



**How does the current culture of mental health services,
support or hinder the mental health nurse's ability to
facilitate spiritual care for individuals with a severe mental
illness who are facing death?**

by

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Glossary of Key Terms

Mental health clinicians	A group of multidisciplinary professionals. These can include mental health nurses, social workers, occupational therapists, psychologists and psychiatrists
Life limiting illness	An incurable illness or condition.
Palliative care	Palliative care offers support and care to individuals with a life limiting illness and their families. Its aim is not curative but to enhance the quality of life. It does this through offering relief from the symptoms in the physical emotional and spiritual domains. Palliative care can include end of life care. https://www.caresearch.com.au/caresearch/tabid/63/Default.aspx#:~:text=Pal liative%20care%20is%20care%20and,%2C%20social%2C%20and%20spiritu al%20needs.
Nurse Practitioner	In Australia, Nurse Practitioners are endorsed through the Australian Health Practitioner Regulation Agency (AHPRA). A Nurse Practitioner an advanced practice nurse has received a master's level qualification. A Nurse Practitioner has a specific clinical 'Scope of Practice'. The nurse practitioner has four domains of practice which includes, clinical, education, research and leadership. Nursing and Midwifery Board APHRA. https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines- Statements/Professional-standards.aspx
Existential Issues	Based on existential philosophy - relating to finding meaning, purpose and hope within the person's experience and existence.
Spiritual care	“Care which recognises and responds to the human spirit when faced with life-changing events (such as birth, trauma, ill health, loss) or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires”. https://blogs.staffs.ac.uk/epicc/files/2020/08/EPICC-Spiritual-Care- Education-Standard.pdf
Death Anxiety	Anxiety caused by the finitude of life. Fear of dying and what lies beyond death (Yalom 2008)
Spiritual Despair	Spiritual despair is profound source of spiritual suffering which can be characterised by a lack of meaning and hope – feeling that one has not control over one's life. It can relate to feeling that one has not lived their life well and may manifest in feeling of guilt. Spiritual despair may also manifest in feelings of loss, grief, loneliness and abandonment (Yalom 2008).
Psychosis	Can be seen in people with a medical diagnosis of schizophrenia, schizoaffective disorders and major affective disorders. Psychosis may manifest in experience of hallucinations and delusions. These hallucinations and delusions maybe highly distressing for the person and can cause severe levels of disability and disturbances in relationships.
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-IV) is a handbook used by mental health clinicians across much of the world. It is used as a guide for the diagnosis of mental health disorders.
Transference	The attributes and consequent feelings brought about by another person, often are transferred or projected onto the therapist.

Abstract

Due to poor physical health, people with severe mental illness are dying up to thirty years earlier than the general population. The limited literature on their experience of dying indicates that they often suffer from structural vulnerability in relation to equity and access to healthcare services and what care they do receive is frequently poor. It is also known that living with both a mental illness and facing death can engender spiritual concerns. Studies have shown that dying at a younger age is a risk factor for existential or spiritual despair. Hence, addressing spiritual concerns can be an important dimension in their nursing care. This study seeks to determine if the current culture of the mental health service in South Australia assists mental health nurses to facilitate spiritual care for individuals with an enduring mental illness who are facing death from a life limiting illness.

The combined methodologies of focused ethnography and autoethnography were used to identify the organisational cultural issues that affected Mental Health Nurses' ability to facilitate spiritual care. A group of Palliative Care Nurses were also included to provide a comparative organisational context. Data from the focused ethnography was collected from 11 Mental Health Nurses and 6 Palliative Care Nurses through semi structured interviews. The data from the autoethnography was based on the researcher's (my) clinical experience as a Mental Health Nurse Practitioner with a primary focus in palliative care. Both methodologies also used data from government documents.

A theoretical framework for the data analysis was used based on the work of nursing theorists. This was predominantly the work of Joyce Travelbee (1926-1973). Results indicated that the culture of the mental health service was in crisis at the time of data collection. Further, the power dynamics within the service privileged the corporate biomedical paradigm. Mental Health Nurses reported that they felt disempowered and some senior nurses felt reluctant or unable to articulate their nursing practice. Hence, their spiritual care and the unique needs of the person facing death became invisible. Both similar and contrasting data from the Palliative Care Nurses offered insights into the professional culture of mental health nursing. These data suggested that despite a lack of organisational support for spiritual care, the skills, knowledge and values of mental health nursing culture underpinned the nurse's ability to provide spiritual care to this highly marginalised and vulnerable population. Recommendations will be suggested to improve organisational support for spiritual care through nursing leadership and policy change. A strongly held professional culture with an emphasis on person-centred care would counter a culture of disempowerment. This professional culture can be further developed through education at both an undergraduate level and within organisational development programmes.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed 

Date: 20 January 2021

Dedication

Thank you to all the people with a lived experience of mental illness. This work is dedicated to you. For all you have shared, for enriching my life and inspiring me to undertake and continue this research. Thank you for sharing your stories, your unique depths, joys and pain. You continually inspire me with your strength and courage. Thank you all for allowing me to be a participant in your journey.

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CHAPTER 1 - INTRODUCTION

This aim of this study was to explore 'how the current culture of mental health services, supported or hindered the mental health nurse's ability to facilitate spiritual care for individuals with a severe mental illness who were facing death?' Further, this study endeavoured to understand the systems and processes which either supported or acted as barriers to the facilitation of spiritual care. It will be argued that spiritual care is an important aspect of care for this population and hence offer strategies to further develop a culture, whereby person-centred, spiritual care can be facilitated. The research is significant as thus far there have been no studies specifically exploring the spiritual care of people with a mental illness who were facing death from a life limiting illness, living within community and inpatient settings. The methods for data collection were through semi-structured interviews with mental health nurses and palliative care nurses and an examination of documents that provided insights into the culture of the mental health services in which the study was undertaken.

The research question for the study was chosen because the author was, and still is employed as a nurse practitioner with people who had a mental illness and were also dying from a life limiting illness. Thirteen years ago, I was employed as a physical health - comorbidity mental health nurse practitioner candidate, yet most of my referrals were in relation to people who had a life limiting illness. Three years later I was employed for 16 months as the research nurse practitioner in a large research project that explored access to and equity of palliative care services for people with a mental illness (Taylor et al. 2012). On return to my previous position as a comorbidity mental health nurse practitioner, the executive of the mental health service transitioned my role to a mental health - palliative care nurse practitioner. The research topic for this thesis stemmed from the work in the project and from my more recent work with people who are facing death (Picot, Glaetzer & Myhill 2015).

Over the past thirteen years my experience has taught me that spirituality is an important dimension in the lives of many people, especially when they are facing death. Spirituality, in its many different forms, provided the individual with comfort, support and meaning. The literature review for this study, which explored both the palliative care and mental health literature, supported my experience. Additionally, the research literature highlights that for many people with an enduring mental illness, spirituality is an important dimension of their life and their recovery. The consensus work by Puchalski et al. (2014, p. 646) defined spirituality as "...a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."

The focus of this study was on individuals who have a pre-existing mental illness as opposed to individuals who develop a mental illness as a response to a diagnosis of a life limiting illness, such as an anxiety or depressive disorder. It focused on individuals with a severe and enduring mental illness. Severe and enduring mental illness is found in a collection of disorders, such as schizophrenia, bipolar affective disorder and major depressive disorder. The above disorders can have a profound effect on interpersonal relationships, cause functional impairment and substantially interfere with everyday activities (Carey & Carey 1999). This chapter will discuss the structural vulnerability and stigmatisation of people who have had a severe and enduring mental illness, within the health system. It will be argued that these health inequities, such as a lack of access to service, stem from processes that are built into government systems and reflect social conditions. This chapter will also examine the lack of access and equity for this group of people in relation to general and palliative care services.

People with a severe and enduring mental illness are dying at a younger age than their cohorts in the general community, due to the adverse effects of psychotropic medications, such as weight gain and hyperlipidaemia, as well as factors such as lifestyle. These life issues include smoking, poor diet and physical inactivity (Firth et al. 2019). Poverty is also

related to an early death. Poor service integration contributes to this disparity in health (Australian Government 2020; Firth et al. 2019). Moreover, dying at a younger age and not fulfilling one's dreams can lead to a severe sense of loss and 'death anxiety' (McHugh 2012; Woods et al. 2008). Thus, this chapter will argue that for the individual with a severe and enduring mental illness, dying at a younger age than the general population puts them at greater risk of experiencing spiritual or existential concerns (Balboni & Balboni 2018; Chochinov et al. 2009). Their risk is greater because of the many losses a person can experience as a result of a lifetime of mental illness, which can compound grief and lead to spiritual distress or 'death anxiety'. Therefore, I will argue that spiritual care is essential for quality end of life care for this population. However, the literature review will highlight the absence of research exploring the spiritual needs of this population and that the research literature on their overall needs is limited (Chochinov et al. 2012; Ellison 2008; Goldenberg, Holland & Schacter 2000; Wilson et al. 2020; Woods et al. 2008). This chapter will also offer an overview of the following seven chapters contained within this thesis.

Structural vulnerabilities and stigma

It has been argued that death is a social justice issue (Reimer-Kirkham et al. 2016). People with a severe and enduring mental illness are dying 15 to 30 years earlier than the general population from physical illness (DeHert et al. 2011; Jayatilleke et al. 2017; Lawrence, Hancock & Kisely 2013; Plana-Ripoll et al. 2019; Scott & Happell 2011;). Evidence has also suggested that they may be dying at a younger age than previously found (Jayatilleke et al. 2017). Due to the nature and effects of the illness itself and societal stigma, individuals with a mental illness and a comorbid life limiting illness are one of the most vulnerable and marginalised groups in contemporary society (Donald & Stajduhar 2019; McNamara et al. 2018; Woods et al. 2008). Their healthcare is fragmented and of poor quality (Butler & O'Brien 2018; Donald & Stajduhar 2019; Jerwood et al. 2018; Lavin et al. 2017; Reimer-Kirkham et al. 2016). Moreover, Wilson et al. (2020)

have argued that given their increased mortality rate, it is particularly concerning that little is known about end of life care for those with a mental illness and a comorbid life limiting illness. Therefore, a robust knowledge base is urgently required.

The participants in a study by Jerwood et al. (2018) which included palliative care and mental health clinicians, highlighted that the stigma of both having a mental illness and a life limiting illness had a significant effect on the care provided to these individuals. This stigma affected referral information, the ways in which risk was managed, assumptions about their care and their involvement in their care planning. Thornicroft et al. (2014) suggested that the effects of stigma on individuals with a mental illness may be worse than the effects of illness itself. Further, levels of funding and low levels of visibility of this population may be related to the stigmatising cultural views in which they are held within the broader Australian society. Individuals with a long-term experience of serious mental illness have frequently experienced a lifetime of stigma and discrimination (Whitley & Campbell 2014). A study by Huang et al. (2018) found that this population underwent more frequent invasive treatments than the general population, had less chemotherapy and fewer advanced diagnostic examinations. The researchers suggested that this difference in care was due to the stigmatisation of this population by the medical profession (Huang et al. 2018).

Access and equity for people with an enduring mental illness

Best practice in caring for people with an enduring mental illness and a life limiting illness should be based on sound palliative care. However, it has been found that people with a severe mental illness were less likely to access palliative care services and receive specialist procedures, such as palliative radiotherapy and pain and symptom management (Butler & O'Brien 2018; Chochinov et al. 2012; McHugh 2012; McNamara et al. 2018; Spilsbury et al. 2018; Woods et al. 2008). Reasons for this disparity in access to services may include the effects of the illness itself such as communication difficulties, isolation and information processing. It can also be the effect of societal stigma and their

disenfranchisement within the health care system (Chochinov 2012; McNamara et al.2018).

An Australian study found that the physical co-morbidities of people with schizophrenia accounted for 60% of premature death (Colton & Manderscheid 2006). A later Canadian study by Chochinov et al. (2012) examining the use of healthcare services, including palliative care, found that it was common for patients with schizophrenia to have poor and insufficient care in their final days. Their data suggested that access to quality palliative care was 'woefully lacking' (Chochinov et al. 2012, p. 3). Chochinov et al. (2012) found that people with schizophrenia were 2 to 3 times less likely to receive palliative care than the general population. In addition, people with a diagnosis of schizophrenia received less hospital and home care and were more likely to die in a nursing home (Chochinov et al. 2012). Lavin et al. (2017) and Wilson et al. (2020) confirmed that for people with a severe mental illness, there was an increased likelihood of dying in a nursing home. Living the final stage of one's life in a nursing home may go against the wishes of the individual and denote disparity in care (Lavin et al. 2017). Further, Chochinov et al. (2012) argued that people with schizophrenia see fewer specialists towards the end of life, apart from a psychiatrist, and even those visits were 2 to 3 times less frequent after becoming terminally ill. Similarly, a New Zealand study by Butler and O'Brien (2018), found that people with a mental illness were 3.5 times less likely to receive specialist palliative services than that of the general population. In contrast, a recent French study found that people with schizophrenia and bipolar disorder are more likely to receive palliative care and less likely to receive high end medical care at their end of life, such as chemotherapy and surgery (Fond et al. 2019; Fond et al. 2020). Despite the contradictions in evidence, inequities in service provision remain.

Ganzini et al. (2010) argued that although the incidence of cancer in people living with a mental illness was no greater than in the general population, there was a 30% higher fatality rate. However, research by Fond et al. (2019) and Fond et al. (2020) found that cancer patients with mental illness died younger and closer to first diagnosis of cancer

than the general population. A diagnosis of advanced cancer may be due to the person's inability to access timely screening and / or appropriate treatment after the initial diagnosis. An inability to access appropriate treatment may again be due to issues relating to the person's mental health such as poor insight into possible symptoms and stigmatisation and stereotyping about mental illness on behalf of medical staff (Fond et al. 2018).

Similarly, Kisely, Crowe and Lawrence (2013) determined that the proportion of patients with metastatic disease on first diagnosis was significantly higher in patients with a severe mental illness. This result may be because people with severe mental illness are less likely to attend cancer screening or have regular check-ups (Ellison 2008). In addition, the symptoms of the mental illness may lead to significant delays for people with severe and enduring mental illness accessing appropriate and timely healthcare (Goldenberg, et al. 2000; Jerwood et al. 2018; Morgan 2016).

The symptoms of the mental illness, such as having severe psychosis, potentially make it difficult for the person to communicate their physical symptoms, leading to the under-reporting of pain (Chochinov et al. 2012; Evenblyg et al. 2016; Woods et al. 2008). Hence, the patient's pain management may be sub-optimal (Chochinov et al. 2012). Moreover, people with a severe and enduring mental illness may fluctuate in their understanding and acceptance of their end-of-life illness (Woods et al. 2008).

To illustrate the effect of delays in treatment, Goldenberg et al. (2000) gave examples from clinical practice of people with schizophrenia who had fungating, and ulcerating breast cancers, or who had myocardial infarctions for which they had not sought treatment. Goldenberg et al. (2000) hypothesised that this phenomenon may be due to a lack of verbalisation of pain, high levels of pain tolerance, or the person incorporating pain into their delusional system. People with an enduring mental illness can be faced with issues of homelessness and substance abuse. These issues can further complicate service provision (Barker 2005; Donald & Stajduhar 2019; McCasland 2006; McHugh 2012; Woods et al. 2008).

In summary, studies have revealed that people with an enduring mental illness are more likely to die at a younger age from chronic health conditions than the general population (Happell, Platania-Phung & Scott 2014; Plana-Ripoll et al. 2019; Scott & Happell 2011). However, little attention has been given to their varying needs when they are facing death (Chochinov et al. 2012; Butler & O'Brien 2018; Donald & Stajduhar 2019; Relyea et al. 2019; Terpstra & Terpstra 2012). Although there has been some literature written on the physical needs of individuals with an enduring mental illness who are facing death, the only research found to date that explored spiritual care in relation to individuals facing death from a life limiting illness was a Dutch study by Evenblij et al. (2016). This study explored the barriers to providing palliative care in Dutch inpatient psychiatric facilities. The study concluded that further research on the spiritual care of this population requires attention. The authors claimed that this attention is especially warranted considering deinstitutionalisation and the changes to mental healthcare provision, including the drive toward community care and the recovery approach. These changes have already occurred in Australia. Treatment for people with mental illness in Australia is now predominantly in community-based settings, as opposed to institutional care. This conclusion by Evenblij et al. (2016) and the lack of research on this type of care, points to a clear knowledge gap.

Given that death and dying frequently activates a spiritual quest (Harrington 2016; O'Callaghan et al. 2020; Zumstein-Shaha, Ferrell & Economou 2020), the next section will examine the spiritual needs of people who are dying at a younger age than the general population, such as individuals with a severe mental illness. It will also examine the effects of stigma and alienation.

Spiritual distress when dying young

Living with a mental illness and facing death can engender spiritual and existential concerns (Harrington 2016; Wilding, Muir-Cochrane & May 2006). Hence, it can be surmised that for people who have a history of serious mental illness who develop a life

limiting illness, spiritual issues or existential concerns are important dimensions to consider in approaching their care. This assertion may be particularly true for individuals with a mental illness who are dying at a younger age, as research has demonstrated that dying at a young age is an indicator for spiritual distress (Balboni & Balboni 2018; Chochinov et al. 2009; Ellison 2008; Hui et al. 2011; Winkelman et al. 2011).

A study by Winkelman et al. (2011) found that dying at a younger age was the only significant predictor of spiritual concerns. Correspondingly, a recent survey-based, multi-site, cross-sectional study by Balboni and Balboni (2018) also found that the only significant predictor of spiritual concerns was that the patient was of a younger age than the general population. One explanation offered was that younger patients were more likely to still have children in their care as well as other life responsibilities that further added to their distress.

Spiritual concerns or distress include being angry with God, doubting God's existence and concerns about being punished or abandoned by God (Phillips & Stein 2007). In a study by Winkelman et al. (2011), it was found that experiencing spiritual concerns was associated with poor psychological outcomes. Spiritual distress for people with a life limiting illness has been described as a sense of disintegration, which threatens their sense of identity (Buxton 2007; Hui et al. 2011). Spiritual distress can also take the form of feeling that one's faith has been shaken or destroyed (Buxton 2007).

Anticipation of death in younger patients can raise a variety of existential concerns (Chochinov et al. 2009). These concerns include feelings of losing control and of not having enough time to live out one's dreams and ambitions (Chochinov et al. 2009; Hui et al. 2011). In addition, for younger people facing death there can be increased "social isolation and a diminished sense of self" (Williams 2004, p. 34). People who die at a younger age and who have experienced marginalisation and stigma, such as people with a mental illness, may experience a greater sense of personal disintegration as they already suffer a diminished sense of personhood (Woods et al. 2008).

Williams (2004) maintained that for younger people, a shortened life span can increase their existential suffering. Williams (2004) highlighted that the people who are dying at a younger age often feel stigmatised as they may believe that dying was their fault. For example, if they have been a smoker or feel that they have not cared for themselves physically in some other way. Moreover, it is not uncommon for people with a severe mental illness to experience negative life impacts due to their mental illness, such as loss of family, education, or potential. Because the effects of stigma may have permeated their lives, people with a mental illness who are dying at a younger age may be doubly stigmatised and suffer even greater spiritual or existential distress (McNamara et al. 2018).

Similarly, a study by Hui et al. (2011) found that 44% of patients in a palliative care unit suffered from spiritual distress. These patients were more likely to be younger, in physical pain and suffer from depression. The authors maintained that pain could limit the patient's interactions with others and engender alienation. Hui et al's. (2011) study found that younger age is "a risk factor for despair, brokenness, helplessness, and meaninglessness" (Hui et al. 2011, p. 267). There has been no research into the spiritual distress or needs of younger people who have both a life limiting illness and a mental illness. Although the Hui et al. (2011) study did not focus on people with a pre-existing mental illness, it can be reasoned that it is likely people with a mental illness who are currently dying at a younger age than the general population, will experience these risk factors for spiritual distress.

This section has identified that people who are dying at a younger age than the general population are more likely to experience spiritual distress. This is particularly significant for people with a mental illness as the research has found that people with mental illness tend to die at a much younger age than the general population (DeHert et al. 2011; Lawrence, Hancock & Kisely 2013; Scott & Happell 2011). The next section will provide an overview of the chapters in this thesis.

Overview of Chapters

Chapter Two will provide the context and background for this study. It will examine the concepts of existential suffering and 'death anxiety' within Western culture. Existential suffering has been described as the experience of groundlessness or being shaken to the core and longing to find ground (Bruce & Boston 2011). The argument will be made that the concepts of existential suffering and 'death anxiety' relate to individuals with a severe mental illness who are dying at a young age. Further, Chapter Two will discuss mandates of the State and National Policy in relation to spirituality and recovery, and the clinical dilemmas nurses have in fulfilling these mandates. To provide further context to these clinical dilemmas, Chapter Two will discuss the intertwining history of religion and psychiatry and the influence of the discipline of psychiatry on Western thought. In addition, it will explore the relationship between the disciplines of psychiatry and anthropology, and how their different underpinning philosophies have influenced the reflective practices of contemporary mental health nursing. It will then explore the contemporary culture of mental health nursing and argue the importance of reflective practice when providing spiritual care.

The chapter will also explore definitions of spirituality, religion and existentialism and discuss how these definitions relate to spiritual care and research. Finally, as this study is exploring cultural issues of spiritual care at end of life, it will examine the interface between cultures of mental health care and palliative care.

In Chapter Three I will review the existing literature in this area. The literature search for this review found that there is currently no literature on the spiritual care needs of people with an enduring mental illness who also have a comorbid life limiting illness. Given that people with a mental illness are dying at a younger age than the general population, which places them at risk of spiritual distress, this lack of research points to a major knowledge gap. As there were no studies found on the spiritual care needs of

people with a severe mental illness who are dying, Chapter Three will examine the themes that relate to spiritual care from both the current palliative and mental health literature.

A key theme that arose from the mental health literature is the importance of the spiritual care to the recovery process. Yamada et al. (2020) claimed that their most significant finding was that most mental health service recipients wanted the mental health system to offer more spiritual support to them and their families as a resource for their recovery. Chapter Three will demonstrate the connection between recovery principles, existentialism and spiritual care. Another major theme which arose from the mental health literature was the importance of spirituality and religion in assisting individuals in their recovery from mental illness, and the deep meaning that spirituality has for many individuals with a mental illness. Themes from both the mental health and palliative care literature reveal the importance of spiritual assessment in identifying the person's unique spiritual needs and in identifying existential pain or spiritual distress. This chapter will also identify themes relating to spiritual care of the dying and the importance of a spiritual assessment and trauma informed service provision.

Chapter Four is the methodology chapter. It will demonstrate the efficacy of using the combined qualitative research methodologies of focused ethnography and autoethnography for this PhD study. The combining of these methodologies provided a rich and layered descriptions of the current culture, while retaining respect and sensitivity for a highly vulnerable group of people. These research methodologies offer a description of the landscape of spiritual care within the current culture of mental health services and explore the guiding question for this study; 'how does the current culture of mental health services, support or hinder the mental health nurse's ability to facilitate spiritual care for individuals with a severe mental illness who are facing death?'

The methodology chapter will provide a definition of 'culture' and discuss the philosophical and historical developments that have led to the emergence of contemporary sub-genres of ethnography. As opposed to traditional ethnography, both focused ethnography and autoethnography are underpinned by insider knowledge

(Higginbottom, Pillay & Boadu 2013). It will be argued that as the researcher, I had relevant insider knowledge due to my role working with people who had an enduring mental illness and were also facing death. The knowledge and experiences gained through my clinical practice will add a deeper, subjective and reflexive dimension to the data. Further, this chapter will demonstrate how the reflective practices of the professional culture of mental health nursing corresponds to and can complement the reflexive nature of qualitative research. This chapter will also provide a theoretical framework, based on nursing theory, which will be used as a lens for analysing the data. The nursing theory will be predominantly based on Joyce Travelbee's work (1926-1973).

Chapter Five will discuss the methods for data collection and identify strategies for the analysis and interpretation of the data. The focused ethnography involved face to face semi-structured interviews with both mental health nurses and palliative care nurses and an examination of relevant documents. Palliative care nurses were recruited into the study as spiritual care is a core competency for this field of nursing, and it was surmised that it would be valuable to understand how they perceived and implemented spiritual care for people with a mental illness, through their end-of-life trajectory. Data collection for the autoethnography involved reflection on my own practice setting and clinical practice. A triangulation process was developed to compare and analyse the data from the focused ethnography and the data from the autoethnography. To ensure reflexivity and transparency regarding personal cultural influences when analysing and interpreting the data, a culture gram adapted from Chang (2008) will provide an overview of my background and cultural identity as the researcher. This chapter will discuss strategies it used for establishing the ethical parameters of the research. It will also provide a clinical context for the study through providing background information on health services in which the data was collected.

Chapter Six will provide the results of the research study. Data from the focused ethnography will include the themes and issues that were constructed from an analysis of the data after an interrogation of relevant government documents and the interviews with

mental health and palliative care nurses. The results of this data suggest that the culture of mental health services, especially community mental health services, were in crisis at the time of the data collection. Despite this crisis, the results of this thesis indicated that mental health nursing practice continued to be based on compassion and guided by mental health nursing theory and professional nursing values.

A key theme that was found through an analysis of the data, was that although the research question asked whether the culture of mental health service assisted in the facilitation of spiritual care, both the mental health nurses and the palliative care nurses the nurses not only facilitated spiritual care, but also provided this care. Chapter Six will discuss the data that demonstrates how mental health nurses provided spiritual care through the therapeutic 'human to human therapeutic relationship'. Moreover, the data suggested that the foundation of their spiritual care was based on love. Although the word 'love' was used in an interview by a palliative care nurse, the deep feelings of fondness, admiration and mutual respect expressed by the mental health nurses, mirrored the aspects of love that philosophers and theorists have described as 'agapé' and 'alterity'. In the context of this research, the word agapé has been used as it is more precise than the word love. Love can mean sexual desire or love of a brother, but in this context, it relates to other-centredness and self-giving love (Harrington 2006). The data further indicate that alterity which has similar and at times overlapping conceptual aspects to that of agapé, also underpinned the spiritual care given by the nurses. Alterity means seeing the humanity of the 'other', especially the 'other' who is suffering. French philosopher Levinas (1906-1995) reasoned that it is through alterity that we do not objectify the 'other'. We "recognize the other as resembling us, but exterior to us; the relationship with the other is a relationship with a Mystery" (Levinas 1989, p. 43). Seeing the suffering of another, brings forth an innate moral obligation to be present to the 'other' (Lévinas 1994; Lavoie, Blondeau & De Koninck, 2008).

Chapter Seven is the discussion chapter. It will discuss the themes and issues that arose in the results chapter in light of relevant literature. This chapter will highlight how

this study makes an original contribution to knowledge. In this chapter it is posited that the motivation for providing this care was based on the values and beliefs of the professional culture of mental health nursing.. This thesis's contribution to knowledge is noteworthy because it examines organisational cultural issues that impact on systems and processes within organisations and effects patient visibility and care.

Chapter Eight is the concluding chapter. This chapter will provide an overview of previous chapters highlight cultural structures that either hindered or supported the provision of spiritual care by mental health nurses.

Recommendations will be made for the further development and recognition of spiritual care. Additionally, this chapter will recommend strategies that will assist mental health services in recognising and developing quality care for individuals who develop a life limiting illness. It will discuss strategies for the development of education, nursing leadership and policy. Within this chapter it will be argued that further research which includes the voice of individuals with a mental illness, is essential for addressing gaps in service delivery (Donald & Stajduhar 2019; Selman et al. 2018).

CHAPTER 2 - BACKGROUND

Introduction

The purpose of this background chapter is to provide the reader with a contextual framework from which to view the remainder of the study. The chapter will offer insights into the ambivalent and often contradictory culture in which mental health nurses currently practice. Despair and 'death anxiety' can be a profound source of spiritual or existential suffering for humankind (Bruce & Boston 2011). This chapter will examine existential suffering and 'death anxiety' as it relates to people with a severe mental illness. It will also discuss the relationship between spirituality and well-being in the general population and the South Australian State and Australian National policy directives mandating that mental health services provide spiritual care in relation to recovery. It will explore dilemmas that mental health professionals have experienced in fulfilling these mandates. These health professionals reported they experienced an uneasy relationship with issues of spirituality and religion. It will be suggested that this unease could have been partially due to historical factors, such the intertwining and oft times discordant history between religion and psychiatry.

To provide further background context to the study question, this chapter examines how the culture of psychiatry has developed and influenced Western thinking. This chapter will discuss the historical factors that have mutually influenced the development of anthropology and psychiatry, and the long and often ambivalent relationship between these disciplines will be explored. It will be argued that the interweaving of the philosophies of anthropology and psychiatry has influenced the current practice of mental health nursing.

Another aspect of mental health nursing is the importance of understanding the human psyche or 'self' and how this construct is formed from an individual and cultural perspective. Both psychiatry and anthropology have had an influence on how the psyche

or 'self' has been constructed within Western culture. Within this chapter I will briefly explore these influences and how they have impacted on the reflective practices of contemporary mental health nursing.

In addition, as lack of a clear definition on the meaning of spirituality can hinder spiritual care (Harrington 2012), this chapter will explore the debate surrounding the definition of spirituality and religion and examine how these definitions effect clinical practice and research. Finally, this chapter will explore the interface between the disciplines of mental health and palliative care. It will be argued that the similarities in ideology and values will assist the two disciplines working together to ensure quality care for individuals with a life limiting illness and a severe mental illness.

Existential suffering and 'death anxiety'

Since the beginning of Western psychiatry, existential psychotherapists have grappled with existential suffering caused by the anxiety engendered by the finitude of life. Rollo May (1975) maintained that humans must face the fact that at some unknown time in the future, they will die. Yalom (2008, p. 202) states that we are finite creatures randomly "thrown alone into existence". A hundred years ago Carl Jung, a highly influential Swiss psychiatrist and psychotherapist, described death as a "fearful piece of brutality... there is no sense pretending otherwise". Jung maintained that death was brutal, not only physically but also psychically. A person "is torn away from us, and what remains is the icy stillness of death" (Jung 1953, p. 83).

Jung maintained that in order to effectively treat patients, the treating person needed to undergo their own healing process. Within this healing process the treating person needed to examine their own psyche. To reflect the process of healing, Jung coined the term 'Wounded Healer' (Jung 1953–83). The concept of the 'Wounded Healer' is echoed in the conclusion of Edwards et al's. (2010 pp. 262- 263) meta study which maintained that awareness of one's own spirituality is essential to spiritual care, as is the importance of

reflecting on one's own personal losses and mortality. Later, through his anthropological studies into other cultures, Jung (1961) argued that there could be joy in death and that a person's life and death was sometimes a cause for celebration. Jung's deeply religious beliefs underscored his work throughout his life. Jung's work will be discussed further in this study, when examining the birth of psychiatry and issues relating to religion.

In contrast to Jung, Irvin Yalom, a contemporary secular existential psychotherapist, states that our fear of death is the mother of all religions and that religion is an attempt to ameliorate the terror and anguish of nonexistence (Yalom 2008). Despite their fundamental differences in their beliefs in the existence and nonexistence of God, both Jung and Yalom highlight that shrinking away from the face of death can cause great anxiety and can rob life of joy and meaning (Jung 1961; Yalom 2008). In his book 'Staring at the Sun', Yalom (2008) discussed Epicurus' belief that our fear of death creates misery and interferes with our joy of living. He referred to Epicurus as a proto-existential psychotherapist.

Yalom (2008) argued that it has been part of the human condition since antiquity, to create aimless activity in order to avoid the pain associated with the fear of dying. Yalom 2008 maintained that really looking into the terror and anguish of dying is like 'staring at the sun'. By staring death in the face, the terror of death can be ameliorated, and life can become enriched. Yalom also argued that there is a correlation between the "fear of death and the sense of a life not lived" (Yalom 2008, p. 49). The premise is that the less a person fulfils their potential dreams, the greater the person's 'death anxiety'. Disappointment in a life not fully lived fuels 'death anxiety'. If this premise is true, then what does it hold for the individual who, because of an enduring mental illness, has not been able to fulfil their dreams? Further, individuals with a mental illness have often experienced more losses, such as opportunities from education and employment, family and friends, than the general population. These losses may have left them isolated and lonely which in turn may have led to a greater propensity toward 'death anxiety'.

Although Yalom (2008) did not discuss people with a severe and enduring mental illness, he worked with patients who experienced 'death anxiety'. He argued that to manage 'death anxiety' through an existential approach was the most effective method in his practice. He also maintained that dying is the loneliest event in a person's life. Death separates a person from others and the world. Yalom (2008) believed that loneliness greatly increased the anguish of dying. He also maintained that Western culture creates a "curtain of silence" around the dying (Yalom 2008, p. 120). Friends and family will often become more distant because they do not know what to say or do and fear upsetting the dying person, or because they fear confronting their own death. The isolation of dying compounds the terror. Again, what does this mean for a person with a severe and enduring mental illness who frequently lives their entire lives in social isolation?

This section has discussed the possible anxieties, fears and need for reconciliation in people facing death. However, for the person with a severe and enduring mental illness, having a sense of reconciliation or acceptance of death may indeed prove particularly difficult. A person who has lived with a severe and enduring mental illness may have lived outside the norm which in turn may give shape to unique grief and needs (Woods et al. 2008).

The next section of this chapter will examine the issue of spirituality across the general population and its relationship to well-being. It will then review the state and national policy directives in Australia that mandate that mental health professionals work with individuals in respect of their spiritual needs, to discuss the importance of spirituality within the recovery process.

Spirituality - well-being and the mandates of the state and national policy in relation to recovery

Research has illustrated the benefits of spirituality and religion on mental health within the general population (Koenig 2009a; Koenig 2010; Koslander, Da Silva & Roxberg 2009). Religious and spiritual involvement has been found to be significantly related to

well-being, happiness and life satisfaction (Haynes et al. 2007; Puchalski et al. 2014). It has also been found that most of the world's population is involved in some form of spiritual practice. Worldwide, more than eight out of ten people have some religious affiliation (The Global Religious Landscape 2013; Hackett & Grimm 2012). In 2016, a census by the Australian Bureau of Statistics (ABS) found that three-fifths of the Australian population (61 per cent, or 14 million people) were connected with a religion or spiritual belief (Australian Bureau of Statistics (ABS) 2018).

In Australia, spiritual care is a mandated dimension of mental healthcare. The National Framework for recovery-oriented mental health services (2013 p. 53) states that mental health providers should “acknowledge the relevance of the person's belief system including cultural, spiritual and religious perspectives”, and to support people in spiritual practices which they find helpful. The South Australian Mental Health and Well-being Policy 2010-2015, recognises the individual's unique spiritual dimension and states that care should be tailored accordingly (South Australia's Mental Health and Wellbeing Policy 2010-2015, 2010).

Definitions of contemporary spirituality are diverse and multifaceted. These include feelings of connection between one's self and others, and sometimes a connection with a higher being (Koenig 2012). They may also include an appreciation of beauty, and a search for meaning and purpose (Candy et al. 2012; Edwards et al. 2010; Harrington 2012; Koenig, King & Carson 2012; Pesut 2008). Spirituality has also been linked to personal growth and well-being (Ivtzan et al. 2013). An Australian study by Jones, Sutton and Isaacs established that for people with a severe mental illness, spirituality included finding “what gave them comfort, tranquillity, strength, happiness, hope and understanding” (2019, p. 351). In addition, defining spirituality for research purposes has been controversial (Koenig 2012) and the ongoing debate will be discussed later in this chapter.

Definitions of recovery from mental illness contain many of the concepts found in the contemporary definitions of spirituality.

One of the most frequently cited definitions of recovery comes from Anthony (1993)

Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony 1993 p. 13, cited in NSW CAG 2009, p. 18)

Although working with the spiritual and religious dimension of the individual is mandated in policy, most of the research on spirituality, religiosity and existential distress occurs outside of the mental health sector (Koenig 2012). In addition, Koslander, Da Silva and Roxberg (2009) pointed out that there is considerable difference between the spiritual care given within mental health services and the spiritual and existential care given by palliative services.

In a text by Swinton (2001), it was highlighted that spirituality is a significant component of the human condition and therefore, to assist human beings to flourish, their spiritual care needs to be considered. Swinton (2001) argued that there is a deep interconnectivity between the psychological, physical and spiritual dimensions of a person. Each dimension of the person impacts upon the other. Swinton (2001) maintained that it was a mistake to assume that even when a person's spirituality becomes distorted due to mental health issues such as psychosis or a depressive illness, that these spiritual issues are aspects of pathology. Discerning between the aspects of the person's spirituality that are impacting on the person, either negatively or positively, can assist them in their recovery.

There are two major influences on the amount of attention given to spiritual care within mental healthcare settings. The first influence is the nature of mental illness itself and the dilemma that mental health professionals have in distinguishing between spiritual concerns and religious delusions and hallucinations. The second is the long and ambivalent history between psychiatry and religion which has influenced current practice

(Swinton 2001). To provide further clarity to the discussion, these two influences will be explored in the following two sections.

Clinical dilemmas - religious delusions and spiritual care

Clinically, it is important to be able to distinguish between religious delusion and religious belief or faith. However, distinguishing between religious faith and delusions can be a complicated process (Huguelet & Mohr 2009). In a review by Koenig (2009b) it was pointed out that there have been limited studies which explore the link between psychosis and religion. Koenig (2009b) highlighted the controversy in the reviewed literature regarding people having a poorer prognosis when they experience religious delusions. Mental health professionals may have difficulty discerning between spiritual experiences and the delusional activity (Wilding, Muir-Cochrane & May 2006). Wilding, Muir-Cochrane and May (2006) also pointed out the importance of discerning whether a person's beliefs may lead to harm, either to the client, themselves or to others. Although people with a mental illness often experience spiritual concerns that may be expressed in psychosis, there is no consensus on how to work with the individual's spiritual or religious needs when they are suffering from a severe psychosis (Koslander, Da Silva & Roxberg 2009). Indeed, spiritual interventions may be contraindicated if the person is delusional (Koslander, Da Silva & Roxberg 2009) as the patient's spiritual or religious beliefs may be incorporated into their delusional system. Moreover, many mental health professionals do not have a clear understanding of the difference between "religiosity, spirituality, and psychotic illness" (Racine 2011, p. 111).

Clinicians are taught to assess religious delusions but not to undertake religious or spiritual assessments. Although the DSM-IV now has a diagnostic category for spiritual or religious problems, it does not provide any criteria for distinguishing between psychosis and genuine spiritual experience (Nolan et al. 2012). Hence, culturally normative spiritual experiences may be mistaken for delusions. The clinician's lack of understanding or

mistrust of spirituality or religious beliefs may explain why issues of spiritual well-being are neglected in clinical practice (Koslander, Da Silva & Roxberg 2009; Sheppard 2012).

Underscoring the importance of spirituality to the recovery process, Clay (1995) spoke of a spiritual crisis from the perspective of an individual who had lived experience of mental illness. Clay (1995, p. 3) declared that, “for me, becoming ‘mentally ill’ was always a spiritual crisis, and finding a spiritual model of recovery was a question of life or death”.

Similarly, Patricia Deegan, who is a prominent individual within the recovery movement stated

Distress, even the distress associated with psychosis, can be hallowed ground upon which one can meet God and receive spiritual teaching...those of us who are diagnosed can have authentic encounters with God (which) encourage the healing process which is recovery. (Deegan 2004, in ‘Remember my name’ online)

An examination of the historical context from which psychiatry has emerged and the intertwining history of religion and psychiatry, may provide useful insights into why clinicians were uneasy exploring spiritual and religious issues. Similarly, it may provide further insights into the lack of spiritual care by some mental health clinicians.

The intertwining history of religion and psychiatry

Until the last century, religious communities were primarily responsible for caring for people with a mental illness. Religion and mental healthcare have a long history of being closely intertwined (Koslander, Da Silva & Roxberg 2009). The care of the people with a mental illness occurred in monasteries or in psychiatric institutions run by religious orders (Koenig 2009b). The eighteenth-century asylums or ‘mad houses’ were brutal and often violent places where ‘the mad’ were frequently treated like animals (Bothwick 2001). Philippe Pinel 1745-1826, a French physician who has been named as the father of psychiatry, led the initial changes to the lives of the people with a mental illness, due to his belief that those with mental illness should be treated with humane psychological methods. Pinel maintained that religious fanaticism could be a causative factor in

madness, and that people with a mental illness should not have access to the symbols and practices of their religion. Instead, they should be taught philosophy and history (Menezes 2010). Thus, it was these methods that started the divide between religion and psychiatry.

In contrast to Pinel's theory that religion should not be part of the treatment of those experiencing a mental illness William Tuke 1732-1822, a Quaker, claimed that care for the people with a mental illness was deeply tied to their spiritual care. Tuke founded the first privately run mental health institution in England, named the 'York Retreat' which is still within operation to this day. (Koenig, King & Larson, 2013). The name intended to convey that the place was one of refuge, where patients may find quiet and safety in a homely environment. Tuke was a pioneer and revolutionary in the humane treatment of the 'insane' in the late eighteenth and early nineteenth century. His methods had a great influence over the public asylums of the day (Bewley n.d). Underpinning Tuke's treatment methods was the principle that no matter how withdrawn or disturbed a patient was, as human beings, they contained the 'Inner Light' of God. The treatment was based on the equality of all humans and the deeper and more transcendent meaning in peoples' lives (Bothwick 2001). The early treatment of people with mental illness was at times based on spiritual care. However, there was a shift in Western thinking that changed their care. Further, the discipline of psychiatry also influenced Western thought, which again in turn influenced psychiatry and mental health nursing.

The influence of the discipline of psychiatry on Western thought

The early 19th century had several great and influential thinkers who significantly influenced current Western thought and contemporary psychiatry. Freud 1856-1939 was highly influential in psychiatry (Thielman 2009). History has reported that he claimed to be an Atheist and taught that religion was an illusion that caused neurosis, hysteria, delusions and other mental pathologies, and that religion fostered immaturity and restricted choice (Thielman 2009). Freud (1928, location 609 of 798, Kindle Ed,) argued

that because religion caused cultural repression and kept 'mankind' in a childlike state, it was "the universal obsessional neurosis of humanity". And as such, the religions of humanity are an example of mass delusions (Freud 1930). Jung who was originally a disciple of Freud, later distances himself from Freud, partially because of Freud's views on spirituality (Jung 1961). In a letter to Jung, Freud wrote "[p]sychoanalysis is in essence a cure through love" (cited in Bettelheim 1983, p.xi).

The writings of Freud continue to have a profound effect not only on psychiatry but also on Western thought generally. Freud has been credited with bringing a scientific approach to the study of the mind, which privileged objectivity and detachment (Lakeman 2013). However, Bettelheim (1984) contested that Freud's writings in English were not accurate translations and that much of the work that was translated into English was seriously defective, as it has lost much of the meaning Freud was trying to convey.

Freud coined the word 'psychoanalysis' from the term 'psyche', meaning 'the soul'. He considered psychoanalysis to be an examination of the soul (Bettelheim 1983). According to (Bettelheim 1983), this aspect of Freud's writings has been lost and the focus of his work has been on the biomedical approach. However, Freud himself spent many years exploring different cultures and their symbolic meaning and wrote prolifically on how these cultures impacted on the unconscious and psychic life of the individual (Freud 1917). Lakeman (2013) has pointed out that there was an agenda in North America to transform psychiatry into a scientific discipline alongside other branches of medicine. Hence, misleading translation has led to a misunderstanding of much of Freud's work and the dominance of the biomedical sciences in psychiatry.

The biomedical view now held by Western psychiatry is fragmentary and reductionist. Psychiatry is undergirded by the dominant explanatory frameworks of science and medicine (Swinton 2001). The assumption within this framework is that all mental health concerns can be explained within the scientific method. However, Swinton (2001, p. 51) argued that "[T]he complexity and uniqueness of human existence cannot be captured by statistical norms and universal generalities" (Swinton 2001, p. 51). All mental health

problems are viewed within material terms. Issues of spirituality fall outside of this framework. Thus, partially explaining Western mental health services neglect of spiritual and existential needs (Green, Gardner & Sandra 2009; Koslander, Da Silva & Roxberg 2009; Koslander, Lindström & Barbosa da Silva 2012). Borrás et al. (2010) argued that the widening gap between psychiatry and religion may be due to the influence of biological and psychological theories, and the rejection of religious values by leaders in the field.

The birth of existential philosophy in the nineteenth century also had a great influence on contemporary Western thought, medicine and mental health care. Friedrich Wilhelm Nietzsche 1844-1900 was a German philosopher and the father of existentialism. Koenig (1994), posited that when Nietzsche proclaimed that “God is dead”, the separation between religion and medicine widened. This history may account for a culture which has systemically influenced the reluctance of mental health clinicians to explore spiritual or religious issues (Koslander, Da Silva & Roxberg, 2009; Sullivan 2009).

Despite the emergence of the biomedical model, existential philosophy is continuing to have a more holistic and humanising effect on psychiatry (Koslander, Lindström & Barbosa da Silva 2012). Not all influential psychoanalysts of the time were anti-religious. Victor Frankl 1905-1997, an Austrian psychiatrist and Jewish holocaust survivor, was a highly influential existential psychotherapist who proclaimed the dignity of people who suffered severe mental illness. From his experience in the concentration camps, he found that it was possible to find meaning through suffering and that even through intense suffering, meaning could create the desire to live. He also maintained that spirituality and meaning are essential to mental health.

Frankl was greatly influenced by Friedrich Nietzsche’s work and frequently quoted him, especially in his famous book, ‘Man’s Search for Meaning’ which was written about his life in the concentration camps. He frequently cited quotes of Nietzsche’s such as “[t]hose who have a 'why' to live, can bear with almost any 'how' and “[t]hat, which does not kill me, makes me stronger.” (Frankl 1992, p. 89). Frankl created logotherapy, which explored existential and spiritual needs, and is still being used in some sectors of healthcare (Frankl

1946; Shantall 2020). Frankl and the later era of existentialism ushered in new understandings of spirituality which may or may not contain the notion of God. Frankl (1948) argued that there was a trend away from denominational religion and if religion was to survive, it needed to become profoundly personal.

An aspect of mental health nursing is understanding the human psyche or 'self' and how this is formed from an individual and cultural perspective. Both psychiatry and anthropology have had an impact on how the psyche or 'self' has been constructed within Western culture. This next section will briefly explore these influences and how they impact contemporary mental health nursing practice.

The influence of anthropology and psychiatry

The models of the development of the individual psyche (psychiatry / psychology) and the social psyche (anthropology) are tightly interwoven (Goodwyn 2014, p. 171). An understanding how these two disciplines interrelate can provide a context and deeper insights into current mental health culture. Like psychiatry's aspiration to become a scientific discipline, anthropology has its underpinnings in the empirical sciences. Traditional anthropology privileged the objective stance of the researcher. This often meant that the 'voice' and experience of the participant were filtered through the paradigmatic lens of the researcher which was usually Eurocentric (Cruz & Higginbottom 2013). In both psychiatry and anthropology, the 'voice' of the patient or the participant was not heard.

The disciplines of psychiatry and anthropology developed their theories at the same time in western history (Goodwyn 2014). There is now a renewed interest by some anthropologists in the scholarship of Freud and Jung, particularly in Jung's work (Goodwyn 2014). However, the relationship between the two disciplines has often been a provocative one, especially around their ontological and epistemological views of how the human psyche developed (Goodwyn 2014). The purist objective anthropological position

was that the human psyche was developed through society and culture whereas psychiatry / psychology maintained that it was through the influence of biology (Geertz 1973).

Despite the turbulent relationship between psychology and anthropology, psychotherapists such as Freud and Jung developed their psychological theories alongside anthropologists such as Durkheim (Goodwyn 2014). Jung and Durkheim knew each other personally and were influenced by each other's theories (Goodwyn 2014). Although empirical science was the foundation of anthropology and psychiatry, Jung (1971) extensively theorised on the nature of the soul and the psyche. Jung (1971) claimed that the structure of the human psyche innately contains symbols in the form of primordial images. Jung's work, which was not based in the biomedical sciences but rather, favoured the anthropological paradigm, adds another layer of complexity and contradiction to the already complex belief systems in which mental health nurses practice.

Understanding the development of the human psyche through an exploration of the historical and divergent influences of both anthropology and psychology on Western cultures, is useful when undertaking research that is within the culture of mental health services. Knowledge of these influences provides a broader platform for researching mental health services, because understanding the human psyche is a fundamental aspect of mental health nursing. The historical beginnings of psychiatry and anthropology both continue to have an influence over current day mental health nursing practice. Despite their frequently objective empirical stance, both psychiatry and anthropology also offer a rich and imbricated tapestry, which can provide a backdrop for viewing the culture of mental health nursing.

Contemporary culture of mental health nursing – Reflective practice in spiritual care

The culture of mental health nursing values the use of reflective practice in developing the foundational skill of mental health nursing practice, referred to as the 'therapeutic use of self' (Australian College of Mental Health Nurses 2010; Australian College of Mental Health Nurses 2011; Australian College of Mental Health Nurses 2013). As there is a complex interaction between the individual and culture, for a mental health nurse to use the 'self' therapeutically, there is a need to understand the nature of human psyche and how culture plays out in the individual. Reflection on how their own psyche has been developed within their professional and personal cultures, will assist mental health nurses in understanding how the psyche of others has been developed. In addition, the method of autoethnography, which will be used in this study, is useful for researching mental health nursing because the potential reflexivity of autoethnography is strongly aligned with reflective practices inherent in contemporary mental health nursing (Foster, McAllister & O'Brien 2006; Jones 2012).

Researchers have argued that both mental health and palliative nurses need to be aware of their own spiritual beliefs in order to provide effective spiritual care for their patients (Edwards et al. 2010; Fukui, Starnino & Nelson-Becker, 2011; Koslander Da Silva & Roxberg 2009; Koslander & Arvidsson 2005; Swinton 2001; Wilding, Muir-Cochrane & May 2006). However, Harrington (2012) highlights that a lack of clear definition on what is meant by spirituality can hinder the provision of spiritual care. And yet, despite a burgeoning interest in spirituality in the palliative sector (Harrington 2016), spirituality remains poorly defined and not well understood in the context of mental health care (Wilding, Muir-Cochrane & May 2006).

The next section of this chapter will explore the contemporary definitions of spirituality in Western culture and the consequent debate surrounding the definition of spirituality and religion within both the palliative and mental health literature. It will also explore the debate on the need for a clear definition in clinical settings. It will examine the commonality

between the concepts of spirituality and existentialism and how these changes affect mental health care.

The aim of exploring the definition of spirituality and religion is not to come to a definitive answer on the meaning of these terms but to gain an understanding of the complexity of the debate and what this means for clinical practice. The section will explore the dimensions of religion, spirituality and existentialism and argue that an understanding of these concepts can assist in providing care for mental health patients who are facing death.

Definitional Issues – The ongoing debate

Over the past decade, researchers in palliative care have undertaken considerable work on the development of a definition of spirituality to enrich further research and improve clinical care. Although there is a plethora of research on spirituality in the palliative care literature, this discipline does not often communicate or overlap with the discipline of mental health (Koenig, 2012). Within research disciplines, such as palliative care, issues of spirituality and religion are discussed and debated. Although there is a lack of consensus on the definition of spirituality in the palliative care literature (Harrington 2012) and a great deal of debate on the definition of spirituality, there is no corresponding debate occurring within the mental health literature (Koenig 2012).

The post-modern definition of spirituality can include concepts such as, feelings of connectedness to one's self and others, and sometimes a relationship with God or a higher being. Definitions of spirituality can also include an appreciation of beauty, such as art, music and nature (Edwards et al. 2010; Kandasamy, Chaturvedi & Desai 2011; Pesut 2008). Other concepts contained within the definition of spirituality may be a personal search for meaning, hope and transcendence (Candy et al. 2012; Harrington 2012; Koenig, King & Carson 2012; Pesut 2008). Egan et al. (2011) claimed that the common descriptors of spirituality being related to God, have changed to the focus of spirituality

being on the 'self'. A meta-study by Edwards et al. (2010) revealed that although a search for meaning featured strongly in many authors' introduction to, or pre-understanding of spirituality, relationships appeared to be the most important dimension of spirituality.

Much of the palliative care literature contends that spirituality may or may not include religious beliefs and affiliation (Candy et al. 2012, Egan et al. 2011; Pesut 2008). However, within the mental health literature, religion remains at the forefront of current research, with few papers that explore the definition of spirituality and religion. Although research and review authors from the mental health sector discuss both the importance of religion to the person with a mental illness and exploring the positive and negative effects of religion in the clinical context, religion and spirituality are rarely distinguished and are frequently used interchangeably (Russinova & Cash 2007). Moreover, the concepts embedded in the definition of spirituality such as existential concepts of meaning and hope intertwine with the concepts of the 'Recovery Movement' which is mandated to be the basis of contemporary mental health care throughout most Western countries (Bellamy et al. 2007; Corrigan et al. 2003; Green, Gardner & Sandra 2009; Fukui, Starnino & Nelson-Becker, 2011; Nolan et al. 2012; Webb et al. 2011; Wilding, Muir-Cochrane & May 2006).

The concept of 'self' and the individual searching for meaning, purpose, connectedness and transcendence, are also the central tenants of the existential paradigm. Most of the current definitions of spirituality within the qualitative research literature, define spirituality as a search for meaning and no real distinction is made between spirituality and existentialism (Edwards et al. 2010). This lack of distinction between spirituality and existentialism has become a problem within some areas of the mental health literature. The notion that existential concepts are aspects of spirituality has been contested. Some authors have argued that the use of existential concepts to define spirituality is un-therapeutic for people with a mental illness (Koenig, King & Carson 2012; Paley 2008a; Salander 2006; Whitehead, 2003). This view is held because for patients who experience existential distress, such as guilt and annihilation of the self, psychological assistance may be of more benefit than spiritual care.

In contrast, a mixed method study by Mako et al. (2006, p. 1110) found that “spiritual pain was both manifested and communicated through the emotional realm”. Participants described their pain using psychological terms such as feeling “despair,” “regret,” or “anxiety”. The authors argued that the use of emotional language to describe spiritual pain may be due to the contemporary Western culture’s language, which is not adept at describing spiritual concepts. On the other hand, from the perspective of those authors (Koenig, King & Carson 2012; Paley 2008a; Salander, 2006; Whitehead, 2003) who argued that despair, regret and anxiety are not spiritual phenomena, it could be reasoned that the participants in the Mako, Galek and Poppito (2006) study, used emotional language because their concerns were within the psychological as opposed to the spiritual realm. However, despair, regret and anxiety are forms of existential pain which further illustrates the problems associated with a lack of clear definition and the overlap of spirituality, existential issues and psychological difficulties.

The current understanding of spirituality is a recent phenomenon. Notions of spirituality in the West separated from religion during the 1950’s (Paley 2008a). Historically, the definition of spirituality was intertwined with religion and the definitions were integral to each other (Candy et al. 2012; Egan et al. 2011). However, the definition of spirituality is now less distinct and reflects the historical and philosophical changes that have occurred in the Western post–modern secular world. Within nursing, the definition has moved from a Judeo-Christian definition of spirituality to having a more secular meaning (Ronaldson et al. 2012). Although interrelated, spirituality is now a broader term that may no longer encompass religious affiliations or practices (Candy et al. 2012; Egan et al. 2011; Pesut et al. 2008). Religion and spirituality have become distinct but related concepts. In some instances, religion has become a subset of spirituality (Pesut et al. 2008). Chochinov (2006) points out that in our secular society God may not be mentioned in definitions of spirituality. Individuals in contemporary Western society now have a choice to believe all aspects of religion or none, and still believe one’s self to be spiritual.

Definitional issues - Religion, spirituality and existentialism

Adding complexity to the idea that concepts such as a search for meaning and purpose are existential concepts as opposed to spiritual concepts, influential theistic existentialists such including Carl Jung, Victor Frankl and Rollo May, used the term spirituality in both an existential and spiritual sense (Jung 1961; May 1975; Koslander, Lindström & Barbosa da Silva 2012). Frankl (1946) coined the term 'will to meaning' and believed the phenomena of searching for meaning was a true manifestation of humanity. Koslander, Lindström and Barbosa da Silva (2012) argued that it is vital to identify the meaning of spiritual experiences for the person and how the meaning impacts on their mental health. Theistic existentialists assert that finding meaning and hope is a part of a spiritual quest (Koslander, Lindström & Barbosa da Silva 2012). Of note, the above theistic existentialists were all psychotherapists who developed their unique therapies based on their existential philosophy.

Chochinov (2006, p. 88), also a psychiatrist, highlights that existential issues are a dimension of spirituality. He maintains that "distinguishing between the terms spirituality and existentialism, particularly in the context of palliative care is perhaps less important than recognizing the common ground between the two terms". The mutual point between spirituality and existentialism is the human urge or yearning to imbue life with purpose, hope and meaning. Does this mean that all human beings are spiritual in essence? What does this notion mean in terms of patient care?

Spirituality has often been defined as a quality inherent in all human beings (Kandasamy, Chaturvedi & Desai 2011; Penman, Oliver & Harrington 2013; Pesut 2008). As early as the beginning of the last century, Jung maintained that all human beings were essentially spiritual (Jung, 1961; Koslander, Lindström & Barbosa da Silva 2012; Thielman 2009). Later, Viktor Frankl (1975) contended that being human is to be spiritual, and that "...religious sense is deeply rooted in each and every man's (sic) unconscious depths" (1975, p.10). He argued that even people who claim to be irreligious may be more

religious than they admit (Frankl 1975). Contemporary researchers such as Pesut (2008, p. 2804), have argued that “to be human is to be spiritual” and even those who have no belief in God have spiritual needs.

