the community who need palliative care. Holistic home-based care delivery and visits, and the provision of psychosocial support and spiritual guidance, are central components of the work of community health care workers (Laurenzi et al., 2020).

In SA, community health workers have a persistently unclear, contested place in the health system and job market (Trafford et al., 2018). With a wide remit, ranging from implementing biomedical interventions and providing psychosocial counselling, to acting as social change agents (Lewin et al., 2010; Werner & Bower, 1982), community health workers, typically a heterogeneous group of lay health care workers, are widely used in SA to bridge the gap between community and health care systems. Murphy (2017) identified two categories of community health care workers' implementation support in SA: those supported by NGOs and those supported by government's departments of health. Both models, while well formulated, show barriers hindering success and which centre on limitations – financial limitations (Jinabhai et al., 2015), leadership limitations (Schneider & Nxumalo, 2017), and policy implementation limitations (Stevenson, 2019).

In the South African context, community health workers are largely stipend workers or volunteers (Allen et al., 2016; Laurenzi et al., 2021; Perry et al., 2017; Swartz, 2013), mostly coming from rural, disadvantaged and previously marginalised communities in SA with limited to no formal training in health care. As is the case with community health workers, spiritual care workers are often trained, supervised, and mentored "on the job" by other care professionals, such as nurses, social workers, and counsellors, to offer spiritual care services at community-based and home-based care levels. The difficulty with this informal training

7s%20Degrees/Master%20of%20Theology%20%28MTh%29/Structured%20option/MTh%20in%20Practical%20Theology_Clinical%20Pastorate.pdf) but most pastoral care work is conducted in the absence of qualifications like these.

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cascade is that spiritual care is not offered as part of a structured training programme, and, consequently, spiritual care training, supervision and mentoring may be largely subjective and shaped by the specific experiences and beliefs of those conducting the trainings. Training may not be grounded on structured and formal credentialed spiritual care training programmes. While within the South African context there is growing recognition that spiritual care services are a meaningful intervention within the health care services package (Drenth et al., 2018; Mthembu et al., 2016), there is still much work to be done to understand how and by whom spiritual care services should be provided and within what intervention models and settings.

4.3 Analysis of Global North spiritual care curricula from a Global South perspective

Having reviewed how palliative care is practised in the Global North and South (Chapter Two) and having looked more closely at how spiritual care is practised in both settings, with focused scrutiny at how spiritual care is practised in SA and at SLCH (Chapter Three), I now turn to a selective review relevant to the other key question of this research project: spiritual care training needs at hospices in SA. In this chapter, I undertake a general analysis of selected[10] programmes put forward in the Global North, from a SA and therefore Global South perspective. While not totally unexpected, there is a dearth of such established spiritual care programmes in the Global South, and in SA, particularly. I looked at detailed expositions of spiritual care training curricula developed from 2018 to 2020 with a view of exploring their adaptability and easy consumption in a South African setting. For the purposes of this study, I identified three contexts (North America, Europe, and Australasia, all in the Global North), as in the period under review these continents produced recognised spiritual care curricula. Conceptually all their ideas are valuable, but several issues arise in a South African context, as I will demonstrate. The curricula[11] reviewed are:

a) Interprofessional Spiritual Care Education Curriculum (ISPEC) (Puchalski et al., 2020) (North America)
b) European Association for Palliative Care (EAPC) White Paper curriculum (Best et al., 2020 (Europe).

[10] I do not claim that I am reviewing all curricula, and it is not my intention to do so – my emphasis is on curricula from different continents which are very recent (2019 is the earliest), easily accessible in the public domain, and having the imprimatur of institutional support.
[11] One of these frameworks is referred to as a curriculum, one as a framework, and one as a White Paper – for ease of discussion I refer to them all as curricula, despite subtle differences in terminology.

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c) Capability Framework for Spiritual Care Practitioners in Health 2020 (Spiritual Care Association, 2020) (Australia).

I will analyse the spiritual care curricula developed by scholars in the Global North, from a Global South perspective, according to the following three criteria as outlined in Table 4.1.

Table 4.1

Criteria for Analysis of Global North Spiritual Care Curricula from a Global South Perspective

Review Criteria	**Implications from a SA perspective on:**
Theoretical basis	• Assumptions of the training curricula (what is applicable and what is left out?)
Practicability issues	• Cost implications • Medium and duration of training
Contextual appropriateness	• Diversities (this includes violence, poverty, colonial, postcolonial and Apartheid engineered inequalities)

4.4 Review of a spiritual care curriculum in the USA: "Interprofessional Spiritual Care Education Curriculum: A Milestone Towards the provision of Spiritual Care" (Puchalski et al., 2020)

4.4.1 Overview of the article

The authors assert that all clinicians require education and support to provide spiritual care services to patients and their families who are terminally ill and conclude that the ISPEC serves as a much-needed training resource to clinicians to improve spiritual care for all people with serious illness. I am in full agreement with the findings, conceptually, and while the ISPEC is a worthy curriculum, its applicability to the South African context is troubling, especially as the authors state in their Setting statement: *"The curriculum is appropriate for all clinical settings in the United States and internationally"* (Puchalski et al., 2020, p. 777). I address these claims below.

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4.4.2 Theoretical applicability of the ISPEC from a South African perspective

4.4.2.1 Assumptions of the ISPEC (what is applicable and what is left out?)

The ISPEC's aim is to provide education and training to health care professionals in spiritual care. It is based on a *"consensus-derived generalist-specialist model of spiritual care, with clinicians providing generalist-spiritual care and trained chaplains providing specialist spiritual care"* (Puchalski et al., 2020, p. 777). The USA has an advanced integration of palliative care into the health care system, where about 67% of hospitals have palliative care and spiritual care programmes (Centeno & Rhee, 2018), with 90% having palliative care programmes if the hospital has 300 beds or more (Dumanovsky et al., 2016). As previously discussed, the picture is very different in SA, with palliative care, and therefore spiritual care, only recently being recognised as part of the health care system.

Spiritual care is embedded in training curricula that are taught at some universities in SA. For example, at the University of Cape Town's (UCT) Faculty of Health Sciences (Continuing Education Unit), an Introduction to Palliative Care course is offered, which consists of eight modules that require five hours of teaching and learning with each module being covered in a two-week period and the entire course being completed within a four-month period. Only one module, Module Seven, covers culture, spirituality, and sexuality. Entry requirements into this course are restricted to health care professionals with a Degree or Diploma in their discipline (professional nurses may have a Diploma; other health care professionals should have a degree for example in social work or psychology, http://www.ceuhealth.uct.ac.za/introduction-palliative-care). Both the ISPEC and most universities in SA preclude non-health care professionals from undertaking courses in spiritual care, which is limiting given the local care context and reliance on non-professionals to undertake this important work. This reality has driven some hospices to develop unaccredited and basic hospice palliative care and spiritual care courses, as discussed in Chapter Three. These courses, which are developed piecemeal, have a broader target audience than the professional sector.

The ISPEC also seeks to teach health care professionals how to develop spiritual guidelines for patient management (Objective: Two), how to detect spiritual distress in patients (Objective: Three), and how to undertake a spiritual assessment with the aim of developing a treatment or care plan (Objective: Six). These objectives and concepts are important for patient management anywhere but may be difficult to implement in a South African context. As discussed, spiritual care is mostly provided by volunteers who have varied professional and non-professional

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backgrounds. In some cases, the spiritual care workers do not have a health care background (see Chapter 8), while the ISPEC is designed only for health care professionals who are familiar with the concepts of professional guidelines, assessments and developing care plans for patients. For the theoretical components of the ISPEC to be utilised in a South African context, major contextual modifications need to be considered regarding the theoretical framework for relevance and easy adaptability to the South African setting.

4.4.3 Practicability of the ISPEC from a South African perspective

4.4.3.1 Cost implications

While there is no mention of an actual cost for the three-component curriculum, it is presented as a multi-year, outcomes-based education initiative to improve spiritual care provision to terminally ill patients and their families in the USA and internationally. From a cost point of view, I question the affordability of this curriculum in the South African context.

As discussed in Chapter Three, while palliative care is relatively new in SA, spiritual care is significantly newer within palliative care, with the latter just being recognised as part of the health care system. The national Minister of Health, Dr Zweli Mkhize, in his foreword in The National Department of Health Annual Performance Plan (2020/21) (Republic of South Africa, 2020), pegs Education, Skills, and Health, as well as the interventions identified in government's Medium Term Strategic Framework for the period 2019–2024, as Priority 3. This suggests that prioritising training (spiritual care training included) in SA is not uppermost in the national health care plans. What does this mean for spiritual care practice and training in SA? My thoughts are that NGOs, where hospice palliative care work largely sits in SA, will have to take on the added responsibility for spiritual care curricula development and training. Consequently, the costs associated with the development of a spiritual care curriculum will probably have to be borne by the NGOs alike, which poses an added financial challenge for NGOs who already depend on dwindling public funding to sustain their work. With finite and limited resources, there will always be prioritisation. Since training is not top priority in the NDoH's health care plans, invariably NGOs developing their self-funded spiritual care curriculum diverts an expensive training system into the NGO sector, which, by all accounts, it cannot afford to implement.

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4.4.3.2 Medium and duration of training

The ISPEC is presented as a curriculum that can be taught in person in a classroom setting, as well as online. The online option must be applauded, especially as face-to-face and group gatherings are being discouraged globally as the world grapples with the COVID-19 pandemic. Strong lockdown rules are being enforced by many counties in the world to stem the spread of the Coronavirus until effective vaccines are fully rolled out. Consequently, and with rising death tolls, especially in patients with comorbidities that make them more vulnerable to the virus, the need for palliative care and spiritual care is heightened, as is the demand for telehealth (Brandstötter et al., 2021; Chip et al., 2021; Demeke et al., 2021; Rosales, 2021). While SA is traversing the same challenges faced the world over regarding the pandemic, SA faces the added burden of electrical power shortages that significantly impact telehealth and online training. "Load Shedding" is the local term for organised rolling blackouts instituted by the state-run energy company, Eskom. Power outages have become more frequent over the last year, with Eskom announcing earlier this year that load shedding is expected to continue well into 2021 as power demand exceeds supply and more downtime is needed for overdue maintenance of the system (Rossignol, 2020). While the power utility tries to schedule rolling blackouts, the lived reality is that often such rollouts are instituted with very limited notice and can last up to four hours at a time depending on the stage[12] of the rollout. The impact of the unplanned and unscheduled rollouts on online training is multi-faceted from a time point of view, cost point of view, and learning point of view.

The other layer to costs associated with online training is the access to technology for remote communication, and the cost of data. SA has a growing population of cell phone users per capita, but the high cost of data makes the use of online teaching platforms effectively unaffordable for many (Gillward, 2020). In his state of the nation address in February 2020, the President of SA, Cyril Ramaphosa, commissioned the country's Competition Commission to instruct mobile operators to adjust their data pricing in a bid to reduce digital inequality in the country. The Research ICT Africa After Access 2018 survey of 10 African countries,

[12] Stage 1: Requires the least amount of load-shedding (up to 1,000 MW) and can be implemented three times over a four-day period for two hours at a time, or three times over an eight-day period for 4 hours at a time.
Stage 2: This stage is double the frequency of Stage 1, where load-shedding happens six times over a four-day period for two hours at a time, or six times over an eight-day period for four hours at a time.
Stage 3: This stage is double the frequency of Stage 2, where load-shedding happens nine times over a four-day period for two hours at a time, or nine times over an eight-day period for four hours at a time.
Stage 4: This stage is double the frequency of Stage 3, with load-shedding happening 12 times over a four-day period for two hours at a time, or 12 times over an eight-day period for four hours at a time (https://loadshedding.eskom.co.za/).

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including South Africa, showed that the price of smart devices was a primary reason for people not being connected to networks. For those that were connected, the cost of data was identified as the reason for their sub-optimal use (Independent Communications Authority of South Africa [ICASA], 2020). Furthermore, reducing data prices without attending to the cost of devices with the capacity to run the software needed for online learning portals may also be insufficient. There may also be challenges with digital literacy, especially in a country where literacy rates in general are low (Spaull & Jansen, 2019). To embrace online training and telehealth, and to make it easily accessible and affordable in a South African setting will see the country having to take a few steps back to redress its Information and Communication Technology (ICT) strategy, which will come at a cost, and to solve its on-going literacy challenges, which is an enormous task.

The ISPEC's Train-the-Trainer Programme component is designed as a 2.5-day programme, with one year of mentoring and two formal evaluations at the 6th month and 12th month mark. This is a valuable model as it allows for on-going support, mentoring and assessments of participants. Within the South African context spiritual care services are often embedded in the services provided by nurses, doctors, and social workers, largely due to funding constraints. With already full workloads, removing key staff out of their core work to attend training will leave a gap in service delivery, as often hospices cannot afford to employ locum staff. Hospices could also run the risk of staff burnout by overburdening staff. Exploring a blended curriculum, as the ISPEC suggests, has a larger on-the-job training component that may alleviate the above constraint while simultaneously giving staff training in spiritual care by not removing them from their workstations for extended periods of time.

4.4.4 Contextual applicability of the ISPEC from a South African perspective

4.4.4.1 Diversities

As discussed throughout this dissertation and in this chapter, SA is a highly diverse country. Besides the cultural, racial, religious, linguistic, and socio-economic divides that still exist in SA, which I have mentioned previously, SA is also a country shaped by poverty and violence. According to the World Bank Group: Poverty & Equity, poverty economist, Sulla and Zikhali (2018), reports that SA has approximately 55.5% (30.3 million people) of the population living in poverty at the national upper poverty line (~ZAR 992), while a total of 13.8 million people (25%) are experiencing food poverty. Sulla and Zikhali (2020) also go on to say that SA is one of the most unequal countries in the world, with inequality having increased since 1994. When

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just over half the population are living in poverty and navigate, daily, basic "bread and butter" issues while barely making a living to sustain themselves, the government's focus is centred more on job-creation, and the citizenry would much rather focus on being trained in skills that enhance their chances of securing employment that yield immediate returns. Given this context of basic survival, a training curriculum, no matter how effective and important, holds little to no value when compared to priorities of life and possible death (starvation). SA's government has many priorities and does not have the time nor luxury to focus on one priority at a time. Should spiritual care training in SA therefore, and more so for the interim, be embedded in all care training curricula both at a tertiary and NGO level? Is a basic – even rudimentary – training curriculum in spiritual care that is contextually fitting better than no training? I do not have the answers to these questions but feel it to be of importance to consider them in mapping spiritual care services and training in SA for the immediate future.

With each year the number of South Africans who have experienced and witnessed violence increases, and so does the extent of national trauma (Lamb, 2019; Roberts & Gordon, 2016). Globally, SA ranks third lowest – the same level as in 2020 – and below only Venezuela and Papua New Guinea in terms of an internationally accredited safety index: SA is considered a high-crime, low-safety country (Overseas Security Advisory Council [OSAC], 2020). Galtung (1988) identifies three main sources of violence in societies: direct, structural, and cultural. Heinecken (2020) contextualises these sources of violence for SA, with direct violence being described as personal violence, including physical, psychological hurt and harm, to the point of killing. In SA acts of direct violence are reflected in the high levels of violent crime – including rape and murder, as well as domestic and gang violence directed at people as seen in high levels of violent protests (Lamb, 2021). Structural violence is defined as social and personal violence arising from unjust, repressive, and oppressive political, economic, and social structures that affect people's chances in life (Heinecken, 2015; Langa & Bowman, 2017). Crucially, structures control access to quality education, employment and health care and affect the basic human needs of survival and welfare. In education, and more so in the context of this review, the inequalities are significant with only a few people being able to afford their own education or to send their children to well-resourced, fee-charging schools, and thereby further widens the inequalities gap (Khumalo, 2019). Heinecken and Soeters (2018) describe cultural violence as symbolic violence where, for example, language, religion, and ideology are used to legitimise or justify direct and structural violence and which feeds into a social culture of discrimination, racism, prejudice, and sexism, which contributes to the

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vicious cycle of violence. Truesdell (2009) suggests that cultural violence is strongly influenced by prevailing attitudes, beliefs and messages that have developed in a country where direct violence is seen as the most effective means to respond to conflict. Soeters and Tresch (2010) go on to explain how cultural violence is reflected in the high level of sexual violence and systemic institutionalised patriarchy that fosters the culture of violence against women.

The challenge is how to turn the situation around, as all three forms of violence are interlinked and mutually reinforcing. Seeking to suppress violent crime in SA through the threat of direct violence by the state, such as by the deployment of the army to combat gangsterism in the Western Cape Province, is not the solution (Barolsky, 2016). Failure to address violence in SA may lead to even more severe levels of violence that could potentially destabilise the state, putting the safety and security of people in even greater jeopardy (Lamb, 2021). The volunteers who may be called upon to provide spiritual care in SA may, typically, come from rural communities where violence at all three levels is high. With so many challenges of basic survival in the face of poverty and violence as their daily realities, I ponder their energy capacities, psychological readiness, and physical stamina to undergo training such as the modules espoused in the ISPEC. With a highly strained health care system, exacerbated by the COVID-19 pandemic, and with a strained fiscus, furthermore, I do not foresee spiritual care training being prioritised by the NDoH anytime soon.

The ISPEC is also targeting professional chaplains as critical professionals to undertake this curriculum. The difficulty with this from a South African perspective is that, in SA, ministry or chaplaincy training is only offered at six of the main universities in SA, with four of these universities which offer church-related ministerial training commonly linked to mainstream Christian denominations (e.g., the University of Pretoria, the University of the Northwest, the University of the Free State, and Stellenbosch University) (Meyer, 2020). Christianity is not the only religion in SA and spirituality is not only a Christian concept. SA has a multitude of religious and cultural diversities, with spirituality being practised in many cultural contexts. The ISPEC, based in a largely Christian context, may rightly or wrong be viewed as discriminatory against other religions, and in conflict with the Constitution[13] of SA. Religion and culture are sensitive, highly contested, and fiercely debated topics in SA, especially as the country tries to reconcile the deep divides that the apartheid regime inflicted on it and its

[13] Chapter 2 of the Constitution of South Africa, containing the Bill of Rights, states that everyone in SA has the right to freedom of religion, belief, and opinion. Section 9 (the Equality clause) prohibits unfair discrimination on religious grounds and other grounds (Republic of South Africa, 1996).

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people. Given this context, the ISPEC in its current model will be problematic within the South African context.

The ISPEC lists its seventh objective as follows: "*Recognise the clinician's spirituality as an integral component of professional development,*" (Puchalski et al., 2020, p. 780). This is an excellent objective and would be helpful if achieved. Self- assessment is a vital component of educational programmes as it may increase the interest and motivations of learners for the subject which could lead to enhanced learning and better academic performance and be helpful for them to develop critical skills for analysing their own work (Sharma et al., 2016). In postgraduate education in SA, however, and despite a strong educational merit, self-assessment has not played as central a role as might be expected. Tewari et al. (2020) explore the missing link between the successes that have been achieved in terms of students' access to higher education and students' success rate. In summary, SA's higher education sector is faced with an "articulation gap", which refers to the misalignment between the learning requirements of higher education programmes and the actual knowledge and competencies of the first-time entering students (Tewari, 2016). Although increased access is a key component of the transformation agenda of higher education in SA, there is an undeniable need for these institutions not only to improve the participation rate, but also to ensure that these participation strategies culminate in a successful outcome (Akoojee & Nkomo, 2007). The quality of higher education in SA is relatively dependent on the learner's preparedness, student–staff ratio, availability of local resources or inputs, student support services, funds from both the government and private institutions, as well as by the number and quality of the lecturers in higher education institutions, among others (Scott & Ivala, 2019). With the latter and seeing as spiritual care and palliative care are new components of care in SA, the added complexity is identifying competent, accredited, and professional trainers in spiritual care to offer this curriculum, especially when the move in SA is to create employment opportunities for its own people and minimise importing skills.

4.5 Review of a spiritual care curriculum in Europe: "An EAPC White Paper on multi-disciplinary education for spiritual care in palliative care" (Best et al., 2020)

4.5.1 Overview of the article

The EAPC White Paper addresses the *"issue of spiritual care education and training for all palliative care professionals as well as to guide health care professionals, spiritual care stakeholders, leaders and decision makers, and national and local curricula development*

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groups responsible for training and education in spiritual care" (Best et al., 2021, p. 46). The EAPC is a revised model of best practise based on evidence-based research outcomes. The aim of this curriculum is to better educate health care practitioners in spiritual care so that they are not distracted by their own fears and prejudices *"while encouraging and facilitating high quality, multi-disciplinary, academically, and financially accessible spiritual care education to all palliative care staff"* (Best et al., 2020, p. 1). My first thought on this curriculum was how ambitious it was, but immediately recognised my own bias, given that I am South African, and that in a Global North context this curriculum is, likely, highly achievable. The EAPC White Paper is also a worthy curriculum and an improved version which further suggests its credibility. Its relevance in a South African context is debatable and will be explored below.

4.5.2 Theoretical applicability of the EAPC White Paper (spiritual care education) from a South African perspective

4.5.2.1 Assumptions of the EAPC White Paper (what is applicable and what is left out?)

In their summary box of "trickle down science", Reidpath and Alotey (2019) conclude that countries in the Global South continue to struggle to train and retain good practitioners to address local, regional, and global health challenges and consequently. There is an on-going reliance on the Global North for solutions to local problems and an inability to develop alternative approaches to problem solving that take local (non-northern) contexts into account. Mulligan and Herbert (2019) note that another significant challenge is when health care professionals and scientists return to the Global South with significant frustrations due to the lack of an enabling environment in which their newly acquired skills can be applied.

Two significant assumptions, as discussed in the above curricula analysis, are also applicable to this curriculum. In addition, this EAPC White Paper's spiritual care curriculum's main thrust is on competencies, with this EAPC White Paper's version being an improvement on the Gamondi competencies (Gamondi et al., 2013). In SA we do not have a recognised set of competencies or formal terms of reference for spiritual care practice. In many respects this research study is a baseline study as it sets out to establish what spiritual care practices are on offer at hospices in SA. Like the ISPEC, the EAPC White Paper's spiritual care curriculum uses language, models and terminologies that may not easily and readily be understood, applied, or seen as relevant in a South African context. For example, the Schwartz Rounds (Lown & Manning, 2010) refers to evidenced-based forums for staff to come together to talk about the emotional and social challenges of caring for patients, with the aim of offering staff

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a safe environment in which to share their stories and offer support to one another. This approach must be lauded. However, the scarcity of well-designed studies which measure the efficacy and contextual-embeddedness of evidence-based interventions in LMIC is well documented (Baingana et al., 2015). Coetzee et al. (2019), who undertook a study in SA, state that LMIC often lack fiscal, infrastructural, and human resources to conduct evidence-based research and suggest that similar constraints may also hinder the application of worthy clinical practice guidelines based on research findings from HIC. Spiritual care has not been prioritised in SA and there are few studies on spiritual care practice, with evidence-based spiritual care studies being non-existent. Therefore, how relevant, and applicable, from an evidence-base perspective, such models as the Schwartz Rounds in the EAPC White Paper may be in the South African context, is debatable.

4.5.3 Practicability of the EAPC White Paper (spiritual care education) from a South African perspective

4.5.3.1 Cost implications

While there is no mention of actual costs, the authors state that this curriculum was commissioned by the EAPC and suggests that the cost of the training may be covered, or part subsidised, by the EAPC. In SA, the HPCA (as discussed in Chapter Three) is navigating financial challenges itself. Consequently, it may be very difficult for the HPCA to fund spiritual care training for all its member organisations. It may also be difficult for HPCA to fund a working group to develop such a curriculum for SA, just yet. While facilitating the development of training material is one of its mandates, and the will is there, the financial costs will remain a stumbling block. Hospices, and specifically SLCH, is currently developing its own curriculum in spiritual care, largely spear-headed by experienced spiritual care volunteers in collaboration with the spiritual care team towards developing a curriculum that is bespoke to SLCH and which will also have relevance for hospices in the Western Cape and SA in general. Here too cost is a stumbling block and that is why SLCH relies heavily on pro-bono work from experts in the field and which largely sees many well-meaning and well-intended hospices opt not to offer spiritual care services.

4.5.3.2 Medium and duration of training

While not clearly stated as, for example, in the curriculum suggested by the ISPEC, this curriculum builds on the existing education health care professionals have in palliative care.

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Within the South African context, this is a significant assumption, and far from what the reality is, because palliative care is still in its early infancy in SA with limited health care professionals being trained in palliative care. The EAPC White Paper on spiritual care education commendably also strongly supports an MDT intervention model for continuous learning, sharing and team growth. In SA spiritual care, when practised, is practised mostly within an IDT model, largely because of palliative care and spiritual care's newness in the health care system. Its outreach into a wider MDT is premature for SA as palliative care is not yet fully entrenched in the health care system. The challenges of professional cluster meetings, sharing, and undertaking joint ward rounds are significantly more stunted in the current COVID-19 pandemic context and must be more vigorously reimagined as to how IDT work will play itself out in a more sustainable manner. The challenges of online training, as explained in the ISPEC review, also holds true for this curriculum. The development of the EAPC curriculum in its current form has been a multi-year effort with multiple rounds of consultations, meetings, curricula content reviews, collaboration, and focused work by palliative care professionals. This suggests a strong EAPC with strong capacity and capabilities – human and capital. The picture is significantly different in SA, with funding constraints seeing the HPCA resorting to a virtual office with just a few core staff driving its mandate. As a result, any curriculum development will have limited or no budget and will depend largely on the hospices to be the main drivers of the curriculum development and its funding. Reflecting as CEO of my hospice, I cannot see where and how extra work, albeit important work, can be assigned to an already over-burdened team, and nor from where additional funding could be sourced.

4.5.4 Contextual applicability of the EAPC White Paper (spiritual care curriculum) from a South African perspective

4.5.4.1 Diversities

I agree with the EAPC White Paper's assertion that the question of culture and cultural competencies emerge frequently in discussions of palliative care and spiritual care, but the evidence on culturally specific needs in palliative care and spiritual care is extremely limited, as this is what I too observed while undertaking this study. The didactic teaching of cultural and religious practices are captured in the Purnell Model for Cultural Competencies which provides a basis for understanding individual cultural needs in self-reflection and in contact with patients and relatives in order to provide holistic, culturally competent interventions in health care (Purnell, 2000).While in SA we do not have such a formalised set of cultural

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competencies, it would be useful to review the Purnell Model for relevance and possible adaptation to the South African setting. It is reassuring to see that there will be multi-lingual versions of the EAPC White paper, which suggests that there is recognition that English alone does not dominate the linguistic global arena. Should SA consider seeking funding support from Europe to develop its own SA culturally bespoke spiritual care curriculum, there will be an appreciation and understanding from the European colleagues to fund multi-lingual versions of a South African spiritual care curriculum for SA as well.

4.6 Review of a spiritual care curriculum in Australia: "Capability Framework for Spiritual Care Practitioners in Health 2020" (Framework) (Spiritual Care Association, 2020)

4.6.1 Overview of the framework

The Framework is a useful tool in the spiritual care toolbox and has much to offer. The Framework, in its current version, was derived after many years of collaboration and group work, which signals that spiritual care services are a recognised part of the Australian health care sector; something that is very new to SA. The Framework seeks to *"inform spiritual care practice within a professional health care setting aligned to identifying stages of professional development and scope of practice in spiritual care"* (Spiritual Care Association, 2020, p. 6). It is interesting to note that spiritual care practitioners are qualified and credentialled according to industry standards and appointed and credentialled by the health service institutions in which they are employed. The contrast to how spiritual care is played out in SA is remarkable. The Framework clearly states that the role of volunteers is not scoped in the Framework. The difficulty, as explained before, from a SA perspective is that, largely, spiritual care services are provided by volunteers. Its relevance is therefore questioned as is its application within a South African context. Further, the Framework talks to and details multi-layered quality standards of practice and professional development. This clearly is an indication of how advanced and prioritised spiritual care interventions are in Australia; again, something that is not mirrored in SA to any significant extent. The Framework makes a distinction between spirituality and spiritual care, when often these terms are used interchangeably. While the interplay between the terms may be subtle, I found the distinction in meaning to be significant because the Framework further goes on to make distinctions between spiritual care (clinical definition) and spiritual care (non-clinical definition). In contrast, we do not have an established definition of

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spirituality and spiritual care that befits the South African context, and which must be considered alongside any spiritual care training curricula SA may seek to put in place.

4.6.2 Theoretical applicability of the Framework from a South African perspective

4.6.2.1 Assumptions of the Framework (what is applicable and what is left out?)

The Framework outlines the expected capabilities and scope of practice for four levels of qualified and credentialled spiritual care practitioners. The Framework is presented in domains and sub-domains, capability levels with indicators and expected outcomes. Within a Global North setting, these are familiar concepts, but from a Global South perspective these may not so readily be the case. The Framework makes several assumptions such as: Capability Frameworks are commonly available and easily understood tools, paying membership is acceptable and expected, and that there is full understanding and inclusion of capabilities, domains, and sub-domains as one progresses from one Capability Level to the next. With SA still being at the primary stages of development in its spiritual care trajectory, it has a long way to go in formalising spiritual care services. Consequently, and at this point in time, the Framework is premature for SA, but provides useful guidelines.

As discussed earlier in Chapter Three, SA has eleven official languages. Consequently, theoretical concepts may not be easily translated in all eleven languages. A large proportion of SA's population experience language barriers which continue to compromise the quality of, and access to, health care services. Research regarding the language barriers in SA, despite international recognition of the importance of appropriate communication in rendering health care services, remains limited (Benjamin et al., 2016; Van den Berg, 2016). How easily can certain theoretical concepts in the Framework be translated into South African languages, and by extension, how accurately will those translations be? Van den Berg (2016) sees an opportunity to find viable solutions to communication challenges that linguo-cultural barriers pose within the multi-linguistic South African population, and a need for collaboration between language practitioners and health care professionals to honour the right of every citizen to equitable health care. Edwards et al. (2019) call for further development, testing, and application of theoretical frameworks that enhance understanding of knowledge translations in African settings. This is encouraging as curricula such as the Framework may be considered for such attention and scrutiny.

With translation comes the added complexity of interpretation. Often these concepts are conflated yet their roles are very distinct. The key differences between interpretation and

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translation centre on what medium and skillset is used: interpreters translate spoken language orally, while translators translate the written language. To address language barriers in the health care sector, interpreters, who are often bilingual relatives (sometimes even children) or non-medical staff, are largely called upon (Hussey, 2012). The use of loosely coordinated and largely informally appointed translators and interpreters raises important ethical dilemmas for patients' rights to confidentiality (Schlemmer & Mash, 2006). Additionally, the lack of medical knowledge on the part of the interpreter can affect the accuracy of the message being conveyed, which creates another ethical dilemma (Kilian et al., 2010), which has decision-making implications for the patient.

With online learning, Google Translate has significantly changed how society engages with multi-lingual communication practises (Vieira et al., 2020). The language used in the Framework does not lend itself to easy machine translation into some, or all, of the official languages in SA, and as such may run the risk of disregarding the complexities of language and could exacerbate social inequalities and put certain communities of users at greater risk (Doherty, 2019). Achieving conceptual equivalence between two languages is a challenge in cross-cultural, cross-language translation (Choi et al., 2012), as in this case the Framework is written in a language that may not be the first language for some users in SA. Therefore, translation provides an additional challenge in cross-cultural curricula sharing.

4.6.3 Practicability of the Framework from a South African perspective

4.6.3.1 Cost implications

While there is no cost mentioned in the Framework, Spiritual Care Australia (SCA) (https://www.spiritualcareaustralia.org.au/membership/membership-criteria) outlines the membership costs for professional development and training in spiritual care. Firstly, while the Australian model is open to international scholars (which is commendable), it may not have as much attraction for palliative care professionals from SA as the unfavourable Rand vs Australian Dollar exchange rate could play a deciding factor regarding affordability. Secondly, the SCA is a closed-membership organisation with strictly controlled entry at the different levels of membership on offer. Membership comes at a financial cost and while accommodation is made for associated membership (non-professional) and associated student membership (undergraduate level), both come at a membership cost, and both have a minimum requirement of a basic certificate in spiritual care. Obtaining a professional qualification in spiritual care is not easy in SA because spiritual care training is largely embedded in other

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health care curricula. With a primarily volunteer spiritual care workforce coming from poor backgrounds, paying a membership fee, even at a reduced rate, may not always be a simple and straightforward transaction.

4.6.3.2 Medium and duration of training

As with the two sets of curricula reviewed above, this Framework makes use of blended learning and the concerns raised elsewhere apply here as well. The Framework also refers to continuous professional development, which is a model widely utilised in SA, and which has much merit as points are awarded to professionals who update and upskill themselves, often with improved financial rewards for them. The constraints in the South African context, given the limited accredited palliative care curricula available, suggests that international training can be obtained but it does come at an added cost. In SA, with spiritual care volunteers not necessarily having health care backgrounds, spiritual care is more a model of learning-on-the-job which comes with its own set of challenges, such as subjective biases, unstandardised spiritual care practises, and ethical implications of spiritual care practises.

4.6.4 Contextual applicability of the Framework from a South African perspective

4.6.4.1 Diversities

Very early on in the Framework, the Wurundjeri people of the Kulin nation are acknowledged as Traditional Owners (reflected as a proper noun) of the land of Australia, as well as for their continuous connection to the land, water, and culture. This is commendable and a positive step in the right direct in the healing process. The Framework goes on to pay respects to their Elders (again, reflected as a proper noun) past, present and future. The similarity to SA to continuously reference the ills of apartheid and thereby glorifying the "victims" of those ills, somewhat patronisingly, could be seen as a parody of the truth and reconciliation processes, if acknowledgement is not truly meant but is enforced, for example, by legislations or laws. Does acknowledging the Aborigines so early in the Framework denote cultural sensitivities? Is this just tokenism or does this Framework have relevance for an Aboriginal population that was, like non-Whites in SA, largely ignored and marginalised in its colonial history?

I turn now to the reviewers of the Framework. From the list of contributors of the Framework – working group, document reviewers, and consultant – what is conspicuously missing is the representation of and by Aborigines in the Framework's appraisal process. Could this Framework be enacting a "put your money where your mouth is" 17th/18th century idiom

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where toads were dubiously passed off by con men as having great medicinal and healing value which, falsely, portrayed them as being caring and helpful? The metaphor may perhaps be considered dramatic, but for too long now in SA we have seen well-meaning and well-intended policies, guidelines and frameworks put in place that optimistically espouse racial inclusivity which, on paper, is commendable, but which when played out in reality, still presents with layered disparities. It would be useful to see how the Framework aims to offer a spiritual care service to the Aboriginal people and to see how issues of cultural sensitivities and diversities are managed contextually. This could be a rich learning exercise for SA.

4.7 Summary of contextual analysis and relevance of three Global North spiritual care curricula in Global South settings

In summary, the three curricula programmes have significant strengths, which gives greater gravitas to spiritual care work within resource-rich Global North countries. However, and despite these useful and beneficial curricula, there remain many real challenges from a South African perspective to contextualise these curricula within a South African setting. I present, in Table 4.2, a brief snapshot of the strengths of the three curricula against SA's troubled health care landscape, which I discussed in detail above.

Table 4.2

Summary of Contextual Analysis and Relevance of Three Global North Spiritual Care Curricula in Global South Settings

Study author and date	**Country**	**Strengths of curriculum**	**South African contextual considerations**
Puchalski et al. (2020)	North America	• Consensus-driven, generalist-specialist model. • Designed for classroom and online teaching and learning. • Developed from needs assessment and course evaluation data.	• Spiritual care in SA is not even on the health care agenda. No spiritual care national model exists in SA. • SA has the added challenges of poverty, violence, funding constraints and "load shedding". • Research into spiritual care in SA is sporadic and poorly coordinated.

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Best et al. (2019)	Europe	• Language, terms and concepts used in the curriculum. • EAPC White Paper culminated from many preliminary draft papers in spiritual care.	• Language and concepts may not easily be translated nor interpreted in a South African context. • HPCA is facing financial and capacity constraints and consequently is currently limited in its support of its members.
Spiritual Care Australia Association. (2020)	Australia	• Framework derived from multi-layered refined standards. • Framework exclusively targets qualified and credentialled health care practitioners. • Supports planning for personal and professional development and clear pathways for career progression.	• Spiritual care is still in its infancy in SA. • In SA most of the care work is undertaken by volunteers (community health care workers). • Spiritual care is not credentialled in SA and is embedded in other heath and care disciplines at tertiary educational levels and as offered by NGOs.

4.8 Chapter summary

In this chapter I presented three reviews of recently developed spiritual care curricula from the Global North and analysed them from a theoretical, practical, and cultural perspective for relevance in SA. The three curricula were from North America, Europe, and Australia, and while each added to the global spiritual care curricula development and training discourse, replication in a South African context, even in part, needs further investigation. This chapter has left me with more follow-on questions such as: Can SA afford a stand-alone curriculum? Should spiritual care training remain integrated and embedded in other care disciplines' curricula, as it currently is? These questions form an implicit backdrop to the issues presented in the empirical chapters of this dissertation, and I return to these issues in the concluding chapter. With this and the previous chapters as a backdrop, I conclude Part 1 of this dissertation.

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I now turn to the views of the participants I surveyed and interviewed to provide further insights into how spiritual care is practised at hospices in a diverse country, SA, and more poignantly, what the spiritual care training needs are at hospices providing palliative care services in a diverse SA.

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PART 2: IMPACT OF DIVERSITY ON TRAINING AND SERVICE PROVISION OF SPIRITUAL CARE WITHIN HOSPICE PALLIATIVE CARE SETTINGS IN SOUTH AFRICA

Preamble

As discussed in Chapter One, this is a three-part study exploring how spiritual care is practised at hospices within palliative care settings in SA. The study further explores what the training needs of spiritual care workers are in hospices in SA. Sub-Study One was an online national study of all hospices registered on the database of HPCA. While only 41% of the hospices participated in this Sub-Study, as discussed at length in Chapter One and will be discussed in Chapter Five, this participation percentage could be considered a limitation of this Sub-Study. However, meaningful baseline data were obtained on how spiritual care is practised, where hospices are located geographically in SA within the context of SA's troubled apartheid past, characterised by inequality and racial segregation of its citizenry, and, critically, what the spiritual care training needs are of hospices providing palliative care services. Sub-Study Two took the form of focus groups discussions with participants from hospices in the Western Cape Province to explore how they practise spiritual care, especially within the context of cultural, linguistic, and religious diversity, and what they consider to be the spiritual care workers' training needs. Sub-Study Three was localised to SLCH, a well-recognised hospice in Cape Town, SA, which offers an established spiritual care service to terminally ill patients and their families in the greater Cape Town area. Being insider experts, I explored how spiritual care is practised by SLCH's spiritual care workers within the diverse populace of Cape Town and what the spiritual care workers' training needs in spiritual care are. Hospices appear to have different management approaches to palliative care services and, consequently, spiritual care is practised and prioritised in different ways in SA. O'Brien et al. (2019) and Pillay-Van Wyk et al. (2016) canvass for the benefits of an MDT approach, while Figure 6 shows that most hospices in SA use IDT as their preferred patient management approach, while 20% use a combination of both IDT and MDT (in Chapter Two I explained these approaches in detail).

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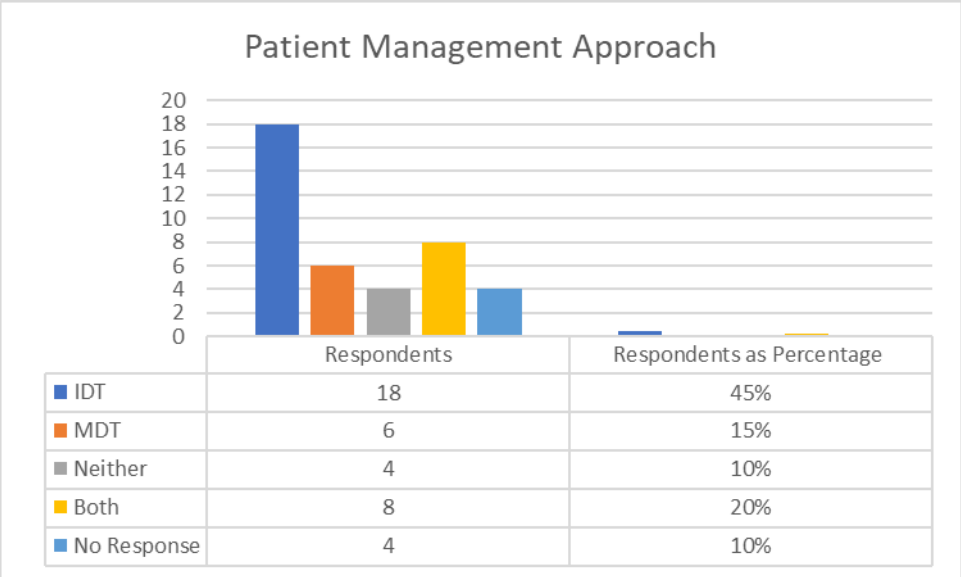
Figure 6

Patient Management Approaches Utilised by Hospices in SA



	Respondents	Respondents as Percentage
IDT	18	45%
MDT	6	15%
Neither	4	10%
Both	8	20%
No Response	4	10%

Findings from Sub-Study One show that only 50% of participating hospices provided spiritual care and palliative care services as an in-patient unit service. The other participating hospices offer limited spiritual care services at an out-patient level, mostly at patients' homes, outsourcing spiritual care services to community structures, or referring patients to FBOs for spiritual care services. The matrix in Figure 7 suggests that the hospices in SA prioritise medical care services, which is followed by psychosocial and bereavement care services, and with spiritual care services being largely offered as a partial care service, thereby again suggesting (which I discussed in greater detail in Chapter Two, and I will discuss in Chapter Five and Chapter Six) that spiritual care has not yet found its rightful place as an equal component of the palliative care service package in SA.

Figure 7

Matrix of Care According to the Four Pillars of Palliative Care

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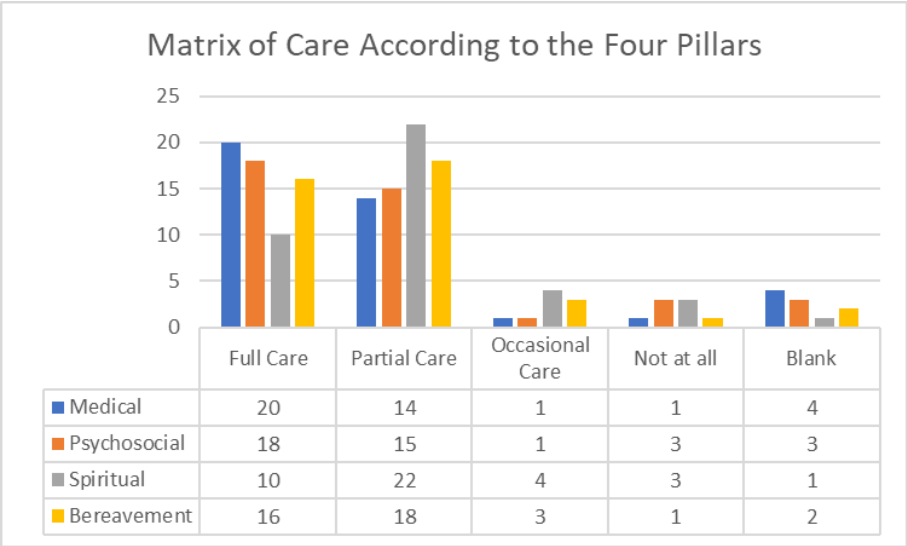

	Full Care	Partial Care	Occasional Care	Not at all	Blank
Medical	20	14	1	1	4
Psychosocial	18	15	1	3	3
Spiritual	10	22	4	3	1
Bereavement	16	18	3	1	2

As an example of diversity, Figure 8 highlights the linguistic diversity amongst spiritual care workers in hospices in SA, with *IsiZulu* (the Bantu language of the Zulu clan and one of the official languages of SA) being the most widely spoken language amongst spiritual care workers, followed by English, *Afrikaans* (a West Germanic language spoken in SA and is another official language in SA), and *IsiXhosa* (the Bantu language of the Xhosa clan spoken in SA and is one of the 11 official languages in SA). A range of other languages accounted for 26% of the languages spoken by spiritual care workers in hospices in SA. These languages included: Portuguese, Chinese, *Tsonga, SiSwati*, and *Sepedi*, with the latter three languages being indigenous to SA.

Figure 8

Languages spoken by Spiritual Care Workers in South Africa

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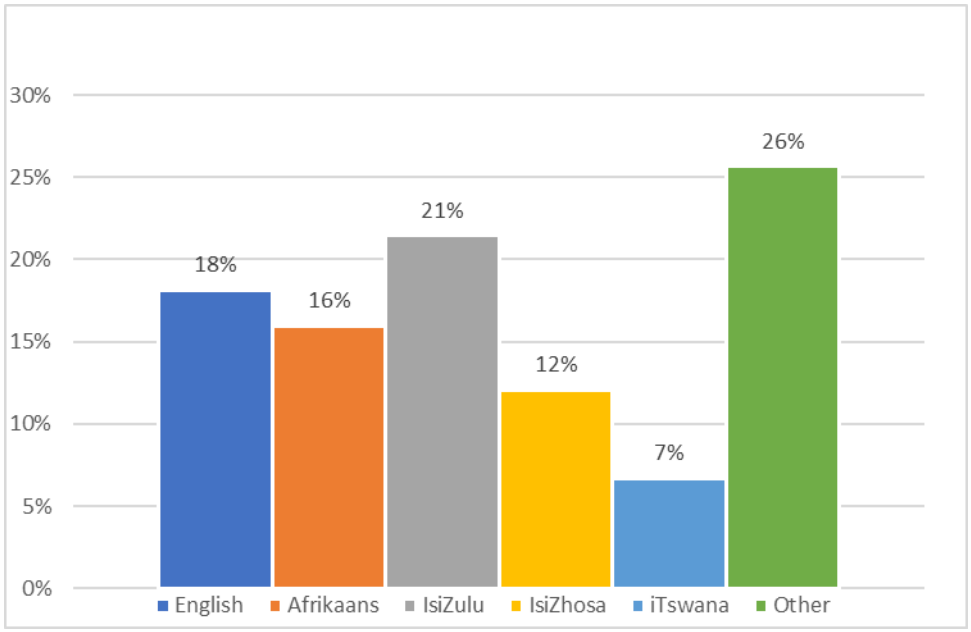

I discuss these diversity dilemmas in more detail in Chapters Five to Seven of this dissertation. Offering culturally, racially, and linguistically appropriate spiritual care services to a diverse SA population may be ambitious in a climate of shrinking funding, scarce human capital, and the complexities of diversity in SA, but is acutely needed. Amidst this seemingly gloomy scenario, in Chapter Three I presented SLCH, as an example, which has managed to incorporate and sustain spiritual care into its overall palliative care service to varying levels of inclusion and success, and in different care approaches, in an attempt to make spiritual care services as accessible to as many patients as its outreach can extend to. Chapters Five to Nine give more insights into how spiritual care is practised and positioned in SA, and at SLCH, and what the spiritual care training needs of spiritual care workers are. I return to these issues in Chapters Five to Nine which are presented as four journal articles and one manuscript, and which replace the traditional Results and Discussion chapters.

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INTRODUCTION TO PART 2

I presented the background and rationale, and I reviewed relevant literature pertaining to and contextualising this study in Part 1. Parts 2 and 3 represent the results sections of this dissertation. In this Part 2, three published articles are presented, focusing on the current spiritual care practices in SA and what the impact of diversity, especially cultural, racial, and linguistic diversity, have on spiritual care training needs and spiritual care service provision by hospices in palliative care settings in SA. Part 3 comprises two papers focusing on hospice spiritual care training needs in SA.

Part 2 therefore comprises two published articles and one in-review manuscript in the following chapters:

i. Chapter Five (Article 1): Challenges and opportunities for spiritual care practice in hospices in a middle-income country.
ii. Chapter Six (Article 2): Spiritual care practices in hospices in the Western Cape, South Africa: The challenge of diversity.
iii. Chapter Seven (Article 3): “I am dying a slow death of White guilt”: Spiritual carers in a South African hospice navigate issues of cultural diversity.

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CHAPTER FIVE

ARTICLE 1

Challenges and opportunities for spiritual care practice in hospices in a middle-income country.

– BMC Palliative Care –

5.1 Introducing Article 1

This chapter contains the first published article which forms part of this dissertation. In this chapter, through a largely quantitative online survey, I examined what the status of spiritual care practises are in SA with a view to understanding what the training needs are in spiritual care within hospices' palliative care settings in SA, as well as how contextual diversity impacts spiritual care service delivery. The findings suggest a chorused need for the development of a national curriculum in spiritual care in SA, with due regard for its diverse and complex context.

This article was published in the journal, *BMC Palliative Care*, as follows:

> Mahilall, R., & Swartz, L. (2021). Challenges and opportunities for spiritual care practice in hospices in a middle-income country. *BMC Palliative Care, 20*, 62. https://doi.org/10.1186/s12904-021-00756-9

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Mahilall and Swartz *BMC Palliative Care* (2021) 20:62
https://doi.org/10.1186/s12904-021-00756-9

BMC Palliative Care

RESEARCH Open Access

Challenges and opportunities for spiritual care practice in hospices in a middle-income country

Ronita Mahilall[1,2*] and Leslie Swartz[1]

Abstract

Background: Spiritual care is a key component of palliative care, but it has been overlooked and understudied in low- and middle-income country contexts, especially in Africa. In this study we sought to establish what the current spiritual care practices are in hospice palliative care settings in South Africa with a focused view on what spiritual care training is currently offered and what training needs still remain unmet.

Methods: We explored spiritual care practices, and training needs, through a national quantitative online study of palliative care organisations in South Africa registered with the Hospice Palliative Care Association of South Africa. A survey was sent to representatives of all member organisations listed on the national database of Hospice Palliative Care Association of South Africa. Viable data from 41% ($n = 40$) member organisations were analysed through the use of simple statistics.

Results: An expressed need (75%; $n = 30$) was recorded for the development of a national spiritual care curriculum. Although 48% ($n = 20$) of the member organisations were willing to participate in the development of a spiritual care curriculum, 37% ($n = 14$) could not participate, citing financial ($n = 27$), time ($n = 31$) and expertise constraints ($n = 22$). A set of hard and soft skills were suggested to suit the diverse South African context.

Conclusions: Spiritual care was seen by participants as a key component of palliative care. International curricula in spiritual care, while useful, do not offer easy adaptation to the diversities of South Africa. A bespoke spiritual care curriculum was called for, for diverse South Africa.

Keywords: Spiritual care, Palliative care, South Africa, Diversity, Hospice

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Introduction

Spiritual care is recognised as an essential element of holistic palliative care [1–3]. Spiritual care workers in the Global North[1] are generally professional social workers [4–6], chaplains [7–9] and professional nurses [10–12], who are accustomed to having formal learning and teaching curricula. There is growing evidence that training in spiritual care may be associated with improved patient care outcomes [13, 14]. There is a plethora of studies in the Global North that support the need to have spiritual care training programmes in place for hospice staff [14–16].

