## Exploring Spiritual Distress and Acceptability in Chronic Disease: State of the Literature and the Perspectives of Patients with Type 2 Diabetes and Healthcare Chaplain Providers

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy (Health Behavior and Health Education) University of Michigan 2024

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## Dedication

To every patient, loved one, and staff member I have had the good fortune to know, I am grateful that our paths crossed, and you made me just a wee bit better than I was before. I am the person and scholar I am today, because of all of you.

## Acknowledgments

There have been a plethora of people standing behind me and supporting my steps forward throughout this dissertation and I doubt I could account for a third of them. I could not have done this without the support of my family, my beloved community of friends, my feathered companions, and all of those who directly or indirectly contributed to this work. I don't think I would be where I am today if it were not for all of you.

I want to acknowledge my dissertation advisor, Dr. K. Rivet Amico, for her curiosity, kindness, and innate ability to teach and mentor. Thank you for walking this path with me and, along the way, becoming a beloved colleague and friend.

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## List of Abbreviations

Abbreviation	Name
ACC	Association Certified Chaplain
ACPE	Association of Clinical Pastoral Educators
AMHC	Association of Mental Health Chaplains
APC	Association of Professional Chaplains
APHC	Association of Protestant Hospital Chaplains
ARMS	Adherences to Refills and Medications scale
BCC	Board Certified Chaplain
CASC/ACSS	Canadian Association for Spiritual Care/Association Canadienne de soins spirituels
CDC	Center for Disease Control and Prevention
CPE	Clinical Pastoral Education
CRD	Chronic Respiratory Disease
CSCAR	Center for Statistical Consultation and Research
CVD	Cardiovascular Disease
DBP	Diastolic Blood Pressure
EBPAS-36	Evidence-Based Practice Attitudes Scale
EPIS	Exploration, Preparation, Implementation, Sustainment Framework
EPP	Existential Positive Psychology
HbA1c / A1C	Glycated Hemoglobin
HDL	High-density lipoprotein
HRBI	Health Risk Behavior Inventory
LDL	low-density lipoprotein
MPSS	Multidimensional Scale of Perceived Social Support
NACC	National Association of Professional Chaplains
NAJC	Neshema: Association of Jewish Chaplains
NHS	National Health Service
OCRBS	Organizational Change Recipients' Belief Scale
PACC	Provisional Associate Certified Chaplain
PBCC	Provisional Board Certified Chaplain
PCC	Population, Concept, and Context
PHI	Partners in Health
PHQ-4	Patient Health Questionnaire for Depression and Anxiety
PRC	Pew Research Center

RSSS	Religious and Spiritual Struggles Scale
SBP	Systolic Blood Pressure
SEM	Socioecological Model
SRE	Spiritual, Religious, Existential
T2DM	Type 2 Diabetes Mellitus
TFA	Theoretical Framework of Acceptability
TJC	The Joint Commission
WHO	World Health Organization

#### Abstract

Spirituality is a resource for coping and support for people with chronic diseases. However, little is known about how spiritual distress, a negative spiritual experience associated with poorer physical and mental health outcomes, presents in persons with chronic diseases or what types of interventions would be acceptable. This research examines how spiritual distress is measured and characterized within chronic disease populations with known risk behaviors and whether chaplaincy-based interventions are acceptable to patients and chaplains. Using multiple methodologies, this dissertation explores the measures and characterization of spiritual distress in persons with chronic disease and the acceptability of chaplain-led interventions to address spiritual distress. Chapter 2 explores how spiritual distress is measured and conceptualized through a scoping review and synthesis paper. Chapter 3 characterizes spiritual distress in patients with a chronic disease (Type 2 Diabetes) and explores the acceptability of chaplain-led interventions for addressing spiritual distress through a cross-sectional online survey. Lastly, Chapter 4 explores healthcare chaplains' perceptions of acceptability for providing support to those with non-acute chronic disease through a cross-sectional online survey. The findings from each of these studies may inform patient care guidelines and direct the development and implementation of chaplain-led interventions to address spiritual distress and potentially provide another mechanism for chronic disease prevention.

#### **Chapter 1 Background**

Spirituality, religion, and medicine have been coupled throughout history from early Mesopotamia to the modern era (Ferngren, 2012). The influence of religion and spirituality may be considered a "potent force" in human life and health with positive (e.g., spiritual well-being) and negative (e.g., spiritual distress) influences on health behaviors and outcomes (Pargament, 2022). In particular, spiritual distress in advanced disease has been linked to multiple adverse physical and mental health outcomes (Delgado-Guay et al., 2011; Hills et al., 2005; Pargament et al., 2004; Velosa et al., 2017), lower quality of life, and life satisfaction (Manning-Walsh, 2005), and increased risk of death (Pargament et al., 2001). Despite connections to negative health outcomes, spirituality is often not included in whole-person or person-centered care models outside of the acute care setting (VanderWeele et al., 2017; Yeary et al., 2020). Further, despite the presence of chaplains in most healthcare institutions, there are no providers identified in healthcare to specifically provide spiritual support or intervention (Cadge et al., 2011; Cadge et al., 2008; Cohen, 2018; Handzo et al., 2017).

This chapter provides a brief overview of the historical relationship between religion and health and more recent evidence regarding the role of spiritual distress and health outcomes. Topics addressed include spiritual distress in relationship to health risk behaviors and chronic disease and, the history, training, and role of healthcare chaplains as a resource for spiritual distress intervention. This background information is used to develop a conceptual model of the relationships between spiritual distress, health risk behaviors, and the development and progression of chronic diseases.

#### 1.1 Religion, spirituality, & health

#### 1.1.1 A historical overview of religion, spirituality, and health

Inextricably linked throughout history, the role of religion and spirituality in physical health has evolved from the 'mystical' (e.g., foul humors, evil spirits) to the biologically scientific (Ferngren, 2012). Humoralism, or the belief that illness and disease are associated with an imbalance in the body (in whole or part), dates back to ancient Greece (6<sup>th</sup>-5<sup>th</sup> century BC) and provided a foundation for understanding health and disease in Western<sup>1</sup> medicine (Nutton, 1993). Within the Judeo-Christian context, morality played a significant role in health, with disease believed to be the result of sinful behavior or an angry God (Caplan, 1993). The belief that health is a sign of "good moral character" and disease is a sign of "moral failure" supported a "duality" between the physical body ("the flesh") and spirit (Caplan, 1993; Porter, 1993). As our understandings of health and disease have changed, so has our approach to religion, spirituality, and health. Early on, the 'institutions' that provided compassionate care for the ill or injured had strong connections to religion but moving into the 20th century, health and medicine became less connected to religion and religious communities<sup>2</sup> (Ferngren, 2012). The Christian tradition, most notable within Catholic religious orders (e.g., nuns, convents), valued charity and developed hospitals or medical facilities where the sick, disabled, or those with other needs could receive supportive care until they recovered or died (Porter, 1993). The historical roots of religion in providing acute and outpatient care remain visible in systems of care in the US with

<sup>&</sup>lt;sup>1</sup> Western medicine dominates much of the conversation in healthcare research in the U.S., but this overlooks other traditional practices of medicine (e.g., Chinese, Ayurvedic; Last, 1993). Although not explored within this chapter, the lasting impact of colonization is tied to the absence and decentralization of non-Western traditions as it relates to modern medicine.

<sup>&</sup>lt;sup>2</sup> There continues to be health systems affiliated with religious groups; most notably, Catholic health systems (e.g., CommonSpirit Health, Ascension, Trinity Health) which represent four of the ten largest health systems in the U.S. (Solomon et al., 2020).

nearly 20% of US hospitals religiously affiliated and nearly half of the top 25 health systems affiliated with Catholicism (Solomon et al., 2020; Uttley & Khaikin, 2016).

Although religion remains an important defining feature of systems of care, it does not appear to drive patient choice in where to receive care (Guiahi et al., 2019). Further, attributions of health outcomes to religious or spiritual transgressions have been replaced with scientific and evidence-based causes. Nonetheless, spirituality remains an important correlate of health, health outcomes, and well-being in specific (Clark et al., 2018) and general populations (Jaberi et al., 2019).

#### 1.1.2 An evolving understanding of religion and spirituality in health

Inquiries into religion and spirituality have increasingly used a rigorous scientific lens. Terms such as spiritual health and concepts of spirituality in relation to locus of control, stress, and coping, and illness representation and beliefs, have become common in health-related inquiry and practice. The past several years has seen a dramatic increase in peer-reviewed research publications on spirituality and health. According to PubMed,<sup>3</sup> while prior to the 1950's less than a hundred articles were published annually (search terms: "relig\* OR spirit\*"), in 2021 there were over 7,000 published articles (Cadge, 2012; 2022).

Religious observance (e.g., church attendance, prayer) has been historically used as an objective measure of religiosity; more recently, there has been growing attention to assessments that focus more on spiritual experiences and less on religious behaviors (i.e., church attendance) (Hall et al., 2008). In 2014 nearly 80% of U.S. adults were affiliated with a religious tradition (70% Christian) and yet less than 40% regularly attended (≥1 time per week) religious services

<sup>&</sup>lt;sup>3</sup> This trend has also been noted in other databases (e.g., PsycInfo, Web of Science) and journal articles highlighting the increased interest in religion and spirituality (Lazenby, 2010; Oman, 2013; Stefanek et al., 2005; Visser et al., 2010).

(Pew Research Center [PRC], 2016). The trend toward secularization in the U.S. continues, with an increase of 16% to 29% of U.S. adults indicating they have no religious affiliation between 2007 and 2021, 33% for whom religion is "not at all" to "not too important" in their lives, 31% attending services at least once a month or more (PRC, 2016, 2021).

Though national trends indicate a steady decline in religious identification it does not reflect significant changes in the way people experience the sacred. The Pew Religious Landscape study (2015b) found an increasing number of people (religiously affiliated and unaffiliated) indicating "a deep sense of wonder" (39% to 46%) and "a deep sense of spiritual peace and well-being" (52% to 59%) 2007 to 2014. This reinforces the need to expand the conceptualization of spirituality to be more inclusive of complex presentations of spirituality. *Religious multiplicity* or *spiritual fluidity* are terms used to describe the "experience of being shaped by, or maintaining bonds to, more than one spiritual or religious community at the same time" (Bidwell, 2018, pp. 1-2).

While the role of religion and spirituality in health in many ways has 're-entered' the conversation, most investigations focus on end-of-life areas of inquiry. This contrasts with how these beliefs were commonly invoked to explain daily health and well-being. Religion and spirituality are core components of health and healthcare that are particularly crucial at end-of-life, where spiritual needs are considered most acute (Puchalski, 2001). Although much of the attention has been focused on the realm of palliative care, there continues to be growing interest in understanding the potential role of religion and spirituality in health promotion more generally (Rumbold et al., 2012).

In the book, *When One Religion is Not Enough*, Duane Bidwell (2018, pp. 31-32) shares a brief narrative of a man ('Jeffery') when asked about his religious affiliation upon admission to the hospital:

[The nurse asked,] "Religious preference?" Jeffery smiled. "Part of me is Tibetan Buddhist," he said, "and part of me is Catholic." The nurse looked at him for the first time. "Which part is having surgery today?" she asked. "Both." [he replied.] The nurse peered over her glasses, "Sir, the form only allows you to have one religious preference. Will it be 'Buddhist' or 'Catholic Christian'?" "I'm both," Jeffery repeated. "I'll just check 'Other," she said. "Unless you prefer 'None."" Jeffery didn't respond [... and it wasn't until after surgery he noticed his official hospital record] read "No Religious Affiliation." [...] Jeffery's suffering was existential, psychosocial, and deeply personal: the hospital had silenced his sense of the sacred and denied his religion because he didn't fit into the official categories. "She erased my spirituality," [he said.]

Spirituality is complex and deeply personal but is also an important component of culturally competent and humble care (Dillard et al., 2021; Kersey-Matusiak, 2018; Swihart et al., 2024). The inclusion of spirituality in primary care settings (Isaac et al., 2016) and preventative precision medicine (Yeary et al., 2020) provides an opportunity to provide holistic support to patients within their own religious, spiritual, or existential frameworks. Barriers to including spirituality into preventative care includes poor definitions of spirituality, knowing which patients want to receive such services, and whether the main providers of spiritual care (e.g., healthcare chaplains) are prepared to provide such services.

Religion and spirituality can influence an individual's health beliefs and behaviors, making them more active or passive in their disease management (Hayward, Krause, Ironson, & Pargament, 2016; Polzer & Miles, 2007; Roger & Hatala, 2017) and has been identified as an essential mechanism of coping for those with chronic disease (Ko et al., 2007; Walton et al., 2004). Extensive research has examined the protective or stress-buffering role of religion and spirituality for health across one's lifetime (Koenig, 2009; Pargament, 2012). A metanalysis of prospective cohort studies of the relationship between religion/spirituality and physical health found that religion/spirituality had a protective effect on all-cause mortality within healthy population but not in diseased populations (Chida et al., 2009). Current literature suggests that spirituality is a significant or important correlates of other well-established factors such as social support or social connection (Greenfield & Marks, 2007; Lim & Putnam, 2010; Wilmoth et al., 2014), psychological well-being and mental health (Fiorito & Ryan, 2007; Greenfield & Marks, 2007; Tix & Frazier, 2005), and substance misuse and addiction (Edlund et al., 2010; Oman, 2018).

However, not all 'positive' experiences of spirituality have positive effects on outcomes. For example, fatalistic beliefs, or the belief that external forces (e.g., God, transcendent 'other') have determined ones fate, can have a negative impact on health (Berardi et al., 2016; Franklin et al., 2007).<sup>4</sup> Hayward and colleagues (2016) found that individuals who believe in miracles and other health "deferring" beliefs had poorer physical health highlighting how religious beliefs that overemphasize "divine control," may lead to negative health outcomes. At end-of-life, positive religious coping (e.g., the belief that God will provide healing or will not 'allow' death to occur) has been associated with greater likelihood receiving mechanical ventilation and other forms of life-sustaining care within the last week of life even when adjusting for age, race, awareness of terminal illness, spiritual support, and advance care planning (Phelps et al., 2009). The potency of religious belief, while often interpreted as positive force, may also contribute to negative outcomes.

<sup>&</sup>lt;sup>4</sup> Fatalistic beliefs are best described as beliefs that events are predetermined or controlled by an external force; in the case of religious fatalism, there is the belief that a divine force is controlling their future (Berardi, 2016).

#### 1.1.3 Spiritual distress & health

Despite these notably protective factors, spirituality has a 'shadow' side that can have a negative influence on health behaviors and outcomes. Spiritual distress (also referred to as *spiritual struggles*) is "tension, conflict, or strain that [centers] on whatever people view as sacred" (Pargament & Exline, 2022, p. 6) and can include feelings of abandonment, punishment, and/or anger at the intrapsychic-, interpersonal, and supernatural/trans-personal<sup>5</sup> levels (Exline, 2013). Spiritual distress is described as a normal, non-pathological human experience regardless of religious affiliation, (including those who identity as non-religious, Weber et al., 2012) and can take different forms depending on the type of struggle an individual may be experiencing (Pargament, 2022; Pargament & Exline, 2022). Psychologists Ken Pargament and Julie Exline have identified six types of spiritual struggles: *divine* (e.g., anger or disappointment with God), demonic (e.g., evil spirits are causing problems, being attacked by demons), interpersonal (e.g., conflict with organized religion, being hurt by others in regards to religious/spiritual issues), *moral* (e.g., not living up to one's standards, struggling with moral principles), *doubt* (e.g., questions about religiousness, religious identity), and ultimate meaning (e.g., questions about the meaning of one's life; Exline, Pargament, et al., 2014; Pargament & Exline, 2022). A recent study from Klimasinski et al. (2022) found that prevalence rates for potential spiritual distress for individuals (n = 204) with chronic disease (14-64%) were comparable (18-53%) for those with serious or advanced disease at (King et al., 2013; Klimasinski et al., 2022; Thune-Boyle et al., 2011; Velosa et al., 2017).

<sup>&</sup>lt;sup>5</sup> The 'trans-personal' level is best described as however an individual understands the Divine (e.g., God, Allah) or however they perceive the sacred or meaningful in their lives; for non-theistic persons, this may present as "transcendence, ultimacy, and boundlessness" or any interpretation of what is meaningful (Pargament & Exline, 2022, p. 6).

Spiritual distress is also associated with negative health outcomes such as increased depressive symptoms and emotional distress (Delgado-Guay et al., 2011; Hills et al., 2005; Manning-Walsh, 2005; Monod et al., 2012; Pargament et al., 2004; Velosa et al., 2017), lower quality of life (Manning-Walsh, 2005; Pargament et al., 2001), increased anxiety, poorer physical well-being (Hills et al., 2005; Siddall et al., 2017), and increased mortality (Pargament et al., 2001). Studies of spiritual distress often involve persons nearing end of life or receiving palliative care (Kamal et al., 2014; Roze des Ordons et al., 2018). A scoping review of spiritual distress within inpatient hospital settings found that spiritual distress was as depersonalizing (e.g., "no longer feeling like themselves"), not knowing (e.g., feelings of uncertainty), concerns about meaning and purpose (e.g., questioning their sense of purpose, loss of meaning), questions about religion (e.g., feeling punished by God), physical changes (e.g., body image), and emotional distress (e.g., fear, overwhelm, doubt, regret; Roze des Ordons et al., 2018). This contrasts with experiences of spiritual well-being, where patients experience a better quality of life (Hills et al., 2005; Kandasamy et al., 2011), lower symptom distress/burden (Balducci, 2019; Hills et al., 2005; Mako et al., 2006), and less decisional conflicts and distress (Johnson et al., 2014).

Although end-of-life and palliative care research have drawn necessary attention to issues and concerns surrounding spiritual distress when faced with advanced or terminal disease, the role of spiritual distress 'upstream' from the end of life has yet to be explored. Spirituality is known to be of support to people with chronic conditions and diseases (Hampton & Weinert, 2006; Muldoon & Norman King, 1991; Reyes-Ortiz, 2006; Roger & Hatala, 2017; Soeken & Carson, 1987; Walton et al., 2004). Nevertheless, the 'shadow side' of spirituality requires similar attention and research to understand its relationship with health behaviors and outcomes.

#### 1.2 Providers to Address Spiritual Distress: Healthcare Chaplains & Chaplaincy

### 1.2.1 Brief History of Healthcare Chaplaincy

In 2012, sociologist Wendy Cadge wrote the book *Paging God: Religion in the Halls of Medicine*, examining the relationship between religion, spirituality, and medicine as well as the role of healthcare chaplains (Cadge, 2012). Although present in multiple institutions (e.g., military, corporate, university/school, and prisons), a majority of professionally trained chaplains work in healthcare settings (Cadge, 2012; Cadge & Konieczny, 2014). Healthcare chaplains are members of interdisciplinary teams that seek to help 'translate' the patient and/or caregiver values within the medical model while bringing the whole person into focus (values, sources of meaning, hope, and their understanding of the transcendent) as they manage an illness or injury (Cadge, 2012, 2019; Kelly & Swinton, 2020b). Chaplains are religious and spiritual *codeswitchers*<sup>6</sup> and cross-cultural communicators who provide patient-specific care (Cadge & Sigalow, 2013). One chaplain described their work in this way, "[a] lot of the work that we as chaplains do is about reconciliation that helps people to feel whole, to bring them back to what has been, to what is, to what can be, either in this life or the next life, depending on what their theological belief system is" (Cadge, 2012, p. 80).

In line with efforts to make healthcare more "person-centered" by taking into consideration all aspects of the person (physical, emotional, spiritual) receiving medical care (Ekman et al., 2011; Puchalski, 2013), chaplains provide a unique service that aligns medical care with the patient's values, encourages positive coping (religious and non-religious), and acts as a "guide through the gruesome" that supports patients during times of pain and despair

<sup>&</sup>lt;sup>6</sup> "Code-switching" is a sociolinguistic phenomenon whereby a person, generally 'fluent' in two or more 'languages' (verbal, cultural, and/or implicit), will adapt their communication style to the context (Nilep, 2006).

(Santana et al., 2018; Snowden et al., 2013). What chaplains provide in the healthcare context has been described as the "safe space for the slow questions" by creating a feeling of acceptance, empathy, and safety (Stobert, 2020). Though arguably all members of healthcare interdisciplinary teams provide some form of spiritual care, healthcare chaplains are specifically trained to provide complementary support utilizing the religious, spiritual, or existential framework of each patient and family they encounter<sup>7</sup> (Cadge & Sigalow, 2013; de Vries et al., 2008).

#### 1.2.2 Chaplaincy Training & Certification

Chaplaincy training typically includes masters-level education with a theological curriculum (e.g., Master of Divinity) and chaplaincy clinical training (Clinical Pastoral Education [CPE]). However, training programs are not standardized<sup>8</sup> and there are no industry standards for chaplaincy training and education in any sector (Association of Professional Chaplains (APC), 2016; Cadge et al., 2019; Cadge et al., 2008; de Vries et al., 2008). CPE is a professional education program that relies heavily on the action-reflection model and brings together students and educators from any or no faith traditions (Association of Clinical Pastoral Education (ACPE), n.d.; Cadge et al., 2019). Historically, chaplains in the U.S. earn a Master of Divinity from a seminary or divinity school associated with a religious tradition. These schools are typically affiliated with Protestant Christian religious denominations that are more generally focused on training future parish clergy than healthcare chaplains working in a pluralistic environment (Cadge et al., 2020; Clevenger et al., 2021). Clinical Pastoral Education is a

<sup>&</sup>lt;sup>7</sup> Although not discussed, healthcare chaplains have become increasingly visible during the COVID-19 pandemic due to their role in providing support to patients and family members separated due to visitor restrictions (Bari, 2020; Dickerman, 2021) and staff (Goldberg, 2020).

<sup>&</sup>lt;sup>8</sup> There have been many attempts to regulate chaplaincy since as far back as the 1940s, but there has been little success in doing so within healthcare (Cadge, 2019). Similarly, there remains tension about chaplains' role and whether they are 'healthcare professionals' when they do not have medical or biological interventions but contribute to patient well-being (Loewy & Loewy, 2007; Swinton, 2020).

requirement for professional certification (minimum of four CPE units for Board Certification, two units for Associate Certified) across all major chaplaincy organizations. However, there are no guidelines for chaplaincy education curriculum either in the academic or clinical setting, and the lack of a standardized curriculum has been debated within the chaplaincy profession, but a clear 'need' for standardization has not been articulated (Cadge et al., 2020). Clinical training programs for chaplains driven by individual educators; the ACPE<sup>9</sup> manual for site accreditation indicates two curriculum requirements: 1) learning that evolves and emerges from human interaction and experience and 2) knowledge and skills students are expected to learn, represented by the CPE Level I/Level II<sup>10</sup> and for Certified Educator CPE (ACPE, 2020).

As a profession, chaplaincy continues to develop as it strives to clarify its purpose and role within healthcare (Cadge, 2019). Healthcare chaplains began formally meeting together in the late 1940s with the development of the Association of Protestant Hospital Chaplains (APHC, 1946) and Association of Mental Health Chaplains (AMHC, 1948)<sup>11</sup> which would later become the Association of Professional Chaplains, the largest chaplaincy certifying body in the U.S. (Cadge, 2019; LaRocca-Pitts, 2021). At present, four main professional certifying bodies ("Strategic Partners") in North America are the Association of Professional Chaplains (U.S. based, any tradition including humanists, spiritual but not religious), National Association of Catholic Chaplains (NACC, exclusively for Catholic chaplains, under the U.S. conference of Catholic Bishops), Neshema: Association of Jewish Chaplains (NAJC, exclusively for Jewish

<sup>&</sup>lt;sup>9</sup> There are several clinical training programs for chaplaincy in the U.S., but the ACPE is the primary organization and typically sets the standards for CPE.

<sup>&</sup>lt;sup>10</sup> The learning objectives for Level I/Level II are focused on pastoral formation, competence, and reflection but does not require competencies for professional certification or intervention training (ACPE, 2020).

<sup>&</sup>lt;sup>11</sup> It is important to note that these initial organizations only included men who were white and affiliated with Protestant denominations (LaRocca-Pitts, 2021). Information about the diversity of these (and later) organizations is limited to positions of leadership that were held by racial/ethnic minorities, women, or non-Protestants as demographic member information was not recorded.

chaplains, under the Network of Jewish Human Services Agencies), and the Canadian Association for Spiritual Care/Association Canadienne de soins spirituels (CASC/ACSS, Canada based, any tradition including humanists, spiritual but not religious). ACPE and APC have explored merger options most recently in 2018 to 2021 when talks were abruptly ended by APC (APC, 2021; Garland, 2021; LaRocca-Pitts, 2021).

In lieu of such standards, individual health systems and healthcare organizations define their employees' specific requirements for chaplaincy certification. As of 2022, there are no chaplaincy organizations that are 'authorized' or endorsed by local, state, or federal authorities to provide chaplaincy certification, nor does The Joint Commission (TJC), the national organization responsible for setting standards and providing accreditation and certification for healthcare organizations, defines who can or should provide spiritual care in healthcare organizations (Cadge et al., 2008). The Joint Commission standards indicate that hospitals must respect "the patient's cultural and personal values, beliefs and preferences" and should "accommodate the patient's rights to religious and other spiritual services" (TJC, 2018) but provide no "prescriptive requirements" for healthcare organizations to meet those standards (TJC, n.d.). Current estimates indicate that most hospitals (61%) employ healthcare chaplains, but only half of the chaplains (51%) employed are board-certified chaplains (Handzo et al., 2017).

The Strategic Partners (APC, ACPE, NAJC, NACC, and CASC/ACSS) identified the *Common Qualifications and Competencies for Professional Chaplaincy* that outlined the standards required for board certification (APC, 2016). Qualifications for board certification include an endorsement from the individual's faith/spiritual tradition, undergraduate and graduate education from an accredited institution, four units of CPE from ACPE, and the associated fees. In order to receive certification, candidates must demonstrate proficiency in thirty-one

competencies across four areas: the integration of theory and practice (6), professional identity and conduct (9), professional skills (11), and organizational leadership (5). These competencies are evaluated through written materials (verbatims and essays), letters of recommendation, 2,000 hours of work experience, and a peer group interview (Board of Chaplaincy Inc. [BCCI], 2020). Associate Certified Chaplains (ACC) and Board-Certified Chaplains (BCC) have the same requirements for certification except for the academic and CPE requirements, which are lower for ACC (48 versus 72 graduate credit hours, two versus four units of CPE; APC, n.d.-a). Both ACC and BCC chaplains (including those with provisional status<sup>12</sup>) are considered 'generalists' and serve across many organizations, including long-term care facilities, hospice organizations, corporations (e.g., Tyson Foods<sup>13</sup>), and healthcare (White et al., 2021). Specialist advanced practice certification is available for palliative care and hospice (began in 2013) and military chaplaincy (began in 2018) and may be obtained following one year of general certification and a minimum of three years of experience in either hospice/palliative care or military chaplaincy (APC, n.d.-b; BCCI, n.d.-b). Standards of Practice for Professional Chaplains bind all certified chaplains (ACC and BCC) and include care delivery standards (e.g., assessment, documentation, confidentiality, respect for diversity), organizational standards (e.g., care for employees and affiliates, leadership), and maintaining skills and competence (e.g., research literacy continuing education, quality improvement, and business acumen; APC, 2020). Lastly, to maintain certification, chaplains must complete fifty hours of continuing education annually, sign an

<sup>&</sup>lt;sup>12</sup> Individuals who have yet to complete their 2000 work hours or only met twenty-four to thirty professional competencies, including all eleven professional skill competencies (APC, n.d.-a).

<sup>&</sup>lt;sup>13</sup> Tyson Foods has about a hundred chaplains working in multiple facilities providing support directly to employees and their chaplaincy program is more than twenty years old and the most established corporate employers (Cato, 2020).

annual ethical accountability form endorsing the Code of Professional Ethics (APC, 2019), conduct a peer review every five years, and pay annual dues (BCCI, n.d.-a).

Although efforts to include chaplains in primary care to improve patient outcomes and reduce healthcare utilization emerged clearly in the late 1980s to early 1990s (McSherry, 1994; McSherry & Nelson, 1987). Currently, chaplains primarily provide care to persons diagnosed with a serious illness (e.g., cancer) or within the acute care setting (Balboni et al., 2017; Fitchett, 2017; White et al., 2021). Presently, only the National Health Service (NHS) in the United Kingdom has formally utilized chaplains outside of the acute care setting to reduce unnecessary medical appointments (Bunniss et al., 2013; Macdonald, 2018). In another example, a study by Lee and colleagues (2018) indicated that a value-based conversational approach led by chaplains, in tandem with primary care visits, resulted in higher completion of advanced care planning documentation (Darnall et al., 2018). Importantly, calls to engage chaplains in preventable chronic disease care and services are particularly relevant in today's "epidemic" of preventable chronic disease (Horton, 2005).

#### 1.3 Chronic Conditions and Disease in the U.S.

Chronic conditions and disease are major contributors to increasing healthcare costs and increases in morbidity and mortality in the U.S.(Bauer et al., 2014; Center for Disease Control and Prevention (CDC), 2020a; World Health Organization (WHO), 2020). Chronic disease is defined as a "physical or mental health condition that lasts more than one year and causes functional restrictions or requires ongoing monitoring or treatment" (Buttorff et al., 2017, p. 1). It includes such conditions as cardiovascular disease (hypertension and stroke), renal disease, malignant neoplasms (cancer), mental health conditions, diabetes, chronic pulmonary disease, and dementia (CDC, 2020a; Holt et al., 2015). More than half of U.S. adults have been

diagnosed with one or more chronic conditions and globally, non-communicable chronic diseases (e.g., cardiovascular disease, chronic respiratory disease, chronic kidney disease) make up more than half of all cases of death and disability (Buttorff et al., 2017). Multiple factors contribute to developing a chronic disease, including genetic predisposition (Wehby et al., 2018), environmental factors, or a history of infectious disease (e.g., hepatitis B and chronic liver disease; O'Connor et al., 2006). However, lifestyle or behavioral factors<sup>14</sup> are critical determinants of developing preventable chronic conditions and subsequent chronic diseases (Adams et al., 2019; Ng et al., 2020).

Not all chronic diseases are associated with specific health risk factors; however, tobacco use, alcohol use, physical inactivity, and poor diet are known modifiable lifestyle or behavioral risk factors associated with the development of chronic disease (Bauer et al., 2014; CDC, n.d.-a). All four health risk behaviors are associated with chronic diseases such as cancer (e.g., digestive, lung; Shield et al., 2014; Stein & Colditz, 2004), cardiovascular disease, and stroke (Keramat et al., 2021; Shield et al., 2014), and Type 2 diabetes (Adams et al., 2017; Keramat et al., 2021; Ng et al., 2020; Willett et al., 2006). Chronic obstructive pulmonary disease (COPD) is an additional risk associated with tobacco use (Institute of Medicine, 2015; *Tobacco, Nicotine, and E-Cigarettes Research Report*, 2022).

Religion and spirituality can influence an individual's health beliefs and behaviors, making them more active or passive in their disease management (Hayward, Krause, Ironson, & Pargament, 2016; Polzer & Miles, 2007) and has been identified as an 'essential' mechanism for coping for those with chronic disease (Ko et al., 2007; Walton et al., 2004). Preliminary data from a health system sample of adults with uncontrolled diabetes found that a fifth of

<sup>&</sup>lt;sup>14</sup> Though not explicitly included, the social determinants of health influence behavioral factors and contribute to an increased risk of developing chronic disease (Cockerham et al., 2017).

participants were identified with probable spiritual distress (Rajaee et al., 2021). Those with probable spiritual/existential distress reported elevated levels of HbA1c, a poorer general diet, more chronic conditions, higher levels of diabetes-related distress, lower levels of social support, higher psychological distress, and greater unmet social needs compared to those who did not (Rajaee et al., 2021). Similar findings indicate poorer medication adherence and lower quality of life among individuals with epilepsy who experience spiritual distress (Lin et al., 2018). These preliminary findings suggest that spiritual distress may impact individuals' health behaviors and outcomes outside the acute care setting.

