Screening for Spiritual Suffering by Nurses

Sayna Bahraini BScN, MScN

A thesis submitted

in partial fulfillment of the requirements

for the Doctorate in Philosophy degree in Nursing

School of Nursing

Faculty of Health Sciences

University of Ottawa

Dedicated to all those patients that strive to find peace and solace when faced with chronic or terminal diseases. It is also dedicated to all strong, selfless nurses that give of themselves unconditionally and help guide these fragile souls to a place of peace and acceptance to face their difficult conditions with dignity and not despair.

Preface

The current doctoral dissertation was conducted in collaboration with my supervisor and committee members. The primary researcher, Sayna Bahraini (S.B.), is responsible for conducting all research activities, and as such, accepts full responsibility for each manuscript and the complete dissertation. S.B. is a registered nurse in Iran and was a critical care nurse in the ICU from 2011 until 2014. She was supported financially for this research by the Board of the Canadian Foundation for Spiritual Care. She held a one-year Ontario Graduate Scholarship and Excellence Scholarship from the University of Ottawa. She also awarded the Nicole Bégin-Heick Scholarship and the International Student Bursaries of the University of Ottawa. In additions, she received a CIHR Integrated Knowledge Translation Research Network Doctoral Fellowship (FDN143237). The funders had no contribution in study design, analysis, decision to publish, or preparation of the dissertation.

S.B. was supported by thesis committee members who collaborated in the development of the research proposal and approved the research plan. All the members provided consultation for the research methods, data analysis, and contributed to the scholarly content of the manuscripts before approving them (Table 1). Thesis supervisors were Ian D. Graham (I.D.G.) and Wendy Gifford (W.G.). I.D.G. is a medical sociologist and Professor at the University of Ottawa, School of Epidemiology. He also is a Senior Scientist at the Ottawa Hospital Research Institute. W.G. is a registered nurse and Associate Professor at the University of Ottawa, School of Nursing, and Co-Director of the Center for Research on Health & Nursing. Thesis committee members were Mary Egan (M.E.), Suzette Brémault-Phillips (S.B.P.), and Rebekah Hackbusch (R.H.). M.E. is an occupation therapist and Professor at the University of Ottawa, School of Rehabilitation

Sciences. S.B.P. is an occupational therapist and Associate Professor at the University of Alberta, Faculty of Rehabilitation Medicine. R.H. is the Coordinator of Spiritual Care at Bruyère - Saint Vincent Hospital.

Other members of the research team who were not members of the thesis committee made important contributions to the research studies (Table.1). Liquaa Wazni (L.W.), doctoral candidate in Nursing at the University of Ottawa, participated in the screening, data extraction, and quality appraisal of studies included in the systematic review (Chapter 2). She also was the second coder in data analysis of the qualitative phase of the dissertation (Chapter 3). Catrine Demers (C.D.), a doctoral candidate in the School of Rehabilitation Sciences at the University of Ottawa at the time of conducting the systematic review, participated in screening of articles for the systematic review (Chapter 2). Lindsay Sikora (L.S.), a librarian at the University of Ottawa helped develop the search strategy and modified it to several databases (Chapter 2).

Table 1. Contribution of the Collaborators

Items	Manuscripts		
	The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings: A Systematic Review	Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to the Spiritual Care Service in the Complex Continuing Care	Study Protocol to Examine the Diagnostic Accuracy of the Peace & Meaning/Joy Measure for Screening Newly Admitted Patients for Spiritual Suffering
Conceptualize & design	SB IDG WG ME SBP RH	SB IDG WG ME SBP RH	SB ME

Collect data	SB LW CD LS	SB RH	Non-Applicable
Analyze & interpret data	SB IDG WG ME SBP RH LW	SB IDG WG ME SBP RH LW	Non-Applicable
Draft manuscript	SB	SB	SB
Revise manuscript for important intellectual content	SB IDG WG ME SBP RH	SB IDG WG ME SBP RH	SB ME IDG WG
Approve final version	SB IDG WG ME SBP RH	SB IDG WG ME SBP RH	SB IDG WG ME SBP RH
Responsible for overall content	SB	SB	SB

Dissertation Abstract

Purpose: To contribute to improved screening of patients for spiritual suffering and subsequently referring to specialized spiritual care services at an urban complex continuing care hospital in Ottawa, Canada.

Methods: I conducted a series of studies using different methods including:1) A systematic review to synthesize the evidence regarding the accuracy of measures to screen adults for spiritual suffering, 2) a qualitative study to iteratively select a measure to screen patients for spiritual suffering and simultaneously plan for its implementation, and 3) A diagnostic test accuracy study protocol that examines the accuracy of the selected screening measure in a complex continuing care hospital.

Findings: In the systematic review, we identified five articles that provided information on 24 spiritual screening measures and their diagnostic accuracy criteria. The methodological quality of all included studies was low. Healthcare providers in the focus group interviews specified eight considerations they believed were important for selecting a spiritual screening measure. Among 24 identified measures in the systematic review, they selected the *Peace and Meaning/Joy* as the measure that best met these considerations. Healthcare providers and patients determined the implementation process of the selected screening measure for their hospital. Participants in my study believed that nurses need special training to use the selected screening measure.

Conclusion: Driven by demands to integrate spiritual care into routine patient care, this research identified evidence-based spiritual measures, contributed to the development of a plan to implement a spiritual suffering screening measure, and development a methodologically rigorous protocol to examine the accuracy of the selected screening measure. Findings from this doctoral

thesis provide information about strategies of screening that can be considered an essential step toward addressing some of the clinical issues and research priorities surrounding identifying patients with spiritual suffering, however, there is much work to be done.

Acknowledgements

I would like to express my sincere gratitude to my supervisors Dr. Ian D. Graham and Dr.Wendy Gifford for the continuous support of my Ph.D study, for their patience and immense knowledge. Their guidance helped me in all the time of research and writing of this thesis. Besides my supervisors, I would like to thank the rest of my thesis committee: Dr. Mary Egan, Dr. Suzette Brémault-Phillips, and Rebekah Hackbusch for their support, feedback, and comments which incented me to widen my research from various perspectives. In particular, I am grateful to Dr. Mary Egan for her insightful comments and encouragement during my study. My sincere thanks also goes to Rebekah Hackbusch who supported me during the recruitment process and data collection. I was fortunate to have such a great and supportive committee members. I would like to thank my family: my parents and my sister for supporting me spiritually throughout writing this doctoral thesis and my life in general.

I was privileged to have funding from the Board of the Canadian Foundation for Spiritual Care, CIHR Integrated Knowledge Translation Research Network Doctoral Fellowship (FDN143237), Ontario Graduate Scholarship, the Nicole Bégin-Heick Scholarship, and the International Student Bursaries of the University of Ottawa – thank you!

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

As a nurse in Iran while I provided care for patients with progressive diseases, I came to realize the importance of the spiritual domain in nursing care and how it related to patients' physical and psychological wellbeing. When I moved to Canada to obtain a PhD in nursing at the University of Ottawa, my interest in spiritual suffering and care continued. As I was looking for a thesis topic, I was introduced to the Coordinator of Spiritual Care at the Saint Vincent Hospital. This hospital is a faith-based institution that provides complex continuing care programs for patients with complex and progressive diseases. During conversations with the Coordinator of Spiritual Care, she revealed that the screening of patients for spiritual suffering had not been routinely happening and that it was a research priority in this institution. There were also concerns about referrals to clinical chaplains for spiritual suffering that were not always appropriate (i.e., some patients were not being referred when they should have been or vice versa). The coordinator, my supervisors, and I then discussed and negotiated an applied research project that I could use for my doctoral thesis, and at the same time the findings would benefit the hospital.

1.1 Research Purpose and Objectives

The overall purpose of this dissertation was to contribute to improved screening of patients for spiritual suffering and subsequent referral to specialized spiritual care services at an urban complex continuing care hospital in Ottawa, Canada. This research aimed to address the following objectives:

Objective 1. Synthesize the evidence regarding the accuracy of measures to screen adults for spiritual suffering.

Objective 2. Identify the perceptions of nurse managers, registered nurses, and clinical chaplains on key considerations in selecting a spiritual screening measure for use at their complex continuing care hospital.

Objective 3. Identify a spiritual screening measure that nurse managers, registered nurses, and clinical chaplains consider most appropriate for use at their complex continuing care hospital.

Objective 4. Determine the perspectives of nurse managers, registered nurses, and clinical chaplains on the process of implementing the selected spiritual screening measure at the complex continuing care hospital.

Objective 5. Determine the perspectives of patients on use of the selected measure at the complex continuing care hospital.

Objective 6. Develop a research protocol to determine the accuracy of the selected spiritual screening measure at the complex continuing care hospital.

1.2 Background

1.2.1 The concept of spirituality

Lack of consensus on what constitutes spirituality and related concepts within the literature poses difficulties when interpreting findings from research studies in this area. There is a myriad of definitions of spirituality in the literature. For example, Puchalski and Ferrell (2010) described 14 definitions of spirituality in their book, *Making Healthcare Whole: Integrating Spirituality into Patients Care,* while Unruh and colleagues (2002) identified 91 definitions in a critical review on definitions of spirituality. According to Villagomeza (2005),

some of the common and overlapping constructs that help us understand this concept of spirituality are:

1- A sense of meaning and purpose in everyday life: The ability of a person to make sense of desirable or undesirable life situations.
2- A sense of connectedness: Manifested in meaningful relationship with self, others, nature, and with God or superbeing.
3- Faith and religious belief system: Spirituality and religion are not the same concepts; however, spirituality is a universal dimension of human health that can encompass religious perspectives.
4- A value system: Relates to a person's cherished standards, worth of thoughts and behaviours.
5- A sense of self-transcendence: Defined as *"*an expansion of personal boundaries beyond the immediate or constricted views of oneself and the world*"*.
6- A sense of inner peace and harmony amidst the chaos of life, and fear and uncertainty when experiencing life-altering or life-threatening illnesses. Spirituality promotes a positive and peaceful state of mind in an individual.
7- A sense of inner strength and energy that is integrative and unifying beyond the physical realm. This energy is a positive and creative life force which create hope and motivation.

Having a clear definition of spirituality could provide a clear lens through which related concepts and research into spirituality could be viewed (Villagomeza, 2005) However, the complexity of the human spirit makes a definition difficult (Puchalski &Ferrell, 2010). Consequently, studying spirituality and related concepts such as spiritual care and spiritual

suffering has unique challenges (Posnanski & Ferri, 2010; Villagomeza, 2005). In 2009, Puchalski and colleagues brought together interdisciplinary experts in the field of spirituality and healthcare and engaged in a consensus process to define the concept. Participants agreed to define spirituality in the context of healthcare as an "aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred" (Puchalski et al., 2009, P887). This definition has been adopted to guide understandings of spirituality within dissertation.

1.2.2 Spiritual suffering

Spiritual suffering is a concept that is used to refer to effects of unmet spiritual needs in human beings (Calderira, 2013). Spiritual needs are conceptualized based on the constructs of spirituality such as having a meaning and purpose in life, connectedness, hope, inner peace, spiritual practices, morality, forgiveness and creativity (Calderira, 2013; Galek et al., 2005). Spiritual suffering can have different degrees of intensity depending on the number and severity of unmet needs (Agora Spiritual care guideline, 2013; Puchalski & Ferrel, 2010; Villagomeza, 2005). Previous research has shown that failure to address spiritual needs can result in spiritual suffering and negative physical, psychological and social consequences such as super imposed diseases (e.g., myocardial infarction or hypertension), harm to self (e.g., substance abuse), or suicide (Villagomeza, 2005). Possible antecedences of spiritual suffering include disease related stressors (e.g., initial cancer diagnosis, fear of unknown, prolonged hospitalization), loss of important relationships (e.g., family member death or illness), or ineffective spiritual coping

strategy (e.g., prolong denial) (Agora Spiritual Care Guideline, 2013; Agrimson & Taft, 2008 ; Villagomeza, 2005).

The following signs and symptoms represent some of the most common manifestations of spiritual suffering (Agora Spiritual Care Guideline, 2013; Caldeira et al., 2017; Villagomeza, 2005).

- Expressing suffering
- Expressing despair and anger or frustration towards others or God
- Feeling separated from personal source of comfort and strength
- Exhibiting alienation
- Expressing inability to accept self (Questioning identity)
- Verbalizing inner conflicts about beliefs
- Verbalizing loss of faith
- Reporting a lack of meaning in life
- Questioning the meaning of own existence
- Expressing lack of serenity
- Experiencing nightmares, insomnia, or sleep disturbances
- Exhibiting fatigue
- Demonstrating inability to experience previous state of creativity
- Questioning the meaning of suffering
- Expressing hopelessness or guilt
- Exhibiting altered behaviour or mood such as anger, crying, preoccupation, anxiety, or apathy
- Describing somatic complaints (physical expression of spiritual suffering)

1.2.3 What is known about spiritual suffering

Patients experience spiritual suffering when their need to find meaning and purpose in life through connectedness with self, others, nature and/or what one holds to be sacred is unfulfilled (Cobb, Puchlaski, & Rumbold, 2012). Spiritual suffering exists in up to 50% of chronically ill and dying patients and has an association with poor physical and mental health outcomes (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Manning-Walsh, 2005; Oshvandi et al., 2018;

Pargament et al., 2004; Tajbakhsh et al., 2018; Vazifeh et al., 2019; Winkelman et al., 2011). Pargament and colleagues (2004) reported that spiritual suffering was associated with increased functional limitations and depressive symptoms in elderly patients. In one study spiritual suffering was also associated with increased risk of mortality, even when controlling for demographic, physical, and mental health factors (Pargament, Koenig, Tarakeshwar, & Hahn, 2001). Other researchers have reported an inverse relationship between patients' spiritual suffering and quality of life, coping with illness, and life satisfaction in different countries (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Manning-Walsh, 2005; Pargament et al., 2004; Pérez-Cruz et al., 2019; Sherman, Plante, Simonton, Latif, & Anaissie, 2009; Szcześniak, et al., 2019; Winkelman et al., 2011). Acknowledging the importance of spiritual suffering, guideline and models for spiritual care (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009) reinforce the importance of early screening and appropriate referrals to specialized care for patients with spiritual suffering.

1.2.4 Spirituality and nursing

Nurses are in a position to identify patients at risk of spiritual suffering (Agora Spiritual Care Guideline, 2013; Neuman & Fawcett, 2011; Puchalski et al., 2009). A theoretical framework that has frequently been used for investigating spirituality in nursing is Betty Neuman's Systems Model (NSM). The NSM is predominantly a holistic model that explains the importance of spirituality and the role of nurses in addressing spiritual concerns (Neuman & Fawcett, 2011). According to Neuman, each human being is a composite of five interacting domains that both influence and are influenced by each other: physiological, psychological, developmental, socio-cultural, and spiritual. In the NSM, how the domains interact determines

the nature and degree of illness and wellness. Neuman defined wellness by the amount of stability, where all five domains are in balance in a human being as a whole.

Neuman gives special attention to the spiritual domain and emphasizes the importance of spirituality in nurses providing truly holistic care for patients (Neuman& Fawcett, 2011). She explains that spirituality encompasses the search for meaning in life, which may or may not include religious beliefs. She views spirituality on a continuum of development that permeates all other domains. Neuman suggests that each person is born with a spiritual energy force. “The spirit controls the mind, and the mind controls the body” (Neuman & Fawcett, 2011, p. 17). When a life event such as a great tragedy impacts the human spirit, the energy of the spirit is mobilized and displays itself through mental and physical expressions of the human being. If the thought patterns are positively affected, the body positively uses the spiritual energy empowerment (e.g., the effect of joy on the improvement of the immune system). By contrast, the negative use of spiritual energy will result in adverse outcomes for the body. Therefore, spiritual development in various degrees empowers human being toward well-being.

Neuman considers nursing to be a unique profession concerned with all five domains: physiological, psychological, developmental, socio-cultural, and spiritual. According to Neuman, the primary focus of nursing is assessing all these domains and help patients to keep them in balance. She (1995) states explicitly that consideration of the spiritual domain is necessary for gaining a genuinely holistic perspective and truly caring for the patient. She emphasizes the importance of considering patients’ spiritual concerns routinely in nursing practice. Thus, within NSM, identifying spiritual suffering in patients and providing appropriate support is part of holistic nursing.

Support for spirituality has been recognized as a multi-professional and cooperative practice (Puchalski & Ferrel, 2010). Nurses, physicians, social workers, psychologists, and clinical chaplains may have different but overlapping roles in providing spiritual care (Walton, Leget, Geer, Graeff, & Slootweg, 2010). Sinclair & Chochinov (2012) outline three levels of spiritual care that healthcare providers, including nurses, can provided to patients. In the following section, I briefly explain levels of spiritual care and the nursing care and interventions that can be applied in each level.

Primary spiritual care is a level of care that can be provided by generalists in spiritual care such as nurses or physicians (Puchalski & Ferrel, 2010). This level of care requires basic skills and interventions to assess and meet patients' spiritual issues such as the using simple instruments, communication skills (e.g., meaningful conversation, active listening**,** presence) to identify patients' spiritual issues, and make referral for additional support. With little training, some of the skills to provide spiritual care at the primary spiritual care level can also be acquired by volunteers or patient's family members.

Supportive spiritual care is a level of spiritual care that is provided by religious leaders, lay ministers, or clinicians such as nurses that have additional training or experience in addressing spiritual issues. Supportive spiritual care includes counseling, administrating religious rituals and more focused interventions related to issues identified at the primary spiritual care level.

Specialized spiritual care is a level of care that is provided by specialists in spiritual care such as clinical chaplains and is associated with in-depth assessments and treatments of

spiritual suffering and emotional distress. Specialized spiritual care is also involved in providing spiritual resources to help patients facing serious health problems.

1.2.5 Nursing interventions regarding levels of spiritual care

In this section, I provided information on primary and supportive spiritual care interventions that nurses can provide to patients. I then discuss screening for spiritual suffering as the focus of my thesis.

1.2.5.1 Primary Spiritual Care

Interventions under the level of the primary spiritual care that nurses can provide are assessment and screening; verbal and non-verbal communications; and referral. It is important to note that patients' spirituality has a sensitive nature and nurses need to establish a therapeutic relationship with patients before providing any type of spiritual intervention (Puchalski & Ferrel, 2010; van Leeuwen, 2006). The therapeutic nurse-patient relationship is a goal-directed connection between a nurse and a patient for the purpose of meeting patient's needs (Nurses Association of New Brunswick, 2015). The therapeutic nurse-patient relationship supports patients' dignity and autonomy and allows the development of trust and respect (Nurses Association of New Brunswick, 2015).

Assessment and screening.

According to the literature, using a spiritual assessment or screening instrument to identify patients' spiritual needs are among the basic activities of healthcare providers including nurses (Dudley, Smith, & Millison, 1995; O'Brein, 2018; Vivat, 2008). This assessment can be performed by means of a specific instrument or through a meaningful conversation (Dudley et al., 1995). (Please see section 1.2.4 *Screening for Spiritual Suffering* (p. 12) for more details).

Verbal or non-verbal Communication.

A meaningful conversation is considered a basic component of spiritual care. Meaningful conversation should not be forced and should flow naturally (Planalp, Trost, & Berry., 2011). Examples of meaningful conversation are discussions of the meaning of life, life stories, death, spirituality, relationships, and patients' source of strength, spiritual support in the past, concerns, attitudes, values, beliefs, confusion, doubts, and current feelings about their illness (Dudley et al., 1995; Planalp et al., 2011; Reblin, Otis-Green, Ellington, & Clayton, 2014; Walter, 1997). Active listening, compassionate presence, therapeutic touch, in addition to providing privacy and treating individuals with dignity, are the main non-verbal supports (Kisvetrová, 2013; Toivonen, 2015).

Referring.

Nurses, family members and volunteers are commonly identified as providers of the primary spiritual care. However, upon the request of patients, or at times of crisis, patients can be referred to specialists in spiritual care such as clinical chaplains, psychologists, or psychiatrists. (Agora Spiritual Care a guideline, 2013; Luxardo, Brage, & Alvarado, 2012; Timmins et al., 2018). According to the Agora Spiritual Care Guideline, (2013) and Puchalski & Ferrel (2010), the following are signs of a patient who may benefit from a referral for supportive or specialized spiritual care:

- Patient's self-report: spiritual suffering or a spiritual crises may not be explicitly expressed, but patients may use phrases such as, "I feel I cannot deal with this anymore" or "I feel lost".

- Changes in patient's usual behavior or staying in a chronic bad and aggressive mood for a significant time (weeks/months).
- Extensive somatization, self-isolation, wishing to die.
- Report of sever despondency of the patient by people around him/her.

In addition, organization polices, resources and consensus between the interdisciplinary team members may facilitate generalists providers to make referrals to specialists in the following circumstances (Agora Spiritual Care Guideline, 2013; Timmins et al., 2018):

- When it is suspected that something more for patients should be done, but it is unclear what or how.
- When patients need re-assessment (e.g., when new change happens in their conditions).
- When Patients experience of guilt and powerlessness.
- When Patients and their families' need rituals.

1.2.5.2 Supportive Spiritual Care

Nurses with additional training or experience can provide a number of interventions that fall under the supportive level of spiritual care such as supportive religious activities or facilitating connections.

Supporting religious activities.

This category includes praying, using spiritual music, reading scriptures, and using religious items (Carr, Hicks-Moore, & Montgomery, 2011; Herlianita et al, 2018; Minton & Isaacson, 2016; Toivonen et al., 2015). Praying with patients, or arranging a prayer session for them, is one of the common supportive nursing care activities mentioned in the literature (Elham, Hazrati, Momennasab, & Sareh, 2015; Stranahan, 2001). Most studies prior to1990 focused on

supporting patients with religious activities, with research tending toward more secular spiritual interventions after 1990 (Emblem, 1992; Musa, 2017).

Facilitating connections.

This category includes supporting individuals to connect to themselves, other people, and nature (Toivonen, 2015). Knowledge of the patient's spiritual background to support his or her spirituality helps facilitate fulfilling this goal (Keast et al., 2010). This category includes non-religious supports which can be a combination of art-therapy and psychological interventions such as, casting; music therapy; meditation; relaxation; guided imagery; providing spiritual literature, or radio or TV programs for the individual; and life reviewing (Ando et al., 2010; Connolly & Moss, 2019; Kisvetrová, Klugar, & Kabelka, 2013; Musa, 2017; Rutenberg, 2008).

1.2.6 Screening for Spiritual Suffering

Clinical chaplains are specialists who have advanced training in providing spiritual care within health care settings (Sinclair & Chochinov, 2012; Summary & Goal, 2004). Clinical chaplains generally visit three categories of patients: (1) those who request specialized spiritual care, (2) patients who clinical chaplains identify on their rounds of new patients, and (3) those who staff refer for specialized spiritual care (Fitchett, Meyer, & Burton, 2000). When it comes to identifying patients with spiritual suffering, the first two categories have serious limitations (Fitchett et al., 2017; Fitchett, Meyer, & Burton, 2000). A study of 200 newly admitted medical and surgical patients several years ago demonstrated the limitations of relying on patient self-referrals (Fitchett, Meyer, & Burton, 2000). In that study, researchers asked patients if they wanted to receive spiritual care from clinical chaplains; approximately one-third of the patients requested the service. The researchers examined whether patients with spiritual suffering were

more likely to request spiritual care. They reported that as the patient's level of need increased, the chance of requesting spiritual care generally increased. However, patients with low spiritual resources were significantly less likely to request spiritual care compared to those with high spiritual resources. They metaphorically described patients with spiritual suffering who have high spiritual needs, but low spiritual resources as "lost sheep", and emphasized the need to use screening measures to identify such patients as they are unlikely to signal their suffering by requesting spiritual care.

Making rounds on all newly-admitted patients is a time-consuming process and not all facilities have sufficient clinical chaplains to do so (Fitchett et al, 2017; Fitchett, Meyer, & Burton, 2000). To date, I could find no study that reported using screening of all newly admitted patients by clinical chaplains in an in-patient setting.

The most effective and practical method to screen patients for spiritual suffering is requesting non-chaplain health care staff to do so and refer those who have positive results to clinical chaplains for in-depth assessment (Puchalski et al, 2009; Agora Spiritual Care Guideline, 2013). According to the Agora Spiritual Care Guideline (2013), a brief measure to screen for spiritual suffering could help staff make appropriate referrals and reduce the time that clinical chaplains spend trying to identify patients who need specialized spiritual care. A spiritual care model and guideline recommend that nurses perform the screening for spiritual suffering (Puchalski et al, 2009; Agora Spiritual Care Guideline, 2013).

Nurses have a longstanding commitment to providing holistic care that includes attention to the patients' spiritual dimension (Carson & Koenig, 2008; Taylor, 2006). Nurses make more referrals to clinical chaplains than do any other healthcare provider (Galek et al., 2009).

However, in practice, nurses' referrals are not likely to help efficiently identify patients with spiritual suffering who require chaplaincy services because nurses mostly refer religious patients with significant levels of spiritual resources to clinical chaplains (Blanchard et al., 2012; Coordinator of Spiritual Care, personal communication, 2017; Fitchett, Meyer,& Burton, 2000). Researchers believe that the use of a spiritual suffering screening measure can improve the ability of nurses to identify and refer patients at the risk of spiritual suffering to the clinical chaplains those (Fitchett et al, 2017; King et al, 2017; Puchalski et al, 2009). Screening by non-chaplain staff such as nurses will also help clinical chaplains focus their attention on patients who are most likely to need their services (Coordinator of Spiritual Care, personal communication, 2017; Fitchett et al., 2017; Puchalski & Ferrell, 2010).

1.2.7 Factors Influencing Nurses' Screening for Spiritual Suffering

Despite nurses' desire to screen patients for spiritual suffering (Blanchard et al., 2012) researchers have reported two main barriers to the identification and referral of patients to clinical chaplains: (1) lack of time (Bakir, Samancioglu, & Kilic, 2017; Balboni et al., 2014; Edwards et al., 2010), and (2) lack of training in the spiritual domain (Balboni et al., 2014; Bar-Sela et al., 2019; Edwards, et al., 2010; Ross, 2006). Based on these barriers, it is preferable that screening patients for spiritual suffering fit into routine nursing activities by use of a short and simple measure that does not require specialized knowledge and skills about spiritual domain (Vlasblom, Van Der Steen, Walton, & Jochemsen, 2015). Spiritual screening measures are brief, and do not require specialized training (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009), and nurses can incorporate them into the existing history that they take when admitting patients to hospital (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009; Vlasblom et

al., 2015). While in recent years many measures have been developed for spiritual assessment or history taking, at the present time we have a limited number of measures that have been developed specifically to screen for spiritual suffering (Bahraini et al, 2019; King et al., 2017).

It is important to note that confusion about the concept of spirituality adds to the difficulties in identifying spiritual suffering. Spirituality has been identified as one of the core components of palliative care, but there is no generally agreed definition of this concept (Koenig, 2009; McSherry, 1998). Although spirituality has become better known within healthcare, the concept is still difficult to interpret. This can be attributed to the subjective nature of spirituality (Draper & McSherry, 2002). Confusion about the definition of spirituality is one of major difficulties in identifying spiritual suffering (McEwan, 2004; Narayanasamy & Owens, 2001). Despite more than 90 content analysis studies on spirituality (Sessanna, Finnell, & Jezewski, 2007), research shows that healthcare providers are unsure of this concept and it's related items such as spiritual suffering. This happens to the extent that an international survey among 85 countries, including Canada, ranked understanding of spirituality and spiritual care as a top research priority in spiritual care globally (Selman et al., 2014). It also may explain the bias which exists in a lot of spiritual research because researchers define spirituality from a personal perspective. The other difficulty in identifying spiritual suffering is related to patients. It may be difficult too for patients to express their spiritual suffering or needs (even within close family members) and the healthcare providers. Fear of being judged is one of the main preventors, however, sometimes, even if patients want, do not know how to articulate their spiritual suffering (The Agora spiritual Care guideline, 2013; Puchalski & Ferrell, 2010).

Among the screening measures available, evidence of their accuracy including their sensitivity (the ability to accurately identify those with spiritual suffering) and specificity (the ability to avoid identifying someone with spiritual suffering who does not have it) is limited (King et al., 2017, Bahraini et al., 2019). For example, to date, researchers have not examined the accuracy of the Negative Religious Coping Scale (N-RCOPE) (Pargament et al., 1998) a commonly used tools (Fitchett et al., 2017; Grossoehme et al., 2016; King et al., 2017) to identify spiritual suffering (Bahraini et al., 2019). Among a few measures with reported accuracy, the majority have been tested in patients in cancer settings (Fitchett et al., 2017, King et al., 2017, Schultz et al., 2017). Therefore, it is unclear whether we can extend the results to different patient populations. In a mixed-methods study, clinicians and researchers from 87 countries, including Canada, ranked identification and evaluation of spiritual screening measures as one of the top research priorities, revealing a need for conducting more research and in different populations to identify whether spiritual screening measures can accurately determine such suffering in patients (Selman et al., 2014).

1.3 Problem in the Clinical Setting

Saint Vincent Hospital (SVH) is Ottawa's sole provider of complex continuing care, a program with the goal of addressing clients' physical, emotional, social and spiritual needs, thereby improving quality of life. Patients at SVH have complex medical problems and are dependent on other people to complete their activities of daily living, specifically bed mobility, transfers, toileting, and feeding (Bruyère, 2019). They usually have progressive diseases such as chronic respiratory and renal failure, comorbid medical conditions, severe and chronic functional impairment, or specialized wound care needs. With research showing that spiritual suffering

exists in approximately half of patients with progressive and chronic health issues (Chaves et al., 2010; Hui et al., 2011), there is a high probability that many patients at SVH are experiencing spiritual suffering.

Currently at SVH, registered nurses ask two spiritual suffering related questions on the admission intake form while assessing newly admitted patients: 1) “Would you like a clergy visit? and 2) Would you like spiritual care incorporated into your plan of care?”. The questions on the SVH admission intake form are not evidence-informed screening questions and according to the coordinator of spiritual care (R.H) and director of therapeutic support service at SVH (K. L), were not effectively screening patients (The coordinator of spiritual care & the director of the therapeutic support service of the hospital, personal communication, April 16, 2017). Therefore, patients who experience spiritual suffering often remain under-identified using the current method. Simultaneously, many patients who are referred to clinical chaplains to address their suffering do not require specialized spiritual care and are deemed inappropriate for referral (The coordinator of spiritual care, personal communication, April 16, 2017). With limited number of clinical chaplains available at the hospital, and spiritual suffering negatively impacting patients’ physical and psychological health outcomes including decreased quality of life and coping with illnesses (Oshvandi et al., 2018; Pargament, Koenig, Tarakeshwar, & Hahn, 2004; Ramirez et al., 2012; Tajbakhsh et al., 2018; Thuné-Boyle et al., 2013; Vazifeh et al., 2019), the director of the therapeutic support service and the coordinator of spiritual care deemed screening for spiritual suffering a top priority for research at the hospital. They emphasized the need to systematically screen patients for spiritual suffering using an effective screening measure and subsequently make an appropriate referral to clinical chaplains for addressing patients’ suffering.

1.4 Conceptual Frameworks

A conceptual model and a spiritual care guideline informed the current research. I used the Inpatient Spiritual Care Implementation Model (ISCIM) to understand the structure of implementing spiritual care in a hospital including screening for spiritual suffering (Puchalski et al., 2009). I employed the Agora Spiritual Care Guideline (2013) to understand the role of nurses and other health care providers in addressing patients' spiritual suffering as well as understanding the characteristics of spiritual suffering screening measures compared to other spiritual tools.

1.4.1 The Inpatient Spiritual Care Implementation Model

Puchalski and colleagues (2009) developed the Inpatient Spiritual Care Implementation Model (ISCIM) to integrate screening for spiritual suffering, as well as spiritual history taking and assessment into the routine care provided by interdisciplinary team members (Figure 1.2). The ISCIM is based on honoring the dignity of all patients. Puchalski and colleagues (2009) claim that healthcare providers ought treat spiritual suffering with the same aim and urgency as they treat pain or any other medical and social problem. Just as pain is screened routinely, screening for spiritual suffering should be part of routine care.

Within the ISCIM, a healthcare provider, such as a nurse, initially screens a patient upon arrival to the hospital to determine whether the patient is experiencing spiritual suffering and requires a referral to a clinical chaplain or a specialized spiritual assessment and care. The ISCIM model considers clinical chaplains as specialists who provide specialized spiritual care including in-depth assessment and treatment. However, other clinicians such as nurses are considered generalists in providing spiritual care and are ideally positioned to provide screening

and referrals to clinical chaplains (Puchalski et al., 2009).

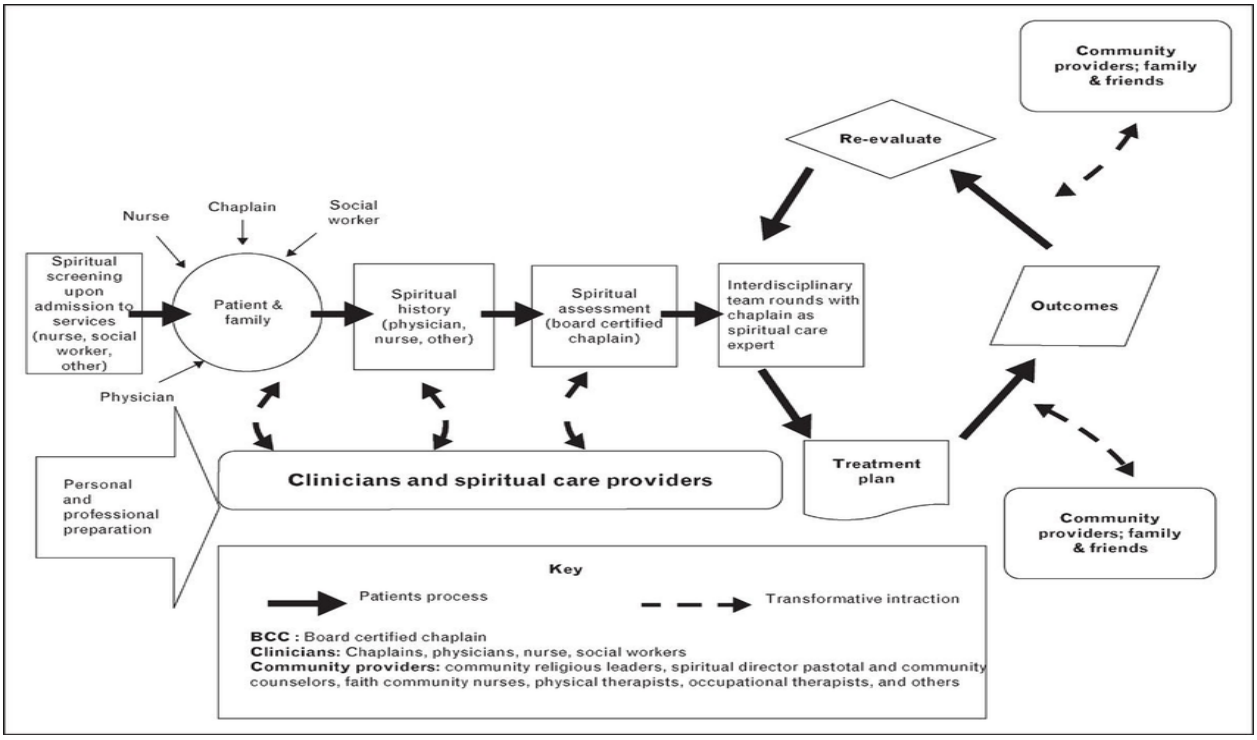


Figure.1.2 The Inpatient Spiritual Care Implementation Model. Reprinted from "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," by C.M. Puchalski, B. Ferrell, R.Virani, S. Otis-Green, P.Baird, J. Bull, …& D. Sulmasy. 2009, *Journal of Palliative Medicine*, p. 891. [Used by permission, Journal of Palliative Medicine]

My thesis is related to the first step (spiritual screening) in the ISCIM. This step involves screening for spiritual suffering by generalists such as nurses in inpatient settings. Using the ISCIM, nurses can screen patients upon arrival to hospital and refer those who are experiencing spiritual suffering to specialists such as clinical chaplains for a spiritual assessment and care (Puchalski et al., 2009). To gain a more fulsome understanding of how screening fits within the ISCIM model, I will briefly explain other steps of the model.

Spiritual history taking is the second step of the ISCIM model to integrate spiritual care into routine care (see Figure 1). Generalists with additional training such as physicians or nurses

can take patients' spiritual histories as a part of the admission history taking. They can use validated tools that are designed specifically for assessing patients' spiritual history. These tools are different from screening measures in terms of their purpose and length. Spiritual history taking tools are longer and generalists need more training to use them compared to using a screening measures. Based on spiritual needs or concerns raised in spiritual history taking, a generalists provider such as a nurse may refer patients to a spiritual care specialist such as a chaplain. Chaplains provide an in-depth assessment of patients who were referred to them through spiritual screening or history taking. The interdisciplinary team can then work with chaplains to develop a treatment plan, who measure outcomes with appropriate re-evaluation and follow up. Community clergy, religious leaders, and spiritual directors may be involved in the care. Chaplains usually coordinate the community spiritual care professionals. Based on the ISCIM, clinicians need to do thoughtful work to gain insight into their own sense of spirituality, meaning, and professional the capacity to provide compassionate and skillful care. The reflective process enables clinicians to be entirely intentional with their patients and lead them to an ability to partner with them fully through illness. The ISCIM model shows a big picture of the structure of implementing spiritual care in a hospital and where screening for spiritual suffering is located in this big picture (Puchalski et al., 2009).

1.4.2 The Agora Spiritual Care Guideline

I used the Agora Spiritual Care Guideline (2013) to understand the role of each discipline (i.e., nurses, physicians, social workers, physiologists, and clinical chaplains) in addressing patients' spiritual concerns.

1.4.2.1 An intradisciplinary guideline

According to a literature review (Rushton, 2014) regarding barriers to providing spiritual care in a hospital setting that included 136 articles, a lack of guidelines is one of the main obstacles to spiritual care to patients as the role of nurses in addressing patients' spiritual concerns has not been clearly outlined. I searched online guideline databases such as the Guidelines International Network, National Institute for Clinical Excellence (NICE), Registered Nurses' Association of Ontario (RNAO), and the New Zealand Guidelines Group for spiritual care guidelines. In line with the result of Rushton's (2014) review, I realized that for healthcare providers such as nurses, spiritual care was embedded in palliative care guidelines with a brief explanation about the spiritual care aspect (National Institute for Clinical Excellence, 2004). The one exception was the Agora Spiritual Care Guideline (2013). To the best of my knowledge, this Spiritual Care Guideline is the only comprehensive and interdisciplinary guideline written for nurses, physicians and other healthcare providers that specifically looks at spiritual care. The guideline is consensus-based although the developers of the guideline have not provided detailed information on the methods of reaching to consensus (e.g., Delphi Technique or Nominal Group Technique) (see Appendix A for details on the score of the guideline based on the AGREE 2 checklist).

1.4.2.2 The spiritual process in patients

According to the Agora Spiritual Care Guideline (2013), patients who encounter crises such as life-threatening diseases go through a spiritual process. The spiritual process includes the following stages:

- Awareness of finiteness, which happens as soon as someone is faced with a critical situation. Awareness of finiteness increases during stable periods of disease when there is more time to think where life may lead to.
- Loss of grip on life, where patients feel as if they have lost all "grip on life." Their previous constructs of meanings of life are not enough to help deal with the new situation. Patients at this stage reveal negative emotions such as anxiety, panic, powerlessness, or loneliness.
- Loss of meaning, when life feels as if it is becoming meaningless. At this stage patients do not engage in activities or make plans. After a few days, the emotional impact of the first shock will typically diminish and patients realize that they are not going to die immediately.
- Bereavement: As the initial reaction of shock diminishes, patients concentrate more on the things that they must let go of such as family and plans.
- Experience of connectedness: At this stage patients unexpectedly experience connectedness to a greater whole. Mostly this phase happens when patients risk confronting their threatening situation. This experience is often difficult for patients to verbalize, and they feel that others may judge them, thus will only share their experiences with people they trust.
- Experience of connectedness: At this stage patients unexpectedly experience connectedness to a greater whole. Mostly this phase happens when patients risk confronting their threatening situation. This experience is often difficult for patients to

verbalize, and they feel that others may judge them, thus will only share their experiences with people they trust.

- Integration of meaning and experience of connectedness: At this phase patient search for meaning of life and connectedness. Patients concentrate more on here and now and gain a new sense of balance in life. Patients may feel that their life has more to offer and at this phase they usually become connected with a higher presence such as God or nature.

At various stages of this process, patients may have spiritual needs that require different levels of support or consultation. For example, patients may be resistant to the reality of their illness or stay in one of the stages in the spiritual process for extended periods of time and they develop negative emotions. Patients may become preoccupied with the things that they have to let go of, or they may become obsessed with negatives thought about their future treatment (i.e., obsessively assume worst case scenario). According to the guideline, there is a need for chaplains or psychologists' referral when preoccupation with negative feelings such as anxiety and meaninglessness prolong overtime or dominate patients' communication and behaviours. This level of spiritual suffering can be harmful and should be addressed through specialists in spiritual care. Not addressing spiritual suffering at this level can lead to mood disorders and/or a "death wish" (Agora Spiritual Care Guideline, 2013, page 4). Patients who exhibit signs such as extensive somatization, self-isolation, severe dependency on others, the desire to die, or experience changes in behaviour such as prolonged bad and aggressive moods lasting for weeks or months require specialized spiritual care (Agora Spiritual Care Guideline, 2013).

1.4.2.3 Role of each discipline

The policy section of this guideline is structured according to the type of situation and the roles of various providers (see Table 1). There are explanations of different types of spiritual care for each discipline depending on the severity of spiritual needs. According to the guideline, physicians or nurses are recommended to use a screening measure to identify and refer patients who are at the risk of spiritual suffering for specialized spiritual care.