However, Paley (2008a; 2008b) disputed the notion that all humans are spiritual beings. He argued that because people who are non-believers, such as atheists, agnostics or secular humanists, may not want to be seen as spiritual, they could potentially be unreceptive to spiritual care. The argument assumed that spiritual care involves proselytising. However, researchers in spiritual care have taken pains to point out that clinicians should never lose sight of the fact that within the therapeutic relationship, it is unethical for them to impose their spiritual or religious beliefs on the people they are treating (Borras et al. 2010).

In summary, it is evident that there is no consensus on the definition of spirituality, particularly within mental health care. What is clear is that in Western culture, changing views on spirituality and religion will influence clinical practice and the spiritual care given to patients. Clinicians bring into practice the cultural beliefs of the society they inhabit. To further understand how spiritual care can be provided, it is essential that research in the area of spirituality continues. Russinova and Cash (2007) claim that conceptual ambiguity in distinguishing between the terms religion and spirituality is a problem for research in the area of mental health. Hence, it follows that clarity in definition is also prerequisite for quality research. The next section will examine the current literature on defining spirituality and religion for research purposes.

Defining spirituality and religion for research purposes

The concept of spirituality has now become nebulous and open to a myriad of interpretations, from the secular to the deeply religious (Russinova & Cash 2007; Steinhäuser et al. 2017; Stephenson & Berry 2015). Steinhäuser et al. (2017), argued that although spirituality is an important aspect of care conceptually, in palliative care, the

construct of spirituality and how it is operationalised and measured for its clinical impact is not well developed. The lack of clear definition of the construct of spirituality “impedes independent investigations from systematically informing one another” (Steinhauser et al. 2017, p. 429).

Reinert and Koenig (2013) argued that for research purposes the definition of spirituality should focus on religious involvement and that this definition will provide a more accurate and consistent measure for evaluating health outcomes. Through reviewing current research, they concluded that religious attendance, involvement and intrinsic religiosity led to reduced mortality rates and enhanced physical and mental health outcomes. Moreover, Reinert and Koenig (2013) maintained that results which stem from an exploration of religious beliefs and practices were not “contaminated” by mental health concepts derived from existentialism, such as having a sense of meaning or purpose. They reasoned that the current definitions of spirituality were ‘contaminated’ with mental health concepts. As such, these concepts in research confound mental health outcomes. For example, a lack of meaning or purpose are symptoms of a depressive or anxiety disorder (Reinert & Koenig 2013). If these symptoms are linked to spirituality in mental health research, it means that negative mental health symptoms are linked to a lack of spirituality. Reinert and Koenig (2013) argue that for research purposes, definitions which are inconsistent and “contaminated” with mental health concepts, may render research findings that explore mental health as meaningless.

Although Koenig, King and Carson (2012) maintain that for research purposes there must be a separation of the spiritual from mental health concepts, it could be argued that the concepts of spirituality, and psychiatry, or mental health are inseparable. The very word psychiatry comes from the word ‘psych’, which is Greek for breath, life or soul (Antonakou & Triarhou 2017).

As Koenig points out

[s]pirituality and mental health are intimately connected to the supernatural and religion. Spiritual care includes a search for the transcendent, and so involves travelling along the path that leads from staunch non-belief to questioning to belief to devotion to surrender. (2010, p. 117)

Religion is characterised by beliefs, practices and rituals related to the transcendent (Koenig, King & Carson 2012).

Despite the differences in the development of spiritual care within the mental health and the palliative care sector, the core values of both disciplines are centred on patient focused care, the involvement of family and respect for autonomy and choice. In addition, both disciplines have a major focus on a compassionate, holistic, relationship-based care (McGrath & Holewa 2004). These common foci can provide an excellent foundation for the facilitation of comprehensive care and the integration of palliative and mental health care when required by the person with a severe mental illness and their families (McGrath & Holewa 2004). The following section will briefly explore the interface between palliative care and mental health.

The interface between mental health care and palliative care

Good communication and effective partnerships between the disciplines of mental health and palliative care are essential for improving end of life care for people with a severe pre-existing mental illness (Ellison 2008). There are some common ideological and professional commonalities between palliative care and mental health which can assist in enhancing communication and working together toward providing quality care for patients with a severe mental illness and a life limiting illness.

Psychiatry has had and is continuing to have an influence on palliative care services. Several influential authors in the palliative care literature mentioned in this thesis, are from the discipline of psychiatry. These include psychiatrists such as Canadian Professor of Psychiatry, Harvey Max Chochinov, who developed the Dignity Model and Dignity

Therapy, and is the Director of the Manitoba Palliative Care Research Unit, and Dr Harold Koenig, the Professor of Psychiatry and Behavioural Sciences at Duke University in North Carolina. Furthermore, much of the literature from the palliative care sector has reflected ideas which were based on Victor Frankl's work. Frankl is frequently cited in both the palliative care and mental health sectors (Koenig 2012; Koslander, Lindström & Barbosa da Silva 2012; Edwards et al. 2010). Existential psychotherapists such as Frankl, viewed serious, life threatening illnesses as an opportunity for growth (Chochinov 2006; Yalom 2008).

Another example of the interface between psychiatry and palliative care is a meaning-centred psychotherapy group developed by Breitbart and based on Victor Frankl's writings. This psychotherapy group aimed to enhance meaning, peace and purpose, and to assist the person in coming to terms with death (Breitbart et al. 2010). Pesut (2008) and Pesut et al. (2011), have also written in both the mental health and palliative sectors. The commonalities in the values between the mental health and palliative care sectors can assist in communication and service collaboration.

Summary

This chapter has provided a background context for studying whether the culture of mental health nursing can facilitate spiritual care for individuals with a comorbid severe mental illness and a life limiting illness, especially within a culture that privileges a biomedical approach. The chapter has demonstrated the difficulties surrounding the definition of spirituality and religion. These definitional difficulties will underscore many of the studies explored in the following literature review. The chapter also explored the historical factors which have led to many clinicians being reluctant to provide spiritual care, and the importance of understanding culture in relation to reflective practice. It has also examined the commonalities between palliative and mental health care that can assist in communication between the two sectors

In the next chapter, the relevant literature is reviewed. As there were no studies found that investigate the spiritual needs of people with a comorbid mental illness and a life limiting illness, searches were undertaken on the spiritual care needs of both the person with a lived experience of mental illness and the spiritual care needs of people facing death from a life limiting illness. The research that identifies an interrelationship between the individual's spirituality and their process of recovery will also be discussed.

CHAPTER 3 - LITERATURE REVIEW

Introduction

Much of the experience and needs of people with a comorbid mental illness and life limiting illness is unknown. It is difficult, if not impossible, to make improvements and provide quality, evidenced based care for this group of people, when so many facets of their care needs remain uninvestigated. The aim of this literature review was to gain greater knowledge and understanding of the spiritual needs of people with a comorbid mental illness and a life limiting illness, and the consequent implications for clinical practice.

3.1 Search strategies

3.1.1 Inclusion Criteria

This literature review focuses on people with severe and enduring mental illness. Severe and enduring mental illness refers to a collection of disorders that have a profound effect on interpersonal relationships, can cause functional impairment, and substantially interfere with everyday activities (Carey et al. 1999). The literature search focused on the diagnostic category from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) for psychotic disorders, such as schizophrenia, schizoaffective disorders and major affective disorders. The age range included adults between the ages of 18 and 65 years, as I wanted to explore the experience of people who were dying at a younger age than the general population. This age range was also the population I cared for as a nurse practitioner. Further, people over 65 years who experienced a mental illness, were provided with another service that worked with the specific issues of aging, such as dementia.

3.1.2 Exclusion criteria

As the focus of this thesis is on individuals with a pre-existing, severe and enduring mental illness, papers exploring issues relating to patients with mental health disorders that occurred after a diagnosis of a life limiting illness, were excluded from the literature search. Also excluded from the search were children, people with organic brain syndromes (such as dementia), alcohol induced or drug induced disorders and intellectual disability, as well as articles specific to care givers. The reason for this exclusion was because these individuals are outside of the scope of the thesis. In addition, people with dementia were not included in this study as they suffer different symptoms, expected illness trajectory and psychosocial issues, than people with a severe and enduring mental illness, such as schizophrenia.

3.1.3 Search strategy rationale

Through a search of the literature, I attempted to find research that examined the spiritual needs of people who have both a mental illness and a life limiting illness. I also wanted to know if there were any studies on the spiritual care offered to this population. Initially, I did a preliminary search of the literature through the search engines of CINAHL, Medline Ovid SP and Scopus. All search strategies included sourcing papers from evidenced-based and peer reviewed journals. From this preliminary search, there were no studies found on the spiritual needs or spiritual care of people suffering from an enduring mental illness and comorbid life limiting illness. However, the mental health literature emphasised the significance of spirituality to people with an enduring mental illness and highlighted that people with a mental illness rated the importance of spirituality higher than the general population (Huguelet et al. 2006; Nolan et al. 2012; Webb et al. 2011). In addition, and in concordance with Harrington (2016), I found that there was a plethora of literature from the palliative care sector that highlights the importance of spiritual care for patients at end of life. The literature from this preliminary search informed the search questions.

3.1.4 Search strategy questions

As there were no research studies exploring the spiritual needs and care of people that have a mental illness and who face death from a life limiting illness, the literature was searched to find original research on the following two questions; 'what are the spiritual needs of people with a mental illness?', and 'what are the spiritual needs of people who have life limiting illness?' A search of electronic data bases was used to answer the above two questions. Initially, four searches were undertaken using the search engines of CINAHL and Medline Ovid SP (see Appendix 1. Search Strategy - Overview chart and strategy outline).

The first four searches were for studies from both the mental health literature and the palliative care literature using CINAHL and Medline Ovid SP. These searches were then combined making a total of six searches. In other words, three from each search engine. The searches for the mental health literature were from 2003 to present. The palliative care searches were from 2007 to present. These different ranges in years were chosen because of the increasing volume and quality of the palliative care literature on spirituality over the previous six years. The equivalent volume and refining of work had not occurred to the same extent within the mental health literature. The search was undertaken between 2014 and 2020. These searches did not find any studies that examined the spiritual needs or care for people with a mental illness, who were also diagnosed with a life limiting illness. To ensure the currency of the literature reviews, studies found after the research themes were constructed, have also been included in this literature review. Additionally, further themes have been constructed from later research papers.

After removing duplicates, there were 25 research articles on spirituality in mental health care and 28 on spirituality in end-of-life care. After reading the papers in depth, one mental health paper was discarded as it was a discussion on clinical work as opposed to a research study. An article on spirituality at end-of-life care was also removed due to the study being undertaken with a non-clinical population. After searching the CINAHL and

Medline Ovid SP databases, further searches were done through the Scopus, ProQuest and PsycInfo on the OVID databases to ensure that the literature search was and complete. All 81 articles are on the Matrix of Research Studies (See Appendix 2. Matrix of research studies).

3.1.5 Snowballing Technique

The above searches provided a set of articles to use with the 'snowballing' technique. The 'snowballing' technique is used to search reference lists in articles and a wide range of literature that was not identified through the earlier structured search strategy (Ridley 2013). Other sources from the literature were also used, such as information from books written by well-respected, authoritative researchers. In addition, historically original sources were examined. Review articles and grey literature, such as governmental guidelines, were examined, as well as relevant secondary sources. The snowballing technique added a further 30 articles to this literature review. The literature search continued until December 2020.

3. 2 Tools used to assess the quality of the data from the research literature

To assess the quality of the data from the research papers, I used the work of Guest, Bunch and Johnson (2006) and Salmon (2013) to assess the qualitative research, and Russell (2005) to assess the quantitative research. There was, however, some overlap in the tools used to assess the quality of the qualitative and quantitative papers. I examined all the research papers to determine whether the authors had identified gaps in the literature (Russell 2005; Salmon 2013). I also examined the depth of the literature review in each paper and how the author's research question built upon existing knowledge (Russell 2005; Salmon 2013). I determined whether the authors had clearly stated and justified the methodological approach they used to collect the data, and how their approach would serve the research question. I also examined the description of their

sampling strategy (Russell 2005; Guest, Bunch & Johnson 2006; Salmon 2013). In reference to qualitative research papers, I questioned whether the researchers had ensured saturation, and whether purposeful sampling had been used as part of the research design. Saturation can occur earlier with purposeful sampling, especially when the sample group is homogenous (Guest, Bunch & Johnson 2006). Additionally, when assessing the studies, I determined whether the research paper had engaged with theory, as this engagement can extend the application of the research findings (Salmon 2013). All the research papers were examined to determine whether the researchers had obtained ethics approval from their relevant authorising bodies.

3.3 Overview of themes from the literature review

Themes were constructed from the literature through a process of firstly, identifying and summarising the themes within each research article and writing these out in note form. In addition, the aims and themes of each of the articles were put on the Matrix of Research Studies (see Appendix 2. Matrix of Research Studies). Secondly, the identified themes from each of the articles were reviewed for similarities and differences and the strength of relationship to the research question. Thirdly, the Matrix and notes were examined together and the themes for this literature review were developed. No software was used in the analysis of the literature.

The themes identified from the review of the literature will be broken up into four sections. The 4th section of this chapter will discuss the literature on the spiritual care concerns and care needs of people with mental illness, across 3 subsections. Subsection 3.4.1 will discuss the literature that highlights the importance of spirituality to the individuals suffering from a mental illness, and to the process of their recovery journey. It will also discuss the spiritual struggles that some people may experience and explore how these negative experiences can adversely affect well-being and recovery. The next subsection, 3.4.2, will discuss the studies in the literature that point to a reluctance by mental health clinicians to address spiritual issues. Subsection 3.4.3 will discuss the

mismatch between the views of people with a mental illness and the views of clinicians on issues of spirituality and religion.

The literature highlights spiritual history taking as an important aspect when caring for people with a mental illness, and in the care of people who are facing death from a life limiting illness. Section 3.5 will examine the importance of taking a spiritual history when caring for both populations.

The palliative care literature has highlighted that the recognition of and response to existential pain and spiritual distress by palliative care clinicians, is essential to patient care (Boston, Bruce & Schreiber 2011; Bruce et al.2011; Chochinov 2006; Lavoie, Blondeau & De Koninck, 2008; Mako, Galek & Poppito 2006). Section 6 will discuss the spiritual concerns and care needs of people with a life limiting illness facing death. The first subsection, 3.6.1, will highlight the spiritual issues that can be engendered by developing a life limiting illness. Subsection 3.6.2 will examine the significance of human connection and nursing presence when providing spiritual care for the dying. Subsection 3.6.3 will discuss an article by Sweers et al. (2013) on the expectations and concerns of people with a mental illness when facing death from a life limiting illness. The participants in this study reflected on the issue of their death which would be at some point in the future. They were not experiencing a life limiting illness at the time of the research. Although these expectations and concerns were not a theme from the literature, the article by Sweers et al. (2013), will be discussed, as it was the only research found that explored the issue of dying from a life limiting illness from the perspective of the person with a mental illness (In addition, after the themes were constructed from the literature review, later studies were found on 'trauma - informed' care. These studies included 'trauma informed' care and spirituality within mental health services, and the need for 'trauma informed' care within palliative services (Ganzel 2018; Isobel & Delgado 2018; Starnino & Sullivan 2016; Starnino 2016b). Subsection 3.6.4 will discuss the studies on Trauma - informed care.

Section 3.7 will discuss the need to consider ethical issues when providing spiritual care to all patients within health services. This theme includes the importance of considering the financial implications that may result from a lack of spiritual care. Finally, this chapter will examine the knowledge gaps that became evident from this literature review and argue the need for further research into the spiritual needs and care of individuals with a mental illness who face death from a life limiting illness.

3.4 The spiritual care concerns and care needs of people with a mental illness

3.4.1 The importance of spirituality to those suffering from a mental illness and to the process of their recovery

This section will discuss the literature that points to the importance of spirituality to individuals with a lived experience of mental illness, regarding how they manage this experience and to the process of their recovery. It will begin the discussion with two landmark studies, as these reports form the basis of other later studies. Corrigan et al. (2003) argued that while previous studies had found that spirituality or religiousness assisted in the psychological well-being of the general population, very little research on this topic had been conducted with people with a mental illness. After a lengthy literature review and consequently identifying a profound knowledge gap, Corrigan et al. (2003) surveyed 1,824 people with a psychiatric disability, to determine whether spirituality or religious beliefs provided them with a sense of psychological well-being. The quantitative study had two major hypotheses. Firstly, the researchers hypothesised that there was a positive association between psychological well-being, including diminished psychiatric symptoms, and spirituality and religiousness. The second hypothesis was that spiritual beliefs were more beneficial to the person, than participation and belief in a doctrinal religion. This hypothesis was based on previous studies that argued that 'religiosity' may be indicative of psychosis. In answering the first hypothesis, the study found that both spirituality and religiosity were both positively associated with increased

well-being and diminished psychiatric symptoms. However, the second hypothesis was not confirmed. To test both their hypothesis Corrigan et al. (2003, P. 490) used the “self – reported measures of religiousness and spirituality”. Other measures used included, “three health outcomes domains: self-perceived well-being, psychiatric symptoms, and life goal achievement”. The study found that there was no discernible difference in the benefits between those who had spiritual beliefs or a faith-based religion. However, the sampling strategy of this study was not clear, nor was it clear whether the participants had been informed and given consent to their participation in the research. Further, there was no evidence of approval from a relevant Ethics committee.

A quantitative study of 1,835 participants, which built on the work of Corrigan et al. (2003), was carried out by Bellamy et al. (2007). This study explored the role of spirituality within the context of recovery and found that two thirds of the participants rated spirituality as important in their lives (Bellamy et al. 2007). Their research also found that spirituality became more important to a person with a mental illness at times of illness or distress. Analogous to recovery principles, spirituality provided hope that their lives would improve. Like Corrigan et al.’s (2003) research article, Bellamy et al.’s (2007) paper did not mention an ethics approval processes, nor did it mention how it ensured the safety and comfort of the participants. Unlike Corrigan et al.’s (2003) study, Bellamy et al. (2007) did not discuss any review of the literature. Nevertheless, both studies strongly pointed to the clear relationship between spirituality, hope and recovery.

Since the time of these studies by Corrigan et al. (2003) and Bellamy et al. (2007), the finding that spirituality was of vital importance to individuals with a mental illness was consistently found throughout the mental health literature. Many research articles reported that people with a mental illness expressed that spirituality gave them hope and meaning in their lives, and was important to their well-being (Bellamy et al 2007; Borrás et al. 2010; Corrigan et al. 2003; Fukui, Starnino & Nelson-Becker, 2011; Danbolt et al. 2011; Bussema & Bussema 2007; Green, Gardner & Sandra 2009; Huguelet et al. 2016; Hustoft et al. 2013; Nolan et al. 2012; Shah et al. 2011; Smith & Suto 2012; Walsh, McSherry, &

Kevern, 2013; Webb et al. 2011; Wilding, Muir-Cochrane & May 2006; Green, Gardner & Sandra 2009).

Spiritual beliefs can aid recovery and lessen psychotic and other symptoms of mental illness (Borras et al. 2010; Corrigan et al. 2003; Das et al. 2018; Harris et al. 2015; Huguelet et al. 2016; Mohr et al. 2012; Revhiem, Greenberg & Citrome 2010). A Norwegian mixed method study with 31 participants, found that religion and spirituality were highly significant to the participants and had a positive influence on their life and ability to cope with their illness (Danbolt et al. (2011)). A larger mixed methods study by Nolan et al. (2012), with 63 participants who had a diagnosis of schizophrenia and a mixed method study by Borras et al. (2010) of 57 mental health clinicians and 221 outpatients of mental health clinic, concluded that having spiritual beliefs could improve self-fulfilment, coping skills and quality of life for those who have a severe mental illness. Recent research concurs with the above study. Adams et al. (2020) found that individuals with religious or spiritual beliefs had significantly higher coping skills, less depression severity and less social anxiety. Jones, Sutton and Isaacs (2019) argued that there is a paucity of literature on the spirituality of people with a lived experience of severe mental illness within the Australian context. Their qualitative research on 16 individuals with a diagnosis of severe mental illness, found that concepts of spirituality were diverse and ranged from finding spirituality in nature, art and faith, as well as practices such as meditation, yoga, prayer and preparing a calming ambience.

Participants in an earlier qualitative study of 6 community mental health patients in Australia, were purposefully selected for their broad experience of mental illness (Green, Gardner & Sandra 2009). All participants in the study reported having religious or spiritual beliefs to varying degrees. Green, Gardner and Sandra (2009) concluded that suffering from a mental illness had transformed the participants' lives, and that they were now more compassionate, caring and soulful. Healing the soul was often part of their recovery process and ongoing mental well-being. The researchers of this study acknowledged that the scale of the study was small. However, each participant was interviewed three times

over a period of 1 to 2 hours. This strategy provided a rich data set, covering several themes that illuminated the connection between spirituality and the recovery process.

Recovery principles have been recognised and supported in Australian mental health care policy since the early 1990's (Rickwood & Reed 2017). Recovery principles assert the importance of personal choice, finding hope and meaning, and the ability of the person with a mental illness to have quality of life, despite having a psychiatric disability. A review of the literature carried out by the Mental Health Foundation (Cornah 2006) highlighted that spiritual beliefs and practices play a central role in the recovery process by offering hope, meaning and comfort to people with a diagnosis of schizophrenia, and assist in reconstructing the person's sense of self. Similar to Corrigan et al.'s (2003) findings that suggested that affiliation with formal religious institutions can provide the social support that the person with a mental illness may otherwise lack and therefore assist in the person's recovery, later studies found that a predictor for well-being and recovery was participation in spiritual activities. Activities such as prayer, meditation, yoga, spiritual group activities and attending religious services, provided support and assisted the individual to cope with their mental illness (Borras et al. 2010; Green, Gardner & Sandra 2009; Fukui, Starnino & Nelson-Becker 2011; Kaplan, Salzer & Brusilovskiy 2012; Nolan et al. 2012; Weisman de Mamani, Tuchman & Duarte 2010; Webb et al. 2011). However, Koenig (2009b) and Koslander, Da Silva and Roxberg (2009) concur that there was little research exploring the negative relationship between spiritual experiences and mental health. Later research has emphasised that spiritual experiences can have a positive or negative effect on the person suffering from a mental illness (Oxhandler, Narendorf & Moffatt 2018; Webb et al. 2011).

3.4.1.1 Spiritual struggles - Well-being and recovery

A quantitative study of 81 people with a mental illness by Webb et al. (2011), expanded upon earlier investigations on the relationship between having religious support and coping with a mental illness. The researchers hypothesised that the person's recovery

would be negatively affected by a 'struggle with God'. This struggle may be characterised by religious doubt, despair, anger, guilt and a disrupted relationship with the religious community. The researchers also hypothesised that having social support from a religious community was a predictive factor for recovery from mental illness. Surprisingly, for these researchers, their results did not fully confirm their hypothesis. Their results advanced previous research findings that having social support from a religious community was not a unique predictive factor for recovery from mental illness. A more unique predictor for recovery was having an enduring faith. However, the study concluded that religious support did assist the person when they were experiencing 'spiritual struggles'. Although this research provided valid insights into how religiosity can effect recovery from mental illness, religiosity was not defined within the research paper. Nor did the authors differentiate between religion and spirituality, even though they highlighted that a 'spiritual struggle' with God can adversely affect the recovery process. The researchers did however provide a balanced argument on the possible positive and negative relationship between religion and recovery from mental illness. Their research article concluded that spiritual struggles may negatively affect a person's recovery journey.

Other studies pointed out how personal struggles with their God could negatively affect the individual's recovery. A mixed methods research report by Mohr et al. (2012) interviewed 276 patients from a mental health outpatient service. They found that for 87% of participants, religion was helpful in coping with their mental illness. However, for 13% of participants, religious belief was a source of suffering and despair. Other research highlighted the impact of negative spiritual experiences for the person (Huguelet et al. 2016; Koslander, Da Silva & Roxberg 2009). These experiences may involve concerns around their God judging their sins, leading to feelings of guilt and worthlessness or tormenting thoughts such as asking themselves 'why me?' (Koslander, Da Silva & Roxberg 2009, p.39).

A qualitative study based on classical texts was undertaken by Koslander, Lindström and Barbosa da Silva (2012). By focusing on the universal features of stories, Koslander,

Lindström and Barbosa da Silva found that negative spiritual experiences such as fear of punishment by God, shame and guilt, can damage the person's "body, psyche and spirit" (2012, p.1). Koenig (2009b) argued that negative spiritual experiences can reinforce neurotic tendencies and increase shame and fear. These experiences may restrict the person's life rather than enhance it (Koenig 2009b).

Later qualitative research by Hustoft et al. (2013), based on an extensive literature review, aimed to further explore the interplay between spirituality and psychosis. This research was an extension of the previously mentioned Danbolt et al. (2011) study. Hustoft et al. (2013) purposefully chose 6 participants from the Danbolt et al. (2011) study to add depth to the data found in this previous research. Hustoft et al. (2013) also used data from the interviews from Danbolt et al. (2011) as a method of triangulation. Participants in the Hustoft et al. (2013) study reported that their spirituality was of vital importance to them, even when their spiritual beliefs were entwined with their delusions. One participant reported that if it were not for his faith, he would have killed himself. All the participants described an experience of 'spiritual struggle' (Hustoft et al. 2013). Disturbingly, it was found that patients were left to interpret their spiritual struggles in solitude (Hustoft et al. 2013).

Van Nieuw Amerongen-Meeuse et al. (2020) found that when patients felt unsupported in their spiritual needs, they experience lower levels of therapeutic rapport. Patients reported that they received the highest benefits from a therapeutic alliance when nurses paid attention to their spiritual needs. Based on the above studies, all clinicians need to understand how their patients experience their spirituality, the meaning of these experiences for the individual, and how spiritual or religious activities affect their life (Borras et al. 2010; Webb 2011; Hustoft et al. 2013; Van Nieuw Amerongen-Meeuse et al. 2020). However, the informants from the research by Hustoft et al. (2013) who had a coherent spiritual belief system, reported that their spirituality itself was their sole support. The informants reported that clinicians had diagnosed their belief systems as delusional, and their spiritual beliefs and struggles were not further explored. The following section

further examines the literature that highlights mental health clinicians' reluctance to address spiritual issues.

3.4.2 Studies that indicated mental health clinician's reluctance to address spiritual issues

The benefits of research discussed in the previous section is that they can inform mental health professionals of the importance of religion and spirituality in the process of recovery from mental illness. However, for a variety of complex reasons, spiritual or religious beliefs and experiences are frequently ignored by mental health clinicians (Huguelet et al. 2006; Hustoft et al. 2013; Koenig 2012; Smith & Suto 2012; Wilding, Muir-Cochrane & May 2006; Van Nieuw Amerongen-Meeuse et al. 2018). Ledger and Bowler (2013) surveyed 235 nurses to ascertain their knowledge and skills in the delivery of spiritual care. The 131 survey responses indicated that the respondents believed that while they agreed that understanding an individual's spirituality was important to the person's recovery journey, they did not feel competent to address these issues. Huguelet and Koenig (2009) suggested that mental health clinicians felt that an exploration of the person's spirituality may offend or even harm the patient. It has also been found that clinicians may be reluctant to raise spiritual issues, as they were concerned that an exploration of spiritual experiences might enflame psychosis (Wilding, Muir-Cochrane & May 2006). Mental health clinicians may ignore the person's spirituality as they fear they are entering unknown territory, without the skills and knowledge to understand the patient on a spiritual level (Huguelet et al. 2006; Huguelet & Koenig 2009). Mental health clinicians may also be unaware of their own spiritual, religious or existential needs, which may make it difficult for the clinician to be able to recognise, understand and work with the patient who is experiencing either negative or positive dimensions of religion or spirituality (Koslander, Da Silva & Roxberg 2009; Swinton 2001).

Some mental health clinicians consider that spiritual and religious beliefs are part of the pathology of the person's mental illness, and thereby dismiss or do not consider their

spiritual concerns (Cornah 2006; Koenig 2012; Pesut et al. 2011; Webb et al. 2011; Wilding, Muir-Cochrane & May 2006). Pathologising of religious beliefs frequently occurs within the mental health sector (Cornah 2006). This pathologising is partially due to historical factors mentioned in the previous chapter (Koenig 2009b). Borrás et al. (2010) argued that leading psychiatrists rejected religious values and constructed theories that pathologised normal religious experiences. Many clinicians either ignored patients' spiritual beliefs or saw them as pathological (Cornah 2006). Yet, Russinova and Cash (2007, p. 279) found that people with a severe mental illness had a "deep, yet finely nuanced understanding of the concepts of religion and spirituality". It should no longer be assumed that the person's religious beliefs are part of their pathology (Webb et al. 2011). One study indicated that people with a mental illness may adopt religious beliefs as a way of interpreting their delusions in a meaningful way (Hustoft et al. 2013).

Individuals with a mental illness would like mental health clinicians to understand the importance of the spiritual dimension in their lives (Fukui, Starnino, & Nelson-Becker 2011; Green, Gardner & Sandra 2009; Wilding, Muir-Cochrane & May 2006). In their interviews with 6 people with mental illness, Wilding, Muir-Cochrane and May (2009) found that individuals receiving a mental health service want to explore spiritual issues with their clinicians, as it would assist them to making sense of their mental illness. Despite this finding, the study concluded that the area of spirituality and religion has been greatly neglected by clinicians.

Working with a person's spiritual beliefs can enhance adherence to treatment (Borrás et al. 2010; Moreira-Almeida, Koenig & Lucchetti 2014). However, in a few cases it was found that religious or spiritual beliefs deepened distress, and lessened adherence to treatment when the person's beliefs were not consistent with therapeutic management (Borrás et al. 2010; Huguelet et al. 2016). Taking medication may also be antithetical to the person's faith or the patient may believe there is a connection with their faith and their symptoms (Koenig 2009a). In contrast, Van Nieuw Amerongen-Meeuse et al. (2020) found that spiritual care did not affect adherence to treatment. However, they concur with

previous researcher that argues that mental health nurses need to offer personalised attention to the patient's spiritual needs and listen sensitively to patient spiritual experiences and the meaning they ascribe to their experiences (Hefti, 2009; Wilding, Muir-Cochrane & May 2006; Van Nieuw Amerongen-Meeuse et al. 2020). Van Nieuw Amerongen-Meeuse et al. (2020) also found that a mismatch between the views of people with a mental illness and mental health professionals on religion and spirituality could also lessen the therapeutic alliance. This will be discussed in more detail in the next section.

3.4.3 Mismatch between the views of people with a mental illness and mental health professionals on religion and spirituality

Research has suggested that the disparity between the views of clinicians and people with a mental illness in regard to religion and spirituality, is likely to be a consequence of mental health professionals not rating spirituality as highly as people with mental illness (Curlin et al. 2005; Huguelet et al. 2006; Borrás et al. 2010; Koslander & Arvidsson 2005). A Swiss study by Huguelet et al. (2006) using a mixed methods approach, compared the importance that 34 clinicians ascribed to spiritual and religious practices, with the perspectives of 100 outpatients with a diagnosis of severe mental illness. They also explored the extent to which clinicians were aware of, and able to discuss spiritual issues with their patients. Their research found that clinicians underestimated and neglected the spirituality of their patients and were usually unaware of the conflict between patients' religious beliefs and mental health treatment. This study also found that both spirituality and religion were highly important to patients. The authors concluded that mental health professionals were less religiously involved than their patients and the general population.

The mismatch between the views of people with a mental illness and clinicians, may lead to a lack of understanding regarding the spiritual needs of individuals in their care. In their mixed methods study, which replicated the study by Huguelet et al. (2006) in different settings, Borrás et al. (2010) investigated the spirituality and religiosity of 57 clinicians and 221 outpatients of mental health services across two countries. One arm of the study was

undertaken in Geneva, and the other in Trois Rivieres in Québec. The researchers hypothesised that clinicians would underestimate the importance of religious practices and spirituality to the patient. They also hypothesised that clinicians were less likely than their patients to use religious practices or spirituality as a way of coping in their daily lives than their patients. Both study sites found that spirituality and religious involvement was vitally important to people with a severe and chronic mental illness and less important to clinicians than the general population. Some patients believed that their religious beliefs were incompatible with treatment, but that most clinicians were unaware of this conflict (Borras et al. 2010). The person's religious belief included beliefs that were not compatible with taking medication or could make them more suspicious of secular therapists (Borras et al. 2010). Unexpectedly, the scores for spirituality and religious affiliation of clinicians in the Quebec cohort were closer to that of the general population and their patients, than the clinicians in Geneva. It was suggested that the similarities may have been because the Catholic Church and religious values were still prominent in Quebec culture. Clinicians in both arms of the study were unaware of the importance of religious involvement in the lives of their patients. They tended to underestimate the importance of spirituality and religion in their patients' lives or neglect the topic altogether.

A qualitative study by Koslander and Arvidsson (2005) in which they interviewed 12 Swedish mental health nurses, provided insights into the mismatch between the views of people with a mental illness and clinicians, by seeking to describe nurses' conceptions of how spirituality was addressed within the psychiatric nurse patient relationship. Their research revealed that even when nurses were willing to provide spiritual care, they failed to recognise the patient's spiritual needs which prevented them from gaining deeper insights into the patient's world. The authors claimed that inferior care occurs as a result of nurses not being aware of or misinterpreting the patient's spiritual dimension. Even though the study interviewed 12 nurses, the researchers believed they had reached saturation after analysing 8 of the interviews, as no new sub-categories of meaning had arisen. This study used a strategically chosen, broad sample of nurses, to ensure that the research

reflected the nursing population and to increase the applicability of results. Yet, the article did not discuss any differentiation between the educated mental health nurses with a more advanced education and those with a basic nursing qualification. This differentiation may have been useful for determining whether differing levels of education could have had an influence on the nurse's ability to provide spiritual care. Nevertheless, the study engaged with theory and the research design was robust, thus enabling the research to build on previous knowledge. Koslander and Arvidsson (2005) argued that to provide quality care, nurses need to have a greater knowledge of their patient's spiritual dimension. Moreover, they need to become more aware of their own spirituality, and comfortable and skilled in discussing spirituality with their patients.

In a similar vein, a review of the literature by Koslander, Da Silva and Roxberg (2009) maintained that mental health care may be unsatisfactory if the clinician did not understand their own spiritual needs or have some knowledge of different religions. Koslander, Lindström and Barbosa da Silva (2012) argued that if the clinician did not have knowledge and understanding of spiritual issues, they may have found it harder listening to the terror that can be engendered by the dark side of spirituality, such as a fear of evil or the devil. Van Nieuw Amerongen-Meeuse et al. (2018) conducted a qualitative research study in the Netherlands, regarding the gap between the religiosity of mental health clinicians and people with a lived experience of mental illness. The researchers explored and compared the needs of people within Christian and secular mental health care settings. They concluded that when there was a mismatch in spiritual views between the clinician and the individual with a mental illness, the individual felt misinterpreted and misunderstood. They also found that due to their feelings of unease about addressing spiritual issues, mental health professionals that worked in a secular setting tended to avoid conversations related to issues of spirituality.

In contrast to these findings, two research articles reported that some mental health clinicians incorporated spiritual issues into their care practices (Charzyńska & Heszen-Celińska 2020; Ho et al. 2016). A Polish study of 121 mental health clinicians by

Charzyńska and Heszen-Celińska (2020), found that some clinicians included spirituality into their therapy, but for the most part, this would only occur when the person with a mental illness brought up the issue of spirituality. Other respondents in their study reported that they were afraid of violating ethical principles when exploring issues of spirituality. A study undertaken in Hong Kong by Ho et al. (2016) interviewed 18 people with a mental illness, and 19 mental health clinicians. Both groups of participants believed that working with the person's spiritual dimension assisted in their well-being and recovery. However, there was a difference between the clinician's interpretation of the role of spirituality and the interpretations of participants with a mental illness. People with a mental illness viewed spirituality as a source of giving and receiving love, and a way of finding peace, stability and growth whereas clinicians viewed spirituality in terms of support and the management of symptoms. The researchers argued that this difference in perspective, points to the importance of developing a spiritual assessment to assist in holistic care.

A later qualitative study by Oxhandler, Narendorf and Moffatt (2018) that explored 55 young adults with serious mental illness who were in a psychiatric crisis, found that issues of spirituality were linked to both positive and negative experiences of spirituality. These discussions of spiritual experiences emerged spontaneously without any prompting from the interviewer. Two thirds of the participants that spoke about their spiritual experiences found them positive. These experiences included finding meaning, support, comfort and protection through their spiritual practices. Negative spiritual experiences included feelings of being stigmatised and excluded from or proselytised by a church member. Like Ho et al. (2016), Oxhandler, Narendorf and Moffatt (2018) highlighted the importance of assessing the effect of the individuals' spiritual experiences. It has previously been argued that clinicians also need to understand that spiritual beliefs are not static and may change over time (Wilding, Muir-Cochrane & May 2006). Hence, continual spiritual assessments assist in consistent, quality care.

The palliative care literature also highlighted the need to take a spiritual assessment as a preliminary step for determining spiritual well-being or distress. Spiritual care could then be based on the patient's individual needs (Harrington 2016; Selman et al. 2018; Wittenberg, Ragan & Ferrell 2017). Koenig, Peteet and VanderWeel (2020) described spiritual history taking as a dance between the patient and the mental health professional, with the clinician gently asking questions and the patient taking the conversation in the direction it needs to go. The following section will discuss the literature that highlights the importance of spiritual history taking with people with a lived experience of mental illness, and people facing death from a life limiting illness.

3.5 Spiritual history taking

Despite studies indicating that there is a neglect of the patient's spiritual needs by mental health clinicians, several studies have argued that there is also a strong need to assess the patient's spiritual history (Borras et al. 2010, Gomi et al. 2014; Hefti 2009; Huguelet et al. 2013; Koenig, Peteet & VanderWeel 2020). Koenig, 2009a; Koslander, Lindström & Barbosa da Silva 2012; Koslander, Da Silva & Roxberg 2009; O'Callaghan et al. 2020; Mohr & Huguelet 2009; Moreira-Almeida, Koenig & Lucchetti 2014). Spiritual or religious history taking can highlight the effect that spirituality or religion has had on the person's mental health (Mohr & Huguelet 2009). It may also reveal potential stress factors that could exacerbate the person's mental illness, and protective factors which could be used to enhance recovery (Mohr & Huguelet 2009; Moreira-Almeida, Koenig & Lucchetti 2014). Koslander Da Silva and Roxberg (2009) recommended that to ensure spiritual interventions are appropriate, an individualised spiritual assessment should be done on each patient to determine spiritual care needs. In addition, taking a spiritual history could improve patient satisfaction, and contribute to spiritual interventions that are cost effective (Moreira-Almeida, Koenig & Lucchetti 2014).

Authors have argued that prior to asking a person with a mental illness questions about spirituality, it is essential that a trusting therapeutic relationship has been established

(Starnino, Gomi & Canda 2014). Starnino, Gomi and Canda (2014) argue that a questionnaire like approach is not appropriate for spiritual history taking. It is through understanding the person's unique spiritual experiences and struggles that clinicians are more able to assist with any distress that these struggles may engender. Mental health clinicians need to be cognisant of the person's spiritual concerns and their readiness to discuss spiritual issues (Starnino, Gomi & Canda 2014; Webb et al. 2011). Further, they should take a broad, inclusive view of what is meant by the term 'spirituality' and be open to exploring the patient's unique spiritual experiences (Koslander, Lindström & Barbosa da Silva 2012; Starnino 2016a; Wilding, Muir-Cochrane & May 2006).

Similarly, a Cochrane Review by Candy et al. (2012) that aimed to describe religious and spiritual interventions with people who had a terminal illness, argued that it is likely that spiritual and religious experiences are very personal. They recommended a person-centred approach in tailoring interventions to the individual's needs. Candy et al. (2012, p.14) maintained that the use of "assessment tools alone may not be the best method to assess needs in this area of care". The highly specific needs of the patient should be identified through a non-judgemental, interpersonal exploration. Nevertheless, Fegg et al. (2010) asserted that through a validated assessment instrument, the unique needs of the patient could be identified, and their care tailored accordingly. The use of a spiritual assessment tool can identify aspects of a person's life that provide support and give them strength (Borneman, Ferrell & Puchalski 2010). The 'FICA' tool (Faith and belief, Importance and influence of spirituality, individual's spiritual Community and Address in care) can provide a framework for addressing spiritual concerns and for opening spiritual discussions in clinical settings (Borneman, Ferrell & Puchalski 2010).

There has been some debate in the palliative care literature about the use of spiritual assessment tools (Selman et al. 2012). While Selman et al. (2012) have argued that some clinicians fear that the use of an assessment tool would turn spiritual care into a tick box activity, they maintained that validated spiritual assessment tools are useful in screening for spiritual distress and may assist in identifying patients who require spiritual support.

The authors also highlighted that an assessment tool could give the clinician greater confidence and competence in their provision of spiritual care. They point out that a lack of confidence in using the tool is a key reason why spiritual care is often neglected. The data from Taylor's (2013) research highlights the importance of training for nurses to be comfortable in doing a spiritual assessment.

Despite the debate in the palliative literature on the use of spiritual assessment tools there have been no validated spiritual assessment tools that assess the spirituality or religious needs of individuals with psychosis, and very little written about recognised spiritual assessment tools in mental health in general (Huguelet & Mohr 2009; Gomi et al. 2014). A systematic review of spiritual assessment tools by Lucchetti, Bassi and Lucchetti (2013) and Moreira-Almeida, Koenig and Lucchetti (2014), concluded that only two assessment tools were specifically designed for use within mental health: The Royal College of Psychiatrists Assessment and the Spiritual Assessment Interview. Lucchetti, Bassi and Lucchetti (2014) found that alongside the FICA tool, the Royal College of Psychiatrists Assessment tool scored very highly for addressing spiritual needs in clinical practice. The Royal College of Psychiatrists Assessment tool, developed by Culliford et al. (2006), to be administered by mental health professionals, was found to be extensive. The Spiritual Assessment Interview tool was given a low score as it was not easy to remember, and questions did not relate aspects of health. Both the Royal College of Psychiatrists Assessment tool and the Spiritual Assessment Interview had not been validated by research.

Moreira-Almeida, Koenig and Lucchetti (2014) found that the FICA tool, which ranked highest amongst the tools, was useful in relation to mental health, especially if time was limited. The FICA tool was developed in 1996 by Puchalski and is frequently used in the palliative setting. This finding on the usefulness of the FICA tool is consistent with Mohr and Huguelet's (2009) suggestion that using the FICA tool for screening can assist clinicians in gaining insights into whether spirituality or religion is important to a person with mental illness. However, Moreira-Almeida, Koenig and Lucchetti (2014) also

highlighted that the assessment tool developed by the Royal College of Psychiatrists, which takes around 15-20 minutes to complete, is more useful with regard to mental health, as it provides the clinician with a comprehensive psychosocial history.

Koenig (2012) argued that the use of some tools was problematic in that they screen for mental health concepts but not spiritual concepts. He specifically cites the FACIT-SP which explores the psychological dimensions. These dimensions include hopelessness versus purpose which may indicate the person has a depressive disorder. Similarly, in a qualitative study that explored the elements of a spiritual assessment by Gomi et al. (2014), when the researchers asked participants to give feedback on a question that asked what motivates them to get out of bed in the morning, several of the participants highlighted that this question was not linked to spirituality. The other questions that examined meaning and purpose, peace and inspiration and joy and satisfaction in the person with a mental illness, were better received by the participants. Gomi et al. (2014) used focus groups as their research method. This group included 23 clinicians and 25 people with a mental illness. The study participants, who had a lived experience of mental illness, offered further questions such as; “what brought inspiration to your life?”, “when did you begin your spiritual journey?” and “was there a time when you were able to reach out to God and did God ever reach back?”. The study concluded that the insights given by the participants could form the basis of a spiritual assessment. In addition, there was an alignment between Gomi et al.s (2014) position that maintained some questions were not linked to spirituality, and Koenig’s previously discussed (2012) argument that some screening tools only screen for mental health or psychological concepts as opposed to spiritual concepts. However, Rodin (2013) suggested that spiritual well-being is a dimension of psychological well-being, and prescribed the use of spiritual tools, such as the FACIT-SP, that could be useful in assessing psychological well-being.

This literature review holds at its core, the needs of patients with a severe mental illness facing death. Hence, reviewing the literature on spiritual needs at end of life is critical in understanding this populations’ experience and needs. Although there is no

literature exploring the needs of people who have both a mental illness and a life limiting illness, this review found that there is burgeoning literature addressing spiritual care in the palliative setting (Harrington 2016). Therefore, to gain an understanding of the care that can be provided, albeit not explicit to those with severe mental health concerns, the next section will discuss the spiritual **concerns** and care needs of people who are facing death due to a life limiting illness.

3.6 The spiritual concerns and care needs of people who are facing death due to a life limiting illness

End of life care, otherwise known as palliative care, “aims to improve quality of life, enhance spiritual and existential well-being and reduce suffering” (Chochinov (2006, p. 97). However, defining the characteristics of spiritual care is challenging (Daaleman et al. 2008; Hanson et al. 2008; Harrington 2012; Ronaldson et al. 2012). Hegarty (2007) drew together both existential and spiritual aspects of care. She argued that a model of care for the spirit is one that has both secular and religious expression, and that in order to develop a spiritual care that transcends religious, ideological and philosophical boundaries, the ‘universality’ of the human spirit needs to be recognised. Hegarty’s (2007) argument raised the question; how do clinicians determine the individual needs of the patient when spiritual needs are so diverse and often secular? Facing death often awakens a unique dimension of spirituality (Daaleman et al. 2008). Through the literature search it was identified that the development of a life-threatening illness can engender or increase spiritual concerns and prompt spiritual reflection (Borneman, Ferrell & Puchalski 2010; Bruce & Boston 2011; Delgado-guay et al. 2011; Edwards et al. 2010; Gielen, Bhatnagar & Chaturvedi 2017; Penman, Oliver & Harrington 2013; O’Callaghan et al. 2020; Ronaldson et al. 2012). This following section will examine the literature that discusses the spiritual issues that can be engendered by developing a life limiting illness.

3.6.1 Spiritual issues that can be engendered by developing a life limiting illness

In the same way that individuals with a mental illness have identified the importance of spirituality in their lives, studies of patients facing the end of life also identify this area as being important (Delgado-guay et al. 2011; Edwards et al. 2010; Hughes et al. 2008; O'Callaghan et al. 2020; Pearce et al. 2012; Selman et al. 2018; Winkelman et al. 2011). In their meta-analysis of qualitative research, Edwards et al. (2010) found several prominent themes on the spiritual needs of the dying. These included, patients needing to find closure, complete 'unfinished business' and to feel they were ready to die without regret, as well as the need for reconciliation, and to forgive or be forgiven. Fulfilling these needs meant that patients could be closer to their relatives and die in peace. For some patients there was a need to make peace with God, and the need to let go and accept the inevitability of death. Some patients also expressed a need to make sense of their lives through reminiscence. This review of their lives can lead to a sense of wholeness and completion (Edwards et al. 2010). However, for people with an enduring mental illness, the long-term effects of stigma and loss may make the process of reviewing their lives confusing and painful.

A study of patients with lung cancer, by Hughes et al. (2008), explored the patient's notion of a 'good death'. Interestingly, it was found that although 60% of patients identified as being religious, only 6% commented on God being an aspect of what they considered to be a 'good death'. Participants associated a 'good death' with being asleep when they died and having a quick death. Hughes et al. (2008) proposed that it is likely that resolving one's relationship with God, allowed the patient to let go of the control of death. However, they stated that their proposition required further research for confirmation. In addition, in their study of what is considered a 'good death', only one patient mentioned fear as an issue. Hughes et al. (2008) hypothesised that many of the participants in the study had already resolved their fears through their religious beliefs, and hence they had differing views on what a 'good death' meant to them. Hughes et al. (2008) pointed out that in

several previous studies, patients frequently used religion or spirituality to transcend anxiety and fear of death, yet research has identified that facing death can engender spiritual pain (Borneman, Ferrell & Puchalski 2010; Delgado-guay et al. 2011; Saunders 2006).

Describing the elusive concept of spiritual pain can be challenging (Mako, Galek & Poppito 2006). Saunders (2006) described the essence of spiritual pain as the “bitter anger at the unfairness of what is happening and at much of what has gone before, and above all a desolate feeling of meaninglessness” (Saunders 2006, p. 218). Dame Cicely Saunders was the founder of the modern hospice movement in England in 1967. She challenged the medical profession, arguing that not all patients can be cured, and that care and comfort should be provided in a home like environment. Pain management was a necessary part of this care. Saunders coined the term ‘total pain’, in which she included the physical, emotional, social and spiritual dimensions of distress (Richmond 2005). Saunders believed that spiritual or existential care was essential for ensuring quality of life (Boston, Bruce & Schreiber 2011; Gielen et al. 2009).

Patients facing their end of life may have numerous spiritual questions. They may be angry with God and question or lose the meaning in their life (Fitchett et al. 2020). They may also question why they developed the illness and struggle with the will to live (Borneman Ferrell & Puchalski 2010; Delgado-guay et al. 2011). In addition, isolation can add to feelings of failure, and an “obscure sense of guilt suffered by many dying patients” (Saunders 2006, p. 176). In a cross-sectional survey of 100 outpatients dying of advanced cancer, Delgado-guay et al. (2011) found that spiritual pain was common and could lead to a lower quality of life. The study hypothesised that spiritual pain can engender an examination of a person’s faith. The hypothesis was partially supported by a lower quality of life with patients who were experiencing spiritual distress. Spiritual pain was associated with lower religiosity. However, the authors argued that further research was required to determine a cause - effect relationship between spiritual pain and religiosity. The study also explored how spiritual pain was associated with physical and emotional symptoms,

and the impact of spiritual pain on quality of spiritual life and coping. In the study, patients who reported spiritual pain were likely to significantly agree that spiritual pain worsened their physical and emotional pain (Delgado-guay et al. 2011). Other studies have found that some patients believed their illness was a punishment from God (Gielen, Bhatnagar & Chaturvedi 2017; Selman et al. 2018). The study by Gielen, Bhatnagar and Chaturvedi (2017) was undertaken in India, and most patients were accepting of the idea that their punishment was because of their misdeeds. However, they described being able to find peace through their belief system.

A mixed methods study by Mako, Galek and Poppito (2006, p. 1111) that purposefully sampled 57 advanced cancer patients with a prognosis of less than six months, concluded that "spiritual pain may be viewed as a symptom that is calling one back home to a sense of authenticity and reconciliation with earlier personal pain and unmet needs". A study by Pearce et al. (2012) found that when people facing end of life issues do not have their spiritual needs met, they are more likely to suffer depressive symptoms and less likely to experience meaning and purpose in their lives. A later study found that patients who engaged in daily spiritual experiences had a significant improvement in well-being and their psychological state (Bovero et al. 2019). In addition, research has suggested that by attending to the patient's spiritual needs, there could be an improved quality of life and a reduction in symptoms of depression (Gryschek et al. 2019). The next section will discuss the elements of spiritual care highlighting the significance of human connection and nursing presence.

3.6.2 The significance of human connection and nursing presence when providing spiritual care for the dying

Emerging from qualitative studies was the importance of relationships and human connection for the person who was dying (Daaleman et al. 2008; Penman, Oliver & Harrington 2013; Selman et al. 2018). These relationships were often with family and friends and at times, the nurse providing care. These relationships may also have been

with a transcendent being, such as God, Jesus, or Buddha. Studies have highlighted that underpinning spiritual care, was the 'presence' of the nurse or the nurse 'being with' the patient (Bruce et al. 2011; Daaleman et al. 2008; Lavoie, Blondeau & De Koninck 2008; Mako, Galek & Poppito 2006; Ronaldson et al. 2017; Rushton et al. 2009; Seno 2010; Wittenberg, Ragan & Ferrell 2017).

Presence means using the qualities of fully focused attention and authenticity when being with the person (Rushton et al. 2009). Bruce et al. (2011) highlighted that 'remaining' or 'being present' with the person as they struggle with fear, anxiety and the pain of confronting death, could assist the patient in the transformational process of an acceptance of death. Data from a study by Rushton et al. (2009) suggested that 'being present' and bearing witness to the patient's suffering is a healing act.

A study carried out in the USA by Hanson et al. (2008), was the first phase of a joint study with Daaleman et al. (2008). The Hanson et al. (2008) arm of the study explored 38 clinicians' perceptions and understandings of the spiritual care they had offered to palliative patients and their families. Their research identified the importance of the clinicians being fully present to the patient or family member. The 12 participants in the second phase of the study by Daaleman et al. (2008), reported that spiritual care was provided through a "series of highly fluid interpersonal processes" as opposed to prescribed and proscribed roles (Daaleman et al. 2008, p. 410). The authors concluded that through their study, an empirically based, conceptual framework of spiritual care was identified. The framework included themes of; 'Being Present', 'Opening Eyes' and 'Co-Creating'. The theme of 'Opening Eyes' was identified when clinicians recognised and affirmed the unique nature of the patients' experiences and stories. This recognition and affirmation revealed the clinician and patient's shared humanity. The process of 'Co-Creating', jointly created a holistic care plan that incorporated the patient and their family's dignity and humanity. The authors argued that clinicians should value, support and nourish these relationships. Also, in accordance with the conceptual framework offered by Daaleman et al. (2008) for spiritual care, an Australian study by Penman, Oliver and

Harrington (2013) found five major themes of spiritual engagement. The themes elucidated the distinct actions of spiritual engagement through; “maintaining relationships with others’, ‘showing and receiving love’, ‘praying’ and ‘participating in other religious practices” (Penman, Oliver & Harrington 2013, p. 45). Spiritual engagement was synonymous with love in action.

Seno (2010) used the existential Heideggerian structure of ‘Being With’ the dying patient and ‘Being Toward’ death, as a background for the study. The purpose of the study was to explicate the tacit wisdom embedded in the practice of nurses who were experienced and effective in ‘being’ with the dying. Seno (2010) asked the nurses questions about what it is like to ‘Be’ with the patient as opposed to ‘Do’ for the patient, with the aim of capturing the participants lived experience of a historical encounter. It was found that the nurses’ narratives were consistent with Heidegger’s structures of advancing toward death. Seno (2010) pointed out that the Heideggerian premise of denial of death or a flight from death, is an ‘inauthentic’ response whereas authentic ‘being’ with the dying, is emotionally appropriate, purposive and responsible. When the nurse is ‘authentic’ and comfortable in ‘being’ with death, an acceptance of death can be facilitated in the patient (Seno 2010). Seno (2010) argued that nurses who wish to practice ‘authentically’ when they are providing care for the patient facing death, need to confront death as an ever-present reality and seek experiences of already ‘authentic’ clinicians. Similarly, later studies by Ronaldson et al. (2017) highlighted the importance of ‘engaging with’, ‘being with’ and ‘listening to’ the patient. The study also highlighted that the nurses were validating the dying person’s experience of hope.

A qualitative study based on grounded theory by Bruce et al. (2011), interviewed 22 participants who had experience and knowledge about end-of-life issues. The researcher’s purposeful sample included patients with cancer, family members and professional healthcare workers. Bruce et al. (2011, p. 6) found that existential or spiritual suffering involves the struggle “to make new meanings and remain in control over one's life”. Yet, sometimes for the dying person, the suffering ceases to exist and they can relax

into 'letting go'. The researchers surmised that this cessation of suffering may have been because the participants found meaning in death or alternatively, that meaning was no longer important. The researchers proposed that when facing death, the person's belief system can be 'transformed', and a search for meaning can become empty or unimportant. This search can be aligned to longing for ground in a groundless world (Bruce et al. 2011). Bruce et al. (2011) also highlighted the importance of the clinician attending to their own discomfort when exploring issues of dying with the patient.

Hanson et al. (2008) sought to describe the spiritual care received by patients and their families. They also examined the relationship between the patient and their family's satisfaction with the care received, the type of care and who provided the care. The study found that satisfaction with the spiritual care provided was lower when care was provided by someone sharing the same faith (Hanson et al. 2008). The researchers posited that this unexpected finding may have been because patients had greater expectations of people from the same faith community when receiving spiritual care. They also found that satisfaction with spiritual care was not related to which discipline provided the care. It was identified that spiritual care was provided from several sources, including healthcare professionals, family and friends. In addition, the study revealed that healthcare professionals were more commonly identified as being of spiritual assistance than clergy. Based on the results of the study the researchers argued that compartmentalising spiritual care to a specific discipline, such as the clergy, needs to be reconsidered. Hanson et al. (2008) and a later study by Wittenberg, Ragan and Ferrell (2017), also highlighted that providing spiritual care required training and dedicated time. Hanson et al. (2008) suggested that health professionals need skills in spiritual history taking. Other research found that barriers to spiritual care included lack of time, inappropriate environment and lack of privacy (Daaleman et al. 2008; Wittenberg, Ragan & Ferrell 2017).

This section has explored the significance of human connection and nursing presence when providing spiritual care to patients facing death. The following section will discuss

the findings of Sweers et al. (2013), regarding the expectations and concerns of people with a mental illness who are also facing death as a result of a limiting illness.

3.6.3 Expectations and concerns of people with a mental illness if facing death from a life limiting illness

To date there were no studies found that examined the spiritual needs of people with pre-existing mental illness, who are also facing death as a result of a limiting illness. The only study found in the literature search that has explored the expectations and concerns of people with an enduring mental illness about their end-of-life care, is a qualitative study by Sweers et al. (2013). This study explored the perspectives of 20 people with a diagnosis of schizophrenia, regarding how they might feel if they developed a life limiting illness, and what their expectations of health services would be. These study participants did not have a life limiting illness.