In Africa, however, though spiritual care has been deemed important in the Global South [17–20], despite the spiritual diversity on the continent and the limitations on amassing meaningful national health care data [21], studies and protocols for the development of palliative care have tended not to focus on spiritual care, but rather on issues such as pain management protocols, for which there are clear indicators [22–25].

In 2017, the National Department of Health launched the South African National Policy Framework and Strategy on Palliative Care 2017–2022 [26]. The NPFSPC, which, like so many documents in SA, is an aspirational document focussing on the four main pillars of palliative care services: medical care services, psychosocial care services, spiritual care services, and bereavement care services.

The current study is based in South Africa (SA), where the previous oppressive apartheid regime used Christian religious ideology to justify oppression [27]. Emerging from a draconian past characterised by racial segregation and apartheid, and although well into its 26th year of democracy, SA still experiences the injustices of resource allocation, unequal educational and sparse learning opportunities. SA is also very diverse culturally, linguistically, and spiritually [28], with spiritual care interventions practised from a range of perspectives [29].

Given the complex South African context, the question arises as to whether there is a need for further training and development of spiritual care practices in palliative care. As part of a larger study, in this study we were interested to know what current spiritual care practices exist within hospice palliative care settings in SA. We were also interested to know from the perspective of hospices themselves, what their spiritual care training needs are and whether they see a need to develop a national curriculum for spiritual care intervention. We address these questions in this article.

[1]There are many debates about how to classify countries. The 'Global North' generally corresponds to countries categorised by the World Bank (World Bank Blog 2021/2022 Atlas) as high-income countries (HICs) – so, for example, Australia, which is a high-income country is commonly viewed as part of the Global North, despite its being in the southern hemisphere. Countries in the 'Global South' generally correspond to the World Bank low and middle-income countries (LMICs) (World Bank Blog 2021/2022 Atlas). South Africa is a middle-income country. The distinction here is based largely on financial resources, though of course other factors are associated with relative wealth.

Methods

We conducted a simple Excel-based quantitative online survey (with some qualitative questions) (see Additional file 1) to address key questions on current spiritual care practices, and their perceived spiritual care training needs. The following are examples of the kinds of questions posed:

- What phrase best describes the extent of spiritual care offered at your hospice? (a. full care; b. partial care; c. occasional care; d. not at all);
- How is spiritual care practiced at hospices? (e.g. Does your organization recognize spiritual care as an integral part of a palliative care service it offers: a. Yes; b. No; c. If No, please elaborate.)
- Spiritual care training needs (e.g. Has a need for spiritual care training been expressed by your organization: a. Yes; b. No; c. We do not know at this time).

The comprehensive national database of Hospice Palliative Care Association (HPCA) of SA lists 104 member organisations. HPCA is a national association operating in all nine provinces in SA and 51 health districts. Some of its voluntary member organisations offer hospice palliative care, some home based care, and others both services. We use the term 'member organisations' rather than 'hospices' because all organisations offer palliative care, but not all call themselves hospices. Ethical approval was obtained from Stellenbosch University (10237) as well as HPCA (02/19). We telephoned the leader of each organisation, generally the Chief Executive Officer (CEO) or General Manager (GM), to position the study and to obtain their consent to be a part of this study. Further we engaged with them to establish who, within their organization, was best placed to participate in the survey. Ninety-six member organisations were contactable. We distributed the survey to all organisations, through their CEO or GM for them to assign to best placed staff to complete. Forty-three responses were received, 40 of which produced viable data. The completed surveys represent 41.6% ($n = 40$) of the contactable HPCA member organisations across SA. Written consent was obtained from participants of each hospice who participated in this study. We conducted a Geographic Information System (GIS) [30], mapping to observe the spatial pattern of responses relative to the location of all organisations (Fig. 1). The GIS mapping further shows the maldistribution of hospices in SA. Although SA is classified as a middle-income country,

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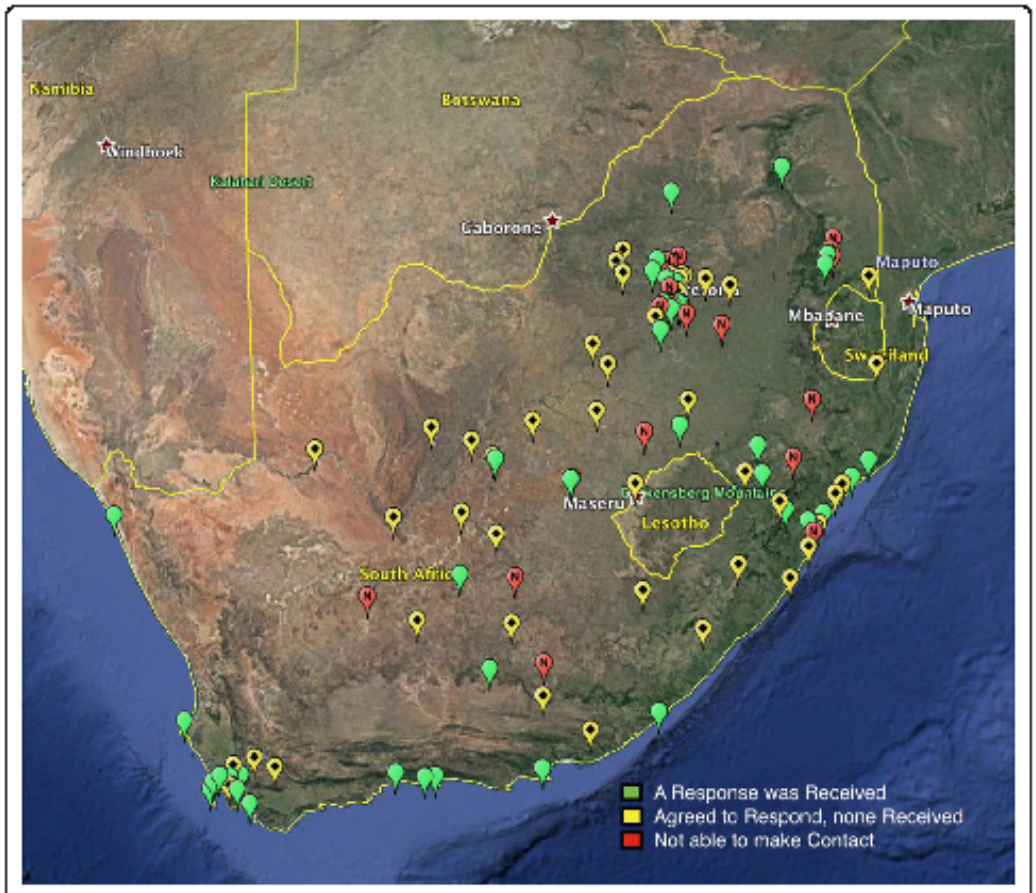

Fig. 1 Mapping of hospices in SA

approximately 33% of the SA population live in rural areas, which by definition, are those areas that are without access to ordinary public services such as water and sanitation and are without a formal local authority, thereby significantly inhibiting rural development (World Bank Blog 2021/2022, Atlas). The survey results were then collated, analysed, and filtered for key issues and overarching themes.

Results

As Fig. 1 shows, there does appear to be a clustering of responses received to the survey, and it appears further that the clusters of response tend to map on to major urban areas of SA, where there tends to be more health and other resources (NPFSPC, 2017–2022). This mapping also highlights the maldistribution of hospices in SA, not an unfamiliar reality given SA's apartheid past. This needs to be borne in mind in the analysis of the data.

Table 1 provides an overview of palliative care service capacity in general in SA, as well as the outreach to patients. All nine provinces were represented. Member organisations reported a cumulative total of 7981 patients per month. When this amount was projected for the entire HPCA member organisations per province, the total number of patients cared for per month was 20,078.

Some member organisations did not offer the full spectrum of palliative care services to their patients. One member organisation did not offer medical care services, and three member organisations did not offer psychosocial care services. Most member organisations described their spiritual care services to patients as 'occasional', with 58% ($n = 23$) making occasional external referrals outside their organisation, and 63% ($n = 25$) rendering occasional

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Table 1 Provincial HPCA Member Organisations, Staff, and Patients' Data

Province	Total Contactable HPCA Member Organisations in SA	Number of respondent HPCA Member Organisations	Total # Staff from Respondent HPCA Member Organisations	Patients per month	Total HPCA Member Organisation Projection of patients per month
Eastern Cape	6	3	77	690	1380
Free State	8	2	24	316	1264
Gauteng	18	8	372	1338	3010
Kwa-Zulu Natal	17	7	164	1385	3364
Limpopo	2	2	26	25	25
Mpumalanga	7	2	20	267	934
North West	8	2	17	615	2460
Northern Cape	14	3	41	864	4032
Western Cape	16		501	2481	3609
Totals	**96**	***n* = 40 (42)**	**1242**	**7981**	**20,078**

internal services. Where spiritual care services were generally available, they were rendered on a partial care basis, primarily through an in-house spiritual care team or this service was outsourced to spiritual care service providers located in the community such as traditional leaders, and faith-based organisations.

When asked to indicate the extent to which spiritual care services were integrated into palliative care at the respective member organisations, 30% ($n = 12$) of the member organisations replied, 'fully integrated', and 20% ($n = 8$) replied 'partially integrated'.

Most ($n = 27$; 68%) member organisations indicated that they did not pay nor give incentives to their spiritual care workers, which suggests that spiritual care as largely a voluntary activity. Spiritual care workers form a diverse group, with isiZulu being the most widely spoken language amongst spiritual care workers, followed by English, Afrikaans and isiXhosa, and then a range of other African and non-African languages. Most spiritual care workers were reported to be Christian ($n = 21$), followed by Buddhist ($n = 6$), Muslim ($n = 4$), and Jewish ($n = 2$).

Only half of the 40 ($n = 20$) member organisations provided data on spiritual care workers' levels of education and qualifications, and some of those that did highlighted that the data may not be accurate. Nine of the member organisations' spiritual care workers had a school leaving certificate,[2] followed by six of the member organisations' spiritual care workers who had a tertiary undergraduate qualification, and five of the member organisations' spiritual care workers who had a postgraduate qualification.

When member organisations were asked to provide details on the nature of spiritual care training the spiritual care workers had received, under two thirds ($n = 25$) of member organisations responded. Of those responses, member organisations indicated that only one in five of them ($n = 8$) had spiritual care workers that received advanced training in spiritual care. Roughly a third ($n = 12$) of member organisations had spiritual care workers who had received no formal training, and a fifth ($n = 8$) of member organisations had spiritual care workers who had received basic training in spiritual care. Considering that over a third of the member organisations did not provide data, the responses from the member organisations suggest significantly low levels of spiritual care training opportunities for their spiritual care workers.

Of the 40 member organisations, only four indicated that they had in place a spiritual care curriculum for training and skills development for spiritual care workers and for their other palliative care staff. Most ($n = 33$) of the member organisations had none. The majority of the member organisations reported that they were unable to provide, nor afford, any in-house spiritual care training and skills development for their spiritual care workers due to funding and expertise constraints ($n = 33$). By contrast, three quarters ($n = 30$) of the member organisations indicated a need for an established national baseline spiritual care curriculum, while only two did not, and two thirds ($n = 26$) of member organisations saw value in their spiritual care staff receiving spiritual care

[2] A school leaving qualification is an academic qualification awarded for the completion of high school. Depending on the country or region, it may alternatively be known as a high school diploma, senior secondary leaving certificate, high school general certificate or school certificate. The National Senior Certificate or NSC is a high school diploma and is the school-leaving certificate in South Africa. This certificate is commonly known as the matriculation (matric) certificate, as grade 12 is the matriculation grade (http://nodoe.ncpg.gov.za/ (accessed 30 March 2021)).

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training. About half ($n = 20$) of the member organisations indicated willingness to participate in the development of a specialised curriculum for palliative care spiritual care training. Suggestions made by member organisations on how they could contribute to the development of such a curriculum included: through workshops ($n = 25$); through focus groups ($n = 31$); through brainstorming/think-tank sessions ($n = 36$).

Though half ($n = 20$) of the member organisations were willing to participate in the development of a spiritual care curriculum, most of them ($n = 14$) indicated that they would prefer not to participate right now. When asked if they would be able to fund sending their spiritual care workers for spiritual care training and skills development, just over half ($n = 22$) of member organisations indicated that they would, but not at the moment. Under a quarter ($n = 9$) stated that they would be willing to pay for such training for their spiritual care workers, and five organizations said they would not be able to afford to pay for such training. Some of the reasons member organisations offered for not participating in the development of a national spiritual care curriculum were: financial ($n = 27$) and time constraints ($n = 31$); and uncertainty as to what value they could bring to this process ($n = 22$).

Member organisations suggested the following sets of skills that ideally spiritual care worker needed to have in order to render quality spiritual care services in a diverse SA. Table 2 outlines those skills in order of prominence.

Table 2 Member organisations' views on essential skills of spiritual care workers

Essential Skills of an Effective Spiritual Care Worker	
Hard Skills[a]	**Soft Skills**[b]
A sound understanding of palliative care, the context of palliative care in SA and its practice. ($n = 32$)	Strong counselling skills ($n = 38$)
Being able to communicate in at least 2 of the official languages in SA. ($n = 29$)	High levels of self-awareness, including insight into one's own spirituality and tolerance for diversity ($n = 31$)
Knowledge and understanding of the integration of palliative care and spiritual issues in hospices and in SA. ($n = 29$)	High levels of acceptance, non-judgmental, and open mindedness. ($n = 28$)
Knowledge of patient rights and being able to clearly identify the needs of the patient. ($n = 27$)	The ability to develop a plan for personal, spiritual and professional growth, self-awareness and self-understanding. ($n = 28$)
Having knowledge of and insight into other cultures and religions and being sensitive when dealing with differences and diversity. ($n = 27$)	Maintains a well-articulated awareness of one's own understanding of spirituality, religion, spiritual health and how to offer spiritual health care in a diverse clinical setting. ($n = 28$)
Knowledge of the medical sector, including professional hierarchies as well as detailed knowledge of the common terminal illnesses patients presents with and consequently being able to understand and respond appropriately to the impact those different illnesses have on the patient. ($n = 21$)	High levels of compassion, motivation, passion and enthusiasm for palliative care. ($n = 23$)

[a]Hard skills are teachable and measurable abilities, such as writing, reading, using computer programmes
[b]Soft skills are the traits that make a good team member, such as etiquette, communication and listening

Discussion

Though member organisations were offering valued spiritual care services, to varying levels, in practice spiritual care services did not receive as much priority as medical or psychosocial services [29]. Funding, and expertise constraints seemed key to the lack of resourcing for spiritual care, and we discuss each in turn.

Funding limitations

Local and international studies support the role of spiritual care in enhancing patient care outcomes [15, 31], yet funding constraints dictate that member organisations have to consciously pick and choose what they can afford to offer, often at the exclusion of spiritual care services. All the member organisations participating in this study are non-governmental organisations (NGOs), depending largely on donor funding to sustain their work. By virtue of being NGOs, member organisations provide a largely free service to the public. With ever-growing funding needs exacerbated by the COVID-19 virus, funding may well decrease rather than increase [32]. This is a clear threat to developing the spiritual care services organisations say they need, especially in a context of existing high palliative care and spiritual care demand and likely increase in demand given the COVID-19 pandemic.

Expertise limitations

Member organisations clearly felt that they had limited expertise in spiritual care, and that this was a barrier in their participation in developing national spiritual care training curricula. This finding is in alignment with what Gijsberts et al. [33] found in a systematic review of recent studies on spiritual care in palliative care in Europe where spiritual care givers saw the provision of spiritual care as part of their role but felt less confident in their spiritual care competencies in that role. Gijsberts et al. [33] also found that there was an expressed desire by palliative care consultants for training to deal with spiritual issues.

The member organisations identified a set of generalist hard and soft skills that a spiritual care worker should ideally have in order to offer an effective spiritual care service, largely in keeping with those outlined elsewhere

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[34]. The hard skills slanted more towards the spiritual care workers having a good understanding of spirituality as a phenomenon; spirituality as a key component of a palliative care service; and a good understanding of the religious, cultural and linguistic diversities underpinning how the spiritual care service would be shaped and delivered in SA settings. Interestingly, a cohort of hospices in the Western Cape Province of SA mentioned similar skills-sets [29]. The soft skills, as suggested by the member organisations, consisted of more intangible and nuanced skills that are typically acquired through practice and experience, such as being present while paying attention to the spirituality of the patient and their hopes; being self-reflective; and bringing peace to the patients. These findings are mirrored by a Dutch study [35] where knowing one's own spiritual background was also considered as part of the self-reflective journey of the spiritual care worker. The skills deficit expressed by member organisations, therefore, may relate not only to hard skills but also to anxiety about providing appropriate, non-discriminatory care in a diverse and highly politicised social environment such as SA. It may be that an important basis of any training would be to address, directly, the political and social context of palliative care, and spiritual care, a key issue for SA, but not addressed to any large degree in the spiritual care literature.

Conclusion

SA is a young democracy, born out of considerable conflict but with aspirations to provide the best for all its diverse citizenry. This reality affects palliative care as it does all other aspects of SA society. Our data demonstrate the gap between actual practice and national policy, a not uncommon feature in SA [36]. Member organisations recognise the importance of spiritual care as a key component of palliative care but are acutely aware of the barriers that hinder such a consolidated approach. It is clear that the international models for the development of training and services in the field of spiritual care have much to offer the development of the field conceptually in SA, but that the local situation of a divided and diverse society, with considerable resource constraints, will necessitate a local, contextually relevant approach. In a number of fields of care in Africa, and in SA in particular, the judicious use of international guidelines tempered with local realities have been attempted [22–25]. We are not yet sure what an ideal model of spiritual care will look like practically in the SA context. In keeping with our informants in this study, however, we believe that this dimension of care is important and should be documented with prominence, and not hidden in palliative care frameworks for Africa.

Abbreviations

GIS: Geographic Information System; HPCA: Hospice Palliative Care Association of South Africa; SA: South Africa

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-021-00756-9.

Additional file 1. Sub-study 1. Online survey of all HPCA member organisations in SA.

Acknowledgements

The national hospice participants for their meaningful engagement with the online survey, as well as their dedication and passion for spiritual care and palliative care. Grateful thanks go to Ian Robertson for assistance with GIS mapping of the member organization, and to the Dr. John Song Memorial Fund managed by Arm In Arm In Africa for the funding of this project.

Authors' contributions

RM was a major contributor to the design and writing of the article. LS contributed to the writing and editing of the article. Both authors read and approved the final manuscript.

Funding

This work was supported by the Dr. John Song Memorial Fund of Arm In Arm In Africa.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from Stellenbosch University Humanities Research Ethics Committee (Project Number: 10237), as well as Hospice Palliative Care Association (02/19). All methods were carried out in accordance with relevant guidelines and regulations. Informed consent was obtained from all participants who were all above the age of 18 years.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Received: 8 February 2021 Accepted: 9 April 2021
Published online: 22 April 2021

References

1. Daute H, d'Archangelo M, Duquette D. Spiritual care training in health care: does it really have an impact? Palliat Support Care. 2019;17:129–37.
2. Paal P, Leget C, Goodhead A. Spiritual care education: results from an EAPC survey. Eur J Palliat Care. 2015;22(2):91–5.
3. Puchalski CM. Religion, medicine and spirituality: What we know, what we don't know and what we do. Asian Pac J Cancer Prev. 2010;11(MECC Supplement 1):45–9.
4. Callahan AM. Key concepts in spiritual care for hospice social workers: how a multidisciplinary perspective can inform spiritual competence. Soc Work Christ. 2015;42(1):43–62.
5. Canda ER, Furman LD. Spiritual diversity in social work practice: The heart of helping. 2nd ed. Oxford: University Press; 2010.
6. Crisp BR. Religion, spirituality and social work: an International perspective. Int J Hum Rights Healthc. 2018;11(2):91–9. https://doi.org/10.1108/IJHRH-10-2017-0060.
7. Damen A, Labuschagne D, Fosler L, O'Mahony S, Levine S, Fitchett G. What Do Chaplains Do: The Views of Palliative Care Physicians, Nurses, and Social Workers. Am J Hosp Palliat Med. 2019;36(5):396–401. https://doi.org/10.1177/1049909118807123.

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8. Jeuland J, Fitchett G, Schulman-Green D, Kapo J. Journal of palliative medicine. May. 2017;20(5):502–8. https://doi.org/10.1089/jpm.2016.0308.
9. McAfee C, Cochrane B, Waldron M, Hasson F, George W. Chaplains working in a hospice palliative care team recount the spiritual challenges at the end-of-life. Health Soc Care Chaplain. 2013;9(2):18–24. https://doi.org/10.1558/hscc.v9i2.18.
10. Balboni T, Balboni M, Paulk ME, Phelps A, Wright A, Peteet J, et al. Support of cancer patients'spiritual needs and associations with medical care costs at the end of life. Cancer. 2011;117(23):5383–91. https://doi.org/10.1002/cncr.26221.
11. Cohen MZ, Holley LM, Wengel SP, Katzman RM. A platform for nursing research on spirituality and religiosity: definitions and measures. West J Nurs Res. 2012;34(6):795–817. https://doi.org/10.1177/0193945912443221.
12. Paley J. Spirituality and nursing: a reductionist approach. Nurs Philos. 2008;9(1):3–18. https://doi.org/10.1111/j.1466-769X.2007.00330.x.
13. Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. Postgrad Med J. 2016;92(1090):466–70. https://doi.org/10.1136/postgradmedj-2015-133368.
14. Yang GM, Tan YY, Cheung YB, Lye WK, Lim SHA, Ng WR, et al. Effect of a spiritual care training program for staff on patient outcomes. Palliat Support Care. 2017;15(4):434–43. https://doi.org/10.1017/S1478951516000894.
15. Paal P, Brandstötter C, Lorenzl S, Larkin P, Elsner F. Postgraduate palliative care education for all healthcare providers in Europe: results from an EAPC survey. Palliat Support Care. 2019;17(5):495–506. https://doi.org/10.1017/S1478951518000986.
16. Puchalski C, Jafari N, Buller H, Haythorn T, Jacobs C, Ferrell B. Interprofessional spiritual care education curriculum: a milestone toward the provision of spiritual care. J Palliat Med. 2019;23(6):777–84. https://doi.org/10.1089/jpm.2019.0375.
17. Bhagwan R. The sacred in traditional African spirituality: Creating synergies with social work practice. In: Crisp BR, editor. The Routledge handbook of religion, spirituality and social work. London: Routledge; 2017. p. 64–72.
18. Chandramohan S, Bhagwan R. Spirituality and spiritual care in the context of nursing education in South Africa. Curationis. 2015;38(1):Art. # 1471 15 pages.
19. Drenth C, Sithole Z, Pudule E, Wast S, GunnClark N, Gwyther L. Palliative care in South Africa. J Pain Symptom Manag. 2018;55(2):S170–7. https://doi.org/10.1016/j.jpainsymman.2017.04.024.
20. Mkandawire-Valhmu L, Kendall N, Dressel A, Scheer M., Kako P, Nieman T, et al. Women's work at end of life: the intersecting gendered vulnerabilities of patients and caregivers in rural Malawi. Glob Public Health. 2020;15(7):1062–72. https://doi.org/10.1080/17441692.2020.1730930.
21. Van Wees SH, Sop Sop MD, Betsi E, Olongo SA, Jennings M. The role of faith-based health professions schools in Cameroon's health system. Glob Public Health. 2020; Advance online publication. https://doi.org/10.1080/17441692.2020.1828985. Accessed 8 Feb 2021.
22. Krawczyk M. "I'm here to help with pain": diagnosing and resolving total pain in hospital palliative care. In: Nissan N, Rizor M, editors. Diagnostic fluidity: working with uncertainty and mutability. Tarragona: Universidad de Tarragona; 2018. p. 149–69.
23. Luyirika EB, Namisango E, Garanganga E, Monjane L, Ginindza N, Madonsela G, et al. Best practices in developing a national palliative care policy in resource limited settings: lessons from five African countries. Ecancermedicalscience. 2016;10:652.
24. Namisango E, Kiyange F, Luyirika EB. Possible directions for palliative care research in Africa. Palliat Med. 2016;30(6):517–9. https://doi.org/10.1177/0269216316647879.
25. Powell RA, Downing J, Radbruch L, Mwangi-Powell FN, Harding R. Advancing palliative care research in sub-Saharan Africa: from the Venice declaration, to Nairobi and beyond. Palliat Med. 2008;22(8):885–7. https://doi.org/10.1177/0269216308098094.
26. Department of Health. National policy framework and strategy on palliative care, South Africa, 2017–2022. 2017.
27. Levey D. Religion, literature and identity in South Africa: the case of Alan Paton. Koers - Bull Christ Scholarsh. 2007;72(1):1–21.
28. Statistics South Africa. Mid-year population estimates. 2018. http://www.statssa.gov.za/publications/P0302/P03022018pdf. Accessed 30 Nov 2020.
29. Mahilall R, Swartz L. Spiritual Care: Motivations and Experiences through the Lenses and Voices of a Cohort of Spiritual Care Workers at an Established Hospice in Cape Town, South Africa. J Relig Health. 2021. https://doi.org/10.1007/s10943-021-01233-7.
30. Procewicz A, Nielsen-Pincus M, Brown G, Schnitzer R. An evaluation of internet versus paper-based methods for public participation geographic information systems (PPGIS). Trans GIS. 2012;16(1):39–53. https://doi.org/10.1111/j.1467-9671.2011.01287.x.
31. Chandramohan S, Bhagwan R. Utilization of spirituality and spiritual care in enursing practice in public hospitals in KwaZulu-Natal, South Africa. Religions. 2016;7(3):23.
32. Goodell JW. COVID-19 and finance: agendas for future research. Financ Res Lett. 2020;35:101512. https://doi.org/10.1016/j.frl.2020.101512.
33. Gijsberts M-JHE, Liefbroer AI, Otten R, Olsman E. Spiritual care in palliative care: a systematic review of the recent European literature. Med Sci. 2019;7:25.
34. Gratz M, Paal P, Emmelmann M, Roser T. Spiritual care in the training of hospice volunteers in Germany. Palliat Support Care. 2016;14(5):532–40. https://doi.org/10.1017/S1478951515001261.
35. Noome M, Beneken Genaamd Kolmer DM, van Leeuwen E, Dijkstra BM, Vloet LCM. The role of ICU nurses in the spiritual aspects of end-of-life care in the ICU: an exploratory study. Scand J Caring Sci. 2017;22:1–16.
36. Rispel L. Analysing the progress and fault lines of health sector transformation in South Africa. S Afr Health Rev. 2016;1:17–23.

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5.2 Chapter summary

I conducted a national online survey of all hospices and member organisations registered with HPCA to establish if, and how, they offered spiritual care services. While 41% of the hospices responded, it became clear that spiritual care services were not prioritised due to financial and spiritual care training constraints. However, there was a chorused need for a national curriculum in spiritual care. In the next chapter, Chapter Six, Article 2 explores how hospices in the Western Cape, SA, navigate the challenges of multi-layered diversities.

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CHAPTER SIX

ARTICLE 2

Spiritual care practices in hospices in the Western Cape, South Africa: The challenge of diversity.

– BMC Palliative Care –

6.1 Introducing Article 2

This article reports on findings from focus group discussions with hospice representatives to explore their spiritual care practices within their hospice palliative care setting in the Western Cape Province, SA, and focussing on how each hospice navigates the challenges of diversity which still impacts all facets of SA as a result of the ravages of apartheid.

This article also explores how the participating hospices of this Sub-Study in the Western Cape, SA, offer spiritual care services in a culturally sensitive and appropriate manner while juggling financial and resources constraints. Useful suggestions are made towards the development of a national spiritual care curriculum that would suit the South African context.

This article was published in the journal, *BMC Palliative Care*, as follows:

> Mahilall, R., & Swartz, L. (2021). Spiritual care practices in hospices in the Western Cape, South Africa: The challenge of diversity. *BMC Palliative Care, 20*(9). https://doi.org/10.1186/s12904-020-00704-z

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Mahilall and Swartz *BMC Palliative Care* (2021) 20:9
https://doi.org/10.1186/s12904-020-00704-z

BMC Palliative Care

RESEARCH ARTICLE Open Access

Spiritual care practices in hospices in the Western cape, South Africa: the challenge of diversity

Ronita Mahilall[1*] and Leslie Swartz[2]

Abstract

Background: South Africa is a very diverse middle-income country, still deeply divided by the legacy of its colonial and apartheid past. As part of a larger study, this article explored the experiences and views of representatives of hospices in the Western Cape province of South Africa on the provision of appropriate spiritual care, given local issues and constraints.

Methods: Two sets of focus group discussions, with 23 hospice participants, were conducted with 11 of the 12 Hospice Palliative Care Association registered hospices in the Western Cape, South Africa, to understand what spiritual care practices existed in their hospices against the backdrop of multifaceted diversities. The discussions were analysed using thematic analysis.

Results: Two prominent themes emerged: the challenges of providing relevant spiritual care services in a religiously, culturally, linguistically and racially diverse setting, and the organisational context impacting such a spiritual care service. Participants agreed that spiritual care is an important service and that it plays a significant role within the inter-disciplinary team. Participants recognised the need for spiritual care training and skills development, alongside the financial costs of employing dedicated spiritual care workers. In spite of the diversities and resource constraints, the approach of individual hospices to providing spiritual care remained robust.

Discussion: Given the diversities that are largely unique to South Africa, shaped essentially by past injustices, the hospices have to navigate considerable hurdles such as cultural differences, religious diversity, and language barriers to provide spiritual care services, within significant resource constraints.

Conclusions: While each of the hospices have established spiritual care services to varying degrees, there was an expressed need for training in spiritual care to develop a baseline guide that was bespoke to the complexities of the South African context. Part of this training needs to focus on the complexity of providing culturally appropriate services.

Keywords: Spiritual care, South Africa, Diversity, Palliative care, Hospice

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Background

Most of what is known about spiritual care comes from well-resourced countries in the global North [1–3]. This article deals with spiritual care in South Africa (SA), a middle-income country, and also a country which is linguistically, racially, culturally and spiritually diverse [4], with inequalities [5], and with a complex political past and present. Apartheid, a system of racial oppression which completely segregated and divided SA, formalising into law many of the informal aspects of segregation and oppression common in colonial contexts, had a profound effect on the emotional and spiritual lives of all its citizens, and despite SA having been a democracy since 1994, it remains a divided society with a long shadow of the past still affecting contemporary spiritual life, health, and, indeed, all aspects of society [6–10].

Spirituality can be defined as a "way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" [11]. Clearly, in thinking about spiritual care in Africa, and in SA specifically, both the historical marginality and the continuing vitality of local approaches to spirituality need to be borne in mind [12, 13].

The modern hospice movement began in the global North in the 1950s with Dame Cicely Saunders [14]. Hospices in Africa began in Zimbabwe in 1980, followed by SA in 1987 and Kenya in 1990. Most countries have palliative care associations that coordinate the work of hospices, especially with regard to sharing best practices, care standards and protocols [15]. The Hospice Palliative Care Association (HPCA) of SA is one such association. The population of SA was 58,78 million according to the 2019 mid-year population estimates [16]. The total number of deaths registered at the South African Department of Home Affairs and processed by Stats SA in 2017 were 446,544. Although it was found that most male deaths are related to tuberculosis and most female deaths are related to diabetes mellitus, cancers are still the leading cause of terminal diagnosis [17]. "The estimated need for palliative care, using only mortality data, is that 0.52% of the population require palliative care in any year" [15].

Arising out of a broader study on spiritual care in SA, this article explores how the hospices in the Western Cape Province of SA offer spiritual care services while navigating the rugged terrain of racial prejudices, social injustices, and cultural segregation.

Theoretical framework

In addressing questions of cultural and spiritual diversity in palliative care, we are influenced by the research tradition on explanatory models of illness and disease, as first formulated by Kleinman and developed by a range of other authors [18–20]. For Kleinman and those that follow his work, all people interpret illness and misfortune in the light of cultural categories that are part of their social world – and both patients and those who care for them have elaborated cultural explanations of illness and distress. Given the socio-political context of SA, it is important to note that explanatory models and systems are profoundly affected by social factors, including histories of exclusion and oppression – culture never exists apart from the socio-political context [21–23].

Methods

Ethical approval was obtained from Stellenbosch University (10237) as well as Hospice Palliative Care Association (HPCA) (02/19). HPCA is a national association operating in all nine provinces in SA and 51 health districts. Some of its voluntary hospices offer hospice palliative care, some home-based care, and others both services. We conducted two focus group discussions (FGDs) with employees of hospices in the Western Cape. Eleven of the 12 registered member organisations (hospices) in the province agreed to participate. Written consent was obtained from all participants. Participants were very diverse in terms of racial and ethnic status, and had diverse qualifications. Table 1 gives an overview of the hospices' representation.

We based discussions on 13 open-ended questions (Appendix 1). The FGDs were recorded, transcribed, and coded, and we analysed the data thematically.

Results

We present the key themes in order of prominence.

Providing relevant spiritual care services in a religiously, culturally, and racially diverse population

By far the most prominent theme from the FGDs focussed on the barriers hindering the provision of effective and relevant spiritual care services within a highly diverse population.

Participants argued that hospice personnel needed to have a basic working knowledge of the main religions in SA.

On the other hand, the ability to engage with patients about spiritual and existential issues without referencing religion was also mentioned as a crucial skill. Participants emphasised the need to be tolerant, sensitive and non-judgemental.

As a participant from Hospice #2 put it:

I was sitting here thinking that should the whole spirituality curriculum then not focus a whole lot on those who do the training to reach highest level of self-awareness because when you are self-aware, your ability to tell and convey to others their worth

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Table 1 Research participants

District	Represented hospice #	No of participants from represented hospices	Designation of participants at the represented hospices	Palliative care background of the hospice participants: Medical, psychosocial, spiritual, bereavement
Eden District, Western Cape	Hospice #1	4	Psychosocial Counsellor (1) Social Worker (1) Manager (1) Pastor (1)	Medical (1) Psychosocial (2) Spiritual (1)
	Hospice #2	3	Professional Nurse (1) Chief Executive Officer (1) Psychosocial Manager (1)	Medical (2) Psychosocial (1)
	Hospice #3	1	Chief Executive Officer (1)	Psychosocial (1)
	Hospice #4	1	Nursing Manager (1)	Medical (1)
Cape Town District, Western Cape	Hospice #5	2	Social Worker (1) Medical Doctor (1)	Medical (1) Psychosocial (1)
	Hospice #6	2	Professional Nurse (1) Social Worker (1)	Medical (1) Psychosocial (1)
	Hospice #7	4	Spiritual Care Coordinator (1) Training Facilitator. Professional Nurse (1) Chief Executive Officer (1) Spiritual Care Worker (1)	Medical (1) Psychosocial (1) Spiritual Care (2)
	Hospice #8	1	In-Patient Unit Manager (1)	Medical (1)
	Hospice #9	3	General Manager (1) Patient Care Manager (1) Social Worker (1)	Medical (1) Psychosocial (2)
	Hospice #10	1	Nursing Manager (1)	Medical (1)
	Hospice #11	1	Chief Executive Officer (1)	Medical (1)

and their value within their existence is just so much easier ... because I think that we are kind of stuck in the thing about spirituality equals religion ... it doesn't and to break that mind-set in people, especially in Christians, I find very difficult.

According to participants, this requires self-knowledge and openness:

And if it's about self-awareness, then if you're not comfortable with homosexuality for example, it would affect you if your patient is requiring, or if your patient who is homosexual needs your help ... (Participant of Hospice #5)

Racial, cultural and linguistic diversity

Participants believed that patients should ideally receive care in their mother tongue. However, the resources required are not often there:

The other thing of course we started looking at (was) *for Xhosa speaking patients we want somebody that can support them in their mother tongue language.* (Participant of Hospice #5)

Specific mention was made of the need to know and respect traditional African beliefs, spiritual practices and bereavement rituals. Hospices need to be tolerant and sensitive to African bereavement rites; and to allow space for these to take place at the hospice in a way that does not negatively impact on the other patients. This is how a participant from Hospice #7 put it:

... the patient died, and the family came back for the spirit ... they want to catch the spirit and they ask us if we can allow them to come catch that spirit because they believe (after the) *patient* (died) *... the spirit stayed behind ... we had to* (allow for this ritual), *but in the specific way where we say we will give you this part of the area* (hospice) *because we have to think about our other patients and protect them and they don't see somebody is looking for a spirit here. So we make space for them and they came and catch the spirit and they spent a few hours in ways to get the spirit and then eventually they leave.*

On the other hand, participants noted that patients did not always want a representative from their official religion or speaking their mother-tongue. Some patients

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may want spiritual guidance and support from a person with whom they have built a close relationship. Navigating the territory between trying to make appropriate spiritual care available on the one hand, and allowing for choices which violate assumptions about cultural and spiritual differences on the other, could be a challenge in practice. As a participant from Hospice #9 put it:

> (A Muslim, Afrikaans-speaking patient) *overheard me speaking to other patients after the* (Christian Xhosa-speaking) *pastor had visited ... about what is going on in spirituality, in the Christian work.* (The Muslim patient asked me): *"Can the pastor come pray for me?" I said, "We've called your Imam* (Islamic priest)*; he's going to help you." But she keeps on asking* (for the Christian pastor). *So there comes a time that they don't understand their religions, I would rather say that.*

The organisational context

Participants felt that spiritual care services were an integral part of the palliative care Inter-Disciplinary Team (IDT), whether provided by a designated person or by a team. It was felt that all IDT members should be able to support the patient's spiritual needs. Hospice participants went on to list intangible resources such as time and effort as a crucial part of spiritual care services.

Hospice-specific palliative care team dynamics and organisational culture

Participants affirmed that working in an IDT helped provide a deeper, more holistic understanding of the patient's situation and challenges. Having a structured inclusion of spiritual care into the IDT consultations and patient assessments was reported to be exceedingly helpful.

On the other hand, participants reported that some colleagues were not comfortable working with spiritual issues. Working in a team would allow such colleagues to hand over to other, better equipped colleagues. As Hospice #1 participant put it:

> *So for me it's working with what you have* (the staff) *and enable that to be completely comfortable and open and that's where we start, because ... a lot of the staff cannot do it* (spiritual care). *They want to run when there's an existential need expressed* (by a patient) ...

There was an expressed need to create spaces where all team members bring different professional, personal and spiritual schools of thought to the table and allow for those differences to be acknowledged, recognised and respected. This creates a tolerant, pluralistic atmosphere for patients as well. Indeed, the smooth functioning of the IDT was viewed as so important that some hospices hired spiritual care staff to fit the team and not necessarily all the ideal requirements of the spiritual care post. In recruitment processes in many hospices, the larger team often gave input into the recruitment and selection of a prospective spiritual care staff member, to ensure that they could all work well together. A participant from Hospice #11 explains:

> *We trust each other ... when we hire ... we hire for a fit on the team ... the person that gets chosen may not have all the qualifications but if they fit in the team ... we can grow* (that person).

Having a larger team that worked together on the patient's overall care plan, and particularly the patient's spiritual care plan, could also ensure that adequate support was provided to the staff, which could reduce stress and burnout. Staff often worked in situations that were difficult or uncomfortable for them. Working in teams could be a better option in difficult situations where workers were struggling, emotionally or professionally, as a participant from Hospice #5 puts it:

> *The ability to know even if you are trained, that if you can't handle a situation, that you need help. I have seen many people go under* (burn out) *because they take on more and more.*
> *You don't go in alone because two is stronger than one.*

The organisational culture of the hospice was cited as another crucial element. Hospice #10 participant explains:

> *What culture the organisation lends itself to ... whether spirituality is embraced or not ... will set the tone in terms of the spiritual care* (that it provides or does not provide).
> *... the culture of spirituality ... in this organisation ... is how we do things and people who come in new will automatically sense the culture of that organisation.*

The calibre of staff working in the spiritual care service team was also mentioned as a crucial factor affecting the quality of spiritual care services. In addition to skills that can be acquired through training and development, staff needed to be empathetic and open to continuous learning, feedback and self-improvement. There was a difference of opinion as to whether there should be dedicated spiritual care service staff or whether all hospice staff should be trained to offer spiritual care services:

> ... *we have a* (formally employed) *spiritual care worker, volunteer spiritual care worker that sits on our IDT, and are* (present) *at all our meetings and*

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we also have a counsellor and our social worker, nurses, doctors.
(Representative of Hospice #12)

However,

Ja (Yes), *so for me ... my thinking is that in terms of addressing spiritual existential needs, one would have to situate* ***all*** *members of the hospice team that at any given time or any given point in the journey with that patient, they are open and available to address any existential need because you can't box that need at any point in time.*
(Representative of Hospice #11)

Having dedicated spiritual care staff could allow for more cost-effective training and skills development for fewer people. However, as the patient decides with whom they wish to talk about spiritual and existential issues, having only one or two spiritual care staff could limit the patient's freedom of choice. Having designated staff also limits the availability of spiritual care services to patients, as patients could decide to talk about these issues whenever the moment seems right to them. The designated spiritual care services staff may not be present at that specific moment, and the present staff would have to deal with the matter as best they can. This could have a negative impact on the quality of spiritual care services provided to the patient.

Conflicting demands

The conflicting demands of the patient's wellbeing – balancing physical care with emotional and spiritual care – contributed additional complexity. All needs were urgent, but finding time to focus on spiritual care in the face of urgent physical care needs could be challenging. There are significantly fewer spiritual care workers compared to other professions represented in hospices.

Participants noted that it is challenging to assess the impact of spiritual care, and this in turn makes it difficult to assess what best practice may be:

And then I just need to say that most of the time we find out that the value of what we do is only seen after we've seen the patient and family and up to two, three months, four months. We get a card or we get a phone call to say thank you that you have helped us through this journey. And every so often our doctor here will come back to me and say (representative's name), *what did you do to that man* (patient)*? And then I will say, well, you asked me to do some support and uh the guy never wanted to be compliant or didn't want to work along with the doctor and the nurse and was always angry or aggressive maybe. Then after I've seen the person* (patient), *the doctor comes back and wants to know what I did. Well, I think I did what I was asked to do.*
(Hospice #11 representative)

Discussion

Much of what was discussed by our participants is similar to what has been reported in the literature [24–26], but the local context of huge diversity, great inequality, and scarce resources, places particular demands on local hospices. The responses of our participants enable us to add to the discussions raised by the few studies in the global South [15, 27, 28]. The issue of diversity in spiritual care is now being discussed in diversifying countries like, for example, the USA [29–31] and in other African contexts [32–34]. There are similarities between our findings and those in other diverse contexts; the particular South African history, though, does create a political context which is probably unique [35].

It is also important to note that the psychology of having to deal with very difficult issues – illness and death – may well have influenced our participants' responses and their discussion of spirituality issues in the South African context. It is well established that people who deal with human pain and suffering may well experience a degree of what has been termed secondary traumatisation or compassion fatigue [36, 37]. The emotional experience of dealing with suffering and death may, of course, also have positive effects and build resilience in carers [38].

It was clear from our data that all our participants indicated that respect for spiritual, cultural and religious diversity is important, and all seemed to draw on their experiences to come to the views they shared with us. It is also important to note that some participants indicated their rejection of a simplistic and neat categorisation, and some will also be troubled by the rather simplistic categorisation of people into separate boxes according to their ascribed cultural and religious status. In SA, given the legacy and continuing pain of its colonial and apartheid past [23], cultural differences map on to concerns about racial oppression and injustice. For South Africans committed to the best possible culturally appropriate spiritual care, it may be more difficult than elsewhere to come to terms with the fact that some people prefer spiritual care from people who are very different culturally and linguistically from them. In this regard, it is interesting that one of our participants, confronted with a situation like this, and wishing to provide the most appropriate care, said, *"So there comes a time that they don't understand their religions"*. Here, the care receivers are (inadvertently, we think) portrayed as deficient – not understanding their own religions – rather than having, as all people are entitled to have, complex and contradictory positions in relation to cultural and spiritual diversity.

Given that much of what is written about spiritual care is from contexts where the patient and spiritual carer have the same cultural, linguistic and religious background, it is

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appropriate that the literature does call upon readers to recognise and be sensitive to cultural and religious differences when they do exist. In SA, though, not uniquely, but crucially for our participants, the idea of protecting cultural differences has been used historically to justify segregation and even oppression [21]. There is a paradox in this – as our participants note, culturally appropriate care is important, but rigid ideas about inherent difference may problematically reinforce old stereotypes and not lead to the best care. It is easy to say in the abstract that in spiritual care we wish to follow the lead of care recipients themselves, but in a context in which there is great anxiety about not wishing to impose [23] or to be culturally insensitive, it may be challenging to deal with people whose expressed needs violate common assumptions about what culturally-based needs are. The wish to be culturally sensitive may, paradoxically, make carers in a divided society anxious and hesitant to provide what patients want, for fear of appearing culturally insensitive. This is an issue globally [39], but takes on a particular valence in the South African context. This, we believe, is a crucial issue to address in the development of spiritual care in SA. In this regard, a recent South African article about family care in the context of intellectual disability [40] notes that even when there are obvious cultural and racial differences between carers and those they care for, there may be surprising areas of commonality between them. Good spiritual care recognises and appreciates differences, just as it honours similarities, and, crucially, allows care recipients themselves to position themselves in contradictory and inconsistent ways in relation to these issues. Finding the right way to engage in this context is challenging, and, of course, there is no single and clear right way.

Given resource constraints, a further aspect to these challenges is the reality that at any one time, people with vastly different views and backgrounds will be recipients of care in the same hospice. Our participants recognised that precisely by wanting to embrace the many cultures their patients represent; hospices sometimes inadvertently fail to meet the cultural needs of all their patients. For example, most patients and families that come into hospices come from heterosexual marriages or relationships. Further, patients admitted into hospices are generally older and less likely to be fully exposed to the concepts of same-sex marriages and partnerships, and the many gender related relationship permutations that have recently emerged and are protected under the South African constitution. Some patients may be offended and upset by being in a small and confined hospice together with people in same-sex relationships, for example, but all people are equally entitled to care and to feeling safe. Where resources are few, this equity may be difficult to achieve in practice.

Similarly, allowing patients and their families to engage in cultural practices at the hospice may be a contentious debate. It is easy to declare that all patients should have equal rights to practice their cultures at the hospice and that the hospice has the obligation to offer freedom of expression to the patients with culturally divergent practices. But as our participant mentioned, in the case of *"the patient died, and the family came back for the spirit ... they want to catch the spirit ..."* , the reality is that most hospices do not have the luxury of space or private patient rooms to assign patients of similar cultures to certain wings of the hospice. The custom of *"catching of the spirit"*, which according to tradition must take place on the ward where the patient died, and is an important spiritual ritual, may upset other patients and families, and in fact they may experience witnessing the ritual as a violation of their own spiritual rights. Navigating such diversity is challenging, at best, and calls for creative and reality-based solutions.

We do not offer any solutions but we offer these challenges as topics for further debate, workshops and focused discussions towards the development of a spiritual care response that embraces the cultural diversity as well as the politics of cultural diversity in SA.

These issues, and all others are profoundly affected by resource constraints. All the hospices that participated in this study are non-governmental organisations (NGOs). NGOs, in a South African context, depend largely on funding from the public to sustain their work. Fundraising is always challenging and is likely to become much more so in the context of the COVID-19 pandemic and its aftermath. Where resources are constrained, there is a danger that there will be a focus, understandably, just on medical care. The gains made by the informality of spiritual care offered in many hospices by unpaid volunteers may be lost if even the very low costs of administering such a service and paying expenses like transport for volunteers may come to be seen as unaffordable.

However, and despite the reality of these challenges, participants felt that the cash versus care argument should not lead to nihilism but to possible rethinking of how care can be best and most efficiently delivered. This represents a real challenge for the future.

Conclusion

It emerged quite clearly from this study that rendering spiritual care services within a diverse palliative care setting, such as the Western Cape, SA, was both essential and challenging. Hospice staff need to be in possession of a broad range of critical skills, knowledge and expertise in order to provide quality spiritual care services against the backdrop of deeply entrenched external constraints such as racial prejudices, religious difference, and social and cultural segregation. The highly individualised nature of spiritual care services, the diverse population, and individual hospices' physical and human resource constraints added additional levels of complexity to spiritual care and palliative care. If spiritual care is to have its rightful place in palliative care globally, these are issues which need to be borne in mind.

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Appendix

Table 2 Guiding questions for semi-structured focus group discussions

Positioning spiritual care services as offered by the hospices in the Western Cape

1. What is your understanding of the South African National Policy Framework and Strategy on Palliative Care 2017–2022 (NPFSPC)?
2. How does the NPFSPC influence service delivery at your hospice?
3. Does your hospice offer spiritual care services?
4. Describe the nature of the spiritual care intervention provided by your organisation.
5. What has the benefit been to the patient/family after receiving spiritual care intervention?

The role of spiritual care within a hospice in a diverse SA context

6. Describe the role of spiritual care as one of the four pillars of palliative care within your hospice.
7. How would you describe the role of the spiritual care workers within the Inter-Disciplinary Team (IDT) or Multi-Disciplinary Team (MDT) at your hospice?
8. Given the range of diversity of SA, how would you say this affects the thinking of spiritual care delivery within your hospice?

Skills and training needs of a spiritual care worker towards the development of a spiritual care training curriculum

9. What skills are needed to provide spiritual care services?
10. What resources are needed to provide spiritual care services?
11. Are your spiritual care workers trained in spiritual care?
12. What would you consider to be the curriculum needs of spiritual care workers?
13. What would you consider to be the curriculum content of a spiritual care training programme within a hospice palliative care setting in SA?

Abbreviations

FGDs: Focus group discussions; IDT: Inter-Disciplinary Team; NGO: Non-governmental organisation; SA: South Africa

Acknowledgements

Varkey George for the excellent co-facilitation of the focus groups discussions; Prof. Dianna Yach, Chairperson of The Mauerberger Foundation Fund – for the funding of this project; and participants and colleagues of the hospices in the Western Cape, South Africa, for their meaningful participation, dedication and passion for spiritual care and palliative care.

Authors' contributions

RM was a major contributor to the design and writing of the article. LS contributed to the writing and editing of the article. Both authors read and approved the final manuscript.