#### 1.4 An 'ounce' of prevention: the use of healthcare chaplains

All members of an interdisciplinary healthcare team may provide some form of spiritual care. However, chaplains are specifically trained to be spiritual care specialists or advanced practice spiritual care providers on healthcare teams and are the most skilled at addressing spiritual distress (Handzo & Koenig, 2004). Although studies confirming links between spiritual distress and health risk behaviors are limited, preliminary evidence suggests that spiritual distress may have a negative influence on health behaviors and results in more risky health behaviors (e.g., tobacco and alcohol use, poor diet, and physical inactivity). This connection has been recently identified in a national study of U.S. adults in which spiritual distress was associated with excess alcohol use, and younger adults were at the most significant risk of problem-drinking (Krause et al., 2018). Patients across the care continuum could benefit from working with a healthcare chaplain to reduce the negative effects of spiritual distress on health risk factors and clinical outcomes. However, this requires more precise conceptual definitions and better measurement of spiritual distress within chronic disease populations, as well as indications that patients and chaplains find chaplain-led preventative interventions acceptable.

#### 1.5 Operational definitions: religion, spiritual/ity, and existential/ism

Religion and spirituality have been operationalized differently across health-related research with variations across time and disciplines (e.g., chaplaincy, psychology, social work; Flannelly et al., 2014; Oman, 2013). Although the concepts of religion, spirituality, and existentialism are intertwined, different concepts and language embody unique perspectives for understanding the human experience of meaning-making. Definitions for these critical concepts are provided to clarify the language used in the proposed conceptual model.

#### 1.5.1 Existentialism

As a humanistic philosophy, existentialism seeks to explain the process and practice of meaning-making and value-in-life within human experience (Winston, 2015). Viktor Frankl, Austrian philosopher, and existential psychiatrist wrote, "[people are] always reaching out for meaning, always setting out on [their] search for meaning; in other words, what I call 'will to meaning' is even to regarded as '[humanity's] primary concern'" (Frankl, 1978). In *Man's Search for Meaning*, Frankl identified three ways *existential* can be understood: 1) "existence itself" (e.g., a person alive in the world), 2) "the meaning of existence," and 3) "the striving to find a concrete meaning in personal existence" or "the *will* to meaning" (Frankl, 1946, p. 100). Where Frankl understood the search for meaning from the experience of suffering, positive psychology does similar work but from the experience of happiness and well-being (Gantt & Thayne, 2014). For the sake of this work, *Existential* or existentialism is used to capture the human experience of meaning-making or the search for meaning.

#### 1.5.2 Religion

Religion is associated with a defined set of beliefs and practices from a particular religious or faith tradition (Lazenby, 2010). Within health-related research, this has included measures of particular behaviors (e.g., attending faith-specific services, prayer) and may be best definable by "clusters of features" (Oman, 2013). In this work, *Religion* is defined as the formal institution of a particular faith community that has a *set of shared beliefs, rituals, and values* (Frankl, 1946; Koenig, 2008, 2015). This definition focuses on the formalized aspects of any faith tradition (e.g., prayer, meditation, and grieving practices) and captures the more 'structured' aspects of meaning-making in the human experience.

#### 1.5.3 Spirituality

Within the literature a clear definition of spirituality has been "elusive" due to the subjective nature of its interpretation (McSherry et al., 2002). For this research, *spiritual* or *spirituality* is defined as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices" (Puchalski et al., 2014, p. 646). This definition, developed by the National Consensus Project for Quality Palliative Care with practitioners from across multiple disciplines (e.g., medicine, nursing, chaplaincy), focused on improving clinical practices and research by using a shared conceptualization and definition of spirituality (Puchalski et al., 2009). In 2014, an international, multi-disciplinary committee refined and reaffirmed the 2009 definition to improve research, education, clinical practices, community engagement, and policy (Puchalski et al.).

As religious affiliation continues to change within the U.S., with more people identifying as *spiritual but not religious* or having "spiritual fluidity" or being "faith fluid" (Bidwell, 2018),

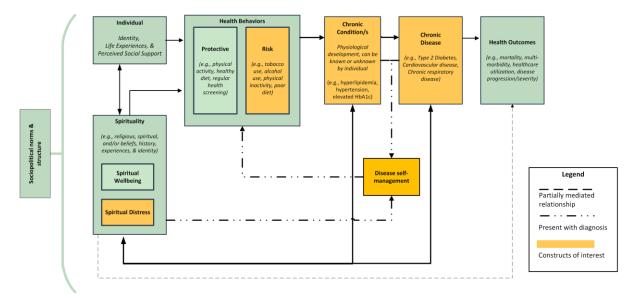
language denoting spirituality needs to be more inclusive. The 2014 National Consensus Project provided a definition of spirituality acceptable across disciplines and will standardize the language used in research and practice. Unless stated otherwise, the term "spirituality" will be used to connect and embrace the range of religious, spiritual, and existential experiences.

#### **1.6 Theoretical influences**

This conceptual model is influenced, directly and indirectly at the macro/meso levels by Bronfenbrenner's Socioecological Model (SEM; 1981) and Practice Theory (Reckwitz, 2007; Weenink & Spaargaren, 2019). At the individual level, the model is informed by Existential Positive Psychology (EPP; Bretherton & Ørner, 2004; Wong, 2016; Wong, 2020), Transactional Model for Stress of Coping (Lazarus & Folkman, 1984, 1987), the Meaning Making Model (Park, 2013), and Pargament and Exline's Framework for Understanding Spiritual Struggles (2022). While not specifically identified within the conceptual model, these theories and models provide an interpretive structure for understanding the relationships between social structures and human behavior. For example, the levels in the SEM influence human health, from individual health behaviors to the policies that govern society. This idea is reinforced through practice theory, which states that 'everyday actions' are created by social structures. Although not the intended focus of this research, sociopolitical structures and norms are linked to individual behaviors from their places of origin, environments, and communities where people live and share their lives with their individual health behaviors and health outcomes (Braveman & Gottlieb, 2014). Individual behavior is not assumed to be isolated from the multitude of factors, structural and otherwise, that enable, constrain, or challenge them. However, the behavioral health risk factors included in the proposed work are assumed to be modifiable.

#### Figure 1.1

#### Conceptual Model: Spiritual Distress, Health Risk Behaviors, and Chronic Disease



Conceptual Model: Spiritual Distress, Health Risk Behaviors, & Chronic Disease

This research is focused on the relationship between spiritual distress, health risk behaviors, and chronic conditions and disease (see boxes in yellow in Figure 1.1) In the following section, the positioning of spiritual distress as an experience of spirituality will be explored, including the hypothesized cyclical relationship between spiritual distress, health risk behaviors, and chronic disease. Other aspects of this model (e.g., individual characteristics, spiritual well-being, protective health behaviors) will be explored to better understand the relationship between spiritual distress and chronic disease.

#### **1.7** Conceptual Model

*Sociopolitical norms and structures* are not centralized in this model but encapsulate the experience and relationship of the individual in the world (historically and presently). The social determinants of health are well-established as influential factors in health and health outcomes, including the development of chronic disease (Braveman et al., 2011; Braveman & Gottlieb,

2014). Individual and population-level health is also influenced by experiences such as structural racism (Sanders Thomson, 1996; Williams et al., 2003) and religious discrimination (Kathawalla & Syed, 2021), which are two types of stressors linked to the downstream development of disease. These macro-level stressors (racism, discrimination) have yet to be explicitly explored in relationship to spiritual distress in the current literature, even so, there is evidence suggesting that psychosocial stressors of various types (*individual life experiences*) contribute to negative health outcomes (Tosevski & Milovancevic, 2006). Research also suggests that spiritual distress contributes to poorer psychological adjustment to stressors (Pomerleau et al., 2020), resulting in negative health outcomes (Lazarus & Folkman, 1984; Shwarzer & Luszczynska, 2013).

Within the sociopolitical structure, the *individual* can be understood in part by their *identity* (e.g., demographic indicators; Nguyen & Park, 2021) and *life experiences* (Link & Phelan, 1995; Stuckler, 2008). As previously stated, psychosocial stressors contribute to the likelihood of developing a chronic disease, and these can include unmet social needs and adverse childhood experiences (Nurius et al., 2016; Piazza et al., 2013; Soto Mas et al., 2019). These stressors, like those experienced on the macro level (e.g., racism, discrimination), have similar negative effects on health and health outcomes but may be more unique given individual characteristics or experiences and contribute to increased allostatic load (McEwan, 1998; McEwan & Seeman, 2006).

*Social support* is the perceived support (informational, instrumental, or emotional) individuals receive from within their social network (Holt-Lunstad & Uchino, 2015; Wethington et al., 2015). Existing evidence suggests that social support acts as a 'buffer' against stressors and has a protective effect on health (Holt-Lunstad & Uchino, 2015; Reblin & Uchino, 2008). One existing source of psychosocial support are communities of support and belonging that come

from both religious and non-religious communities. Engagement in a religious community has well-documented benefits to health and well-being (Koenig et al., 2014).

Frequent attendance of religious services is associated with longer life (Strawbridge et al., 2001), lower physical disability, and greater life satisfaction (Hall et al., 2008; Idler, 2014; Idler et al., 2017). This remains true for those who are shifting away from communities associated with a particular religious identity. Many individuals have found meaning within a religious faith community, but as the U.S. becomes less religious, we can expect the growth of non-religious groups where there is a shared sense of meaning and/or belonging centered around identity or set of identities (Layman, 2015; Thurston & Kuile, 2016). Like religious communities, these new "communities of belonging" may develop a common set of shared values and/or beliefs, but they are situated within a non-religious framework. Emerging evidence suggests that members of these non-religious communities may experience better physical health (lower BMI, less chronic illness) than religious communities (Hayward, Krause, Ironson, Hill, et al., 2016; McCaffree, 2019).

In this model, *spirituality* represents the breadth of experiences, beliefs, and identities an individual may have over the course of their lifetime. Prior research confirms the role of *spirituality* and *spiritual well-being* as broadly protective factors across the lifespan (Koenig, 2009; Oman & Syme, 2018; Pargament, 2012). However, there is also evidence that positive religious coping (e.g., divine control) can also contribute to deferring or rejecting health behaviors resulting in poorer outcomes (Oman & Syme, 2018; Phelps et al., 2009). While spirituality has a protective effect, there is also evidence of a 'shadow' side highlighting a relationship between negative health outcomes and *spiritual distress* (Cohen et al., 2019; Shwarzer & Luszczynska, 2013; Tosevski & Milovancevic, 2006).

Although direct links between spiritual distress and health risk behaviors are not clearly defined in the literature, there is evidence to suggest that increased spiritual distress is associated with excessive alcohol use (Krause et al., 2018). Alcohol use, a known *health risk behavior*, is associated with several *chronic conditions* (e.g., hypertension, elevated glucose) and the subsequent development of *chronic disease* (e.g., malignant neoplasms, cardiovascular disease, stroke; Schwarzinger et al., 2017; Shield et al., 2014). *Health outcomes* such as multi-morbidity, disease progression, disability, and premature death have all been attributed to known health risk behaviors and chronic disease (Anderson & Horvath, 2004; Aspen Health Strategy Group, 2019; Bauer et al., 2014; Buttorff et al., 2017).

Within chronic disease, effective *self-management* of one's illness is critical to the severity of the disease and functions as a secondary prevention strategy (Dineen-Griffin et al., 2019). Health behaviors (tobacco and alcohol use, physical activity, and diet) are important predictors of health and well-being and are the focus of many individual-level interventions (Park & Iacocca, 2014). In this model, disease self-management is oriented between spirituality (spiritual well-being and spiritual distress) and health behaviors (protective and risk). The underlying assumption is that disease management follows the diagnosis of a chronic condition but is integrated into an individual's health behaviors. Different disease processes may require different behaviors (e.g., reducing salt intake, changing smoking habits for harm reduction), which is why it is separated from the broader umbrella of 'health behaviors. However, like general health behaviors, spiritual distress may influence the individual's disease management. Additionally, self-management can be perceived as a burden for those coping with a chronic illness at the individual and structural level (e.g., lack of healthy options, low income),

influencing not only the affected person but other members of their family whereby experiences of spiritual distress negatively modify self-management behaviors (Gonzalez et al., 2016).

This model incorporates a cyclical relationship between spiritual distress and chronic disease. Spiritual distress is known to be a common experience over one's lifetime, increasing the likelihood that it can and will occur (Pargament & Exline, 2022). Secondly, spiritual distress is associated with adverse health outcomes, and it seems plausible that spiritual distress influences this relationship by increasing health-risk behaviors. Once a chronic condition or disease is known and diagnosed, this may further exacerbate experiences of spiritual distress (e.g., feeling 'punished' by God or the divine) and may increase the likelihood that an individual will engage in health-risk behaviors in the future.

## 1.8 Approach to research: Worldview & Positionality

My experience as a clinical healthcare chaplain over the last two decades has influenced and shaped this research. Most of my career was spent working in oncology with individuals who self-described as "spiritual but not religious" and assessing how, if at all, spiritual distress was impacting their lives. This perspective has provided me insight into some of the questions I propose to explore in this dissertation and, along with the thousands of conversations I have had with patients over my career, inspires me to do this work. This research is in memory of those who allowed me to discuss their fears, values, hopes, and despair. Their lives are woven into the tapestry of my life, and without them, this work would not exist.

I am also a first-generation college student and American who grew up (and lives) in a multi-religious, multi-cultural household. As an Iranian-Irish-English-American, perceptions of my ethnic identity have varied throughout my life. They are best described as 'ambiguous', thus allowing me access to unexpected and vulnerable spaces. Living in these intersectional and

liminal places shapes my positionality and stance towards research and is a part of my evolution as a practitioner and researcher.

Religion and spirituality have substantially influenced my development and perception of the world. I perceive religion and spirituality as an aspect of human existence that actively and passively influences all levels of life and that the consequences of spirituality impact individual health behaviors (intrapersonal level) to the environment and realities of climate change (society/policy). Experiences in communities affiliated with conservative Evangelical, progressive Mainline Protestants and Catholics, and the growing number of people who identify as 'spiritually fluid' have provided me with unique insight into how spirituality and religion influence our lives both directly and indirectly.

While in seminary, I quickly realized that though I appreciated the theoretical nature of systematic theology, I was drawn more towards *practical* theology, a form of study that uses the human experience to understand the sacred and vice versa (Willows & Swinton, 2000). Although grounded in the Christian religious tradition, practical theology is a more pragmatic, empathetic, and nuanced way of exploring meaning-making and human behavior (Dingemans, 1996). My approach to research shares some similarities in that I am more inclined towards pragmatic approaches that are focused on functional and sensible solutions to public health problems (Creswell & Plano Clark, 2018).

# **1.9 Research Objectives**

The purpose of this research is to explore and examine how spiritual distress is measured and characterized within chronic disease populations with known risk behaviors and whether chaplaincy-based interventions are acceptable to patients and chaplains. In paper one, I utilize a

scoping literature review to understand better what has (and has not) been explored in spiritual distress and chronic disease research, including how the concept has been defined and examining what measures have been used. Paper two continues to explore the role of spiritual distress in a sample of individuals living with and managing Type 2 Diabetes and to explore the acceptability of chaplaincy-based interventions. The third paper highlights chaplains' perceptions of acceptability, willingness, and readiness to provide chaplaincy-based interventions for individuals with chronic diseases with known behavioral risk factors, more specifically, Type 2 Diabetes.

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# Chapter 2 Measures of Spiritual, Religious, and Existential Distress and Chronic Diseases Associated with Known Health Risk Behaviors: A Scoping Review

As the prevalence of chronic disease increases, so have the public health interventions to mitigate or lower this upward trend by focusing on modifiable behavioral risk factors such as poor diet, low physical activity, and tobacco and alcohol use (Remington et al., 2011; Tulchinsky & Varavikova, 2014). In the U.S. alone, chronic diseases make up 90% of healthcare costs spread across 60% of the total U.S. adult population (Buttorff et al., 2017). Spirituality is considered an important factor among individuals with serious illness and extensive research highlights the health protective effect of religion and spirituality (Balboni et al., 2022; Hayward, Krause, Ironson, & Pargament, 2016; Polzer & Miles, 2007; Roger & Hatala, 2017). For those with a chronic disease, religion and spirituality are considered important for influencing positive disease self-management and coping (Ko et al., 2007; Walton et al., 2004). The research literature exploring the impact of spiritual distress on chronic modifiable disease is expanding and could offer important guidance in the development and implementation of interventions targeting the management of chronic disease. To date, however, the state of the literature focusing on how chronic disease and spiritual distress have been conceptualized and operationalized has not been synthesized.

*Spiritual distress* (also referred to as *spiritual struggles*) is described as "tension[s], conflict[s], or strain that [centers] on whatever people view as sacred" (Pargament & Exline, 2022, p. 6) and can include feelings of abandonment, punishment, and/or anger at the

intrapsychic-, interpersonal, and supernatural/trans-personal<sup>15</sup> levels (Exline, 2013). It may present as "the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, other, art, music, literature, nature and/or a power greater than oneself" (Hall et al., 2019). These and related definitions suggest that some degree of spiritual distress across the life course is a normal, non-pathological aspect of human experience, regardless of religious affiliation, including those who identity as non-religious (Weber et al., 2012). The degree of impairment and consequences to daily functioning can take different forms depending on the struggle an individual may be experiencing (Pargament, 2022; Pargament & Exline, 2022). Spiritual distress has been correlated with adverse physical and mental health outcomes in acute care settings as well as advanced illness (Pargament & Exline, 2022; Stauner et al., 2016), suggesting that addressing and reducing spiritual distress earlier in the care continuum may be beneficial. As attention to the role of spiritual distress expands to encompass preventative and chronic care, a careful review of this literature can provide essential insights and guidance for future research, intervention development, and the implementation of programs targeting spiritual well-being in chronic disease.

We conducted a scoping review of scientific, peer-reviewed literature to identify how spiritual distress is described and measured among individuals diagnosed with chronic disease with known associations with modifiable behavioral risk factors. We focused specifically on diseases and conditions that strongly impact life expectancy and quality of life (Buttorff et al., 2017; CDC, 2020a; Center for Disease Control and Prevention, 2021) and are commonly associated with tobacco use (Adams et al., 2017, 2019; Ng et al., 2020; Stein & Colditz, 2004),

<sup>&</sup>lt;sup>15</sup> The 'trans-personal' level is best described as however an individual understands the Divine (e.g., God, Allah) or however they perceive the sacred or meaningful in their lives; for non-theistic persons, this may present as "transcendence, ultimacy, and boundlessness" or any interpretation of what is meaningful ((Pargament & Exline, 2022, p. 6)

alcohol use (Ng et al., 2020; Schwarzinger et al., 2017; Shield et al., 2014; Stein & Colditz, 2004), poor diet (Adams et al., 2017, 2019; Ng et al., 2020; Stein & Colditz, 2004), and physical inactivity (Adams et al., 2017, 2019; Anderson & Durstine, 2019; Booth et al., 2012; Marques et al., 2018; Ng et al., 2020; Stein & Colditz, 2004), specifically cardiovascular disease, type 2 diabetes, chronic respiratory disease. This scoping review contributes to a better understanding of spiritual distress and chronic disease by systematically exploring what language, concepts, and measures are used outside of the end-of-life context to describe spiritual distress. The guiding research question centered on *How spiritual distress is defined and measured in patients with chronic diseases associated with modifiable risk factors.* To date, there are no published scoping reviews in the peer-reviewed literature that explicitly seek to identify measures used to determine or evaluate spiritual distress among individuals with chronic disease.

# 2.1 Methods

### 2.1.1 Protocol and Registration

The protocol was drafted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews (Aromataris & Munn, 2021) and the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols - Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). A PRISMA-ScR checklist was completed (see Table 2.3 in Appendix). A search for existing scoping reviews in PubMed, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* on spiritual distress and chronic disease did not identify any current or underway reviews. The final protocol was registered prospective of the full-text review with the University of Michigan document repository Deep Blue on March 3, 2023 (DOI: https://dx.doi.org/10.7302/7044). Inclusion and exclusion of manuscripts are presented using a PRISMA 2020 formatted chart (Page et al., 2021).

# 2.1.2 Eligibility criteria

The Population, Concept, and Context (PCC) framework was used to define inclusion criteria. To be considered for this scoping review, studies needed to focus on adult persons diagnosed with preventable non-communicable diseases associated with modifiable health behaviors (Stampfer et al., 2004; WHO, 2005) and include measures of religious, spiritual, or existential distress (see Table 2.1). The phenomena of spiritual, religious, or existential distress in adults with chronic disease may use language that includes struggle, needs, or the lack of wellbeing, and studies that provided language that had negative or positive directionality were considered. Peer-reviewed studies were included without any restrictions on date of publication and were available in the English language. Only quantitative and mixed-method studies with at least one quantitative aim were included. Studies were excluded if they focused on communicable or congenital disease/s, end-of-life, or palliative care. Adult student participants ages 18 to 75, inclusive of any geographic locations (e.g., North America, Europe, Middle East), religious traditions (e.g., Christianity, Islam, Judaism), racial/ethnic groups in any practice settings (e.g., acute care, outpatient care) apart from hospice care will also be included within this review. Additionally, studies that focused on non-patients (e.g., caregivers or other care providers), complementary or alternative medicine (e.g., yoga, meditation, mindfulness), or death and dying were excluded from this review.

#### Table 2.1

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Inclusion and exclusion criteria for eligible studies

	Criteria	Description
	Chronic Disease/s	Cardiac, Renal, Diabetes, Respiratory, &
		Hepatic disease
а	Measure/s of Spiritual, Religious, or Existential	
usion	distress	
Inclus	Study Type	Quantitative, Mixed-Methods
	Type of publication	Peer-reviewed journal

	Age of participants	18 – 75 (sample mean)
	Participant diagnosis	Must be a patient currently diagnosed with included chronic disease/s
	General	All dates
		Any location
		Available in English
	Congenital or Communicable Disease	
	Terminal or life-threatening disease state	End-of-life, end-stage, Hospice, Palliative
		Care, potential for death within 6 -12
		months
	Complementary/Alternative Medicine or	Only focused on prayer, religious
	Religious/Spiritual Behavior	attendance, meditation, yoga, etc.
	Study type	Qualitative
	Type of publication	Books (including chapters), reviews,
		opinion papers, grey literature, etc.
	Age of participants	<18 years of age
		>75 years of age
n	Participant diagnosis	Not patient-focused (e.g., caregivers,
Exclusion		nurses, etc.) or not currently diagnosed with
clı		a chronic condition
	General	Not available in English
Note	A more extensive description of the inclusion and exclusion cri	teria can be found in Table 2.5

# 2.1.3 Search strategy

To identify potential studies, the following databases were searched in July 2022: MEDLINE (PubMed), Embase (Elsevier), CINAHL Complete (EBSCO), PsycInfo (EBSCO), Scopus (Elsevier), Health and Psychosocial Instruments (EBSCO), and Web of Science (Clarivate). Detailed search details are included in Table 2.5. The search strategy was developed in consultation with an experienced health sciences librarian (K.S.), and an iterative process was undertaken using a limited search of PubMed, CINAHL, and SCOPUS to identify articles on the topic. Text from titles and abstracts, keywords, and index terms were used to develop the full search strategy. This strategy was adapted for each database included in this scoping review. All published studies were included without restrictions on the date of publication. The cloud-based platform Rayyan was used for the title/abstract review before transitioning to Covidence for the full-text review and data extraction (*Covidence systematic review software*, n.d.; Ouzzani et al., 2016).

### 2.1.4 Selection of sources of evidence

Two independent reviewers screened identified titles and abstracts. Reviewers pilot-tested the inclusion criteria by double-coding 50 manuscripts to ensure clarity and consistency. Inclusion and exclusion criteria were discussed, edited for clarity as needed, and documented throughout the process. Reasons for exclusion were recorded based on a full-text review. Disagreements between the reviewers at each stage of the selection process were resolved through discussion or by a third reviewer as necessary. The results of the search at all stages are reported and presented using the PRISMA-ScR flow diagram (see Figure 2.1).

### 2.1.5 Data Extraction

The data extraction form (see Table 2.6 in Appendix) was completed by an independent reviewer with confirmation by a second independent reviewer. The cloud-based Covidence platform was used in the development and use of the data extraction tool, and it was revised as necessary. We abstracted data on article characteristics (e.g., country of origin), study design, participants (e.g., age, sex/gender, race/ethnicity, etc.), study location (e.g., acute care hospital, outpatient primary care, etc.), disease groups and specific diagnoses or conditions, and the measures used in the study (e.g., name, number of items, subscales, etc.). Each manuscript was searched for stated definitions of SRE distress and, when available, were extracted. Disagreements between the reviewers were resolved through discussion or by an additional reviewer as needed.

Study characteristics were described using frequencies and percentages for categorical variables and mean scores with standard deviations for continuous variables. All frequencies and percentages were generated using STATA 18 (StataCorp, 2023). Studies were grouped both by disease (e.g., cardiac/vascular, diabetes, renal, and respiratory) and measure (e.g., RCOPE,

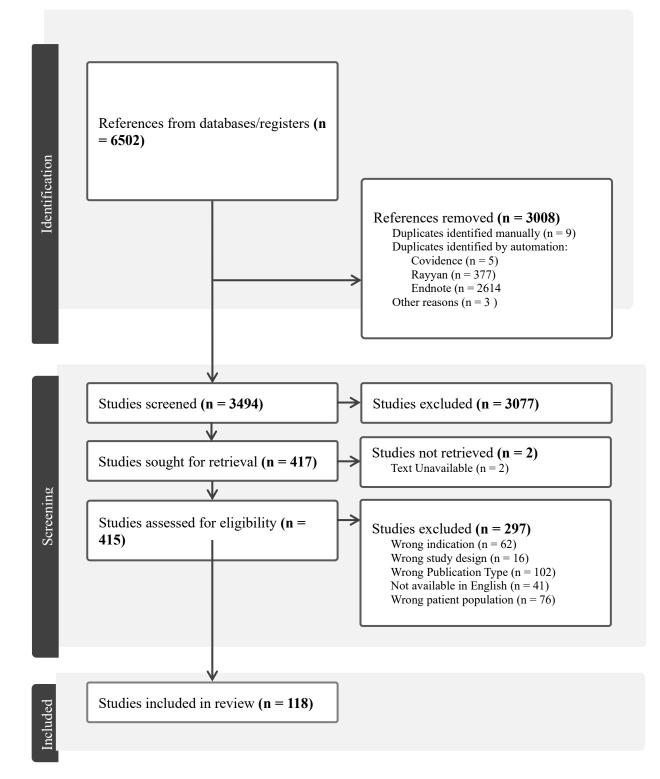
Spiritual Well-being Scale, etc.) before examining the types of settings and populations. Countries, where the studies were conducted, were later classified by region and subregion utilizing the United Nations M49 geographic classification system (United Nations Statistics Division, n.d.). Thematic coding identified the main themes in definitions of SRE distress (or a reasonable equivalent). Only studies providing definitions were included in the thematic analysis; studies with no definition or only abbreviated definitions (i.e., "negative religious coping," "spiritual distress") or only focused on the positive aspects of spirituality (i.e., "spiritual well-being," "spiritual strengths") were not included in the thematic analysis.

# 2.2 Results

Following the removal of duplicates (n=3,008), 3,494 articles were included in the title and abstract screening, and 415 were included in the full-text review. As indicated in Figure 2.1, 118 studies met the inclusion criteria and were selected for data extraction (see Table 2.7 in the Appendix for a list of manuscripts by disease group). Cohen's Kappa on inter-rater reliability for the full-text review suggested consistent application of screening criteria ( $\kappa$ : 0.94).

# Figure 2.1

# PRISMA-ScR Flowsheet

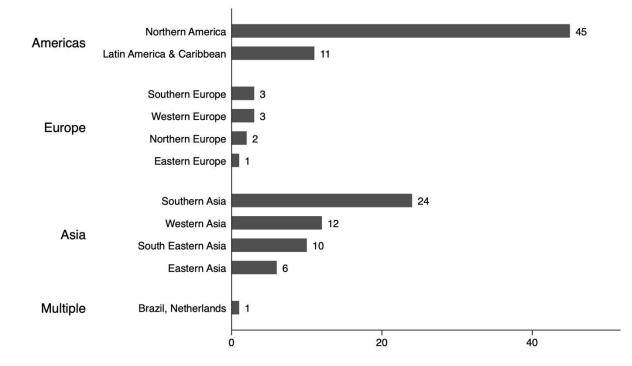


#### 2.2.1 Study Characteristics

Included studies were from Northern America (n = 45, 38.1%), Southern Asia (n = 24, 20.3%), Western Asia (n = 12, 10.2%), Latin America, and the Caribbean (n = 11, 9.3%), Southeastern Asia (n = 10, 5.1%), Eastern Asia (n = 6, 5.1%), Western Europe (n = 3, 2.5%), Southern Europe (n = 3, 2.5%), Northern Europe (n = 2, 1.7%), Eastern Europe (n = 1, 0.9%), and from multiple regions (n = 1, 0.9%) (see Figure 2.2). Nearly sixty percent of all the studies were from two nation-states, the United States (n = 45, 38.1%) and Iran (n = 23, 19.5%). Fifty-six percent of studies were published between 2015 and 2022, with increasing frequency from the early 2000s to 2022 (see Figure 2.3 in the Appendix). Over half of the included studies were cross-sectional (n = 69, 59.5%), followed by cohort (n = 24, 20.3%), experimental (randomized control and quasi-experimental, n = 21, 17.8%), and case/control (n = 4, 3.4%). Studies included cardiac and vascular conditions (CVD, n = 69), diabetes (DM, n = 21), renal conditions (KD, n = 15), respiratory (RpD, n = 12), and multiple conditions (n = 1),<sup>16</sup> no studies with hepatic or other forms of liver disease met the inclusion criteria.

<sup>&</sup>lt;sup>16</sup> This study was classified as "cardiac" for the purposes of this scoping review as 69.3% of participants had a cardiac condition (hypertension).

### Figure 2.2



Frequency of included studies by region, subregion

Most studies recruited participants from outpatient primary care or a specialty care clinic (n = 61, 51.7%), with many of those coming from a disease specialty provider (n = 48, 40.7%). Other recruitment sites were acute care hospitals (n = 30, 25.4%), rehabilitation centers (n = 5, 4.2%), community or religious organizations (n = 6, 5.1%), dialysis centers (n = 5, 4.2%), ambulatory care centers (n = 4, 3.4%) and multiple locations (n = 7, 5.9%). Of the studies that provided data on race or ethnicity of their participants, the average percent White was 79.2% (*SD* = 0.14, n = 36), Black was 31.6% (*SD* = 0.32; n = 25 ), Middle-Eastern/North African was 68% (*SD* = 0.55; n = 3), Asian was 69.2% (*SD* = 0.43; n = 11), Indigenous/Native American was 14.1% (*SD* = 0.32; n = 9), Latinx/Hispanic was 3% (*SD*= 0.02, n = 10), Pacific Islander was 2% (*SD* = <0, n = 2), and Multiple or Other race or ethnicity averaged 12.9% (*SD* = 0.12, n = 16). Some studies (n = 67) did not identify the racial-ethnic makeup of their participants; these

studies were completed in Southern Asia (n = 23), Western Asia (n = 11), Latin America and the Caribbean (n=9), Northern American (n = 7), South-Eastern Asia (n = 5), Eastern Asia (n = 4), Western Europe (n = 3), Southern Europe (n = 2), and at least one study from Northern Europe, Eastern Europe, and a single study with participants from Brazil and the Netherlands. Several religious and spiritual traditions were represented in the participants across the included studies: Christian (e.g., Protestant, Catholic, and Orthodox), Jewish, Muslim, Hindu, Buddhist, Atheist/Agnostic, and Other/Unknown (see Table 2.8 in the Appendix).

#### 2.2.2 Measures of Spiritual Distress.

Forty-seven measures were used across the included studies derived from thirty-nine original measures. Most frequently used were the Spiritual Well-Being Scale (SWBS, n = 30), Functional Assessment in Chronic Illness Treatment – Spirituality (FACIT-Sp, n = 25), and the Religious Coping Scale (RCOPE, n = 15). Over 75% of the assessments used were stand-alone, independent measures (n = 89) and 25% were items or a sub-scale on a different measure (n = 29). Measures were considered 'stand-alone' if they were not included as a subscale in another, more broadly defined measure. For the stand-alone, independent measures, the number of items per instrument varied from 2 to 38. For measures where spiritual distress was noted using an item (or items) or a subscale, the number of items varied from one to nine per instrument. Depending upon the measure, there were vastly different constructs included in the other subscales that were more existential in nature (e.g., connectedness, meaning in life, awe and wonder, spiritual practices) to the behavioral and psychological (e.g., self-awareness, stress management, social support, etc.). Many measures focused on the positive (i.e., spiritual wellbeing, spiritual growth) rather than explicitly exploring negative experiences (e.g., spiritual

distress). Most studies (n = 106) only used one measure to describe spiritual distress, with 11 studies using two and one study using three measures.