Table 1 - Types of spiritual care per discipline

		Doctors and nurses	**Medical social workers, psychologists**	**Healthcare chaplains**	
	Primary focus, access, and frame of reference	*Somatic*	*Psychosocial*	*Spiritual*	
A	**Attention** (always)	Listening supporting, recognizing and screening*	Listening supporting, recognizing and screening *	Listening supporting, recognizing screening * and interpreting	Representing and connecting
B	**Counselling** (upon request of the patient)	Following the search process, referring, and assessing*	Following the search process, referring, ( ), and assessing*	Following the search process, ( ) referring, assessing*, interpreting and appraising*	
C	**Crisis intervention** (if indicated)	Detecting, referring	Recognizing counselling, treating and referring ( )	Recognizing counselling, (sometimes) treating, ( ) referring interpreting and appraising*	

Note: reprinted from the Agora Spiritual Care Guideline (2013). Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf [used by permission, Integraal Kankercentrum Nederland (IKNL)]

Table.2 Recommendations for Nurses to Create Safe and Trusting Atmosphere for Patients

- Provide a trusting relationship.
- Be present in the moment, without imposing yourself.
- Tune yourself in to the patient's needs.
- Show authentic interest and attention for the patient's feelings.
- Listen and observe attentively.
- Have an open attitude and reply patients with empathy.
  Suspend any judgment.
- Offer advice and solutions at the right moment. Enable person to make contact with his own strengths.
- Do not take patients' negative emotions personally. Remain available for the patients even though there is nothing else that can be done for them.

Section A (Table.1) shows that along with being attentive to the spiritual dimension (listening and supporting), screening is recommended (i.e., briefly checking the spiritual situation of every patient). Nurses can screen patients using a few screening questions to establish any need for specialized spiritual care. This guideline clarifies that screening patients for spiritual suffering differs from spiritual history taking or in-depth assessment. The purpose of screening is to identify people at risk of spiritual suffering so that nurses or physicians can refer them for specialized spiritual care. A general healthcare provider such as a nurse can screen patients without special training in the spiritual domain, and the duration of time for using a screening measure is often brief. The developers of the guideline did not introduce any evidence-based screening measure. Rather, they offered examples of possible screening questions:

· Is there at this time anything in particular that you are concerned about?

· Where did you previously find support in difficult situations?

· Who would you like to have near you? From whom would you like to have support?

The aforementioned questions, while not evidence-based, were presented as a sample of brief screening questions that nurses can use in the absence of training. The developers of the guideline did not present any response options nor threshold for these sample questions to determine whether a patient required specialized spiritual care based on his/her response.

The content of the Agora Spiritual Care Guideline is aligned with ISCIM. For example, this guideline differentiates spiritual screening from spiritual history taking and in-depth assessment of patients. It also provides more details on signs of spiritual suffering and general recommendations for providing spiritual care that can enhance nurses' understanding of this type of suffering and how to provide appropriate support. Compared to the ISCIM, the guideline provides more information to understand the professional boundaries between generalists (e.g., nurses) and specialists (e.g., clinical chaplains) for screening and providing care to patients experiencing spiritual suffering.

1.4.3 Application of the Model and Guideline in the Thesis

I used the spiritual screening measure as a recommended approach in the guideline and model for identifying patients at risk of spiritual suffering in an in-patient setting. Together the model and guideline reveal the structure of implementing spiritual care and locates screening for spiritual suffering within the process of spiritual care and the roles of each discipline regarding screening. Understanding the roles of different disciplines toward screening for spiritual suffering helped me select participants for my study (Chapter 3). I conducted focus group

interviews with nurse-managers, nurses and clinical chaplains regarding the healthcare providers' role toward screening both in the guideline, as well as in the ISCIM model, and by using available human resources at the hospital. At the SVH few social workers and psychologists were available, therefore, there were human resource limitations. We had a discussion with K.L and R.H to determine professions who can attend to our focus group interviews according to the suggested professions from the guideline and model. Eventually, we invited nurses and nurse managers as representors of non-chaplain healthcare providers at SVH. I also invited clinical chaplains who were specialists in spiritual care and according to the guideline and model, are professions who should receive referrals from non-chaplain healthcare providers. In the focus group interview questions, I used items that were highlighted in the guideline and model in order to incorporate the screening into routine care such as timing of the screening and disciplines that should screen or accept the referral. For example, I asked the participants of my focus group interviews that when and by which profession screening should be done (items that were discussed in the guideline and model).

Researchers categorize spiritual tools differently; I used characteristics that the guideline and model defined to distinguish different spiritual tools in my study. Generally, there are three types of spiritual tools: screening, history taking and in-depth assessment tools. The Agora spiritual care guideline (2013) clarifies that the purpose of screening is to identify people at risk of spiritual suffering so that a general healthcare provider such as a nurse can refer them for specialized spiritual care. A spiritual screening measure consists of a few simple questions that generalists do not need training to use. This information helped me to analyze the results of my

systematic review (Chapter 2) in terms of the types of included tools. Nevertheless, all the identified tools could be located in the spiritual screening category.

1.5 The Structure of the Dissertation

The content and structure for this thesis by articles is outlined in Table 1.2. The first article (Chapter 2) is a systematic review to synthesize the research evidence on the accuracy of measures used to screen adults for spiritual suffering and addresses the first objective of the doctoral thesis. I identified the accuracy of 24 measures that were used to screen patients for spiritual suffering. The second article (Chapter 3), which addresses objectives number two to five of the dissertation, relates to selecting and planning the implementation of a screening measure to refer patients with spiritual suffering to the spiritual care service. In this article, I presented the identified measures to healthcare providers (registered nurses, nurse managers, and clinical chaplains) at a hospital and conducted a study to understand their perceptions of key considerations when selecting a spiritual screening measure (Objective 2). I then asked them to select a measure (Objective 3) and think about what should be included in an implementation plan (Objectives 4). In the next step, I presented the selected measure and implementation plan to patients to determine their perspectives on them (Objective 5). The third article (Chapter 4) is a protocol to determine the accuracy of the selected screening measure at the SVH (Objective 6). In the final chapter (Chapter 5), I discussed findings and identified implications for nursing practice, education, and research.

Table. 3 The Content and Structure of the Dissertation

Chapter	Chapter title	Thesis Objectives	Study Design	Manuscript (citation if applicable)
1	Introduction	-	-	-
2	The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings: A Systematic Review	Objective 1. Synthesize the evidence regarding the accuracy of measures to screen adults for spiritual suffering.	Systematic Review	**Published** Bahraini, S., Gifford, W., Graham, I. D., Wazni, L., Bremault-Phillips, S., Hackbusch, R., Demers, C., Egan, M.(2019).The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings: A Systematic Review. *Journal of Palliative and Supportive Care.* DOI: https://doi.org/10.1017/S1478951519000506
3	Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to Spiritual Care Service in the Complex Continuing Care	Objective 2. Identify the perceptions of nurse managers, registered nurses, and clinical chaplains on key considerations in selecting a spiritual screening measure for use at their complex continuing care hospital. Objective 3. Identify a spiritual screening measure that nurse managers, registered nurses, and clinical chaplains consider most appropriate for use at their complex continuing care hospital. Objective 4. Determine the perspectives of nurse managers, registered nurses, and clinical chaplains on the process of implementing the selected spiritual screening measure at	Qualitative study	**Manuscript prepared for submission to International Journal of Studies in Nursing** Sayna Bahraini, Ian D Graham, Wendy Gifford, Rebekah Hackbusch, Liquaa Wazni, Suzette Bremault-Phillips, Mary Egan.

		the complex continuing care hospital. Objective 5. Determine the perspectives of patients on use of the selected measure at the complex continuing care hospital.		
4	Study Protocol to Examine the Diagnostic Accuracy of the Peace & Meaning/Joy Measure for Screening Newly Admitted Patients for Spiritual Suffering	Objective 6. Develop a research protocol to determine the accuracy of the selected spiritual screening measure at the complex continuing care hospital.	Diagnostic Accuracy Study	**Manuscript prepared for Submission to British Medical Journal** Sayna Bahraini, Mary Egan, Ian D Graham, Wendy Gifford
5	Discussion	-	-	-

1.6 Reference List

Agora spiritual care guideline. (2013). Spiritual Care Nation-wide Guideline (Version: 1.0). *Integral kankercentrum Nederland*. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Agrimson, L. B., & Taft, L. B. (2009). Spiritual crisis: a concept analysis. *Journal of advanced nursing*, *65*(2), 454-461

Ando, M., Morita, T., Akechi, T., Okamoto, T., & Japanese Task Force for Spiritual Care. (2010). Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *Journal of pain and symptom management*, *39*(6), 993-1002.

Bahraini, S., Gifford, W., Graham, I. D., Wazni, L., Bremault-Phillips, S., Hackbusch, R., Demers, C., Egan, M.(2019).The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings:A Systematic Review. *Journal of palliative and supportive care.* DOI: https://doi.org/10.1017/S1478951519000506

Bakir, E., Samancioglu, S., & Kilic, S. P. (2017). Spiritual experiences of Muslim critical care nurses. *Journal of religion and health*, *56*(6), 2118-2128.

Balboni, M. J., Sullivan, A., Enzinger, A. C., Epstein-Peterson, Z. D., Tseng, Y. D., Mitchell, C., ... & Balboni, T. A. (2014). Nurse and physician barriers to spiritual care provision at the end of life. *Journal of pain and symptom management*, *48* (3), 400-410.

Bar-Sela, G., Schultz, M. J., Elshamy, K., Rassouli, M., Ben-Arye, E., Doumit, M., ... & Ozalp, G. (2019). Training for awareness of one's own spirituality: A key factor in overcoming

barriers to the provision of spiritual care to advanced cancer patients by doctors and nurses. *Palliative & supportive care*, *17*(3), 345-352.

Blanchard, J. H., Dunlap, D. A., & Fitchett, G. (2012). Screening for spiritual distress in the oncology inpatient: a quality improvement pilot project between nurses and chaplains. *Journal of nursing management,* 20(8), 1076-1084.

Bruyère. (2019). Complex Continuing Care. Retrieved from: https://www.bruyere.org/en/complex-continuing-care

Caldeira, S., Carvalho, E. C., & Vieira, M. (2013). Spiritual distress—Proposing a new definition and defining characteristics. *International journal of nursing knowledge*, *24*(2), 77-84.

Carr, T. J., Hicks-Moore, S., & Montgomery, P. (2011). What's so big about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia. *Dementia*, 1471301211408122.

Carson V.B. & Koenig H.G. (eds) (2008) Spiritual Dimensions of Nursing Practice, revised edition. Templeton Foundation Press, West Conshohocken, PA.

Chaves, E. D. C. L., Carvalho, E. C. D., Terra, F. D. S., & Souza, L. D. (2010). Clinical validation of impaired spirituality in patients with chronic renal disease. *Revista latino-americana de enfermagem*, *18*(3), 309-316.

Cobb, M., Puchlaski, C. M., & Rumbold, B. (Eds.). (2012). Oxford textbook of spirituality in healthcare. OUP Oxford.

Connolly, L., & Moss, H. (2019). Music, spirituality and dementia: Exploring joint working between pastoral care professionals and music therapists to improve person-centred care for people with dementia (Innovative Practice). *Dementia*. DIO: 1471301219885560.

Curlin, F.A, Lawrence, R.E., Chin, M.H., Lantos, J.D. (2007). Religion, conscience, and controversial clinical practices. *New England Journal of Medicine* N Engl J Med., 356 (6:),593–600.

Draper, P., & McSherry, W. (2002). Editorial. *Journal of advanced nursing*, *39*(1), 1-2.

Dudley, J. R., Smith, C., & Millison, M. B. (1995). Unfinished business: Assessing the spiritual needs of hospice clients. American Journal of hospice and palliative medicine, 12(2), 30-37.

Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliative medicine*, 24(8), 753-770.

Elham, H., Hazrati, M., Momennasab, M., & Sareh, K. (2015). The Effect of Need-Based Spiritual/Religious Intervention on Spiritual Well-Being and Anxiety of Elderly People. *Holistic nursing practice, 29* (3), 136-143.

Emblen, J.D. (1992). Religion and spirituality defined according to current use in nursing literature. *Journal o f Professional Nursing, 5*(1), 41-47.

Fitchett, G., Meyer, PMand., Burton LA. (2000). Spiritual care in the hospital: Who requests it? Who needs it? *The journal of pastoral care*, 54(2), 173–186.

Fitchett, G., Murphy, P., & King, S. D. (2017). Examining the validity of the Rush Protocol to screen for religious/spiritual struggle. *Journal of health care chaplaincy*, *23*(3), 98-112.

Galek, K., Flannelly, K. J., Vane, A., & Galek, R. M. (2005). Assessing a patient's spiritual needs: a comprehensive instrument. *Holistic nursing practice*, *19*(2), 62-69.

Galek, K., Vanderwerker, L. C., Flannelly, K. J., Handzo, G. F., Kytle, J., Ross, A. M., & Fogg, S. L. (2009). Topography of referrals to chaplains in the Metropolitan Chaplaincy Study. *Journal of pastoral care & counseling*, *63*(1-2), 1-13.

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and Negative Religious Coping and Well-Being in Women with Breast Cancer. Journal of Palliative palliative *Medicinemedicine*, 12(6), 537–545. http://doi.org/10.1089/jpm.2008.0250

Herlianita, R., Yen, M., Chen, C. H., Fetzer, S. J., & Lin, E. C. L. (2018). Perception of spirituality and spiritual care among Muslim nurses in Indonesia. *Journal of religion and health*, *57*(2), 762-773

Hui, D., de la Cruz, M., Thorney, S., Parsons, H. A., Delgado-Guay, M., & Bruera, E. (2011). The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. *American Journal of hospice and palliative medicine®*, *28*(4), 264-270.

Keast, K., Leskovar, C., & Brohm, R. (2010). A systematic review of spirituality and dementia in LTC. *Annals of Long Term Care, 18*, 41-48.

King, S. D., Fitchett, G., Murphy, P. E., Pargament, K. I., Harrison, D. A., & Loggers, E. T. (2017). Determining best methods to screen for religious/spiritual distress. *Supportive care in cancer*, *25*(2), 471–479. doi:10.1007/ s00520-016-3425-6

Kisvetrová, H., Klugar, M., & Kabelka, L. (2013). Spiritual support interventions in nursing care for patients suffering death anxiety in the final phase of life. *International journal of palliative nursing*, *19* (12), 599-605.

Koenig, H. G. (2009). Research on religion, spirituality, and mental health: A review. *Canadian journal of psychiatry*, *54*(5), 283-291.

Luxardo, N., Brage, E., & Alvarado, C. (2012). An examination of advanced cancer caregivers' support provided by staff interventions at hospices in Argentina. C*ancer medical science*, *6*.

Manning-Walsh, J. (2005). Spiritual Struggle. *Journal of Holistic holistic Nursingnursing*, *23*(2), 120–140. http://doi.org/10.1177/0898010104272019

McEwan, W. (2004). Spirituality in nursing: What are the issues?. *Orthopaedic nursing*, *23*(5), 321-326.

McSherry, W. (1998). Nurses' perceptions of spirituality and spiritual care. *Nursing standard*, *13*(4), 36-40.

Melhem, G. A. B., Zeilani, R. S., Zaqqout, O. A., Aljwad, A. I., Shawagfeh, M. Q., & Al-Rahim, M. A. (2016). Nurses' perceptions of spirituality and spiritual care giving: A comparison study among all health care sectors in Jordan. *Indian journal of palliative care*, *22*(1), 42.

Minton, M. E., Isaacson, M., & Banik, D. (2016). Prayer and the Registered Nurse (PRN): nurses' reports of ease and dis-ease with patient-initiated prayer request. *Journal of advanced nursing*, *72*(9), 2185-2195

Musa, A. S. (2017). Spiritual care intervention and spiritual well-being: Jordanian Muslim nurses' perspectives. *Journal of holistic nursing*, *35*(1), 53-61

Narayanasamy, A., & Owens, J. (2001). A critical incident study of nurses' responses to the spiritual needs of their patients. *Journal of advanced nursing*, *33*(4), 446-455.

National Institute for Clinical Excellence. (2004). Guidance on cancer services. Improving

supportive and palliative care for adults with cancer. The manual. London: NICE, 2004

Neuman, B. M. (1995). *The Neuman systems model* (3rd ed.). Norwalk, CT: Appleton & Lange.

Neuman, B., & Fawcett J. (2011). *The Neuman systems model* (5th ed.). USA, NJ: Pearson.

Nurses association of New Brunswick. (2015). *Standards for the Therapeutic Nurse-Client Relationship*. Canada.

O'Brien, M. E. (2018). *Spirituality in nursing*. Jones & Bartlett Learning. United State of America.

Oshvandi, K., Amini, S., Moghimbeigi, A., & Sadeghian, E. (2018). The effect of spiritual care on death anxiety in hemodialysis patients with end-stage of renal disease: A Randomized Clinical Trial. *Journal of hayat*, *23*(4), 332-344.

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2001). Religious struggle as a predictor of mortality among medically ill elderly patients: A 2-year longitudinal study. *Archives of internal medicine*, *161*(15), 1881-1885.

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of health psychology*, *9*(6), 713-730.

Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the scientific study of religion, 37*, 710–724.

Pérez-Cruz, P. E., Langer, P., Carrasco, C., Bonati, P., Batic, B., Tupper Satt, L., & Gonzalez Otaiza, M. (2019). Spiritual Pain Is Associated with Decreased Quality of Life in Advanced Cancer Patients in Palliative Care: An Exploratory Study. *Journal of palliative*

medicine, *22*(6), 663-669.

Planalp, S., Trost, M. R., & Berry, P. (2011). Spiritual feasts: meaningful conversations between hospice volunteers and patients. *American journal of hospice and palliative medicine*, 1049909111398238.

Prince-Paul, M. (2008). Relationships among communicative acts, social well-being, and spiritual well-being on the quality of life at the end of life in patients with cancer enrolled in hospice. *Journal of palliative medicine, 11*(1), 20-25. doi:http://dx.doi.org/10.1089/jpm.2007.0119

Puchalski, C. M., & Ferrell, B. (2010). Making health care whole: Integrating spirituality into patient care. West Conshohocken, PA: Templeton Press

Puchalski, C. M., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., … Sulmasy, D. (2009). Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of palliative medicine*, *12*(10), 885–904. http://doi.org/10.1089/jpm.2009.0142

Ramirez, S. P., Macêdo, D. S., Sales, P. M. G., Figueiredo, S. M., Daher, E. F., Araújo, S. M., … Carvalho, A. F. (2012). The relationship between religious coping, psychological distress and quality of life in hemodialysis patients. *Journal of psychosomatic research*, *72*(2), 129–135. http://doi.org/10.1016/j.jpsychores.2011.11.012

Reblin, M., Otis-Green, S., Ellington, L., & Clayton, M. F. (2014). Strategies to Support Spirituality in Health Care Communication A Home Hospice Cancer Caregiver Case Study. *Journal of holistic nursing*, 0898010114531856.

Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *Journal of clinical nursing*, *15*(7), 852-862.

Rushton, L. (2014). What are the barriers to spiritual care in a hospital setting? British Journal of

Rutenberg, M. (2008). Casting the spirit: a handmade legacy. *Art therapy*, *25* (3), 108-114.

Schultz, M., Meged-Book, T., Mashiach, T., & Bar-Sela, G. (2017). Distinguishing Between Spiritual Distress, General Distress, Spiritual Well-Being, and Spiritual Pain Among Cancer Patients During Oncology Treatment. *Journal of pain and symptom management*, *54*(1), 66-731–88.

Selman, L., Young, T., Vermandere, M., Stirling, I.,& Leget, C. (2014). Research Priorities in Spiritual Care: An International Survey of Palliative Care Researchers and Clinicians. *Journal of pain and symptom management*, Article in press.

Sessanna, L., Finnell, D., & Jezewski, M. A. (2007). Spirituality in nursing and health-related literature a concept analysis. *Journal of holistic nursing*, *25* (4), 252-262.

Sherman, A. C., Plante, T. G., Simonton, S., Latif, U., & Anaissie, E. J. (2009). Prospective study of religious coping among patients undergoing autologous stem cell transplantation. *Journal of behavioral medicine*, *32*(1), 118-128

Sinclair, S., & Chochinov, H. M. (2012). Communicating with patients about existential and spiritual issues: SACR-D work. *Progress in palliative care*, *20*(2), 72-78.

Sinclair, S., & Chochinov, H. M. (2012). The role of chaplains within oncology interdisciplinary teams. *Current Opinion in Supportive and Palliative Care*, *6*(2), 259–68. http://doi.org/10.1097/SPC.0b013e3283521ec9

Stranahan, S. (2001). Spiritual perception, attitudes about spiritual care, and spiritual care practices among nurse practitioners. *Western journal of nursing research*, *23*(1), 90-104.

Summary, E., & Goal, O. (2004). Literature Review - Testing the Efficacy of Chaplaincy Care, 1–88.

Szcześniak, M., Bielecka, G., Bajkowska, I., Czaprowska, A., & Madej, D. (2019). Religious/Spiritual Struggles and Life Satisfaction among Young Roman Catholics: The Mediating Role of Gratitude. *Religions*, *10*(6), 395.

Tajbakhsh, F., Hosseini, M., Fallahi-Khoshknab, M., Rokofian, A., Rahgozar, M., & Mary Davidson, P. (2018). The effect of spiritual care on depression in patients following coronary artery bypass surgery: A randomized controlled trial. *Religions*, *9*(5), 159.

Taylor, E.J. (2006). Spiritual assessment. In Textbook of Palliative Nursing (B.R. Ferrell & N. Coyle eds), Oxford University Press, Oxford. pp. 581–594.

Thuné-Boyle, I. C. V, Stygall, J., Keshtgar, M. R. S., Davidson, T. I., & Newman, S. P. (2013). Religious/spiritual coping resources and their relationship with adjustment in patients newly diagnosed with breast cancer in the UK. *Psycho-Oncology*, *22*(3), 646–658. http://doi.org/10.1002/pon.3048

Timmins, F., Caldeira, S., Murphy, M., Pujol, N., Sheaf, G., Weathers, E., ... & Flanagan, B. (2018). The role of the healthcare chaplain: A literature review. *Journal of health care chaplaincy*, *24*(3), 87-106.

Toivonen, K., Stolt, M., & Suhonen, R. (2015). Nursing Support of the Spiritual Needs of Older Adults Living With Dementia: A Narrative Literature Review. *Holistic nursing practice*, *29*(5), 303-312.

Unruh, A. M., Versnel, J., & Kerr, N. (2002). Spirituality unplugged: A review of commonalities and contentions, and a resolution. *Canadian journal of occupational therapy*, *69*(1), 5-19.

Van Leeuwen, R., Tiesinga, L. J., Middel, B., Post, D., & Jochemsen, H. (2008). The effectiveness of an educational programme for nursing students on developing competence in the provision of spiritual care. *Journal of clinical nursing*, *17*(20), 2768-2781.

Vazifeh, M. D., Hojjati, H., & Farhangi, H. (2019). Effect of Spiritual Care Based on Ghalbe Salim on Anxiety in Adolescent with Cancer. *Journal of religion and health*.

Villagomeza, L. R. (2005). Spiritual distress in adult cancer patients: toward conceptual clarity. *Holistic nursing practice*, *19*(6), 285-294.

Vivat, B. (2008). Measures of spiritual issues for palliative care patients: A literature review. *Palliative medicine, 22*, 859-868.

Vlasblom, J. P., Van Der Steen, J. T., Walton, M. N., & Jochemsen, H. (2015). Effects of nurses' Screening of spiritual needs of hospitalized patients on consultation and perceived nurses' support and patients' spiritual well-being. *Holistic nursing practice,* 29(6), 346-356.

Walter, T. (1997). The ideology and organization of spiritual care: three approaches. *Palliative medicine*, *11*(1), 21-30.

Walton, M., Leget, C., Geer, J. V., Graeff, M., Slootweg, H. (2010). Spiritual care: Nation-wide guideline. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., …

Balboni, T. A. (2011). The Relationship of Spiritual Concerns to the Quality of Life of Advanced Cancer Patients: Preliminary Findings. *Journal of Palliative Medicine*, *14*(9), 1022–1028. http://doi.org/10.1089/jpm.2010.0536

Chapter 2: The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings: A Systematic Review

Authors: Sayna Bahraini, Wendy Gifford, Ian D Graham, Liquaa Wazni , Suzette Bremault-Phillips, Rebekah Hackbusch, Catrine Demers, Mary Egan

Palliative and Supportive Care Journal, 2019, https://doi.org/10.1017/S1478951519000506

Abstract

Objective: Guidelines for palliative and spiritual care emphasize the importance of screening patients for spiritual suffering. The aim of this review was to synthesize the research evidence on the accuracy of measures used to screen adults for spiritual suffering.

Methods: A systematic review of the literature. We searched five scientific databases to identify relevant articles. Two independent reviewers screened, extracted data, and assessed study methodological quality.

Results: We identified five articles that yielded information on 24 spiritual screening measures. Among all identified measures, the 2-item Meaning/Joy & Self-Described Struggle has the highest sensitivity (82-87%) and the revised Rush protocol has the highest specificity (81-90%). The methodological quality of all included studies was low.

Significance of Results: While most of the identified spiritual screening measures are brief (comprise 1 to 12 number of items), few have sufficient accuracy to effectively screen patients for spiritual suffering. We advise clinicians to use their critical appraisal skills and clinical judgment when selecting and using any of the identified measures to screen for spiritual suffering.

KEYWORDS: Screening, Suffering, Spirituality, Diagnostic Test Accuracy, Systematic Review

2.1 Introduction

Patients experience spiritual suffering when their need to find a meaning and purpose in life through connectedness with self, others, nature and/or what one holds to be sacred is unfulfilled (Cobb, Puchlaski, & Rumbold, 2012). Suffering of this nature may also be identified as spiritual distress (Herdman & Kamitsuru, 2014), spiritual pain (Mako, Galek, & Poppito, 2006), spiritual struggle (Grossoehme, Teeters, Jelinek, Dimitriou, & Conard, 2016), spiritual crises (Agora Spiritual Care Guideline, 2013), and negative religious coping (Pargament, Feuille, & Burdzy, 2011). Some researchers consider these concepts different, for example, "spiritual crisis" is often used in emergency situations, whereas "spiritual pain" has been used where patients have spiritual issues for a longer period of time (Agora Spiritual Care Guideline, 2013; Puchalski & Ferrell, 2010). For the purpose of this study, we use the term spiritual suffering to include all the aforementioned concepts in which health care providers deem it necessary to refer patients for consultations and interventions by specialized spiritual care providers.

Spiritual suffering is a common problem, occurring in about 40% of chronically ill and dying patients (Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2013; Tarakeshwar et al., 2006; Fitchett et al., 2004). Different authors have reported harmful physical and psychological effects associated with spiritual suffering (Pargament, Koenig, Tarakeshwar, & Hahn, 2001; Thuné-Boyle et al., 2013; Ramirez et al., 2012). For example, Pargament and colleagues (2004) reported that among elderly patients followed for two years after hospitalization, those experiencing spiritual suffering had increased functional limitations and levels of depressive symptoms, compared to those not experiencing spiritual suffering at baseline or follow-up. They also associated high levels of spiritual suffering with greater risk of mortality, even after controlling for demographic, physical, and mental health factors (Pargament, Koenig,

Tarakeshwar, & Hahn, 2001). Other research has shown an inverse relationship between patients' spiritual suffering and quality of life (Pargament, 2004; Manning-Walsh, 2005), and life satisfaction (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Winkelman et al., 2011).

Guidelines for palliative and spiritual care (National Comprehensive Cancer Network, 2010; Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009) acknowledge the importance of identifying spiritual suffering, and recommend screening and appropriate referrals for specialized spiritual care when it appears that patients may be experiencing spiritual suffering. Health care providers such as nurses and physicians are well-positioned to screen patients for specialized spiritual care. Accurate screening measures, however, are required for health care providers to effectively screen patients for this kind of suffering (Puchalski et al., 2009). Using a standard approach with an accurate measure can ensure that all health care providers, with or without special training, consider spiritual needs of their patients. The identified need for specialized spiritual care can then be made explicit in the patient's medical file and better integrated into care offered by the multidisciplinary team (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009). A number of measures have been identified in previous reviews that assess different aspects of spirituality (Best et al, 2015; Brémault-Phillips, Sacrey, Olson, Weis, & Cherwick, 2016). Measures that have been tested for accuracy of screening spiritual suffering, however, have not been systematically identified or evaluated.

The objective of this review was to synthesize the evidence regarding the accuracy of measures used to screen adults for spiritual suffering. The review questions to be addressed were as follows: What measures have been used to screen for spiritual suffering among adults receiving health care services, and what is the accuracy of these measures?

2.2 Methods

We used the methodology outlined in the Joanna Briggs Institute (JBI) Reviewers' Diagnostic Test Accuracy Manual (2015) to conduct the systematic review. The review protocol has been registered in PROSPERO (registration number: CRD42018082602). The study inclusion criteria included: (1) studies published in English, (2) primary studies published as full-text papers or dissertations, (3) studies that examined measures used to screen adults (18 years and older receiving health care services) for spiritual suffering (including, spiritual history, assessment, and diagnostic tools, if the measure has been used to screen /refer individuals for spiritual suffering to spiritual care services), and (4) studies that have compared a measure used to screen adults for spiritual suffering to a reference test, such as another assessment of spiritual suffering or a clinical chaplain evaluation, and report one or more of the following criteria: sensitivity, specificity, predictive values, likelihood ratios, and receiver operating characteristics.

2.2.1 Search Strategy

The search strategy was conducted in consultation with a librarian specialized in systematic reviews of health research and entailed three steps (JBI, 2015). First, we performed an initial search of Medline and CINAHL to identify the text words contained in titles and abstracts and index terms used to describe these articles. We used an iterative process to ensure we captured diagnostic test studies that have been conducted with a broad range of conceptualizations of spiritual suffering. We developed search terms (see Table 2.1) based on the results of the initial searches (see Appendix B for the complete search terms).

Second, we used all the recognized search terms to search CINAHL, PubMed, Embase, PsycINFO, and ProQuest – Nursing and Allied Health Source Dissertations. All bibliometric

databases were searched from their inception to November 5, 2017. Last, we conducted hand-searching of reference lists of identified articles for additional studies. Three reviewers (S.B., L.W., and C.D.) independently screened the identified studies.

2.2.2 Methodological Quality of the Studies

Two independent authors (S.B. and L.W.) assessed included articles for methodological quality using the QUASAD 2 (Quality Assessment of Diagnostic Accuracy Studies 2) appraisal tool (Appendix B). We did not exclude any study from the review based on quality. The first author (S.B.) contacted three corresponding authors of the included papers for additional information as deemed necessary.

2.2.3 Data Extraction

We used a modified Joanna Briggs Institute (JBI) data extraction form to collect data from included studies. Two authors (S.B. and L.W.) independently extracted and entered data from each article into a standardized template in Microsoft Excel. Disagreements were resolved through discussion.

2.2.4 Data Synthesis

We undertook a narrative synthesis of extracted data. We presented diagnostic criteria (e.g., sensitivity and specificity) of the identified screening measures in a tabular format to enable comparison of diagnostic performance of the measures along with other relevant study information.

2.3 Results

2.3.1 Description of studies

The search produced a total of 7979 articles. Three reviewers (S.B., L.W., & C.D.) screened title and abstract of the studies and retrieved 92 studies for full-text screening. Of the 92 studies, we excluded studies because they did not either: (a) test the diagnostic accuracy of the screening measures (n=82 studies), (b) provide enough information to calculate diagnostic criteria (n=2 studies), (c) provide information in English (n=2 studies), or (d) test the accuracy of the measures in adult population (n=1 study). (See Appendix C for more detailed information on the excluded studies). Five studies met inclusion criteria and were subjected to data extraction. Of the five corresponding authors contacted about relevant studies that might have been missed in the search, three responded and suggested five articles, of which one had not been identified in the database search. After full-text screening, the study that had not been identified in the database search was excluded as it did not test the diagnostic accuracy of a measure. Figure 2.1 outlines the study selection process.

2.3.2 Characteristics of included studies

The five included studies were published between 2009-2017, and the majority (80%) were from the United States (see Table 2.2). Three were conducted with patients at cancer centers (Fitchett, Murphy, & King, 2017; King et al., 2017, Schultz et al., 2017). One study was conducted with patients admitted to an acute medical rehabilitation center (Fitchett & Risk, 2009), and one with parents of children with cystic fibrosis (CF) at a hospital CF center (Grossoehme & Fitchett, 2013). All studies, except one (Fitchett & Risk, 2009), reported demographic information of participants. In total, 3245 patients participated in the five included studies. Between 32 to 51.8 % of participants were male. The majority of study participants reported that they were Christian and older than fifty years of age.

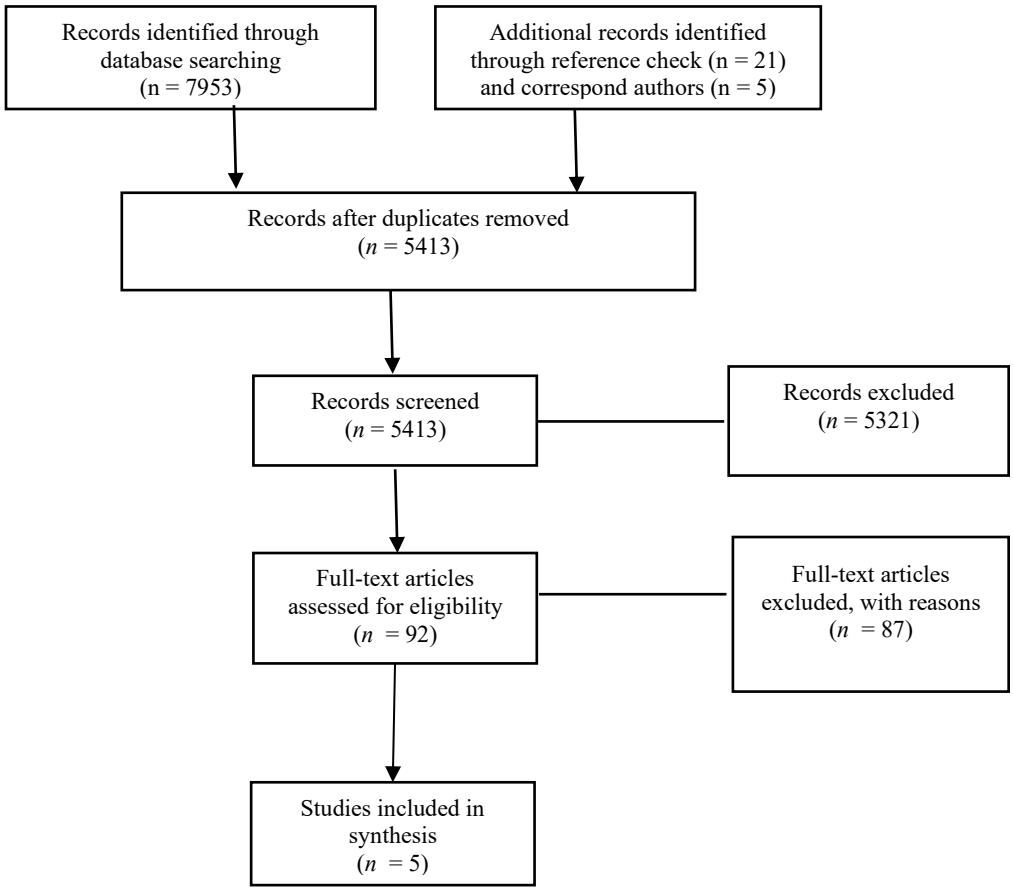


Figure 2.1: Flow Chart Outlining the Study Selection Process

2.3.3 Methodological quality of the studies

The QUASAD 2 tool evaluates the risk of bias and applicability of primary diagnostic accuracy studies. The QUASAD 2 consists of four main domains including: (1) patient selection, (2) index test, (3) reference test, and (4) flow/timing. The risk of bias is examined in all four domains. The first three domains (i.e., patient selection, index test, reference test) were also assessed in terms of the applicability of the studies. Applicability reveals congruency between information of the included study and the review question. To assess applicability of a study,

review authors should match information regarding the patient selection, index test, and reference test with their review question. Risk of bias and applicability was judged as "low," "high," or "unclear". If a study was judged as "high" or "unclear" in any of the four domains of risk of bias, we judged the study to be "at risk of bias". If a study was judged as "high" or "unclear" in one or more domains of applicability, we determined the study to have "concerns regarding applicability."

Table 2.4 details how included studies performed against individual QUASAD 2 items regarding the risk of bias. All the included studies were determined at risk of bias since they were judged as high or unclear in at least one domain. Overall, selection bias, spectrum bias, partial verification bias, incorporate bias, differential verification bias, and disease/condition progression bias were minimized with one exception. Grossoehme & Fitchett (2013) reported a 27-day interval between assessments using the index spiritual screening measure and reference test, increasing the risk of disease/condition progression bias (See Table 2.4). Blinding of index spiritual screening measures and reference test results was poorly reported across all studies which results in risk of information bias. The risk of misclassification bias in studies that used the N-RCOPE and self-reported Spiritual Distress as a reference test is high because these tests cannot be considered a true gold standard for identifying a harmful level of spiritual suffering that needs referral to the specialists (King et al, 2017, Fitchett, Murphy, & King, 2017; Grossoehme & Fitchett, 2013). All studies were determined to have low concerns in terms of applicability.

2.3.4 Review Findings

Prevalence of spiritual suffering, as identified by reported reference tests, ranged from 13.6% to 32%. None of the studies reported adverse effects from screening with spiritual screening measures. Respectively, the Negative Religious Coping measure (N-RCOPE) (*n* = 3 studies) and the Rush protocol (*n* = 4 studies) were the most commonly used reference test and spiritual screening measure. The original version of the Rush protocol was used by Fitchett and Risk (2009). Researchers of other studies used the revised (King et al, 2017; Grossoehme & Fitchett, 2013) and modified (Fitchett, Murphy, & King, 2017) versions of this measure (See Table 2.3 for details).

Three reference tests were used in the five included studies: (1) the negative subscale of Religious Coping (N-RCOPE) (*n* = 3 studies, Fitchett, Murphy, & King, 2017; King et al., 2017; Grossoehme & Fitchett, 2013), (2) the self-reported Spiritual Distress (*n* = 1 study, Schultz et al., 2017), and (3) a chaplain assessment (*n* = 1 study, Fitchett & Risk, 2009).

Four out of the five studies (24 measures) reported sensitivity and specificity of the screening measures, which were often individual or combined items of different measures (Fitchett, Murphy, & King, 2017; King et al., 2017; Schultz et al., 2017; Grossoehme & Fitchett, 2013). Fitchett & Risk (2009) reported a positive predictive value (see Table 2.2) where chaplain assessments were the reference test used, but only for patients who were identified with potential spiritual suffering according to the screening measure. While chaplains identified some newly admitted patients with spiritual suffering who screened negative on the spiritual screening measure, no estimate of true or false negatives could be ascertained from the study because chaplain assessments were not conducted on all patients who screened negative (Fitchett & Risk,

2009). The information from this study was not sufficient to calculate sensitivity and specificity of the screening measure.

Some researchers suggested an accurate spiritual screening measure should have a cut-off point for sensitivity (King et al., 2017; Fitchett, Murphy, & King, 2017) and specificity (Fitchett et al., 2017) of at least 85%. The only measure identified in this review with such an acceptable sensitivity was the 2-item Meaning/Joy & Self-Described Struggle, with a sensitivity of 82-87% (King et al., 2017). The R/S Concern (King et al., 2017), Comfort/ Strength (King et al., 2017), Peace subscale of FACIT-Sp-12 (Schultz et al, 2017), New Israel Items (Schultz et al, 2017), revised Rush protocol (King et al, 2017; Grossoehme & Fitchett, 2013), and modified Rush protocol-path A-peace (Fitchett, 2017) all have acceptable specificity of 85 to 90% (see Table 2. 2). The revised Rush Protocol (King et al., 2017) has the highest specificity (81-90%), and the single item Spiritual Pain (Schultz et al., 2017) has the greatest balance of sensitivity (74%) and specificity (76%) among all the identified measures.

2.4 Discussion

This is the first review to systematically identify screening measures for spiritual suffering that have been tested for accuracy among adults receiving health care. The broad inclusion criteria of this review resulted in a considerable number of spiritual screening measures (n = 24) being included (given the limited size of the field being researched). Among all identified measures, the 2-item Meaning/Joy & Self-Described Struggle (King et al., 2017) had the highest sensitivity (82-87%), the revised Rush protocol (King et al., 2017) had the highest specificity (81-90%), and the single item Spiritual Pain (Schultz et al., 2017) had the greatest balance of sensitivity (74%) and specificity (76%).

Although there is no consistently agreed upon definition for spiritual suffering, suffering on a spiritual level has been recognized in palliative models and guidelines (Canadian Hospice Palliative Care Association, 2013; National Institute for Clinical Excellence, 2004; Puchalski et al., 2009). Different studies have identified different aspects of spiritual suffering and the negative effect it has on patients' physical and psychological outcomes (Pargament, Koenig, Tarakeshwar, & Hahn, 2001; Thuné-Boyle et al., 2013; Ramirez et al., 2012). For example, spiritual suffering has been associated with increased emotional distress, poorer quality of life, and decreased functional status (Exline, 2013; Hebert, Zdaniuk, Schulz, & Scheier, 2009; Pargament, Koenig, Tarakeshwar, & Hahn, 2004; Park, Wortmann, & Edmondson, 2011). In the current study, we identified measures that have been evaluated in a systematic way to determine spiritual suffering. Driven by demands to integrate spiritual care into routine patient care (Selman, Young, Vermandere, Stirling, & Leget, 2014; Puchalski et al., 2009), our review identified a substantial number of spiritual measures, highlighting clinicians and researchers recognition of the importance of using evidence-based measures. Given the current state of the research, we suggest more methodologically rigorous studies are needed to ensure the accuracy of measures for screening for spiritual suffering.

People often experience spiritual suffering when they are adjusting to new life circumstances such as the diagnosis of chronic or life-limiting disease, palliative care or an acute physical crisis such as lower or upper-extremity amputation (Agora Spiritual Care Guideline, 2013). As many different religious and non-religious beliefs exist, it is recommended that screening be conducted for all people in inpatient and outpatient facilities to identify those who

could benefit from receiving care from a spiritual specialist (Agora Spiritual Care Guideline, 2013; Puchalski & Ferrell, 2010).