Funding

The Mauerberger Foundation Fund provided funding for the study, and played no further role in the design, data collection or writing of the article.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

Ethical approval was obtained from Stellenbosch University (10237) as well as Hospice Palliative Care Association (HPCA) (02/19). Written consent was obtained from participants of the study and is available from the corresponding author.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Received: 20 August 2020 **Accepted:** 28 December 2020
Published online: 11 January 2021

References

1. Callahan AM. Key concepts in spiritual care for hospice social workers: How a multidisciplinary perspective can inform spiritual competence. Soc Work Christianity. 2015;42(1):43–62.
2. Steinhauser KE, Balboni TA. State of the science of spirituality and palliative care research Research landscape and future directions. J Pain Symptom Manage. 2017;54(3):426–7. https://doi.org/10.1016/j.jpainsymman.2017.02.020.
3. Puchalski C, Jafari N, Buller H, Haythorn T, Jacobs C, Ferrell B. Interprofessional spiritual care education curriculum: A milestone toward the provision of spiritual care. J Palliat Med. 2019;23(6):777–84. https://doi.org/10.1089/jpm.2019.0375.
4. Chandramohan S, Bhagwan R. Spirituality and spiritual care in the context of nursing education in South Africa. Curationis. 2015;38(1) Art. # 1471:15. https://doi.org/10.4102/curationis.v38i1.1471.
5. Swatuk LA, Black DR, editors. Bridging the rift: The new South Africa in Africa. Boulder CO and Oxford: Westview Press; 2019.
6. Nicholls L, Rohlieder P, Bozalek V, Carolissen R, Leibowitz B, Swartz L. Apartheid was your past, not mine. In: Leibowitz B, Swartz L, Bozalek V, Carolissen R, Nicholls L, Rohlieder P, editors. Community, self and identity: Educating South African university students for citizenship. Cape Town: HSRC Press; 2012. p. 73–86.
7. Meyer J. Investigating the nature of and relation between masculinity and religiosity and/or spirituality in a postcolonial and post-apartheid South Africa. HTS Theological Studies. 2020;76(1):1–10. https://doi.org/10.4102/hts.v76i1.5663.
8. Apostolides A. South African fantasy: Identity and spirituality. HTS Theological Studies. 2016;72(1):1–5. https://doi.org/10.4102/hts.v72i3.3255.
9. Hodes R. Questioning 'fees must fall'. African Affairs. 2017;116(462):140–50. https://doi.org/10.1093/afraf/adw073.
10. Nyamnjoh F. FeesMustFall: nibbling at resilient colonialism in South Africa. Bamenda, Cameroon: Langaa Research and Publishing CIG; 2016.
11. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. J Palliat Med. 2009;12(10):885–904. https://doi.org/10.1089/jpm.2009.0142.
12. Bhagwan R. The sacred in traditional African spirituality: Creating synergies with social work practice. In: Crisp BR, editor. The Routledge handbook of religion, spirituality and social work. London: Routledge; 2017. p. 64–72.
13. Crisp BR. Religion, spirituality and social work: An international perspective. Int J Hum Rights Healthc. 2018;11(2). https://doi.org/10.1108/IJHRH-10-2017-0060.
14. Saunders CM. Cicely Saunders: selected writings 1958–2004. Oxford: Oxford University Press; 2006.
15. Drenth C, Sithole Z, Pudule E, Wust S, GunnClark N, Gwyther L. Palliative Care in South Africa. J Pain Symptom Manage. 2018;55(2S):S170–7. https://doi.org/10.1016/j.jpainsymman.2017.04.024.
16. Statistics South Africa. Mortality and causes of death in South Africa: Findings from death notification. 2011. https://www.statssa.gov.za/publications/P03093/P030932017.pdf. Accessed 14 Nov 2020.
17. Statistics South Africa. Population characteristics. 2017. http://www.statssa.gov.za/?p=12362. Accessed 14 Nov 2020.
18. Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. Soc Sci Med B. 1978;12:85–93. https://doi.org/10.1016/0027-9536(78)90014-8.

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19. Bhui K, Bhugra D. Explanatory models for mental distress: Implications for clinical practice and research. Br J Psychiatry. 2002;181(1):6–7. https://doi.org/10.1192/bjp.181.1.6.
20. Mayston R, Fitsa S, Tekola B, Hanlon C, Prince M, Feleke A. Explanatory models of depression in sub-Saharan Africa: Synthesis of qualitative evidence. Soc Sci Med. 2020;246:112760. https://doi.org/10.1016/j.socscimed.2019.112760.
21. Swartz L. Issues for cross-cultural psychiatric research in South Africa. Cult Med Psych. 1985;9:59–74. https://doi.org/10.1007/BF00048537.
22. Swartz L. The reproduction of racism in South African mental health care. S Afr J Psychol. 1991;21:240–6. https://doi.org/10.1177/008124639102100407.
23. Lapperman M, Swartz L. Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital. Psychodyn Pract. 2019;25:325–41. https://doi.org/10.1080/14753634.2019.1670093.
24. Sinclair S, McConnell S, Raffin Bouchal S, Ager N, Booker R, Enns B, et al. Patient and healthcare perspectives on the importance and efficacy of addressing spiritual issues within an interdisciplinary bone marrow transplant clinic: A qualitative study. BMJ Open. 2015;5(11):e009392. https://doi.org/10.1136/bmjopen-2015-009392.
25. Isaac KS, Hay JL, Lubetkin EI. Incorporating spirituality in primary care. J Relig Health. 2016;55(3):1065–77. https://doi.org/10.1007/s10943-016-0190-2.
26. Flitchett G. Recent progress in chaplaincy-related research. J Pastoral Care Counsel. 2017;71:163–75. https://doi.org/10.1177/1542305017724811.
27. Gonzalez L. Need to rethink palliative care in South Africa. Health-E News. 19 Sep 2013. https://health-e.org.za/2013/09/19/need-rethink-palliative-care-south-africa/. Accessed 13 Aug 2020.
28. Van Niekerk L, Raubenheimer PJ. A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town, South Africa. S Afr Med J. 2014;104(2):138–41. https://doi.org/10.7196/SAMJ.7262.
29. Ejem DB, Barrett N, Rhodes RL, Olsen M, Bakitas M, Durant R, et al. Reducing disparities in the quality of palliative care for older African Americans through Improved Advance Care Planning: study design and protocol. J Palliat Med. 2019;22(S1):S–90. https://doi.org/10.1089/jpm.2019.0146.
30. Elk R, Emanuel L, Hauser J, Bakitas M, Levkoff S. Developing and testing the feasibility of a culturally based tele-palliative care consult based on the cultural values and preferences of southern, rural African American and White community members: a program by and for the community. Health Equity. 2020;4(1):52–83. https://doi.org/10.1089/heq.2019.0120.
31. Elk R. The need for culturally-based palliative care programs for African American patients at end-of-life. Journal of Family Strengths. 2017;17(1):14 https://digitalcommons.library.tmc.edu/jfs/vol17/iss1/14.
32. Agom DA, Neill S, Allen S, Poole H, Sksmith J, Onyeka TC, Ominyi J. Construction of meanings during life-limiting illnesses and its impacts on palliative care: Ethnographic study in an African context. Psychooncology. 2019;28(11):2201–9. https://doi.org/10.1002/pon.5208.
33. Githaiga JN, Swartz L. Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions. BMC Palliat Care. 2017;16(1):40. https://doi.org/10.1186/s12904-017-0222-z.
34. Githaiga JN, Swartz L. 'You have a swelling': The language of cancer diagnosis and implications for cancer management in Kenya. Patient Educ Couns. 2017;100:836–8. https://doi.org/10.1016/j.pec.2017.01.003.
35. Jansen J, Walters C, editors. Fault lines: A primer on race, science and society. Stellenbosch: AFRICAN SUN MeDIA; 2020.
36. Samson T, Shvartzman P. Secondary traumatization and proneness to dissociation among palliative care workers: A cross-sectional study. J Pain Symptom Manage. 2018;56(2):245–51. https://doi.org/10.1016/j.jpainsymman.2018.04.012.
37. Cross LA. Compassion fatigue in palliative care nursing: A concept analysis. J Hosp Palliat Nurs. 2019;21(1):21. https://doi.org/10.1097/NJH.0000000000000477.
38. Zanatta F, Maffoni M, Giardini A. Resilience in palliative healthcare professionals: a systematic review. Support Care Cancer. 2020;28(3):971–8. https://doi.org/10.1007/s00520-019-05194-1.
39. Kai J, Beavan J, Faull C, Dodson L, Gill P, Beighton A. Professional uncertainty and disempowerment responding to ethnic diversity in health care: A qualitative study. PLoS Med. 2007;4(11). https://doi.org/10.1371/journal.pmed.0040323.
40. Coetzee O, Swartz L, Adnams C. Finding common ground in the context of difference: A South African case study. Cult Med Psychiatry. 2019;43:277–89. https://doi.org/10.1007/s11013-018-9615-6.

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Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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6.2 Chapter summary

This article presented a deeper understanding of what the current spiritual care practices are at hospices in the Western Cape, South Africa, and more crucially, how a multitude of diversities such as cultural diversity, linguistic diversity, racial diversity, religious diversity, and socio-economic diversity impact the hospices' preparedness to provide spiritual care services, or not, within a milieu of such diversities. In Chapter Seven I present Article 3 which focusses on a case study of how spiritual care is practised at an established hospice in Cape Town – SLCH – where the spiritual care workers, considered as insider experts of spiritual care practice, navigate the complexities of diversity.

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CHAPTER SEVEN

Article 3

"I am dying a slow death of White guilt": Spiritual carers in a South African hospice navigate issues of cultural diversity.

– Culture, Medicine, and Psychiatry –

7.1 Introducing Article 3

This article has a similar theme to the previous two papers, as this paper explores spiritual care service provision within the context of diversity at a hospice – SLCH – in Cape Town, SA. Chapter Five presented, on a national level, what spiritual care services are on offer at hospices proving palliative care and how these services are prioritised given the diversities SA represents. In Chapter Six I focused regionally, and within the Western Cape Province in particular, to explore how hospices navigate the many issues of diversity in their provision of spiritual care services.

The participants of this study, as presented in this chapter, shared their experiences as spiritual care workers, often referred to as insider experts, offering spiritual care services within a diverse terminally ill patient population registered as patients of SLCH.

This article was published in the journal, *Culture, Medicine, and Psychiatry*, as follows:

> Mahilall, R., Swartz, L. 'I am Dying a Slow Death of White Guilt': Spiritual Carers in a South African Hospice Navigate Issues of Race and Cultural Diversity. Cult Med Psychiatry (2021). https://doi.org/10.1007/s11013-021-09750-5

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Cult Med Psychiatry
https://doi.org/10.1007/s11013-021-09750-5

ORIGINAL PAPER

'I am Dying a Slow Death of White Guilt': Spiritual Carers in a South African Hospice Navigate Issues of Race and Cultural Diversity

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Accepted: 26 August 2021
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Abstract Culturally appropriate spiritual care is increasingly recognised as a crucial component of spiritual care. As part of a larger study, we were interested in cultural and racial issues as experienced by spiritual carers in a hospice in Cape Town, South Africa. We conducted one-on-one interviews and focus group discussions with a cohort of spiritual care workers, who, being volunteers and relatively privileged South Africans, discussed their sensitivity to cultural issues, but also mentioned a host of political, racial and identity issues which profoundly affect their work. The data suggest that the concept of culturally appropriate care must be understood and acted on contextually. We note that the work of transformation of care cannot be separated from broader questions of social inequality and change.

Keywords Hospice spiritual care · Cultural diversity · South Africa · Apartheid · Colonialism · Race

Introduction

Emerging from centuries of colonialism and fragmentation which underpinned the apartheid era, the post-apartheid democratic administration was tasked with addressing the disempowerment and weakened health care system in South Africa (SA) (Coovadia et al. 2009; De la Porte 2016). Twenty-seven years on, there has been a notable lack of progress in addressing health care inequalities. The current

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Published online: 13 September 2021

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global pandemic—SARS-CoV-2 adenovirus, that causes the COVID-19 disease—has further accentuated the interplay between inherited and acquired vulnerabilities and how one's positionality on the uneven playing field of life in SA plays out in the quality of health care received (Baldwin-Ragaven 2020). The people of SA are still divided along cultural, racial, and linguistic lines, and SA remains one of the most unequal, if not the most unequal, societies in the world (Francis and Webster 2019; Jansen and Walters 2020).

There is a substantive body of work in the global South, and in SA in particular, that explores the issue of cultural diversity in health care settings and the impact on care outcomes (Chandramohan and Bhagwan 2016; Matthews and Van Wyk 2018; Swartz 1991). Palliative care has very recently obtained recognition in SA, taking its rightful place on the continuum of health care platform (Republic of South Africa 2017). Spiritual care interventions, within the overarching hospice end-of-life care service, seek to support the patient with their 'total pain' (Saunders 2006), and palliative care policies recognise that a terminal diagnosis affects a patient physically, psychologically, spiritually and emotionally. Spiritual care also recognises that patients with terminal illnesses approach their situation in the context of their cultural, religious and racial beliefs and experiences, whether explicitly or implicitly (Mthembu, Wegner, and Roman 2016). The issue of the need for sensitivity regarding culture, religion and ethnicity in palliative care interventions are currently gaining impetus in the global North as a specialised area (Cain, et al. 2018; Curtis, 2019; Elk, et al. 2020). Given SA's history and divided society, however, issues of cultural and spiritual diversity, and race and racism, have long been core concerns in the development of health care interventions, including palliative care interventions (Baldwin-Ragaven, London, and De Gruchy 1999; De Beer and Chipps 2014; Drenth et al. 2018; Swartz 1985, 1998; Mahilall and Swartz 2021a).

The question of how health care workers in SA navigate and deal with issues of racial, cultural, linguistic, religious and spiritual diversity has been studied in a number of areas, including Human Immunodeficiency Virus (HIV) care (Petros et al. 2006); paediatric asthma (Levin 2005); diabetes care (Bosire et al. 2020); emergency services (Penn, Watermeyer, and Nattrass 2017); obstetric care (Lappeman and Swartz 2019) and mental health care (Swartz et al. 2019). Historically, in SA, questions regarding the provision of culturally appropriate care have been bound up with questions of race, racism and racial oppression (Swartz 1986, 1987), not least because a key way in which discriminatory practices were justified ideologically was with the claim that different services were necessary out of respect for cultural difference (Swartz 1985, 1991, 1996). Service providers working in SA have at times felt caught between the wish to provide culturally appropriate care and the fear that providing different services to different people may appear discriminatory (Swartz 1985).

There are numerous problems in the use of terminology around race, culture and ethnicity in SA. A recent volume focussing on this question (Jansen and Walters 2020) notes that in SA, there is considerable slippage across terms, and an added problem is that terms which have in the past been used for purposes of racial and class oppression can also be avoided, with terms like "culture" being used

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euphemistically for crude and unscientific divisions of people, often quite arbitrarily, for purposes of oppression. The is a long and contested history of racial and other labelling in SA (Dubow 1995), and there is not the space in this article to unpack all of the issues. For the purposes of our argument, though, it is important to acknowledge the complexity of labelling, and how often there is terminological slippage.

Palliative care as a field is less developed in SA and other parts of Africa than are other fields of care (Court and Olivier 2020). The authors of a recent review on integrating palliative care into health systems in Africa have as their first recommendation (what they describe as 'top tips') the following:

> Make the patient central…by providing responsive care and investigating the PC (palliative care) needs of patients, as well as what type of care is culturally appropriate and desired. (Court and Olivier 2020:14)

Given South Africa's racial history (and, indeed, much of the colonial past on the African continent as a whole), it is interesting that in policy recommendations like this there is no troubling of the term "culturally appropriate'', and that it is implicitly assumed that what is ''culturally appropriate" must also be "desired". Discursively, the history of the use of "cultural appropriateness" as a smokescreen for racial oppression and exclusion which we have shown elsewhere to be a feature of South African discourse (Swartz 1985, 1986, 1987) and is part of broader colonial history in Africa and elsewhere (Moshabela et al. 2016, Swartz2019), is effaced in this usage.

Given these concerns, in this article, we explore the views of, and dilemmas faced by, spiritual care providers at a hospice in Cape Town, SA, in an attempt to provide what is termed culturally appropriate spiritual care. We demonstrate that concerns about race and racism trouble the idea of "culturally appropriate care" in the context of contemporary South African realities.

Method

St Luke's Combined Hospices (SLCH), a leading hospice organisation in Cape Town, SA, offers a comprehensive palliative care service across a range of physical locations, and in patients' homes in the community. At SLCH, the spiritual care services are offered predominantly by volunteers, with three being paid staff, of whom two are part-time employees. Spiritual care services are offered by very few organisations in SA, with SLCH having one of the largest cohorts of spiritual care workers in SA (Mahilall and Swartz, 2021b).

SLCH currently has 23 registered spiritual care workers, of whom 15 are actively providing spiritual care services. The eight inactive spiritual care workers cited advanced age and personal illness as the main reasons why they have significantly limited their work at SLCH, resulting in their inactive status. We approached all active spiritual care workers to participate in our study, which forms part of a larger national investigation into spiritual care issues in palliative care in SA.

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Ethical approval for the study was obtained from the [anonymised for peer review] University (10,237), Hospice Palliative Care Association (HPCA) (02/19), and SLCH itself. HPCA is a national association which has 104 member organisations affiliated to it (Drenth, et al. 2018), with SLCH as one of those member organisations. Nine active spiritual care workers volunteered to be part of this study. The other six active spiritual care workers did not offer a reason for non-participation.

This was a qualitative study using one-on-one interviews and focus group discussions (FGD) from a set of semi-structured questions (see Appendix 1). Table 1 provides biographical data on the nine participants. Face-to-face interviews and FGD were not possible due to lockdown regulations in light of the COVID-19 pandemic. Consequently, interviews were conducted via virtual means such as Zoom and Skype. The interviews were recorded, transcribed, coded and analysed thematically.

Findings

Through one-on-one interviews and FGD with a cohort of spiritual care workers from SLCH, Cape Town, SA, the participants shared their experiences of navigating cultural diversities in their provision of spiritual care services to terminally ill patients. This study identified three prevalent themes, which are listed below and will be discussed in turn:

1. The complexity of race and culture.
2. Culture and superstitions—the (racial) 'elephant in the room'.
3. Organisational culture and constraints to cultural expression.

The Complexity of Race and Culture

The participants unanimously agreed that cultural sensitivities are central to their spiritual care work. To navigate cultural sensitivities, the participants cited having a basic knowledge and understanding of the different cultures, religions and practices in SA as being crucial. Participant 8 explained:

> You should never meet a patient or family with your own preconceived ideas just based on where they live, their surname, their profession…because post-apartheid there are now mixed marriages, freedom of residency, more open access to jobs and education. Because we have this great historic diversity you must first ask a few questions; get to know where the patient and family are at; understand what is important to them; what their belief systems are before you arrive at a spiritual care plan. (Participant 8)

Participant 6 said that in some traditions, displaying affection in public, especially between spouses, is forbidden. Bearing this in mind, he had to weigh the burden of cultural sensitivities against what the distraught husband was feeling and what the

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Table 1 Biographical information on research participants

Participant number and race[4] (B-Black; C-Coloured; W-White)	Gender (M- Male; F- Female)	Qualifications	Years of practice and experience as a spiritual care worker	Years of practice and experience as a spiritual care worker at SLCH	Religion	Languages spoken
1 (W)	F	BCom Honours (Economics)	3 years	3 years	Christian by birth Currently, none	English, Afrikaans
2 (C)	F	Higher Dip. Education; Dip. Special Ed (Remedial); MPsych(clinical)	2 years	2 years	Islam by birth Currently: none	English Afrikaans
3 (W)	F	Certified Lifeline Counsellor	30 years	28 years	Christian by birth Currently: none	English
4 (B)	M	Grade 12 Lay councillor in Church	25 years	7 years	Christian	English, Afrikaans, Xhosa, Zulu
5 (W)	F	BA (Social Work) Certificate: Family Constellation Certificate: Gender Reconciliation Capacitar (Energy healing)	35 years	10 years	Quaker (Historical Christian denomination)	English, Afrikaans

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Table 1

Participant number and 'race' (B-Black; C-Coloured; W-White)	Gender (M- Male; F- Female)	Qualifications	Years of practice and experience as a spiritual care worker	Years of practice and experience as a spiritual care worker at SLCH	Religion	Languages spoken
6 (C)	M	BSc (Psychology) BA (Psychology)	25 years	15 years	Islam by birth but embraces all religions	English, Afrikaans
7 (B)	M	MA (Practical Theology) MA (Missiology)	15 years	13 years	Christian	English, Afrikaans, Xhosa
8 (C)	M	Dip in Theology BA (Hons)	35 years	3 years	Christian by birth but embraces all religions	English, Afrikaans
9 (W)	M	Dip. Interior Design Dip. Interior Architecture	6 years	6 years	Christian by birth Currently: none	English, German, French

'In South Africa, as elsewhere, the use of 'racial' terminology is complex and contested, and certainly still a source of debate and great pain. We make no claim for the scientific validity of the different 'racial' categories, but the labels used still have social significance (Jansen and Walters 2020). In the South African context, the term 'Coloured', which may well be the most contested, is an official term still used in government documents and refers to a very diverse group of people of mixed and diverse origin, with Afrikaans being the predominant language spoken (Jansen and Walters 2020). By contrast, the term 'Black African' commonly refers to people who speak indigenous languages such as isiXhosa, spoken in the Western Cape. Under apartheid, the Western Cape was viewed as a preferential area in which 'Coloured' people could live and work, whereas 'Black Africans' were viewed as not being citizens of South Africa, but of racially defined 'homelands'.

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dying wife was yearning for, by giving the husband cultural permission to show affection to his wife:

> That is so inhuman to not to be able to express your love and affection to someone who is dying who happens to be your wife… I happened to be sitting at reception with a husband that was sitting on a chair and his wife was lying on the bed, so I asked the man how are you feeling? And he said, I am actually crying inside. I asked him if his wife knows that you are crying inside, he said no I don't know, so I said would you want to sit on the bed with your wife and he looked at me as if there was something wrong with me. I put him on the bed, and he sat on the bed and I said to him, wouldn't you like to put your arm around your wife? And again, he looked at me as if I was crazy. The minute he put his arm around his wife, his wife gave me such a look as if she won the jackpot or something, that was all she was waiting for. For me that was such a worthwhile experience. (Participant 6)

Participant 5 discussed a similar case study that focussed on racial sensitivities which saw her give the son of a dying mother cultural permission by modelling for him that touching his mother was acceptable:

> I think they were Fish Hoek (a predominantly middle to upper-middle class largely White suburb in the Western Cape, SA) ordinary, pale people (White people) but he (the son) didn't know what to do as she (the mother) was slipping away, and so I stroked her and reassured her, and I actually took his hand and said 'it's ok'. So sometimes non-verbals help you to go where words can't go and I think in the subject of touch, you are touching somebody's soul…you have to be so in tune with yourself and in tune with them because you are touching their soul. (Participant 5)

Participants recognised that there are different layers to culture that are at play in the therapeutic relationship. How the participants navigated their own cultural encapsulation and the level to which they were able to separate themselves, culturally, from the therapeutic relationship determined the quality of that relationship as Participant 3 put it:

> I think you have to be finely tuned into yourself… I mean as a leafy middle-class White woman I have to deal with my own privilege, my own guilt by virtue of my birth… I think again it's sensitivity and the capacity to relate to someone and you're not projecting your own stuff… I have sometimes seen people (colleagues) go…fall over backwards trying to make up for having lived a privileged life…so it's like being centred and being led by the patient's need at the time. (Participant 3)

Participant 3 went on to personify her guilt as a 'leafy middle-class White woman' as an eidetic manifestation of a potential terminal disease that may show up in her future, something we come back to in the discussion:

> I will not be surprised if I develop cancer of the chest or the heart because of the guilt I carry of being a privileged, hierarchical White. I have to constantly

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> re-centre myself to know that the patient is the apex because I am more vulnerable than a terminal, actively dying patient… I am dying a slow death of White guilt…this work I do brings me some peace as I unburden myself through my work. (Participant 3)

With racial differences come linguistic divides. The participants further recognised the multiple languages that exist in SA that are protected by the South African Constitution, and the importance of speaking in a language the patient is familiar with even if that meant having to refer a patient to another spiritual care colleague who speaks the same language as the patient. As Participant 5 lamented:

> I know that the one thing that I really can't forgive myself for often is we have so many Black people who come and I don't speak Xhosa (the first language of many SLCH clients). Thankfully I've got massage (therapy) I can fall back on until my Xhosa speaking colleague comes but I still feel that's not good enough that a patient must wait; especially a dying patient. (Participant 5)

Racial tolerance and acceptance of racial difference was identified as a key attribute for an effective spiritual care worker, especially working within a diverse SA context. Participant 4 exemplifies this further:

> I have noticed that the main African belief is in ancestry and spirituality. If you talk about spirituality to them (Black patient and family), they will receive you plentifully. And there are certain words which you must not use with Africans. For example, you never tell a person you are going to die. Don't use that word 'die'. That word alone is a taboo word. You have to use something else instead like…'the ancestral spirits have come to show you the way'. Even after a patient has passed on…we are dealing with a lot of people from the Eastern Cape…the body (corpse) has to be transported to the Eastern Cape. There must be somebody to 'talk to that body' while it is being transported from the current house to the ancestral house in the Eastern Cape. (Participant 4)

Participants recognised that being conscious and aware of such diversities could potentially guide what a spiritual care approach and intervention regime could look like. Participants noted that when facing end-of-life patients' cultural, religious and racial diversity issues tended to hold significantly less value and prominence for them. Being acutely aware and conscious of being culturally sensitive sometimes posed a challenge for the participants on how to respond to patients who had 'abandoned' their culture towards the end of life. Participant 6 explains:

> …the interfaith marriages and the polygamous marriages…for example when you find someone terminally ill and all of a sudden you have another family pitching up…and instead of dealing with the palliating patient and the family, you've got to deal with a second wife or girlfriend because of the Islamic culture of polygamy. Sometimes in spite of the fact that the person was born Muslim there was an interfaith marriage, and at the time of dying then they want to revert back (to religion of birth)…all their clashes and conflicts concerning how the person can retire from his Muslim tradition arise. You need a broader understanding about why people do certain things. Death is a

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> great leveller and it's one's presence that is important, but you have to be sensitive to what that person needs or wants, and in that why my background in psychology and religion helps me with this kind of work (spiritual care work). (Participant 6)

Culture and Superstition—The (Racial) 'Elephant in the Room'

Two participants raised the issue of what they termed 'superstition' as an issue in spiritual care. They distinguished between 'good superstition' that is helpful in understanding cultural beliefs and practices, and superstitions that they described as 'bad' and which may evoke fear. Participant 6 had this to say on the role superstition plays in culture, likening it to what he termed the 'elephant in the room' that is not often openly addressed or discussed:

> …there are issues regarding religion or faith but also separated from beliefs which are perhaps irrational but carried on through tradition, like climbing the mountain to find saints, and the family would want to visit the shrine in the mountains. I think one has to differentiate between these practices and pure superstition. An experienced counsellor from the same background would know the difference between what is religion, what is culture, what is custom, what is superstition and while the family or the patient indulges in superstition, as a counsellor one has to be non-judgmental and just go along with it. (Participant 6)

Participant 4, by contrast, regards what others may term 'superstition' as central in the lives of people who speak Xhosa and Zulu (a cognate indigenous language), but in danger of being lost or damaged in the context of the COVID-19 pandemic:

> …with Xhosa and Zulu in connection with spirituality, it is a strong thing to them, and they believe in spirituality fully and they like to observe and follow what their thoughts are about spirituality so they can't be separated from that (superstition) and they will mix it with cultural things and do cultural things. Because they believe if they do not follow what they have heard by or told by a seer or *sangoma* (traditional healer) about but instead just happen to a particular person, more wrong things can happen to a person. That is why they so strongly believe in that (superstitions) and if somebody also says I dream about my father who has passed on and told me to do this and that and if I ignore that, certain bad things will happen. The strong feeling about spirituality and superstition in African people does exist. Except not since we have this COVID-19 pandemic we are having; things are not going right as they used to do, and you'll find that they are complaining because they fear of losing that thread of spirituality that they used to talk with the people that have passed on. This is another thing that is happening, and people are not happy about it. (Participant 4)

South African indigenous belief systems depend heavily on the role of ancestors in maintaining health in a balanced spiritual ecology (Swartz 1991). Participant 4 noted that patients will go to great lengths to consult with and act according to the

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wishes of the ancestors, sometimes in hope of reversing a terminal diagnosis, and always in trying to prepare an appropriate burial process. Participant 4 explains:

> I listened yesterday or the day before about the nurse that passed away…and the family was not happy about the way they burials took place because they didn't go according to their cultural tradition to talk to the spirit of that body, and they were not happy. It is not just the family; many people are not happy about this COVID-19. Before they used to know what to do when they are going to bury someone, they need to talk to the spirit of that particular person and now they were not given the chance to do that. This is another angle which a new thing which we are looking are, we are not sure how far it will go, will they go back and do which they used to do out of fear or will they change their practices because of the pandemic. It is a big question mark, but spiritually, African people strongly believe in it and they have to do it so they know that they are at peace with those who have passed on. (Participant 4)

Organisational Culture and Constraints to Cultural Expression

Though issues of culture, as commonly understood, may refer to beliefs held by people from different backgrounds, participants also discussed their work in relation to the culture of SLCH as an organisation.

Participants expressed concern that there is an expectation of the interdisciplinary[1] team to separate hospice care services along the distinct four pillars of palliative care, shaped largely by Western influence, and expressed that while this may be a good model on paper, in practice this was sometimes challenging to achieve. Participant 5 explained:

> …my cousin died on the ward, X (name of spiritual care worker) had a good relationship with my niece, and it was a fantastic moment, and it was incredibly important. She was then referred to bereavement (counselling service) but sometimes that only happens six weeks later, and she needed some holding and I tried to get something going but I didn't want to push too much. It was X that my niece really needed to speak to. There is a lot of variation, and we don't connect with everyone on the ward, we can't follow up with everybody because they say there's a professional service but (we must remember that there is) also a human-needs service. (Participant 5)

There are questions here about the range of work of spiritual carers, and how they fit into the larger pattern of care.

Given resource constraints, almost all of the spiritual care work done for SLCH is done on an unpaid, voluntary basis. The organisation does not have the funding to support culturally expressive activities as part of spiritual care. Participant 5, for example, expressed the need to have assistive tools available to support spiritual care:

[1] The interdisciplinary team at SLCH consists of a clinical palliative care staff such as a medical nurse, doctor, social worker, spiritual care worker and bereavement care worker.

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> …hearing is the last facility that goes (in the dying stages) and that is something we haven't got on the ward, and I noticed there was one patient who had gospel music playing from her cell phone and I thought, wouldn't it be fantastic to have a music system where she could play her music from. I would want music… It is a gap. (Participant 5)

Overall, participants believed that because of its voluntary nature and because of lack of resources, spiritual care, though overtly strongly supported by the organisation, did not have as firm a position in the organisation as did other aspects of care.

Discussion

In our interaction with participants, we gained the impression of a strong commitment of the spiritual carers to respect racial cultural, spiritual, and religious diversity – this was clear throughout. But there was also an acute awareness of the complexity of the issue of culture in spiritual care work at SLCH in Cape Town, SA. All participants wished to enact respect for cultural, racial, and religious diversities (Bhagwan 2017; Cain et al. 2018; Elk et al. 2020; Swartz 1991) but the enactment of that sensitivity was more fraught.

Participant 5's reference to 'Fish Hoek ordinary, pale people' and Participant 3's description of herself as a 'leafy middle class White woman' together tell a story about the context of the attempt to provide culturally appropriate palliative care in the contemporary SA context. As in other settler societies, but probably to a greater degree than others, given the particularities of apartheid as a formalised system of racial domination, SA has a history of the denigration and disavowal of indigenous spiritual practices as primitive, damaging, and even evil (Wallace 2015). Even prior to the formal end of apartheid rule, there was recognition of the damage caused by such stigmatising typification of indigenous spiritual practices (Bührmann 1984; Swartz 1985). Indigenous spiritual beliefs are formally recognised and valorised in contemporary SA, to the extent of formal recognition of traditional healing as part of a suite of health services accessed by South Africans (Moshabela et al. 2016; van Niekerk 2012). But the legacy of suspicion and disavowal remain, within a broader social context in which there is widespread dissatisfaction with what is viewed as continued White dominance in many areas of public life, and especially in the economy (Aboobaker 2019) and in education (Cini 2019), as well as in health care (Swartz et al. 2016).

In writings about the continuing spatial inequality in SA, a common trope is that which contrasts 'leafy suburbs' (formerly White areas, some of which remain predominantly White, especially in Cape Town) and 'dusty streets' (referring to impoverished, almost exclusively Black areas) (Baines 2003; Parker 2016). Similarly, the use of the word 'pale' in 'ordinary pale people', as Participant 5 puts it, has a cultural resonance in contemporary SA. For example, a White journalist well known for his anti-apartheid writings titled his memoir *Pale Native* (Du Preez 2011), and White men are commonly referred to as 'pale males',

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especially during talk about the incompleteness of economic and social transformation (Morrell 2002; Wesson and du Plessis 2008). So, when participants refer to 'pale people' and their own status as 'leafy', they are signalling a recognition of, and discomfort with, their own continuing privilege. Despite the commitment to providing culturally appropriate spiritual care, this awareness of privilege may signal a view that, by virtue of their Whiteness, participants may feel unequal to providing the best, most culturally appropriate care. This issue is even more strongly addressed by Participant 3's comment, 'I am dying a slow death of White guilt'. Her use of a metaphor of death is of course especially striking in the context of a discussion about providing care for dying people. The metaphor conveys a sense of concern both about her own vulnerability (and the possibility of mortality for her, something which she says she does not fear), but also, crucially, about what she is and is not able to offer to a wide range of patients, given her own social positioning and her discomfort with it.

These issues play out against the background of the history and culture of SLCH itself, embedded and entwined as these are in the broader history of SA. SLCH was founded during the apartheid era, in 1980, and historically served a White clientele. It is currently a diverse organisation, and the first statement in the value proposition of the organisation reads, 'We commit ourselves to professional, loyal, honest, responsible and respectful conduct that engenders trust and values diversity' (https://stlukeshospice.co.za/about/), putting the issue of valuing diversity at the top of the list of SLCH values. But the use by Participant 5 of the word 'ordinary' as a prefix to the use of 'pale people' tells its own cultural story. In this use of 'ordinary' is the implicit signalling that historically, and possibly still today, Whiteness was what was seen as unmarked and normative in the provision of care by SLCH. Though the organisation may have officially changed, as Participant 5 implies that part of what it is doing may be involved in the reproduction of White cultural values and Whiteness itself through its work. There seems to be little question about Participant 5's discomfort with this, and her frankness is to be applauded, but she is raising a broader question of the cultural and implicit racial positioning and role of the organisation as a whole, especially in a fractured society. Is, then, spiritual care as offered by SLCH, however sensitively offered and helpful to many, also, inevitably, partially an enactment of Whiteness?

This is a complex question which we cannot fully answer, but part of the answer lies in the reality of the spiritual care service as provided by volunteers. Participants believe that their volunteer status contributes to them being side-lined, and to an extent invisible, to the broader workings of the SLCH services. But it is not by chance that in a country in which White people are in a minority, most of the spiritual carers are White, and very few are what in South African terms are called 'Black African'. Epidemiologically, 'race' remains a predictor of poor health in SA (Day and Gray 2017), with Black African South Africans as a group facing greater health challenges, and greater likelihood of having poorer access to care offered in their own language, especially in the Western Cape Province (Swartz et al. 2016; Deumert 2010).

Because White South Africans on average earn more than South Africans of colour, they may have more resources to be able to volunteer their time for spiritual

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care work; hence the over-representation of White spiritual carers at SLCH. This volunteering is laudable, helpful, and crucial to the work of SLCH. It may also, through no fault of the spiritual carers or other individuals, reproduce the character of SLCH as the services it offers, as culturally 'White', despite all efforts at transformation. Ultimately, this is a resource issue—SLCH is unable to fundraise sufficiently to have as diverse a cadre of spiritual care providers as the organisation, and, indeed, the spiritual carers themselves, may view as ideal. This lack of resources, though, may contribute to an ongoing degree of cultural encapsulation for the organisation.

In this regard, it is interesting that the only two participants to discuss the issue of 'superstition' in relation to cultural beliefs were people of colour. It may well be that the use of what to some may be viewed as a pejorative description of cultural beliefs, a description linked to a history of colonial subjugation (Frosh 2013), could not be articulated by White participants wishing to avoid any possibility of appearing racist (Swartz 1985). It may be that the participants of colour in the group were less concerned about this potential appellation.

Scholars writing about race and culture in relation to spiritual care in the USA suggest that by being immersed in a different culture from one's own may allow for cultural awareness, understanding and tolerance (Elk et al. 2020). While this is a right step forward, our data suggest that there are added layers which need to be considered, certainly in SA, but probably more broadly. A tolerance model, useful though it is, may overlook the possibility embedded in the provision of cross-racial care, that there may well be issues of guilt, which may affect care (Swartz 2007). These issues may be difficult to talk about, but definitely bear discussion. Curtis, et al. (2019) make a call for 'cultural safety' for the purpose of achieving health equity and cultural tolerance. We support such an assertion. Spiritual care workers, and all health care workers for that matter in SA, should be empowered to work through their own prejudices, anger, and guilt to be able to accept their positioning in the apartheid era, and to be supported to negotiate new positions as the post-apartheid landscape takes shape. This working through, though, is not just a question of individual commitment and personal will to provide the best and the most context-sensitive care, something we saw clearly in our participants' responses. It is also an issue to be considered at the organisational and political level, a level over which the spiritual carers themselves, as individuals, have no control.

In this regard, it is important to remember that though culture within the context of spiritual care is commonly understood as people's individual sense of spiritual beliefs and practices, the organisational culture within which the spiritual care service is positioned is also important to consider. Participants mentioned their positionality as playing a decisive role in how they undertake their spiritual care work. The participants' beliefs about patient centeredness apparently did not always align smoothly with organisational imperatives. The organisation has the added real burden of ensuring its financial viability, which made the participants sometimes feel that they were not taken seriously by management; hence 'the gap', as mentioned by one participant. There appeared to be a feeling that people in management seem to be interested only in measurable outcomes that they can take

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to funders, or that people in management are not really aware of the value of spiritual care work. The spiritual carers seemed to believe that their voices were not always taken seriously by management; and this may have something to do with their largely volunteer status. This perception of a lack of fit is probably inevitable, given resource constraints and demands, but what they have to say has important implications for the organisation and how it delivers care.

Conclusion: Unpacking Whiteness

Spiritual care is a highly valued service offered as part of a bouquet of services under the umbrella of palliative care at SLCH. SLCH has one of the largest cohorts of spiritual care workers in SA offering services to a multicultural, multilingual and multiracial terminally ill patient population in the greater precinct of Cape Town, SA. From other data we have collected in our research, and from our discussions with the spiritual carers, we do not doubt that care at the individual level is being offered with a high degree of competence and with very good intention. But this admittedly very small study raises broader, and more complex, questions about the enactment of whiteness in the welfare sector in contemporary SA and elsewhere. As Gregory (2021) has noted in relation to social work in the USA, the role of whiteness as a key factor structuring the provision of care services has tended to be overlooked historically, but is very important not least because models of charity are inextricably intertwined with relationships of power and domination. In this regard, it is not irrelevant that central to the history of care services in SA (including palliative care services) was the establishment of social work as a profession catering in the first instance not to the population as a whole but to dealing with what in the 1930s and subsequently was referred to as the "poor white" problem (Willoughby-Herard 2007). In her work on contemporary whiteness in SA, Steyn (2001) notes the importance of ideas of mastery and control to South African whiteness; and it may be argued that the care infrastructure in SA, transformation notwithstanding, may reproduce domination, with charity and care, however well-intentioned, as part of an armamentarium of control.

Given these realities, what becomes difficult analytically is allowing for a bifurcated view of the transformation of care. On the one hand, it is important to recognise, value and expand the benefits of well-intentioned work which is helpful to individuals in distress. On the other hand, the more challenging work of transformation requires a recognition of the patterns of social reproduction of inequality which may be furthered precisely by well-intentioned work which is of individual benefit. We believe that spiritual care is important in palliative care in SA, as elsewhere, as is shown in much of the literature. What is more discomforting is the question of having to engage with questions about spiritual care as reproducing broader inequalities while at the same time doing good by and for individuals. This kind of dilemma can be seen as embodied in the words of our participants working in a particular organisational context. As with many, if not all organisations in SA, the work of transformation of care to be fully appropriate to the SA cultural context is something we believe our participants are committed to, but

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the work of change is not yet complete. It has become something of a cliché to refer to South Africa's transition to democracy as unfinished, with continuing inequality being a key feature of South African life (Schotte, Zizzamia, and Leibbrandt 2018). This is reflected in unequal health and care systems, as is well established (Conradie 2018; Omotoso and Koch 2018). What is less explored is how even services which are offered free of charge and with the best of intentions may reproduce inequality. As we have suggested in this article, the question of "cultural appropriateness" of care is far from neutral and is embedded in specific and global power relationships and their histories. In SA, technically, a non-racial democracy now for over 25 years, issues at the intersection between racial oppression and the discourse of culturally appropriate care (something we discussed in this journal almost 40 years ago— Swartz 1985)—remains of concern.

Appendix 1: Guiding Questions for Semi-structured Interviews

Collapsed interview questions	Original questions
A-how and why you became a spiritual care worker	1. Tell me about how you became a spiritual care worker?
	2. Tell me about why you became a spiritual care worker?
B-Positive highlights of spiritual care work	3. Share with me some of the highlights of your work in spiritual care
	4. Can you cite some examples to illustrate those highlights?
C-chat	
D-Difficulties experienced in spiritual care work	5. Share with me some of the difficulties of your work in spiritual care
	6. Can you cite some examples to illustrate those difficulties?
	7. How did you mitigate those difficulties and challenges?
E-Skills and training needed for SCW	8. What would you consider to be your training needs as a spiritual care worker?
	9. What would your thoughts be in professionalising spiritual care?
	10. How would you envisage this happening?
F-Describe your spiritual care work and spiritual care work in general	11. How would you describe your work as a spiritual care worker at SLCH?
	12. Could you perhaps share your experiences of how you engaged with patients as a spiritual care worker?
	13. What is your understanding of spiritual care?
G-Is there a distinction between religion and spirituality	14. For you is there a distinction between spirituality and religion?
H-What role does your religious faith play in your spiritual care work	15. What role does your religious faith play, if any, in your delivery of spiritual care services?

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Collapsed interview questions	Original questions
I-What is the spiritual care framework you use	16. What is the framework within which you provide spiritual care intervention?
J-IDT and spiritual care services	17. Can you describe your understanding of the IDT at SLCH?
	18. What role does spiritual care play within the IDT?
	19. How would you describe your work as a spiritual care worker within the IDT?
	20. How would you describe your work within the spiritual care team at SLCH?
	21. Do you feel that having spiritual care workers working at SLCH brings about positive change to the service the hospice offers?
	22. Can you cite examples to illustrate that?
	23. Do you feel that having spiritual care workers working in an IDT at SLCH brings about positive change to the approach of the IDT to the patient?
	24. Can you please cite examples to illustrate that?
K-Diversity and spiritual care	25. Given the range of diversity in SA how would you say this affects the manner in which you provide spiritual care within your hospice?

Acknowledgements The authors would like to acknowledge the passionate, dedicated and selfless spiritual care workers of St Luke's Combined Hospices, Varkey George for conducting the one-on-one interviews and Arm-in-Arm-in-Africa: The Dr John Song Memorial Fund for the financial funding of this project.

Author Contributions RM was a major contributor to the design and writing of the article. LS contributed to the writing and editing of the article. Both authors read and approved the final manuscript.

Funding This work was supported by Arm-in-Arm-in-Africa: The Dr John Song Memorial Fund.

Data Availability Data supporting the results can be obtained from the corresponding author upon reasonable request.

Declarations

Conflict of interest The authors declare no potential conflicts of interests with respect to the research and authorship.

Ethical Approval Ethical approval for the study was obtained from Stellenbosch University (10237), Hospice Palliative Care Association (HPCA) (02/19), and St Luke's Combined Hospices. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to Participate All participants gave written and verbal consent.

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References

Aboobaker, Adam
2019 Visions of Stagnation and Maldistribution: Monopoly Capital, 'White Monopoly Capital' and New Challenges to the South African Left. Review of African Political Economy 46(161):515–523.

Baines, Gary
2003 On Location: Narratives of the South African City of the Late 1940s and 1950s in Film and Literature. South African Historical Journal 48(1):35–46.

Baldwin-Ragaven, Laurel
2020 Social Dimensions of COVID-19 in South Africa: A Neglected Element of the Treatment Plan. Wits Journal of Clinical Medicine 2(SI):33–38.

Baldwin-Ragaven, Laurel, Leslie London, and Jeanelle De Gruchy, editors
1999 An ambulance of the wrong colour: Health professionals, human rights and ethics in South Africa. Juta and Company.

Bhagwan, Raisuyah
2017 The Sacred in Traditional African Spirituality: Creating Synergies with Social Work Practice. In The Routledge Handbook of Religion, Spirituality and Social Work. B.R. Crisp, ed., pp. 64–72. Routledge.

Bosire, Edna, Emily Mendenhall, Shane Norris, and Jane Goudge
2020 Patient-Centred Care for Patients with Diabetes and HIV at a Public Tertiary Hospital in South Africa: An Ethnographic Study. International Journal of Health Policy and Management. Article in press. https://doi.org/10.34172/IJHPM.2020.65

Bührmann, M. Vera
1984 Living in Two Worlds: Communication Between a White Healer and her Black Counterparts. Human & Rousseau.

Cain, L. Cindy, Antonella Surbone, Ronit Elk, and Marjorie Kagawa-Singer
2018 Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making. Journal of Pain and Symptom Management 55(5):1408–1419.

Chandramohan, Sandhya, and Raisuyah Bhagwan
2016 Utilization of Spirituality and Spiritual Care in Nursing Practice in Public Hospitals in KwaZulu-Natal, South Africa. Religions 7(3):23.

Cini, Lorenzo
2019 Disrupting the Neoliberal University in South Africa: The #FeesMustFall Movement in 2015. Current Sociology 67(7):942–959.

Conradie, Ina
2018 Social Policy in South Africa: the challenges of Poverty, Inequality and Exclusion. Social Work & Society 16(2)

Coovadia, Hoosen, Rachel Jewkes, Peter Barron, David Sanders, and Diane McIntyre
2009 The Health and Health System of South Africa: Historical Roots of Current Public Health Challenges. The Lancet 374(9692):817–834.

Court, Lara, and Jill Olivier
2020 Approaches to Integrating Palliative Care into African Health Systems: A Qualitative Systematic Review. Health Policy and Planning 35(8):1053–1069.

Curtis, Elana, Rhys Jones, David Tipene-Leach, Curtis Walker, Belinda Loring, Sarah-Jane Paine, and Papaarangi Reid
2019 Why Cultural Safety Rather than Cultural Competency is Required to Achieve Health Equity: A Literature Review and Recommended Definition. International Journal for Equity in Health 18:174.

Day, Candy, and Andy Gray
2017 Health and Related Indicators. In South African Health Review. A. Padarath and P. Barron, eds., pp. 217–339. Health Systems Trust.

De Beer, Jennifer, and Jennifer Chipps
2014 A Survey of Cultural Competence of Critical Care Nurses in KwaZulu-Natal. Southern African Journal of Critical Care 30(2):50–54.

Stellenbosch University https://scholar.sun.ac.za

De la Porte, André
2016 Spirituality and Healthcare: Towards Holistic People-Centred Healthcare in South Africa. HTS Teologiese Studies/Theological Studies 72(4):a3127.
Deumert, Ana
2010 'It Would Be Nice If They Could Give Us More language'—Serving South Africa's Multilingual Patient Base. Social Science & Medicine 71(1):53–61.
Dreyth, Cornelia, Zodwa Sithole, Esme Pudule, Sheryl Wust, Nicola GunnClark, and Liz Gwyther
2018 Palliative Care in South Africa. Journal of Pain and Symptom Management 55(S2):S170–S177.
Dubow, Saul
1995 Scientific Racism in South Africa. Cambridge University Press.
Du Preez, Max
2011 Pale Native: Memories of a Renegade Reporter. Penguin Random House.
Elk, Ronit, Linda Emanuel, Joshua Hauser, Marie Bakitas, and Sue Levikoff
2020 Developing and Testing the Feasibility of a Culturally Based Tele-Palliative Care Consult Based on the Cultural Values and Preferences of Southern, Rural African American and White Community Members: A Program By and For the Community. Health Equity 4(1):52–83.
Francis, David, and Edward Webster
2019 Poverty and Inequality in South Africa: Critical Reflections. Development Southern Africa 36(6):788–802.
Frosh, Stephen
2013 Psychoanalysis, Colonialism, Racism. Journal of Theoretical and Philosophical Psychology 33(3):141–154.
Gregory, J. R.
2021 Social Work as a Product and Project of Whiteness, 1607–1900. Journal of Progressive Human Services 32(1):17–36.
Jansen, Jonathan, and Cyrill Walters, eds.
2020 Faultlines: A Primer on Race. SunPress: Science and Society.
Lappeman, Maum, and Leslie Swartz
2019 Rethinking obstetric violence and the "neglect of neglect": the silence of a labour ward milieu in a South African district hospital. BMC International Health and Human Rights 19(1):30. https://doi.org/10.1186/s12914-019-0218-2.
Levin, Michael E.
2005 The Importance of Language and Culture in Paediatric Asthma Care. Current Allergy & Clinical Immunology 18(1):8–12.
Mahilall, Ronita, and Leslie Swartz
2021a Challenges and opportunities for spiritual care practice in hospices in a middle-income country. BMC Palliative Care 20:62. https://doi.org/10.1186/s12904-021-00756-9.
2021b Spiritual care practices in hospices in the Western cape, South Africa: the challenge of diversity. BMC Palliative Care 20:9. https://doi.org/10.1186/s12904-020-00704-z.
Matthews, Margaret, and Jacqueline Van Wyk
2018 Towards a Culturally Competent Health Professional: A South African Case Study. BMC Medical Education 18:112.
Morrell, Robert
2002 Men, Movements, and Gender Transformation in South Africa. The Journal of Men's Studies 10(3):309–327.
Moshabela, Mosa, Thembelihle Zuma, and Bernhard Gaede
2016 Bridging the Gap Between Biomedical and Traditional Health Practitioners in South Africa. South African Health Review 2016(1):83–92.
Mthembu, Thuli G, Wegner Lisa, and V. Roman Nicolette
2016 Teaching Spirituality and Spiritual Care in Health Sciences Education: A Systemic Review. African Journal of Physical Activity and Health Sciences 22(4:1):1036–1057.
Omotoso, Kehinde O, and F. Koch Steven
2018 Assessing changes in social determinants of health inequalities in South Africa: A decomposition analysis. International Journal for Equity in Health 17(1):1–13.
Parker, Alexandra
2016 Urban Film and Everyday Practice: Bridging Divisions in Johannesburg. Springer.