The SWBS (Ellison, 2018) was used in studies across all disease groups and multiple countries. This measure includes twenty items with subscales for religious well-being (10 items) and existential well-being (10 items). It uses a summed score to indicate if a respondent has lower or higher spiritual or existential well-being. Some studies using the SWBS focused on the positive aspects of spiritual well-being, including experiences of inner peace or peacefulness (Ghodsbin et al., 2015; Soleimani et al., 2018; Vollman et al., 2009), a sense of purpose or meaning (Arnold et al., 2007; Chaves Ede et al., 2011; da Silva et al., 2009; Izadi Avanji et al., 2021; Martínez & Custódio, 2014; Newlin et al., 2010), connectedness to self, others, or the sacred (Jahani et al., 2014; Newlin et al., 2003; Ramesh et al., 2021), and a mechanism for buffering or regulating negative emotions and improving overall life satisfaction (Besharat et al., 2018; Ebrahimi et al., 2021; Izadi Avanji et al., 2021; Moeini et al., 2016). Other studies described the absence or reduction of spiritual well-being as a loss of connection with the self, others, or the sacred and increased isolation and loneliness (Moeini et al., 2012), a loss of meaning, and a greater likelihood of experiencing anxiety or depression (Ebrahimi et al., 2021; Ramesh et al., 2021). Chaves et al.(2011) used the term "spiritual anguish" to describe the "impaired ability to experience and integrate meaning and purpose in life through connectedness to self, others, art, music, literature, nature, and/or a power greater than oneself."

The Functional Assessment in Chronic Illness Treatment – Spirituality (FACIT-Sp, n = 25) was used in its abbreviated 12-item form (n = 23), with two studies using the expanded version (23 items). While no studies in this review used the original measure (39 items, subscales for physical, social, familial, emotional, functional, and spiritual well-being), all forms of the

FACIT-Sp are part of a larger 'family' of measures initially used with oncology patients. There are currently multiple measures attuned to several concerns, including, different diseases (i.e., cancer [any], multiple sclerosis, etc.), treatment options (i.e., bone marrow transplant, immune therapy, enteral feeding, etc.), symptoms (i.e., fatigue, anemia, cognitive function, etc.), and other related health and social needs (i.e., caregivers, finances, palliative care, etc.; FACIT group, n.d.). The FACIT-Sp-12 and FACIT-SP-Ex use a five-point Likert scale and have similar scoring methods where higher scores indicate higher spiritual well-being. The FACIT-Sp-12 uses three subscales (Meaning, Peace, and Faith), each with four items; the FACIT-Sp-Ex adds an additional 11 items to the FACIT-Sp-12 that include items such as: "I feel connected to a higher power (or God)," "I feel hopeful," "I am able to forgive others for any harm they have ever caused me," and I feel a sense of appreciation for the beauty of nature." Some studies included in the review focused on positive aspects of spirituality (Kearns et al., 2020; Zhang et al., 2020) or the positive outcomes associated with spiritual well-being (Bean et al., 2009; Chen et al., 2021; Ischaq Nabil Asshiddigi et al., 2021; Jafari et al., 2014). Others were more expansive by including 'negative' experiences.' Larsen et al. (2006) used the language of "spiritual discontent" to describe participants' experiences with a lack of spiritual well-being and its association with depressive symptoms. Others indicated how a lack of purpose or meaning in life could negatively influence them (Larsen et al., 2006; Saiz et al., 2020; Wang et al., 2022) and leave them with a "shattered" worldview (Pedersen et al., 2013).

The RCOPE was primarily used in its brief form (n = 12) compared to the full form (n = 3). The Brief-RCOPE has 14 items (positive coping = 7, negative coping = 7), whereas the full measure has 103 items with ten positive coping subscales (65 items) and seven negative subscales (35 items). No studies used all of the sub-scales of the full RCOPE. Many of these

studies broadly described how individuals use their religious or spiritual perspectives to cope with stressors. Greer and Abel (2017) succinctly described religious coping as "efforts to understand and deal with life stressors in a way that relates to the sacred." Compared to the SWBS, the RCOPE used more religious language by using the term 'God' and referring to religious communities. Positive religious coping was described as benevolent religious appraisal, including forgiveness and a 'secure relationship' with God or the Divine (Nascimento et al., 2019). In contrast, negative religious coping was described as punishing God reappraisals (Ai et al., 2007; Ai & Peterson, 2009; Bay et al., 2008; Nascimento et al., 2019; Ngo et al., 2021), anger at God (Bay et al., 2008), demonic reappraisal (Ai et al., 2007; Ai & Peterson, 2009), perceived abandonment by the Divine (Fincham et al., 2018; Nascimento et al., 2019; Ngo et al., 2021) and, more broadly, as "spiritual discontent" (Ai et al., 2007; Ai & Peterson, 2009). Within communities, this was described as discord and conflict (Ai & Peterson, 2009; Fincham et al., 2018) or the perceived abandonment by one's religious community (Fincham et al., 2018; Nascimento et al., 2019; Ngo et al., 2021).

While the SWBS, FACIT-Sp, and RCOPE were most commonly used, quite a few other measures were identified in this review. Some of these were only used once (i.e., Attitude towards God [ATG], Meaning in Life [MiL], Positive States of Mind [PSMS], Royal Free Interview [RFI], Spiritual Orientation Inventory [SOI], etc.) and included some indication of negative existential experiences. For example, the MiL scale included subscales that assessed the *will to meaning, existential vacuum,* and *life purpose* (Shao et al., 2014), while the Ways of Coping with Problems Scale included a subscale focused on the *Search for religious practices and wishful thinking* which may address aspects of spiritual distress not reflected in other measures. Some scales were tailored for a specific disease group (e.g., diabetes, pulmonary;

Berardi et al., 2016; Delgado, 2007; Sukkarieh-Haraty et al., 2019). A clear example of this is the Diabetes Fatalism Scale (DFS), which is oriented to those diagnosed with diabetes and includes subscales for despair (emotional distress), powerlessness (perceived self-efficacy), and hopelessness (religious/spiritual coping; Egede & Ellis, 2010). Only one measure was specifically designed for a religious sub-group (Muslims) with the Islamic Religious Coping scale (RCS; Celik et al., 2022; Celik et al., 2021), which is a subscale of the Psychological Measure of Islamic Religiousness (PMIR; Abu Raiya et al., 2008). No other measure was explicitly designed for a religious faith group.

### 2.2.3 Defining Spiritual Distress.

Nearly half of the included studies did not include a discernable definition of spiritual distress, struggle, negative coping, or lack of well-being (n = 58). Some studies only focused on the positive aspects of spirituality (n = 15), described as experiences of "spiritual well-being." Forty-five studies providing evaluable definitions identified 12 positive (see Table 2.9 in the Appendix) and 12 negative (Table 2.2) non-orthogonal themes. Across these studies, religion and spirituality were most often connected to positive and negative coping behaviors or interpreted spirituality as only having a positive influence on health outcomes (i.e., lower levels of depression, buffer disease stressors). Twelve positive themes describing spiritual well-being were identified in the studies, and these were primarily drawn from studies that used the SWBS, BMMRS, RCOPE, and FACIT-SP.

The most frequently identified theme is best described as *Religious Coping* with several measures identifying religious, spiritual, or existential coping of notable concern; these definitions typically were oriented to the responses that people may have to stressful or difficult life events (RCOPE, RCS, SCS, RCAS, COPE). Few papers used the terms "spiritual distress" or

"spiritual struggle" among all the included articles (Bay et al., 2008; Celik et al., 2022; Fincham et al., 2018; Mendes et al., 2022; C. L. Park et al., 2008; Trevino & McConnell, 2014) whereas the other articles used other descriptors. Only ten of the included measures were associated with papers that included a description of spiritual distress: SWBS, RCOPE, FACIT-Sp, BMMRS, RCAS, RCS, SRS, COPE, DFS, and P&PSS. No measure was included in all of the twelve identified themes, but the RCOPE was identified in all but one theme.

The experience of *Punishment* was included in most studies (n = 11) and was primarily interpreted as an act perpetuated by God/sacred<sup>17</sup>. Punishment was often perceived as a response to difficult life events or other stressors (i.e., disease; Pedersen et al., 2013; Shamsalinia et al., 2016; Yilmaz et al., 2021) or was assigned to an individual's "transgressions" (Ngo et al., 2021). Questioning or Doubt about the power, love, or existence of God/sacred (Ai et al., 2007; Ai & Peterson, 2009; Fincham et al., 2018; Nascimento et al., 2019; Park & Dornelas, 2012; Pedersen et al., 2013; Yilmaz et al., 2021); was a theme that was primarily attributed to God/sacred, although one study included feelings of doubt toward others (Pedersen et al., 2013). Similarly, the theme of Disconnection or Discontent was most often described as a general feeling of "spiritual" or "religious" discontent (Ai et al., 2007; Ai & Peterson, 2009; Larsen et al., 2006; Crystal L. Park et al., 2008), but was also experienced in relationship to God/sacred, others, nature (Ai et al., 2007; Chaves Ede et al., 2011; Miller et al., 2007), and the self (Chaves Ede et al., 2011; Moeini et al., 2012). Tension was primarily associated with religious or spiritual beliefs (Celik et al., 2022; Fincham et al., 2018; Magyar-Russell et al., 2014) but also with God/sacred (Mendes et al., 2022); this theme was attributed to descriptions of strain and feelings of struggle.

<sup>&</sup>lt;sup>17</sup> The term "God/sacred" will be used throughout this paper to describe the transcendent (i.e., S/sacred, H/higher power, D/divine 'other', G/god, G/g-d, etc.); as appropriate, more specific language will be used and not the phrase "God/sacred".

Theme	Description	Measures
Punishment	By God/sacred Responsible for negative life events/stressors	BMMRS RCOPE RCS FACIT-Sp
Questioning or Doubt	God's/sacred's Love Care	RCOPE FACIT-Sp
	Existence Power	BMMRS RCS
Disconnection or	God/sacred	SWBS
Discontent (with)	Self	RCOPE
	Others	RCAS
	Art (music, literature) Nature	BMMRS FACIT-Sp
Tension/s	Spiritual or Religious:	RCAS
10115701775	Struggle Strain	RCOPE
	Religious beliefs, because of	
Abandonment (by)	God/sacred	SWBS
	Religious community	RCAS
		SRS
		P&PSS
		FACIT-Sp
		RCOPE
Despair <sup>a</sup>	Hopelessness	DFS
	Powerlessness (Vulnerability)	SWBS
	Discouragement	RCOPE
	Discomfort	
Meaninglessness	World view described as shattered, threatening, or	SWBS <sup>b</sup>
"Spiritual Anguish"	tenuous	RCAS
	Sense of loss	FACIT-Sp <sup>c</sup>
	Inability to integrate meaning/purpose in life	RCOPE <sup>c</sup>
		SRS <sup>b</sup>
		P&PSS <sup>b</sup>
Isolation	God/sacred	SWBS
	Others	RCS
	Loneliness Alienation	BMMRS <sup>d</sup>
	<b>XX7' (1 1 1 / XX7' (1 1 '</b>	RCOPE <sup>d</sup>
	Withdrawal /Withdrawing	

# Conceptual themes of spiritual distress

Anger	Directed at God/sacred General feeling of	RCOPE
Demonic influence	Stressors are instigated by the <i>devil, evil spirits,</i> or <i>demons</i>	BMMRS RCOPE
Conflict/s	Relationships with: God/sacred Self Others (includes religious and non-religious communities)	RCAS RCOPE FACIT-SP
Avoidance or Denial	Negative coping strategies	COPE
	and the state to the t	

a. Clinical descriptions of anxiety and depression were mentioned but were omitted.

b. The SWBS, SRS, and P&PSS were used in one study, and the SWBS was used independently in two others associated with Meaninglessness

c. The RCOPE and FACIT-Sp were both used

d. RCOPE and BMMRS were both used

The theme of *Abandonment* by God/sacred (Celik et al., 2021; Nascimento et al., 2019; Ngo et al., 2021; Park & Dornelas, 2012) and by religious communities (Fincham et al., 2018) was identified in studies that used the RCOPE, BMMRS, and RCS. *Meaninglessness* or a deep sense of loss was described by difficulty in finding purpose (Chaves Ede et al., 2011; Ebrahimi et al., 2021) and greater feelings of vulnerability (Moeini et al., 2012). Descriptions also included language where one's perception of the world is hostile (Miller et al., 2007), traumatizing (Pedersen et al., 2013), and leaves them in a state of "spiritual anguish" (Chaves Ede et al., 2011). Similarly, the theme of *Despair* describes the sense of hopelessness (Sukkarieh-Haraty et al., 2019) and discouragement (Moeini et al., 2012) that can be experienced during times of spiritual distress; despair was also the only theme that was associated with the clinical diagnoses of anxiety and depression (Ebrahimi et al., 2021; Ramesh et al., 2021).

*Isolation* was described as experiences of separation or withdrawal from others (Celik et al., 2021; Ebrahimi et al., 2021; Moeini et al., 2012; Shamsalinia et al., 2016) and *Anger* at God/sacred (Bay et al., 2008; Park & Dornelas, 2012; Pedersen et al., 2013) or feelings of anger in response to stressors (Crystal L. Park et al., 2008) were both identified in four studies. Themes

that included *Demonic* elements were typically associated with reappraisal of stressful or difficult life events (Ai et al., 2007; Ai & Peterson, 2009; Bay et al., 2008; Fincham et al., 2018) and were only associated with the RCOPE. The themes of *Conflict/s* and *Avoidance* were less frequently associated with spiritual distress. Conflicts were often associated with God/sacred (Nascimento et al., 2019; Trevino & McConnell, 2014) but also with others (Pedersen et al., 2013). Avoidance or denial is described as negative coping strategies present when someone is experiencing spiritual distress (Chaves Ede et al., 2011; C. L. Park et al., 2008).

#### 2.2.4 Synthesis of results

In this scoping review, we identified 118 studies that included measures of spiritual distress among individuals living with a non-communicable disease published across multiple countries from the 1990s to June 30, 2022. Multiple measures were used across studies to operationalize spiritual distress, the most common being the Spiritual Well-Being Scale. Only 38% of the studies included a discernable definition of spiritual distress (or well-being), with most focused on positive forms of spirituality among individuals with non-communicable diseases. Of the 12 themes identified across articulated definitions of spiritual distress, the only measure that addressed nearly all the themes was the RCOPE.

#### 2.3 Discussion

## 2.3.1 Summary of Evidence

At the start of this scoping review, we intended to focus solely on experiences of spiritual, existential, or religious distress or struggles. However, when we began creating our search strategy, we found very few articles that addressed spiritual distress or struggles in people living with and managing their chronic diseases. This led us to expand our language to include

articles exploring positive and negative religious/spiritual coping and spiritual well-being. Whereas this accommodated more of the existing literature, it suggested at the onset that distress was less often a focus of inquiry than spiritual well-being. Nonetheless, a robust literature emerged that attempted to link spiritual functioning to disease, disease outcomes, and health in individuals with non-communicable diseases.

One striking feature of this review was the number of different measures used across and within each condition. With 47 measures represented, harmonization of measurement should be a priority in future research. Apart from the DFS and Ferrans and Power's Quality of Life Index— Pulmonary Version III, none of the measures seemed to be tailored to a specific disease condition. Although each disease category is associated with modifiable lifestyle behaviors, differing levels of impact on a person's life may not be easily identified with a single measure.

There appeared to be a lack of transparent explanation of how spiritual distress and/or well-being was conceptualized in manuscripts. Less than half of the studies provided a clear definition of spiritual distress despite measuring it for potential impact on disease, disease progression, or health functioning. Combined with the myriad of measures used to operationalize spiritual distress, discerning a consistent or shared understanding of spiritual distress used in the current literature was not possible. Themes that appeared in definitions of spiritual distress included states of discomfort (tension, conflict, anger, despair) and isolation (disconnections, isolation, abandonment) attributed to a transition away from having a sense of meaning, order, or purpose (questioning/doubt, punishment, meaninglessness).

Unsurprisingly, the most clearly aligned measure with the identified themes was the RCOPE, created by Kenneth Pargament, the leading expert of spiritual and religious struggle. Pargament and collaborator Julie Exline developed the Religious and Spiritual Struggles scale

(RSS) in 2014, refining items to represent six domains: *divine*, *demonic*, *interpersonal*, *moral*, *doubt*, and *ultimate meaning* (Exline, Grubbs, et al., 2014; Exline, Pargament, et al., 2014). Although this measure did map onto several themes that emerged from extracted definitions of spiritual distress, none of the studies included in this review reported using the RSS.

### 2.3.2 Limitations

Results from our scoping review must be considered within the context of some limitations. We purposefully used expansive language to describe spiritual, religious, or existential distress to capture a broader range of measures beyond those that are more explicitly religious. This also meant that we often erred on the side of inclusion of measures that had some indication of directionality (positive and/or negative) to get a better sense of what measures were being used. Because of this, our findings may include studies that did not intend to explore spiritual distress and thus did not include a clear definition or understanding of spiritual distress. Similarly, some of the studies included may have used some of the same sources (i.e., the work of Kenneth Pargament) for their descriptions, which would skew our findings to have better alignment with the RCOPE compared to other measures. Secondly, the reporting of participants' ages varied, with some studies providing a mean age while others only provided a range of ages. This may mean that we included some studies that would have been excluded due to a mean age greater than seventy-five. Additionally, this scoping review only reflects the literature through to June 2022. Recent innovations in measures or the adoption of a harmonized definition of spiritual distress are not captured. Lastly, this review only included quantitative studies and their descriptions of spiritual distress; qualitative studies may describe spiritual distress differently or in a way that diverges from what has been published in the studies included in this review.

#### 2.3.3 Conclusions

Despite the extensive collection of research that includes spirituality as an important area of inquiry, there remains a lack of detailed, focused research on spiritual distress in people living with and managing chronic diseases. Efforts to harmonize measures of spiritual distress are important, but attention to harmonizing conceptual definitions of the phenomenon must precede measurement identification. An essential first step in refining our understanding of spiritual distress as it applies in the context of diverse chronic diseases would be rigorous qualitative research to help describe the experience of spiritual distress from the perspective of those living with chronic disease. A better, patient-centered definition of spiritual distress could identify common features and characteristics, offering a definition that could be consistently adopted and more clearly measured. Harmonizing these in the future literature can assist in culling across diverse areas of inquiry to determine the evidence for the role of spiritual distress in chronic disease and health outcomes and ultimately for intervention development and evaluation on health and health behaviors.

## 2.4 Funding

The University of Michigan Rackham Dissertation Research Grant funded this scoping review.

# 2.5 Appendices

## Table 2.3

## Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #	
FITLE			OTTINOL II	
Title	1	Identify the report as a scoping review.	51	
ABSTRACT				
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	NA	
INTRODUCTION				
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	51	
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	52	
METHODS				
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	53	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	54	
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	53	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	55	
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	56	
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently	56	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		or in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	56
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	56
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	57
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	59
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	61
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	69
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	69
Limitations	20	Discuss the limitations of the scoping review process.	71
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	71
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	72

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

<sup>†</sup> A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

<sup>‡</sup> The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document). (Tricco et al., 2018)

Search	Query	Records Retrieved from PubMed
#1	(("Humanism"[Mesh] OR "Existentialism"[Mesh] OR "Secularism"[Mesh] OR	21,768
Spiritual	"Spirituality"[Mesh] OR Spiritual[tiab] OR Spiritualities[tiab] OR religious[tiab] OR	
distress	existential[tiab] OR religion[tiab] OR religions[tiab] OR psychospiritual[tiab] OR	
	Secularism[tiab] OR Secular[tiab]) AND ("Psychological Distress"[Mesh] OR "stress,	
	psychological"[MeSH Terms] OR Distress[tiab] OR struggle[tiab] OR needs[tiab] OR	
	"well being"[tiab] OR wellbeing[tiab] OR resilience[tiab] OR resilient[tiab] OR	
	concerns[tiab] OR concern[tiab] OR transformation[tiab] OR coping[tiab] OR	
	cope[tiab] OR struggling[tiab] OR suffering[tiab] OR suffer[tiab] ))	
#2	"Neoplasms"[Mesh:NoExp] OR "Liver Neoplasms"[Mesh] OR "Gastrointestinal	4,187,972
Chronic	Neoplasms"[Mesh] OR ((Liver[tiab] OR hepatic[tiab] OR colorectal[tiab] OR	
disease	colon[tiab] OR rectal[tiab] OR digestive[tiab] OR esophageal[tiab] OR esophagus[tiab])	
	AND (cancer[tiab] OR oncology[tiab])) OR "Liver Disease"[tiab] OR "Liver	
	Diseases"[Mesh] OR "Type 2 Diabetes"[tiab] OR "Kidney Disease"[tiab] OR "Chronic	
	Renal Disease"[tiab] OR "Chronic Kidney Disease"[tiab] OR "Pre Diabetic"[tiab] OR	
	prediabetic[tiab] OR pre-diabetic[tiab] OR diabetic [tiab]OR "diabetes mellitus, type	
	2"[MeSH Terms] OR "Prediabetic State"[MeSH Terms] OR "Renal	
	Insufficiency"[MeSH Terms] OR "Diabetes Insipidus"[MeSH Terms] OR "Diabetic	
	Nephropathies"[MeSH Terms] OR "Renal Artery Obstruction"[MeSH Terms] OR	
	"Chronic respiratory disease"[tiab] OR "chronic obstructive pulmonary disease"	
	[tiab]OR "Pulmonary Hypertension"[tiab] OR Emphysema[tiab] OR "Chronic	
	Bronchitis"[tiab] OR Asthma[tiab] OR "lung diseases, obstructive"[MeSH Terms] OR	
	"Carotid Artery Diseases"[MeSH Terms] OR "Cardiovascular Disease"[tiab] OR "Heart	
	Disease"[tiab] OR "Heart Failure" [tiab]OR "Congestive Heart Failure"[tiab] OR "Heart	
	Attack"[tiab] OR "Myocardial infarction"[tiab] OR stroke[tiab] OR "coronary artery	
	disease"[tiab] OR "coronary arterial disease"[tiab] OR "Heart valve disease"[tiab] OR	
	cardiomyopathy[tiab] OR "metabolic syndrome"[tiab] OR "Metabolic disease"[tiab] OR	
	"Ischemic Stroke"[tiab] OR "Transient Ischemic Stroke"[tiab] OR TIA OR "Mini	
	stroke"[tiab] OR "High Blood Pressure"[tiab] OR hypertension[tiab] OR	

## Results from PubMed (Medline) literature search

dyslipidemia[tiab] OR "Pulmonary Heart Disease"[MeSH Terms] OR "Ventricular	
Dysfunction"[MeSH Terms] OR "Myocardial Stunning"[MeSH Terms] OR "Myocardial	
Ischemia"[MeSH Terms] OR "Heart Valve Diseases"[MeSH Terms] OR "Heart	
Failure"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Heart	
Arrest"[MeSH Terms] OR "Cardiomegaly"[MeSH Terms] OR "Lipid Metabolism	
Disorders" [MeSH Terms] OR "Metabolic Syndrome" [MeSH Terms] OR "Ischemic	
Stroke"[MeSH Terms] OR "Heart Disease Risk Factors"[MeSH Terms] OR	
"hypertension, pulmonary"[MeSH Terms]	
#3 #1+#2	2,918
Note: No limits were placed on dates; completed April 19, 2022	

## Detailed inclusion and exclusion criteria

Category	Description/s			
Chronic Disease/s	Cardiac or vascular disease	Renal & Liver Disease <sup>a</sup>	Diabetes	<b>Respiratory Disease</b>
includes	Cardiovascular (Heart) Disease: Coronary Ischemic	Chronic Renal (Kidney) Disease	Type 2 Diabetes	Chronic Respiratory Disease
	Congestive Heart Failure / Heart Failure	Liver Disease / Fatty Liver Disease	Pre-Diabetic	Emphysema
	Myocardial Infarction; Heart Attack		Diabetic ulcers	Pulmonary Hypertension
	Stroke: Ischemic Transient Ischemic (TIA) Mini			Chronic Obstructive Pulmonary Disease (COPD)
	Coronary Artery (Arterial) Disease			Chronic Bronchitis
	Heart Valve Disease			Asthma
	Cardiomyopathy			
	Metabolic Syndrome / Disease			
	Hypertension / High Blood Pressure			
	Arterial Dyslipidemia			
Measures	"Spiritual"	"Distres	s"	
includes	Existential	Wellbein	g	
	Religious	Pain		
	Spiritual	Anguish		
	Secular	Struggle		
	Humanism	Concern		
	Psychospiritual	Coping		
		Suffering Resilienc		
		Growth/c		

Publication & Study TypesStudy TypePublication TypeQuantitative Mixed-MethodsPeer-reviewed journalParticipant AgeLower LimitUpper Limit1875 (mean)GeneralAll datesAny location					
Mixed-Methods       Participant Age     Lower Limit       18     75 (mean)					
18 75 (mean)					
	<b></b>				
General All dates Any location Available in English	հ				
Exclusion Criteria					
Category Description					
Study PopulationCongenital diseaseCommunicableTerminal/life- threateningNot Patient FocusedOr	Organ donation				
	Donation				
	Recipient				
End-stage Parents					
Palliative Care Experts					
Hospice Program Development					
Anticipate death within 6-12 months Program Evaluation					
	Note: Study participants must be diagnosed with one of the described conditions at the time of recruitment				
Measures         Complementary/alternative medicine         Religiosity					
Yoga Religious Attendance ONLY					
Meditation Prayer ONLY					
e	Fasting ONLY				
Pilgrimages					
Publication & Study TypesPublication TypesStudy Types					
Reviews Qualitative					
Opinion papers Protocols					
Grey literature Scale validation					
Background literature Scale translation					
Books/ Book chapter/s Historical trends					
Book reviews					

Conference publications / Abstracts		
Lower limit	Upper Limit	
18	75 (mean)	
Pediatrics		
Children		
Text		
Text not available in English		
Text unavailable		
	Lower limit         18         Pediatrics         Children         Text         Text not available in English	Lower limitUpper Limit1875 (mean)Pediatrics75 (mean)Children75 (mean)TextText not available in English

## Data extraction instrument

	General Study Information
Author/s	[text]
Year of publication	[numeric]
Journal name	[text]
Country	[text]
Study Site / Context	Acute Care Hospital
-	Dialysis Clinic
	Specialty Care (outpatient, e.g., cardiology, endocrinology, etc.)
	Organization, Community
	Organization, Religious
	Pain Center
	Primary Care (outpatient)
	Other (includes multiple sites)
	Rehabilitation Center
	Rehab, Cardiac
	Rehab, Pulmonary
	Unknown (UNK)
Sample size	[numeric]
Aim of study	[text]
Study design	Randomized controlled trial
	Quasi-experimental
	Case-control
	Cohort (Prospective & Retroactive)
	Cross-sectional
	Unknown (UNK)
Disease Group	Cardiac/Vascular
	Diabetes/Endocrine
	Renal/Kidney
	Respiratory
Diagnoses	[text]
Age	[numeric]
	Mean/SD
	Median/Range

Gender	[numeric]
Gender	% Male
	% Female
	% Other
	Unknown (UNK)
Race/Ethnicity	[numeric/text]
Race/ Lumerty	% White
	% Black
	% Asian (East & South)
	% Latinx, Hispanic
	% Middle Eastern/North African
	% Pacific Islander
	% Indigenous
	% Other
	% Multiple
	Unknown (UNK)
Religious Affiliation	[numeric/text]
Religious / Himatoli	% Protestant Christian (non-specific "Christian")
	% Catholic
	% Jewish
	% Muslim
	% Hindu
	% Buddhist
	%Orthodox (Greek/Russian)
	% Other
	% No affiliation
	% Atheist/Agnostic
	Unknown (UNK)
Religious Affiliation – General	[numeric/text]
6	Religious (general, no specific tradition)
	Non-religious
Marital Status	[numeric/text]
	% Married/Partnered (includes cohabitating)
	% Divorced/Separated
	% Single/Unmarried
	% Widowed

	% Divorced/Single/Widowed
	Unknown (UNK)
Study information and results	
Definition of S/R/E Distress	[text]
Measure/instrument for S/R/E distress - 1	[text]
	e.g., the Religious and Spiritual Struggles Scale, FACIT-SP, R-COPE
Measure/instrument for S/R/E distress – 2	[text]
	e.g., the Religious and Spiritual Struggles Scale, FACIT-SP, R-COPE
Measure/instrument for S/R/E distress – 3	[text]
	e.g., the Religious and Spiritual Struggles Scale, FACIT-SP, R-COPE
Independent Measure	Yes
	No
Number of Items – 1	[numeric]
Number of Items – 2	[numeric]
Number of Items – 3	[numeric]
Measure/Instrument Subscale -1	[numeric/text]
Measure/Instrument Subscale – 2	[numeric/text]
Measure/Instrument Subscale -3	[numeric/text]
Measure/Instrument Citation – 1	[text]
Measure/Instrument Citation – 2	[text]
Measure/Instrument Citation –3	[text]
Measure/Instrument Scoring – 1	[numeric/text]
-	e.g., how was it interpreted, what are the cut-points or indicators used
Measure/Instrument Scoring – 2	[numeric/text]
Measure/Instrument Scoring – 3	[numeric/text]

First Author (Year)	Full Citation	Disease Group
Abdi (2022)	Abdi, A., Ai, A. L., Ai, A. L., & Carretta, H. (2022). Relationship of spiritual well-being with life expectancy and quality of life for patients living with heart failure. Int J Palliat Nurs 28(6), 262-269. https://www.ncbi.nlm.nih.gov/pubmed/35727830	Cardiac
Ai (2007)	Ai, A. L., Abel, W. M., Ai, A. L., Kara, Fahriye Şeyma, & Ai, A. L. (2007). Psychosocial mediation of religious coping styles: A study of short-term psychological distress following cardiac surgery. Personality and Social Psychology Bulletin 33(6), 867-882. https://www.ncbi.nlm.nih.gov/pubmed/17483394	Cardiac
Anoopa (2017)	Anoopa, K. R. & Sacco, S. J. (2017). Spiritual wellbeing of patients with stroke and their experience on spiritual care competence of nurses. International Journal of Research in Ayurveda and Pharmacy 8(3), 130-133. https://www.embase.com/search/results?subaction=viewrecord&id=L617389183&from=export http://dx.doi.org/10.7897/2277-4343.083158	Cardiac
Anwar (2020)	Anwar, S., Dunning, T., & Arnold, S. (2020). The importance of spirituality, physical activity and sleep duration to prevent hypertension among elderly in Aceh-Indonesia. Systematic Reviews in Pharmacy 11(11), 1366-1370. https://www.embase.com/search/results?subaction=viewrecord&id=L2010613039&from=export http://dx.doi.org/10.31838/srp.2020.11.194	Cardiac
Arnold (2007)	Arnold, S., McConnell, T. R., Babamohamadi, H., & McConnell, T. R. (2007). Spiritual well-being, emotional distress, and perception of health after a myocardial infarction. Internet J. Adv. Nurs. Pract. 9(1), . https://www.scopus.com/inward/record.uri?eid=2-s2.0- 48149095857&partnerID=40&md5=f77da09eafc615152f3577a567e89378	Cardiac
Babamohamadi (2020)	Babamohamadi, H., McConnell, T. R., Bay, Paul S., & Yeung, S. M. (2020). The Effect of Spiritual Care Based on the Sound Heart Model on the Spiritual Health of Patients with Acute Myocardial Infarction. J Relig Health 59(5), 2638-2653. https://link.springer.com/article/10.1007/s10943-020-01003-w	Cardiac
Bay (2008)	Bay, Paul S., Yeung, S. M., Bean, M. K., Fincham, F. D., & Carretta, H. (2008). The effect of pastoral care services on anxiety, depression, hope, religious coping, and religious problem solving styles: A randomized controlled study. Journal of Religion and Health 47(1), 57-69. https://www.ncbi.nlm.nih.gov/pubmed/19105001	Cardiac