This research is an important step toward addressing some of the practical issues surrounding the provision of spiritual care and referring patients for specialized spiritual services (Selman et al., 2014; Rushton, 2014), specifically, how best to screen for spiritual suffering. Health care providers may have difficulty identifying spiritual suffering because of: (1) difficulty that patients may have in articulating the concept of spiritual suffering (Boston et al., 2011; Fitchett, Meyer, & Burton, 2000), and/or (2) clinicians' lack of knowledge regarding the incorporation of the spiritual dimension into routine care (Balboni et al., 2014; Milligan, 2004; Walter, 2002; Selman et al; 2014). An accurate screening measure can help overcome barriers in identifying spiritual suffering. The results of this study will help to inform researchers, clinicians, and policy-makers about the accuracy of available spiritual screening measures when selecting a measure that best meets their needs.

It is important to take into consideration the limitations of the included studies in this review. One of the most important limitations is that currently there is no tool that can be used as a "true" gold standard for measuring spiritual suffering (Grossoehme &Fitchett, 2013). Researchers who have used the N-RCOPE as a reference test declare that this tool cannot be considered a true gold standard for identifying a harmful level of spiritual suffering (King et al., 2017; Grosseohme & Fitchett, 2013; Fitchett, Murphy, & King, 2017). One reason suggested is because the N-RCOPE items mainly assess struggles with the Divine, which is only one of three types of spiritual struggle (Pargament et al., 2005). The other two types of spiritual struggle, interpersonal (i.e., struggle with other people) and intrapersonal (i.e., struggle with one's own

life purpose or values), are not well covered by this scale (King et al., 2017; Grosseohme & Fitchett, 2013; Fitchett, Murphy, & King, 2017). Therefore, the N-RCOPE scale can underestimate spiritual suffering because it covers only one dimension of spiritual suffering.

The Spiritual Distress self-report measure is another measure that has been used as a reference test for diagnosing spiritual suffering (Schultz et al., 2017). This measure, consisting of one question "Are you experiencing spiritual distress?," is consistent with the definition of spiritual distress outlined by the North American Nursing Diagnosis Association (i.e., the impaired ability to experience and integrate meaning and purpose in life through the individual's connectedness with self, others, art, music, literature, nature, or a power greater than oneself) (Herdman & Kamitsuru, 2014). Strong similarities (Kappa=0.92 - 0.94) between patient's self-diagnosis of spiritual distress and a professional diagnosis have been reported in other studies, justifying the use of this question as a reference test (Caldeira et al, 2017; Chaves et al., 2011). Schultz and colleagues (2017) used the self-reported Spiritual Distress measure to identify general rather than harmful levels of spiritual suffering which would require specialized spiritual care. The self-reported measure of spiritual distress, then, can overestimate spiritual suffering as it is a one-item question with a "yes" and "no" response and does not indicate the complexity of spiritual suffering or a threshold above which a specialists' referral, for example from a chaplain, psychologist, specialized nurse or social worker, would be required. Fitchett and colleagues (2000) noted that not all patients who believe they are having spiritual suffering would benefit from specialized spiritual care or a referral to a spiritual specialist because many of them may have basic spiritual or religious needs (such as praying, presence of beloved ones) that can be addressed by their family members or non-specialists. It is therefore important that screening

measures used in clinical practice can differentiate between high levels of spiritual suffering that requires specialist's referral and other spiritual needs that can be addressed by non-specialists.

Currently, assessment by professional specialists who are trained in spiritual care such as psychologists, clinical chaplains[1], or medical social workers, are the only true gold standard for identifying spiritual suffering as they have the professional skills and judgement to determine high levels of spiritual suffering (Agora Spiritual Care Guideline, 2013; Grossoehme &Fitchett, 2013). Only Fitchett and Risk (2009) used chaplain assessment as a reference test. However, they did not have chaplains assess spiritual suffering among patients who screened negative, which resulted in the inability to determine the sensitivity and specificity of the measure. We recommend use of specialists' assessment in future research as a reference test to confirm the presence of spiritual suffering identified by spiritual screening measures.

Our review demonstrated limited methodological quality of the included studies which was mainly the result of insufficient reporting of methods and results. Although evidence for the effectiveness of identified spiritual screening measures is limited, the measures can none-the-less be valuable in initiating a discussion with patients and consequently initiating a conversation with providers of spiritual suffering. In the absence of a validated spiritual screening measure with documented sensitivity and specificity, we emphasize the importance of clinicians using their clinical judgment when using any of the identified screening measures. Patient's behaviors, condition, and individual needs should be taken into consideration with the result of the screening measure when making final decisions about whether or not to refer patients for

[1] Clinical chaplains have advanced training in providing spiritual care for patients with different religious or non-religious worldviews (Jankowski, Handzo, & Flannelly, 2011; Sinclair & Chochinov, 2012; Agora Spiritual Care Guideline, 2013).

specialized spiritual care. Complete dependency on the results of the screening measures without using clinical judgment and building a relationship with patients may result in a failure to detect spiritual suffering that requires referral to spiritual care specialists. We suggest that clinicians with limited training in the spiritual domain collaborate with specialists in spiritual care who have additional expertise in determining spiritual suffering. Specialists can advise members of the healthcare team about verbal and non-verbal indicators of spiritual suffering in patients (Caldeira et al., 2017). Being aware of these indicators can help improve clinical judgment in clinicians and increase accurate referral of patients with spiritual suffering to spiritual care services (Caldeira et al., 2017).

Guidelines for spiritual care suggest three criteria for choosing an appropriate spiritual screening measure for use in clinical settings that include accuracy, brevity and simplicity (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009). The current review has focused on evidence regarding the accuracy of spiritual screening measures. In order to address major barriers to incorporating spiritual care into routine practice, such as insufficient time (Edwards, Pang, Shiu, & Chan, 2010; Balboni et al., 2014) and knowledge (Edwards, et al., 2010; Ross, 2006; Balboni et al., 2014), we suggest that brevity and simplicity of measures be taken into consideration by clinicians when choosing a measure to screen for spiritual suffering.

Spiritual suffering is a complex concept. Results of my systematic review shows different screening measures focus on different elements of this concept. Generally speaking, spiritual suffering is conceptualized across the identified measures as having issues in at least one of the constructs of spirituality (Villagomeza, 2005) (see Table 2.5 for constructs of spirituality). The most common constructs that were considered across the identified measures were sense of:

Inner strength and energy, meaning and purpose in life; peace; connectedness; faith and religious believe system. In addition to constructs of spirituality, two other less frequent elements that were considered for spiritual suffering were having negative feelings such as anger, guilt, curse, and wish to die (e.g., Spiritual Injury Scale, and New Israeli Items), and ineffective spiritual coping strategy (e.g., denial) (see the New Israeli Items) (See appendix D for assessment of screening measures against constructs and elements of spirituality).

Each identified measure in the current study focus on specific constructs of spirituality. For examples some measures focus more on faith and religious believe system and some more on existential constructs such as peace and meaning of life. Clinicians may choose to use a measure based on their clinical setting. For example, for a faith-based setting, clinicians may consider measures that have included questions regarding patient's faith and religious believe system. Spirituality may conceptualize differently across various countries and cultures; therefore, a measure can be chosen to be used in a region that is more compatible with what majority of people with the same culture consider spirituality is. In the ideal situation, clinicians can choose a screening measure based on what spirituality means to a certain patient. In order to do so, I suggest clinicians to interview patients and get familiar with the patients' worldview. This can be happened in a few clinical settings such as small hospices that have enough trained healthcare providers who can work one on one with patients. However, it is not a feasible strategy for the majority of settings where clinicians have lack of time and training in spiritual domain.

There are a number of limitations to this systematic review that should be noted. First, we may not have identified all relevant test accuracy studies, as some authors may not present their

research as a test accuracy study and many databases do not have indexing terms for labelling test accuracy studies (Centre for Reviews and Dissemination, 2009). To increase the likelihood of capturing all relevant studies, we used topic-specific terms rather than using diagnostic test accuracy as an index term or study design as a filter (Whiting et al., 2011). We also widened the search to five databases. Second, spiritual suffering is a broad concept which has been described differently by authors in the literature. We therefore used a search strategy to allow for common concepts for spiritual suffering such as religious or existential distress. The distinction between these individual concepts is not explored in this review.

2.5 Conclusion

This review was conducted to synthesize the research evidence on the accuracy of measures used to screen adults for spiritual suffering. While most of the identified spiritual screening measures are brief and simple to use, a few measures have sufficient accuracy to effectively screen patients for spiritual suffering. However, due to poor methodological quality of all included studies which assessed the accuracy of the measures, we advise clinicians to use their critical appraisal skills and clinical judgment when selecting and using any of the identified measures. We also suggest the assessment by a spiritual care specialist as the reference test in the future studies to determine the diagnostic accuracy of spiritual screening measures while an accurate screening measure is developed.

2.6 Acknowledgment

This review will contribute towards the requirements of a Ph.D. through the University of Ottawa and is funded by the Board of the Canadian Foundation for Spiritual Care. Sayna

Bahraini has received a CIHR Integrated Knowledge Translation Research Network Doctoral Fellowship (FDN143237). IDG is a recipient of a CIHR Foundation Grant (FDN #143237)

Table 2.1 Search Terms for Spiritual Suffering

Spiritual			Suffering
Spirituality	Existentialism	Funeral rite	Distress
Spiritual therapies	Existential	Ceremonial Behavior	Suffer
Spirit	Transcendent	Peace	Crisis
Religion	Faith		Pain
Christian	Pray		Struggle
Islam	Hope		Trauma
Buddhism	Culture		Psychological stress
Judaism	Superstition		Demoralization
	Taboo		Hopelessness

Table 2.2 Characteristics of included studies

Author	Setting	Study population	Sample size	Age, y	Sex, %M	Religion	Prevalence of spiritual suffering	Screening measure(s)	Sensitivity %	Specificity %	Positive Predictive value	Reference test
Fitchett, Murphy, & King, 2017	Major cancer treatment center, USA	Cancer survivors who had received a hematopoietic cell transplantation (HCT)	1399	72.2% of subjects ≥50	51.8	67.9% Christian 12.6% with no religion 6.2% agnostic or atheist.	13.6% identified by the gold standard 21.9% identified by unmodified Rush Protocol	1- Revised Rush (2-3 items) 2- modified Rush-path A-peace (2-3 items) 3- modified Rush-path B-meaning /joy (2-3 items)	42.1 40.0 42.6	81.3 86.1 83	Not reported	N-RCOPE[2]
King et al, 2017	Major cancer center, USA	Cancer survivors who had received a	1449	72% of subjects ≥50	51	68 % Christian	- 14% identified by the gold standard	1- Revised Rush (2-3 items **Single item screeners:**	42[3]-31[4]	81[a]-90[b]	Not reported	N-RCOPE

[2] The Negative Subscale of Religious Coping
[3] whole sample
[4] Sample of 2 year or less since transplant

	hematopoietic cell transplantation (HCT)	13 % Other 13 % No preference 6 % Agnostic /Atheist	38% by Meaning/joy -27% by R/S Struggle -22% by Peace -22% by Rush -19% by R/S comfort -13% by spiritual concern	2- Meaning/Joy 3- Self-Described R/S Struggle 4- Peace 5- Comfort/ Strength 6- R/S Concerns **Combination of single-item screeners** 7- Meaning/Joy & Self-Described Struggle 8- Peace & Meaning/Joy 9- Comfort/ Strength & Meaning/Joy 10- Peace & Self-Described Struggle	60- 65 54-61 45-55 42-43 27-25 82-87 78-84 77-80 75-83 73-78	65-58 77-75 83-80 85-85 89-87 50-44 54-47 56-50 64-60

								11- Comfort/ Strength & Self-Described Struggle		65-64		
								12- R/S Concerns & Meaning/Joy	71-74	58-51		
								13- Comfort/ Strength & Peace	68-74	70-68		
								14- R/S Concerns & Self-Described Struggle	66-71	69-65		
								15-Peace & R/S Concerns	60-66	73-70		
								16- Comfort/ Strength & R/S Concerns	58-57	76-74		
Schultz et al, 2017	oncology day care clinic, Israel	Cancer patients with diversity of oncologic conditions	202	86% of subjects ≥50	40	82% Jewish 7% Muslim 7% Christian	23% identified by the gold standard	1-Distress Thermometer (numeric)	41	76	Not reported	self report Spiritual Distress
								2-FACIT-Sp-12 (12 items) -Peace subscale	57	72		

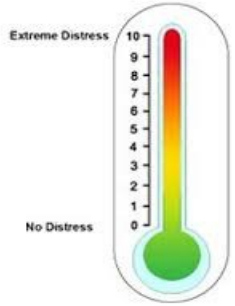
						3% Druze	3-Spiritual Injury Scale (8 items)	45	85		
							- 1+ items				
							- 2+ items	83	54		
								64	79		
							4-New Israeli Items.	43	86		
							5-Spiritual Pain (one-item).	72	76		
Grossoehme & Fitchett, 2013	cystic fibrosis center at the academic pediatric hospital, USA	parents of children with cystic fibrosis	22	22.7% of subjects 18-30 45.5% of subjects	32	72 % Christian 24% None/Other 4.5% Jewish	32% identified by the gold standard 18% identified by Rush	Revised Rush (2-3 items)	29	87	Not reported	N-RCOPE

				31-35 31.7% of subjects ≥36								
Fitchett & Risk, 2009	acute medical rehabilitation unit at the Rush University Medical Center, USA	medical rehabilitation new admitted patients (amputation, neurological disease, stroke, deconditioning, and orthopedic surgeries, including spine surgery and joint replacements)	173	N/A	N/A	N/A	7% identified by Rush	Rush (original)	Not reported	Not reported	92%	chaplain assessment

*King et al (2017) and Fitchett, Murphy, & King (2017) used the same data in their research.

Table 2.3 Summary Table of the Screening Measures

#	Screening measures	Sensitivity	Specificity	Reference Test	Question and Response Options (Response options in grey reveal potential spiritual suffering)
1	Spiritual Injury Scale (Berg, 2011): - 1+ items - 2+ items	83 64	54 79	Self-reported Spiritual Distress	**1- How often do you feel guilty over past behaviors?** **2- Does anger or resentment block your peace of mind?** **3- How often do you feel sad or experience grief?** **4- Do you feel that life has no meaning or purpose?** **5- How often do you feel despair or hopeless?** **6- Do you feel that God/life has treated you unfairly?** **7- Do you worry about your doubts/disbelief in God?** **8- How often do you think about death?** Response options to each question: Never, Sometimes, Often,Very often. *Positive responses to at least one item indicate a diagnosis of spiritual injury.
2	Spiritual Pain (Schultz et al, 2017)	72	76	Self-reported Spiritual Distress	**Are you experiencing spiritual pain, defined as a pain deep in your soul (being) that is not physical?** Response options: Yes, No
3	FACIT-Sp-12 (Cella et al., 1993) -Peace subscale	57 45	72 85	Self-report Spiritual Distress	**1. I feel peaceful** **2. I have a reason for living** **3. My life has been productive** **4. I have trouble feeling peace of mind** **5. I feel a sense of purpose in my life** **6. I am able to reach down deep into myself for comfort** **7. I feel a sense of harmony within myself** **8. My life lacks meaning and purpose** **9. I find comfort in my faith or spiritual beliefs** **10. I find strength in my faith or spiritual beliefs**

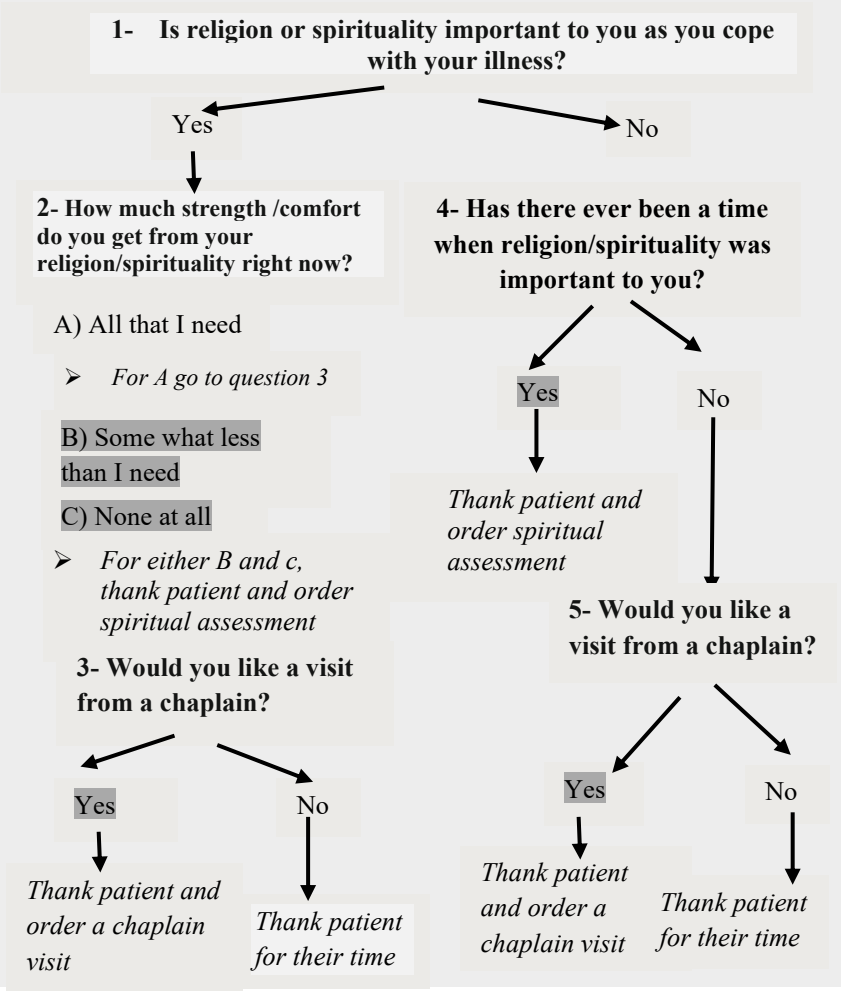
					11. My illness has strengthened my faith or spiritual beliefs **12. I know that whatever happens with my illness, things will be okay** Response options to each question: Not at all, A little bit, Somewhat, Quite a bit, Very much *There is no established cut-off score for poor spiritual well-being or spiritual suffering.
4	General Distress Thermometer (NCCN, 2007)	41	76	Self-report Spiritual Distress	 *Scores of eight or higher are indicator of distress.
5	New Israeli Items (Schultz et al, 2017)	43	86	Self-report Spiritual Distress	Indicators of spiritual suffering: **- Not able to accept that this is happening to me.** **- On my own in dealing with this.** **- Feeling cursed.** Response options: Not reported
6	Meaning/Joy (King et al, 2017)	60[5]- 65[6]	65[1]-58[2]	N-RCOPE	**Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal

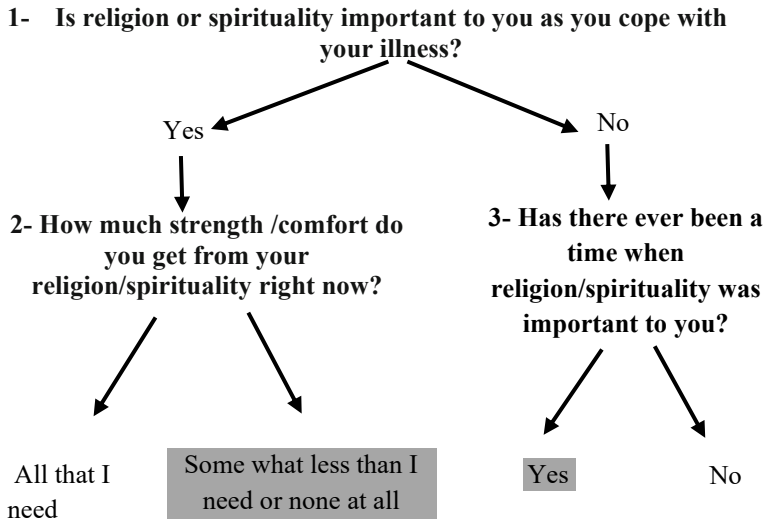
[5] whole sample

[6] Sample of 2 year or less since transplant

7	Self-Described R/S Struggle (King et al, 2017)	54 -61	77 -75	N-RCOPE	**Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
8	Peace (Steinhauser et al., 2008)	45 -55	83-80	N-RCOPE	**Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely
9	Comfort/Strength (King et al, 2017)	42-43	85-85	N-RCOPE	**Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal
10	R/S Concerns (King et al, 2017)	27-25	89-87	N-RCOPE	**Do you have any spiritual/religious concerns?** Response options: Yes, No
11	Meaning/Joy & Self-Described Struggle (King et al, 2017)	82-87	50-44	N-RCOPE	**1-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal **2-Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
12	Peace & Meaning/Joy (King et al, 2017)	78-84	54-47	N-RCOPE	**1- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely **2-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal
13	Comfort/Strength & Meaning/Joy (King et al, 2017)	77-80	56-50	N-RCOPE	**1- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **2-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal
14	Peace & Self-	75-83	64-60	N-RCOPE	**1- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely

	Described Struggle (King et al, 2017)				**2- Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
15	Comfort/Strength & Self-Described Struggle (King et al, 2017)	73-78	65-64	N-RCOPE	**1- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **2- Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
16	Comfort/Strength & Peace (King et al, 2017)	68-74	70-68	N-RCOPE	**1- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **2- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely
17	Comfort/Strength & R/S Concerns (King et al, 2017)	58-57	76-74	N-RCOPE	**1- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **2- Do you have any spiritual/religious concerns?** Response options: Yes, No
18	R/S Concerns & Meaning/Joy (King et al, 2017)	71-74	58-51	N-RCOPE	**1- Do you have any spiritual/religious concerns?** Response options: Yes, No **2- Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal
19	R/S Concerns & Self-Described Struggle (King et al, 2017)	66-71	69-65	N-RCOPE	**1- Do you have any spiritual/religious concerns?** Response options: Yes, No **2- Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal

20	Peace & R/S Concerns (King et al, 2017)	60-66	73-70	N-RCOPE	**1- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely **2- Do you have any spiritual/religious concerns?** Response options: Yes, No
21	Rush protocol (original) (Fitchett and Risk, 2009)	Sensitivity: Not reported *Positive predictive value: 92%	Not reported	Chaplain assessment	

22	Revised Rush protocol			N-RCOPE	
	(Fitchett et al, 2017)	42.1	81.3		
	(King et al, 2017)	42-31	81-90		
	(Grossoehme &Fitchett, 2013)	29	87		

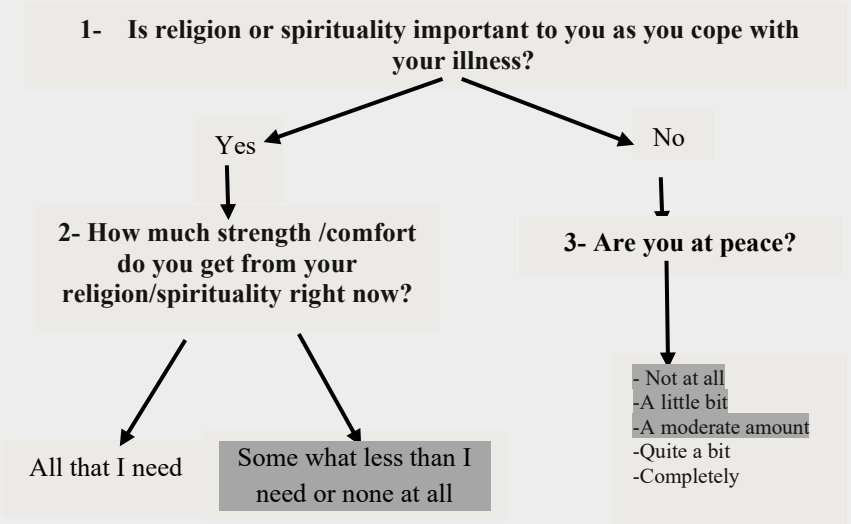
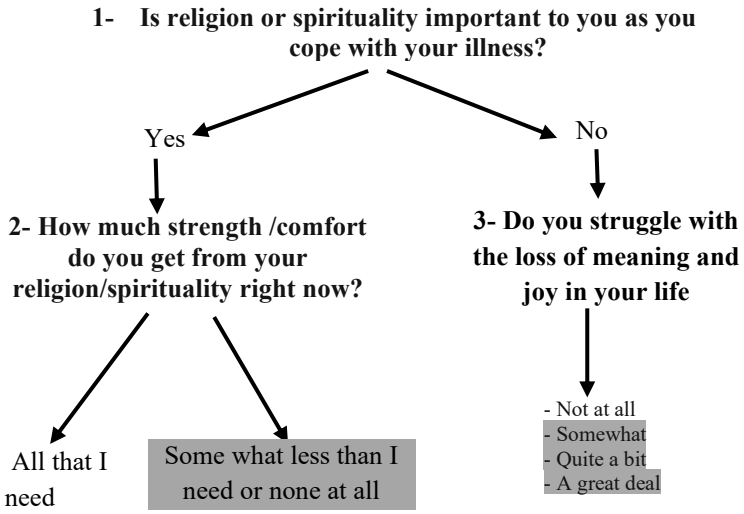
23	Modified Rush-path A-peace (Fitchett et al, 2017)	40	86.1	N-RCOPE	
24	Modified Rush-path B-meaning /joy (Fitchett et al, 2017)	42.6	83	N-RCOPE	

Table 2.4 Critical Appraisal Checklist for Diagnostic Test Accuracy Studies Regarding the Risk of Bias

Domains	**Patient selection**			**Index test**		**Reference Test**		**Flow and timing**		
Author	**Was a consecutive or random sample of patients enrolled?**	**Was a case control design avoided?**	**Did the study avoid inappropriate exclusion?**	**Where the index test results interpreted without knowledge of the results of the gold standard?**	**If the threshold was used, was it prespecified?**	**Is the gold standard likely to correctly classify the target condition?**	**Were the gold standard results interpreted without knowledge of results of the index test?**	**Was there an appropriate interval between the index test and the gold standard?**	**Did all patients receive the same gold standard?**	**Were all patients include in the analysis?**
Fitchett et al, 2017	+	+	+	?	+	-	?	+ (same time)	+	-
King et al, 2017	+	+	+	?	+	-	?	+ (same time)	+	-
Schultz et al, 2017	+	+	+	?	-	?	?	+ (same time)	+	+
Grossoehme & Fitchett, 2013	+	+	+	?	?[7]	-	?	- (27 days)	+	+
Fitchett et al, 2009	+	+	+	+	-[8]	+	-	+ (usually a day after but maybe more)	+	+

+ (yes); ? (unclear); - (no)

[7] The authors explained that Rush had good specificity (87%) and relatively low sensitivity (29%), but didn't explain what was the threshold.

[8] Based on chaplain's judgment

Table 2.5 Constructs of Spirituality

1- Sense of meaning and purpose in everyday life
2- Connectedness that is having meaningful relationship with self; other; nature; and with God or Super Being.
3- Faith and religious believe system
4- Value system: Relates to person's cherished standards, worth of thoughts and behaviors.
5- Sense of self-transcendence. Defined as *"*an expansion of personal boundaries beyond the immediate or constricted views of oneself and the world*"*.
6- Sense of **i**nner peace and harmony
7- Sense of inner strength and energy that is integrative and unifying beyond the physical realm. This energy is a positive and creative life force which create hope and motivate.

2.7 Reference List

Agora spiritual care guideline. (2013). Spiritual Care Nation-wide Guideline (Version: 1.0). *Integraal kankercentrum Nederland*. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Balboni, M. J., Sullivan, A., Enzinger, A. C., Epstein-Peterson, Z. D., Tseng, Y. D., Mitchell, C., ... & Balboni, T. A. (2014). Nurse and physician barriers to spiritual care provision at the end of life. *Journal of pain and symptom management*, *48* (3), 400-410.

Berg, G. (2011). The relationship between spiritual distress, PTSD and depression in Vietnam combat veterans. *Journal of Pastoral Care & Counseling*, *65*(1), 1-11.

Best, M., Aldridge, L., Butow, P., Olver, I., Price, M., & Webster, F. (2015). Assessment of spiritual suffering in the cancer context: A systematic literature review. *Palliative & Supportive Care*, *13*(5), 1335–1361. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=25386699

Brémault-Phillips, Suzette; Sacrey, Lori-Ann R.; Olson, Joanne; Weis, Jeanne; Cherwick, T. (2016). Measures of spirituality for use in military contexts: a scoping review. *Journal of Military, Veteran and Family Health*, *2*(1), 55–69. http://doi.org/10.3138/jmvfh.3627

Caldeira, S., Timmins, F., Carvalho, E. C., & Vieira, M. (2017). Clinical validation of the nursing diagnosis spiritual distress in cancer patients undergoing chemotherapy. *International journal of nursing knowledge*, *28*(1), 44-52.

Canadian Hospice Palliative Care Association. *2013.* A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association.

Chaves, E. D. C. L., Carvalho, E. C. D., Beijo, L. A., Goyatá, S. L. T., & Pillon, S. C. (2011). Efficacy of different instruments for the identification of the nursing diagnosis spiritual distress. *Revista latino-americana de enfermagem*, *19*(4), 902-910

Cella, D., & Nowinski, C. J. (2002). Measuring quality of life in chronic illness: the functional assessment of chronic illness therapy measurement system. *Archives of physical medicine and rehabilitation*, *83*, S10-S17.

Centre for Reviews and Dissemination. (2009). Systematic Reviews CRD's guidance for undertaking reviews in health care. University of York. UK. Retrieved from: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf

Cobb, M., Puchlaski, C. M., & Rumbold, B. (Eds.). (2012). Oxford textbook of spirituality in healthcare. OUP Oxford.

Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliative Medicine, 24(8), 753-770

Exline, J. J. (2013). Religious and spiritual struggles. In K. I. Pargament, J. J. Exline, & J. Jones (Eds.), APA handbook of psychology, religion, and spirituality (Vol. 1, pp. 459–475). Washington, DC: American Psychological Association Press

Fitchett, G., Murphy, P. E., Kim, J., Gibbons, J. L., Cameron, J. R., & Davis, J. A. (2004). Religious struggle: prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. *International Journal of Psychiatry in Medicine*, *34*(2), 179–196. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=15387401

Fitchett, G., Meyer, P. M., & Burton, L. A. (2000). Spiritual care in the hospital: Who requests it? Who needs it? *The Journal of Pastoral Care*, *54*(2), 173–186.

Fitchett, G., & Risk, J. L. (2009). Screening for spiritual struggle. *Journal of Pastoral Care & Counseling*, *63*(1-2), 1-12

Fitchett, G., Murphy, P., & King, S. D. (2017). Examining the validity of the Rush Protocol to screen for religious/spiritual struggle. *Journal of health care chaplaincy*, *23*(3), 98-112

Grossoehme, D. H., & Fitchett, G. (2013). Testing the validity of a protocol to screen for spiritual struggle among parents of children with cystic fibrosis. *Research in the social scientific study of religion*, *24*, 281

Grossoehme, D. H., Teeters, A., Jelinek, S., Dimitriou, S. M., & Conard, L. A. E. (2016). Screening for spiritual struggle in an adolescent transgender clinic: Feasibility and acceptability. *Journal of health care chaplaincy*, *22*(2), 54-66.

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and Negative Religious Coping and Well-Being in Women with Breast Cancer. *Journal of Palliative Medicine*, 12(6), 537–545. http://doi.org/10.1089/jpm.2008.0250

Herdman, T.H. & Kamitsuru, S. (Eds.). (2014). *NANDA International Nursing Diagnoses: Definitions & Classification*, 2015–2017. Oxford: Wiley Blackwell

King, S. D. W., Fitchett, G., Murphy, P. E., Pargament, I., Harrison, D. A., & Loggers, E. T. (2017). Determining best methods to screen for religious/spiritual distress. *Supportive Care in Cancer*, *25*(2), 471–479. http://doi.org/10.1007/s00520-016-3425-6

Manning-Walsh, J. (2005). Spiritual Struggle. *Journal of Holistic Nursing*, *23*(2), 120–140. http://doi.org/10.1177/0898010104272019

Mako, C., Galek, K., & Poppito, S. R. (2006). Spiritual Pain among Patients with Advanced

Cancer in Palliative Care. *Journal of Palliative Medicine*, *9* (5), 1106–1113. http://doi.org/10.1089/jpm.2006.9.1106

National Comprehensive Cancer Network. (2003). Distress management. Clinical practice guidelines. *Journal of the National Comprehensive Cancer Network: JNCCN*, *1*(3), 344.

National Institute for Clinical Excellence. (2004). Guidance on cancer services. Improving supportive and palliative care for adults with cancer. The manual. London: NICE, 2004

Pargament, K., Feuille, M., & Burdzy, D. (2011). The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping. *Religions*, *2*(4), 51–76. http://doi.org/10.3390/rel2010051

Pargament, K. I., Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology*, 9(6), 713–730. doi:10.1177/1359105304045366

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2001). Religious struggle as a predictor of mortality among medically ill elderly patients: a 2-year longitudinal study. *Archives of Internal Medicine*, *161*(15), 1881–1885. http://doi.org/ioi00736 [pii]

Park, C. L., Wortmann, J. H., & Edmondson, D. (2011). Religious struggle as a predictor of subsequent mental and physical well-being in advanced heart failure patients. *Journal of Behavioral Medicine*, 34(6), 426–436. doi:10.1007/ s10865-011-9315-y

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

Puchalski, C. M., & Ferrell, B. (2010). Making health care whole: Integrating spirituality into patient care. West Conshohocken, PA: Templeton PressRamirez, S. P., Macêdo, D. S., Sales, P. M. G., Figueiredo, S. M., Daher, E. F., Araújo, S. M., … Carvalho, A. F. (2012). The relationship between religious coping, psychological distress and quality of life in hemodialysis patients. *Journal of Psychosomatic Research*, *72*(2), 129–135. http://doi.org/10.1016/j.jpsychores.2011.11.012

Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *Journal of clinical nursing*, *15*(7), 852-862.

Rushton, L. (2014). What are the barriers to spiritual care in a hospital setting? *British Journal of Nursing, 23*(7), 370-4. doi:10.12968/bjon.2014.23.7.370

Schultz, M., Meged-Book, T., Mashiach, T., & Bar-Sela, G. (2017). Distinguishing Between Spiritual Distress, General Distress, Spiritual Well-Being, and Spiritual Pain Among Cancer Patients During Oncology Treatment. *Journal of pain and symptom management*, *54*(1), 66-731–88.

Selman, L., Young, T., Vermandere, M., Stirling, I., & Leget, C. (2014). Research Priorities in Spiritual Care: An International Survey of Palliative Care Researchers and Clinicians. *Journal of Pain and Symptom Management, 48*, 518–531.

Sinclair, S., & Chochinov, H. M. (2012). The role of chaplains within oncology interdisciplinary teams. *Current Opinion in Supportive and Palliative Care*, *6*(2), 259–68. http://doi.org/10.1097/SPC.0b013e3283521ec9

Jankowski, K. R., Handzo, G. F., & Flannelly, K. J. (2011). Testing the efficacy of chaplaincy care. *Journal of Health Care Chaplaincy*, 17(3-4), 100-125

Tarakeshwar, N., Vanderwerker, L. C., Paulk, E., Pearce, M. J., Kasl, S. V., & Prigerson, H. G.

(2006). Religious Coping is Associated with the Quality of Life of Patients with Advanced Cancer. *Journal of Palliative Medicine*, *9*(3), 646–657. http://doi.org/10.1089/jpm.2006.9.646

The Joanna Briggs Institute [JBI]. (2015). *Joanna Briggs Institute Reviewers' Manual 2015: The systematic review of studies of diagnostic test accuracy*. The Joanna Briggs Institute.

Thuné-Boyle, I. C. V, Stygall, J., Keshtgar, M. R. S., Davidson, T. I., & Newman, S. P. (2013). Religious/spiritual coping resources and their relationship with adjustment in patients newly diagnosed with breast cancer in the UK. *Psycho-Oncology*, *22*(3), 646–658. http://doi.org/10.1002/pon.3048

Villagomeza, L. R. (2005). Spiritual distress in adult cancer patients: toward conceptual clarity. *Holistic nursing practice*, *19*(6), 285-294.

Walter, T. (2002). Spirituality in palliative care: opportunity or burden?. *Palliative Medicine*, *16* (2), 133-139.

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., … Balboni, T. A. (2011). The Relationship of Spiritual Concerns to the Quality of Life of Advanced Cancer Patients: Preliminary Findings. *Journal of Palliative Medicine*, *14*(9), 1022–1028. http://doi.org/10.1089/jpm.2010.0536

Whiting, P. F., Rutjes, A. W., Westwood, M. E., Mallett, S., Deeks, J. J., Reitsma, J. B., ... & Bossuyt, P. M. (2011). QUADAS-2: a revised tool for the quality assessment of diagnostic accuracy studies. Annals of internal medicine, 155(8), 529-536.

Chapter 3: Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to Spiritual Care Service in Complex Continuing Care

Authors: Sayna Bahraini, Ian D Graham, Wendy Gifford, Rebekah Hackbusch, Liquaa Wazni, Suzette Bremault-Phillips, Mary Egan.

Prepared for submission to International Journal of Studies in Nursing

---

Abstract

Background: Spiritual suffering exists in approximately 25-50% of chronically ill and dying patients and has an association with poor physical and mental health outcomes. **Purpose:** To assist clinical chaplains and other staff at a complex continuing care hospital to identify a process to better screen patients experiencing spiritual suffering. Specifically, we sought to: (1) identify key considerations when selecting a measure to screen patients for spiritual suffering, (2) select a screening measure, and (3) determine the process of implementing the screening measure. **Methods:** We conducted three consecutive focus group interviews with registered nurses, nurse managers, patients, and clinical chaplains. We used an inductive analytical method to analyze the data. **Findings:** Healthcare providers specified eight considerations they felt were important for selecting a spiritual screening measure. They selected the *Peace and Meaning/Joy* as the measure that best met these considerations. Participants of the study suggested that screening process should be conducted in two stages, with the nurses screening patients using the two simple questions within 48 hours to seven days of admission, and referring patients who had screened positive in the initial stage to clinical chaplains for specialized screening using the *Peace and Meaning/Joy measure*. **Conclusion:** We conducted three focus group interviews to address a concern raised by hospital staff and provide a strategy to screen for spiritual suffering. Future studies should determine the accuracy of the *Peace and Meaning/Joy measure* that has not been validated in complex continuing care context.

KEYWORDS: Spiritual Suffering; Screening Measures; Implementation, Complex Continuing Care

3.1 Introduction

Patients experience spiritual suffering when their need to find meaning and purpose in life through connectedness with self, others, nature and/or what one holds to be sacred is unfulfilled (Cobb, Puchlaski, & Rumbold, 2012). Many researchers have associated spiritual suffering with poor physical and psychological health outcomes including decreased quality of life and coping with illnesses (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Manning-Walsh, 2005; Pargament et al. 2004; Sherman, Plante, Simonton, Latif, & Anaissie, 2009; Tajbakhsh et al., 2018, Vazifeh et al., 2019; Winkelman et al., 2011). Pargament and colleagues (2004) found that spiritual suffering was associated with increased functional limitations and depressive symptoms in elderly patients. Spiritual suffering was also associated with increased risk of mortality, even when controlling for demographic, physical, and mental health factors (Pargament, Koenig, Tarakeshwar, & Hahn, 2001).

Spiritual care guidelines reinforce the importance of screening and referring patients who might be experiencing spiritual suffering to specialized spiritual care (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009). The Inpatient Spiritual Care Implementation Model (ISCIM) which was developed by Puchalski and colleagues (2009) to integrate spiritual screening into routine care, recommends screening patients for spiritual suffering upon admission. The ISCIM suggests that clinicians such as nurses use a screening measure and refer patients with positive results to specialists such as clinical chaplains who have advanced training to provide specialized spiritual care (Sinclair & Chochinov, 2012).

Despite the importance of early screening and the need for appropriate referral to spiritual care services, spiritual screening remains inadequate in clinical settings (Puchalski & Ferrell, 2010; Selman et al., 2014;). A study by Selman and colleagues (2014) revealed that identifying

spiritual suffering is an international concern among clinicians. Some researchers have conducted studies on the barriers that prohibit healthcare providers from identifying patients who need a referral to spiritual care services (Balboni et al., 2014; Bar-Sela et al., 2019; Edwards, Pang, Shiu, & Chan, 2010; Ross, 2006). As the most common barriers to spiritual suffering screening, they have identified lack of time (Balboni et al., 2014; Edwards, Pang, Shiu, & Chan, 2010), and lack of training (Balboni et al., 2014; Edwards, et al., 2010; Ross, 2006).

In this study, we planned to collaborate with healthcare administrators of a Canadian hospital that provides a complex continuing care program in Ontario. Complex continuing care is essentially long-term care for people with complex medical needs (Bruyère, 2019). In this particular institution, spiritual care staff felt that screening for spiritual suffering was inconsistent and ineffective (The coordinator of spiritual care of the hospital, personal communication, April 16, 2017). The director of therapeutic support services (K.L.) and the coordinator of spiritual care (R.H.) mentioned that patients with spiritual suffering often remain under-identified as they are not systematically screened nor referred at their hospital. Simultaneously, many patients who nurses refer to spiritual care specialists did not require specialized care; thus, unnecessarily utilizing limited specialist resources. With a limited number of spiritual care specialists such as clinical chaplains available, and spiritual suffering negatively impacting patients' health (Pargament, et al, 2004;Tajbakhsh et al., 2018, ; Thuné-Boyle et al., 2013; Vazifeh et al., 2019;), hospital directors deemed screening for spiritual suffering a top research priority of the hospital. We planned to use an Integrated Knowledge Translation (iKT) approach to address this issue.

IKT involves the co-production of research through continuous collaboration of researchers with knowledge-users, including those who are affected by or in charge of action on the issue being studied (Canadian Institute of Health Research [CIHR], 2015). IKT aims to

increase knowledge-users' participation in research for enhanced research uptake, sustainability, and more positive health outcomes (Macaulay et al., 2011). In the iKT approach researchers and knowledge users share equal power throughout the research process to co-create evidence based and practical knowledge (CIHR, 2015; Straus, Tetroe, & Graham, 2013). The primary investigator of the study (S.B.) and one of the co-investigators (W.G.) had several meetings with the director of therapeutic support services (K.L.) and coordinator of spiritual care (R.H.) to define the clinical problem and how to addressed it through this research. The research team and the hospital healthcare administrators decided to use a measure to screen patients for spiritual suffering and determine the implementation process for using the selected measure. Specifically, we aimed to conduct a study to (1) identify key considerations when selecting a measure to screen patients for spiritual suffering, (2) select a screening measure, and (3) determine the process of implementing the screening measure.