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Penn, Claire, Jennifer Watermeyer, and Rhona Nattrass
2017 Managing Language Mismatches in Emergency Calls. Journal of Health Psychology 22(14):1769–1779.
Petros, George, Collins O. Airhihenbuwa, Leickness Simbayi, Shandir Ramlagan, and Brandon Brown
2006 HIV/AIDS and 'Othering' in South Africa: The Blame Goes On. Culture, Health & Sexuality 8(1):67–77.
Republic of South Africa
2017 National Policy Framework and Strategy on Palliative Care 2017–2022. Accessed February 5, 2021. File:///C:/Users/User/Downloads/Final%20NPFSPC%20August%202017.pdf
Saunders, Cicely M.
2006 Cicely Saunders: Selected Writings 1958–2004. Oxford University Press.
Schotte, Simone, Rocco Zizzamia, and Murray Leibbrandt
2018 A Poverty Dynamics Approach to Social Stratification: The South African Case. World Development 110:88–103.
Steyn, Melissa
2001 Whiteness Just Isn't What it Used to be: White Identity in a Changing South Africa. Suny Press.
Swartz, Leslie
1985 Issues for cross-cultural psychiatric research in South Africa. Culture, Medicine and Psychiatry 9:59–74.
1986 Transcultural psychiatry in South Africa. Part I. Transcultural Psychiatric Research Review 23:273–303.
1987 Transcultural psychiatry in South Africa. Part II. Transcultural Psychiatric Research Review 24:5–30.
1991 The reproduction of racism in South African mental health care. South African Journal of Psychology 21:240–246.
1996 Culture and mental health in the rainbow nation: Transcultural psychiatry in a changing South Africa. Transcultural Psychiatric Research Review 33:119–136.
1998 Culture and mental health: A southern African view. Cape Town: Oxford University Press.
2007 The virtues of feeling culturally incompetent. Monash Bioethics Review 26(4):36–46.
Swartz, L, and J Bantjes
2016 Disability and global health. *In* Disability in the Global South. S Grech and K Soldatic, eds., pp. 21–33. Switzerland: Springer International Publishing.
Swartz, Leslie, and Maria Marchetti-Mercer
2018 Disabling Africa: the power of depiction and the benefits of discomfort. Disability and Society 33:482–486. https://doi.org/10.1080/09687599.2017.1400240.
Swartz, Rebecca
2019 Education and Empire: Children, Race and Humanitarianism in the British Settler Colonies. pp. 1833–1880. Palgrave/Springer.
Van Niekerk, J.P 2012 Traditional Healers Formalised? SAMJ: South African Medical Journal 102(3)
Wallace, Dale
2015 Rethinking Religion, Magic and Witchcraft in South Africa: From Colonial Coherence to Postcolonial Conundrum. Journal for the Study of Religion 28(1):23–51.
Wesson, Murray, and Max Du Plessis
2008 Fifteen Years On: Central Issues Relating to the Transformation of the South African Judiciary. South African Journal on Human Rights 24(2):187–213.
Willoughby-Herard, T.
2007 South Africa's Poor Whites and Whiteness Studies: Afrikaner Ethnicity, Scientific Racism, and White Misery. New Political Science 29(4):479–500.

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7.2 License to publish

I obtained written license to publish Article 3 in my dissertation (Addendum 18).

7.3 Chapter summary

The participants of this study expressed their views on professionalising spiritual care and suggesting that developing a spiritual care training curriculum will bring greater uniformity to spiritual care practice in a diverse SA. In the next two chapters, Chapter Eight and Chapter Nine, which forms Part 3 of this dissertation, I will discuss this topic of spiritual care training in greater depth.

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PART 3: SPIRITUAL CARE WORKERS' TRAINING NEEDS WITHIN HOSPICE PALLIATIVE CARE SETTINGS IN SOUTH AFRICA

Preamble

In Chapter One I outlined my reasoning for conducting the national study, followed by the provincial study and the local study, in that sequence. It was important first to capture an overarching national view of spiritual care in SA and to establish what spiritual care practices are at play in SA. Thereafter, I explored these points provincially and then locally which gave greater texture to the findings. I then contextualised the study within the Western Cape Province and, thereafter, carried out a localised exploration of how a local hospice – SLCH in Cape Town – practises spiritual care work within the diversities that abound in SA. In Chapter Four I contextually analysed three Global North spiritual care curricula from a SA perspective for relevance and applicability to hospice palliative care settings in SA.

The first three results chapters, Chapters Five, Six and Seven, (which made up Part 2) discussed how spiritual care is practised in hospice palliative care settings in SA and, critically, the impact of diversity on spiritual care practice and service provision. Some suggestions for a national spiritual care training curriculum also emerged from these chapters.

In Part 3, I present two papers. First, in Chapter Eight, I explore the expressed spiritual care training needs of insider experts already providing spiritual care at an established hospice in Cape Town – SLCH. In Chapter Nine, I fan out to the broader context, looking at expressed spiritual care training needs of hospices providing palliative care nationally, in SA.

Part 3 therefore, comprises the following articles:

i. Chapter Eight (Article 4): Spiritual care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa.

ii. Chapter Nine (Article 5): Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial, and local voices.

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CHAPTER EIGHT

ARTICLE 4

Spiritual care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa.

– Journal of Religion and Health –

8.1 Introducing Article 4

This article explores who the spiritual care workers are and their motivations and experiences in undertaking spiritual care work at SLCH. This article further goes on to explore how spiritual care services can be sustained into the future, with suggestions for developing a spiritual care training curriculum that is bespoke to the SA hospice palliative care needs.

This article was published in the *Journal of Religion and Health*, as follows:

> Mahilall, R., & Swartz, L. Spiritual Care: Motivations and experiences through the lenses and voices of a cohort of spiritual care workers at an established hospice in Cape Town, South Africa. *Journal of Religion and Health* (2021). https://doi.org/10.1007/s10943-021-01232-7

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Journal of Religion and Health
https://doi.org/10.1007/s10943-021-01232-7

ORIGINAL PAPER

Spiritual Care: Motivations and Experiences through the Lenses and Voices of a Cohort of Spiritual Care Workers at an Established Hospice in Cape Town, South Africa

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Accepted: 9 March 2021
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Abstract
While palliative care is beginning to gain prominence in South Africa, spiritual care remains less understood. Spiritual care is less prioritised and, consequently, this service, if offered, is mostly entrusted to volunteers. It therefore becomes prudent to understand who these volunteers are, what motivates them to volunteer, and how they see spiritual care being sustainable in the future. A cohort of spiritual care workers from a prominent hospice in Cape Town, South Africa, participated in this qualitative study. The participants made suggestions about formalising spiritual care as well as making a call for a basic entry requirement into spiritual care work.

Keywords Spiritual care · Palliative care · Hospice · South Africa

Introduction

Palliative care in South Africa (SA) has, in relative terms, only recently been formalised as a discipline (Republic of South Africa, 2017). Both locally (Bhagwan, 2017; Chandramohan & Bhagwan, 2015; Ratshikana-Moloko et al., 2020) and internationally (Abel et al., 2013; Koper et al., 2019; Paal et al., 2015; Puchalski et al., 2019) there is consensus that spiritual care should play a pivotal role in palliative care.

There are many debates regarding how to classify countries. The "Global North" generally corresponds to countries categorised by the World Bank Atlas (World Bank Blogs, 2020) as high-income countries (HICs)—so, for example, Australia, which is a high-income country, is commonly viewed as part of the Global North, despite it being in the southern hemisphere. Countries in the

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Published online: 23 March 2021

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"Global South" generally correspond to the World Bank low- and middle-income countries (LMIC) (World Bank Blogs, 2020). South Africa is a middle-income country. The distinction here is based largely on financial resources, though of course other factors are associated with relative wealth. In the Global North, where there are more resources, spiritual care workers are commonly health care professionals such as trained nurses (Balboni et al., 2007), medical doctors (Mati, 2016; Yang et al., 2017), and social workers (Callahan, 2015), or people with graduate qualifications in religion (Flannelly et al., 2003), but the picture is different elsewhere. In the Islamic world, for example, there is not a great deal of systematic research on spiritual care, despite the importance of spirituality as part of the Islamic faith (Asadi-Lari et al., 2008). In Africa, palliative care protocols tend to focus on more tangible aspects of palliative care such as medications and pain relief (Merriman & Harding, 2010). In SA, where the current study is situated, spiritual care is slowly being incorporated into the training programmes for nurses (Chandramohan & Bhagwan, 2015), social workers (Bhagwan, 2017), trained traditional healers (Campbell & Amin, 2014), and professional multidisciplinary teams (O'Brien et al., 2019). Despite this, we found from a national hospice survey that spiritual care is generally not prioritised at hospices, with the exception of hospices which are better resourced than others (Mahilall & Swartz, under review). Even in these better resourced South African hospices, though, unlike in the Global North, spiritual care services are often provided by volunteers rather than paid staff. These volunteers come from a range of backgrounds and may or may not have professional qualifications related to the provision of care.

There is a substantive body of work that explores volunteering within health care settings in SA, such as in hospitals (Lourens & Daniels-Felix, 2017), in primary health care clinics (Isaac et al., 2016; Johnson et al., 2020), community-based health care facilities (Swartz & Colvin, 2015), and home-based health care settings (Akintola, 2011; Morton et al., 2018). Much scholarly work talks about volunteers undertaking health care work in impoverished communities in SA (Akintola & Chikoko, 2016; De Wet, 2012; Nxumalo et al., 2016). Many of the volunteers themselves come from lower socio-economic ranks of society (Akintola, 2011; Barnard & Furtak, 2020). Care volunteers largely volunteer out of a desire to "give back" to their communities (Akintola, 2011) or extrinsically, in the hope of receiving a stipend (Morton et al., 2018). By contrast, spiritual care volunteering in hospice settings in SA, according to the limited data we have (Mahilall & Swartz, under review), seems more likely to be undertaken by older volunteers (some of them retired from formal employment) from higher socio-economic sectors, not with the expectation of receiving a stipend or moving into formal employment (Mahilall& Swartz, under review).

Therefore, there is a dependency and reliance on volunteers at quite a high skills level to offer spiritual care within a broader bouquet of hospice services (Mahilall & Swartz, 2021). It therefore becomes critically important to understand who volunteers as a spiritual care worker, what draws them to their work and sustains them in it, and what they believe is needed to sustain spiritual care into the future. With

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these questions in mind, we spoke to spiritual care providers at a hospice in Cape Town, SA.

Method

St Luke's Combined Hospices (SLCH), a prominent hospice in Cape Town, SA, offers a comprehensive palliative care service across a range of physical locations such as in-patient units, community-based day hospices where people who are terminally ill but not actively dying can congregate and receive care during the day, and in patients' homes. Spiritual care services at SLCH are offered largely by volunteers.

SLCH currently has 23 registered spiritual care workers, of whom 15 are actively providing spiritual care services. The eight inactive spiritual care workers cited advanced age and personal illness as the main reasons why they have significantly limited their work at SLCH, resulting in their inactive status. We approached all active spiritual care workers to participate in our study, which forms part of a larger investigation into spiritual care issues in palliative care in SA.

Ethical approval for the study was obtained from the Stellenbosch University (10,237), Hospice Palliative Care Association (HPCA) (02/19), and SLCH itself. HPCA is a national association which has 104 member organisations affiliated to it (Drenth et al., 2018), with SLCH as one of those member organisations. Nine active spiritual care workers volunteered and gave written consent to be part of this study. The other six active spiritual care workers did not offer a reason for non-participation.

This was a qualitative study utilising an in-depth interviewing methodology which allowed for the capturing of rich, descriptive data (Hollway & Jefferson, 1997). One-on-one interviews were conducted which were approximately 90 min in duration. Prior to setting up the interviews, the participants gave both written and verbal consent. Ahead of the interviews the participants were given an Information Leaflet which highlighted, amongst other important information, confidentiality, protection of the data, and freedom to withdraw from the interviewing process or raise alternative views and arguments. As this is a sensitive topic, provision was made for psychological support for the participants at no cost to them. The interviews and subsequent three rounds of focus group discussions (FGDs) of approximately 120 min each were guided by a set of semi-structured questions (Appendix 1). Table 1 provides biographical data on the nine participants. Face-to-face interviews and FGDs were not possible due to lockdown regulations considering the COVID-19 pandemic. Consequently, interviews were conducted via virtual means such as Zoom and Skype, with the consent of the participants. As both authors are familiar with SLCH (one author works at SLCH and the other author conducted other research at the hospice), a co-facilitator knowledgeable in qualitative research was engaged to minimise researcher biase. The participants were informed and consented to this arrangement. The co-facilitator signed a pledge of confidentiality. The co-facilitator also facilitated the FGDs supported by the authors. The data obtained from the interviews and FGDs were recorded and transcribed. Through thematic analysis, a qualitative research method defined by Braun and Clarke as "identifying,

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Table 1 Biographical information on research participants

Participant number and "race" (B—black; C—coloured; W—white)	Gender (M—male; F—female)	Qualifications	Years of practice and experience as a spiritual care worker	Years of practice and experience as a spiritual care worker at SLCH	Religion	Languages spoken
1 (W)	F	BCom Honours (Economics)	3 years	3 years	Christian by birth Currently: none	English, Afrikaans
2 (C)	F	Higher Dip Education; Dip. Special Ed (Remedial); MPsych (clinical)	2 years	2 years	Islam by birth. Currently: none	English Afrikaans
3 (W)	F	Certified Lifeline Counsellor	30 years	28 years	Christian by birth Currently: none	English
4 (B)	M	Grade 12, Lay counsellor in Church	25 years	7 years	Christian	English, Afrikaans, Xhosa, Zulu
5 (W)	F	BA (Social Work), Certificate: family constellation, Certificate: gender reconciliation, capacitar (Energy healing)	35 years	10 years	Quaker (Historical Christian denomination)	English, Afrikaans
6 (C)	M	BSc (Psychology) BA (Psychology)	25 years	15 years	Islam by birth but embraces all religions	English, Afrikaans
7 (B)	M	MA (Practical Theology), MA (Missiology)	15 years	13 years	Christian	English, Afrikaans, Xhosa
8 (C)	M	Dip in Theology, BA (Hons)	35 years	3 years	Christian by birth but embraces all religions	English, Afrikaans
9 (W)	M	Dip. Interior Design, Dip. Interior Architecture	6 years	6 years	Christian by birth. Currently: none	English, German, French

"In South Africa, as elsewhere, the use of "racial" terminology is complex and contested, and certainly still a source of debate and great pain. We make no claim for the scientific validity of the different "racial" categories, but the labels used still have social significance (Volmink et al., 2020). In the South African context, the term "Coloured", which may well be the most contested, is an official term still used in government documents, refers to a very diverse group of people of mixed and diverse origin, with Afrikaans being the predominant language spoken (Volmink et al., 2020). By contrast, the term "Black African" commonly refers to people who speak indigenous languages such as isiXhosa, spoken in the Western Cape. Under apartheid, the Western Cape was viewed as a preferential area in which "Coloured" people could live and work, whereas "Black Africans" were viewed as not being citizens of South Africa, but of racially defined "homelands"

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analyzing and reporting patterns within data" (2006, p. 79), the data were coded and reviewed for emerging themes and subthemes. The themes and subthemes were then defined and named and analysed thematically.

Results

Nine participants from SLCH, registered as active spiritual care workers at the organisation, volunteered to be part of this study. Through one-on-one interviews and FGD the participants shared their experiences as spiritual care workers providing spiritual care services to terminally ill patients in the larger prescient of Cape Town, SA. Three key themes emerged which we discuss in turn:

1. Becoming a spiritual care worker;
2. Being a spiritual care worker; and
3. Sustaining spiritual care services into the future.

Becoming a Spiritual Care Worker

Varied Paths into Spiritual Care

The nine participants had varied and diverse entry points into spiritual care work, varied backgrounds, and a wide range of formal qualifications. Two participants were religious leaders such as pastors, as explained by Participant 7:

> …well, let me say I'm a priest by calling. And now I started working here at St. Luke's hospice as a volunteer, visiting people and doing sort of counselling and listening… (Participant 7)

Another participant began working in palliative care as a volunteer due to her personal interests in spirituality. Participant 2 shared her entry into spiritual care:

> … I called SLCH's Athlone [name of a community in Cape Town] Day-Hospice and said can I come and observe… So I went along that day…at the end of that the spiritual care coordinator invited me along to spiritual care. Initially it was just attending meetings and then when there was a gap in the ward they asked me to actually start visiting the ward as well. (Participant 2)

Participant 3 became a spiritual care worker by chance. Participant 3 explained:

> …it evolved for me…I went in as a caregiver, I did training in both caregiving and lay counselling… I then joined Lifeline [a volunteer-based telephone counselling service similar to the Samaritans in the United Kingdom] and… the spiritual thing just evolved somehow… (Participant 3)

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His personal interest and experiences motivated Participant 6 to volunteer at the hospice in another capacity, as an administration volunteer, but he later transferred into spiritual care work. Participant 6 explained:

> …needing a volunteer to come and assist with palliative care…to the terminally ill Muslim patients… They needed a male particularly, who was Muslim and who had an interfaith background. And that's how I got started in spiritual care in 2008 at St. Luke's hospice. (Participant 6)

Only one of the participants indicated that he began his spiritual care work through a formal job application for a vacant post. The varied entry points into spiritual care could have implications for how spiritual care is viewed within and outside the hospice. We unpack this for implications in greater detail later on.

The Role of Religion

Although some of the participants had specific religious affiliations at birth, such as Christianity, as participant 8 explained:

> …as a Christian, in the Christian faith there is a scripture that says that God is the God who heals. Many a time we find people coming here with that same conviction. But the doctor says you are dying and they still live with that hope and conviction that they will be healed; but they die…it's like God verse science… Personally I would say my idea of God has changed… I would not necessarily follow the route of exclusivity [as a Christian] where I did that in the past. (Participant 8)

and Islam, as Participant 2 explained:

> …when you look at me I am Muslim, but I don't wear a scarf and I'm really more spiritual than religious… My dad I saw as the embodiment of a particularly spiritual person. But he never went to the mosque, but he sat with prayer beads in his hands all his life. You know, so I grew up in a much more liberal kind of way from…and respect for everybody. (Participant 2)

participants tended to adopt a flexible and philosophical approach to religion and spirituality. The participants described their religious beliefs largely in spiritual and existential terms, and not in conventional religious dogma. As Participant 3 put it:

> …Sunday School, Gentle Jesus, all those simplistic religious things; I know that there is something bigger than me. I know it! I know, I talk about God with patients on a daily basis. The word God doesn't impact me. In fact, the spirituality assists in the religious side, it gives me more of an 'in' [into] spirituality. I didn't find my spirituality through my belief in God. It's the other way around. (Participant 3)

Participant 9 had this to say about his religiosity and that of the patients in his care:

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> It is appropriate to always consider a patient's cultural, religious, social and or any other circumstances and situations as well as to be aware of mine. However, I found in my, by now seven years of practical counselling of palliative patients who are approaching their end of life stage, that these differences appear to fade into the background, and a universal understanding between all humans emerges, as long as there is a movement in consciousness from an intellectual understanding of the prevalent conditions of the patient, to a more heartfelt approach to the patient's suffering. (Participant 9)

There was consensus from all participants that to listen to patients with compassion and to be guided by the patient in their spiritual journey, as opposed to their own as spiritual care workers, and to go with the patient to wherever that conversation may lead to, was fundamental to a meaningful therapeutic relationship. Participant 1 captured this in the following way:

> I've read so much, I've been on these courses [counselling courses]…but you need to obviously always look at the whole person, not just looking at someone's religion or what you read in a book. You're looking at their body, their emotions, their spirit—you're looking at the whole of that person in front of you…really you're led by the person…if a dying person wants to talk, they want to talk about something that's in their head…you just listen with compassion and go where the patient leads you. (Participant 1)

Being a Spiritual Care Worker

Finding Joy in the Work

The participants expressed satisfaction and fulfilment with the spiritual care work that they undertake and highlighted the positive benefit spiritual care services bring to the terminally ill patient and, as a result, to them as spiritual care workers, something we come back to in the discussion. Participant 2 explored the different ways in which patients can derive spiritual support, such as from outings, and using art and music to open discussions on existential issues. She shared this case study that brought her and the patient closer in the spiritual care session:

> I asked the patients to give me the name of a song that had special relevance for them and then I got the songs on a play list for them… This particular uncle Tienie was an 85-year-old man who told us about how he came from a rural area and how he came to Cape Town. The story that he told around the song was absolutely amazing… So you actually get people talking to each other, really seeing each other and as I say there's nothing like music to remind you of the past and when you were healthy and happy and all of that. So that is one of the big highlights and ways to get my patients talking and brings me such joy. (Participant 2)

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An Individualised Approach

These observations draw attention to the highly individualised nature of spirituality, and that spiritual comfort can be obtained from a variety of activities, and not only from counselling. Some such activities are storytelling. Participant 8 highlighted the importance of storytelling which helped his patient resolve unfinished issues with the patient's mother:

> He said that he had grown up in school hostels all his life. So he was still bearing that resentment [against his mother for sending him to boarding school] and he opened up to me and he said that he needed to get to the point where he could consider forgiving his mother and reconciling with his mother who was at that time already 81 to 82 years old. Then I got his mother to come and see him a few days before he died and they had made peace and as I said he died a few days after that. (Participant 8)

Spiritual Care in Context

Participant 2 referred to the simple things, such as getting a favourite cool drink for a patient, as rewarding as a spiritual care worker:

> I made a cake on her [patient] birthday which she had in the ward and all the nurses came to sing for her…she [the patient] hadn't been eating for days and she felt like drinking Spar berry drink [cool drink] and I fetched it for her and I felt as close to being a death doula for her as one can in this South African context. (Participant 2)

For Participant 3, it was simply listening to patients tell stories about who they were when they were younger or healthier that brought satisfaction and inspiration to her as a spiritual care worker:

> I had a lady, from another African country, who was dying of HIV and cancer. She was in a wheelchair. She was really exquisite, a really beautiful bone structure. We chatted for a while and she was extremely depressed. And I said to her, 'tell me who you are, what were you before all of this?' She said, 'I was a dancer'. And the change in that woman was instant. And I said, 'tell me about the dancing? What did dancing mean to you?' She just spoke for an hour until she was exhausted…happy but exhausted. That has lived with me for a long time because she became animated. She became a human being. She didn't become the HIV or the cancer. (Participant 3)

Participant 7 highlighted how he engaged with spiritual and existential issues outside of the conventional frameworks of religion and how he allowed for the patient to lead the session on the patient's own terms and in ways that the patient found meaningful to them:

> Another patient said to me, 'You know this is the first time a person listens to me. Many people will come with advices saying do ABCD, and God is doing

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this and that. But a person who listens and I talk, I air out what is going on. What is within myself. You listen and after that you don't even say can we pray? If I want prayer, I will say would you please Father pray?' That also was a very good lesson for me. (Participant 7)

Sustaining Spiritual Care Services into the Future

The participants had diverse academic and professional backgrounds (see Table 1) and expressed the need to professionalise spiritual care services, something we come back to later in the discussion. Participant 8 explained:

I would like to be trained or helped to understand family dynamics better. And then also because in many homes we meet the children of patients who are drug addicts so I would also like to become au fait with ways of helping those guys. Say maybe rehabilitation principles…and to understand the medical terms that won't normally be understood by [lay] people. There are a lot of medical terms that are brandished about here in the discussions, especially in ward round and from time to time I have to ask, hey, just explain to me what you mean by that. And then psychology, the psychological side. And it would be good to let people know the laws surrounding social work practice because many a time there is the idea of children who need to be taken care of after mom has died and maybe when it comes to Wills and a person need to decide what's going to happen to his assets and the spiritual carer is often the person to whom they want to talk about it because they do not understand the legal side, so maybe some of the training that social workers would get in the laws regarding Wills and adoptions, and a number of other things, can be given to us as well. So yes, you heard right, we must professionalise spiritual care work. (Participant 8)

Participants recognised that people can become involved in spiritual care work through a variety of different career paths. Participant 6 suggested a qualification that could be an ideal basic academic foundation for spiritual care workers, something we come back to in the discussion:

I think that…you would need to have…some knowledge of psychology… you would need to understand human behaviour…you need to understand emotions…you need to understand why people or some people are angry, or resentful, in a sense of depression, what to do, how to handle depression and anxiety, and familiarise yourself…so I think a course or two or three in psychology or sociology, and social welfare work and so on would be necessary. …but they should have some accreditation or diplomas to that affect. Otherwise, you know it could go haywire. (Participant 6).

Alongside finding an equitable balance between professionalising and standardising spiritual care services, the participants felt strongly that it was critical to achieve this without making spiritual care services so rigid that more informal

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creative approaches such as using art and music may then be excluded. Participant 3 and Participant 5 stated the following:

> We can professionalise it (spiritual care services), but we would still have to have trained people like myself or our team that could work and who did not have the (academic) degree. I wouldn't like to put it (spiritual care) in a box again. (Participant 3).
> I have brought poetry onto the ward if it is appropriate and I remember there was a woman who told me that Tina Schouw was her favourite singer and I brought a CD and she played it when we had a CD recorder and she wanted that at her funeral. We can work on the creativity, I won't go into the whole writing letters and making cards, and images. There was a woman who was reported to be a Buddhist and we knew very little about her but she had her iPad and she was looking at what Buddhists do and right back to her childhood, she was looking back at pictures and through her failed marriage and into Buddhism and she shared that with me. What have people got next to their beds, what are their books, what are their things that they have next to their beds. We can pick up and enlarge a part of them that they are presenting in a creative way… We had an American woman, who came to St Luke's with her students and there were a couple that were with someone who was dying and she gave them a cello concerto that was such a beautiful farewell with the husband and the wife. (Participant 5)

The participants further expressed that given the highly individualised approach to spiritual care services any standardisation and professionalisation that could take place should still allow for a practical skills development component, typically in the form of mentoring or an internship of some kind for face-to-face learning to take place. Participant 5 expressed the following (the "volunteer's programme" referred to here by participant 5 is an orientation programme, sometimes referred to as a "screening" programme or "Basic Hospice Course", offered to all prospective volunteers to SLCH that seeks to showcase the multiple avenues in which volunteer work can be undertake):

> There is a basic need that if somebody has done the volunteer's programme, you don't just become a spiritual counsellor. I mean people do a volunteers programme and they hear one person speak for one session of spiritual care and they think death is quite sexy at the moment…we need experiential training for spiritual carers and we need mentoring, we need people that have had the experience to run a peer group or talk it through or they will fall through the gaps. So if you are working as a team, certainly in the ward [in-patient unit], the opportunity to discuss and to be mentored and co-counselled with somebody else that for me was a very big growing point. We used to have case discussion as well and go in [home visits] with the nurses too and that is where the growing is. You should go through these process and then you should have a mentor and then you should… come onto the ward [after] having actually experienced the community-based day hospices, because you know some people might come from backgrounds where they've never had any contact with somebody who's from Gugulethu or from

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> Grassy Park [predominantly marginalised communities result from the apartheid regime]. (Participant 5).

Discussion

We discuss the following three themes which emerged with prominence.

Spiritual Care Practice

It became clear that the participants of this study were committed to the spiritual care services they provided and that they served as a synergistic satisfier (Max-Neef, 1987) in which the mutual benefit of the patient/carer relationship was symbiotic. The participants in this study negotiated entry into spiritual care services at SLCH through diverse touch points and for various personal reasons. This was expected, as it is well documented, locally, and internationally that volunteers volunteer for a myriad of personal reasons (Akintola, 2011; Daute et al., 2019; Mati, 2016; Morris et al., 2015; Tapp et al., 2019). We were struck by the seemingly diverse backgrounds and qualifications of the participants drawn to spiritual care work which intimated that there was no clear career path leading into spiritual care work and neither did it appear that there was a basic prerequisite qualification for entry into spiritual care work. Research abounds on the importance of spiritual care workers in palliative care, but this is largely premised on the presumption that spiritual care workers have a health care background (Best et al., 2020; Kestenbaum et al., 2017; Paal et al., 2018). This is not the case in the South African context.

Credentialing Spiritual Care

In SA, spiritual care seems not to be ensconced in a core or formal curriculum, but rather it appears to be an ancillary course taught at some institutions of higher learning (Linda et al., 2015). Germane to this and emerging from a national study of training needs of spiritual care workers in hospice palliative care settings, a set of soft and hard skills were suggested as a key skills-set for spiritual care workers in SA (Mahilall & Swartz, under review). Similarly, in the northern hemisphere, there is increasing consensus on the importance of training for spiritual care workers in spiritual care (Isaac et al., 2016; Paal et al., 2018; Puchalski et al., 2019). Advocacy for postgraduate palliative care education for all health care workers in Europe has gained momentum by seeing the voices of the World Health Organization (WHO Global Observatory for eHealth, 2010) and European Association for Palliative Care (EAPC) joining the call. In SA, while still very new as a recognised health care service, palliative care is gaining momentum, as the National Department of Health (NDoH) has prioritised palliative care at the primary, intermediary, and tertiary health care levels (Republic of South Africa, 2017). Consequently, the NDoH has also prioritised the scaled-up training of cohorts of different health

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care professionals, community health workers and care volunteers in palliative care (Gwyther et al., 2018). This is a positive step in the right direction in establishing palliative care, and especially spiritual care, as it begins to gain some ground towards professionalising and standardising this important work by providing some guidelines for spiritual care practice.

The participants of this study felt that part of the process of sustaining spiritual care services at hospices would be to provide recognised training in spiritual care, to develop a spiritual care code of ethics, and to have spiritual care services registered with a professional body. Similar calls have been made by Linda et al. (2015) for formal education in spiritual care in nursing; Mthembu et al. (2016) for formal education in spiritual care in health sciences; Bhagwan (2017) for formal education in spiritual care for social workers; and Gwyther et al. (2018) for training for hospital-based professionals. Participants expressed the importance of screening potential spiritual care volunteers who are looking to enter into spiritual care work, not only to assess their skills and competencies, but also to assess their personal attributes and motivation for wanting to do spiritual care work; nuggets of suggestions which call for greater investigations and understanding and which could have value to SLCH and other hospices in SA in the recruitment of spiritual care volunteers, as well as positioning spiritual care within the palliative care framework at hospices in SA.

Spiritual Care as a Crisis Intervention

The current global pandemic has not only brought about a global financial crisis but has also forced health care systems to focus more acutely on end-of-life care (Baldwin-Ragaven, 2020). Communities and families have historically found comfort in each other in times of personal or national disasters through religion and philosophy (Mati, 2016). Roman et al. (2020) suggest a more contemporary view that spiritual care is part of the human psyche and consequently forms part of human care, as well as care for society, families, patients, and care providers. Studies have also shown that patients' reliance on spiritual care increases during life-altering events (Mthembu et al., 2017), but while many health care professionals recognise the value of spiritual care interventions for their patients, many felt inadequate in providing that care themselves (Mthembu et al., 2016). While Roman et al. (2020) call for a collaboration of spiritual care practitioners to address the accelerated need for spiritual care during the COVID-19 pandemic, this pandemic has also shown that there is an immediate need to better equip existing health care professionals with skills and training in spiritual care as well as grow a volunteer force of adequately trained spiritual care workers, something the participants of this study called for as well.

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Limitations of this Study

While some important perspectives and views about spiritual care practice and understanding the motivations of spiritual care workers in doing this work were identified in this study, it is important to acknowledge the limitations of this study. The first limitation was that only spiritual care workers from one hospice, SLCH (albeit the oldest and largest hospice in the Western Cape, SA) were included in this study. The second limitation was that the methods for this research were limited to individual interviews and FGDs. An expansion of these methods, to include, for instance, observations or photo voice research methods, could have provided additional rich data in understanding the experiences of spiritual care workers providing care in hospice palliative care settings. Thirdly, whilst this study cannot be generalised in the statistical sense of the word, there was widespread representation (albeit purposive sampling of only spiritual care workers) across all communities serviced by SLCH, suggesting that these triangulated findings have some integrity.

Conclusion

The importance of spiritual care services in palliative care is well documented both locally and internationally. While the literature in the Global North supports this assertion, it is imperative to bear in mind that the large body of such research is based on the premise that spiritual care workers have a prior recognised care background in, for example, medicine, psychology, or chaplaincy before entering the spiritual care services field, whereas the reality in the Global South, and in SA in particular, is that spiritual care work is taken up largely by volunteers with diverse backgrounds and educational qualifications. Amongst our participants, admittedly a small group, but insider experts, there emerged a felt need to grow spiritual care practitioners and to formalise spiritual care services in hospice palliative care settings in SA. The time is now ripe to explore these issues as palliative care negotiates its rightful place in the national continuum of health care system.

Recommendations

This study suggests many directions for future research. Some suggestions for future research include:

Entry Requirements

This study highlighted the diverse qualifications and entry paths into spiritual care work in the SA hospice context, which suggests that there does not exist a basic entry requirement into spiritual care work at hospices in SA. Is a basic

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entry requirement necessary? This study further suggests that according to people currently doing the work, this may well be necessary. We call for open dialogue and more empirical studies to be undertaken in other provinces in SA, as well as extended further to the Global South, with the aim of understanding and addressing entry criterion into spiritual care work.

Further Research on Understanding the Motivations of Spiritual Care Workers

It may also be helpful to understand the motivations of prospective spiritual care workers to undertake spiritual care work at a hospice. Further open dialogue and research are needed on this topic, which may be helpful to hospices seeking to employ spiritual care workers.

Satisfaction Assessments

It may also be useful to undertake satisfaction surveys and further empirical studies with practicing spiritual care workers with a view to using that data to scope spiritual care as a recognised discipline in palliative care.

Appendix 1: Guiding Questions for Semi-Structured Interviews

Collapsed Interview Questions	Original Questions
A: How and why you became a spiritual care worker	1. Tell me about how you became a spiritual care worker?
	2. Tell me about why you became a spiritual care worker?
B: Positive highlights of spiritual care work	3. Share with me some of the highlights of your work in spiritual care?
	4. Can you cite some examples to illustrate those highlights?
C: Chat	
D: Difficulties experienced in spiritual care work	5. Share with me some of the difficulties of your work in spiritual care
	6. Can you cite some examples to illustrate those difficulties?
	7. How did you mitigate those difficulties and challenges?
E: Skills and training needed for SCW	8. What would you consider to be your training needs as a spiritual care worker?
	9. What would your thoughts be in professionalising spiritual care?
	10. How would you envisage this happening?

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Collapsed Interview Questions	Original Questions
F: Describe your spiritual care work and spiritual care work in general	11. How would you describe your work as a spiritual care worker at SLCH?
	12. Could you perhaps share your experiences of how you engaged with patients as a spiritual care worker?
	13. What is your understanding of spiritual care?
G: Is there a distinction between religion and spirituality?	14. For you, is there a distinction between spirituality and religion?
H: What role does your religious faith play in your spiritual care work?	15. What role does your religious faith play, if any, in your delivery of spiritual care services?
I: What is the spiritual care framework you use?	16. What is the framework within which you provide spiritual care intervention?
J: IDT and spiritual care services	17. Can you describe your understanding of the IDT at SLCH?
	18. What role does spiritual care play within the IDT?
	19. How would you describe your work as a spiritual care worker within the IDT?
	20. How would you describe your work within the spiritual care team at SLCH?
	21. Do you feel that having spiritual care workers working at SLCH brings about positive change to the service the hospice offers?
	22. Can you cite examples to illustrate that?
	23. Do you feel that having spiritual care workers working in an IDT at SLCH brings about positive change to the approach of the IDT to the patient?
	24. Can you please cite examples to illustrate that?
K: Diversity and spiritual care	25. Given the range of diversity in SA how would you say this affects the way you provide spiritual care within your hospice?

SCW spiritual care workers, *SLCH* St Luke's combined hospices, *IDT* inter-disciplinary team,*SA* South Africa

Acknowledgements The participants; spiritual care workers from St Luke's Combined Hospices, Cape Town, South Africa, for their meaningful participation, dedication, and passion for spiritual care and palliative care. Varkey George for the excellent facilitation of the one-on-one interviews and co-facilitation of focus groups discussions. Prof. Dianna Yach, Chairperson of The Mauerberger Foundation Fund—for the funding of this project.

Author Contributions RM was a major contributor to the design and writing of the article. LS contributed to the writing and editing of the article. Both authors read and approved the final manuscript.

Funding This study was funded by the Mauerberger Foundation Fund.

Availability of Data and Materials The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Consent to Participate Written informed consent was obtained from all individual participants included in the study.

Declarations

Conflicts of Interest The authors declare that they have no conflict of interest.

Ethical Approval Ethical approval for the study was obtained from Stellenbosch University (10237), Hospice Palliative Care Association (HPCA) (02/19), and St Luke's Combined Hospices. Written consent was obtained from participants of the study and is available from the corresponding author. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

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References

Abel, J., Walter, T., Carey, L., Rosenberg, J., Noonan, K., Horsfall, D., Leonard, R., Rumbold, B., & Morris, D. (2013). Circles of care: Should community development redefine the practice of palliative care? *BMJ Supportive & Palliative Care, 3*(4), 383–388. https://doi.org/10.1136/bmjspcare-2012-000359

Akintola, O. (2011). What motivates people to volunteer? The case of volunteer AIDS caregivers in faith-based organizations in KwaZulu-Natal, South Africa. *Health Policy and Planning, 26*(1), 53–62. https://doi.org/10.1093/heapol/czq019

Akintola, O., & Chikoko, G. (2016). Factors influencing motivation and job satisfaction among supervisors of community health workers in marginalized communities in South Africa. *Human Resources for Health, 14*, 54. https://doi.org/10.1186/s12960-016-0151-6

Asadi-Lari, M., Madjd, Z., & Goushegir, S. A. (2008). Gaps in the provision of spiritual care for terminally ill patients in Islamic societies—A systematic review. *Advances in Palliative Medicine, 7*(2), 73–80. https://core.ac.uk/download/pdf/268447604.pdf

Balboni, T., Vanderwerker, L., Block, S., Paulk, M., Lathan, C., Peteet, J., & Prigerson, H. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology: official journal of the American Society of Clinical Oncology, 25*(5), 555–560. https://doi.org/10.1200/JCO.2006.07.9046

Baldwin-Ragaven, L. (2020). Social dimensions of COVID-19 in South Africa: A neglected element of the treatment plan. *Wits Journal of Clinical Medicine, 2*(SI), 33–38. https://doi.org/10.18772/26180197.2020.v2nSIa6

Barnard, A., & Furtak, A. (2020). Psychological resilience of volunteers in a South African health care context: A salutogenic approach and hermeneutic phenomenological inquiry. *International Journal of Environmental Research and Public Health, 17*(8), 2922. https://doi.org/10.3390/ijerph17082922

Stellenbosch University https://scholar.sun.ac.za

Best, M., Leget, C., Goodhead, A., & Paal, P. (2020). An EAPC white paper on multi-disciplinary education for spiritual care in palliative care. *BMC Palliative Care, 19*(9), 1–10. https://doi.org/10.1186/s12904-019-0508-4

Bhagwan, R. (2017). The sacred in traditional African spirituality: Creating synergies with social work practice. In B. R. Crisp (Ed.), *The Routledge handbook of religion, spirituality and social work* (pp. 64–72). Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Callahan, A. M. (2015). Key concepts in spiritual care for hospice social workers: How a multidisciplinary perspective can inform spiritual competence. *Social Work & Christianity, 42*(1), 43–62.

Campbell, L., & Amin, N. (2014). A qualitative study: potential benefits and challenges of traditional healers in providing aspects of palliative care in rural South Africa. *Rural and Remote Health, 14*, 2378. https://doi.org/10.22605/RRH2378

Chandramohan, S., & Bhagwan, R. (2015). Spirituality and spiritual care in in the context of nursing education in South Africa. *Curationis, 38*(1), 15. https://doi.org/10.4102/curationis.v38i1.1471

Daute, H., d'Archangelo, M., & Duquette, D. (2019). Spiritual care training in health care: does it really have an impact? *Palliative and Support Care, 17*, 129–137. https://doi.org/10.1017/S1478951517001134

De Wet, K. (2012). Redefining volunteerism: the rhetoric of community home-based care in (the not so new) South Africa. *Community Development Journal, 47*(1), 111–125. https://doi.org/10.1093/cdj/bsq066

Drenth, C., Sithole, Z., Pudule, E., Wüst, S., GunnClark, N., & Gwyther, L. (2018). Palliative care in South Africa. *Journal of Pain and Symptom Management, 55*(2), S170–S177. https://doi.org/10.1016/j.jpainsymman.2017.04.024

Flannelly, K. J., Weaver, A. J., Smith, W. J., & Oppenheimer, J. E. (2003). A systematic review on chaplains and community-based clergy in three palliative care journals: 1990–1999. *American Journal of Hospice and Palliative Medicine®, 20*(4), 263–268.

Gwyther, L., Krause, R., Cupido, C., Stanford, J., Grey, H., Credé, T., De Vos, A., Arendse, J., & Raubenheimer, P. (2018). The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. *South African Medical Journal, 108*, 86–89. https://doi.org/10.7196/SAMJ.2018.v108i2.12524

Hollway, W., & Jefferson, T. (1997). Eliciting narrative through the in-depth interview. *Qualitative Inquiry, 3*(1), 53–70. https://doi.org/10.1177/107780049700300103

Isaac, K. S., Hay, J. L., & Lubetkin, E. I. (2016). Incorporating spirituality in primary care. *Journal of Religion and Health, 55*(3), 1065–1077. https://doi.org/10.1007/s10943-016-0190-2

Johnson, H. C., Gossner, C. M., Colzani, E., Kinsman, J., Alexakis, L., Beauté, J., Würz, A., Tsolova, S., Bundle, N., & Ekdahl, K. (2020). Potential scenarios for the progression of a COVID-19 epidemic in the European Union and the European Economic Area. *Eurosurveillance, 25*(9), 2000202. https://doi.org/10.2807/1560-7917.ES.2020.25.9.2000202

Kestenbaum, A., Shields, M., James, J., Hocker, W., Morgan, S., Karve, S., Rabow, M. W., & Dunn, L. B. (2017). What impact do chaplains have? A pilot study of spiritual AIM for advanced cancer patients in outpatient palliative care. *Journal of Pain and Symptom Management, 54*(5), 707–714. https://doi.org/10.1016/j.jpainsymman.2017.07.027

Koper, I., Pasman, H. R. W., Schweitzer, B. P. M., Kuin, A., & Onwuteaka-Philipsen, B. D. (2019). Spiritual care at the end of life in the primary care setting: Experiences from spiritual caregivers—A mixed methods study. *BMC Palliative Care, 18*(98), 1–10. https://doi.org/10.1186/s12904-019-0484-8

Linda, N. S., Klopper, H. C., & Phetlhu, D. R. (2015). Students' voices on spiritual care at a higher education institution in the Western Cape. *Curationis, 38*(2), 1520. https://doi.org/10.4102/curationis.v38i2.1520

Lourens, G. M., & Daniels-Felix, D. K. (2017). Hospital volunteerism as human resource solution: Motivation for both volunteers and the public health sector. *SA Journal of Human Resource Management/SA Tydskrif vir Menslikehulpbronbestuur, 15*, a813. https://doi.org/10.4102/sajhrm.v15i0.813

Mahilall, R., & Swartz, L. (2021). Spiritual care practices in hospices in the Western cape, South Africa: The challenge of diversity. *BMC Palliative Care, 20*(1), 9. https://doi.org/10.1186/s12904-020-00704-z.

Mahilall, R., & Swartz, L. (under review). "'I am dying a slow death of white guilt': Spiritual carers in a South African hospice navigate issues of cultural diversity.

Stellenbosch University https://scholar.sun.ac.za

Merriman, A., & Harding, R. (2010). Pain control in the African context: The Ugandan introduction of affordable morphine to relieve suffering at the end of life. *Philosophy, Ethics, and Humanities in Medicine, 5*(10), 1–6. https://doi.org/10.1186/1747-5341-5-10

Mati, J. M. (2016). Horizontality: The ignored particularity of African volunteering. In: *Conference paper: The third sector in transition: Accountability, transparency, and social inclusion, Stockholm Volume: 12th international ISTR conference.*

Max-Neef, M. A. (1987). Economics, politics and health: The challenge of future trends (a think-piece). In D. Schwefel (Ed.), *Indicators and trends in health and health care, Health systems research series*. Springer. https://doi.org/10.1007/978-3-642-71537-2_12

Morris, S. M., King, C., Turner, M., & Payne, S. (2015). Family carers providing support to a person dying in the home setting: A narrative literature review. *Palliative Medicine, 29*(6), 487–495. https://doi.org/10.1177/0269216314565706

Morton, D., Mayekiso, T., & Cunningham, P. (2018). Structural barriers to South African volunteer home-based caregivers providing quality care: The need for a policy for caregivers not affiliated to primary healthcare clinics. *African Journal of AIDS Research, 17*(1), 47–53. https://doi.org/10.2989/16085906.2017.1397719

Mthembu. T. G., Wegner, L., & Roman, N. V. (2016). Teaching spirituality and spiritual care in health sciences education: A systemic review. *African Journal of Physical Activity and Health Sciences, 22*(4:1), 1036–1057. https://www.researchgate.net/publication/308414596_Teaching_spirituality_and_spiritual_care_in_health_sciences_education_A_systematic_review

Mthembu, T. G., Wegner, L., & Roman, N. V. (2017). Barriers to integration of spirituality and spiritual care in occupational therapy education in a South African context. *Journal of Spirituality in Mental Health, 19*(1), 61–79. https://doi.org/10.1080/19349637.2016.1206843

Nxumalo, N., Goudge, J., & Manderson, L. (2016). Community health workers, recipients' experiences and constraints to care in South Africa—a pathway to trust. *AIDS Care, 28*(sup4), 61–71. https://doi.org/10.1080/09540121.2016.1195484

O'Brien, M. R., Kinloch, K., Groves, K. E., & Jack, B. A. (2019). Meeting patients' spiritual needs during end-of-life care: A qualitative study of nurses' and healthcare professionals' perceptions of spiritual care training. *Journal of Clinical Nursing, 28*(1–2), 182–189. https://doi.org/10.1111/jocn.14648

Paal, P., Leget, C., & Goodhead, A. (2015). Spiritual care education: Results from an EAPC survey. *European Journal of Palliative Care, 22*(2), 91–95. Retrieved from https://www.eapcnet.eu/Portals/0/EJPC22%282%29Paal.pdf

Paal, P., Neenan, K., Muldowney, Y., Brady, V., & Timmins, F. (2018). Spiritual leadership as an emergent solution to transform the healthcare workplace. *Journal of Nursing Management, 26*(4), 335–337. https://doi.org/10.1111/jonm.12637

Puchalski, C., Jafari, N., Buller, H., Haythorn, T., Jacobs, C., & Ferrell, B. (2019). Interprofessional spiritual care education curriculum: A milestone toward the provision of spiritual care. *Journal of Palliative Medicine, 23*(6), 777–784. https://doi.org/10.1089/jpm.2019.0375

Ratshikana-Moloko, M., Ayeni, O., Tsitsi, J. M., Wong, M. L., Jacobson, J. S., Neugut, A. I., Sobelkwa, M., Joffe, M., Mmoledi, K., Blanchard, C. L., & Mapanga, W. (2020). Spiritual care, pain reduction, and preferred place of death among advanced cancer patients in Soweto, South Africa. *Journal of Pain and Symptom Management, 60*(1), 37–47. https://doi.org/10.1016/j.jpainsymman.2020.01.019

Republic of South Africa. (2017). *National policy framework and strategy on palliative care 2017–2022.* Retrieved from file:///C:/Users/User/Downloads/Final%20NPFSPC%20August%202017.pdf

Roman, N. V., Mthembu, T. G., & Hoosen, M. (2020). Spiritual care—'A deeper immunity'—A response to Covid-19 pandemic. *African Journal of Primary Health Care & Family Medicine, 12*(1), e1–e3. https://doi.org/10.4102/phcfm.v12i1.2456

Swartz, A., & Colvin, C. J. (2015). 'It's in our veins': caring natures and material motivations of community health workers in contexts of economic marginalisation. *Critical Public Health, 25*(2), 139–152. https://doi.org/10.1080/09581596.2014.941281

Tapp, A., Nancarrow, C., Morey, Y., Warren, S., Bowtell, N., & Verne, J. (2019). Public responses to volunteer community care: Propositions for old age and end of life. *PLoS ONE, 14*(7), e0218597. https://doi.org/10.1371/journal.pone.0218597

Volmink, J., Hendricks, L., Mazibuko, L., & Swartz, L. (2020). Race and health: Dilemmas of the South African health researcher. In J. Jansen & C. Walters (Eds.), *Faultlines: A primer on race, science and society* (pp. 113–127). Stellenbosch: SunPress.

Stellenbosch University https://scholar.sun.ac.za

WHO Global Observatory for eHealth. (2010). *Telemedicine: opportunities and developments in member states: report on the second global survey on eHealth.* World Health Organization. Retrieved from https://apps.who.int/iris/handle/10665/44497

World Bank Blogs. (2020). New World Bank country classifications by income level: 2020–2021. Retrieved from https://blogs.worldbank.org/opendata/new-world-bank-country-classifications-income-level-2020-2021

Yang, G. M., Tan, Y. Y., Cheung, Y. B., Lye, W. K., Lim, S. H. A., Ng, W. R., Puchalski, C., & Neo, P. S. H. (2017). Effect of a spiritual care training program for staff on patient outcomes. *Palliative & Supportive Care, 15*(4), 434–443. https://doi.org/10.1017/S1478951516000894

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8.2 License to publish

I obtained written license to publish Article 4 in my dissertation (Addendum 19).

8.3 Chapter summary

In this study a cohort of spiritual care workers from a prominent hospice in Cape Town, SA – SLCH – participated. They made suggestions about formalising spiritual care as well as making a call for a basic entry requirement into spiritual care work. In the next chapter I explore in-depth the national, provincial, and local spiritual care training needs of SA's hospices as well as what they envisage to be the way forward for spiritual care practice in hospices in SA.

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CHAPTER NINE

ARTICLE 5

Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial, and local voices.

– Journal of the Study of Spirituality –

9.1 Introducing Article 5

This article ties together the three-tiered sub-studies with a focused view on scoping the expressed national, provincial, and local training needs in spiritual care within hospice palliative care settings in SA. Key barriers that could potentially hinder the development of a national training curriculum in spiritual care are identified and explored.

This article was published in the *Journal of the Study of Spirituality*, as follows:

> Mahilall, R., & Swartz, L. (2021). Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial, and local voices. *Journal of the Study of Spirituality, 11*(2). https://doi.org/10.1080/20440243.2021.1922257

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JOURNAL FOR THE STUDY OF SPIRITUALITY
https://doi.org/10.1080/20440243.2021.1922257

Spiritual care training needs in hospice palliative care settings in South Africa: Chorused national, provincial and local voices

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ABSTRACT

Globally, spiritual care is recognized as an important component of palliative care. In the Global North spiritual care training is gaining momentum and being prioritized, but not so in the Global South. This study seeks to establish what the national spiritual care training needs are in hospice palliative care settings with formalized spiritual care services in a middle-income country in the Global South. This was a three-part study: a quantitative national online survey of hospices in South Africa establishing what their spiritual care training needs were – survey results were collated, analyzed and filtered for key issues and overarching themes; a qualitative study consisting of focus group discussions with hospices in the Western Cape Province, South Africa, who have formalized spiritual care services, with the aim of understanding their spiritual care practices and workforce needs – the discussions were analyzed using thematic analysis; and a qualitative study drawing on the experiences of a cohort of spiritual care workers from an established hospice in Cape Town to understand their training needs in spiritual care and explore their workforce issues. Results revealed a chorused need for the development of a national training curriculum in spiritual care for hospices providing palliative care in South Africa and a chorused recognition that spiritual care services are nuanced and require both formalization and flexibility for spiritual care workers to be led by patient needs. Two elements – finance and human capital – were identified as key barriers to developing a spiritual care curriculum.