# Citation list of included articles by disease group

First Author (Year)	Full Citation	Disease Group
Bean (2009)	Bean, M. K., Fincham, F. D., Carretta, H., Beery, T. A., & Peng, L. S. (2009). Psychosocial factors, quality of life, and psychological distress: ethnic differences in patients with heart failure. Prog Cardiovasc Nurs 24(4), 131-40. https://www.ncbi.nlm.nih.gov/pubmed/20002337	Cardiac
Beery (2002)	Beery, T. A., Peng, L. S., Mahmudiono, T., & Bekke-Hansen, S. (2002). Spirituality in persons with heart failure. J Holist Nurs 20(1), 5-25; quiz 26. https://www.ncbi.nlm.nih.gov/pubmed/11898688	Cardiac
Bekke-Hansen (2014)	Bekke-Hansen, S., Ramesh, S., Moghimi, E., Berardi, Vincent, Park, C. L., & Gutierrez, I. A. (2014). The role of religious faith, spirituality and existential considerations among heart patients in a secular society: relation to depressive symptoms 6 months post acute coronary syndrome. J Health Psychol 19(6), 740-53. https://www.ncbi.nlm.nih.gov/pubmed/23568950	Cardiac
Besharat (2018)	Besharat, M. A., Celik, S., & Taskin Yilmaz, F. (2018). Spiritual health mediates the relationship between ego-strength and adjustment to heart disease. Health Psychol Open 5(1), 2055102918782180. https://www.ncbi.nlm.nih.gov/pubmed/29977588	Cardiac
Black (2006)	Black, G., Taskin Yilmaz, Feride, Anataca, Gulden, Carney, L. M., & Otaghi, M. (2006). The relationship between spirituality and compliance in patients with heart failure. Prog Cardiovasc Nurs 21(3), 128-33.	Cardiac
Carney (2020)	Carney, L. M., Otaghi, M., & Mami, S. (2020). Religious beliefs and well-being and distress in congestive heart failure patients. J Behav Med 43(3), 437-447. https://www.ncbi.nlm.nih.gov/pubmed/31745691	Cardiac
Celik (2022)	Celik, M., Izgu, N., & Ozdemir, L. (2022). Depression and Religious Coping in Patients with Acute Coronary Syndrome in Turkey. Journal of Religion and Health (), . https://www.ncbi.nlm.nih.gov/pubmed/35332422	Cardiac
Chang (2010)	Chang, B. H., Trevino, K. M., Klinger, T. A., & Chaves, C. (2010). Relaxation response and spirituality: Pathways to improve psychological outcomes in cardiac rehabilitation. J. Psychosom. Res. 69(2), 93-100. https://www.ncbi.nlm.nih.gov/pubmed/20624507	Cardiac
Chaves (2016)	Chaves, C. & Chaves, E. C. L. (2016) Differential pathways of positive and negative health behavior change in congestive heart failure patients. J Health Psychol. 21(8), 1728-38. https://www.ncbi.nlm.nih.gov/pubmed/25564470	Cardiac
de Eston Armond (2022)	de Eston Armond, R., Noorhamdani,, Kristianto, H., & Delgado, C. (2022). Spiritual Well-Being and Its Association with Coronary Artery Disease. J Relig Health 61(1), 467-478. https://www.ncbi.nlm.nih.gov/pubmed/33226573	Cardiac
Faria (2020)	Faria, E. C., Pargament, K. I., Appel, H. B., & Kronfol, Z. (2020). Unna boot therapy impact on wellbeing, hope and spirituality in venous leg ulcer patients: a prospective clinical trial. J Wound Care 29(4), 214-220. https://www.ncbi.nlm.nih.gov/pubmed/32281511	Cardiac

First Author (Year)	Full Citation	Disease Group
Flint (2019)	Flint, K. M., Kadkhodaei-Elyaderani, H., Ebrahimian, A., & Ghorbani, R. (2019). Does heart failure-specific health status identify patients with bothersome symptoms, depression, anxiety, and/or poorer spiritual well-being?. Eur Heart J Qual Care Clin Outcomes 5(3), 233-241. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6613596/pdf/qcy061.pdf	Cardiac
Ganz (2022)	Ganz, F. D., Baas, L. S., Fowler, C., Allen, G.Gemmell, L. A., Casey, A., & Dusek, J. A. (2022). Distress among hospitalized patients with acute coronary syndrome. Nurs Crit Care 27(2), 165-171.	Cardiac
Ghodsbin (2015)	Ghodsbin, F., de Eston Armond, J., Konstantyner, T., Rodrigues, C. L., & Giaquinto, S. (2015). The effect of positive thinking training on the level of spiritual well-being among the patients with coronary artery diseases referred to Imam Reza specialty and subspecialty clinic in Shiraz, Iran: A randomized controlled clinical trial. ARYA Atheroscler 11(6), 341-8. <go isi="" to="">://WOS:000374295400005</go>	Cardiac
Giaquinto (2010)	Giaquinto, S., Loiola, T., Salomé, G. M., & Ferreira, L. M. (2010). Religious and spiritual beliefs in stroke rehabilitation. Clin Exp Hypertens 32(6), 329-34. https://www.ncbi.nlm.nih.gov/pubmed/21028994	Cardiac
Ginting (2015)	Ginting, H., Fairclough, D. L., Spertus, J. A., & Bekelman, D. B. (2015). Spirituality and Negative Emotions in Individuals With Coronary Heart Disease. J Cardiovasc Nurs 30(6), 537-45. https://www.ncbi.nlm.nih.gov/pubmed/25350528	Cardiac
Greer (2017)	Greer, D. B. & Sittner, K. J. (2017). Religious/spiritual coping in older African American women. Qual. Rep. 22(1), 237-260. <go isi="" to="">://WOS:000397412200005</go>	Cardiac
Griffin (2007)	Griffin, M. T., Masoudi Alavi, N., Akbari, H., Saroladan, S.Haverkamp, G. L. G., Farajzadegan, Z., & Loghmani, A. (2007). Spirituality and well being among elders: differences between elders with heart failure and those without heart failure. Clin Interv Aging 2(4), 669-75. <go isi="" to="">://WOS:000208238600021</go>	Cardiac
Hooker (2017)	Hooker, S. A., D'Eramo Melkus, G., Chyun, D., Jefferson, V.Ischaq Nabil Asshiddiqi, M., Pedersen, Christina G., & Pargament, Kenneth I. (2017). Denver Spirited Heart: Mixed-Methods Pilot Study of a Psychospiritual Intervention for Heart Failure Patients. J Cardiovasc Nurs 32(3), 226-235. https://www.ncbi.nlm.nih.gov/pubmed/27076391	Cardiac
Jahani (2014)	Jahani, A., Lin, C. Y., Chen, H., Pakpour, A. H., & Javanmardifard, S. (2014). Spiritual wellbeing of Iranian patients with acute coronary syndromes: A cross-sectional descriptive study. J. Res. Nurs. 19(6), 518-527. <go isi="" to="">://WOS:000213194300011</go>	Cardiac
Johnstone (2008)	Johnstone, B., Zarabadi-Pour, S., Motalebi, S. A., Allen, K. A., & Kacerovsky-Bielesz, G. (2008). Relationships among religiousness, spirituality, and health for individuals with stroke. J Clin Psychol Med Settings 15(4), 308-13. https://www.ncbi.nlm.nih.gov/pubmed/19104988	Cardiac

First Author (Year)	Full Citation	Disease Group
Kearns (2020)	Kearns, Nathan T., Zamanian, H., Foroozanfar, S., Afsahi, S.Kütmeç Yilmaz, Cemile, Musabak, I., & Gok, D. E. (2020). Increased spiritual well-being following cardiovascular surgery influences one-year perceived posttraumatic growth. Psychology of Religion and Spirituality 12(3), 288-293. <go isi="" to="">://WOS:000558639000004</go>	Cardiac
Larsen (2006)	Larsen, Karin E., Park, C. L., Bu, Huang, Rodgers, W., & Tice, T. N. (2006). Depression in Women with Heart Disease: The Importance of Social Role Performance and Spirituality. Journal of Clinical Psychology in Medical Settings 13(1), 39-48. <go isi="" to="">://WOS:000237663200006</go>	Cardiac
Lum (2016)	Lum, H. D., Ramjan, L., Glew, P., Randall, S.Salamonson, Y., Magyar-Russell, G., & Beckman, Daniel (2016). Burdensome Physical and Depressive Symptoms Predict Heart Failure-Specific Health Status Over One Year. J Pain Symptom Manage 51(6), 963-70. https://www.ncbi.nlm.nih.gov/pubmed/26921492	Cardiac
Magyar-Russell (2014)	Magyar-Russell, G., Beckman, Daniel, Trippi, James, Gunderman, Richard, Terry, Colin, & Maria, G. C. (2014). In search of serenity: religious struggle among patients hospitalized for suspected acute coronary syndrome. J Relig Health 53(2), 562-78. <go isi="" to="">://WOS:000332482600023</go>	Cardiac
Maria (2021)	Maria, G. C., Gibson, D., Flattery, M., Duncan, A., & Hess, M. (2021). Adjustment Mechanisms in the Acute Phase of Myocardial Infarction in Men. Psychol Rep (), 332941211040425. https://www.ncbi.nlm.nih.gov/pubmed/34455859	Cardiac
McConnell (2011)	McConnell, T. R., de Carvalho, E. C., & Beijo, L. A. (2011). Demographic differences in religious coping after a first-time cardiac event. J Cardiopulm Rehabil Prev 31(5), 298-302. https://www.ncbi.nlm.nih.gov/pubmed/21623215	Cardiac
Miller (2007)	Miller, Joan F., Yadollahpour, M. H., & Akbarzadeh Pasha, A. (2007). Religiosity and spirituality: Influence on quality of life and perceived patient self-efficacy among cardiac patients and their spouses. Journal of Religion and Health 46(2), 299-313. <go isi="" to="">://WOS:000246184300010</go>	Cardiac
Mills (2015)	Mills, P. J., Safaei, M., Jahanbin, I., Ostovan, M. A.Keshvarzi, S., Moeini, M., Emery, C. F., Kozora, E., Diaz, P. T., Make, B. J., Moeini, M.Rejeh, N., Heravi-Karimooi, M., Vaismoradi, M., Jasper, M., Mohamed, N. F., Heidari, S., Sanjari, M., & Yazdanmehr, M. (2015). Depressive symptoms and spiritual wellbeing in asymptomatic heart failure patients. J Behav Med 38(3), 407-15. https://www.ncbi.nlm.nih.gov/pubmed/25533643	Cardiac
Mills (2015)	Mills, P. J., Seibert, G. S., May, R. W., Wilson, C. M.Lister, Z. D., Mills, P. J., Safaei, M., Jahanbin, I., Ostovan, M. A., Keshvarzi, S., & Moeini, M. (2015). The Role of Gratitude in Spiritual Well- being in Asymptomatic Heart Failure Patients. Spiritual Clin Pract (Wash D C ) 2(1), 5-17. https://www.ncbi.nlm.nih.gov/pubmed/26203459	Cardiac

First Author (Year)	Full Citation	Disease Group
Moeini (2012)	Moeini, M., Emery, C. F., Kozora, E., & Diaz, P. T. (2012). The effect of spiritual care on spiritual health of patients with cardiac ischemia. Iran J Nurs Midwifery Res 17(3), 195-9. https://www.ncbi.nlm.nih.gov/pubmed/23833611	Cardiac
Moeini (2016)	Moeini, M., Rejeh, N., & Heravi-Karimooi, M. (2016). Effect of Islam-based religious program on spiritual wellbeing in elderly with hypertension. Iran J Nurs Midwifery Res 21(6), 566-571. https://www.ncbi.nlm.nih.gov/pubmed/28194194	Cardiac
Mohamed (2018)	Mohamed, N. F., Heidari, S., Sanjari, M., Yazdanmehr, M., & Shirazi, F. (2018). Development and Validation of a Cross-Cultural Heart Failure-Specific Quality of Life Questionnaire. Sultan Qaboos Univ Med J 18(4), e494-e500. https://www.ncbi.nlm.nih.gov/pubmed/30988969	Cardiac
Ngo (2021)	Ngo, L. H., Ghazali, S. R., Yaacob, N. A., Rahim, A. A. A.Maskon, O., Nogueira, M., & Silva, Gpfd (2021). Plasma protein expression profiles, cardiovascular disease, and religious struggles among South Asians in the MASALA study. Sci Rep 11(1), 961. <go isi="" to="">://WOS:000621765000114</go>	Cardiac
Nogueira (2012)	Nogueira, M. & Silva, Gpfd (2012). Central pain due to stroke: cognitive representation and coping according to gender. Arq Neuropsiquiatr 70(2), 125-8. <go isi="" to="">://WOS:000300650300010</go>	Cardiac
Ozdemir (2022)	Ozdemir, S., Moehl, Bennett, Fenster, Juliane R., Suresh, D. P.Bliss, Debbie, Park, C. L., Ramos, Cristiana, & Lobarinhas, Armanda (2022). Associations Between Prognostic Awareness, Acceptance of Illness, and Psychological and Spiritual Well-being Among Patients With Heart Failure. Journal of Cardiac Failure 28(5), 736-743. https://www.ncbi.nlm.nih.gov/pubmed/34655774	Cardiac
Park (2008)	Park, C. L., Cheawchanwattana, A., Kanjanabuch, T., Buranapatana, M., & Chanthapasa, K. (2008). Coping, meaning in life, and quality of life in congestive heart failure patients. Qual Life Res 17(1), 21-6. https://www.ncbi.nlm.nih.gov/pubmed/18034319	Cardiac
Park (2008)	Park, Crystal L., Zhang, Q., Lin, T., Shen, J., & Li, D. (2008). Religiousness and treatment adherence in congestive heart failure patients. Journal of Religion, Spirituality & Aging 20(4), 249- 266. <go isi="" to="">://WOS:000212769300002</go>	Cardiac
Park (2012)	Park, C. L. & Ramos, Cristiana (2012). Is religious coping related to better quality of life following acute myocardial infarction?. J Relig Health 51(4), 1337-46. https://link.springer.com/article/10.1007/s10943-010-9446-4	Cardiac
Park (2012)	Park, C. L., Soleimani, M. A., & Allen, K. A. (2012). Expanding coping goodness-of-fit: religious coping, health locus of control, and depressed affect in heart failure patients. Anxiety Stress Coping 25(2), 137-53. https://www.ncbi.nlm.nih.gov/pubmed/22272787	Cardiac
Park (2017)	Park, C. L. and Sharif, S. P. (2017). Heart failure patients' desires for spiritual care, perceived constraints, and unmet spiritual needs: relations with well-being and health-related quality of life. Psychol Health Med 22(9), 1011-1020. https://www.ncbi.nlm.nih.gov/pubmed/27838924	Cardiac

First Author (Year)	Full Citation	Disease Group
Park (2020)	Park, C. L. & Yildizeli, S. O. (2020). Unique effects of religiousness/spirituality and social support on mental and physical well-being in people living with congestive heart failure. J Behav Med 43(4), 630-637. https://www.ncbi.nlm.nih.gov/pubmed/31522357	Cardiac
Peng (2021)	Peng, J. R., Uwakwe, R., Odinka, P. C., Ndukuba, A. C.Muomah, C. R., Ohaeri, J. U., & Pereira, M. Graça (2021). Role of an e-Health Intervention in Holistic Healthcare: A Quasiexperiment in Patients Undergoing Cardiac Catheterization in Taiwan. J. Healthc. Eng. 2021(), . https://www.ncbi.nlm.nih.gov/pubmed/33815732	Cardiac
Prasomsri (2014)	Prasomsri, J., Bellettiere, John, Nativ, Orit, & Ladislav, Slezak (2014). Walking and stair climbing abilities in individuals after chronic stroke with and without mental health problem. J Med Assoc Thai 97(), S10-5.	Cardiac
Ramesh (2021)	Ramesh, S., Colet, P. C., & Alquwez, N. (2021). Spiritual well-being and coronary artery diseases severity: Mediating effects of anger rumination and worry. Health Education Journal 80(5), 501-512. https://www.embase.com/search/results?subaction=viewrecord&id=L2007675336&from=export http://dx.doi.org/10.1177/0017896920976697	Cardiac
Safabakhsh (2015)	Safabakhsh, L., Nascimento, F. A., Macêdo, T. P., & Morano, M. T. (2015). The Effect of Health Promoting Programs on Patient's Life Style After Coronary Artery Bypass Graft-Hospitalized in Shiraz Hospitals. Glob J Health Sci 8(5), 154-9. https://www.ncbi.nlm.nih.gov/pubmed/26652073	Cardiac
Saiz (2020)	Saiz, J., Afshar, P. F., Bagheri, T., Naderi, N.Amin, A., Khalili, Y., Shahbazi, H., Moulaert, V. R., & van Heugten, C. (2020). Is Belonging to a Religious Organization Enough? Differences in Religious Affiliation Versus Self-ratings of Spirituality on Behavioral and Psychological Variables in Individuals with Heart Failure. Healthcare (Basel) 8(2), .	Cardiac
Shao (2014)	Shao, J., Terhorst, L., Jhamb, M., Unruh, M., & Myaskovsky, L. (2014). Well-being of elderly stroke survivors in Chinese communities: mediating effects of meaning in life. Aging Ment Health 18(4), 435-43. https://www.ncbi.nlm.nih.gov/pubmed/24188409	Cardiac
Soleimani (2018)	Soleimani, M. A., Lee, Y. H., Salman, A., Seo, Y., & Marin, P. A. (2018). Exploring the Relationship Between Spiritual Well-Being and Death Anxiety in Survivors of Acute Myocardial Infarction: Moderating Role of Sex, Marital Status and Social Support. J Relig Health 57(2), 683-703. <go to<br="">ISI&gt;://WOS:000427648100023</go>	Cardiac
Soleimani (2020)	Soleimani, M. A., Ross, K., Masters, K. S., & Park, C. L. (2020). Predictors of Quality of Life in Patients with Heart Disease. J Relig Health 59(4), 2135-2148. https://www.ncbi.nlm.nih.gov/pubmed/31894523	Cardiac

First Author (Year)	Full Citation	Disease Group
Taghavi (2020)	Taghavi, S., Austin Argentieri, M., Dillon, S. T., Kent, B. V., Kanaya, A. M., & Shields, A. E. (2020). The Relationship Between Spiritual Health and Quality of Life of Heart Transplant Candidates. J Relig Health 59(3), 1652-1665. <go isi="" to="">://WOS:000534796200035</go>	Cardiac
Trevino (2014)	Trevino, K. M. and Warner, E. T. (2014). Religiosity and religious coping in patients with cardiovascular disease: change over time and associations with illness adjustment. J Relig Health 53(6), 1907-17. https://www.ncbi.nlm.nih.gov/pubmed/24908582	Cardiac
Trevino (2015)	Trevino, K. M. and Soares, Rces (2015). Religiosity and Spirituality During Cardiac Rehabilitation: A LONGITUDINAL EVALUATION OF PATIENT-REPORTED OUTCOMES AND EXERCISE CAPACITY. J Cardiopulm Rehabil Prev 35(4), 246-54. https://www.ncbi.nlm.nih.gov/pubmed/25730095	Cardiac
Vollman (2009)	Vollman, M. W., Lee, J. J., & Malhotra, C. (2009). Existential well-being predicts perceived control in adults with heart failure. Appl Nurs Res 22(3), 198-203. https://www.ncbi.nlm.nih.gov/pubmed/19616168	Cardiac
Wachelder (2016)	Wachelder, E. M., Hinderliter, Alan L., Blumenthal, James A., Sherwood, Andrew, Steffen, P. R., & Hinderliter, A. L. (2016). Dealing with a life changing event: The influence of spirituality and coping style on quality of life after survival of a cardiac arrest or myocardial infarction. Resuscitation 109(), 81-86. https://www.ncbi.nlm.nih.gov/pubmed/27737773	Cardiac
Wang (2022)	<ul> <li>Wang, Z., Malaguti, C., Dos Anjos Sena, L., Lucchetti, G.de Jesus, L. A. S., Vitorino, L. M.,</li> <li>Mesquita, R., Lee, A. L., Oliveira, C. C., &amp; Warber, S. L. (2022). Needs for nurses to provide</li> <li>spiritual care and their associated influencing factors among elderly inpatients with stroke in China:</li> <li>A cross-sectional quantitative study. Palliat Support Care 20(3), 407-416. <go li="" to<=""> <li>ISI&gt;://WOS:000792164100001</li> </go></li></ul>	Cardiac
Warber (2011)	Warber, S. L., Pung, M. A., Wilson, K. L., Pruitt, C.Rutledge, T., Redwine, L., Taub, P. R., Greenberg, B. H., Mills, P. J., & Wong, F. K. Y. (2011). Healing the heart: a randomized pilot study of a spiritual retreat for depression in acute coronary syndrome patients. Explore (NY) 7(4), 222-33. https://www.ncbi.nlm.nih.gov/pubmed/21724155	Cardiac
Yaghoobzadeh (2018)	Yaghoobzadeh, A., Ingerman, S., Moura, V. L., Wunder, J., & Northrop, A. (2018). Relationship Between Spiritual Well-Being and Hope in Patients with Cardiovascular Disease. J Relig Health 57(3), 938-950. <go isi="" to="">://WOS:000430308500012</go>	Cardiac
Nuraeni (2018)	Nuraeni, A., Malone, M. R., & Suresh, D. P. (2018). Relationship of Spiritual-Wellbeing with Anxiety and Depression in Patients with Cardiac Heart Disease. Belitung Nurs. J. 4(1), 45-50. <go to ISI&gt;://WOS:000558626600008</go 	Cardiac

First Author (Year)	Full Citation	Disease Group
Ai (2009)	Ai, A. L. & Kara, Fahriye Şeyma (2009). The Temporal Nature of Direct Faith Effect on Global Functioning and Vitality in Patients Undergoing Open-Heart Surgery. (), 59-83.	Cardiac
Wong (2015)	Wong, F. K. Y. and Zhao, H. (2015). Effects of a 4-week transitional care programme for discharged stroke survivors in Hong Kong: a randomised controlled trial. Health Soc. Care Community 23(6), 619-631. https://www.ncbi.nlm.nih.gov/pubmed/25470529	Cardiac
Kütmeç Yilmaz (2021)	Kütmeç Yilmaz, C. & Musabak, I. (2021). The effect of spiritual well-being on adaptation to chronic illness among people with chronic illnesses. Perspectives in Psychiatric Care 57(1), 318-325.	Cardiac <sup>1</sup>
Dabrowska- Bender (2017)	Dabrowska-Bender, M., LaMontagne, L. L., Wallston, K. A., Darvishi, A., & Sabanciogullari, S. (2017). The Impact of Ischemic Cerebral Stroke on the Quality of Life of Patients Based on Clinical, Social, and Psychoemotional Factors. J. Stroke Cerebrovasc. Dis. 26(1), 101-107. https://www.ncbi.nlm.nih.gov/pubmed/27746082	Cardiac
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Fincham (2018)	Fincham, F. D., Herrick, L. M., Pankratz, V. S., Mueller, P. S., & Flint, K. M. (2018). Religious Coping and Glycemic Control in Couples with Type 2 Diabetes. J Marital Fam Ther 44(1), 138-149. https://www.ncbi.nlm.nih.gov/pubmed/28589560	Diabetes
Gonzalez (2021)	Gonzalez, M. B., Sarno, S., Dall'Armi, V., & Spiridigliozzi, C. (2021). Spiritual connectedness through prayer as a mediator of the relationship between Indigenous language use and positive mental health. Cultur Divers Ethnic Minor Psychol 27(4), 746-757. https://www.ncbi.nlm.nih.gov/pubmed/34291975	Diabetes

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Ischaq Nabil Asshiddiqi (2021)	Ischaq Nabil Asshiddiqi, M., Pedersen, Christina G., & Pargament, Kenneth I. (2021). Predictors of diabetes distress among older persons with type 2 diabetes mellitus in Indonesia. J. Res. Nurs. 26(4), 307-317. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85092495425&doi=10.1177%2f1744987120943936&partnerID=40&md5=16e80ec99da503bd768a 95809806a4f1	Diabetes
Jafari (2014)	Jafari, N., Jahantigh, M., Nosratzehi, S., & Navabi, S. (2014). Spiritual well-being and quality of life of Iranian adults with type 2 diabetes. Evid Based Complement Alternat Med 2014(), 619028. https://www.ncbi.nlm.nih.gov/pubmed/24600478	Diabetes
Javanmardifard (2020)	Javanmardifard, S., Ghajari, H., Shakerinejad, G., Ghofranipour, F., & Johnstone, B. (2020). The relationship between spiritual well-being and hope, and adherence to treatment regimen in patients with diabetes. J Diabetes Metab Disord 19(2), 941-950. https://www.ncbi.nlm.nih.gov/pubmed/33520814	Diabetes
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Landis (1996)	Landis, B. J. (1996). Uncertainty, spiritual well-being, and psychosocial adjustment to chronic illness. Issues in Mental Health Nursing 17(3), 217-231. https://www.ncbi.nlm.nih.gov/pubmed/8707542	Diabetes
Newlin (2003)	Newlin, K., Vickers, Kristin S., Sampson, Shirlene, & Netzel, Pamela (2003). The relationship of spirituality and health outcomes in black women with type 2 diabetes. Ethnicity and Disease 13(1), 61-68. https://www.ncbi.nlm.nih.gov/pubmed/12723014	Diabetes
Newlin (2008)	Newlin, K., Christos, A. P., Theodoros, D. K., Ioannis, A. N., & Charalambos, I. K. (2008). Relationships of religion and spirituality to glycemic control in Black women with type 2 diabetes. Nurs Res 57(5), 331-9. https://www.ncbi.nlm.nih.gov/pubmed/18794717	Diabetes
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Nozari (2014)	Nozari, M., Melkus, G. D., & Tappen, R. (2014). Spiritual Development and Death Attitude in Female Patients With Type II Diabetes. Iran J Psychiatry Behav Sci 8(3), 58-64. https://www.ncbi.nlm.nih.gov/pubmed/25780376	Diabetes
Parsian (2009)	Parsian, N. and Xue, G. F. (2009). Spirituality and coping in young adults with diabetes: A cross- sectional study. European Diabetes Nursing 6(3), 100-104.	Diabetes

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Saffari (2019)	Saffari, M., Ximenes, M. A. M., Eloia, S. C., & Galindo Neto, N. M. (2019). The role of religious coping and social support on medication adherence and quality of life among the elderly with type 2 diabetes. Qual Life Res 28(8), 2183-2193. <go isi="" to="">://WOS:000475577200016</go>	Diabetes
Shahbazi (2020)	Shahbazi, H., Moulaert, V. R., van Heugten, C., & Gorgels, T. (2020). Survey on relationship of spirituality with the perception of suffering and quality of life in patients with type 2 diabetes. Health Educ. Health Promot. 8(3), 141-147. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85102248235&partnerID=40&md5=afa699eef8e91d91cf87b5eb6cc83392	Diabetes
Shamsalinia (2016)	Shamsalinia, A., Raanan, O., & Shafir, G. (2016). The Relationship Between Hope and Religious Coping Among Patients With Type 2 Diabetes. Global journal of health science 8(1), 208-216. https://www.embase.com/search/results?subaction=viewrecord&id=L608627179&from=export http://dx.doi.org/10.5539/gjhs.v8n1p208	Diabetes
Sukkarieh-Haraty (2019)	Sukkarieh-Haraty, O., Carey, E. P., Fairclough, D., & Plomondon, M. E. (2019). Diabetes fatalism and its emotional distress subscale are independent predictors of glycemic control among Lebanese patients with type 2 diabetes. Ethn Health 24(7), 767-778. <go isi="" to="">://WOS:000477732300003</go>	Diabetes
Tuncay (2008)	Tuncay, T., Braam, A. W., Loosman, W. L., & van den Beukel, T. O. (2008). The relationship between anxiety, coping strategies and characteristics of patients with diabetes. Health Qual Life Outcomes 6(), 79. <go isi="" to="">://WOS:000260337000001</go>	Diabetes
Yundarini (2018)	Yundarini, N. M. C., Kanjanabuch, T., & Puapatanakul, P. (2018). Factors Related to Resilience in Type 2 Diabetes Mellitus Patients in Denpasar Based on Self-Concept Mode of Roy Adaptation Model. Belitung Nurs. J. 4(4), 373-379. <go isi="" to="">://WOS:000558627700003</go>	Diabetes
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Cheawchanwattan a (2022)	Cheawchanwattana, A., Khalilian, A., Dousti, Y., Chen, Z.Mirwanti, R., Anna, A., Cruz, J. P., Sacco, S. J., Edmondson, D., da Silva, G. P., Besharat, M. A.Nough, H., da Silva, M. S., Pourghaznein, T., Parsa, M., Dabrowska-Bender, M., LaMontagne, L. L., Wallston, K. A., & Darvishi, A. (2022). Spiritual well-being and its relationship with patient characteristics and other patient-reported outcomes in peritoneal dialysis patients: Findings from the PDOPPS. Nephrology (Carlton) 27(7), 621-631. https://www.ncbi.nlm.nih.gov/pubmed/35238113	Renal

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Darvishi (2020)	Darvishi, A., Davies, S. J., & Davis, B. A. (2020) The Effectiveness of Spiritual Therapy on Spiritual Well-Being, Self-Esteem and Self-Efficacy in Patients on Hemodialysis. J Relig Health. 59(1), 277-288. https://www.ncbi.nlm.nih.gov/pubmed/30673996	Renal
Ebrahimi (2021)	Ebrahimi, A., Hall, D., Pargament, K., Tice, T. N., & Eloia, S. M. C. (2021). The relationship between spiritual health and resilience in hemodialysis patients. Journal of Babol University of Medical Sciences 23(1), 135-141. https://www.embase.com/search/results?subaction=viewrecord&id=L2007234508&from=export	Renal
Eloia (2021)	Eloia, S. M. C., Hopp, F., Tice, T. N., Koenig, H., Faria, E. C., & Pargament, K. I. (2021). Religious coping and hope in chronic kidney disease: a randomized controlled trial. Rev Esc Enferm USP 55(), e20200368. https://www.ncbi.nlm.nih.gov/pubmed/34435610	Renal
Gemmell (2016)	Gemmell, L. A., Casey, A., Dusek, J. A., Benson, H.George, Login S., Kimura, M., & Stelmach, R. (2016). Gender and Racial Differences in Stress, Coping, and Health-Related Quality of Life in Chronic Kidney Disease. J Pain Symptom Manage 52(6), 806-812. https://www.ncbi.nlm.nih.gov/pubmed/27697565	Renal
Haverkamp (2020)	Haverkamp, G. L. G., Farajzadegan, Z., Loghmani, A., Majlesi, M.Helvaci, A., Ghasemi, T. M., Yousefi, H., & Abedi, H. (2020). Religiousness and Symptoms of Depression in Native and Immigrant Chronic Dialysis Patients in the Netherlands. J Clin Psychol Med Settings 27(1), 127- 138. https://www.ncbi.nlm.nih.gov/pubmed/31087239	Renal
IzadiAvanji (2021)	Izadi Avanji, F. S., Jalayondeja, C., Bovonsunthonchai, S., & Khemthong, S. (2021). Self-Care and Its Predictive Factors in Hemodialysis Patients. J Caring Sci 10(3), 153-159. https://www.ncbi.nlm.nih.gov/pubmed/34849359	Renal
Loureiro (2018)	Loureiro, A. C. T., Seymour, E. Mitchell, Tice, Terrence N., Kronfol, Ziad, & Bolling, Steven F. (2018). The influence of spirituality and religiousness on suicide risk and mental health of patients undergoing hemodialysis. Compr Psychiatry 80(), 39-45. https://www.ncbi.nlm.nih.gov/pubmed/28972917	Renal
Martínez (2014)	Martínez, B. B. & Davis, B. A. (2014). Relationship between mental health and spiritual wellbeing among hemodialysis patients: A correlation study. Sao Paulo Medical Journal 132(1), 23-27. https://www.embase.com/search/results?subaction=viewrecord&id=L372225407&from=export http://dx.doi.org/10.1590/1516-3180.2014.1321606	Renal