3.2 Setting

This study was conducted at a bilingual (i.e., English and French), 350 bed faith-based hospital. This hospital is a provider of complex continuing care services to medically complex patients who require sub-acute, geriatric or palliative care in Ontario, Canada. The institution has eight units and an average admission rate of three to four patients per day. Patients usually have progressive diseases, multiple medical conditions, severe and chronic functional impairment, or specialized wound care needs. Those who are admitted require higher levels of care and are usually dependent on others for performing daily living activities. Care is provided by a team of interdisciplinary healthcare providers including physicians, registered nurses (RNs), registered practical nurses (RPNs), social workers, and spiritual care providers. The interprofessional health care team works closely with patients and families to develop an individualized care plan. The

care plan is continuously adjusted and evaluated as the patient's care requirement change. The goal of the hospital is to meet each patient's physical, emotional, social and spiritual needs, thereby achieving an improved quality of life. Staff RNs and RPNs are responsible for all routine nursing duties, including providing and coordinating patient care; RNs are responsible for taking medical history upon admission. As a Catholic organization, this hospital inspired by the values and legacy of Mother Élisabeth Bruyère. These values include respect, compassion, collaboration, accountability and learning. Although organization is faith-based, they do provide spiritual care for all people with different, faiths, non-faiths, worldviews. As the organization's mission states, this health care organization committed to providing compassionate and holistic care, respecting the dignity and diversity of all people.

3.3 Methods

A qualitative description design (Sandelowski, 2000) guided the qualitative methods of inquiry to generate clinically relevant knowledge and consequently inform solutions for the participating organization's clinical context. We planned to use an Integrated Knowledge Translation (iKT) approach (CIHR, 2015) which involved engaging knowledge users in an iterative process of co-producing a solution to address the organization's concern of identifying and addressing patients' spiritual suffering. In this approach, researchers and knowledge users collaboratively make decision at each stage of the research such as the research question, selection of the methods, and data collection (Jull, Giles & Graham, 2017; Straus, Tetroe, & Graham, 2013). while sharing power to produce feasible and evidence-based solutions (Straus, Tetroe, & Graham, 2013).

The coordinator of spiritual care (R.H.) and the director of therapeutic support services (K.L.) had been involved in identifying the research problem and aim; R.H. was actively

engaged throughout all stages of the research process. Healthcare providers including nurse managers, RNs, clinical chaplains, and patients were also engaged in addressing the research problem through focus group interviews. In this study, the knowledge users reviewed the evidence on available screening measures, identified considerations for measure selection they felt were critical to their setting, identified implementation considerations, and revised their decisions to address the feedback they received from patients.

We initially planned to conduct two focus groups, the first (FG#1) with healthcare providers to select a screening measure and determine the implementation process for the measure, and the second (FG#2) with patients to understand their perspectives on the selected measure and proposed implementation process. As the patient focus group revealed some issues with the selected measure and planned implementation process, the research team decided that a third focus group (FG#3) was required for the healthcare providers to inform them and enable them to respond to patient concerns. A description of the composition of the focus groups and interview questions follows.

3.3.1 Focus Group Interview #1: Healthcare Providers

The purpose of the first focus group was to determine key considerations in selecting a measure to screen patients for spiritual suffering, select a screening measure, and determine an implementation process.

Participants: Healthcare providers included clinical chaplains, RNs, and nurse managers. We used a purposive sampling method to select participants who were able to make a valuable contribution to determination of the most appropriate spiritual screening measure and an implementation process that would support its integration into the staff workflow at the hospital.

The inclusion criteria for this study included clinicians who could speak English and had experience and interest in incorporating spiritual screening into routine care (see Appendix I for the recruitment process).

Methods: In preparation for the focus group interviews, the PI (S.B.) undertook a systematic review to synthesize information about the available screening measures and their accuracy in identifying patients with spiritual suffering (Bahraini et al., 2019). A week prior to the focus group interview, the PI (S.B.) shared the focus group outline (Appendix G) and a summary of the systematic review findings with the participants (see Appendix H for the pre-reading material). She (S.B.) asked them to select the top three measures that could be used at their hospital. Participants were able to select a measure based on their experience, knowledge and the available evidence on the diagnostic accuracy of the measures.

A one-hour focus group was facilitated by the PI (S.B.) and the coordinator of spiritual care at the hospital. At the beginning of the focus group, the PI interpreted the diagnostic accuracy criteria of the identified measures and answered participants' questions. The facilitators then inquired about key considerations in selecting appropriate measures, and asked participants to both vote on the most appropriate screening measure and decide how to implement the selected measure in their hospital.

At the end of discussion for each sub-question (see Appendix I for the interview questions), facilitators asked the group to make a final decision on answers for the related key questions. Participants made final decisions regarding (1) the screening measure deemed to be most appropriate for use at the designated hospital, and (2) a process for implementing the spiritual screening measure (e.g., who will administer the measure, when it would be administered, strategies to introduce it into routine practice). Decisions were consensus-based,

and the facilitator reviewed and confirmed participants' final decisions in the focus group session.

3.3.2 Focus Group Interview #2: Patients

The purpose of the FG#2 was to understand patients' perspectives on the selected measure and the planned implementation process of the measure at the hospital.

Participants: We used purposive sampling to select patients from the participating hospital who could make a valuable contribution. Clinical chaplains and nurse managers helped the coordinator of spiritual care (R.H.) to identify participants who met one or more of the following criteria: previous experience of spiritual suffering or receiving spiritual care, and interest in discussing spiritual issues. Eligible patients had to be (1) able to hold a conversation, (2) English-speaking, (3) able to participate in a sixty-minute focus group, and (4) in a stable physical condition and cognitive status determined by the unit RN. If the time and date of the focus group interfered with the patient's routine care, they were excluded from the study (see Appendix I for the FG#2 recruitment process).

Methods: The coordinator of spiritual care (R.H.) provided participants with an outline of the focus group interview before the session (Appendix L). At the beginning of the session, the facilitators provided an overview of the aims of the project, the importance of screening patients for spiritual suffering, and results of the previous focus group (i.e., the selected spiritual screening measure and the proposed process for implementation of the measure by healthcare providers). They asked the participants to provide their feedback on the proposed questions (see Appendix I for the FG#2 interview questions).

3.3.3 Focus Group Interview #3: Healthcare providers

The purpose of the third focus group was to explore ways of integrating patients' feedback into the screening process.

Participants: We conducted this focus group with a subset of participants from the first focus group (RN's, nurse managers and clinical chaplains). The inclusion criteria were participation of at least one representative of each profession from the first focus group who is willing to attend in this focus group interview (see Appendix I for the FG#3 recruitment process).

Methods: The coordinator of spiritual care (R.H.) and the PI (S.B.) facilitated a 45-minute focus group interview. At the beginning of the session, they presented the aim of the session and results of the first and second focus group interviews. For the remainder of the session, participants reflected on patients' feedback and tried to reach consensus on how to address patients' concerns. A semi-structured interview guide with open-ended question was used to facilitate the discussion (see Appendix I for the FG#3 interview questions). Participants' recommendations were made based on consensus and the facilitator reviewed and confirmed all the recommendations that were made, at the end of the session with the participants.

All focus group interviews were transcribed verbatim. Research ethics approval was obtained from the University of Ottawa and Hospital Research Ethics Boards.

3.4 Data Analysis

Each focus group interview was analyzed separately, and all data were analyzed using an inductive analytical method (Thorn, 2016). The qualitative analysis process occurred in several stages: 1) Coding participants' responses using the words of participants - each transcript was reviewed for codes related to each question; 2) Development of categories - initial categories

were identified after organizing codes around study's aims; 3) Re-organization of initial categories to generate overarching and main categories; The aforementioned process was an iterative, and the identified categories were determined individually by the PI and then confirmed by L.W. who reviewed the transcripts and data analysis. L.W. read each focus group transcript along with the related codes and categories developed by the PI. The PI and L.W. discussed and resolved conflicts that arose through meetings. 4) Development of condensed tables for each focus group analysis including all the categories, quotes, and participants' verbatum recommendations, and the researcher's interpretation and reflection about each category; 5) Discussion on the condensed tables with supervisors and the thesis committee including R.H., the knowledge-user on the team; and 6) Refinement of categories based on discussion with supervisors and the thesis committee.

3.5 Results

In total, there were 23 participants including five RNs, five clinical chaplains, five nurse managers, and eight patients who participated in the three focus group interviews. More specifically, four RNs, four clinical chaplains (all work part-time), and three nurse managers participated in the FG#1; eight patients participated in FG#2, and a clinical chaplain, an RN, and two nurse managers participated in FG#3. A total of four men (three patients and one nurse manager) and 19 women took part in the focus group interviews.

3.5.1 Focus Group Interview #1: Healthcare Providers

- **Determining key considerations in selecting a measure to screen patients for spiritual suffering**

Healthcare providers identified eight key considerations they thought were important when selecting a measure to screen patients for spiritual suffering. Analysis of these considerations

revealed four major categories: content and wording, length, accuracy, and contextual circumstance. Participants' rational for selecting each key consideration and representative quotes are provided in Table 3.1.

Table 3.1 Key Considerations for Selecting an Appropriate Spiritual Screening Measure for the Hospital by Healthcare Providers

Category	The Measure Should Be:	Participants' Rational	Example Quote
Content and Wording	**Simple and to the point**	1-Non-chaplain clinicians may not be trained in the spiritual field. 2-Distressed patients require a simple and to the point measure.	**Nurse manager**: *"If we're including other disciplines in asking the question, I believe from a nursing standpoint and that's nursing focus, it needs to be simple and to the point…."*.
	Broad	Spiritual suffering is a broad concept that encompasses various factors such as spiritual, religious, existential, and emotional suffering. An ideal spiritual screening measure should cover all these dimensions. However, to make the questions on a measure congruent with patients' beliefs, clinicians may adapt some of the questions having had a conversation with patients.	**Chaplain:** *"… it does seem like those two questions (peace & meaning /joy) encompass a lot of spiritual suffering….and they're fairly broad …if a person doesn't relate to religion or spirituality comfortably, it still opens the door to a conversation about suffering or existential suffering*."
	In a lay rather than clinical format	To open the conversation easily with patients.	**Chaplain:** *"… Are you at Peace? … it's a good layperson's kind of question… it just kind of opens the conversation very broadly and easily…"*
	Clearly worded	Questions on the screening measures should be easily understood.	**Manager:** *"I like something that has simple and clear [wording] …. than number one, it's just like spiritual pain… it might be hard to define"*.
Length	**Brief (the measure and the response options)**	1- Screening should be a quick assessment of patients' condition. 2- Distressed patients cannot answer lots of different questions. 3- On admission, patients are bombarded with different assessment questions. A long screening measure may	**Chaplain:** *"[It should be brief] Because it's a screening, not meant to open the door to a huge conversation…So maybe I'd pick one question from it [a long measure]; one or two questions"*. **Chaplain:** "*You know, there's enough people asking them a lot of questions. So if it can be a yes or a no... like not this elaborate scale"*.

		make patients overwhelmed and influence the accuracy of their responses.	
Accuracy	**Highly sensitive and specific**	Everyone can benefit from spiritual care, but screening should be about detecting the right patients. ***Consensus-based:** Participants preferred measures with high sensitivity over measures with high specificity.	**Chaplain:** "*…the Peace and Meaning/ Joy. And I was, I was kind of interested to note that it has a 78-84% sensitivity".* **Manager:** "*…I like how it rated its sensitivity and its specificity".*
	Focused on identifying patients with high levels of spiritual suffering	Screening is about detecting patients who have high level of spiritual suffering and need immediate referral to a clinical chaplain.	**Nurse:** "*… it was said before, everyone could benefit from a chaplain so are we trying to get more specific and really get those people*…".
Contextual Circumstances	**Useful for the clinical context** The discipline which is going to screen patients, the timing of screening, and the context where the screening is taking place should be taken into consideration when selecting a measure.	Various factors can influence patients' responses including the context and timing of the screening, type of healthcare provider (doctor, nurse, clinical chaplain, etc.) and their questioning techniques.	**Nurse**: *"… maybe different screening tools would be useful at different times. So, upon admission, there's something different that you're looking after. But then when I think of patients that I've cared for when they are going from Supportive or let's say Restorative and then they change, their condition changes, and then they're having to be End of Life, that's a very traumatic time for the patient, and they... to ask them at that point is challenging, say, "Oh maybe, do you think you need to…" you know, "you've lost meaning"? It's a silly question to ask, clearly they have".* **Chaplain:** *"…By whom [the questions on the screening measure will be asked]. ?...And in what context?[are other considerations for selecting a measure]".*

- **Selecting the screening measure to be used in the hospital**

Healthcare providers initially selected the following 9 measures from the 24 spiritual screening measures (see Appendix H) isolated in the course of our systematic review (Bahraini et al., 2019): *The Peace (*Steinhauser et al., 2006)*, Spiritual Pain (*Schultz et al., 2017)*, Peace and Meaning/Joy* (King et al., 2017)*, Spiritual Injury Scale (*Berg , 2011)*, 2-item Peace & Self Described R/S Struggle* (King et al., 2017) *, New Israeli Items (*Schultz et al., 2017)*, Self*

Described R/S Struggle (King et al., 2017)*, Meaning/Joy* (King et al., 2017)*, and Meaning/Joy & Self Described R/S Struggle* (King et al., 2017)*.* We then asked the participants to vote for their preferred screening measure. In the first voting round, the *Peace and Meaning/Joy measure* (King et al., 2017) along with the *Spiritual Pain measure (*Schultz et al., 2017) received the greatest number of votes (3 each). We then conducted a second round of voting in which participants voted on these two measures. The majority of participants (n = 10) selected the *Peace and Meaning/Joy measure* (King et al., 2017) for use at the hospital. This measure consists of the following two questions: 1) Are you at peace? and 2) Do you struggle with the loss of meaning and joy in your life? This measure has Likert type scale response categories. However, the healthcare providers suggested using Yes/No in keeping with the consideration that the measure be brief.

- **Incorporating the selected screening measure into practice**

To implement the selected screening measure into practice, participants provided suggestions on who should administer the measure as well as how, and when the measure ought to be used at the hospital (see Table 3.2 for more details).

Who: Healthcare providers considered RNs to be the best group to screen patients using the *Peace and Meaning/Joy measure* because nurses are constantly available, thereby increasing the likelihood of establishing the best relationship with patients.

How: Healthcare providers identified five ways for nurses to facilitate effective implementation of the screening measure. Before asking the screening questions, they suggested that nurses establish a rapport with patients and explain the clinical chaplains' role using a pamphlet. While asking the screening questions, they ought to demonstrate a non-judgmental attitude toward patients, and use their clinical judgment in assessing a patient's need for referral

for spiritual suffering. Following the screening, nurses should ensure that follow-up opportunities are available to patients (see Table 3.2). Healthcare providers suggested the following strategies to help incorporate screening for spiritual suffering into routine care at the hospital:

- **Adding the screening questions along with clinicians' comment option to the electronic intake system of the hospital:** Healthcare providers believed that patients' responses to the screening questions are not sufficient to determine high levels of spiritual suffering. To give both patients and nurses the opportunity to make a decision about the existence of spiritual suffering, healthcare providers decided that clinicians' comment option should be added to the screening questions. In order to make a referral to clinical chaplains, clinicians' comment should be congruent with patients' responses. Therefore, they suggested that the hospital establish three items (two screening questions of the *Peace and Meaning/Joy measure* and a clinician comment) on its intake system. However, they emphasized that nurses needed training to improve their clinical judgment and ability to recognize signs of spiritual suffering in order to make an appropriate comment on the intake system. Healthcare providers also suggested defining some parameters and setting an automatic reminder for following up with patients.
- **Adding information about the role of clinical chaplain and available spiritual services in the admission booklet or making a handout/pamphlet which includes this information:** According to healthcare providers, patients may have misunderstandings of what clinical chaplains and available spiritual services offer. They thought that patients might associate clinical chaplains and spiritual resources

solely with religious issues which may result in some patients being resistant to meeting a chaplain. One of the nurse managers suggested using written information about clinical chaplains' roles at the hospital.

The timing for distribution of the written information was also important. Clinical chaplains suggested that written information should not be handed out to patients immediately upon arrival to the hospital. They believed patients to be overwhelmed by all the information they receive at the time of admission, potentially creating difficulties in reading and understanding what they have been provided. They thought that staff should also receive training about clinical chaplains' role and available spiritual resources in order to explain those to patients.

- **Training nurses to improve their communication techniques and clinical judgment in order to better recognize signs of spiritual suffering in patients:** Participants in the FG#1 emphasized that, before asking screening questions, nurses need to build a trusting relationship with patients so that patients feel comfortable disclosing and revealing their feelings and spiritual concerns. They suggested that nurses' approaches and attitudes towards patients can influence patients' responses to the screening questions. According to the healthcare providers, nurses require training as to how to establish a trusting relationship with patients before asking the screening questions. They believed that building a trusting relationship with patients can positively affect nurses' clinical judgment specific to identifying spiritual suffering. The healthcare providers explained that clinical judgment requires observation of patients' behaviors and assessment of their feelings in relation to the situation. Clinical chaplains believed that relying on patients' responses to the screening questions

without using clinical judgment could increase the risk of missing patients who are experiencing spiritual suffering.

When: The healthcare providers mentioned that the screening should be done any time after the first 48 hours, but not later than a week post-admission. They believed that the timing of screening for spiritual suffering could influence patients' responses. For example, asking the screening questions upon arrival to the hospital could increase the chance of false negative or positive results. Healthcare providers commented that allowing some time for patients to adjust to their new circumstance could make their responses to the spiritual questions more valid.

They also mentioned that patients' condition may change after the screening. Therefore, the primary determination of a patient as not having spiritual suffering may increase the risk of eliminating further investigation. Healthcare providers believed that it is important that nurses use their clinical judgment and follow up with patients at pre-determined time points (e.g., every three months) or when changes occur in a patient's condition (Table 3.2).

Table 3.2 Incorporation of the Screening Measure into the Routine Practice from the HealthCare Providers' Perspective

Category	Sub-Category	Behaviors (codes)	Participants' Rational	Example Quotes	Participants' Recommendation:
How	**Before Screening**	Defining clinical chaplain's role to patients and families.	Many patients may not capture or may misunderstand what the need is to meet a clinical chaplain and what a clinical chaplain's role is, therefore, they may refuse a visit from them.	**Nurse:** *"And a definition. A definition of what a Chaplain does because I always constantly have to say, well it's, it's not just religion, it's not just… Yeah, because they automatically assume it's the God Squad…"*	Adding information about chaplain's role in the admission booklet or developing a handout/pamphlet which includes this information.
		Establishing a relationship or rapport with patients prior to	To build trust with patients and make them feel comfortable.	***Chaplain:*** *"…is there a relationship, or some sort of rapport already established [when asking the screening questions]?_…. So you can say, 'are you at peace', or you*	

		asking the screening questions		*know, you've had a conversation and then 'so, are you at peace'? [the later make patients comfortable to answer the spiritual screening questions because you have established a relationship]".*	
	During Screening	Having a non-judgmental attitude toward patients	Clinicians' personality and spiritual beliefs may influence their clinical judgment in identifying patients' spiritual suffering.	**Chaplain:** "*... the type of personality that's asking it, what their own beliefs are about this. Sometimes they get transposed onto those questions, people's assumptions about spiritual care too, that we're the God Squad ...".*	
		Using clinical judgement	Relying on the measure without using clinical judgment may increase the risk of missing patients who have spiritual suffering (False negative results). [Participants explained that clinical judgment includes skills of observation of patients' behaviours and assessment of their feeling and situation]	**Chaplain*: "...*** *And I think for me the assessment is I ask-- I teach when I'm teaching the nurses, to use their clinical judgement. ... because if you ask the question, 'are you at peace?' some people don't even know they're not at peace... but they may answer to this, "Yeah, I'm at peace" so there now the door's closed to spiritual care because no, no, they're fine".*	**Using clinical judgment along with the screening measure** Alongside the two questions on the Peace & Meaning/Joy screening measure (the selected measure), we can add a clinicians' comment option on the electronic intake system of the hospital. The clinicians' comment should be congruent with patients' responses in order to make a referral.
	After Screening	Not closing the doors after screening (following up patients)	Patients may incorrectly respond to the screening questions or their condition may change after the first screening.	**Manager: "…** *you have to reassess. So you might want to define when that reassessment [re-screen] would take place which then would eliminate it's closed after the initial question".*	Clinicians should follow up patients after the first screening (Recommended time is every 3 months, after changes in patients' condition, or based on staffs' clinical judgments).
When	-	**- screening:** within the first week (but not right after admission). **– follow up:** every 3 months, after changes in patients' condition, or	**[Something about why not right away]** Some patients are angry at the time of admission and could incorrectly be identified as experiencing	**Manager:** "*Not right away".* **Nurse**: "*Within a week".*	Adding the initial screening questions to the hospital's electronic system and setting a reminder for following up based on the defined parameters.

		based on staff's clinical judgment.	spiritual suffering. Some patients are also overwhelmed upon arrival to the hospital and may intentionally answer the questions positively to prevent more visits and inquiries from healthcare providers.		
Who		Nurses are the best resource to screen patients.	Nurses are at the forefront of patient care and spend more time with patients compared to other healthcare providers. This provides them with the opportunity to build rapport and a therapeutic relationship with patients.	**manager**: *"Yes. They're (nurses) the front line".* **Chaplain:** "*They're (nurses)the ones who see the patient most often".* **manager:** "*Yeah. The best rapport probably".*	Allied healthcare providers that assess patients are also able to screen patients, but nurses are the best resource.

3.5.2 Focus Group Interview #2- Patients

The second focus group was conducted with eight patients (three men and five women), to understand their perspectives on the selected measure and the potential implementation processes.

- **Patients' response to the *Peace and Meaning/Joy measure***

Four patients in the focus group considered the choice of the *Peace and Meaning/Joy measure* (King et al., 2017) to be appropriate and acceptable. The other four patients were less enthusiastic, considering it 'vague' or 'scary'. Patients' perspectives on each question are presented in Table 3.3. Three patients suggested alternative screening questions that they believed were clearer and less-threatening, for example, is there anyone/anything you need to

speak to/about? Do you want to talk to someone about how you're feeling? Are you feeling low today?

- **Patients' views on suggestions for incorporating the selected measure into practice**

Who: Five patients reported past negative experiences discussing spiritual issues with some nurses. This made them think that nurses might not be the best professional to do the screening. These patients believed that nurses would not be able to use the *Peace and Meaning/Joy measure* because they do not have enough time to build a relationship with patients. Some patients also felt that some nurses may not have enough compassion and experience to deal with patients who have spiritual suffering. They suggested that social workers might be better at doing the screening than nurses.

How: Similar to healthcare providers, patients emphasized the importance of taking certain steps prior to screening. Specifically, they felt that it was important that the person doing the screening define clinical chaplains' roles and establish a relationship or rapport with patients before screening. They also highlighted the importance of using communication skills when approaching patients for screening. For example, they indicated that the manner in which the questions are asked and the "tone" used by clinicians when asking the questions had to be taken into consideration (see Table 3.4). According to patients, effective communication techniques help patients build a trusting relationship, and this is essential for them to be able to disclose their feelings and provide an accurate response to spiritual screening questions. They emphasized that nurses at this hospital need training on how to establish a trusting relationship with patients before asking the screening questions.

When: Patients were also in agreement with healthcare providers that screening should be done after 48 hours, but within a week of patients' arrival to the hospital. They agreed that giving

patients some time to adapt to the new situation would produce more dependable responses to the spiritual questions. Patients suggested that clinicians should follow up with patients in two weeks from the initial screening (if patients' response is negative to a clinical chaplain visit) or when changes occur in a patients' condition.

Table 3.3 Patients' Perspectives on the *Peace and Meaning/Joy* Screening Questions

	Screening question	**Patients' perceptions of the screening question**	**Explanation and quotes**	**Patients' Recommendation**
Screening questions selected by health care providers	1-Are you at peace?	-**Broad** (can encompass many faiths or a secular orientation) -**Vague** (con: unclear; pro: can be interpreted in different ways) -**Scary** (seems like a palliative care question, implies immanent death)	Participants had different perspectives on this question. This question has been described as "***vague***" by one participant, however, the vagueness has been considered an advantage of this question by another participant because, "... [***it] leaves it open so people can interpret being at peace however they want to***". This question also has been labelled as "***scary*****"** for elderly patients, since it may give them the impression that ***"they are going to die, so they give up".***	1- Change the wording of this question to make it less scary and vague. 2-Do not ask this question right away on admission as patients at that moment are often distressed and the question can be overwhelming for them..
	2-Do you struggle with a loss of meaning and joy in your life?	-Gives the impression that the patient is **down/depressed**	Generally, patients preferred this question over the one, Are you at peace? However, one patient considered this question to be misleading, pointing to the negative burden of the question. "[asking these kind of questions] ***make me identify the fact that I am down, and if I identify it, I have to deal with it…[but] I want to be in charge of how I deal with it***".	-
Screening questions suggested by patients	-Is there anyone/ anything you need to speak to/about? -Do you want to talk to someone about how you're feeling? -Are you feeling low today?	- Simple - Direct - Not vague - Not scary - Doesn't sound like you're having a mental exam - More personal - More approachable - More personal - Makes patients open up	Patients suggested three questions that are non-threatening and simple to them. These questions are (1) Is there anyone/ anything you need to speak to/about? (2) Do you want to talk to someone about how you're feeling? (3) Are you feeling low today?	

3.5.3 Focus Group Interview #3- Healthcare Providers

The third focus group was conducted with a subset of four participants from FG#1 to explore ways of integrating patients' feedback into the screening process. At the beginning of FG#3, the PI presented the issues raised by patients and presented their concerns.

- **Decision about the screening measure**

Upon reflection, participants of the FG#3 agreed with the patients that questions on the *Peace and Meaning/Joy measure* could be interpreted as threatening or unclear if healthcare providers who are less experienced in the spiritual domain pose them. However, they were concerned that the suggested questions by patients were too general for screening for spiritual suffering and not evidence-based. Thus, they decided to break down the screening into a two-step process involving an initial 'screening' (guided by the patients' suggested questions). This step would be followed by a screening of patients with positive results on the initial screening by clinical chaplains using the *Peace and Meaning /Joy* measure. Healthcare providers agreed that the initial screening measure should encompass the following two questions that were variations of the questions proposed by the patients: (1) Are you feeling unease? (2) Is there anything/anyone you need to speak about/to? They used the word "unease" as it was a more neutral term compared to "feeling low" which patients initially had suggested. Moreover, participants believed that all RNs with basic training have the capability of performing the initial screening at this hospital. Patients who respond yes to both questions would then be referred to clinical chaplains for screening using the *Peace and Meaning/Joy measure*.

- **The decision about which profession should screen patients**

In response to patients' feedback, healthcare providers reported that their facility has one social worker for each unit and requesting them to screen and follow up with all patients for

spiritual suffering was not feasible. Therefore, they decided that nurses should be trained to use the two initial screening questions *(Are you feeling unease?; Is there anything/anyone you need to speak about/to?)* instead of the *Peace and Meaning/Joy* screening measure. Patients who answered positively to the initial screen would then be referred to the clinical chaplain to use the *Peace and Meaning/Joy measure* to screen for their suffering. They also concurred with patients that nurses should use their clinical judgment and follow up with patients at pre-determined periods (e.g., every two weeks), or when a patient's condition changes. All healthcare providers agreed that nurses should be trained to provide the initial screening. They agreed that nurses should get training to improve their knowledge of spirituality, clinical judgment and communication skills. They believed with enough training nurses can also be able to use the *Peace and Meaning/Joy* screening measure in future at this setting. They suggested having clinical chaplains instruct RNs about important considerations regarding spiritual conversations that help build a trusting relationship with patients, moreover, RNs would benefit from training to realize signs of spiritual suffering and its attributing factors.

Table 3.4 Patients' Perspectives on the Implementation of the *Meaning/Joy Screening Measure* at the Hospital

Category	**Patients' reasons**	**Explanation and quotes**	**Patients' suggestions**
***Who should do the screening:** -Social workers	They have more time and experience than other health care providers	-Unlike health care providers, patients believed **nurses** to be unsuitable for screening patients with *the Peace and Meaning/Joy measure* for the following reasons: (a) they do not have enough time ***(by the time the nurse gets to you, you've forgotten all the questions yourself)***, (b) they cannot build a relationship with patients ***("they're rushing…you sit there for an hour … to come in to help you. By the time they come in they are too frustrated to even want to chat with them")*.** (c) many are young and do not have experience with people ***("[it is] not just the health business but life")]***, *(d)* nurses see nursing as a just a job and they do not have compassion **(*"Some [nurses] are just there for the paycheque")***, *(e)* they do not know how to deal with	The person who is going to ask the question, whether it is a nurse or social worker, should be someone who is personable and has adequate training and time.

		patients' suffering (***"If I start crying they say, "Oh don't do that"…so you're not allowed emotions").*** - According to patients, **<u>young volunteers</u>** cannot do the screening as they are inexperienced with people (***"If you're talking to a 17-year-old, no").*** -Patients suggested **<u>social workers</u>** to ask the screening questions, however, not all believed the social worker to be the most qualified person (**"*[social workers] need to be screened as well…the one that I have now, or whatever, she's very good, a really nice person [but that has not always been my experience with social workers].*** **<u>- Chaplains</u>** also have a limited time and they are in rush**. *("… When you're asking to see somebody and you feel like you're rushed in 15 minutes to say all the things that are bothering you, you feel like what's the point in starting? Because you need to build trust with a person you're opening up to").***	
***When to do the screening based on patients' opinion:** **-First screening:** First 2 days up to a week (but not right after admission). **-Following up:** two weeks after the initial screening or based on nurses' clinical judgment.	Right after admission patients are often in distress and asking these questions may be overwhelming. These questions should be asked when patients get used to the new situation.	***" …And, you know, it's yes or no and sometimes a lot of people say no but down the road… like maybe the nurse can see that maybe they might like to see somebody".***	-
***How to do the screening:** **-** Establishing a relationship or rapport with patients before asking the screening questions. -Using "communication techniques". -Cleary defining chaplains' role and spiritual service to patients.	-Patients are more likely to open up and disclose information if they trust their healthcare provider. -How the questions are asked will influence patients' responses. -Patients do not ask for chaplains because they do not know what resources are	***"… it's the first thing you're taught is it's not what you say, it's how you say it and the tone. The tone is very, very important [when asking the screening questions]".*** ***"I've been here for six months and I still don't know what we have".***	-

-Allocating enough clinical chaplain staff	available at this hospital. This program would not work if the hospital does not have enough chaplain staff to visit and listen to referred patients	***"My worry is well, you can put this in place, but if you don't have sufficient chaplain staff to come and see me and listen to you. you're setting people up for disappointment almost".***	

3.6 Discussion

This study adds to knowledge about screening for spiritual suffering among people who have progressive diseases and were admitted to a complex continuing care hospital. We engaged healthcare providers and patients in an iterative fashion to produce a solution to the organization's concern. The knowledge users at the setting were engaged from the beginning to formulate the aims of the research, determine the selection process of the spiritual screening questions and implementation, and interpret the study findings. Engaging knowledge-users in different stages of the study can enhance research uptake and eventually sustainability at the setting (Macaulay et al., 2011).

Planning to use an iKT approach, we aimed to provide an evidence-based and practical solution to the problem in the clinical setting where patients who were experiencing spiritual suffering and need the specialized spiritual care were not referred to clinical chaplains, and those who do not need specialized spiritual care (e.g., those who could be cared for by volunteers) were being referred to the clinical chaplains. However, we did not meet iKT principles in the second and third focus group interviews as patients and healthcare providers selected solutions that were non-evidence-based and impractical.

Patients in the second focus group interview suggested their own screening questions which were not evidence-based since there was no research about how those questions function in identifying people with risk of spiritual suffering. Healthcare providers in the third focus group interview insisted on including the patients' suggested questions. Therefore, they suggested a two-stage process for screening with the nurses screening patients using patients' suggested questions, and referring patients who had screened positive in the initial stage to clinical chaplains for screening using the *Peace and Meaning/Joy measure*. This solution was neither evidence-based nor practical because it would potentially increase the workload of clinical chaplains who now would have to be part of screening as well as treatment. Although participants in the second and third focus group interviews provide valuable information about the process issues, they did not support evidence-based and practical solutions (expected outcome of an iKT study). I felt that I did not have equal power with knowledge users to persuade them to choose a practical and evidence informed solution in the second and third focus groups. Therefore, I considered all the participants' responses, although they were not necessarily leading to a feasible and evidence informed solution. The– impractical and non-evidence informed solutions could have been prevented by setting clear expectations with the participants and following a framework to facilitate shared decision-making in a focus group (Straus, Tetroe, & Graham, 2013). Based on my experience, a simple description of the roles and expectations of researchers and knowledge-users in using an iKT approach, at the beginning of a focus group session, may not have been enough to create mutual understanding. While no clear guidelines exist on how to conduct iKT research or how to facilitate a focus group using this approach, researchers may want to hold a session with knowledge users or share pre-reading documents to communicate clear expectations.

Another contributing factor that may leaded to the non-production of evidence-based and practical solutions in the second and third focus group was the lack of time. I believe conducting more focus group interviews could provide a chance to work through disagreements and produce more evidence-based and feasible solutions. I also think conducting a focus group interview with both patients and healthcare providers could have presented opportunities for them to directly discuss their disagreements on the screening measures and implementation plan. However, in order to conduct one focus group with patients and healthcare providers, researchers should provide a clear strategy to prevent power issues.

In the current study, healthcare providers and patients believed that nurses require more education and greater support in order to use the *Peace and Meaning/Joy measure* competently at their hospital. Clinical chaplains could train nurses how to approach patients with different spiritual beliefs in the most ethically sensitive manner (Rieg, Mason, & Preston, 2006) to identify suffering without halting the conversation or crossing their boundaries. Indicators of spiritual suffering in patients (Caldeira et al., 2017) is another important area that nurses need to be aware of in order to enhance their clinical judgment. Caldeira and colleagues (2017) defined lack of meaning in life as one of the most important characteristics for spiritual suffering that is often accompanied by other symptoms such as anxiety, crying, and fear in patients with spiritual suffering. Our findings align with those of Caldeira and colleagues (2017) who believed that recognition of the indicators of spiritual suffering are helpful for improving clinical judgment of nurses and they suggested to use these indicators for education in nursing.

Our findings suggest that a spiritual screening measure for patients in a complex continuing care hospital should encompass broad, simple, clear, and short questions. The measure should also be accurate (high sensitivity /specificity) for identifying high levels of

spiritual suffering. Our findings are also consistent with spiritual care guidelines that suggest accuracy, brevity, and simplicity as important characteristics of appropriate screening measures for identifying spiritual suffering (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009). Those three characteristics have been selected by spiritual care guidelines to enable busy clinicians who may not have spiritual training to incorporate screening into their routine care (Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009). Findings of the current study contribute to what is known about screening for spiritual suffering and described further considerations from both healthcare providers and patients' point of view to select an appropriate screening measure.

In our study, healthcare providers believed that the two-item *Peace and Meaning/Joy measure* had the key criteria for screening patients for spiritual suffering at the designated hospital. *The Peace and Meaning/Joy measure* was initially presented by King and colleagues (2017) as a brief screening measure for spiritual suffering. They tested the measure in cancer survivors in the United States and reported a sensitivity of 78-84%. In a systematic review on the accuracy of measures to screen adults for spiritual suffering (Bahraini et al., 2019), the *Peace and Meaning/Joy measure* was one of the measures with the highest sensitivity among the other 24 identified spiritual screening measures. Although this measure was considered an accurate and appropriate measure by King and colleagues (2017) and healthcare providers in our current study, some patients did not consider it as suitable for use by non-trained nurses.

The collaborative approach of identifying patients with spiritual suffering through assigning tasks to healthcare providers in our study are consistent with the spiritual care guideline (Agora Spiritual Care Guideline, 2013) and the Inpatient Spiritual Care Implementation Model [ISCIM] (Puchalski et al., 2009). Inline with the ISCIM model,

healthcare providers in our study believed that nurses should screen patients for spiritual suffering and refer them to specialists in spiritual care. However, unlike the ISCIM that requires nurses to screen patients upon arrival to the hospital, participants of our study suggested the initial screening of patients to be performed between the first 48 hours up to a week after admission to allow patients to adapt to the new situation.

3.7 Strengths and limitations

We engaged the perspective of different members of the interdisciplinary team along with patients to strengthen our results, research uptake, and eventually increase sustainability at the designated hospital. The PI reviewed decisions that had been made by the participants at the end of each focus group interview to ensure they confirm the outcome of the focus group interviews and therefore increase credibility of the findings. Another researcher (L.W.) read each focus group transcript and the related codes and categories to enhance the dependability of the findings of the study. Limitations of the study relate to the relatively low number of participants in this research (15 healthcare providers and eight patients) which may reduce the variety of perspectives. Acquiring additional perspectives regarding acceptability and feasibility through a larger field-test study would be beneficial. Further, findings are limited to one hospital potentially limiting the transferability of study results.

3.8 Conclusion

Knowledge users, in the current study, selected screening questions and determined time, profession and strategies to incorporate them into routine care. It is possible that results from this study could inform policy makers by presenting specific questions to facilitate identification of patients with spiritual suffering as well as help determine an implementation process of the selected spiritual screening measure. Engaging knowledge users in this process, has not, to our

knowledge, been previously conducted on this topic. Further research, however, is required to assess the sensitivity and specificity of the selected screening questions for identifying spiritual suffering at this setting.

Results of our study suggest that nurses should be offered training to optimize their knowledge and skills to confidently and effectively screen patients for spiritual suffering using available screening measures isolated in the literature. Part of this relates to less-developed communication skills regarding sensitive subjects such as the spiritual domain. Therefore, there is a need to develop education programmes designed specifically for nurses to improve their ability to appropriately screen for spiritual suffering. Future research should assess nurses' comfort level with screening patients for spiritual suffering and identify the most effective strategies to address nurses' educational needs.

3.9 Reference List

Agora spiritual care guideline. (2013). Spiritual Care Nation-wide Guideline (Version: 1.0). *Integraal kankercentrum Nederland*. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Bahraini, S., Gifford, W., Graham, I. D., Wazni, L., Bremault-Phillips, S., Hackbusch, R., Demers, C., Egan, M.(2019).The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings:A Systematic Review. *Journal of palliative and supportive care.* DOI: https://doi.org/10.1017/S1478951519000506

Balboni, M. J., Sullivan, A., Enzinger, A. C., Epstein-Peterson, Z. D., Tseng, Y. D., Mitchell, C., ... & Balboni, T. A. (2014). Nurse and physician barriers to spiritual care provision at the end of life. *Journal of pain and symptom management*, *48* (3), 400-410.

Bar-Sela, G., Schultz, M. J., Elshamy, K., Rassouli, M., Ben-Arye, E., Doumit, M., ... & Ozalp, G. (2019). Training for awareness of one's own spirituality: A key factor in overcoming barriers to the provision of spiritual care to advanced cancer patients by doctors and nurses. *Palliative & supportive care*, *17*(3), 345-352.

Bruyère. (2019). Complex Continuing Care. Retrieved from: https://www.bruyere.org/en/complex-continuing-care

Caldeira, S., Timmins, F., Carvalho, E. C., & Vieira, M. (2017). Clinical validation of the nursing diagnosis spiritual distress in cancer patients undergoing chemotherapy. *International journal of nursing knowledge*, *28*(1), 44-52.

Canadian Institute of Health Research. (2015). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retieved from: http://www.cihr-

irsc.gc.ca/e/45321.html

Cobb, M., Puchlaski, C. M., & Rumbold, B. (Eds.). (2012). Oxford textbook of spirituality in healthcare. OUP Oxford.

Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliative medicine*, *24*(8), 753-770.

Fitchett, G., & Risk, J. L. (2009). Screening for spiritual struggle. *Journal of pastoral care & counseling*, *63*(1-2), 1-12.

Fitchett, G., Murphy, P., & King, S. D. (2017). Examining the validity of the Rush Protocol to screen for religious/spiritual struggle. *Journal of health care chaplaincy*, *23*(3), 98-112.

Grossoehme, D. H., Teeters, A., Jelinek, S., Dimitriou, S. M., & Conard, L. A. E. (2016). Screening for spiritual struggle in an adolescent transgender clinic: Feasibility and acceptability. *Journal of health care chaplaincy*, *22*(2), 54-66.

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and Negative Religious Coping and Well-Being in Women with Breast Cancer. *Journal of palliative medicine*, *12*(6), 537–545. http://doi.org/10.1089/jpm.2008.0250

Herdman, T.H. & Kamitsuru, S. (Eds.). (2014). *NANDA International Nursing Diagnoses: Definitions & Classification*, 2015–2017. Oxford: Wiley Blackwell

Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation science*, *12*(1), 150

King, S. D. W., Fitchett, G., Murphy, P. E., Pargament, I., Harrison, D. A., & Loggers, E. T. (2017). Determining best methods to screen for religious/spiritual distress. *Supportive*

care in cancer, *25*(2), 471–479. http://doi.org/10.1007/s00520-016-3425-6

Macaulay, A. C., Jagosh, J., Seller, R., Henderson, J., Cargo, M., Greenhalgh, T., … Pluye, P. (2011). Assessing the benefits of participatory research: a rationale for a realist review. *Global Health Promotion*, *18*(2), 45–48. http://doi.org/10.1177/1757975910383936

Manning-Walsh, J. (2005). Spiritual Struggle. *Journal of holistic nursing*, *23*(2), 120–140. http://doi.org/10.1177/0898010104272019

National Comprehensive Cancer Network. (2010). Practice guideline in oncology-distress management (version 1.2010). Retrieved from: https://www.nccn.org/professionals/physician_gls/f_guidelines.asp

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of health psychology*, 9(6), 713-730.