KEYWORDS

Spiritual care; palliative care; training curriculum; hospice; South Africa; training barriers

Introduction

The global movement towards incorporating palliative care into healthcare systems has gained significant ground (Connor 2018; Drenth et al. 2018; Gwyther et al.; Daute, d'Archangelo, and Duquette 2019; Paal et al. 2019; Jones et al. 2020; Mason et al. 2020; Puchalski et al. 2020). The World Health Organization (WHO) recommends equitable access to palliative care for all people living with life-limiting illnesses (World Health Organization 2014). There is a clear understanding of the components of palliative care, with the medical, psychosocial and bereavement components being well documented, with clear indicators and outcomes (Steinhauser et al. 2017). Increasingly, there

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is growing recognition of the key role spiritual care plays as part of the holistic palliative care experience (Paal et al. 2019; Selman et al. 2014; Chandramohan and Bhagwan 2016; De la Porte 2016; McCaffrey et al. 2016; Mthembu, Wegner, and Roman; Best et al. 2020).

The importance of spiritual care and the effective provision of spiritual care services, as a central component of palliative care, has relevance for healthcare systems in Africa. Also, in Africa, there is documented evidence suggesting the centrality of issues of spirituality within and for healthcare (James et al. 2018; Oman 2018; Kimera et al. 2019; Ojagbemi and Gureje 2020; Omenka, Watson, and Hendrie 2020). Despite this, in several studies on palliative care in Africa, spiritual care is barely mentioned, if at all (Mpanga Sebuyira 2006; Volmink and Dare 2005; Powell et al. 2008; Bogopa 2010; Dalal et al. 2011; Mahilall and Swartz 2021). The current study begins to address this disjunction by exploring views on the need for training and development of spiritual care workers in South Africa (SA).

In SA, the National Department of Health (Republic of South Africa 2017a) launched the *National Policy Framework and Strategy on Palliative Care 2017–2022* (NPFSPC 2017–2022) in 2017, giving palliative care and spiritual care prominence on the continuum of healthcare. Beset by the injustices of the apartheid past, 26 years into its democracy SA is still grappling with many inequalities, marginalities, and racism. This is evidenced in unequal resource allocations, continuing social divisions and inequality, lack of adequate engagement with cultural diversity and linguistic divides, all contributing to healthcare disparities (Coovadia et al. 2009; Watermeyer, and Swartz 2016; Kaunda 2017; Baldwin-Ragaven 2020; Roman, Mthembu, and Hoosen 2020). Palliative care and, by extension, spiritual care as part of healthcare, is not offered to all citizens of SA despite basic healthcare being enshrined as a right in the Constitution of the Republic of South Africa (Republic of South Africa 2017b). Recognizing the role of spiritual care and spiritual care workers in palliative care towards improved care plans for palliating patients is the first step in highlighting spiritual care workforce issues in an African context.

There are many studies in the Global North[1] emphasizing the importance of training of healthcare professionals in spiritual care (Paal et al. 2019; Puchalski et al. 2020; Best et al. 2020; Crisp 2018; Kruizinga et al. 2018; Gardner 2020; Tan et al. 2020). Further, many spiritual care frameworks have been suggested, such as the Spiritual Health Association's *Guidelines for Quality Spiritual Care in Health* (Spiritual Health Association 2020) and *Spiritual Care in Medical Records: A Guide to Reporting and Documenting Spiritual Care Services in Health* (Spiritual Health Association 2020) which are aimed at ensuring that the spiritual care workforce has the capabilities needed to respond to the diverse spiritual needs of patients, carers, and staff. In the Global South, however, there is a dearth of such studies and frameworks (Chandramohan and Bhagwan 2016; Mthembu, Wegner, and Roman 2016).

According to the WHO, the main barrier to increased access to palliative care, and spiritual care in particular, is a lack of trained healthcare professionals (World Health

[1]There are many debates about how to classify countries. The 'Global North' generally corresponds to countries categorised by the World Bank (World Bank Blog 2021/2022 Atlas) as high-income countries (HICs) – so, for example, Australia, which is a high-income country is commonly viewed as part of the Global North, despite it being in the southern hemisphere. Countries in the 'Global South' generally correspond to the World Bank low and middle-income countries (LMICs) (World Bank Blog 2021/2022 Atlas). South Africa is a middle-income country. The distinction here is based largely on financial resources, though of course other factors are associated with relative wealth.

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Organization 2014). Farahani et al. (2019) and Kruizinga et al. (2018) echo this, and further suggest that including spiritual care as part of the medical curriculum would raise awareness of medical practitioners, thus viewing the patient as having spiritual needs as well. Koenig (2014) refers to 'spiritual care teams' (a term coined by Emmer and Browne 1984) which consists of healthcare professionals, largely consisting of nurses, medical doctors, social workers, and chaplains, and other staff who seek to integrate spiritual care in the care plan of the patient and advocate for spiritual care to be incorporated into all academic curricula for all healthcare professionals. Baldacchino (2015) and Puchalski and Guenther (2012) further suggest that restoring and recreating spirituality in the lives of healthcare professionals, in conjunction with developing healthcare professionals academically, is a good starting point for bringing spiritual care into prominence. This assertion, however, assumes that spiritual care is offered by trained professionals who have a healthcare background, or by chaplains who commonly have tertiary and even postgraduate qualifications.

In SA, it is largely volunteers, who do not necessarily have a healthcare background or formal training in spiritual care, who undertake such services (Mahilall and Swartz under review). This contrasts with the situation in the Global North, with the spiritual care workforce in countries like SA comprising people with a range of qualifications (or no formal qualifications), and with very diverse backgrounds. A study at an established hospice in Cape Town, SA, showed a myriad of academic and professional backgrounds of volunteers undertaking spiritual care work, thereby suggesting that the credentialing of spiritual care as a core discipline is lacking and potentially not easy to obtain (Mahilall and Swartz 2021). Spirituality within African contexts is typically not seen as separate from cultural practices (Mpanga Sebuyira et al. 2003). Consequently, spiritual care is seen as a seamless extension of family care and support (Munthali 2006). Additionally, and not surprisingly, religion and spirituality are seemingly deliberately conflated in an offering as cultural and traditional rituals and practices (Bogopa 2010).

With spiritual care rapidly gaining momentum in the Global North but being very recently considered as a component of palliative care in the Global South, defining spirituality within the context of palliative care, and the larger healthcare system remains in flux. Several definitions of spirituality have been proffered, with the most established definition being coined at a Consensus Conference in 2009 in America as: '… the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred' (Puchalski et al. 2009; Puchalski et al. 2014). For the purposes of this study, this definition was largely adopted, but with recognition of the sensitivities around diversity in SA – culturally, religiously, and racially – and how these play themselves out when building a competent spiritual care workforce. Clearly there is much more work that needs to be done in centralizing spirituality and spiritual care in SA, and this study is a step in the right direction in determining what the needs are for formalizing a spiritual care workforce within a hospice palliative care setting. It is hoped that further research will result in a more bespoke South African definition of spiritual care, as well as addressing the training needs of a spiritual care workforce.

If spiritual care is to assume its rightful place as part of palliative care in SA, it is important to understand what the training and workforce needs are for the provision

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of this service, given local diversity constraints and social challenges. In this article, we present and discuss our findings in relation to this question.

Methods

In order to obtain an overview of spiritual care training needs in palliative care in SA, and also to obtain more fine-grained information from organizations already providing such care, we conducted a three-part study.

Sub-study 1: National online survey

We conducted a simple Excel-based quantitative online survey (with some open-ended questions) of all hospices and related organizations which are registered members of the Hospice Palliative Care Association (HPCA)[2] of SA. It has 104 member organizations[3] across all nine South African provinces. Ethical approval was obtained from the university with which we are affiliated (10237) and the HPCA (02/19).

The survey sough to establish whether spiritual care practices were in place at each hospice. The following are examples of the kinds of questions posed:

- What phrase best describes the extent of spiritual care offered at your hospice? (a. full care; b. partial care; c. occasional care; d. not at all);
- How is spiritual care practiced at hospices? (e.g. Does your organization recognize spiritual care as an integral part of a palliative care service it offers: a. Yes; b. No; c. If No, please elaborate.)
- Spiritual care training needs (e.g. Has a need for spiritual care training been expressed by your organization: a. Yes; b. No; c. We do not know at this time).

Only 96 member organizations were contactable via telephone and email. We telephoned the leader of each of the 96 organization to position the study and explored their willingness to participate. We distributed the survey electronically to all 96 member organizations and 43 responses were received, 40 of which produced viable data. Three follow-up contacts (via telephone and email) were made with the remaining 53 member organizations who had not responded. The three common reasons for a non-response were a lack of time to respond (26%), lack of available staff to assign the survey to for a response (17%), and some member organizations felt that the survey was not applicable to them because of the limited provision of spiritual care services being offered (15%).

The completed surveys represent 41.6% ($n = 40$) of the contactable HPCA member organizations across SA. We conducted a Geographic Information System (GIS) (Procewicz et al. 2012) mapping to observe the spatial pattern of responses relative to the location of all organizations (Figure 1). Through simple statistical calculations the online survey results were then collated, analyzed, and filtered for key issues and

[2]HPCA is a national association operating in all nine provinces in SA, including 51 health districts. Some of its voluntary member organizations offer hospice palliative care, some home-based care, and others both services.
[3]We use the term 'member organizations' rather than 'hospices' because all organizations offer palliative care, but not all call themselves hospices.

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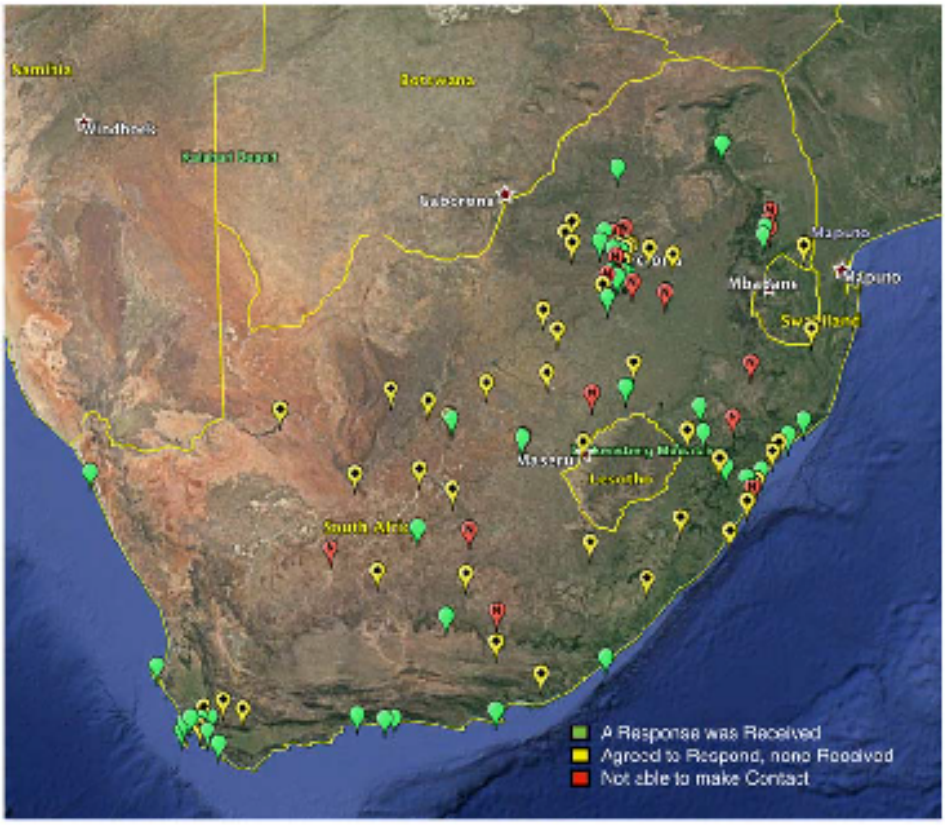

Figure 1. Mapping of hospices in South Africa.

overarching themes. Participation in this study was voluntary. Written consent to participate in the study was sought and all participants were given an Information Pamphlet positing the study which highlighted, amongst other important information, issues of confidentiality, protection of the data, and freedom to withdraw from the interviewing process or raise alternate views and arguments.

Sub-study 2: Qualitative focus groups in the Western Cape Province

Through our familiarity with the field of palliative care in SA (Mahilall works in this field and Swartz has conducted research it), we knew that much of the formalized practice of spiritual care in palliative care in SA is taking place in the Western Cape Province, where access to healthcare in general may be better than in the rest of the country (Fusheini and Eyles 2016; Omotoso and Koch 2018). Further, we both live and work in the Western Cape Province and consequently convenience was another consideration. A co-facilitator, skilled in quantitative research, was formally engaged to facilitate the two focus group discussions (FGD) for objectivity and to guard against, and limit, researcher bias. Participation in this study was purely voluntary. Ethical approval was obtained from the university to which we are both affiliated, and from the HPCA (02/19).

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There are 12 hospices in the Western Cape Province, 11 hospices voluntarily participated with participants being in managerial and/or clinical roles. 23 participants were part of the study, consisting of Chief Executive Officers who either had a nursing or social work background; clinical nursing managers; professional nurses; social workers; spiritual care workers; and medical doctors. All had years of service at their hospices. Participants gave written consent and were given an Information Pamphlet ahead of the FGD.

The aim of the two FGDs was to establish how spiritual care was practiced at hospices in the Western Cape Province. Issues were raised such as: describe the nature of the spiritual care intervention provided by your organization, and given the range of diversity in SA, how would you say this affects the spiritual care service delivery within your hospice? Regarding what the hospices' spiritual care training needs were, the discussions were guided by questions such as, for example, what resources are needed to provide spiritual care services, and what would you consider to be the curriculum needs of spiritual care workers? The data were recorded and transcribed. Through thematic analysis, a qualitative research method defined by Braun and Clarke (2006, 79) as 'identifying, analyzing and reporting patterns within data', the data were coded and reviewed for emerging themes and subthemes which were then defined, named, and analyzed thematically.

Sub-study 3: Qualitative interviews and focus groups with spiritual care workers

To inform our understanding of training needs in relation to spiritual care work in palliative care in SA, we drew on the experiences of spiritual care workers providing spiritual care services at a large hospice association in Cape Town, Western Cape (St Luke's Combine Hospices – SLCH). Ethical approval was obtained from the university with which we are affiliated (10237) and HPCA (02/19), as well as SLCH.

SLCH has 23 registered spiritual care workers, of which 15 are actively engaged in spiritual care work. The eight inactive spiritual care workers cited advanced age and personal illness as the main reasons for their inactive status. Participation in this study was voluntary. Ahead of the data collection process each participant gave written consent and was given an Information Pamphlet on the study and the process. This was a qualitative study utilizing an in-depth interviewing methodology which allowed for the capturing of rich, descriptive data (Hollway and Jefferson 1997). Nine spiritual care workers volunteered to participate in this study. The biographical profile of the participants was varied with six males and four females, and three of the four main race groups in SA being represented (Black, Coloured[4], Indian, and White). Participants had varied religious backgrounds, including Islam and Christianity. The participants all spoke multiple languages, the most spoken being English, *IsiXhosa* (the Bantu language of the Xhosa

[4]In South Africa, as elsewhere, the use of 'racial' terminology is complex and contested, and certainly still a source of debate and great pain. We make no claim for the scientific validity of the different 'racial' categories, but the labels used still have social significance (Swartz et al. 2020). In the South African context, the term 'Coloured', which may well be the most contested, is an official term still used in government documents, refers to a very diverse group of people of mixed and diverse origin, with Afrikaans being the predominant language spoken (Swartz et al. 2020). By contrast, the term 'Black African' commonly refers to people who speak indigenous languages such as isiXhosa, spoken in the Western Cape. Under apartheid, the Western Cape was viewed as a preferential area in which 'Coloured' people could live and work, whereas 'Black Africans' were viewed as not being citizens of South Africa, but of racially defined 'homelands'.

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clan, one of 11 official languages in SA) and *Afrikaans* (a West Germanic language which is another official language in SA), being. The participants had varied educational backgrounds; all had a tertiary qualification. Their career tracks included theology, counseling, architecture, psychology, social work, and alternative therapy.

As the study dealt with a sensitive topic, provision was made for psychological support for the participants if needed, at no cost to them. Given the close association both of us have with SLCH, a co-facilitator, experienced in qualitative research, was engaged to undertake one-on-one interviews with each participant (lasting approximately 90 min each), and to facilitate three sets of FGDs (lasting, on average 120 min each). Face-to-face interviews and FGDs were not possible due to lockdown regulations resulting from the COVID-19 pandemic. Consequently, interviews were conducted via virtual means such as Zoom and Skype, with the consent of the participants. We both attended the FGD. The data collection process was guided by a set of qualitative questions which sought to explore what motivated the participants to undertake spiritual care work (e.g. how and why you became a spiritual care worker?); to explore their spiritual care training needs (e.g. what would you consider to be your training needs as a spiritual care worker?); and to explore how spiritual care is being practiced (e.g. what role does your religious faith play, if any, in your delivery of spiritual care services?; and, given the range of diversity in SA, how would you say this affects the manner in which you provide spiritual care within your hospice, as well as the associated challenges?). FGD were conducted to seek clarity on certain key points raised and to further and more deeply discuss the themes and sub-themes that emerged from the one-on-one interviews. The data were recorded, transcribed and then analyzed and coded through thematic analysis (Braun and Clarke 2006). Themes and sub-themes emerged which were defined and named.

Results

While thematically analyzing the data from the three sub-studies we were struck by the similarity of the three prominent themes that emerged across all three study parts. We will therefore discuss them as consolidated results:

(a) An expressed need for a standardized training curriculum in spiritual care for hospice palliative care workers.
(b) Suggestions of core outcomes of a spiritual care training curriculum.
(c) Potential barriers to the development of a spiritual care training curriculum.

(a) An expressed need for a standardized training curriculum in spiritual care for hospice palliative care workers

At all three levels of the study there was a call for the development of a spiritual care training curriculum for hospices undertaking palliative care work. An expressed need (75%; $n = 30$) was recorded for the development of a national spiritual care curriculum from the national survey. Only 10% ($n = 4$) of member organizations indicated that they had a spiritual care curriculum currently in place. Only 25% ($n = 10$) of member

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organizations offered spiritual care services as part of their palliative care service, with 58% ($n = 23$) referring patients out externally for spiritual care services. As one participant said:

> This is a very important … baseline study. Anything that emerges from this study will … only enhance the call for a curriculum for spiritual care training in hospices. (Participant of Hospice S101)

Participants from the provincial study felt that, to provide quality spiritual care services, workers would need to be trained in spiritual care as well as self-care:

> … the training … curriculum should look … at empowering the individual to be a spiritual care worker and … simultaneously supporting me as a carer. (Participant of Hospice 1)

Participants working as spiritual care workers at SLCH agreed, but warned against rigidity, wanting the curriculum to allow for flexibility, innovation, and creativity:

> We can professionalize it (spiritual care services) … but … I wouldn't like to put it in a box again. (Participant 3)

(b) Suggestions of core outcomes of a spiritual care training curriculum

Consensus emerged on core outcomes of a spiritual care curriculum. Of all member organizations, 20% ($n = 8$) had spiritual care workers who had received advanced training in spiritual care, 13% ($n = 5$) had spiritual care workers with no formal training in spiritual care, and 10% ($n = 4$) had spiritual care workers who received basic training in spiritual care. 53% ($n = 23$) had spiritual care services embedded in interventions provided by other care professionals such as nurses, social workers, medical doctors, and counselors. Just under half, 48% ($n = 19$), of the member organizations were willing to assist in developing a national spiritual care curriculum. This indicates a positive perception of the value and utility of spiritual care training for the palliative care sector in SA.

The two expected spiritual care training outcomes expressed at all three levels of this study were improved skill sets – soft skills and hard skills – and care and self-care for the carer. As participants put it:

> … developing a curriculum that includes an aspect for personal, spiritual and professional growth, self-awareness and self-understanding and the use of soft/hard skills … a well-articulated awareness of one's own understanding of spirituality, religion, spiritual health … how to offer spiritual healthcare in a diverse clinical setting. (National study Participant from Hospice S089)

> … when you train a person, you can do all these other things like basic knowledge of different religions and health conditions and skills … but not how do you care for yourself. This curriculum must focus on self-care too. (Provincial study Participant from Hospice 5)

Some of the suggested hard skills were: A sound understanding of palliative care, the context of palliative care in SA and its practice (82%); being able to communicate in at least two of the official languages in SA (75%); and knowledge and understanding of the integration of palliative care and spiritual issues in hospices and in SA (72%). Some of the suggested soft skills were: Strong counseling skills (90%); high levels of self-awareness, including insight into one's own spirituality and tolerance for

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diversity (82%); and high levels of acceptance, being non-judgmental, and open mindedness (76%).

(c) Potential barriers to the development of a spiritual care training curriculum

Participants identified a range of barriers to implementing training. Most member organizations from the national study (82%; $n = 33$) reported being unable to provide, or afford, any in-house spiritual care training and skills development for their spiritual care workers due to lack of funding and expertise. When asked if they would be able to fund sending their spiritual care workers for spiritual care training and skills development, 66% ($n = 26$) of member organizations indicated that they would, but not currently due to staff shortages (53%; $n = 23$) and affordability challenges (13%; $n = 5$). Only 23% ($n = 9$) of member organizations stated that they could currently pay for such training and release their staff for the duration of such training. Therefore, low training participation levels could be a reflection of financial and staffing constraints and not a lack of interest – given that 75% ($n = 30$) of member organizations in SA expressed a felt need for the development of a national spiritual care curriculum.

One of the recurring themes from the provincial study was navigating the challenges of diversity. There was recognition that SA is a highly religiously, linguistically, and culturally diverse and complex country:

> I think there needs to be respect for everybody in the team and the patient/family for bringing their own thing (beliefs, culture, religion) … and not expecting everybody to think the same as I do … that creates the space for the patient to be more open … because there is respect for what I believe and what the patient believes. (Participant from Hospice 6)

The participants of the local study at SLCH spoke of the need for a careful balance that provides appropriate levels of structure without undermining the very individual, fluid, and nuanced nature of spiritual care services; and the recognition of spiritual care services as part of the functional Inter-Disciplinary Team (IDT)[5] where the spiritual care workers are respected as health care professionals providing spiritual care services as part of the larger palliative care IDT:

> I do think we are an integral part (of the IDT) and it's very hard to qualify or measure … because we change the experience for the patient in the ward from being just a patient like at a hospital to being seen as a person in a different way … I think our added layer of companionship, support and presence changes a hospice from a hospital. I think it's one of the very big differentiating things. (Participant 1)

Discussion

Overall, there was a clear need expressed for training in, and the development of, a spiritual care curriculum for hospices, which is in line with the literature (Gwyther et al. 2018; Paal et al. 2019; Jones et al. 2020; Mason et al. 2020; Puchalski et al. 2020; Chandramohan and Bhagwan 2016; De la Porte 2016; Mthembu, Wegner, and Roman 2016; Best et al. 2020; Puchalski et al. 2020). Largely, and in keeping with findings outlined elsewhere

[5]The interdisciplinary team at SLCH consists of a clinical palliative care staff such as a medical nurse, doctor, social worker, spiritual care worker and bereavement care worker.

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(Gratz et al. 2016), the participants identified a set of hard and soft skills that a spiritual care worker should ideally have in order to offer an effective spiritual care service. Resource constraints – financial and human capital – constituted key barriers in the development and advancement of a national spiritual care curriculum in SA. Training in spiritual care at hospices in SA is not currently prioritized, as funds typically are redirected to immediate care needs such as pain control (Mahilall and Swartz 2021). Participants in our study believe that spiritual care should not be overlooked in the local context. Clearly, there is more work to be done to build spiritual care practice in this context.

It is important to emphasize that in SA we are not building spiritual care on a base that, as in the Global North, is already established. Rather, we are dealing with fundamental challenges of providing counseling services in a low resourced, skills diverse, impoverished, and high-conflict country.

A significant part of care work, including spiritual care work, centers on counseling. The HIV/AIDS pandemic has led to an emphasis on counseling (Swartz 1985), as does the current global health pandemic – SARS-CoV-2 (COVID-19). One of the issues is: what is appropriate counseling for spiritual care in the SA context? In the actual practice of HIV care in SA, there is some evidence that what is termed 'counselling' may at times involve simply telling people what to do and what not to do (such as using a condom or limiting one's number of sexual partners) (Kagee, Nothling, and Coetzee 2012; Coetzee, Kagee, and Bland 2016). There may well be a similar challenge with developing spiritual care training for palliative care in SA.

Counseling within the context of this study centers on emotionally and psychologically supporting patients and families to come to terms with their terminal diagnosis; to explore their fears about death; and to explore other existential topics. It is largely patient led. As our participants show, there is a strong need to develop soft skills and insider community knowledge. It is also important to have the knowledge of palliation; the healthcare system; functioning of an IDT; roles of each discipline; pain care; and so on. These are hard-knowledge issues that would go into a spiritual care curriculum, and the combination of skills and knowledge may be challenging to implement.

Limitations of this study

While some important views and perspectives about how spiritual care at hospices in SA emerged, it is important to acknowledge the limitations of this study. The first limitation is that, while SA has nine provinces, only one province was included in this study. A similar limitation with sub-study three is that only one hospice was included. A further limitation is that only interviews and FGD qualitative research methods were used. An extension of those methods to include observations or photo-journaling could have provided additional rich data.

Whilst this study cannot be generalized in the statistical sense of the word, there was, nevertheless, widespread representation suggesting that these triangulated findings do have some integrity.

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Conclusion

We have presented only one limited three-part study in one African country but, if spiritual care in palliative care is to be fully international, we need to identify how spiritual care is taught, learnt, and practiced in places other than in the Global North. However, much can be learnt from the Global North, such as from a longitudinal project where, for example, through the Enhanced Competence in Providing Spiritual Care through Innovative Education and Compassionate Care (EPICC) Network, nursing educators and practitioners, alongside allied health professionals, are developing innovative solutions to the advancement of spiritual and person-centred care (Ross et al. 2016). We would like to see more studies in SA relative to many middle-income countries. Spiritual care in resource-constrained countries, more so in the Global South, is complicated and not prioritized (Mahilall and Swartz 2021). It is frequently claimed that religion and spirituality are more prominent in the lives of people in Africa and other contexts in the Global South than they are in the Global North (Amzat and Razum 2018). If this is so, then the gap between the need for spiritual care services and actual provision may be even greater than may at first appear in these poorly resourced contexts.

We are very interested in how the building of truly international spiritual care practices in the field of palliative care can be taken forward with due attention both to universal concerns and to the diverse needs of different contexts.

Acknowledgements

The authors thank the passionate and dedicated participants of this three-part study; Varkey George for co-facilitating; and Prof. Dianne Yach, Chairperson of The Mauerberger Foundation Trust, for the financial funding of this project.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by The Mauerberger Foundation Fund.

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References

Amzat, J., and O. Razum. 2018. *Towards a Sociology of Health Discourse in Africa*. Cham: Springer.
Baldacchino, D. 2015. "Spiritual Care Education of Health Care Professionals." *Religions* 6 (2): 594–613. doi:10.3390/rel6020594.
Baldwin-Ragaven, L. 2020. "Social Dimensions of COVID-19 in South Africa: A Neglected Element of the Treatment Plan." *Wits Journal of Clinical Medicine* 2 (SI): 33–38. doi:10.18772/26180197.2020.v2nSIa6.
Best, M., C. Leget, A. Goodhead, and P. Paal. 2020. "An EAPC White Paper on Multi-Disciplinary Education for Spiritual Care in Palliative Care." *BMC Palliative Care* 19: 9. doi:10.1186/s12904-019-0508-4.
Bogopa, D. 2010. "Health and Ancestors: The Case of South Africa and Beyond." *Indo-Pacific Journal of Phenomenology* 10 (1): 1–7. doi:10.2989/IPJP.2010.10.1.8.1080.
Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2): 77–101. doi:10.1191/1478088706qp063oa.
Chandramohan, S., and R. Bhagwan. 2016. "Utilization of Spirituality and Spiritual Care in Nursing Practice in Public Hospitals in KwaZulu-Natal, South Africa." *Religions* 7 (3): 23. doi:10.3390/rel7030023.
Coetzee, B., A. Kagee, and R. Bland. 2016. "Shortcomings of Adherence Counselling Provided to Caregivers of Children Receiving Antiretroviral Therapy in Rural South Africa." *AIDS Care* 28 (sup2): 60–65. doi:10.1080/09540121.2016.1176675.
Connor, S. R. 2018. *Hospice and Palliative Care*. New York: Routledge.
Coovadia, H., R. Jewkes, P. Barron, D. Sanders, and D. McIntyre. 2009. "The Health and Health System of South Africa: Historical Roots of Current Public Health Challenges." *The Lancet* 374 (9692): 817–834. doi:10.1016/S0140-6736(09)60951-X.
Crisp, B. R. 2018. "Religion, Spirituality and Social Work: An International Perspective." *International Journal of Human Rights in Healthcare* 11 (2): 91–99.
Dalal, S., J. J. Beunza, J. Volmink, C. Adebamowo, F. Bajunirwe, M. Njelekela, D. Mozaffarian, et al. 2011. "Non-Communicable Diseases in Sub-Saharan Africa: What We Know Now." *International Journal of Epidemiology* 40 (4): 885–901. doi:10.1093/ije/dyr050.
Daute, H., M. d' Archangelo, and D. Duquette. 2019. "Spiritual Care Training in Health Care: Does it Really Have an Impact?" *Palliative & Supportive Care* 17: 129–137.
De la Porte, A. 2016. "Spirituality and Healthcare: Towards Holistic People-Centred Healthcare in South Africa." *HTS Teologiese Studies/Theological Studies* 72 (4): 1–9. doi:10.4102/hts.v72i4.3127.
Drenth, C., Z. Sithole, E. Pudule, S. Wust, N. GunnClark, and L. Gwyther. 2018. "Palliative Care in South Africa." *Journal of Pain and Symptom Management* 55: S170–S177.
Emmer, R., and P. Browne. 1984. "Program Helps Nurses Develop Spiritual Care Skills." *Hospital Progress* 65 (2): 64–66.
Farahani, A. S., M. Rassouli, N. Salmani, L. K. Mojen, M. Sajjadi, M. Heidarzadeh, Z. Masoudifar, and F. Khademi. 2019. "Evaluation of Health-Care Providers' Perception of Spiritual Care and the Obstacles to its Implementation." *Asia-Pacific Journal of Oncology Nursing* 6 (2): 122–129.
Fusheini, A., and J. Eyles. 2016. "Achieving Universal Health Coverage in South Africa Through a District Health System Approach: Conflicting Ideologies of Health Care Provision." *BMC Health Services Research* 16: 558. doi:10.1186/s12913-016-1797-4.
Gardner, F. 2020. "Adding Critical Reflection to Spiritual Care: Complementing Current Pastoral Care Training." *Journal for the Study of Spirituality* 10 (2): 127–139. doi:10.1080/20440243.2020.1812885.

Stellenbosch University https://scholar.sun.ac.za

Gratz, M., P. Paal, M. Emmelmann, and T. Roser. 2016. "Spiritual Care in the Training of Hospice Volunteers in Germany." *Palliative and Supportive Care* 14: 532–540.

Gwyther, L., R. Krause, C. Cupido, J. Stanford, H. Grey, T. Credé, A. De vos, J. Arendse, and P. Raubenheimer. 2018. "The Development of Hospital-Based Palliative Care Services in Public Hospitals in the Western Cape, South Africa." *South African Medical Journal* 108: 86–89.

Hollway, W., and T. Jefferson. 1997. "Eliciting Narrative Through the In-depth Interview." *Qualitative Inquiry* 3 (1): 53–70. doi:10.1177/107780049700300103.

James, P. B., J. Wardle, A. Steel, and J. Adams. 2018. "Traditional, Complementary and Alternative Medicine Use in Sub-Saharan Africa: A Systematic Review." *BMJ Global Health* 3 (5), e000895. doi:10.1136/bmjgh-2018-000895.

Jones, K. F., J. Pryor, C. Care-Unger, and G. Simpson. 2020. "'Spirituality is Everybody's Business': An Exploration of the Impact of Spiritual Care Training upon the Perceptions and Practice of Rehabilitation Professionals." *Disability and Rehabilitation*, 1–10. doi:10.1080/09638288.2020.1820586.

Kagee, A., J. Nothling, and B. Coetzee. 2012. "The Perspectives of Users of Antiretroviral Therapy on Structural Barriers to Adherence in South Africa." *South African Family Practice* 54 (6): 540–544. doi:10.1080/20786204.2012.10874289.

Kaunda, C. J. 2017. "Hijacking Subaltern's History (Broken Bodies, Broken Voices): Decolonial Critique of 'Subaltern Whiteness' in South Africa." *HTS Teologiese Studies/Theological Studies* 73 (3): a4619. doi:10.4102/hts.v73i3.4619.

Kimera, E., S. Vindevogel, J. De Maeyer, D. Reynaert, A.-M. Engelen, F. Nuwaha, J. Rubaihayo, and J. Bilsen. 2019. "Challenges and Support for Quality of Life of Youths Living with HIV/AIDS in Schools and Larger Community in East Africa: A Systematic Review." *Systematic Reviews* 8 (1): 64. doi:10.1186/s13643-019-0980-1.

Koenig, H. G. 2014. "The Spiritual Care Team: Enabling the Practice of Whole Person Medicine." *Religions* 5 (4): 1161–1174.

Kruizinga, R., M. Scherer-Rath, H. J. B. A. M. Schilderman, C. M. Puchalski, and H. H. W. M. van Laarhoven. 2018. "Toward a Fully Fledged Integration of Spiritual Care and Medical Care." *Journal of Pain and Symptom Management* 55 (3): 1035–1040. doi:10.1016/j.jpainsymman.2017.11.015.

Mahilall, R., and L. Swartz. Under review. "'I am Dying a Slow Death of White Guilt': Spiritual Carers in a South African Hospice Navigate Issues of Cultural Diversity".

Mahilall, R., and L. Swartz. 2021. "Challenges and Opportunities for Spiritual Care Practice in Hospices in a Middle-Income Country." *BMC Palliative Care*, 20, 62. https://doi.org/10.1186/s12904-021-00756-9

Mason, S., P. Paal, F. Elsner, C. Payne, J. Ling, A. Noguera, and D. Mosoiu. 2020. "Palliative Care for all: An International Health Education Challenge." *Palliative & Supportive Care*, 1–3. doi:10.1017/S1478951520000188.

McCaffrey, N., S. Bradley, J. Ratcliffe, and D. C. Currow. 2016. "What Aspects of Quality of Life are Important from Palliative Care Patients' Perspectives? A Systematic Review of Qualitative Research." *Journal of Pain and Symptom Management* 52 (2): 318–328.e5. doi:10.1016/j.jpainsymman.2016.02.012.

Mpanga Sebuyira, L. 2006. "Overview of HIV and Palliative Care." In *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa*, edited by L. Gwyther, A. Merriman, L. Mpanga Sebuyira, and H. Schietinger, 9e25. Kampala: African Palliative Care Association.

Mpanga Sebuyira, L., F. Mwangi-Powell, J. Pereira, and C. Spence. 2003. "The Cape Town Palliative Care Declaration: Home-Grown Solutions for Sub-Saharan Africa." *Journal of Palliative Medicine* 6 (3): 341–343. doi:10.1089/109662103322144646.

Mthembu, T. G., L. Wegner, and N. V. Roman. 2016. "Teaching Spirituality and Spiritual Care in Health Sciences Education: A Systemic Review." *African Journal of Physical Activity and Health Sciences* 22 (4:1): 1036–1057.

Stellenbosch University https://scholar.sun.ac.za

Munthali, A. C. 2006. "Health Problems That Require no "Medication": The Case of Ancestor-Related Illnesses among the Tumbuka of Northern Malawi." *Nordic Journal of African Studies* 15 (3): 367–379.

Ojagbemi, A., and O. Gureje. 2020. "The Importance of Faith-Based Mental Healthcare in African Urbanized Sites." *Current Opinion in Psychiatry* 33 (3): 271–277. doi:10.1097/YCO.0000000000000590.

Oman, D., ed. 2018. *Why Religion and Spirituality Matter for Public Health: Evidence, Implications, and Resources*. New York: Springer.

Omenka, O. I., D. P. Watson, and H. C. Hendrie. 2020. "Understanding the Healthcare Experiences and Needs of African Immigrants in the United States: A Scoping Review." *BMC Public Health* 20 (1): 1–13. doi:10.1186/s12889-019-8127-9.

Omotoso, K. O., and S. F. Koch. 2018. "Assessing Changes in Social Determinants of Health Inequalities in South Africa: A Decomposition Analysis." *International Journal for Equity in Health* 17 (1): 181. doi:10.1186/s12939-018-0885-y.

Paal, P., C. Brandstötter, S. Lorenzl, P. Larkin, and F. Elsner. 2019. "Postgraduate Palliative Care Education for all Healthcare Providers in Europe: Results from an EAPC Survey." *Palliative & Supportive Care*, 1–12. doi:10.1017/S1478951518000986.

Powell, R. A., J. Downing, L. Radbruch, F. N. Mwangi-Powell, and R. Harding. 2008. "Advancing Palliative Care Research in Sub-Saharan Africa: From the Venice Declaration, to Nairobi and Beyond." *Palliative Medicine* 22: 885–887. doi:10.1177/0269216308098094.

Procewicz, A., M. Nielsen-Pincus, G. Brown, and R. Schnitzer. 2012. "An Evaluation of Internet Versus Paper-Based Methods for Public Participation Geographic Information Systems (PPGIS)." *Transactions in GIS* 16 (1): 39–53. doi:10.1111/j.1467-9671.2011.01287.x.

Puchalski, C., B. Ferrell, R. Virani, S. Otis-Green, P. Baird, J. Bull, H. Chochinov, et al. 2009. "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference." *Journal of Palliative Medicine* 12 (10): 885–904. doi:10.1089/jpm.2009.0142.

Puchalski, C. M., and M. Guenther. 2012. "Restoration and Re-Creation: Spirituality in the Lives of Healthcare Professionals." *Current Opinion in Supportive and Palliative Care* 6 (2): 254–258.

Puchalski, C., N. Jafari, H. Buller, T. Haythorn, C. Jacobs, and B. Ferrell. 2020. "Interprofessional Spiritual Care Education Curriculum: A Milestone Toward the Provision of Spiritual Care." *Journal of Palliative Medicine* 23 (6): 777–784. doi:10.1089/jpm.2019.0375.

Puchalski, C. M., R. Vitillo, S. K. Hull, and N. Reller. 2014. "Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus." *Journal of Palliative Medicine* 17 (6): 642–656.

Republic of South Africa. 2017a. *National Department of Health. National Policy Framework and Strategy on Palliative Care, South Africa, 2017–2022*. Accessed November 15, 2020. file:///C:/Users/User/Downloads/Final%20NPFSPC%20August%202017%20(2).pdf.

Republic of South Africa. 2017b. *The Constitution of the Republic of South Africa*. Accessed November 1, 2020. http://www.gov.za/DOCUMENTS/CONSTITUTION/constitution-republic-south-africa-1996-1.

Roman, N. V., T. G. Mthembu, and M. Hoosen. 2020. "Spiritual Care – 'A Deeper Immunity' – A Response to Covid-19 Pandemic." *African Journal of Primary Health Care & Family Medicine* 12 (1): e1–e3. doi:10.4102/phcfm.v12i1.2456.

Ross, L., T. Giske, R. van Leeuwen, D. Baldacchino, W. McSherry, A. Narayanasamy, P. Jarvis, and A. Schep-Akkerman. 2016. "Factors Contributing to Student Nurses'/Midwives' Perceived Competency in Spiritual Care." *Nurse Education Today* 36: 445–451.

Selman, L., P. Speck, R. C. Barfield, M. Gysels, I. J. Higginson, and R. Harding. 2014. "Holistic Models for End of Life Care: Establishing the Place of Culture." *Progress in Palliative Care* 22 (2): 80–87. doi:10.1179/1743291X13Y.0000000063.

Spiritual Health Association. 2020. *Capability Framework for Spiritual Care Practitioners in Health*. Melbourne, Australia. https://spiritualhealth.org.au/standards.

Steinhauser, K. E., G. Fitchett, G. F. Handzo, K. S. Johnson, H. G. Koenig, K. I. Pargament, C. M. Puchalski, et al. 2017. "State of the Science of Spirituality and Palliative Care Research Part I:

Stellenbosch University https://scholar.sun.ac.za

Definitions, Measurement, and Outcomes." *Journal of Pain and Symptom Management* 54 (3): 428–440. doi:10.1016/j.jpainsymman.2017.07.028.

Swartz, L. 1985. "Issues for Cross-Cultural Psychiatric Research in South Africa." *Culture, Medicine & Psychiatry* 9: 59–74. doi:10.1007/BF00048537.

Swartz, L., J. Bantjes, H. Lourens, and B. Watermeyer. 2020. "Disability: The Forgotten Side of Race Science." In *Fault Lines: A Primer on Race, Science and Society*, edited by J. Jansen, and C. Walters, 145–159. Stellenbosch: AFRICAN SUN MeDIA.

Tan, H., B. Rumbold, F. Gardner, D. Glenister, A. Forrest, and L. Bowen. 2020. "How is Spiritual Care/Pastoral Care Understood and Provided in General Hospitals in Victoria, Australia? – Staff Perspectives." *Journal for the Study of Spirituality* 10 (2): 114–126. doi:10.1080/20440243.2020.1812886.

Volmink, J., and L. Dare. 2005. "Addressing Inequalities in Research Capacity in Africa." *BMJ* 331: 705–706. doi:10.1136/bmj.331.7519.705.

Watermeyer, B., and L. Swartz. 2016. "Disablism, Identity and Self: Discrimination as a Traumatic Assault on Subjectivity." *Journal of Community & Applied Social Psychology*, 26 (3): 268–276.

World Health Organization. 2014. "Strengthening of Palliative Care as a Component of Integrated Treatment Throughout the Life Course." *Journal of Pain & Palliative Care Pharmacotherapy* 28 (2): 130–134. doi:10.3109/15360288.2014.911801.

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9.2 License to publish

I obtained written license to publish Article 5 in my dissertation (Addendum 20).

9.3 Chapter summary

There was a chorused need for the development of a national training curriculum in spiritual care for hospices providing palliative care in SA. Further, there was a chorused recognition that spiritual care services are nuanced and require both formalisation and flexibility for spiritual care workers to be led by patient needs. Finance and human capital were identified as two key barriers to developing a spiritual care curriculum. In Part 4, Chapters Ten and Eleven, I share my dissertation journey and my concluding thoughts.

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PART 4: CONCLUDING THOUGHTS

Preamble

In Part 4, I conclude this dissertation by reflecting on my research experiences. I also draw together the various findings and discuss potential next steps for taking my research questions and findings beyond this dissertation.

Part 4 comprises the following chapters:

i. Chapter Ten: Research experience and self-reflection.
ii. Chapter Eleven: Concluding thoughts.

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CHAPTER TEN

RESEARCH EXPERIENCE AND SELF-REFLECTION

10.1 Introduction

In qualitative research, the process of self-reflection is an important step in interpreting and analysing research data (Gilgun, 2010). According to Etherington (2004), reflexivity allows for the researcher to critically assess his or her own personal beliefs and to seek to understand how these beliefs influence their engagement with the participants as well as with the data. Being the CEO of SLCH and representing a member hospice at HPCA immediately makes me an insider to palliative care and to spiritual care, the focus of this study. By virtue of this, I had to be conscious of reflecting on my roles in this study, both as researcher and as a role-player in hospice and palliative care work. This self-reflection process allowed me to take into consideration the existing relationships I shared with the participants and the degree of influence that this may potentially exert on the research process, and vice versa.

Reflexivity was an on-going process for me during this study, and, through discussions with my supervisor, it allowed me to refine my work at the different stages of the research process (Sandeen et al., 2018). Each of the sections below represents an area of self-awareness and learning that I experienced during this process. During my fieldwork, I kept records, both written and audio, of my experiences while negotiating the landscape of my research arena. I drew heavily on those records, as well as the many deep conversations with my supervisor, as I reflected on my data collection experiences and writing experiences.

10.2 Understanding and respecting the "missed opportunity syndrome"

When I decided to undertake this research, I was hopeful and confident that it would be well-received and supported within the hospice world, especially in SA. Largely, it was indeed well-received, and the support from colleagues directly and indirectly was overwhelmingly positive. Being a relative newcomer to the palliative care world (I joined SLCH in late 2016, as discussed in Chapter One), I quickly had to learn about all facets of palliative care as well as the written and unwritten guidelines that underpin this specialist work. Given my position as CEO, my initial engagement inevitably involved dealing with issues of power and status in the organisation. I had also come to learn about and respect the deep personal connections many

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of my colleagues had with their work. These were committed people, with a great deal of experience, and my coming in as an outsider both to the province where SLCH is situated and to palliative care itself, was not without its challenges. I brought to the context, of course, my own history and ambitions, and my wish to make my own distinctive mark on an organisation that was already mature, and with its own existing explicit and implicit rules. I was interested to see that during the process of data collection, and especially during focus group discussions, undertones of rivalry emerged. In the focus groups the rivalry focussed largely on differences in how spiritual care was practised at each hospice, with competing hospices each claiming, explicitly or otherwise, that their methods were best. I was able to see a similarity between these dynamics and attempts to define and claim best practices and my own process of negotiating a sometimes difficult (but ultimately rewarding) entry as an outsider into a leadership role at SLCH.

Given this contextual history, it is probably not surprising that some of the rivalry across hospices focussed on questions of leadership – both the question of how hospices were led, and managed, and which hospices assumed that their own practices were ahead of those of others. I was a researcher, but also the leader of the best-resourced and best-known hospice in the region, the hospice in the metropole. There was an appreciation and understanding that hospices are in open competition with one another to raise funds to sustain their work (in Chapter Three I discussed in detail how hospices – NGOs – depend on public funding to sustain themselves). How did this affect the data? It is impossible, of course, to give a complete answer to this question, but I did have to bear in mind that some of what was said to me could have been motivated with a desire to prove to me that hospices wary of being provincial or less advanced, may in fact have advantages the hospice I run does not have. This is no judgement on the participants – I was of course at the same time trying to create a favourable impression, in this case of openness and willingness to listen.

Very early in the project I experienced a hurdle in the process which in my view (partial though that view always is) linked to a degree to substantive concerns about the quality of my work, but more centrally, it felt to me, to issues of competition and fights over territory. I will not go into details about the nature of the conflict, because I do not have permission to do so, but it will suffice to say that I believed that a hurdle put in the way of this study at the inception was put there deliberately, and not primarily out of concern for the welfare of research participants or the quality of the research. I was able to discuss this at some length with my supervisor, who is very experienced in working with care organisations and their dynamics, and he agreed that

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there was probably an element of rivalry in what was happening. With my supervisor's help, I was able to resolve the difficult barrier with the person concerned and I was able to continue, I hope without disrespecting the concerns which had been raised. Three things emerged from this experience. First, I was reminded how personal hospice care work is to all of us who work in it, and I took this knowledge into the data collection and analysis process. Second, I had to accept that I would not please everybody with this work – there would always be those who did not like or support what I did. Third, and crucially, I realised that I might feel uncomfortable at the thought of being scrutinised and researched by others, but that if I believed that research could help spiritual care and hospice work more generally, I had a responsibility to encourage others (even, and possibly especially, those with whom I do not have an easy relationship) to conduct their own research with a view to improving our work. I am pleased to report that my dissertation journey has inspired some of my colleagues to undertake their own PhD journeys. Sadly, it has also seen some of my colleagues reach out to me to lament their missed opportunity of not undertaking their PhD journeys sooner, or at all.

10.3 Re-confronting the impact of apartheid

I was born in SA, and I am of Indian descent. Within the apartheid era race categorisation, South African Indians were classified as non-White and consequently seen as inferior to Whites. I grew up in Durban, Kwa-Zulu Natal, a province on the east coast of SA, and where there is a large Indian population. I relocated to Cape Town, Western Cape, in late 2016. Racism, while it permeated throughout SA, and to an extent still does despite its 26-year-old democracy, was not as acutely felt by me in Durban as I sometimes experience it in Cape Town. What I also found interesting was that racism was not displayed in everyday engagements and interactions, but I perceived it to be subtly present, especially within some higher circles of power. Being the CEO of SLCH, I often find myself in some of those higher circles and at which I occasionally experienced racism, albeit subtly, and especially when I could not neatly be categorised into a box. I am usually the only Indian female in these meetings, and it sometimes seems to me that there is a subtle assumption that people of my background do not fit easily in such contexts. I do not think there is any intentional or conscious racism, and I am aware that many with whom I interacted will not view these interactions as racist in any way. I share with Shabalala (2020), another South African female of colour who studied for a PhD at my university, the visceral experience of being construed as matter out of place, not legitimately part of things. This experience of being disavowed, often unconsciously, is of course a feature of implicit sexism and racism, but occurs as well with other excluded groups,

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such as people with disabilities (Watermeyer, 2017), old people, and, indeed, with people who are dying. With my personal experience of marginalisation as a backdrop, I turn now to my experience when I engaged with the data on the impact of diversity very largely created by SA's apartheid past. The data reignited in me the pain of the far-reaching impact of the apartheid practices and a shared pain for the victims of apartheid. In Chapter Three I discussed how health care was unequally provided in SA, based primarily on race, and in Chapter Five I discussed how the location of hospices were shaped by apartheid.

However, I was struck also by the pain of certain participants, especially White participants, who did not subscribe to apartheid and yet who, like people of colour, had no choice but to live that practice. I discussed this in greater detail in Chapters Seven and Eight where the participants share their "white guilt" and their helplessness with the system. At some level this was a healing process for me.

10.4 The publication experience

My decision to do this dissertation in the publication format came primarily from my (then) naïve understanding that it was a "quick and easy" PhD route to take! Like any project of significance, my decision came with advantages and certain challenges too. By undertaking my dissertation through publication, it gave me the opportunity to engage with and analyse the data in smaller units first – when I wrote each manuscript – before analysing and assessing the bigger data as a collective. I undertook a three-part study at a national, provincial, and local level based in SA, and consequently the amount of data obtained was overwhelming. Undertaking the research by publication was a useful way of understanding my data step-by-step. One of the challenges that became immediately apparent was that spiritual care (especially as practised in the Global South) did not readily, neatly, and easily fit into the genres of most journals. This resulted in journal rejections which were disappointing, but ironically also reassuring. Rejections were based largely on journal misfit as opposed to the content of the manuscript. Undertaking a dissertation by publication also required that I approach each manuscript differently, based on the specifications of the journal to which I sought to submit. My publishing experience also debuted me into the world of peer review, which gave me insight into how others were engaging with my work. I also learned that the peer-review process was partially a subjective one, with some reviewers' suggestions potentially altering the intended focus of a paper. As Merga (2015) explained, the opportunity for external review and scrutiny may constitute an extension of supervision and can serve to expand one's own

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expertise. These were invaluable lessons, and, through my supervisor's expertise and guidance, I learned how to engage with journals through the submission process all the way to publication.