The study found that fear of death was absent in 15 out of 20 participants. The participants reported that their most significant concerns when facing a life limiting illness would be not having quality of life and dying alone. The participants also highlighted the importance of seeking meaning through spirituality, religion and philosophy. In addition, the participants reported they would like mental health clinicians to continue to provide their care when they developed a life limiting illness. However, their attitudes to dying may change if they were later diagnosed with a life limiting illness.

Mako, Galek and Poppito (2006) identified that early childhood trauma can re-emerge when a person is faced with the immanence of death. More recent studies identified that amongst people with a severe mental illness there is a high rate of early psychological trauma (Isobel & Delgado 2018; Starnino & Sullivan 2016; Starnino 2016b). Facing death from a life limiting illness can compound this trauma (Ganzel 2018). Research has suggested that both mental health services and palliative care services need to provide Trauma Informed Care (Ganzel 2018; Isobel & Delgado 2018).

3.6.4 Trauma - Informed Care

Studies suggest that there is an interrelationship between trauma, severe mental illness and spirituality (Chochinov 2006; Cornah 2006; Starnino & Sullivan 2016; Starnino 2016b). Negative spiritual experiences, such as feeling that the person has been abandoned by God or that they are being punished by God, can result from the traumatic experience. Starnino (2016b) found that positive emotions such as hope, gratitude and forgiveness can assist the individual to cope with the symptoms of their mental illness. Their study mirrors earlier research that recognised that spirituality can be an important resource for recovery.

Trauma Informed Care is philosophically aligned to recovery principles and mental health nursing practices, such as the 'therapeutic use of self' (Isobel & Delgado 2018). Isobel and Delgado (2018) maintained that services that provide trauma 'informed care' need to provide physically and emotionally safe environments for the individual who has experienced trauma in their lives. Trauma Informed Care is increasingly espoused by mental health services as a model of service delivery. However, there is disconnect between the espousal of Trauma Informed Care and the increasing dilution of the mental health nurse's core skills (Isobel & Delgado 2018). Isobel and Delgado (2018) argue that mental health nurses need to reconsider their role within Trauma Informed Care services and use their core skills of communication and presence within the 'therapeutic relationship'.

Palliative services also need to be 'trauma -informed' as there are many patients in hospices who are struggling with trauma histories, including the trauma of some medical interventions and the imminent threat of death (Ganzel 2018). This threat may also reactivate memories of previous traumas. Ganzel's (2018) views were especially pertinent to patients with a mental illness who were receiving palliative services. However, to date the literature has not explored the effects of earlier trauma on individuals with a mental illness who are facing death. Thus far, the literature has identified that human connection,

presence and ensuring the patient's emotional safety, are essential when providing spiritual care. It is important to explore the ethical issues within such profound relationships. The final section of this chapter will discuss the theme of ethical issues found in the literature.

3.7 Ethical issues when providing spiritual care for all patients at end of life

Spirituality has been an aspect of providing healthcare for centuries (Polzer Casarez & Engebretson 2012). However, the secularisation of healthcare has raised ethical concerns in relation to spiritual care, as clinicians hold differing viewpoints on the meaning of spirituality. Polzer Casarez and Engebretson (2012) undertook a discourse analysis to examine the ethics of including spirituality in clinical practice. The analysis found that there was significant discourse around the ethical concerns of omission and commission. Ethical concerns of omission may occur when healthcare professions feel incompetent and lack training or omit spiritual care due to feelings of personal discomfort in working with the patient on spiritual issues. Personal discomfort in the clinician may result in the patient not having their vital needs met. Polzer Casarez and Engebretson (2012) argue that such omissions are an example of maleficence or 'doing harm'.

Ethical concerns of commission relate to inappropriate spiritual care and include coercion by the healthcare provider and overstepping one's level of competence (Polzer Casarez & Engebretson 2012). Pesut and Sawatzky (2006) identified two approaches to spiritual care that were prescriptive and descriptive. Ethical concerns of commission may be raised when a health professional is prescriptive and attempts to impose their beliefs or spiritual goals on their patients, such as finding meaningful purpose, forgiveness, or reframing beliefs. Conversely, the descriptive approach defines what the nurse does in response to identified patient needs, which include listening, establishing trust and supporting the patient. Pesut (2008, p. 98) maintained the importance of a more nuanced definition of spirituality in order to "illuminate how spirituality is understood within a diverse

society". She conceptualised and explored three spiritual typologies, which represent quite diverse viewpoints.

These typologies were based on the analyses of nursing theorists who have written about spirituality. They are underpinned by the philosophical categories of the humanist, theist and monist. Pesut (2008) claimed that the three typologies have significant implications for nursing epistemology, ontology and for critiquing nursing practice. However, Polzer, Casarez and Engebretson (2012) argue that Pesut and Sawatzky's (2006) spiritual typologies may be coercive. They reason that within the humanistic approach, coercion may come in the form of an objective reality, by which the nurse can judge the patients spiritual state through the nursing process and using tools such as structured assessment. Such a process may be intrusive and objectify the patient. The theistic approach could potentially lead to ethical concerns when the nurse believes that they are bound to share their beliefs about God with the patient. The monistic view may introduce alternative or complimentary therapies such as yoga or meditation, which may conflict with the patient's spiritual or religious beliefs. Pesut and Sawatzky (2006) argue that for nurses to practice spiritual care ethically, they must be able to clearly articulate the nature of the care they are providing and have adequate education to be competent. Moreover, as spiritual experiences may be pathologised within healthcare systems as opposed to revered (Pesut et al. 2011), education exploring specific religions can assist nurses in understanding the differing beliefs that patients may hold (Polzer Casarez & Engebretson 2012). Starnino (2016a) argued that as an initial step toward integrating spiritual care into recovery-oriented practice, mental health clinicians need to understand the different ways spirituality is defined and conceptualised by the individual with a mental illness. Training would offer clinicians knowledge of different belief systems and skills to provide culturally competent care (Gielen, Bhatnagar & Chaturvedi 2017; Polzer Casarez & Engebretson 2012; Selman et al. 2018).

Other barriers to ethical care include health professionals' lack of time, or a belief that spiritual care is not a part of their role (Selman et al. 2018). In addition, the settings in

which they are providing care may not be conducive to spiritual care, which is not seen as a priority (Daaleman et al. 2008; Hanson et al. 2008; Polzer Casarez & Engebretson 2012). As well as the personal cost of lack of spiritual care, such as undiminished spiritual pain or despair, spiritual distress can lead to increased use of health-care (Edwards et al. 2010). Koenig (2012) points out that research has shown that failure to address the spiritual needs of patients at end-of-life care, can adversely affect the patients' health and may therefore prolong health-care, and consequently, healthcare costs.

Personal and health related financial considerations can be considered an ethical issue when the cost is brought about by inadequate or insufficient care. Prolonged hospital care not only increases personal costs, but also greatly increases healthcare costs. Balboni and Balboni (2011) undertook a prospective, multisite study to ascertain whether the omission of spiritual care within the healthcare system impacted on the cost of end-of-life care. They studied 339 advanced cancer patients from an outpatient setting between 2002 and 2007, following through until the patient's died. The cost of the last week of end-of-life care for patients who felt spiritually unsupported was compared with patients who felt spiritually supported. End-of-life costs were higher when patients reported that their spiritual needs were inadequately supported. Low spiritual support was associated with more aggressive end of life care, such as ICU, which was more costly than hospice care. The researchers suggested that the resolution of spiritual needs, such as finding peace meant that the patient was not opting for more aggressive interventions (Balboni and Balboni 2011).

Summary

This review of the literature examined the themes that relate to spirituality and mental illness and spirituality at end-of-life. Within this review it was found that a spiritual search can be precipitated by the experience of a mental illness (Wilding, Muir-Cochrane & May 2006), and that people with a mental illness frequently have a strong spiritual or religious dimension in their life that can assist in their recovery process (Corrigan et al. 2003;

Green, Gardner & Sandra 2009; Fukui, Starnino & Nelson-Becker 2011; Nolan et al. 2012; Webb et al. 2011; Wilding, Muir-Cochrane & May 2006).

Dying at a younger age is a risk factor for spiritual despair (Hui et al. 2011; Williams, 2004). Therefore, as people with a severe mental illness are dying at a younger age than the general population, they are particularly vulnerable to experiencing spiritual despair. In addition, this literature review found that facing death can precipitate a spiritual search. Facing death can also provide the impetus for people to review their life and re-evaluate their values and sense of meaning (Chochinov 2006). As there was no literature exploring the spiritual care of people with both mental illness and a life limiting illness, it is uncertain whether their spiritual care needs are being considered at the end of life.

From these findings it is surmised that people with a severe mental illness who are nearing death may have spiritual or existential concerns, given the prominence of this dimension throughout their lives and their unique vulnerabilities. It is also clearly highlighted in the literature that people with an enduring mental illness want their mental health care providers to continue working alongside them when they are dying. Yet, despite mental health clinicians having the skills and values to be able to provide spiritual care, it was found that they are often reluctant to do so.

Given that mental health nurses work within the broader culture of mental health services which privilege the biomedical approach, the central question that has arisen from this literature search is 'how does the current culture of mental health services, support or hinder the mental health nurse's ability to facilitate spiritual care for individuals with a severe mental illness who are facing death?' A cultural analysis of this question will provide an understanding of the history, traditions and beliefs that have shaped mental health nursing practice and explore the current barriers and support for providing spiritual care. This cultural analysis will also provide mental health services with a deeper understanding of how care can be best provided for individuals at end of life.

CHAPTER 4 - METHODOLOGY

Introduction

This PhD study will examine the broader culture of mental health services and explore how this culture impacts on the mental health nurse's ability and willingness to provide spiritual care, when the individual they are caring for has a life limiting illness. This chapter will illustrate the efficacy of using the qualitative research methodologies of focused ethnography and autoethnography, in answering the thesis question. The combined methodologies of focused ethnography and autoethnography provide a rich and layered description of the culture of mental health services and the provision of spiritual care.

This chapter will initially analyse the definitions of 'culture' and 'subcultures' and will explore how these aspects of culture are expressed through their own unique language and ambiguities. It will then explore the historical changes that have led to contemporary ethnography. As qualitative research methodologies are guided by philosophical principles (de Laine 1997), it follows that qualitative researchers are also philosophers (Denzin 2011). Therefore, this chapter will explore the philosophical foundation for **qualitative research methodologies** and the ontological and epistemological assumptions underpinning these methodologies. Denzin and Lincoln (2011) highlight that ontology is a study of what it is to be human and the nature of reality. Epistemology is the study of knowledge and how it is determined (Denzin & Lincoln 2011). The chapter will demonstrate how philosophical changes regarding views of reality, have led to the emergence of qualitative ethnography and the contemporary subgenres of focused ethnography and autoethnography. The methodologies of focused ethnography and autoethnography, their data collection methods, limitations and criticisms from different authors, will then be discussed.

Focused ethnography and autoethnography use the background or insider knowledge of the researcher as essential data (Anderson 2006; Butz & Besio 2009; Higginbottom,

Pillay & Boadu 2013). Within this study, the researchers' experiences and insights can provide important data, particularly within autoethnography. As a mental health nurse of almost forty years, the researcher has relevant insider knowledge. Reflexivity is the hallmark of sound qualitative research (Cohen et al. 2008). This chapter will demonstrate how the corresponding nature of reflective practice inherent in mental health nursing, can complement the reflexivity of qualitative research. The argument will be made that the insider data collected through the autoethnography will add a deeper, more reflexive dimension to the data collected from the focused ethnography. Finally, a theoretical lens through which the data from this research can be viewed, will be discussed.

4.1 The definitions of culture and the unique language of subcultures

Davis (2009), a social anthropologist, highlighted that it is difficult to articulate a precise definition of culture. According to Davis (2009, p. 33) culture is recognised through “the study of its language, religion, social and economic organization, decorative arts, stories, myths, ritual practices”. Culture embraces the actions of people, their aspiration and metaphors. A meaningful definition would identify each culture as unique and constantly changing (Davis 2009).

A culture is a collective phenomenon that holds at its core, shared and emotionally charged belief systems through which people navigate the uncertainties and chaos of human life (Trice & Beyer 1993). These belief systems are largely hidden. Schein and Schein (2017) have argued that the most intriguing aspect of an exploration of culture is that it can reveal unconscious phenomena that lie beneath the surface. The concept of culture is useful as it can offer an understanding of the “hidden and complex aspects of life in groups, organizations, and occupations” (Schein & Schein 2017, pp. 8-9). Hidden aspects of culture include taken for granted assumptions and values. Observable aspects of an organisational culture include artefacts such as signage and assigned office spaces, norms such as dress style and common jargon (Hatch & Cunliffe 2013).

Geertz (1973) an influential anthropologist, stated that he agreed with Max Weber (1864 -1920), philosopher and social theorist, when Weber argued that human beings are 'animals' that suspend themselves in webs of significance and that culture are those webs. Everyone has a culture from which to draw meaning, and in contemporary society individuals may have multiple cultures through which meaning can be found (Van Maanan 2008; Van Maanan 2011). Like a Russian nesting-babushka doll, there are subcultures within cultures. These subcultures exist within the organisation as distinct groups. They may be made up of professionals, such as nurses and medical practitioners, with their unique professional or occupational identities and traditions (Hatch & Cunliffe 2013). Mental health nursing is one such culture. Mental health nursing is a sub-culture within the larger mental health services culture and general society. There are multiple truths about mental health nursing practice (Lakeman 2013). A cultural analysis can provide an understanding of the ambiguities and conflicting beliefs within mental health services culture, and how traditions and history continue to affect current mental health nursing practice (Lakeman 2013).

Different subcultures or occupational groups may also use the same language (Davies & Mannion 2013). Language is the vehicle through which the soul of the culture expresses the concepts it holds about itself and the world (Davis 2009). Language produces meaning and constructs and organises social realities (Richardson & Adams St. Pierre 2005). Through language, power is defined and contested, and one's sense of self is created (Richardson & Adams St. Pierre 2005). The language of psychiatry and mental health has had a powerful influence on clinicians who share this culture (Lakeman 2013). Therefore, by examining the language of psychiatry, the ambiguities faced by mental health nurses can be revealed.

From an organisational perspective, different occupations or disciplines adopt not only specific skills and knowledge but also the values and norms that define their occupation (Schein & Schein 2017). Psychiatry has always aspired to be a scientific discipline and because of this aspiration, the language of psychiatry is expressed through the language

of biomedical scientific discourse (Lakeman 2013). The predominant language of psychiatry is abstract and impersonal, whereas according to prominent mental health nursing theorists, mental health nursing is based on compassion and the formation of the therapeutic relationship, in which there is a 'human-to-human' search for meaning of the individual's unique experience (Paterson & Zderad 1988; Peplau 1991; Travelbee 1971). However, Lakeman (2013) maintains that in the psychiatric setting, personal experiences are filtered through the language of psychiatry which transforms experience into medical problems. Hence, deeply personal meanings can get lost in translation and the culture of mental health nursing can become subsumed by the more dominant culture of medicine and psychiatry (Lakeman 2013). Therefore, analysis of culture should be interpretive and in search of meaning (Geertz 1973).

Contemporary ethnography has emerged as a qualitative methodology that offers interpretive explanations on what people believe and value and how they act within a particular timeframe and location (LeCompte & Schensul 1999). Nursing theorist Madeleine Leininger was the first nurse to use ethnography. She studied the phenomena of care from a cultural perspective within nursing research, and coined the term 'transcultural nursing' care, as she believed that nurses should be culturally competent (Leininger 1997). This next section will examine ethnography, its history and philosophical development. It will then discuss the sub genres of both focused ethnography and autoethnography as these will be the methodologies used in this study.

4. 2 Historical changes leading to contemporary ethnography

Ethnography developed over a century ago as anthropologies main method for studying culture (de Laine 1997). Contemporary ethnographers learn about people from people rather than studying them as objects or 'subjects' (Morse & Field 1996; Roper & Shapira 2000). To learn about people, ethnographers become intimately involved with their study participants and endeavour to develop reciprocal, trusting relationships to gain access to the participant's world view, and to ethically gather data (LeCompte & Schensul

1999). In doing so the ethnographic researcher seeks to discover how members of a community actively shape their world (Morse & Field 1996).

Research methodologies are guided by philosophical principles that shape a particular world view (de Laine 1997). Over the past fifty years significant philosophical and epistemological influences have challenged our understanding of culture (Tyler 1986) and the methods through which culture is explored (Angrosino 2005). In the mid-1980's, influenced by the French school of philosophy, anthropologists began to question the legitimacy of the ways in which reality was represented (Butz & Besio 2009; Cruz & Higginbottom 2013; Tyler 1986). At the time, reality was viewed as objective and knowledge generation stemmed from empirical science. The mid-80's heralded the 'crisis of representation' (Butz & Besio 2009; p. 1661; Clifford 1986, p.251), It was at this time that Clifford (1986), a prominent figure in anthropology, argued that the ethnographic ideology of an objective representation of reality through the writing of descriptive texts, had crumbled.

Through the 'crisis of representation', the writing of text moved from description, to an exploration of power, resistance, constraints and innovation (Clifford 1986). Tyler (1986) argued that rather than representing reality through observation and description, ethnography needed to be freed from 'representation' through the practice of 'evocative' writing or texts which evolve collaboratively with the participants. Tyler (1986) argued that ethnography could 'evoke' the readers into viewing reality from new and even sacred perspectives. The research methodology of autoethnography that will be used in this study, has its roots in the 'evocative' writing of texts.

The 'crisis of representation' transformed the values of ethnography to align with the values of postmodernism and qualitative research methodologies. As opposed to modernism which valued objective forms of evidence, based on positivistic research methodologies, postmodernism rejected all 'truth' claims and argued that no one 'truth' or research method could be privileged above another. The reality of objectivity and indeed the need for objectivity, was questioned (Angrosino 2005).

From a postmodern viewpoint, truth has many perspectives and parts (Angrosino 2005). There is no longer any room for monologue or the authoritative voice of the researcher, who in the past, has been the arbiter of knowledge with claims to objective truth (Richardson & Adams St. Pierre 2005). Rather, postmodern ethnography privileges dialogue between researchers and participants (Angrosino 2005; Tyler 1986).

Tyler (1986) used the metaphor of polyphony to describe ethnography. Polyphony 'evokes' the hearing of multiple voices to which the reader's voice can be included. The paradigm of research ensuring that all voices are heard within the study, is congruent with the mental health nursing theory position of making subjective experience more visible (Foster, McAllister & O'Brien 2006). In postmodern ethnographic research, subjectivity consists of multiple and contradictory discourses which are historically and contextually located (Richardson & Adams St. Pierre 2005). Postmodern ethnography rejects the notion of observer and observed (Tyler 1986). Hence, the individuals involved in the research are referred to as 'participants' as opposed to 'subjects' (Angrosino 2005; National Statement on Ethical Conduct in Human Research 2007). The position of the researcher becomes one of a subjective participant as opposed to a neutral observer (Morse & Field 1996).

In summary, contemporary ethnography is a qualitative research methodology that has been strongly influenced by the philosophies of postmodernism. The next section will briefly explore the philosophy of qualitative research methodologies in general and highlight the continually evolving nature of these methodologies.

4. 3 Philosophy underpinning qualitative research methodologies

Postmodern ethnographic research is a qualitative research methodology. In terms of underpinning philosophy, Denzin (2011) argues that there is no philosophical paradigm that encapsulates all the variants of qualitative research methodologies. Hence, there is perpetual resistance against imposing an umbrella paradigm over qualitative research

(Denzin 2011). Qualitative research methodologies have arisen from a variety of philosophical backgrounds such as European schools of thought, including the Frankfurt School and the School of British Cultural Studies. The Frankfurt School built upon the works of Karl Marx (1818–1883) and critical theory. Its aim was to reduce social inequalities (Tashakkori & Teddlie 2010). The British School which was mainly represented by the Birmingham School, had a strong orientation toward grounded theory and was known for examining the effects of popular culture such as media, on propagating social inequalities (Jin 2011). Qualitative research also includes more recent additions, such as the ethnomethodologies for example, from queer, feminist and African American strands of methodologies (Denzin 2011).

Qualitative research has multiple research methodologies that include interconnected terms, concepts and assumptions (Denzin & Lincoln 2011). Denzin and Lincoln (2011, p.12) use the metaphor of a quilt maker or 'bricoleur' to describe the attributes of a qualitative researcher. Bricoleur is a French word coined by the anthropologist Levi-Strauss, meaning 'jack of all trades'. Quilt makers and bricoleurs use aesthetic and material tools to craft their work. They stitch, edit and put pieces of reality together. They have a range of methods and techniques to choose from and in addition, if old tools do not work, the researcher may be required to make new tools (Denzin 2011). Both focused ethnography and autoethnography are examples of such tools.

Despite being unable to situate qualitative research under one paradigm, there are some ontological and epistemological assumptions underpinning qualitative methodologies. The ontological assumption is that reality is multifaceted, and the epistemological assumption is that data arises out of the interactions of the researcher and participants (Whybrow 2013; Polit & Beck 2004). In addition, subjectivity and the researchers' values are an aspect of research that needs consideration (Morse & Field. 1996). These assumptions will be reflected through the data analysis of both focused ethnography and autoethnography.

In summary, the development of qualitative research methodologies has seen a proliferation of several subgenres of methodologies (de Laine 1997; Knobault 2005, Richardson & Adams St. Pierre 2005). Ethnography is no exception. However, the main goal of ethnography remains as the study and analysis of culture (de Laine, 1997). A central tenet of ethnography continues to be the offering of “thick descriptions” of the culture under study (Geertz 1973; Morse & Field 1996). For the purposes of this study, ethnography will make a substantial contribution to nursing knowledge by offering a rich description of the landscape of mental health nursing practice and an understanding of how culture affects individual nursing care (Peterson 2015). In addition, through a deeper understanding of the culture and its effects on spiritual care, this study will be able to make suggestions for the provision of culturally relevant services.

The research methodologies and methods in this study are underscored by changes that have occurred in ethnography since the ‘crisis of representation’. These methodologies and methods of focused ethnography and autoethnography are subgenres of ethnography. The next section will discuss the contemporary subgenres of ethnography and argue that these subgenres of ethnography will be useful methodologies for examining mental health nursing culture.

4.4 Contemporary subgenres of ethnography

Branches of contemporary ethnography include critical ethnography, medical ethnography, focused ethnography and autoethnography (de Laine 1997 Morse & Field 1996; Richardson & Adams St. Pierre 2005; Roper & Shapira 2000). Critical ethnography is used to expose structural inequalities within a system (de Laine 1997). The relationship ethnography has to power is complex and potentially anti-hegemonic (Clifford 1986). Truth or knowledge claims can mask and serve a particular cultural or political interest (Richardson & Adams St. Pierre 2005). Hence, a critical ethnography examines issues of power and asks questions about whose interests are being served by a particular value, belief, or structure (de Laine 1997). Other branches, such as healthcare or medical

ethnography are used to expose culturally embedded norms that drive health behaviours. The knowledge gained from this form of research can assist in making healthcare provision more culturally sensitive (Morse & Field 1996, p. 22). Originally stemming from cultural anthropology, medical or health ethnography has focused on illuminating cultural beliefs and their meaning and how these meanings impact on health seeking behaviours and practices (Cruz & Higginbottom 2013; Morse & Field 1996; Roper & Shapira 2000).

An adaptation of ethnography known as focused ethnography, has evolved from medical ethnography in order “to study distinct and delineated health concepts” (Roper & Shapira 2000, p. 7). Focused ethnography can be used to study cultural phenomenon within subcultures, such as in the practice of nursing (Cruz & Higginbottom 2013; Roper & Shapira 2000, p. 9). Knoblauch (2005) argues that focused ethnography complements traditional ethnography by offering thick descriptions of people’s life worlds, particularly when cultures are specialised. The use of a focused ethnography to study the culture of mental health nursing is useful, as this subculture of nursing is highly specialised.

Autoethnography, another subgenre of ethnography, provides an additional lens for viewing culture. However, Pratt (1985) maintained that autoethnography is not an invention of modern ethnography. Pratt (1985) argued that personal narrative has always been a part of conventional ethnographies, especially in opening chapters and in setting the scene for the research. Clifford (1986) highlighted that in the sixties the conventional balance between the ethnographer’s objectivity and subjectivity was challenged (Clifford 1986). Since this time, the ethnographer’s personal experiences and empathy are no longer on the margins of ethnography but an essential part of the writing. The ethnographer’s own interactions and emotional states add another layer to the research (Angrosino 2005). Angrosino (2005) maintained that ethnographers require a deep understanding of their own situation, class and gender, and how this is interpreted and given meaning. An autoethnography can provide this perspective. The genres of focused ethnography and autoethnography will now be examined in more depth.

4.4.1 Focused ethnography

Knoblauch (2005) maintains that focused ethnography has been a feature of sociological ethnography since the 1950's and that its roots can be traced back to Goffman (1961) and his work examining the so called 'mental asylums' (Goffman 1961). The use of this hybrid form of ethnography, otherwise known as micro or mini ethnography, began to further evolve around the 1980's. Traditional ethnography became modified into micro or focused ethnography due to time and scope limitations in disciplines such as nursing (de Laine 1997).

The methodology of focused ethnography has been found to be a useful tool for understanding organisational culture (De Chesnay 2015). Rather than observing a culture, the methodology of focused ethnography studies specific aspects of complex organisations (Knoblauch 2005). This specificity means there can be a shorter time frame for data collection (Cruz & Higginbottom 2013; de Laine 1997; Knoblauch 2005). Focused ethnography is used in healthcare to understand specific problems and improve professional healthcare practices by making them culturally appropriate (Cruz & Higginbottom 2013; de Laine 1997; Higginbottom, Pillay & Boadu 2013).

Furthermore, Knoblauch (2005) maintains that 'alterity', or understanding the 'other's' point of view rather than 'strangeness', is a prerequisite for focused ethnography. 'Alterity' is also a key methodological feature of sociological ethnographies. Sociological ethnography has a long tradition of looking inside one's own culture whereas traditionally, anthropological ethnographers researched cultures outside of their own. The research subject was a stranger or 'other'. 'Alterity' provides a different orientation within sociological ethnography. Within the concept of 'alterity' there is a common backdrop to the social world and the world of the ethnographer, who can themselves hold the same cultural knowledge (Knoblauch 2005). As the researcher in this study, I held in depth knowledge specific to mental health nursing culture. Therefore, I was more able to

understand the 'others' point of view which is analogous to Knoblauch's suggestion that understanding 'otherness' is essential for a focused ethnography.

Similarly, Higginbottom, Pillay and Boadu (2013) argue that in a focused ethnography, the researcher frequently holds background knowledge and experience in the field in which they are researching as opposed to a traditional ethnography, where there is an ongoing relationship with a key informant who provides intimate, insider knowledge on the culture (Higginbottom, Pillay & Boadu 2013). In a focused ethnography the research can be undertaken in the researcher's own work environment as opposed to the researcher going into a new or different environment (Cruz & Higginbottom 2013). Moreover, focused ethnography provides a different approach to deductive observational studies and can offer a more holistic perspective than traditional ethnography (Higginbottom, Pillay & Boadu 2013).

4.4.1.1 Differences between the data collection methods of focused ethnography and traditional ethnography

There has been some debate on the modification of the methods of ethnography. Morse (2015) argues that the methods of ethnographic research are becoming weakened as they have excluded important aspects such as observation. She argues that by excluding aspects of traditional ethnography, ethnographic studies lose their depth and richness. This view contradicts her earlier premise, that when considering the needs of the patient, there are times when changing the traditional data collection methods to new or modified methods is necessary (Morse 2007). Morse maintained that some researchers have dropped the participant observation component of ethnography altogether, relying solely on interviews and documents (Morse 2007). Morse (2007, p. 864) highlighted that "[t]he method is still ethnography but modified".

Moreover, it can be reasoned that Morse's (2015) argument for a need to return to more traditional methods for ethnography, is a backward step because it does not account for the changes to the philosophy of ethnography, which occurred through the 'crisis in

representation'. Although participant observation has been the mainstay of orthodox ethnography, the postmodern critique of participant observation has shown this method to be problematic. The question was raised whether observational objectivity was desirable or even feasible (Angrosino 2005; Clifford 1986; Cruz & Higginbottom 2013). Angrosino (2005) argued that from a postmodern perspective, ethnographers can no longer operate from a distance with their research. Angrosino (2005) asked what values are held that justify seeking knowledge through participant observation. He maintained that researchers need to rethink observation as a method of ethnographic research. Researchers need to ask what knowledge observation generates and what explanatory frameworks are used to analyse the objectively recorded data (Angrosino 2005). As previously mentioned, mental health and palliative care are areas in which patients are highly vulnerable. With vulnerable people, such as those with a mental illness and a life limiting illness, participant observation is neither a feasible nor appropriate method.

In addition, Tyler (1986) maintained that rather than the representation of reality through observation and description, ethnography can become freed through the practice of evocative writing and avoid "the absurdity of 'describing' nonentities such as 'culture' or 'society' as if they were fully observable" (Tyler 1986, p. 130). The evocative writing style of the autoethnography will add another layer of data to the study and provide the depth and richness that Morse (2015) argues is lost through lack of observational data. Another difference in data collection methods articulated by Morse (1996), was that rather than the research topic emerging from the data collection and analysis seen in traditional ethnography, in a focused ethnography the topic can be decided upon prior to the commencement of research. The researcher's own knowledge can inform the research question rather than the topic arising out of the data (Cruz & Higginbottom 2013), as will be the case in this study.

In addition, a focused ethnography may be problem focused and context specific in nature (Cruz & Higginbottom 2013; Knoblauch 2005). Therefore, this research methodology will be useful when examining the culture of mental health services and

questioning whether the culture assists in the facilitation of spiritual care for an individual with both a mental illness and a life limiting illness. The methodology can also explore how to overcome problems or difficulties mental health nurses may face in providing such care.

Another difference between focused and conventional ethnography is that focused ethnographies are data intensive. Although data collection occurs over a shorter amount of time than conventional ethnographies, large amounts of data are collected in a smaller timeframe (Knoblauch 2005). The following table (Figure 4.1) provides a snapshot of the differences between a traditional ethnography, focused ethnography and autoethnography.

Figure 4.1 - Table Comparison between conventional ethnography, focused

Conventional ethnography	Focused ethnography	Autoethnography
Long-term field visits	Short-term field visits	Extended time in field
Experientially intensive	Data/analysis intensity	Data focus on variations (Anderson 2006)
Time extensity	Time intensity	Longitudinal view over time
Writing	Recording	Writing
Solitary data collection and analysis data	Session groups	Behaviour of self, both past and present (Chang 2008)
Open	Focused	Multiple focus (Anderson 2006)
Social fields	Communicative activities	Dialogic engagement (Anderson 2006)
Participant role	Field-observer role	Complete member research (Anderson 2006)
Insider knowledge	Background knowledge	Insider knowledge (Anderson 2006; Butz & Besio 2009)
Subjective understanding	Conservation	Analytical reflexivity
Notes	Notes and transcripts	Field notes
Coding	Coding and sequential analysis	Coding and simultaneous data collection and analysis (Chang 2008)

Despite the difference between conventional ethnography and focused ethnography, understanding culture remains a defining feature of any ethnography (LeCompte & Schensul 1999). Researchers who use focused ethnography still need to attend to traditions that characterise ethnography, such as providing a rich description which will

offer shape and colour to a variety of responses within a culture or subculture and add depth to the interpretation of meaning (de Laine 1997; Morse & Field 1996).

4.4.1.2 Limitations of focused ethnography

One limitation of the methodology is that there is little guidance in the literature on the use of focused ethnography, especially in the nursing literature (Cruz & Higginbottom 2013). Critics of focused ethnography claim that the hyper focused nature of the methodology may cause studies to become cut off from larger societal concerns (Knoblauch 2005). However, Knoblauch (2005) counters this point by arguing that focused ethnography is the study of highly differentiated fragments of culture and thereby examines the basic building blocks of society.

To augment the findings of the focused ethnography, the research methodology of autoethnography was also used in this study. An autoethnography adds to the data collected through the focused ethnography by offering another layer of data which is congruent with tenets of focused ethnography.

4.4.2 Autoethnography: Another layer of data

Autoethnography is a branch of ethnography that focuses on self-narrative and the analyses and interpretation of the self within a cultural context (Butz & Besio 2009; Chang 2008). This focus means that the researcher is undertaking an ethnographic study of the self within their unique culture. Autoethnography demonstrates culture flowing back and forth between the subjective experience of the researcher and the social world (Grant 2010; Peterson 2015). Autoethnography has become an emerging methodology of research in nursing that allows the nurse's voice to be heard (Peterson 2015).

The term autoethnography originated from Hayano's 1982 ethnographic work, 'Poker Faces: The Life and Work of Professional Card Players' (Liggins Kearns & Adams 2013; Manning 2005; Peterson 2015). The research was based in the world of poker playing,

where the researcher became so immersed in the gambling world that he could no longer distinguish himself from his informants (Hayano 1982). Hayano's (1982) research was completely interwoven with his personal experience and he reported that he did not have to play a role or deceive other informants. Hayano (1982) became the source of his information and he went on to describe his work as looking into a many angled mirror where one observes the self and others from different perspectives.

Hayano's work is similar to what Butz and Besio (2009) describe as complete member autoethnography. In this category of autoethnography the researcher has complete or insider's membership of the culture they are studying. In complete membership autoethnography the researcher uses their 'insiderness' as a methodological tool. The researcher's attention focuses on both the outside world and the world within (Liggins, Kearns & Adams 2013). In this study, as the researcher, I had complete membership in the culture of mental health nursing, thereby using the 'self' as a methodological tool.

The initial groundswell of autoethnographic research stemmed from Ellis and Bochner's (2000) methodology, known as 'evocative' autoethnography (Pace 2012). Evocative autoethnography is the polar opposite of empirical research, which is underpinned by the value of objectivity. Evocative autoethnography is grounded in personal experience. Ellis, Adams and Bochner (2011) maintain that through identification with the text, a sense of participation and a deep empathic response can be 'evoked' in the reader. Furthermore, evocative writing can inspire the reader to act ethically (Butz & Besio et al. 2009; Liggins Kearns & Adams 2013; Tyler 1986). Through powerful use of rhetoric and imagery, evocation can encourage the reader to reflect on situations from a different point of view (Van Maanen 2011). Hence, through the process of 'evocation', autoethnography can move both the researcher and the reader to understand their world in new and different ways. Through cultural artefacts, such as stories and poetry, new understandings of multiple realities can be revealed within the research.

Nevertheless, the past decade has seen the development of different approaches to autoethnography, which unlike 'evocative' autoethnography, values objectivity (Anderson

2006; Chang 2008; Denshire 2014). Anderson (2006) proposed a new approach to autoethnography, which he termed analytical autoethnography. This new approach takes a more objective stance that is committed to analytical processes and consequently greater theoretical understandings of the culture being studied. Analytical reflexivity values self-conscious reflection on the self and the influences of others within the social context. This approach complements the reflective practices in mental health nursing. Reflexivity also enhances the quality of the research by ensuring rigour (Cohen 2008).

This study will take a combined approach to the autoethnography. It will use the approach offered by Chang (2008), which values analytical reflexivity and interpretation. Chang's (2008) approach reflects Anderson's (2006) focus on reflexivity in data analysis. In addition, Chang's (2008) approach will be combined with the 'evocative' writing style as espoused by Denzin (2006) and Ellis, Adams and Bochner (2011). Through 'evocation' the reader may be reinspired to reflect on their own experience and the lived experience of individuals with a mental illness (Foster, McAllister & O'Brien 2006). Combining methods such as evocative and analytical autoethnography can offer insights and add to the researcher's tool chest (Pace 2012).

Liggins, Kearns and Adams (2013) argue that autoethnography has been underused as a research methodology within the mental health setting. Evocative autoethnography is an important strategy for the development of mental health nursing, as it can provide mental health nurses with an opportunity to further honour subjectivity and narrative (Foster, McAllister & O'Brien 2006; Liggins, Kearns & Adams 2013). The insider's or complete member perspective, can add depth to the phenomena under investigation, and can encourage the reader to engage with the story, reflect on their own personal experiences and connect these understandings to larger cultural processes (Butz & Besio et al. 2009; Liggins, Kearns & Adams 2013; Peterson 2015).

4.4.2.1 Criticisms of autoethnography

When reflecting on one's life it is difficult to avoid 'dead end' solipsism (Butz & Besio 2009). It is possible that reflexivity can become naval gazing and self-indulgent (Foster, McAllister & O'Brien 2006; Van Maneen 2008). Van Maneen (2008) maintains that self-indulgent reflexivity can contaminate the work through an overabundance of the researcher's characteristics and preferences. Hence, ethnographic detail can be lost. To avoid this highly self-referential form of text, the author needs to craft narratives that are meaningful to the reader and make an "explicit effort to inform readers' understandings of some aspect of the social world that exceeds the autoethnographer's individual experience" (Butz & Besio 2009, p. 1666).

In addition, Foster, McAllister and O'Brien (2006) highlight that within autoethnographic research there needs to be a willingness from the researcher to be vulnerable throughout the process of self-disclosure and evocation of emotion (Foster, McAllister & O'Brien 2006). In offering a different view, Chang (2008) argues that self-exposure without a profound cultural analysis and interpretation becomes simply an autobiography. In addition, Tolich (2012) and Morse (2007) warn that the researcher must temper self-disclosure to the level which ensures their own emotional safety.

An autoethnography can offer an opportunity for mental health nurses as readers, to examine their own experience. It is through this reflection on their experience that the nurse can further develop their practice and enhance the lives of others (Peterson 2015). Autoethnographic research can also provide an opportunity to extend mental health nursing care by examining everyday practice and through the analysis of quality and accountability that is akin to the process of 'clinical supervision' (Foster, McAllister & O'Brien 2006).

I chose to use focused ethnography and autoethnography as opposed to critical ethnography. A critical ethnography may have given greater insights into issues of power. However, at the time of deciding on the methodology, issues of power and power

imbalances were not as prominent within the service being studied as they became after the data was analysed and interpreted. However, in making this point, the literature had highlighted issues of inequity within the culture of the health system that could not have been ignored. Interpretive autoethnography can highlight issues of injustice and social inequality in particular moments and places (Denzin 2013). Through the autoethnography I hoped to capture the experience and concerns of those with a mental illness who were also facing death. I chose the methodologies of focused ethnography and autoethnography as both of these methodologies would allow me as a researcher, to be able to study the culture of mental health services from an insider perspective. Furthermore, embedded in the methodology of focused ethnography is the concept of 'alterity' that I believed was essential for understanding the experience and point of view of the nurses, especially in relation to the cultural barriers and support for their spiritual care provision.

4. 5 The corresponding nature of reflective practice in mental health nursing and the reflexivity in qualitative research

Mental health nursing is underpinned by the 'therapeutic use of self', which is developed through reflective practice (Foster, McAllister & O'Brien 2006; Travelbee 1971). The 'therapeutic use of self' is the foundation of contemporary mental health nursing practice. Travelbee (1971) posited that the nurses own spiritual values or philosophy on suffering, illness and death may determine the extent to which the nurse assists the individual to find meaning (1971, p. 16). Travelbee (1971, p. 19) described the 'therapeutic use of self' in mental health nursing, as the "[C]onscious use of her own [sic] personality to effect therapeutic change in another individual". Reflective practice mirrors the importance of reflexivity within qualitative research. The 'therapeutic use of self' is developed through reflective practices which enhance self-awareness and self-knowledge (Foster, McAllister & O'Brien 2006). Reflective practices include evaluating one's skills, limitations and values. A mandated method for developing reflective practice is through the process of 'clinical supervision'. Mental health nurses within Australia are expected to

participate in 'clinical supervision'. The Australian College of Mental Health Nurses (ACMHN-online) 2020 Clinical Supervision Special Interest Group's position statement declared that "clinical supervision is a core component of contemporary professional mental health nursing practice and central to practicing" within the standards. Clinical supervision is a formal process through which the nurse reflects on their clinical practice. Participants engage in reflective conversations, whether in a group or one on one, to evaluate and develop their clinical competence (Chapman 2017; King, Edlington & Williams 2020).

The autoethnography described here will capture the essence of the experience of the researcher and move the reader to understand their own world in new and different ways (Peterson 2015). Through the autoethnography the reader may be encouraged to reflect on their own experience and explore how their experience may impact on their clinical practice. In addition, a focused ethnography will explore the experience of the mental health nurse when providing care for people with a life limiting illness. This layered approach will provide a rich description of the cultural factors that affect the mental health nurse's ability to provide spiritual care to individuals who are facing death and provide a framework for improving clinical practice.

This section of the chapter has discussed the 'therapeutic use of self' which has long been identified as a major factor in developing the therapeutic relationship and is the foundation of mental health nursing practice (Foster, McAllister & O'Brien 2006). As the unique knowledge and values of the culture of mental health nursing are developed through nursing theory, this theory will be used as a lens through which the results of the study will be analysed. The next section will further discuss the rationale for using nursing theory as an analytical tool.

4.6 Theoretical lens for analysis of the research

Contemporary mental health nursing theorists recognise the connection between nursing theory and mental health recovery principles (Buchanan-Barker & Barker 2008). Recovery principles are the foundation of mental health service delivery across most of the Western world. Recovery principles assert the importance of finding hope, purpose and meaning. Furthermore, these concepts intertwine and underpin the practice of spiritual care. Nursing practice is guided by nursing theory, and the mental health service standards are underpinned by recovery principles. Further, Younas & Quennell, (2019) argued that although most nursing theory was developed in the USA, they have been found to be useful cross culturally around the world. Nursing theories are also invaluable in the domain of research. Therefore, nursing theory with a strong focus on the work of Joyce Travelbee, a mental health nursing theorist (1926-1973), will be used as a lens to analyse the results from the research question.

From Florence Nightingale to current nursing theorists such as Martinsen, Oye and Mekki (2016), Eriksson (2007), Watson (2003) and Watson (1979), nursing theory has had an abiding heritage of including spirituality in patient care. According to mental health nursing theorists, mental health nursing is based on compassion, kindness and the formation of the therapeutic relationship (Marriner-Tomey 2006; Paterson & Zderad 1988; Peplau 1991; Travelbee 1971). Travelbee (1971) highlighted that the major task of the mental health nurse is to assist the individual to find meaning in everyday life and in the experience of suffering and illness and to engender hope.

While Travelbee was a mental health nursing theorist, her theoretical model was based on interpersonal processes and hence had a strong confluence with, and influence within the palliative care movement (Parola et al. 2020). Therefore, Travelbee's theory was an ideal lens for this thesis. A basic assumption of Travelbee's theory was that suffering can be an emotional, physical and spiritual experience and that the patient's spiritual values can determine their perceptions of their illness (Shelton 2016; Travelbee 1971).

Travelbee's theoretical formulations were grounded on existentialist philosophy (Parola et al. 2020). Her theoretical assumptions were based on the work of existentialist philosophers Soren Kierkegaard and Viktor Frankl (Current Nursing, 2020).

The purpose of mental health nursing is the 'human to human' relationship (Travelbee 1971, p. 1). Travelbee (1971) coined the term 'human to human' relationship as opposed to the nurse patient relationship and maintained that it was in the 'human to human' relationship that the nurse and the patient see each other as unique human beings. It is in the 'human to human' relationship, that the barriers of role and status are transcended. The person's experience of illness and suffering is more important than their diagnosis (Hansson 2011).

Elements of Travelbee's nursing theory include rapport, empathy, sympathy and compassion. Travelbee (1963 p. 70) maintained that rapport is a process comprised of an interrelated cluster of thoughts and feelings that include an "... interest in, and concern for, others; empathy, compassion, and sympathy". Rapport is also the ability to communicate these feeling both verbally and non-verbally and to guide intelligent and creative action.

The element of empathy within Travelbee's model, is the intellectual understanding of the person's suffering, whereas sympathy has a greater emotional aspect and engenders an urge to act to relieve the suffering of the other and provide hope (Travelbee, 1963). According to Travelbee's theory, empathy is a precursor to sympathy. Travelbee (1964; 1963), argued that to sympathise is an act of courage. When sympathising the nurse is giving part of themselves to the other. It is in this deeply personal act of sharing that the nurse becomes vulnerable. Through this act the patient does not have to bear their suffering alone. The nurse is motivated to act by the feelings of compassion that underlie the emotion of sympathy. Travelbee (1964) argues that sympathy and compassion lie at the heart of nursing (Travelbee 1964).

Summary

To understand the specific cultural barriers and enablers in providing spiritual care for individuals with a mental illness, the combined methodologies of focused ethnography and autoethnography will be used in this study. The methodology of focused ethnography will examine the organisational culture of mental health services and the contexts in which mental health nurses felt able and willing to provide effective and appropriate spiritual care. Through the methodology of autoethnography, the study will connect the researcher's subjective experience to cultural processes (Liggins, Kearns & Adams 2013) and will assist in the exploration of whether the culture of mental health services facilitates mental health nurses in providing spiritual care for people with a life limiting illness. Through both methodologies, this study will explore strategies for embedding quality spiritual care, especially for individuals with a life limiting illness, into clinical practice. This chapter also offers nursing theory, with a focus on the therapeutic relationship, as a lens through which the results will be viewed.

The following chapter will discuss the methods used in undertaking this study, as well as provide the cultural background and identity of the researcher. It will also provide the reader with the clinical context in which the research took place and the demographic data of the interview participants.

CHAPTER 5 - METHODS

Introduction

This chapter will provide an overview of the methods that were used to collect and analyse the research data. The first section of this chapter covers the principles used for the sampling and size of the data collection, the recruitment process and the data collection methods for the focused ethnography. It will also outline the interview process for the focused ethnography and the data collection methods that were used for the autoethnography. The methodologies of both the focused ethnography and the autoethnography include the use of relevant documents as data. The search strategy for retrieving relevant government documents will also be discussed in this section.

The second section of this chapter will discuss the methods used for the analysis and interpretation of the data collected for this study. A method of triangulation was developed to compare and analyse the data from the interviews, focused ethnography and the stories from the autoethnography. The autoethnographic data from this study has been used to provide further contextual information on the culture of mental health services and to confirm, reject or complement the data from the focused ethnography (Chang 2008). Triangulation was used as a strategy to test the validity of one set of data against the validity of the other set of data (Chang 2008; Cohen & Crabtree 2008; Roper & Shapira 2000; Tong, Sainsbury & Craig 2007). The strategy for triangulation was developed for this study by combining Roper and Shapira's (2000) technique for analysis of data for ethnography, with Chang's (2008) 10 strategies for analysis and interpretation of data for autoethnography. Lastly, as an analysis of relevant documents assisted in adding to the credibility of the data for both the autoethnography and the focused ethnography (Bowen 2009; Cruz & Higginbottom 2013), the process used for the analysis of government documents will be discussed within this section.

As reflexivity is the hallmark of sound qualitative research, the third section in this chapter will discuss the use of reflexivity within this thesis (Cohen & Crabtree 2008). Further, to assess the influence of the researcher's background on interpretations of data, a culture gram adapted from Chang (2008) will highlight the researcher's identity and cultural background. In addition, as it is imperative that human research is underpinned by a solid ethical base, the fourth section will describe how ethical parameters were ensured within this research, including a subsection on informed consent. To offer the reader the clinical context for this study, the fifth section of this chapter will provide an overview of the health services in which the data was collected.

5.1. Sampling and Size, Recruitment and Data Collection

5.1.1 Sampling and size

Morse and Field (1996) maintain that two principles of appropriateness and adequacy guide qualitative sampling. Appropriateness in this context refers to choosing the participants that can best inform the theoretical aspects of the research. As the purpose of this study relates to a very specific cultural group, purposeful sampling of participants with background knowledge was essential for ensuring appropriateness. Focused ethnography uses key participants who have knowledge and experience specific to the culture being studied (Higginbottom, Pillay & Boadu 2013). Hence, participants were selected on their knowledge of the culture and willingness to discuss their views and experiences (Morse & Field 1996).

The other guiding principle, adequacy, refers to having enough data to provide rich description (Morse 1995; Morse & Field 1996) or a sense that all possible knowledge, themes and concepts have emerged from the data (Morse 1997; Tong, Sainsbury & Craig 2007; Ross 2014). Richness of data is dependent on detailed description as opposed to the frequency of times something is mentioned (Morse 1995). Richness of data in this study was enabled using four different data sources. These data sources included

interview data from mental health nurses and palliative care nurses, as well as relevant government documents and an autoethnography.

Guest, Bunch and Johnson (2006) claimed that the researcher knows that saturation has occurred when no new themes or information are observed in the data. This study ensured adequacy and found that saturation had been reached when in the process of data analysis, meaning that no new knowledge, concepts or themes could be found (Morse 1997; Ross 2014; Tong Sainsbury & Craig 2007). In addition, Morse (1995) has highlighted that quantity of data does not reflect its theoretical importance. She argued that in qualitative analysis, it is often the outlier or “infrequent gem that puts the other data into perspective”, and that this ‘gem’ can be the key to understanding the data (Morse 1995, p. 148).

The data collected for the focused ethnography was through semi-structured interviews with 17 nurses. These participants included 6 community mental health nurses and 5 inpatient mental health nurses. Also interviewed were 4 community palliative nurses and 2 inpatient palliative care nurses. Interviewing two sets of nurses allowed for a comparison between the two subgroups. In addition, as palliative nurses may also care for individuals with a lived experience of mental illness at end of life, interviewing the two groups also offered a “better understanding of the complexities of common situations” (Roper & Shapira 2000, p. 9) and a rich description of the landscape of care.

Morse (2007) argued that the researcher must take particular care if they research in their own setting. They need to be mindful of the day-to-day norms of the culture and recognise that as an insider, the researcher may not recognise the norms as readily as an external researcher would. In addition, Roper and Shapira (2000) argued that it is important to understand how one has internalised the bias of one’s own culture. Therefore, it is useful to undertake research within another culture. Although reflexivity has assisted in examining my own cultural biases as a nurse who works predominantly in mental health, the same questions regarding spiritual care of people with a mental illness were asked of participants who work as palliative care nurses. In addition, as spiritual care

is a core competency for palliative nurses, it was assumed that their skills and knowledge in delivering spiritual care could inform future mental health service improvements when providing spiritual care for people with a mental illness at end of life.

5.1.2 Recruitment

There was fair and open recruitment of participants. An ethical decision based on the value of justice, underpinned the choice of who was invited to participate in the research and who was not invited. This decision was based on the scope and objectives of the study (The Australian Government National Health and Medical Research Council 2007). Nurses from the mental health and palliative care settings were invited into the study. The inclusion criteria for both sets of cohorts was that nurses were caring for or had cared for a person with a severe and enduring mental illness who also had a life limiting illness. Their patient age range was between 18 and 65 years of age.

I sought permission for the Directors of the mental health and palliative care services to engage their nurses in the research. Once these permissions had been obtained, I outlined the research project and the details of the participant's involvement in the study with the 'Heads of Units' or 'Unit Directors' of each of the mental health and palliative care sites. These sites included inpatient units and community sites within the South Australian health system. I then sent out a general email to the prospective sites which invited potential participants into the study and attached flyers to walls where potential participants would see them (See Appendix 3. Invitation to Mental Health and Palliative Nurses to Participate in Research).

The original aim for the research was to interview 10 mental health nurses and 10 palliative nurses to achieve saturation (Guest, Bunch & Johnson 2006). This study used purposeful sampling with a homogenous group of nurses. Saturation was reached with 11 mental health nurses and 6 palliative nurses (Guest, Bunch & Johnson 2006). I believe this research reached saturation when the following 2 signals occurred through the data

analysis. The first signal occurred when no new knowledge, concepts or themes could be found in the data. The second indicator was congruent with Morse's (1995) argument and occurred when an 'infrequent gem' or 'outlier' was discovered and put the other unexpected data into perspective (Morse 1995). Morse (1995) pointed out that in quantitative research, frequency is key to the analysis and the 'outlier' is abhorred and discarded. However, in qualitative research the converse is true.

The interviews took approximately 45 minutes to 60 minutes. The time taken for the interview was able to fit into the professional development allotment time for inpatient nurses. I interviewed the nurses at their work site, at a time that was suitable for the participant. Community nurses from both mental health and palliative care services had more flexibility with their time and I interviewed them at their convenience, at a location that suited them. On one occasion the interview was in the nurse's home. Other interviews were held in my office or an office in the clinical unit in which the nurse worked. It was ensured that regardless of the locations used for the interview, confidentiality was maintained. Prior to the interview the participants were provided with detailed information about the research and asked to complete the written consent form (See Appendix 4. Participant Information and consent form).

5.1.3 Data collection

Focused ethnography permits data collection methods to suit the various needs of different populations (Morse 2007). The data collection method used for the focused ethnography was in-depth, semi structured interviews around a specific topic, using open ended questions and the examination of relevant documents. These documents can be used to confirm or contrast interview findings (Higginbottom, Pillay & Boadu 2013).

Interview questions for the focused ethnography were based on the literature review (See Appendix 5. Interview questions). Due to the logistical and ethical issues involved in the direct observation of spiritual care of people with a mental illness who are facing death

from a life limiting illness, observation as a form of data collection was not used. To assist in ensuring the validity of the data, the researcher asked the same open-ended questions to each participant (Roper & Shapira 2000). The interview questions had three main aims. Firstly, the questions were aimed to investigate the nurses' understandings of the spiritual needs of people with a mental illness who have a life limiting illness; and secondly, to explore the cultural influences that informed these understandings. Finally, the questions aimed to understand the professional and workplace cultural barriers or enablers for providing spiritual care. The questions were open ended, allowing the unique understandings and experience of the participant to be elicited. This process added depth and richness to the data.

The study established trustworthiness or truth value by reporting the views of the participants as accurately and as clearly as possible (Morse & Field 1996). With the permission of the participants, interviews were audiotaped. Audio recording and transcription offers a more accurate method of reflecting on the participant's views than the researcher's notes alone (Tong, Sainsbury & Craig 2007). To assist with transparency and trustworthiness, the research data provided in the results section of this thesis, includes verbatim parts of the transcripts from all the participants (Tong, Sainsbury & Craig 2007). I transcribed 2 interviews to gain an understanding of the transcribing process. The remainder of the interview were transcribed by a professional transcriber.

The autoethnographic dimension of the study offered me, as the researcher, the opportunity to reflect on my own experiences, thereby adding another layer to the description and further understanding of the culture (Ellis, Adams & Bochner 2011). The data collection for the autoethnography was heavily anchored in my own lived experiences as a mental health - palliative care nurse practitioner (Chang 2008). Data was collected through self-observation and self-reflection of my experiences in the clinical area and kept in a field journal (Chang 2008). For examples, see pages 133, 134-135, 158-162 of this thesis. The autoethnographic data was collected over a 6-month period. There were 11 ethnographic stories that formed part of the data analysis. Although no formal questions

were used to reflect on the autoethnographic data, questions I ask as a mental health – palliative care nurse practitioner guided my reflection. For example, are they frightened about dying, what meaning does death hold for them and what gives their life meaning now? This data ensures anonymity by not including identifying characteristics of any of the people involved in the personal experiences and reflections, other than those of the author.

As suggested by (Bowen 2009) to ensure credibility and trustworthiness, a range of documents were collected. In identifying government documents relating to the culture of mental health services, a systematic search was initially undertaken using the Government of South Australia's Health search engine. I used the search queries of 'Culture Mental Health' and 'Community Mental Health'. Further, the governance documents for guiding South Australian Mental Health Service delivery were used as a data source.

5.2 Data analysis

Within the methodology of ethnography, data collection and analysis can occur simultaneously (Ellis, Adams & Bochner 2011). Therefore, I did not wait until all interviews were completed to commence the data analysis (Kuper, Lingard & Levinson 2008; Morse & Field 1996). In addition, as data analysis for ethnography does not occur in a linear fashion, the analysis for this study moved back and forth, comparing and contrasting data in order to look for meaningful patterns, including differences and similarities in the data (Chang 2008; Roper & Shapira 2000). The data analysis was through a "iterative, cyclic, and self-reflective process" (Higginbottom, Pillay & Boadu 2013, p. 6). Continual re-reading of data was essential as themes were identified. The data was searched for meanings, key words and recurrent issues (Boadu & Higginbottom 2014).

5.2.1 Triangulation strategy

This study drew upon the 10 strategies identified by Chang (2008, p. 129) for the analysis and interpretation of data from the autoethnography. These strategies were: (1) searching the data for reoccurring themes and patterns, (2) searching for cultural themes;, (3) identifying exceptional occurrences, (4) analyse inclusions and omission, (5) connect the past and present, (6) analysing relationship between self and others, (7) comparing self with others in study, (8) conceptualise broadly, (9) compare social science constructs and ideas and (10) frame with theories. The study used memoing for reflective remarks and descriptive coding to identify patterns (Chang 2008; Roper & Shapira 2000), (See Appendix 6 Excerpt data set analysis and Appendix 7. Process for triangulation analysis and interpretation of interview and autoethnographic data - Steps and analysis of documents).

To further enhance the credibility of both the focused ethnographic data and the autoethnographic data, the process of triangulation was used. Triangulation is used for multiple sources of data collection. The researcher analysed the data collected from the focused ethnography and compared this data against the data collected from the autoethnography (Chang 2008; Cohen & Crabtree 2008; Roper & Shapira 2000; Tong, Sainsbury & Craig 2007). Triangulation for this study was developed from Chang's (2008) 10 strategies for analysis and interpretation of data, combined with Roper and Shapira's (2000) technique for analysis (see Figure 5. 1).