Pargament, K., Feuille, M., & Burdzy, D. (2011). The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping. *Religions*, *2*(4), 51–76. http://doi.org/10.3390/rel2010051

Puchalski, C. M., & Ferrell, B. (2010). Making health care whole: Integrating spirituality into patient care. West Conshohocken, PA: Templeton Press

Puchalski, C. M., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., … Sulmasy, D. (2009). Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of palliative medicine*, *12*(10), 885–904. http://doi.org/10.1089/jpm.2009.0142

Ramirez, S. P., Macêdo, D. S., Sales, P. M. G., Figueiredo, S. M., Daher, E. F., Araújo, S. M., …

Carvalho, A. F. (2012). The relationship between religious coping, psychological distress and quality of life in hemodialysis patients. *Journal of psychosomatic research*, *72*(2), 129–135. http://doi.org/10.1016/j.jpsychores.2011.11.012

Rieg, L. S., Mason, C. H., & Preston, K. (2006). Spiritual care: Practical guidelines for rehabilitation nurses. *Rehabilitation nursing*, 31(6), 249-256.

Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *Journal of clinical nursing*, *15*(7), 852-862.

Sandelowski, M. (2000). Whatever happened to qualitative description?. *Research in nursing & health*, *23*(4), 334-340.

Selman, L., Young, T., Vermandere, M., Stirling, I., & Leget, C. (2014). Research Priorities in Spiritual Care: An International Survey of Palliative Care Researchers and Clinicians. *Journal of pain and symptom management, 48*, 518–531.

Sherman, A. C., Plante, T. G., Simonton, S., Latif, U., & Anaissie, E. J. (2009). Prospective study of religious coping among patients undergoing autologous stem cell transplantation. *Journal of behavioral medicine*, *32*(1), 118-128.

Sinclair, S., & Chochinov, H. M. (2012). The role of chaplains within oncology interdisciplinary teams. *Current opinion in supportive and palliative care*, *6*(2), 259–68. http://doi.org/10.1097/SPC.0b013e3283521ec9

Steinhauser, K. E., Voils, C. I., Clipp, E. C., Bosworth, H. B., Christakis, N. A., & Tulsky, J. A. (2006). “Are you at peace?”: one item to probe spiritual concerns at the end of life. *Archives of internal medicine*, 166(1), 101-105.Summary, E., & Goal, O. (2004). Literature Review - Testing the Efficacy of Chaplaincy Care, 1–88.

Straus, S., Tetroe, J., & Graham, I. D. (Eds.). (2013). Knowledge translation in health care: moving from evidence to practice. John Wiley & Sons.

Tajbakhsh, F., Hosseini, M., Fallahi-Khoshknab, M., Rokofian, A., Rahgozar, M., & Mary Davidson, P. (2018). The effect of spiritual care on depression in patients following coronary artery bypass surgery: A randomized controlled trial. *Religions*, *9*(5), 159

Thuné-Boyle, I. C. V, Stygall, J., Keshtgar, M. R. S., Davidson, T. I., & Newman, S. P. (2013). Religious/spiritual coping resources and their relationship with adjustment in patients newly diagnosed with breast cancer in the UK. *Psycho-Oncology*, *22*(3), 646–658. http://doi.org/10.1002/pon.3048

Vazifeh, M. D., Hojjati, H., & Farhangi, H. (2019). Effect of Spiritual Care Based on Ghalbe Salim on Anxiety in Adolescent with Cancer. *Journal of religion and health*.

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., … Balboni, T. A. (2011). The Relationship of Spiritual Concerns to the Quality of Life of Advanced Cancer Patients: Preliminary Findings. *Journal of palliative medicine*, *14*(9), 1022–1028. http://doi.org/10.1089/jpm.2010.0536

Chapter 4: Study Protocol to Examine the Diagnostic Accuracy of the Peace & Meaning/Joy Measure for Screening Newly Admitted Patients for Spiritual Suffering

Authors: Sayna Bahraini, Mary Egan, Ian D Graham, Wendy Gifford

Prepared for Submission to the British Medical Journal

Abstract

Introduction: Guidelines for palliative and spiritual care have recommended screening patients with an accurate measure to help identify those who need specialized spiritual care. This is a protocol for a study aiming to determine the diagnostic accuracy of the Peace & Meaning/Joy measure to identify spiritual suffering in newly admitted patients at the complex continuing care hospital.

Methods and Analysis: We will undertake a prospective diagnostic accuracy study. We will consecutively recruit 615 newly admitted patients to a complex continuing care hospital who are able to express themselves verbally to answer study related questions. All participants will complete the Peace & Meaning/Joy measure and will undergo a chaplain's assessment blinded to the results of the screen. The outcome of the study is to assess the sensitivity, specificity, predictive value, and likelihood ratio of the Peace & Meaning/Joy measure.

Discussion: The curent study will evaluate the accuracy of a sprititual screening measure which is one of the top international research priorities in spiritual care. The findings of this study may introduce an accurate screening measure that not only assists with effective identification of patients experiencing spiritual suffering, but also reduces unnecessary referral, related costs, and patient-burden by safely excluding not experiencing spiritual suffering from a large proportion of patients.

4.1 Introduction

Approximately 25-50% of chronically ill and dying patients experience spiritual suffering during their illness (Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2013; Tarakeshwar et al., 2006; Fitchett et al., 2004). Despite the harmful effects of spiritual suffering, such as increased emotional distress, poorer quality of life, and decreased functional status (Vazifeh et al., 2019; Tajbakhsh et al., 2018, Exline, 2013; Hebert, et al., 2009; Pargament et al., 2004; Park, Wortmann, & Edmondson, 2011), many remain under-identified, and chaplains are not enough to assess every single patient (Puchalski et al., 2009, Rebekah Hackbusch, personal communication, April 16, 2017). Guidelines for palliative and spiritual care have recommended screening patients with an accurate measure to help identify those who need specialized spiritual care (National Comprehensive Cancer Network, 2010; Agora Spiritual Care Guideline, 2013; Puchalski et al., 2009).

This protocol is part of a larger study with the goal of implementing an effective screening process for spiritual suffering among new patients of a complex continuing care hospital in Ottawa, Canada. Complex Continuing Care is a specialized program of care for medically complex patients who require a hospital stay, regular on-site physician/ nursing care, and active care management by spiritual care staff. This program aims to improve and maintain function for patients with complex care needs by providing them with required services, support and a possibility of transition back to the community. Patients at this complex continuing care hospital usually have progressive diseases such as chronic respiratory and renal failure, multiple comorbid medical conditions, severe and chronic functional impairment, or specialized wound care needs (Bruyère, 2019).

Results of a systematic review on the *Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings* (Bahraini et al., 2019) informed the identification of some measures most likely to result in an accurate determination of patients experiencing spiritual suffering. Of 24 measures identified, the two-item *Peace & Meaning/Joy measure* (King et al, 2017) demonstrated 78-84% sensitivity in identifying cancer patients experiencing spiritual suffering (King et al., 2017). Findings of our focus groups with healthcare providers and patients (Chapter 3) informed considerations for implementation of this measure in their complex continuing care hospital. The purpose of this protocol is to determine the diagnostic accuracy of the *Peace & Meaning/Joy measure* to identify spiritual suffering in newly admitted patients at the complex continuing care hospital.

4.2 Methods

We will undertake a prospective study (Cohen et al., 2016) of the accuracy of the two-item *Peace & Meaning/Joy measure* (1. Are you at peace? and 2. Do you struggle with the loss of meaning and joy in your life?) to identify spiritual suffering severe enough to require intervention among newly admitted patients. The *Quality Assessment of Diagnostic Accuracy Studies 2* (QUADAS 2) (Whiting et al., 2011) was used to guide the protocol development .

4.2.1 Participants

Consecutive, newly admitted patients to a complex continuing care hospital who meet the eligibility criteria will be invited to participate in the study.

4.2.2 Inclusion and Exclusion Criteria

All participants who are able to express themselves verbally in English and provide their own informed consent will be eligible for the study. Patients who are too ill to answer the questions or have cognitive impairment (a score below 24 points on the *Mini Mental Status*

Exam as determined in their medical file or by the RN who is administering the measure), will be excluded.

4.2.3 Sample Size

Patients at Saint Vincent Hospital (SVH) predominantly have chronic and complex conditions. Results of previous studies reveal that approximately 25-50% of patients with chronic conditions experience high levels of spiritual suffering that require specialized spiritual care (Hui et al., 2011).We estimated sample size of 615 patients based on formulas that were recommended by Jones and colleagues (2003)(see Appendix P for more details).

4.2.4 Index Measure: Peace & Meaning/Joy

The index measure will be the *Peace & Meaning/Joy measure* (King et al., 2017). The Peace component of the measure was previously developed by Steinhauser and colleagues (2008) as a single-item measure to identify spiritual concerns. In 2017, King and colleagues created the single-item *Meaning/Joy measure* and, by adding it to the *Peace measure* (Steinhauser et al., 2008), developed the two- item *Peace and Meaning/Joy measure* for screening cancer patients for spiritual suffering. The *Peace and Meaning/Joy measure* consists of the following two questions: (1) Are you at peace? with response options of: “Not at all,” “A little bit,” “A moderate amount,” “Quite a bit,” and “Completely,” and (2) Do you struggle with the loss of meaning and joy in your life? with the response options of “Not at all,” “Somewhat,” “Quite a bit,” and “A great deal.” If patients respond “Not at all,” “A little bit,” and “A moderate amount” to the first question, or respond “Somewhat,” “Quite a bit,” “A great deal” to the second question, we will consider their screening result positive.

4.2.5 Reference Standard: Chaplain Assessment

Assessments provided by trained professionals in the spiritual domain such as clinical chaplains is the only true gold standard for identifying spiritual suffering requiring specialized spiritual care (Grossoehme &Fitchett, 2013; Bahraini et al., 2019). Clinical chaplains have advanced training in identifying spiritual suffering in patients with different religious or non-religious worldviews (Sinclair & Chochinov, 2012; Agora Spiritual Care Guideline, 2013). In this study, we will use chaplain assessments as a reference standard, whereby clinical chaplains will assess patients for spiritual suffering using their knowledge and clinical judgment.

4.2.6 Data Collection

A trained registered nurse will administer the index measure (i.e., the *Peace & Meaning/Joy measure)* within 2-7 days of a patient's admission. After obtaining the patient's informed consent, nurses will collect the persons demographic information (see Table 4.1) and screen them using the index measure. One of the concerns of the healthcare providers in the previous phase was the amount of time that it could take to screen patients using a measure with Likert-type response options. Therefore, we will ask nurses to record the amount of time taken for them to perform the screen.

After completing the screening, nurses will inform clinical chaplains that the screening has been completed of a particular patient on a unit, but not provide any information regarding the results of the screening to them. To minimize disease condition bias, a clinical chaplain will assess patients for spiritual suffering within 5 days of completing the index measure.

4.2.7 Training

Registered nurses who have volunteered to screen eligible patients with the index measure and clinical chaplains who will assess patients to confirm existence of spiritual suffering

will receive study-specific training prior to initiation of the study. Training relates to the research purpose, study protocol, and informed consent. Registered nurses will also receive training on administration and scoring of the index measure, communication skills and the therapeutic relationship. The last two topics aim to respond to concerns by patients expressed in the focus group regarding nurses' lack of skills in establishing a trusting relationship when screening for spiritual suffering. To maximize the potential of using consistent criteria by chaplains in identifying patients with spiritual suffering, R.H. (the coordinator of spiritual care and the co-investigator of the project) or one of her assigned clinical chaplains will select an appropriate spiritual assessment tool to be used by participating chaplains. R.H. and a clinical chaplain will provide face to face training for participating RNs and clinical chaplains, and subsequent re-training via telephone or in person as requested if concerns/questions arise.

4.2.8 Statistical Analysis

We will provide a participant flow diagram (Figure 4.1) including participants recruitment, number of patients undergoing the index measure and the reference standard, number of participants who did not receive either the index measure or the reference standard, and the reasons.

The distribution of the patient characteristics, sex, age, and religious affiliation will be presented descriptively (Table 4.1). Sensitivity and specificity of the screening measures will be calculated in the conventional manner (Athanasiou et al., 2010) (Table 4.2). In practice, patients who screen negative probably will not receive spiritual care. Therefore, high sensitivity is desirable to minimize the proportion of false negatives. As well, inaccurately testing positive for spiritual suffering may cause unnecessary distress for patients and waste valuable chaplaincy resources; therefore, high specificity of the measure is also important (Fitchett, Murphy, & King,

2017). That being said, since sensitivity declines as specificity rises, and vice versa, it is desirable to identify the more important parameter. Healthcare providers in a focus group in the previous phase of the study recommended giving privilege to sensitivity over specificity (Chapter 3). Therefore, we will consider the index measure adequate in screening patients for spiritual suffering if it obtains at least 85% in sensitivity. We will further consider the measure an adequate screening tool if it demonstrates a minimum of 60% for specificity. King and colleagues study (2017) previously have reported a sensitivity of 78-84% and specificity of 47-54 % of this measure in cancer patients.

4.2.9 Managing Missing Data and Inconclusive Results

To avoid bias in the data analysis phase, we will ensure that we have included all patients who entered the study in the analysis and if not, we have explained all inconclusive test results (Whiting et al., 2011). Inconclusive results can be applied to both index measure and reference standard and refer to those results that are neither positive or negative (Cohen et al., 2016). The frequency of the inconclusive results shows the feasibility and the clinical usefulness of the index measure or the reference standard (Cohen et al., 2016). We will report the frequency of inconclusive results in the participant flow diagram (Figure 4.1). To reduce the risk of bias in analysis, as outlined by Cohen and colleagues (2016), we will use the "worst-case scenario" for handling the inconclusive test results. Therefore, we will consider all inconclusive results from the index measure as being false-negative (in participants who have the target condition according to the reference standard) or false-positive (in all others) (Cohen et al., 2016). In case of missing data on the index and reference standard, we will report the number of cases with missing data, and also will use the "worst-case scenario." For example, all missing index

measure results are considered false positive or negative regarding the reference standard and vice versa (Cohen et al., 2016).

4.2.10 Reporting

Accurate, transparent and complete reporting is essential in diagnostic accuracy research as it allows readers to evaluate internal validity, the generalizability, and applicability of results (Bossuyt, 2003; Cohen et al., 2016). We will follow the *Standards for Reporting of Diagnostic Accuracy Studies* (STARD) (Cohen et al., 2016) to ensure quality reporting in any reporting or publication of the results from this study.

4.2.11 Ethical Consideration

Before recruitment, we will obtain approval from the Bruyère Research Ethics Board and the University of Ottawa Research Ethics Board. Participation in the study will be voluntary and informed consents would be obtained prior to data collection. Potential participants will be informed that they can withdraw from the study at any time without penalty.

In order to maintain confidentiality, participants will remain anonymous. Participants' names will not be reported in any oral or written reports and publications. A numerical identification code will be assigned to each participant in the study for tracking purposes. The list of participant names and the corresponding identification code will be secured in a locked location at the University of Ottawa Nursing Department.

4.3 Discussion

The diagnostic accuracy of measures that are currently available to screen patients for spiritual suffering have received little empirical investigation with few exceptions (King et al, 2017; Fitchett, Murphy, & King, 2017; Schultz et al., 2017; Fitchett & Risk, 2009) that were all conducted with poor methodological qualities (Bahraini et al., 2019). The results of the current

study will add to a small, but significant body of research, and will help to inform researchers and clinicians about the accuracy of a spiritual screening measure that is examined by a robust study methodology in a complex continuing care setting.

The curent study addresses one of the top international research priorities in spiritual care which is evaluation of spiritual screening measures (Selman et al., 2014). The findings of this study may present an accurate screening measure that will not only assist with effective identification of patients with spiritual suffering, but also reduce unnecessary referral, related costs, and burden on patients by safely excluding those not experiencing spiritual suffering in a large proportion of patients.

4.4. Strengths and Limitations

Using inappropriate reference standards for identifying spiritual suffering was one of the main limitations of previous studies that negatively affected the methodological quality of them (King et al., 2017; Grosseohme & Fitchett, 2013; Fitchett et al, 2017). Those studies mostly compared their index measures with the Negative Religious Coping scale (Pargament, 1998) that was not a true gold standard for identifying spiritual suffering (King et al., 2017; Grosseohme & Fitchett, 2013; Fitchett et al, 2017). The current study will be the first one that minimizes the misclassification bias by using a true gold standard that is a chaplain assessment (Grossoehme & Fitchett, 2013).

To minimize the selection bias, we will consider all eligible patients and consecutively enroll them. We will avoid inappropriate exclusion of participants, for example excluding patients with specific conditions, those who are receiving special treatments, or are “difficult to diagnose” (Cohen et al., 2016; Whiting et al., 2011). In our study, the reference standard and index measure are performed separately to decrease the risk of incorporation bias (Cohen et al.,

2016). In order to diminish the information bias, nurses and chaplains will blindly interpret the index measure and the reference standard's results (Cohen et al., 2016). This means nurses will conduct and interpret the index measure (*the Peace & Meaning/Joy measure)* without knowledge of the reference standard's (chaplain assessment) results and vice versa. To reduce the verification bias, we will ensure that all patients undergo both the reference standard and index measure (Cohen et al., 2016; Whiting et al., 2011). If any patient did not receive index measure or reference standard during the study, we will reveal the reason in the flow diagram (Figure 4.1). We will also use STARD's recommendation for managing the missing and inconclusive results to avoid analyzing bias (Cohen et al., 2016).

There are a number of limitations with this protocol that should be noted. First, nurses and chaplains should administer the index measure and reference standard at the same time to avoid the risk of disease/condition progression bias (Whiting et al., 2011). The rationale is that if a delay occurs or if treatment begins between administering index measure and reference standard, patients' condition may deteriorate or improve that leads to under- or over-estimation of the accuracy of the measure (Whiting et al., 2011). Nevertheless, due to the high workload of nurses and chaplains at the hospital, it will not be feasible to ask them to screen all eligible newly admitted patients at the same time. According to QUADAS 2, a delay of a few days between administering index measure and reference standard will not be problematic for patients with chronic conditions (Whiting et al., 2011). Therefore, we will explain the importance of minimizing the time interval between index and reference tests to nurses and chaplains and will ask chaplains to visit patients as soon as possible after nurses screening by index measure. However, with consideration of the fact that spiritual suffering is not an acute condition that occurs and heals within a short period of time (Puchalski & Ferrell, 2010; Agora Spiritual Care

Guideline, 2013), we will set a maximum 5-day interval between performing index measure and reference standard and believe this interval will not increase risk of disease/condition progression bias in our study population (Whiting et al., 2011). We can also pilot the study first to assess this strategy. The second limitation of the study is generalizability of the findings. We will only examine the accuracy of the *Peace and Meaning/Joy measure* in patients in one setting. As generalizability must be established through multiple studies in multiple contexts, more studies should be done to assure the accuracy of the *Peace and Meaning/Joy* measure in screening for spiritual suffering in complex continuing care hospitals.

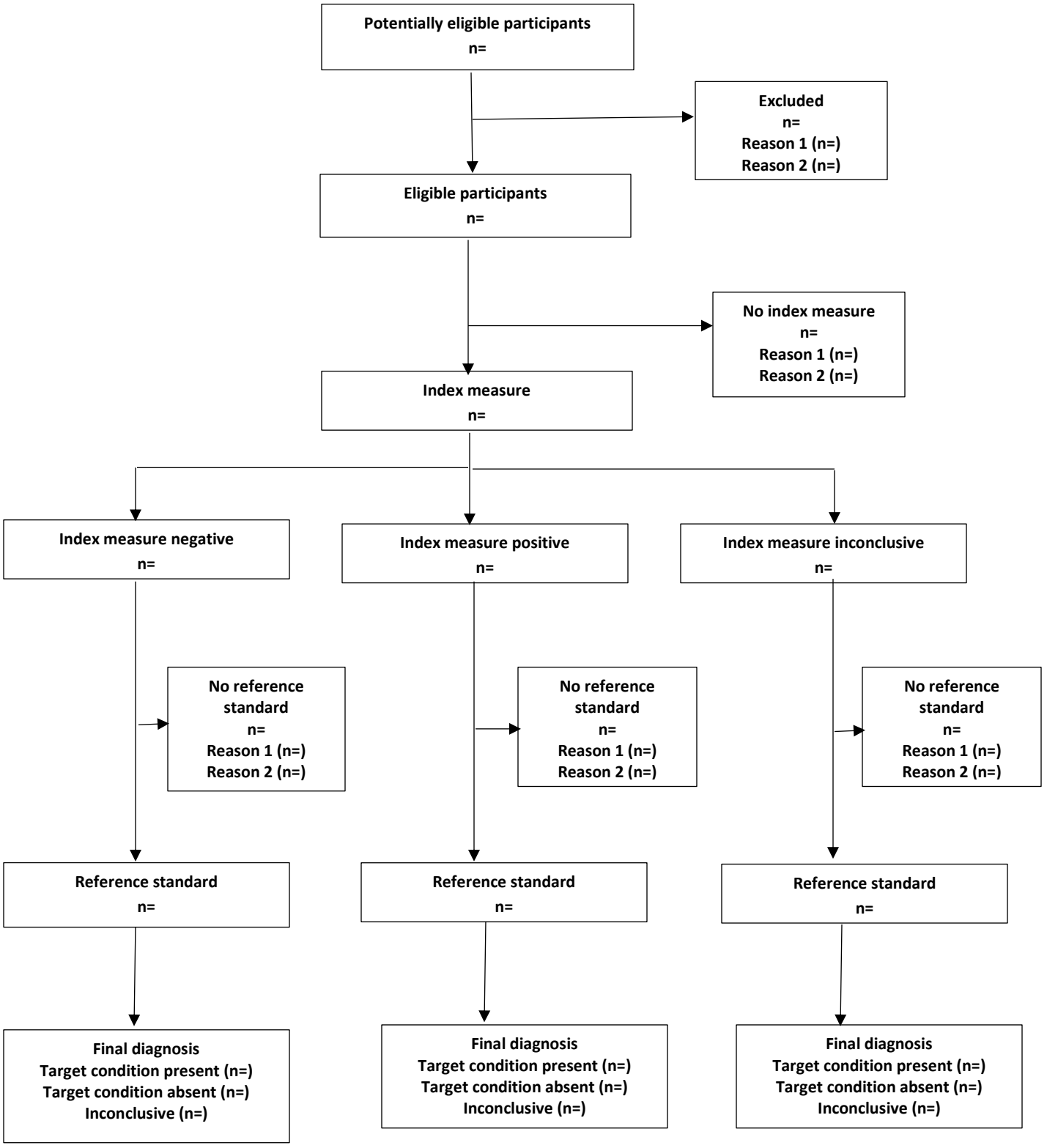


Figure 4.1 Participant Flow Diagram

Table 4.1 Sample Characteristics

Items	N (%)
Age (mean & SD) **Category** 18–39 40–49 50–64 ≥65	
Sex Male Female	
Gender Man Woman	
Ethnicity American Indian Alaska Native Asian African American White Middle Eastern	
Religion Christian Muslim Other No Preference/ None Agnostic/Atheist	
Time took to complete the screening (range & mean)	

Table 4.2 Classification of Patients' Index Measure Results by Condition Status

Index Measure Outcome	Reference Standard Positive	Reference Standard Negative	Total
Index Measure Positive (T+)	True Positives (TP)	False Positives (FP)	Test Positives (TP+FP)
Index Measure Negative (T-)	False Negatives (FN)	True Negatives (TN)	Test Negatives (FN+TN)
Total	Reference Positives (TP+FN)	Reference Negatives (FP+TN)	N (TP+FP+FN+TN)

4.5 Reference List

Agora spiritual care guideline. (2013). Spiritual Care Nation-wide Guideline (Version: 1.0). *Integraal kankercentrum Nederland*. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Athanasiou, T., Debas, H., Darzi, A (eds.). (2010). Key Topics in Surgical Research and Methodology. Springer-Verlage Berlin Heidelberg**.**

Bahraini, S., Gifford, W., Graham, I. D., Wazni, L., Bremault-Phillips, S., Hackbusch, R., Demers, C., Egan, M.(2019).The Accuracy of Measures for Screening Adults for Spiritual Suffering in Health Care Settings:A Systematic Review. *Journal of Palliative and Supportive Care.*DOI: https://doi.org/10.1017/S1478951519000506

Balboni, M. J., Sullivan, A., Enzinger, A. C., Epstein-Peterson, Z. D., Tseng, Y. D., Mitchell, C., ... & Balboni, T. A. (2014). Nurse and physician barriers to spiritual care provision at the end of life. *Journal of pain and symptom management*, *48* (3), 400-410.

Bossuyt, P. M., Reitsma, J. B., Bruns, D. E., Gatsonis, C. A., Glasziou, P. P., Irwig, L. M., ... & Lijmer, J. G. (2003). The STARD statement for reporting studies of diagnostic accuracy: explanation and elaboration. *Annals of internal medicine*, 138(1), W1-12

Boston, P., Bruce, A., & Schreiber, R. (2011). Existential suffering in the palliative care setting: An integrated literature review. *Journal of Pain and Symptom Management*, *41*(3), 604–618. http://doi.org/10.1016/j.jpainsymman.2010.05.010

Bruyère. (2019). Complex Continuing Care. Retrieved from: https://www.bruyere.org/en/complex-continuing-care

Bujang, M. A., & Adnan, T. H. (2016). Requirements for minimum sample size for sensitivity

and specificity analysis. *Journal of clinical and diagnostic research: JCDR*, *10*(10), YE01

Caldeira, S., Timmins, F., Carvalho, E. C., & Vieira, M. (2017). Clinical validation of the nursing diagnosis spiritual distress in cancer patients undergoing chemotherapy. *International journal of nursing knowledge*, *28*(1), 44-52.

Chaves, E. D. C. L., Carvalho, E. C. D., Beijo, L. A., Goyatá, S. L. T., & Pillon, S. C. (2011). Efficacy of different instruments for the identification of the nursing diagnosis spiritual distress. *Revista latino-americana de enfermagem*, *19*(4), 902-910

Chaves, E. D. C. L., Carvalho, E. C. D., Terra, F. D. S., & Souza, L. D. (2010). Clinical validation of impaired spirituality in patients with chronic renal disease. *Revista latino-americana de enfermagem*, *18*(3), 309-316

Cobb, M., Puchlaski, C. M., & Rumbold, B. (Eds.). (2012). Oxford textbook of spirituality in healthcare. OUP Oxford.

Cohen, J. F., Korevaar, D. A., Altman, D. G., Bruns, D. E., Gatsonis, C. A., Hooft, L., ... & Bossuyt, P. M. (2016). STARD 2015 guidelines for reporting diagnostic accuracy studies: explanation and elaboration. *BMJ open*, 6(11), e012799.

Exline, J. J. (2013). Religious and spiritual struggles. In K. I. Pargament, J. J. Exline, & J. Jones (Eds.), APA handbook of psychology, religion, and spirituality (Vol. 1, pp. 459–475). Washington, DC: American Psychological Association Press

Fitchett G., Murphy P.E., Kim J., Gibbons J.L., Cameron J.R. & Davis J.A. (2004) Religious struggle: Prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. *International journal of psychiatry in medicine, 34* (20), 179–196

Fitchett, G., Meyer, P. M., & Burton, L. A. (2000). Spiritual care in the hospital: Who requests it? Who needs it? *The journal of pastoral Care*, *54*(2), 173–186.

Fitchett, G., Murphy, P., & King, S. D. (2017). Examining the validity of the Rush Protocol to screen for religious/spiritual struggle. *Journal of health care chaplaincy*, *23*(3), 98-112

Grossoehme, D. H., & Fitchett, G. (2013). Testing the validity of a protocol to screen for spiritual struggle among parents of children with cystic fibrosis. *Research in the social scientific study of religion*, *24*, 281

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and Negative Religious Coping and Well-Being in Women with Breast Cancer. *Journal of palliative medicine*, *12*(6), 537–545. http://doi.org/10.1089/jpm.2008.0250

Hui, D., de la Cruz, M., Thorney, S., Parsons, H. A., Delgado-Guay, M., & Bruera, E. (2011). The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. *American Journal of hospice and palliative medicine®*, *28*(4), 264-270

Jones, S. R., Carley, S., & Harrison, M. (2003). An introduction to power and sample size estimation. *Emergency medicine journal*, *20*(5), 453-458.

King, S. D. W., Fitchett, G., Murphy, P. E., Pargament, I., Harrison, D. A., & Loggers, E. T. (2017). Determining best methods to screen for religious/spiritual distress. *Supportive Care in Cancer*, *25*(2), 471–479. http://doi.org/10.1007/s00520-016-3425-6

King, S. D., Fitchett, G., Murphy, P. E., Pargament, K. I., Martin, P. J., Johnson, R. H., … Loggers, E. T. (2017). Spiritual or religious struggle in hematopoietic cell transplant survivors. *Psycho-Oncology*, *26*(2), 270–277. http://doi.org/10.1002/pon.4029

National Comprehensive Cancer Network. (2010). Practice guideline in oncology-distress management (version 1.2010). Retrieved from: https://www.nccn.org/professionals/physician_gls/f_guidelines.asp

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of health psychology*, *9*(6), 713–730. doi:10.1177/1359105304045366

Park, C. L., Wortmann, J. H., & Edmondson, D. (2011). Religious struggle as a predictor of subsequent mental and physical well-being in advanced heart failure patients. *Journal of Behavioral Medicine*, 34(6), 426–436. doi:10.1007/ s10865-011-9315-y

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

Puchalski, C., & Ferrel, B. (2010). Making Health Care Whole: Integrating Spirituality Into Health Care.West Conshohocken

Rushton, L. (2014). What are the barriers to spiritual care in a hospital setting? *British Journal of Nursing, 23*(7), 370-4. doi:10.12968/bjon.2014.23.7.370

Schultz, M., Meged-Book, T., Mashiach, T., & Bar-Sela, G. (2017). Distinguishing Between Spiritual Distress, General Distress, Spiritual Well-Being, and Spiritual Pain Among Cancer Patients During Oncology Treatment. *Journal of pain and symptom management*, *54*(1), 66-73

Selman, L., Young, T., Vermandere, M., Stirling, I., & Leget, C. (2014). Research Priorities in Spiritual Care: An International Survey of Palliative Care Researchers and Clinicians. *Journal of Pain and Symptom Management, 48*, 518–531.

Sinclair, S., & Chochinov, H. M. (2012). The role of chaplains within oncology interdisciplinary teams. *Current Opinion in supportive and palliative care*, *6*(2), 259–68. http://doi.org/10.1097/SPC.0b013e3283521ec9

Steinhauser, K.E., Voils, C. I., Clipp, E. C., et al. (2008). Are You at Peace? One Item to Probe Spiritual Concerns at the End of Life. *Arch Intern Med.* 166:101–105.

Tajbakhsh, F., Hosseini, M., Fallahi-Khoshknab, M., Rokofian, A., Rahgozar, M., & Mary Davidson, P. (2018). The effect of spiritual care on depression in patients following coronary artery bypass surgery: A randomized controlled trial. *Religions*, *9*(5), 159

Tarakeshwar, N., Vanderwerker, L. C., Paulk, E., Pearce, M. J., Kasl, S. V., & Prigerson, H. G. (2006). Religious Coping is Associated with the Quality of Life of Patients with Advanced Cancer. *Journal of palliative medicine*, *9*(3), 646–657. http://doi.org/10.1089/jpm.2006.9.646

The Joanna Briggs Institute [JBI]. (2015). *Joanna Briggs Institute Reviewers' Manual 2015: The systematic review of studies of diagnostic test accuracy*. The Joanna Briggs Institute.

Thuné-Boyle, I. C. V, Stygall, J., Keshtgar, M. R. S., Davidson, T. I., & Newman, S. P. (2013). Religious/spiritual coping resources and their relationship with adjustment in patients newly diagnosed with breast cancer in the UK. *Psycho-Oncology*, *22*(3), 646–658. http://doi.org/10.1002/pon.3048

Vazifeh, M. D., Hojjati, H., & Farhangi, H. (2019). Effect of Spiritual Care Based on Ghalbe Salim on Anxiety in Adolescent with Cancer. *Journal of religion and health*.

Chapter 5: Intergrative Discussion

My research aim was to contribute to improved screening of patients for spiritual suffering and subsequently referring to specialized spiritual care services at an urban complex continuing care hospital in Ottawa, Canada. In this chapter, I summarize the findings of my studies, share my experiences and challenges, reflect and discuss how findings of my studies contribute to the broader literature, and propose future directions.

5.1 Summary of Dissertation Findings

5.1.1 Systematic Review Findings, Objective 1: Synthesize the Evidence Regarding the Accuracy of Measures to Screen Adults for Spiritual Suffering

I used the Joanna Briggs Institute (JBI) Reviewers' Diagnostic Test Accuracy Manual (2015) approach (Chapter 2) to conduct the systematic review. I searched five databases for relevant articles. Five articles provided information on 24 screening measures. Of the measures, King and colleagues (2017) reported the highest sensitivity (82-87%) for the 2-item *Meaning/Joy & Self-Described Struggle* and the highest specificity (81-90%) for the revised *Rush Protocol*. From this review, I concluded that there are a number of spiritual screening measures in the literature that can be used to screen patients for spiritual suffering. However, the methodological quality of all included studies was poor. Therefore, I suggested clinicians use their critical appraisal skills and clinical judgment when selecting and using these screening measures.

5.1.2 Qualitative Study, Objectives 2-5: To Determine Key Considerations, a Screening Measure, and Process of Implementing the Measure from Healthcare Providers' and Patients' Perspectives.

Three focus groups were held with healthcare providers (i.e., registered nurses, clinical chaplains, and nurse managers) and patients to iteratively determined (1) key considerations when selecting a measure to screen patients for spiritual suffering, (2) a screening measure to be used at the designated hospital, and (3) the process of implementing the selected screening measure (Chapter 3). In total 23 participants comprised of healthcare providers and patients participated in these focus group interviews.

Healthcare providers specified eight considerations they felt were important for selecting a spiritual screening measure. According to them an appropriate spiritual measure should be: (1) simple and to the point, (2) broad, (3) in lay rather than clinical format, (4) clearly worded, (5) brief, (6) highly sensitive and specific, (7) focused on identifying patients with high levels of spiritual suffering, and (8) useful for the clinical context. From 24 measures identified in our systematic review (Chapter 2), they selected the *Peace and Meaning/Joy* as the measure that best met these considerations. Healthcare providers suggested that nurses screen patients using these questions between 48 hours and seven days post-admission. Some patients, however, were not enthusiastic about the selected questions and recommended three alternative questions. Some patients were also concerned that nurses were not the most suitable to screen patients, suggesting that they do not have enough sensitivity and knowledge about spiritual suffering.

When briefed on what patients had revealed, healthcare providers in the third focus group felt the screening process should be conducted in two stages, with the nurses screening patients using the two simple questions within 48 hours to seven days of admission, and referring patients who had screened positive in the initial stage to clinical chaplains for screening using *the Peace and Meaning/Joy measure*. The study participants also indicated that nurses needed training from

clinical chaplains in order to screen patients with the *Peace and meaning/Joy measure* in the future.

5.1.3 Protocol for a Diagnostic Accuracy Study, Objective 6: Develop a Research Protocol to Determine the Accuracy of the Selected Spiritual Screening Measure at the Complex Continuing Care Hospital.

In my second study (Chapter 3), knowledge-users (i.e., registered nurses, clinical chaplains, and nurse managers) selected the *Peace and Meaning/Joy measure* as the best evidence-based measure that met their considerations for selecting an appropriate screening measure. They chose this measure as the main screening measure for their hospital. Therefore, using the *Quality Assessment of Diagnostic Accuracy Studies 2* (QUADAS2) (Whiting et al., 2011) and *Standards for Reporting of Diagnostic Accuracy Studies* (STARD) (Cohen et al., 2016), I developed a methodologically rigorous protocol to examine the diagnostic accuracy of the *Peace and Meaning/Joy measure* among residents of a complex continuing care hospital (Chapter 4). In this protocol, I described the study design, including the study population, eligibility criteria, index measure, reference standard, sample size, data collection, and training. I also described the data analysis, ethical considerations, and the limitations of the protocol. A study that follows the protocol may introduce an accurate screening measure that not only assists with effective identification of patients experiencing spiritual suffering, but also reduces unnecessary referral by safely excluding patients not experiencing spiritual suffering from a large proportion of patients.

5.2 Reflecting on My Experiences and Challenges

5.2.1 The iKT Approach

An Integrated Knowledge Translation (iKT) approach is aimed at developing applicable evidence that addresses problems of knowledge users (Canadian Institute of Health Research [CIHR], 2015; Jull, Giles & Graham, 2017). In order to conduct a research project using this approach, researchers and knowledge users should collaboratively make decisions at each stage of the research such as the research question, selection of the methods, data collection, and interpretation of the findings (Jull, Giles & Graham, 2017; Straus, Tetroe, & Graham, 2013). It is important that researchers and knowledge users share decision-making power and mutual respect to produce feasible and evidence-based solutions (Straus, Tetroe, & Graham, 2013).

In this research, I engaged knowledge users from the beginning of the project and collaborated with them for the development of the research questions, selection of methods, data collection, and interpretation of the findings. Our intention was to identify an evidence-based and feasible way to screen patients for spiritual suffering by using relevant and current research and clinical expertise. However, the solution that came out of this study (Chapter 3) was not evidence-based or feasible. The following reflections on my experience can help future researchers who may want to use an iKT approach anticipate potential tensions so as to better manage related challenges.

5.2.1.1 Challenges and Tensions in My Study:

The overarching aim of this research was to contribute to improving screening of patients for spiritual suffering to facilitate efficient referral to specialized spiritual care services. In partnership with knowledge users, my thesis committee and I agreed on conducting a systematic review to identify evidence-based measures in the literature for screening spiritual suffering in

patients (Chapter 2). We then shared the results of the systematic review with healthcare providers in a focus group interview and facilitated the group selection of an evidence-based screening measure that could accommodate the local context for a feasible implementation plan (Chapter 3-FG#1). The clinical chaplains and nurses that participated in the focus group interview selected the *Peace and Meaning/joy measure* and suggested that nurses were best suited to undertake the screening.

We held the second focus group with patients to obtain their perspectives on the decisions made in the first focus group (Chapter 3). With patient engagement emphasized as an important focus in research (CIHR, 2011; Patient-Centered Outcomes Research Institute, 2013), blending a qualitative method with iKT allowed us to incorporate patients' input for meaningful findings (Banner et al., 2019). The challenge for me as the researcher was the tension that developed between the differing views and decisions of the healthcare providers and patients. In the second focus group, some patients disagreed with the selected screening measure (*Peace & Meaning/ Joy*) because from their perspective, the questions on the measure were 'vague' or 'scary'. They proposed their own screening questions (e.g., Is there anyone/anything you need to speak to/about?). Some patients in this focus group interview also disagreed that nurses should be the ones to conduct the screening with the *Peace and Meaning/ Joy measure* because they felt they may not be sufficiently emphathetic or have the time to build the necessary relationships with patients. I then held a third focus group with the healthcare providers to share these perspectives.

In the third focus group, I asked healthcare providers' perspectives on patients' viewpoints (FG#1). A tension occurred between healthcare providers and researchers when the healthcare providers suggested it was important to incorporate all the patients' feedback, which resulted in an impractical and non-evidence-based solution. Healthcare providers decided to use

patients' proposed questions that were not evidence-based and too broad to target spirituality (i.e., were not targeting concepts that spiritual questions encompass such as meaning and purpose in life, connectedness, and/or transcendence [Hardman, 2014]). They also decided to ask nurses to use patients' proposed questions. Then clinical chaplains, who are few in number at the setting (making this proposal infeasible), would use the *Peace & Meaning/ Joy measure* to screen those who test positive on the patients' proposed questions. I now realize I should have made more clear to the focus group participants what their roles were and how we would co-create an evidence informed approach to screening.

Although we maintained the principles of engaging knowledge users from the beginning and throughout the project, we were not able to maintain other criteria of conducting iKT which includes providing feasible and evidence-based solutions in the second and third focus group interviews. Since researchers and knowledge users often see the research problem through different lenses, different and unexpected viewpoints from each group can be considered normal in an iKT approach (Bowen & Martens, 2005; Caplan ,1979; Kothari & Wathen, 2013). However, as a researcher, I felt that I did not have equal power to knowledge users to convince them to choose a feasible and evidence-based solution (FG #2&3). Therefore, the second and third focus group interviews meet a principle of a participatory research approach and not iKT because I considered all the participants' voices even though they were not necessarily leading to a practical and evidence-based solution. Setting clear expectations from each group (researchers and knowledge users) prior to data collection and following a clear framework to facilitate shared decision-making in a focus group (Straus, Tetroe, & Graham, 2013) could have prevented producing an infeasible and non-evidence-based solution. Another contributing factor was the lack of time to hold more focus group sessions to address disagreements. I believe holding more

focus group sessions to work through disagreement would have provided an opportunity for discussions between patients and healthcare providers that could have resulted in more evidence-based and practical solutions.

5.2.1.2 Suggestions for Researchers Who Want to do iKT

I suggest the following strategies for future iKT projects to help manage the tensions that I encountered in my research.

- Preparing knowledge-users: According to the Canadian Institution of Health Research [CIHR] (2015), knowledge users may not fully understand the 'lingo' of researchers due to their lack of scientific training. They suggest that researchers explain their concepts and methods in a non-technical, lay language (CIHR, 2015). I believe that researchers should also introduce knowledge users to the purpose of using an iKT approach and the type of knowledge that is expected to be produced. Researchers should ensure that everyone has a complete understanding of the approach to help establish mutual goals and directions. Prior to data collection, researchers should also set clear expectations and specify the role and contribution of each group (i.e., researchers and knowledge users) to help prevent misconceptions and promote trust (Gagliardi et al., 2015). Based on my experience, a simple explanation at the beginning of a focus group may not be enough to establish mutual understanding of the goals, roles and expectations of researchers and knowledge-users in using an iKT approach. While no clear guidelines currently exist on how to conduct iKT research, researchers may want to hold a session with knowledge users or sharing pre-reading materials in a simple and clear language to establish clear expectations.

- Preparing facilitators: Having a knowledge user who was familiar with the setting and the research as a facilitator alongside me was extremely helpful. R.H., who was the Coordinator

of Spiritual Care at the participating setting was one of the knowledge users on my thesis committee who was engaged from the earliest stages in this research. As a co-facilitator she was critical in establishing a good connection and relationship with the focus group participants. She was also familiar with my research, the organization's policy, and available resources at the setting which helped me and other knowledge users to better understand each other's perspectives. Nevertheless, all facilitators should understand what an iKT approach entails to ensure that participants' perspectives are compatible with the approach. According to Bush and Trembly (2017), one of the facilitators' roles in collaborative research approaches such as iKT is to understand the group's dynamic and guide the group through a collaborative decision-making process. More specifically the outcome of this collaborative decision-making with an iKT approach should be feasible and evidence-based solutions (CHRI, 2015). Therefore, having a clear framework or guidance on how to facilitate a focus group session is necessary, however, to the best of my knowledge, such a framework does not exist for iKT research.