10.5 Summary of researcher experience

My experiences in undertaking this PhD research were multi-layered and varied. At all times I had to constantly remind myself of several personal characteristics which influenced my positionality and my decision-making. In particular, my employment title and that I represented a hospice in SA that is well established, well known and well recognised as one of the forerunners in hospice palliative care work, and more specifically in spiritual care work, in SA. Being shaped by an apartheid history, as all South Africans are, I had to regularly check my personal feelings during the research process. Here I found the deep conversations with my supervisor to be invaluable. Through this process, and in addition to the outcomes relating to the research, I have also experienced personal growth and greater maturity, and a renewed appreciation for my background and culture. Through this process I have gained awareness of my capabilities as an academic through publishing.

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CHAPTER ELEVEN

CONCLUDING THOUGHTS

11.1 Introduction

In this study my aim was to explore if hospices in palliative care settings in SA offered spiritual care services, how spiritual care services were offered, and, crucially, to explore their training needs and if there was a need for developing a national training curriculum in spiritual care. In order to answer these questions, I conducted a three-tiered study. In Sub-Study One, I conducted an online survey of all hospices registered at HPCA in SA. In Sub-Study Two, I conducted focus group discussions with hospices in the Western Cape, SA, and one-on-one interviews and focus group discussions were held with participants who are practicing spiritual care workers registered with SLCH, in Cape Town, as part of Sub-Study Three.

This dissertation is presented in a "thesis-by-publication" format. In this, the concluding chapter, I shall summarise how the different papers together provide important information regarding spiritual care practices at hospices in SA, the impact of multiple layers of diversities on how spiritual care is offered (or not offered), and, more pointedly, what the spiritual care training needs are at hospices in SA. I will also share my thoughts regarding the potential implications of my findings and ideas about what these may mean for the anticipated development of spiritual care services in SA. I will conclude this chapter and this dissertation with some thoughts on future directions for spiritual care services in SA.

11.2 How is spiritual care practised at hospices in a diverse South Africa?

Palliative care is gaining momentum in SA. Spiritual care is largely recognised as an important component of palliative care and hospice work. However, how spiritual care services are offered and prioritised depends largely on the hospices' ability to fund this service and to have the necessary skilled spiritual care staff in place to offer this specialised service. Hospices gave much thought to the recruitment of spiritual care workers, with some hospices hiring for skill and some hiring for the right attitude and then training the workers for the necessary skills. Suggestions of what soft and hard skills spiritual care workers should have, were also made with examples of each skillset being identified and explored. There was an expressed and clear understanding that spirituality and religion are not the same, but that religious tolerance and

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other diversities synonymous to SA must be the cornerstone of any intervention hospices' offer and plan to offer. Not many hospices were able to prioritise the spiritual care component of palliative care and, consequently, this service was embedded in the services that are offered by the medical, nursing, and psychosocial teams, or referred out to other service providers such as FBOs, or spiritual care services were not offered at all. In hospice settings where spiritual care services were offered, largely an IDT model of intervention existed, but there were concerns raised that, especially in those hospices where spiritual care was undertaken by designated spiritual care workers, their role within the IDT was less recognised. It became clear that while hospices strived to offer culturally sensitive services often this was limited from a financial and infrastructural point of view, especially, in the case of the latter, when families of palliating patients sought to perform cultural rituals in communal ward settings. The HPCA is itself navigating financial challenges and, consequently, is not able to fully fulfil its own local and global mandate, despite having a strong will to do so. Hospices in SA are grappling with aligning their mandate of offering holistic patient-centred care while navigating actual realities of multiple levels of inequalities, multiple layers of diversities, skills shortages, and financial constraints.

11.3 How is training in spiritual care perceived by hospices in a diverse South Africa?

There was recognition and respect for each hospice's efforts in undertaking its work, especially spiritual care work, within the confines and restrictions of their individual contexts. There emerged an expressed need from all three sub-studies for formalised training in spiritual care as it was a specialist component of palliative care and a nuanced, niche service that needed to be formally recognised. By extension, there emerged an expressed call for the development of a spiritual care curriculum in spiritual care that was bespoke to the South African setting. The two main reasons why hospices could not develop their own training curriculum in spiritual care were centred on funding and time constraints, as many hospices reported having staff fulfil multiple roles when there are gaps in the teams, which consequently spoke to staff shortages: something all too familiar within the health care sector in SA. There was a chorused offer by the hospices to be part of the development of a national spiritual care curriculum for SA if they did not have to fund the project. It was interesting to note that if funding were secured for the development of the curriculum, then the hospices would plan to free some of their staff to be part of the project. There was consensus regarding the pooling of current training modules on spiritual care that some hospices have, as well as what WC-HPCA and HPCA have as a starting point towards the development of a national spiritual care curriculum. It became clear, as

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elucidated in Chapters Six to Nine, that there are rich case studies and lessons that the hospices have to offer, that resonate with the South African context, and which could easily be included in a national curriculum, and which will have relevance and applicability in most hospice settings in SA. While the call for a national curriculum in spiritual care for hospices in SA was a strong one, there was an equally strong cautionary watchdog voice guarding against making the curriculum too rigid (See Chapter Six and Chapter Eight). As discussed in Chapter Four, there are several established spiritual care curricula developed in the Global North which are available to the international audience. However, what the contextual relevance and replicability of these Global North curricula have for the Global South settings should be carefully considered as the disparities between these two global regions cannot be overlooked, which has significance for how spiritual care services are practised in the Global North and the Global South.

11.4 Limitations of the study

Although I identified some important perspectives and views in this study, there were limitations which are important to acknowledge. The first limitation was that only one province and one hospice in SA were included in two sub-studies, respectively. Although the decision to focus on the Western Cape Province (Sub-Study Two) and SLCH (Sub-Study Three) was taken for practical reasons, it resulted in an exclusion of participants from the other provinces and hospices of the country. Whilst these two sub-studies cannot be generalised in the statistical sense of the word, there was widespread representation within the Western Cape Province (eleven of twelve hospices participated) and SLCH (nine of 15 spiritual care workers participating worked in the larger Cape Town precinct) suggesting that these triangulated findings have some integrity. Secondly, confining the study only to hospices registered with HPCA to recruit participants may have resulted in my overlooking some non-member HPCA hospices, such as those offering private hospice palliative care, or those choosing not to be a part of the association. This again suggests that the findings are not generalisable as they exclude privately run and unaffiliated HPCA hospices (as discussed in Chapter Three, HPCA, like all palliative care associations globally, are voluntary associations and membership is voluntary). Thirdly, the types of participants that I interviewed were limited to hospice staff. I did not include patients and/or their caregivers in this study. The views and perspectives of these service users could provide additional nuance on the health seeking avenues in spiritual care in SA, as well as the effectiveness of the spiritual care services already in place. In addition, exploring the views of the NDoH and provincial department of health could have lent

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a different perspective. In a similar way, their views as policymakers and health leadership could have provided further layers of discussion. Despite these apparent limitations, the findings of this study are potentially useful for hospices as pathways are explored for scaling up spiritual care services and training in spiritual care in SA.

11.5 Conclusions and questions for future directions

I went into this study keen to understand how spiritual care is being practised nationally, provincially, and locally in SA. I was also very keen to understand what the spiritual care training needs are at hospices offering palliative care services in SA. As I engaged with the data it became very clear that there was a clear call for the development of a national spiritual care curriculum that suited the complexities and diversities of SA. However, when I engaged with the work of the Global North (especially) on spiritual care curricula that are already in place, I was continually thrown out by typically South African contextual issues. For example, in Cape Town the racial dynamics may be different to those in other provinces. How would diversities of race, culture, religion, and other inherent inequalities affect training and how would I take account of them? I do not have ready answers, but these questions must be accounted for, and easy generalisations guarded against when engaging with issues of spiritual care practice and training, especially when viewing what spiritual care curricula are on offer in the Global North.

The challenges of funding cannot be ignored nor underestimated. The impact and implications of the financial constraints, although now largely an accepted reality in SA, was sobering, as were the limitations and barriers these present at the different levels of health care. Without funding, the greatest of plans and the best of intensions for improved patient care become largely unfulfilled dreams. Global North countries have developed spiritual care curricula which they feel will have relevance internationally (as described in Chapter Four); an assertion which I question. SA has seen some positive movement in recent years at local university level to provide palliative care training courses in which spiritual care training is embedded in the medical curricula, nursing curricula, theology curricula and social work curricula. I found this to be how some hospices too teach spiritual care courses in SA. It struck me that SA and other Global South countries should collaborate more, and more meaningfully, with their colleagues in the Global North to bring lived and experienced diversity issues into the Global North curricula for the curricula to have more relevance in Global South contexts. In other words, do not reinvent the wheel, but build onto the wheel.

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A set of skills – hard and soft skills – were suggested and which, when unpacked in the sub-studies, indicated that there needs to be more consideration regarding the balance between these two skills sets as they may be more personal and experiential than was originally thought. Indeed, the Global North suggests skills and attributes that spiritual care providers should have, but I feel these need to be tempered carefully to the South African context.

Throughout the data collection and analysis processes I found myself oscillating between, on the one hand, what the data were revealing (i.e., there is a need for the development of a spiritual care curriculum that fits the South African context) and, on the other hand, the realities, and implications of a lack of funding on how spiritual care is currently practised and taught. I feel that perhaps two issues are being conflated here which need further consideration:

a. Spiritual care workers feel left out and consequently see formalising spiritual care services by developing a standalone training curriculum as being a big step in the direction of gaining importance and recognition; and
b. Perhaps we should not have designated spiritual care workers at all, but we should make available spiritual care training to all health care and care workers, which will allow for spiritual care to be taught in the model that currently exists (i.e., embedded in other health care, social sciences, and theology curricula, and as training modules at hospices).

I end this dissertation having gained an added wealth of knowledge, understanding and respect for hospice work in SA, and particularly how spiritual care is practised despite the barriers that block this specialist work. I clearly saw emerge from the data the need for spiritual care training and for the development of a spiritual care curriculum. But when I looked at the data against the realities of SA and the priorities SA currently has, centred largely on addressing inequalities, growing its economy, and navigating the COVID-19 pandemic, I am not sure that the time is ripe just yet for the development of a standalone spiritual care curriculum for SA. I hope that the questions I raise in this chapter, and the dissertation as a whole, will provide directions of interest for further work which can inform the best way of recognising spiritual care services and spiritual care training needs in SA, which will ultimately improve the care for palliating patients and their families.

For my part, I plan to keep researching and thinking about these issues. I came to this study assuming that I knew that SA would need a spiritual care curriculum and that I would be able to suggest how this should look and be implemented. I end the dissertation with much less

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certainty about the way forward. I am aware of an implicit pressure for academic studies (and, perhaps, PhD studies in particular) to end with a programmatic set of recommendations. In part, I feel that the work of my PhD is unfinished. But this is also something in which I take comfort. Research may lead to practicable solutions, but it is also the function of research to disrupt and to cause discomfort. As a practical person who has spent all my professional life dealing with the business of running services and trying to solve problems, something I continue to do and enjoy, I expected the dissertation to solve more problems. The fact that the research did not do this makes me uncomfortable (Boler, 1999), but discomfort, as a research tradition going back some twenty years shows, can be highly generative for productive thinking (Zembylas, 2017). One well-established consequence of discomfort can be what has been termed "research-mindedness". In my case, the fact that I am left unsure and somewhat discomfited by what I have found by completing this research is, I believe, a good thing. I am not quite sure where I will go as a researcher, but I know that the discomfort I feel at the end of this study is indeed generative – I will keep thinking and working on the issues I have discussed here.

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Reference List

This reference list is a compilation of all the references listed in the various parts of this dissertation, excluding references used in the articles. Invariably there may be overlapping of references cited given that this dissertation is a thesis-by-publication.

Abe, T. K., Beamon, B. M., Storch, R. L., & Agus, J. (2016). Operations research applications in hospital operations: Part I. *IIE Transactions on Healthcare Systems Engineering, 6*(1), 42–54. https://doi.org/10.1080/19488300.2015.1134727

Abu-Odah, H., Molassiotis, A., & Liu, J. (2020). Challenges on the provision of palliative care for patients with cancer in low- and middle-income countries: A systematic review of reviews. *BMC Palliative Care, 19*, 55. https://doi.org/10.1186/s12904-020-00558-5

Adams, L., Jeri, S., Miller, L., & Grady, P. A. (2016). The spectrum of caregiving in palliative care for serious, advanced, rare diseases: Key issues and research directions. *Journal of Palliative Medicine, 19*(7), 698–705. http://doi.org/10.1089/jpm.2015.0464

Addiss, D. G. (2018). Spiritual themes and challenges in global health. *The Journal of Medical Humanities, 39*(3), 337–348. https://doi.org/10.1007/s10912-015-9378-9

African National Congress. (1994). *A national health plan for South Africa.* Government Printer. https://www.sahistory.org.za/sites/default/files/a_national_health_plan_for_south_africa.pdf

Agom, D. A., Neill, S., Allen, S., Poole, H., Sixsmith, J., Onyeka, T. C., & Ominyi, J. (2019). Construction of meanings during life-limiting illnesses and its impacts on palliative care: Ethnographic study in an African context. *Psychooncology, 28*(11), 2201–2209. https://doi.org/10.1002/pon.5208

Akinola, A. O., & Uzodike, U. O. (2018). Ubuntu and the quest for conflict resolution in Africa. *Journal of Black Studies, 49*(2), 91-113. https://doi.org/10.1177/0021934717736186

Akintola, O. (2011). What motivates people to volunteer? The case of volunteer AIDS caregivers in faith-based organizations in KwaZulu-Natal, South Africa. *Health Policy and Planning, 26*(1), 53–62. https://doi.org/10.1093/heapol/czq019

Akoojee, S., & Nkomo, M. (2007). Access and quality in South African higher education: The twin challenges of transformation. *South African Journal of Higher Education, 21*(3), 385–399. http://hdl.handle.net/20.500.11910/5584

Stellenbosch University https://scholar.sun.ac.za

Allen, C. G., Brownstein, N., Satsangi, A., & Escoffery, C. (2016). Capacity building and training needs for community health workers working in health care organizations. *Journal of Community Medicine & Health Education, 6*(1), 403. https://www.omicsonline.org/open-access/capacity-building-and-training-needs-for-community-health-workers-workingin-health-care-organizations-2161-0711-1000403.php?aid=69048

Ataguba, J. E-O., Day, C., & McIntyre D. (2015). Explaining the role of the social determinants of health on health inequality in South Africa. *Global Health Action, 8*(1), 1–11. https://doi.org/10.3402/gha.v8.28865

Baingana, F., al'Absi, M., Becker, A. E,, & Pringle, B. (2015). Global research challenges and opportunities for mental health and substance-use disorders. *Nature, 527*, S172–S177. https://doi.org/10.1038/nature16032

Balboni, T. A., Balboni, A. C., Enzinger, A. C., Gallivan, K., Paulk, M. E., Steinhauser, K., VanderWeele, T. J., & Prigerson, H. G. (2013). Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA internal medicine, 173*(12), 1109–1117. https://doi.org/10.1001/jamainternmed.2013.903

Balboni, T. A., Vanderwerker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S., Peteet, J. R., & Prigerson, H. G. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology, 25*(5), 555–560. https://doi.org/10.1200/JCO.2006.07.9046

Barnard, A., & Furtak A. (2020). Psychological resilience of volunteers in a South African health care context: A salutogenic approach and hermeneutic phenomenological inquiry. *International Journal of Environmental Research and Public Health, 17*(8), 2922. https://doi.org/10.3390/ijerph17082922

Barolsky, V. (2016). Is social cohesion relevant to a city in the global South? A case study of Khayelitsha township. *SA Crime Quarterly, 55*, 17–30. http://hdl.handle.net/20.500.11910/10044

Barron, P., & Padarath, A. (2017). Twenty years of the South African Health Review. In A. Padarath, J. King., & R. English (Eds.), *South African Health Review 2017* (pp. 1–10). Health Systems Trust.

Battle, M. (2007). *Reconciliation: The ubuntu theology of Desmond Tutu*. Pilgrim Press.

Stellenbosch University https://scholar.sun.ac.za

Baur, N., Centeno, C., Garralda, E., Connor, S., & Clark, D. (2019). Recalibrating the 'world map' of palliative care development. *Wellcome open research, 4*, 77. https://doi.org/10.12688/wellcomeopenres.15109.1

Beckford, J. A. (2003). *Social theory and religion.* Cambridge University Press.

Ben-Arye, E., Schiff, E., Karkabia, K., Keshet, Y., & Lev, E. (2011). Exploring association of spiritual perspectives with complementary medicine use among patients with Type 2 diabetes in Israel. *Ethnicity & Health, 16*(1), 1–10. https://doi.org/10.1080/13557858.2010.510181

Benjamin, E., Swartz, L., Hering, L., & Chiliza, B. (2016). Language barriers in health: Lessons from the experiences of trained interpreters working in public sector hospitals in the Western Cape. In A. Padarath, J. King, E. Mackie, & J. Casciola (Eds.), *South African Health Review 2016* (pp. 73–82). Health Systems Trust. http://www.hst.org.za/publications/south-african-health-review-2016

Berger, P. L. (1969). *The sacred canopy: Elements of a sociological theory of religion.* Doubleday.

Best, M., Leget, C., Goodhead, A., & Paal, P. (2020). An EAPC white paper on multi-disciplinary education for spiritual care in palliative care. *BMC Palliative Care, 19*, 9. https://doi.org/10.1186/s12904-019-0508-4

Best, M., McArdle, M. B., Huang, Y., Clayton, J., & Butow, P. (2019). How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt list?. *Patient Education and Counseling, 102*(12), 2208–2213. https://doi.org/10.1016/j.pec.2019.06.016

Best, M., Rajaee, G., & Vandenhoeck, A. (2021). A long way to go understanding the role of chaplaincy? A critical reflection on the findings of the survey examining chaplaincy responses to Covid-19. *Journal of Pastoral Care & Counseling, 75*(1_suppl), 46–48. https://doi.org/10.1177/1542305021992002

Beyer, P. (2006). *Religions in global society.* Routledge.

Boler, M. (1999). *Feeling power: Emotions and education.* Psychology Press.

Bone, A. E., Evans, C. J., & Higginson, I. J. (2018). The future of end-of-life care. *The Lancet, 392*, 915–916. https://doi.org/10.1016/S0140-6736(18)31823-3

Bowers du Toit, N. F. (2019). Unapologetically faith based: The nature of donor engagement in the context of South African faith-based organisations. *HTS Teologiese Studies/Theological Studies, 75*(4), a5529. https://doi.org/10.4102/hts.v75i4.5529

Stellenbosch University https://scholar.sun.ac.za

Bowman, C. A., Mohamed, N., & Rahim, A. (2021). The telehealth policy changes enacted for short-term control of the coronavirus disease 2019 (COVID-19) pandemic present an opportunity to address the fundamental gap in health care underutilization. *The American Journal of Managed Care, 27*(1), 9–11. https://doi.org/10.37765/ajmc.2021.88571

Boyd, K. M. (2000). Disease, illness, sickness, health, healing and wholeness: Exploring some elusive concepts. *Medical Humanities, 26*, 9–17. http://dx.doi.org/10.1136/mh.26.1.9

Brandstötter, C., Firuzan, S. K., & Paal, P. (2021). Spiritual well-being, attitude, involvement, perceptions and competencies: Measuring the self-perception of nursing students during 2018, 2019 and the first wave of COVID-19 in 2020. *Health and Social Care Chaplaincy, 9*(2), 175–190. https://journals.equinoxpub.com/HSCC/article/view/42734

Brennan, F. (2007). Palliative care as an international human right. *Journal of Pain and Symptom Management, 33*(5), 494–499. https://doi.org/10.1016/j.jpainsymman.2007.02.022

Brighton, L. J., Koffman, J., Hawkins, A., McDonald, C., O'Brien, S., Robinson, V., Khan, S. A., George, R., Higginson, I. J., & Selman, L. E. (2017). A systematic review of end-of-life care communication skills training for generalist palliative care providers: Research quality and reporting guidance. *Journal of Pain and Symptom Management, 54*, 417–425. https://doi.org/10.1016/j.jpainsymman.2017.04.008

Bross, W. L., & DeAngelo, P. (2012). Strategic planning: A basis for all infrastructure development and growth within spiritual/pastoral care. In S. B. Roberts (Ed.), *Professional spiritual and pastoral care* (pp. 313–329). Skylight Paths.

Brunsdon, A. R. (2019). A culture-sensitive palliative pastoral care with a focus on the African context. *In die Skriflig, 53*(1), a2424. https://doi.org/10.4102/ids.v53i1.2424

Buljac-Samardzic, M., Doekhie, K. D., & van Wijngaarden, J. D. H. (2020). Interventions to improve team effectiveness within health care: A systematic review of the past decade. *Human Resources for Health, 18*, 2. https://doi.org/10.1186/s12960-019-0411-3

Buqa, W. (2015). Storying Ubuntu as a rainbow nation. *Verbum et Ecclesia 36*(2), 1–8. https://doi.org/10.4102/ve.v36i2.1434

Bush, S. H., Gratton, V., Kabir, M., Enright, P., Grassau, P. A., Rice, J., & Hall, P. (2021). Building a medical undergraduate palliative care curriculum: Lessons learned. *Journal of Palliative Care, 36*(1), 29–37. https://doi.org/10.1177/0825859720916565

Stellenbosch University https://scholar.sun.ac.za

Cadge, W., Calle, K., & Dillinger, J. (2011). What do chaplains contribute to large academic hospitals? The perspectives of pediatric physicians and chaplains. *Journal of Religion & Health, 50*(2), 300–312. https://doi.org/10.1007/s10943-011-9474-8

Callahan, A. M. (2012). A qualitative exploration of spiritually-sensitive hospice care. *Journal of Social Service Research, 38*(2), 144–155. https://doi.org/10.1080/01488376.2011.619425

Callahan, A. M. (2013). A relational model for spiritually-sensitive hospice care. *Journal of Social Work in End-Of-Life & Palliative Care, 9*(2–3), 158–179. https://doi.org/10.1080/15524256.2013.794051

Callahan, A. M. (2015). Key concepts in spiritual care for hospice social workers: How a multidisciplinary perspective can inform spiritual competence. *Social Work & Christianity, 42*(1), 43–62.

Callahan, A. M. (2017a). Relational spirituality. *Social Work Today. Web exclusive.* https://www.socialworktoday.com/archive/exc_0217.shtml

Callahan, A. M. (2017b). *Spirituality and hospice social work.* Columbia University Press.

Callahan, A. M. (2018, May). *Relational spirituality: An opportunity for social work in long-term care* [Poster presentation]. 6th European Conference on Religion, Spirituality and Health and the 5th International Conference of the British Association for the Study of Spirituality in Coventry, England.

Cameron, D., & Johnston, B. (2015). Development of a questionnaire to measure the key attributes of the community palliative care specialist nurse role. *International Journal of Palliative Nursing, 21*(2), 87–95. https://doi.org/10.12968/ijpn.2015.21.2.87

Carrasco, J. M., Lynch, T. J., Garralda, E., Woitha, K., Elsner, F., Filbet, M., Ellershaw, J. E., Clark, D., & Centeno, C. (2015). Palliative care medical education in European universities: A descriptive study and numerical scoring system proposal for assessing educational development. *Journal of Pain and Symptom Management, 50*(4), 516–523. https://doi.org/10.1016/j.jpainsymman.2015.04.019

Centeno, C., & Rhee, J. Y. (2018). Organization of palliative care in different parts of the world. In R. MacLeod & L. van den Block (Eds.), *Textbook of palliative care* (pp. 37–75). Springer.

Centeno, C., Sitte, T., de Lima, L., Alsirafy, S., Bruera, E., Callaway, M., Foley, K., Luyirika, E., Mosoiu, D., Pettus, K., Puchalski, C., Rajagopal, M. R.; Yong, J., Garralda, E., Rhee, J. Y., & Comoretto, N. (2018). White paper for global palliative care advocacy: Recommendations from a PAL-LIFE expert advisory group of the pontifical academy

Stellenbosch University https://scholar.sun.ac.za

for life, Vatican City. *Journal of Palliative Medicine, 21*(10), 1389–1397. https://hdl.handle.net/10171/56051

Chandramohan, S., & Bhagwan, R. (2016). Utilization of spirituality and spiritual care in nursing practice in public hospitals in KwaZulu-Natal, South Africa. *Religions, 7*(3), 23. https://doi.org/10.3390/rel7030023

Chaudhary, B., & Aswal, M. (2013). Imparting spiritual intelligence curriculum in our classrooms. *European Academic Research, 1*(7), 1508–1515.

Choi, J., Kushner, K. E., Mill, J., & Lai, D. W. L. (2012). Understanding the language, the culture, and the experience: Translation in cross-cultural research. *International Journal of Qualitative Methods, 11*(5), 652–665. https://doi.org/10.1177/160940691201100508

Cipriano-Steffens, T., Cursio, J. F., Hlubocky, F., Sumner, M., Garnigan-Peters, D., Powell, J., Arndt, N., Phillips, L., Lassiter, H. Rev., Gilliam, M., Petty, L. E., Onque, S. Rev., Malec, M., Fitchett, G., & Polite, B. (2021). Improving end of life cancer outcomes through development and implementation of a spiritual care advocate program. *American Journal of Hospice and Palliative Medicine®.* Advance online publication. https://doi.org/10.1177/1049909121995413

Clark, M., & Emerson, A. (2020). Spirituality in psychiatric nursing: A concept analysis. *Journal of the American Psychiatric Nurses Association, 27*(1), 22–32. https://doi.org/10.1177/1078390320902834

Clark, P. G., Spence, D. L., & Sheehan, J. L. (1986). A service/learning model for interdisciplinary teamwork in health and aging. *Gerontology Education, 6*(4), 3–16. https://doi.org/10.1300/j021v06n04_02

Clelland, D., van Steijn, D, Whitelaw, S., Connor, S., Centeno, C., & Clark, D. (2020). Palliative care in public policy: Results from a global survey. *Palliative Medicine Reports, 1*(1), 183–190. https://doi.org/10.1089/pmr.2020.0062

Cockell, N., & McSherry, W. (2012). Spiritual care in nursing: An overview of published international research. *Journal of Nursing Management, 20*(8), 958–969. https://doi.org/10.1111/j.1365-2834.2012.01450.x

Coetzee, O., Swartz, L., & Adnams, C. (2019). Finding common ground in the context of difference: A South African case study. *Culture, Medicine, and Psychiatry, 43*, 277–289. https://doi.org/10.1007/s11013-018-9615-6

Cohen, L., Manion, L., & Morrison, K. (2011). *Research methods in education* (7th ed.). Routledge.

Stellenbosch University https://scholar.sun.ac.za

Cohen, M. Z., Holley, L. M., Wengel, S. P., & Katzman, M. Rabbi. (2012). A platform for nursing research on spirituality and religiosity: Definitions and measures. *Western Journal of Nursing Research, 34*(6), 795–817. https://doi.org/10.1177/0193945912444321

Compion, S. (2016). *Volunteering and democratization in Southern Africa: A structural and cultural analysis* [Doctoral dissertation]. University of Kentucky. https://uknowledge.uky.edu/sociology_etds/30/

Connor, S. (2017). The worldwide hospice palliative care alliance. *Journal of Pain and Symptom Management, 55*(2S). https://doi.org/10.1016/j.jpainsymman.2017.03.020

Connor, S., De Lima, R., Downing, L., Ling, J., Quilliam, P., & Radbruch, L. (2020): The Berlin Declaration: A collaborative roadmap to advance global hospice and palliative care. *Journal of Palliative Medicine, 23*(1), 22–23. https://doi.org/10.1089/jpm.2019.0557

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet, 374*(9692), 817–834. https://doi.org/10.1016/S0140-6736(09)60951-X

Court, L., & Olivier, J. (2020). Approaches to integrating palliative care into African health systems: A qualitative systematic review. *Health Policy and Planning, 35*(8), 1053–1069. https://doi.org/10.1093/heapol/czaa026

Daniele, M. A. S., Martinez-Alvarez, M., Etyang, A. K., Vidler, M., Salisbury, T., Makanga, P. T., Musitia, P., Flint-O'Kane, M., Brown, T. W., Diallo, B. A., Boene, H., Stones, W., von Dadelszen, P., Magee, L. A., Sandall, J., & the PRECISE NETWORK. The contribution of qualitative research within the PRECISE study in sub-Saharan Africa. *Reproductive Health, 17*(58). https://doi.org/10.1186/s12978-020-0875-6

Dantas, M. M. F., & Amazonas, M. C. L. A. (2016). The illness experience: Palliative care given the impossibility of healing. *Revista da Escola de Enfermagem da USP, 50*(spe), 47–53. https://doi.org/10.1590/S0080-623420160000300007

Ddungu, H. (2011). Palliative care: What approaches are suitable in developing countries? *British Journal of Haematology, 154*(6), 728–735. https://doi.org/10.1111/j.1365-2141.2011.08764.x

De la Porte, A. (2016). Spirituality and healthcare: Towards holistic people-centred healthcare in South Africa. *HTS Teologiese Studies/Theological Studies, 72*(4), a3127. http://dx.doi.org/10.4102/hts.v72i4.3127

Stellenbosch University https://scholar.sun.ac.za

Demeke, H. B., Merali, S., Marks, S., Pao, L. Z., Romero, L., Sandhu, P., Clark, H., Clara, A., McDow, K. B., Tindall, E., Campbell, S., Bolton, J., Le, X., Skapik, J. L., Nwaise, I., Rose, M. A., Strona, F. V., Nelson, C., & Sizaet, C. (2021). Trends in use of telehealth among health centers during the COVID-19 pandemic — United States, June 26–November 6, 2020. *Morbidity and Mortality Weekly Report, 70*(7), 240–244. https://www.cdc.gov/mmwr/volumes/70/wr/mm7007a3.htm

Dempers, C., & Gott, M. (2017). Which public health approach to palliative care? An integrative literature review. *Progress in Palliative Care, 25*(1), 1–10. https://doi.org/10.1080/09699260.2016.1189483

Derrickson, P. (2012). Shifting expectations for chaplains. *Chaplaincy Today, 28*(2), 3. https://www.professionalchaplains.org/files/publications/chaplaincy_today_online/volume_28_number_2/28_2derrickson.pdf

Dladla, N. (2017). Towards an African critical philosophy of race: Ubuntu as a philo-praxis of race. *Filosofia Theoretica: Journal of African Philosophy, Culture and Religions, 61*(3), 39–68.

Doherty, S. (2019). Translation technology evaluation research. In M. O'Hagan (Ed.), *The Routledge handbook of translation and technology* (pp. 339–353). Routledge.

Downing, C., & Hastings-Tolsma, M. (2016). An integrative review of Albertina Sisulu and ubuntu: Relevance to caring and nursing. *Health SA Gesondheid, 21*, 214–227. https://doi.org/10.1016/j.hsag.2016.04.002

Drenth, C., Sithole, Z., Pudule, E., Wust, S., GunnClark, N., & Gwyther, L. (2018). Palliative care in South Africa. *Journal of Pain and Symptom Management, 55*(S2), S170–S177. http://dx.doi.org/10.1016/j.jpainsymman.2017.04.024

Dumanovky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D. E., & Morris, R. S. (2016). The growth of palliative care in U.S. hospitals: A status report. *Journal of Palliative Medicine, 19*(1), 8–15. https://doi.org/10.1089/jpm.2015.0351

Duncombe, J., & Jessop, J. (2005). "Doing rapport" and the ethics of "faking friendship." In M. Mauthner, M. Birch, J. Jessop, & T. Miller (Eds.), *Ethics in qualitative research* (pp. 107–122). SAGE Publications.

Durkheim, E. (1995) *The elementary forms of religious life.* Free Press. (Original work published 1917)

Du Toit, N. B. (2019). Does faith matter? Exploring the emerging value and tensions ascribed to faith identity in South African faith-based organisations. *HTS Teologiese Studies/Theological Studies, 75*(4), a5530. **https://doi.org/10.4102/hts.v75i4.5530**

Stellenbosch University https://scholar.sun.ac.za

Edwards, A., Zweigenthal, V., & Olivier, J. (2019). Evidence map of knowledge translation strategies, outcomes, facilitators and barriers in African health systems. *Health Research Policy and Systems, 17*, 16. https://doi.org/10.1186/s12961-019-0419-0

Eliastam, J. (2015). Exploring *ubuntu* discourse in South Africa: Loss, liminality and hope. *Verbum et Ecclesia, 36*(2), a1427. https://doi.org/10.4102/ve.v36i2.1427

Elk, R. (2017). The need for culturally-based palliative care programs for African American patients at end-of-life. *Journal of Family Strengths, 17*(1), Article 14. https://digitalcommons.library.tmc.edu/jfs/vol17/iss1/14

Elk, R., Emanuel, L., Hauser, J., Bakitas, M., & Levkoff, S. (2020). Developing and testing the feasibility of a culturally based tele-palliative care consult based on the cultural values and preferences of southern, rural African American and White community members: A program by and for the community. *Health Equity, 4*(1), 52–83. https://doi.org/10.1089/heq.2019.0120

Elsner, F., Larkin, P., Lorenzl, S., & Paal, P. (2017) Breaking barriers: Towards a WHO policy for strengthening palliative care education for all healthcare professionals. *European Association for Palliative Care Blog.* https://eapcnet.wordpress.com/2017/11/13/breaking-barriers-towards-a-who-policy-for-strengthening-palliative-care-education-for-all-healthcare-professionals/

Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research.* Jessica Kingsley Publishers.

Etkind, S. N., Bone, A. E., Gomes, B., Lovell, N., Evans, C. J., Higginson, I. J., & Murtagh, F. E. M. (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine, 15*(1), 102. https://doi.org/10.1186/s12916-017-0860-2

Ferraz, S. L., O'Connor, M., & Mazzucchelli, T. G. (2020). Exploring compassion from the perspective of health care professionals working in palliative care. *Journal of Palliative Medicine, 23*(11), 1478–1484.

Fraser, B. A., Powell, R. A., Mwangi-Powell, F. N., Namisango, E., Hannon, B., Zimmermann, C., & Rodin, G. (2018). Palliative care development in Africa: Lessons from Uganda and Kenya. *Journal of Global Oncology, 4*, 1–10. https://doi.org/10.1200/JGO.2017.010090

Fricchione, G. (2011). *Compassion and healing in medicine and society: On the nature and uses of attachment solutions to separation challenges.* Johns Hopkins.

Stellenbosch University https://scholar.sun.ac.za

Friedman, I. (2005). CHWs and community caregivers. Towards a unified model of practice. In A. Gray, M. Govender, T. Gengiah, & J. Singh (Eds.), *South African health review 2005* (pp. 176–188). http://www.hst.org.za/generic/29

Frosh, S. (2003). Psychosocial studies and psychology: Is a critical approach emerging? *Human Relations, 56*(12), 1545–1567. https://doi.org/10.1177/00187267035612005

Frosh, S. (2013). Psychoanalysis, colonialism, racism. *Journal of Theoretical and Philosophical Psychology, 33*(3), 141–154. https://doi.org/10.1037/a0033398

Frosh, S., & Baraitser, L. (2008). Psychoanalysis and psychosocial studies. *Psychoanalysis, Culture & Society, 13*(4), 346–365. https://doi.org/10.1057/pcs.2008.8

Frosh, S., & Saville-Young, L. (2008). Psychoanalytic approaches to qualitative psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (1st ed., pp. 109–126). SAGE Publications.

Galtung, J. (1988 [1987]). What is meant by peace and security? Some options for the 1990s. In J. Galtung (Ed.), *Transarmament and the Cold War: Peace research and the peace movement (Essays in peace research Vol. 6)* (pp. 61–71). Christian Ejlers.

Gamondi, C., Larkin, P., & Payne S. (2013). Core competencies in palliative care: An EAPC white paper on palliative care education - Part 2. *European Journal of Palliative Care, 20*(3), 140–145.

Gielen, J., Bhatnagar, S., & Chaturvedi, S. (2016). Spirituality as an ethical challenge in Indian palliative care: A systematic review. *Palliative and Supportive Care, 14*(5), 561–582. https://doi.org/10.1017/S147895151500125X

Gilgun, J. F. (2010). Reflexivity and qualitative research. *Current Issues in Qualitative Research, 1*(2). https://www.scribd.com/document/35787948/Reflexivity-and-Qualitative-Research

Gillward, A. (2020, 2 April). Digital equality: South Africa still has a long way to go. *Mail & Guardian.* https://mg.co.za/article/2020-04-06-digital-equality-south-africa-still-has-a-long-way-to-go/

Githaiga, J. N., & Swartz, L. (2017a). Socio-cultural contexts of end-of-life conversations and decisions: Bereaved family cancer caregivers' retrospective co-constructions. *BMC Palliative Care, 16*(1), 40. https://doi.org/10.1186/s12904-017-0222-z

Githaiga, J. N., & Swartz, L. (2017b). 'You have a swelling': The language of cancer diagnosis and implications for cancer management in Kenya. *Patient Education and Counseling, 100*, 836–838. https://doi.org/10.1016/j.pec.2017.01.003

Stellenbosch University https://scholar.sun.ac.za

Gray, A., & Vawda, Y. (2019). Health legislation and policy. In T. Moeti & A. Padarath (Eds.), *South African Health Review 2019* (pp. 3–16). Health Systems Trust. http://www.hst.org.za/publications/Pages/SAHR2019

Griggs, L. B., & Louw, L-L. (1995). *Valuing diversity: New tools for a new reality.* McGraw-Hill.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261–280. https://doi.org/10.1177/1077800403262360

Gureje, O., Nortje, G., Makanjuola, V., Oladeji, B. D., Seedat, S., & Jenkins, R. (2015). The role of global traditional and complementary systems of medicine in the treatment of mental health disorders. *The Lancet. Psychiatry, 2*, 168–177. https://doi.org/10.1016/S2215-0366(15)00013-9

Gwyther, E. (2018). *How is palliative care part of the right to health? The South African evidence* [Doctoral dissertation]. University of Cape Town. http://hdl.handle.net/11427/30368

Gwyther, L., Krause, R., Cupido, C., Stanford, J., Grey, H., Credé, T., de Vos, A., Arendse, J., & Raubenheimer, P. (2019). The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. *South African Medical Journal, 108*(2), 86–89. https://doi.org/10.7196/SAMJ.2018.v108i2.12524

Hall, E., Hughes, B., & Handzo, G. (2019). Time to follow the evidence – Spiritual care in health care. *Ethics, Medicine and Public Health, 9*, 45–56. https://doi.org/10.1016/j.jemep.2019.04.011

Hall, K. (2014). *Mindful living everyday.* Oak Haven Press.

Haralambos, H. M. (1985). *Sociology themes and perspectives.* University Tutorial Press.

Harding, R. (2018). Palliative care as an essential component of the HIV care continuum. *The lancet. HIV, 5*(9), e524–e530. https://doi.org/10.1016/S2352-3018(18)30110-3

Harding, R., Stewart, K., Marconi, K., O'Neill, J., & Higginson, I. J. (2011). Current HIV/AIDS end-of-life care in sub-Saharan Africa: A survey of models, services, challenges and priorities. *BMC Public Health, 3*, 33. https://doi.org/10.1186/1471-2458-3-33

Hasson, F., Nicholson, E., Muldrew, D., Bamidele, O., Payne, S., & McIlfatrick, S. International palliative care research priorities: A systematic review. *BMC Palliative Care, 19*, 16. https://doi.org/10.1186/s12904-020-0520-8

Stellenbosch University https://scholar.sun.ac.za

Hedt-Gauthier, B. L., Jeufack, H. M., Neufeld, N. H., Alem, A., Sauer, S., Odhiambo, J., Boum, Y., Shuchman, M., & Volmink, J. (2019). Stuck in the middle: A systematic review of authorship in collaborative health research in Africa, 2014–2016. *BMJ Global Health, 4*, e001853. https://gh.bmj.com/content/bmjgh/4/5/e001853.full.pdf

Heinecken, L. (2015). Are women 'really' making a unique contribution to peacekeeping? *Journal of International Peacekeeping, 19*(3–4), 227–248. https://doi.org/10.1163/18754112-01904002

Heinecken, L. (2020). *South Africa's post-Apartheid military: Lost in transition and transformation.* Springer.

Heinecken, L., & Soeters, J. (2018). Managing diversity: From exclusion to inclusion and valuing difference. In G. Caforio & M. Nuciari (Eds.), *Handbook of the sociology of the military.* Handbooks of sociology and social research series. Springer. https://doi.org/10.1007/978-3-319-71602-2_16

Helm, J., AhmadBeygi, S., & Van Oyen, M. (2011). Design and analysis of hospital admission control for operational effectiveness. *Production and Operations Management, 20*(3), 359–374. https://doi.org/10.1111/j.1937-5956.2011.01231.x

Herzig van Wees, S., & Holmer, H. (2020). Global health beyond geographical boundaries: Reflections from global health education. *BMJ Global Health, 5*, e002583. https://gh.bmj.com/content/bmjgh/5/5/e002583.full.pdf

Hickman, R. (2009). *To say thank you and serve. The story of St Luke's Hospice, Kenilworth, Cape Town.* Self-published by author. Cape Town, South Africa.

Higginson, I. J. (1997). Health care needs assessment: Palliative and terminal care. In A. Stevens & J. Raftery (Eds), *Health care needs assessment* (pp. 183-260). Wessex Institute of Public Health Medicine.

Himonga, C. (2013). The right to health in an African cultural context: The role of Ubuntu in the realization of the right to health with special references to South Africa. *Journal of African Law, 57*(2). https://doi.org/10.1017/S0021855313000089

Hitlin, S. (2006). Parental influences on children's values and aspirations: Bridging two theories of social class and socialization. *Sociological Perspectives, 49*(1), 25–46. https://doi.org/10.1525/sop.2006.49.1.25

Hodge, D. R., & Bushfield, S. (2006). Developing spiritual competence in practice. *Journal of Ethnic & Cultural Diversity in Social Work, 15*(3–4), 101–127. https://doi.org/10.1300/J051v15n03_05

Stellenbosch University https://scholar.sun.ac.za

Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently: A psychosocial approach.* SAGE Publications.

Holmes, C. (2018). Stakeholder views on the role of spiritual care in Australian hospitals: An exploratory study. *Health Policy, 122*(4), 389–395. https://doi.org/10.1016/j.healthpol.2018.02.003

Hoosen, M., Roman, N. V., & Mthembu, T. G. (2020). The development of guidelines for the inclusion of spirituality and spiritual care in Unani Tibb practice in South Africa: A study protocol. *Journal of Religion and Health*. Advance online publication. https://doi.org/10.1007/s10943-020-01105-5

Horii, M. (2019). Historicizing the category of "religion" in sociological theories: Max Weber and Emile Durkheim. *Critical Research on Religion, 7*(1), 24–37. https://doi.org/10.1177/2050303218800369

Horsfall, D. (2018). Developing compassionate communities in Australia through collective caregiving: A qualitative study exploring network centred care and the role of the end of life sector. *Annals of Palliative Medicine,* 7(Suppl 2), S42–S51. https://doi.org/10.21037/apm.2018.03.14

Hussey, N. (2012). The language barrier: The overlooked challenge to equitable health care. *South African Health Review, 2012/2013*, 189–195. https://hdl.handle.net/10520/EJC133688

Idoniboye-Obu, S., & Whetho, A. (2013). Ubuntu: "You are because I am" or "I am because you are"? *Alternation, 20*, 229–247. http://utlo.ukzn.ac.za/Files/Alternation%2020.1%20(2013).pdf

Ikwuagwu, O. A. (2007). *Initiation in African traditional religion: A systematic symbolic analysis with special reference to aspects of Igbo religion in Nigeria* [Dissertation]. Julius-Maximilians Universität, Würzburg. https://opus.bibliothek.uni-wuerzburg.de/opus4-wuerzburg/frontdoor/deliver/index/docId/1705/file/dissertation_ikwuagwu.pdf

Independent Communications Authority of South Africa (ICASA). (2020). The state of the ICT sector report in South Africa. https://www.icasa.org.za/uploads/files/State-of-the-ICT-Sector-Report-March-2020.pdf

International Association for Hospice and Palliative Care (IAHPC). (2017). *APCA atlas of palliative care in Africa.* www.africanpalliativecare.org/images/stories/pdf/APCA_atlas.pdf

Stellenbosch University https://scholar.sun.ac.za

International Association for Hospice and Palliative Care (IAHPC). (2019). *2020-2024 Strategic plan.* IAHPC.

Javanmardifard, S., Heidari, S., Sanjari, M., Yazdanmehr, M., & Shirazi, F. (2020). The relationship between spiritual well-being and hope, and adherence to treatment regimen in patients with diabetes. *Journal of Diabetes and Metabolic Disorders, 19*(2), 941–950. https://doi.org/10.1007/s40200-020-00586-1

Jinabhai, C. C., Marcus, T. S., & Chaponda, A. (2015). Rapid APPRAISAL of ward based outreach teams. Albertina Sisulu Executive Leadership Programme in Health. https://www.up.ac.za/media/shared/62/COPC/COPC%20Reports%20Publications/wbot-report-epub-lr-2.zp86437.pdf

Johnson, J., Hayden, T., True, J., Simkin, D., Colbert, L., Thompson, B., Stewart, D., & Martin, L. (2016). The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members. *Journal of Palliative Medicine, 19*(2), 143–148. https://doi.org/10.1089/jpm.2015.0238

Karsten, L., & Illa, H. (2005). Ubuntu as a key African management concept: Contextual background and practical insights for knowledge application. *Journal of Managerial Psychology, 20*(7), 607–630.

Khumalo, S. S. (2019). Implications of school violence in South Africa on socially just education. *Journal of Social Sciences and Humanities, 16*(8), 1–11. https://ejournals.ukm.my/ebangi/article/viewFile/34835/9766

Kilian, S., Swartz, L., & Joska, J. (2010). Competence of interpreters in a South African psychiatric hospital in translating key psychiatric terms. *Psychiatric Services, 61*(3), 309–312. https://doi.org/10.1176/appi.ps.61.3.309

Kirby, E., Lwin, Z., Kenny, K., Broom, A., Birman, H., & Good, P. (2018). "It doesn't exist…": Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care, 17*, 90. https://doi.org/10.1186/s12904-018-0343-z

Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Kwete, X. J., Arreola-Ornelas, H., Gómez-Dantés, O., Rodriguez, N. M., Alleyne, G. A. O., Connor, S. R., Hunter, D. J., Lohman, D., Radbruch, L., Madrigal, M. R. S., Atun, R., Foley, K. M., Frenk J., Jamison, T., … on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. (2018). Alleviating the access abyss in palliative care and pain relief—An imperative of universal health coverage: the *Lancet* Commission

Stellenbosch University https://scholar.sun.ac.za

report. *The Lancet, 391*(10128), P1391–1454. http://dx.doi.org/10.1016/S0140-6736(17)32513-8

Koenig, H. G., King, D. E., & Carson, V. B. (2012). *Handbook of religion and health* (2nd ed.). Oxford University Press.

Krakauer, E. L., Muhimpundu, M-A., Mukasahaha, D., Tayari, J-C., Ntizimira, C., Uhagaze, B., Mugwaneza, T., Ruzima, A., Mpanumusingo, E., Gasana, M., Karamuka, V., Nkurikiyimfura, J-L., Park, P., Barebwanuwe, P., Tapela, N., Elmore, S. N., Bukhman, G., Leng, M., Grant, L., Binagwaho, A., & Sezibera, R. 2018. Palliative care in Rwanda: Aiming for universal access. *Journal of Pain and Symptom Management, 55*(2S), S77–S80. https://doi.org/10.1016/j.jpainsymman.2017.03.037

Kumar, G. (2019). Public health panorama of operational research: A narrative review. *International Journal of Preventive Medicine, 10*, 43. https://doi.org/10.4103/ijpvm.IJPVM_93_16

Lamas, D., & Rosenbaum, L. (2012). Painful inequities — Palliative care in developing countries. *New England Journal of Medicine, 366*(3), 199–201. https://doi.org/10.1056/NEJMp1113622

Lamb, G. (2019). Social cohesion and violence in South Africa: Constructing a puzzle with missing pieces. *Crime, Law and Social Change, 72*, 365–385. https://doi.org/10.1007/s10611-019-09828-7

Lamb, G. (2021). Safeguarding the republic? The South African police service, legitimacy and the tribulations of policing a violent democracy. *Journal of Asian and African Studies, 56*(1), 92–108. https://doi.org/10.1177/0021909620946853

Langa, M., & Bowman, B. (2017). The drivers of violence in South Africa: Current knowledge, community-level differences and new possibilities for advancing violence prevention scholarship. Centre for the Study of Violence and Reconciliation.

Laurenzi, C. A., Skeen, S., Coetzee, B. J., Notholi, V., Gordon, S., Chademana, E., Bishop, J., & Tomlinson, M. (2021). Instructive roles and supportive relationships: Client perspectives of their engagement with community health workers in a rural South African home visiting program. *International Journal for Equity in Health, 20*, 32. https://doi.org/10.1186/s12939-020-01377-z

Laurenzi, C. A., Skeen, S., Rabie, S., Coetzee, B. J., Notholi, V., Bishop, J., Chademana, E., & Tomlinson, M. (2020). Balancing roles and blurring boundaries: Community health workers' experiences of navigating the crossroads between personal and professional

Stellenbosch University https://scholar.sun.ac.za

life in rural South Africa. *Health & Social Care in the Community.* Advance online publication. https://doi.org/10.1111/hsc.13153

Leininger, M. (1996). Culture care theory, research and practice. *Nursing Science Quarterly, 9*(2), 71–78. https://doi.org/10.1177/089431849600900208

Lewin, S., Munabi-Babigumira, S., Glenton, C., Daniels, K., Bosch-Capblanch, X., van Wyk, B. E., Odgaard-Jensen, J., Johansen, M., Aja, G. N., Zwarenstein, M., & Scheel, I. B. (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database of Systematic Reviews, 2010*(3), CD004015. https://doi.org/10.1002/14651858

Liefbroer, A. I., & Berghuijs, J. (2019). Spiritual care for everyone? An analysis of personal and organizational differences in perceptions of religious diversity among spiritual caregivers. *Journal of Health Care Chaplaincy, 25*(3), 1–20. https://doi.org/10.1080/08854726.2018.1556549

Liefbroer, A. I., Wierstra, I. R., Janssen, D. J. A., Kruizinga, R., Nagel, I., Olsman, E., & Körver, J. W. G. (2021). A spiritual care intervention for chaplains in home-based palliative care: Design of a mixed-methods study investigating effects on patients' spiritual wellbeing. *Journal of Health Care Chaplaincy, 23*, 1–14. Advance online publication. https://doi.org/10.1080/08854726.2021.1894532

LoGiurato, B. (2013, December 10). Obama's tribute to Nelson Mandela at memorial service. *Business Insider.* https://www.businessinsider.com/obama-nelson-mandela-memorial-service-speech-full-text-2013-12?IR=T

Long, W. M. (2000). *Health, healing and kingdom: New pathways to Christian health ministry in Africa.* Regnum.