Figure 5.1 Triangulation Strategy – Data Analysis

Adapted from - Chang (2008) and Roper. & Shapira (2000)

Focused ethnography analysis	Triangulation	Autoethnography analysis
From Roper and Shapira 2000-ethnographic analysis		From Chang's 2008 autoethnography method of analysis
Step 1. Initial coding - for descriptive labels -codes are assigned to research questions or unexpected questions or concepts – summarise the content of segments		Step 1. Initial coding - use Roper and Shapira's 2000 coding for consistency
Step 2. Combine Roper and Shapira 2000 and Chang 2008		Step 2. Chang's 2008 10 phases
Roper and Shapira 2000 - Sort for patterns		1. Search for recurring topics
Use Chang's 2. Look for cultural themes	Look for cultural themes across both AE and FE	2. Look for cultural themes
Step 3. Roper and Shapira 2000 - Sort for outliers	Combine Chang 2008 and Roper & Shapira 2000 i.e. Identify exceptional occurrences and sort for patterns and outliers occurring for both AE and FE	3. Identify exceptional occurrences
4. Same as autoethnography		4. Analyse inclusions and omissions
5. Same as autoethnography		5. Connect the past with the present
6. Same as autoethnography		6. Analyse relationships between self and others
7. Same as autoethnography		7. Compare yourself with other people's cases
8. Contextualise broadly		8. Contextualise broadly
9. Same as autoethnography		9. Compare with social science constructs and ideas
10. Generalise constructs and theories		10. Frame with theories

Through this technique of triangulation, a broader and more complex understanding of the phenomenon was revealed (Roper & Shapira 2000; Tong, Sainsbury & Craig 2007).

New insights were then constructed through this complete immersion in both sets of data (Morse & Field 1996).

5.2.2 Analysis of documents

An analysis of relevant documents assisted in understanding and developing insights into the culture being studied (Bowen 2009; Cruz & Higginbottom 2013). Bowen (2009) argued that document analysis needs to be a systematic process through which documents are analysed and interpreted in order to elicit their meaning. These documents can include items such as press releases, background papers and institutional reports. The additional data found in a document analysis can also guard against single researcher bias (Bowen 2009).

The documents were analysed by using the suggestions of Bowen (2009). The process included an initial skimming or superficial examination of the documents to determine their relevance to the research and whether they fitted with the conceptual framework of the study. To ensure trustworthiness and quality of documents, the original purpose for which the document was written and the author's credibility, were considered in the examination of the documents. To ensure consistency in the method used for analysis of other data within the study, there was a deeper reading of the documents to look for patterns and emerging themes. (See Process for Documents, p. 340 of thesis Appendix 7.) Retrieved documents matched the timeline of this study (2014 - 2020).

5.3 Reflexivity

Within qualitative research, a high level of reflexivity is required to ensure rigour (Cohen & Crabtree 2008; Cruz & Higginbottom 2013). Reflexivity highlights power relationships, especially if there is a power differential between the researcher and the participant. This study highlighted my role as a senior nurse with experience in the field that was being researched. This difference in level and type of experience could have

possibly influenced the data being collected. However, most of the participants were also senior nurses with many years' experience. Hence, there was no clear power differential between the researcher and the participants.

Cohen and Crabtree (2008) highlighted that an essential assumption within the interpretive paradigm is that knowledge is not fixed but co-constructed between the researcher and the participant. This study was underpinned by self-reflection and reflexivity. Through a process of negotiation between myself as the researcher and the participant, I explored the interpretation of meanings that the participants gave to their responses to questions. Within the interview I checked with the participants if my interpretations were correct. To ensure transparency I stated my personal interest in undertaking the research and my assumptions behind the research question when talking with the research participants about the research (Tong, Sainsbury & Craig 2007).

Similarly, reflexivity involved reflecting on how my chosen methodology and methods may have influenced the research outcomes (Cruz & Higginbottom 2013; Higginbottom, Pillay & Boadu 2013). Research findings are inevitably shaped by the processes chosen by the researcher (Cruz & Higginbottom 2013). For example, my choice of using focused ethnography as opposed to critical ethnography was shaped by my belief that this methodology would be useful when researching specialities and subcultures such as nursing. Furthermore, the focus of the methodology was on making improvements in health outcomes and as such, would best serve individuals with a lived experience of mental illness. Through self-conscious reflection, I examined my own values and beliefs and have acknowledged their influence when interpreting and drawing conclusions from the data (Cruz & Higginbottom 2013). This reflexivity allowed me to establish the credibility of the study as opposed to being an expression of my own ideology (Cruz & Higginbottom 2013).

Since the 'self' is a carrier of culture, the autoethnographic component of the analysis of the researcher's own behaviours, both verbal and nonverbal, was also aimed at gaining greater cultural understanding (Chang 2008). Self-conscious reflection was demonstrated

through a continual examination of the researcher's values and attitudes as they arose through the study. As the researcher's tacit knowledge is an essential feature of high-quality research (Cohen & Crabtree 2008), I attempted to demonstrate my tacit knowledge within the autoethnographic stories.

Two field journals were kept for this study. Field journals were used for both the autoethnography and ethnography. For the ethnography, a journal was used to record observations and personal reflections during interviews. The journal for the autoethnography was used to record reflections on clinical experiences. These reflections were later analysed and interpreted. Chang (2008) argues that through methodically separating subjective and interpretive data in a field note journal, self-absorption in the autoethnographic process can be minimised.

To ensure auditability, I developed an audit trail which clearly articulated the insights, choices and decisions I made throughout the research (Delaine 1997; Morse & Field 1996; Roper & Shapira 2000). The research credibility was improved as my identity, credentials, experience and gender were made clear to the readers. This identification can assist the reader in assessing how the researcher's observation and interpretations have been influenced by the researcher's background (Tong, Sainsbury & Craig 2007). These details have been provided in the introductory chapter of this thesis.

The following culture gram (Figure. 5.2) adapted from Chang (2008), further highlights my identity and cultural background. It provides my primary identities, values and what gives meaning to my life. As a researcher, this culture gram is the cultural lens through which I view, analyse and interpret the data. My primary identities, such as being a nurse practitioner in full time employment, places me in a position of privilege, as does my Anglo-Saxon heritage. Patients and other nurses may have potentially viewed me as having some power. I was cognisant of this potential power imbalance throughout the interviews and in my clinical experiences of listening to patient stories. I believed my values and beliefs assisted in ameliorating some of this power imbalance. I valued my interactions with people and their kindness and generosity in allowing me to listen to their

stories and views. I feel privileged to have been able to listen to these stories and views. I also believe in speaking truth to power, which I am aware can cause me to view and potentially respond to data emotionally. From an autoethnographic perspective, this emotional response can be considered as part of the data. However, this emotional data should not taint the other data collected. Hence, the emotional data needs to be balanced with academic rigour. My own love of spirituality and philosophy will affect the interpretation of the data as this is a lens through which I view the world.

Figure 5. 2 Culture Gram



5.4 Ethics

The research methods for this study were conducted in a respectful, humane and honest manner (Cohen & Crabtree 2008). I facilitated the development of respect and trust through an open and reflective dialogue with the participants. Trust generated accurate data that is essential in ensuring rigour as participants are more likely to be honest in an atmosphere of trust (De Chesnay 2015). I briefly discussed possible issues of power through a process of open dialogue with the participants and I collaboratively explored how power imbalance (if any) could be moderated. Further, the research

embodied the values of empathy collaboration (Cohen & Crabtree 2008). I used my skills and experience as a mental health nurse to assist in developing empathy and a good rapport with the participants.

The research design for this study was based on ethical principles and conduct. The National Statement on Ethical Conduct in Human Research (2007) articulates four values for undertaking ethical research. These values are merit, justice, beneficence and respect. This study followed these guidelines and the ethical value of respect was woven throughout the study design, reflecting the intrinsic value of human beings.

The study demonstrated merit, as the research has potentially important benefits for people with a mental illness. Justice was demonstrated by examining the worth of the study and the benefits for humankind and by ensuring that all the participants were treated fairly. As the researcher, I demonstrated beneficence by examining any potential harm the study may cause society as a whole and will continue to manage these risks. I also demonstrated beneficence by assessing the potential risk to any of the participants and by minimising and managing those risks. Within the interview process I was continuously aware of welfare and well-being of the participants and demonstrated genuine concern and respect for the participant's welfare (Higginbottom, Pillay & Boadu 2013). For example, being aware of any signs of distress, discomfort or inconvenience, and taking appropriate action to ameliorate or manage these issues.

Morse (2007) highlighted that qualitative research has the potential to cause emotional harm, as the participants may be revealing sensitive aspects of themselves. It was imperative that I was aware of this potential and if the participants exhibited signs of emotional harm, I would have offered to provide them with assistance or counselling from an external source. It was also important to be aware of and respect that the participants had offered their valuable time to me. I told them I was grateful for their time and did not use this time wastefully (Morse 2007). The participant's confidentiality and anonymity continue to be protected by the use of pseudonyms and the participants were informed that they could withdraw at any time.

Tolich (2012) argued that the researcher also needs to be aware of their own vulnerability and take steps to minimise any harm to self through exposure. Similarly, Morse (2007) argued that the researcher also needs to reflect on their level of vulnerability to ensure their own emotional safety. This reflection was done in consultation with my supervisors.

Roper and Shapira (2000) highlighted that when working within one's own culture or subgroup, such as when using focused ethnography and autoethnography as a methodology, it is important to examine one's own beliefs, values and socialisation. Through a reflective journal, I examined my own beliefs and values, and reflected on how these influenced my interactions with everyone involved in the research. This reflection included working with department heads to negotiate how the research will take place in their individual clinical units, providing information to the nurses working in the units and discussing the interview process with participants. This use of reflexivity has further ensured that the research has an ethical base (Kuper, Lingard & Levinson 2008).

To ensure the participants gave informed consent, they were provided with written material that included full details of the research and their participation (see Appendix 4. Participant Information and consent form). The material explained their involvement in the research process how their data would be stored and reported on. There was no coercion or pressure for clinicians to participate in the research. Participants were made aware that consent is an ongoing process and as such, they could withdraw their consent at any time and their data would be destroyed. Participants were informed that their de-identified data would be stored for a period of 7 years after the last publication of the research.

The issue of consent in the autoethnographic component of the research was not as straightforward as that of the focused ethnography. Although conventional informed consent was not required as the research participant is the autoethnographer, there was a lack of consensus in the literature over gaining consent of the individuals involved in the ethnographer's narrative (Peterson 2015). Chang (2008) highlights the potential difficulties in protecting the confidentiality of others involved in the narratives contained in the

autoethnography. Chang (2008) and Tolich (2012) agreed that protecting confidentiality within an autoethnography is as important as it is in other forms of human subject research, despite inherent difficulties, such as narratives that have occurred in the past. Tolich (2012) questioned whether retrospective consent is possible without coercion. However, it is essential that the rights and anonymity of the individual within the narrative are protected. This protection can be done through changing the name of the participants and other identifying details (Ellis, Adams & Bochner 2011; Peterson 2015). In addition, Tolich (2012) argued that others who may be identified in the research should be subject to the same informed consent processes as other voluntary participants, as outlined by the National Guidelines. It was not necessary for me to seek informed consent during the autoethnography because the data included no identifying patient information, ensuring anonymity. Ethics consent was granted by the [REDACTED] Adelaide Clinical Human Research Ethics Committee on the 8th June 2016 – OFR # 146- HREC/16/SAC/123.

5.5 Overview of Health Services

To provide context for the reader, the remainder of this chapter will provide an overview of the discrete health services used for data collection.

5.5.1 Adult mental health services

Public mental health services in South Australia work in collaboration with private sector health providers and non-government organisations. Adult services are available to assist adults aged 18 to 64 years with mental health issues. The adult mental health services had inpatient units with speciality psychiatric intensive care units and acute care units. Other units focused specifically on recovery and rehabilitation goals. The adult mental health services also included several community-based services.

5.5.2 The palliative care service

The palliative care service was a multidisciplinary specialist service that provided services to a local region in South Australia. It offered inpatient consultation, medical outpatient services and community nursing care coordination for people with advanced life-limiting illnesses.

Summary

This chapter discussed the data collection and identified the strategies for analysis and interpretation of the data. It included a culture gram of the researcher's background and cultural identity and included the demographic data of the participants. It demonstrated how the research was undertaken within ethical parameters. This chapter also provided the reader with a clinical context through background information on the health services involved in the data collection. The following chapter will provide the results of the research study. It will focus on the themes and issues that emerged through the data and will provide data from the government documents, interviews with mental health and palliative nurses and the autoethnography.

CHAPTER 6 - RESULTS

Introduction

This chapter will provide the results of the research study through the themes that were constructed from an analysis of the data. This chapter is divided into four sections. The first section will provide the reader with the demographic data of the participants. The second section will discuss the themes from the analysis of government documents that relate to the organisational culture of mental health services. They provide the organisational context of mental health services within the state of South Australia and its effect on the participant's ability to provide spiritual care. These themes will offer a backdrop from which to view the results from the interviews and the autoethnographic data. The data in this section points to a culture in crisis. It will highlight the issues of bullying, intimidation and overwhelming workloads that were found throughout the data collection process. Data from the government documents indicated that mental health clinicians felt burnout and powerless. The data from some of the participants interviewed in this study mirrored the issues highlighted in the government documents and their comments will also be discussed in this section.

The third section will discuss the themes that denote cultural support for the facilitation of spiritual care. Participants indicated that the support was mainly through nursing leadership. In addition, in sharp contrast with the data from section 2 that will indicate that clinicians' workloads were overwhelming, section 3 will discuss the data that highlights that the mental health nurses believed they had the necessary time to facilitate and provide spiritual care. Also, to illuminate the complexity of common nursing situations and to gain a greater understanding of the internalised cultural biases or unreflected assumptions or beliefs of mental health nurses, the contrasting data from nurses working within a different health setting (Roper & Shapira 2000), will be included in the analysis.

The fourth section entitled the 'Sphere of Nursing', will discuss the themes that relate to the spiritual care provided by both the mental health nurses and the palliative care nurses.

6.1 Demographic data of participants

Most participants were in the older age group, with 7 out of the 10 mental health nurses being over 50 years of age at the time of the research. According to the Australian Institute of Health and Welfare, almost a third of mental health nurses in Australia are over 55 (Australian Government n.d). Workforce modelling undertaken by a local South Australian health network, found that the average age of mental health nurses was 47 years, with 61% being aged 45 and above. Thirty percent were aged 55 years and older. It was expected that 50% of the mental health nursing workforce will retire in the next 10 years (Nursing and Midwifery Office 2018).

Similarly, the average age of palliative care nurses in 2015 was 47 years of age (Australian Government n.d). All the palliative nurses in this study were over 50 years of age. Hence, the age of participants in this study was slightly higher than the nursing population in Australia. Mental health nurses make up around 1 in 15 of the nursing population of Australia whereas palliative care nurses make up around 1 in every 90 nurses. Four of the 10 mental health nurses in this study were male. This number is similar to the national average, as 3 in 10 mental health nurses are male. Nationally, 1 in 10 palliative care nurses are male (Australian Government 2016). However, all palliative nurses in this study were female.

Figure 6.1 displays the demographic information asked of participants. It shows the number of years the participants have been nursing and the age of the participants. Most participants had been nursing for over 21 years. One nurse had been nursing for 45 years.

Figure 6.1 Participant Demographic Information

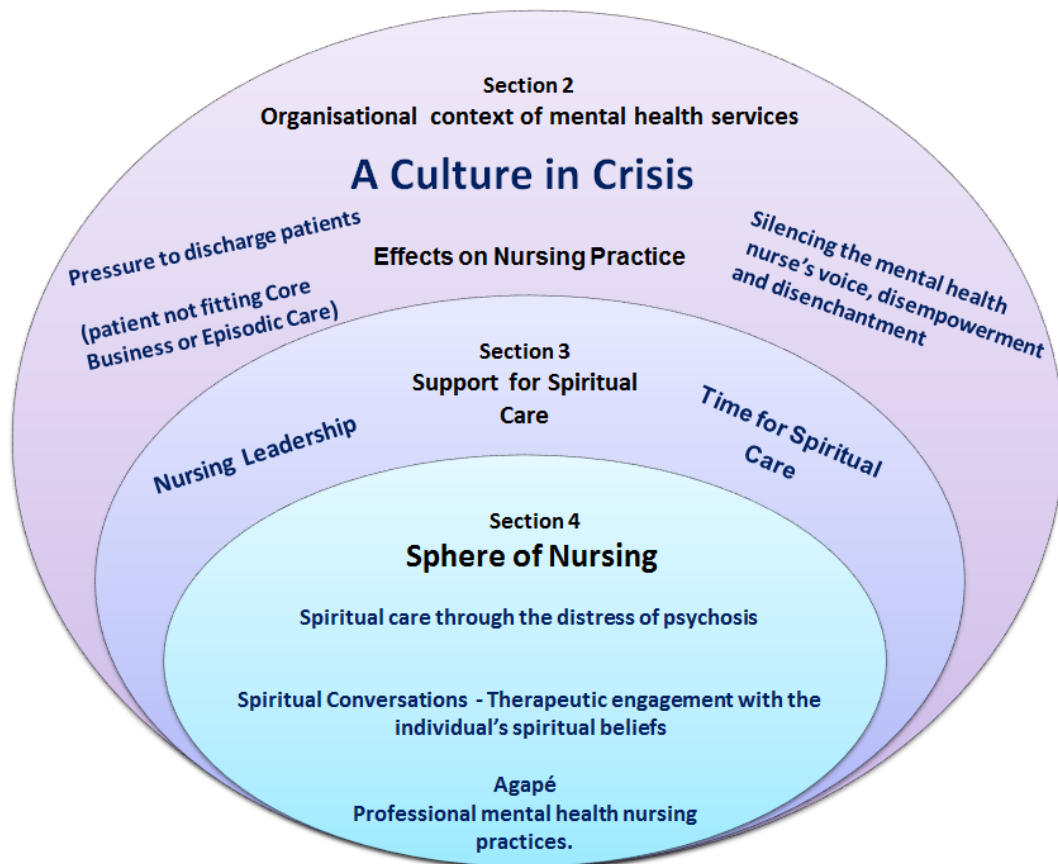
Names	Area of Practice	Years of Nursing	Age of Participant
P1 Sabine	Community Mental Health Nurse	16-20	30-40
P2 Jo-Ann	Community Palliative Care Nurse	21+	50-60
P3 Steve	Community Mental Health Nurse	21+	50-60
P4 Sheryl	Inpatient Mental Health Nurse	21+	60+
P5 Colette	Inpatient Palliative Care Nurse	40+	50-60
P6 Suzanne	Community Palliative Care Nurse	21+	50-60
P7 Bess	Community Palliative Care Nurse	21+	50-60
P8 Sophie	Inpatient Palliative Care Nurse	21+	50-60
P9 Charisma	Inpatient Mental Health Nurse	11 +	50-60
P10 Larsa	Community Mental Health Nurse	21+	40-50
P11 Jessie	Community Mental Health Nurse	21+	50-60
P12 Christine	Community Mental Health Nurse	21+	50-60
P13 Frank	Inpatient Mental Health Nurse	11+	40-50
P14 Linda	Community Mental Health Nurse	40+	60+
P 15 Roger	Inpatient Mental Health Nurse	40+	50-60
P16 Bianca	Inpatient Mental Health Nurse	30+	50-60
P17 Lillie	Community Palliative Care Nurse	40+	50-60

Participants stated that they volunteered for the study for several reasons. Some stated that they would like to speak of their experience of nursing a person with a mental illness who was dying, as this experience was a significant point in their nursing lives. Some participants said that they had not spoken with anyone about the experience and this study presented an opportunity. One nurse wanted to discuss her experience, as she believed the person she was attempting to care for was “a bit of a hero really” (Community

Mental Health Nurse, CMHN P12, p. 7) and that she thought the patient's story needed to be told (from journal entries).

The main themes in the following three sections of this chapter are illustrated in a diagrammatic conceptual framework (see Figure 6. 2). This conceptual framework was based on the finding from the themes constructed through the triangulation process. As mentioned previously, section 2 of this chapter discusses the themes from an analysis of government documents that elucidate a culture in crisis and the effects of this crisis on nursing practice. These effects include a detrimental pressure to discharge patients and the silencing and disempowerment of nurses. Section 3 of the diagrammatic conceptual framework illustrates the organisational support for spiritual care. Section 4, the 'Sphere of Nursing', undergirds the first two sections of the diagram. This section will firstly discuss the theme that relates to the spiritual care of individuals who were experiencing a psychosis. Secondly, it will discuss the theme of therapeutic engagement with the individual's spiritual beliefs through spiritual conversations. Finally, it will discuss the themes that relate to the concept of 'agapé' and its relationship to professional mental health nursing practices.

Figure 6.2 Conceptual Framework



6. 2 Organisational culture of mental health services

The methodologies of both focused ethnography and autoethnography use relevant documents as a form of data collection. The following reports commissioned by the South Australian Health Department provided rich insights into the local culture of mental health services. An analysis of this data found issues within the culture that may have impacted on the facilitation of spiritual care by mental health nurses.

The first three reports highlight critical issues within the culture of community mental health services. The Deloitte Report 2015, the Douglass Report 2016 and the Stevens 2017 Report were specifically commissioned by the South Australian Health Department.

Two further reports then identified the pressure placed on clinicians to discharge patients, even if it might be detrimental to their health (Fjeldsoe et al. 2017; Principle Community Visitor Annual Report 2017).

6.2.1 Reports that indicate a culture in crisis

Data from the Deloitte Report (2015) into Community Mental Health Services revealed that the 'core business' of the metropolitan mental health services was poorly defined. Also poorly defined were the role expectations of clinicians. Moreover, the Deloitte Report (2015) found that within some teams there were serious trust and morale issues. As a result of the Deloitte Report (2015), in 2016 the South Australian Health Department (SA Health) commissioned Deloitte and the Australian Nurses and Midwifery Federation's South Australian branch (ANMF SA), to explore operational issues within the Community Mental Health Teams (CMHTs). Consultations with staff occurred across metropolitan Adelaide from May 2016 to July 2016. A total of 156 staff were interviewed. The summary from these consultations is entitled the Douglass Report.

The report maintained that;

The current community mental health system is extremely dysfunctional. The system is "in crisis", with fragmented care leading to perceived poor services for consumers and a highly unsatisfactory workplace for clinicians. This has led to increased sick leave and staff absences, high levels of burn out and an exodus of more experienced staff particularly in some teams. (Douglass Report 2016, p. 1)

The report also stated that mental health nurses in community settings had become generic workers (Douglass 2016). Therefore, within their everyday duties their unique professional and discipline specific knowledge and skills were not being utilised. The culture was described as highly 'risk averse' (Douglass 2016). Risk-aversion within the culture of mental health organisations can be defined as a defensive process that focuses on organisational risk at the expense of therapeutic care (Manuel & Crowe 2014).

The report highlighted that many clinicians found their work environment was hostile, and they worked within 'toxic' team cultures (Douglass 2016). There were high levels of dissatisfaction, disillusionment and a lack of hope amongst clinical staff (Douglass 2016). It was also found that there was a lack of clarity around the term 'core business' (Deloitte 2015; Douglass 2016). The term 'core business' related to a specific diagnostic population who were viewed as having a priority for treatment within the service (Deloitte 2015; Douglass 2016). However, this term was not articulated in the mental health service's governance documents (Government of South Australia Adult 2010a; Government of South Australia 2013).

Following on from the Douglass report, SA Health commissioned an independent reviewer to further explore the issues raised in the Douglass Report. This report is known as the Stevens Report (2017). Stevens (2017) was charged with the mandate to identify issues within the community mental health teams and to provide staff with the opportunity to make formal allegations of bullying, harassment and disrespectful behaviour. Stevens was also required to provide a formal report to the South Australian Health Department (SA Health). Stevens interviewed 149 clinicians. These interviews occurred in early 2017. Stevens (2017, p. 2) heard several allegations of "bullying, harassment, intimidation and other similar behaviours" and concluded that clinicians did not have an effective complaint process.

Stevens found that

The formal allegation process is regarded with so much suspicion and mistrust that it is not being utilised is of great concern. To put it bluntly it means, if true, that there are Adelaide Community Mental Health employees who should have been investigated, and had findings made about their behaviour, who are free to continue with those behaviours. (Stevens, 2017 p. 6)

Stevens (2017) also identified a group of older nurses (a similar demographic to the nurses interviewed for this thesis) who reported "burn-out, and a high degree of negativity and helplessness." (Stevens, 2017 p. 3).

The nurses were

...typically, in the age group 50 to 60 years. Most of these had a minimum of 25 years overall mental health nursing experience.... Many of them did not believe they would “last the distance” unless conditions improved. (Stevens, 2017 p. 4)

The Stevens report concluded that employees were in ‘survival mode’ and that it was “quite remarkable that most teams are working as cooperatively and collegially as they seem to be.” (Stevens 2017, p. 6).

6.2.2 Culture of ‘Flow’- Detrimental pressure to discharge patients

Two further reports highlighted the pressure within the inpatient units of the mental health service in South Australia at the time of the data was being collected for this study. These reports are the Principle Community Visitor Scheme’s (PCVS) annual report (2017) and the Audit of Actions undertaken by Mental Health Services (2017).

Both reports emphasised that the pressure to discharge patients had a detrimental effect on patient care. It was highlighted that pressure had been placed on psychiatrists to rapidly transition mental health patients through emergency departments. The report stated that there was an “...increase in people being discharged earlier than preferred and still with significant health/nursing needs (Principle Community Visitor Annual Report 2017, p. 12). This pressure in one area of the mental health system increased the pressure on other areas of the mental health service (PCVS 2017). “The emphasis on access and flow has led to considerable pressure on these units and the system overall” (Principle Community Visitor Annual Report 2017, p. 4).

...this has become routine practice which tends to override consumer preference and need... There is evidence that clinical and non-clinical programs delivered in the community have been in a state of decline as resources have been directed to hospital-based service development to respond to the bed flow and access challenges of 2015 (Principle Community Visitor Annual Report 2017, p. 5).

Similarly, the Audit of Actions undertaken by inpatient Mental Health Services (2017) in response to reviews and accreditation surveys found “...all networks have a very strong

focus on patient flow” (Fjeldsoe et al. 2017, p. 23). “Many commented on the focus of management on flow, in their view to the detriment of the quality of care provided” (Fjeldsoe et al. 2017, p. 26).

‘Flow’ is potentially a euphemism for discharging patients as quickly as possible. The pressure to increase ‘flow’ and discharge individuals who are not seen as ‘core business’, affected the facilitation of spiritual care by nurses. The interview data from Senior Mental Health Nurse Sabine, was reflective of the data from the government reports. Sabine discussed two patients with a life limiting illness she had cared for. The following data highlighted how the issues of pressure to discharge patients and ‘core business’ affected her nursing care.

Sabine:

When it comes to considering the interventions that I was providing at the time compared to the usual ‘core business’, the superficial issues that we do within the team... ..he didn’t really fit..... it was hard because there were no real barriers to discharge him but there was nobody else really in his life that was providing mental health care...his care just didn’t fit within the usual realm of the service... a clear definition of ‘barriers to discharge’ tends to be legal orders, forensic licences, on clozapine or depot medication... but if I was not caring for him then he would have been left alone, really, and quite at risk really (CMHN P1, p. 5).

...his care and his diagnostic category did not fit. The way the ‘model of care’ in the team is going, it’s very much short or long term.... because with my patient, I didn’t know whether he was going to be short or long term... because he had a life limiting illness (CMHN P1, p. 8).

Sabine’s clinical judgement was that the man she was looking after had a suicide risk (CMHN P1, p. 8) and yet, from a service perspective, he had no clear ‘barrier to discharge’. Moreover, as the spiritual care Sabine was providing did not fit the usual criteria for care, she found it difficult to articulate her practice. The team’s focus of care was medico-legal as opposed to Sabine’s spiritual care and her focus on what gave the patient a sense of joy.

Sabine:

... we needed to identify what he could do given his side effects and yes, he did get a sense of joy (CMHN P1, p. 3).

...often if people need counselling or any kind of therapy, the service outsources that kind of thing, we don't necessarily provide it. There's a big push on getting outside agencies to do therapeutic work with people (CMHN P1, p. 8).

Jessie, another senior mental health nurse, spoke about his response to feeling pressured to discharge his patient who was also suffering with lung cancer. He highlighted the importance for this individual of 'ongoing care' as opposed to 'episodic care'.

Jessie:

Psychiatrists and other senior mental health clinicians would say ...we have got to discharge her. What are we doing for her? ...But she is really not taking up a lot of my time... I am the go-to person... just someone she can connect with if she needs to. I don't think it is a big drain. She is not a big drain on our services ...why do we need to discharge her?

I think if she had a crisis and she was in 'episodic care', I would have to take a referral for her to come back to me... That whole process would take 24 hours - 48 hours before anything happened... whereas I can respond now... if she was referred to a crisis service by the time they got there the crisis would be over ...but her level of distress right at that time ...that's when she needs some response...I think she would get quite despondent and say "stuff you guys..."

... In ED she would get a whole range of different stereotypes, labels that would not make her feel good about herself. She would go in there with vomiting and with diarrhoea that really needs some intense IV fluids and they would say "here she comes again", but if I engaged with her early, I could get her to a GP... (CMHN P11, p. 15).

Linda, a mental health nurse, felt pressure to discharge the woman she was looking after, who was suffering from ovarian cancer. However, she was able to negotiate with the psychiatrist on a more suitable discharge plan. She was able to continue caring for the patient until both she and the patient agreed it was the right time for her to be discharged.

Linda:

...I mean there have been times, with the woman with ovarian cancer, when I have felt a little bit of pressure to discharge her but with - you know, talking to her psychiatrist, having the 'clinical reviews', having the meetings and taking her needs into account we've managed to not to discharge, we've managed to keep her a bit longer. (CMHN P14, p. 18).

Both Jessie and Linda described that the edict of 'episodic care' with pressure to discharge patients did not fit with the ongoing care needs of individuals who have both a life limiting illness and a mental illness. The following theme will provide data from this thesis that suggests that medically dominated organisational processes silenced the mental health nurses 'voice' and led to nurses feeling disempowered and disenchanted.

6.2.3 Culture of Silencing - disempowerment and disenchantment

The 'Clinical Business Rules' of the community mental health services of SA Health, directed the clinical review process (Government of South Australia 2013). This document stressed that 'clinical reviews' were to be multidisciplinary and led by a psychiatrist or medical officer. This approach occurred even when it was a junior medical officer and the nurses in the room have 40 years of experience and knowledge.

Within this thesis the data has indicated that organisational processes such as 'clinical reviews' can highlight issues of power. Sabine, the mental health nurse discussed in section 2.2, elaborated on her difficulties in articulating her practice. She reported that her nursing care reflected her nursing knowledge and experience, and that while she felt confident in her interventions, she found it difficult to articulate her interventions within 'clinical reviews' (CMHN P1, p. 8).

Sabine stated:

I didn't go to anybody for support... I didn't avoid 'clinical reviews' but I found it very hard to articulate my interventions.... And you know, its evidence-based interventions ... I felt that I was equipped; otherwise, I wouldn't have done it (CMHN P1, pp. 7-8).

And;

It was quite hard to articulate to other clinicians at times what I was doing because he didn't fit the usual criteria for the usual care that we give...And it was hard to justify my interventions at times within the normal criteria of care in the team. (CMHN P1, p. 4)

I am not quite sure what I would have said in 'clinical reviews' ... because he was not usual 'core business' (CMHN P1, p. 8).

I think clinicians need to feel okay about talking about individual needs...even if they don't fit the model of care. (CMHN P1, p. 18)

Due to the disjunction between Sabine's nursing care with the patient and medically led clinical review process, Sabine did not discuss her evidenced-based interventions. This data highlighted that she did not have a voice and hence her nursing care became invisible. Sabine's comments reflected the data given by clinicians in the Deloitte (2015) and Douglass (2016) reports in that the patient did not fit 'core business' because his length of stay could not be determined and so his unique care needs were not explored at a collegial level.

Mental health nurse Sheryl was an experienced nurse who worked night duty on an inpatient unit. She described her care of a patient who was dying from end stage cancer. She started her shift at 19:30 and she reported that she had plenty of time to spend with this patient and talk about issues that were meaningful for him (MHN P4, p. 5). She reported that she had worked with patients in end-of-life care previously and through the viewpoint of her experience, she believed that the care her patient was receiving from the psychiatrists was inadequate. She reported that she felt helpless and unable to influence the situation.

Sheryl:

I think the doctors here just decided they'd manage it themselves. But it was very poorly done I think. (Inpatient Community Mental Health Nurse IMHN P4, p. 2)

I felt quite helpless, when you've been a nurse for so long and I haven't only just done mental health, I've done lots nursing ... All different areas, so aged care, and end of life.... I've done all that, I felt quite helpless. (IMHN P4, pp. 3-4)

There wasn't an end-of-life plan done. Nothing...the whole kit and caboodle to do with death and dying and getting ready for death, planning, ...And to talk about it, and say this is what you might expect of this and that and this is what we can do to help with this...And we do night shift...we're not around during the day to grab the doctors... You can suggest...write in the notes 'patient could benefit from this or that'...And you'd hand it over to the senior nurse but...they're so busy...that takes a lot of extra time, to push for things like that. (IMHN P4, pp. 8-9)

Sheryl believed that the end-of-life care that was offered to this patient by the psychiatrists was poor. She felt powerless to influence them. Although Sheryl was an experienced nurse and she spent a lot of quality time with the patient, she had no team 'voice' in the patient's end of life care.

Another highly experienced senior mental health nurse Jessie, spoke about the need to break rules in order to practice according to his nursing values. He felt he would not be supported by the organisational processes.

Jessie:

I probably break rules, I know I do ...I probably do things that the organisation would not necessarily support, but I use my clinical judgement to support this (CMHN P11, p. 13).

Jessie then reflected upon his disenchantment with the organisation and the role of human connection.

I don't know what it is all about sometimes. I struggle with that ... it is almost like we have lost that connection with people; I haven't let go of that role ...that human connection with people (CMHN P11, p. 13).

I think we have lost some of that humanity (CMHN P11, p. 14).

I say it is a matter of being able to be responsive to the person's situation (CMHN P11, p. 15).

As a nurse practitioner, I have very rarely discussed my spiritual care in mental health 'clinical reviews'. The focus of the reviews tended to be on risk management, such as risk of suicide or violent behaviour as opposed to mental health nursing interventions, such as care based in the 'therapeutic use of self'.

Excerpt from Researcher's Journal:

Every time I go into a clinical review with Dr J. I don't know what to expect. It is very anxiety provoking... 'clinical reviews' with him can be so frustrating as the individuals I care for don't fit into the usual boxes. He does not want to hear the work I am doing with patients. The focus is always on risk.

In summary, the government reports have highlighted that the South Australian mental health system was in crisis at the time of the data collection. Clinician's workloads were unsustainable and there was constant pressure on clinicians to discharge patients, despite the impact that this may have on patients or their family and carers. There was a lack of consensus around the 'core business'. The data from the participants indicated that there was a discrepancy between the values of mental health nursing and the dominant bureaucratic medico-legal discourse. Further, this discourse reflected a power imbalance that had the effect of silencing the nurse's 'voice'.

The following section of the chapter has three themes. The first two themes denote the differing aspects of the organisational culture that supported the mental health nurse's spiritual care. The foundation of spiritual care is being present with the patient and listening to their stories (Edwards et al. 2010; Rushton et al. 2009). Being present and listening can take time and a conducive environment. The first theme highlights data that suggested that the spiritual care provided by mental health nurses was sanctioned by the units in which they worked. This data also suggested that it was nursing leadership that predominantly supported their spiritual care. The second theme in this section will discuss the data that pointed to mental health nurses having the time to provide spiritual care. Data from the autoethnography supported the data from the mental health nurses that suggested that there was organisational support for spiritual care through nursing leadership and the availability of time. This data will be discussed in the first two themes of Section 3. The third theme in this section will discuss the contrasting data from nurses from a different care setting.

6.3 Cultural support for spiritual care

6.3.1 Cultural support through nursing leadership

Four of the five inpatient mental health nurses reported that there was organisational support for the facilitation of spiritual care in the units where they were employed. There

was also an understanding of the unique spiritual needs of the patient. The following example given by mental health nurse, Charisma, from a nurse-led inpatient unit, points to the support offered within her unit for the facilitation of spiritual care through collaboration with the patient's church. Through listening to the patient, Charisma discovered that having more time with her priest and going to church was important to her.

Charisma:

When you talk to people, you talk to people and you don't overlook anything they say (IMHN P9, p. 16).

... she didn't have long to live. That is why she wanted more time with her priest, and we (the unit) allowed the priest to come and talk to her. ... We also encouraged that on Sundays if she wants to go to church, she can go to church (IMHN P9, p. 5).

I remember on occasions when she was a little bit poorly, someone (staff) would drive her to the church, and then talk to the priest and ask that after service if he could bring her back to the unit. Church members would visit her at times (IMHN P9, p. 6).

Charisma's spiritual care was underpinned by her understanding of the patient's spiritual needs. These needs were based on the patient's desire to engage with her faith community. Spirituality and hence spiritual care may or may not encompass religious affiliations or practices (Candy et al. 2012; Egan et al. 2011; Pesut et al. 2008). In this instance, the patient's spirituality and her care were linked to her religious affiliation.

Charisma also highlighted her unit's openness to working therapeutically with a person's spiritual beliefs, even when it is possible the beliefs were intertwined with delusions.

Charisma:

...with a person's mental illness, their spiritual beliefs can be mixed up and ignored at times. I remember we had one [woman] who would pray when taking tablets and clinicians were saying 'I think that's delusional'. We had a discussion... "let's look at it from a different angle". Maybe as a child she was brought up that you pray before you eat, to say grace. - so now, whenever she is taking tablets, she prays." ...We agreed if we want her to take the medication, then give her time to pray. Then it's a win/win situation (IMHN P9, pp. 14 -15).

A community mental health nurse, Larsa, said that she did not feel discouraged by organisational processes from exploring spiritual issues with her patients and reported that

she documented the individuals' spiritual needs and connections within the patient's individual care plan.

...it's not a formal support. There's nothing labelled anywhere that I've seen that says 'we support you in this and encourage you' but certainly I don't feel unsupported or discouraged (CMHN P10, p. 13).

What I tend to do is give the person the care plan, get them to fill it in and then I come back, and we go through it with them. Then if they haven't put spiritual/religious issues in, I will ask them about it...And if somebody says that they're particularly connected to a church I will actually put that in there (CMHN P10, p. 14).

Roger, a senior mental health inpatient nurse, affirmed that spiritual discussions were supported in the unit where he worked. He reported that different forms of religion and spirituality would be accepted.

Researcher:

So, what you are saying is that getting someone to talk to them about their Buddhist beliefs or other religions, would be accepted? (Researcher, p. 15)

Roger:

We wouldn't blink ...Most of us would be pretty interested, you know, something different (IMHN P15, p.15).

Researcher:

Can the nurses talk to them about what's important to them at their end of life, no matter what that would be, whether that's their family, friends, reminiscing, any kind of religion, spirituality? (Researcher, p. 17).

Roger:

It wouldn't be a challenge for us to cover any of those (IMHN P15, p. 17).

The statement made by Roger was confirmed by another nurse from the same inpatient unit. Bianca also reported that exploring issues of spirituality was part of the unit culture.

Bianca:

Well, I always do (explore the patient's different religious beliefs) ...very much, we always try to help people with non-pharmacological means of reducing anxiety and so most of the staff on the ward have their own way of how they do that with a patient. (IMHN P16, pp. 13-14)

...our doctors now, like the RMOs, will actually write in their case notes 'please try nonpharmacological means first before giving the 'PRN'...it is part of our culture. ...the doctors will actually document that they would like us to do that (IMHN P16, p. 16-17).

Bianca also described the different forms of spiritual care she provided for her patients.

Bianca:

I taught her a natural breath mantra. This lady is actually quite deaf but if she floats in the pool and repeats the mantra with her breath, she can hear it underwater and that really worked beautifully [for her] and so her hydrotherapy became even more of a beautiful experience for her (IMHN P 16, p. 14).

Researcher:

Has (your spiritual care) always been accepted? (Researcher, p. 15)

Bianca:

It has been because Ward [Blank] has an openness to this, which is wonderful. (IMHN P16, p. 15)

I became curious to know where the openness to spiritual care in this ward was coming from:

Researcher:

Where's that (openness to spiritual care) coming from? (Researcher, p. 15)

Bianca:

That started I think from the three level (ward nursing leader) nurses, about three years ago, not our current level three, but she continues to support it (IMHN P16, p. 15).

Similarly, Frank, another inpatient mental health nurse believed he had good support from his nursing managers to provide nursing care that reflected his nursing values. Although,

he did not specifically talk about spiritual issues with the patient with a life limiting illness, he did have support for the exploration of issues that were meaningful to the patient.

Frank:

Certainly not at senior levels. At local management levels, yes, I did... Because I think they're good managers. I had a great manager at [blank]. I have good managers here and I think they recognise the value in the patients. They'd also been nurses themselves and they knew the clients (IMHN P13, pp. 10-11).

On the other hand, community mental health nurse Linda's response was mixed. When asked if the organisation supported the facilitation of spiritual care, she stated;

It's (spiritual care) not given much airtime. They (the organisation) don't talk about it much, do they?

Perhaps as individuals we might explore the client's spirituality, but the organisation? I don't know how they would do that. I don't know how the organisation would support the client's spirituality (CMHN P14, p. 21)

However, Linda went on to say that a senior nurse had been influencing the culture and encouraging spiritual care:

I believe there are pockets of that happening (spiritual care) ...I'm sure there is - there is a particular nurse leader who has worked with us ...and brought out this belief. He has the ability to nurture this spirituality in people and we culturally have become more accepting of consumers' difficulties with these – struggles. You know these kinds of spiritual struggles, and when you accept these struggles that people have, then there's a way that you can support them to manage these things better (CMHN P14, p. 22).

Charisma worked in a nurse-led unit and Frank, Bianca and Linda all identified that they had nursing leaders who were supportive of mental health nurses providing spiritual care. Bianca also spoke about the doctors who insisted on non-pharmacological interventions, such as meditation, yoga and calming techniques, such as working with the person's breath. Bianca explained that when using these techniques, the clinician needed to understand the patient's spiritual belief system so that there was congruence between the therapeutic techniques used and the unique beliefs and values of the patient.

An excerpt from my research journal also suggested that the organisation's nursing leadership was supportive of the care of people with a mental illness and co-morbid life limiting illness. Although it had not been explicitly stated in my role as a nurse practitioner that I provide spiritual care for individuals at the end of life, the mental health service acknowledged the importance of my work and allowed me the necessary time to offer quality care which is based in the therapeutic relationship.

Excerpt from Researcher's Journal:

I had a meeting with the director of the service today. Apparently, another director higher than her had asked if they could take me offline to do research. She said 'no' - that my work in palliative care was really important. This was so affirming for me as I so often work outside of the normal organisational processes.

I also told the director of a problem I was having with one of the Heads of Units who wanted me to discharge people, as they see mental health services as an acute service and my case load frequently isn't. The people I care for may have some periods of mental OKness or stability. The director (also an RN) was very supportive of me saying that person centred care is more important than patient flow and if I had any problems to get back to her.

In contrast to the medically dominated organisational processes, the following journal entry expresses the concerns from the professional culture of psychiatry.

Excerpt from Researcher's Journal:

Most psychiatrists are great and support my work. Several have even said they are envious as they would like more time to spend with patients in a meaningful way. They often speak about the pressures of being so busy that they cannot do the work for which they became psychiatrist for in the first place.

This section has indicated that organisational support for the provision of spiritual care was predominantly nursing leadership. In addition, the autoethnographic data reflected that I was afforded the time by the organisation to unhurriedly listen to the patients' stories. The telling of their stories required time for the development of mutual rapport and trust. Time was a significant resource within organisations (Carr & Hancock 2006). The

following data indicates that mental health nurses were able draw upon this resource to provide spiritual care.

6.3.2 Cultural support through sufficiency of time

Spiritual care is reflected in having enough time to engage with the patient and discuss spiritual issues (Daaleman et al. 2008). Earlier in this chapter, both the Douglass (2016) and Stevens (2017) reports emphasised that the clinicians' workloads were unmanageable, processes were inefficient and there were unrealistic expectations of staff from managers.

Stevens (2017) reported the pressure and perceived consequences of unsustainable and uncapped workloads

Other clinicians who are still working in the system, have been "run down" by the relentless pressure of unsustainable and uncapped workloads, and of poor treatment by certain managers past and present.... Many staff feared that plugging the gaps that arose on a daily basis put them and their colleagues at risk of missing something important that could result in dire consequences if not dealt with. (Stevens 2017, p. 2)

Although the reports stated that there were significant time pressures placed on clinicians, all mental health nursing participants, with the exception of Georgie, whose patient did not wish to engage with the service, felt able to shape their workday and ensure they had sufficient time to provide spiritual care. Starnino, Gomi and Canda (2014) pointed out in the literature review that discussions on spiritual issues require the development of a trusting relationship with the individual and a time commitment. When asked the question, "do you feel that you have necessary time for you to facilitate spiritual care?", inpatient mental health nurses Charisma and Bianca and community mental health nurses Larsa and Linda, all reported that they did have the time required.

Charisma:

Yes, we had the time to do that (IMHN P9, p.12-13)

Bianca:

On Ward [Blank], yes (IMHN P16, p. 11

Larsa:

Absolutely, because we manage our own diaries, we can do that within our schedule ... It wouldn't be an issue for me (CMHN P10, p. 12).

Linda:

I felt that I did, yes (CMHN P14, p. 15).

Community mental health nurse Steve reported that he was well supported by the team and was able to offer the individual the time he required. Moreover, Steve still had the time to continue providing care even when the patient was moved to another team. The sanctioning of this nurse to continue to provide care to a patient that was no longer in that care team, suggests a commitment by the team leaders to provide person-centred care to patients who had a life limiting illness.

Steve:

I had unlimited time to give...And I think that's important ...if people need a bit of extra help with care. I don't see any trouble with crossing over the teams periodically (CMHN P3, p. 6-7).

Data from the interviews suggested that some mental health nurses had support from the organisational culture, both in terms of time and team governance. Together these two aspects assisted the mental health nurse in facilitating spiritual care. In contrast, other mental health nurses, including inpatient and community nurses, reported that they had to make the necessary time to facilitate spiritual care by prioritising their time and being flexible.

Frank, an inpatient mental health nurse disclosed that although he did not always have the time, he made time for his patient who had a life limiting illness.

Frank:

No, not always, this is just being honest ...you know, when you've got your favourite patients you make the time (IMHN P13, p. 5).

Similarly, when Sabine a community nurse was discussing one of her patients with a life limiting illness, she stated;

I made time... And I was very flexible, I had to literally bend over backwards because we had to fit in between his treatments and we had to fit in between his good and his bad days ...I had to be really, really flexible which was really hard (CMHN P1, p. 9).

Likewise, Jessie another community nurse said that time was patient-driven and that he would drop what he was doing to see his patient if she required it.

Jessie:

She tends to determine the time.... if I got a call from her now, I could drop everything and see her...I don't see that as being a big issue, to provide that kind of support (CMHN P 11, pp. 14-15).

Except for Georgie, a community mental health nurse, all the mental health nurses (whether they worked in inpatient or community areas of practice) said that they had enough time or could make time to explore meaningful issues with their patients.

The following journal entries suggest that the organisational hierarchy sanctioned my role as nurse practitioner through which I was able to work with the patient's spiritual distress as I had the necessary time to develop a trusting, therapeutic relationship with the person and be with them in their distress. Through the reflective practices that are an essential component of professional mental health nursing practice, I explored my therapeutic interactions with Poppy, a young woman dying from metastatic cancer.

Excerpt from Researcher's Journal:

One of the usual questions I ask of patients is; "what is helping you cope with issues around dying and the thought of death itself?". I ask this in many different ways but that is the gist of the question. A lot of the time people will tell me straight away it is their spiritual beliefs or relationship to God that helps them. Other times they say their love of their

family, especially children and sometimes they say they have had a bad life and are happy enough to die.

Excerpts from Autoethnography:

Poppy had suffered a psychotic depressive disorder in the past and now had end stage lung cancer. Poppy and I discussed the things that are worrying her. Poppy spoke about friends in her life whom she thought had abandoned her as they could not cope with her illness and dying. She was very upset by this abandonment and by friends and family who denied her illness and talked with her as if her life would go on forever. Poppy thinks frequently about dying. She becomes highly anxious with these thoughts, especially at night. When breathless Poppy panics in fear she will possibly die at that very moment or die in her sleep. Poppy frequently asks me what will happen after she dies. By this she means how will her daughter and husband cope after she dies and what will happen to herself. i.e., where will she herself be? Poppy says that she does not believe in God but does not believe there was simply nothing after you die either. Poppy had no religious spiritual beliefs that we could look at together to give her some comfort.

Although we looked at her hopes and strengths and what gave her life meaning, I had no answers to her questions. No real way of soothing her fears. We spoke about the joy of the moment and enjoying her daughter now and at times she was able to achieve this and at other times she was overwhelmed with sorrow. She told me that she was grateful that I was there for her and that knowing that I would listen to her helped.

The following are excerpts from the autoethnography are from conversations I had conversations with within my clinical practice.

Conversations with Jason:

Jason has end stage cancer and a major depressive disorder and is now suffering from acute anxiety. Jason often speaks to me about his thoughts about "what's on the other side of death?" He also speaks about being scared of leaving his family who he really loves. He is scared about how they will manage without him. He said to me "Everything I love I will be leaving". I wonder what it is like for him to experience the knowledge that within a week or two weeks he will lose all he loves. Like Poppy he was deeply saddened by leaving his family and like Poppy he identified that he had no spiritual beliefs.

Conversations with Kevin:

Kevin also had end stage lung cancer and a severe and incapacitating lived experience of mental illness. In conversations with Kevin, he said he was scared of dying but also happy

as he would be with his God. When talking with Kevin it was like talking with a wise old man. He would say things like "...the only thing important in this world was love". And also, that "...we reflect God in our relationships with others". I feel such an enormous privilege in working with Kevin.

Conversations with Susan:

Susan told me that she had mixed feelings about dying. She said that she knew she would be with God and so she was happy about that – but she did not want to leave her animals and that she did not know how to die. "I don't know how to die. I have never died before".

These stories describe the fears associated with dying. They reinforce the need for spiritual care for this population. In addition, my spiritual care was supported by my knowledge and the values that stem from my professional culture. These values included listening to what is meaningful for the person and providing a safe space for them to express their concerns and anxieties. I felt a deep sense of trust and connection with the people telling the stories. I felt an immense privilege in listening to them.

The following results are from the data from the palliative care nurses. One piece of data is similar to the mental health nurses' responses to the question about having enough time to provide spiritual care. However, some of the data from the palliative care nurses also points to not having enough time for spiritual care and having different care priorities than the mental health nurses.

6.3.3 Culture of the nurses from a different setting - Capacity to offer spiritual care

Spiritual care is a mandated dimension of care in palliative care service delivery (Palliative Care Australia 2018) and an essential domain of palliative care nursing (Witt, Sherman & Free 2015). Therefore, I assumed that understanding their organisation's cultural support for spiritual care within palliative services could provide a contrasting nursing environment to the barriers and support for spiritual care. However, the ways in which the data contrasted was unexpected. Sophie, an inpatient palliative care nurse described how she was able to provide spiritual care. Like mental health nurses Frank,

Sabine and Jessie, Sophie made time to explore spiritual issues with her patient by doing her physical care very slowly.

Sophie:

I had the time. He was allocated to me and dressings were time consuming. So, I was lucky with that... they were massive hour-long dressings. Without the dressings I probably would not have had the opportunity or my allocation of nursing time. It was almost like a bit of an excuse for me. I would particularly take time doing the dressings. I would do them very slowly (Inpatient Palliative Care Nurse IPCN P8, pp. 4 - 5).

Like the mental health nurses, Sophie also described how she worked with her patient to assist him to find meaning and purpose at the end of his life.

Sophie:

... he wanted to do his eulogy ...He needed something to refocus him. He said "I want to speak about my life. I want to think about my life. I want to tell the story", and then he had a purpose... he focused on the eulogy and his whole disposition of his mental health had changed (PCN P8, p. 3). ...when he started doing his eulogy he obviously had been thinking quite deeply about his Christian beliefs. (IPCN P8, p. 8)

However, some community palliative care nurses spoke about a lack of time and capacity for exploring spiritual issues.

Jo-Anne, a senior community palliative care nurse commented

No, I thought they were closed doors really. Maybe we just dealt with the superficial things that gave her pleasure and comfort rather than all those other things that were potentially much bigger and more worrying. (Community Palliative Care Nurse CPCN P2, p. 8)

Maybe it is a bit like Pandora's Box - that if you actually started to undo those (issues of meaning), how much time and how much capacity was there to deal with that? (CPCN P2, p. 8)

Some of the community palliative care nurses described clinical issues, such as the person's physical pain, as having priority over spiritual concerns. Lillie and Bess spoke about clinical or practice issues having priority over issues of spirituality.

Lillie:

...very often you have an agenda. This person's falling or he's got pain. They are always those clinical things that sort of supersede... but everyone's different so we feel our way with each patient. (CPCN P17, p. 26)

I did not see him often because that's the nature of our work now. It's changed; we don't have the capacity to see people often...Which is frustrating for us because we would like to do more routine follow- ups... Now our way of working is different, so we just don't have the capacity. I would see him every few months (CPCN P17, p. 25).

Time is always an issue because of the situation at the moment and I think we're all feeling time pressures. We don't have time to go into depth... (CPCN P17, p. 25)

Bess:

I think her care is focusing on what needs to be done, the practical issues, so we haven't really had a lot of time to explore issues of meaning. (CPCN P7, p. 2)

Suzanne, a community palliative care nurse stated

...we spend more time on paperwork now than seeing our patients. And that is true. ...it's true. So consequently, our patients are suffering. (CPCN P6, pp. 10 -11)

When it came to having enough time to offer spiritual care, there was a distinct difference between the palliative care nurses and mental health nurses' data. Moreover, when discussing the issue of time for spiritual care in most cases, the frustration and sadness of the palliative nurses was palpable (from journal entries). In addition, some of the community palliative care nurses expressed discomfort about offering their patients spiritual care. When the following palliative care nurse was asked about the support she was given to offer spiritual care to her patients, she focused specifically on issues of religion. Religion can be seen be an aspect of spirituality (Candy et al. 2012; Egan et al. 2011; Pesut 2008).

Suzanne expressed her discomfort and concerns about discussing religion with her patients and her perception that nurses need to be politically correct.

Suzanne:

.... the spirituality thing is really complex because ... you've got to be very carefully bringing it up, because you don't want them thinking that you're putting your ideas onto them, which is totally unacceptable. And so, you have to ask open-ended questionsto try to work out what helps them and supports them. So, religion is very tricky ... if they've got some strong belief, they may bring it up with you, but you can't just roll with it...you've got to be really careful... I guess we have to be really careful of talking about it because we want to be politically correct as well.... (CPCN P6, p. 5)

...you don't want them to feel judged either and/or you don't want them to think that you're some full-on Christian, ...that's just not appropriate... especially if they're not religious. It's a tricky one... I'd be very careful how I acknowledge that because you just don't really want to give away what your beliefs are. (PCN P6, p. 6).

Similarly, community palliative nurse Lillie stated

...we've got to be very careful we don't talk about our beliefs or religion... (CPCN P17, p. 11). I would just say "I have similar beliefs", ... I reaffirm what they're saying but I'm very careful how I walk along that road ... here (in current position in South Australia) we're not, allowed to talk about it... (CPCN P17, p. 13).

Because we're not really allowed to bring religion into things... (CPCN P17, p. 25).

However, Lillie also said that;

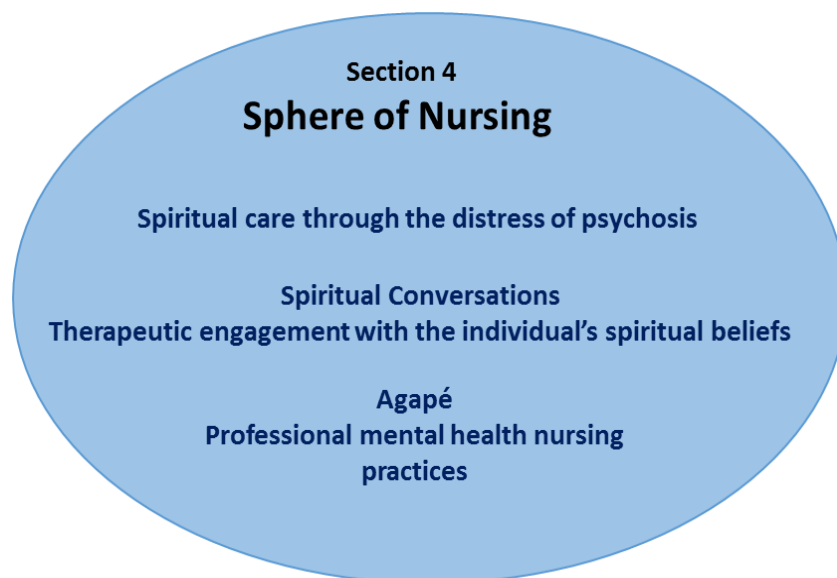
It is on our assessment and sometimes I would ask 'do you have any spiritual beliefs?' I don't do it to every person... I feel my way. If I don't feel it's right and appropriate or it's just not the right time, I don't do it but I try to get there but it's not every first visit... I normally say spiritual or religious beliefs so that they know it's not just religious, or anything that's meaningful to you or gives you hope... (CPCN P17, pp. 8 - 9).