-**Providing an opportunity for both healthcare providers and patients to directly discuss their opinions:** I conducted separate focus groups with healthcare providers and patients in this study with the intent of minimizing power issues and promoting a permissive environment where participants felt comfortable to express their perspectives (Carey, 1994; Jayasekara, 2012; Krueger, 2000). However, having both groups (patients and healthcare providers) in one focus group interview could have presented opportunities for healthcare providers to directly address the concerns of patients in relation to the screening measures and implementation process, and the results could have been different. I think that being a mediator and presenting each group's perspectives in their absence and not providing a chance for direct discussion can result in unforeseeable outcomes that may hinder the process of producing evidenced-based and feasible

solutions. However, in order to conduct a focus group with patients and healthcare providers, researchers should set boundaries around possible actions and provide a clear structure in the potential decisions to prevent power issues.

5.3 Contribution of Findings to the Literature

In this section, I discuss the contribution of findings of my studies to the broader literature and its implication to nursing practice, education, and future research.

5.3.1 Research Priorities in Spiritual Care

In 2014, Selman and colleagues conducted a study in 87 countries, including Canada, to determine research priorities of clinicians/researchers in spiritual care and thus inform future research in this area. They asked respondents to choose the most important research priorities from a list of topics. A total of 971 responses from palliative care physicians, nurses, and chaplains were received. Identification and evaluation of measures to screen patients for spiritual suffering as well as determination of the implementation process (e.g., who/when/ how) were among the top research priorities in their study (Selman et al., 2014).

Findings of my studies contribute to addressing the research priorities identified by, Selman and colleagues (2014). By conducting the systematic review (Chapter 2), I identified screening measures and synthesized the evidence regarding the accuracy of them to screen adults for spiritual suffering. Healthcare providers (i.e., nurses, nurse managers and chaplains) selected a measure from identified measures in my systematic review based on their determined key considerations (Chapter 3). They also provided their perspectives on the implementation process of the selected screening measure in their setting (Chapter 3). In the end, I developed a research protocol to evaluate the accuracy of the selected spiritual screening measure at the complex

continuing care hospital (Chapter 4). In the following, I will provide more explanation on research priorities in spiritual care and contribution of research findings in addressing them.

5.3.1.1 Identification of Measures to Screening Patients for Spiritual Suffering

Screening for spiritual suffering is a brief process for detecting patients with high spiritual needs and low spiritual resources (i.e., beliefs, practices and/or relationships that people often turn to in times of spiritual suffering) that may put them at risk for further physical and psychological health issues (Agora Spiritual Care Guideline, 2013; Fitchett, Meyer,& Burton, 2000; Puchalski & Ferrell, 2009). Early identification of patients at risk for spiritual suffering facilitates their referral to clinical chaplains who can provide an in-depth assessment to determine the existence of spiritual suffering and develop a plan for specialized spiritual care (Agora spiritual Care guideline, 2013; Puchalski et al., 2009).

The differentiation between spiritual assessment and spiritual screening is important. Spiritual assessment is a detailed process, whereas spiritual screening is similar to triage (Agora Spiritual Care Guideline, 2013; Hodges, 1999; Puchalski et al., 2009). In recent years, researchers have developed many measures for spiritual assessment (Best et al., 2015), but at the present time there are only a small number of measures that have been specifically designed to screen patients for spiritual suffering (King et al., 2017). Among these measures, only a few have been tested for their diagnostic accuracy (King et al., 2017; Fitchett et al., 2017; Risk & Fitchett, 2009; Schultz et al., 2017). Information on the diagnostic accuracy of a screening measure (e.g., sensitivity and specificity) is essential to determine if the measure can effectively detect risk of spiritual suffering in patients (Cohen et al., 2016; Whiting et al., 2011). As no systematic review of screening measures existed, I conducted a systematic review of the literature (Chapter 2) to synthesize the evidence regarding the diagnostic accuracy of measures to screen adults for

spiritual suffering. I identified 24 screening measures for spiritual suffering that have been tested for their diagnostic accuracy (Chapter 2).

The authors of the ISCIM (Puchalski et al., 2009) and Agora Spiritual Care Guideline (2013), identify diagnostic accuracy, as well as the simplicity and brevity of the measures as characteristics of an effective screening measure. A brief, simple and accurate screening measure helps gather information without asking a lot of questions and allows non-chaplain staff to make appropriate referrals to spiritual care services (Agora Spiritual Care Guideline, 2013, Puchalski et al., 2009). Healthcare providers in the current research suggested more key considerations for an effective spiritual screening measure in addition to accuracy, simplicity, and brevity (Chapter 3). According to them, a spiritual screening measure should be (1) broad to encompasses various dimensions of spiritual suffering such as spiritual, religious, existential, and emotional suffering; (2) in a lay rather than clinical format to open the conversation easily with patients; (3) clearly worded to be easily understood; and (4) suitable for the contextual circumstance that will be used since various factors can influence patients' responses including the context and timing of the screening, type of healthcare provider (physicians, nurse, clinical chaplain, etc.) who administers the measure, and their questioning techniques (Chapter3).

The identified key considerations that were suggested by eleven healthcare providers including nurse managers, clinical chaplains, and registered nurses can be considered as additional criteria for selecting screening measures. To date and to the best of my knowledge, no study has involved healthcare providers to understand their perspectives on the key considerations for selecting a spiritual screening measure. The only study that has mentioned some considerations in selecting a measure is Piotrowski's (2013) study in which the researcher selected two spiritual screening measures based on clarity, comprehensiveness, and ease of

administration. However, she did not explain how these criteria were selected. In Piotrowski's (2013) study, the "clarity" of the measure and "comprehensiveness" that can correspond to "broadness" were in line with what healthcare providers in my study selected (Chapter 3). Nevertheless, the screening measures in Piotrowski's (2013) study were not evaluated for the main characteristics of diagnostic accuracy and brevity that were suggested by the Agora Spiritual Care Guideline (2013) and ISCIM model (Puchalski et al., 2009), therefore, the measures were long and lacked evidence on their accuracy.

5.3.1.2 Evaluation of Measures for Screening Patients for Spiritual Suffering

I have reported spiritual screening measures and their diagnostic test accuracy criteria in my systematic review (Chapter 2), however, the methodological quality of the included studies was poor and there is a need for more rigorous study designs to ensure accuracy of the measures. In the fourth chapter of the thesis, I provided a protocol to test the diagnostic accuracy of the *Peace &Meaning/Joy measure*. I followed the *Quality Assessment of Diagnostic Accuracy Studies 2* (QUADAS 2) (Whiting et al., 2011) and *Standards for Reporting of Diagnostic Accuracy Studies* (STARD) (Cohen et al., 2016) to ensure rigor and high-quality study design (Chapter 4). In addition, I addressed the limitations of previous diagnostic test accuracy studies (Fitchett, Murphy, & King, 2017; Fitchett & Risk, 2009; Grossoehme & Fitchett, 2013; King et al, 2017, Schultz et al, 2017).

Misclassification bias was one of the major limitations of previous diagnostic test accuracy studies, which occurred as a result of not using a true reference standard for comparing the screening measures. Previous diagnostic test accuracy studies compared their index measures with either the *Negative Religious Coping scale* (Pargament, 1998) or *Self-Reported Spiritual Distress* (Schultz et al., 2017); neither a true reference standard for identifying spiritual suffering

(Fitchett et al., 2017; Grosseohme & Fitchett, 2013; King et al., 2017). Only chaplains and other specialists' assessment would be the true reference standard for identifying such suffering in patients (Fitchett et al., 2017; Grosseohme & Fitchett, 2013; King et al., 2017).

Previous diagnostic test accuracy studies on screening for spiritual suffering also did not report power calculation and lacked information on how they have managed missing or inconclusive data (Fitchett, Murphy, & King, 2017; Fitchett & Risk, 2009; Grossoehme & Fitchett, 2013; King et al., 2017, Schultz et al., 2017). Power calculations are important for ensuring statistically significant and generalizable findings (Chohen et al., 2016; Whiting et al., 2011). Another important limitation of the previous studies (Fitchett, Murphy, & King, 2017; Fitchett & Risk, 2009; Grossoehme & Fitchett, 2013; King et al., 2017, Schultz et al., 2017) was insufficient reporting and lack of clarity in their methodology (Chapter 2).

In the fourth chapter of this thesis, I proposed using chaplain's assessment as a reference standard for comparing the results of the *Peace & Meaning/Joy measure* to overcome misclassification bias. The fourth chapter of this thesis also elaborates on the power calculation and management of missing or inconclusive data. I have also addressed the limitation of lack of clarity in the methodology by following the QUADAS 2 (Whiting et al., 2011) and suggested using STARD (Cohen et al., 2016) for high quality reporting of the results for future screening accuracy study in that chapter.

In almost all of the previous diagnostic test accuracy studies, the screening measures were administered to patients by researchers (Fitchett, Murphy, & King, 2017; Grossoehme & Fitchett, 2013; King et al., 2017, Schultz et al., 2017). Although screening for spiritual suffering is within the nursing scope of practice (;Agora Spiritual Care Guideline, 2013; Neuman & Fawcett, 2011), none of the studies included nurses administering the screening measure. In the

current study (Chapter 3), healthcare providers believed nurses were the most appropriate professionals to screen for spiritual suffering at their setting once they received training. Therefore, I designed the diagnostic test accuracy protocol so that nurses would screen patients using the *Peace & Meaning/Joy measure*.

According to the ISCIM (Puchalski et al., 2009) and Agora Spiritual Care Guideline (2013), there is no need for the non-chaplain staff to get special training to use brief and simple spiritual screening measures. However, both patients and healthcare providers in my study suggested that nurses required training before using a spiritual screening measure in their setting (Chapter 3). They recommended training nurses in communication techniques, building trusting relationships, and using clinical judgment in order to appropriately recognize signs and symptoms of spiritual suffering in patients who may not verbalize them. Healthcare providers believed clinical chaplains were the best resource for training nurses at their hospital (Chapter 3).

Geer et al. (2018) conducted a spiritual care pilot training study for physicians and nurses in eight hospitals in the Netherlands. Their study showed that nurses have a positive attitude toward receiving spiritual care training and that chaplain-led training of nurses is feasible for implementing spiritual care in hospitals (Geer et al., 2018). Piotrowski's study (2013) that was conducted in Lebanon to instruct nurses and other health care providers about spiritual screening also reported a positive effect of the educational sessions on nurses' awareness about the nature of care that should be provided. Nevertheless, Piotrowski (2013) did not provide details on the educational components of the training sessions, number of referrals, or account of clinicians who began screening patients for spiritual suffering after the training sessions. The third chapter of my thesis provides information on the training and educational needs (i.e., communication techniques, establishing trusting relationship when screening for spiritual suffering, improving

nurses' clinical judgment in identification of spiritual suffering) of nurses at the designated hospital. These findings can be taken into consideration by clinicians who are interested in incorporating spiritual screening measures into nurses' routine patient care.

I would like to emphasize that "communication techniques" and "establishing a trusting relationship" with patients are areas that registered nurses usually receive education on in nursing schools. However, as spirituality is a very sensitive aspect of a human being (Puchalski & Ferrell, 2009), the healthcare providers and patients in my study believed that nurses need more education in order to achieve adequate competency in this area. Many patients may not verbalize their spiritual issues as a result of feeling judged, shamed and mistreated (Puchalski & Ferrell, 2009). Getting extra training from clinical chaplains was considered essential by participants of my study for establishment of a trusting relationship with patients in order to get through their defensive wall without crossing their personal boundaries (Chapter 3). As a result, I have included training of registered nurses by chaplains to use the *Peace & Meaning/Joy measure* in the protocol.

5.3.1.3 Planning for Implementation of the Screening Measure

Screening and addressing spiritual suffering for promoting spiritual well-being of patients is one of the fundamental steps in spiritual care (Puchalski et al., 2009). The results of different studies indicate that there is a lack of information and ambiguity about the ideal timeframe and type of healthcare professionals who can administer spiritual screening measures (Lo, 2002; Selman et al., 2014). In the third chapter of my thesis, healthcare providers at Saint Vincent Hospital gave insight into these gaps (Chapter 3).

Unlike, the authors of the ISCIM (Puchalski et al., 2009) and the Agora Spiritual Care Guideline (2013) who suggested immediate screening upon patients' arrival, participants of my study

believed that immediate screening may increase the risk of false positive or negative results. They suggested the screening to take place between 48 hours and seven days post-admission, allowing patients time to adjust to their new situation. Among included studies in the systematic review (chapter 2) only Fitchett and Risk (2009) provided some information about the timing of the screening in their study. They mentioned that screening was done on the medical rehabilitation newly admitted patients. However, the exact timing of the screening (e.g., first day, first week) or any information on the frequency was not provided. Researchers in other studies on screening for spiritual suffering either did not provide information on the timeframe for screening (Piotrowski, 2013), or used the screening measure immediately upon arrival to hospital (Blanchard et al., 2012). I did not find any study that have provided information on the frequency of screening for spiritual suffering. Only the Agora Spiritual Care Guideline (2013), briefly pointed to re-assessment of patients when their life expectancy suddenly and dramatically changes.

Screening for spiritual suffering is within the scope of nursing practice (Agora Spiritual Care Guideline, 2013; Neuman & Fawcett, 2011). Healthcare providers in my research (Chapter 3) also believed that registered nurses can and should screen patients as they spend more time with patients compared to other healthcare providers. However, participants of my study suggested that nurses receive education and training before using the *Peace and Meaning/Joy measure*.

5.4 Implications for Nursing

The findings from this set of studies have implications for nursing practice, education, and research.

5.4.1 Nursing Practice

Nurse managers are in charge of determining clinical priorities in a setting (Blanchard, et al., 2012). While considering patients' spiritual concerns should be a routine aspect of holistic nursing practice (Neuman & Fawcett, 2011), high workloads and lack of training, may prevent nurses from identifying patients who are experiencing spiritual suffering and subsequently referring them to specialists. Nurse managers should advocate for effective screening for spiritual suffering to prevent the harmful effects of this kind of suffering on patients physical and psychological health outcomes such as increased functional limitations and depressive symptoms (Hebert, Zdaniuk, Schulz, & Scheier, 2009; Manning-Walsh, 2005; Pargament et al. 2004; Sedlar et al., 2018; Winkelman et al., 2011). According to Taylor and colleagues (2017), a significant number of nurses (33%) have never completed a spiritual screening during their job timeframe. However, results of Blanchard and colleagues' (2012) study showed that busy nurses are receptive of training to incorporate a brief spiritual screening measure into their practice. Blanchard and colleagues (2012) trained 10 oncology nurses to use a brief screening measure to identify patients at the risk of spiritual suffering upon admission. Nurses in their study believed a spiritual screening measure helped them to productively screen patients (Blanchard, et al., 2012).

Findings of my study are not generalizable to other settings, however, nurse managers and nurses in other settings can consider the approaches we used to select a spiritual screening measure for their hospital and plan an implementation process for it. For example, they can select their measure from the 24 identified screening measures in my systematic review (Chapter 2). They can determine their own key-considerations for selecting an appropriate measure and vote for a measure that meet the majority of them. Participants of my study pointed to the training needs of nurses in order to screen patients effectively at their setting (Chapter 3). Nurse

managers or educators in other settings also may determine if their nurses need more support and education before screening patients for spiritual suffering.

5.4.2 Nursing education

Some patients who participated in our focus group interview believed nurses needed more training on spiritual suffering and in skills in approaching patients. Healthcare providers in this study suggested training for nurses to improve their awareness, and skills in the suggested areas (Chapter 3). Evidence supports that training enhances nursing awareness about the importance of spirituality and their competency in providing spiritual screening and care (Blanchard et al., 2012; van Leeuwen et al., 2008). For example, Blanchard and colleagues' (2012) in their quality improvement pilot project trained nurses about the importance of screening for spiritual suffering and how to incorporate a brief spiritual screening measure into their practice. They reported an increase in number of referrals to clinical chaplains by trained nurses. In their study, researchers who were also members of the spiritual care service, were responsible for training nurses (Blanchard et al., 2012).

Training novice and/or experienced nurses can be achieved in various ways. First, several theory-based tutorials can be used to introduce nurses to fundamental information in this area including the concept of spiritual suffering, screening measures, and related resources to support patients with spiritual suffering. To the best of my knowledge, such theory-based tutorials on screening for spiritual suffering does not exist. In these tutorials, an overview of the therapeutic communication can be provided (Wittenberg, Ragan, & Ferrell, 2017). Second, nurses can practice the screening measures using simulated patients or role play (Fink et al., 2014; Greenstreet, 1999; LaBine, 2015) and foster their communication skills under the supervision of clinical chaplains (Evangelista et al., 2016; Piotrowski, 2013; Selli & Alves, 2007). Such

activities could include skill-building in how to approach patients and ask spiritual screening questions, documentation of patients' spiritual suffering, and proper follow-up in accordance with patients' needs or expressed preferences. These activities could ensure that professional standards related to therapeutic relationship and documentation are met (College of Nurses of Ontario, Professional Standards, 2002; RNAO, Establishing Therapeutic Relationship, 2006). Third, nurses can follow role models (i.e., experts with knowledge beyond their peers) to improve their skills (Baldacchino, 2015; Giske, 2012). Role modeling is a useful learning resource for nurses to enhance their skills in the spiritual domain such as spiritual screening (Baldacchino, 2015; Giske, 2012). Therefore, nurses who are successful in previous learning sessions can serve as role models and provide support for other nurses in different units. Nurse preceptors can also shadow clinical chaplains to improve their skills in approaching patients with spiritual suffering and then, provide support and mentorship for other nurses (Piotrowski, 2013). The Canadian Nurses Association (2010) has suggested workplace support and mentoring as a helpful approach to enhance nurses' skills in the spiritual domain.

Despite spiritual care, including screening for spiritual suffering, being one of the entry-level competencies for registered nurses (College of Nurses of Ontario, Competencies for Registered Nurses, 2014), many nurses believe they do not receive appropriate education on this domain in nursing schools (Frouzandeh, Aien, Noorian, 2015; McSherry & Jamieson, 2011). Adding spiritual care course to the nursing curriculum can prepare nurse students to efficiency approach patients with spiritual suffering and providing appropriate care in their future practice (Baldacchino et al., 2008; Frouzandeh, Aien, Noorian, 2015; Maddox, 2001; Van Leeuwen et al., 2008;). In such a course, the students should learn about the concepts of spirituality and its

derivatives such as spiritual suffering, and how to provide spiritual care including screening for spiritual suffering (Frouzandeh, Aien, Noorian, 2015; Greenstreet, 1999; Piotrowski, 2013).

As spirituality is an aspect of care that should be "caught" rather than "taught" (Bradshaw, 1997), participatory and student-centered approaches such as using simulated patient, role play, and discussions are effective methods to teach spiritual concepts to students (Fink et al., 2014; Greenstreet, 1999; LaBine, 2015). Researchers have conducted studies on the effectiveness of a spiritual course on nursing students, and many of them were successful (Baldacchino et al., 2008; Frouzandeh, Aien, Noorian, 2015; Van Leeuwen et al., 2008). These studies reported the willingness of the students to participate in such courses and also the positive effect of the courses on the students' knowledge, professional attitude, and competency in providing spiritual related care (Baldacchino et al., 2008; Frouzandeh, Aien, Noorian, 2015; Van Leeuwen et al., 2008).

5.4.3 Future Research

Although researchers have developed a number of measures to screen patients for spiritual suffering, the accuracy of almost all of these measures has not been assessed using rigorous study designs (Chapter 2). In order to ensure the accuracy of screening measures for spiritual suffering, researchers should follow a rigous study design. I recommend using the *Quality Assessment of Diagnostic Accuracy Studies 2* (QUADAS 2) (Whiting et al., 2011) and the *Standards for Reporting of Diagnostic Accuracy Studies* (STARD) (Cohen et al., 2016) to ensure all the diagnostic test accuracy research fundamentals have been considered and reported. As the main limitaion of the preivious diagnostic accuracy studies was using an inappropriate reference standard (Fitchett et al., 2017; Grossoehme & Fitchett, 2013; King et al., 2017), I also advise researchers to use specialists' assessment (e.g., clinical chaplains, psychologist, and social

worker) as the only true reference standard for identifying spiritual suffering in patients (Grossoehme & Fitchett, 2013).

After ensuring the accuracy of a measure in the target population, the next step can be a qualitative or quantitative study to assess the acceptability and feasibility of the measure and implementation process in some units of the hospital. The effectiveness of the screening process also can be evaluated by comparing the number of the appropriate referral to spiritual care services with the pre-intervention level (Blanchard, et al., 2012; Vlasblom et al., 2015). I also suggest researchers assess barriers and facilitators of the screening process at the administrative, staff, and patients' levels using individual or focus group interviews.

In order to integrate spiritual screening into routine patients care, researchers should address the key barriers of the screening process for a larger scale study. One of these barriers that has been mentioned in the literature is nurses' lack of knowledge and skills in screening patients with spiritual suffering (Balboni et al., 2014; Edwards, et al., 2010; Geer et al., 2018; Ross, 2006). Some researchers advocate training nurses to screen patients for spiritual suffering (Blanchard, et al., 2012; Leeuwen et al., 2013; Piotrowski, 2013; Vlasblom et al., 2015). However, very little research has been conducted to assess the long-term effects of such training on appropriate referrals to spiritual care services (Vlasblom et al., 2015). The only study is Vlasblom and colleagues unpublish research (2011) that showed, although trained nurses effectively screened patients, the number of referrals returned to the pre-training level after 6 months (Vlasblom et al., 2015). I suggest researchers evaluate the long-term effect of training nurses on the number of appropriate referrals to the spiritual care service.

5.5 Conclusion

Driven by demands to integrate spiritual care into routine patient care (Puchalski, King , Ferrell, 2018; Puchalski et al., 2009; Selman, et al., 2014), in this research I systematically reviewed spiritual screening measures (Chapter 2) and developed a methodologically rigorous protocol (Chapter 4) to examine the accuracy of the selected measure by participants of the current study (Chapter 3). Findings from this dissertation provide information about strategies of screening (Chapter 4) that can be considered a step toward addressing some of the clinical issues and research priorities surrounding identifying patients with spiritual suffering (Rushton, 2014; Selman et al., 2014), however, there is much work to be done. I suggest more methodologically rigorous studies are needed to ensure the accuracy of screening measures for spiritual suffering in different settings.

Although screening patients for spiritual suffering is within the scope of the nursing profession (Agora Spiritual Care Guideline, 2013; Neuman & Fawcett, 2011), healthcare providers and patients in our study believed that nurses at the designated hospital require more education and greater support in order to effectively screen patients for spiritual suffering. More research is needed to examine the competency of nurses in screening patients for spiritual suffering. Then, identified gaps in nurses' knowledge and skills, can be addressed by education programs designed specifically for nurses to improve their ability to successfully screen and refer patients with risk of spiritual suffering to spiritual care services.

5.6 Reference List

Agora spiritual care guideline. (2013). Spiritual Care Nation-wide Guideline (Version: 1.0). *Integral kankercentrum Nederland*. Retrieved from http://www.eapcnet.eu/Portals/0/Clinical/Spiritual%20care/Publications/SpiritualCareGuideline_English_2014.pdf

Balboni, M. J., Sullivan, A., Enzinger, A. C., Epstein-Peterson, Z. D., Tseng, Y. D., Mitchell, C., ... & Balboni, T. A. (2014). Nurse and physician barriers to spiritual care provision at the end of life. *Journal of pain and symptom management*, *48* (3), 400-410.

Baldacchino, D. (2015). Spiritual care education of health care professionals. *Religions*, *6* (2), 594-613.

Baldacchino, D. R. (2008). Teaching on the spiritual dimension in care: The perceived impact on undergraduate nursing students. *Nurse education today*, *28*(4), 501-512.

Banner, D., Bains, M., Carroll, S., Kandola, D. K., Rolfe, D. E., Wong, C., & Graham, I. D. (2019). Patient and Public Engagement in Integrated Knowledge Translation Research: Are we there yet. *Research involvement and engagement*, *5*(1), 8.

Blanchard, J. H., Dunlap, D. A., & Fitchett, G. (2012). Screening for spiritual distress in the oncology inpatient: a quality improvement pilot project between nurses and chaplains. *Journal of nursing management,* 20(8), 1076-1084.

Bowen S, Martens PJ. (2005). The need to know team. Demystifying "knowledge translation": learning from the community. *journal of health services research & policy,10* (4), 203–10.

Bradshaw, A. (1997). Teaching spiritual care to nurses: an alternative approach. *International Journal of palliative nursing*, *3*(1), 51-57.

Bush, P. L., Tremblay, M. C., & OPR Recommendations Working Group. (2017). Organizational participatory research: Practice guide.

Canadian Institute of Health Research. (2015). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retieved from: http://www.cihr-irsc.gc.ca/e/45321.html [Retrieved 10 Jan 2019]

Canadian Institutes for Health Research. (2011). Strategy for Patient-Oriented Research: Improving health outcomes through evidence-informed care. http://www.cihr-irsc.gc.ca/e/44000.html. [Retrieved 10 Jan 2019]

Canadian Nursing Association (2010). Spirituality, Health and Nursing Practice. Retrieved from: https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/ps111_spirituality_2010_e.pdf?la=en&hash=0F2E61A2C3E07A08291F88506C523D485DC49BE7 [Retrieved April 23, 2019].

Caplan, N. (1979). The two-communities theory and knowledge utilization. American Behavioral Scientist 1979, 22,459–60.

Carey, M. A. (1994). The group effect in focus groups: Planning, implementing, and interpreting focus group research. *Critical issues in qualitative research methods*, 225, 41.

Cohen, J. F., Korevaar, D. A., Altman, D. G., Bruns, D. E., Gatsonis, C. A., Hooft, L., ... & Bossuyt, P. M. (2016). STARD 2015 guidelines for reporting diagnostic accuracy studies: explanation and elaboration. *BMJ open*, 6(11), e012799.

College of Nurses of Ontario (2002). Professional Standards – Revised 2015. Toronto, Canada: Author. Retrieved from www.cno.org/globalassets/docs/prac/41006_profstds.pdf. [Retrieved April 4, 2019].

College of Nurses of Ontario (2014). Competencies for entry-level Registered Nurse Practice.Toronto, Canada: Author. Retrieved from http://www.cno.org/en/news/2014/january-2014/rn-competencies-document-revised/ [Retrieved April 4, 2019].

Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. *Palliative medicine, 24*(8), 753-770.

Evangelista, C. B., Lopes, M. E. L., Costa, S. F. G. D., Abrão, F. M. D. S., Batista, P. S. D. S., & Oliveira, R. C. D. (2016). Spirituality in patient care under palliative care: A study with nurses. *Escola Anna Nery*, *20*(1), 176-182.

Fink, M., Linnard-Palmer, L., Ganley, B., Catolico, O., & Phillips, W. (2014). Evaluating the use of standardized patients in teaching spiritual care at the end of life. *Clinical simulation in nursing*, *10*(11), 559-566.

Fitchett, G., Meyer, PMand., Burton LA. (2000). Spiritual care in the hospital: Who requests it? Who needs it? *The Journal of pastoral care*, *54*(2), 173–186.

Fitchett, G., Murphy, P., & King, S. D. (2017). Examining the validity of the Rush Protocol to screen for religious/spiritual struggle. *Journal of health care chaplaincy*, *23*(3), 98-112

Frouzandeh, N., Aein, F., & Noorian, C. (2015). Introducing a spiritual care training course and determining its effectiveness on nursing students' self-efficacy in providing spiritual care for the patients. *Journal of education and health promotion*, *4,34.*

Gagliardi, A. R., Berta, W., Kothari, A., Boyko, J., & Urquhart, R. (2015). Integrated knowledge translation (IKT) in health care: a scoping review. *Implementation science*, *11*(1), 38.

Geer, J. V. D., Visser, A., Zock, H., Leget, C., Prins, J., & Vissers, K. (2018). Improving

Spiritual Care in Hospitals in the Netherlands: What Do Health Care Chaplains Involved in an Action-Research Study Report? *Journal of health care chaplaincy*, *24*(4), 151-173

Giske, T. (2012). How undergraduate nursing students learn to care for patients spiritually in clinical studies–a review of literature. *Journal of nursing management*, *20*(8), 1049-1057

Greenstreet, W. M. (1999). Teaching spirituality in nursing: a literature review. *Nurse Education Today*, *19*(8), 649-658.

Grossoehme, D. H., & Fitchett, G. (2013). Testing the validity of a protocol to screen for spiritual struggle among parents of children with cystic fibrosis. *Research in the social scientific study of religion*, *24*, 281

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and Negative Religious Coping and Well-Being in Women with Breast Cancer. *Journal of palliative medicine, 12*(6), 537–545. http://doi.org/10.1089/jpm.2008.0250

Jayasekara, R. S. (2012). Focus groups in nursing research: methodological perspectives. *Nursing outlook, 60*(6), 411-416.

Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. *Implementation science*, *12*(1), 150

King, S. D., Fitchett, G., Murphy, P. E., Pargament, K. I., Martin, P. J., Johnson, R. H., … Loggers, E. T. (2017). Spiritual or religious struggle in hematopoietic cell transplant survivors. Psycho-Oncology, 26(2), 270–277. http://doi.org/10.1002/pon.4029

Kothari, A., & Wathen, C. N. (2013). A critical second look at integrated knowledge translation. *Health policy, 109*(2), 187-191

Krueger, R. A., & Casey, M. A. (2014). Focus groups: A practical guide for applied research.

Sage publications.

LaBine, N. L. (2015). Teaching the spiritual dimension of nursing care: A survey of associate degree nursing programs in the southeast United States. Electronic Theses and Dissertations. Paper 2615. http://dc.etsu.edu/etd/2615

Maddox, M. (2001). Teaching spirituality to nurse practitioner students: The importance of the interconnection of mind, body, and spirit. *Journal of the american academy of nurse Practitioners*, *13*(3), 134-139.

Manning-Walsh, J. (2005). Spiritual Struggle. *Journal of holistic nursing*, *23*(2), 120–140. http://doi.org/10.1177/0898010104272019

McSherry, W., & Jamieson, S. (2011). An online survey of nurses' perceptions of spirituality and spiritual care. *Journal of clinical nursing*, *20*(11-12), 1757-1767.

Neuman, B., & Fawcett J. (2011). *The Neuman systems model* (5th ed.). USA, NJ: Pearson.

Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the scientific study of religion, 37*, 710–724.

Pargament, K. I., Koenig, H. G., Tarakeshwar, N., & Hahn, J. (2004). Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of health psychology*, 9(6), 713-730

Patient-Centered Outcomes Research Institute. (2013). PCORI's strategic plan. https://www.pcori.org/sites/default/files/PCORI-Strategic-Plan.pdf. [Retrived 10 Jan 2019].

Piotrowski, L. F. (2013). Advocating and educating for spiritual screening assessment and

referrals to chaplains. *OMEGA-Journal of Death and Dying*, *67*(1-2), 185-192.

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

Puchalski, C. M., King, S. D., & Ferrell, B. R. (2018). Spiritual considerations. *Hematology/oncology clinics of north america*, *32*(3), 505-517.

Puchalski, C. M., Ferrell, B. (2010). Making Health Care Whole: Integrating Spirituality Into Patient Care. West Conshohocken, PA: Templeton Press

Registered Nurses' Association of Ontario (2006). Establishing Therapeutic Relationships. (rev. suppl.) Toronto, Canada: Registered Nurses' Association of Ontario.

Ross, L. (2006). Spiritual care in nursing: an overview of the research to date. *Journal of clinical nursing*, *15*(7), 852-862.

Rushton, L. (2014). What are the barriers to spiritual care in a hospital setting? *British Journal of Nursing, 23*(7), 370-4. doi:10.12968/bjon.2014.23.7.370

Schultz, M., Meged-Book, T., Mashiach, T., & Bar-Sela, G. (2017). Distinguishing Between Spiritual Distress, General Distress, Spiritual Well-Being, and Spiritual Pain Among Cancer Patients During Oncology Treatment. *Journal of pain and symptom management*, *54*(1), 66-73.

Sedlar, A., Stauner, N., Pargament, K., Exline, J., Grubbs, J., & Bradley, D. (2018). Spiritual struggles among atheists: links to psychological distress and well-being. *Religions*, *9*(8), 242.

Selli, L., & Alves, J. D. S. (2007). Ocuidado espiritual ao paciente terminal no exercício da

enfermagem e a participação da bioética. *Revista Bioethikos, Centro Universitário São Camilo*, *1*(1), 43-52.

Selman, L., Young, T., Vermandere, M., Stirling, I., & Leget, C. (2014). Research Priorities in Spiritual Care: An International Survey of Palliative Care Researchers and Clinicians. *Journal of pain and symptom management, 48*, 518–531.

Straus, S., Tetroe, J., & Graham, I. D. (Eds.). (2013). Knowledge translation in health care: moving from evidence to practice. John Wiley & Sons.

Taylor, E. J., Mamier, I., Ricci-Allegra, P., & Foith, J. (2017). Self-reported frequency of nurse-provided spiritual care. *Applied nursing research*, *35*, 30-35.

Van Leeuwen, R., Schep-Akkerman, A., & van Laarhoven, H. W. (2013). Screening patient spirituality and spiritual needs in oncology nursing. *Holistic nursing practice,* 27(4), 207-216.

Van Leeuwen, R., Tiesinga, L. J., Middel, B., Post, D., & Jochemsen, H. (2008). The effectiveness of an educational programme for nursing students on developing competence in the provision of spiritual care. *Journal of clinical nursing*, *17*(20), 2768-2781.

Vlasblom, J. P., Van Der Steen, J. T., Walton, M. N., & Jochemsen, H. (2015). Effects of nurses' Screening of spiritual needs of hospitalized patients on consultation and perceived nurses' support and patients' spiritual well-being. *Holistic nursing practice,* 29(6), 346-356.

Whiting, P. F., Rutjes, A. W., Westwood, M. E., Mallett, S., Deeks, J. J., Reitsma, J. B., ... & Bossuyt, P. M. (2011). QUADAS-2: a revised tool for the quality assessment of diagnostic accuracy studies. *Annals of internal medicine*, 155(8), 529-536.

Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., …

Balboni, T. A. (2011). The Relationship of Spiritual Concerns to the Quality of Life of Advanced Cancer Patients: Preliminary Findings. *Journal of palliative medicine*, *14*(9), 1022–1028. http://doi.org/10.1089/jpm.2010.0536

Wittenberg, E., Ragan, S. L., & Ferrell, B. (2017). Exploring nurse communication about spirituality. *American Journal of hospice and palliative medicine*, *34*(6), 566-571.

Appendices

Appendix A

Appraisal of the Spiritual Care Guideline

AGREE II	
Domains	**Result**
Scope and Purpose	100%
1. The overall objective(s) of the guideline is (are) specifically described	7
2. The health question(s) covered by the guideline is (are) specifically described	7
3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described	7
Stakeholder Involvement	26.31%
4. The guideline development group includes individuals from all relevant professional groups.	1
5. The views and preferences of the target population (patients, public, etc.) have been sought.	1
6. The target users of the guideline are clearly defined.	6
Rigour of Development	2.08%

7. Systematic methods were used to search for evidence.	1
8. The criteria for selecting the evidence are clearly described.	1
9. The strengths and limitations of the body of evidence are clearly described.	1
10. The methods for formulating the recommendations are clearly described.	1
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.	1
12. There is an explicit link between the recommendations and the supporting evidence.	2
13. The guideline has been externally reviewed by experts prior to its publication.	1
14. A procedure for updating the guideline is provided.	1
Clarity of Presentation	68.42%
15. The recommendations are specific and unambiguous.	5
16. The different options for management of the condition or health issue are clearly presented	7
17. Key recommendations are easily identifiable	4

Applicability	8.33%
18. The guideline describes facilitators and barriers to its application.	1
19. The guideline provides advice and/or toolson how the recommendations can be put into practice.	3
20. The potential resource implications of applying the recommendations have been considered.	1
21. The guideline presents monitoring and/or auditing criteria.	1
Editorial Independence	0
22. The views of the funding body have not influenced the content of the guideline	1
23. Competing interests of guideline development group members have been recorded and addressed	1

Appendix B

Search History of the Systematic Review

a) MEDLINE (20/7/2017)

#	Searches	Results
1	Spirituality/	6789
2	exp spiritual therapies/	11996
3	exp Religion/	58784
4	Existentialism/	1766
5	Transcenden*.tw.	2211
6	faith.tw.	6089
7	pray*.tw.	2883
8	spirit*.tw.	24035
9	religio*.tw.	31845
10	Judaism*.tw.	323
11	Christian*.tw.	7759
12	islam*.tw.	4427
13	Buddhism*.tw.	410
14	existential*.tw.	3799
15	Culture/	32310
16	superstition*.tw.	583
17	taboo*.tw.	2117
18	(funeral adj2 rite*).tw.	30
19	(Ceremonial adj3 Behav*).tw.	2
20	"sensitivity and specificity"/ or roc curve/	376142
21	(Predictive adj2 Value*).tw.	97662
22	(likelihood adj2 ratios*).tw.	4480
23	predictive value*.tw.	96725
24	specificity*.tw.	424374
25	sensitivity*.tw.	718911

26	validity*.tw.	152422
27	(assess or assessing or assessment).tw.	1699662
28	measurement*.tw.	1017112
29	history*.tw.	591098
30	((screen* or diagnostic*) adj3 (tool* or test* or protocol* or model*)).tw.	161601
31	exp Adult/	6868578
32	aged*.tw.	506505
33	adult*.tw.	1112143
34	elder*.tw.	236142
35	or/1-19	143976
36	Hopelessness.tw.	3723
37	suffer*.tw.	278141
38	pain.tw.	552086
39	(Crisis or crises).tw.	51262
40	stress, psychological/	110928
41	(demoraliz* or demoralis*).tw.	765
42	anguish*.tw.	691
43	distress*.tw.	108320
44	(struggle or struggling).tw.	13091
45	(faith or peace or hope).tw.	52490
46	trauma*.tw.	326382
47	or/20-30	4149800
48	or/31-34	7654832
49	or/36-46	1374871
50	35 and 47 and 48 and 49	2875

b) CINAHL (22/7/2017)

Print Search History

#	Query	Results
S48	S44 AND S45 AND S46 AND S47	1,208
S47	S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43	250,642
S46	S30 OR S31 OR S32 OR S33	669,117
S45	S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29	874,695
S44	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16	46,568
S43	TI trauma* OR AB trauma*	55,805
S42	TI ((faith or peace or hope)) OR AB ((faith or peace or hope))	17,185
S41	TI ((struggle OR struggling)) OR AB ((struggle OR struggling))	6,698
S40	TI anguish* OR AB anguish*	308
S39	TI ((demoraliz* OR demoralis*)) OR AB ((demoraliz* OR demoralis*))	283
S38	(MH "Stress, Psychological")	24,150
S37	TI (Crisis or crises) OR AB (Crisis or crises)	12,495
S36	TI pain OR AB pain	121,298

S35	TI suffer* OR AB suffer*	30,794
S34	TI hopelessness OR AB hopelessness	1,173
S33	TI elder* OR AB elder*	56,033
S32	TI adult* OR AB aged*	135,283
S31	TI aged* OR AB aged*	80,125
S30	(MH "Adult")	541,666
S29	TI (screen* or diagnostic*) OR AB (screen* or diagnostic*) OR TI (tool* or test* or protocol* or model*) OR AB (tool* or test* or protocol* or model*)	581,863
S28	TI history* OR AB history*	74,096
S27	TI measurement* OR AB measurement*	85,100
S26	TI assessment OR AB assessment	234,262
S25	TI assessing OR AB assessing	38,644
S24	TI assess OR AB assess	115,997
S23	TI validity* OR AB validity*	32,514
S22	TI sensitivity* OR AB sensitivity*	42,366
S21	TI specificity* OR AB specificity*	20,452
S20	TI predictive N2 value* OR AB predictive N2 value*	10,352
S19	TI likelihood N2 ratios* OR AB likelihood N2 ratios*	812
S18	TI Predictive N2 Value* OR AB Predictive N2 Value*	10,352

S17	(MH "Sensitivity and Specificity") OR (MH "ROC Curve")	41,034
S16	TI Ceremonial N3 Behavior* OR AB Ceremonial N3 Behavior*	1
S15	TI funeral N2 rite* OR AB funeral N2 rite*	17
S14	TI taboo* OR AB taboo*	663
S13	TI superstition* OR AB superstition*	85
S12	(MH "Culture")	16,774
S11	TI existential* OR AB existential*	1,918
S10	TI Buddhism* OR AB Buddhism*	164
S9	TI islam* OR AB islam*	1,196
S8	TI Christianity* OR AB Christianity*	195
S7	TI Judaism* OR AB Judaism*	83
S6	TI religio* OR AB religio*	10,319
S5	TI spirit* OR AB spirit*	14,177
S4	TI pray* OR AB pray*	1,464
S3	"Existentialism"	49
S2	(MH "Religion and Medicine") OR (MH "Prayer") OR (MH "Judaism") OR (MH "Islam") OR (MH "Hinduism")	4,762
S1	(MH "Spirituality")	9,767

Appendix C

Reasons for Excluding Articles in the Systematic Review

- **Not tested for diagnostic accuracy of screening measure(s)**

1- A., Bussing; A., Gunther; K., Baumann; E., Frick
Spiritual dryness as a measure of a specific spiritual crisis in catholic priests: Associations with symptoms of burnout and distress
Evidence-based Complementary and Alternative Medicine // 2013;2013():246797-246797

2- A.E., Molzahn
Field testing the WHOQOL-100 in Canada
Canadian Journal of Nursing Research // 2006;38(3):106-123

3- A.J., Brown; C.C., Sun; D.L., Urbauer; D.C., Bodurka; P.H., Thaker
Feeling powerless: Locus of control as a potential target for supportive care interventions to increase quality of life and decrease anxiety in ovarian cancer patients
Gynecologic Oncology // 2015;138(2):388-393

4- A.J., Brown; C.C., Sun; D., Urbauer; D.S., Zhukovsky; C., Levenback; M., Frumovitz; P.H., Thaker; D.C., Bodurka
Targeting those with decreased meaning and peace: a supportive care opportunity
Supportive Care in Cancer // 2015;23(7):2025-2032