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Taheri Kharame (2014)	Taheri Kharame, Z., Su, H. C., Lin, C. P., & Chen, C. C. (2014). Religious wellbeing as a predictor for quality of life in Iranian hemodialysis patients. Glob J Health Sci 6(4), 261-9. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4825247/pdf/GJHS-6-261.pdf	Renal
Vitorino (2018)	Vitorino, L. M., da Silva, G. P. F., do Nascimento, F. A. B., Holanda, M. A.Mont'Alverne, D. G. B., de Oliveira Junior, P. V., & Janssen, D. J. A. (2018). Two Sides of the Same Coin: The Positive and Negative Impact of Spiritual Religious Coping on Quality of Life and Depression in Dialysis Patients. J Holist Nurs 36(4), 332-340. https://www.ncbi.nlm.nih.gov/pubmed/28836475	Renal
Zhang (2020)	Zhang, Y. J., Wilson, K., Iqbal, N., Iqbal, F., & Alvarez, M. (2020). Factors related to spiritual health in Chinese haemodialysis patients: A multicentre cross-sectional study. Nurs. Open 7(5), 1536-1543. https://www.ncbi.nlm.nih.gov/pubmed/32802374	Renal
Chen (2021)	Chen, Z., Mirwanti, R., Anna, A., Cruz, J. P., & Sacco, S. J. (2021). Resilience as a Mediator of the Association between Spirituality and Self-Management among Older People with Chronic Obstructive Pulmonary Disease. Healthcare (Basel) 9(12), . https://www.ncbi.nlm.nih.gov/pubmed/34946360	Respiratory
daSilva (2009)	da Silva, M. S., Pourghaznein, T., Parsa, M., & Dabrowska-Bender, M. (2009). Quality of life and spiritual well-being in chronic obstructive pulmonary disease patients. Rev. Escola Enferm. 43(), 1186-1191. https://www.scopus.com/inward/record.uri?eid=2-s2.0- 84875260364&doi=10.1590%2fS0080- 62342009000600007&partnerID=40&md5=c404d92a9dfc3873fd56dba9382028d0	Respiratory
daSilva (2018)	da Silva, G. P., da Silva, G. P. F., da Silva, M. S., Dabrowska-Bender, M., Dall'Armi, V., & Darvishi, A. (2018). Religious coping and religiosity in patients with COPD following pulmonary rehabilitation. Int J Chron Obstruct Pulmon Dis. 13(), 175-181. https://www.ncbi.nlm.nih.gov/pubmed/29379282	Respiratory
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Green (2011)	Green, M. R., Näring, G., Kwakkenbos, L., Becker, E. S., & Greer, D. B. (2011). Religious and spiritual coping and quality of life among patients with emphysema in the National Emphysema Treatment Trial. Respir Care 56(10), 1514-21. https://www.ncbi.nlm.nih.gov/pubmed/21513606	Respiratory

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Mendes (2022)	Mendes, N. S., Jiang, Y., Chen, M., Baiyila, N.Nan, J., Mesquita, R., Milewska, M., Golabek, A., & Duda-Zalewska, A. (2022). Spirituality and religiosity are associated with physical and psychological status in patients with chronic obstructive pulmonary disease. J Clin Nurs 31(5), 669-678. https://www.ncbi.nlm.nih.gov/pubmed/34164870	Respiratory
Mesquita (2021)	Mesquita, R., Milewska, M., Golabek, A., Duda-Zalewska, A.Staniszewska, A., Miller, Joan F., Yadollahpour, M. H., & Akbarzadeh Pasha, A. (2021). Religiosity and Religious Coping in Patients with COPD: A Cross-Sectional Comparison Between Brazil and the Netherlands and Associations with Physical and Psychological Health. J Relig Health (), .	Respiratory
Nascimento (2019)	Nascimento, Fabd, Franklin, K. L., Yoon, D. P., Burris, J., & Shigaki, C. (2019). Assessment of religious coping in patients with COPD. J Bras Pneumol 46(1), e20180150. https://www.ncbi.nlm.nih.gov/pubmed/31644700	Respiratory
Pedersen (2013)	Pedersen, Heidi Frølund, Peterson, C., Tice, T. N., & Rodgers, W. (2013). Coping without religion? Religious coping, quality of life, and existential well-being among lung disease patients and matched controls in a secular society. Research in the Social Scientific Study of Religion 24(), 163- 192. http://proxy.lib.umich.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=psyh &AN=2013-20899-007&site=ehost-live&scope=site ORCID: 0000-0001-9076-3068 hefpe@psy.au.dk	Respiratory
Sagmen (2020)	Sagmen, S. B., Brown, I. T., Edara, I. R., Smith, M. T., & Marine, J. E. (2020). The effects of anxiety and depression on asthma control and their association with strategies for coping with stress and social acceptance. Rev. Fr. Allergol. 60(5), 401-406. <go isi="" to="">://WOS:000561643700003</go>	Respiratory
Yilmaz (2021)	Yilmaz, F. T., Redwine, L., & Wilson, K. (2021). The Effect of Religious Coping on the Satisfaction with Life Among Turkish Patients with Chronic Obstructive Pulmonary Disease. J. Relig. Health (), . https://link.springer.com/article/10.1007/s10943-021-01236-3	Respiratory

# Table 2.8

	Al	l Articles	(	Cardiac	Ι	Diabetes		Renal	Re	spiratory
<i>n</i> =118	п	M (SD) [CI]	п	M (SD) [CI]	п	M (SD) [CI]	п	M (SD) [CI]	п	M (SD) [CI]
Age	87	59.5 (8) [22.7, 74.4]	56	62.5 (5.7) [41, 74.4]	21	53.8 (10.2) [22.7, 70.2]	10	54.2 (4.4) [48, 64]	10	54.2 (4.4) [48, 64]
Race / Ethnicity										
White	36	79.2% (0.1) [0.47, 1]	32	81% (0.1) [0.47, 1]	2	58.5% (0.1) [0.51, 0.66]	2	71.5% (0.1) [0.65, 0.78]	2	25% (0.1) [0.19, 0.31]
Black	25	31.6% (0.3) [0.04, 1]	19	22.4% (0.2) [0.04, 1]	4	78.8% (0.4) [0.15, 1]	2	25% (0.1) [0.19, 0.31]	2	94.5% (0.1) [0.89, 1]
Asian	11	69.2% (0.4) [0.01, 1]	7	67.3% (0.4) [0.05, 1]	2	50.5% (0.7) [0.01, 1]	2	94.5% (0.1) [0.89, 1]		
Latinx / Hispanic	10	3% (0) [0.01, 0.08]	9	2.4% (0) [0.01, 0.04]	1	8% (0) [0.08, 0.08]			5	100% (0) [1, 1]
Middle Eastern / North African	25	96.2% (0.2) [0.04, 1]	13	100% (0) [1, 1]	7	86.3% (0.36) [0.04, 1]	5	100% (0) [1, 1]		
Indigenous / Native American	9	14.1% (0.3) [0, 1]	7	3.7% (0) [0, 0.07]	2	50.5% (0.7) [0.01, 1]				
Pacific Islander	2	2% (0) [0.02, 0.02]	2	2% (0) [0.02, 0.02]					3	15.7% (0.2) [0.03, 0.33]
Multiple / Other Race	16	14.4% (0.1) [0.01, 0.38]	12	12.5% (0.1) [0.01, 0.38]	1	34% (0) [0.34, 0.34]	3	15.7% (0.2) [0.03, 0.33]		
Religious Identity										

Demographics of all included studies and by disease group

	Al	l Articles	(	Cardiac	Ι	Diabetes		Renal	Re	spiratory
Protestant	28	63.8% (0.3) [0.13, 1]	23	65.9% (0.3) [0.14, 0.94]	1	83% (0) [0.83, 0.83]	4	47% (0.4) [0.13, 1]	2	58.5% (0.3) [0.38, 0.79]
Catholic	17	47.7% (0.3) [0.06, 0.84]	15	46.3% (0.3) [0.06, 0.84]			2	58.5% (0.3) [0.38, 0.79]		
Jewish	6	2.7% (0) [0.01, 0.05]	6	2.7% (0) [0.01, 0.05]					2	58% (0.6) [0.16, 1]
Muslim	11	52.2% (0.5) [0.01, 1]	8	44.8% (0.4) [0.01, 1]	1	100% (0) [1, 1]	2	58% (0.6) [0.16, 1]		
Hindu	5	23.2% (0.3) [0.01, 0.6]	4	14% (0.2) [0.01, 0.41]	1	60% (0) [0.6, 0.6]			1	100% (0) [1, 1]
Buddhist	4	31.8% (0.5) [0.02, 1]	3	9% (0.08) [0.02, 0.17]			1	100% (0) [1, 1]		
Orthodox	1	2% (0) [0.02, 0.02]	1	2% (0) [0.02, 0.02]					2	7% (0) [0.04, 0.1]
Other	16	13.1% (0.1) [0.01, 0.42]	14	13.9% (0.1) [0.01, 0.42]			2	7% (0) [0.04, 0.1]	1	2% (0) [0.02, 0.02]
Atheist / Agnostic	5	3.8% (0.1) [0.01, 0.13]	4	4.3% (0.1) [0.01, 0.13]			1	2% (0) [0.02, 0.02]		
Religiosity										
Religious	9	59.6% (0.4) [0.1, 0.97]	4	44.5% (0.4) [0.1, 0.87]	2	87% (0.03) [0.85, 0.89]	3	61.3% (0.43) [0.14, 0.97]	3	37.3% (0.43) [0.03, 0.86]
Not Religious	7	36.4% (0.3) [0.03, 0.86]	3	44% (0.4) [0.13, 0.84]	1	11% (0) [0.11, 0.11]	3	37.3% (0.43) [0.03, 0.86]		

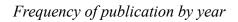
# Table 2.9

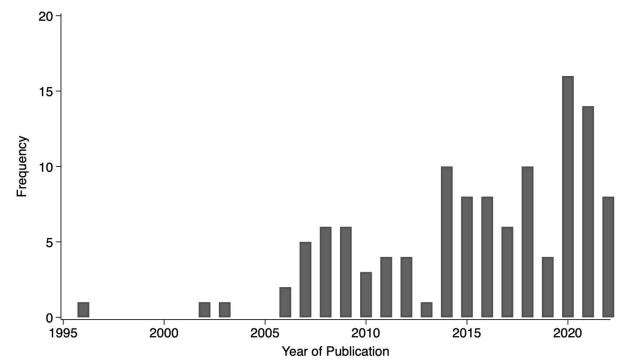
# Themes for spiritual well-being

	Positive Themes					
Theme		Description	Measures			
Meaningful connection Relationship/s that nurture and celebrate wholeness	God/sacred Others Community, any	Community, Religious	SWBS FACIT-Sp RCOPE	RCAS MQOL		
	Society	Close relationships				
	Self Environment / Nature					
Meaning in Life; Sense of Purpose Ability to seek/find	Meaning Making Will of meaning Belief in one's purpose		MQOL SWBS COPE FACIT-Sp MiL	SuWB RCOPE BMMRS RCS SQ		
Seeking (support)	God/sacred: Affection; p Others: Religious Comm		BMMRS RCOPE	RSC RCAS		
Affirmation of life	Reverence of life Satisfaction with life ( <i>Lij</i> Quality of life	fe satisfaction)	SWBS COPE	PTGI FACIT-SP		
Secure relationship with God/sacred	Security; safety Cooperation / Cooperativ	/e	SWBS FACIT-SP	SQ		
Inner Peace	Sense of and Appreciatio Unity	n for: Harmony	RCOPE RCS BMMRS	SWBS RCS FACIT-SP		

Benevolent Religious Appraisals	Positive appraisal of life events Religious involvement Trusting God's/sacred's love (for self, others) Buffers "Existential Vacuum"	BMMRS RCOPE	MIL SuWB
Positive reappraisal	Revaluation of stressors Prevent/alleviate negative emotions Forgiveness Compassion for others	RCOPE SWBS PTGI	COPE RCS
Inner strength	Resilience; Stability (in life)	SWBS RCOPE	RSC BMMRS
Facilitate positive coping	Collaborative religious coping and integration Stressful events, during/after Health behaviors, engagement with	SRC SCS	FACIT-SP
Spiritual Health	Growth Change	BMMRS	
Balance (of)	Values Goal Beliefs Relationships (self/others)	PTGI COPE	FACIT-SP

# Figure 2.3





# 2.6 References

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# Chapter 3 Characterizing Spiritual Needs of Individuals with Type 2 Diabetes and Acceptability of Chaplaincy Intervention

Non-communicable diseases (NCD), like Type 2 Diabetes Mellitus (T2DM), are the leading contributors to an increase in morbidity and mortality and the rise of healthcare costs in the U.S (Bauer et al., 2014; Buttorff et al., 2017; Centers for Disease Control and Prevention [CDC], n.d.-a; CDC, n.d.-b). T2DM is a chronic condition affecting 1 in 11 adults around the globe (Zheng et al., 2018). In the U.S., some 34 million adults are living with T2DM, placing them at elevated risk for premature death as well as multiple other negative health outcomes (CDC, 2020b; Fang et al., 2021). Although many factors underlie health outcomes for people with T2DM, including genetics (Wehby et al., 2018), environmental factors, or comorbid infectious disease (e.g., hepatitis B; O'Connor et al., 2006), several documented modifiable factors are important for both its development and control or remission (Adams et al., 2019; Ng et al., 2020; Zhang et al., 2023).

For many NCDs, lifestyle factors and behaviors can facilitate or create barriers to the best possible health outcomes. The four modifiable lifestyle factors most associated with diabetes are: diet, physical activity, tobacco use, and alcohol use (Adams et al., 2017; Keramat et al., 2021; Ng et al., 2020; Willett et al., 2006). Each of these are, in part, a function of structural determinants of health (e.g., food access and insecurity, housing instability, access to preventative/quality care, marketing and placement of unhealthy foods, alcohol, tobacco) (Cockerham et al., 2017). A lasting impact on lowering T2DM prevalence and improving management could be realized through high-level structural change. However, individual-level supportive interventions tailored

to specific unmet needs can also have success (ADA, American Diabetes Association Professional Practice, 2024b). Efforts to expand intervention and support programs to include new approaches for engaging people with T2DM could provide spiritual support and/or addressing a client's spiritual distress as they navigate and implement lifestyle changes.

A person's spiritual beliefs (inclusive of any religious, spiritual, or existential frameworks of meaning-making) can influence their health beliefs and behaviors, making them more active or passive in their disease management (Hayward, Krause, Ironson, & Pargament, 2016; Polzer & Miles, 2007). Spirituality and spiritual beliefs are considered 'essential' coping resources for those with chronic disease (Ko et al., 2007; Walton et al., 2004). Although positive aspects of spiritual well-being dominate the literature on spirituality and NCDs (Rajaee, Chapter 2), there is also evidence that challenges to or loss of spirituality can negatively influence individuals, leading to more destructive outcomes (Pargament & Exline, 2022). Spiritual distress (also referred to as 'spiritual struggles'), including feelings of abandonment, punishment, and/or anger at the intra-, inter-, and trans-personal levels (Exline, 2013), can have a negative influence on health and well-being, including increased depressive symptoms and emotional distress (Delgado-Guay et al., 2011; Hills et al., 2005; Manning-Walsh, 2005; Monod et al., 2012; Pargament et al., 2004; Velosa et al., 2017), lower quality of life (Manning-Walsh, 2005; Pargament et al., 2001), increased anxiety, poorer physical well-being (Hills et al., 2005; Siddall et al., 2017), and increased mortality (Pargament et al., 2001). Literature on acute conditions suggests that 18-53% of adult patients experiencing an acute injury or illness indicate spiritual distress (King et al., 2013; Thune-Boyle et al., 2011; Velosa et al., 2017). Preliminary data from a health system sample of adults with uncontrolled diabetes found that a fifth of participants were identified with potential spiritual distress (Rajaee et al., 2021). Those with potential spiritual,

religious, or existential distress (SRE-D) reported elevated levels of HbA1c, a poorer general diet, more chronic conditions, higher levels of diabetes-related distress, lower social support, higher psychological distress, and greater unmet social needs compared to those who did not (Rajaee et al., 2021).

These preliminary findings suggest that spiritual distress may impact health behaviors and outcomes outside the acute care setting. Evidence of similar findings of poorer medication adherence and lower quality of life among individuals with spiritual distress and epilepsy supports the possibility that SRE-D negatively influences health behaviors (Lin et al., 2018). A national study by Krause, Pargament, Hill, and Ironson (2018), found that individuals with spiritual struggles were more likely to engage in problem drinking than those not experiencing spiritual struggles; further, younger individuals were at greater risk of engaging in excess alcohol use, a health behavior known to influence the development, improvement, and resolution of chronic conditions and disease (Adams et al., 2019). This initial work suggests that SRE-D may play a role in health outcomes for people with T2DM; however, explorations of SRE-D in people with T2DM are not well represented in the literature published to date. Such explorations can offer new insights into whether and how support programs and approaches could be strengthened by including content focused on spiritual distress and well-being as people navigate lifestyle changes associated with T2DM.

Healthcare chaplains are a potential avenue for delivering and/or complementing lifestyle change interventions that enhance the inclusivity of support approaches for people with T2DM. Within healthcare settings, chaplains work as part of healthcare teams and are well represented across 57% of all hospital settings (White et al., 2021). Although most chaplains are typically involved in end-of-life and acute issues, expanding outpatient services to support those with

NCDs is increasingly being considered (Kelly & Swinton, 2020a; McSherry et al., 2016; Patel et al., 2023). With adequate preparation, chaplains could assist or provide lifestyle change interventions or support. However, it is unclear if people with T2DM would desire consultation with a chaplain if one were available (Cadge et al., 2022; Rajaee & Patel, 2021). If spiritual distress is relevant to one's experiences with T2DM and its management, chaplains may be uniquely skilled in providing tailored support. The current study examines some of these issues within a group of adults with T2DM registered in the medical care system at a large Midwest University-affiliated hospital. Specifically, we sought to characterize levels of spiritual distress among survey respondents, examine the association between spiritual distress and T2DM management and outcomes, and determine the general acceptability of chaplaincy-provided services for T2DM in outpatient care settings.

### 3.1 Methods

#### 3.1.1 Study Design & Setting

This exploratory cross-sectional study of individuals diagnosed with T2DM was conducted with participants recruited from a large Midwestern academic health system. The primary objective of this study was to describe and measure spiritual distress and the acceptability of chaplaincy services in individuals living with and managing their T2DM. Aim 1 was *to characterize spiritual distress among patients with T2DM and identify correlates of distress*. We hypothesized that spiritual distress would be uniquely associated with poorer clinical measures (i.e., HbA1c, blood pressure, and cholesterol), self-rated health, and poorer disease self-management. Aim 2 was *to determine if chaplaincy-based support services are acceptable to people with T2DM*. We hypothesized that higher awareness about chaplain services would be uniquely associated with greater acceptability of chaplaincy-based services and that participants who place higher importance on religion will indicate greater acceptability of chaplaincy-based services.

Participants were identified and recruited using a database of individuals diagnosed with T2DM associated with an academic health system. Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Michigan (Harris et al., 2009; Harris et al., 2019). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.

Following consent to participate and to allow for the use of their private health information (PHI), participants were directed to the online survey where they were asked about their diabetes management, health behaviors, religious, spiritual, and personal beliefs (including spiritual distress), and experiences and acceptability of chaplains. The University of Michigan Medical School Institutional Review Board (IRBMED) reviewed and approved this study.

#### 3.1.2 Participants

A non-probability convenience sample was identified using a health system database that provided access to electronic medical records and other private health information. Participants were recruited through an emailed survey link and offered a \$20 e-gift card as an incentive to complete the survey. As indicated in Table 3.1, enrollment into the survey was based on age (18 to 75 years of age), living with T2DM, and availability of lab results over the past 12 months. Those who were currently receiving end-of-life (EOL) or palliative care services, were admitted to the hospital (in-patient care) six months before recruitment, had a congenital basis for their

disease state, or had type 1 diabetes mellitus (T1DM) or gestational diabetes were excluded from participation. Recruitment for the study was planned to remain open until recruitment goals were met or within three months of recruitment, whichever occurred first.

## Table 3.1

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul> <li>18 – 75 years old</li> <li>Diagnosis of T2DM</li> <li>Metabolic and lipid panels completed within the previous 12 months</li> </ul>	<ul> <li>&gt; 75 years of age</li> <li>Receiving EOL or palliative care services</li> <li>Admitted to the hospital within the past six months</li> <li>Have a congenital basis for their disease state</li> <li>Have T1DM and Gestational Diabetes</li> </ul>

## 3.1.3 Survey Development

The self-administered online survey included sections for sociodemographic information, spiritual distress, behavioral factors, psychosocial factors, and aspects of chaplaincy services for preventative care and related behavioral contributors to chronic conditions. The survey underwent an iterative development process with testing by non-diabetic volunteers, averaging about 15 minutes to complete. Electronic medical records data extraction included past year HbA1c, cholesterol, comorbidities, and T2DM-related health outcomes.

# 3.1.4 Measures

**Sociodemographic and Health Status Factors.** Questions included basic demographic factors (e.g., age, gender identity, race/ethnicity, education, marital status) and a single-item self-rated health question used to describe how participants viewed their health. To understand how long participants have lived with their T2DM diagnosis, they were asked to provide the year they received their diagnosis. If they could not remember the exact year, they were encouraged to

provide an estimate if they could not remember the exact year. An indicator variable for gender (female, non-female) was created to use for regression analyses. Self-rated health was used as a continuous variable (1 = "poor" to 5 = "very good") in regression analyses with higher scores indicating better self-rated health.

**Religious affiliation.** The PEW Research Center's Religious Landscape Survey (PRC, n.d.) was used to categorize participants' affiliation with religious, spiritual, or faith traditions (i.e., Protestant, Muslim, Jewish, Buddhist, etc.). Response options included faith traditions (i.e., Protestant, Muslim, Jewish, Buddhist, Hindu, etc.), non-religious traditions (i.e., atheist, agnostic, spiritual but not religious, etc.), and an option to self-describe. Those who indicated they were from one of the Christian traditions (e.g., Protestant, Catholic, Orthodox) were asked if they identified as an Evangelical. Participants were later assigned to one of five categories: Christian (Protestant Christian, Catholic, Orthodox), atheist/agnostic, spiritual but not religious (*"nothing in particular"*), other/multiple, and prefer not to say. A variable with four categories (*Christian, atheist/agnostic, spiritual but not religious*, and *other*) was created and used in regression analyses.

**Religious, Spiritual, and Personal Beliefs.** The WHOQOL-SRPB BREF questionnaire was used to assess participants' overall spiritual well-being and the extent to which they consider themselves spiritual, religious, or holding strong personal beliefs (Skevington et al., 2013; WHO, 2012). Subscales included: 1) Connection to a spiritual being, 2) Meaning and purpose in life, 3) Awe and wonder, 4) Wholeness and integration, 5) Spiritual strength, 6) Inner peace, 7) Hope and optimism, and 8) Faith. These subscales are also attributed to religious beliefs (1, 4, 5, and 8) and existential concerns (2, 3, 6, and 7). Items were scored using a 5-point Likert scale (1 = "Not at all" and 5 = "An extreme amount") and summed to create an overall total score, scores for

religious beliefs and existential concerns, and each of the eight subscales. The importance of religious, spiritual, or personal beliefs was measured using three items from the WHOQOL-SRPB BREF where participants were asked: "To what extent do you consider yourself to 1) be a *spiritual* person, 2) be a *religious* person, 3) have *strong personal beliefs*?" Response options included "Not at all" (1) to "An extreme amount" (5), with higher scores indicating strong spiritual, religious, or personal beliefs.

#### 3.1.5 Behavioral and Psychosocial Factors

**Health Risk Behavior Inventory.** The Health Risk Behavior Inventory (HRBI) was used to assess specific health risk behaviors (i.e., physical inactivity, diet, smoking, and alcohol use) and is validated for use in both clinical and research contexts (Irish, 2011; Monni & Scalas, 2022). A health risk behavior score was created using a total of all items for each of the four subscales: physical activity (5 items), diet (4 items), alcohol use (6 items), and smoking (6 items). Response options used a five-point Likert scale (1 = "Never true" to 5 = "Always true"), with some items requiring reverse coding. Higher HRBI scores (total and subscales) indicate greater engagement in health-risk behaviors (Monni & Scalas, 2022).

**Diabetes Self-Management**. The Diabetes Self-Management Questionnaire (DSMQ) was used to describe self-reported management of T2DM (Schmitt et al., 2013). Items used a 4-point Likert scale (1 = "Applies to me very much" to 4 = "Does not apply to me") with some items reverse coded for scoring. Scores for the DSMQ are created by the sum of the item scores, which are divided by three times the number of items completed by a participant and then multiplied by ten (Schmitt et al., 2013; Schmitt et al., 2016). The analyses used total scores where higher scores indicated less engagement in diabetes self-management (Lam & Fresco, 2015).

**Depression & Anxiety.** The Patient Health Questionnaire for Depression and Anxiety (PHQ-4) was used to identify anxiety and depression symptoms in participants (Kroenke et al., 2009). This four-item measure consists of two questions to assess depressive symptoms and two questions to assess the presence of anxiety. Like the longer version of the Patient Health Questionnaire for Depression and Anxiety (PHQ-9), this brief measure uses the same question stem ("Over the last two weeks, how often have you been bothered by the following problems?") with four response items (0= "not at all"; 1 = "several days"; 2 = "more than half the days"; 3 = "nearly every day") with a range of scores from 0 to 12 with higher scores indicating greater depression and anxiety. Indicator variables identifying individuals who may be experiencing anxiety or depression were created using a cut-off score of < 3 (no indication) and  $\ge 3$  (suggesting the presence of depression or anxiety). The PHQ-4 total score was categorized as "normal" (0-2), mild (3-5), moderate (6-8), and severe (9-12) and was used for descriptive purposes (De Maria et al., 2018; Zimet et al., 1988). A continuous PHQ-4 score for depressive/anxiety symptoms was used in regression analyses.

## 3.1.6 Spiritual Distress.

Spiritual distress is 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" (Schultz et al., 2017, p. 66) and include feelings of abandonment, punishment, and/or anger at the intra-, inter-, and trans-personal level (Exline, 2013). Because there is no clear measure for SRE-D in chronic diseases, we used two measures to assess for potential spiritual distress.

**Religious and Spiritual Struggles Scale – 14 (RSS-14).** The RSS-14 includes six domains present in spiritual distress: *divine*-concerns related to beliefs or perceptions about God;

*demonic*-evil spirits or the devil are the sources of negative events; *interpersonal*-conflict within a religious community or about religious beliefs with others; *moral*-conflict or wrestling with values/morals; *doubt*-questions about beliefs that causes concern; and *ultimate meaning* deeper meaning and purpose in one's life (Exline, Grubbs, et al., 2014; Exline, Pargament, et al., 2014). Items for the RSS-14 were rated on a five-point Likert scale (1 = "not at all" to 5 = "a great deal"). An indicator variable was created using the mean total score, where >2.0 was interpreted as indicative of spiritual distress.

**Three-Q (3Q).** A three-item screener (3Q) was also included to identify potential spiritual distress and was adapted to focus on diabetes (e.g., "I am at peace with my diabetes diagnosis;" King et al., 2017). Items for the 3Q were rated on a five-point Likert scale (1 = "not at all" to 5 = "a great deal"). The 3Q was calculated using a mean score of all three items, with higher scores indicating a greater likelihood of potential spiritual distress. An indicator variable was created to help identify those who could be classified as having potential spiritual distress based on their responses. Cut points for each item (>1 for items meaning and joy and spiritual/religious struggle; >2 for being at peace) were used in the creation of the indicator (King et al., 2017).

### **Combined SRE-D Scale.**

*Continuous SRE-D Measure*. A composite scale with the RSS-14 and 3Q items was considered. A correlation matrix was used to determine the relationship between each item included in the RSS-14 and 3Q to create a composite spiritual distress score. Inter-item consistency was evaluated across all items in the RSS-14 and the 3Q using a determination rule of Cronbach alpha of .80 or greater. A composite spiritual distress score was created where individuals with higher scores indicate a greater spiritual distress.

*Indicator of SRE-D*. A spiritual distress indicator variable (indicated as having spiritual distress on either or both measures at the higher threshold) was created where individuals met the criteria for either scale for potential spiritual distress (RSS-14 or 3Q > 2).

## 3.1.7 Chaplaincy Services

To gauge the acceptability of healthcare chaplain services, participants were evaluated on their knowledge about the role and function of chaplains, as well as their preferences for services often provided by chaplains, previous experience/s with chaplains, and the acceptability of chaplaincy-based services. In addition, participants were asked if they had "someone *in [their] life (e.g., friend, religious leader/clergy, etc.)*" [and] "someone *on [their] healthcare team*" that supported their religious, spiritual, or personal beliefs and if having their beliefs included in their medical care was important to them (response options: Yes; No; Maybe). Previous experience with a chaplain was also explored with items about interactions with a chaplain in the past (as a patient or a loved one/family member) in a healthcare context or another context (e.g., military, correctional facility, workplace).

**Factual knowledge about chaplains.** Participant knowledge about healthcare chaplains was assessed using a survey designed to determine how much an individual knows about the role and function of chaplains (Stavig et al., 2022). Using a series of ten true/false questions, this measure determined the level of knowledge about chaplains, such as their relationship with institutional religion, the application of religion and related practices, and how they function in healthcare settings (Stavig et al., 2022). The chaplaincy knowledge score was calculated using the number of questions answered correctly divided by the total number of items. For descriptive purposes, participants were later separated into four categories of correct answers (0 = 50%, 1 = 50% to 70%, 2 = > 70% to 90%, and 3 = > 90%).

**Preferences for chaplaincy-related services.** Participants rated the importance of services often provided by healthcare chaplains. Types of chaplaincy services were derived from the Chaplaincy Taxonomy (initially developed to improve and standardize charting by chaplains in electronic medical records) and a survey developed to determine the preferences for chaplaincy-related services from a national sample of U.S. adults (HCCN, 2019; Massey et al., 2015; Rajaee & Patel, 2021). These 14 items use a five-point Likert scale (1 = "Not important" to 5 = "Very important") and were primarily used for descriptive purposes.

Acceptability of chaplaincy services. Utilizing the Theoretical Framework of Acceptability (TFA) developed by Sekhon and colleagues, participants indicated the acceptability of receiving support from healthcare chaplains (Sekhon et al., 2017, 2022). Items used a five-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree), four items focused on T2DM, specifically capturing the TFA constructs of affective attitude (feelings about chaplain support), perceived effectiveness (chaplaincy support can achieve its intended purpose), intervention coherence (understand the purpose of the intervention), self-efficacy (confidence in their engagement/interaction with a chaplain), ethicality (aligns with values), burden (engagement efforts appropriate) and a single item for general acceptability (Sekhon et al., 2017, 2022). An overall acceptability score was calculated using the mean score of all items or the single-item general acceptability response indicating participants' acceptance of receiving support from a healthcare chaplain. A correlation matrix was used to determine the relationship between each item included to create an overall acceptability score. Inter-item consistency was evaluated across all acceptability items using a determination rule of Cronbach alpha of .80 or greater.

#### 3.1.8 Clinical Factors

T2DM clinical indicators were extracted from the lab and clinic data in the participant's electronic medical record over the twelve months preceding the study. For individuals diagnosed with T2DM, cardiovascular diseases are the "leading cause of morbidity and mortality," (ADA, 2024d, p. S179) and may contribute to diabetes complications. Extracted data included T2DM-related lab results (HbA1c, blood glucose) and cardiovascular conditions (dyslipidemia, hypertension).

**Cholesterol.** Atherogenic dyslipidemia (AD) is a significant risk factor for cardiovascular disease in individuals with T2DM, and poorer glycemic control may contribute to lipid abnormalities (Arvanitis & Lowenstein, 2023; Feingold, 2023; Mooradian, 2009). Elevated triglycerides and low-density lipoprotein cholesterol (LDL) and a decrease in high-density lipoprotein cholesterol (HDL) are indicators of an increased risk of developing cardiovascular disease (ADA, 2024d; Arvanitis & Lowenstein, 2023; Feingold, 2023). Results from participant's HDL, LDL, triglycerides, and total cholesterol were used to create a mean score for each indicator (e.g., HDL, LDL, etc.). Categorical variables for HDL, LDL, and triglycerides were made to help describe the metabolic profile of the participants (see Table 3.2). Indicator variables of clinical targets for each measure of cholesterol were created to identify participants with normal or 'abnormal' results. Cut-offs for normal and elevated (or low) cholesterol were identified as LDL cholesterol <100 mg/dL, HDL >40 mg/dL in men >50 mg/dL in women, and triglycerides <150 mg/dL (Solano & Goldberg, 2006). A combined measure indicating increased risk for metabolic dyslipidemia (MD) was created with three categories using the indicator variables: 1) normal triglycerides and normal HDL levels, 2) high triglycerides and normal HDL levels or normal triglycerides and low HDL levels, and 3) high triglycerides and low HDL levels (Kaze et al., 2021). Participants with a normal level of either triglycerides or HDL in conjunction with low HDL or high triglycerides are at increased risk for MD, whereas those with both low

HDL and high triglycerides indicate MD.