What does this contrasting data from the palliative care nurses suggest about the culture of mental health services and its support for the mental health nurses to provide spiritual care? Why was it that when both sets of nurses under time pressures, the mental health nurses were able to offer their patient's spiritual care, whereas the palliative care nurses found it more difficult? The data points to different care priorities between the two sets of nurses. Moreover, two palliative care nurses believed that their spiritual care would not be sanctioned by their organisation. This dichotomy between the two sets of nurses pinpointed that the core skills of the profession of mental health nursing, such as human

connection, listening and seeking meaning in the person's life, mirror the core skills required for spiritual care. Therefore, mental health nurses were better positioned to provide spiritual care. However, other contrasting data provided by the palliative care nurses in this study suggested that they were able to offer spiritual care. Hence, the data in this section from both sets of nurses suggests that the professional culture of nursing, no matter which speciality, enabled the nurses in this study to provide spiritual care.

Section 4 of this chapter is entitled the 'Sphere of Nursing' (see Figure 6.3). It was so named as the data from both sets of nurses denoted the connection between the values and knowledge embedded in the professional culture of nursing and the nurse's spiritual care.

Figure 6. 3 Sphere of Nursing



6.4 The 'Sphere of Nursing'

The first theme in this section will discuss the data that indicated that mental health nurses provided spiritual care even when the patient was suffering from the distress of a psychotic illness. The second theme will discuss the data that indicated that the mental health nurses engaged in spiritual conversations. The data suggests that this engagement with the individuals' spiritual beliefs was therapeutic. Also, from the data, it was identified

that there was a need for shared reflective practices to ensure ethically based spiritual care.

The final theme in this chapter arose from two pivotal points in my research journey. The first pivotal point arose from an interview with a senior palliative care nurse. This interview indicated that within the inpatient palliative care setting, nursing practice may be underpinned by love. The use of the word 'love' will illuminate a paradox found in the contrasting language used within the cultures of the different nursing specialities. In this theme I have used the term 'agapé' as it is more specific than the word 'love'. In the English language the word 'love' has several meanings, such as love as sexual desire or 'eros', and 'phileo', meaning love of a brother or family. Agapé however, is aligned with other-centredness and self-giving love (Harrington 2006).

The second pivotal point occurred when I was listening to participants speak about their patients. This pivotal point also conflated with the concept of agapé. Agapé was reflected in the fondness, admiration and reciprocal connection between the nurses and their patients. The last theme was generated from the data that indicated that when the mental health nurses practiced in alignment with their professional knowledge, skills and values they were not disillusioned and no longer practiced from a space of disenchantment.

6.4.1 Spiritual care through the distress of psychosis

Despite the depth and clear importance of spiritual beliefs to the recovery of people with a mental illness, several authors have claimed that for various reasons, mental health clinicians dismiss the person's spiritual concerns (Cornah 2006; Huguelet et al. 2006; Koenig 2012; Pesut et al. 2011; Webb et al. 2011; Wilding, Muir-Cochrane & May 2006). However, the data from this thesis does not support this claim that nurses dismissed the persons' spiritual beliefs as an aspect of the person's pathology, or that they did not have the skills and knowledge to understand the person's spiritual concerns. The data from this

study suggests that through understanding and connecting with the patient about their spiritual concerns or struggles, that mental health nurses were able to provide spiritual care even if the person was experiencing psychosis.

Mental health nurses in this study reported being comfortable discerning between the person's delusional beliefs and spirituality. Moreover, they considered the importance of the individual's spiritual beliefs on their mental health. The following data demonstrated Charisma's ability to discern between the person's ongoing spiritual beliefs and delusions.

Charisma:

Let's look seriously at this person's beliefs. You might say that the person is delusional, but if you go deep into her background and her beliefs were Christian ... when she came to us already, she was connected to the church (IMHN P9, p. 6).

It wasn't delusional. When she was talking about her Christian life it was not like 'I'm God. I'm Jesus'; she was talking about her Christian journey (IMHN P9, p. 9).

Charisma also considered the need to explore the person's background which is analogous to spiritual history taking as the basis for spiritual care (Borras et al. 2010; Koslander, Lindström & Barbosa da Silva 2012; Starnino, Gomi & Canda, 2014).

Charisma then articulated that rather than putting the person's spiritual concerns down to the person being delusional, in the inpatient mental health unit in which she worked, (as opposed to a typically busy acute ward) she had time to sit down with the person and explore spiritual issues. Listening and valuing the experience of the patient is also foundational to spiritual care (Edwards et al. 2010; Hegarty 2007; Foster, McAllister & O'Brien 2006; Penman, Oliver & Harrington 2013).

The following excerpt further articulates Charisma's spiritual care.

Charisma:

...you cannot divide a person. Religion is part and parcel of any person, whether they are mentally ill or not. (IMHN P9, p. 7).

When you are in a typically busy ward and the patient is talking about God, everything they say may be taken as delusional. Because of the pressure of time, you might not be able to

look at their spiritual beliefs. Here we are able to sit down with people... I talk to people and I don't overlook anything they say. (IMHN P9, pp. 15 -16)

Similarly, Larsa spoke about the importance of exploring what the individual's spiritual beliefs were prior to the person experiencing psychosis, thus also using spiritual history taking to inform her therapeutic care.

Larsa:

I think that's the thing, we often see people in a quite manic or psychotic state where they are very overt and almost evangelical with their faith, which is not in line with their usual presentation. I think we should never discount it as just being psychotic and manic, but we should actually get collateral information around that and find out what's usual ... to find out what their normal is (CMHN P10, pp. 16 -17).

The literature review identified the importance of spiritual history when offering care to people with a mental illness. Larsa spoke about a woman whose delusions were of a spiritual nature and that her spiritual beliefs were enmeshed with her psychosis. Larsa voiced that the person's beliefs should not be discounted, even during a psychotic episode. She used her listening skills to interpret what was important to the person and was aware that people experiencing a mental illness may not reveal what is important to them, such as their faith or talk about what is happening in their psychotic world. Her listening and not rejecting the spiritual aspects of the person's delusions, enabled her to provide spiritual care while the person was experiencing a psychosis and also once they stabilised.

Larsa:

...what was really good was while her psychosis was settling. I could just listen while she talked about all this psychotic sort of connection, but once she stabilised and she started going back to church she played piano, she sang at church, she was part of a choir, so those things that she spoke about became really important (CMHN P10, p. 17).

Larsa further explained:

I actually think that clinicians should not be frightened about asking about people's faith, as in don't assume the person doesn't have faith. I think some people keep it quite under cover too, particularly people who've experienced psychosis or mania. They may have

been admitted in those times they've said some things that they do remember and even they see it as like 'oh man, I was crazy'.

They still have a faith but they're too frightened to discuss their faith some of the time. I think it's about us as clinicians being able to have the conversations so that they have a level of comfort and can explore the difficulties within the psychosis, or the mania, and know what is normal and what is not, because it's people who experience a lot of religiosity stuff and... visions and everything when they're psychotic they find that really hard to process and they're too frightened to talk about it because they're frightened, they're going to be detained into hospital again. It's about reassuring them that they're stable and then having a discussion about what happens in psychosis or mania to cause that to happen, but that doesn't change their belief. It changes their experience but not their beliefs.
(CMHN P10, pp.17-18)

Larsa also spoke of initiating spiritual conversations and connecting with the person in order to understand their spiritual world and thus she was better placed to provide spiritual care. Her listening, reassurance and non-judgmental approach would have provided a safe space for the person to discuss their spiritual concerns. These skills reflect the professional aspects of the mental health nursing culture.

Larsa:

I think as clinicians we should be able to instigate spiritual discussions because sometimes clients won't. You might be working with somebody assuming they don't have a faith and yet it might be something really important to them that you can connect into that is lying dormant underneath because they're too fearful of disclosing it. (CMHN P10, p. 18)

In concert with Larsa, the following statement by Linda highlighted that rather than ignoring the psychotic experience, the delusions and hallucinations may be part of a person's spirituality and hence inform her therapeutic care. Linda voiced her concern that the individuals' spiritual beliefs may not always be valued and supported. However, she also stated that she felt relieved that the culture is now changing.

Linda:

I worry that perhaps (as an organisation) we don't address the spiritual care of people that we look after sometimes, whether they have a religious belief or a spiritual belief. I think sometimes we (as an organisation) don't value their spiritual beliefs and may not support them ...; because they might be thought to be a delusion belief.I think it's important

that we (as an organisation) give respect to their belief system and find a way to support them as well as supporting their mental health. (MHN P14, p. 20)

I think the culture's changing, thank goodness, but in the past when people have come up with delusional beliefs or hallucinations, whatever, psychotic phenomena, we've tended to say "oh no, you can't believe that, no, that's not acceptable; you must have some medication for that". "We must get rid of that", but thank goodness the culture's changing and we are more accepting of peoples' spiritual beliefs. People can manage these beliefs rather than having to get rid of them because it's part of them as well, the person's spirituality. That's just my personal opinion. (CMHN P14, p. 22)

Mental health nurses in this study highlighted the importance of exploring the person's background in order to ascertain whether the person's presenting beliefs were congruent with their spiritual history. Furthermore, they expressed the view that listening to and valuing the individual's spiritual beliefs can be therapeutically important and may assist in the recovery process.

Zumstein-Shaha, Ferrell and Economou (2020), argued that spiritual care is provided when the nurse assists the person to examine their beliefs and through the practices of listening and being present. The following section will offer data that suggests that mental health nurses in this study were offering spiritual care by practicing in alignment with the values and knowledge of their professional culture of listening and being present, while exploring the person's unique belief system.

6.4.2 Spiritual Conversations - Professional culture of therapeutic enquiry, listening and presence

Although not asked as an interview question, both community and inpatient mental health nurses spontaneously spoke about the therapeutic importance of understanding the individual's spiritual beliefs when caring for a person with a mental illness. Bianca articulated that precedence needs to be given to tailoring spiritual care in accordance with the person's belief system. Like Charisma and Larsa, whose data was discussed in the last subsection, Bianca was also doing a form of history taking, ensuring that she could tailor her care to the needs of the person.

Bianca:

I always ask, do they have a particular belief system, which is really important (In planning nonpharmacological interventions such as mindfulness, mantras and breath work). For some people, it may be words of significance to them and so I'll run through some words just as examples and just ask 'did any of those resonate with your heart?' ... I'm very aware of people's backgrounds and beliefs and I'm very respectful of that... Care has got to be tailored to that person. (IMHN P16, pp. 13 -14)

Larsa spoke about the importance of considering the individual's beliefs within the therapeutic context. She articulated her understanding of the importance of connecting with the person on a level that drew out the ways their spiritual beliefs gave them emotional strength. Larsa's use of her self-understanding of what would give her emotional strength demonstrates the use of the 'therapeutic use of self' in the provision of spiritual care.

Larsa:

...because I have a faith that is really important to me, I accept that faith is important to other people, so it makes it easier for me to consider faith as important thing ... if I had a mental illness and somebody didn't consider my faith then the chances are, I probably wouldn't do well or I wouldn't get well as quickly. (CMHN P10, p. 15)

...from a mental health perspective if I had a problem with my mental health, my faith would be one of the first places that somebody would need to connect with me on, because that is where I draw most of my strength, my emotional strength. (CMHN P10, p. 15 -16)

Linda spoke about 'pockets' of the culture of mental health services becoming more aware of individuals' spiritual struggles and how they can be supported through these struggles. She highlighted working in ways that can empower the person to manage their spiritual distress.

Linda:

If you get rid of those beliefs with some people, it's almost like they're empty. That's not how I see them. Or they might feel as if they've lost something. Whereas, if you can accept, support and focus more on managing the distress that some of these experiences cause them, you can give them then the power, or whatever it is, to take control and manage their own mental health. (CMHN P14, p. 22)

Linda's spiritual care was based on acknowledging and nurturing the person's spiritual beliefs. Linda stated that considering an individual's spiritual needs is as important as medication.

Linda:

I think it's important that we give respect to their belief system and find a way to support them as well as supporting their mental health or their physical health. (CMHN P14, p. 20)

I think acknowledging them, (spiritual beliefs) supporting them and nurturing them is as important as medication and all the other therapy that we can offer ... Spiritual needs are just as important as anything else in their lives... (CMHN P14, p. 21)

The following excerpt demonstrates that Charisma, an inpatient mental health nurse, believed that it was important to have conversations with people about their spiritual beliefs. She reported that her usual conversation with patients would encourage ongoing spiritual support.

Charisma:

...what we encourage is "okay, if you have other help from your religion, contact them, talk to them, visit them". If you say "Okay you want to go to church"...If someone said "I'm a Buddhist" you say okay, what is it? I don't know about it, "tell me about it", then they will tell you. (IMHN P9, p. 16)

Mental health nurse Sabine's conversation with her patient explored the issue of meaning and joy toward the end of his life.

Sabine:

... he was able to articulate and push himself really hard to achieve some things that he wanted to do, ...that brought him joy during his treatment - he did get a sense of joy and that was good (CMHN P1, p. 3).

Mental health nurse Bianca described spiritual conversations she would have with patients within the context of the person experiencing severe trauma. Past war experiences can have a profound impact on the person's spiritual well-being and be the cause of deep spiritual distress at end of life (Chang, Stein & Skarf 2015).

Bianca:

...also, some of them do have quite a fear of death because they've seen a lot of awful death because they've been involved in war. They've killed people. They've seen a lot of dead people. They've seen very traumatic death and so for me personally, it's about reassuring them that we will always care for them, that whatever discomfort they have we will do our absolute best to alleviate that. (IMHN P16, p. 9)

Working with issues of meaning, the distress of having lived an imperfect life and 'unfinished business', are aspects of spiritual care (Fitchett et al. 2020). Bianca demonstrated spiritual care by discussing issues that can cause spiritual distress, such as 'unfinished business'.

Bianca:

...I'll say things like "you know, I've met people that", so I won't make it specific to them and say "some people that I've met" ..., they're not ready to relax and accept that moment when it comes because there's unfinished business. "Do you reckon you might have some unfinished business?" "Is there somebody that you want to talk to that you haven't spoken to for a long time?" I kind of feel my way there as well because you don't ever want to express judgment at anything that you're aware of that they've done through their lives. (IMHN P16, p. 10)

Spiritual care for Bianca was in building rapport with the person and sensitively broaching spiritual issues.

Bianca:

I mean someone who's close to death is very vulnerable and you need to be very sensitive in the way that you broach these subjects. I guess being able to show somebody, whether you call it reframe or to just give an alternative perspective that they may have not thought about before, and so saying something like 'God, being an all loving, being an all-consciousness' whatever word you're comfortable with. So, it's about the wording and usually because you've had an ability to build rapport over time and so if you have rapport with that person, they're open to listening to you so you can't always go there if you're brand new. Once again, it's about feeling your way (IMHN P 16 pages 10 -11). ...To die in comfort. To die without pain because they have seen so much traumatic death...very important. (IMHN P16, p. 18)

I'll actually ask people what is their fear? Is their fear that they don't know what's going to happen when they take their last breath? "Are you scared because you think it's going to

be all darkness or is it the fear of the unknown?" "If you believe in God, do you believe in - as a lot of religions actually have this concept of a punishing God" and I will always say "well, you know what, I actually believe that we have an all-loving God and that certainly gives me comfort" and I'll just share with them. (MHN P16, p. 9)

I will gently feel my way as to where I can go with that conversation. (IMHN P16, p. 10)

Spiritual care has been described as being present with the patient, listening to their stories and being with them in darkness or pain (Edwards et al. 2010; Boston, Bruce & Schreiber 2011). In the above quote Bianca offered a self-disclosure to the patient about her belief in an all-loving God. This level of self-disclosure could be seen as analogous to the nursing theorist's notion of the 'therapeutic use of self' (Barker 2009; Travelbee 1971). Alternatively, Bianca may have practiced beyond her professional and ethical boundaries.

Researcher:

When you go to 'clinical reviews' can you talk about this - your clinical interventions?

Bianca:

I don't go to 'clinical reviews' (IMHN P16, p. 15).

Bianca did not go to 'clinical reviews' because nurses who worked night shifts do not attend 'clinical reviews'. Hence, one might question what the review processes and quality mechanisms were in place for her clinical practice. Bianca stated that she felt comfortable and well supported by her colleagues when she explored spiritual concerns with her patients. She also reported that she documented the spiritual care she offered and was always happy to discuss these entries with others who have read them (IMHN P16, p. 15). Moreover, earlier in this chapter, Sabine reported that she found it difficult to articulate her evidenced based interventions within 'clinical reviews' and did not go to anyone for support for her care. Inpatient mental health nurse Sheryl said she felt powerless as she was unable to influence the medical staff in the care of the patient with whom she was spending many hours. She did not go to any clinical reviews. Jessie, the community mental health nurse, felt he had to break rules to practice according to his nursing values. For various reasons, like Bianca, these senior and highly experienced nurses did not have

their practices reviewed through the organisation's formal review processes. Therefore, not only did this lack of formal review render their nursing care and their patient invisible, it also raised ethical questions regarding why their spiritual care was not being reviewed.

In summary, the themes discussed so far in the 'Sphere of Nursing', have indicated that there was a recognition of the importance of the individual's spiritual beliefs and that the mental health nurses in this study could discern between psychotic delusions and ongoing personal spiritual beliefs. Moreover, it was possible, even when these beliefs were intertwined with psychotic phenomenon that the mental health nurses, through listening with a broad and inclusive approach, assisted in alleviating the distress that the delusional beliefs may have been causing the person. These themes have also highlighted the spiritual conversations nurses were having with their patients.

The final theme in this chapter arose from two pivotal points in my research journey. This theme was constructed from the data that suggested there was a point where the professional values of the two subcultures of nursing merged. Although the word love was not articulated by the mental health nurses in this study, the connectedness, fondness and admiration they felt for their patients, mirrored aspects of love in the form of agapé. The following section focuses on the concept of agapé and its relationship to the spiritual care offered by the nurses. This care was engendered by the values of the professional culture of both mental health nursing and palliative care nursing. The data indicates that both mental health nurses and palliative care nurses engaged in a 'human to human' therapeutic relationship and practices inherent within the concept of agapé.

Harrington (2006) presented agapé as a new term for palliative care nursing practice. In the following section I will offer further development of Harrington's (2006) theory and argue that agapé also underpinned the mental health nurse's spiritual care. The term 'agapé', stemming from Greek philosophy, is another word for love and is aligned with compassion (Rumbold 2012). It is the core of several religious traditions (Rumbold 2012).

6.4.3 Agapé - Pivotal points in my research journey

Agapé as an underpinning concept in the provision of spiritual care by mental health nurses arose through 'epiphanic' moments'. Denzin's (2013) notion of the 'epiphanic moment' is defined as a moment in the research journey that creates ruptures or schisms in the way the autoethnographer views everyday situations. These ruptures or schisms can illuminate a larger cultural story.

The first 'epiphanic moment' I had was a pivotal point in the research journey and initially occurred when listening to a palliative care nurse's statement on love. The second occurred when I was listening to participants speak about their patients. It was from these points that the theme of care based in agapé came into perspective. The theme that 'altruistic love' or agapé was an aspect of mental health nursing when caring for individuals who are facing death, was unexpected and emerged across several interviews. Although it is not unusual for nurses to form strong bonds with their patients, the feelings of fondness and admiration expressed by participants were striking.

The first pivotal point occurred when Colette, a senior inpatient palliative care nurse, offered the following data that reflected the care given by the mental health nurses in this study. However, Colette's use of language (as a palliative care nurse) was not the language used in mental health nursing. Yet the data from the mental health nurses were reflected in her words. The following data was the infrequent 'gem' or 'outlier', as discussed in the methods chapter, when I believed the data had reached saturation (Morse 1995).

Colette:

And I know that we see love demonstrated in all fields of nursing where you get a connection with someone, but I think you see it consistently in a palliative care unit (IPCN P5, p. 13).

Colette's use of the word 'love' was an example of an 'internalised bias' as espoused by Roper and Shapira (2000). The use of the word 'love' by a palliative care nurse,

highlighted an internalised bias that I have found within the mental health culture. As a mental health nurse, I never heard the word love being used by a senior clinician in relation to patient care or by any clinician. The word 'love' is seen as a 'taboo' within the mental health setting (Stickley & Freshwater 2002). This comment by Colette provided a contrast between palliative care nursing culture, where the use of the word 'love' is acceptable and the culture of mental health nursing, where it is not admissible.

I was interested to know more of Colette's notions of care which centred on nurturing and love, and how this care works with people who have a mental illness.

Colette explains;

...I do think that that's why you can use the word 'love' in a palliative care unit, because of what you are dealing with there's no room for anything artificial or superficial. It's cut through to the crux of whatever's going on and try and help someone get some sense of resolution. (PCN P5, p. 14)

...I think it's because we nurse humans and we come from a human baseline. He's not a machine...you hold each patient in whatever shape they come to you. (IPCN P5, p. 15).

Colette also spoke about the response of the nursing team to a man with a severe and enduring mental illness and how he was cared for in a very loving way.

I think he came across as a vulnerable person and he endeared himself to absolutely everyone and so everybody's maternal streak came out. So, I think he was nursed with a very strong protective flavour and he was, you know, had a bit of a wicked twinkle in his eye and he was about to get people to do.... almost everything that he wanted! He was cheeky! You know, staff were vigilant, they were watching him, they would ask him if he had any pain or discomfort....it was just that he had a child likeness to him, which made people feel a bit more protective to him and he probably needed to be told things more than once but not in an annoying way. You know it was always done in a very loving way with him. (IPCN P5, p. 13)

How does the contrasting data about love, human connection and the seemingly paradoxical data from the previous palliative care nurses inform the research question on the support for spiritual care by the culture of mental health services? Firstly, Colette's words on 'love' disrupted my assumptions as a mental health nurse of therapeutic care. Also, the way she described the care offered by nurses as maternal, contrasted with a

founding mental health nursing theorist's notion of therapeutic engagement not being a parent to child relationship (Peplau 1997). However, when Colette spoke of "nursing humans", "connection" and "holding them in whatever shape they come to you", she reflected the concept of agapé as espoused by nursing theorist Travelbee (1971) and the therapeutic care offered by the mental health nurses in this thesis. Secondly, when Colette spoke of nurses being fond of the patient, she mirrored the feelings of fondness expressed by the mental health nurses towards their patients.

Spiritual care is underpinned by recognising our shared humanity and engaging in a reciprocal relationship (Edwards et al. 2010; Penman, Oliver & Harrington 2009). The second pivotal point arose when both mental health nurses and palliative care nurses spoke with fondness and admiration of their patients. They spoke of their reciprocal connection with the person and their strength. When they did so, they became animated and passionate. Their words captured the person's nature and in some instances, how happy each person appeared. The nurse's words demonstrated that their care was underpinned by compassion. The following data illustrates the phenomena of the privilege, admiration, mutual trust and fondness that occurred when mental health nurses were caring for a person with a life limiting illness.

Frank:

I just remember how lovely she was. She was a lovely lady... she really struck a chord with me... I nursed her on and off over about four or five years... and she was just lovely, just a delight. (IMHN P13, p. 2)

It's just lovely to see someone that's happy to see you in mental health: because you don't always have that experience. She is always smiling and then you can find a positive in the negatives. (IMHN P13, pp. 5 – 6)

I was grateful to have known her. I just felt that, that it was such a privilege to have known her ...Not to sound selfish, because I appreciated so much that I knew I had a positive impact on her; so, it was just a lovely little connection. I knew that I did everything I could for her and then, you know, that was nice to know that in a life that was probably filled with a lot of negative stuff, I was something that was positive. (IMHN P13, p. 21)

Jessie:

It's amazing that she still comes out smiling every time. Happy! She has an attitude to other people as well, people like her because of that positive attitude. It is such a pity there are not more people like her in the world. ... I think she is a good example of someone who is able to kind of bring all her strengths together. (CMHN P11, p. 3)

...she still bounces back with a smile and that is the amazing part about her... She is lovely; I really enjoy her, spending time with her. (MHN P11, p. 5)

Christine:

...you know, she's a bit of a hero really, isn't she? (MHN P12, p. 7)

It's just nice to talk about her because, you know, she's a bit of a heroine really (CMHN P12, p. 19).

Linda:

That kind of connection gives me the warmth and the satisfaction that, you know, if I didn't have that I probably wouldn't do this sort of job (MHN P14, p. 17).

In a similar manner, Jo-Ann a palliative care nurse, expressed gratitude for the bond they had formed:

...when I think of her life and I feel like she had a unique way of bonding with some people... and I feel grateful that we had a bond that helped me to accept the other difficulties around her management, particularly in the community (CPCN P,2 p. 4).

Admiration is a moral attraction to the goodness or inner beauty of the other (Kidd 2019). It demonstrates that the qualities of the person being admired are valuable to the other person (Archer 2019). Admiration is linked to agapé, as agapé is the simple, yet profound recognition of the worthiness and goodness of the person, resulting in the "unconditional willing of the good" for that person (Delio 2013, p. 42). Respect and admiration are interrelated concepts that are underpinned by esteem for the other person. Respect and admiration honour the inherent worth felt and demonstrated toward the other person (Rewakowski 2018). Linda spoke about both of her patients with admiration and respect and discussed the development of a good relationship.

Linda:

She's very clear and I have to admire her strength, her strength of mind, strength of character and her desire to be independent (MHN P14, p. 4) ...so there's a lot to admire about her. (MHN P14, p. 6)

...We've developed a good relationship over the years, and I have a lot of respect for her. (MHN P14, p. 8)

Likewise, as a mental health nurse, there were many times I felt in congruence with my fellow nurses when caring for a person with a mental illness and a life limiting illness. The following excerpt is an example of how special I thought my patient was, but also how palliative clinicians regarded her in a similar way.

Excerpts from Autoethnography:

I saw Poppy about every three weeks for around 18 months. She was always generous and warm even through her darkest days. Poppy had an amazing sense of humour and love of life which seemed to be carrying her through. When she died several palliative clinicians and I went to her funeral which was unusual for the palliative clinicians. They all spoke about how special Poppy was to them.

In similar fashion to the mental health nurses, the palliative care nurse Jo-Ann spoke with admiration about her patient.

Jo-Ann:

I really admired her because I thought she had an amazing attitude to her being in this world. She made the most of every part of that journey she was on. She was incredibly uncomplaining, very stoic around symptoms...pretty happy with the things life provided for her (CPCN P2, p. 7).

Spiritual care extends permission to healthcare professionals to be themselves and to treat the patient as if they are family, sharing in a vulnerable reciprocal relationship (Edwards et al. 2010). A study by Laugharne et al. (2012) found that patients viewed the formation of trust as a mutual process and that both the clinicians and the patient had a shared responsibility for the development of a trusting relationship. Jessie demonstrated agapé for the person he was caring for; he also experienced a mutual trust with his patient which he believed was important therapeutically.

Jessie:

I trust her as well; I trust her to call me if she needs me. (CMHN P11, p. 15)

Similarly, Frank spoke of mutual caring;

...I felt a little bit blessed, because out of all the people I could've met, I met her, at that point that helped me in my career (IMHN P13 page 21)... it is my job to care for the patients, but she always cared for me as well. (IMHN P13, p. 6)

Sophie, a palliative care nurse, expressed a comparable sentiment that highlights a human connection and agapé.

Sophie:

...it was amazing...it broke my heart...you know...it broke my heart to think we both really liked each other. (IPCN P8, p. 4)

Stickley and Freshwater (2002) argued that when nurses practice agapé, there is a sense that we are all related, and that nurses can care for complete strangers as if they were family. Something that Jessie indicated he believes.

Jessie:

I would like our patients to be treated like someone in my own family. (CMHN P11, p. 12)

Within the data, the professional culture of mental health nursing was expressed through the values of human connection, mutuality and a deep feeling of fondness. These aspects of their professional culture were foundational to the nurse's ability to provide spiritual care. The methodology chapter of this thesis introduced a nursing theory as a theoretical lens through which the data would be analysed. This lens stressed the importance of the 'human to human therapeutic relationship'. Travelbee (1971) maintained that it was within the 'human to human' relationship that the nurse and the patient see each other as unique human beings. The nurses in this study indicated that they saw their patients as unique individuals. Some nurses described mutual caring between themselves and the individuals in their care.

The methodology chapter of this thesis also highlighted the concept of 'alterity' or understanding the 'other's' point of view rather than 'strangeness', as part of focused ethnography (Knoblauch 2005). Although this concept of understanding the 'others' point of view was in relation to the researcher's understanding of the participants, it can also be apprehended in the participants seeing the 'other' in their care.

Jewish French philosopher Emmanuel Levinas (1906-1995) reasoned that it is through 'alterity' that we do not objectify the 'other'. It is through 'alterity' that one has an ethical obligation to bear responsibility for the other (Levinas 1998). Levinas' theory of 'alterity' is mirrored in the intersubjectivity found within the 'human to human' relationship and can be a space in which emotional healing occurs (Daaleman et al. 2008; Paterson & Zderad 1988; Ramezani et al. 2014; Travelbee 1971). Through seeing the face of the 'other', one can bear witness to the infinite, agapé and love (Thorkidsen, Eriksson & Råholm 2015). This phenomenon emerged through agapé which was identified within the 'Sphere of Nursing'.

The 'human to human therapeutic relationship' and the 'therapeutic use of self' are core skills of the profession of mental health nursing (Australian College of Mental Health Nurses 2010; Foster, McAllister & O'Brien 2006; Travelbee 1971). Results from this study highlighted that both the mental health and palliative nurses were engaging in the 'human to human therapeutic relationship'. The following data given by the community mental health nurses, highlighted agapé within the therapeutic relationship.

Sabine:

I'm a big believer in that 'therapeutic use of self' as well ...the old-fashioned kind of sense of commitment and engagement ...of course, was what maintained him through the interventions. (CMHN P1, p. 9)

Jessie:

I think we have to be really aware of people and what they are going through, the suffering they are going through. Just understanding the everyday of people life, what they are dealing with. (CMHN P11, p. 12)

Through understanding the importance of human connection and what gave the person's life meaning and their strengths, Larsa's spiritual care was underpinned by the 'therapeutic relationship'.

Larsa:

It's about connecting with a person and finding out what is important for them. (CMHN P10, p. 10)

Tapping into something that's going to be a strength... Because it's a whole dimension that is not understood about a person if you don't tap into it. (CMHN P10, p. 20)

Linda also discussed how her beliefs and values impacted on her care.

Linda:

...to make that connection, that personal connection as well as the professional care... that kind of genuine interaction. (CMHN P14, P. 17)

I'm not a religious person but I have spiritual beliefs and my values..., I value their autonomy and I am somebody that doesn't like to impose my beliefs on others, but I like to give what I can of my spirit to them so whatever - in whatever way will support them. (CMHN P14, p. 17)

As opposed to 'episodic care' as espoused by the organisational culture of mental health services, mental health nurses Bianca and Sabine spoke about the benefits of building rapport over a long period of time.

Bianca:

... usually, because you've had an ability to build rapport over time and so when you have rapport with that person, they're open to listening to you. (IMHN16, p. 10)

It's very much about rapport. (IMHN P16, p. 10 -11)

In relation to the second patient Sabine reported that:

...in essence we deviated from the initial plan because as you know when people's needs change over time and his needs changed too much for a limited engagement. That is what he needed; he needed engagement. (CMHN1, p. 17)

In a similar manner Sophie, an inpatient palliative care nurse, discussed the development of trust within the 'human to human therapeutic relationship' through a deep connection with her patient.

Sophie:

I particularly worked very closely with him and won his trust and we did a lot of things together. (IPCN P8, p.3)

We had a really good nurse - patient relationship and there was a lot of respect there. There was heaps of trust! He could not wait for me to come.... he'd wait...he would talk about stuff he had never talked to anyone about any time in his life. (IPCN P8, p. 4)

He had heaps of trust in me...that was the thing, it was about not being judgemental and it is about having your ears open. (IPCN P8, p. 4)

The following two autoethnographical stories support and confirm the previous data given by the nurses. The stories highlight the development of the 'therapeutic relationship' intrinsic to the professional culture of mental health nursing in the provision of spiritual care. Similar to Sabine, Jessie, Larsa, Linda and Frank's data, the following stories highlight the need to connect with the person and find out what gives their life meaning and strength. They are also reflective of palliative care nurse Sophie's data; in that she highlighted the need for trust within the therapeutic relationship.

Excerpt from Autoethnography:

My journey with Kevin (the same man previously discussed).

Kevin was referred to me by palliative care services. The referrer told me they could not connect with him, as he was refusing to see them. I first met Kevin in the doorway of his clean little housing trust home. His psychiatric diagnosis was paranoid schizophrenia. He also had end stage cancer. Kevin had spent time in a major psychiatric facility around 30 years ago, but he had no known contact with mental health services since that time. He said had not really spoken with many people since that time and preferred to keep it that way. He said he saw his GP who prescribed his medication and he also interacted with the local pharmacist. He said he did not want people coming into his home. I asked if he minded if I came to the door every few weeks to see how he was, and he said "yes" he would be happy with that.

Over time Kevin invited me into his life. Kevin's appearance reminded me of a monk and his lifestyle reflected monk like habits. We spoke about what gave meaning to his life, which was the safety of his little unit, the music he played on his guitar and the bible which he read daily. He found joy in sitting in the sun and watching the birds outside. I asked him how he felt about dying and he would talk about going to be with God but also that he was terrified and did not want any more pain, and he was not exactly sure what was going to happen to him.

A few months later Kevin went into the hospice. He did not have his bible and was really distressed by this. I found him a bible on the ward and the social worker went to his home to get his own copy for him. I think what was clinically important in this situation, was to know what was important to him and that he felt that reading his bible was nurturing, healing and supportive. Also, when at the final stages of his life Kevin went into a delirium, clinicians knew that when he tore up his bible that his distress was deep. At one point Kevin thought he was back in the psychiatric institution and that the nurses were hitting him. He then started hitting at the palliative nurses.

Reflection of Autoethnography:

Knowing Kevin's background and having a therapeutic alliance with him, assisted in his care in his final days of care. I was privileged to be able to sit with him and take him for walks in the garden. I could also talk with palliative clinicians about the importance of his beliefs, what gave his life meaning and that this was not part of his delirium (except when he tore up his bible) and how to distinguish between his spiritual beliefs and delirium.

Chang (2008, p26) highlights that autoethnographer's use their personal experiences of the 'self' as primary sources of data and that the stories told from these experiences need to be analysed within their broader cultural context. "cultural self-analysis rests on the understanding that self is a part of a cultural community". Insights derived from the analysis are valued and intentionally integrated into the research (Chang 2008). My knowledge, skills and values from my mental health nursing practice enabled me to not push with Kevin, but to go very slowly and allow time for the development of trust and mutual rapport. Moreover, working with Kevin brought me joy. He shared with me deep insights into his personal world. Within this reciprocal relationship, Kevin not only reinforced in me the importance of spiritual care, he also gave meaning to my work and through the deep connection we had, he allowed me to see his unique being, and he enriched my own spiritual dimension.

Denzin (2013, p. 10) points out that performance writing is embodied and evocative. It is “always inconclusive and open-ended. It is nervous writing, it hesitates and stutters, moving from one charged moment to the next, with a sense of urgency”. The following is my attempt at such a story and analysis.

Excerpts from Autoethnography:

Shadows of the asylum

It was a cold, winter Monday morning. I went to the hospice first thing that morning, expecting to see Kevin and have our usual small chat together. Can it ever be usual when working with the dying?

Instead of seeing Kevin's crinkled, smiling face, I saw a tiny, thin man sitting bolt upright and naked on the bed. He was struggling to breathe. He looked freezing cold. Several nurses and a doctor were standing around him in a semi-circle. They looked at me expectantly when I walked in. *Two code blacks were called this weekend* a nurse whispered to me as I walked in. Two staff members injured.

Kevin's eyes looked at me in terror. I sat at the end of the bed. He stared at me. He didn't seem to know me. I was also really scared, worried that I would make the situation worse. I felt as if I was floundering, and they were all watching us. Kind, worried eyes. I can't remember what I said to Kevin. He seemed to go in and out of knowing who I was. He looked at me and said I'm glad you are here, in a cheery, kind of voice. Then the next second, he would look at me with a white, frightened face and say *who are you, what are you doing here?* Kevin and I looked at each other in this way for quite some time.

After a while, his breathing settled. Someone then got him a warm blanket and I was able to put it over his shoulders. Kevin told me he kept thinking he was back in the asylum and nurses are hitting him. Later in the morning Kevin and I walked in the garden in warm sunlight. Again, the privilege I felt was overwhelming. Kevin went into a coma that night and died two days later.

This story was situated in a liminal space. Anthropologist Turner (1969), described liminal space as the “betwixt and between”. It is a rupture in everyday experience. Liminal spaces are ambiguous but also creative. Denzin (2013) describes these liminal spaces or moments as epiphanies and asserted that the autoethnographer enters these liminal or strange spaces and connects them to culture, social structures and history. He argued

that these moments can have lasting effects on people's lives. The story of Kevin is a pivotal moment in mine.

Reflection of Autoethnography: (Shadows of the asylum)

Reflecting on the situation that Monday morning with Kevin, I had no idea what I was walking into. I was uncertain about how to manage the situation. Yet I knew as a mental health nurse practitioner that it was expected of me that I would manage the situation. But I was scared. I felt like I was on show. But more than anything I was really worried for Kevin. This kindly, gentle man was obviously in terror.

Things I did know almost instinctively (culture) as a mental health nurse; don't sit too close, don't stand over him, sit, don't turn away, talk softly, appear calm and breathe. Things that were immediately apparent to me from the situation were that I had the ability to be flexible with my time. I could rearrange my morning so that there was no rush. I could not imagine what it would be like if I had to rush out of the hospice. Not rushing is so different from the current busy culture of nursing. Due to my role, I did not have to rush. I had the necessary time to spend with the patient when they were sanctioned by the organisation's leadership. The professional cultures of nursing and psychiatry supported my role. The Executive that mandated my role as mental health – palliative care nurse practitioner was made up of head psychiatrists and the leaders from all disciplines.

What else to do I bring from my culture? I was around at the time when Kevin was hit by mental health nurses. I never witnessed it, but knew it was going on. I remember those days with biting shame. I wonder how many other mental health nurses carry these kinds of memories as part of their cultural history and how it may affect their ability to provide care. Does this cultural memory affect the self-esteem of mental health nurses?

Denzin (2013) states that autoethnography is always interventionist as it promotes conflict, criticism, curiosity and reflection. It must tell the story of those who are denied a voice. Especially the story of those on the wrong side of power relationships (Denzin 2013).

Excerpt from Autoethnography:

My journey with Sally

Sally was a single mother who lived with her three children in a small housing trust home. Sally had two girls and a boy, all under the age of 15 years. Sally lived an isolated existence. She said she "kept herself alone" because she was really scared that someone would abuse her daughters as she had been abused. Sally had been diagnosed with schizophrenia 10 years ago and end stage cancer three months prior to my initial visit.

On my first visit to Sally it was 42 degrees and the air-conditioning was not working so well. She was sitting in a dark, airless room. Her legs were badly swollen. There were bruises on her arm where one of the children had hit and bitten her. She said the children did this because she was eating too much, and she was too fat and that was why she was going to die. Because of the heat and the difficult living conditions, respite care was found for Sally and her children.

I then visited Sally in the respite facility and asked her what it was that was getting her through these difficult days. She said each night in her bed she prayed to God. And she knew that God was there with her. Sally could also sit in her backyard and see the cross for her local church which she said gave her comfort. I asked Sally if she would like to talk with someone from the local church. She said she would love to, once the abuse from her child stopped as she felt so ashamed and did not want to see anyone at the moment.

It took another 6 months for her to see the minister from the local church. This visit was a consequence of another nurse from a respite unit asking Sally the same question that I did about how she managed to get through her difficult days. The nurse then arranged for Sally to be visited by the priest and Sally reported that the Church extended a warm welcome to her and her family. Sally died two weeks later.

Reflection on Autoethnography – (My journey with Sally):

When asking Sally what assisted her to get through her difficult days, I was genuinely interested in how she managed to keep moving forward in her life. I also thought that the question would offer insights into what her strengths were, and what gave her life meaning. My experience in both mental health nursing and palliative care prompted the question. At times I find it hard to differentiate between the two nursing cultures. I believed that understanding what gave her life meaning through her dark times, assisted me in providing care that focused on her unique needs and strengths. Moreover, working with people at end of life and my education in palliative care has taught me that people with a life limiting illness are often awake in the middle of the night feeling very fearful and thinking about death. My experience in palliative care has also taught me the importance of knowing whether the person has beliefs that may sustain and assist them as they move toward their end of life.

Sally had been seen by mental health services for the past 6 years and I could not find any mention of her spiritual beliefs in her case notes. It is possible that if questions of spirituality were asked and spiritual care had been given that these had not been documented. It is also possible that no one had asked her about her spirituality or offered spiritual care. Later however, it was a nurse from the respite centre that asked similar spiritually based questions about Sally and as a consequence organised for Sally to go to church.

Zumstein-Shaha, Ferrell and Economou (2020, p. 5), found that when nurses provided spiritual care for patients with a life limiting illness, they felt it was a life changing

experience. One nurse in their study stated that she felt “personally touched by her patient to this day”. The interview data from the participants in this thesis and my own clinical experiences reflected the feelings of the nurses from the Zumstein-Shaha, Ferrell and Economou (2020) study. These feelings embody the concept of alterity and the call to compassion as espoused by the philosopher Levinas (1998). The profound suffering of the dying person opens an interhuman pathway between the suffering person and the other, through which there is a “refusal of indifference” (Lavoie, Blondeau & De Koninck 2008, p.95).

This autoethnographic data confirms the previous data that suggested some mental health nurses were providing spiritual care through the skills, knowledge and values that are foundational to their profession. This section has suggested that the professional culture of nursing has empowered nurses to provide spiritual care. In addition, nurses spoke of the importance of connecting with their patients and building rapport and trust. Neff (2020) maintains that when the nurse’s work connected them with people, their practice enables them to experience a sense of enchantment. Enchantment can be found within deep connections and interpersonal therapeutic relationships that are grounded in respect and compassion (Neff 2020; Redinger 2020).

Summary

The findings in this chapter demonstrated that the culture of mental health services, especially community mental health services, was in crisis at the time of data collection. The data in Section 2 indicated that the culture was toxic, with high levels of bullying and harassment, as well as unsustainable workloads and unclear professional role definition. The data signposted that a biomedical culture directed organisational processes that focused on ‘episodic care’ and ‘core business’ as opposed to person-centred care. The data also suggested that there was pressure to discharge people early, thus negatively affecting the nurse’s ability to offer spiritual care.

The distinct contrast between care based on 'core business' and 'episodic care' and the care offered by mental health nurses, highlights the dissonances between care delivery philosophies within the organisational care priorities. The mental health nurses' stories are replete with care, based on the therapeutic relationship and person-centred care which underpin the philosophy of the professional culture of mental health nursing. Whereas care based on 'core business' and 'episodic care', did not always serve the patient and may even serve to time limit the 'flow' of patients through the organisation.

A prerequisite for providing effective spiritual care is the ability of the healthcare provider to develop deep human connections (Selman et al. 2018.) The results suggested that these deep connections to the 'other' were reflected in the concept of agapé and the nurse's spiritual care. However, as the mental health nurses did not voice their practice, their spiritual care became largely invisible. Moreover, due to the organisation's business model, individuals with a mental illness and a life limiting illness became invisible as they did not fit usual 'core business' or 'episodic care'.

The next chapter will discuss the major themes arising from the results of this chapter. Through these themes it will demonstrate an original and significant contribution to knowledge. This contribution to existing knowledge was revealed through the examination of cultural structures that were a barrier to the provision of spiritual care and the aspects of the culture that supported this care.

CHAPTER 7 - DISCUSSION

Introduction

The previous chapter discussed the themes constructed from the data on the current culture of mental health services and the effect of the culture on how mental health nurses practiced their craft. The original and significant contribution to knowledge of this thesis is threefold. Firstly, it highlights that the power of the dominant biomedical and the bureaucratic corporate culture of mental health services, affected the mental health nurse's ability to discuss their practice within review processes and hence their work became hidden. Secondly, it has shown how the language and values of the bureaucratic corporate culture created a rhetoric through which the individual facing death did not fit the service delivery model and as a result, they became invisible. And thirdly, despite the barriers of the biomedical model, the mental health nurses in this study were able to provide spiritual care through the 'human to human therapeutic relationship' in both inpatient and community settings. The chapter will also demonstrate that the juxtaposing data from mental health and palliative care nurses assisted in the development of this original and significant contribution to knowledge.

It was theorised in the last chapter that underpinning spiritual care were the enactments of agapé and alterity; seeing the humanity of the 'other'. Up until now, there have not been any studies specifically exploring issues around the spiritual care of this population within both community and inpatient settings. A study by Donald and Stajduhar (2019) highlighted that research has failed to explore organisational and system level factors within palliative care and mental health care settings that impact on patient care. This thesis's contribution to knowledge is noteworthy, as it examines organisational cultural issues such as the biomedical model, that impact on systems and processes within the organisation that effect patient visibility and their care.

The intent within this thesis has not been to demonise the biomedical paradigm. It is through this model that vast health improvements throughout most of the world have occurred. However, this model has limitations within mental health service provision and spiritual care. The language of biomedicine alone cannot answer questions of meaning, hope, or love. Within this thesis, the biomedical model is aligned with bureaucratic corporate management practices that are reflective of sociologist Max Weber's sense of meaninglessness and disenchantment (Crosby 2013). The nurses' feelings of powerlessness were driven through this form of disenchantment. Despite an environment of disenchantment, it will be asserted that when nurses practiced their craft as described within the Sphere of Nursing, they were practicing within a field of enchantment.

This chapter will discuss the concept of disenchantment as it relates to the organisation of mental health services and propose strategies for the re-enchantment of mental health nursing. Further, it will be argued that it is essential that nursing leadership reclaim enchanted spaces, where nursing knowledge is used to develop improved processes for the articulation of mental health nursing practices. In this chapter I will discuss the stories of enchantment as found within the data analysis and argue that these stories of resilience and resistance can assist the discipline of mental health nursing in further developing its professional culture (Cope, Jones & Hendricks 2016).

This chapter will be presented in five sections. The first section will discuss the different cultures within the mental health services. These cultures included the dominant organisational cultures of the business oriented corporate culture and the culture of biomedicine. Other cultures identified were the professional cultures, such as those of nursing and other disciplines, including the professional culture of psychiatry. Section 1.1 will discuss the displacement and destabilisation of these professional cultures by the more dominant cultures. It will also discuss the findings from the themes that indicated how these cultures can hinder or support spiritual care. It will be argued that there were three hindrances to spiritual care. These were the corporate business culture, with its emphasis on risk aversion as opposed to therapeutic care, the tradition of biomedicine,

with its focus on maintaining a hierarchical relationship with nurses and finally, these cultures' use of language and symbols in maintaining cultural dominance the impact this dominance had on the professional culture of nursing.

Through an examination of the contrasting findings from researching the different nursing specialities, the second section of this chapter will discuss the knowledge gained by interviewing both the palliative care nurses and mental health nurses. The section will identify the palliative care nurses' barriers to spiritual care and begin the discussion on the supportive elements of culture such as therapeutic nursing practices.

The third section of this chapter will discuss the themes suggesting that support for spiritual care was through the Sphere of Nursing. The Sphere of Nursing within the context of spiritual care provision is underpinned by the culture of the nursing professions. It will be argued that the values of the professional cultures of nursing that include those based in agapé and alterity, such as compassion and the desire to alleviate spiritual suffering, underpinned by supportive of spiritual care. It will also be argued that intrinsic motivation and professional agency enabled time for spiritual care. This section will highlight the importance of recognising the therapeutic value of spiritual care, especially when working with individuals with psychotic symptoms.

The fourth section will argue the importance of mental health nurses maintaining their professional standards when providing spiritual care, by reflecting on practice through professional review processes such as clinical supervision. This section will also discuss concerns about the future of the culture of mental health nursing, especially if mental health nurses did not articulate their unique knowledge and practices. The fifth section will explore the social construct of disenchantment as it relates to the cultures within the mental health services. It will also suggest strategies for re-enchanting the profession of mental health nursing to reclaim the nurses' power and voice, thus enabling the development of future spiritual care practices.

7.1 Organisational cultures and hindrances to spiritual care

7.1.1 Organisational culture and the displacement of professional cultures

Through the analysis of the data, distinct yet interrelated cultural groups within the organisation of the local mental health service were identified. These cultural groups included the dominant biomedical culture which was aligned to the bureaucratic corporate culture. The analysis of the data also identified and focused on the professional cultures of mental health and palliative care nursing. This subsection will provide greater clarity on organisational cultures and highlight how the values of the business-oriented corporate culture displaced and destabilised the professional cultures within the organisation.

Schein (1992), who was influential in the early development of the theory of organisational culture, maintained that the concept of an organisation is ambiguous and ubiquitous, and not easily defined. No single definition of organisational culture exists within the literature (Davies & Mannion 2013; Scott-Findlay & Estabrooks 2006).

Organisations are complex and inherently dynamic and cannot be simplified through any reductionist explanatory frameworks (Mick Shay & Goldberg 2014). Different occupational groups within an organisation may have shared ways of thinking, assumptions and values which are reflected in their work behaviour (Beardsmore & McSherry 2017). However, the meaning may be different between the groups and fundamental beliefs and assumptions may also differ (Davies & Mannion 2013).

Suddaby et al. (2017) argued that the traditions of the professions have been displaced and taken over by more bureaucratic forms of operation. The rhetoric of risk management and ensuring that patients fit 'core business' found within the data, suggested that the practices and values of the organisation have become more aligned to a bureaucratic corporate model underpinned by hierarchy and control as opposed to the professional cultures and philosophies. When health professionals such as psychiatrists or nurses, focus on corporate issues of risk management, 'flow', episodic care and 'core business' as opposed to patient care, to some extent they have forgone their professional values. They

have imbued a version of business-related corporate values as opposed to the traditional values of their profession, which includes good communication, dignity, fairness, humility and respect (Richards & Lloyd 2017). This change in values may occur in any discipline and its effects can be felt not only by nurses, but also by allied health professionals and other medical professionals. This can lead to tension and no clear-cut boundary between clinicians operating from a corporate culture or a professional culture. Both psychiatrists and nurses can enact their roles somewhere on a continuum between the two cultures. Or indeed at times, within both cultures.

The literature suggests that practices embedded in the mental health services in Australia are aligned to the values of the corporate culture and the ideologies of business as opposed to an alignment with the professional cultures and therapeutic care (Clancy & Happell 2014; Clancy, Happell & Moxham 2014; Manuel & Crowe 2014). This alignment to corporate culture is reflected in the name of guiding documents, such as the 'Clinical Business Rules' that guide the day-to-day operations of clinicians (Government of South Australia 2013). This alignment also points to the values and beliefs of the professional cultures being destabilised within this corporate business-oriented culture.

The data from the participants indicated that they provided care that was congruent with the beliefs and values of the professional culture of mental health nursing. However, the data from government reports highlighted that the South Australian mental health system was in crisis at the time of data collection, with a focus on business practices, such as risk management as opposed to therapeutic care. The following sub-section will discuss how the corporate culture of risk aversion affected the professional culture of mental health nursing.

7.1.2 Cultural Hindrances - Corporate culture of risk aversion and workplace stress versus therapeutic care

The data from government documents, such as the Douglass (2016) and Steven's (2017) reports, revealed allegations of bullying, harassment and intimidation which led to

serious trust and morale issues within the mental health service. In addition, within these documents there were reports of unsustainable workloads and poor role definition. The reports stated that the culture of mental health services in South Australia was highly 'risk averse'. Mental health nurses within the same demographic as those interviewed, described feelings of helplessness and burn out (Stevens 2017). Consistent with the Douglass (2016) and Steven's (2017) reports were the findings from three Australian studies by Clancy and Happell (2017), Clancy, Happell and Moxham (2014) and Lakeman and Malloy (2017). These studies highlighted that within the Australian context, mental health work has been driven by the ideologies and language of risk management. The risk regime of mental health services has led to an avalanche of paperwork for nurses (Clancy & Happell 2017; Lakeman & Malloy 2017).

Risk as a discourse was seen through 'Key Performance Indicators'. The data from the report by Douglass (2016) highlighted that as generic workers, nurses must fulfil performance indicators that are not related to mental health nursing. The 'Model of Care' for Community Mental Health Services in South Australia mandates that all mental health clinicians complete Key Performance Indicators as identified by senior management. The reports on the Key Performance Indicators, or activity targets, are to be monitored monthly. These Key Performance Indicators include activities such as completing risk assessments (Government of South Australia Adult 2010a). The study by Clancy, Happell and Moxham (2014) found that resources were allocated according to perceived risk. The focus of care that was driven through organisational processes was on risk management, as opposed to person-centred therapeutic care. This focus on risk as opposed to therapeutic care was also reflected through the data from the autoethnography. Within mental health services, the medical paradigm had become wedded to these risk adverse business practices through empirically based interventions (Hurley and Ramsay 2008). Empirically based interventions focus on what can be quantified. Spiritual care is not so easily measured. Hence, within the discourse of risk management there is little place for the spiritual care for individuals with a mental illness who are also facing death.

Mental health nurse Jessie reflected that the organisation had almost lost its humanity and connection with people but that he had not let go of that role. Jessie reported, "I don't know what it is all about sometimes. I struggle with that" (from results Chapter 6 CMHN P 11, p 124). This data suggests that Jessie's role as a mental health nurse had been destabilised. He felt he was working against the culture of mental health services. Jessie struggled with his professional values and the culture of the organisation. A Victorian study of mental health nurses by Hercelinskyj et al (2014) similarly found that organisational requirements conflicted with their professional identity. Their participants experienced role conflict and stress in meeting organisational performance indicators and that a lack of role definition and unclear boundaries were responsible for developing a 'creeping genericism' within the mental health workforce. In the same vein, another Victorian study by Foster et al. (2019), examined workplace stressors for mental health nurses and found that high caseloads, multiple demands on time and pressure to meet KPI's, were significant stressors for mental health nurses within the Australian context. The researchers found that caring behaviours which included being positively connected to another's experience and being ready to help them, were the lowest of four subscales for caring behaviours. The research hypothesised that the mental health nurses' willingness to connect with others may have been affected by workload demands, staffing issues and other factors.

The stated aim of 'risk management' in mental health care is to manage the risks of suicide, violence and vulnerability, however, the risk-averse culture of mental health organisations is a defensive process that focuses on organisational risk at the expense of therapeutic care (Manuel & Crowe 2014). Furthermore, the language of risk can erode the therapeutic relationship and lead to further marginalisation as this language does not include the 'voice' of the person with the mental illness (Clancy & Happell 2014). Indeed, it could be asserted that the very use of the word 'consumer' echoes economic and business models and not the participatory nature nor mutuality of the 'human to human therapeutic relationship' (Barker & Buchanan-Barker 2009). Additionally, the use of

narrowly focused assessment or “one size fits all” tools based on biomedical and risk approaches, has eclipsed assessments which explore the individual’s personal story and meaning. Hence, the possibility of therapeutic engagement has become limited (Clancy & Happell 2017; Clancy, Happell & Moxham 2014).

Further to the hindrances to spiritual care caused by the organisation’s corporate culture, the cultural tradition of biomedicine may also have influenced the nurse’s ability to discuss and further develop their spiritual care. The following subsection will now explore the tradition of medicine and how it has impacted on the current nursing culture.

7.1.3 Cultural Hindrances -The traditional culture of medicine and its impact on current nursing culture

Most of the nurses in this study were senior nurses with many years’ experience. How then is it possible that within a contemporary healthcare system, experienced senior nurses felt helpless, disempowered and unable to articulate their practice? Within this thesis, the data has indicated that organisational processes, such as 'clinical reviews', can highlight issues of power and the privileging of one voice over another. The data indicated that the dominance of the bureaucratic corporate culture and the medical paradigm had the effect of disempowering and silencing the voice of the nurses. As power within organisations is multifaceted, this disempowerment and silencing of the nursing voice require examination from differing perspectives. In this next section I will explore the tradition of medicine and its impact on nursing.

From a historical perspective, Darbyshire and Thompson (2018) and Stein’s (1967) work can offer some illumination on the disempowerment of nurses found within the data for this thesis. A feature article by Darbyshire and Thompson (2018) which discussed the Gosport report, found that poor communication, hierarchical doctor – nurse games or the ‘dance of deference’ led to many patient deaths. The findings from the Gosport report parallel the silencing of the nursing voice that was occurring within the mental health organisation in which the data for this thesis was collected. Darbyshire and Thompson

(2018, p. 2) stressed that silence could be lethal, and that silence and subservience are endemic within the healthcare system and that "perverse charades and their calamitous consequences are what passes for communication amongst health professionals". The authors drew on Stein's (1967) article which described the 'doctor-nurse game'. This game is historically shared and enacted between nurses and 'doctors' (Stein 1967). Stein (1967) argued that the genesis of the doctor-nurse game commences for the medical practitioners in medical school, where they are taught that they are 'warriors' in the fight against death and disease. Therefore, they feel the burden of personal responsibility for the lives of their patients (Stein 1967). The consequences of making a mistake could be intolerable and to cover this vulnerability, medical practitioners tend to embrace omnipotence (Stein 1967). Stein's (1967) view that 'doctors' are taught to be 'warriors' is echoed by the comment by Allison, Goodall and Bastiampillai (2016, p. 225) writing of the psychiatrist perspective in South Australia, where they contended that "[D]octors used to be trained as 'heroic lone healer'". Therefore, some of the remnants of this viewpoint could still be affecting the medical subculture. Thus, requiring a continuation of the doctor-nurse game.

As long as nurses and medical practitioners are educated through segregated and divergent methods, there is potential for communication styles that reflect the doctor–nurse game (Curtis, Tzannes & Rudge 2011). Darbyshire and Ion (2018) suggested that cooperation and communication can be engendered through collegial learning spaces, where nurses and medical practitioners share educational and practical experiences.