5- A., Kestenbaum; M., Shields; J., James; W., Hocker; S., Morgan; S., Karve; M.W., Rabow
What Impact Do Chaplains Have? A Pilot Study of Spiritual AIM for Advanced Cancer Patients in Outpatient Palliative Care
Journal of Pain and Symptom Management // 2017;():

6 - A., Waller; A., Girgis; P.M., Davidson; P.J., Newton; C., Lecathelinais; P.S., MacDonald; C.S., Hayward
Facilitating needs-based support and palliative care for people with chronic heart failure: Preliminary evidence for the acceptability, inter-rater reliability, and validity of a needs assessment tool
Journal of Pain and Symptom Management // 2013;45(5):912-925

7- A., Waller; S.L., Groff; N., Hagen; B.D., Bultz
Characterizing distress, the 6th vital sign, in an oncology pain clinic
Current Oncology // 2012;19(2):e53-e59

8 - Abraham, Adam; Kutner, Jean S; Beaty, Brenda
Suffering at the end of life in the setting of low physical symptom distress.
Journal of palliative medicine // 2006;9(3):658-665

9- Agarwal, Jayant; Powers, Karen; Pappas, Lisa; Buchmann, Luke; Anderson, Layla; Gauchay, Lisa; Rich, Anne
Correlates of elevated distress thermometer scores in breast cancer patients.
Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer // 2013;21(8):2125-2136

10- Agli, Oceane; Bailly, Nathalie; Ferrand, Claude
Validation of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp12) on French Old People.
Journal of religion and health // 2017;56(2):464-476

11- Alesi, Erin R; Ford, Timothy R; Chen, Christina J; Fletcher, Devon S; Morel, Thomas D; Bobb, Barton T; Lyckholm, Laurel J
Development of the CASH assessment tool to address existential concerns in patients with serious illness.
Journal of palliative medicine // 2015;18(1):71-75

12- Allen, Rebecca S; Harris, Grant M; Burgio, Louis D; Azuero, Casey B; Miller, Leslie A; Shin, Hae Jung; Eichorst, Morgan K; Csikai, Ellen L; DeCoster, Jamie; Dunn, Linda L; Kvale, Elizabeth; Parmelee, Patricia
Can senior volunteers deliver reminiscence and creative activity interventions? Results of the legacy intervention family enactment randomized controlled trial.
Journal of pain and symptom management // 2014;48(4):590-601

13- B.J., Gomez-Castillo; R., Hirsch; H., Groninger; K., Baker; M.J., Cheng; J., Phillips Pollack; Gomez-Castillo, Blanca J; Hirsch, Rosemarie; Groninger, Hunter; Baker, Karen; Cheng, M Jennifer; Phillips, Jayne; Pollack, John; Berger, Ann M
Increasing the Number of Outpatients Receiving Spiritual Assessment: A Pain and Palliative Care Service Quality Improvement Project.
Journal of pain and symptom management // 2015;50(5):724-729

14- Bai, Mei; Dixon, Jane K
Exploratory factor analysis of the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale in people newly diagnosed with advanced cancer.
Journal of nursing measurement // 2014;22(3):404-420
United States 2014 //

15- Baile, Walter F; Palmer, J Lynn; Bruera, Eduardo; Parker, Patricia A
Assessment of palliative care cancer patients' most important concerns.
Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer // 2011;19(4):475-481

Germany 2011 //

16- Bartlett, Susan J; Piedmont, Ralph; Bilderback, Andrew; Matsumoto, Alan K; Bathon, Joan M
Spirituality, well-being, and quality of life in people with rheumatoid arthritis.
Arthritis and rheumatism // 2003;49(6):778-783
United States 2003 //

17- Bausewein, Claudia; Fegg, Martin; Radbruch, Lukas; Nauck, Friedemann; von Mackensen, Silvia; Borasio, Gian Domenico; Higginson, Irene J
Validation and clinical application of the german version of the palliative care outcome scale.
Journal of pain and symptom management // 2005;30(1):51-62
United States 2005 //

18- C, Thomas; NandaMohan, V; MK, Nair; Pandey, M; Thomas, Bejoy C; Nair, Madhvan K; Pandey, Manoj
Gender, age and surgery as a treatment modality leads to higher distress in patients with cancer.
Supportive Care in Cancer 02// 2010;18(2):239-250
Department of Psychosocial Oncology, Tom Baker Cancer Centre, Calgary, AB, Canada Springer Science & Business Media B.V. 2010 02//

19- Bekelman, David B; Dy, Sydney M; Becker, Diane M; Wittstein, Ilan S; Hendricks, Danetta E; Yamashita, Traci E; Gottlieb, Sheldon H
Spiritual well-being and depression in patients with heart failure.
Journal of general internal medicine // 2007;22(4):470-477
United States 2007 //

20- Bekelman, David B; Parry, Carla; Curlin, Farr A; Yamashita, Traci E; Fairclough, Diane L; Wamboldt, Frederick S
A comparison of two spirituality instruments and their relationship with depression and quality of life in chronic heart failure.
Journal of pain and symptom management // 2010;39(3):515-526
United States 2010 //

21- Bell, Iris R; Cunningham, Victoria; Caspi, Opher; Meek, Paula; Ferro, Lynn
Development and validation of a new global well-being outcomes rating scale for integrative medicine research.
BMC complementary and alternative medicine // 2004;4():1-1

22- Bell, Iris R; Lewis, Daniel A 2nd; Lewis, Sabrina E; Brooks, Audrey J; Schwartz, Gary E; Baldwin, Carol M
Strength of vital force in classical homeopathy: bio-psycho-social-spiritual correlates within a complex systems context.
Journal of alternative and complementary medicine (New York, N.Y.) // 2004;10(1):123-131

23- Bernardo, Allan B I; Estrellado, Alicia F
Measuring hope in the Philippines: Validating the short version of the locus-of-hope Scale in Filipino.
Social Indicators Research // 2014;119(3):1649-1661
Bernardo, Allan B. I.: Department of Psychology, University of Macau, PLG334 Pearl Jubilee Building, Avenida Padre Tomas Pereira, Taipa, Macau, allanbibernardo@umac.mo Springer 2014 //

24- Bhatnagar, Sushma; Gielen, Joris; Satija, Aanchal; Singh, Suraj Pal; Noble, Simon; Chaturvedi, Santosh K
Signs of Spiritual Distress and its Implications for Practice in Indian Palliative Care.
Indian journal of palliative care // 2017;23(3):306-311
India 2017 //

25- BK, Baines; Norlander, L
The relationship of pain and suffering in a hospice population.
American Journal of Hospice & Palliative Care 09// 2000;17(5):319-326
Hospice of the Lakes, HealthPartners, Inc., Minneapolis, Minnesota Sage Publications Inc. 2000 09//

26- Blaksley, Mary Ann
A sacred place for wounded souls.
Dissertation Abstracts International Section A: Humanities and Social Sciences // 2016;76(8-A(E)):No-Specified
US ProQuest Information & Learning 2016 //

27- Blesch, Pamela
Can Spiritual Care be TAUGHT via Simulation?.
Journal of Christian nursing : a quarterly publication of Nurses Christian Fellowship // 2015;32(4):232-235

28- Bolano, Marielle; Ahalt, Cyrus; Ritchie, Christine; Stijacic-Cenzer, Irena; Williams, Brie
Detained and Distressed: Persistent Distressing Symptoms in a Population of Older Jail Inmates.
Journal of the American Geriatrics Society // 2016;64(11):2349-2355

29- Breland, Louis J
The Love of God scale and its relationship to psychological well-being
ProQuest Dissertations and Theses // 2010;():64-64
Ann Arbor New Orleans Baptist Theological Seminary 2010 //

30- Brewczynski, Jacek
Spirituality and borderline personality organization: Examination of the psychometric properties of the Inventory of Personality Organization (IPO) and its relationship to the Expressions of Spirituality Inventory (ESI) in a sample of university students
ProQuest Dissertations and Theses // 2012;():155-155
Ann Arbor University of Detroit Mercy 2012 //

31- Brown, Alaina J; Thaker, Premal H; Sun, Charlotte C; Urbauer, Diana L; Bruera, Eduardo; Bodurka, Diane C; Ramondetta, Lois M
Nothing left to chance? The impact of locus of control on physical and mental quality of life in terminal cancer patients.
Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer // 2017;25(6):1985-1991

32- BS, Cole; CM, Hopkins; Tisak, J; JL, Steel; BI, Carr
Assessing spiritual growth and spiritual decline following a diagnosis of cancer: reliability and validity of the spiritual transformation scale.

Psycho-Oncology 02// 2008;17(2):112-121

33- Burke, Laurie A; Neimeyer, Robert A; Holland, Jason M; Dennard, Sharon; Oliver, Linda; Shear, M Katherine
Inventory of complicated spiritual grief: development and validation of a new measure.
Death studies // 2014;38(1-5):239-250

34- Burke, Laurie A; Neimeyer, Robert A; Young, Amanda J; Bonin, Elizabeth Piazza; Davis, Natalie L
Complicated spiritual grief II: a deductive inquiry following the loss of a loved one.
Death studies // 2014;38(1-5):268-281

35- Bussing, Arndt
The SpREUK-SF10 questionnaire as a rapid measure of spiritual search and religious trust in patients with chronic diseases.
Zhong xi yi jie he xue bao = Journal of Chinese integrative medicine // 2010;8(9):832-841
China 2010 //

36- Bussing, Arndt; Koenig, Harold G
The BENEFIT through spirituality/religiosity scale--a 6-item measure for use in health outcome studies.
International journal of psychiatry in medicine // 2008;38(4):493-506

37- Büssing, Arndt; Reiser, Franz; Michalsen, Andreas; Baumann, Klaus
Engagement of Patients With Chronic Diseases in Spiritual and Secular Forms of Practice: Results with the Shortened SpREUK-P SF17 Questionnaire.
Integrative Medicine: A Clinician's Journal 02// 2012;11(1):28-38

38- C., Barbaret; C., Brosse; W., Rhondali; M., Ruer; L., Monsarrat; P., Michaud; A.M., Schott; M., Delgado-Guay; E., Bruera; S., Sanchez
Financial distress in patients with advanced cancer
PLoS ONE // 2017;12(5):e0176470-e0176470
M. Filbet, Department of Supportive and Palliative Care, Centre Hospitalier Lyon-Sud, Lyon, France.

39- C., Beato Zambrano; C., Calderon; P., Jimenez Fonseca; A., Carmona-Bayonas; T., Garcia; A., Ramchandani; M.D.M., Munoz; B., Castelo; E., Martinez De Castro; M.D., Fenor; J., Rogado Revuelta; M., Mangas Izquierdo; M.A., Vicente; I., Ghanem; A., Fernandez; A., Padilla; M.P., Solis Hernandez; O., Donnay; M.D.M., Soriano
Psychometric properties of the functional assessment for chronic illness therapy-spiritual wellbeing (FACIT-Sp) and its relationship wtih quality of Life on patients with non-metastatic resected cancer
Annals of Oncology // 2016;27():
C. Beato Zambrano, Medical Oncology, Clinica Sagrado Corazon, Seville, Spain Oxford University Press 2016 //

40- Caldeira, Silvia; Carvalho, Emilia Campos de; Vieira, Margarida
Between spiritual wellbeing and spiritual distress: possible related factors in elderly patients with cancer.
Revista latino-americana de enfermagem // 2014;22(1):28-34

41- Linda E Carlson, Barry D Bultz, Donald G Morris
Individualized quality of life, standardized quality of life, and distress in patients undergoing a phase I trial of the novel therapeutic Reolysin (reovirus).

Health and quality of life outcomes // 2005;3():7-7

42- Chochinov, Harvey Max; Hassard, Thomas; McClement, Susan; Hack, Thomas; Kristjanson, Linda J; Harlos, Mike; Sinclair, Shane; Murray, Alison
The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care.
Journal of pain and symptom management // 2008;36(6):559-571

43- Stefanie M Monod, Etienne Rochat, Christophe J Büla,Guy Jobin, Estelle Martin, and Brenda Spencer
The spiritual distress assessment tool: an instrument to assess spiritual distress in hospitalised elderly persons;
BMC Geriatr. 2010; 10: 88.

44- Clark, Steve Richard
Protestant Evangelical Christian fathers and their intentional involvement in the relational Christian spiritual formation of their children
ProQuest Dissertations and Theses // 2013;():391-391

45- Clements, Andrea D; Fletcher, Tifani R; Cyphers, Natalie A; Ermakova, Anna V; Bailey, Beth
RSAS-3: validation of a very brief measure of Religious Commitment for use in health research.
Journal of religion and health // 2015;54(1):134-152

46- Cooke, Chad Alexander
The Contrition Assessment Scale (CAS): The development and preliminary validation of a scale to assess a person's disposition to the spiritual emotion of contrition
ProQuest Dissertations and Theses // 2010;():269-269

47- Cummings, Jeremy P; Carson, Cody S; Shrestha, Srijana; Kunik, Mark E; Armento, Maria E; Stanley, Melinda A; Amspoker, Amber B
Santa Clara Strength of Religious Faith Questionnaire: Psychometric analysis in older adults.
Aging & Mental Health // 2015;19(1):86-97

48- Davis, Don E; Hook, Joshua N; Van Tongeren, Daryl R; DeBlaere, Cirleen; Rice, Kenneth G; Worthington, Everett L Jr
Making a decision to forgive.
Journal of counseling psychology // 2015;62(2):280-288

49- Delaney, Colleen
The spirituality scale: Development, refinement and psychometric testing of an instrument to assess the human spiritual dimension
ProQuest Dissertations and Theses // 2003;():142-142
Ann Arbor University of Connecticut 2003 /

50- Delgado-Guay, Marvin Omar; Chisholm, Gary; Williams, Janet; Frisbee-Hume, Susan; Ferguson, Andrea O; Bruera, Eduardo
Frequency, intensity, and correlates of spiritual pain in advanced cancer patients assessed in a supportive/palliative care clinic.
Palliative & supportive care // 2016;14(4):341-348
England 2016 //

51- Delgado-Guay, Marvin Omar; Parsons, Henrique A; Hui, David; De la Cruz, Maxine G; Thorney, Steven; Bruera, Eduardo
Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer.
The American journal of hospice & palliative care // 2013;30(5):455-461
United States 2013 //

52- E., Benito; A., Oliver; L., Galiana; P., Barreto; A., Pascual; C., Gomis
Development and validation of a new tool for the assessment and spiritual care of palliative care patients
Journal of Pain and Symptom Management // 2014;47(6):1008-1008

53- E.C., Fradelos; K., Tsaras; F., Tzavella; E., Koukia; I.V., Papathanasiou; V., Alikari; J., Stathoulis; A., Tsaloglidou; M., Kourakos
Clinical, social and demographics factors associated with spiritual wellbeing in end stage renal disease
Advances in Experimental Medicine and Biology // 2017;987():77-88

54- Edmonds, P; Higginson, I; Altmann, D; Sen-Gupta, G; McDonnell, M
Is the presence of dyspnea a risk factor for morbidity in cancer patients?.
Journal of pain and symptom management // 2000;19(1):15-22

55- EM, Butter; KI, Pargament
Development of a model for clinical assessment of religious coping: initial validation of the Process Evaluation Model.
Mental Health, Religion & Culture 07// 2003;6(2):175-194

56- EM, Redinbaugh; Baum, A; Tarbell, S; Arnold, R
End-of-life caregiving: what helps family caregivers cope?
Journal of Palliative Medicine 12// 2003;6(6):901-909

57- Iranmanesh, Sedigheh; Tirgari, Batool; Tofighi, Maryam; Azizzadeh Forouzi, Mansooreh
Spiritual wellbeing and perceived uncertainty in patients with multiple sclerosis in south-east Iran.
International Journal of Palliative Nursing 10// 2014;20(10):483-492

58- J.N., Berning; A.D., Poor; S.M., Buckley; K.R., Patel; D.J., Lederer; N.E., Goldstein; D., Brodie
A novel picture guide to improve spiritual care and reduce anxiety in mechanically ventilated adults in the intensive care unit
Annals of the American Thoracic Society // 2016;13(8):1333-1342

59- Johnson, Kimberly S; Tulsky, James A; Hays, Judith C; Arnold, Robert M; Olsen, Maren K; Lindquist, Jennifer H; Steinhauser, Karen E
Which domains of spirituality are associated with anxiety and depression in patients with advanced illness?.
Journal of general internal medicine // 2011;26(7):751-758

60- Ku, Ya-Lie; Kuo, Shih-Ming; Yao, Ching-Yi
Establishing the validity of a spiritual distress scale for cancer patients hospitalized in southern Taiwan.
International journal of palliative nursing // 2010;16(3):134-138
England 2010 //

61- Lunder, Urska; Furlan, Maja; Simonic, Anja
Spiritual needs assessments and measurements.
Current opinion in supportive and palliative care // 2011;5(3):273-278

62- M., Juliao; A., Barbosa
Efficacy of dignity therapy in psychological and existential distress of terminally-ill patients: Randomized controlled trial
Palliative Medicine // 2012;26(4):440-440

63- M.Z., Al-Shahri; A., Eldali
Suffering measured on a numerical scale for patients with advanced cancer
Psycho-Oncology // 2011;20():43-43

64- Monod, Stefanie; Brennan, Mark; Rochat, Etienne; Martin, Estelle; Rochat, Stephane; Bula, Christophe J
Instruments measuring spirituality in clinical research: a systematic review.
Journal of general internal medicine // 2011;26(11):1345-1357

65- Monod, Stefanie M; Rochat, Etienne; Bula, Christophe J; Jobin, Guy; Martin, Estelle; Spencer, Brenda
The spiritual distress assessment tool: an instrument to assess spiritual distress in hospitalised elderly persons.
BMC geriatrics // 2010;10():88-88

66- Manning-Walsh,
Spiritual struggle: effect on quality of life and life satisfaction in women with breast cancer.
Journal of Holistic Nursing, 23(2), 120-140

67- Monod, Stefanie; Martin, Estelle; Spencer, Brenda; Rochat, Etienne; Bula, Christophe
Validation of the Spiritual Distress Assessment Tool in older hospitalized patients.
BMC geriatrics // 2012;12():13-13

68- Stranahan, Susan
A spiritual screening tool for older adults.
Journal of religion and health // 2008;47(4):491-503

69- V., Gherghina
Spiritual distress assessment tool a valid instrument for elderly patients in the intensive care unit
Intensive Care Medicine // 2012;38():S304-S304

70- Y.L., Ku; S.M., Kuo
Establishing the validity of a spiritual distress scale for cancer patients hospitalized in southern Taiwan
International journal of palliative nursing // 2010;16(3):134-138

71- Kristin Larson,
The importance of spiritual assessment: One clinician's journey
Geriatric Nursing // 2003;24(6):370-371
K. Larson, Division of Nephrology, Medical University of South Carolina,

72- Wade T. Swenson
Survey of spiritual quality of life among survivorship and distress guidelines
Journal of Clinical Oncology // 2016;34():

73- Maxine A. Adegbola
Relationships among spirituality, self-efficacy and quality of life in adults with sickle cell disease
American Journal of Hematology // 2009;84(8):E175-E177
M.A. Adegbola, University of Texas at Arlington, Arlington, TX 76019, United States Wiley-Liss Inc. 2009 //

74- Kliewer, S
Allowing spirituality into the healing process.
Journal of Family Practice, 53(8), pp.616-625.

75- Sílvia Caldeira, Fiona Timmins, Emília, Campos de Carvalho & Margarida Vieira
Spiritual Well-Being and Spiritual Distress in Cancer Patients Undergoing Chemotherapy: Utilizing the SWBQ as Component of Holistic Nursing Diagnosis
J Relig Health DOI 10.1007/s10943-017-0390-4

- **Not evaluating spiritual screening measures**

76- Cécile Barbaret, Christelle Brosse, Wadih Rhondali, Murielle Ruer, Léa Monsarrat, Patrick Michaud, Anne Marie Schott, Marvin Delgado-Guay, Eduardo Bruera, Stéphane Sanchez, Marilène Filbe
Financial distress in patients with advanced cancer
PloS one 12, no. 5 (2017): e0176470.

77-Johnston Taylor, E., Hopkins Outlaw, F., Bernardo, T. R., & Roy, A.
Spiritual conflicts associated with praying about cancer
Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 8(5), 386-394.

78- Keefe, F. J., Affleck, G., Lefebvre, J., Underwood, L., Caldwell, D. S., Drew, J., ... & Pargament, K.
Living with rheumatoid arthritis: The role of daily spirituality and daily religious and spiritual coping
The Journal of Pain, 2(2), 101-110.

79- Selman, L., Harding, R., Gysels, M., Speck, P., & Higginson, I. J. (2011).
The measurement of spirituality in palliative care and the content of tools validated cross-culturally
Journal of Pain and Symptom Management, 41(4), 728-753

- **Validation of nursing diagnosis of spiritual distress, not a screening measure**

80- Caldeira Sílvia, Timmins Fiona, Campos de Carvalho Emília, and Vieira Margarida,

Clinical Validation of the Nursing Diagnosis Spiritual Distress in Cancer Patients Undergoing Chemotherapy
International journal of nursing knowledge, 28(1), 44-52.

81- Erika de Cássia Lopes Chaves, Emilia Campos de Carvalho, Fabio de Souza Terra, Luiz de Souza
Clinical Validation of Impaired Spirituality in Patients with Chronic Renal Disease
Rev. Latino-Am. Enfermagem 2010 May-Jun; 18(3):309-16

82- Caldeira, Silvia; Timmins, Fiona; de Carvalho, Emilia C; Vieira, Margarida
Nursing Diagnosis of "Spiritual Distress" in Women With Breast Cancer: Prevalence and Major Defining Characteristics.
Cancer nursing // 2016;39(4):321-327

- **Not English**

83- Alves de Oliveira, Nathalia; Nestor Souza, Érica; Moretti Luchesi, Bruna; Inouye, Keika; Iost Pavarini, Sofia Cristina
Estresse e otimismo de idosos cuidadores de idosos que residem com crianças.
Revista Brasileira de Enfermagem 07// 2017;70(4):730-736
Universidade Federal de São Carlos, Programa de Pós-Graduação em Enfermagem. São Carlos-SP, Brasil
Associacao Brasileira de Enfermagem 2017 07//

84- Erika de Cássia Lopes Chaves, Emília Campos de Carvalho, Sueli Leiko Takamatsu Goyatá, Cristina Maria Galvão
Spiritual distress: integrative review of literature
Online Brazilian Journal of Nursing, 2008;7 (2).

- **Not enough information to calculate diagnostic criteria**

85- Stephen D. W. King & George Fitchett & Donna L. Berry
Screening for religious/spiritual struggle in blood and marrow transplant patients
Supportive Care in Cancer, 21(4), 993-1001.

86- Chaves EC, Carvalho EC, Beijo LA, Goyat a SLT, Pillon SC.
Efficacy of different instruments for the identification of the nursing diagnosis spiritual distress1
Revista latino-americana de enfermagem, 19(4), 902-910.

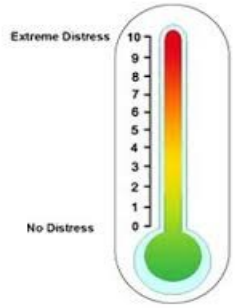
- **Not congruent with the population criteria**

87- Daniel H. Grossoehme, Alexis Teeters, Sue Jelinek, Sophia M. Dimitriou & Lee Ann E. Conard
Screening for Spiritual Struggle in an Adolescent Transgender Clinic: Feasibility and Acceptability
Journal of health care chaplaincy 22, no. 2 (2016): 54-66.

Appendix D

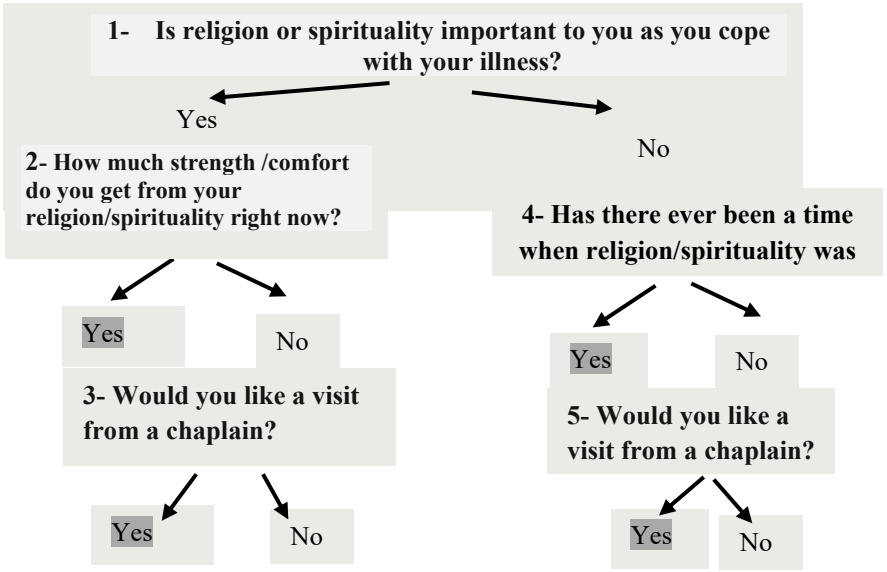
Assessment of the Screening Measures Against Constructs elements of Spirituality

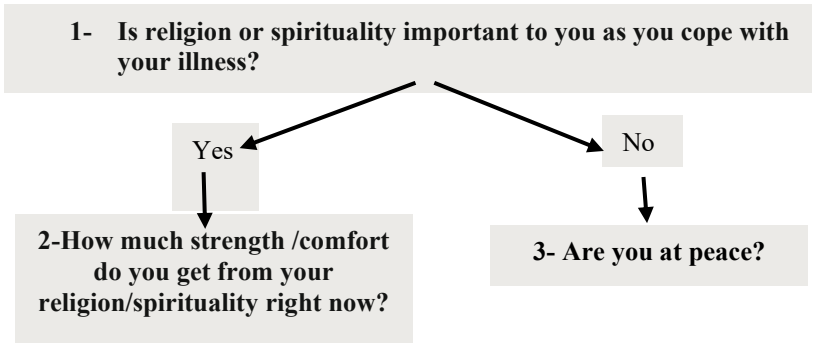
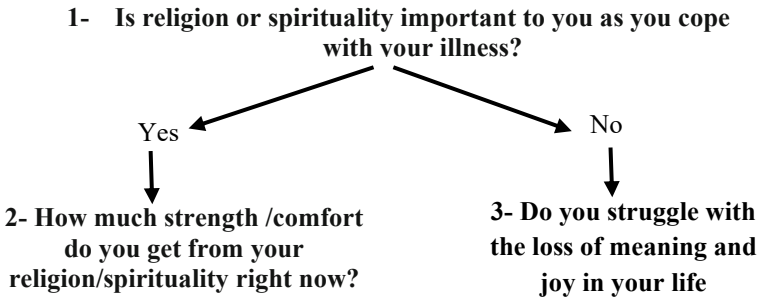
	Screening measures	Meaning and purpose	Connectedness	Faith and religious believe	Value system	Sense of self-transcendence	Peace	Inner strength and energy	Negative feeling	Impaired coping mechanism	Question and Response Options
1	Spiritual Injury Scale:	✓	✓	✓			✓	✓	✓		**1. How often do you feel guilty over past behaviors?** **2. Does anger or resentment block your peace of mind?** **3. How often do you feel sad or experience grief?** **4. Do you feel that life has no meaning or purpose?** **5. How often do you feel despair or hopeless?** **6. Do you feel that God/life has treated you unfairly?** **7. Do you worry about your doubts/disbelief in God?** **8. How often do you think about death?**
2	Spiritual Pain								✓		**Are you experiencing spiritual pain, defined as a pain deep in your soul (being) that is not physical?**
3	FACIT-Sp-12	✓	✓	✓			✓	✓			**1. I feel peaceful** **2. I have a reason for living** **3. My life has been productive** **4. I have trouble feeling peace of mind** **5. I feel a sense of purpose in my life** **6. I am able to reach down deep into myself for comfort** **7. I feel a sense of harmony within myself**

											8. My life lacks meaning and purpose **9. I find comfort in my faith or spiritual beliefs** **10. I find strength in my faith or spiritual beliefs** **11. My illness has strengthened my faith or spiritual beliefs** **12. I know that whatever happens with my illness, things will be okay**
	Screening measures	Meaning and purpose	Connectedness	Faith and religious believe	Value system	Sense of self-transcendence	Peace	Inner strength and energy	Negative feeling	Impaired coping mechanism	**Question and Response Options**
4	General Distress Thermometer								✓		
5	New Israeli Items								✓	✓	Indicators of spiritual suffering: **- Not able to accept that this is happening to me.** **- On my own in dealing with this.** **- Feeling cursed.**
6	Meaning/Joy	✓									**Do you struggle with the loss of meaning and joy in your life?**
7	Self-Described	✓	✓	✓	✓	✓	✓	✓			**Do you currently have what you would describe as religious or spiritual struggles?**

	R/S Struggle										
8	Peace						✓				**Are you at peace?**
	Screening measures	Meaning and purpose	Connectedness	Faith and religious believe	Value system	Sense of self-transcendence	Peace	Inner strength and energy	Negative feeling	Impaired coping mechanism	**Question and Response Options**
9	Comfort/Strength							✓			**Does your religion/spirituality provide you all the strength and comfort you need from it right now?**
10	R/S Concerns	✓	✓	✓	✓	✓	✓	✓			**Do you have any spiritual/religious concerns?**
11	Meaning/Joy & Self-Described Struggle	✓	✓	✓	✓	✓	✓	✓			**1- Do you struggle with the loss of meaning and joy in your life?** **2- Do you currently have what you would describe as religious or spiritual struggles?**
12	Peace & Meaning/Joy	✓					✓				**1- Are you at peace?** **2- Do you struggle with the loss of meaning and joy in your life?**
13	Comfort/Strength & Meaning/Joy	✓						✓			**1- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** **2- Do you struggle with the loss of meaning and joy in your life?**

14	Peace & Self-Described Struggle	✓	✓	✓	✓	✓	✓	✓			1- Are you at peace? 2- Do you currently have what you would describe as religious or spiritual struggles?
	Screening measures	**Meaning and purpose**	**Connectedness**	**Faith and religious believe**	**Value system**	**Sense of self-transcendence**	**Peace**	**Inner strength and energy**	**Negative feeling**	**Impaired coping mechanism**	**Question and Response Options**
15	Comfort/Strength & Self-Described Struggle	✓	✓	✓	✓	✓	✓	✓			1- Does your religion/spirituality provide you all the strength and comfort you need from it right now? 2- Do you currently have what you would describe as religious or spiritual struggles?
16	Comfort/Strength & Peace						✓	✓			1- Does your religion/spirituality provide you all the strength and comfort you need from it right now? 2- Are you at peace?
17	Comfort/Strength & R/S Concerns	✓	✓	✓	✓	✓	✓	✓			1- Does your religion/spirituality provide you all the strength and comfort you need from it right now? 2- Do you have any spiritual/religious concerns?
18	R/S Concerns &	✓	✓	✓	✓	✓	✓	✓			1- Do you have any spiritual/religious concerns? 2- Do you struggle with the loss of meaning and joy in your life?

	Meaning/Joy										
19	R/S Concerns & Self-Described Struggle	✓	✓	✓	✓	✓	✓	✓			**1- Do you have any spiritual/religious concerns?** **2- Do you currently have what you would describe as religious or spiritual struggles?**
		Meaning and purpose	Connectedness	Faith and religious believe	Value system	Sense of self-transcendence	Peace	Inner strength and energy	Negative feeling	Impaired coping mechanism	
20	Peace & R/S Concerns	✓	✓	✓	✓	✓	✓	✓			**1- Are you at peace?** **2- Do you have any spiritual/religious concerns?**
21	Rush protocol (original) (Fitchett and Risk, 2009)							✓		✓	

		Meaning and purpose	Connectedness	Faith and religious believe	Value system	Sense of self-transcendence	Peace	Inner strength and energy	Negative feeling	Impaired coping mechanism	
23	Modified Rush-path A-peace						✓	✓		✓	
24	Modified Rush-path B-meaning /joy	✓						✓		✓	

Appendix E

Invitation Letter for Participants of the Focus group #1

(with chaplains and nurses)

Dear Sir/Madam ……..

You are invited to participate in a focus group (small discussion group) to select a measure to screen patients for spiritual suffering and to determine how the measure should be implemented at Saint Vincent Hospital. This study is part of doctoral research conducted by Sayna Bahraini, PhD(C).

The ninety-minute focus group will be held on ……..(date) and will be hosted at ……(location). at ……Am/Pm. The outline of the session along with the list of brief (one or two-item) spiritual screening measures will be sent to you ahead. The focus group session will be audio recorded. Participants in this session will receive an honorarium of $15. If you willing to participate in this discussion session, please provide your name and phone number.

Name_____Phone Number_____

Sincerely,

Appendix F

Information/Consent Form for the Focus Group #1

(with chaplains and nurses)

Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to the Spiritual Care Service in Complex Continuing Care

RESEARCHERS

Principal Investigator

Sayna Bahraini, PhD (c)

University of Ottawa

Faculty of Health science

Supervisors

Ian Graham, MA, PhD, FCAHS, FNYAM, FRSC

Professor, School of Epidemiology and Public Health, University of Ottawa

Senior Scientist, Ottawa Hospital Research Institute

Wendy Gifford, RN, PhD

Associate Professor

Co-Director, Nursing Best Practice Research Center (NBPRC)

Faculty of Health science

University of Ottawa

Site Investigator

Rebekah Hackbusch

Coordinator, Spiritual and Religious Care, Therapeutic Support services, Bruyere Continuing Care- Saint Vincent Hospital

Bruyère

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Sayna Bahraini, Ian Graham, Wendy Gifford, and Rebekah Hackbusch. This Research has been funded by Canadian Association of Spiritual care.

Purpose of the Study: This research is part of SB's doctoral thesis to improve screening patients for spiritual suffering at Saint Vincent Hospital (SVH). You are invited in a focus group (small discussion group) to (1) identify key considerations in selecting and implementing a spiritual screening measure for use at Bruyère SVH, and (2) select a spiritual screening measure and the process of implementation of the measure at Bruyère SVH.

Participation: Your participation will consist of attending one focus group that will last no more than ninety minutes. Prior the session, you will receive the session outline and a list and description of existing spiritual screening measures to read. During the session, you will participate in a discussion to select an appropriate spiritual screening measure this hospital. You will participate in developing a process for how the measure will be implemented (i.e., who should administer it, how, and when). Key considerations in selecting and implementing a spiritual screening measure will be also discussed. The focus group will be facilitated by the coordinator of spiritual care at Saint Vincent Hospital (Rebekah Hackbusch) with the assistance of the researcher (Sayna Bahraini). A number of registered nurses, nurse managers, chaplains, and chaplain student will participate in this group discussion. Decision made during the discussion will be based on consensus. The session will be held in ……(location) at Saint Vincent Hospital on …….(date) at ……..(time).

Risk: Your participation in this focus group involves you giving your opinion on the topics of discussion. Some group members may disagree with your views which may cause you to feel uncomfortable. The researcher has set some general rules to run the session such as respecting each other turn to speak and emphasizing that there are no "wrong answers" to the questions. These rules will be provided in the focus group outline which will be sent in advance to me and other participants. The facilitator will also review these rules with the participants in the beginning of the session and will make sure that everyone has the opportunity to speak and share their opinions. Your participation is voluntary, and you can stop taking part at any time without any negative consequences. The research team will keep the participants' responses confidential. We will also ask participants to keep the responses that they hear from other participants in the focus group confidential. Keeping the confidentiality of the responses from other participants cannot be guaranteed from the research team.

Benefits: Your participation in this study will give you the opportunity to be involved in choosing an appropriate spiritual screening measure for the hospital that you work in, and also to share your views on how and when to implement the selected measure to get the best result at SVH. You may gain satisfaction from being part of this decision-making process as improved screening of patients for spiritual suffering and a subsequent appropriate referral to spiritual care service may minimize the harmful physical and psychological effects of spiritual suffering in patients.

Confidentiality and anonymity: You have received assurance from the researcher that the information you will share will remain confidential. The researcher will audio record the session to revisit the accurately describing in the thesis and subsequent journal articles. Your confidentiality will be protected in the following ways:

- Your name will not be associated in any way with the study;
- Your name will not be seen on any information collected and will not be reported in any oral or written report;
- A numerical identification code will be used on the electronic and paper copies of tape recording transcriptions, notes, and reports of the data for the tracking purposes only;
- Your identity will not appear in quotes used in reports or publications.
- Your managers and coworkers may know that you are involved in the study and therefore privacy of participation cannot be guaranteed.
- You should inform the researcher in case you would like to be acknowledged by name in the reports or publications for my advisory role in this research.

Conservation of data: Transcripts, invitation letters, list of participants names and corresponding identification code, consent forms and any notes will be kept in the locked research office at the University of Ottawa, Nursing Best Practice Research Center. The data will be retained for 5 years after the completion of the project in December 2018. The researchers named in the consent form, the examiners of the thesis, and the Bruyere Research Board will have access to the data and that is for auditing purposes. Dr. Wendy Gifford, the supervisor of the thesis, will dispose of this data as per University of Ottawa policy at the end of the storage period (December 2023).

Compensation: You will receive an honorarium of $15. Compensation will be paid in full at the beginning of the focus group. If you choose to withdraw from the study, you will keep your honorarium.

Voluntary Participation: you are under no obligation to participate and if you choose to participate, you can leave the focus group at any time and/or refuse to answer any questions, without suffering any negative consequences. However, we cannot determine the identity of the person who was expressing his/her opinion on the audio tape and the subsequent

transcripts. Therefore, if you chose to withdraw from the study, the information you shared in the focus group will not be able to be withdrawn (removed).

Acceptance: I, ……(Name of participant), agree to participate in the above research study conducted by Sayna Bahraini, PhD(C),School of Nursing, Faculty of Health Sciences, University of Ottawa which research is under the supervision of Dr. Ian Graham and Dr. Wendy Gifford. I understand that this focus group will be audio taped.

If you have any questions about any part of the research being conducted, you may contact the researcher or her supervisor.

If you have any questions regarding the ethical conduct of this study, you may contact the

Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall or the the Protocol

Coordinator of the Bruyère Research Ethics Board

There are two copies of the consent form, one of which is yours to keep.

Participant's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Appendix G

Outline of the Focus Group #1

(with chaplains and nurses)

Purpose of the session:

1. To identify key considerations in selecting and implementing a spiritual screening measure
2. To select a spiritual screening measure and determine the implementation process of the measure at SVH

Welcome and introduction

Introduce the purpose and format of the session

Ground Rules

This will allow us to get the best out of the session:

- Only one person speaks at a time. This is doubly important as our goal is to make a written transcript of our conversation. It is difficult to capture everyone's experience and perspective on our audio recording if there are multiple voices at once.
- Please avoid side conversations.
- Everyone doesn't have to answer every single question, but we'd like to hear from each of you as the discussion progresses.
- This is a confidential discussion in that I will not report who said what to your colleagues or supervisors. Names of participants will not even be included in the final report about this meeting. However, if you would like to be acknowledged by name in the reports or publications for your advisory role in this research please let us know at the end of the session.
- We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.
- There are no "wrong answers," just different opinions. Say what is true for you, even if you're the only one who feels that way. Don't let the group sway you. But if you do change your mind, let me know.
- Let the facilitator know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.

Presentation on the existing screening measures for spiritual suffering

A fifteen-minute presentation

Discussion Questions

Summing up and Closing

Appendix H

Pre-Reading Material for the First Focus Group with Healthcare Providers

Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to the Spiritual Care Service in Complex Continuing Care

Researchers:

Sayna Bahraini,
PhD (c),University of Ottawa, Faculty of Health science
Ian Graham, MA, PhD, FCAHS, FNYAM, FRSC
Professor, School of Epidemiology and Public Health, University of Ottawa
Wendy Gifford, RN, PhD
Associate Professor,Co-Director, Nursing Best Practice Research Center (NBPRC),Faculty of Health science, University of Ottawa
Rebekah Hackbusch,
Coordinator, Spiritual and Religious Care, Therapeutic Support services, Bruyere Continuing Care-

Patients who experience spiritual suffering are often not identified or referred for specialized chaplaincy service at this hospital. Of those referred, many do not require specialized spiritual care and chaplaincy services. With limited resources and spiritual suffering negatively impacting patients' health, there is a need for patients to be effectively screened for spiritual suffering and appropriately referred to spiritual care service.

We have gathered 24 screening measures to identify patients with spiritual suffering. We are asking you to select the top three measures that you think would best screen patients for spiritual suffering and identify them for chaplaincy referral at this hospital. Please make this decision based on your experience, knowledge and the evidence we have provided in table 1 regarding each measure.

Information that you need to know to interpret measures in table 1:

Sensitivity and *specificity* indicate the accuracy of a screening measure. The higher the score, the more accurate the measure.

- ***Sensitivity*** is the ability of the screening measure to correctly identify those with the condition of interest. In this case, a measure with 100% sensitivity would correctly identify all patients with spiritual suffering. A measure with 80% sensitivity would detect 80% of patients with spiritual suffering and 20% of those with spiritual suffering would go undetected.

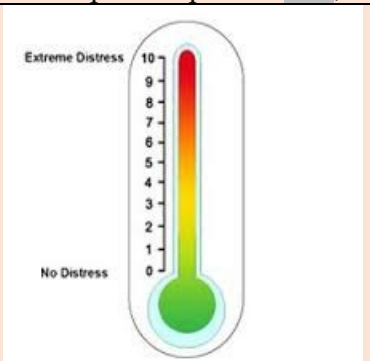
- ***Specificity*** is the ability of the screening measure to correctly identify those without the condition of interest. Therefore, a measure with 100% specificity correctly identifies all patients without spiritual suffering. In other words, all patients that do not have spiritual suffering would be correctly not identified as having spiritual suffering. A measure with 80% specificity correctly identifies 80% of patients as not having spiritual suffering, but 20% of patients without suffering are incorrectly identified as having spiritual suffering.

Sensitivity and specificity are determined by comparing the results of the measure of interest to a *gold standard*. The best gold standards for identifying spiritual suffering are (1) chaplain assessment, (2) Self -Report Spiritual Distress, and (3) N-RCOPE (Negative- Religious Coping scale). This means that Chaplain assessment or Self-Report Spiritual Distress are more reliable as a gold standard than N-RCOPE.