# Table 3.2

Indicators of meaningful clinical values for cholesterol (HDL, LDL, and Triglycerides) and blood pressure

Measure	Category	<b>Clinical Guidelines</b>
HDL <sup>a</sup>	Low	<40
	Mid-range	40 to 60
	High	≥60
LDL <sup>a</sup>	Optimal	<100
	Near optimal	100 to 129
	Borderline high	130 to159
	High	160 to 189
	Very High	>190
Triglycerides <sup>a</sup>	Normal	<150
(Hypertriglyceridemia)	Mild	150 to 499
	Moderate	to 866
	Very High/Severe	>866
Blood Pressure <sup>b</sup>		Systolic Diastolic
	Normal	<120 and <80
	Elevated	$120 - 129$ and $<\!\!80$
	Stage 1 Hypertension	130 - 139 or $80 - 89$
	Stage 2 Hypertension	$\geq 140$ or $\geq 90$
<sup>a</sup> mg/dL units <sup>b</sup> mm Hg units		

**Blood pressure.** Systolic blood pressure (SBP) and diastolic blood pressure (DBP) results were averaged across the year for each participant. Mean scores were placed into categories describing normal to hypertensive ranges based on clinical recommendations: *Normal* (SBP = <120 mmHg and DBP <80 mmHg), *Elevated* (SBP = 120 – 129 mmHg and DBP = <80 mmHg), *Stage 1 Hypertension* (SBP = 130 - 139 mmHg *or* DBP = 80 - 89 mmHg), and *Stage 2 Hypertension* (SBP =  $\geq$ 140 mmHg *or* DBP  $\geq$ 90 mmHg)(Flack & Adekola, 2020; Grundy et al., 2019).

**Glycated Hemoglobin (A1C).** A1C is a clinical measure used to diagnose and manage T2DM and reflects a person's average blood glucose level over the previous three months (ADA,

2020a; ADA, 2024a). A1C levels are often used to detect prediabetes (5.7 - 6.4%) or diagnoses diabetes (>6.4%), but for those with T2DM, A1C is also used to determine glycemic control (ADA, 2020a; ADA, 2020b; ADA, 2024a; ADA, 2024e). A mean score of results from lab results for A1C was used for analyses and to develop a variable to identify participants with elevated A1C scores:  $\geq$ 7.0% for18 to 65 years of age;  $\geq$ 8.0% for 65+ years of age (ADA, 2024a; ADA, 2024c; ADA, 2024c; ADA, 2024e). Available blood glucose lab results were also averaged and used as an indicator of glycemic control with a normal range of 72 to 108 mg/dL; levels that are above or below are described as hyperglycemia and hypoglycemia, respectfully (ADA, 2024c; Davidson et al., 2020; Mathew et al., 2023).

**Elixhauser Comorbidity Index.** Developed using the International Classification of Diseases [ICD], the Elixhauser Comorbidity Index (ECI) is often used to predict hospital length of stay and mortality. Using a series of dichotomous indicator variables, the El provides a summary score of thirty-one conditions (or *indicators of concern*) that indicate if a person is (1) or is not (0) diagnosed with any of the described conditions (e.g., alcohol abuse, drug use) or communicable or non-communicable diseases (e.g., HIV/AIDs congestive heart failure, liver disease, renal disease; Li et al., 2008). The most recent scores (for individual items and total score) were used as recorded in each participant's medical record. Higher total EI scores indicate more diagnosed comorbidities and greater potential mortality risk.

### 3.1.9 Sample Size

The targeted enrollment of 150 participants was calculated using G\*Power 3.1.9.6 based on a small, estimated effect size for the primary outcome (association of spiritual distress with health outcomes). Assuming an effect size of 0.03 to 0.1 ("very small"=0.01 to "small"=0.2, Sawilowsky, 2009) with a power of 1 -  $\beta$  = 0.90, using a multiple linear regression model

(predictors=5, two-tailed,  $\alpha = 0.05$ ) 108 (effect size  $f^2 \ 0.1$ ), participants would be needed for this study to have 90% power to detect these sized effects. Balancing the desire for adequate power, feasibility of study implementation, and interest in identifying relationships that have meaningful influence, we set the enrollment target at 150 participants.

#### 3.1.10 Statistical methods

All data were analyzed using Stata/BE 18.0 (StataCorp, 2023). Phases of data analyses included data preparation (data cleaning procedures), examination of distributions, and model building. Participants who consented and completed the survey were retained for analysis. After confirming the integrity of the data set, item, variable, and scale distributions were examined, and summary statistics were reported (i.e., frequencies, measures of central tendency, confidence intervals) to describe the sample as well as spiritual distress and acceptability of chaplaincy care. The appropriateness of creating a single measure of SRE-D using responses to the RSS-14 and the 3Q was evaluated through examination of the item-level correlation matrix and inter-item consistency (Cronbach alpha  $\geq =.80$ ) with attention to individual item contribution. A composite score was considered to provide greater efficiency and model parsimony. Bivariate associations using Pearson's  $\chi^2$  and Fisher's Exact Test (tabulate *options*: exact chi2) and two-sided ttests (ttest option: unequal) were used to describe the characteristics of the sample by indicating potential spiritual distress using robust tests (robvar) when unequal variances were detected. Pairwise correlation coefficients (pwcorr) were used to describe the relationship between spiritual distress and demographics and other potential covariates to characterize the sample and identify covariates ( $p \le .10$ ) to include in a two-step model-building process for the primary analyses. Non-parametric tests of association (Kruskal-Wallis test [kwallis] and Spearman's correlation coefficient [spearman]) were used with skewed data.

Multivariable linear regression models (nested: regress) were constructed to evaluate correlates of spiritual distress. Model 1 included demographic covariates associated with composite SRE-D scores ( $p \le .10$ ) in univariate analyses. Model 2 (added to Model 1) included factors consistent with our conceptualization of the aspects of disease and disease management (clinical indicators, health risk behaviors, diabetes self-management) as well as identified correlates of spiritual distress (spiritual well-being, depression and anxiety). The unique contribution of Model 2 variables was examined with the  $r^2$  change and contributions of each of the Model 2 variables were evaluated with the associated standardized beta and significance of that value (t distribution, alpha .05 two-tail). Log transformations (ladder, gladder) and additional regression analyses using robust measures (rreg, regress option: vce(robust)) were explored to determine the appropriate use of multiple linear regression. Assumptions of linear regression were evaluated.

Multivariable linear regression models (nested: regress) were constructed to evaluate correlates of spiritual distress. Model 1 included demographic covariates associated with composite SRE-D scores ( $p \le .10$ ) in univariate analyses. Model 2 (added to Model 1) included spiritual well-being (WHO-QOL-SRPB), diabetes self-management (DSMQ), self-rated health, depression and anxiety (PHQ-4), diet health risk behaviors (HRBI-Diet), and mean LDL values, The unique contribution of Model 2 variables was examined with the  $r^2$  change. Unique contributions of each of the Model 2 variables were evaluated with the associated standardized beta and significance of that value (t distribution, alpha .05 two-tail). Log transformations (ladder, gladder) and additional regression analyses using robust measures (rreg, regress option: vce(robust)) were explored to determine the appropriate use of multiple linear regression. Assumptions of linear regression were evaluated. The same approach was applied to the SRE-D indicator variable using multivariable logistic models (nested: logistic).

Aim 2 explored acceptability, overall, and sub-constructs in the TFA (affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and selfefficacy) and awareness of chaplaincy-based services. Using an approach similar to Aim 1, correlates of acceptability were identified through univariable tests of association (correlation or mean difference depending on distribution), and those associated at  $p \leq 0.10$  were included in a multivariable model of acceptability of chaplaincy services.

To assess the acceptability of chaplaincy services, a nested multivariable linear regression model was used to evaluate the overall and unique contributions of demographic and healthrelated factors (Model 1), spiritual factors and knowledge of and previous experience with chaplains (Model 2) on mean acceptability scores. Model 1 included demographic covariates (education, religious affiliation) and years living with T2DM which were identified as associated with the dependent acceptability variable ( $p \leq ... 10$ ) in univariate analyses. Model 2 (added to Model 1) included spiritual, religious, and personal beliefs, knowledge about the role and function of chaplains, and if participants have ever worked with a healthcare chaplain. The combined contributions of spiritual and personal beliefs and specific knowledge about chaplains were examined with the  $r^2$  change, while unique contributions of the specific variables were evaluated with the associated standardized beta and significance of that value (t distribution,  $\alpha$ =.05 two-tail) once all variables were entered into the model. Log transformations (ladder, gladder) and additional regression analyses using robust measures (rreg, regress option: vce (robust)) were explored to determine the appropriate use of multiple linear regression. Assumptions of linear regression were evaluated and determined to be acceptable.

# 3.2 Results

Three-hundred and forty-five people consented to participate in the survey with a completion rate of 63% (n = 216). Participants who both consented and completed the survey were included in the final sample. Tests comparing the differences between participants who completed versus those who did not complete the survey did not differ by age, race, or gender. However, there were significant differences in representation by religion (p = .01) with our final sample including a greater proportion of people who are atheist or agnostic (9.3% compared to 1.9%) and a slightly smaller proportion who are spiritual but not religious or no specific affiliation (19% compared to 27%).<sup>18</sup>

Data extracted from medical records for lab results were only available for some participants: LDL (n = 109), triglycerides (n = 109), total cholesterol (n = 110), HDL (n = 110), A1C (n = 194), blood glucose (n = 197), and systolic (n = 193) and diastolic blood pressure (n =191).<sup>19</sup> The mean age was 58.5 (SD = 13, range 20-76)<sup>20</sup> with the majority of participants over 55 (65%). As indicated in Table 3.3, the sample was 51% female, predominately white (75%), married (61%), and completed a bachelor's degree or more (50%). Participants described themselves as Christian (57%), *spiritual but not religious* (SBNR) or "*nothing in particular*" (19%), *Atheist or Agnostic* (5% and 4%), or some other system of belief (i.e., Jewish, Muslim, Multi-religious, Buddhist, 15%). Of those who described themselves as Christian, only 30% indicated they identified as Evangelical. Over half of the participants endorsed holding strong

<sup>&</sup>lt;sup>18</sup> Demographic data for those who did not complete the survey was derived from medical records rather than self-report, limiting the accuracy of these comparisons (Ehrenstein et al., 2019; Yemane et al., 2024).

<sup>&</sup>lt;sup>19</sup> Examination of factors associated with missing lab values (like LDL) suggested only self-reported health (better reported health), when used as a continuous variable, was associated with having missing lab values (p = .02). Missing lab values was not associated with spiritual distress scores, nor was it associated with acceptability scores. Lab values were included in univariate analyses but were not included in regression modeling due to low sample size for these variables.

<sup>&</sup>lt;sup>20</sup> Three participants were 75 during the time initial recruitment period and retained for all analyses.

personal (69%) and spiritual (49%) beliefs, in contrast to a third indicating holding strong

religious beliefs (33%).

# Table 3.3

Sample characteristics: demography, psychological, behaviors, clinical and experience with chaplains

General Demographics	n	%	М	SD
Age	216		58.5	13
Gender				
Male	100	46.7		
Female	109	50.9		
Gender non-conforming/Non-binary	5	2.3		
Race / Ethnicity				
White	162	75.4		
Black	25	11.6		
Other / Multiple	29	13.4		
Education <sup>a</sup>				
Some high school or high school graduate / GED	65	30.1		
Vocational or associate's degree	42	19.4		
Bachelor's degree	55	24.6		
Master's degree	34	15.7		
PhD or other terminal degree	15	6.9		
Marital Status				
Married	132	61.4		
Single	42	19.5		
Divorced / separated	31	14.4		
Widow/er	10	4.7		
Religious affiliation				
Christian (Protestant; Catholic; Orthodox)	123	56.9		
Atheist/Agnostic	20	9.3		
SBNR/Nothing in particular	41	19		
Other/Multiple	31	14.8		
Behavioral and Physical Health	n	%	Μ	SD
Depression and anxiety <sup>c</sup>	216		0.6	0.9
Normal	136	63		
Mild	46	21.3		
Moderate	18	8.3		
Severe	16	7.4		
Health Risk Behavior Inventory				
Mean	216		3.68	0.4
Alcohol use			4.8	0.4

Physical activity use			2.2	0.9
Diet use			3.3	0.7
Diabetes Self-Management			6.18	1.75
Self-Rated Health	214		2.67	0.8
Poor	10	4.7		
Fair	79	36.9		
Good	98	45.8		
Very Good	27	12.6		
Years with Type 2 Diabetes	208		16.4	10.2
Regular Insulin Use <sup>b</sup>				
No	93	43.1		
Yes	123	56.9		
Elixhauser Comorbidity Index <sup>b</sup>	216		9.2	4.1
Low	123	56.9		
High	93	43.1		
Comorbidities Indicators <sup>b</sup>				
Diabetes, complicated	213	94		
Pulmonary disease	99	45.8		
Congestive heart failure	44	20.4		
Hypertension, complicated	65	30.1		
Liver Disease	86	39.8		
Renal Failure	75	34.7		
Clinical Indicators	n	%	Μ	SD
High-Density Lipoproteins	110		44.4	11.2
Normal	45	43.3		
Reduced	59	56.7		
Low-Density Lipoproteins	109		75	37.48
Normal	86	78.9		
Elevated	23	21.1		
Triglycerides	109		167.46	101.5
Normal	60	55.1		
Elevated	49	45		
	12			
	103			
		28.2		
Metabolic Dyslipidemia	103	28.2 41.75		
Metabolic Dyslipidemia Normal	103 29			
<b>Metabolic Dyslipidemia</b> Normal At risk Indicator of MD	103 29 43	41.75		
<b>Metabolic Dyslipidemia</b> Normal At risk Indicator of MD	103 29 43 31	41.75		
Metabolic Dyslipidemia Normal At risk Indicator of MD Blood Pressure	103 29 43 31 185	41.75 30.1		
Metabolic Dyslipidemia Normal At risk Indicator of MD Blood Pressure Normal	103 29 43 31 185 34	41.75 30.1 18.4		
Metabolic Dyslipidemia Normal At risk Indicator of MD Blood Pressure Normal Elevated	103 29 43 31 185 34 55	41.75 30.1 18.4 29.7		
Metabolic Dyslipidemia Normal At risk Indicator of MD Blood Pressure Normal Elevated Stage 1 Hypertension	103 29 43 31 185 34 55 52	41.75 30.1 18.4 29.7 28.1	130.1	15

Blood Glucose	197		155.2	63.4
Hemoglobin A1c	194		7.5	1.7
Normal	110	56.7		
Elevated	84	43		
Experience with Chaplains	n	%	Μ	SD
Yes, in a healthcare setting	87	40.9		
Yes, in a non-healthcare setting only	18	8.5		
None	108	50.7		
Knowledge of Chaplains				
Score (% correct)	216		80.1	.16
$\leq 50\%$	12	5.6		
$> 50\%$ to $\le 70\%$	53	24.5		
$> 70\%$ to $\le 90$	113	52.3		
>90%	38	17.6		

<sup>a</sup> Does not include 24 participants who did not indicate any information about their educational attainment <sup>b</sup> Only individuals who indicate each of these conditions/disease states

<sup>c</sup> Sample mean

A majority of participants did not indicate anxiety or depression (63%). Participants indicated that their health was good to very good (58%), with many of them living with T2DM for an average of 16.4 years (SD = 10.2; Range: <1 - 45). while more than half indicated their health was good to very good (58%). The time range since being diagnosed with T2DM was <1 to 45 years (M = 16.4, SD = 10.2). The mean score of the sample for the Health Risk Behavior Inventory and the Diabetes Self-Management Questionnaire were 3.7 (SD = 0.4) and 6.2 (SD = 1.8), respectively. Mean of available HDL values over the past 12 months indicated that 56% of the sample had lower than desirable HDL (M = 44.4 mm/dL, SD = 11.2; range: 22-76), 21% with elevated LDL (M = 153.3 mm/dL, SD = 50.4, Range: 77-397), 45% with elevated triglycerides (M = 167.5, SD = 101.51, Range: 52-624) and mean total cholesterol of 153.3 mm/dL (SD = 50.4, Range: 77-397). An outlier for triglycerides (value >3000 mm/dL) was removed from the analyses. Only 18% had blood pressure levels that were considered normal, 30% had elevated results, and over half had an indication of Stage 1 (28%) to Stage 2 (24%) hypertension. Mean A1C was 7.5%, slightly above the recommended 7.0% threshold for adults with T2DM.

The sample had an average total SRE-D score of 21.1 (SE = 0.54; M = 1.52, SE = 0.04) on the RSS-14, with 86% % indicated as having potential SRE-D at a liberal cut-off of >1 and 15% at the more conservative cut-off of >2 (see Table 3.8). For the 3Q, the mean score was 1.87 (SE = 0.05), and 80% were indicated as potentially having SRE-D at the liberal cut-off (one or higher) and 32% at the more conservative cut-off (two or higher). Using the identified cut-points for the 3Q (>1 for meaning and joy and spiritual/religious struggle items; >2 for the peace item), 63% indicated potential SRE-D. Table 3.4 presents the pairwise correlation coefficients of the total and subscales of the RSS-14, the total and items for the 3Q, and the composite score for spiritual distress ( $\alpha = .89$ ). Over a quarter of participants (38%) had a mean score >2 on either the RSS-14 or 3Q.

**Correlates of potential spiritual distress.** All spiritual distress items were evaluated using a p < .05 threshold for significance. The RSS-14 total score was correlated with poorer diabetes self-management (p < .01) and self-rated health (p < .05) and with an elevation of LDL cholesterol (p < .01) with increases in spiritual distress. Each of the RSS-14 subscales, except for *Interpersonal*, was correlated with at least one measure. RSS-14 correlated with poorer diabetes self-management (subscales: Divine, Doubt, Ultimate Meaning, and Moral), poorer self-rated health (subscales: Divine, Ultimate Meaning, and Demonic), and elevated LDL cholesterol (subscales: Divine, Moral). Only the Ultimate Meaning subscale was correlated with health risk behaviors (negative) and elevated diastolic blood pressure (positive). None of the RSS-14 subscales or the total score were correlated with A1C, HDL, triglycerides, or systolic blood pressure. The 3Q total score was significantly correlated (p < .05) with diabetes self-management, selfrated health, A1C, and diastolic blood pressure. Each of the items of the 3Q were also positively correlated with A1C, and only the spiritual/religious struggles item was not correlated with selfrated health. Lack of peace was also correlated with HDL cholesterol and diastolic blood pressure. Having spiritual/religious struggles associated with their T2DM diagnosis was positively correlated with LDL cholesterol. The composite score of the RSS-14 and 3Q was correlated with poorer diabetes self-management and greater indication of depression and anxiety (p < .001), poorer self-rated health (p < .01), worse dietary health behaviors (p < .05) and increases in total and LDL cholesterol (p < .05, see Table 3.4). Differences in potential spiritual distress varied by age (r(214) = -.29, p = <.0001), race ( $\chi^2_{(2, 214)} = 9.41$ , p = <.01), educational attainment ( $\chi^2_{(3, 208)} = 8.25$ , p = <.05), marital status ( $\chi^2_{(3, 212)} = 7.38$ , p = <.05), and religious affiliation ( $\chi^2_{(3, 213)} = 9.6$ , p = <.05). Years with T2DM and marital status trended towards significance with p-values between 0.05 and 0.06.

## Table 3.4

	M	SD	r	$\chi^2$	р
Age			-0.29		< 0.001
Gender				1.58	0.21
Female	27.17	9.21			
Non-Female <sup>a</sup>	25.94	8.58			
Race				9.38	0.009
White	25.66	8.16			
Black	32.36	11.99			
Other/Multiple	26.79	8.51			
Education (Highest)				8.26	.04
Some HS / HS or GED	27.83	9.66			
Vocational / associate's degree	24.29	8.69			
Bachelor's Degree	28.29	9.80			
Graduate Degree <sup>b</sup>	25.27	6.68			
Marital Status				7.74	0.05
Married	25.70	8.53			
Single	28.81	9.11			
Divorced/Separated	28.90	10.63			
Widow/er	22.50	4.40			
Religion				9.6	0.02
Christian	25.89	9.08			

Composite SRE-D Mean scores and measures of association with demographics, health behaviors, self-rated health, and clinical indicators

Atheist/Agnostic       23.75       6.16         SBNR/Nothing in particular       29.44       9.09         Other/Multiple       27.41       9.03         Spiritual Well-being       -0.31       0.02         Religious Beliefs       0.02       -0.06         Personal Beliefs       -0.06       -0.06         Years with Type 2 Diabetes       -0.13       -0.13         Self-Rated Health c       9.36       9.36         Poor       30.90       16.16       -         Fair       28.38       8.57       -         Good       25.13       8.00       -         Very Good       25.11       9.20       -         Depression/Anxiety (PHQ-4) d       37.24       -       37.24         Normal       24.17       6.78       -         Mild       28.00       9.61       -         Moderate       31.67       10.99       -         Severe       37.38       10.16       -         DSMQ Score       0.23       -       0.23         Health Risk Behavior Inventory       -       -       -	<0.00 0.78 0.41 0.41 0.06
Other/Multiple       27.41       9.03         Spiritual Well-being       -0.31         Spiritual Beliefs       0.02         Religious Beliefs       -0.06         Personal Beliefs       -0.06         Years with Type 2 Diabetes       -0.13         Self-Rated Health °       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	0.78 0.41 0.41
Spiritual Well-being       -0.31         Spiritual Beliefs       0.02         Religious Beliefs       -0.06         Personal Beliefs       -0.06         Years with Type 2 Diabetes       -0.13         Self-Rated Health c       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23       0.23	0.78 0.41 0.41
Spiritual Beliefs       0.02         Religious Beliefs       -0.06         Personal Beliefs       -0.06         Years with Type 2 Diabetes       -0.13         Self-Rated Health c       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23       0.23	0.78 0.41 0.41
Religious Beliefs       -0.06         Personal Beliefs       -0.06         Years with Type 2 Diabetes       -0.13         Self-Rated Health c       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	0.41 0.41
Personal Beliefs       -0.06         Years with Type 2 Diabetes       -0.13         Self-Rated Health c       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23	0.41
Years with Type 2 Diabetes       -0.13         Self-Rated Health °       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23	
Self-Rated Health c       9.36         Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	0.06
Poor       30.90       16.16         Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	
Fair       28.38       8.57         Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	0.02
Good       25.13       8.00         Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	
Very Good       25.11       9.20         Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	
Depression/Anxiety (PHQ-4) d       37.24         Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory	
Normal       24.17       6.78         Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory	
Mild       28.00       9.61         Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	< 0.001
Moderate       31.67       10.99         Severe       37.38       10.16         DSMQ Score       0.23         Health Risk Behavior Inventory       0.23	
Severe37.3810.16DSMQ Score0.23Health Risk Behavior Inventory	
DSMQ Score 0.23 Health Risk Behavior Inventory	
Health Risk Behavior Inventory	
	< 0.001
Mean Score -0.08	
	0.27
Alcohol Subscale -0.04	0.54
Tobacco Subscale 0.05	0.48
Physical activity subscale -0.09	0.21
Diet Subscale -0.15	0.03
Elixhauser - Total 0.08	0.21
Cholesterol	
Total Cholesterol 0.26	0.01
HDL 0.04	0.68
LDL 0.23	0.01
Triglycerides -0.01	0.91
Blood Pressure	
Systolic -0.09	0.23
Diastolic 0.11	0.12
Normal 29.82 12.94	0.93
Elevated 26.27 7.42	
Stage 1 Hypertension26.168.32	
Stage 2 Hypertension 24.00 0.00	
A1C 0.12	

Note: Tests of association for categorical variables include Kruskal Wallis and Pearson's r for continuous variables

<sup>a</sup> Includes male and gender non-conforming/non-binary participants <sup>b</sup> Includes Master's, PhD, and other professional terminal degrees <sup>c</sup> Continuous variable for self-rated health is r(-0.18), p < .001<sup>d</sup> Continuous variable for PHQ-4 is r(0.43), p < .0001

Nested linear regression models on combined SRE-D scores (continuous composite of RSS-14 and 3Q; see Table 3.8) included age, race, education, marital status, religion, and years living with diabetes for Model 1. Model 2 added spiritual well-being, years with T2DM, diabetes self-management, self-rated health, anxiety/depression (PHQ-4), and diet health risk behaviors (HRBI-diet). Results (see Table 3.5) indicated that the linear combination of demographic (covariate) variables accounted for 17% of the variance of spiritual distress in Model 1 ( $r^2 =$ 0.17, F(13, 186) = 2.89, p < .05. Model 2 (correlates of SRE-D) increased variability account for to 32% (Model 2  $r^2 = 0.32$ , F(18, 181) = 4.80, p < 0.001) with a  $\Delta r^2 = 0.16$ . Inspection of unique contributions suggested that those who are older in age ( $\beta = -0.23$ , SE 0.06, p < .01) or are atheist/agnostic (compared to those who are Christian) reported lower spiritual distress ( $\beta = -$ 0.21, SE 2.2, p < .001). Those with greater spiritual well-being (p < .01) reported less spiritual distress, whereas those with more symptoms of depression and anxiety ( $\beta = 0.31$ , SE 0.72, p <.0001) and poorer diabetes self-management ( $\beta = 0.14$ , SE 0.34, p < .05) were all uniquely associated with greater spiritual distress scores (Model 2). Poorer dietary health behaviors trended towards significance (p = 0.06). Regression diagnostics suggested no substantial violations of basic assumptions of linear regression, including tests that evaluated heteroskedasticity, multicollinearity, and linear relationships.

#### Table 3.5

	Mod	Model 1		
	β	SE	β	SE
Age	-0.30***	0.06	-0.23**	0.06
Race				
Black	0.09	2.12	0.06	1.99
Other/Multiple	-0.03	1.85	-0.01	1.70
Education				

Estimated coefficients from a series of nested regression analyses of spiritual distress, by sociodemographic covariates and correlates of SRE-D (n = 200)

Vocational / Associate's	-0.06	1.79	-0.04	1.69
Bachelor's	0.12	1.68	0.11	1.56
Graduate <sup>a</sup>	0.03	1.74	0.05	1.63
Religion				
Atheist/Agnostic	-0.16*	2.26	-0.21**	2.20
Spiritual but not religious	0.02	1.71	-0.10	1.64
Other/Multiple	0.00	1.85	-0.06	1.72
Marital Status				
Single	0.03	1.73	0.03	1.59
Divorced / Separated	0.13	1.80	0.08	1.67
Widow/er	-0.04	3.01	-0.02	2.77
Years with T2DM	0.00	0.06	0.08	0.06
Spiritual well-being			-0.23**	0.08
Diabetes Self-Management			0.14*	0.34
Self-Rated Health <sup>b</sup>			-0.01	0.82
Depression / Anxiety <sup>b</sup>			0.31***	0.72
HRBI Diet			0.13 <sup>T</sup>	0.95

Note: Nested linear regression models with Model 1 including covariates age, race, education, religion, and marital status. Model 2 includes spiritual well-being, years with T2DM, self-rated health, depression/anxiety (PHQ-4), diabetes self-management, and dietary health risk behaviors, , adjusted by Model 1

<sup>a</sup> Includes Master's, PhD, and other professional terminal degrees

<sup>b</sup> Uses a continuous scale

<sup>T</sup> Trend towards significance, p < .07

\* *p* < .05, \*\* *p* < .01, \*\*\* *p* < .001

Of note, a repeated analysis on the sub-sample with LDL data available produced a total model  $r^2$  of 0.5 and the profile of findings suggested that age, religion, and diabetes self-management were not related to spiritual distress whereas poorer dietary habits was. (see Table 3.9 in the Appendix).

Logistic regression models using SRE-D Indicator. Using an indicator variable to identify

those with or without potential spiritual distress, logistic regression modeling was completed (see

Table 3.6). Univariate associations with the SRE-D indicator included age, gender, race, religion,

marital status, spiritual well-being, depression and anxiety, and the Elixhauser Comorbidity

Index (p < .1). Using nested logistic regression, only religion (spiritual but not religious, OR =

2.44, SE = 0.98 p < .05) was significant. None of the Model 1 covariates were significant once

Model 2 was added. Model 2 correlates included spiritual well-being, diabetes self-management,

depression and anxiety, self-rated health, and the Elixhauser Comorbidity Index. Adjusting for the covariates of Model 1, Model 2 indicated that higher levels of spiritual well-being were associated with slightly decreased odds of spiritual distress (OR = 0.95, SE = 0.02, p < .05), whereas symptoms of anxiety and depression were associated with greater odds of spiritual distress (OR = 1.88, SE = 0.38, p < .05).

## Table 3.6

	Model 1		Mod	lel 2
	OR	SE	OR	SE
Age	1.0	0.01	1.02	0.02
Gender				
Non-Female	0.73		0.69	0.24
Race				
Black	2.11	1.06	2.16	1.19
Other/Multiple	1.15	0.5	1.41	0.68
Religion				
Atheist/Agnostic	0.89	0.5	0.67	0.43
Spiritual but not religious	2.44*	0.98	1.62	0.72
Other/Multiple	1.17	0.53	1.1	0.53
Marital Status				
Single	2.02	0.82	2.06	0.91
Divorced / Separated	1.77	0.77	1.49	0.7
Widow/er	0.47	0.39	0.59	0.51
Spiritual well-being			0.95*	0.02
Diabetes Self-Management			1.04	0.1
Self-Rated Health <sup>a</sup>			1.05	0.24
Depression / Anxiety <sup>a</sup>			1.88**	0.38
Elixhauser Comorbidity Index			1.02	0.39

Odds ratios from a series of nested logistic regression analyses of spiritual distress, by sociodemographic covariates and correlates of SRE-D Indicator variable

Note: Nested logistic regression models with Model 1 including covariates age, gender, race, religion, and marital status. Model 2 includes spiritual well-being, self-rated health, depression/anxiety (PHQ-4), diabetes self-management, and the Elixhauser Comorbidity Index, adjusted by Model 1 <sup>a</sup> Uses a continuous scale

\* *p* < .05, \*\* *p* < .01

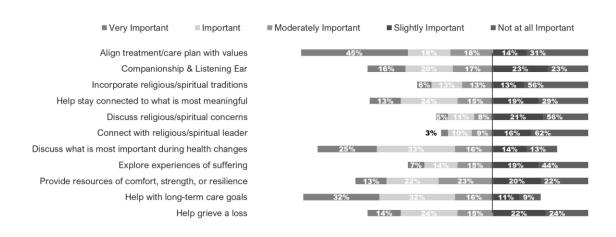
## Preferences for chaplaincy-relevant services. Figure 3.1 presents participants'

perceived importance of services relevant to chaplains on healthcare teams. Three-quarters of the

sample indicated that it would only be *slightly* to *not at all important* to have someone on their medical team help connect them with a religious or spiritual leader (77%) or to discuss their religious or spiritual concerns (78%). However, most participants prioritized a tailored approach to T2DM care with 80% of the sample indicating that it was moderately to very important for someone on their healthcare team to help support their long-term care goals, and 73% reporting it would be important to discuss what is most important to them as their health changes. Half or more of the participants also indicated it was moderately to very important to align their values to their treatment plan (55%); to help them stay connected to what is most meaningful to them (52%); to experience companionship and a listening ear from someone on their healthcare team (54%); to receive support with adjusting to losses/grief (54%); and to have resources provided to them that provide comfort, strength, or resilience (58%).

## Figure 3.1

#### Preferences for chaplain-relevant services on the medical team



Acceptability of chaplaincy support and identified correlates. The mean acceptability in the sample was 3.07 (SD = .45, range 1.8 - 5). The single acceptability item was slightly higher (M = 3.21, SD = 95, range 1 - 5), with nearly half of the participants indicating they were

"unsure/no opinion" (46.5%) when asked about working with a healthcare chaplain, a third indicating it was "acceptable to completely acceptable" (37.1%), and a minority indicating it would be "unacceptable to completely unacceptable" (16.4%). At the univariate level, differences in mean acceptability (see Table 3.10 in the Appendix) were identified by religious affiliation ( $\chi^2$ (3, 213) =15.48, p = <.01), spiritual well-being (r(214)= 0.19, p = <.01, spiritual beliefs (r(214)= 0.27, p = <.0001, religious beliefs (r(214)= .23, p = <.001, and LDL cholesterol (r(107)= .20, p = <.05). Level of education trended towards significance at p = 0.07.

For Aim 2, data were analyzed using nested multiple linear regression models with the identified outcome of the mean acceptability score of chaplaincy support. Model 1 included religious affiliation, education, and years living with T2DM. Model 2 included depression/anxiety, spiritual well-being, strength of spiritual, religious, and personal beliefs, experience with chaplains, and knowledge about the role of chaplains. Results (see Table 3.7) indicated that the linear combination of Model 1 variables accounted for 9% of the variance of acceptability ( $r^2 = 0.09$ , F(7, 192) = 3.19, p < .01) which increased to 17% of the variance with the addition of variables in Model 2 ( $r^2 = 0.17$ , F(15, 184) = 3.01, p < 0.05) for a non-significant change in  $r^2$  of 8%. Being an atheist or agnostic was associated with a lower acceptability of chaplaincy services ( $\beta = 0.2$ , SE 0.1, p < .01) compared to those who identify as Christian only in Model 1. No variables in the final model (Model 2) demonstrated a significant association with acceptability of chaplaincy support. Regression diagnostics suggested no substantial violations of basic assumptions of linear regression, including tests that evaluated heteroskedasticity, multicollinearity, and linear relationships.