Relevant to contemporary mental services culture, Stein (1967) maintained that the major disadvantage of the doctor-nurse game is the shutting down of open dialogue. Similarly, the data for this thesis indicated that nurses felt they had to keep silent. Therefore, the patient and their nursing care were both rendered invisible. The question of what created a reality where the nurses felt disempowered and silenced can be examined through the lens of linguistically induced power imbalances (Hatch & Cunliffe 2013). The next section will discuss how the power of language and cultural symbols can be used to

shape reality and disempower and silence those whose cultural values are from one paradigm, while privileging another practitioner.

7.1.4 Cultural Hindrances - The power of language and symbols in silencing others maintaining dominance

The results of this thesis indicate that even though the nurses were confident in their skills, they felt unable to articulate their work. One nurse stated that she felt helpless (from results Chapter 6 Sheryl IMHN P4 chapter 6, p. 123) Another nurse reported that he needed to break rules to be able to practice nursing in accordance with his clinical judgement and educational background (from results Chapter 6 Jessie CMHN P11, p. 124). Mental health nurse Sabine reported that both the individuals she was caring for and the therapeutic care she gave, did not fit within the organisation's Model of Care (Sabine P1 chapter 6, p.120 &122)

Organisational theory maintains that work is structured through language communities (Hatch & Cunliffe 2013). Language communities dictate what can and cannot be said. These discourses shape the reality through which people engage, and consequently shapes their actions (Hatch & Cunliffe 2013). Within the organisational culture of mental health services, language was structured through the biomedical paradigm. The biomedical view of illness adopts the 'medical gaze' and views itself as detached and value-free (Giddens & Sutton 2017). It also views itself as the superior model of care (Giddens & Sutton 2017). The organisational culture of mental health services privileged the language of biomedical paradigm culture. In addition, the language of the business culture that was aligned to corporate culture within mental health services, designated individuals as 'consumers' and gave precedence to terms such as 'core business' and the 'Clinical Business Rules'. Hence, the language community of the biomedical paradigm and the business-related corporate culture through which power was held and maintained, made it difficult for nurses in this study to articulate their practice through the language of their unique professional ethos. The ethos of nursing centres on human connection and

person-centred care. The phenomena found in the data from this thesis of experienced and senior nurses feeling powerless, helpless and silenced, may also be explained using 'symbols of authority' (Hatch & Cunliffe 2013).

'Symbols of authority', such as titles, are used to support and maintain power (Hatch & Cunliffe 2013). Within the mental health service in this thesis, the 'symbols of authority' are aligned with the title of psychiatrist or the head of the unit. This power can be used to privilege the knowledge of one group while devaluing, discrediting and silencing another. In some instances, this privileging may be so deep that the privileged do not recognise their dominance in shaping culture (Hatch & Cunliffe 2013).

Despite spending much of their day doing repetitive computer work and completing business related tasks such as performance indicators and risk management protocols, nurses in this study were able to find the time to provide spiritual care for their patients (from results Chapter 6, Roger, Larsa, Charisma, Linda, Bianca, Steve, Frank, Sabine, Jessie & the autoethnographer). However, the data suggested that some palliative care nurses did not feel comfortable in providing spiritual care and that they believed they needed to prioritise their time to enable them to provide other forms of care as opposed to spiritual care.

Section 2 of this chapter will discuss the barriers and support for spiritual care from the different nursing specialties. Firstly, the contrasting data from the different specialties will be discussed. Secondly, the barriers the palliative care nurses reported in offering spiritual care will also be discussed. Finally, it will be argued that the values and skills embedded in the mental health nurse's professional culture that were based on therapeutic nursing practices, supported their ability to provide spiritual care.

7.2 Barriers and support for spiritual care from different nursing specialties

7.2.1 Contrasting data from the different specialties

Spiritual care is a mandated dimension of care in palliative care service delivery (Palliative Care Australia 2018). Yet some of the palliative care nurses revealed that they believed their spiritual care would not be sanctioned by their organisation (from results Chapter 6, Suzanne CPCN P; Lillie CPCN. P17, p.138). Both nurses interpreted the spiritual care question in terms of a person's religious beliefs as opposed to the broader concepts inherent in the definition of spiritual care. In addition, several palliative care nurses reported that physical care and symptom management took priority over spiritual care whereas all mental health nurses apart from one, offered spiritual care.

The issue of time availability for spiritual care was sharply contrasted between mental health nurses and palliative care nurses. This contrast did not mean that spiritual care was unimportant to the palliative care nurses. Indeed, they expressed frustration and sadness when reporting that they struggled to find the time for spiritual care. Akin to the mental health nurses, palliative care nurses reported that they were spending more time on paperwork, which was diminishing the time they could spend with their patients. However, one difference between the two groups of nurses was that palliative nurses were concerned about "political correctness" (from results Chapter 6, Suzanne CPCN P6, p.138), not feeling allowed to discuss religion, (from results Chapter 6, Lilly CPCN P17 chapter 6, p. 138) and their need to give priority to other issues, such as symptom control (chapter 6, Lillie CPCN P17 pp.138; chapter 6 Bess CPCN P7, p.137). How can the difference between the spiritual care given by the two sets of nurses be explained? Moreover, what does this unexpected and contrasting data between the two sets of nurses add to knowledge on the culture of mental health services and the cultural support for the facilitation of spiritual care?

7.2.2 Palliative care nurses - Barriers to offering spiritual care

Colette's and Sophie's patients were in an inpatient setting whereas the other palliative nurses were in a community setting. It could be surmised that the priority the community palliative care nurses gave to the physical symptoms of patients was indeed a necessity. Due to their time constraints, they would have to prioritise their physical care over spiritual care within the community context. The phenomena of palliative care nurses not having the time to provide spiritual care, was mirrored in an international qualitative study by Selman et al. (2018). Selman et al. (2018) explored the spiritual needs of patients with a life limiting illness and their care givers. Their study which was undertaken across nine countries and spanning four continents, revealed that there was widespread neglect of the patients' spiritual needs by palliative care clinical staff and concluded that it was not simply a lack of time that led to this neglect, but a prioritisation of care. The findings of their study also suggested that palliative care clinicians were concerned that spiritual care was not part of their role and that they were inadequately trained to provide this type of care. The theme that palliative nurses did not have enough time for spiritual care and that they needed to give priority to physical symptom management also resonates with an Australian study by Keall, Clayton and Butow (2014).

In contrast to some studies which have argued that time is not necessarily a precursor to spiritual care, Zumstein-Shaha, Ferrell and Economou (2020), found that time was required for instigating spiritual care practices, such as listening, being present and assisting the person in examining their beliefs. The finding of this PhD study concurs with Zumstein-Shaha, Ferrell and Economou (2020). Hence, to enable spiritual care, the organisation needs to commit to ensuring that the nurses have the time to provide this care. The data in this thesis has suggested that palliative care nurses had difficulties in having enough time to attend to the spiritual needs of their patients and that physical symptom management took priority. Yet, this difficulty may be a mis-conceptualisation of spiritual care and how it is practiced. Within this thesis, palliative care nurse Sophie spoke about being able to engage in a therapeutic relationship that focused on spiritual

concerns, despite competing clinical demands. Nevertheless, she described having to do the patient's dressing very slowly, so she would be able to spend the necessary time to provide spiritual care as she was doing this (from results Chapter 6, Sophie IPCN P8 chapter 6, p.136). In this way Sophie was able to claim some of her power as a palliative care nurse. Caldeira and Timmins (2015) argued that the issue of the time required for spiritual care needs to be reconceptualised. As opposed to Daaleman's (2012) argument that spiritual care should be unencumbered by competing clinical demands, Caldeira and Timmins (2015) maintained that each moment can provide an opportunity for spiritual care.

Spiritual care is about how the nurse connects to the patient and the nurse's 'therapeutic use of self' and healing presence. Spiritual care is about creating spiritually nurturing environments and does not require more time than usual interventions (Caldeira & Timmins 2015). Therefore, it is possible that the palliative care nurses were providing spiritual care to their patients through their presence, their 'therapeutic use of self', engagement and care for their patient. However, challenging how spiritual care is conceptualised in terms of time, does not explain the reasons the palliative care nurses felt they were unable to discuss religion with their patients and felt the need to be 'politically correct' and 'careful' (from results Chapter 6, Suzanne CPCN P6, p.138; Lillie PCN P17 chapter 6, p. 138). This data calls for further study into this area as spiritual care is one of the core areas of care of the dying (Palliative Care Australia 2018).

Another key difference between the practice of palliative care nurses and mental health nurses is that mental health nurse's core competencies are around connection and understanding of what gives hope and meaning to the individual as opposed to physical care (Australian College of Mental Health Nurses 2010). Other studies have found that mental health nurses frequently provided spiritual care compared to nurses in other settings (Evenblij et al. 2016) and that mental health nurses had time to build a therapeutic relationship with individuals with a mental illness at end of life (Morgan 2016).

7.2.3 Support for spiritual care based on therapeutic nursing practices

Researchers have pointed out that spiritual care involves being fully present with the patient (Bruce et al. 2011; Daaleman 2012; Rushton et al. 2009; Seno 2010). Spiritual care is based on the 'therapeutic use of self' and includes exploring the patient's spiritual perspective and understanding what gives the person's life meaning (Ramezani, et al. 2014). Therefore, it could be contended that spiritual care is synonymous with the skills mental health nurses use in everyday practice. The core of mental health nursing is human connection and the therapeutic relationship which is not constrained by time as opposed to physical care. Within the therapeutic relationship, all interactions, whether they are five minutes or several hours, can contain the same elements of presence and connection. Thus, one reason mental health nurses may have felt able to provide spiritual care was that the mental health nurses used and conceptualised their time which was also limited, in a different way to the palliative nurses. However, despite palliative care nurses feeling they did not have the necessary time to provide spiritual care, they may have been unknowingly providing this care.

Engaging in physical care does not preclude spiritual care. These dimensions of care can be done concurrently and may be viewed as aspects of emotional labour. Theodosius (2008) builds on the work of sociologist Russell Hochschild, when she posits that nurses use emotional labour in daily their interactions with patients and indeed when developing therapeutic relationships with their patients. Hochschild first coined the term emotional labour when researching flight attendants and their emotional work (Theodosius 2008). Emotional labour is the ability to use one's personality to offer compassionate care and demonstrate kindness, thereby to eliciting feelings of safety, security and comfort in another. Organisations rely on this emotional work to ensure a good company image. In her research, Theodosius (2008) found that the pace and demands of nursing, marginalised the emotional labour of nurses. Kindness and compassionate care were not seen as valuable. Further, emotional labour was regarded with less status than that of medical care. This marginalisation of emotional labour can lead to nurses feeling alienated

from their own sense of self and a diminished value of their nursing work. They can feel guilty as they are unable to offer the patient the care, they believe the patient requires (Theodosius 2008).

A later study by Theodosius et al. (2021) examined the effects of emotional labour on nurse's levels of burnout. They identified that burnout was associated with the enactment of emotional labour on a superficial or surface level, such as when nurses act out compassion, as opposed to feeling it. It was found that this surface emotional labour was associated with burnout, whereas congruent emotional labour that enhanced quality communication and was patient focused did not have this association. In the light of Theodosius et al's (2021) study, it is possible, given the high level of emotional labour provided by palliative care nurses in this study, that they were experiencing burnout.

A thematic analysis of the literature by Broadhurst and Harrington (2015) found that having good pain and symptom control assisted in the generation of hope. As hope is an aspect of spiritual well-being, through the generation of hope, the palliative care nurses in this study were offering an element of spiritual care, albeit without them being aware that they were providing this form of care in their daily practice.

The differences between specialties were also revealed through the language used by the nurses. Despite palliative care nurses reporting that their spiritual care would not be sanctioned, a senior palliative care nurse reported that love is consistently seen within the palliative care setting (from results Chapter 6, Colette IPCN P5, p.150). The word 'love' was used about patients being cared for within the palliative care setting whereas within the mental health setting the word 'love' is seen as a taboo. However, the data suggests that both sets of nurses practiced a form of love, or agapé and alterity which were foundational to their spiritual care.

The following section will further argue that cultural support for spiritual care was enacted through the professional culture of nursing. It will be argued that the desire to alleviate suffering and feelings of privilege were intrinsic motivators for the nursing

behaviours as revealed in the data. Intrinsic motivation may be defined as the nurse's internal personal and professional reward for providing quality care. The following section will also argue that the culture of professional nursing, in part, used the power embedded in their use of professional agency to ensure enough time for spiritual care. Finally, this section will further discuss the data that indicated that mental health nurses were able to recognise the therapeutic value of spiritual care and distinguish between psychotic phenomena and the person's spiritual concerns.

7. 3 Cultural Support - The Sphere of Nursing within professional culture of nursing

Denzin (2013) argues that epiphanies are moments and experiences that are turning points that culminate and add meaning to the research. Section 7. 3 is the outcome of these epiphanies. They were pivotal points within my research journey.

7. 3.1 Epiphanies within the research journey

In the results section of this thesis, it was theorised that the nursing values and practices embedded within the 'human to human therapeutic relationship', enriched agapé and alterity, were the foundations of the nurse's spiritual care. This insight arose from two pivotal points within the research journey. The first was from the interview with a senior palliative care nurse who spoke about the notion of love within the palliative care setting (from results Chapter 6, Colette IPCN P5, pp. 150-151). The second pivotal point emerged across several interviews with both the sets of nurses. This conceptual realisation emerged when I was listening to how fond the nurses were of their patients and the admiration they felt (from results Chapter 6, Frank IMHN P13, Jessie CMHN P11, Christine CMHN P12, Linda CMHN P14, Jo-Anne CPCN P2, pp.152-155). When the nurses spoke of their patients, they became passionate and animated. The extent of their fondness and willingness to go beyond usual practice left strong impressions on myself as

the interviewer. This self-giving was a form of agapé. Agapé and alterity are aligned to spiritual care and as such is a supportive cultural factor.

7.3.2 Agapé and Alterity - the desire to alleviate spiritual suffering

Colette's statement on love being consistently seen in palliative care, illustrated the differences in the culture and discourse of palliative care nurses and mental health nurses. The use of the word love is seen as taboo by many nurses within the mental health setting in Australia, yet the practices of the mental health nurses in this study, aligned to aspects of love in the form of agapé. They ensured they had time to provide care for these patients, even if it meant bending or breaking organisational rules. Similarly, alterity or being present with the 'other' and desire to alleviate their suffering, underpinned nursing practice.

Why then is the word love never used in contemporary mental health practice? Several contemporary nursing theorists maintained that nursing practices are founded on love (Ryker, Eriksson & Råholm 2015; Stickley & Freshwater 2002; Thorkildsen, Eriksson & Råholm 2013). The founders of the nursing profession would not have flinched at the notion that nursing care was based on love for the patient (Stickley & Freshwater 2002). Nevertheless, because there is often confusion around the different manifestations of love, these feelings can be buried or denied, affecting the nurse's ability to engage in the therapeutic relationship (Stickley & Freshwater 2002). Several nursing theorists have asserted that connectedness and love are core concepts in nursing (Eriksson 2007; Eriksson & Råholm 2013; Harrington 2005; Rykkje, Eriksson & Råholm 2015; Stickley & Freshwater 2002; Thorkildsen, Eriksson & Råholm 2015; Watson 2018).

People with severe mental illness who die at a younger age than the general population often suffer a lifetime of stigma, grief and loss which could add to their spiritual despair. Spiritual despair can manifest in feelings of guilt, shame or anxiety, fuelled by dying at a young age (Chochinov et al. 2009; Hui et al. 2011). Thus, the nurses' feelings of

privilege, induced compassion and an inner desire to alleviate the suffering of their patients, can be aligned to agapé, alterity and spiritual care which was not diminished by the organisational culture exposed by the Douglass (2015) and Stevens (2017) reports.

7.3.3 Compassion and intrinsic motivation within the professional cultures of nursing

My understanding of the impact of the nurse's internal drive to care for others, despite working within a culture of crisis, arose from the data that emphasised the deep feelings of fondness and connection for their patients expressed by both the mental health nurses and the palliative care nurses. Motivation for this spiritual care was based on compassion, which is inherent in the values of the professional cultures of nursing and was an intrinsic motivating factor in caring for this population of patients. Legitimate tasks, such as working with the skills and knowledge of the profession of nursing, as opposed to fulfilling tasks that are unrelated to nursing, increase intrinsic motivation (Muntz & Dormann 2020). McAllister, Happell and Bradshaw (2013) identified that the intrinsic rewards of mental health nursing were linked to the appreciation of the trust placed in them to bear witness to human distress and authentic connection with others. Similarly, Gilbert et al. (2017) found that compassion grew out of caring motivation and sensitivity to the suffering of others and desire to alleviate that suffering.

The nurses within this thesis were motivated by strong feelings of fondness and admiration, and a sense of privilege to be working with the person. Mental health nurse Frank reported feeling grateful to have known the person he was caring for and that it was a privilege to have known her. He stated, "I just felt that, that it was such a privilege to have known her" (From results chapter 6, IMHN P13, Frank p. 152). "I felt a little blessed" (IMHN P13, Frank p.155). Data from the autoethnography about individuals who were dying having the courage to talk with the nurse about their fears and sometimes terror, suggested trust and connection between the patient and the nurse. Feelings of privilege in listening to these patients was a strong intrinsic motivator for continuing to care for this

population (From results chapter 6, autoethnographer p. 135). Out of this intrinsic motivation and alignment to professional values, the nurses made conscious choices about how they enacted their roles.

Earlier in this chapter it was highlighted that the participants in this thesis were practising within a broader organisational culture in which the biomedical paradigm and corporate culture were the dominant discourses. It discussed the disempowering nature of these discourses. I will now argue that professional agency assisted nurses to have the time to provide spiritual care. Professional agency enabled nurses to retain some of their power and continue practising their craft despite, as the data indicated, overwhelming workloads.

7.3.4 Professional agency - Enabling time for spiritual care

The pressure of time is a contextual element within all organisations (Hoff 2014). There can be a tension between organisational time pressures and the values and beliefs that drive workers, such as nurses in the enactment of their role (Hoff 2014). The time given to an intervention, such as spiritual care, may be reflected in this tension. The mental health nurses in the study reported they were able to shape their workday and ensure they had enough time to have meaningful conversations with their patients. Similarly, a Swedish study by Gabrielsson et al. (2016), concluded that sound professional nursing practice occurs when nurses are confident and take responsibility for shaping their own nursing care. Professional care ensued when nurses chose to make the patient their primary concern, as opposed to completing their administrative duties and sometimes going against the rules to be able to spend meaningful time with the patient.

Hoff (2014) theorised that due to their differing roles and identities, healthcare workers have a degree of autonomy. This autonomy provides a sense of agency through which the individual worker can make a conscious choice about how they enact their roles. Underpinning their agency is an emphasis on self-reflection and choice. Hence, the

healthcare worker has opportunities to interact emotionally with their patients. In this context, human agency takes the form of professional agency and provides the nurse with a degree of autonomy. However, there remains a tension between the pressures the organisation places on the worker to enact their roles and healthcare worker agency (Hoff 2014).

In this thesis, these tensions manifested in the pressure to adhere to corporate processes, such as completing Key Performance Indicators, 'episodic care', 'core business' and risk management as opposed to therapeutic care. Hoff's (2014) viewpoint is that the healthcare worker agency can be secondary to the organisational pressures placed on the worker when enacting their roles. However, Giddens and Sutton (2017) assert that organisational structure and human agency are not separate and fixed entities. Rather, they are intertwined and malleable and can give rise to creative processes. This assertion is infinitely more hopeful when one wants to reclaim a voice within a system as the interchange between the system and human agency is more fluid, allowing professional values to more easily influence the corporate culture.

Human agency, as asserted by Giddens and Sutton (2017) is demonstrated in the spiritual care provided by the participants in this study. Despite mental health nursing practising within a toxic culture where nurses felt disempowered, a thread of love and connection continued to weave its way through as central to the participant's nursing practice. Although the mental health nurses within this study had overwhelming corporate demands made on their time, they ensured they had time for meaningful conversations with their patients. Giddens (1984) explained that capable and educated individuals will only submit to organisational mandates for part of the day. Usually, as a trade-off for submitting to these demands, they are then freed. The data suggests that although the participants were working in a culture with overwhelming organisational demands, they were able to free themselves, thus allowing enough time to provide spiritual care.

Professional agency was also demonstrated when mental health nurses connected therapeutically with individuals through their spiritual struggles and fears, including the

distress of psychosis. The following subsection will discuss the spiritual care provided by nurses through the distress of psychosis and the importance of therapeutic engagement with the individual's spiritual dimension.

7.3.5 Recognising the therapeutic value of spiritual care and working with psychotic symptoms

Mental health nurses pointed out that by acknowledging and working with the person's spiritual beliefs, therapeutic effectiveness was enhanced (From results chapter 6, CMHN's Larsa, Charisma and Linda Chapter 6, pp. 151-156). Research has also found that working with a person's spiritual beliefs can enhance adherence to treatment (Borras et al. 2010). Similarly, it was stressed within the data from this thesis that if the person's spiritual dimension is not considered, the person may not respond as well to care as their emotional strength could be linked to their spiritual beliefs (From results chapter 6, CMHN's Larsa, Charisma and Linda Chapter 6, pp.143-145).

Previous researchers were concerned that mental health nurses were often reluctant or unable to provide spiritual care and that they had difficulty discerning between the person's spiritual concerns and delusions or hallucinations (Huguelet & Koenig 2009; Huguelet et al. 2006; Koenig 2012; Wilding, Muir-Cochrane & May 2006). Data from this thesis firmly indicates that mental health nurses can discern between psychosis and spiritual beliefs. Mental health nurses in this study were not reluctant to tease apart the person's spiritual concerns and delusions or hallucinations. Moreover, some nurses highlighted the importance of exploring the person's background in order to ascertain whether the persons' presenting beliefs were congruent with their spiritual history. It is possible however, that mental health nurses less experienced than the participants in this study, may not have had the same confidence in teasing apart psychotic phenomena from spiritual beliefs.

The data from this thesis indicated that mental health nurses understood and could work with spiritual distress. One mental health nurse spoke about the culture of mental

health services changing and that there is more acceptance and support for managing the individual's spiritual struggles (From results chapter 6, Linda MHN P14 Chapter 6, p.127). Linda spoke about managing the distress that some spiritual issues can cause. When the nurse perceived the person's spiritual struggle, they have recognised the fundamental value and significance of the human spiritual dimension (Koslander 2012). Rather than avoiding a discussion on their spiritual beliefs which are a dimension of that person, Linda identified that it is important to work through these struggles and empower the individual to take control of their lives and their mental health. These remarks are congruent with prominent recovery movement writers, such as Clay (1995) and Deegan (2004), who highlighted that mental illness itself may be a spiritual crisis and that spiritual distress, even distress associated with psychosis, can be hallowed ground and a place of spiritual growth.

The ability to bear witness to human suffering was clear in the data given by the research participant Bianca. She demonstrated a sound understanding of spiritual despair and the desire to alleviate the suffering that this despair or death anxiety engendered. Mental health nurse Bianca also demonstrated a sound understanding of spiritual distress when she gave an example of speaking with her patients about their fear of death and fear of the darkness or the unknown. In addition, she demonstrated 'therapeutic use of self' in her report in that she gently felt her way into the conversation (From results chapter 6, Bianca IMHN P16, p.145). She demonstrated that she understood the need for some people to work through 'unfinished business' (IMHN P16 p.145). However, while she was happy to discuss her practice if other clinicians asked her, she did not attend formal review processes such as 'clinical reviews'. Therefore, unless she spoke about her work with a colleague or someone read her documentation, her work was not reviewed.

Unlike other mental health nurses, Bianca was not required to discuss her care at 'clinical reviews'. The only place she discussed her clinical practice was within her documentation. This lack of review raises the question about whether the following self-disclosure was appropriate when Bianca told the patient, "I actually believe that we have

an all-loving God, and that certainly gives me comfort” (From results chapter 6, IMHN P16, p.145,). Lack of review of patient care is a professional practice issue. The following sections will discuss the issue of self-disclosure within the therapeutic alliance and discuss the professional issues raised by a lack of review on clinical practice. As a corollary, it will highlight the need for reflective practice and clinical supervision as a basis for professional practice and spiritual care.

7.4 Maintaining mental health nursing professional practice

7.4.1 Spiritual care and the requirement for shared reflective practices

It is essential for provision of quality spiritual care that the professional standards are maintained. Some may argue that Bianca’s personal disclosure was overstepping her professional boundaries. The use of self-disclosure continues to be controversial and it is questioned whether self-disclosure is an appropriate way of developing a therapeutic alliance (Seuber & Pollard 2018; Unhjem, Vatne & Hem 2018). Understanding the issue of self-disclosure from a historical perspective may be useful. Freud spoke of the need for the therapist to remain closed, so that the patient could transfer their feelings, usually about their parent/s, onto the therapist, (Unhjem, Vatne & Hem 2018). Peplau, who has been called the mother of mental health nursing, also maintained that it was important for the nurse not to disclose personal information (Peplau 1997; Unhjem, Vatne & Hem 2018). However, as early as 1971, mental health nursing theorist Joyce Travelbee argued that it is "through the human-to-human relationship, where individuals experience the humanity of the other, there is no need for 'distancing tactics', stereotypes are forever shattered" (Travelbee, 1971 p. 152). Moreover, there has been a paradigm shift in many areas from the psychodynamic approach of Freud and Peplau to more recovery-based models of care. Recovery-based approaches are based in human connection and reciprocity (Commonwealth of Australia 2013; Department of Health 2011). Therefore, from a recovery-based perspective, self-disclosure which benefits the patient, may be an aspect of psychotherapeutic care (Barker 2009). Through engaging in a reciprocal

relationship which reflected shared humanity, it could be argued that Bianca's self-disclosure was an element of spiritual care (Edwards et al. 2010).

Nevertheless, as her work was not reviewed within a clinical review process, other clinicians were not benefiting from her knowledge and experience, nor were they able to critique her practice. The use of self-disclosure is an ethically-based contextual decision and so it is critical to reflect on the therapeutic use of the self-disclosure and ensure that guidance and support for the use of this strategy is reviewed through professional development mechanisms (Seuber & Pollard 2018). Taylor, Park and Pfeiffer (2014) argue that nurses with religious beliefs should not dissociate from beliefs.

The concepts of professional boundaries and boundary violation stem from Freudian psychoanalytic theory (Lear 2009; Evans 2007). Boundary violation is related to the phenomenon of transference. It is often through transference and countertransference that boundary violations, such as the need for love on the part of the therapist impacts on their ability to maintain professional boundaries (Dickeson, Roberts & Smout (2020).

Within therapeutic relationship, professional boundaries are created and maintained to ensure a safe space in which the healing can occur (Gardner, McCutcheon & Fedoruk 2017). However, the discourse of boundary violation is often "...confused, ambiguous, and even contradictory" (Radden 2014, p. 288). Radden (2014) highlights that judgments made about boundary violations are frequently inconsistent subjective and open to disagreement. Boundary violations can include physical contact along a continuum from pats and hugs to sexual intercourse. They may include gift giving and receiving. It can include self-disclosure or entering into a business or social relationship with the patient or any form of exploitation of the therapeutic endeavour.

Self-disclosure may also be seen as a boundary violation (Radden 2014). A recent South Australian study by Dickeson, Roberts & Smout (2020), found that female practitioners were more vulnerable to committing compassion driven boundary violations due to their self-sacrificing tendencies. They were more likely to commit minor boundary

violations, such as initiating a hug, than their male counterparts, who were more likely to engage in erotic boundary violations. A study by Gardner, McCutcheon & Fedoruk (2017) found that within mental health nursing practice, there was not only areas of black and white in boundary violation, there were shades of grey. The study concluded that professional therapeutic boundaries were culturally and contextually based (Gardner, McCutcheon & Fedoruk 2017).

Psychoanalytic theory is also useful in understanding the interpersonal complexities unpinning the therapeutic relationship (Badin Toledo & Garcia 2018; Evans 2007; Gallop & O'Brien 2003). The basis of psychoanalytic theory is the belief that the individual's sense of self is developed during their childhood and this sense of self continues to impact on the individual psyche, whether consciously or unconsciously, throughout their life (Badin Toledo & Garcia 2018; Gallop & O'Brien 2003). From the viewpoint of Freudian psychoanalytic theory, psychological healing and growth occur when current problems that have arisen due to issues that developed in the person's childhood are emotionally resolved (Badin Toledo & Garcia 2018; Gallop & O'Brien 2003). Within the psychoanalytic paradigm, transference occurs when attributes and consequent feelings brought about by another person, often the parent are transferred or projected onto the therapist (Brooks 2019 Evans 2007; Lear 2009). The use of transference is the ground for important therapeutic work (Badin Toledo & Garcia 2018; Evan 2007; Gallop & O'Brien 2003). The use of transference to assist the person to resolve issues from the person's childhood and heal damaged psychic structures (Lear 2009).

Lev (2017) argued that according to Freud, it is the love that occurs in therapy, otherwise known as transference love, that is a healing factor within the therapeutic relationship. An understanding of the transference phenomenon is critical within the nurse - patient relationship. Transference can be seen as an attachment to the nurse by the patient (Evans 2007; Badin Toledo & Garcia 2018; Gallop & O'Brien 2003). This concept offers an understanding of the strengths of the attachment the patient may have for the nurse. Through the use of transference love, the mental health nurse can assist the

patient to work through the suffering that arose from its initial cause in childhood (Badin, Toledo & Garcia 2018).

Further, from the perspective of the psychoanalytical paradigm, the mental health nurse needs to understand their own inner world and how their own psych interacts with the psychic structures of their patients (Badin Toledo & Garcia 2018; Gallop & O'Brien 2003). The phenomena of counter transference is also an aspect of psychodynamic theory. Countertransference occurs when the clinician's own unconscious psychic structure influences the relationship between themselves and the person within their care. Gallop & O'Brien (2003) pointed out that nurses, at a minimum, nurses need to understand how their own inner world affects the interpersonal relationship and the person's progress within that relationship toward recovery.

Freud's concepts of psychoanalysis were developed through his work on the ancient classics. The Freudian notion of transference arose from Diotima a female character in Plato's Symposium (The drinking party), (Brooks 2019). In the story Diotima was the teacher Socrates. Diotima offered the idea that souls could be pregnant with words and deeds and is on a ladder toward great beauty and the eternal. Brooks (2019) suggested that therapy may be a place of such pregnancy and that through therapeutic conversations birth is given.

In their work on Freudian analysis both Lear (1990, p. 40) and Gabbard (2017, p. 28) highlighted that within Freud's writings he suggested that "psychoanalysis itself is a manifestation of love" that transcends erotic love. Plato's depiction on love was influential on Freud's development of his psychoanalytic theory (Lear 2009). It is an all-inclusive love that was described by Plato in the speech by Socrates in the symposium (Gabbard 2017, Lear 2009). From the perspective of Freud, love is not only located in the human body but also permeates the world. Love is the psychic structure of a loving world. The outcome of love is the development of human psychic structures known as individuation (Lear 2009). From a Freudian perspective, individuation was the development of ever increasing complex psychic structures that occur through the receiving and giving back of love to a

loving world (Lear 2009). This developmental process happens because love is an active force and its nature is to pull human beings to ever more complex unities. Love is manifested in the human world through the process of individuation. (Lear 2009).

Yet, Gabbard (2017) maintained that within the psychotherapeutic context, the word love was the most complicated word and as such was the most difficult to define. He suggested that within therapeutic actions, forms of love such as patience, care and empathy became manifest. Gabbard (2017) contemplated whether forms of transcendence, such as the love as seen in some spiritual traditions, were inherent in the psychotherapeutic process. Lev (2017) argued that the daily work of offering compassion and love can be seen in some of the world's great spiritual traditions. Within these traditions love of this nature "...requires discipline, knowledge, practice" (Lev 2017, p.235). Lev, (2017) argues psychotherapy can be seen as a spiritual practice as it enables the unconditional love in its practitioners to emerge.

The issue of self-disclosure has raised the point that all mental health nurses providing spiritual care require some form of review mechanisms and collaborative reflective practice with other clinicians to ensure safety and high-quality care. The review of the literature identified ethical concerns regarding spiritual care. These concerns included the possibility of inappropriate spiritual care, including overstepping one's level of competence (Polzer Casarez et al. 2012). It was identified in the data that the spiritual care provided by nurses was not discussed in the clinical review processes and hence it was possible that they may have worked beyond their level of competence. Their spiritual care may include the use of alternative or complimentary therapies, such as yoga or meditation, which may conflict with the patient's spiritual or religious beliefs (Polzer Casarez et al. 2012). Pesut and Sawatzky (2006) highlighted that for nurses to practice spiritual care ethically, they must be able to clearly articulate the nature of the care they are providing. As the nurses in this thesis identified that their spiritual care was not discussed in review processes, their spiritual practice became hidden. Hence, there was no shared reflection on practice and

no shared learning. It remains important that those within the discipline of nursing reflect on how their beliefs can be used appropriately to enhance their spiritual care.

The Australian College of Mental Health Nurses Standards of Practice (ACMHN 2011) maintain that engaging in clinical supervision is central to practicing within the mental health nursing standards. Clinical supervision and reflective practice are an essential element of eight of the nine practice standards for mental health nurses. Standard 4 of the Australian College of Mental Health Nurses (2010, online) competencies states that evaluation of practice in the form of clinical supervision promotes ethically based care. In addition, the need for reflective practice and clinical supervision is firmly indicated for all mental health nurses and in South Australia this is supported by a policy directive (Government of South Australia 2010b). Moreover, the Nursing and Midwifery Board of Australia, Standards of Practice for Registered Nurses (2016, p. 4) states that nurses need to actively foster “a culture of safety and learning that includes engaging with health professionals”. Morgan (2016) found that due to the draining nature of their work, nurses caring for people with a mental illness who are facing death, require formal support mechanisms and a safe place to reflect on their emotional reactions and their care. In South Australia, all mental health nurses are encouraged to access clinical supervision as a mechanism for developing and maintaining professional competence and providing support (Government of South Australia 2010b, online). The data from this thesis indicated that spiritual care was occurring within the mental health setting. Therefore, to ensure the development and safety in the delivery of spiritual care and to ensure nurses are supported, it is essential that clinical supervision and reflective practice is held as a priority.

If mental health nursing is to continue as a profession, nurses need to reflect upon and articulate their unique practices. Data from the government reports discussed within this thesis, have suggested that mental health nurses were becoming generic workers. Lakeman and Malloy (2017) argued that when mental health nurses become generic mental health workers under the mental health services corporate model of practice, the

reflective and creative practitioner is no longer required. Hence, from this perspective mental health nursing practices are no longer at the core of care and mental health nursing in Australia is now under threat (Hurley & Ramsay 2008; Holmes 2006; Lakeman & Malloy 2017).

7.4.2 The potential demise of the professional culture of mental health nursing

As early as 2006, Holmes (2006) heralded the slow death of mental health nursing within the Australian context. He claimed that mental health nursing is seen as a moribund profession. Similarly, in their paper titled “Mental health nursing: sleepwalking towards oblivion?” Hurley & Ramsay (2008) claim that mental health nursing is under the impending threat of becoming non-existent. This death is partially due to the decline in mental health nurses participating in post-registration programmes and the poor retention of mental health nurses within the mental health sector (Hurley & Ramsay 2008).

Mental health nurses are the largest population of mental health service providers in Australia and it is expected that in South Australia, 50% of the mental health nursing workforce will retire within the next 12 years (Australian Government 2019; Nursing and Midwifery Office 2018). Thus, the spiritual care offered through the culture of mental health nursing would be lost. Spiritual care may fall to other disciplines. In addition, Standard 5 of the Australian College of Mental Health Nurses Standards (2010) maintained that mental health nursing practice is comprehensive and evidenced-based. Standard 4 also maintained that the mental health nurse “collaboratively plans and provides ethically-based care consistent with the mental, physical, spiritual, emotional, social and cultural needs of the individual” (Australian College of Mental Health Nurses 2010, p. 11). The loss of the unique and holistic care offered through these standards, that highlight the cultural values of mental health nursing, would be detrimental to individuals with a life limiting illness.

Van Nieuw Amerongen-Meeuse et al. (2020) found that patients were more likely to talk with nurses about their spiritual struggles than any other discipline. A Dutch study by Evenblij et al. (2016) concluded that mental health nurses have a crucial role in providing spiritual care during the patient's end of life trajectory, as they often have the closest relationship to the patient. Barker asserted that when people with a lived experience of mental illness talk about what sustained them on their recovery journey, they speak about people who offered comfort and presence, people "who nourished their souls (2011, p. 4). Barker (2011) concluded that apart from family and friends, these people were invariably mental health nurses.

With so many mental health nurses due to retire over the next decade, the current mental health workforce will be greatly diminished. Who then will provide spiritual care? A large, new workforce is emerging within the mental health system where clinical skills are not necessary. These workers come from a variety of work experiences and have no clear professional background. They frequently have 'on the job' training (Smith-Merry et al. 2015). A study by Smith-Merry et al. (2015) found that understanding of recovery approaches by these generic care workers was partial at best. If the profession of mental health nursing is lost, individuals facing death may not receive the same standard of spiritual care that is provided by mental health nurses.

The data from this thesis has highlighted that mental health nurses provide therapeutic care that is connected to recovery approaches and is therefore, an essential service. Especially to those who have a life limiting illness. Yet, the demise of mental health nursing has been assiduously chronicled by many authors with little or no impact on public policy or preparatory courses for mental health nurses (Happell & McAllister 2014; Hurley & Ramsay 2008; Holmes 2006; Lakeman & Malloy 2017). Lakeman and Malloy (2017) blamed the increase in medical hegemony, protocol-driven practices, lack of sound leadership and the ascendancy of allied health professionals, particularly psychologists, as contributing to the demise of mental health nursing. They polemically named this

phenomenon; the "rise of the zombie institution" and questioned whether mental health nursing was a "zombie category" (Lakeman & Malloy 2017, p. 1).

Lakeman and Malloy (2017) also argued that to save mental health nursing in Australia, a swift and aggressive response needs to be taken by mental health nurses, .Otherwise, the Australian demise of mental health nursing may serve as a salutary tale to the rest of the world. Sadly, Hurley and Ramsay (2008) maintained that mental health nurses are doing little to resist their demise. This trend may be especially true if mental health nurses do not find a way to articulate, reflect upon and develop their practice within both the multidisciplinary team and the broader community. Nevertheless, data from this study suggested that mental health nurses are continuing to practice the art of the 'human to human therapeutic relationship'. They are not, as Lakeman and Malloy (2017) described, a "zombie category". This demise of mental health nursing has not yet occurred. Although mental health nursing has been described as a dead speciality (Lakeman & Malloy 2017), the data from this thesis challenges that claim.

As it is essential for the professional culture of mental health nurses to continue to provide and develop their spiritual care practices, what then would be needed for the mental health nurses to have the courage to articulate their professional values, knowledge and skills and challenge the power imbalances that renders their practice and the patient who is facing death, invisible? Effective resistance to disempowering managerial practices within healthcare, requires a huge commitment and passionate professionalism (Cope, Jones & Hendricks 2016). The data from this thesis found instances of resistance to managerial practices that disempowered nurses from practicing according to their knowledge and skills. Jessie, a senior and experienced nurse spoke about "breaking rules" and "doing things the organisation would not necessarily support". However, he believed he used his clinical judgement to support his practice (from results Chapter 6, CMHN P11, p. 124). Similarly, palliative care nurse Sophie, who was passionate in her care for her patient, bent rules so she could have enough time to provide spiritual care (from results Chapter 6, IPCN P8 Chapter 6, p.136)

A study by Jerwood, et al. (2018) which examined the care of people with severe mental illness who also have a life limiting illness, mirrored some of the responses found in this thesis. Their study found that when clinicians described their care as effective, there was often a caveat of bending the rules. As opposed to seeing their approach as being flexible and person-centred, participants reported that they felt their care was covert and therefore needed to be hidden. Jerwood et al. (2018) called for organisational permission for clinicians to have a greater level of autonomy in the development of individualised care planning for people who have both a life limiting illness and a mental illness. In 2002, Stickley and Freshwater (2002) argued that what is required is a re-enchantment of the profession. Boje and Baskin (2011, p. 420) highlighted that a “particularly poignant example of people striving for an enchanted work life experience, is nursing”. Boje and Baskin (2011) argued that when nursing practice is congruent with nursing theory and that when nurses are fully involved in the care of their patients, they experience an enchantment and a sense of empowerment within their work environment.

The nursing voice is essential for developing new models of care and ensuring patient safety (Ferrell 2019). Ferrell (2019) argued that nurses are at their most confident in using their nursing voice when they are passionate about something. However, despite the nurses in this study being passionate about the care of their patients and not lacking in confidence in their skills and knowledge, they did not articulate their practice. What then could assist nurses to claim and use their voice? Strategies for re-enchanting the profession and inspiring nurses to articulate their practice will be discussed in the following section of this chapter.

7.5 Re-Enchanting the profession of mental health nursing

7.5.1 Weber and the myth of dis-enchantment

The theoretical construct of disenchantment and enchantment feature within the organisational and change management literature (Boje & Baskin 2011; Redinger 2020;

Suddaby, Ganzin & Minkus 2017; Tyler 2011). These constructs have also emerged within the nursing literature (Neff 2020). Enchantment in nursing is found within the nurse's connection to their patients (Neff 2020). Disenchantment in the nursing field is generated when the dominant narrative of the physician's medical knowledge is elevated above nursing knowledge (Boje & Baskin 2011).

The use of sociologist Max Weber's treatise on the disenchantment of the world will be used to underscore more deeply the effects of the corporate and medical culture on disempowering and silencing the voice of nurses. The purpose of this exploration is to understand the construction of disenchantment, challenge its validity and offer strategies to re-enchant the profession of mental health nursing. Thus, safeguarding the continuation and development of spiritual care for individuals with a mental illness.

Weber used the term 'Entzauberung der Welt' or dis-enchantment of the world (George 2017; Grosby 2013) to describe the effects of the belief that humans can master all things through scientific knowledge, progressive rationalisation, calculation and cool intellect as opposed to one's heart and soul (George 2017; Grosby 2013; Weber 1919). Weber (1919) claimed that the privileging of scientific knowledge has caused human life to become meaningless or dis-encharnted. Weber (1919, p. 139) contended that as there are "no mysterious incalculable forces that come into play...the world is disencharnted". From a Weberian viewpoint, questions of meaning are subsumed by empirical science and technology and are no longer of importance. Contemporary corporate management practices mirror this sense of disencharntment (Suddaby, Ganzin & Minkus 2017). In this technical world, as described by Weber, with no spiritual mystery, death becomes meaningless. Weber argued that if death is meaningless, so is life (Weber 1919). From this viewpoint, spiritual care for individuals facing death within the biomedical and bureaucratic corporate culture of mental health services, where both spiritual mysteries such as love and death are taboo, the effects of disencharntment become apparent within organisational language and processes. Given both these taboos, it is little wonder that individuals facing death and their spiritual nursing care, became invisible.

Bureaucratisation and the ever-increasing intrusiveness of the government into the daily life of individuals, results in meaninglessness as spirituality is eliminated (Grosby 2013). Weber described an 'iron-cage', where the individual has become profoundly changed by bureaucratic mechanisms (cited in Mills, Weatherbee & Durepos 2014). However, there is an anomaly between the data from this study and Weber's views on individuals within bureaucracies developing an 'iron cage'. The anomaly is that when undertaking the interviews for this study, I was struck by the change in the demeanour of nurses when they were articulating their work and connections with their patients; they became more animated and seemed more joyful. Although the bureaucratic corporate culture has led to disenchanted processes, could it be that some enchantment remained within the practices of the nurses in this study? Was enchantment alive within their spiritual care in the 'human to human relationship' which was flowing beneath the surface of a bureaucratic 'iron - cage'? Challenging the hegemony of rationality could assist nurses in articulating practices that are inherent in enchantment, such as the healing effects of human presence or the cultivating and holding of hope.

If as Suddaby, Ganzin and Minkus (2017) argue, humans are not disenchanted, it remains that the bureaucratic cultures continue to reflect Weber's view on disenchantment. George (2017) argued that the world is not disenchanted. Human beings would never tolerate disenchantment. When the participants in this study spoke with animation and compassion, they were not disenchanted. Disenchanted practice would resemble Lakeman and Malloy's (2017) notion of the 'zombie' mental health nurse. When nurses found time for spiritual care and explored issues of meaning, they were not practicing from a space of disenchantment. Yet, within corporate processes, nurses did not articulate their practice. Their spiritual care with the dying was in the realm of enchantment and did not fit the bureaucratic dis-enchanted discourse.

Enchantment is seeing the beauty, mystery and meaning within the ordinariness of everyday life. Within both mental health and palliative care nursing this ordinariness occurred in the connections between human beings. The nurses were able to easily

articulate their practice within the interview setting, but not in 'clinical reviews'. If nurses shared these articulations of their work within the clinical processes of the organisation, it would demonstrate a valuing of the nursing practice and may reinvigorate person-centred care. Re-enchanting the profession would mean privileging the value of 'human to human therapeutic relationships' above bureaucratic standardised practices and procedures and re-examining the taboo subject of love or agapé within mental health nursing practice (Stickley & Freshwater 2002).

Ironically, nurses are also complicit in constructing the same organisational culture that silenced them. Nurses can take either a dis-encharnted or enchanted approach to their work. The dis-encharnted approach is maintained by the belief in the dominant biomedical narrative (Boje & Baskin 2011). It is through the recognition of our complicity that nurses will have the ability to change the system with the same creative force that made it (Hatch & Cunliffe 2013). If nurses do not recognise their complicity in the construction of organisational processes, even ones in which they feel disempowered and silenced, they confine themselves to the same routines and expectations (Hatch & Cunliffe 2013). Consequently, an organisational culture of disenchantment is maintained.

The dominant discourse of bureaucratic management styles is underpinned by control and disenchantment. However, people within these organisations will often work diligently to recapture the meaning and purpose within their work, and to reclaim power (Boje & Baskin 2011). In the data from this thesis, mental health nurse Jessie stated that he would drop everything to support his patient. He spoke of the importance of being responsive to the person's situation. In this way, Jessie reclaimed power and worked in a way which was meaningful. He demonstrated a sense of agency which is creating a partially enchanted workspace (From results chapter 6, CMHN P11, Chapter 6, p.133).

The data revealed that other nurses were also practicing within a partially enchanted working space. The mental health nurses were able to provide care that explored issues of meaning with their patients. Charisma, for example, who practiced in a primarily nurse-led unit, reflected on the support within her unit for the facilitation of spiritual care (From

results chapter 6, IMHN 9 Chapter 6, p.126). Indeed, it could be argued that when the nurses from this study practiced agapé within the Sphere of Nursing and provided spiritual care, they were working in an enchanted space, perhaps even creating it. However, when Jessie (From results chapter 6, CMHN P11 Chapter 6, pp. 124) reflected upon his disappointment with the organisation, an example of a disenchanting workplace emerged. He believed the organisation had lost humanity and human connection with people. Other nurses in this study felt powerless and unable to articulate their practice, which also lies in the realm of disenchantment.

Tyler (2011) argues that individuals' stories can be silenced or ignored in the face of larger dominant narratives. He maintains the importance of listening as means of organisational change and re-enchantment. An enchanted or disenchanting workplace can be reinforced through storytelling (Boje & Baskin 2011). Stories are the thread through which culture is woven (Boje & Baskin 2011; Yiannis, 2018). Boje and Baskin (2011) propose that hospitals are storied spaces that interplay with the dominant, historical cultural narratives. As communicative tools, stories both shape social relationships and the settings in which these stories occur (Beigi, Callahan & Michaelson 2019). Storytelling within organisations can disrupt conventional and dominant narratives (Beigi, Callahan & Michaelson 2019). Boje and Baskin (2011) coined the term anti-narrative; these are stories that lie beneath the dominant narrative. Shared stories have the capacity to sustain nurses in difficult and challenging times (Cope, Jones & Hendricks 2016). These stories can enrich the present and lead to shaping the future and the further development of nursing agency (Beigi, Callahan & Michaelson 2019; Boje & Baskin 2011; Tye-Williams & Krone 2015). Through storytelling mental health nurses can create a professional culture in which their practice including their spiritual care can be articulated, reflected upon and developed.

7.5.2 Shared stories – resistance, reflective practice, leadership

The data from this study suggested that organisational support for facilitating spiritual care was primarily due to nursing leadership. Mental health nurse Frank reported that he was supported by his managers who were nursing leaders. He felt able to provide spiritual care that was in alignment with his nursing values (From results chapter 6, IMHN P13 chapter 6, p. 129). Similarly, another nurse Linda reported that a nurse leader had the ability to inspire nurses and nurture the spirituality of others especially in time of difficulty and struggle (CMHN P14 chapter 6, p. 129).

Nursing leaders can offer storytelling spaces where nurses can talk about their challenges and concerns. Listening to their stories can provide a deeper understanding of their culture (Baskin 2008; Boje & Baskin 2011). By having managers that listen to their stories, nurses can feel affirmed and experience an enchanted workplace and culture (Boje & Baskin 2011). Relevant to the South Australian mental health nurse context is a Queensland study by McAllister, Happell and Bradshaw (2013). Their study highlighted that "in the face of chaos, disintegration, and dehumanisation," mental health nursing stories that illustrate human kindness, are important as they challenge the myths of mental health nurses as asylum workers (Happell & Bradshaw 2013, p. 663). Their study argued that mental health nursing leaders can inspire nurses to recognise the value of their complex and highly sophisticated practices. If mental health nursing is to survive within the Australian context, stories of compassionate care, steeped in deep connection to the patient, need to be told. Storytelling reinforces a positive professional identity and can inspire potential mental health nurses (Harrison, Hauck & Hoffman 2014).

When nurses practice their craft, they work from an enchanted space. Sharing stories and reflecting on their practices that occur within the Sphere of Nursing can validate and affirm their work. Standard 9 of the Australian College of Mental Health Nurses competencies (2010), maintained that as advanced practice nurses with specialist skills, all mental health nurses are required to model nursing leadership within the practice

setting. If within 'clinical reviews' mental health nurses claimed their leadership mandate and followed the Australian College of Mental Health Nurses (2010) standards that maintained that practice is underpinned by reflective practice, the dominant biomedical paradigm would be disrupted. In this new space, all clinicians involved in patient care would be able to share their reflections from the standpoint of their unique professional cultures. A polyphony of stories and voices which can weave multiple and contested narratives could shape a future where all voices are heard (Beigi, Callahan & Michaelson 2019; Cunliffe et al. 2012).

Boje and Baskin (2011) argued that the difference between an enchanted and a disenchanted workplace, is whether people experience a storied space which is supportive. Listening to each other's' clinical stories, personal observations and challenges faced by clinicians, can improve collaboration and subsequent patient care (Cohen & Stewart 2016; Rushton et al. 2009). Storytelling and re-enchanting the profession of mental health nursing could lead to cultural change and assist in attracting nurses to the profession, provide current mental health nurses with a more fulfilled working life and assist them in making the ignored populations visible.

Another related domain in which storytelling has been used to empower people is within the Recovery Movement. Connecting with peoples' stories of their lived experience of mental illness, is foundational to recovery principles. A way forward for leading cultural change for mental health nurses would be to have greater alignment with the recovery movement and being instrumental in finding hope, (Barker & Buchanan-Barker 2011), as opposed to mental health nurses being "an instrument of psychiatry" (Hurley & Ramsay 2008 p.15).

7.5.3 Philosophical alignment with Recovery Movement - A storied space of empowerment

As the principles of the recovery movement correlate with mental health nursing theory and the current standards of practice, a greater overt alignment with the recovery

movement would become philosophically and ethically coherent. I argue that there is a deep intertwining between the conceptual approaches of agapé, nursing spiritual care practices, the Mental Health Nursing Standards and recovery-oriented practices. When these conceptual connections are understood, strategies for the further development of the professional nursing culture and the empowerment of nurses to give voice to their practice can be created.

Figure 7.1 provides a snapshot of the overlapping elements of agapé, spiritual care practices, the Mental Health Nursing Standards, and recovery-oriented practice. Elements of these approaches in Figure 7.1 can also be seen in organisational re- enchantment theory, and in organisations that value spirituality, meaning, personal interaction and reflexivity (Suddaby, Ganzin & Minkus 2017). In this context, reflexivity is the “uniquely human capacity for creative insight and self-awareness” (Suddaby, Ganzin & Minkus 2017, p. 192).

Figure 7.1 Overlapping conceptual elements

Agapé	Spiritual Care Practice - Nursing	Mental Health Nurse Standards	Recovery Oriented Practice
Love, compassion alleviate spiritual suffering meaning - connection	Therapeutic use of Self	Therapeutic use of Self	Meaningful engagement - Connection
Mutual giving and receiving of love	Development of trust	Development of trust	Trustworthiness Reciprocity
Listening - active caring	Active listening	Active listening	Active Listening
Acceptance	Nonjudgmental	Nonjudgmental	Uses non-judgmental affirming language
Self-giving love	Unconditional acceptance of feelings	Unconditional positive regard, empathy	Demonstrates warmth, honest empathy
Fosters and maintains dignity valued human being self-worth	Respect, dignity, values and beliefs	Promotes dignity Respect Integrates cultural perspectives – spiritual needs considered	Respect values beliefs, culture and aspirations
Source of healing	Healing presence	Therapeutic relationship - a healing process	Culture of healing
Source of hope – source of strength	Exploring sources of strength and hope	Cultivates and holds hope	Instils hope - promotes a culture of hope – personal strengths
Source of meaning	Meaning centred intervention purpose	Recovery oriented practice – assist finding meaning	Meaning purpose choice
Source of unity and connection shared humanity	Partnership	partnership, professional intimacy	Collaborative Partnership
Ethical practice	Patient centred	Person-centred approaches	Person-centred Recognition that the individual is the centre of their care
		Reflective practice And learning	Reflection and learning

Sources: (Australian College of Mental Health Nurses 2013; Barker & Buchanan-Barker 2011; Commonwealth of Australia 2013; Eriksson 2007; Framework for recovery-oriented practice 2011; Ramezani et al. 2014; Rykkje, Eriksson & Råholm, 2015; Stickley & Freshwater 2002; Thorkildsen, Eriksson & Råholm 2013).

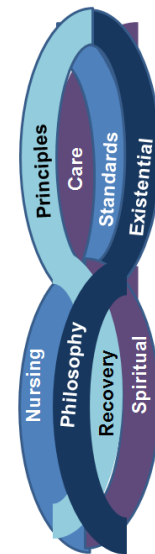
Contemporary mental health nursing theorists Barker and Buchanan-Barker (2011), recognise the connection between the Australian College of Mental Health Nurses Standards and the Mental Health Recovery approach. Due to the similarities between nursing philosophy and the ethos of the recovery movement, mental health nurses are well placed to lead collaborative recovery-based services (Hurley & Ramsay 2008; Raeburn et al. 2015; Scottish Executive 2006b). The literature review identified that recovery principles mirror aspects of existential philosophy.

Existentialism acknowledges the value of the individual's lived experience and the meaning, purpose and values individuals ascribe to their everyday lives (Chochinov 2006). Recovery approaches include the importance of finding hope, meaning and purpose in one's life. Similarly, the Results Chapter of this thesis concluded that there was also an interrelationship with recovery approaches and the spiritual care given by the nurses in the study. These concepts are braided together, to provide a visual overview of the interconnecting elements of the approaches (see Figure 7. 2).

The discussion chapter furthered this conclusion by emphasising the interrelationship between agapé, spiritual care, the mental health nursing standards and recovery principles. These intertwining concepts may be likened to a braid, where several different concepts overlap and touch each other.

This concept braiding is significant for the future of mental health nursing. The entwining philosophies and approaches demonstrate that spiritual care is an essential aspect of care within mental health services. Especially given that recovery approaches are espoused for mental health service by the National and State policy makers in Australia and for much of the Western world. This concept braid underscores that mental health nurses are not only required but are in an ideal position to continue providing spiritual care for individuals who have a life limiting illness.

Figure 7. 2 Conceptual Braid



The development of the professional culture of mental health nurses and the empowering of nurses to give voice to their spiritual practice, could be enhanced through a greater alignment with the recovery movement and joint sharing of stories. The values embedded within recovery principles such as deep listening, the illuminating of meaning and collaborative partnership is intertwined with the values, philosophy and standards of practice of mental health nursing. When mental health nurses listen to peoples' stories about their experience of mental illness, as opposed to acquiescing to the power of the dominant biomedical psychiatric discourses, they have greater capacity to understand and work with the individual's social and spiritual needs (Cutcliffe & Happell 2009). It is in the sharing of stories of adversity that human beings connect to one another in meaningful engagement (Cutcliffe & Happell 2009).

Summary

The data for this study indicated that mental health nurses were able to facilitate spiritual care for individuals facing death, despite the broader organisational culture of mental health services. Mental health nurses provided spiritual care through developing deep connections with their patient through the human-to-human relationship and engaging in spiritual conversations. Despite broader organisational pressures, the data suggested that nurses maintained their nursing agency and practised according to their nursing values. The ethos of the professional culture of mental health nursing, as well as nursing leadership, assisted the mental health nurses in facilitating spiritual care. Albeit at times, nurses needed to bend the rules, to make time to work with their patients.

This chapter highlighted the contrasting priorities of care between the practice field of mental health and palliative care nursing. Surprisingly, it was found that some palliative care nurses believed there was no organisational support for spiritual care and that the priority of care was physical symptom management. However, the similarities between the different fields of nursing were demonstrated in the feelings of deep fondness and

admiration for their patient who suffered both a life limiting illness and pre-existing mental health issue.

The literature review for this study found that spirituality is of high importance to this population. It is asserted in this thesis that considering the unique spiritual needs of individuals with a mental illness who are facing death is an essential aspect of high-quality person-centred care. Of concern, the current literature heralds the demise of mental health nursing in Australia. What would this mean for the spiritual care of a person with a life-limiting illness? What would be lost, if the profession of mental health nursing no longer existed?