Lown, B. A., & Manning, C. F. (2010). The Schwartz center rounds: Evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Academic Medicine, 85*(6), 1073–1081. https://doi.org/10.1097/ACM.0b013e3181dbf741

Lynch, T., Connor, S., & Clark, D. (2013). Mapping levels of palliative care development: A global update. *Journal of Pain & Symptom Management, 45*(6), 1094–1106. https://doi.org/10.1016/j.jpainsymman.2012.05.011

Lyner-Cleophas, M. M. (2016). *Staff and disabled students' experiences of disability support, inclusion and exclusion at Stellenbosch University* [Doctoral dissertation]. Stellenbosch University, South Africa.

Stellenbosch University https://scholar.sun.ac.za

Lysaght, H. S., Welsh, D., Roy, K., & Godzik C. (2020). Bridging the gap: A hospice nurse residency program. *The Journal of Continuing Education in Nursing, 51*(8), 371–376. https://doi.org/10.3928/00220124-20200716-07

MacRae, M. C., Fazal, O., & O'Donovan, J. (2020). Community health workers in palliative care provision in low-income and middle-income countries: A systematic scoping review of the literature. *BMJ Global Health, 5*(5), e002368. https://gh.bmj.com/content/5/5/e002368

Magezi, V. (2012). From periphery to the centre: Towards repositioning churches for meaningful contribution to public health care. *HTS Teologiese Studies/ Theological Studies, 68*(2), Art. #1312, 8 pages. http://dx.doi.org/10.4102/hts.v68i2.1312

Mahlangeni, N. T., Moodley, R., & Jonnalagadda, S. B. (2014). Elemental composition of *Cyrtanthus obliquus* and *Lippia javanica* used in South African herbal tonic, Imbiza. *Arabian Journal of Chemistry, 1800*(1). https://doi.org/10.1016/j.arabjc.2014.07.007

Malterud, K. (2001*).* Qualitative research: Standards, challenges, and guidelines. *The Lancet, 358*, 483–488. https://doi.org/10.1016/S0140-6736(01)05627-6

Mamman, A., & Zakaria, H. B. (2016). Spirituality and Ubuntu as the foundation for building African institutions, organizations and leaders. *Journal of Management, Spirituality & Religion, 13*(3), 246–265. https://doi.org/10.1080/14766086.2016.1159976

Manda, L. M. (2016). Africa's healing wisdom: Spiritual and ethical values of traditional healthcare practices. In R. Nicolsan (Ed.), *Persons in community: African ethics in a global culture* (pp. 125–139). University of KwaZulu-Natal Press.

Mangaliso, M. (2001). Building competitive advantage from Ubuntu: Management lessons from South Africa. *The Academy of Management Executive, 15*(3), 23–34. https://doi.org/10.5465/ame.2001.5229453

Mason, S., Paal, P., Elsner, F., Payne, C., Ling, J., Noguera, A., & Mosoiu, D. (2020). Palliative care for all: An international health education challenge. *Palliative and Supportive Care, 1*–3. https://doi.org/10.1017/S1478951520000188

McDermott, E., Selman, L., Wright, M., & Clark, D. (2008). Hospice and palliative care development in India: A multi-method review of services and experiences. *Journal of Pain and Symptom Management, 35*(6), 583–593. https://doi.org/10.1016/j.jpainsymman.2007.07.012

McIntosh, R., Ironson, G., & Krause, N. (2021). Keeping hope alive: Racial-ethnic disparities in distress tolerance are mitigated by religious/spiritual hope among Black Americans.

Stellenbosch University https://scholar.sun.ac.za

Journal of Psychosomatic Research, 144, 110403. https://doi.org/10.1016/j.jpsychores.2021.110403

McIntyre, D., & Klugman, B. (2003). The human face of decentralisation and integration of health services: Experience from South Africa. *Reproductive Health Matters, 11*(21), 108–119. https://doi.org/10.1016/s0968-8080(03)02166-9

Meessen, B., Kouanda, S., Musango, L., Richard, F., Ridde, V., & Soucat, A. (2011). Communities of practice: The missing link for knowledge management on implementation issues in low-income countries? *Tropical Medicine & International Health, 16*(8), 1007–1014. https://doi.org/10.1111/j.1365-3156.2011.02794.x

Merga, M. (2015). Thesis by publication in education: An autoethnographic perspective for educational researchers. *Issues in Educational Research, 25*(3), 291–308. https://www.iier.org.au/iier25/merga.html

Metz, T., & Gaie, J. B. R. (2010). The African ethic of Ubuntu/Botho: Implications for research on morality. *Journal of Moral Education, 39*, 273–290. https://doi.org/10.1080/03057240.2010.497609

Meyer, J. (2020). Developing pastoral therapy as a professional qualification in South Africa: Rationale and motivation. *HTS Teologiese Studies/Theological Studies, 76*(2), a5659. https://doi.org/10.4102/hts.v76i2.5659

Mhlongo, E. M., Lutge, E., & Adepeju, L. (2020). The roles, responsibilities and perceptions of community health workers and ward-based primary health care outreach teams: A scoping review. *Global Health Action, 13*(1). https://doi.org/10.1080/16549716.2020.1806526

Mills, J. (2019). Tracking progress in Palliative Care: Developments and contributions past, present and future. *Progress in Palliative Care, 27*(1), 1–3. https://doi.org/10.1080/09699260.2019.1603594

Minikel-Lacocque, J. (2018). The affect responsive interview and in-depth interviewing: What we can learn from therapy research. *Qualitative Inquiry, 25*(9–10), 1039–1046. https://doi.org/10.1177/1077800418792941

Mji, G., Gcaza, S., Swartz, L., MacLachlan, M., & Hutton, B. (2011). An African way of networking around disability. *Disability & Society, 26*(3), 365–368. http://dx.doi.org/10.1080/09687599.2011.560419

Stellenbosch University https://scholar.sun.ac.za

Mok, E., Wong, F., & Wong, D. (2010). The meaning of spirituality and spiritual care among the Hong Kong Chinese terminally ill. *Journal of Advanced Nursing, 66*, 360–370. https://doi.org/10.1111/j.1365-2648.2009.05193.x

Moosa, S. A. H. (2006). Community-Oriented Primary Care (COPC) in district health services of Gauteng, South Africa. *South African Journal of Family Practice, 48*(4), 6–8. https://doi.org/10.1080/20786204.2006.10873365

Morgan, S. N., & Okyere-Manu, B. (2020). The belief in and veneration of ancestors in Akan traditional thought: Finding values for human well-being. *Alternation, 2020*(30), 11–31. https://doi.org/10.29086/2519-5476/2020/sp30a2

Mpanga Sebuyira, L. (2006). Overview of HIV and palliative care. In L. Gwyther, A. Merriman, L. Mpanga Sebuyira, & H. Schietinger (Eds.), *A clinical guide to supportive and palliative care for HIV/AIDS in sub-Saharan Africa* (pp. 9–25). African Palliative Care Association.

Mpanga Sebuyira, L., Mwangi-Powell, F., Pereira, J., & Spence, C. (2003). The Cape Town Palliative Care Declaration: Home-grown solutions for Sub-Saharan Africa. *Journal of Palliative Medicine, 6*(3), 341–343. https://doi.org/10.1089/109662103322144646

Mthembu, N. (2019). Afrocentric science education approach in a transformed curriculum in post-apartheid South Africa. *Open Journal for Educational Research*, *3*(2), 67–80. https://doi.org/10.32591/coas.ojer.0302.03067m

Mthembu, T. G., Wegner, L., & Roman, N. V. (2016). Teaching spirituality and spiritual care in health sciences education: A systemic review. *African Journal of Physical Activity and Health Sciences, 22*(4:1), 1036–1057.

Mulligan, A., & Herbert, R. (2019). *Research futures: Drivers and scenarios for the next decade: Summary report.* https://www.elsevier.com/__data/assets/pdf_file/0007/847960/Research-Futures_Summary.pdf

Murphy, J. (2017). Beyond "religion" and "spirituality": Extending a "meaning systems" approach to explore lived religion. *Archive for the Psychology of Religion, 39*(1), 1–26. https://doi.org/10.1163/15736121-12341335

Musyimi, C. W., Mutiso, V. N., Nandoya, E. S., & Ndetei, D. N. (2016). Forming a joint dialogue among faith healers, traditional healers and formal health workers in mental health in a Kenyan setting: Towards common grounds. *Journal of Ethnobiology & Ethnomedicine, 12*(4), 1–8. https://doi.org/10.1186/s13002-015-0075-6

Mwangi-Powell, F. (2011). Palliative care in Africa: an overview. *Africa Health, 33*(5), 19.

Stellenbosch University https://scholar.sun.ac.za

Mwangi-Powell, F. N., Powell, R. A., & Harding, R. (2013). Models of delivering palliative and end-of-life care in sub-Saharan Africa: A narrative review of the evidence. *Current Opinion in Supportive and Palliative Care, 7*(2), 223–228. https://doi.org/10.1097/SPC.0b013e328360f835

Mwipikeni, P. (2018). Ubuntu and the modern society. *South African Journal of Philosophy, 37*(3), 322–334. https://doi.org/10.1080/02580136.2018.1514242

Ndaikile, R. V., Amukugo, H. J., Shilunga, A. P. K., & Karera, A. (2018). Spiritual care rendered by registered nurses at a state hospital in Windhoek Namibia. *Nursing & Care Open Access Journal, 5*(4), 230–236. https://doi.org/10.15406/ncoaj.2018.05.00153

Ngubane, H. (1992). Clinical practice and organization of indigenous healers in South Africa. In S. Feierman & J. Jansen (Eds.), *The social basis of health and healing in Africa* (pp. 366–375). University of California Press.

Ngubane-Mokiwa, S. A. (2018). Ubuntu considered in light of exclusion of people with disabilities. *African Journal of Disability, 7*, a460. https://doi.org/10.4102/ajod.v7i0.460

Nita, M. (2019). 'Spirituality' in health studies: Competing spiritualities and the elevated status of mindfulness. *Journal of Religion and Health, 58*, 1605–1618. https://doi.org/10.1007/s10943-019-00773-2

Nolan, S., Saltmarsh, P., & Leget, C. (2011). Spiritual care in palliative care: Working towards an EAPC task force. *European Journal of Palliative Care, 18*(2), 86–89.

Nolte, A., & Downing, C. (2019). Ubuntu–the essence of caring and being: A concept analysis. *Holistic Nursing Practice, 33*, 9–16. https://doi.org/10.1097/HNP.0000000000000302

Ntizimira, C. R., Nkurikiyimfura, J. L., Mukeshimana, O., Ngizwenayo, S., Mukasahaha, D., & Clancy, C. (2014). Palliative care in Africa: A global challenge. *Ecancermedicalscience, 8*, 493. https://doi.org/10.3332/ecancer.2014.493

Nweke, V. C. A. (2014). From African logic to the development of traditions of logic in African philosophy: An integrative perspective. *Journal of Integrative Humanism – Ghana, 4*(1), 22–39. https://www.researchgate.net/publication/322486503_FROM_AFRICAN_LOGIC_TO_THE_DEVELOPMENT_OF_TRADITIONS_OF_LOGIC_IN_AFRICAN_PHILOSOPHY

O'Brien, V., Jenkins, L. S., Munnings, M., Grey, H., North, Z., Schumann, H, & De Klerk-Green, E. (2019). Palliative care made visible: Developing a rural model for the

Stellenbosch University https://scholar.sun.ac.za

Western Cape Province, South Africa. *African Journal of Primary Health Care & Family Medicine, 11*(1), a2147. https://doi.org/10.4102/phcfm.v11i1.2147

O'Callaghan, C., Seah, D., Clayton, J. M., Welz, M., Kissane, D., Georgousopoulou, E. N., & Michael, N. (2019). Palliative caregivers' spirituality, views about spiritual care, and associations with spiritual well-being: A mixed methods study. *American Journal of Hospice and Palliative Medicine®, 37*(4), 305–313. https://doi.org/10.1177/1049909119877351

O'Connor, M., Fisher, C., & Guilfoyle, A. (2006). Interdisciplinary teams in palliative care: A critical reflection. *International Journal of Palliative Nursing, 12*, 132–137. https://doi.org/10.12968/ijpn.2006.12.3.20698

Ogude, J. (2012). Whose Africa? Whose culture? Reflections on agency, travelling theory and cultural studies in Africa. *Kunapipi: Journal of Postcolonial Writing and Culture, 34*(1), 12–27. https://ro.uow.edu.au/kunapipi/vol34/iss1/3

Omonzejele, P. F. (2008). African concepts of health, disease and treatment: An ethical inquiry. *Explore, 4*, 120–123. https://doi.org/10.1016/j.explore.2007.12.001

Omotoso, K. O., & Koch, S. F. (2018). Assessing changes in social determinants of health inequalities in South Africa: A decomposition analysis. *International Journal for Equity in Health, 17*, 181. https://doi.org/10.1186/s12939-018-0885-y

Oni, T., Smit, W., Matzopoulos, R., Hunter Adams, J., Pentecost, M., Rother, H-A., Albertyn, Z., Behroozi, F., Alaba, O., Kaba, M., van der Westhuizen, C., King, M. S., Levitt, N. S., Parnell, S., & Lambert, E. V. (2016). Urban health research in Africa: Themes and priority research questions. *Journal of Urban Health, 93*(4), 722–730. https://doi.org/10.1007/s11524-016-0050-0

Oppenheimer, G. M., & Bayer, R. (2007). *Shattered dreams? An oral history of the South African AIDS epidemic.* Oxford University Press.

Overseas Security Advisory Council (OSAC). *South Africa 2020 crime & safety report.* https://www.osac.gov/Content/Report/63e37d80-c040-462d-a868-181c51cf7188

Paal, P., Brandstötter, C., Bükki, J., Elsner, F., Ersteniuk, A., Jentschke, E., Stähli, A., & Slugotska, I. (2020). One-week multidisciplinary post-graduate palliative care training: An outcome-based program evaluation. *BMC Medical Education, 20*(1), 276. https://doi.org/10.1186/s12909-020-02200-7

Paal, P., Brandstötter, C., Lorenzl, S., Larkin, P., & Elsner, F. (2019). Postgraduate palliative care education for all healthcare providers in Europe: Results from an EAPC survey.

Stellenbosch University https://scholar.sun.ac.za

Palliative and Supportive Care, 17(5), 1–12. https://doi.org/10.1017/S1478951518000986

Parke, R. D., & Buriel, R. (2006). Socialization in the family: Ethnic and ecological perspectives. In N. Eisenberg, W. Damon, & R. M. Lerner (Eds.), *Handbook of child psychology: Social, emotional, and personality development* (6th ed., pp. 429–504). John Wiley & Sons.

Pastrana, T., Vallath, N., Mastrojohn, J., Namukwaya, E., Kumar, S., Radbruch, L., & Clark, D. (2010). Disparities in the contribution of low- and middle-income countries to palliative care research. *Journal of Pain and Symptom Management, 39*(1), 54–68. https://doi.org/10.1016/j.jpainsymman.2009.05.023

Pearson, B., & Piazza, N. (1997). Counselor preparation classification of dual relationships in the helping professions. *Counselor Education and Supervision, 37*, 89–99. http://still-waters-counseling.com/wp-content/uploads/2017/10/Pearson-Counselor-Preparation.pdf

Penman, J. (2012). Motivations driving spiritual engagement based on a phenomenological study of spirituality amongst palliative care clients and caregivers. *Journal of Nursing Education and Practice, 2*(3), 135–147. https://doi.org/10.5430/jnep.v2n3p135

Perry, H., Crigler, L., Lewin, S., Glenton, C., LeBan, K., & Hodgins, S. (2017). A new resource for developing and strengthening large-scale community health worker programs. *Human Resources for Health, 15*(1), 13. https://doi.org/10.1186/s1296 0-016-0178-8

Pesut, B., Potter, G., Stajduhar, K., Sawatzky, R., McLeod, B., & Drabot, K. (2015). Palliative approach education for rural nurses and health-care workers: A mixed-method study. *International Journal of Palliative Nursing, 21*(3), 142–151. https://doi.org/10.12968/ijpn.2015.21.3.142

Pillay-Van Wyk, V., Msemburi, W., Laubscher, R., Dorrington, R. E., Groenewald, P., Glass, T., Nojilana, B., Joubert, J. D., Matzopoulos, R., Prinsloo, M., Nannan, N., Gwebushe, N., Vos, T., Somdyala, N., Sithole, N., Neethling, I., Nicol, E., Rossouw, A., & Bradshaw, D. (2016). Mortality trends and differentials in South Africa from 1997 to 2012: Second national burden of disease study. *The Lancet Global Health, 4*(9), e642–e653. https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(16)30113-9/fulltext

Powell, R. A., Downing, J., Radbruch, L., Mwangi-Powell, F. N., & Harding, R. (2008). Advancing palliative care research in Sub-Saharan Africa: From the Venice

Stellenbosch University https://scholar.sun.ac.za

declaration, to Nairobi and beyond. *Palliative Medicine, 22*(8), 885–887. https://doi.org/10.1177/0269216308098094

Prinsloo, E. D. (2001). A comparison between medicine from an African (Ubuntu) and Western philosophy. *Curationis, 24*(1), 58–65. https://doi.org/10.4102/curationis.v24i1.802

Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J, Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K., & Sulmasy, D. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *Journal of Palliative Medicine, 12*(10), 885–904. https://doi.org/10.1089/jpm.2009.0142

Puchalski, C., Jafari, N., Buller, H., Haythorn, T., Jacobs, C., & Ferrell, B. (2020). Interprofessional spiritual care education curriculum: A milestone toward the provision of spiritual care. *Journal of Palliative Medicine, 23*(6), 777–784. https://doi.org/10.1089/jpm.2019.0375

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the spiritual dimension of whole person care: Reaching national and international consensus. *Journal of Palliative Medicine, 17*(6), 642–656. https://doi.org/10.1089/jpm.2014.9427

Purnell L. (2000). A description of the Purnell model for cultural competence. *Journal of Transcultural Nursing, 11*(1), 40–46. https://doi.org/10.1177/104365960001100107

Radbruch, L., De Lima, L., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E. C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, K., Goh, C., … Pastrana, T. (2020). Redefining palliative care—A new consensus-based definition. *Journal of Pain and Symptom Management, 60*(4), 754–764. https://doi.org/10.1016/j.jpainsymman.2020.04.027

Radbruch, L., & Richter, C. (2020). To suffer the slings and arrows of outrageous fortune – researching resilience and spirituality. *European Association for Palliative Care (EAPC Blog).* https://eapcnet.wordpress.com/2020/02/03/to-suffer-the-slings-and-arrows-of-outrageous-fortune-researching-resilience-and-spirituality/

Rajagopal, M. R., & Venkateswaran, C. (2003). Palliative care in India: Successes and limitations. *Journal of Pain & Palliative Care Pharmacotherapy, 17*, 121–128.

Ratshikana-Moloko, M., Ayeni, O., Tsitsi, J. M., Wong, M. L., Jacobson, J. S., Neugut, A. I., Sobekwa, M., Joffe, M., Mmoledi, K., Blanchard, C. L., Mapanga, W., Ruff, P., Cubasch, H., O'Neil, D. S., Balboni, T. A., & Prigerson, H. G. (2020). Spiritual care,

Stellenbosch University https://scholar.sun.ac.za

pain reduction and preferred place of death among advanced cancer patients in Soweto, South Africa. *Journal of Pain and Symptom Management, 60*(1), 37–47.

Rawlinson, F., Gwyther, L., Kiyange, F., Luyirika, E., Meiring, M., & Downing J. (2014). The current situation in education and training of health-care professionals across Africa to optimise the delivery of palliative care for cancer patients. *ecancermedicalscience, 8*, 492. https://doi.org/10.3332/ecancer.2014.492

Rego, F., Gonçalves, F., Moutinho, S. Castro, L., & Nunes, R. (2020). The influence of spirituality on decision-making in palliative care outpatients: A cross-sectional study. *BMC Palliative Care, 19*, 22. https://doi.org/10.1186/s12904-020-0525-3

Rego, F., & Nunes, R. (2019). The interface between psychology and spirituality in palliative care. *Journal of Health Psychology, 24*(3), 279–287. https://doi.org/10.1177/1359105316664138

Reidpath, D. D., & Allotey, P. (2019). The problem of 'trickle-down science' from the Global North to the Global South. *BMJ Global Health, 4*, e001719. http://dx.doi.org/10.1136/bmjgh-2019-001719

Republic of South Africa. (1996). *Constitution of the Republic of South Africa No. 108 of 1996.* https://www.gov.za/sites/default/files/images/a108-96.pdf

Republic of South Africa. (2004). *National Health Act No. 61 of 2003.* http://www.kznhealth.gov.za/legislation/nationalhealt%20act.pdf

Republic of South Africa. (2015). *White Paper on National Health Insurance.* https://www.gov.za/sites/default/files/gcis_document/201512/39506gon1230.pdf

Republic of South Africa. (2017). *National policy framework and strategy on palliative care 2017 – 2022.* file:///C:/Users/User/Downloads/Final%20NPFSPC%20August%202017.pdf

Republic of South Africa. (2020). *Annual Performance Plan 2020/21.* https://static.pmg.org.za/National_Department_of_Health_Annual_Performance_Plan_2020-2021_1.pdf

Rhee, J. Y., Garralda, E., Namisango, E., Luyirika, E., Lima, L. D., Powell, R. A., Robinson, C. A., & Centeno, C. (2018). Factors affecting palliative care development in Africa: In-country experts' perceptions in seven countries. *Journal of Pain and Symptom Management, 55*(5), 1313–1319. https://doi.org/10.1016/j.jpainsymman.2018.01.009

Richardson, P. (2014). Spirituality, religion and palliative care. *Annals of Palliative Medicine, 3*(3), 150–159. https://doi.org/10.3978/j.issn.2224-5820.2014.07.05

Stellenbosch University https://scholar.sun.ac.za

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers.* SAGE.

Roberts, B., & Gordon, S. (2016). Pulling us apart? The association between fear of crime and social cohesion in South Africa. *SA Crime Quarterly, 55*, 49–60. http://hdl.handle.net/20.500.11910/9706

Robinson, J., Gott, M., & Ingleton C. (2014). Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliative Medicine, 28*(1), 18–33. https://doi.org/10.1177/0269216313487568

Rosales, R. J. J. (2021). A year of COVID-19 and the spiritual well-being of the people. *Journal of Public Health (Oxf).* Advance online publication. https://doi.org/10.1093/pubmed/fdab071

Rosenberg, J. P., & Yates, M. P. (2010). Health promotion in palliative care: The case for conceptual congruence. *Critical Public Health, 20*(2), 201–210. https://doi.org/10.1080/09581590902897394

Ross, R. (1999). *A concise history of South Africa.* Cambridge University Press.

Rossignol, Z. (2020). South African utility: Rolling blackouts and Day Zero – Airshare: A Workforce Globalization Blog. https://airshare.air-inc.com/south-african-utilities-rolling-blackouts-and-day-zero

Ryan, S., Wong, J., Chow, R., & Zimmermann, C. (2020). Evolving definitions of palliative care: Upstream migration or confusion? *Current Treatment Options in Oncology, 21*, 20. https://doi.org/10.1007/s11864-020-0716-4

Safrina, N., Hariyati, R. T. S., & Pujasari, H. (2021). Nurses' experiences in providing spiritual care to end of life patients. Enferm Clin. 31 Suppl 2:S348-S351. English, Spanish. PMID: 33849197. https://doi.org/10.1016/j.enfcli.2020.09.025

Sandeen, E., Moore, K. M., & Swanda, R. M. (2018). Reflective local practice: A pragmatic framework for improving culturally competent practice in psychology. *Professional Psychology: Research & Practice, 49*(2), 142–150. https://doi.org/10.1037/pro0000183

Saunders, C. M. (2006). *Cicely Saunders: Selected writings 1958-2004.* Oxford University Press.

Saunders, D. C. (1988). Spiritual pain. *Journal of Palliative Care, 4*(3), 29–32. https://doi.org/10.1177/082585978800400306

Schlemmer, A., & Mash, B. (2006). The effects of a language barrier in a South African district hospital. *South African Medical Journal, 96*(10), 1084–1087.

Stellenbosch University https://scholar.sun.ac.za

Schmidt, K. (2019). How do I best provide spiritual care to Hispanic patients?. *Journal of Christian Nursing, 36*(2), 125. https://doi.org/10.1097/cnj.0000000000000595

Schneider, H., & Nxumalo, N. (2017). Leadership and governance of community health worker programmes at scale: A cross case analysis of provincial implementation in South Africa. *International Journal for Equity in Health, 16*, 72. https://doi.org/10.1186/s12939-017-0565-3

Schroeder, K., & Lorenz, K. (2018). Nursing and the future of palliative care. *Asia-Pacific Journal of Oncology Nursing, 5*, 4–8.

Schultz, M., Czamanski-Cohen, J., Bentur, N., Mohsen-Byadsi, S., Artsieli, Y., & Bar-Sela, G. (2020). Multidisciplinary staff perspectives on the integration of spiritual care in a new setting: Israel. *Palliative and Supportive Care, 18*(4), 431–436. https://doi.org/10.1017/S1478951519000877

Scott, C. L., & Ivala, E. N. (2019). *Transformation of higher education institutions in post-apartheid South Africa.* Routledge.

Selman, L., Siegert, R., Harding, R., Gysels, M., Speck, P., & Higginson, I. J. (2011). A psychometric evaluation of measures of spirituality validated in culturally diverse palliative care populations. *Journal of Pain and Symptom Management, 42*(4), 604–622. https://doi.org/10.1016/j.jpainsymman.2011.01.015

Selman, L., Speck, P., Barfield, R. C., Gysels, M., Higginson, I. J., & Harding, R. (2014). Holistic models for end of life care: Establishing the place of culture. *Progress in Palliative Care, 22*(2), 80–87. https://doi.org/10.1179/1743291X13Y.0000000063

Selman, L., Speck, P., Gysels, M., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K., Moll, T., Sebuyira, M. L., Ikin, B., Higginson, I. J., & Harding, R. (2013). 'Peace' and 'life worthwhile' as measures of spiritual well-being in African palliative care: A mixed-methods study. *Health and Quality of Life Outcomes, 11*, 94. https://doi.org/10.1186/1477-7525-11-94

Seymour, J., & Cassel, B. (2017). Palliative care in the USA and England: A critical analysis of meaning and implementation towards a public health approach. *Mortality, 22*(4), 275–290. https://doi.org/10.1080/13576275.2016.1270262

Shabalala, L. (2020). Feeling some typ'a way: A young Black woman's experience of education in South Africa. *South African Journal of Higher Education, 32*(4). https://doi.org/10.20853/32-4-2067

Stellenbosch University https://scholar.sun.ac.za

Shanmugasundaram, S., Chapman, Y., & O'Connor, M. (2006). Development of palliative care in India: An overview. *International Journal of Nursing Practice, 12*(4), 241–246. https://doi.org/10.1111/j.1440-172X.2006.00576.x

Sharma, R., Jain, A., Gupta, N., Garg, S., Batta, M., & Dhir, S. K. (2016). Impact of self-assessment by students on their learning. *International Journal of Applied & Basic Medical Research, 6*(3), 226–229. https://www.ijabmr.org/text.asp?2016/6/3/226/186961

Shiffman, J. (2015). Global health as a field of power relations: A response to recent commentaries. *International Journal of Health Policy and Management, 4*(7), 497–99. https://doi.org/10.15171/ijhpm.2015.104

Simon, J. (2018). Who needs palliative care?. *Canadian Medical Association Journal, 190*(9), E234–E235. https://doi.org/10.1503/cmaj.170956

Sinclair, S., McConnell, S., Raffin Bouchal, S., Ager, N., Booker, R., Enns, B., & Fung, T. (2015). Patient and healthcare perspectives on the importance and efficacy of addressing spiritual issues within an interdisciplinary bone marrow transplant clinic: A qualitative study. *BMJ Open, 5*(11), 5e009392. https://doi.org/10.1136/bmjopen-2015-009392

Snapp, M., & Hare, L. (2021). The role of spiritual care and healing in health management. *Advances in Mind-Body Medicine, 35*(1), 4–8.

Soeters, J., & Tresch, S. T. (2010). Towards cultural integration in multinational peace operations. *Defence Studies, 10*(1), 272–287. https://doi.org/10.1080/14702430903155175

Soto-Rubio, A., & Sinclair, S. (2018). In defense of sympathy, in consideration of empathy, and in praise of compassion: A history of the present. *Journal of Pain and Symptom Management, 55*(5), 1428–1434. https://doi.org/10.1016/j.jpainsymman.2017.12.478

Spaull, N., & Jansen, J. (Eds.) (2019). *South African schooling: The enigma of inequality.* Springer.

Speck, P. (2016). Culture and spirituality: Essential components of palliative care. *Postgraduate Medical Journal, 92*, 341–345.

Spiritual Care Association. (2020). *Capability framework for spiritual care practitioners in health.* Spiritual Care Association. file:///C:/Users/User/Downloads/Capability_Framework_2020_FIN.pdf

Statistics South Africa. (2011). *Mortality and causes of death in South Africa: Findings from death notification.* https://www.statssa.gov.za/publications/P03093/P030932017.pdf

Stellenbosch University https://scholar.sun.ac.za

Statistics South Africa. (2012). *Census 2011*. Statistics South Africa. https://www.statssa.gov.za/publications/P03014/P030142011.pdf

Statistics South Africa. (2018). *Mid-year population estimates.* http://www.statssa.gov.za/publications/P0302/P03022018.pdf

Steinhauser, K. E., Fitchett, G., Handzo, G. F., Johnson, K. S., Koenig, H. G., Pargament, K. I., Puchalski, C. M., Sinclair, S., Taylor, E. J., & Balboni, T. A. (2017). State of the science of spirituality and palliative care research Part I: Definitions, measurement, and outcomes. *Journal of Pain and Symptom Management, 54*(3), 428–440. https://doi.org/10.1016/j.jpainsymman.2017.07.028

Stevenson, S. (2019). Spotlight on NHI: What has actually changed in the new Bill? *Spotlight.* https://www.spotlightnsp.co.za/2019/08/23/spotlight-on-nhi-what-has-actually-changed-in-the-new-bill/

St Luke's Combined Hospices. (2020). *St Luke's Combined Hospice's centre for palliative learning.* St Luke's Combined Hospices.

St Luke's Combined Hospices. (2020, November). *Health services department report.* St Luke's Combined Hospices.

St Luke's Combined Hospices. (2021, January). *Community development: Khayelitsha report.* St Luke's Combined Hospices.

Sulla, V., & Zikhali, P. (2018). Overcoming poverty and inequality in South Africa: An assessment of drivers, constraints and opportunities (English). World Bank Group. http://documents.worldbank.org/curated/en/530481521735906534/Overcoming-Poverty-and-Inequality-in-South-Africa-An-Assessment-of-Drivers-Constraints-and-Opportunities

Swartz, A. (2013). Legacy, legitimacy, and possibility: An exploration of community health worker experience across the generations in Khayelitsha, South Africa. *Medical Anthropology Quarterly, 27*(2), 139–154. https://doi.org/10.1111/maq.12020

Swartz, L., Bantjes, J., Lourens, H., & Watermeyer, B. (2020). Disability: The forgotten side of race science. In J. Jansen & C. Walters (Eds.), *Fault Lines: A primer on race, science and society* (pp. 145–157). African Sun Media. https://doi.org/10.18820/9781928480495/09

Swartz, L., Hutton B., & Brand, M. (Eds.). (2015). *Opening a window: The story of spiritual care at St Luke's Hospice.* SunMedia.

Stellenbosch University https://scholar.sun.ac.za

Swinton, J., & Pattison, S. (2010). Moving beyond clarity: Towards a thin, vague, and useful understanding of spirituality in nursing care. *Nursing Philosophy, 11*(4), 226–237. https://doi.org/10.1111/j.1466-769X.2010.00450.x

Tacey, D. (2004). *The spirituality revolution: The emergence of contemporary spirituality.* Taylor & Francis Group.

Taghavi, M., Johnston, G., Urquhart, R., Henderson, D., Tschupruk, C., & Tupala, B. (2020). Workforce planning for community-based palliative care specialist teams using operations research. *Journal of Pain and Symptom Management*. Advance online publication. https://www.jpsmjournal.com/article/S0885-3924(20)30738-7/fulltext

Taghavi, M., Tupala, B., & Johnston, G. (2018). Collecting palliative care nursing data for use in workforce planning. In *International Congress on Palliative Care*. Montreal.

Takyi-Amoako, E. J., & Assié-Lumumba, N. T. (2018). Introduction: Re-visioning education in Africa—Ubuntu-inspired education for humanity. In E. Takyi-Amoako & N. Assié-Lumumba (Eds.), Re-visioning education in Africa. Palgrave Macmillan. https://doi.org/10.1007/978-3-319-70043-4_1

Tao, Z., Wu, P., Luo, A., Ho, T-L., Chen, C-Y., & Cheng, S-Y. (2020). Perceptions and practices of spiritual care among hospice physicians and nurses in a Taiwanese tertiary hospital: A qualitative study. *BMC Palliative Care, 19*, 96. https://doi.org/10.1186/s12904-020-00608-y

Taylor, R. J., Chatters, L. M., Woodward, A. T., & Brown, E. (2013). Racial and ethnic differences in extended family, friendship, fictive kin and congregational informal support networks. *Family Relations, 62*, 609–624. https://doi.org/10.1111/fare.12030

Tewari, D. D. (2016). South African higher education sector and its goals: Reflections and future needs. *Interdisciplinary Journal of Economics and Business Law, 5*(4), 1–16.

Tewari, D. D, & Ilesanmi, K. D. (2020). Teaching and learning interaction in South Africa's higher education: Some weak links. *Cogent Social Sciences, 6*, 1. https://doi.org/10.1080/23311886.2020.1740519

Tjale, A. A., & De Villiers, L. (2008). *Cultural issues in health care: A resource book for Southern Africa* (1st ed.). Juta.

Titler, M. G. (2008). The evidence for evidence-based practice implementation. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses.* Agency for Healthcare Research and Quality. https://www.ncbi.nlm.nih.gov/books/NBK2659/

Stellenbosch University https://scholar.sun.ac.za

Trafford, Z., Swartz, A., & Colvin, C. J. (2018). "Contract to volunteer": South African community health worker mobilization for better labor protection. *New Solutions: A Journal of Environmental and Occupational Health Policy, 27*(4), 648–666. https://doi.org/10.1177/1048291117739529

Truesdell, A. (2009). Achieving political objectives: South African defense priorities from the apartheid to the postapartheid era. *African Studies Review, 52*(3), 107–125. https://doi.org/10.1353/arw.0.0279

Tupala, B., Johnston, G., & Taghavi, M. (2020). *Workforce planning survey of palliative care program nurses in 2018 in Nova Scotia, Canada.* https://cdn.dal.ca/content/dam/dalhousie/pdf/sites/nels/Reports/Palliative%20Care%20Nursing%20Workforce%20Planning%20Survey-%20March%2026.pdf

United Nations Human Rights Council. (2009). *Access to medicine in the context of the right to everyone to the enjoyment of the highest attainable standard of physical and mental health: Resolution 12/24.* United Nations. https://www.ohchr.org/EN/Issues/Development/Pages/AccessToMedicines.aspx

Uwland-Sikkema, N. F., Visser, A., Westerhof, G. J., & Garssen, B. (2018). How is spirituality part of people's meaning system? *Psychology of Religion and Spirituality, 10*(2), 157–165. https://doi.org/10.1037/rel0000172

Van den Berg, V. L. (2016). Still lost in translation: Language barriers in South African health care remain. *South African Family Practice, 58*(6), 229–231. https://doi.org/10.1080/20786190.2016.1223795

van Ginneken, N., Lewin, S., & Berridge, V. (2010). The emergence of community health worker programmes in the late apartheid era in South Africa: An historical analysis. *Social Science & Medicine, 71*, 1110–1118. https://doi.org/10.1016/j.socscimed.2010.06.009

van Laarhoven, H. W. M., Schilderman, J., Bleijenberg, G., Donders, R., Vissers, K. C., Verhagen, C. A. H. H. V. M., & Prins, J. B. (2011). Coping, quality of life, depression, and hopelessness in cancer patients in a curative and palliative, end-of-life care setting. *Cancer Nursing, 34*(4), 302–314. https://doi.org/10.1097/NCC.0b013e3181f9a040

Van Niekerk, b. (2018). Religion and spirituality: What are the fundamental differences?. *HTS Teologiese Studies/Theological Studies, 74*(3), a4933. https://doi.org/10.4102/hts.v74i3.4933

Vidal, C. (1988). Godparenting among Hispanic Americans. *Child Welfare, 67,* 453–459.

Stellenbosch University https://scholar.sun.ac.za

Vieira, L. N., O'Hagan, M., & O'Sullivan, C. (2020). Understanding the societal impacts of machine translation: A critical review of the literature on medical and legal use cases. *Information, Communication & Society*. Advance online publication. https://doi.org/10.1080/1369118X.2020.1776370

Walsh, A., Brugha, R., & Byrne E. (2006). "The way the country has been carved up by researchers": Ethics and power in north–south public health research. *International Journal for Equity in Health, 15*, 204. https://doi.org/10.1186/s12939-016-0488-4

Ward, E. D. (2015). Cultural diversity in sickness and healing: The domain of caring in South African traditional cultures. In K. Federschmidt & D. J. Louw (Eds.), *Intercultural and interreligious pastoral caregiving* (pp. 172–180). SIPCC.

Wasner, M., Longaker, C., Fegg, M. J., & Borasio, G. D. (2005). Effects of spiritual care training for palliative care professionals. *Palliative Medicine, 19*(2), 99–104. https://doi.org/10.1191/0269216305pm995oa

Watermeyer, B. (2017). "I don't have time for an emotional life": Marginalization, dependency and melancholic suspension in disability. *Culture, Medicine, and Psychiatry, 41*(1), 142–160. https://doi.org/10.1007/s11013-016-9503-x

Watson, J., & Smith, M. C. (2002). Caring science and the science of unitary human beings: A trans-theoretical discourse for nursing knowledge development. *Journal of Advanced Nursing, 37*(5), 452–461. https://doi.org/10.1046/j.1365-2648.2002.02112.x

Weissman, D. E., & Meier, D. E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from The Center to Advance Palliative Care. *Journal of Palliative Medicine, 14*(1), 17–23. https://doi.org/10.1089/jpm.2010.0347

Werner, D., & Bower, B. (1982). *Helping health workers learn.* Hesperian Foundation.

White, M. S., Govender, P., & Lister, H. E. (2017). Community health workers lensed through a South African backdrop of two peri-urban communities in KwaZulu-Natal. *African Journal of Disability, 6*(1), a294. https://doi.org/10.4102/ajod.v6i0.294

White, N., Oostendorp, L. J., Minton, O., Yardley, S., & Stone, P. (2019) Palliative care training in undergraduate medical, nursing and allied health: A survey. *BMJ Supportive & Palliative Care.* Advance online publication. https://spcare.bmj.com/content/early/2019/12/13/bmjspcare-2019-002025

Willig, C., & Stainton-Rogers, W. (2008). Introduction. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 1–12). Sage.

Stellenbosch University https://scholar.sun.ac.za

Wilson, M. N. (1992). Perceived parental activity of mothers, fathers, and grandmothers in three-generational Black families. In A. K. H. Burlew, W. C. Banks, H. P. McAdoo, & D. A. Azibo (Eds.), *African American psychology: Theory, research, and practice* (pp. 87–104). Sage.

World Health Organization. (2014). Strengthening of palliative care as a component of integrated treatment throughout the life course. *Journal of Pain & Palliative Care Pharmacotherapy, 28*(2), 130–134. https://doi.org/10.3109/15360288.2014.911801

World Health Organization. (2018). World health statistics 2018; monitoring health for the SDGs, sustainable development goals. World Health Organization.

Worldwide Palliative Care Alliance. (2014). *Global atlas of palliative care at the end of life.* World Health Organization. https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Wright, M., Clark, D., Wood, J., & Lynch T. (2008). Mapping levels of palliative care development: A global view. *Journal of Pain & Symptom Management, 35*(5), 469–485. https://doi.org/10.1016/j.jpainsymman.2007.06.006

Whyle, E. B., & Olivier, J. (2016). Models of public-private engagement for health services delivery and financing in Southern Africa: A systematic review. *Health Policy and Planning, 31*, 1515–1529. https://doi.org/10.1093/heapol/czw075

Wu, L. F., & Lin, L. Y. (2011). Exploration of clinical nurses' perception of spirituality and spiritual care. *Journal of Nursing Research, 19*(4), 250–256. https://doi.org/10.1097/JNR.0b013e318236cf78

Yildirim, J. G., & Ertem, M. (2021). Professional quality of life and perceptions of spirituality and spiritual care among nurses: Relationship and affecting factors. Perspect Psychiatr Care. Epub ahead of print. PMID: 33834515. https://doi.org/10.1111/ppc.12794

Young, M. (2016). *Private vs. public healthcare in South Africa* [Honours thesis]. Western Michigan University. https://scholarworks.wmich.edu/honors_theses/2741

Zahan, D. (1979). *The religion, spirituality and thought of traditional Africa* (K. E. Martin & L. M. Martin, Trans.) The University of Chicago Press.

Zeiss, A. M., & Steffer, A. M. (1996). Interdisciplinary health care teams: The basic unit of geriatric care. In L. L. Carstensen, B. A. Edelstein, & L. Dornbrand (Eds.), *The practical handbook of clinical gerontology* (pp. 423–449). Sage Publications.

Zembylas, M. (2017). Practicing an ethic of discomfort as an ethic of care in higher education teaching. *Critical Studies in Teaching and Learning, 5*(1), 1–17. https://journals.co.za/doi/pdf/10.14426/cristal.v5i1.97

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Addenda

Addendum 1: National Online Survey

Sub-study 1: National online survey of all HPCA member organisations in SA

Field Number	Field Name	Description	First Response	Expanded Comment
	Guidelines and instructions	Please complete the questionnaire as best you can. Please respond on the "First Response" column. For further comments please use the "Expanded Comments" column as and when you feel you need to.	**Information**	
F001	**Your Name**	Please identify yourself as the person responding to this questionnaire. (First Name, Surname)		
F002	**Designation**	Your role/designation in your organisation, e.g., CEO		
F003	**Date**	The date you started completing this questionnaire, dd/mm/yyyy		
F004	**Contact Number**	A contact number we may use if we wish to discuss your responses with you		
F005	**E-mail Address**	An email address we can use to ask clarifying questions		
F006	**Name of Member Organisation**	The name your organisation operates under		
F007	**Member Organisation's address**	The street address of your organisation. (The building where the work of your organisation is managed from).		
F008	**Province**	The province in which your organisation is situated, e.g., Western Province		
F009	**Land Line**	The phone number a member of the public would use to contact your organisation, e.g., 021 555 1234		
F010	**Website Address**	If you operate a website, what is your organisation's website address? eg., www.hospice.co.za		
F011	**NPO Number**	If your organisation is registered as a Non-Profit Organisation, please provide your NPO Number		

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F012	**HPCA Accreditation**	If your organisation has been accredited by the Hospice Palliative Care Association (HPCA) please indicate your rating followed by the year, e.g., Three Star/2018		
F013	**Staff: Full Time**	The number of people who are paid for a full day of work. (Including contract workers).		
F014	**Staff: Part Time**	The number of people paid for part of a day or week worked. (Including contract workers).		
F015	**Registered patients**	Please state the average number of patients your organisation offers services to per month, e.g., 226 patients per month		
F016	**Medical Doctor**	Based on the average number of patients registered at your organisation per month and as cited above, please indicate, using a ratio, the access your patients have to a Medical Doctor, e.g., one part-time Doctor and one full-time Doctor would equal 1,5:266 (This means 1,5 Doctors care for 266 patients per month)		
F017	**Registered Professional Nurses**	Based on the average number of patients registered in your organisation per month, please indicate, using a ratio, the access your patients have to a Registered Professional Nurse, e.g., 12 full-time Registered Nurses equals 12:226. (This means that 12 Registered Prof Nurses care for 266 patients per month)		
F018	**Community Health Care Workers (CHCW)**	Based on the average number of patients registered in your organisation per month, please indicate, using a ratio, the access your patients have to a CHCW, e.g., 15 full-time CHCW equals 15:226. (This means that 15 CHCW care for 266 patients per month)		
F019	**Social Workers**	Based on the average number of patients registered at your organisation per month, please indicate using a ratio the access patients have to Social Workers, e.g., 6 full-time Social Workers equals 6:266		
F020	**Auxiliary Social Workers**	Based on the average number of patients registered at your organisation per month, please indicate using a ratio, the access patients have to Aux Social		

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		Workers, e.g., 3 full-time Social Workers equals 3:266		
F021	**Psychologists**	Based on the average number of patients registered at your organisation per month, please indicate using a ratio, the access patients have to a psychologist, e.g., 1 part-time Psychologist equals 0.5:266		
F022	**Spiritual Care Workers**	Based on the average number of patients registered at your organisation per month, please indicate using a ratio, the access patients have to Spiritual Care Workers, e.g., 1 part-time Spiritual Care Worker equals 1:266		
F023	**Bereavement Care Workers**	Based on the average number of patients registered at your organisation per month, please indicate using a ratio, the access patients have to Bereavement Care Workers, e.g.., 3 full-time Bereavement Care Workers equals 3:266		
F024	**Other Workers**	Please indicate what other category of workers or volunteers offer services to at your organisation. Please express this as a ratio, e.g.., 1 part-time Occupational Therapist equals 0,5:266. Please use the "Expanded Comments" column to describe the types of workers you are considering in this response.		
F025	**Patient Management Approach**	Choose one of the following to describe the Patient Management Approach your organisation uses: a) Inter-Disciplinary Team (IDT) b) Multi-Disciplinary Team (MDT) c) Neither d) Both e) Other. (Please use the "Expanded Comments" column to better describe your selection)		
F026	**Patient Management Team**	If your organisation has formed working teams to manage each patient's need, please identify the disciplines from the list that are regularly represented at team meetings / collaborations. **for the purpose of this questionnaire I shall use the term Inter Disciplinary Team (IDT) to refer to the Patient Management Team*		

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F027	**IDT Doctor**	Doctor: a) Yes b) No c) Partly		
F028	**IDT Registered Prof Nurse**	Nurse: a) Yes b) No c) Partly		
F029	**IDT Community Health Care Worker (CHCW)**	CHCW: a) Yes b) No c) Partly		
F030	**IDT Social Worker**	Social Worker: a) Yes b) No c) Partly		
F031	**IDT Aux Social Worker**	Aux Social Worker: a) Yes b) No c) Partly		
F032	**IDT Psychologist**	Psychologist: a) Yes b) No c) Partly		
F033	**IDT Spiritual Care Worker**	Spiritual Care Worker: a) Yes b) No c) Partly		
F034	**IDT Bereavement Care Worker**	Bereavement Care Worker: a) Yes b) No c) Partly		
F035	**IDT Other Worker**	Other type of Worker: a) Yes b) No c) Partly (Please specify in the "Expanded Comments" column)		
F036	**IDT Monthly**	Do the disciplines get together and meet to discuss patients on a monthly cycle? A) Yes b) No c) Different Type of meeting. (Please specify if a different type of meeting is held).		

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F037	**IDT Weekly**	Do the disciplines get together and meet to discuss patients on a weekly cycle? a) Yes b) No		
F038	**IDT WhatsApp**	Do the disciplines work together using a tool like WhatsApp to co-ordinate patient management? a) Yes, b) No, c) Different Type of tool. (Please specify if a different type of tool is used).		
F039	**IDT e-mail**	Do the disciplines work together using e-mail to manage patients? a) Yes b) No c) Other. (Please specify if another type of written communication is used)		
F040	**In-Patient Unit (IPU)**	Does your organisation operate its own In-Patient Care Unit (IPU)? a) Yes, b) No, c) Other. If another way of providing the service is offered, please describe. **if your organisation does not have an IPU please go to questions F043*		
F041	**IPU Beds Active**	Please indicate how many IPU beds are in operation to care for patients?		
F042	**IPU Occupancy Rate**	What would be the average bed occupancy rate per month?		
F043	**Day-Care services**	Does your organisation offer day-care service? a) Yes b) No. **if your organisation does not offer day-care services, please go to question F045*		
F044	**Day-Care services**	Are patients transported to a central point for the day to benefit from these day-care services? a) Yes b) No		
	Palliative Care Service Pillars	The National Policy Framework and Strategy on Palliative Care (NPFSPC) focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care.	**Information**	

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F045	**Pillar Medical Care Services**	What phrase best describes the extent of Medical Care offered by your organisation? a) Full Care, b) Partial Care, c) Occasional Care, d) Not at all		
F046	**Pillar Psycho-Social Care Services**	What phrase best describes the extent of Psycho-social Care offered by your organisation? a) Full Care, b) Partial Care, c) Occasional Care, d) Not at all		
F047	**Pillar Spiritual Care Services**	What phrase best describes the extent of Spiritual Care offered by your organisation? a) Full Care, b) Partial Care, c) Occasional Care, d) Not at all		
F048	**Pillar Bereavement Services**	What phrase best describes the extent of Bereavement Care offered by your organisation? a) Full Care, b) Partial Care, c) Occasional Care, d) Not at all		
F049	**Spiritual Care Services**	What definition does your organisation utilise to describe Spiritual Care?		
F050	**Key components of Spiritual Care**	If your organisation does not have a definition of Spiritual Care, what word/s from the following would you feel best describes the essence of Spiritual Care? a) Reverence b) Meaning and purpose c) Religion d) Connectedness. (Please add other words in the "Expanded Comments" column that you feel best describes spiritual care)		
F051	**Spiritual Care as a pillar of palliative care: organisation**	Does your organisation recognise Spiritual Care as an integral part of the palliative care service it offers as an organisation? a) Yes b) No		
F052	**Spiritual Care as a pillar of palliative care: patient**	Do your patients recognise Spiritual Care as an integral part of the palliative care experience expected from your organisation?		

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		a) Yes b) No		
F053	**Spiritual Care: Referral**	Are patients referred to external service providers for their Spiritual Care needs? a) Mostly b) Occasionally c) Not at all		
F054	**Spiritual Care Service Providers**	To what extent does your organisation co-ordinate with outside service providers for the spiritual needs of your patients? a) On a regular basis b) Occasionally c) Not at all.		
F055	**Spiritual Care Workers: Recruitment**	Does your organisation experience difficulty recruiting staff/volunteers to provide Spiritual Care service to your patients? a) Yes b) No c) Service not offered d) Other. (Please describe your reason in the "Expanded Comments" column if "Other" was selected).		
F056	**Spiritual Care: Funding**	Does a lack of funding limit the extent to which a Spiritual Care Service is offered by your organisation? a) Yes b) No c) To some extent d) Service not offered.		
F057	**Spiritual Care: Qualifications**	Have you experienced difficulty finding staff and volunteers correctly qualified for the role of a Spiritual Care Worker? a) Yes b) No		
F058	**Spiritual Care: Staff/Workers**	Are some of your Spiritual Care Workers formal employees of your organisation? a) Yes b) No c) Service not offered		
F059	**Spiritual Care: Volunteer Numbers**	How many Spiritual Care Workers are volunteers helping your organisation in providing a service?		