Please choose your top three screening measures in the box below.

1-
2-
3-

Table 1. Spiritual Screening Measures

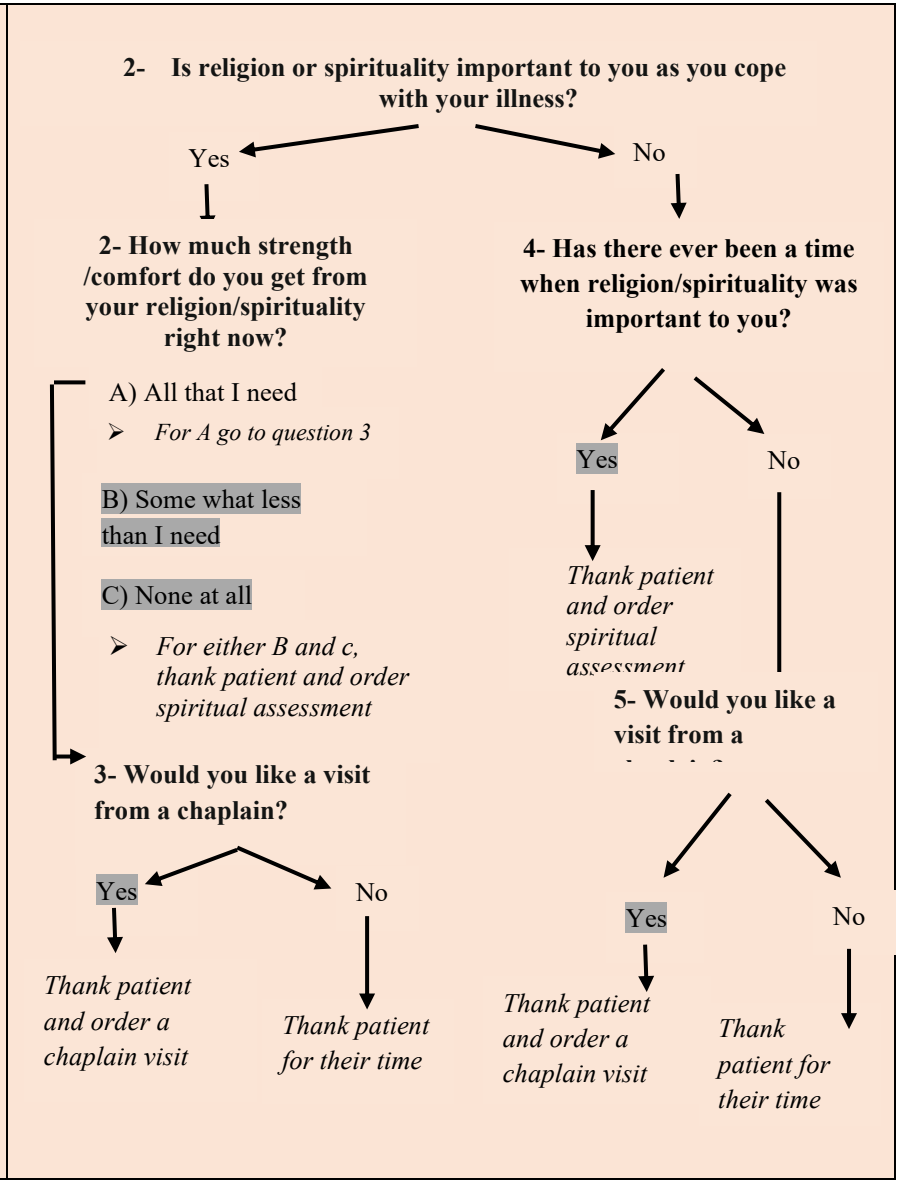
#	Screening measures	Sensitivity	Specificity	Gold Standard	Question and Response Options (Response options in grey represent potential spiritual suffering)
1	Spiritual Pain	72 (moderate)	76 (moderate)	Self-report spiritual distress	**Are you experiencing spiritual pain, defined as a pain deep in your soul (being) that is not physical?** Response options: Yes, No
2	General Distress Thermometer	41 (low)	76 (moderate)	Self-report spiritual distress	 *Scores of eight or higher are indicator of distress.
3	New Israeli Items	43 (low)	86 (high)	Self-report spiritual distress	Indicators of spiritual suffering: **- Not able to accept that this is happening to me.** **- On my own in dealing with this.** **- Feeling cursed.** Response options: Not reported in the literature
4	Meaning/joy	60- 65 (moderate)	58-65 (moderate)	N-RCOPE	**Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal

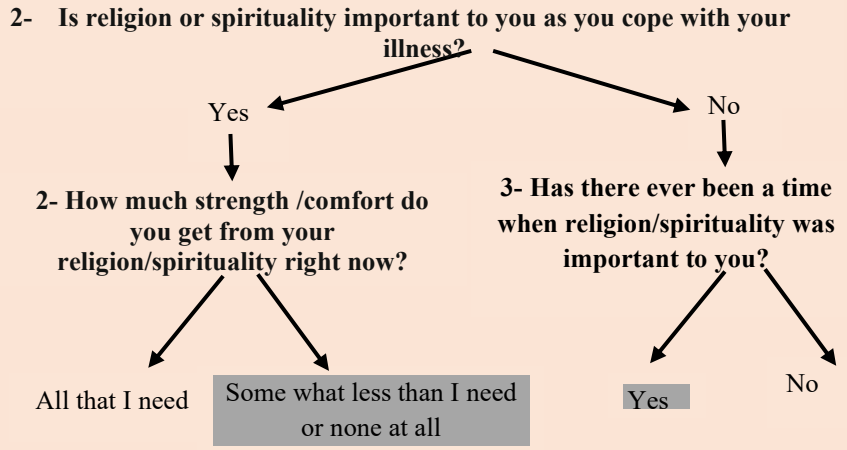
5	Self-described R/S struggle	54 -61 (moderate)	75 -77 (moderate)	N-RCOPE	**Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
6	Peace	45 -55 (moderate)	80-83 (moderate)	N-RCOPE	**Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely
7	Comfort/strength	42-43 (low)	85 (high)	N-RCOPE	**Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal
#	**Screening measures**	**Sensitivity**	**Specificity**	**Gold Standard**	**Question and Response Options** (Response options in grey represent potential spiritual suffering)
8	R/S concerns	25-27 (low)	87-89 (high)	N-RCOPE	**Do you have any spiritual/religious concerns?** Response options: Yes, No
9	Meaning/joy & self-described struggle	82-87 (high)	44-50 (low)	N-RCOPE	**1-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal **2-Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
10	Peace & meaning/joy	78-84 (moderate)	47-54 (moderate)	N-RCOPE	**3- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely **2-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal

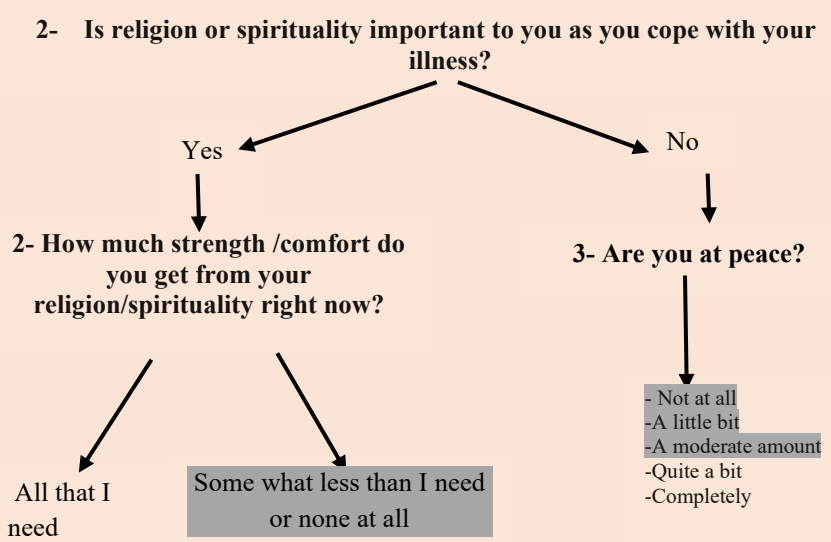
11	Comfort/strength & meaning/joy	77-80 (moderate)	50-56 (moderate)	N-RCOPE	**3-Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **4-Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal
12	Peace & self-described struggle	75-83 (moderate)	60-64 (moderate)	N-RCOPE	**3-Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely **4-Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
13	Comfort/strength & self-described struggle	73-78 (moderate)	64-65 (moderate)	N-RCOPE	**3-Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **4-Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
14	Comfort/strength & peace	68-74 (moderate)	68-70 (moderate)	N-RCOPE	**3-Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal

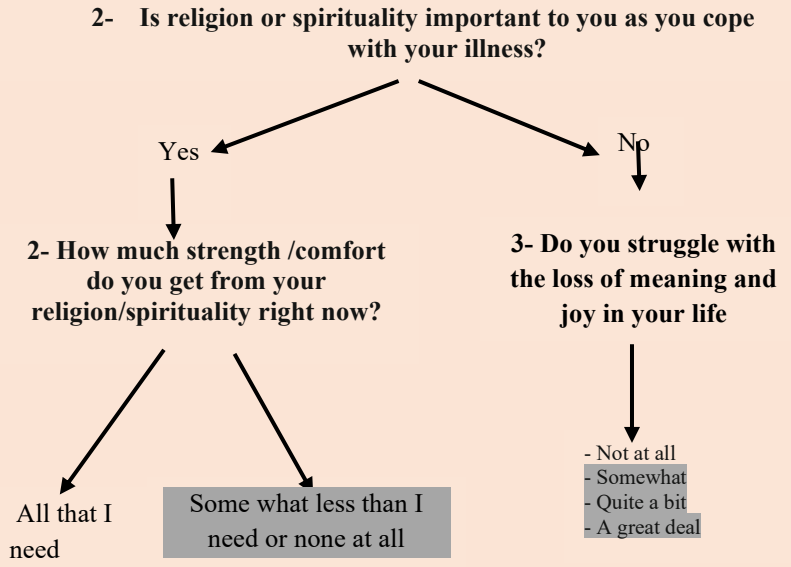
					4-Are you at peace? Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely
#	**Screening measures**	**Sensitivity**	**Specificity**	**Gold Standard**	**Question and Response Options** (Response options in grey represent potential spiritual suffering)
15	Comfort/strength & R/S concerns	57-58 (moderate)	74-76 (moderate)	N-RCOPE	**3- Does your religion/spirituality provide you all the strength and comfort you need from it right now?** Response options: Not applicable, Not at all, Somewhat, Quite a bit, A great deal **4- Do you have any spiritual/religious concerns?** Response options: Yes, No
16	R/S concerns & meaning/joy	71-74 (moderate)	51-58 (moderate)	N-RCOPE	**3- Do you have any spiritual/religious concerns?** Response options: Yes, No **4- Do you struggle with the loss of meaning and joy in your life?** Response options: Not at all, Somewhat, Quite a bit, A great deal
17	R/S concerns & self-described struggle	66-71 (moderate)	65-69 (moderate)	N-RCOPE	**3- Do you have any spiritual/religious concerns?** Response options: Yes, No **4- Do you currently have what you would describe as religious or spiritual struggles?** Response options: Not at all, Somewhat, Quite a bit, A great deal
18	Peace & R/S concerns	60-66 (moderate)	70-73 (moderate)	N-RCOPE	**5- Are you at peace?** Response options: Not at all, A little bit, A moderate amount, Quite a bit, completely **6- Do you have any spiritual/religious concerns?** Response options: Yes, No
19	Spiritual Injury Scale:	83 (moderate)	54 (moderate)	Self-report spiritual distress	**9- How often do you feel guilty over past behaviors?** **10- Does anger or resentment block your peace of mind?** **11- How often do you feel sad or experience grief?** **12- Do you feel that life has no meaning or purpose?** **13- How often do you feel despair or hopeless?**

	- positive response to at least one item - positive response to at least 2 items	64 (moderate)	79 (moderate)		**14- Do you feel that God/life has treated you unfairly?** **15- Do you worry about your doubts/disbelief in God?** **16- How often do you think about death?** Response options to each question: Never, Sometimes, Often,Very often. *Positive responses to at least one item indicate a diagnosis of spiritual injury.
#	**Screening measures**	**Sensitivity**	**Specificity**	**Gold Standard**	**Question and Response Options** (Response options in grey represent potential spiritual suffering)

20	Rush protocol (original)	47.42 (low)	-	Chaplain Assessment	

#	Screening measures	Sensitivity	Specificity	Gold Standard	Question and Response Options (Response options in grey represent potential spiritual suffering)
21	Revised Rush Protocol	29- 42 (low)	81-90 (high)	N-RCOPE	

22	Modified Rush-path A-peace	40 (low)	86.1 (high)	N-RCOPE	
#	**Screening measures**	**Sensitivity**	**Specificity**	**Gold Standard**	**Question and Response Options** (Response options in grey represent potential spiritual suffering)
23	Modified Rush-path B-meaning /joy	42.6 (low)	83 (moderate)	N-RCOPE	

					
24	FACIT-Sp-12	57 (moderate)	72 (moderate)	Self-report spiritual distress	**13. I feel peaceful** **14. I have a reason for living** **15. My life has been productive** **16. I have trouble feeling peace of mind** **17. I feel a sense of purpose in my life** **18. I am able to reach down deep into myself for comfort** **19. I feel a sense of harmony within myself** **20. My life lacks meaning and purpose** **21. I find comfort in my faith or spiritual beliefs** **22. I find strength in my faith or spiritual beliefs** **23. My illness has strengthened my faith or spiritual beliefs** **24. I know that whatever happens with my illness, things will be okay** Response options to each question: Not at all, A little bit, Somewhat, Quite a bit, Very much

Appendix I

The Interview Questions and Recruitment Process of Focus Group Interviews in Chapter 3

Recruitment process FG#1:In order to gain access to RNs and nurse managers at the hospital, the primary investigator (S.B.), along with the hospital's coordinator of the spiritual care (R.H.), held a meeting with the director of nursing of the hospital. The director of nursing introduced the coordinator of the spiritual care (R.H.) to the potential nurse managers and RNs of the inpatient units for recruitment. Being the coordinator of spiritual care and knowing the hospital's clinical chaplains, she (R.H.) approached chaplains to complete the recruitment. She (R.H.) explained the project to the potential participants and provided them with an invitation letter (Appendix E) and information/ consent form (Appendix F). Participants who were interested in participating in the focus group provided their contact information. Those who met the inclusion criteria were later selected and contacted by R.H. Together, R.H. and the PI (S.B.) obtained the written informed consent forms prior to data collection. In preparation for the focus group, the facilitators reviewed their roles and discussed any potential challenges that may occur during the session and how to address them.

FG#1 Interview Questions

Focus Group #1 Questions	
Key-question #1	**Which spiritual screening measure is the most appropriate one for use at your hospital?**

Sub-questions	○ Do you prefer a spiritual screening measure with a higher sensitivity or specificity for use? ○ What other criteria should we take into consideration in selecting an appropriate spiritual screening measure for this hospital? How come?
Final decision on the most appropriate measure.	
Key-question #2	**How should the measure be implemented at the hospital?**
Sub-questions	○ By whom? Why? ○ The timing of administration of the measure to newly admitted patients? ○ How can the measure be incorporated into routine practice? Why you prefer this approach?
A final decision on the process of implementation of the measure	

Recruitment process FG#2: The coordinator of spiritual care (R.H.) asked the clinical chaplains and nurse managers to identify potential patients. She (R.H.) approached the introduced patients to explain the study and provided them with an invitaion letter (Appendix J) and information/consent form (Appendix K). Participants provided their contact information (phone number or room number). Together, S.B. and R.H. obtained the written informed consents before starting data collection at the focus group session. The coordinator of spiritual care (R.H.) and invitation letter the PI (S.B.) facilitated a one-hour focus group interview. A similar process was used to review the facilitators' roles and how to mitigate potential challenges as was done in FG#1.

Focus Group #2 Questions	
Questions associated with the selected spiritual screening measure	**Facilitator:** Nurses and clinical chaplains have selected the Meaning/Joy and Peace measure among other available measures to screen patients for spiritual suffering at this hospital. We are here to ask your opinions on the selected spiritual screening measure (pointing to the selected measure on a flip chart). **Questions:** o How clear and easy to understand is this spiritual screening measure for you? What about other patients? Do you think it is clear for other patients? o How comfortable would you or other patients be answering the questions on the screening measure? o What suggestions and concerns do you have regarding this measure?
Questions associated with the process of implementation of the measure	**Facilitator:** The Meaning/Joy and Peace measure will be used by nurses to screen patients in the first 48 hours to 7 days of their arrival to the hospital. They are going to add this measure on the electronic intake system and re-screen patients every three months or after patient's changes in condition. They believed that the clinical chaplains' role should be defined for patients and nurses should establish a trusting relationship with patients before asking the screening questions. **Questions:** o What do you think of the timing for the screening measure? What other patients may feel about it? Would you like to have the screening later or earlier in your hospital stay? o How comfortable would you be if nurses ask you the questions on the screening measure? What other patients may think? Which health care providers do you prefer to ask those questions, or you are more comfortable to answer? What other patients may prefer? Why? o How comfortable would you be if the screening measure is added on electronic intake system to re-screen patients every 3 months or after changes in patient's condition? why? What about other patients? o What suggestions and concerns do you have regarding the process of using the spiritual screening measure?

Recruitment FG#3: The coordinator of spiritual care (R.H.) approached the participants of the first focus group to explain the purpose of conducting an additional group discussion and provided them with an invitation letter (Appendix M) and information/consent form (Appendix N). Participants who were interested in volunteering to participate in the focus group provided their contact information. Together S.B. and R.H. obtained written informed consent before starting data collection at the focus group session.

Focus Group #3 Questions
• Health care providers have chosen the Peace and Meaning/Joy measure, and patients have proposed other screening questions (questions were explained). What do you think? How can we incorporate the patients' viewpoints?
Final decision on the screening measure.
• Health care providers selected RNs as a profession who should screen patients. Patients selected social workers. What do you think?
A final decision on the profession who should screen

Appendix J

Invitation Letter for Participants of the Focus group #2
(with patients)

Dear Sir/Madam ……..

You are invited to participate in a focus group (small discussion group) to share your opinions on how spiritual suffering will be screened at this hospital. This study is part of doctoral research that will be conducted by Sayna Bahraini, PhD (c).

The ninety-minute session will be held on ……..(date) and will be hosted at ……(location) at ……Am/Pm. The session will be audio recorded. If you have any specific needs, please let us know beforehand, so we can accommodate you. Participants in this session will receive an honorarium of $15. If you willing to participate in this focus group session, please provide your name, phone number or your unit and room number.

Name_____

Phone number_____ OR unit and room number_____

Sincerely,

Appendix K

Information/ Consent Form for the Focus Group #2 (with patients)

Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to the Spiritual Care Service in Complex Continuing Care

RESEARCHERS

Principal Investigator

Sayna Bahraini, PhD (c)

University of Ottawa

Faculty of Health science

Supervisors

Ian Graham, MA, PhD, FCAHS, FNYAM, FRSC

Professor, School of Epidemiology and Public Health, University of Ottawa

Senior Scientist, Ottawa Hospital Research Institute

Wendy Gifford, RN, PhD

Associate Professor

Co-Director, Nursing Best Practice Research Center (NBPRC)

Faculty of Health science

University of Ottawa

Site Investigator

Rebekah Hackbusch

Coordinator, Spiritual and Religious Care, Therapeutic Support services, Bruyere Continuing Care- Saint Vincent Hospital

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Sayna Bahraini, Ian Graham, Wendy Gifford, and Rebekah Hackbusch. This Research has been funded by Canadian Association of Spiritual care.

Purpose of the Study: This research is part of SB's doctoral thesis to improve screening patients for spiritual suffering at Saint Vincent Hospital (SVH). You are invited in a focus group (small discussion group) to assess patients' opinions on how spiritual suffering will be screened at Saint Vincent Hospital.

Participation: Your participation will consist of attending one focus group session that will last no more than ninety minutes. Prior the session, you will receive the outline of the session to read. During the session, you will share your opinions on a spiritual screening measure and process for using the measure at SVH (i.e., who should administer it, how, and when). The session will be facilitated by the coordinator of spiritual care at Saint Vincent Hospital (Rebekah Hackbusch) with the assistance of the researcher (Sayna Bahraini). A number of patients at SVH will participate in this focus group. The session will be held in ……(location) at Saint Vincent Hospital on …….(date) at ……..(time).

Risk: Your participation in this focus group involves you giving your opinion on the topics of discussion. Some group members may disagree with your views which may cause you to feel uncomfortable. The researcher has set some general rules to run the session such as respecting each other turn to speak and emphasizing that there are no "wrong answers" to the questions. These rules have been provided in the session outline which will be sent in advance to you and other participants. The facilitator will also review these rules with the participants in the beginning of the session and will make sure that everyone has the opportunity to speak and share their opinions. Your participation is voluntary, and you can stop taking part at any time without any negative consequences. The research team will keep the participants' responses confidential. We will also ask participants to keep the responses that they hear from other participants confidential. Keeping the confidentiality of the responses from other participants cannot be guaranteed from the research team.

Benefits: Your participation in this study will give you the opportunity to share your opinions on a spiritual screening measure selected by health care providers to use at SVH, and also to discuss your views on how and when to use the selected measure to get the best result at SVH. You may gain satisfaction from being part of this decision-making process as improved screening of

patients for spiritual suffering and a subsequent appropriate referral to spiritual care service may minimize the harmful physical and psychological effects of spiritual suffering in patients.

Confidentiality and anonymity: You have received assurance from the researcher that the information you will share will remain confidential. The researcher will audio record the session to revisit the accurately describing in the thesis and subsequent journal articles. Your confidentiality will be protected in the following ways:

- **Your name will not be associated in any way with the study;**
- Your name will not be seen on any information collected and will not be reported in any oral or written report;
- A numerical identification code will be used on the electronic and paper copies of tape recording transcripts, notes, and reports of the data for the tracking purposes only;
- Your identity will not appear in quotes used in reports or publications.
- The nurse manager and the nurses of the unit that you are hospitalized in may know that you are involved in the study and therefore privacy of participation cannot be guaranteed.

Conservation of data: Transcripts, invitation letters, list of participants names and corresponding identification code, consent forms and any notes will be kept in the locked research office at the University of Ottawa, Nursing Best Practice Research Center. The data will be retained for 5 years after the completion of the project in December 2018. The researchers named in the consent form, the examiners of the thesis, and the Bruyere Research Ethics Board will have access to the data and that is for auditing purposes. Dr. Wendy Gifford, the supervisor of the thesis, will dispose of this data as per University of Ottawa policy at the end of the storage period (December 2023).

Compensation: You will receive an honorarium of $15. Compensation will be paid in full at the beginning of the focus group. If you choose to withdraw from the study, you will keep your honorarium.

Voluntary Participation: You are under no obligation to participate and if you choose to participate, you can leave the focus group at any time and/or refuse to answer any questions, without suffering any negative consequences. However, we cannot determine the identity of the person who was expressing his/her opinion on the audio tape and the subsequent transcripts. Therefore, if you chose to withdraw from the study, the information you shared in the focus group will not be able to be withdrawn (removed).

Acceptance: I, ……(Name of participant), agree to participate in the above research study conducted by Sayna Bahraini, PhD(C),School of Nursing, Faculty of Health Sciences, University of Ottawa which research is under the supervision of Dr. Ian Graham and Dr. Wendy Gifford. I understand that this focus group will be audio taped.

If you have any questions about any part of the research being conducted, you may contact the researcher or her supervisors.

If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, or the the Protocol Coordinator of the Bruyère Research Ethics Board.

There are two copies of the consent form, one of which is yours to keep.

Participant's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Appendix L

Outline of the Focus group #2

(with patients)

Purpose of the focus group:

To share your opinions on how spiritual suffering will be screened at Saint Vincent Hospital.

Welcome and introduction

Introduce the purpose and format of the session

Ground Rules

This will allow us to get the best out of the session:

- Only one person speaks at a time. This is doubly important as our goal is to make a written transcript of our conversation. It is difficult to capture everyone's experience and perspective on our audio recording if there are multiple voices at once.
- Please avoid side conversations.
- Everyone doesn't have to answer every single question, but we'd like to hear from each of you as the discussion progresses.
- This is a confidential discussion in that I will not report who said what to your health care providers. Names of participants will not even be included in the final report about this meeting. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.
- There are no "wrong answers," just different opinions. Say what is true for you, even if you're the only one who feels that way. Don't let the group sway you. But if you do change your mind, let me know.
- Let the facilitator know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.

Presentation on spiritual suffering and a spiritual screening measure

A fifteen-minute presentation

Discussion Questions

Summing up and Closing

Appendix M

Invitation Letter for Participants of the Focus group #3
(with chaplains and nurses)

Dear Sir/Madam ……..

You are invited to participate in a focus group (small discussion group) to share your perspective on the results of the current study. This study is part of doctoral research conducted by Sayna Bahraini, PhD(C).

The ninety-minute focus group will be held on ……..(date) and will be hosted at ……(location). at ……Am/Pm. The focus group session will be audio recorded. If you willing to participate in this discussion session, please provide your name and phone number.

Name_____Phone Number_____

Sincerely,

Appendix N

Information/ Consent Form for the Focus Group #3

(with chaplains and nurses)

Selecting and Planning the Implementation of a Screening Measure to Refer Patients with Spiritual Suffering to the Spiritual Care Service in Complex Continuing Care

RESEARCHERS

Principal Investigator

Sayna Bahraini, PhD (c)

University of Ottawa

Faculty of Health science

Supervisors

Ian Graham, MA, PhD, FCAHS, FNYAM, FRSC

Professor, School of Epidemiology and Public Health, University of Ottawa

Senior Scientist, Ottawa Hospital Research Institute

Wendy Gifford, RN, PhD

Associate Professor

Co-Director, Nursing Best Practice Research Center (NBPRC)

Faculty of Health science

University of Ottawa

Bruyère

Site Investigator

Rebekah Hackbusch

Coordinator, Spiritual and Religious Care, Therapeutic Support services, Bruyere Continuing Care- Saint Vincent Hospital

Invitation to Participate: You are invited to participate in the abovementioned research study conducted by Sayna Bahraini, Ian Graham, Wendy Gifford, and Rebekah Hackbusch. This Research has been funded by Canadian Association of Spiritual care.

Purpose of the Study: This research is part of SB's doctoral thesis to improve screening patients for spiritual suffering at Saint Vincent Hospital (SVH). You are invited in a focus group (small discussion group) to discuss your perspectives on the result of the current study.

Participation: Your participation will consist of attending one focus group that will last no more than ninety minutes. During the session, you will participate in a discussion to share your perspectives on the result of the current study. The focus group will be facilitated by the coordinator of spiritual care at Saint Vincent Hospital (Rebekah Hackbusch) with the assistance of the researcher (Sayna Bahraini). A number of registered nurses, nurse managers, chaplains, and chaplain student will participate in this group discussion. Decision made during the discussion will be based on consensus. The session will be held in ……(location) at Saint Vincent Hospital on …….(date) at ……..(time).

Risk: Your participation in this focus group involves you giving your opinion on the topics of discussion. Some group members may disagree with your views which may cause you to feel uncomfortable. The researcher has set some general rules to run the session such as respecting each other turn to speak and emphasizing that there are no "wrong answers" to the questions. These rules will be provided in the focus group outline which will be distributed to you and other participants. The facilitator will also review these rules with the participants in the beginning of the session and will make sure that everyone has the opportunity to speak and share their opinions. Your participation is voluntary, and you can stop taking part at any time without any negative consequences. The research team will keep the participants' responses confidential. We will also ask participants to keep the responses that they hear from other participants in the focus group confidential. Keeping the confidentiality of the responses from other participants cannot be guaranteed from the research team.

Benefits: Your participation in this study will give you the opportunity to be involved in choosing an appropriate spiritual screening measure for the hospital that you work in, and also to share your views on how and when to implement the selected measure to get the best result at SVH.

You may gain satisfaction from being part of this decision-making process as improved screening of patients for spiritual suffering and a subsequent appropriate referral to spiritual care service may minimize the harmful physical and psychological effects of spiritual suffering in patients.

Confidentiality and anonymity: You have received assurance from the researcher that the information you will share will remain confidential. The researcher will audio record the session to revisit the accurately describing in the thesis and subsequent journal articles. Your confidentiality will be protected in the following ways:

- Your name will not be associated in any way with the study;
- Your name will not be seen on any information collected and will not be reported in any oral or written report;
- A numerical identification code will be used on the electronic and paper copies of tape recording transcriptions, notes, and reports of the data for the tracking purposes only;
- Your identity will not appear in quotes used in reports or publications.
- Your managers and coworkers may know that you are involved in the study and therefore privacy of participation cannot be guaranteed.
- You should inform the researcher in case you would like to be acknowledged by name in the reports or publications for my advisory role in this research.

Conservation of data: Transcripts, invitation letters, list of participants names and corresponding identification code, consent forms and any notes will be kept in the locked research office at the University of Ottawa, Nursing Best Practice Research Center. The data will be retained for 5 years after the completion of the project in December 2018. The researchers named in the consent form, the examiners of the thesis, and the Bruyere Research Board will have access to the data and that is for auditing purposes. Dr. Wendy Gifford, the supervisor of the thesis, will dispose of this data as per University of Ottawa policy at the end of the storage period (December 2023).

Voluntary Participation: you are under no obligation to participate and if you choose to participate, you can leave the focus group at any time and/or refuse to answer any questions, without suffering any negative consequences. However, we cannot determine the identity of the person who was expressing his/her opinion on the audio tape and the subsequent transcripts. Therefore, if you chose to withdraw from the study, the information you shared in the focus group will not be able to be withdrawn (removed).

Acceptance: I, ……(Name of participant), agree to participate in the above research study conducted by Sayna Bahraini, PhD(C),School of Nursing, Faculty of Health Sciences, University of Ottawa which research is under the supervision of Dr. Ian Graham and Dr. Wendy Gifford. I understand that this focus group will be audio taped.

If you have any questions about any part of the research being conducted, you may contact the researcher or her supervisor.

If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, or the the Protocol Coordinator of the Bruyère Research Ethics Board.

There are two copies of the consent form, one of which is yours to keep.

Participant's signature: _____ Date: _____

Researcher's signature: _____ Date: _____

``````
``````

Appendix O

Outline of the Focus group #3

Purpose of the focus group:

To share your opinions on the result of the current research

Welcome and introduction

Introduce the purpose and format of the session

Ground Rules

This will allow us to get the best out of the session:

- Only one person speaks at a time. This is doubly important as our goal is to make a written transcript of our conversation. It is difficult to capture everyone's experience and perspective on our audio recording if there are multiple voices at once.
- Please avoid side conversations.
- Everyone doesn't have to answer every single question, but we'd like to hear from each of you as the discussion progresses.
- This is a confidential discussion in that I will not report who said what to your health care providers. Names of participants will not even be included in the final report about this meeting. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.
- There are no "wrong answers," just different opinions. Say what is true for you, even if you're the only one who feels that way. Don't let the group sway you. But if you do change your mind, let me know.
- Let the facilitator know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.

Presentation on the finding of our research

A fifteen-minute presentation

Discussion Questions

Summing up and Closing

Appendix P

Sample Size Calculation

- **Sample size based on sensitivity**

$$TP + FN = Z^2 \frac{\left(SN(1-SN)\right)}{W^2} = 1.96^2 \frac{\left(0.85(1-0.85)\right)}{0.05^2} = 3.841 \ \frac{0.1275}{0.0025} = 195.891$$

$$(\mathbf{sN}) = \frac{TP + FN}{P} = \frac{195.891}{0.4} = 489.727$$

- **Sample size based on specificity**

$$FP + TN = Z^2 \frac{\left(SP(1-SP)\right)}{W^2} = 1.96^2 \frac{\left(0.60(1-0.60)\right)}{0.05^2} = 3.841 \ \frac{0.24}{0.0025} = 368.736$$

$$\mathbf{N(sP)} = \frac{FP + TN}{1-P} = \frac{368.736}{1-0.4} = 614.56$$

TP stands for true positive and FN for false negative. FP is false positive and TN is true negative. Z is confidence interval normal distribution value that is 1.96 for 95% confidence interval. SN stands for the expected level of sensitivity which was 85% and SP for the expected level of specificity that was 60%. P is prevalence of the diseases in the test population that is 40% (average of 25-50% reported prevalence) and W is accuracy that is 0.05. We calculated sample size based on both sensitivity and specificity.

*****We will take the greater sample size from both sensitivity and specificity (Jones, Carley, & Harrison; 2003) that is 614.56 ≃ 615**

Appendix Q

Descriptive Qualitative

I conducted the second phase (chapter 3) of this dissertation to assist healthcare providers at a complex continuing care hospital to identify a process to better screen patients experiencing spiritual suffering. I used a qualitative descriptive approach, as outlined by Sandelowski (2000) to address the research objectives (see Chapter 1-Table 1.2). In this section, an overview of qualitative descriptive approach is discussed in addition to the reflexivity, protection of human subjects, and rigor.

Overview of Approach

Sandelowski (2000) discussed qualitative descriptive research as a valuable research approach that draws from the naturalistic inquiry and allows researchers to make choices about what they want to describe. Naturalistic inquiry, which is embedded in the constructivist paradigm (Lincoln & Guba, 1989), aims to explore the everyday experiences of participants regarding a phenomenon in their natural setting where complexities and interactions with other phenomenon abound (Lincoln & Guba, 1985). In qualitative descriptive approach, the descriptions of the phenomena under study cover meanings closer to what participants attributed to it; therefore, this approach involves less researchers' interpretation (Sandelowski, 2000). Results from qualitative descriptive inquiries have low–inference interpretation and therefore, likely result in greater consensus among researchers and knowledge users (Sandelowski, 2000).

In contrast to other qualitative approaches, qualitative descriptive studies are considered the least "theoretical'' research. Sandelowski (2000) suggest researchers conducting such studies are *"the least encumbered by pre-existing theoretical and philosophical commitments"* (p.337) which has roots in naturalistic inquiry where there is no a priori commitment to a theoretical

view for a targeted phenomenon. This allows the phenomenon under study to show itself in a natural situation (Lincoln & Guba, 1985). Although Sandelowski (2000) suggested researchers review theoretical and empirical literature when conducting a study, she warned them to be aware of preconceptions and be willing to move away from them.

Design Features of a Qualitative Descriptive study

Qualitative descriptive designs are usually combination of sampling, data collection, analysis, and re-presentational techniques. In the following, I have situated my study (chapter 3) regarding each design feature of the qualitative descriptive approach.

Data collection: In qualitative description studies, the typical data collection techniques include minimal to moderately structured individual and/or groups interviews, observation, and the examination of documents (Sandelowski, 2000). I used semi-structure focus group interviews in my study to gain a broad range of information to address my research questions.

Sampling: Sandelowski (2000) recommended using purposive sampling technique to obtain data from informative participants. In the current study, we used this technique to select participants who made a valuable contribution in the focus groups (see inclusion criteria-Chapter 3).

Data analysis: The analysis strategy of choice in qualitative descriptive is inductive content analysis (Sandelowski, 2000). Qualitative content analysis is a reflective, dynamic and iterative method of analysis of verbal, written and visual data that is oriented toward summarizing the content of the data with the least amount of interpretation (Cole, 1988; Sandelowski, 2000). The inductive content analysis process is represented as three main phases: (1) preparation (i.e., selecting unit of analysis regarding the research question), (2) organization (i.e., coding, creating categories and abstraction), and (3) reporting (i.e., the content and structure

of concepts should be reported systematically and carefully in a clear and understandable way). In my data analysis (Chapter 3), description of the informational data with minimal level of interpretation was performed. Steps that I took have been explained in the data analysis section of the third chapter.

Data Re-Presentation

In Qualitative descriptive studies researchers can present the result in different ways, such as a chronological order of events, most prevalent to least prevalent, and progressive focusing (i.e., moving from the broad contexts to particular cases or vice versa) (Sandelowski, 2000). In my study, I conducted three consecutive focus groups and presented the results in a chronological order in narrative and tabular format (see chapter 3-result section).

Study Rigor

In this section I discuss the strategies that I used to enhance the trustworthiness of the findings of this study. The terms credibility, transferability, dependability, and confirmability as discussed by Lincoln and Guba (1985) were used.

Credibility represented how truthful the the research findings were and whether findings represent acceptable information drawn from the participants' original data (Lincoln and Guba,1985). Triangulation is one of the strategies to enhance credibility by using different data sources (i.e., gathering data from different types or levels of people) and/or methods of data collection (i.e., using different data collection strategies such as interview, focus group, and observation (Korstjens & Moser, 2018; Lincoln and Guba,1985). I used data source triangulation in my study as I collected the information from nurses, nurse managers, clinical chaplains, and patients. To increase credibility of the findings, I also reviewed decisions that had been made by

the participants at the end of each focus group interview to ensure they confirm the outcome of the focus group interviews.

Dependability and Confirmability: Dependability relates to the consistency of the findings (Lincoln and Guba,1985). It is the ability of another researcher to follow the decision trail for data analysis and formulate the same or comparable conclusions given the same data, perspective, and situation. Confirmability is neutrality of findings (Lincoln and Guba,1985). The interpretation of the findings should be based in the original data and not researchers' preferences. An audit trail is one of the strategies to enhance both dependability and confirmability of a qualitative study (Lincoln & Guba, 1985). In this strategy, another investigator reviews the research process. In the current study, decisions made during the research process and emergence of the findings were reviewed in team meetings with the thesis committee members. In addition, L.W (a PhD candidate in nursing) reviewed the data analysis process of the research. She read each focus group transcript along with the tables of related codes and categories developed by me. We, then, through meetings, discussed and resolved conflicts that arose.

Transferability shows whether the findings of the study have applicability in other contexts (Lincoln and Guba, 1985). Thick description of the research process is a strategy to enable the reader to judge if findings are transferable to their own setting (Korstjens & Moser, 2018; Lincoln and Guba, 1985). To enhance transferability of my study, I provided detail information on the context in which the research was carried out, research participants, recruitment strategy, inclusion and exclusion criteria, and research methods (including focus groups procedure and questions).

Reflexivity

I come from a fairly traditional country, Iran, where family relationships and religious beliefs are extremely prominent. As connectedness with others and Super Being is one of the major factors for spiritual wellbeing (Ramezani, Ahmadi, Mohammadi, &Kazemnejad, 2014), it may be expected that patients with progressive diseases in countries such as Iran reveal less spiritual issues. However, according to my personal experience as an ICU nurse, patients even with strong sense of connectedness face spiritual suffering and pose questions about the purpose of life. Addressing patient's spiritual suffering, however, was a complex issue and most of the nurses did not know how to deal with this type of suffering. When I moved to Canada to obtain a PhD in nursing, I realized that spiritual suffering is not well supported in this country, as well. I was introduced to the Coordinator of Spiritual Care at the Saint Vincent Hospital, where screening for spiritual suffering and appropriate referral was one of the research priorities in her organization.

I do not practice any religion and I have an existential worldview toward spirituality. For me spirituality is having sense of inner peace and I respect what brings inner peace to other people. This can be their religious beliefs, existential worldviews, values, sense of connectedness and so far. I'm also a fan of holistic care that considers the whole person: mind, body, and spirit. My concern, as a nurse, is to bring back peace to patients who have difficulties in coping with their life-threatening conditions. This research project provided a great opportunity for me to work on one of my research interests' areas.

I align myself philosophically with the pragmatic paradigm. I believe truth is not based in a "*dualism between reality independent of the mind or within the mind. Truth is what works at the time*" (Cresswell, 2007, p. 23). Pragmatism emphasizes the importance of conducting

research that best address the research problem. Therefore, the most important aspect of research is the problem being studied and the question asked about the problem. I focus on the 'what' and 'how' of the research problem and I believe outcomes of research are more important than antecedent conditions (Cresswell, 2013; Mackenzie & Knipe, 2006). Paragmatism is not committed to any specific system of reality. Thus, researchers are free to choose the methods and procedures of research that best address their research problem (Cresswell, 2013).

Protection of human subjects

Ethical considerations are essential when human participants are involved in research. I employed many safeguards to maintain protection, anonymity, confidentiality, and rights of the participants. There were two informed consent forms (one for the participants to keep and the other for the researcher) for each focus group interview, describing the study in its entirety including the rights and responsibilities of the participants, potential risks and benefits of participation, and contact information of me, my supervisors, and the Ethics Research Board of Bruyère and University of Ottawa (see appendix for consent forms). I collected data after completion of consent forms by the participants.

I informed participants that during the focus group interview some group members may disagree with the participant's views which may cause him/her to feel uncomfortable. To reduce such feeling, I set some ground rules for the session such as respecting each other turn to speak and emphasizing that there are no "wrong answers" to the questions. I provided the ground rules in the session outline that was sent in advance to the participants and also reviewed in the beginning of the session to ensure that everyone has the opportunity to speak and share their perspectives. I also informed participants that the session will be audio recorded to revisit the accurately describing in the thesis and subsequent journal articles.

In order to maintain confidentiality, participants' name was not associated in any way with the study and seen on any information collected. Participants' name was not reported in any oral or written reports, transcripts, notes from the discussion session and quotes used in reports or publications. A numerical identification code was assigned to each participant in the study for the tracking purposes. Electronic and paper copies of transcriptions of audio-recorded data along with all the consent forms, and list of participants name and corresponding identification code were secured in a locked location at the University of Ottawa Nursing department. The abovementioned data will be retained for 5 years after the completion of the project in December 2018. Dr. Wendy Gifford, the supervisor of the thesis, will dispose these data as per University of Ottawa policy at the end of the storage period (December 2023). I informed nurses and chaplains who participate in the first and third focus group that their managers and coworkers may know that they are involved in the study and therefore privacy of participation cannot be guaranteed from this aspect.

With the topic of spiritual suffering, participants may feel uncomfortable due to the personal and sensitive nature of the topic. I informed participants that their attendance to the focus group is voluntary, and they can stop taking part at any time without any negative consequences. However, no risk was identified with participation in this regard and no one withdrew the session. I gave a 15$ gift card to each participant in order to appreciate their time at the beginning of the focus groups. However, participants were informed that they can keep their honorarium If they choose to withdraw from the study.