It could be surmised that without the expertise of mental health nursing knowledge and skills, the now hidden/forgotten population will be further disenfranchised unless they are fortunate enough to enter a palliative care service that understands their unique needs. However, it was found in the background for this study, that individuals with a mental illness have less access to palliative services than the wider population. Moreover, it was evident that the organisational culture of mental health services was in crisis at the time of data collection. Some clinicians took on the cultural values of the corporate culture with a focus on 'core business' and 'episodic care' as opposed to their professional culture. A strongly held professional culture with an emphasis on person-centred care could counter a more corporate organisational culture. However, from the data collected within this thesis, the collective professional culture of mental health nursing was undermined by their own 'silence'.

It is crucial, if mental health nursing in South Australia is to survive, that there is a re-enchantment and strengthening of its professional culture. This re-enchantment and strengthening of the culture would require strong, visionary nursing leadership. Shared stories of resistance and resilience need to be told. It is through these stories that nurses can transform their own reality (Cope, Jones & Hendricks 2016). These shared stories articulate nursing practice. This articulation of practice can form the basis of professional reflective practice. 'Clinical reviews' could become a space for shared clinical reflection

and learning between all disciplines. In concert with the recovery approach these stories can promote a culture of collaborative engagement and trust. They can foster the elucidation of meaning and the instilling of hope. Thus, the spiritual care as offered by mental health nurses can be made visible and celebrated.

CHAPTER 8 - CONCLUSION

Introduction

This research journey began because I wanted to explore more deeply, the spiritual care needs of the patients that I cared for within my role as a mental health - palliative care nurse practitioner. Further, I believed there was a need to explore the spiritual care offered to these people within the culture of mental health services. In my experience of over forty years as a mental health nurse, I have had many conversations with patients (either impromptu or formal), that have centred on spiritual issues. It did not seem to matter if the person was experiencing a psychosis or not, spiritual issues were important. The literature confirmed my beliefs on the importance of spirituality for people with a mental illness. In the words of Russinova and Cash (2007, p. 279), individuals with lived experience of mental illness have a deep and finely nuanced understanding of spirituality.

The research question for this study was; 'how does the current culture of mental health services, support or hinder the mental health nurse's ability to facilitate spiritual care for individuals with a severe mental illness who are facing death?' To answer this question, this study examined the various layers of cultures within a mental health services in South Australia. These layers include the corporate, biomedical culture and the professional culture of nursing. The research explored how the layers of culture impacted upon the mental health nurse's ability to provide spiritual care, especially when the individual they were caring for had a life limiting illness. It was found that mental health nurses not only facilitated spiritual care but were also offering this dimension of care.

In the light of data from this thesis, the following section of the chapter will discuss how this thesis has made an original contribution to existing knowledge. It will consider aspects of culture that were either a barrier or an enabler of spiritual care. This chapter will then offer reflections on my personal values and beliefs that may have influenced the research, and how the research has influenced my practice. This chapter will also discuss the

strengths and limitations of the study, including the strength of interviewing palliative nurses alongside mental health nurses. Lastly, this chapter will discuss the limitations of the research and argue the practical implications for informing education, policy and further research.

Original contribution to existing knowledge

Previous studies have highlighted the importance of the spiritual dimension in therapeutic engagement with an individual with a mental illness (Huguelet et al. 2006; Koslander, Lindström & Barbosa da Silva 2012; Nolan et al. 2012; Webb et al. 2011). The literature is also replete with studies arguing the importance of spiritual care with patients who have a life limiting illness (Daaleman et al. 2008; Delgado-guay et al. 2011; Edwards et al. 2010; Hughes et al. 2008; Pearce et al. 2012; Winkelman et al. 2011). However, thus far there have been no studies specifically exploring the spiritual care of people with a mental illness who were facing death from a life limiting illness, living within community and inpatient settings. Nor has there been any research examining the organisational structures and system factors that impact on patient care (Donald & Stajduhar 2019).

Denzin and Lincoln (2011) pointed out that the purpose of ethnography is not to find timeless truths but to capture certain moments in time. In this spirit, within this study I have discovered moments of significance which assisted in the generation of knowledge. Ethnographies offer interpretive explanations of what people believe and how they act within a particular time frame and location (LeCompte et al. 1999). I have offered a snapshot of a moment in time in a specific context and culture.

Barriers and enablers of spiritual care within the organisational culture

Government reports highlighted that the culture of mental health services in South Australia was in crisis at the time of data collection and the power dynamics within the organisation privileged the biomedical paradigm and the bureaucratic corporate culture.

Mental health nurses reported that they felt disempowered, and some senior nurses felt reluctant or indeed silenced and unable to articulate their nursing practice within 'clinical reviews'. One mental nurse did not attend 'clinical reviews' within the ward she was practicing. In these instances, shared reflections on clinical practice did not occur within the context of 'clinical reviews'. Hence, their nursing spiritual care was not reviewed, and a culture of learning and safety was not fostered.

However, despite a lack of organisational support, the data revealed that within the subculture of mental health nursing, the unique spiritual needs of the individuals were attended to. Also, the values of nursing which are inherent in nursing theory, such as the therapeutic relationship, underpinned clinical practice. Within the professional culture of mental health nursing there was a sense of agency through which they were able to make time for spiritual care. The interview data suggested that within the culture of nursing, described as the 'Sphere of Nursing', nurses were able to have conversations regarding spiritual matters with their patients, even if the person was experiencing a psychosis. It was found that nurses had developed deep feelings of fondness and admiration toward their patients and it was suggested that these feelings were aligned to agapé and a sense of being privileged. Inherent in these feelings of privilege, admiration and fondness, are the elements of nursing culture that values the 'other' as a unique human being which is integral to the concept of 'alterity'. The enactment of 'alterity' supported the nurse's spiritual care.

Support for spiritual care through the practice of 'Alterity' - a dimension of the professional culture of nursing

Within both the methodology and discussion chapters of this thesis, it was suggested that 'alterity' or understanding the 'other's' point of view rather than 'strangeness', was prerequisite for both the research methodology of focused ethnography and the practice of spiritual care. Through my research journey I have gained a greater understanding of 'alterity'. In traditional ethnographies, the subject of the ethnography is the 'stranger' or the

'other'. Knoblauch (2005) argued that when the study participants and ethnographer hold the same cultural knowledge, the concept of 'alterity' could provide a common backdrop for understanding the culture. This concept of 'alterity' enables the researcher to further understand the 'others' point of view (Knoblauch 2005) and is also an important dimension of spiritual care. Although Knoblauch (2005) was using the concept of 'alterity' in relation to the focused ethnography, I also found this concept useful when analysing data from both the focused ethnography and the autoethnography, especially when analysing the participants' stories of care. These identified a deep understanding and feelings of privilege within the encounter with an 'other'. It is within this field of deep seeing of the other, that agapé and alterity are linked. It is in this field that spiritual care and healing occurs.

Although mental health nurses were practicing in a culture of crisis and palliative care nurses were practicing in a culture in which they found the provision of spiritual care difficult, both sets of nurses expressed feeling honoured and privileged to be able to care for individuals with a lived experience of mental illness who were facing death. Nursing philosophy and theory was reflected in the spiritual care the mental health nurses provided in this study. Nursing values such as compassion and kindness were intrinsic motivators and supported the nurse's ability to provide care, despite working in a broader culture that largely did not value such care. Also assisting in the provision of spiritual care was the recognition by mental health nurses that the strength embedded in a person's spiritual beliefs could be used therapeutically. The ACMHN (2010) standards maintain that mental health nurses offer a holistic approach to care that includes spiritual care. This holistic care is important as it aligns with recovery approaches which are mandated as the cornerstone of mental health service delivery within Australia (Commonwealth of Australia 2013; Department of Health 2011).

Reflections on personal values and beliefs that may have influenced the research

I made several assumptions when embarking on this research journey. The subjectivity of the researcher's values needs to be considered as an aspect of the research (Morse & Field 1996). As argued in the methodology chapter, it is important to reflect on and make transparent my values and beliefs as they may have influenced the interpretation of the data (Cruz & Higginbottom 2013). These personal values and beliefs will now be discussed.

Firstly, I value the concepts inherent in nursing theory and knowledge. This valuing of nursing theory came from my experience. Several years ago, I worked as a nurse educator teaching nursing theory. I chose to develop and teach this unit due to the fact that in my previous mental health nursing work, nursing theory gave me a way to articulate my practice with clinicians of other disciplines. Working within a solid nursing knowledge base, I had a nursing place within the multi-disciplinary team as opposed to working within the knowledge base of another discipline.

The ethnographer's emotional states add another layer to the research and personal experiences are not on the margins, but an essential aspect of ethnography (Angrosino 2005). Hence, with my belief that nursing knowledge and skills are essential aspects of patient care, I feel frustration and anger when the biomedical paradigm is privileged within mental health services. I believe this paradigm should be only one voice amongst many voices. Secondly, the valuing of spirituality in my own life not only influenced the research question but possibly my interpretation of the data. Explicitly, my belief is that all religious traditions provide a colourful and varied backdrop through which human beings find meaning, joy and hope. This meaning, joy and hope can also be found through art, beauty and loving connections. These connections can be toward other humans, the land, animals or whatever else a person feels is a lovingly connection towards. My personal belief is that love and spirituality are intertwined. Hence, when the palliative nurse spoke of 'love' I was drawn to this concept whereas someone without my values and beliefs may

not have been. Similarly, my valuing of human connection influenced my ability to see the fondness and mutuality within the 'Sphere of Nursing'.

How the research has influenced my practice

The research has influenced my practice in two predominant ways. The first is that every time I went into the 'clinical review' of another nurse, I asked this nurse what they brought to their practice and the care they were providing within a therapeutic context. The literature review reinforced my knowledge of the importance of the therapeutic relationship. I became frustrated when the nurses were not encouraged to discuss the interpersonal care they offer to their patients. Secondly, by reviewing the literature that stressed the importance of spiritual care, as well as the elements of this care, I felt more confident in my own spiritual care and my ability to articulate it.

Strengths and limitations of the research

Strengths

For this research I chose to combine the methodologies of focused ethnography with an autoethnography because my role of nurse practitioner in this area is unique within Australia. I believed that my experience (giving voice through an autoethnography) would add richness to the data. Also, from an organisational perspective, I was given the capacity to be with my patients for lengthy periods of time. This meant that they could explore their end-of-life issues, such as grief and loss, lack of hope, and fears of what their death means to themselves and their family. I was able to have conversations about end-of-life issues in a way that ensured that they did not feel rushed and at a time when they felt ready to talk about these issues. There was time for these spiritual conversations. My experience in being able to take the time to explore spiritual issues was also similar to the mental health nurses in the focused ethnography. Hence, the data from the autoethnography reflected the data in the focused ethnography. This combined data

strengthened the argument that mental health nurses had the time to provide spiritual care, even if this was not explicitly provided by their organisation. Within ethnography, mutuality and trust are necessary to gain access to the participant's world view (LeCompte et al. 1999). As a mental health palliative care nurse practitioner, I work across several mental health units, both inpatient and community. I have also spent time seeing patients with palliative nurses and see my patients when they are in the hospice. I believe that through my clinical work I have gained some access to the participants world view. This mutuality with the participants led to having trusting relationships through which nurses could talk to me openly about their experiences. This open dialogue enriched the research data.

Another strength of this research was interviewing the palliative nurses. I hoped that by interviewing both sets of nurses I would get a richer description of the different specialities, and how their unique cultures affected the spiritual care of people with a mental illness who were facing death. I also hoped that I would get an indication of the support the two groups of nurses received for spiritual care from their respective organisational cultures. I assumed that as spiritual care is a core clinical mandate of palliative services, the nurses would get support from their organisation and that the knowledge gained through understanding how the culture of palliative care services supported spiritual care, could assist mental health services in enhancing their provision of spiritual care. I further assumed that palliative nurses would be able to discuss the ways in which they provided spiritual care and that this care could be analysed against the data that described the ways in which mental health nurses provided spiritual care. However, my assumptions that palliative nurses would provide spiritual care including support by the organisation, was challenged by the data. The answers to interview questions given by the palliative nurses highlighted the disparate care priorities between the specialities.

Spiritual care is a core competency for palliative care nurses. As such, the differences highlighted in the results and discussion sections of this thesis regarding palliative care nurses feeling that they were not able to provide spiritual care, were concerning. Some

palliative care nurses within the interviews expressed frustration and sadness at their belief they were not sanctioned by their organisation to provide spiritual care. On the other hand, one of the senior palliative nurses highlighted the concept of love. She stated that the patient was 'loved here' (within the palliative care service) and that love could be seen in palliative care nursing. As argued in the discussion chapter, contemporary nursing theorists maintain that nursing practices are founded on love (Rykkje, Eriksson & Råholm 2015; Stickley & Freshwater 2002; Thorkildsen, Eriksson & Råholm 2013). Moreover, the data suggested that both sets of nurses practiced a form of agapé. An argument has been made that agapé is linked to spiritual care (Harrington 2006).

From the viewpoint of Freud who wrote, "[p]sychoanalysis is in essence a cure through love" (Bettelheim 1983, p.xi). However, the word love is a taboo in mental health nursing. These contradictions are significant as they illuminate the complexities and ambiguities within the cultures that are providing care. The data from the palliative care nurses is significant as there is a push from mental health services to discharge patients who do not fit the model of service provision. The supposition is that palliative services will provide care for these patients. Palliative services may provide excellent care, especially when their care is based on love. This research has suggested that all the nurses were offering spiritual care through agapé and alterity, which ran in parallel and paradoxically to the palliative care nurses who felt unable or reluctant to provide spiritual care. However, patients who have a lived experience of mental illness require spiritual care underpinned by deep listening which takes time and skill. Therefore, the patients would be without the essential spiritual care required for this unique population as they face the end of their life.

The data indicating that some palliative care nurses felt unable or reluctant to provide spiritual care raises a point which contrasts from literature reviewed in this thesis. The literature suggested that there was some difference between the spiritual care given within mental health services and the spiritual and existential care given by palliative services (Koslander, Da Silva & Roxberg 2009). Koslander, Da Silva and Roxberg (2009) argued that mental health care was provided from the biomedical paradigm, which is reductionist,

while palliative care is more holistic and explored the patients' spiritual needs. This study contests this assertion. In this study, spiritual and existential care were provided by mental health nurses, albeit invisibly and outside of the biomedical paradigm.

Another area from this research data that differs from the literature is that spiritual care can be provided in a short time frame. Caldeira and Timmins (2015) maintain that each moment can provide an opportunity for spiritual care. It is acknowledged that there can be differing depths of spiritual care and that all interactions with patients can have a spiritual component no matter how long or short the time frame. However, the data from both the autoethnography and the focused ethnography indicated that in-depth spiritual care takes time. Especially when the patient requires time to reflect on their circumstances, how it is affecting their lives and the lives of those close to them. This assertion arose through the data in the autoethnography which highlighted my experience of having the required time to facilitate spiritual care in an unrushed manner (Excerpt from the Autoethnography, Chapter 6, p. 23). It was also suggested in the interview data when the nurse took longer than necessary to do dressings so that she could provide specific, ongoing spiritual care for the patient (Chapter 6, p. 136).

The lack of time to provide spiritual care was of concern to the palliative nurses and contrary to the standards of palliative care service provision (Palliative Care Australia 2018). Furthermore, within the literature review it was identified that it is an ethical issue when a health professional does not have the necessary time to provide spiritual care (Daaleman et al. 2008). As the data from this thesis is from a small cohort and only from one region of South Australia, further research needs to be carried out to identify if palliative care nurses in other locations believe that they do not have time for spiritual care.

Limitations of the research

This study had several limitations. It was a small study, undertaken in one area of South Australia. Therefore, issues such as nurses not articulating their practice and the patient with a life limiting illness being rendered invisible, may not be occurring in other mental health services elsewhere. However, this study could be a cautionary tale to other mental health services and even palliative care services.

Some participants chose to be interviewed because they had an interest in spiritual care. This factor may have influenced the data as those who were not interested in spiritual care may not have come forward to be interviewed. Hence, the data and outcomes may not be an accurate representation of all mental health or palliative care nurses.

Within the autoethnography none of the patients discussed were from Indigenous, Muslim or Asian backgrounds; meaning that the findings offer no new knowledge in regard to these populations. It could be theorised that these populations are even more hidden.

Difficulties in the research journey

I have argued in the methods chapter that within ethnography, data collection and analysis need to occur simultaneously and that researcher should not wait until all the interviews are completed to commence data analysis (Ellis, Adams & Bochner 2011; Kuper, Lingard & Levinson 2008; Morse & Field 1996). However, as I was working full time through the interview process, I was unable to find the time to start my data analysis before another participant was booked in for an interview. I analysed much of the data at one time. However, had saturation not occurred I would have undertaken more interviews. In addition, with the help of my supervisors, I was able to reflect on my interview style which meant I was able to collect richer data. Initially, I finished the participants' sentences as a way of clarification and affirmation. My interview style was more like a counsellor than a researcher. I learnt that for clarification, all I had to do was to ask the participant if they could elaborate on their responses.

Recommendations for education, leadership and policy development

This section will offer recommendations for education, leadership and policy development aimed at effecting cultural change and addressing issues found in the thesis. The literature review identified that there was a need for spiritual care for individuals with a mental illness who are facing death. It was also identified that these individuals would like mental health services to continue their care (Sweers et al. 2013). In addition, the literature has identified that this population frequently fall through the cracks when using services (Jerwood et al. 2018; McNamara et al. 2018).

Reimer-Kirkham et al. (2016) argued that palliative care is often provided informally by community-based organisations. Moreover, this care often goes unrecognised. This lack of recognition is mirrored within care given by mental health nurses interviewed for this thesis. Further, the data from the thesis indicated that this population has been largely invisible within the broader organisation. Hence, there is a need for the organisation of mental health services to recognise these issues and provide appropriate services. In addition, the effect of the dominant biomedical culture was the disempowering and silencing of the nursing voice in the care of this population. As a result, suggestions will be made from an educational, leadership and policy perspective on effecting organisational cultural change which can empower nurses and assist them in regaining their voices.

Cultural change through education and leadership

Education

As Pesut and Sawatzky (2006) point out, education needs to be provided to ensure ethical and competent spiritual care. A recent study by Mamier, Taylor and Winslow (2019) found that when nurses had some form of education in spiritual care, they were more likely to practice it. This finding demonstrates that mental health nursing education providers need to offer education on how to carry out a spiritual needs assessment and

develop the student's spiritual care knowledge and skills. The EPICC Standard developed for pre-registration nurses was based on a consensus work exploring spirituality and spiritual care across 21 countries in Europe and explored the core skills knowledge and attitudes required for offering spiritual care (Leeuwen et al. 2021). Although this education tool was developed for pre- registration nurses, these competencies have had promising results for professional development in several areas of healthcare (Leeuwen et al. 2021; McSherry et al. 2020). Research based on the EPICC standard has developed competencies that focus on what is important to people, and as such fit with current person centred care models of healthcare. These competencies have the potential to influence education, policy and further research (McSherry et al. 2020).

This study found that mental health nursing culture reflected elements of nursing theory, such as valuing therapeutic connection within the human-to-human relationship. This knowledge can affirm the importance of having nursing theory within the mental health nursing curriculum. Recent literature exploring the care of people with both a life limiting illness and mental illness has revealed that both mental health and palliative clinicians have reported that they believe their care of this population would be enhanced if they were provided with education and collaborative training opportunities (Cobb, Dowrick & Lloyd-Williams 2012; Donald & Stajduhar 2019; Evenbij 2016; McNamara et al. 2018; Morgan 2016). Therefore, both undergraduate and post graduate curricula need to offer education on how to recognise, advocate and deliver care to this population.

The results indicated that the discourse of the dominant biomedical culture had the effect of mental health nurses feeling unable to articulate their nursing practices. This cultural effect needs to inform mental health nursing education in South Australia. Educators need to consider methods of education that will provide mental health nurses with the confidence to articulate their practice within other paradigms, so that their voices are heard and their practices are made visible.

Shared reflection can create learning environments that lead to safe, higher quality practices and can contribute to advances in nursing knowledge (Picard & Henneman

2007). The development of collegial learning spaces in which nurses and medical practitioners share educational and practical experiences would be useful in engendering cooperation and communication between the disciplines (Darbyshire & Ion 2018; Rushton et al. 2009). Similarly, shared reflective sessions between nurses, psychiatrists and allied health professionals in which they discuss their therapeutic work from a discipline perspective, would enhance understanding and provide multiple clinical perspectives that in turn could affect cultural change that does not have the effect of silencing the nursing voice.

Organisational cultures and storytelling are inextricably linked. Shared stories consisting of multiple voices can create understandings about the clinical episteme of other disciplines. Hence, storytelling spaces where all clinicians can talk about their therapeutic interventions and their concerns can provide an environment of shared support, as well as opportunity for reflective practice that can enhance clinical practice for all disciplines. Narratives from people with a lived experience of mental illness are essential to this polyphony of voices. The understanding and acceptance of various and at times contradictory paradigms, where different meanings are revealed, can lead to colourful and enchanted workspaces. Redinger (2020) argues that psychiatry is an enchanted discipline when it focuses on interpersonal relationships that are grounded in respect and compassion. This focus needs to continue for it to remain enchanted (Redinger 2020). Joint reflective sessions could assist the development of an organisational culture where spiritual care can be openly discussed, enhanced and evaluated.

Nursing leadership

The interview data indicated that the nursing culture was supported to provide spiritual care through nursing leadership. Mental health nursing leaders would continue to develop a culture in which nurses are supported in their spiritual care by focusing on the cultural structures and processes of the organisation that are either a barrier or an enabler of this

care, and through the development of approaches that improve and evaluate spiritual care delivery (Daaleman 2012). They can also continue to inspire nurses to articulate and develop spiritual care practices. In addition, nursing leaders can further develop a sense of agency in nurses through the facilitation of reflective spaces where stories can be told and where the future of mental health nursing can be shaped (Beigi, Callahan & Michaelson 2019; Boje & 2011; Gabrielsson et al. 2016; Picard & Henneman 2007; Tye-Williams & Krone 2015). Nursing leaders can assist nurses to recognise and take responsibility for being complicit in undermining their profession by their own silence and disempowerment. Nurse leaders need to work alongside nurses to develop a strongly held professional culture of nursing which is recognised and valued.

Policy

Donald and Stajduhar (2019) highlight that the most glaring gap in the literature regarding people with a severe mental illness facing death is that systems-level issues have not been addressed. This thesis found that people with a life limiting illness were not visible within the bureaucratic corporate culture of local mental health services. Furthermore, other studies concur that a siloed approach to care exists in which extremely marginalised people, such as individuals with a mental illness facing death, often fall through the cracks in service provision (Jerwood et al 2018; McNamara et al 2018). Therefore, both mental health and palliative care services need to work collaboratively to optimise care for these individuals (McNamara et al. 2018).

There is also a lack of policies and guidelines addressing care requirements of people with a mental illness who have a life limiting illness (McNamara et al. 2018). These policies and guidelines need to include strategies for timely and appropriate care (Butler & O'Brien 2018). Services for this population need to be shaped according to their unique care needs. As spiritual care has been emphasised as a predominant need for individuals with a mental illness, this form of care needs to be included in care plan design.

Further Research

Research in other areas of Australia and the world, would assist in finding out whether the results of this study were unique to this region of South Australia. Further research needs to be undertaken with palliative care nurses to ascertain the barriers to providing spiritual care within their organisation.

In addition, there needs to be further research exploring the patient's experience of living with a life limiting illness from their perspective, what they believe their spiritual needs are and how they can best be met by both mental health and palliative services (Ledger & Bowler 2013; Mamier, Taylor & Winslow 2019; Selman et al. 2018). Moreover, future research must include the voice of individuals with a mental illness (Donald & Stajduhar 2019; Jerwood et al. 2018)

Summary

The 'human-to-human therapeutic relationship' is at the core of mental health nursing practice. This study indicates that mental health nurses can use the skills and knowledge inherent within this relationship to attend to the spiritual needs of individuals who are facing death.

Within mental health services in South Australia the biomedical model privileges those clinicians who adhere to it and disempowers and silences the voices of others whose beliefs and values stem from different paradigms, including clinicians from other disciplines. Through articulating their care, as opposed to being silenced and disempowered by bureaucratic corporate management practices and the dominance of the medical paradigm, mental health care practices can be reflected upon, reviewed and developed. In addition, for mental health nurses, articulating their practice would assist in reclaiming their theoretical base and give voice to the healing potential inherent in their nursing skills.

In this research the nurse's silence rendered both the patient and the nurses' spiritual care invisible. This finding is significant as this group of patients is highly marginalised and vulnerable and their access to services is poor. It is now crucial that mental health services listen to the nurses' stories about their patient's experience and the care they offer them. It is also crucial that this population is considered in organisational planning. Moreover, it is imperative that strategies are put in place through which the voice of the individual who is facing death can be heard within the mental health services.

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APPENDICES

Appendix 1. Search strategy overview chart and strategy outline

Search Strategy overview chart

CINAHL–Mental Health 2003 to current Boolean /Phase	CINAHL Palliative care 2007 to current Boolean /Phase –	Medline Ovid SP 2003 to current Mental Health	Medline Ovid SP Palliative care 2007 to current
<p><u>Psychotic Disorders</u> or Major terms</p> <ul style="list-style-type: none"> Bipolar Disorder Paranoid Disorders Affective Disorders, Psychotic Disorders Schizoaffective Disorder and Psychosis <p>=8856</p>	<p><u>Spirituality</u> or Major terms</p> <ul style="list-style-type: none"> Spirituality Spiritual Care Assessing spiritual needs <p>=15437</p>	<p><u>Psychotic Disorders</u> or Search terms</p> <ul style="list-style-type: none"> Mood disorders Schizophrenia and disorders with psychotic features <p>=11,791</p>	<p><u>Spirituality</u> or Search Terms</p> <ul style="list-style-type: none"> Religion <p>=5,184</p>
<p><u>Spirituality</u></p> <p>Spiritual care or spiritual distress or spiritual wellbeing or spiritual support</p> <p>=12,577</p>	<p><u>Palliative Care</u> or Major terms</p> <ul style="list-style-type: none"> Hospice Palliative Nursing <p>=13,426</p>	<p><u>Spirituality</u> or Search term</p> <ul style="list-style-type: none"> Religion <p>=5,184</p>	<p><u>Palliative Care</u> or Search Terms or</p> <ul style="list-style-type: none"> Palliative Care Adult, Terminal care <p>=2687</p>
<p>Combine searches</p> <p>= 63 articles</p>	<p>Combine searches with AND</p> <p>= 69 articles</p> <p>= 30 After abstracts</p>	<p>Combine searches with AND</p> <p>= 29 articles</p> <p>=16 after abstracts</p>	<p>Combine results with AND</p> <p>=80 articles</p> <p>After abstracts = 27</p>
	<p>Final –</p> <p>palliative care =13,475</p> <p>spirituality =15,466</p> <p>combine with AND =48</p> <p>Then combine Palliative Care 13,475 combine Psychosis = 8,856</p> <p>=7 - after abstracts = 1 relevant</p>		<p>Final –</p> <p>Palliative Care Or -Search term</p> <ul style="list-style-type: none"> Terminal Care <p>=15,968</p> <p>Combine palliative care 15,968 and psychosis- =11,652 =19 after abstracts</p> <p>= 2 relevant</p>
	<p>then all with spirituality</p> <p>= 0</p>		<p>Combine all searches with AND spirituality</p> <p>= 0</p>

Search Strategy Outline

The first search on CINAHL search for the literature on ‘psychotic disorders’ and spirituality.

The search was from 2003 to 2013. The major search terms used were “Bipolar Disorder” OR “Paranoid Disorders”, OR “Affective Disorders”, OR “Psychotic Disorders”, OR

“Schizoaffective Disorders” OR “Psychosis.” This search yielded 8856 items. The search terms for spirituality were “Spirituality” OR “Potential for Enhanced Spiritual Well Being” OR “Spiritual Care” OR “Spiritual Comfort” OR “Spiritual Distress” OR “Spiritual State Alteration” OR “Spiritual Support” OR “Spiritual Well-Being” OR “Psychological Well-Being” Spirituality yielded 12,577. The searches were then combined yielding 63 articles.

The second search was to review the literature on the issue of spirituality in palliative care. The first step in the search reviewed articles on spirituality. The Major terms were “Spirituality”, OR “Spiritual Care”, OR “Assessing Spiritual Needs”. As the area of spirituality in palliative care is a burgeoning field several filters were used. These were English Language; Blind Peer Reviewed; Journal Article; Adult: 19-44 years, Middle Aged: 45-64 years. This search yielded 15,437 papers. Palliative Care or Major terms were “Hospice” “Palliative Nursing”. This component of the search yielded 13,426. I then combined the searches on spirituality and palliative care. This search generated 69 articles and after reviewing abstracts, 26 articles remained as 43 were not relevant.

To enable the author to find articles relating to people with a mental illness and a life limiting illness, I did a third search on CINAHL and then combined a ‘Palliative Care’ search with 13,475 articles and a ‘Mental Illness’ search with 8,856 and produced a total of 7 articles which explored issues relating to palliative care and mental illness and after reviewing the abstracts 2 relevant articles remained. These articles were combined with the articles on “Spirituality”. Again, no research literature found on spirituality, mental illness and end of life care.

In the first search on Medline Ovid SP search, I looked for Psychotic Disorders using the Search terms “Mood disorders” “Schizophrenia” and “Disorders with Psychotic Features”. This search yielded 11,791 articles. I then searched the data bases for Spirituality and used the search terms “Spirituality” OR “Religion”. This yielded 5,184 articles. I then combined searches on Psychotic Disorders and spirituality and yielded 29 articles. After examining the abstracts on spirituality and mental illness and discarding those which were not relevant, 14 articles remained.

In the second search using Medline Ovid SP the I combined the last search on spirituality which yielded the 5,184 articles with a search on Palliative Care, using Search Terms “Palliative Care” or “Terminal Care” using filter “Adult” and which yielded 2,687. I then combined the results using “AND” which gave 80 articles and after reviewing abstracts I obtained 27 articles.

A final search for palliative care was undertaken which used the search terms “Palliative Care” OR “Terminal Care” was done which yielded 15,968 articles. These were combined with a search for psychosis yielding 11,652. I then combined these and after reviewing the abstracts 2 articles were relevant. I combined these with “AND” spirituality and 0 articles were found which meant there were not articles found at the time which examined the spiritual issues for people with a mental illness who suffered a life limiting illness.

After searching the CINAHL and Medline Ovid SP databases, the Scopus data base was explored, using the search terms “mental illness” OR “mental disorders” AND spirituality 2003 to 2013 - limited to articles and English and after discarding for duplications 3 further articles on mental illness and spirituality were found. Using the search terms “palliative care” OR “end of life” AND spirituality OR religion 2007 -2013 limited to articles and English, a further 8 new articles on spirituality at end of life were retrieved. The search query “palliative care” OR “end of life” AND “mental illness” AND NOT suicide 2003 –2013 was then used. No new articles were found. I then combined all Scopus searches and 0 relevant articles found on spirituality, end of life care and mental illness.

I also searched the ProQuest database for peer reviewed journal articles from 2003 - 2013 using the search terms “serious mental illness” AND spirituality and found a further 2 articles on and spirituality mental illness. A search was done using the search terms on spirituality AND palliative and no research articles were found. To ensure the search on mental illness, [palliative care and spirituality was complete, the PsycInfo on the OVID database (limits 2003-2013 was searched. The search was limited to peer reviewed journals - using the map search terms spirituality or religiosity OR religious beliefs OR spiritual care and combined with mental disorders OR serious mental illness and yielded 18 articles. After discarding for

not relevant and duplicates this search yielded no further research articles. Using the search terms “palliative care” AND spirituality 48 articles were found. However, again after reading abstracts for relevance and discarding for duplications 0 new articles were found. After a full reading of all the articles 44 remained on mental health and spirituality and 37 on palliative care and spirituality. All 81 articles are on the Matrix of Research Studies. However more articles were later found from going through research articles reference lists and ongoing searches.

Appendix 2. -Matrix of Research Studies

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Spirituality in mental health care Bellamy et al. 2007 Aim: Explore variables that predict the importance of spirituality in participants' lives. USA	N= 1835 Recruited from Consumer centred services – Club Houses and Consumer run drop-in centres. Multisite study.	Quantitative - Interview 53% or self-administered questionnaires 47%. Descriptive statistics. Then Binary logistic regression analysis.	Study revealed that two thirds of the participants rated spirituality as important in their lives and demonstrates the importance of spirituality for people attending Consumer run services.	Self - stated limitations of study include was exploratory, did not have a measure to assess level of spiritual involvement and did not define spirituality. Study Critique Although this was one of the earlier studies in this field - it had a limited review of the literature. Further, the researchers did not mention ethics approval processes nor did they mention how they ensured the safety and comfort of the participants.
Borras et al. 2010 Aim: 1. Comparison of clinician's use of religion or spirituality for coping in Geneva and Quebec 2. Explore if spirituality or religion is more important for their patients than clinicians. Switzerland and Canada	N= 57 MH clinicians and N= 221 outpatients of mental health services. Patients met the ICD-10 criteria for schizophrenia and other non-affective psychosis.	Mixed method Replication of study in Switzerland – Interviews- Huber's centrality scale, Positives and Negative Syndrome Scale and the Clinical Global Impression. Analysed using SPSS version 15.	<ol style="list-style-type: none"> 1. Clinicians in Quebec area had similar closer S/R than did the Geneva clinicians. 2. Clinicians and patients have divergent ways of experiencing religion. 3. Both sets of clinicians underestimated the importance of the R/S dimension in their patients' lives. 	Self – identified. Studies limited to 'Western' parts of the world. Differing clinical contexts such as ambulatory and hospital may have led to differences in patient typology. Study Critique Well rounded study – sound depth of literature review (albeit mostly findings from their own research). This study built upon existing knowledge and identified a gap in the knowledge as a basis for this study. - Cross referencing of data from different continents added depth to the finding and generalisability /confirmability to the findings.
Bussema & Bussema 2007 Aim: Build upon the work of the author's previous studies –It aimed to	N = 61 participants from mental health rehabilitation services.	Quantitative Survey.	A high proportion of participants - 71% - reported that their spirituality was important within their recovery process. It gave them a sense of peace, meaning	Self-identified Small sample size and the authors being affiliated with a faith-based agency –hence

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>explore the person with a mental illness's spirituality and faith and how these constructs impacted on their coping and recovery process – both adaptive and non-adaptive processes.</p> <p>USA</p>			<p>and purpose and provided a frame of reference for understanding their illness. It also assisted them feeling as if they were part of a trusted community.</p>	<p>perhaps biasing the participants responses being more positively toward effective religious coping.</p>
<p>Chiu et al. 2005 Aim: To investigate the treatment choices made by South and East Asian immigrant women who had a serious mental illness -in relation to unique spirituality – it also aimed to explore how these beliefs intersected with issues of gender and their cultural belief system.</p> <p>British Columbia</p>	<p>N =30 first-generation Asian immigrant women - Ages were between 26-67 years.</p>	<p>Qualitative purposeful sampling face-to-face, semi-structured interviews.</p>	<p>It was found that the women's ability to make choices were significantly entwined with their cultural and spiritual worldviews. The Chinese worldview has been dominated thousand years by Confucianism, Taoism, and Buddhism. In addition, they experienced limited options due to their gender roles and other related issues, issue as roles within the family - such as mothering in tandem with having a mental illness and issues of stigma, discrimination and limited access to services.</p>	<p>Self-identified Small sample size. The interviews were carried out by representatives of conventional medicine and hence the responses may have been biased. Issues of translation may have created discontinuities of meaning.</p>
<p>Cornah 2006 Aim- to explore the impact of spirituality on people with a mental health problem.</p> <p>London</p>	<p>Report written by the UK Mental Health Foundation.</p>	<p>Literature Review</p>	<p>There is a link between mental illness, trauma and spirituality and post traumatic growth. Many clinicians either ignored patients' spiritual beliefs or saw them as pathological.</p> <p>Hope meaning and comfort may be found in spiritual practices Increased social support from religious or spiritually based organisations families or groups.</p>	<p>NA Not a research study. However, this government document contained valuable information for this thesis.</p>
<p>Corrigan et al. 2003 Aim: Determine whether religiousness or spirituality provides similar benefits for people with a psychiatric disability to those of the general population.</p> <p>USA</p>	<p>N =1,824 People with severe mental illness and significant functional disability resulting from the MI. Participants were from Consumer Operated Services. Multisite study.</p>	<p>Quantitative Self-reported interview-based measures. The Recovery Assessment Scale, Quality of life Interview, Hearth Hope Index and the Empowerment Scale, Hopkins symptom checklist, Addiction Severity Scale, Mental Health Statistical Improvement Program Consumer Survey.</p>	<p>Spirituality and religiousness were positively associated with increased wellbeing and diminished psychiatric symptoms and the person acting more effectively in their lives. Nil constant finding that there is a difference in outcome if the person self-identified as spiritual as opposed to religious. High rate 90% of participants who identified as spiritual or religious.</p>	<p>Nil-identified</p> <p>Study Critique Nil ethics approval noted. It does not seem from the paper that the participants were informed about the study or gave their consent. Nil limitations mentioned.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Curlin et al. 2005) Aim- to explore the religious characteristics of physicians and compare these to the general USA population. And to ascertain.</p> <p>USA</p>	<p>N =1,144 physicians completed the survey.</p>	<p>Quantitative Survey sent to 2,000 practicing physicians.</p>	<p>Physicians' religious characteristics differ from the general population In that they are more likely to regularly attend religious services. However, they are less likely apply their beliefs to other areas of their lives. And are less reliant on God for decision making.</p>	<p>Self-identified Incomplete representation of how religious beliefs are embodied.</p> <p>Study Critique Well-rounded study – engaged with previous research, method ie survey questionnaire matched research question. Researcher reflected well on study limitations.</p>
<p>Danbolt et al 2011 Aim: Assess the features and significance of religion and spirituality in people with a diagnosis schizophrenia, identify existential issues and describe possible relationship between R/S and psychopathology.</p> <p>Norway</p>	<p>N=31 individuals with a schizophrenia spectrum disorder.</p>	<p>Mixed method Interview questions were formulated out of discussion groups with MH 40 clinicians and developed further by scholars. Most question were quantitative i.e., yes, no answers - however the interviewed allowed for elaboration on questions by the participants.</p>	<p>Religion and spirituality were highly significant to the participants and had a positive influence in their life and ability to cope with their illness; Individuals with a faith in God were less likely to experience rumination on existential questions such as the meaning of life. There was a relationship between delusions, spiritual experiences and psychopathology.</p>	<p>Self-identified – limited sample -did not have statistical powered -no control group – however variables were internally consistent.</p> <p>Study Critique The development of their interview questionnaire did not include the input from people suffering schizophrenia – this could have added a more lived experience element to the questions. However, the article acknowledged the cross cultural differences in spirituality and religion and the existential questions that the person with a diagnosis of schizophrenia may face – They acknowledged that the diagnosis of schizophrenia might be outdated and so the researchers used psych- phenomena in their categories. Hence demonstrated sound knowledge and engagement with theory and philosophy.</p>
<p>Eeles et al. 2003 Aim: To elicit features of what MH nurses consider</p>	<p>N=14 mental health nurses. 7 male 7 female</p>	<p>Qualitative – Semi-structured interviews with</p>	<p>Nurses demonstrated a tolerance for ambiguity. They evaluated the patient's spiritual experience</p>	<p>Nil - identified</p> <p>Study Critique</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>important when interpreting and evaluating patients' spiritual experiences and how the nurse's own beliefs impact on their interpretation.</p> <p>UK</p>	<p>Convenience sample –nurses employed by single NHS service.</p>	<p>vignettes of spiritual type experiences – Based on Alistair Hardy Religious Experience Research Centre UK. Interviews lasted 60-90 minutes. Thematic analysis using Colaizzi's 1978 framework.</p>	<p>through the lens of the patient's values and beliefs. Nurses also used their own values and meaning to interpret and evaluate patient spiritual experience producing different evaluations of the patient's mental health.</p>	<p>The researchers did not identify their own limitations nor their methodology. They spoke very briefly about how they analysed the data. However excellent engagement with theory both in choice of study design and discussion on outcome.</p>
<p>Follow up study from previous Danbolt et al. 2011</p> <p>Hustoft et al. 2013 Aim: To add qualitative data to the Danbolt et al. 2011 study - thereby to describe and deepen the interplay between spirituality and psychosis and the understand how spirituality is experienced daily with Individuals with diagnosis of schizophrenia.</p> <p>Norway</p>	<p>Participants selected from the Danbolt et al's 2011 study original sample. The sample was purposefully chosen by the researcher – 3 participants who believed in God and 3 participants who believed in a Supreme Power</p> <p>N=6 Individuals with diagnosis of schizophrenia.</p>	<p>Qualitative Semi structured interviews Also use as triangulation – data from the interviews from the Danbolt et al 2011 study.</p>	<p>Patients described their spirituality of vital importance – were left alone in their spiritual struggles.</p>	<p>Self-identified Limited number of participants Study Critique The researchers did not identify the concept of saturation or if saturation was reached.</p>
<p>Fukui et al. 2012 Aim: Identify potential resources for assisting people with a psychiatric disability to reach their Recovery goals.</p> <p>USA</p>	<p>N=47 People over 18 with a severe and persistent mental illness were eligible. Six consumer run originations asked for participants using flyers and word of mouth.</p>	<p>Quantitative - Used the Spirituality Index of Well-being. Data was collected using an interventions workbook entitled Pathways to Recovery: A Strengths Recovery Self-Help Workbook, Spiritual Index of Wellbeing For convergent validity Rosenberg Self Esteem Scale was used.</p>	<p>Having a sense of control, attending religious activities and expanding social network can enhance spiritual wellbeing.</p>	<p>Self-identified Cross sectional design with small convenience sample – not randomised sample.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Gomi, Starnino & Canda 2014 Aim- Address the gap in spiritual assessment taking in MHS. USA	6 Clinician and service user focus groups- including 48 participants.	Qualitative	People with a lived experience of mental illness reported that spirituality gave them ways to cope with life, increase social support, to grow and to feel motivated. Clinicians added that for some individual's spirituality gave them ways to manage their symptoms and protect them against suicidality.	Self-identified Study participants were spirituality oriented as they opted to join the spirituality group - further research needs to occur with broader cohort.
Hefti 2009 Aim: to offer recommendations for integrating spiritual care into treatment programmes.	4 group programmes.	Book chapter – “Integrating Spiritual Issues into Therapy”.	Study highlighted the importance of spiritual history taking sensitive and inclusive understanding of patient’s spiritual beliefs. Individualised spiritual assessment.	
Huguelet et al. 2006 Aim: Spirituality of outpatients with diagnosis of schizophrenia - compared with clinicians – And the degree to which clinicians were aware of and able to discuss their patient S/R involvement. Switzerland	N=100 patients from Geneva’s four outpatient facilities – patients were aged between 18 and 65 And met ICD-10 criteria for a diagnosis of schizophrenia or other non-affective psychoses. N= 35 Clinicians Psychiatrists 19, Nurses 11 Social workers 5. N=1,561 Comparison sample of general population 1999.	Quantitative audiotaped interviews then Positive and Negative Syndrome Scale and the Clinical Global Impression were then administered. “Psychosocial adaptation was evaluated with axis V of DSM-IV. Subjective quality of life was evaluated with a visual analogue scale.	Religion important to the majority of patients and high levels of spirituality were important coping mechanism. Health professionals were less religiously involved than their patients Clinicians underestimated and neglects spirituality. Clinicians usually unaware of the conflict between patient's R/S - and MH treatment.	Self – identified Smaller number of clinicians than patients –especially social work numbers – Authors state this study should be considered as exploratory. From one particular culture in Switzerland.
Huguelet et al. 2007 Aim: To explore the relationship between religion and suicide attempts. Switzerland	N= 115 outpatients with ICD-10 criteria for schizophrenia or schizoaffective disorder N=30 inpatients without psychotic symptoms and met ICD-10 criteria for diagnoses of depressive or	Quantitative Semi-structured interview assessing religiousness / Spirituality. Past suicide attempts examined.	Religion was important for most participants -Most were involved in religious activities. 43% of participants with psychosis had a previous suicide attempt. 25% reported protective role and 1 in 10 reported an ‘incentive role’ of religion i.e., hope for something better after death -Religion played a role in restoring meaning and hope.	Self – identified The group of non – psychotic patients was small and different heterogenous-socio-demographic characteristics between groups. – Sample size lacks statistical power. Initial

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
	<p>anxiety disorders, personality disorders or substance dependencies who had attempted suicide.</p> <p>Participants were between 18 and 65 years of age.</p>			and exploratory findings.
<p>Kaplan et al. 2012 Aim: Community Participation as a factor in Recovery <i>(Not specific to spirituality –however relevant findings)</i></p>	<p>233 emerging adults and 1,594 mature adults.</p>	<p>Quantitative Ten areas of participation were examined: including friendships, intimate relationships, and engagement in religious/spiritual activities and their relationship with recovery, quality of life, and meaning of life.</p>	<p>Community participation which can include spiritual activities and having meaning in their life may be a predictor for wellbeing for young adults recovering from mental illness.</p>	<p>Self-identified Spirituality, was a more abstract concept than other domains of the study.</p>
<p>Koenig 2009b Aim: Discuss the relationship between anxiety disorders and religion. Canada</p>		<p>Review Article</p>	<p>Practices long been linked hysteria, neurosis delusions – mental pathology -However also psych and social powerful resource for coping with stress. Makes sense of suffering. -90% of world involved in spiritual practices. Religion and mental health closely aligned - monasteries history MH and moral treatment Charcot and Freud hysteria and neurosis – separation from religion. Define religion and spirituality –history of spirituality- No agreed definition. Role models in sacred writings as models of coping through suffering.</p>	<p>Nil -identified</p>
<p>Koenig 2009 a Aim: Book chapter discussing case studies on how spirituality and anxiety can interrelate and options for treatment. New Koenig 2009 not in original count. Canada</p>			<p>Assess whether patient finds comfort or is distressed by spiritual beliefs.</p>	

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Koenig 2012 Aim: Offer an overview of studies both mental health and physical health and their relationship to religion/spirituality.</p> <p>Canada</p>	<p>Review of 3,300 articles.</p>	<p>Literature review of quantitative literature between 1872 and 2010.</p>	<p>Many studies indicated that religious /spiritual beliefs significantly assist in coping with stress and adaption to health problems. Most patients with mental health issues and palliative care patients have unmet spiritual needs.</p>	<p>Nil -identified</p>
<p>Koslander et al. 2005 Aim: Describe nurses' conceptions of how spirituality is addressed within the nurse patient relationship.</p> <p>Sweden</p>	<p>N=12 mental health nurses from 6 different wards from different clinics across southern Sweden – to ensure a broad sample –different informant variables such as age, experience and education, were selected. Participants reflected the general composition of the population of nurses.</p>	<p>Qualitative – Phenomenographic approach. Interviews.</p>	<p>Three descriptive categories were found. 1.Recognising the spiritual dimension 2. Being a good carer 3. The difficulty of capturing the spiritual dimension within NP relationship</p>	<p>Nil -identified</p> <p>Study Critique Even though the study interviewed 12 nurses, the researcher believed they had reached saturation after analysing 8 of the interviews, as no new subcategories of meaning had arisen. This study used a strategically chosen broad sample of nurses to ensure that the study reflected the population of nurses and increase the applicability of results. Yet the article did not discuss if there was a differentiation between the educated mental health nurses and those nurses with a basic nursing qualification when looking at the results of the data. This differentiation may have been useful in understanding if the mental health nurse's education had an influence on their ability to provide spiritual care. The study engaged with theory and the research design was robust, thus enabling the research to build on previous knowledge. The review of the literature</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
				stressed the importance of the connection between spiritual care and the expression of love. This aspect of spiritual care was congruent with the discussion on the data.
Koslander et al. 2007 Aim: Describe patients' conception of how spiritual issues are addressed in the mental health services. Sweden	N=12	Qualitative– Phenomenographic approach. 2nd order perspective explores how phenomena appears to the person.	Patients wish to have their spiritual needs addressed. Patients actively seek assistance from nurses and patients lack confidence in discussing spirituality with nurses - participants found spiritual community with other patients.	Self – identified Small sample size from one area in Sweden – self identified data which cannot describe actual nursing care given.
Koslander, Da Silva & Roxberg 2009 Aim: a review exploring whether patients' needs are holistically addressed in Western health care system as little research had been done exploring the negative relationship between spiritual experiences and mental health. Sweden		Review of research	Discusses the existential needs and spiritual needs and how these needs relate to the person's mental health and well-being.	NA
Koslander et al. 2012 Aim: Describe the meaning of patient's spiritual experience and how this impact on their MH care Sweden	N= 32 narratives collected from Williams James book 1956 -"the varieties of Religious Experience.	Qualitative - Hermeneutic interpretation inspired by Gadamer's work.	Confirmed the importance of having faith, to give and receive forgiveness, to hope and to experience the power of love. The authors argue that great suffering can occur from negative spiritual experiences -The terror of the dark side can damage the whole person.	Nil -identified
Ledger & Bowler 2013 Aim- to determine staff training needs in issues of spirituality. Great Britain	Initial survey 131 mental health clinicians.	Initial survey to inform training programme on spirituality in Recovery - post training evaluation.	Spirituality is important to holistic care in MHS and although spirituality is important for recovery –Although clinicians acknowledge the importance of spirituality it is often neglected by clinicians, Training is important	Nil -identified

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Mohr et al. 2010 Aim: Explore the relationship with religious coping and religious delusion in people with schizotypal disorders.</p>	<p>N=236 Outpatients with schizophrenia or schizoaffective disorders.</p>	<p>Mixed method Pooled data from the Quebec and Geneva studies – Previous - Borras et al. (2010).</p>	<p>for clinicians to develop confidence and people with a lived experience mental illness could be involved in this training.</p> <p>Patients with delusions that contain religious content do not have a worse clinical picture than patients with non-religious delusions –However they are more antagonist to MH care and receive less support from religious communities. Relationship between delusions and religion may not be pathological. -Religious content may not be a marker of more severe pathology.</p>	<p>Self –identified Lack of longitudinal data to show how religious content may vary over time. Lack of cross-cultural contexts. Study Critique Not much definition of spirituality- not much discussion on non-theistic spirituality.</p>
<p>Mohr et al. 2011 Aim: Does religiosity remain stable over a period of time.</p> <p>Germany</p>	<p>Follow-up up study - Huguelet et 2006 - 3 years post initial study 20 % dropped out.</p> <p>N= 115 outpatients with ICD-10 criteria for schizophrenia or schizoaffective disorder. Participants were between 18 and 65 years of age.</p>	<p>Mixed Method Longitudinal Study Positive and Negative Syndrome Scale (Kay, 1992, Clinical Global Impression (Guy,1978) and Global assessment of Functioning (APA, 2000) MINI (Sheehan et al., 1998) and semi-structured Interview allowed clinician to grasp participants S&R world view –range and intensity of practices and how these are used to cope with illness Visual Analogue Scale was also used in interview cc cv 30-minute interviews.</p>	<p>Religion was stable for 63% of patients Positive for 20% negative for 17%. The study shows that helpful use of spirituality is predictive of a better outcome. For the majority of participants religion gave meaning hope and comfort and assisted coping. 11% identified and antagonism between religion and medication. 12% antagonism toward supportive therapy Harmful N=13, Helpful N=76 fewer negative symptoms for participants with higher importance of spirituality in daily life and better outcome of negative symptom –meaning in life was associated with higher quality of life.</p> <p>N=3.No religious interests</p>	<p>Self – identified No blind dependant variables. Gross differences in sample sizes. between helpful vs. harmful use of religion limited statistical power. One region of Switzerland. Did not measure mood at baseline and therefore did not have the possibility to check whether or not positive and negative mood could have had an influence on outcome.</p>
<p>Mohr et al. 2012 Aim: To assess the importance of religious or spiritual coping for individuals with severe mental illness across three countries.</p>	<p>N= 276 - outpatients with a diagnosis of schizophrenia or schizoaffective disorder</p>	<p>Mixed method Semi structured interviews and questionnaires.</p>	<p>- Religion was helpful for most participants and was associated with better overall functioning. However, for 10% religion was a source of suffering. -Patients with negative religious experience were more severely ill. --Patients</p>	<p>Self Identified - Different methods of sampling used across three sites. Cross sectional design did not allow for causality between</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Canada Switzerland and USA	<p>Aged between 18-65 years and duration of illness of more than two years.</p> <p>Participants = -92 from - Switzerland, -121 from Canada, and -63 from The United States.</p>		<p>who had either positive or negative R/S whose beliefs brought them into conflict with psychotropic medication has a poorer clinical status.</p>	<p>religious and clinical data.’ Small sample size of negative coping limited statistical analysis. Abstract gave an overview of all three studies however the paper was looking at the US and Canadian studies which became confusing. Also, there interchange between their terms religion and R/S was inconsistent. And also, that spirituality was subsumed under the notion of religion is going against the current paradigm. And no mention here of the differentiation between mental health and spiritual concepts and the notion of “contamination”.</p>
Moreira-Almeida, Koenig & Lucchetti 2014 Aim: to review current evidence re integration of spirituality into clinical practice. Brazil, USA Saudi Arabia.	<p>Review of 1,109 research papers.</p>	<p>Literature review.</p>	<p>Spiritual history taking improves health outcomes, compliance, and patient satisfaction with care.</p>	<p>NA</p>
Nolan et al. 2012 Aim: to explore the relationship between positive and negative religious coping on quality of life - no development disability coping. USA	<p>N=63 adults 18-65 years of age. Outpatients with a diagnosis of schizophrenia or schizoaffective disorder over the past 2 years.</p>	<p>Mixed methods- semi structured interviews surveys. Cross sectional study RCOPE, life - BREF data -</p>	<p>Most participant reported participating in both private 91% and public 68% religious or spiritual activities negative religious coping - lowered quality of life - numbers not significant in controlled model -However positive religious coping higher quality of life.</p>	<p>Self-identified The instruments designed for people with a diagnosis of schizophrenia, nor any culturally specific data.</p>
O’Connor et al. 2005 Aim: To assess pathognomonic significance of different religious believes - three hypothesis. 1. Mainstream religious beliefs: less likely to be considered pathological 2. Less pathological when identified as an ‘Article of Faith’ 3. Beliefs with high	<p>N=110 Mental health professionals.</p>	<p>Quantitative ‘Pathological Beliefs Questionnaire’ with vignettes with three different categories Catholicism, Mormonism, and the nation of Islam.</p>	<p>Clinicians viewed patient from a Catholicism faith as less pathological than other two sets of religious belief. The Nation of Islam beliefs were seen as significantly more pathological -these were not influenced by the issue of harm. Clinicians did not always follow DSM 1V manual for diagnosis.</p>	<p>Self-identified Authors identify limitations as a vignette not being the same as a clinical situation in which the clinician has more time for a detailed mental health assessment.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>levels of threat more pathological.</p> <p>USA</p>				
<p>Pesut et al. 2011 Aim: To systematically review empirical studies that explore the relations between individuals with a bipolar disorder and R/S.</p> <p>Canada</p>	<p>N=6 Systematic review of empirical studies.</p>	<p>Review conducted by multidisciplinary team –studies that addressed R/S as a major consideration were included or study contained clear sample of people with Bipolar Disorder.</p>	<p>R/S strategies may be important in the management of people with bi-polar affective disorder. R/S can adversely affect people with the disorder and may have potentially protective effects.</p>	<p>Self –identified Only English articles reviewed and reflect dominant culture. ie Spiritual experiences may be revered in some cultures and pathologised in Western culture. Small sample size.</p>
<p>Phillips and Stein 2007 Aim: To explore how young people with a diagnosis of schizophrenia or bipolar disorder, use religion for meaning making and coping with their illness.</p> <p>USA</p>	<p>N= 48 young adults with a diagnosis of serious mental illness.</p>	<p>Mixed methods semi-structured interviews and surveys.</p>	<p>The study found that some participants used aspects of religion that were considered healthy and were associated with personal growth and not loss, or distress. Their religious beliefs gave meaning to their mental illness. However, when participants believed their illness was a punishment from God the belief was a stressor that may hinder longer term adjustment.</p>	<p>Self –identified Small sample size Limited by self-reported data – it only looked at two aspects of religion and mental illness.ie meaning making and coping.</p>
<p>Reinert & Koenig 2013 Aim: Explore the current definition of spirituality and its limitation in nursing care. Propose a definition which will capture more accurately the role of spirituality for health outcomes</p> <p>Canada</p>	<p>searches from 2007–2011 - 20 articles</p>	<p>Literature Review Through search of Medline and CINAHL and Scopus</p>	<p>Current definitions of spirituality were ‘contaminated’ with mental health concepts. As such, these concepts in research confound mental health outcomes</p>	<p>Nil–identified</p>
<p>Revhiem et al. 2010 Aim: To explore differences, between patients who voluntarily attended spirituality group and those who did not attend and Recovery.</p> <p>USA</p>	<p>N=20 Group attendees N=20 Non group attendees All were in- patients of state hospitals diagnosed with schizophrenia One hour study session.</p>	<p>Quantitative, cross-sectional survey - using measures of demographic profiles, spirituality, self-efficacy, quality of life, and hopefulness, religiousness.</p>	<p>Significant differences between the groups The higher the self-reported spiritual status of attendee the more they felt they were able to deal with psychiatric symptoms.</p>	<p>Self –identified Study limited by quasi-experimental design - correlations cannot be interpreted as cause and effect.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Russinova & Cash 2007 Aim: Examined the meanings people with a serious mental illness attributed to the concepts of spirituality and religion. USA	N=40 purposeful sample selected from the participants of larger study who had a serious mental illness and had used alternative healing methods.	Qualitative - arm of a larger study exploring alternative medicine and recovery. In-depth semi-structured interviews.	People with a mental illness recognise the spiritual dimension in their lives and All study participants differentiated between what spirituality and religion meant to them participants who recognised the presence of a spiritual dimension in their lives had “a deep yet finely nuanced understanding of the concepts of religion and spirituality” p. 179.	Self-identified Participants may not reflect the usual cohort of people with a mental illness and maybe further along in their recovery journey as they had been actively seeking alternative healing methods predominantly from one religious faith - Christian.
Shah et al. 2011 Aim: to explore the relationship between spirituality and Quality of Life(QOL) in individuals with residual schizophrenia and to examine whether spirituality contributes to other domains, such as both physical and psycho-social QoL issues. India	N =103 participants who had residual schizophrenia.	Quantitative	Spirituality and religiosity significantly affected the QOL of individuals with residual schizophrenia. Hence, non-pharmacological management should be considered - Two domains. - Inner peace and spirituality significantly, contributed to QOL in all other domains.	Self-identified Purposive sampling was limited to a single subtype of mental illness from the outpatient services. Hence the results cannot be generalised to other patient populations
Smith & Suto 2012 Aim: Explored the meaning of religion/spirituality with people who have a diagnosis of schizophrenia. Canada	N=9 people living in the community -19 years or older with one of more hospital admissions for diagnosed with schizophrenia but not within 6 months prior to study – recruited from community mental health teams –use of McSherry and Cash’s (2004) continuum of individuals’ worldviews and spiritual language.	Qualitative – Hermeneutic, phenomenological , symbolic interactionism - dialogic approach used triad reflexivity (three-way dialog) – Bracketing using naivety and uniformed curiosity –Semi structured interviews.	Five core dimensions of spirituality were identified. Participants used religion or spiritual practice to assist them to cope with symptoms of their mental illness and find meaning. The development of the term “religious or spiritual agency”.	nil–identified
Starnino, Gomi & Canda 2014 same as above study – by Gomi Starnino & Canda different journal article.				
Sweers et al. 2013 Aim: To explore End of Life perspectives for	N=20 Individuals with diagnosis of schizophrenia aged	Qualitative Grounded theory.	Absence of fear of death - preserving Quality of Life – (in domains of physical, social,	Self-identified Small sample size and patients did not have a

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
people with schizophrenia. Belgium	between 35 and 65 years currently in remission.		spiritual and psychological) Existential wellbeing – meaning and skilled companionship were important at EOL End of life discussions reassuring and possibly therapeutic.	life limiting illness – no precognitive testing.
Walsh, McSherry & Kevern 2011 Aim: To evaluate the efficacy of care plans in capturing and making use of the information on the spiritual and religious issues of mental health service users. UK	N=71 service users	Quantitative Questionnaire and exploration of the same person's electronic records.	It was found that for many study participants spirituality and religion were important, however this information was not reflected in their electronic records. Or if it was recorded it was wrongly or wrongly nuanced.	NA
Webb et al. 2011 Aim: - Assess the relationship between religiosity and Recovery from mental illness – *Distress/struggle in relationship with God - *Disruption/tension within religious communities. USA	N=81, 43 female, 36 male, 2 unidentified, participants from mixed cultural backgrounds. Mixed severe psychiatric diagnosis.	Quantitative– Study measured Recovery, religious support, and struggle and endurance with faith. Questionnaires - 5-point Likert - type scale, Correlational analysis using Suffering with God scale.	Confirmed that there is a relationship between religiosity and mental health and that the relationship can either promote or hinder mental health outcomes. Religious support can assist in the 'struggle with God' and the recovery process. However, it was not confirmed that religious community support enhanced Recovery.	Self –identified Limited using of survey data –behavioural observation of participation will improve research. I.e., Questionnaires may have been challenging for some participants due to possible cognitive issues– Cross- sectional design limited interpretation of results. Study Critique The research paper did not define religiously, nor did it differentiate between religion and spirituality, even though the researchers highlighted that a 'spiritual struggle' with God can adversely affect the recovery process.