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F060	**Spiritual Care Volunteers: Remuneration**	Do the Spiritual Care volunteers get financially remunerated for their time in any way? a) Yes b) No c) Travel expenses only d) Other. If "Other" please explain in the "Expanded Comments" Column what these would be.		
F061	**Spiritual Care Volunteers: Incentives**	Please describe your incentive programme if any, for your spiritual care workers.		
F062	**Spiritual Care Workers: Male**	How many Spiritual Care Workers are male?		
F063	**Spiritual Care Workers: Female**	How many Spiritual Care Workers are female?		
F064	**Spiritual Care Worker: Age**	What is the median age of a Spiritual Care Worker? a) Between 20- and 40-years old b) Between 40 and 65 years old c) Older than 65 years?		
F065	**Spiritual Care: Language English**	What percentage of patients are spoken to in English?		
F066	**Spiritual Care: Language Afrikaans**	What percentage of patients are spoken to in Afrikaans?		
F067	**Spiritual Care: Language isiZulu**	What percentage of patients are spoken to in isiZulu?		
F068	**Spiritual Care: Language isiXhosa**	What percentage of patients are spoken to in isiXhosa?		
F069	**Spiritual Care: Language isiTswana**	What percentage of patients are spoken to in isiTswana?		
F070	**Spiritual Care: Language Other**	What percentage of patients are spoken to in another language? Please explain what that language is.		
F071	**Spiritual Care Worker: Christian**	What percentage of your Spiritual Care Worker base are Christian?		
F072	**Spiritual Care Worker: Hindu**	What percentage of your Spiritual Care Worker base are Hindu?		
F073	**Spiritual Care Worker: Islam**	What percentage of your Spiritual Care Worker base are Islamic?		
F074	**Spiritual Care Worker: Judaism**	What percentage of your Spiritual Care Worker base are Judaists?		
F075	**Spiritual Care Worker: Buddhism**	What percentage of your Spiritual Care Worker base are Buddhists?		

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F076	**Spiritual Care Worker: Baha'i**	What percentage of your Spiritual Care Worker base are Baha'i?		
F077	**Spiritual Care Worker: Other**	What percentage of your Spiritual Care Worker base are of another religion? Please can you explain what those religions are?		
F078	**Spiritual Care Worker: Matric/Grade 12**	What percentage of your Spiritual Care Workers achieved a matriculation certificate?		
F079	**Spiritual Care Worker: Graduate**	What percentage of your Spiritual Care Workers achieved a graduate degree?		
F080	**Spiritual Care Worker: Post-graduate**	What percentage of your Spiritual Care Workers achieved a post-graduate degree?		
F081	**Spiritual Care: Training**	What level of formal training in spiritual care does your Spiritual Care Workers have? a) No formal training. b) Basic training c) Inter-mediate training d) Advanced training e) Other (Please explain in the "Expanded Comments" column)		
F088	**Spiritual Care Qualification: Principal/Lead**	What level of formal training in spiritual care does your principal/lead Spiritual Care Worker have? a) No formal training. b) Basic training c) Inter-mediate training d) Advanced training e) Other (Please explain in the "Expanded Comments" column)		
F082	**Spiritual Care Qualification: Patient Management Team**	What level of formal training in spiritual care does your Patient Management Team have? a) No formal training. b) Basic training c) Inter-mediate training d) Advanced training e) Other (Please explain in the "Expanded Comments" column)		
F083	**Spiritual Care Team: years of service**	What are the median years of service at your organisation of your Spiritual Care Workers? a) Under 5 years b) Between 5- and 10-years c) Over 10 years?		
F084	**Spiritual Care: Training Curriculum**	Does your organisation offer training in Spiritual Care? a) Yes b) No		

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F085	**Spiritual Care: Training Curriculum**	Does your organisation have a Spiritual Care training curriculum? a) Yes b) No		
F086	**Spiritual Care: Training Curriculum**	If yes, did your organisation develop its own training curriculum in Spiritual Care or was the training outsourced? a) Developed our own b) Outsourced		
F087	**Spiritual Care: Training Curriculum**	Is your organisation aware that Hospice Palliative Care Association (HPCA) has developed and has available some training curricular in Spiritual Care? a) Yes b) No		
F088	**Spiritual Care National Curriculum**	Do you feel that there needs to be a national curriculum on spiritual care for member organisations in palliative care settings? a) Yes b) No c) Undecided		
F089	**Spiritual Care training Progress**	Has your organisation made any progress in developing its own spiritual care curriculum? a) Yes b) No		
F090	**Spiritual Care national curriculum skills**	What do you feel are the skills that would be needed in developing a national curriculum in spiritual care within a palliative care setting?		
F091	**Spiritual Care Cost of Training**	In your opinion would your organisation be able to fund the course fees and time to send a Spiritual Care Worker for training in a national spiritual care course? a) Yes b) No c) To some extent. (Please comment further in the "Expanded Comments" column		
F092	**Spiritual Care No Requirement**	What would you suggest is your organisation's level of interest in the development of such a national curriculum in Spiritual Care? a) Not interested b) Interested c) No sure at this time		

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F093	**Spiritual Care No Demand**	Do you think that the Spiritual Care Workers are interested in being trained further in spiritual care; has a need for training been expressed by them that you know about? a) Yes, a need has been expressed b) No, a need has not been expressed c) We do not know at this time		
F094	**Spiritual Care Curriculum Content**	Are there any suggestions that you may have that could inform the content of a national curriculum in spiritual care? a) Yes, we would like to make further content contributions to a curriculum, b) No, we do not wish to participate, c) Not sure at this time		
F095	**Spiritual Care Curriculum Content**	Could you please elaborate more on those suggestions, as above in the "Expanded Comments" column?		
F096	**Spiritual Care Curriculum Participation**	Should a national curriculum in Spiritual Care be developed, would your organisation be interested in being part of that curriculum development? a) Yes b) No c) Not at this time		
F097	**Spiritual Care Curriculum Participation**	What skills and resources would you say your organisation's Spiritual Care Team would be able to bring to the process of developing a national curriculum in spiritual care? a) Yes, we would contribute with our experience and time towards developing a curriculum; b) No, we cannot participate c) We cannot comment at this time		
F098	**Spiritual Care: integration**	What would best describe the relationship of the Spiritual Care Workers with the other members of your organisation? a) Fully integrated b) Partially integrated c) Not integrated d) Other. (Please feel free to describe this relationship more fully in the "Expanded Comments" column)		

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F099	**Spiritual Care: Poor Integration**	What would best describe why the spiritual care workers do not work within the Patient Management Team? a) N/A as integration is good b) No role for spiritual care to play within the Patient Management Team c) Lack of understanding of what role spiritual care can play in the Patient Management Team d) Spiritual care is not a recognised profession e) There is not any recognised training offered in spiritual care. (Please feel free to unpack this question more fully in the "Expanded Comments" column)		
F100	**General Comments**	I will be grateful for any additional comments you may have regarding the national curriculum needs for Spiritual Care pertaining to your organisation. You may respond on the "Expanded Comments" column		

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Addendum 2: Recruitment Material (Online Survey)

Recruitment Material (Online Survey)

Electronic Request to Participate in a Hospice Study (online survey)

From: ronitam@stlukes.co.za

Date: Sat, June 15, 2019, at 11:53 AM

Subject: Request to participate in an online survey to establish if there is a need for a national curriculum in spiritual care to be developed for hospice work in South Africa

Dear ……. *(As I would have already spoken telephonically to the CEO/Health Services Manager, I would address him/her by name)*

As previously discussed, and presented to you on …… *(I will insert the date I made that call and the email of thanks where I attached the proposal, and the 3 ethical clearance certificates)*. I am currently completing my PhD in Psychology at Stellenbosch University. The title of my PhD is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study."

I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC) by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care.

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While there is a substantive body of research about course curricula related to spirituality and religion in university settings in the global north, there is a significant gap in addressing the development of a national spiritual care curriculum for practice within hospice palliative arenas in SA. Significantly, there also appears to be limited documented formal training programmes in spiritual care in a hospice palliative care setting in South Africa yet there is an expressed need to establish spiritual care as a key pillar of palliative care. This study seeks to establish what the national curriculum needs are of hospices with regards to spiritual care and to establish if in fact there is an appetite for a national curriculum in spiritual care.

I kindly request your assistance in completing the electronic questionnaire. The questionnaire has been created in a user-friendly online format and should not take more than thirty minutes to complete. Please complete and return by no later than …… (*I will suggest a date)*

For a resend of the summary of the research proposal and the ethical clearance letters please send an email request to my email address ronitam@stlukes.co.za

Thanking you in advance for your contribution.

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

Please click or copy/paste the following link in your browser:

(I will attach the link)

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Addendum 3: Participant Information Leaflet (Online Survey)

Participant Information Leaflet (Online survey)

Date: ……

Study title:

Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study.

Introduction:

I am Ronita Mahilall, and I am currently undertaking my PhD in Psychology at Stellenbosch University. The title of my research project is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study." I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC), by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care.

While there is a substantive body of research about course curricula related to spirituality and religion in university settings in the global north, there is a significant gap in addressing the development of a national spiritual care curriculum for practice within hospice palliative arenas in SA. Significantly, there also appears to be limited documented formal training programmes

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in spiritual care in a hospice palliative care setting in South Africa yet there is an expressed need to establish spiritual care as a key pillar of palliative care. This 3-part study seeks to establish what the national curriculum needs are of hospices in SA with regards to spiritual care and to establish if in fact there is an appetite for a national curriculum in spiritual care; what the spiritual care practices are in the Western Cape; and then a case study of an established hospice with an established spiritual care programme. This hospice has been identified as St Luke's Combined Hospices

This study, Sub-Study One: seeks to establish what the national curriculum needs are of member organizations with regards to spiritual care and to establish if in fact there is an appetite for a national curriculum in spiritual care. This is the 1st part of the study. This Sub-Study One will be an online or electronic survey. The questionnaire has been created in a user-friendly online format and should not take more than thirty minutes to complete.

You may ask as many questions as you wish because it is important that you fully understand the study. As a participant, you are under no obligation to commit at this stage. I am the primary researcher. I hold a master's degree in social science (Social Work). I am currently employed as the CEO of St Luke's Combined Hospices. I am undertaking this PhD/doctoral research study through Stellenbosch University. My supervisor is Prof Leslie Swartz, with whom I have a formal supervisor/supervisee agreement. He will be guiding me through this research process. He will also be my co-researcher. This research will be funded by a grant made available by my Prof Leslie Swartz.

This study has been approved by the HPCA Research Ethics Committee *(for the purpose of this document I am working from the premise that the ethical approval is granted)* and it complies with the S SA Good Clinical Practice Guidelines. This study has also been approved by the Research and Ethics Committee of Stellenbosch University and ethical clearance has been obtained from St Luke's Combined Hospices' Research and ethics Committee as well. The Research and Ethics Committees of either three entities (as above) may inspect the research site, view data collection sheets, signed consent forms and records of interviews.

All the information that you share with me will be held in the strictest of confidence. Other than me, my supervisor will have access to that information in its original, raw format. You are free to withdraw from the process at any time you choose. This study will hopefully bring due attention to the role spiritual care plays in the palliative care experience. We will get better

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insights into what the current training needs are in spiritual care. Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all electronic data will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed. Data will be safely and securely stored for 2 years following publication or 6 years without publication.

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

If you have any questions or concerns about this study, please feel free to contact Ronita Mahilall on 0846161024 or on email: ronitamahilall@gmail.com. My supervisor Prof Leslie Swartz can be contacted on 0824593559 or on email: lswartz@sun.ac.za. The Hospice Palliative Care Association's Research and Ethics Committee can also be contacted: Cheryl Borresen on cheryl.borresen@gmail.com

The final report will be discriminated electronically, via hard copies, at conferences and workshops and I will avail myself to present the report if invited to do so.

Thank you greatly for your engagement in this research project.

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 4: Electronic Consent to Participate (Online Survey)

Electronic Consent to Participate (Online Survey)

Dear Prospective Participant

I am Ronita Mahilall, and I am currently undertaking my PhD in Psychology at Stellenbosch University. The title of my research project is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study."

I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa. Please take some time to read the information presented here, which will explain the details of this project.

Your participation is entirely voluntary, and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. The purpose of this study: We are all celebrating the newly passed National policy on Palliative Care. This is a very exciting piece of legislation that firmly puts palliative care as in integral part of the health care system. Palliative Care has 4 pillars to it: medical/nursing care, psychosocial care, spiritual care, and bereavement care. While there are significant protocols on nursing, psychosocial and bereavement care, spiritual care is still clouded in mystery. There seems not to be much insight into what the other hospices in SA are doing as part of their spiritual care work especially around issues of training in spiritual care. This study will seek to establish what those training needs are nationally, what the provincial practices are in the Western Cape, and we will do a case study of the programme that exists at St Luke's Combined Hospices. This will be a 3-part study taking the form on an online survey nationally with all hospices in SA. Then there will be focus group discussions with the key spiritual care and management staff in the Western Cape hospices. The 3rd part of the study will include interviews and focus group discussions with the spiritual care volunteers registered at St Luke's Combined Hospices.

The online survey will take approximately 30 minutes to complete and will contain a combination of open and closed ended questions covering the training needs of your hospice

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with regard to spiritual care in a hospice palliative care setting. Identifying details of your hospice will be asked for. However, you are not obliged to fill this out.

You have the right to decline answering any questions and you can exit the survey at any time without giving a reason. You are not waiving any legal claims or rights because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Mrs Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development at Stellenbosch University. The Hospice Palliative Care Association's Research and Ethics Committee can also be contacted: Cheryl Borresen on cheryl.borresen@gmail.com

To save a copy of this text, please go to 'File' then 'save as' then chose where you would like to save this document in your 'browser', then click 'save'.

I confirm that I have read and understood the information provided for the current study	YES	NO
I agree to take part in this survey	YES	NO

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University

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Addendum 5: Sub-Study Two – Guiding Questions for Semi-Structured Focus Group Discussions

Positioning spiritual care services as offered by the hospices in the Western Cape	
1.	What is your understanding of the South African National Policy Framework and Strategy on Palliative Care 2017–2022 (NPFSPC)?
2.	How does the NPFSPC influence service delivery at your hospice?
3.	Does your hospice offer spiritual care services?
4.	Describe the nature of the spiritual care intervention provided by your organisation.
5.	What has the benefit been to the patient/family after receiving spiritual care intervention?
The role of spiritual care within a hospice in a diverse South African context	
6.	Describe the role of spiritual care as one of the four pillars of palliative care within your hospice.
7.	How would you describe the role of the spiritual care workers within the Inter-Disciplinary Team (IDT) or Multi-Disciplinary Team (MDT) at your hospice?
8.	Given the range of diversity of SA, how would you say this affects the thinking of spiritual care delivery within your hospice?
Skills and training needs of a spiritual care worker towards a development of a spiritual care training curriculum	
9.	What skills are needed to provide spiritual care services?
10.	What resources are needed to provide spiritual care services?
11.	Are your spiritual care workers trained in spiritual care?
12.	What would you consider to be the curriculum needs of spiritual care workers?
13.	What would you consider to be the curriculum content of a spiritual care training programme within a hospice palliative care setting in SA?

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Addendum 6: Recruitment Materials (Focus Group Discussions)

Electronic Request to Participate in a Hospice Study (Focus Group Discussions)

From: ronitam@stlukes.co.za

Date: Sat, June 15, 2019 at 11:53 AM

Subject: Request to participate in a hospice study: Focus Group Discussions

Dear ……. *(As I would have already spoken telephonically to the CEO/Health Services Manager, I would address him/her by name)*

Thank you for participating on the Sub-Study One which was an online survey conducted on …… *(I will insert the date)*. That survey sought to establish if there was a need for a national curriculum in spiritual care to be developed.

I am now engaging with the Sub-Study Two which seeks to explore the current spiritual care practices in the 11 hospices in the Western Cape. As previously explained, I am currently completing my PhD in Psychology at Stellenbosch University. The title of my PhD is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study." I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC), by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care.

As I continued reviewing literature on spiritual care, I found that there is a paucity of relevant and current literature, which addresses the role of spiritual care, spiritual care education, and models of spiritual care, within hospice Palliative Care settings in South Africa. While there

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are a significant number of studies done on spiritual care in nursing, and spiritual care in social work in sub-Saharan Africa, focused research on spiritual care as an independent discipline is significantly lacking in a South African context. While many hospices in SA undertake spiritual care work there appears to not be a clear documentation of such work.

This study seeks to establish what the regional spiritual care practices are within the Western Cape Province. This study will take the form of a focus group discussion where the CEOs/Health Services Managers/Social Services Managers/identified Spiritual Care staff member would engage in discussions around specific questions pertaining to this study. The focus group discussion will take place on …… (*I will give a date, time, venue, and directions).* I anticipate the discussion to last approx. 90 minutes. You will be reimbursed for your travel expenses. Refreshments will be provided.

Please can you RSVP by no later than ……. *(I will suggest a date)* confirming your willingness to participate in this focus group discussion.

For a resend of the summary of the research proposal and the ethical clearance letters please send an email request to my email address ronitam@stlukes.co.za

Thanking you in advance for your cooperation.

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 7: Participant Information Leaflet (Focus Group Discussions)

Participant Information Leaflet (Focus Group Discussions)

Date: ……

Study title:

Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study.

Introduction:

I am Ronita Mahilall, and I am currently undertaking my PhD in Psychology Stellenbosch University. The title of my research project is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study." I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC), by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care. While there is a substantive body of research about course curricula related to spirituality and religion in university settings in the global north, there is a significant gap in addressing the development of a national spiritual care curriculum for practice within hospice palliative arenas in SA. Significantly, there also appears to be limited documented formal training programmes in spiritual care in a hospice palliative care setting in South Africa yet there is an expressed need to establish spiritual care as a key pillar of palliative care.

This 3-part study seeks to establish what the national curriculum needs are of hospices with regards to spiritual care and to establish if in fact there is an appetite for a national curriculum

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in spiritual care; what the spiritual care practices are in the Western Cape; and then a case study of an established hospice with an established spiritual care programme. This part of the study will be focus group discussions. Focus group discussions will be held (possibly 2 to 3 for on average 90 mins) with key role-players CEO/Health Services Manager/Social Services Manager/Spiritual Care staff member) within hospices in the Western Cape to establish what their provincial practices are in spiritual care within hospice palliative care settings. You may ask as many questions as you wish because it is important that you fully understand the study. As a participant, you are under no obligation to commit at this stage.

I am the primary researcher. I hold a master's degree in social science (Social Work). I am currently employed as the CEO of St Luke's Combined Hospices. I am undertaking this PhD/doctoral research study through Stellenbosch University. My supervisor is Prof Leslie Swartz, with whom I have a formal supervisor/supervisee agreement. He will be guiding me through this research process. He will also be my co-researcher. This research will be funded by a grant made available by my Prof Leslie Swartz. This study has been approved by the HPCA Research Ethics Committee *(for the purpose of this document I am working from the premise that the ethical approval is granted)* and it complies with the S SA Good Clinical Practice Guidelines. This study has also been approved by the Research and Ethics Committee of the Stellenbosch University and ethical clearance has been obtained from St Luke's Combined Hospices' Research and ethics Committee as well. The Research and Ethics Committees of either three entities (as above) may inspect the research site, view data collection sheets, signed consent forms and records of interviews.

All the information that you share with me will be held in the strictest of confidence. Should you become uncomfortable sharing some sensitive or emotional information and you may need added counselling support this will be made available to you at no cost to you. Other than me, my supervisor will have access to that information in its original, raw format. You are free to withdraw from the process at any time you choose. This 3-part study seeks to establish what the national curriculum needs are of hospices in SA with regard to spiritual care and to establish if in fact there is an appetite for a national curriculum in spiritual care; what the spiritual care practices are in the Western Cape; and then a case study of an established hospice with an established spiritual care programme. This hospice has been identified as St Luke's Combined Hospices

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This is the 2nd part of the research project. This Sub-Study Two will bring attention to the role spiritual care plays in the palliative care experience and in particular give better insights into what the current practices are in spiritual care in the Western Cape hospices. Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all electronic data will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed. Data will be safely and securely stored for 2 years following publication or 6 years without publication.

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all notes or recordings taken will be stored in a secure, locked strong room. I am the only person who will have access to that strong room. Any electronic information will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed. With you written permission the FGD may be recorded. All recordings will be made available to you to review. Once the information is accessed the recordings will be deleted from all devices. You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study. If you have any questions or concerns about this study, please feel free to contact Ronita Mahilall on 0846161024 or on email: ronitamahilall@gmail.com. My supervisor Prof Leslie Swartz can be contacted on 0824593559 or on email: lswartz@sun.ac.za. The Hospice Palliative Care Association's Research and Ethics Committee can also be contacted: Cheryl Borresen on cheryl.borresen@gmail.com

The final report will be discriminated electronically, via hard copies, at conferences and workshops and I will avail myself to present the report if invited to do so.

Thank you greatly for your engagement in this research project.

Kind regards

Ronita Mahilall

Stellenbosch University https://scholar.sun.ac.za

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 8: Confidentiality and Non-Disclosure Agreement

Confidentiality and Non-Disclosure Agreement

I, ……., ID Number ……., in my capacity as co-researcher working with Ronita Mahilall on the research study titled "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study", agree to maintain full confidentiality and non-disclosure in regards to any and all information received during my duties as a co-researcher engaged in this project.

Further, I agree:

1. To hold in strictest confidence any and all information gleaned during my engagement in this study.
2. To not share any or all information gleaned during my engagement in this study with anyone unless with the expressed and written consent of Ronita Mahilall.
3. To not make copies of any or all information gleaned during my engagement in this study with anyone unless with the expressed and written consent of Ronita Mahilall.
4. To store any or all study-related materials in a safe and secure location as long as such materials are in my possession.
5. To return any or all information gleaned during my engagement in this study to Ronita Mahilall in a complete and timely manner.
6. To delete any or all electronic files containing study-related information from my computer hard drive and any back-up devices.
7. None of the content of my engagement in, during and after the study will be discussed or shared with any third party under any circumstance.

…….

Signature Date

Kind regards

Stellenbosch University https://scholar.sun.ac.za

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 9: Consent to Participate in Research

Consent to participate in research

You are invited to take part in a study conducted by Ronita Mahilall, from the Faculty of Psychology at Stellenbosch University. You were approached as a CEO or the Health Services Manager of your organization and because of your work at your organization especially in the spiritual care field.

1. **Purpose of the study**

We are all celebrating the newly passed National policy on Palliative Care. This is a very exciting piece of legislation that firmly puts palliative care as in integral part of the health care system. Palliative Care has 4 pillars to it: medical/nursing care, psychosocial care, spiritual care, and bereavement care. While there are significant protocols on nursing, psychosocial and bereavement care, spiritual care is still clouded in mystery. There seems not to be much insight into what the other hospices in SA are doing as part of their spiritual care work especially around issues of training in spiritual care. This study will seek to establish what those training needs are nationally, what the provincial practices are in the Western Cape, and we will do a case study of the programme that exists at St Luke's Combined Hospices. This will be a 3-part study taking the form on an online survey nationally with all hospices in SA. Then there will be focus group discussions with the key spiritual care and management staff in the Western Cape hospices. The 3rd part of the study will include interviews and focus group discussions with the spiritual care volunteers registered at St Luke's Combined Hospices.

For the purposes of this "Consent to Participate in Research" this will be in respect of Sub-Study Two: Focus group discussions will be held (possibly 2 to 3 for on average 90 mins) with key role-players CEO/Health Services Manager/Social Services Manager/Spiritual Care staff member) within hospices in the Western Cape to establish what their provincial practices are in spiritual care within hospice palliative care settings.

2. **What will be asked of me?**

If you agree to take part in this study, you will be asked to share your experiences as a member of hospice working in the spiritual care arena. The group discussion will be led by key questions to facilitate discussion. The interviews will be one on one with a co-researcher, Prof Swartz and will have a set of questions as well. You will be free to share as much as you choose.

3. **Possible risks and discomfort?**

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All the information that you share with me will be held in the strictest of confidence. Other than me, my supervisor will have access to that information in its original, raw format. You are free to withdraw from the process at any time you choose. Should you become uncomfortable sharing some sensitive or emotional information and you may need added counselling support this will be made available to you at no cost to you.

4. Possible benefits to participants and /or the society

This study will hopefully bring due attention to the role spiritual care plays in the palliative care experience. We will get a better understanding of what the current practices are in the Western Cape hospices around spiritual care services.

5. Payment for participation

Participants will be given a travel and meal allowance made available by a grant for my supervisor.

6. Protection of your information, confidentiality, and identity

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all notes or recordings taken will be stored in a secure, locked strong room. I am the only person who will have access to that strong room. Any electronic information will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed.

All recordings will be made available to you to review, either by direct engagement with me or electronically via a password protected email, or via a password protected copy on an independent flash-drive. Once the information is accessed the recordings will be deleted from all devices.

7. Participation and withdrawal

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you do not want to answer and still remain in the study. The researcher may withdraw you from this study if it is found that the participant was being dishonest or displaying behaviour that was harmful to the other participants of the study.

Researchers' contact information

Stellenbosch University https://scholar.sun.ac.za

If you have any questions or concerns about this study, please feel free to contact Ronita Mahilall on 0846161024 or on email: ronitamahilall@gmail.com. My supervisor and co-researcher Prof Leslie Swartz can be contacted on 0824593559 or on email: lswartz@sun.ac.za

Rights of research participants

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims or rights because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development of Stellenbosch University and HPCA Research Ethics Committee for any human rights, welfare, and ethics queries. (e-mail cheryl.borresen@gmail.com – telephone: 031 261 7868, cell 082 797 1023).

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.
- I confirm that I have been informed about the above study by …….....
- I have also received, read (or had explained to me), and understood the study as explained in the Participant Information Leaflet.
- I understand that my personal details (any identifying data) will be kept strictly confidential.
- I understand that I may, at any stage, withdraw my consent and participation in the study and will continue to receive the appropriate standard of care.
- I consent to the audiotaping of my interview.

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- I have had sufficient opportunity to ask questions and am prepared to participate in the study.

By signing below, I _____ *(name of participant)* agree to take part in this research study, as conducted by Ronita Mahilall.

_____ _____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal researcher,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition, I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator if applicable (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Researcher **Date**

Kind regards

Stellenbosch University https://scholar.sun.ac.za

Ronita Mahilall

Cell: 0846161024

University of Stellenbosch Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, University of Stellenbosch.

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Addendum 10: Sub-Study Three – Guiding Questions for Semi-Structured Interviews

Number	Guiding questions
1	What are the spiritual care training needs at SLCH?
2	What is practicable, in your experience, when offering spiritual care services?
3	What accords with your experience as a spiritual care worker offering spiritual care services in a hospice palliative care setting?
4	What are the gaps, if any, that could assist in making your task easier?
5	What is the emphasis in spiritual care intervention at SLCH?
6	What are the concerns about spiritual care services at SLCH into the future and what would you suggest being done to address and overcome these concerns?

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Addendum 11: Recruitment Materials (One-on-One Interview)

Recruitment Materials (One-on-One Interview)

Electronic Request to Participate in a Hospice Study (One-on-One interview)

From: ronitam@stlukes.co.za

Date: Sat, June 15, 2019, at 11:53 AM

Subject: Request to participate in a hospice study: One-on-One Interview

Dear ……. *(As I would have already spoken telephonically to the CEO/Health Services Manager, I would address him/her by name)*

Thank you for participating on the Sub-Study One which was an online survey conducted on …… *(I will insert the date)*. That survey sought to establish if there was a need for a national curriculum in spiritual care to be developed.

I am now engaging with the Sub-Study Three which seeks to explore how spiritual care is practised at St Luke's Combined Hospices, Cape Town, South Africa. As previously explained, I am currently completing my PhD in Psychology at the Stellenbosch University. The title of my PhD is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study." I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC), by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care.

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As I continued reviewing literature on spiritual care, I found that there is a paucity of relevant and current literature, which addresses the role of spiritual care, spiritual care education, and models of spiritual care, within hospice Palliative Care settings in South Africa. While there are a significant number of studies done on spiritual care in nursing, and spiritual care in social work in sub-Saharan Africa, focused research on spiritual care as an independent discipline is significantly lacking in a South African context. While many hospices in SA undertake spiritual care work there appears to not be a clear documentation of such work.

This study seeks to establish what the local spiritual care practices are at St Luke's Combined Hospices, Cape Town. This study will take the form of one-on-one interviews and focus group discussion where necessary. A trained co-facilitator will undertake these interviews. The one-on-one interviews will take place on …… (*I will give a date, time, venue, and directions).* I anticipate the discussion to last approx. 90 minutes. You will be reimbursed for your travel expenses. Refreshments will be provided.

Please can you RSVP by no later than ……. *(I will suggest a date)* confirming your willingness to participate in this focus group discussion.

For a resend of the summary of the research proposal and the ethical clearance letters please send an email request to my email address ronitam@stlukes.co.za

Thanking you in advance for your cooperation.

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 12: Participant Information Leaflet (One-on-One Interview)

Participant Information Leaflet (One-on-One interview)

Date: ……

Study title: Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study.

Introduction:

I am Ronita Mahilall, and I am currently undertaking my PhD in Psychology at Stellenbosch University. The title of my research project is "Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study." I have been employed in the health and welfare sector for over 25 years. Of that time, I was employed for 15 years in a hospital setting and since the past 2,5 years as CEO of St Luke's Combined Hospices, one of the largest and longest standing hospices in the Western Cape, South Africa.

With the launch of the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (NPFSPC), by the National Department of Health's (DoH) National Health Council in October 2017, Palliative Care has finally found its rightful place on the continuum of health care platform in South Africa. The NPFSPC also focuses significantly on the four main pillars of Palliative Care intervention: medical care, psychosocial care, spiritual care, and bereavement care. Spiritual care is an essential element of the holistic palliative care experience. However, spiritual care appears to be shrouded in mystery and abstraction. By extension there appears to be a lack of professionalism around this pillar of care.

While there is a substantive body of research about course curricula related to spirituality and religion in university settings in the global north, there is a significant gap in addressing the development of a national spiritual care curriculum for practice within hospice palliative arenas in SA. Significantly, there also appears to be limited documented formal training programmes in spiritual care in a hospice palliative care setting in South Africa yet there is an expressed need to establish spiritual care as a key pillar of palliative care. This 3-part study seeks to establish what the national curriculum needs are of hospices in SA with regards to spiritual care and to establish if in fact there is an appetite for a national curriculum in spiritual care; what the spiritual care practices are in the Western Cape; and then a case study of an established

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hospice with an established spiritual care programme. This hospice has been identified as St Luke's Combined Hospices

This is the 3rd part of the study. This Sub-Study Three will be a case study conducted at St Luke's Combined Hospices which will give us more insight into a functional spiritual care programme and the experiences of the spiritual care workers in this programme. You, as the spiritual care workers at SLCH will be engaged with to explain this study. Your participation will be purely voluntary. This case study will take the format on one-on-one interviews. As I am also the CEO of SLCH, I will be engaging a co-researcher, Prof Leslie Swartz, who is also my university supervisor, to assist undertake these interviews. You may ask as many questions as you wish because it is important that you fully understand the study. As a participant, you are under no obligation to commit at this stage.

I am the primary researcher. I hold a master's degree in social science (Social Work). I am currently employed as the CEO of St Luke's Combined Hospices. I am undertaking this PhD/doctoral research study through the Stellenbosch University. My supervisor is Prof Leslie Swartz, with whom I have a formal supervisor/supervisee agreement. He will be guiding me through this research process. He will also be my co-researcher. This research will be funded by a grant made available by my Prof Leslie Swartz. This study has been approved by the HPCA Research Ethics Committee (for the purpose of this document I am working from the premise that the ethical approval is granted) and it complies with the S SA Good Clinical Practice Guidelines. This study has also been approved by the Research and Ethics Committee of Stellenbosch University and ethical clearance has been obtained from St Luke's Combined Hospices' Research and ethics Committee as well. The Research and Ethics Committees of either three entities (as above) may inspect the research site, view data collection sheets, signed consent forms and records of interviews.

All the information that you share with me will be held in the strictest of confidence. Should you become uncomfortable sharing some sensitive or emotional information and you may need added counselling support this will be made available to you at no cost to you. Other than me, my supervisor will have access to that information in its original, raw format. You are free to withdraw from the process at any time you choose. Data will be safely and securely stored for 2 years following publication or 6 years without publication. This study will hopefully bring due attention to the role spiritual care plays in the palliative care experience. We will get better insights into what the current spiritual care practices are in a well-established hospice such as

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SLCH. Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all electronic data will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed.

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all notes or recordings taken will be stored in a secure, locked strong room. I am the only person who will have access to that strong room. Any electronic information will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed. With you written permission the interview may be recorded. All recordings will be made available to you to review. Once the information is accessed the recordings will be deleted from all devices. As the CEO of SLCH, I am aware that some of the spiritual care workers are very artistic and creative; they utilise visual effects in their spiritual care work at SLCH such as poems, drawings, arts, and crafts. With your permission, I will photograph and catalogue these assets, and which will form the basis of future discussions. After the interviews and based on a basic thematic analysis of data I will arrange a 2-hour feedback meeting where initial findings will be shared with the participants. My co-researcher would be present at this initial feedback session. It is important, from an ethical point of view, to provide feedback to the participants at intervals. You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you do not want to answer and still remain in the study. If you have any questions or concerns about this study, please feel free to contact Ronita Mahilall on 0846161024 or on email: ronitamahilall@gmail.com. My supervisor Prof Leslie Swartz can be contacted on 0824593559 or on email: lswartz@sun.ac.za. The Hospice Palliative Care Association's Research and Ethics Committee can also be contacted: Cheryl Borresen on cheryl.borresen@gmail.com

Thank you greatly for your engagement in this research project.

Kind regards

Stellenbosch University https://scholar.sun.ac.za

Ronita Mahilall

Cell: 0846161024

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 13: Consent to Participate in Research (One-on-One Interview)

Consent to Participate in Research (One-on-One Interview)

You are invited to take part in a study conducted by Ronita Mahilall, from the Faculty of Psychology at Stellenbosch University. You were approached as a CEO or the Health Services Manager of your organization and because of your work at your organization especially in the spiritual care field.

1. **Purpose of the study**

We are all celebrating the newly passed National policy on Palliative Care. This is a very exciting piece of legislation that firmly puts palliative care as in integral part of the health care system. Palliative Care has 4 pillars to it: medical/nursing care, psychosocial care, spiritual care, and bereavement care. While there are significant protocols on nursing, psychosocial and bereavement care, spiritual care is still clouded in mystery. There seems not to be much insight into what the other hospices in SA are doing as part of their spiritual care work especially around issues of training in spiritual care. This study will seek to establish what those training needs are nationally, what the provincial practices are in the Western Cape, and we will do a case study of the programme that exists at St Luke's Combined Hospices. This will be a 3-part study taking the form on an online survey nationally with all hospices in SA. Then there will be focus group discussions with the key spiritual care and management staff in the Western Cape hospices. The 3rd part of the study will include interviews and focus group discussions with the spiritual care volunteers registered at St Luke's Combined Hospices.

For the purposes of this "Consent to Participate in Research" this will be in respect of Sub-Study Three: This part of the study will be a case study and will take the format on one-on-one interviews. As I am also the CEO of SLCH, I will be engaging a co-researcher, Prof Leslie Swartz, who is also my university supervisor, to assist undertake these interviews.

2. **What will be asked of me?**

If you agree to take part in this study, you will be asked to share your experiences as a member of hospice working in the spiritual care arena. The interviews will be one on one with a co-researcher, Prof Swartz and will have a set of questions as well. You will be free to share as much as you choose.

3. **Possible risks and discomforts**

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All the information that you share with me will be held in the strictest of confidence. Other than me, my supervisor will have access to that information in its original, raw format. You are free to withdraw from the process at any time you choose. Should you become uncomfortable sharing some sensitive or emotional information and you may need added counselling support this will be made available to you at no cost to you.

4. Possible benefits to participants and/or society

This study will hopefully bring due attention to the role spiritual care plays in the palliative care experience. The case study that we intend conducting at St Luke's Combined Hospices will give us more insight into a functional spiritual care programme and the experiences of the spiritual care workers in this programme.

5. Payment for participants

Participants will be given a travel and meal allowance made available by a grant for my supervisor.

6. Protections of your information confidentiality, and identity

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by ensuring that all notes or recordings taken will be stored in a secure, locked strong room. I am the only person who will have access to that strong room. Any electronic information will be password protected and all information will be backed up to an internal and external server which will also be password protected. If direct quotes need to be included in the report these will be coded so that anonymity is guaranteed.

All recordings will be made available to you to review, either by direct engagement with me or electronically via a password protected email, or via a password protected copy on an independent flash-drive. Once the information is accessed the recordings will be deleted from all devices.

7. Participation and withdrawal

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you do not want to answer and still remain in the study. The researcher may withdraw you from this study if it is found that the participant was being dishonest or displaying behaviour that was harmful to the other participants of the study.

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Researcher's contact information

If you have any questions or concerns about this study, please feel free to contact Ronita Mahilall on 0846161024 or on email: ronitamahilall@gmail.com. My supervisor and co-researcher Prof Leslie Swartz can be contacted on 0824593559 or on email: lswartz@sun.ac.za

Rights of research participants

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims or rights because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development of Stellenbosch University and HPCA Research Ethics Committee for any human rights, welfare, and ethics queries. (e-mail cheryl.borresen@gmail.com – telephone: 031 261 7868, cell 082 797 1023).

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.
- I confirm that I have been informed about the above study by …….....
- I have also received, read (or had explained to me), and understood the study as explained in the Participant Information Leaflet.
- I understand that my personal details (any identifying data) will be kept strictly confidential.
- I understand that I may, at any stage, withdraw my consent and participation in the study and will continue to receive the appropriate standard of care.

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- I consent to the audiotaping of my interview.
- I have had sufficient opportunity to ask questions and am prepared to participate in the study.

By signing below, I _____ *(name of participant)* agree to take part in this research study, as conducted by Ronita Mahilall.

_____ _____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal researcher,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition, I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator if applicable (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Researcher **Date**

Kind regards

Ronita Mahilall

Cell: 0846161024

Stellenbosch University https://scholar.sun.ac.za

Stellenbosch University Student Number: 23384735

Supervisor: Professor Leslie Swartz – Department of Psychology, Faculty of Human Sciences, Stellenbosch University.

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Addendum 14: Ethics Approval from Stellenbosch University

Ethics Approval from Stellenbosch University

UNIVERSITEIT STELLENBOSCH UNIVERSITY

NOTICE OF APPROVAL

REC: SBER - Initial Application Form

31 May 2019

Project number: 10237

Project Title: Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study.

Dear Ms Ronita Mahilall

Your REC: SBER - Initial Application Form submitted on 10 May 2019 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
30 May 2019	29 May 2020

GENERAL COMMENTS:

INFORMED CONSENT PROCESSES AND FORMS

1) The informed consent forms (ICF) attached for review are in order, however, please note that the ICF for the online survey states that 15 minutes will be required to complete the questionnaire, but the participant leaflet states that 30 minutes is required. Please confirm the correct estimation of the time required to complete the questionnaire. [CORRECTION REQUIRED]

2) Sub-studies 1 and 2 do not include invasive or sensitive questions, but sub-study 3 does as it explores difficulties the spiritual care givers experience in their work and to give examples of these. However, counselling and debriefing by a social worker or psychologist will be provided upon request. The researcher only mentions these services in the informed consent form. Please identify these service-providers and provide their contact details in the informed consent form. [ACTION REQUIRED]

Please supply the REC with the final informed consent form which includes the suggestions above.

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (10237) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	PhD proposal_R Mahilall_3 March 2019_Final	03/03/2019	Final
Budget	Budget for research project_R Mahilall	03/03/2019	Final
Data collection tool	Interviews and FGD	03/03/2019	Final

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Data collection tool	Focus Group Discussions	03/03/2019	Final
Data collection tool	Online survey	03/03/2019	Final
Default	CV of Prof L Swartz2019	01/05/2019	latest
Investigator CV (PI)	Ronita Mahilall CV - May 2019	01/05/2019	Latest abridged
Proof of permission	Research site permission letter	01/05/2019	Final
Proof of permission	Ethics Approval_SLCH_6 May 2019	06/05/2019	Final
Non-disclosure agreement	Confidentiality and Non Disclosure Agreement	09/05/2019	Final
Informed Consent Form	SU HUMANITIES Consent form template_Written 1 (6)	09/05/2019	Final
Informed Consent Form	SU HUMANITIES Consent template_electronic survey (1)	09/05/2019	latest
Information sheet	Participant Information Leaflet	09/05/2019	Latest
Recruitment material	Recruitment Materials	09/05/2019	Final

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

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Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review.The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes.If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events.Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

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Addendum 15: Ethics Approval from HPCA

Ethics Approval from HPCA

HPCA CARE & SUPPORT
Hospice Palliative Care Association of South Africa

2nd Floor, DBM Gardens Building, Golf Park, Raapenberg Road, Mowbray, 7700 |
Tel: 021 531 0277 | Fax: 021 531 1706
Email: info@hpca.co.za | www.hpca.co.za

28th August 2019

Mrs R Mahilall
e-mail : ronitam@stlukes.co.za

Professor L Swartz, University of Stellenbosch
e-mail : lswartz@sun.ac.za

Dear Mrs Mahilall

PROTOCOL Title : Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study. R Mahilall, University of Stellenbosch. Ref.: 02/19

The above protocol was reviewed by the Hospice Palliative Care Association Research Ethics Committee at its meeting held on 11th June 2019. Queries raised have now been addressed and the protocol is given full ethics approval.

Please note the following :

- Copies of the translated Information to Participants and Informed Consent documents, together with an undertaking from a person competent in both the local language and English, that the translations are accurate needs to be submitted;
- An original signed copy of the amended protocol and supporting documentation (as approved) must be submitted to the HPCA offices in Cape Town.
- Ethics approval is valid for one year only;
- Application for recertification of the protocol should be submitted a couple of months prior to the 11th June 2020 to ensure continuous approval;
- **ANY** changes to an approved protocol must be reviewed by the Research Ethics Committee.

It would also be appreciated if, once the study has been completed, an End of Study Report be completed and submitted to the Research Ethics Committee together with a summary of the results for inclusion on the HPCA web-site.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

DR N MALAN
Acting Chair : Hospice Palliative Care Research Ethics Committee
Reg. No. : REC-250408-005

no end to caring

Palliative Care is an approach that improves the quality of life of patients and their families facing life-threatening illnesses, 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.

Hospice Palliative Care Association of South Africa NPC. Reg no.1986/001887/08. NPO no.003-462

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Addendum 16: Ethics Approval from SLCH

Ethics approval from SLCH

ST LUKE'S COMBINED HOSPICES **CENTRE FOR PALLIATIVE LEARNING**

APPLICATION TO CONDUCT RESEARCH AT ST LUKE'S COMBINED HOSPICES

RESEARCHER DETAILS

Name & Surname	Ronita Mahilall	Title	Mrs
Email address	ronitam@stlukes.co.za	Cell	0846161024
Institution	Univ of Stellenbosch		
Academic Qualification/s	MA (SW)		

DETAILS OF PROPOSED RESEARCH

Project Title
Spiritual care in a hospice palliative care setting in South Africa: national curriculum needs; description of provincial services; and a local case study.

Brief summary of the research question
What are the current spiritual care practices within hospice palliative care settings in SA?
Is there a need to develop a national curriculum for spiritual care intervention?

In order to ask those questions I need to establish if there is in fact an appetite, wider than expressed at SLCH, for such a curriculum.
As this is uncharted territory, I am going to utilise a mixed methods research approach towards exploring and understanding what the current national spiritual care practices are and if there is a perceived need to establish a national curriculum for spiritual care intervention within hospice palliative care settings in SA. This will be a three-tiered study utilising an online survey, focus groups discussions, and one-on-one interviews.

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Brief description of proposed research methods

Sub-study 1 will take the format of an online survey. According to the Hospice Palliative Care Association of SA (HPCA) there are 93 registered hospices in SA. The online survey will seek to establish if these hospices see a need for a national curriculum in spiritual care to be developed. There is both a quantitative and a qualitative component to this sub-study.

Sub-study 2 of the project, I will engage with my provincial peers of the Western Cape, South Africa, largely through focus group discussions, to develop relevant questions around a national curriculum in spirituality, and to explore what practices are at play at their hospices, bearing in mind the complexities and diversities in this province from a socio-economic, demographic and socio-political perspective.

Sub-study 3 of the research project will look at what the day to day spiritual care practices are in a well-established hospice in the Western Care, South Africa. SLCH is one such well established 5-Star hospice and has been in existence since 1980.

Benefits that this research will have to St Luke's Combined Hospices and/or the field of palliative care

1. Greater understanding of the national needs for a training curriculum in Spiritual Care
2. Greater understanding of the training trends in the WC in spiritual care in hospice settings
3. Greater understanding of the SLCH spiritual care training programmes
4. Hopefully a clearer picture will emerge that would define a way forward in the development of a curriculum in spiritual care in a hospice palliative care setting in SA

Has the research been approved by another Research and Ethics Committee? Yes [ ] No [X]

However submissions will be made to HPCA on 6 May 2019 and Univ of Stellenbosch on 9 May 2019.

If yes, by which REC? ~

Proposed start date Jan 2020

Proposed end date Dec 2021

Signed 6/5/2019 Date

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HEAD OF DEPARTMENTS FEEDBACK / MOTIVATION

Signed by Chairs of SLCH Board and SLH Board at my appraisal on Feb 2019

Approval given at SLCH Board meeting 2 May 2019

* Unavailable @ present. However, signed docs as above are available from Michelle Lehman on request. ie relevant sections thereof.

Signed

Date

FOR ADMINISTRATIVE PURPOSES

Date application was received	23/04/2019
Date application was circulated to SLCH REC	29/04/2019
Date feedback consolidated	06/05/2019
Date feedback given to applicant	06/05/2019

APPROVED [X] DECLINED [ ]

M. Hlalele.

REC Chairperson

06/05/2019

Date

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Addendum 17: SLCH's CPL's Palliative Care Course Outline

SLCH's CPL's Palliative Care Course Outline

ST LUKE'S COMBINED HOSPICES NPC

CENTRE FOR PALLIATIVE LEARNING

St Luke's Combined Hospices, through its Centre for Palliative Learning offers the following training programmes:

2020

INTRODUCTION TO PALLIATIVE CARE COURSE FOR THE INTERDISCIPLINARY TEAM

Description and Duration	40-hour attendance course presented over 6 days, introducing the fundamentals of palliative care to health care professionals.
Modules include	*Palliative Care Principles *Palliative Care and Ethics * Communication skills in Palliative Care *Breaking Bad news and Building Hope * Pain Assessment * Pain Management in Adults and Children * Clinical Guidelines * Psychosocial Aspects of Loss, Grief and Bereavement * Cultural Aspects in Palliative Care * Spirituality in Palliative Care *Sexuality in Palliative Care *Team Approach in Palliative Care* Care for the Care Giver and Resilience *The Family in Palliative Care
Training manual	Developed by the Hospice and Palliative Care Association of South Africa (HPCA)

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INTRODUCTION TO PALLIATIVE CARE COURSE FOR COMMUNITY CARE WORKERS / HOME BASED CARERS

Description and Duration	A 30-hour attendance course, presented over 5 days, designed to equip community health workers and home-based carers to care for people with life threatening illnesses.
Modules include	*Understanding Palliative Care *Basic communication skills *Ethical issues in palliative care *Pain and symptom assessment and basic management *Cultural sensitivity and spirituality at end of life *Loss and grief * Self-care for the caregiver
Training manual	Adapted from the Hospice and Palliative Care Association of South Africa (HPCA)

BASIC HOSPICE COURSE FOR VOLUNTEERS

Description and Duration	A 7-morning session course aimed at people who wish to volunteer their time to work with patients and families. It is also available to lay people (space permitting) who do not necessarily want to volunteer but wish to learn more about this field of care.
Modules include	*What is palliative care? *Effective communication and basic counselling skills *Family dynamics *Emotional and psychological issues *Spiritual issues *Pain and symptom control *End of life Care * Loss and grief * Self-care
Training manual	Adapted from the Canadian Hospice Palliative Care Association Volunteer Training Programme

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CERTIFICATE COURSE IN PALLIATIVE NURSING FOR PNS AND ENS

Description and Duration	The CCPN is an HPCA certificate course run over 8 months from February to September each year, on a day-release (weekly classes) or E-learning basis. It involves theoretical and practical assessment. It is for professional and enrolled nurses.
Modules include	4 main modules: *Principles and Practice of PC *Pain and Symptom Management * Communication Skills *Psychosocial Issues
Training manual	Hospice and Palliative Care Association

BEREAVEMENT SUPPORT COURSE

Duration	A 35-hour intensive course held over 5 days, aimed at health care professionals/ counsellors and lay people who wish to support others in bereavement
Modules include	*Introduction to Counselling *Grief and Bereavement Theory * Bereavement counselling skills *Families, children, and adolescents *Diversity of culture and belief systems *Bereavement support after suicide * Ending the Counselling relationship * Self-care for the bereavement support
Training manual	Hospice Palliative Care Association

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WORKSHOPS

Description and Duration	We also facilitate 3-hour workshops on a number of different topics (including topics of your own choice)
Modules include	• Understanding Palliative care • Pain Management and Myths around Morphine • Specific symptom management • Spirituality at End of Life • Cultural Sensitivity in Palliative care • Empathy and Communication skills • How to break bad news • Ethics and ethical dilemmas at end of life • Loss, Grief and Bereavement. • Psychosocial and family car • Caring for the elderly towards the end of life • Advance care planning
Training manual	Handouts

Please note that we can facilitate tailor-made training.

Contact	The Centre for Palliative Learning Tel. 021 797-5335 (ext. 7169) Email training@stlukes.co.za

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Proposed Title of Article:	'I am Dying a Slow Death of White Guilt': Spiritual Carers in a South African Hospice Navigate Issues of Race and Cultural Diversity	(the 'Article')
Author(s) [Please list all named Authors]:	Ronita Mahilall, Leslie Swartz	(the 'Author')
Corresponding Author Name:	Ronita Mahilall	

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Manuscript Number:	JORH-D-20-00705R2	
Proposed Title of Article:	Spiritual Care: Motivations and Experiences through the Lenses and Voices of a Cohort of Spiritual Care Workers at an Established Hospice in Cape Town, South Africa	
Author(s) [Please list all named Authors]:	Ronita Mahilall, Leslie Swartz	(the 'Author')
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