## Table 3.7

Multivariable regression models for acceptability of chaplaincy serve	ices
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|--|

	β	SE	β	SE
Education				
Vocational / Associate's	0.15	0.12	0.17	0.1
Bachelor's	-0.03	0.08	-0.01	0.08
Graduate <sup>a</sup>	0.11	0.09	0.14	0.09
<b>Religious Affiliation</b>				
Atheist/Agnostic	-0.2*	0.1	-0.07	0.15
Spiritual but not religious	-0.07	0.08	-0.03	0.1
Other / Multiple	-0.02	0.11	0.02	0.12
Years with T2DM	-0.03	0.003	-0.03	0.003
Depression/Anxiety			0.18	0.05
Spiritual well-being			0.16	0.02
Spiritual beliefs			0.17	0.06
Religious beliefs			-0.05	0.07
Personal beliefs			-0.14	0.04
Chaplain Experience				
None			-0.13	0.07
Only outside of healthcare			0.03	0.14
Chaplain knowledge			-0.01	0.26

Notes: Model 1 includes education and religious affiliation. Model 2 includes depression/anxiety, years with T2DM, the strength of spiritual, religious, and personal beliefs, healthcare chaplaincy experience, and knowledge of chaplains while adjusting for factors included in Model 1. \*p < .05, \*\*p < .01, \*\*\*p < .001

#### **3.3 Discussion**

To our knowledge, this is the first quantitative study to explore spiritual distress in people living with and managing T2DM and the acceptability of chaplaincy support in the outpatient care setting. The primary findings identified significant associations between poorer diabetes self-management and higher symptoms of depression and anxiety with higher levels of (continuous) spiritual distress and lower spiritual well-being and greater symptoms of anxiety and depression associated with increased odds of spiritual distress. Over a third of the sample indicated that working with a chaplain was acceptable. Univariate associations with spiritual distress scores were identified for a number of variables (e.g., race, age, marital status, religious affiliation, years living with T2DM, dietary habits, T2DM self-management, depression/anxiety, self-rated health, and spiritual well-being). However, multivariable nested modeling found only diabetes self-management, depression/anxiety, years living with T2DM, and spiritual well-being retained significant associations with diet trending towards significance in the linear regression model. Additionally, when considered as a dichotomous variable, lower spiritual well-being, symptoms of depression, and anxiety were significantly associated with odds of being classified as having spiritual distress, although no indication of a relationship with diabetes selfmanagement or diet were not significant correlates.

As we explored spiritual distress within individuals living with T2DM, we found that the existing measures for spiritual distress may not have the specificity needed to identify spiritual distress. Depending on the thresholds, the percentage of individuals who may have spiritual distress were identified at 14 – 95%. Although we made the decision to use a more conservative approach, it is unclear what the true prevalence of spiritual distress is within this sample. When reviewing the correlation between the item, subscales, and total scores for spiritual distress for the RSS-14 and 3Q, there appeared to be different patterns in the correlations. At face value, the RSS-14 appears better at detecting behavioral correlates while the 3Q was better with lab values. Despite the uncertainty and differences between each of these measures, the composite score may help identify those who may benefit by attending to their spiritual distress.

One indicator that addressing spiritual distress may be beneficial to those with T2DM was the association between poorer diabetes self-management and levels of spiritual distress. While there is research that acknowledges the positive aspects of spirituality on health and health behaviors (Bozek et al., 2020; Jesse & Reed, 2004; Park et al., 2009), understanding the impact on health of spiritual distress is often overlooked. The protective effects associated with religiosity are important to consider in patient care settings. Further, attention to potential contributors to engagement in health risk behaviors, like spiritual distress, may be beneficial to

address during routine medical visits. Participants who were atheist/agnostic were associated with less spiritual distress compared to those who were Christian. It remains unclear if the association is due to differences in spiritual distress between these two groups or if the measures used are less effective with those who are not religious.

There were several differences observed between the continuous spiritual distress and the dichotomous variable indicating potential spiritual distress. For the indicator variable, we explored two cut-off points (none versus any indication or spiritual distress and a higher cut-off of >2) with vastly different proportions of individuals identified as having potential spiritual distress. Given the uncertainty of the cut-off points, models using the SRE-D indicator should be interpreted with caution. The acceptability of chaplaincy services did not identify any significant factors that would otherwise be associated with lower or higher acceptability including strength of religious, spiritual, or personal beliefs or religious affiliation. More than half of the participants indicated they desired to receive services that are in alignment with services chaplains offer, but that was not true for the more explicitly religious services that were considered less important. Unexpectedly, we did not find an association between spiritual, religious, and personal beliefs with acceptability of chaplaincy support. Both the single item from the TFA and the composite TFA scale score pointed to uncertainty or possible ambivalence given the mean values landing at the Likert scale's midpoint. Nonetheless, on the single item acceptability question about working with a healthcare chaplain, nearly 40% of participants reported that they were open to the idea, while nearly half indicating that they were unsure.

Our findings on preferences for chaplaincy-related services align with previous research that explored the preferences for chaplaincy support in a national sample (Rajaee & Patel, 2021). Participants in our present study indicated less importance for religiously oriented services.

Although not explored in this paper, this may be tied to individual level religiosity, however it does align with national trends toward 'spiritual' over and above religious orientations. Chaplains have historically been aligned with faith communities and required endorsement from a religious 'home,' but this may not be reflective of the needs of patients across all levels of acuity (Piatt et al., 2021). The chaplaincy profession may need to consider how it will continue to address this ever-widening gap between the religious and non-religious in how it trains and certifies future chaplains.

## 3.4 Strengths & Limitations

This study sought to investigate the spiritual needs of persons diagnosed with chronic diseases and the acceptability or preference for chaplaincy services. At present, there is little known about spiritual distress and chronic disease and the role it may play in helping or hindering the self-management of disease. It is also unclear if chaplains could be used to provide interventions that would mitigate the influence of spiritual distress. This study provides valuable information that will help craft future research exploring the connections between spiritual distress and health behaviors and the acceptability of working with healthcare chaplains. This study also contributes valuable evidence highlighting the associations between spiritual distress and poorer disease management in T2DM. While more research is needed to understand how spiritual distress presents in those with a chronic disease like T2DM, this study may help highlight the importance of including spirituality within all care settings.

Limitations in our study included use of convenience sampling, data extraction from medical records, self-report survey methodology, and focus on a single region of the US Participants were recruited on a first-come, first-serve basis and those who enrolled in the study may not be reflective of the larger T2DM community. Despite efforts to focus recruitment on

those who would have lab data available from the EMR, some participants did not have lab values available for our analyses and were unable to be included. We do note that this was infrequent and likely did not impact on overall findings. Our work focused largely on self-report survey data. Given that spiritual distress in NCDs may be unique from the kinds of distress experienced in acute or end-of-life contexts- the context in which most measures of spiritual distress were developed- our survey instruments may miss important factors. Future work should include qualitative methods to explore experiences with spiritual distress among people with T2DM specifically and focus on measure development. Finally, our sample engaged participants from a single region of the Midwest and may make it difficult to generalize these findings. More research is needed with more geographically diverse participants to gain a clearer understanding of spiritual distress in T2DM.

## 3.5 Funding

Funding for this study will be obtained from the University of Michigan and Transforming Chaplaincy, an organization dedicated to expanding chaplaincy research.

## **3.6 Appendices**

## Table 3.8

*Measures, subscales, items, and composite scores of spiritual distress and frequency of distribution of indicator variables* 

distribution of indicator variables			95% CI		
	Μ	SE	LL	UL	
RSS-14					
Total	21.1	0.54	20.0	22.11	
Mean <sup>a</sup>	1.52	0.04	1.44	1.59	
RSS-14 Subscales					
Divine	1.41	0.05	1.3	1.51	
Doubt	1.42	0.04	1.34	1.51	
Ultimate Meaning	1.58	0.07	1.45	1.71	
Moral	1.64	0.05	1.53	1.74	
Interpersonal	1.72	0.06	1.59	1.84	
Demonic	1.3	0.05	1.21	1.4	
3Q					
Total	5.53	0.16	5.21	5.84	
Mean	1.87	0.05	1.76	1.98	
3Q Items					
Loss of Meaning & Joy <sup>b</sup>	1.66	0.07	1.52	1.8	
Lack of Peace <sup>c</sup>	2.76	0.1	2.57	2.96	
Spiritual / Religious Struggles <sup>b</sup>	1.2	0.04	1.12	1.28	
Composite SRE Distress					
Total	26.59	.61	25.39	27.79	
Mean	1.58	0.04	1.51	1.65	
SRE Indicators	No SRE-I	-D Potential SF		RE-D	
	n	%	n	%	
<b>RSS-14</b> (>1)	30	13.89	186	86.11	
<b>RSS-14</b> (>2)	184	85.19	32	14.81	
3Q (>1)	44	20.47	171	79.53	
3Q (>2) °	147	68.37	68	31.63	
3Q (Score)	78	36.79	134	63.21	
Composite SRE (>1)	9	4.17	207	95.83	
Composite SRE (>2)	133	61.57	83	38.43	
RSS-14(>1) or 3Q (>1)	9	4.17	207	95.83	
RSS-14(>2) or 3Q (>2)	133	61.57	83	38.43	

Note: Correlation and regression analyses used the Composite SRE Distress score (Total). For indicator variables, the RSS-14 (>2) or 3Q (>2) was used when dichotomizing participants into groups of no or potential spiritual distress.

a Mean score for the RSS-14 was used to create SRE indicator variables

b Cut-off >1 indicates potential SRE distress for the 3Q score

c Cut-off >2 indicates potential SRE distress for the 3Q score

e Uses item-specific cut-offs for identifying potential SRE distress

## Table 3.9

	Model	1			Model 2			
			95% CI				95% C	I
	b	SE	LL	UL	b	SE	LL	UL
Age	-0.19	0.08	-0.36	-0.03	-0.11	0.08	-0.3	0.05
Race								
Black	6.43	3.34	-0.21	13.06	6.60	3.37	-0.1	13.32
Other/Multiple	-2.18	2.58	-7.31	2.96	-1.94	2.20	-6.3	2.43
Education								
Vocational /								
Associate's	-0.14	2.75	-5.61	5.33	0.50	2.46	-4.4	5.39
Bachelor's	3.63	2.35	-1.05	8.31	2.05	2.05	-2.0	6.13
Graduate <sup>a</sup>	1.24	2.39	-3.51	5.98	2.32	2.15	-2.0	6.59
Religion								
Atheist/Agnostic	-2.71	3.09	-8.86	3.43	-4.63	2.87	-10.3	1.09
Spiritual but not								
religious	3.90	2.42	-0.91	8.72	-0.28	2.19	-4.6	4.09
Other/Multiple	1.54	2.78	-4.0	7.08	0.28	2.46	-4.6	5.17
Marital Status								
Single	-0.78	2.36	-5.48	3.92	-0.47	2.04	-4.5	3.59
Divorced /								
Separated	5.21	3.02	-0.80	11.21	-0.02	2.76	-5.5	5.47
Widow/er	-2.47	5.13	-12.67	7.74	-0.31	4.47	-9.2	8.58
Years with T2DM					0.18*	0.08	0.0	0.35
Spiritual well-being	g				-0.37**	0.11	-0.6	-0.14
Diabetes Self-								
Management					0.42	0.50	-0.6	1.43
Self-Rated Health	b				1.90	1.12	-0.3	4.12
Depression /								
Anxiety <sup>b</sup>					3.77***	1.03	1.7	5.83
HRBI Diet					2.79*	1.36	0.1	5.49
Mean LDL					0.04	0.02	0.0	0.09

Estimated coefficients from a series of nested regression analyses of potential spiritual distress, by sociodemographic covariates and correlates (including LDL cholesterol) of SRE-D (n=100)

Note: Nested linear regression models with Model 1 including covariates age, race, education, religion, and marital status. Model 2 includes spiritual well-being, years with T2DM, self-rated health, depression/anxiety (PHQ-4), diabetes self-management, dietary health risk behaviors, and LDL cholesterol, adjusted by Model 1

a Includes Master's, PhD, and other professional terminal degrees

b Uses a continuous scale

\* p < .05, \*\* p < .01, \*\*\* p < .001

# Table 3.10

Mean scores and correlation coefficients for acceptability of chaplaincy interventions, health behaviors, self-rated health, and clinical indicators

	Μ	SD	r	$\chi^2$	Р
Age			-0.03		0.70
Gender				0.14	0.71
Female	3.08	0.48			
Non-Female <sup>a</sup>	3.05	0.42			
Race				1.34	0.51
White	3.04	0.45			
Black	3.14	0.53			
Other/Multiple	3.11	0.37			
Education (Highest)				7.08	0.07
Some HS / HS or GED	3.02	0.46			
Vocational / Associate's degree	3.19	0.53			
Bachelor's Degree	2.96	0.37			
Graduate Degree <sup>b</sup>	3.12	0.44			
Marital Status				1.47	0.69
Married	3.04	0.39			
Single	3.12	0.61			
Divorced/Separated	3.07	0.40			
Widow/er	3.16	0.56			
Religion				15.48	0.002
Christian	3.13	0.41			
Atheist/Agnostic	2.74	0.37			
SBNR/Nothing in particular	3.02	0.44			
Other/Multiple	3.09	0.55			
Spiritual Well-being			0.19		0.007
Spiritual Beliefs			0.27		< 0.001
Religious Beliefs			0.23		< 0.001
Personal Beliefs			0.08		0.23
Years with Type 2 Diabetes			0.19		0.01
Self-Rated Health <sup>c</sup>				3.44	0.33
Poor	3.32	0.58			
Fair	3.06	0.43			
Good	3.09	0.44			
Very Good	2.93	0.50			
Depression/Anxiety (PHQ-4) <sup>d</sup>				4.38	0.22
Normal	3.02	0.44			
Mild	3.14	0.49			
Moderate	3.21	0.44			
Severe	3.10	0.43			
DSMQ Score			0.00		0.97

Health Risk Behavior Inventory					
Mean Score			-0.01		0.91
Alcohol Subscale			0.06		0.36
Tobacco Subscale			-0.01		0.92
Physical activity subscale			-0.04		0.36
Diet Subscale			-0.05		0.45
Elixhauser - Total			0.08		0.97
Cholesterol					
Total Cholesterol			0.19		0.05
HDL			0.11		0.28
LDL			0.20		0.04
Triglycerides			-0.02		0.82
Blood Pressure					
Systolic			-0.02		0.82
Diastolic			-0.06		0.41
Normal	3.06	0.52		6.04	0.20
Elevated	3.18	0.45			
Stage 1 Hypertension	2.98	0.41			
Stage 2 Hypertension	3.03	0.42			
A1C			0.10		0.17
Note: Tests of association for categorical variables in <sup>a</sup> Includes male and gender non-conforming/non-bina <sup>b</sup> Includes Master's, PhD, and other professional term <sup>c</sup> Continuous variable for self-rated health is $r(-0.11)$ , <sup>d</sup> Continuous variable for PHQ-4 is $r(0.11)$ , $p = .10$	ary participants		arson's <i>r</i> for co	ntinuous varia	ibles

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# Chapter 4 The Acceptability, Attitudes, and Beliefs of Healthcare Chaplains About Providing Support to Persons with Chronic Disease Associated With Known Health Risk Behaviors

Chronic health conditions affect the lives of 60% of the US population and account for more than half of all cases of death and disability (Buttorff et al., 2017). Research suggests that these chronic conditions and diseases are expected to markedly increase over the next two decades as the US population ages (Ansah & Chiu, 2022). The high prevalence and expected increase of incidents have made chronic disease prevention of significant importance across healthcare organizations and disciplines in the US (Rattay et al., 2017). Chaplains, already well embedded within care systems, are turning their attention to possible roles in population health and chronic disease management; in particular, the role of chaplains in outpatient settings with people living with and managing chronic health conditions (Kelly & Swinton, 2020a; Patel et al., 2023). Although chaplains have historically provided care within acute care settings and hospice organizations providing support during an acute injury or illness, expansion into non-acute care settings is on pace with transitions taking place on the United States.

According to the US Centers for Disease Control and Prevention (CDC), 60% of US adults currently have at least one chronic condition, and 40% have two more diagnosed conditions (CDC, n.d.-a). Chronic conditions account for 90% of the \$4.1 billion in healthcare expenditures, with \$327 billion attributed to diabetes alone (CDC, 2022, n.d.-b). Recent projections estimate that by 2050, the prevalence of ≥1 chronic condition will increase by 119% among US adults (Ansah & Chiu, 2022). Chronic diseases are a significant contributor to rising

healthcare costs and in increased morbidity and mortality in the U.S. (Bauer et al., 2014; Centers for Disease Control and Prevention (CDC), 2020a; World Health Organization (WHO), 2020). Public health efforts, such as the federal program *Healthy People 2030* and the American Association of Public Health's (APHA) *Plan4Health project*, advocate for capacity building and multi-level interventions to reduce the prevalence of chronic disease (n.d.; *Plan4Health*, n.d.; Rattay et al., 2017), in part through addressing modifiable health behaviors. The World Health Organization identifies four specific modifiable health behaviors – tobacco use, alcohol use, poor diet, and physical inactivity – as major contributors to the development and exacerbation of chronic/non-communicable diseases (WHO, 2005; World Health Organization, 2002). Chaplains are potentially well-positioned to contribute to shifting priorities to provide behavioral health support within primary care settings.

In the United States, acute care hospitals employ the majority of chaplains (57%), who are often utilized for difficult patient encounters and near end-of-life or other critically ill or injured patients (Tartaglia et al., 2024; White et al., 2021). While most chaplains receive some degree of training in end-of-life care and acute care settings (Cadge et al., 2019; Cadge et al., 2020; Clevenger et al., 2021), exposure to outpatient settings for those with preventable chronic diseases is less common. Presently, outpatient chaplaincy is primarily limited to oncology or palliative care settings (Gomez-Castillo et al., 2015; Sprik et al., 2019) with chaplaincy training generally limited to acute care settings. Despite variability in education programs, chaplains may be well-positioned to implement evidence-based interventions for assisting individuals with chronic diseases influenced by modifiable health behaviors. Moreover, expanding chaplain services to provide primary or secondary level interventions with people with chronic disease diagnoses (focused on modifiable behavioral health factors such as diet, physical activity,

tobacco use, and alcohol use) may provide an efficient opportunity to increase patient access and options for support (White et al., 2021). The skills chaplains develop in helping individuals and their families manage spiritual distress in acute settings may prove transferable to managing distress that contributes to the worsening of chronic diseases influenced by health behaviors. However, the degree to which chaplains feel prepared to or even interested in providing care in the context of outpatient services for people with chronic disease is largely unknown. Acceptability and feasibility of, and readiness and willingness to provide chaplaincy-based services in outpatient settings to individuals struggling with chronic conditions *from the perspective of chaplains* is an important factor to consider in further deliberation of service expansion and can guide next steps in program development, preparing for training needs, and planning for implementation.

Acceptability and feasibility are two factors in the successful development and implementation of health interventions (Klaic et al., 2022). The acceptability of a proposed intervention is the "subjective evaluation made by individuals [...] who deliver (or expect to deliver) an intervention" (Sekhon et al., 2017, p. 10), which can include the perceived 'fit' or 'appropriateness' of an intervention, an evaluation of the opportunity costs, and/or the perceived efficacy. Feasibility assesses how practical an intervention is and, in the context of a proposed intervention, it can help identify if a person is willing and ready to engage or if there are any perceived barriers ("Examination of Feasibility," 2021). Applied within the Exploration, Preparation, Implementation, Sustainment (EPIS) framework, understanding chaplains' acceptability, readiness, and willingness to provide support services in outpatient settings guides the steps needed to develop, implement, and sustain evidence-based programs (Aarons et al., 2011; *EPIS Framework*, n.d.; Moullin et al., 2019).

This study aimed to contribute to the future training and the implementation of interventions that could utilize healthcare chaplains to address spiritual distress as a unique aspect of the complex state of chronic disease in the U.S. To this end, we sought to understand the perspectives of healthcare chaplains and their attitudes and beliefs (willingness and readiness) and the acceptability of providing chaplaincy-based services to persons with chronic diseases and behavioral risk factors in outpatient settings. Additionally, we explored potential biases that may exist for behavioral risk factors that are considered more (alcohol or tobacco use) or less (physical inactivity or poor diet) stigmatized.

#### 4.1 Materials and Methods

## 4.1.1 Study Design & Setting

This exploratory cross-sectional study of board-certified chaplains in the U.S. was conducted with chaplains recruited from the membership rosters the main U.S.-based certifying bodies (APC, NACC, and NAJC) that have shared competencies and are considered to be the best pathway towards professional certification (White et al., 2021). The study had three specific aims. Aim 1 was to characterize the acceptability, willingness and readiness (attitudes and beliefs) of chaplaincy-based services to people diagnosed with a non-acute chronic disease (T2DM) in outpatient settings by healthcare chaplains. We hypothesized that a majority of chaplain participants would indicate that providing care to people with non-acute chronic disease (and associated health risk behaviors) is acceptable and express both readiness and willingness to provide care. Aim 2 was to identify the correlates of overall acceptability of providing chaplaincy-based services to people with non-acute chronic disease (e.g., T2DM) in outpatient settings by healthcare chaplains. We hypothesized that readiness to provide support to people with non-acute chronic disease as well as the number of years working as a chaplain would be uniquely associated with higher levels of acceptability. Aim 3 was *to determine chaplain participants' acceptability of chaplaincy-based services for modifiable behavioral risk factors and if perceptions varied by condition or behavioral risk factors.* We used perceived involvement of spiritual distress in different conditions and modifiable behaviors as an indicator of acceptability- specifically reflecting the perceived fit between chaplains' areas of expertise and chronic conditions and behavior that elevate risks for developing or worsening chronic conditions. We hypothesized that perceived levels of involvement of spiritual distress would differ across conditions and behaviors (i.e., tobacco use, physical activity, diet, alcohol use).

Participants were recruited via email and from social media sites hosted by their respective certifying organizations. Data were collected from a quantitative online survey using the cloud-based Qualtrics software. Participants were asked about their knowledge, skills, and confidence to provide care for persons with chronic disease (focused on individuals diagnosed with T2DM) outside of the acute care setting in the role of a healthcare chaplain. This study was approved and deemed exempt by the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board (IRB-HSBS).

### 4.1.2 Participants

A non-probability convenience sample of professionally certified chaplains in the U.S. was recruited to participate in this study. Inclusion criteria for participation was boardcertification (as a chaplain) from one of three main certifying organizations in the U.S. (APC, NACC, and NAJC) prior to the start of the survey and being actively or recently (previous 12 months) employed by a healthcare organization. Participants who were provisionally or fully certified as an associate or board-certified member were all considered eligible. Retired, student, affiliate, and non-certified members, or chaplains who have never worked for a healthcare organization were excluded from participation. Participants were entered into a random drawing to win one of five \$100 gift cards as an incentive for participation, and winners were notified via email following the close of survey data collection.

## 4.1.3 Survey Development

The self-administered online survey included sections on sociodemographic/professional information and acceptability, attitudes, and beliefs around chaplaincy-based interventions for persons with chronic diseases. The survey underwent an iterative development process with testing by chaplain and non-chaplains. The EPIS framework (an implementation model that helps clarify the steps needed to develop, implement, and sustain evidence-based programs) was used to determine areas of inquiry in this survey (Aarons et al., 2011; *Dissemination & Implementation Models: Measure Constructs*, n.d.; *EPIS Framework*, n.d.; Moullin et al., 2019; Weiner et al., 2020).

## 4.1.4 Measures

**Sociodemographic/Professional information**. Questions included basic demographics (e.g., age, sex/ and gender, race, ethnicity), level of training, certification status (e.g., Associate Certified Chaplain versus Board Certified Chaplain), number of CPE units, years of practice, and clinical specialties (i.e., types of specialties, care setting, etc.). Indicator variables were created for gender(male/female), race (white/non-white) and experience working with patients diagnosed with T2DM (no/yes).

**Burnout**. Self-reported burnout was measured using the 16-item Oldenburg Burnout Inventory (OLBI) and describes participants' experiences of exhaustion and disengagement at work (Demerouti et al., 2001; Demerouti et al., 2003). The OLBI is scored using a four-point Likert scale (1 = Strongly Agree to 4 = Strongly Disagree) with a potential range of scores of 16 – 64 with higher scores indicating greater burnout.

**Religious affiliation**. The PEW Research Center's Religious Landscape Survey (PRC, n.d.) was used for categorizing participant's affiliation with religious, spiritual, or faith traditions (i.e., Protestant, Muslim, Jewish, Buddhist, etc.). Response options included faith traditions (i.e., Protestant, Muslim, Jewish, Buddhist, Hindu, etc.), non-religious traditions (i.e., Atheist, Agnostic, Spiritual but not Religious, etc.), and an option to self-describe. Participants from Protestant traditions provided their denominational affiliation and were further classified as Mainline, Black Protestant, Evangelical, or Other using the PRC categories (PRC, 2015a). Participants were later categorized as either Christian (Protestant Christian, Catholic, Orthodox) or non-Christian (Buddhist, Muslim, Agnostic, Jewish, Atheist, etc.) for analytical purposes.

Acceptability. Utilizing the Theoretical Framework of Acceptability (TFA) developed by Sekhon and colleagues, the acceptability of providing care to those diagnosed with a non-acute chronic disease (NCD) and those living with and managing T2DM was assessed (see Table 4.6 in the Appendix; Sekhon et al., 2017, 2022). Items used a five-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree), four items focused on T2DM, specifically capturing the TFA constructs of affective attitude (feelings about providing an intervention), perceived effectiveness (providing an intervention can achieve its intended purpose), self-efficacy (confidence that the person could provide an intervention), and a single item for general acceptability (Sekhon et al., 2017). Similarly, participants were asked questions modified to align with support for NCDs. Within each condition (T2DM, NCDs), a mean score was created, and the association between these scales was considered for potential consolidation to represent an overall combined

acceptability score (overall combined acceptability) for providing outpatient services for these conditions. Inter-item consistency was evaluated across all acceptability items for the two conditions using a determination rule of Cronbach's  $\alpha > .80$  supporting combining the items. A single score for acceptability across conditions would create a more parsimonious approach while retaining the interpretability of the score, reflecting the overall acceptability of providing care and evidence-based support for conditions commonly treated in outpatient settings.

Acceptability of providing care for MHB. The TFA was also used to measure the acceptability of providing care to address modifiable health behaviors. Items used a five-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree) and included statements such as "Chaplains have a role in providing support to help people address their health behaviors" (affective attitude), "Chaplains can effectively support positive health behavior change" (perceived effectiveness), "I am confident I could support someone to improve their health behaviors (e.g., physical inactivity, tobacco use, poor diet, or excessive alcohol consumption)" (self-efficacy), and "Providing chaplaincy care to a person who wants to address their health behaviors (e.g., physical activity, tobacco use, diet, or alcohol consumption) is an acceptable use of my time (single item for 'general acceptability'; Sekhon et al., 2017). Using items for affective attitude, perceived effectiveness, and self-efficacy, a mean score for the acceptability for supporting MHB was created. Inter item consistency was evaluated across all items using a determination rule of Cronbach's  $\alpha > .80$  to support combining the three items. Additionally, the correlation between the composite score of acceptability was evaluated using a determination rule of Cronbach's  $\alpha > .80$  in order to identify differences between the composite score (affective attitude, perceived effectiveness, and self-efficacy) with the single item general acceptability score. The composite score for MBH was used in analyses.

*Involvement of Spiritual Distress in specific Modifiable health behaviors, T2DM and NCDs.* A set of single items asking about perceptions of spiritual distress associated with specific modifiable health behaviors (MHB: tobacco use, excessive alcohol use, marijuana use, physical inactivity, poor diet, and illegal drug use), T2DM, and NCDs were used to explore the acceptability of providing chaplaincy services, reflecting the ethicality dimension of acceptability (Sekhon et al., 2017). Participants were asked to rate the likelihood that spiritual distress contributed to each of the MHBs, T2DM, and NCDs. Participants were asked about individuals with an NCD ("a person with a non-communicable disease"), engaging in MHBs ("a person engaged in unhealthy behaviors (e.g., physical inactivity, tobacco use, poor diet, or excessive alcohol use)"), and with T2DM ("a person living and managing their Type 2 Diabetes"). Items were phrased as a statement indicating that spiritual distress was a part of the behavior or condition with responses on a five-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree).

Attitudes & Beliefs. An adaptation of the Evidence-Based Practice Attitudes Scale (EBPAS-36) and the Organizational Change Recipients' Belief Scale (OCRBS) was used to assess participant attitudes toward working with individuals with chronic disease (Armenakis et al., 2016; Rye et al., 2017). This included assessing chaplain participants' willingness and readiness to provide support and beliefs about interventional support to those diagnosed with non-acute chronic conditions, such as T2DM.

*Willingness*. Utilizing specific sub-scales from the EBPAS-36, mean scores for willingness (by subscale and overall) were calculated with higher scores indicating greater willingness to provide evidence-based chaplaincy care (EBC) for those with non-acute chronic conditions or T2DM. Subscales included openness (to provide an EBC intervention), divergence

(from current chaplaincy practices), limitations (of using EBC interventions), balance (between individual skills and evidence informed practices), organizational support (perception of leadership/department support for EBCs), appeal ("intuitive" interest in EBCs), requirements (adopting an evidence-based intervention if expected), and fit (perception of alignment; Rye et al., 2017). All items were scored on a five-point Likert scale; higher total mean scores indicate greater positivity towards adopting a new evidenced-based practice. Because of the potential overlap between reflections on NCDs and on T2DM, we considered a combined score where subscales between these were combined into a single score reflecting a willingness to provide outpatient services for chronic manageable conditions. Willingness items were framed using language for both NCDs and T2DM and provide a mean score of general willingness. Inter-item consistency was evaluated across all willingness items and sub-scales using a determination rule of Cronbach alpha of .80 or greater supporting combining the willingness subscales ('general willingness').

*Readiness.* The OCRBS assesses five domains of organizational change: discrepancy (is there a need for change), appropriateness (is this the right change), efficacy (ability or capacity to change), principal support (organizational and interpersonal support for the change), and valence (motivation or interest in the change; Armenakis et al., 2016). Survey items were adapted to determine if chaplain participants were ready to change their practices to include interventional support to those with NCD or T2DM based on the perception of individual, department (i.e., spiritual care department, manager), system (i.e., hospital, hospice, etc.), and organizational (national chaplaincy certifying bodies) readiness. Items were scored on a seven-point Likert scale with high mean scores indicating greater readiness for change (1 = Strongly disagree to 7 = Strongly Agree). Readiness items specific to providing T2DM and to NCD were considered for

consolidation; inter-item consistency was evaluated across all willingness items and sub-scales using a determination rule of Cronbach alpha of .80 or greater supporting combining the NCD and T2DM scales in an overall readiness score ('overall readiness').

#### 4.1.5 Sample Size

Targeted sample size was calculated using G\*Power 3.1.9.6 based on a small estimated effect size for the primary outcome (acceptability of providing chaplaincy-based services). Assuming an effect size of 0.03 to 0.1 ("very small"=0.01 to "small"=0.2, Sawilowsky, 2009) with a power of  $1 - \beta = 0.90$ , using a multiple linear regression model (predictors=5, two-tailed,  $\alpha = .05$ ), a sample size of 108 (effect size = 0.1) to 353 (effect size = 0.03) would be needed. Balancing the desire for adequate power, feasibility of study implementation, and interest in identifying relationships that have meaningful influence, we set the enrollment target at 150 participants.

#### 4.1.6 Statistical methods

All data were analyzed using Stata/BE 18.0 (StataCorp, 2023). Phases of data analyses included data preparation (data cleaning procedures), examination of distributions, and model building. Only participant records with 100% completion were retained. After confirmation of the integrity of the data set, item, variable, and scale distributions were examined and summary statistics reported (i.e., frequencies, measures of central tendency, confidence intervals) to describe the sample and levels of acceptability, readiness, and willingness of chaplains to provide care to individuals with a NCD in particular T2DM. During analyses, the research team evaluated the appropriateness of combining the subscales from all conditions (T2DM, NCD), assuming that moderate to high associations across conditions would suggest an overall rating

for conditions typically managed through outpatient services provided greater efficiency and model parsimony.