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Weisman de Mamani et al. 2012 Aim: Examines whether religion or spirituality should be incorporated into the treatment of people with a severe and persistent mental illness.</p> <p>New Zealand</p>	<p>N=3</p>	<p>Qualitative – Literature review Case studies</p>	<p>Spiritual practices provide people with a severe mental illness support and was a resource for them coping with their illness.</p>	<p>Nil-identified</p> <p>Study Critique Extensive engagement with the literature and theory – case studies relevant to literature and theory.</p>
<p>Wilding et al. 2006 Aim: 1. Contribute to the discussion on spirituality within mental health nursing. 2. Explore the meaning of spirituality for a person with a mental illness.</p> <p>Australia</p>	<p>N=6 -3 male 3 female aged between 40 and 60 years of age. Recruited via staff of two Rural Community Clinics.</p>	<p>Qualitative - Phenomenology using a Heideggerian philosophical approach. -Semi structured detailed interviews –use of open-ended questions. Length one and half hours.</p>	<p>1. Spirituality was unique to the person suffering a mental illness 2. Spirituality became vitally important to the participants when they became mentally unwell 3. Developing a mental illness can be a trigger for embarking on a spiritual journey 4. Spiritual beliefs can be life sustaining.</p>	<p>Self – identified All participants from Anglo-Saxon cultural background and from a similar age group. Mental health staff had control over recruitment process.</p> <p>Study Critique Although the researchers acknowledged the small sample size, hence the study was unlikely to reflect diversity. The researchers did not state whether saturation had occurred.</p>
<p>Young 2010 Aim: To examine how self-esteem in people with severe mental illness was affected by their spirituality.</p> <p>Hong Kong</p>	<p>N= 149 participants -community mental health service users.</p> <p>Ages were between 23-71years</p>	<p>Quantitate self-administered questionnaires.</p>	<p>Spirituality such as a closeness with the Transcendent can improve self-esteem.</p>	<p>Self-identified Small non-randomised sample small size.</p>
<p>Life limiting illness and spirituality</p>				

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Boston, Bruce & Schreiber 2011 Aim: To examine research that explores the existential and spiritual concerns of palliative patients - conceptual frameworks and interventions.</p> <p>Canada</p>	<p>Search yielded a total of 156 articles.</p>	<p>Literature review</p>	<p>There is a lack of consistency in the definition of existential suffering and how it is understood. Spiritual despair is one of the most debilitating conditions at end of life.</p>	<p>Nil-identified</p> <p>Study Critique This study looked broadly at the literature and included variations in focus from different parts of the world. It engaged well with the theories related to existential suffering and included the view of philosophers which given the focus of the review was on a philosophical concept ensured soundness of analysis.</p>
<p>Bruce et al. 2011 Aim: To understand the process of engaging with the patient suffering from existential concerns at the end of life.</p> <p>Canada</p>	<p>N=22 participants including patient's family and health care professionals.</p>	<p>Qualitative approach grounded theory approach.</p>	<p>Participants' definitions of existential suffering were a varied as in the literature. Existential suffering begins with a feeling of instability groundlessness which is anxiety provoking. Findings emphasise a fluid and dynamic of existential suffering. The language of the social is inadequate as it does not describe existential suffering whereas poetry and literature may.</p>	<p>Nil identified</p> <p>Study Critique Highly thought provoking paper. In critiquing this article, it met all the criteria for a sound research paper ie the use of grounded theory was well explained in relation to the research question which was a process question and therefore matched the new theories emerging the analysis of the data. Highly respectful of participants and again matching theory with data in that they did not give a definition of existential suffering but asked for a definition from the participants. The paper engaged well with theory and philosophy and highlighted the similar nature of their findings to the theorists. However, this paper did not discuss its limitations. This research article affected my clinical practice more than any other research article.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Chochinov 2006 Aim: Review the evidence on recognising and addressing spiritual distress at end of life.</p> <p>Canada</p>		<p>Evidence review – expert opinion.</p>	<p>The importance of meaning purpose and hope and how these can change in the face of a life limiting illness and death - Facing death can also provide the impetus for people to review their lives and to re-evaluate their values and meaning Psychiatric diagnoses such as depressive and anxiety disorders provide to narrow a framework to contain the broad spectrum of end-of-life distress.</p>	<p>NA</p>
<p>Cobb, Dowrick & Lloyd-Williams 2012 Aim: To examine the literature on what is known about the spiritual care requirements of patients receiving palliative care.</p>	<p>N= 35 studies.</p>	<p>Literature review</p>	<p>Spiritual care is significantly beneficial in palliative care setting and contributes to holistic care.</p>	<p>NA</p>
<p>Delgado-Guay et al. 2011 Aim: To examine the prevalence and intensity of spirituality, religiosity and spiritual pain and how spiritual pain was associated with symptoms, quality of spiritual life and coping.</p> <p>USA</p>	<p>N=100 diagnosed with advanced cancer - outpatient clinic –Median age 53 years- range 21-85 years</p>	<p>Quantitative</p>	<p>98% of participants identified as spiritual. -98% identified as religious.</p> <p>-spiritual pain was reported in 44% of patients</p> <p>–spiritual pain was significantly associated with lower self-perceived religiosity and spiritual quality of life.</p> <p>Spiritual pain contributed to physical and emotion pain, however not statistically significant after Bonferroni correction.</p>	<p>Self-identified Small sample size in specific geographic location - Cross sectional design makes the establishment causality impossible - High enrolment rate, did not collect data on people who declined to participate. - Uni - dimensional and quantitative so did not capture the complexity or qualitative nature of concepts. Prior discussion at clinic may have influenced participants. Study Critique Built on existing knowledge. Generalisability -</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
				Compared results to previously mentioned study found similar results in a different context. Researchers could have spent more time considering overlapping concepts such as spiritual pain and issues revealed from the EDAS and the HADs scales - ie differentiating between what was psychological pain and what was spiritual pain.
<p>Edwards et al. 2010 Aim: To synthesise qualitative literature on spirituality and spiritual care at the end of life to an understanding of these.</p> <p>Wales and Hong Kong</p>	N=11 patient articles N=8 articles with healthcare providers.	Systematic meta-study of qualitative research.	Barriers to care include lack of time. Lack of education, fast patient turnover space and lack of professional education -high emotional cost (compassion fatigue).	Self-identified Anglo Judaic background with cancer elderly unable to generalise to greater population.
<p>Egan et al. 2011 Aim: To investigate and understand the definition of spirituality and to understand spiritual practices within New Zealand's hospice care services.</p> <p>New Zealand</p>	<p>N=52 Semi structured Interviews –1. Patients with terminal cancer with prognosis less than 1 year. - 18 years and older –non-Maori. 2. Family 18 years and older –non-Maori. 3. Staff – Experienced with some knowledge of spiritual care. (Adviser consultation to study -patients and family needed to be non-Māori as 1st author does not have a Māori background) .</p> <p>N=642 National Cross Survey -18 years and older – non-Maori.</p> <p>Patients, family and staff from NZ's hospices.</p>	Mixed Methods - abductive Qualitative design and analysis to understand patients' experiences of spirituality and spiritual care – Survey gave sample-based understanding. 23 item FACIT-sp-ex.	Spirituality is a broadly defined concept – important and useful.	<p>Self-identified Selection bias was acknowledged. Only 1 hospital site was included in study. (seven hospices and one hospital oncology).</p> <p>Study Critique Exceptional engagement with literature –sound theoretical engagement Well-constructed and explained methodologies well-reasoned internally consistency with research design and research question.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Fegg et al. 2010 Aim: Compare 'meaning of life' (MiL) in palliative care with a representative sample of the general population. Germany	N= 50 palliative care patients -18 year of age or older, nil psychiatric illness or significant cognitive impairment.	Quantitative The authors developed the validated assessment instrument - Schedule for Meaning in Life Evaluation (SMiLE) validated in student populations -for assessing MiL in palliative populations.	Overall, the high importance ratings for MiL for palliative care patients were: family, partner, health, and spirituality.	Self-identified Respondent-generated listings were assigned to a priori categories.
Gielen et al. 2009 Aim: Explore the religious world views of Flemish nurses. Belgium	N = 415 palliative care nurses.	Quantitative Questionnaire.	Many Flemish nurses interested in religion and the majority believed in a transcendent power. Nurses in the study believed in personal choice.	Self-identified Study was not able to compare their results with other studies.
Hanson et al. 2008 Aim: Describe spiritual care received by patients and families and question the type of care and its relationship to satisfaction with care. USA	N= 38 Patients and N= 65 Caregivers from a variety of settings- patients recruited 2005-2006 -13 months duration –Both sets were asked about their spiritual care from caregivers.	Mixed Method Structured interviews using Donabedian's Quality of Care Framework plus two items screening for depressive symptoms and a Likert scale question on satisfaction and value of spiritual care - SPSS 15.	Most common type of assistance was in coping with illness 87% and least common was intercessory prayer 4%. Satisfaction is not related to who provided the care.	Self-identified Structured interview questions –more qualitative inductive may reveal more aspects to spiritual care. - Participants were from a single site –study combined patients and caregivers, Patient number small. Measures not based on conceptual framework of a standardised - validated tool.
Hughes et et al. 1 Aim: Examine the patient perspective on what is a "Good Death". USA	N=100 patients over 18 years of age diagnosed with lung cancer at a multi-disciplinary cancer centre.	Qualitative Cross-sectional design – interview data coded using SPSS V13.	Four central themes 1. Dying while asleep 2. Pain free 3. Peaceful 4. Quick.	Self-identified Question re 'Good Death' could have been expanded upon.

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Hui et al. 2011 Aim: To determine frequency of that spiritual distress and its relationship to symptom severity USA	N=113 patients from an acute palliative unit.	Quantitative Electronic chart review of assessed symptom severity using the Edmonton Symptom Assessment scale (ESAS) and spiritual distress identified by the chaplain on first visit.	44 % of patients suffered spiritual distress. These patients were more likely to be younger, in pain and depression.	Self-identified Small sample size and a retrospective data collection. The use of an assessment tool that had not been fully validated -first visits may be a full representation of spiritual pain.
Kandasamy et al. 2011 Aim: the influence of spiritual well-being on quality of life -including symptoms of distress and depression. India	N= 50 Patient above 16 years with an advanced cancer with not further curative treatment Patients with a bipolar major depression and substance abuse including alcohol was excluded.	Descriptive and cross sectional using various instruments.	The mean score of SpWB in this sample was 24.48... traditional and spiritual lifestyle of the patients, as has been reported for Indian subject ...suggests that spiritual wellbeing is a key component of the quality of life of advanced cancer patients and is closely related to the physical and psychological symptoms of distress. SpWB is closely correlated with both physical and psychological indicators of distress.	Self-identified Scoring may have been influenced by other factors such as mood at the time and environment factors. Personality factors were not assessed. No control group.
Kang et al. 2012 Aim: To investigate how the religious and spiritual needs of palliative patients form different faiths were being addressed by health care staff. And how spiritual care impacts on quality of life. Korea	N=98 Patients with advanced cancer 18 years or older 33 inpatient and 9 outpatient palliative centres participated in the study.	Quantitative Cross sectional multicentre survey.	-Most patients considered it appropriate for health care staff to address their spiritual or religious needs. -Older patients were more likely to get their spiritual needs met -Patients with the same religious affiliation as the care centre were more likely to get there needs met (although the last finding was not significant) Patients whose spiritual needs were addressed had higher on quality of life scores.	Self-identified -Small sample size -Did not explore the aspect quality of care from f health professionals Study Critique I question why there was no discussion about why elderly patients were more likely to have their religious or spiritual needs met.
Keall et al. 2013 Aim: To examine the feasibility of nurses facilitating a specific spiritually based intervention (Outlook) and its potential applicability for the use of nursing staff in the Australian healthcare clinical setting. Australia	N=10 participants with advanced cancer	Mixed methods A 3-armed randomised trial.	The nurse-facilitated tool Outlook was a novel and feasible tool for use by nurses exploring the existential and of care. The tool was portable.	Self –identified Small sample size and some dropouts. Study results had insufficient power to demonstrate statistical significance. It did not have a control arm; -Therefore it had questionable efficacy.

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>Kisvetrová, Klugar, & Kabelka 2013 Aim: To determine which Spiritual Support From the Nursing Interventions Classification (NIC) were useful in clinical practice with patients with the nursing diagnosis of 'Death Anxiety'.</p> <p>Czech Republic</p>	<p>N= 468 Czech nurses</p>	<p>Quantitative questionnaire with Likert scales.</p>	<p>'Treat individual with dignity and respect' was the most frequently used activity. 'Pray with the individual' was the least used. The most feasible activity was 'Treat individual with dignity and respect.' In addition, there were some significant differences found between hospice nurses and nurses practicing at other sites. There were also differences between religious believers and those who did not have a faith.</p>	<p>Self –identified The participants gave little response to the open questions relating to the circumstances associated activity use.</p>
<p>Lavoie, Blondeau & De Koninck, 2008 Aim: Explore the experience of dying from an existential perspective and if existential philosophy can have a humanising effect in palliative care.</p> <p>Canada</p>		<p>Philosophical discussion - review article based on Heidegger's "being with" dying and "being toward "death.</p>	<p>Existential philosophy can be a resource for humanising palliative care nursing - Existential philosophy helps the clinician remember that the patient is a whole person – including having a spiritual dimension.</p>	<p>Nil–identified</p>
<p>Mako, Galek, & Poppito 2006 Aim: explore the multidimensional nature of spiritual pain.</p> <p>USA</p>	<p>N= 57 participants - advanced cancer patients with a prognosis of less than six months.</p>	<p>Mixed Methods</p>	<p>In this study 96% of the patients reported experiencing spiritual pain at some point in their lives and 61% reporting pain at the time of interview. "...spiritual pain was both manifested and communicated through the emotional realm" (Mako et al. 2006, p.1110). Participants described their pain using psychological terms such as feeling "despair," "regret," or "anxiety". The use of emotional language to describe spiritual pain may be due to the contemporary Western culture's language which is not adept at describing spiritual pain.</p>	<p>Nil–identified Study Critique This study did not state its strengths or limitations- it did not describe how it ensured saturation in the qualitative arm of the study.</p>
<p>McGrath & Phillips 2008 Aim: To determine what palliative care services were provided for traditional indigenous people from rural and remote areas of Australia and whether these services met their needs. In addition, this research aimed to develop a culturally appropriate model of care and to identify strategies</p>	<p>N= 72 interviews from 10 Patients 19 Aboriginal Health Workers 30 Health Care Workers 2 interpreters.</p>	<p>Qualitative Interviews with a cross-section of participants.</p>	<p>The Aboriginal person's Christian beliefs sometimes gave them strength in times of adversity. However, the health professionals did not recognise the prevalence of the Aboriginal people's Christian beliefs. Alongside of these beliefs, traditional Aboriginal peoples may have believed in "black magic" and that spirits may have caused the person's illness. The study data demonstrated the significance of the Aboriginal person's need to die at home with</p>	<p>Self –identified The researchers could only report on data that the Aboriginal people were prepared to offer to a westerner. – i.e., Information needs to be earned.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
<p>to develop and implement the model.</p> <p>Australia</p>			<p>their family in their own” death country’.</p> <p>It was indicated that Aboriginal people may be reluctant to talk about their beliefs to western health care professionals for fear of ridicule. They may also have a distrust of western medicine in that some westerners did not understand the role of traditional healing practices.</p>	
<p>McGrath 2007 Aim: As above</p> <p>Australia</p>	As above	As above	<p>This research provided a clear articulation of the Aboriginal people’s connection to their land and families. It confirmed their strong wishes to die at home in their ‘death country’, thus ensuring that the person’s ‘animal spirit’ can return to their land. The finding from the data highlighted of the importance of an appropriate family member receiving the dying person’s sacred knowledge and the imperative that the ‘right person from the family network is able to provide end of life care.</p>	As above
<p>Mishra et al. 2010 Aim: Identify prevalence of psychosocial concerns in palliative care population.</p> <p>India</p>	N=100 inpatient palliative care patients over a one year period	Quantitative Patients’ spiritual needs were explored in a descriptive questionnaire that looked at psychological acceptance and emotional distress.		Nil–identified
<p>Mok, Wong, & Wong 2010 Aim: to explore the spirituality and the spiritual care of Hong Kong Chinese patients at end of life.</p> <p>Hong Kong</p>	N= 15 Chinese patients	Qualitative interviews convenience sample.	<p>Participants reported that spirituality was an abstract concept. Personal beliefs provided strength and meaning. Meaning was found in connectedness to others and self-reflection on whether they had fulfilled their responsibilities and obligations They described spirituality as an integration of body and mind. “The acceptance of death was a “process in life and ‘letting go’ leads to serenity and peace of mind” (Mok, Won & Wong 2010, p. 360). Nurses were not expected to provide them with spiritual care – however when it occurred it</p>	<p>Self–identified The small sample size which was inadequate for transferability. It was not ascertained whether the participants’ concepts on spirituality changed over time. The duration of the Interviews was relatively short due to patient vulnerability – multiple interviews were therefore required.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
			provided strength and was found to be spiritually supportive.	
<p>Pearce et al. 2012 Aim: To find if advanced cancer patients are provided with spiritual care consistent with their needs.</p> <p>USA</p>	<p>N=150 advanced cancer patients recruited from 2008-2010.</p>	<p>Quantitative The Functional Assessment of Chronic Illness Therapy—Spiritual Well-being (FACITSp) The Functional Assessment of Cancer Therapy-General (FACT-G) Center for Epidemiological Studies Depression (CES-D) Symptoms Index Short Form, and 11 items were developed to explore the patient’s spiritual needs and the care received.</p>	<p>91% of patients had spiritual needs and most received spiritual care from their health care providers. A small but significant number reported not receiving spiritual care. Those patients who received less spiritual care that they would have likely reported more depressive symptoms.</p>	<p>Self-identified Cross sectional design excludes causality Sample drawn from one area in the USA which has a high level of highly religious people.</p>
<p>Penman et al. 2013 Aim: Analysis and elucidate the essence of spiritual engagement from the lived experience of palliative patients and care givers.</p> <p>Australia</p>	<p>N=14 participants (4 = palliative care patients and N=10 care givers).</p>	<p>Qualitative The study was guided by Van Manen’s hermeneutic phenomenological approach –In depth interviews.</p>	<p>Recognising and supporting the person when they are trying to make sense of their experience is key to spiritual engagement. Five major themes of spiritual engagement of distinct actions such as “‘maintaining relationships with others’, ‘showing and receiving Love’, ‘praying’ and ‘participating in other religious practices’” (page 45).</p>	<p>Self-identified No single phenomenological description that can take into consideration the complexity of spirituality and spiritual engagement.</p>
<p>Pesut & Sawatzky 2006 Aim: To describe the underlying assumptions of prescriptive approach to spiritual care.</p> <p>Canada</p>		<p>Feature article - expert opinion</p>	<p>Two approaches to spiritual care were identified. These approaches were prescriptive and descriptive. Generic or prescriptive spiritual goals can be coercive whereas a descriptive approach is undertaken through the use of listening and establish trust and</p>	<p>NA</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
			recognises the mystery of the other.	
Pesut 2008 Aim: Explore the meaning of spirituality from a theistic, monistic and humanistic positions. Canada	Constructed from a review of selected nursing literature.	Theoretical debate. -A narration with three hypothetical participants, representing the typologies of spirituality through which she discussed their understanding of spirituality and religion and how these understandings effect spiritual nursing care.	Spiritual care at end-of-life needs a more nuanced understanding of spirituality which fitted to the unique needs of the patient.	NA
Pesut et al. 2008 Aim: To discuss some of the challenges of conceptualising spirituality and religion for healthcare. Canada		Critical review	Religion has become a subset of spirituality. Spirituality and hence spiritual care may or may not encompass religious affiliations or practices. Conceptualising spirituality within a globalised and diverse society requires a theological and philosophical understanding of individual and social historical developments.	NA
Polzer Casarez et al. 2012 Aim: To provide a discourse analysis on ethical issues relating to the incorporation of spirituality and religion into the clinical setting. USA	N= 21 research articles and 14 theoretical / discussion papers.	Discursive Paper Thematic analysis examined the discourse from professional literature through six electronic data bases.	Uncovered four themes 1. Ethical concerns of omission 2. Ethical concerns of commission 3. Conditions under which health care providers prefer to provide spiritual care 4. Strategies for integrating appropriate spiritual care.	NA
Rodin 2013 Aim: Commentary on the impact of social and psychological factors impacting on wellbeing in end of life care - a discussion of the development of		Review article – invited expert opinion.	Argument - spiritual wellbeing is a dimension of psychological wellbeing –however the construct of spiritual care is not well understood by clinicians.	NA

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
psychosocial research in palliative care. Canada				
Ronaldson et al. 2012 Aim: Identify and compare the spiritual care given by RN's from acute areas to RN's from palliative practice areas. And correlations of spiritual care between groups and barriers for both groups. Australia	N = 42 Palliative RN's N = 50 Acute care RN's 7 Inner metro Sydney hospitals.	Quantitative Cross sectional design comparing different clinical environments of palliative care and acute nursing – Self completed questionnaires- Spiritual Perspective Scale (SPS) and the Spiritual Care Practice Questionnaire (SCPQ).	Palliative care RN's were significantly older as acute care nurses. Palliative care nurse had higher spirituality perspectives and more advanced practice in spiritual care. Both sets of nurses identified lack of time as a barrier to spiritual care. Acute care nurses found lack of privacy and rapid patient turnover a barrier to spiritual care.	Self-identified To limit diversity nurses were targeted and recruited for acute care hospitals.
Rushton et al. 2009 Aim: Impact of a contemplative end-of-life training program: Being with dying programme. Canada	92 surveys 61 of these did phone interview.	Mixed methods	The quality of presence within the clinician and bearing witness to the patients and their family's suffering are in themselves healing acts.	Self-identified Limited generalisability as the samples were not representative of all the participants who have been part of the programme. Participants ethnicity was not identified.
Selman et al. 2012 Aim: To determine Spiritual Wellbeing (SWB) in a palliative population in Uganda and South Africa and whether the 8 items from an assessment tool - Missoula Vitas Quality of Life Index -Subscales of Wellbeing and Transcendence could be used as a valid assessment tool. Africa	N=285 patient aged 18 years and over. Mean age was 40.1 predominately HIV patient.	Quantitative Cross sectional survey using eight items from the Missoula Vitas Quality of Life Index (MVQOLI). The "spirit 8" was used to determine spiritual wellbeing in Ugandan and South African palliative patients. Factor and Rasch analysis.	Spiritual distress was identified in 57% of patients. The "spirit 8" seems to be a robust uni-dimensional assessment tool for meaning spiritual well-being. -Tool able to identify patient who are at risk of spiritual distress.	Self-identified Services involved not randomly selected. Some details of spiritual care in some services are unknown.
Seno 2010 Aim: To explicate the tacit wisdom embedded in the practice of nurses experienced and effective in being with the dying.	N=6 nurses known for their ability to assist in a peaceful death –ages ranged from 40- to 56 years -all female. Mean years of practice was 22 years.	Qualitative Interpretive hermeneutic phenomenological study based on Heidegger's "being with" dying and "being toward" death. In-depth interviews –on	Five patterns emerged woven together in presence of 'being'. 1. Acceptance of death 2. Personal experience of death assisted nurse to engage 3. Optimistic authentic state of mind 'Being -toward –death' 4. Calling forth what the other knew 5. Situated and regulated	Nil-identified

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
		<p>how the nurses were 'Being' as opposed to 'Doing' in the encounter. "Living experience of historical encounter" (page 378) Interview time one and half to two hours. Two hundred and forty pages of textual data from interviews achieving satisfactory saturation.</p>	<p>interpersonal space -for person and family. Nurses narratives.</p> <p>Consistent with Heidegger's structures of advancing toward death.</p>	
<p>Simha, Noble & Chaturvedi, 2013. Aim: To examine the types of spiritual concerns of Hindu cancer patients within hospice care.</p> <p>India</p>	<p>N= 50 patients, aged over 18 years,</p>	<p>Qualitative Semi-structured interviews.</p>	<p>The most common spiritual concerns reported were the benefits of "pooja, faith in God, concern about the future, concept of rebirth, acceptance of one's situation, belief in karma, and the question "Why me?" No individual participant expressed all four of the concerns studied: These were- Loneliness, need of seeking forgiveness from others, not being remembered later, and religious struggle."</p>	<p>Self-identified The researcher's used a "relatively small sample size restricted to South Indian Hindu patients who were admitted to a single hospice and based on a single interview (Simha Noble, & Chaturvedi, 2013, p.99). -The study population was homogenous. "The interviews were conducted in the person's mother tongue, which would give a richer account of their experiences than if it were conducted in another less familiar language". (Simha Noble, & Chaturvedi, 2013, p104).</p>
<p>Taylor 2013 Aim: To measure and explore the comfort of hospice nurses when doing a spiritual assessment and associated factors.</p> <p>New Zealand</p>	<p>N= 60 hospice nurses from 3 different hospices in New Zealand.</p>	<p>Mixed-methods Cross-sectional, descriptive study.</p>	<p>The comfort of the hospice nurses was associated with receiving training and perceiving they had some preparation in doing a spiritual assessment, The nurses perceived that a spiritual assessment was important. It was found that the nurse's comfort was not related to age, years of nursing, and the nurses own spirituality.</p>	<p>Self –identified Small sample size which was limited to one location.</p>

Year - Authors - Aim – Country	Participants	Methodology	Findings	Limitations
Vachon et al. 2011 Aim: To explore the palliative care nurses' spiritual and existential experience of a meaning-centered intervention (MCI) based on Frankl's approach and to describe the effects of the MCI from the nurses' point of view. Canada	N = 10 palliative care nurses	Qualitative interpretative phenomenological analysis.	The intervention did assist the research participants to develop their spiritual and existential awareness. by increasing their awareness of life's finiteness, and by opening them up to new meanings and purposes of suffering. It also provided access their own ability to be mindful with their peer group	Self-identified The research design did not allow for drawing relationships between the variables. It did not specifically assess the intervention outcome.
Winkelman et al. 2011 Aim: To examine the relationship between spiritual concerns and quality of life in the palliative setting. USA	N=69 patients with incurable cancer and over age 21 years receiving palliative radiotherapy.	Quantitative Survey based study	Being of younger age was the only statistically significant predictor of total SCs It was found from the results spiritual care should be a core component of palliative care.	Self-identified Cross sectional design made it difficult to understand the associations between spiritual concerns and quality of life. Nor how spiritual concerns evolve through end of life.

References for Matrix of Research Studies

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Appendix 3. Invitation to mental health nurses and palliative care nurses to participate in research



Invitation to Mental Health and Palliative Nurses to Participate in Research

Study title

“Facilitating spiritual care for individuals with a mental illness and life limiting illness”.

Background

Due to poor physical health, people with severe mental illness are dying up to thirty years earlier than the general population. However, current general knowledge about the individual’s experience of dying is poor. This research aims to understand from your experience the spiritual care needs of individuals with a mental illness and a life limiting illness. The study also aims to explore whether the values, practice beliefs and processes of your service assisted you in facilitating spiritual care.

If as a either a mental health nurse or palliative nurse you have cared for or are caring for an individual who has a palliative illness and a mental illness, I would like to interview you for around for around 45 minutes to 60 minutes. Interviews will be carried out in a mutually agreed place which ensures your anonymity and confidentiality. The interview will be confidential and your name will not be identified in the research. Your participation in the study will be entirely voluntary. The information you provide will assist in understanding how to provide better services to individuals who have an enduring mental illness and a life threatening illness.

Ethics

This study has been reviewed by the [REDACTED] Adelaide Clinical Human Research Ethics Committee. If you wish to enquire further about the study, please contact Sharon Picot on 0434815754. Her email address is pico0003@flinders.edu.au. Thank you for your attention and your assistance.

Sharon Picot Research Leader - School of Nursing & Midwifery Flinders University

Appendix 4. Participant Information and consent form



Participant Information Sheet / Consent form

Health/Social Science Research - *Adult providing own consent*

██████████ Adelaide Local Health Network

Title

“Facilitating spiritual care for individuals with a mental illness and life limiting illness”.

Principal Researcher

Sharon Anne Picot

PhD Candidate School of Nursing & Midwifery

Flinders University

Associate Researchers

Associate Professor Ann Harrington

School of Nursing & Midwifery

Flinders University

Professor Jeffrey Fuller

School of Nursing & Midwifery

Flinders University



Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which aims to understand from your experience the spiritual care needs of individuals with a mental illness and a life limiting illness.

The study also aims to explore whether the values, practice beliefs and processes of your service assisted you in facilitating spiritual care.

You have been invited to take part in the project because you are either a mental health nurse or palliative care nurse, working within the [REDACTED] and you have cared for or are caring for an individual with a severe mental illness and a life limiting illness.

This Participant Information Sheet and Consent Form will inform you about the research project. It will explain the processes involved in taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a colleague, friend or relative.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to be involved in the research described

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

Purpose of the study:

A recent search of the literature indicates there are no available studies focusing on the spiritual \ existential needs or associated care provision for people with a severe and enduring mental illness who are facing death. This lack of research points to a clear knowledge gap. Hence, this

study will endeavour to understand the spiritual / existential care provision within mental health culture for this population.

Description of the study:

This study will examine how the culture of the nurse's work impacts on their ability and willingness to facilitate and support spiritual care for individuals with a mental illness and a comorbid end of life illness. Interview questions will be aimed at gaining an understanding of any spiritual or existential issues which may have arisen when the nurse was caring for the person with a mental illness who was dying. Questions will also be aimed at exploring what these issues were and whether the nurse felt that the values, beliefs and clinical processes of the service, such as clinical reviews, assisted them facilitating care around these issues.

There are similarities in the values and practices of the mental health and palliative sectors which can assist in collaborative care of the patient. However, the large amount of literature from the palliative sector on the spiritual or existential care of the patient is not reflected by the mental health literature. The literature from the palliative sector highlights the importance of the nurse engaging with patient around spiritual issues. For a comparison of cultural influences, both mental health and palliative care nurses will be invited into the study.

The term severe and enduring mental illness refers to a collection of disorders that have a profound effect on interpersonal relationships, can cause functional impairment and substantially interferes with everyday activities. This includes psychotic disorders, such as schizophrenia, schizoaffective disorders and major affective disorders. The term 'life-limiting illness' is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and non-malignant nature.

This study is supported by Flinders University, School of Nursing & Midwifery. This research has been initiated by the principal researcher, Sharon Anne Picot, PhD Candidate, Flinders University and Nurse Practitioner [REDACTED]. The results of this research will be used by the principal researcher to obtain a Doctor of Philosophy (PhD) degree.

3 What does participation in this research involve?

Your consent form will need to be signed prior to you being involved in the study. You will then be screened for eligibility for the study. To be eligible you need to be a registered nurse and have cared for or are caring for an individual with a mental illness and a life limiting illness. This needs to have been within the last three years.

What will you be asked to do?

If you are eligible for the study you will be invited to attend an interview with the PhD candidate, Sharon Picot who will have a conversation with you about your experience and views on working with an individual with a mental illness who also had a co-morbid end of life illness. The interview will take about 45 – 60 minutes.

The research will be monitored through the regular processes of Flinders University, such as ongoing academic supervision with the Principal Researchers' academic supervisors.

This research project has been designed to make sure the researchers interpret the results in a fair and rigorous way.

There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

Approximately eight mental health nurses from the adult services of [REDACTED] will be recruited for the study. To get a broad range of data, both inpatient and community nurses from both the palliative and mental health sectors will be targeted for participation in the study.

Study Duration:

Recruitment and Interviews will be undertaken from May 2016 to May 2017.

5 Do I have to take part in this research project?

.Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with any of the researchers or your relationship with [REDACTED] or Flinders University.

6 What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research. However, the sharing of your experiences will lead to a great understanding of the needs of this cohort of individuals which could inform future care delivery.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team. If you decide to withdraw from the study your data will not be used.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as illness or other unforeseen events in the life of the primary researcher.

10 What happens when the research project ends?

Outcomes from the project will be given to you by the researcher if you would like to see them.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

The researcher does not need your name and you will be anonymous. The interviews will be recorded using a digital voice recorder. Once recorded, the interview will be transcribed and stored as a computer file within the secure University's research unit shared drive that only Ms Sharon Picot will be able to access. The voice file will then be destroyed. Your responses to questions will be held for a period of 7 years after the last publication from this PhD.

By signing the consent form you consent to the research team collecting and using your clinical experiences for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. All information will be de-identified.

It is anticipated that the results of this research project will be published and presented in a variety of forums. In any publication or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. However, within presentations and publications from this study, it will be revealed that the data came from a mental health and palliative setting in Adelaide and that the researcher was a student at the Flinders University of South Australia.

In accordance with relevant Australian and/or South Australia privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you

disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

12 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by ██████████ Adelaide Clinical Human Ethics Research Committee (██████AC HREC).

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the Principal Researcher Sharon Picot on 0323815754 sharon.picot@sa.gov.au or any of the following people:

Research contact person

Name	Ann Harrington
Position	Associate Professor [Flinders University
Telephone	8201348
Email	Ann. Harrington @ flinders. edu.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Name	██████████
Position	Manager, ██████████ Office for Research
Telephone	██████████
Email	████████████████████

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC name	██████████ Adelaide Clinical Human Research Ethics Committee
HREC Executive Officer	██████████
Telephone	██████████
Email	████████████████████@██████████.u

Local HREC Office contact (Single Site -Research Governance Officer)

Name	[REDACTED]
Position	Research Governance Officer
Telephone	[REDACTED]
Email	[REDACTED]



Consent Form - *Adult providing own consent*

Title: "Facilitating spiritual care for individuals with a mental illness and life limiting illness".

Coordinating Principal Researcher

Sharon Picot

PhD Candidate School of Nursing & Midwifery

Flinders University

Associate Researchers

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Associate Professor Ann Harrington

School of Nursing & Midwifery

Flinders University

Professor Jeffrey Fuller

School of Nursing & Midwifery

Flinders University

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____
Signature _____ Date _____

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher [†] (please print)	
Signature _____	Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 5 Interview questions

Introduction Good morning / afternoon –Thank you for coming - my name is Sharon Picot and I am from the School of Nursing and Midwifery. The conversation we will be having today will be used as data in my PhD. - Discuss researcher audiotaping interview and note taking and re explain what the study is about. - -Further checking if participant is giving Informed Consent- This template was based on the:

Safety Diagnosis Tool Kit for Local Communities, Guide to Organizing Semi-Structured Interviews, With Key Informants. Institut national de santé publique du Québec in cooperation with the ministère de la sécurité publique du Québec.

Preliminary questions -		
- How long the participant has been nursing? 2 to 5 years. 5 to 10 years 10 to 15 years 15 to 20 years 20 years and over?	Age of participant 20-30 years of age 30-40 years of age 40-50 years of age 50-60 years of age 60 years or over?	The approximate age of the person who was dying? 20-30 years of age 30-40 years of age 40-50 years of age 50-60 years of age 60 years or over
- In what field of nursing?	Mental Health	Palliative care
Main Question	Cues - Informed from Literature Review	Prompts
What were the main concerns of the person you were caring for?		
Tell me about your experience/s of working with a person with a mental	How did the individual respond to having a life limiting illness? I.e.	Can u tell me more about that?

<p>health illness who had a life limiting illness.</p> <p>(Check how many occasions the participant has had this experience so each experience can be reviewed)</p>	<ul style="list-style-type: none"> • Distressed that they had not fulfilled their potential? • That in some ways because of their mental illness they had failed others? • Their spiritual beliefs, faith in God or a higher power gave them solace? • They felt their belief system shatter because of the diagnosis? • They blamed themselves for their illness? 	<p>What else you remember about that?</p>
<p>What supports did the individual have?</p>	<ul style="list-style-type: none"> • Family and friends • Faith group? • Meditation group? 	<p>Continually check the participant's body language for cues of distress.</p>
<p>Did you feel that you had: -Sufficient skills and knowledge to explore the individual's spiritual or existential concerns?</p>	<ul style="list-style-type: none"> • Counselling/listening/trust building skills? • Assess possible psychotic symptoms enmeshed with the individual's belief system? 	
<p>What further support do you think could have been helpful for the individual and the significant people involved in the person's life?</p>		

<p>Was there anything hindered you in providing what you believed was the best possible care for this person and the significant people in their lives?</p>	<p>Did you feel that you had enough:</p> <ul style="list-style-type: none"> • Time to explore issues that were meaningful to the individual? • Access to appropriate place which ensured privacy? 	
<p>Did your own belief system in any way impact on your care?</p>	<p>Either in a positive or negative way?</p>	
<p>Conclusion of Interview - Leave 5-10 minutes to wind down interview</p>		
<p>Let the participant know that we should be finishing in around and ask if there is anything else they wanted to let me know.</p>	<p>Check that the participant emotionally OK prior to leaving interview.</p>	<p>Talking about the death or dying can be distressing. Has the interview caused the participant any distress or unease? How can I assist with this distress or unease</p>
<p>If you could work in an ideal system to provide care for individuals with a life limiting illnesses that are facing death, what would that system look like?</p>		

Appendix 6 Excerpt -Data set analysis

PNO:	Post Interview	Analysis 2		My Memos
P1 MH	<p>Participant issue</p> <ul style="list-style-type: none"> - Participant was quite emotional - particularly toward the end of the interview <p>Interviewer reflection</p> <p>When participant was talking about her patient not fitting into the usual criteria of care – I knew how she felt especially during review mechanisms</p> <p>-</p> <p>Interview style - I finished participant’s sentences – And I agree with supervisors – I need to encourage elaboration</p> <p>Supervisors comment Interviewer needs to encourage further discussion <i>i.e. Breaking Rules</i> – My style is more like a counsellor than interviewer – I need to ask the participant to elaborate more –</p>	<p>Themes from Interview questions Patient 1</p> <ul style="list-style-type: none"> -(1a)No external support for patient -(4a)No self-blame -(5a)Lack of achievement -(3a)Low self esteem -Feelings of worthlessness –not worth treating -Wanting to achieve goals now -(2a)Loneliness isolation a factor -(6a) Poor quality of life (8a)Meaning was cycling group – joy -(7a) Nil known religious beliefs 	<p>Themes from Interview questions Patient 2</p> <ul style="list-style-type: none"> -(2a)Physical health needs couldn’t be met in an SRF which would have far met better his social and emotional needs -Afraid of stigma - fear his mental illness would not be understood in a RCF -(2a)Staff of RCF treated him like a baby which was his worst fear he was a “social butterfly” - he couldn’t connect with the rest of the residents -. (2a)It was a mismatch of service provision. It didn’t meet his social needs or his cognitive needs. - (5a)Regret in not following through normal health checks due to MI. - MI affected relationships 	<p>My Memos</p> <ul style="list-style-type: none"> - (1)Breaking Rules - Clinician needed to keep quiet about what she was doing with patient as it was not core business - <i>avoidance of review mechanisms</i> – there is a huge push for discharge and patients going to other services for counselling

PNO:	Post Interview	Analysis 2		My Memos
	Perhaps ask participant for a second interview		-(9a) Fear of mental illness symptoms emerging (8a) Meaning -music painting relationships (7a) Accepted spiritual care at end of life	-

Appendix 7 Process for triangulation analysis and interpretation of interview and autoethnographic data - Steps and analysis of documents

Step 1.

Initial coding - for descriptive labels -codes are assigned to research questions or unexpected questions or concepts – summarise the content of segments - use of Roper and Shapira’s 2000 coding for consistency. Codes and categorical labels taken from the set analysis set analysis –Appendix 7 and autoethnographic journal.

Codes and Categorical labels from research questions

No: and Colour code:	Categorical labels from Interviews and Autoethnography	Summarise
1b	<u>Organisational support</u>	Mental Health nurses did feel they were supported at a local level, however at the level of medically driven processes such as clinical reviews. Nurses were concerned about feelings of disempowerment through medically dominated processes. And the effects of episodic care.
2b	Time –organisational support	Mental health nurses either had the time or made the time for spiritual care.
3b	<u>Comfort in talking about spiritual issues</u>	Mental health nurses identified that they were comfortable in talking about spiritual issues, however some palliative care nurses were not comfortable due to organisational concerns - Mental health nurses identifying issues relating to meaning whereas palliative care nurses identified both spiritual needs.

4b	<u>Comfort with skill level</u>	Mental health nurses re comfortable with their skill level
5b	<u>Congruence in values/ethics</u>	There was strong congruence between nurses for mental health nurses in working within their own. ethical values.
6b	<u>Resources</u>	<u>Material resources was not discussed - further professional development in the area was recommended by many mental health and palliative care nurses.</u>
7b	<u>Collaboration with palliative team and mental health team</u>	<u>Occurred at time.</u>

Codes and Categorical labels -Unexpected concepts

No: and Colour code:	Categorical labels	Summarise
1.c Blue	Very high positive regard patient's attitude -	Both mental health and palliative care nurses spoke often with high regard for their patient and the patient's attitude toward life and their life limiting illness.
2.c Red	Breaking/ bending rules	Both mental health and palliative care nurses spoke about breaking or bending rules to provide quality care.
3.c	Importance of the Therapeutic relationship	Mental health nurses and palliative care nurses spoke of the importance of the Therapeutic relationship in the provision of care.

Lime green –		
4.c Purple	Humour	Humour arose as important for both groups.
5.c yellow	Flexibility	Both mental health and palliative care nurses spoke about the need to be flexible, especially in terms of time to be able to care for this population.
6c Tan -	Encounter leaving deep mark on clinician - pivotal experiences	Mental health and palliative care nurses spoke about the experience of working with a person who had both am mental illness and life leaving illness them leavening a deep impression on them.

Example of thematic coding in text interviews

0047 1c you know, when you've got your favourite patients you make the time; do you know what I mean?

Interviewer: Yes

0047 You do, whereas if someone is antisocial to you and you've got other time pressures maybe they might not get the same time, which sounds terrible but...

Interviewer: No, it doesn't.

0047 I'm listening to myself but, no, I mean...

Interviewer: We're human.

0047 Yeah we are human. Yeah, absolutely.

Interviewer: You know, people who you can engage with therapeutically, you know, and it's not - I don't think it's just therapeutic in that, I don't know, traditional sense, it's really an engagement with that person and it sounds like you had that engagement with that person.

0047 You know, maybe the people that aren't engaging maybe need more time, [I'm not denying that] but, look, [1c she was one of my favourites so I made time for her, yeah. She made me feel better for coming to work.](#)

Interviewer: How did she make you feel better?

0047 Because it's just lovely to see someone that's happy to see you in mental health because you don't always have that experience and is [1c always smiling and then can find a positive in the negatives. I mean that's what...](#)

Example of thematic coding in text autoethnography

Journal Reflection on therapeutic relationship with [REDACTED]

I saw [REDACTED] about every three weeks for around 18 months. 7c I was deeply affected by her death as were other palliative clinicians. 1c (Several palliative clinicians came to her funeral as that believed that RW was very special and they were very fond of her). She was always generous and warm even through her darkest days. [REDACTED] had an 4c amazing sense of humour and love of life which seemed to be carrying her through.

I think one of the hardest things I have had to deal with as a clinician was [REDACTED]'s fear of dying and the unknown. I wanted to ally her fears, but I had no answers to her questions. No real way of soothing her fears. We spoke about the joy of the moment and enjoying her daughter now and at times she achieved this and at other times she was overwhelmed with sorrow. [REDACTED] had no religious spiritual beliefs that we could look at together to give her some comfort.

What I am grateful for was that as a NP 2b I was afforded the time by the organisation to spend time with RW and her family. I could work across services and do practical things around ensuring good communication between palliative care services and mental health. I did believe and still do not believe that professional distance was the way to engage therapeutically with RW. (I will unpack this point further from a cultural perspective)

When I find my work seems too hard, I often think of [REDACTED] Her memory makes me smile and I feel like 'Yep: this is important'. I think ... "If she could go through it with such courage, I can manage".

Example of use of memos in transcript analysis

P1: I didn't go to anybody for support. **Memo – Clinician did not go to anyone for support**

SP: You didn't? Yeah.

P1: I didn't avoid clinical reviews but I found it very hard to um, hard to articulate my interventions....**Memo avoidance of review mechanisms because of difficulty in articulation of therapeutic intervention**

SP: Yep, .do you think people would have understood?

P1: Well, I did bring him to a clinical review because I was concerned about his mood at one point um, and I needed a psychiatrist to review him.....

SP: So it was more around that suicidality that you were concerned?

P1: Yes, and ambivalence, yeah but I remember thinking you know, oh just as well something's changed because I would have had to have discussed him at a three month point

SP: Uh-huh

P1: not quite sure what I would have said!

SP: (Laughter) uh-huh.....

P1: I'm not sure I should be saying this.....but um, because it's not usual core business – **Memo - not core business**

SP: As a nurse, as a therapeutic nurse I would imagine that you felt that you had, you needed to do this....

P1: I did. And you know, its evidence-based interventions and I have done a....years ago I did a model, um, as part of my second degree I did a module in uni on grief and loss counselling

SP: Yep, yeah...

P1: so I felt that I was equipped otherwise I wouldn't have done it.

SP: It sounds like you're actually equipped too...

P1: But, um, the way the model in team is going it's very much short or long term and um, you know what are the evidence-based interventions and he didn't fit. Because we didn't know whether he was going to be short or long term. Because he had a life limiting illness **memo- different needs of people with a life limiting illness and mental illness.**

Step 2.

Chang's first 7 steps

2.1 Sort for patterns - Search for recurring topics

All of the concept's codes for research questions and the reoccurring concepts with the exception for the humour and resource concepts were strongly identified as reoccurring themes from the data.

- Pattern can be grouped under professional therapeutic relationship combine categories - Congruence in values/ethics, Comfort in talking about skill level and discussing spiritual issue.

2.2. Look for cultural themes

- Prompt -Look within the three sets of ethnography data i.e. from a focussed ethnography (Roper and Shapira 2000) and auto ethnography (Chang 2008).

- Culture of organisational support from nursing leadership and time availability
- Professional culture within the therapeutic relationship –spiritual care with people suffering psychosis
- Culture of silencing/ disempowering of nurses –medically dominated processes and the breaking or bending rules
- Culture of episodic care.

2.3 Identify exceptional occurrences

Combination of Roper and Shapira (2000) Sort for outliers and Chang's (2008) Identify exceptional occurrences

- Concept of 'love' palliative participant 5. (See Data Set Analysis appendix 6)

2.4 Analyse inclusions and omissions

Prompt - Omissions point to the autoethnographer's unfamiliarity, dislike, and devaluation of a phenomena (Change 2008)

From Inclusions

- Very high positive regard patient's attitude
- Encounter leaving deep mark on clinician - pivotal experiences
- Palliative care nurse feeling unable to provide spiritual care.

From Omissions

- Boundary issue arising from mental health nurse

- The potential demise of the professional culture of mental health nursing.

2.5 Connect the past with the present

This was analysed in the section on the traditional culture of medicine and its impact on current nursing culture.

2.6 Analyse relationships between self and others

Prompt –“...fundamental to autoethnographic interpretation (Chang, 2008 p. 134)”.

This step overlapped with Changs (2008) steps 3 and 4.

The issue of love was analysed in relation the nurses relationship to self and others It was interpreted as agapé and alterity; that is seeing the humanity of the ‘other’.

2.7 Compare yourself with other people’s cases

A) I analysed the concepts from the autoethnography using the same process and was used for the interviews with the mental health and palliative care nurses. Broadly most of the concepts were the same as from the other nurses. What was different was that these concepts occurred with greater frequency through the autoethnographic stories – this is probably due to the nature of the journal activity itself which was more focused on the relationship between myself and the person I was working with as opposed to the research questions.

Excerpt from autoethnographic journal demonstrating analysis process. (Same process as Step 1. of interview data)

Journal Reflection on therapeutic relationship with [REDACTED]

I saw [REDACTED] about every three weeks for around 18 months. 7c I was deeply affected by her death as were other palliative clinicians. 1c (Several palliative clinicians came to her funeral as that believed that RW was very special and they were very fond of her). She was always generous and warm even through her darkest days. [REDACTED] had an 4c amazing sense of humour and love of life which seemed to be carrying her through.

I think one of the hardest things I have had to deal with as a clinician was [REDACTED]'s fear of dying and the unknown. I wanted to ally her fears, but I had no answers to her questions. No real way of soothing her fears. We spoke about the joy of the moment and enjoying her daughter now and at times she achieved this and at other times she was overwhelmed with sorrow. [REDACTED] had no religious spiritual beliefs that we could look at together to give her some comfort.

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B) This is also demonstrated by the section on the contrasting data from the different specialities.

Step 3. Roper and Shapira 2000 and Chang 2008 both state the process of contextualising broadly

-Prompt- Zoom in and out –interpret data in connection with events that explain data, ie “sociocultural, political, economical, religious, historical, ideological...” Chang 2008, p.136.

The step of zooming in and out occurred predominantly in the research and consequent writing of the section of Weber **and the myth** of dis-enchantment and the exploration of the philosophical alignment with Recovery Movement - A storied space of empowerment.

Step 4. Compare with social science constructs and ideas

This is demonstrated in section on the displacement of professional cultures culture of risk aversion and workplace stress versus therapeutic care, and the sections exploring the power of language and symbols in silencing others maintaining dominance.

Step 5. Roper and Shapira 2000 Generalise constructs and theories and Chang’s 2008 Frame with theories

- I used Travelbee theory to generalise constructs and theories
- Framed with theory of Sphere of Nursing.

ANALYSIS PROCESS FOR DOCUMENTS

As per Bowen (2009) and triangulation of FE and AE data analysis process

- Identify documents through government search engine using search queries 'culture' 'culture mental health' and 'community mental health'.
- Used initial skimming or superficial examination of the documents to determine their relevance to the research – all documents were relevant.
- To ensure consistency in the method used for analysis of other data within the study, there was a deeper reading of the documents to look for patterns and emerging themes.
- Use descriptive labels recurring topics - used same process as with interview and autoethnographic data.
- Look for cultural themes - used same process as with interview and autoethnographic data.
- Compare with other data sets -Identify overlap with themes from the interview participants and autoethnography.

Documents identified as a source of data	Issues identified-	Cultural themes and patterns that align with other data sources
<p>The Deloitte Report 2015.</p> <p>Deloitte, prepared for Department for Health and Ageing, 2015, <i>Transforming Health, A report from the Implementation Partner</i>, Community Mental Health report, Government of South Australia</p>	<p>Poorly defined role expectations of clinicians</p> <p>serious trust and morale issues</p>	<p>The first three reports indicated a culture in crisis.</p>
<p>The Douglass Report, 2016</p> <p>Douglass, J 2016, <i>Summary of consultations with mental health staff in adult community mental health teams May- July 2016, SA</i></p>	<p>Fragmented care increased sick leave and staff absences</p> <p>high levels of burn out</p>	

<p>Health/ANMF, viewed 10 September 2018, <http://www.australiacouncil.gov.au/workspace/uploads/files/risk-management-policy-frameworko-544f3b1beeb16.pdf>.</p>	<ul style="list-style-type: none"> -Staff leaving -Risk aversion -Hostile work environment <p>generic workers</p> <p>must fulfil performance indicators that are not related to mental health nursing</p> <p>bullying harassment and intimidation</p> <p>Cinicians' workloads were unmanageable, processes were inefficient and there were unrealistic expectations of staff from managers.</p>	
<p>The Stevens Report 2017.</p>	<p>Staff mistrust of organisation</p>	

<p>Stevens, G 2017, <i>Adult Community Mental Health</i>, commissioned by the South Australian Health Department. Viewed 5 March 2018, <psu.asn.au/.../Adult-Community-Mental-Health-Greg-Stevens-report-July-2017.pdf>.</p>	<p>Staff in survival mode</p> <p>...bullying harassment and intimidation</p> <p>...run down” by the relentless pressure of unsustainable and uncapped workloads, and of poor treatment by certain managers past and present.... Many staff feared that plugging the gaps that arose on a daily basis put them and their colleagues at risk of missing something important that could result in dire consequences if not dealt with.</p> <p>...helplessness and burnout clinicians’ workloads were unmanageable; processes were inefficient</p>	
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	and there were unrealistic expectations of staff from managers.	
<p>Principle Community Visitor Scheme's (PCVS) annual report.</p> <p>Principle Community Visitor Annual Report Mental Health Services 2017, Community Visitors Scheme – Presented to the Minister September 2016-2017. ISSN 2201-6614.</p> <p>port (2017).</p>	...people being discharged earlier than preferred and still with significant health/nursing needs.	Detrimental pressure to discharge patients.
<p>The Audit of Actions undertaken by Mental Health Services (2017).</p> <p>Fjeldsoe, K Burnett, P Whitecross, F & Meehan, T 2017, <i>Audit of Recommendations</i></p>	Management focus on patient flow.	Pressure to discharge patients.

<p><i>Arising from Recent Reviews and Accreditation Surveys South Australian Government Inpatient Mental Health Services</i>, report prepared for the Chief Executive, South Australian Department of Health and Ageing, South Australia.</p>		
<p>'Clinical Business Rules' Government of South Australia 2013, <i>Clinical Business Rules Metropolitan, Adelaide Adult Integrated Community Mental Health Teams</i>, Government of South Australia, South Australia. Government of South Australia n.d. a viewed 10 January 2018, https://www.sahealth.sa.gov.au/wps/wcm/con</p>	<p>Used to clarify issues raised by participants in interviews such as this that occurred in clinical reviews. Document used to direct the 'clinical review' process.</p>	<p>Multidisciplinary team to be led by a psychiatrist or medical officer.</p>

<u>nect/public+content/sa+health+internet/health+services/mental+health+services/adults+mental+health+services</u>		
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