Univariate statistics were used to determine the association between the characteristics of the sample population and the overall level of acceptability, readiness, and willingness of chaplains. Pairwise correlation coefficients (pwcorr) between acceptability, readiness, and willingness were evaluated to describe the relationship between participants' perspectives. Bivariate statistics were used to characterize the acceptability of providing care n non-acute care settings. Given the negative skew of the condition-specific and combined acceptability outcome, non-parametric bivariate associations (Kruskal-Wallis test [kwallis] and Spearman's Correlation coefficient [spearman]) were used to describe the characteristics of the sample by acceptability. Associations of  $p = \le .10$  were used to identify correlates of combined acceptability scores in a two-step model building process.

Multivariable linear regression models (nested:regress) were constructed to identify potential correlates between demographic and professional factors (Model 1) and experience factors (Model 2) to overall acceptability. Model 1 included descriptive covariates (age, gender race, religion) as well as demographic covariates identified as associated with overall combined acceptability ( $p \le .10$ ) in univariate analyses and if the participant worked with patients diagnosed with T2DM. Model 2 (added to Model 1) included burnout, diabetes knowledge, an overall readiness score (combining readiness for T2DM and NCD work), overall willingness score (combined willingness for T2DM and NCD work) and years as a chaplain (used as a proxy for potential accumulation of skills that could be applied in outpatient settings). The unique contribution of model 2 covariates was examined with the  $r^2$  change, while unique contributions of the specific variables were evaluated with the associated standardized beta and significance of

that value (*t* distribution, alpha .05 two-tail) generated in model 2. Log transformations (ladder, gladder) and additional regression analyses using robust measures (rreg, regress option: vce(robust)) were explored to determine the appropriate use of multiple linear regression.

Multi-level mixed effects models were used to determine the differences within participants' acceptability of chaplaincy support for specific modifiable health behaviors as well as general questions regarding NCDs, MHBs, and T2DM. Variables were transformed into long format prior to applying multi-level mixed effects models (mixed). Fixed effects were included in the model by condition (tobacco use, alcohol use, drug use, physical inactivity, poor diet, marijuana use, NCD, MHBs, and T2DM) with random effects to identify the variability within participants' responses. The lowest condition/behavior was used as the reference category which, in this case, was marijuana. Predictive margins and pairwise comparisons (margins, option pwcompare (pv)) were used to describe the differences in participant responses to the fixed effects.

### 4.2 Results

Two-hundred and fifty-three people consented to participate in the survey with a completion rate of 70% (n=176). Only surveys with a 100% completion were included in the final analysis. Tests comparing the differences between participants who completed the survey and those who did not complete the full survey did not indicate significant differences by age, race, gender, or religious affiliation. Only individuals with demographic data available (n=58) were included in these comparisons. Post-hoc power calculations using Stata/BE 18.0 suggest the study was sufficiently powered. Mean age was 52.3 (SD = 11.6, range: 29-78) with the majority of participants between the ages of 45 to 65 (56%). As indicated in Table 4.1, the sample was

majority female (57%), and predominantly non-Hispanic white (82%), and affiliated with a Christian religious tradition (84%). Of those who identified as Christian, 75% were affiliated with Protestant traditions and 29% identified as Evangelical. Most participants had an MDiv or other religious degree (64%) and were board-certified without additional specialization (96%). Range of time as a chaplain varied from 3 - 43 years (M = 13.4, SD = 7.8). Participants endorsed moderate levels of burnout (M = 35, SD = 6.8, range 21-52 although less than 5% reached cutoffs for exhaustion or disengagement. Eighty percent of participants scored <75% on the Diabetes Knowledge test and a majority (70%) reported providing care to patients with T2DM in the inpatient (57%), outpatient (3%), or both inpatient and outpatient (9%) settings.

## Table 4.1

Sample characteristics: Demography, Professional Qualifications and Service, Burnout, and	
Experiences with and knowledge of T2DM	

	%	
	M (SD)	n
Age <sup>a</sup>	52.3 (11.6)	176
Gender Identity		
Man / Masculine	40%	71
Woman / Feminine	57%	100
Gender non-conforming / Non-binary	3%	5
Race/Ethnicity		
White	82%	141
Black/African American	6%	10
Other	7%	12
Multiple	6%	10
Geographic Categories		
New England (CT, ME, MA, NH, RI, VT)	9%	15
Middle Atlantic (NJ, NY, PA)	9%	15
East North Central (IN, IL, MI, OH, WI)	21%	37
West North Central (IA, KS, MN, MO, NE, ND, SD)	16%	28
South Atlantic (DE, FL, GA, MD, NC, SC, VA, WV, DC)	15%	26
East South Central (AL, KY, MS, TN)	5%	9
West South Central (AK, LA, OK, TX)	7%	13
Mountain (AZ, CO, ID, NM, MT, UT, NV, WY)	5%	8
Pacific (AK, CA, HI, OR, WA)	14%	25
Highest level of education completed		

MDiv/Religious Graduate Degree	64%	113
Other Graduate (Master) degree	18%	32
Doctoral Degree	17%	31
Religious, Spiritual, Faith Tradition	1,70	01
Christian (Protestant, RC, Orthodox)	84%	148
Jewish	3%	6
Spiritual but Not Religious	3%	5
Other	10%	17
Protestant Denomination Affiliation (n=141)		
Mainline	65%	85
Black Protestant	0.8%	1
Evangelical	29%	38
Other	5%	7
Highest Level of CPE completed		
CPE Level 1 / Basic	6%	10
CPE Level 2 / Advanced	90%	158
CPE Supervisory	2%	4
Do not remember	2%	4
Chaplaincy Certification Status		
Certified Chaplain (BCC, ACC, & Provisional)	96%	169
Certified Chaplain with additional Specialization	4%	7
Professional Affiliation		
APC, NAJC, NACC	97%	171
NAVAC, SCA, CPEI	2%	3
Multiple	1%	2
Years as a chaplain <sup>a</sup>	13.4 (7.8)	
Burnout <sup>a</sup>		
Total	35 (6.8)	
Exhaustion	17 (4.1)	
Disengagement	18 (3.4)	
Diabetes knowledge (% correct)		_
$\geq$ 95 %	2%	3
$\geq 85\%$ to $< 95\%$	6%	11
$\geq$ 75% to < 85%	13%	22
$\geq 60\%$ to < 75%	35%	61
< 60%	45%	79
Average score for diabetes knowledge <sup>a</sup> (% correct)	58% (19.7)	
Current work w/T2DM		
Yes	70%	122
No a Mean Score	30%	52

4.2.1 Acceptability, Willingness and Readiness.

Mean acceptability scores (see Table 4.2 ) for each condition were M = 4.72, = 0.44 ( $\alpha =$ 0.78) for NCDs and M = 4.25 SD = 0.69 ( $\alpha = 0.88$ ) for T2DM; when acceptability items for NCD and T2DM were combined, the resulting scale had a high interitem consistency ( $\alpha = 0.84$ ). The coverall combined mean acceptability score was 4.42 (SD = 0.45). Mean scores for readiness were NCD =  $5.23 \pm 0.79$  ( $\alpha = 0.92$ ) and T2DM =  $4.98 \pm 0.81$  ( $\alpha = 0.93$ ); when readiness items for NCD and T2DM were combined, they had a high level of interitem consistency ( $\alpha = 0.96$ ). The combined mean readiness score was 4.85 (SD = 0.69). Mean score for willingness was 3.79 $(SD = 0.38, \alpha = 0.86)$ . All subscales and overall scores were negatively skewed (see Figure 4.1in the Appendix). There was a significant positive relationship between acceptability and willingness (r(174)= .18, p < 0.05) and readiness (r(174) = .44, p < .0001) and between readiness and willingness (r(174) = .21, p = <.01). The pattern of correlations between the scales suggests similar but unique constructs. The higher the acceptability of providing chaplaincy led care for NCD and T2DM, the higher the readiness scores and the higher the willingness to provide such services. A majority of participants endorsed high levels of acceptability with 90% of participants indicating they "Agree" to "Strongly Agree" with providing support to individuals with NCDs or T2DM in non-acute care settings. Over half indicated that they felt ready (65%, "Somewhat Agree" to "Strongly Agree") and willing (64%, "Agree" to "Strongly Agree") to provide care for this population.

#### Table 4.2

Mean scores and correlation matrix for acceptability, readiness, and willingness

			95% C	95% CI		n	
Variable	Μ	SD	LL	UL	Accept.	Ready	Willing
Combined Acceptability <sup>a</sup>	4.52	0.50	4.45	4.59	-		
Combined Readiness <sup>b</sup>	4.85	0.69	4.75	4.96	0.44**	-	

Willingness <sup>c</sup>	3.79	0.38	3.73	3.85	0.18**	0.21**	-	
*p<0.05, **p<0.01								
<sup>a</sup> Skew: -0.99; Kurtosis	s: 3.61							
<sup>b</sup> Skew: -0.28; Kurtosis	s: 2.9							
c Skew: -0.39; Kurtosi	s: 3.25							

# 4.2.2 Correlates of overall acceptability.

Differences in overall acceptability (see Table 4.3) were identified by gender identity  $(\chi^2_{(2, 176)} = 6.61, p = <.05)$ , level of burnout (r(174) = -.20, p = <.05), diabetes knowledge (r(174) = .19, p = <.05), and current work those with T2DM ( $\chi^2_{(3, 176)} = 14.22, p = <.01$ ). Level of education and years as a chaplain trended towards significance with p-values between 0.06 and 0.07.

# Table 4.3

	Μ	SE	р
Age			0.28
$\leq 30$	3.9	0.36	
$>30 \text{ to } \leq 45$	4.5	0.06	
>45 to ≤65	4.5	0.05	
>65	4.5	0.08	
Gender Identity			0.04
Man / Masculine	4.6	0.05	
Woman / Feminine	4.4	0.05	
Gender non-conforming / non-binary	4.6	0.3	
Race/Ethnicity			0.87
White	4.5	0.04	
Black/African American	4.6	0.12	
Other	4.5	0.18	
Multiple	4.5	0.11	
Highest level of education completed			0.06
MDiv/Religious Graduate Degree	4.5	0.04	
Other Graduate (Master) degree	4.6	0.1	
Doctoral Degree	4.7	0.06	
Years as a chaplain			0.06
<i>≤</i> 5	4.3	0.46	
$<5$ to $\geq 10$	4.3	0.49	

Demographic bivariate statistics for the overall scores of acceptability

<10 to ≥15	4.4	0.49	
$<\!15 \text{ to } \ge 25$	4.6	0.36	
<25	4.5	0.33	
Burnout			0.01
Low	4.5	0.46	
High	4.4	0.44	
Diabetes knowledge score			0.01
$\geq$ 95 %	5	0.05	
$\geq$ 85% to < 95%	4.6	0.13	
$\geq$ 75% to < 85%	4.7	0.08	
$\geq$ 60% to < 75%	4.5	0.06	
< 60%	4.4	0.06	
Current w/T2DM			< 0.001
Yes, inpatient and outpatient	4.6	0.04	
Yes, only inpatient	4.7	0.18	
Yes, only outpatient	4.3	0.07	
No	4.8	0.09	

Nested multiple linear regression models on combined acceptability scores (see Table 4.4) included age, gender, race, education, and working with T2DM patients (Model 1) and then added burnout, diabetes knowledge (score), readiness, willingness, and years as a chaplain (Model 2). Indicator variables were used for gender, race, religion, and working with T2DM. Results indicated that that the linear combination of variables accounted 12% of the variance of acceptability in Model 1 ( $r^2 = 0.12$ , F(7, 163) = 3.20, p <.01) and 32% of the variance in Model 2 ( $r^2 = 0.316$ , F(12, 158) = 6.08, p <.001) with a significant  $\Delta r^2 = 0.20$ . Unique contributions suggested that higher levels of readiness (p <.01) and years as a chaplain (p < .05) were associated with higher overall combined acceptability. In addition, those with a doctoral degree (Doctor of Ministry (DMin) or PhD; p <.05) were uniquely positively associated with acceptability. Participants who identified as female or non-binary/gender non-conforming had lower acceptability compared to those of male gender were significant in model 1 (p <.05) but this was not the case in Model 2 (p = .124). Similarly, those who currently work with patients with T2DM were significant in Model 1 (p <.01) but not Model 2 (p = .08). Although burnout

was associated with differences in combined overall acceptability in the bivariate associations (see Table 4.3), after controlling for other variables in the model, burnout did not uniquely contribute to overall combined acceptability scores. Regression diagnostics evaluated violations of basic assumptions of linear regression with no indication of concern despite the skewed dependent variable.

## Table 4.4

	Model 1 <sup>a</sup>		Model 2 <sup>b</sup>	
	Coefficient	SE	Coefficient	SE
Age (years)	0.001	0.003	-0.003	0.004
Female and Non- Binary	-0.153*	0.17	-0.1	0.07
Non-White	-0.04	0.09	-0.03	0.08
Education				
(MDiv/Religious Master's Degree)				
Non-Religious Master's Degree	0.07	0.09	0.11	0.08
Doctoral (DMin, PhD)	0.18	0.10	0.18*	0.09
Non-Christian Tradition	-0.013	0.09	0.16	0.09
Works with T2DM	0.24**	0.08	0.13	0.07
Burnout (Total Score)			-0.003	0.005
Diabetes Knowledge Score (%)			0.003	0.002
Combined Readiness			0.22**	0.002
Combined Willingness			0.16	0.1
Years as a chaplain			0.01*	0.004

Estimated coefficients from a series of nested OLS models of combined acceptability, by sociodemographic factors and burnout, readiness, willingness, and years of experience

Notes:  ${}^{a}r^{2} = 0.1207$ ;  ${}^{b}r^{2} = 0.316$ 

\*p < 0.05\*\*p < 0.01

<sup>a</sup>Model 1 includes Age, Gender, Race, Education, Religious tradition, and experience with working with T2DM <sup>b</sup>Model 2 includes Burnout, Diabetes knowledge, Combined Readiness, Combined Willingness, Years as a chaplain, adjusted for items included in Model 1

## 4.2.3 Acceptability of Working with Modifiable Behaviors

**Involvement of spiritual distress.** Table 4.5 presents the results from the mixed effects model of within-participant differences of the perception of the involvement of spiritual distress in specific stigmatized health behaviors (tobacco use, excessive alcohol use [ETOH], physical inactivity, poor diet, illegal drug use ['drugs'], and marijuana use [THC]) as well as perceptions

of chronic conditions (NCDs), general modifiable health behaviors (MHBs), and T2DM. Level of spiritual distress involved in marijuana use was used as the reference for all models. All conditions indicated significant differences in rated level of involvement of spiritual distress (p<.05) from the reference (THC), except for tobacco use and poor diet (see Table 4.5). Pairwise comparisons of the marginal differences in rated involvement of spiritual distress between each condition or behavior suggested that the only comparable ratings were for (1) tobacco and physical activity, diet, and marijuana use; (2) illegal drug use and excessive alcohol use; and (3) poor diet and physical inactivity and marijuana (see Table 4.7 in the Appendix). Involvement of spiritual distress in drug use, NCDs, MHBs (general), and alcohol averaged in the "agree" range, while all other conditions (marijuana use, tobacco use, poor diet, physical inactivity, T2DM diagnosis, MHB (general), and alcohol use) averaged in the "neither agree nor disagree" range.

Acceptability of chaplaincy care for modifiable health behaviors. In addition to asking about experience of spiritual distress in relation to MBH, participants were also asked about the acceptability of providing support to address tobacco use, poor diet, physical inactivity, and alcohol use. Using a composite score (e.g., affective attitude, perceived efficacy, and self-efficacy), participants indicated a mean score of M = 4.26 (SD = 0.69,  $\alpha = 0.89$ ) which was significantly associated with the overall combined acceptability (r (176) = .42, p <0.001).

## Table 4.5

				_	95%	o CI
Fixed effects <sup>a</sup>	M <sup>b</sup>	SD °	Est.	Z	LL	UL
THC (ref)	3.16	0.92				
Tobacco	3.18	0.89	0.02	0.35	-0.10	0.15
Diet	3.23	0.91	0.07	1.05	-0.06	0.20
Phys Act	3.30	0.95	0.14*	2.10	0.01	0.26
T2DM	3.49	0.81	0.33**	5.08	0.20	0.46

Fixed and mixed effects from multilevel regression spiritual distress involvement ratings

MHB	3.76	1.0	0.60**	9.20	0.47	0.72
ЕТОН	3.99	0.93	0.83**	12.79	0.70	0.96
Drugs	4.05	0.93	0.89**	13.76	0.76	1.02
NCD	4.19	0.8	1.03**	15.86	0.90	1.16
			Est. ( <i>SE</i> )			
Constant			3.16 (0.07)	46.35	3.03	3.29
					95%	6 CI
Random effects (Participant) <sup>a</sup>			Est.	SE	LL	UL
var(cons)			0.45	0.05	0.36	0.56
var(Residual)			0.37	0.01	0.34	0.40
ICC			0.55	0.03	0.49	0.61
		ll(null)	ll(model)	df	AIC	BIC
Null model		-	-1940.35	3	3886.71	3902.80
Full model		-	-1677.97	11	3377.93	3436.98
					$\Delta 508.77$	$\Delta 465.83$

Notes: THC = Marijuana use; T2DM = Individual item for Type 2 Diabetes Mellitus; NCD = Individual item for noncommunicable diseases; ETOH = Excessive alcohol use; MHB = Individual item that includes all modifiable health behaviors <sup>a</sup> 1,584 observations

<sup>b.</sup> Marginal means using pairwise comparisons, SE = 0.06; Range 1-5

<sup>c</sup> Mean score across all participants

\*p<.05, \*\*p<.001

#### 4.3 Discussion

To our knowledge, this is the first quantitative study to assess chaplain perceptions of acceptability of providing support to those with non-acute forms of chronic disease and their readiness and willingness to engage in a chaplaincy-based intervention. The primary finding from this study is the high levels of acceptability across the participants with lower levels of readiness and willingness to provide support. Demographic characteristics and levels of burnout were not associated with levels of acceptability; however, higher diabetes knowledge and experience in providing diabetes care was associated with higher general acceptability for chaplain-provided care for non-communicable, manageable conditions. Although acceptability for providing chaplaincy services in the context of outpatient care for NCDs was generally high, the degree to which spiritual distress was implicated in different conditions and modifiable behaviors did suggest closer alignment between chaplain support and drug use, alcohol use and

NCDs in general, versus tobacco use, poor diet, physical inactivity or marijuana use. The profile of results suggests that chaplains may be more inclined to find some conditions immediately relevant to their current skillsets, while other conditions that contribute to poorer health outcomes may require further exploration and explanation to establish relevance.

The most notable outcome of this study was the high levels of acceptability indicated by chaplains on providing care within the outpatient context. One potential reason for this may come from the familiarity of working with patients diagnosed with chronic diseases within the acute care settings. Participants may be extrapolating on their professional experiences onto patients who have non-acute presentation and assuming that the needs of non-acute patients may be similar to patients admitted to the hospital. However, the needs of those newly diagnosed with a NCD or those living with and managing their condition day-to-day, likely have different needs from those experiencing an acute crisis or nearing the end of their life. Additional exploration of how chaplains perceive the outpatient care and population health initiatives and their role in those contexts is needed. Developing or utilizing training programs to strengthen preparedness and provide experience opportunities are important next steps to consider.

Currently, there are no clear curriculum guidelines in the U.S. for academic or clinical settings from a national accrediting body (Cadge et al., 2019; Cadge et al., 2020; Clevenger et al., 2021). Clinical pastoral education (CPE) providers often build their clinical programs independently, using unique educational milestones (e.g., CPE Level I/Level II) and interpretations of the competencies required for board certification (2020; APC, 2016). Ongoing tensions between chaplaincy as a '*ministry*' (as spiritual or vocational practice) versus a '*profession*' (as evidence-based practice) contributes to the slow movement towards standardization. Hospice and palliative care services have academic and professional

certifications (n.d.-b; *Essentials of Palliative Care Chaplaincy*, n.d.). While there are no certifications available for the specialization of providing chaplaincy care in the context of preventable chronic diseases, there are reasonable alternatives available. For example, the specialized training for *Diabetes Community Care Coordinators* (DCCC) provides support that aligns with diabetes self-management recommendations (Association of Diabetes Care and Education Specialists, 2023). This training provides a baseline education to help a chaplain (or other non-diabetes educator) have a better general understanding of diabetes and diabetes self-management. Further, this type of training could help chaplains align their interventions with healthcare goals and support patient needs.

We expected readiness and willingness to be uniquely associated with acceptability; however, only readiness was found to be a significant contributor despite both having moderately high scores. Although we did not explicitly explore barriers in this study, it seems possible that there are unexplored barriers that make it difficult for chaplains to be willing to spend their time with patients who are less critically ill. This may be due to a lack of knowledge, which could be improved by increasing access to additional training. It may also be related to the perceived burden this transition would have on their department or health system. Tartaglia et al. (2024), found that the chaplain-to-patient ratio has decreased despite increasing in overall staffing. This likely makes it difficult for chaplains to imagine increasing their scope to include outpatient care for non-critical patients.

Responses to perceived spiritual distress associated with specific health behaviors were somewhat unexpected. We used this series of questions as a proxy for capturing a 'need' for spiritual support and most participants indicated that they did not agree or disagree (neutral). It is possible that some chaplains saw these questions as value judgements though this was not

explored in this study. Curiously, participants agreed that those "diagnosed with chronic disease" are likely to be experiencing spiritual distress. However, many of the health behaviors typically associated with NCDs were not interpreted the same way. It remains unclear why the condition (NCDs) was seen as involving spiritual distress but less so for the kinds of health behaviors (the mechanisms) that often led to a diagnosis. Additional exploration into chaplain perceptions of spiritual distress and health behaviors as well as knowledge of NCD disease processes may help shed light on these results.

### 4.4 Strengths & Limitations

Current evidence indicates that spirituality is an important component of disease selfmanagement for individuals with chronic disease, and this study supports that chaplains find it acceptable to be resources for early intervention for disease prevention and maintenance (Nguyen et al., 2022). This may improve patient-centered care and optimize additional leverage points to improve chronic disease health outcomes. Given the financial and social implications for chronic disease in the U.S. and globally, this may have a positive long-term impact without additional pressures on other healthcare staff (e.g., nurses, social workers) to be training in providing spiritually based interventions. To our knowledge, chaplaincy educational models typically do not include training to address behavioral risk factors but there are multiple training and practice avenues that could create these opportunities. The results of the current study provide potential guidance to leaders of chaplaincy education and certification programs that can be adapted to future competencies for the next generation of healthcare chaplains. Limitations in the current study are important to consider in interpretation and application of findings. First, acceptability, readiness, and willingness were self-reported by self-selected healthcare chaplains and did not include or determine what specific skills or training they

objectively have or if they require additional training. We do envision that self-report bias may have been somewhat reduced by the anonymous nature of survey, and self-selection may reflect the real-world parallel of chaplains ultimately self-selecting into training and working with NCD-related outpatient care. Second, we did not include chaplaincy educators or administrators with no clinical duties, those working towards certification, or current CPE students.<sup>21</sup> Results may reflect the unique experience of practicing, credentialed chaplains. Additionally, the current sample has an overrepresentation of White participants (82%) compared to actively registered board-certified chaplains (63%) in the U.S. (White et al., 2021). Results should be replicated with a more diverse sample of chaplains. Finally, it is important to know that this survey was also cross-sectional and, as such, cannot speak to the order or causality of associations identified. Despite limitations, the current findings can assist in guiding future exploration using qualitative, mixed methods and longitudinal approaches with a wider sampling of chaplains.

### 4.5 Conclusion

Our exploration of chaplains' perceptions of acceptability for providing support in outpatient contexts to people with non-acute chronic conditions suggests that although chaplains do find it acceptable to provide care in outpatient contexts, there are barriers to their perceptions of readiness and willingness to do so. Chaplains' hesitance may be due to their lack of knowledge of chronic health conditions or, conversely, their levels of acceptability may be reflections of their experiences within acute care settings. The profile of results does suggest that chaplains are well positioned to engage in providing outpatient care for individuals with NCDs like T2DM, as well as some modifiable behaviors that exacerbate NCDs. Preparing chaplains for

<sup>&</sup>lt;sup>21</sup> Some educators are credentialed as board certified chaplains and clinical pastoral educators but being a certified chaplain is not a requirement for CPE educators.

this work could make substantial contributions to expanding the cadre of professionals assisting people with NCDs and offering patients greater choice in the types of support services available.

# 4.6 Appendices

# Table 4.6

Acceptability crosswalk for NCDs and T2DM using the TFA

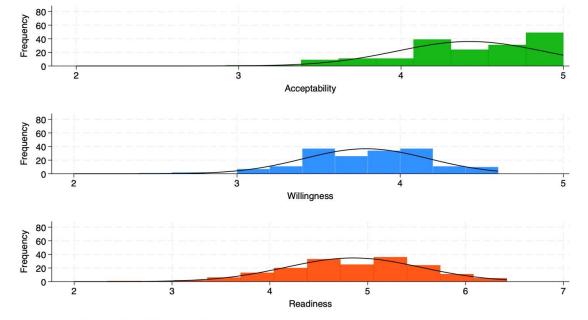
	NCD	T2DM
Affective	Chaplains have a role in providing supp	port
Attitude	to people with non-communicable diseases.	to people with diabetes.
	I am confident that I could help someon	ne
Self-Efficacy	with a non-communicable disease.	with diabetes.
Perceived	Chaplains can effectively support	
Effectiveness	people with a non-communicable disease.	people with diabetes.
Opportunity Costs	It is equally important to address the sp	iritual needs of someone
	with a non-acute illness or injury as much as it is for those critically ill or injured.	
General	Providing chaplaincy care to	is an acceptable use of my time.
(Single item)	a person living with a non- communicable disease	a person with diabetes

# Table 4.7

	Tobacco	Drugs	ETOH	THC	Diet	Phys Act	NCD SRE	Gen HB SRE
Tobacco								
Drugs	0.87**							
ЕТОН	0.81**	-0.06						
ТНС	-0.02	-0.89**	-0.83**					
Diet	0.05	-0.82**	-0.76**	0.07				
Phys Act	0.11	-0.76**	-0.69**	0.14*	0.07			
NCD SRE	1.01**	0.14*	0.2*	1.03**	0.96**	0.89**		
MHB SRE	0.57**	-0.3**	-0.23**	0.6**	0.53**	0.46**	-0.43**	
T2DM SRE	0.31**	-0.56**	-0.5**	0.33**	0.26**	0.19*	-0.7**	-0.27**
Notes:*p<.05; **p<.01								

Pairwise comparisons of perceptions of spiritual distress across health risk behaviors, NCDs, MHB, and T2DM

# Figure 4.1



Frequency of mean scores for acceptability, willingness, and readiness of healthcare chaplains

Note: Scales are 2 - 5 for Acceptability and Willingness and 2 - 7 for Readiness

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### **Chapter 5 Conclusion**

The primary objective of this dissertation was to explore the connections between spiritual distress and chronic disease through an exploration of the literature and quantitative study of both patients and healthcare chaplains. In addition, this dissertation sought to explore the perceptions of acceptability of receiving and providing chaplaincy support within the primary care settings and expanding the possibilities of chaplains engaging in patient care beyond their 'traditional' roles in palliative and acute care settings. In Chapter 2, a scoping review of the existing literature was employed to help identify how spiritual distress was being described in measured in non-communicable diseases. Chapter 3 examined the perceptions of people who are presently living with T2DM and investigated the associations between spiritual distress, chronic disease, and health behaviors as well as the acceptability of healthcare chaplains in non-acute care settings. Chapter 4 focused on chaplain providers to examine their perceptions of acceptability, readiness, and willingness of providing support to those living with and managing non-acute chronic diseases. While all distinct research projects, each of these studies are helping to build a foundation for future research on spiritual distress and chronic disease management.

The scoping review of existing measures for spiritual distress among individuals with a chronic condition or disease associated with the four most common health risk behaviors provided a retrospective examination of previous research. We identified 47 measures used cardiovascular, renal, pulmonary, and T2DM diseases that varied by region and disease group. While there were some commonly used measures (SWBS, FACIT-Sp, and RCOPE), there was

considerable variability in the measures used. While some variability is likely due to our broad inclusion parameters as to what defines spiritual distress, it also highlighted the larger issue of a lack of consistency across the research and the tendency to focus on the positive aspects of spirituality. We also found that studies often did not offer operational definitions with their measures for spirituality; many of these studies acknowledge the 'direction' (positive or negative) but did not offer further explanation. Given that research that focuses on spirituality is often critiqued for being an 'elusive' area of inquiry, this serves as a reminder how important it is to provide an operational or conceptual definition in research.

In Chapter 3, we examined the relationships between spiritual distress and chronic disease by surveying people who were diagnosed with T2DM and sought to understand their general perceptions of acceptability for chaplaincy services. When examining spiritual distress, participant responses identified significant associations with poorer diabetes self-management, religious affiliation (atheist/agnostics indicating less spiritual distress), and older participants indicating less distress than their younger counterparts. In addition, we identified several potential correlates for future study including health risk behaviors and differences within religious affiliation. Our exploration into the acceptability of chaplaincy services provided a better picture of people's likely receptivity to chaplaincy support. While we found no significant associations in our models, this was a significant finding. Chaplains have long been aligned with religious ideologies and, after adjusting for our demographic covariates, we did not find any significant differences between those who have strong religious, spiritual, or personal beliefs. The results from this study are, to our knowledge, the first of its kind and will help craft future studies that examine spiritual distress in chronic disease management.

Our final study in Chapter 4 turned to healthcare chaplains to understand their perspectives on acceptability of providing support to people with non-acute chronic conditions like T2DM. While our findings indicated that chaplains expressed overwhelming acceptance of the idea of providing support to patients outside of the acute care setting, there appeared to be less indication that they are ready or willing to do so. Specific barriers were not explored in this study, but the notable indication of overall acceptability may benefit from further exploration.

Although each of these studies were unique and utilized vastly different sources for data, they help to provide a better understanding of the state of the literature and current perspectives of chaplains and patients as it relates to spiritual distress and chronic disease. While our scoping review did not identify a distinct measure to be used to identify spiritual distress in people living with chronic disease, it did help provide a better understanding of how spiritual distress is being discussed and conceptualized in academic and clinical settings. Our studies with patients with T2DM and health chaplains speak to perceptions of acceptability as well as the presence of spiritual distress in patients and chaplain perceptions of the relationship between chronic disease, health risk behaviors, and spiritual distress.

#### 5.1 Limitations

As with all research, this dissertation is not without its limitations. Our scoping review did not include qualitative studies which would have provided a potentially richer understanding of spiritual distress. Through our focus on quantitative studies, we were able to begin to create a framework to understand spiritual distress more clearly populations experiencing chronic disease. Secondly, in our study with people with T2DM, we lacked critical lab values to include in our analyses. While regression analyses may have been significantly powered to merit limiting the number of included participants, the loss of half our sample would have been difficult to

defend. Despite working with members of the health database team at the University of Michigan to ensure the data was available, most recent medical data was simply not available in half of our sample. While the learning curve for new services or programs (like DataDirect) were steep, the 'art' of developing a well-crafted survey was more easily done in hindsight. While we captured valuable information in each of our studies, there were lingering questions that arose as we examined the data.

#### **5.2 Future directions**

There are multiple avenues of research that could evolve from this research. First, a rigorous qualitative or mixed methods study would provide immeasurable benefit in the quest to understand how spiritual distress is described in chronic disease. It is difficult to know if the current measures are accurately identifying those with spiritual distress. Work evaluating current measures and developing new measures (or items) would be an important next step.

Existing literature examining spiritual distress in people with chronic diseases like T2DM is woefully thin and more research in how it presents in the experiences of patients may help craft future interventions. Additionally, while the focus here was on people who are presently living with a diagnosis of T2DM, there is also an opportunity to explore the role of spiritual distress in people who are at risk of developing diabetes due to genetic risk factors or elevated HbA1c. While I would anticipate differences between those with or without genetic risk factors for T2DM, there may be different notable differences between those with controlled or uncontrolled diabetes.

While many disciplines in the public health and medical fields are aware of and working in population health, that is less true within the field of chaplaincy with few centers engaged in work outside the walls of their healthcare center/s. While the research on this topic has yet to be explored, our study suggests there may be an opportunity to educate chaplains to consider the role of public health within their communities to improve the lives of those whom they serve. If our results are even remotely generalizable, then addressing spiritual distress is one potential lever to make a positive impact in chronic disease prevention and management.