Title: Spiritual, Religious, and Existential Distress and Chronic Disease with Known Health Risk Behaviors: Scoping Review Protocol

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Introduction

Religion and spirituality are sources of support for people living with chronic disease and 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, Brownson, Centers for Disease, & Prevention, 2011; Tulchinsky & Varavikova, 2014). In the U.S. alone, chronic disease makes-up 90% of healthcare costs but represents only 60% of the total U.S. adult population (Buttorff, Ruder, & Bauman, 2017). There are several factors associated with chronic disease but the relationship between chronic disease and spiritual distress, and how spiritual distress is measured and conceptualized in the literature, needs more thoughtful consideration.¹

The purpose of this scoping review is to improve our understanding of how spiritual distress is measured and described among individuals diagnosed with chronic disease with known associations with modifiable behavioral risk factors. These diseases and conditions (e.g., cardiovascular disease, type 2 diabetes, chronic respiratory disease) are commonly associated with tobacco use (Adams, Grandpre, Katz, & Shenson, 2017, 2019; Ng, Sutradhar, Yao, Wodchis, & Rosella, 2020; Stein & Colditz, 2004), alcohol use (Ng et al., 2020; Schwarzinger, Thiebaut, Baillot, Mallet, & Rehm, 2017; Shield, Parry, & Rehm, 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, Roberts, & Laye, 2012; Marques, Santos, Martins, Matos, & Valeiro, 2018; Ng et al., 2020; Stein & Colditz, 2004). Given the large percentage of healthcare costs attributed to chronic disease as well as the impact to life expectancy and quality of life (Buttorff et al., 2017; CDC, 2020, 2021), interventions inclusive of spirituality may provide an innovative approach to improving health outcomes.

Spiritual distress may be one dimension of spirituality of concern in order to improve health outcomes given the association between spiritual distress and negative physical and mental health in acute care or advanced illness (Pargament & Exline, 2022; Stauner, Exline, & Pargament, 2016). *Spiritual distress* (also referred to as *spiritual struggles*) is the "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-personal² levels (Exline, 2013). Spiritual distress is

¹ The terms "distress" and "struggle" are used interchangeably for similar phenomena.

² 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

described a normal, non-pathological human experience regardless of religious affiliation, (including those who identify as non-religious, Weber, Pargament, Kunik, Lomax, & Stanley, 2012) and can take different forms depending on the type of struggle an individual may be experiencing (Pargament, 2022; Pargament & Exline, 2022). These experiences may be described as "a disturbance in meaning and purpose in life; disturbance in connection to self, God/power greater than self, others, and the world; and disturbance in transcendence" (Caldeira, Carvalho, & Vieira, 2013). Within oncology, spiritual distress is included in the clinical guidelines for distress management by The National Comprehensive Cancer Network (NCCN) and is one of the few areas where spirituality and spiritual care is identified a patient need requiring specialized care in healthcare (*Distress Management*, 2010; Handzo, Bowden, & King, 2019; Holland et al., 2010). In a recently published study from Poland, the prevalence of potential spiritual distress of spiritual distress in adults with serious or advanced disease at 18-53% (King, Fitchett, & Berry, 2013; Klimasinski et al., 2022; Thune-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2011; Velosa, Caldeira, & Capelas, 2017).

Given the relationship between spiritual distress and poorer health outcomes (Pargament & Exline, 2022), there is reason to suspect that spiritual distress may be associated or potentially contribute to the health risk behaviors underlying preventable chronic diseases. Additionally, given the likely differences in disease severity, individuals with a chronic condition or disease may experience spiritual distress differently than individuals at the end-oflife. This scoping review contributes towards a better understanding of spiritual distress and chronic disease in order to determine if additional interventions are necessary to mitigate the effect of spiritual distress on health and health outcomes.

A preliminary search for existing scoping reviews on spiritual distress and chronic disease did not identify any current or underway reviews. A search was conducted in PubMed, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis*. To our knowledge, there are no current scoping reviews or other syntheses that the describe the current state of the science of chronic disease and spiritual distress nor how spiritual distress is defined, conceptualized, and measured for those with chronic disease.

The proposed scoping review will be conducted 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). The *Population, Concept, and Context* (PCC) framework will be used to define the inclusion criteria for this review to be described in more detail below.

Review question

The guiding research question for this scoping review is: In the context of spiritual distress and chronic disease, *how is spiritual distress conceptualized, operationalized and measured with patients with chronic diseases associated with modifiable risk factors?* The

present as "transcendence, ultimacy, and boundlessness" or any interpretation of what is meaningful (Pargament & Exline, 2022, p. 6).

primary objective is to identify the measures used to determine or evaluate spiritual distress (e.g., R-COPE, Religious and Spiritual Struggles Scale, Spiritual Well-being Scale) through a scoping review of the literature. Additional secondary analyses will also be completed to examine the manner in which spiritual distress presents in the context of preventable chronic conditions and the behavioral health risk factors (i.e., tobacco use, alcohol use, physical activity, and diet) are described.

Eligibility criteria

Participants

This scoping review will consider studies that focus on adult persons (18+ years of age) with a specific set of chronic disease diagnoses (see, Appendix I) associated with the identified behavioral risk factors (Stampfer, Ridker, & Dzau, 2004; WHO, 2005) and include concepts related to religious, spiritual, or existential distress. Studies will be excluded if they are focused on communicable or congenital disease/s, end-of-life, or palliative care. Additionally, studies that focus on non-patients (e.g., caregivers or other care providers), complementary or alternative medicine (e.g., yoga, meditation, mindfulness) or on death and dying will be excluded from this review.

Concept

The concept of interest in this proposed scoping review is the phenomena of spiritual, religious, or existential distress in adults with chronic disease. Examples of spiritual, religious, or existential (S/R/E) distress may use language that includes struggle, needs, or the lack of wellbeing. Measures used to assess for S/R/E distress will be extracted and included in the mapping of the concepts.

Context

The context of this scoping review is the experience of chronic disease in adult populations inclusive of any geographic locations (e.g., North America, Europe), religious traditions (e.g., Christianity, Islam, Judaism), or racial/ethnic groups. All practice settings (e.g., acute care, outpatient care) apart from hospice care will also be included within this review.

Types of Sources

This scoping review will consider quantitative and mixed methods designs in peer reviewed literature. This includes observational, experimental, and quasi-experimental designs such as randomized controlled trials, non-randomized control trials, before and after studies, prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies. Qualitative designs, reviews, opinion papers, and grey literature will not be considered for inclusion in this review.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews and the PRISMA-ScR checklist for standardization (Page et al., 2021;

Peters et al., 2020; Tricco et al., 2018). A completed flow chart using the PRISMA 2020 formatting will be included following the completion of the review (Page et al., 2021).

Search strategy

The search strategy for this review underwent an iterative process to locate published studies and was developed in consultation with an experienced university health sciences librarian. A limited search of PubMed, CINAHL and SCOPUS was undertaken to identify articles on the topic. From there, text from titles and abstracts of relevant articles, keywords, and index terms were used to develop the full search strategy. This strategy will be adapted for each database included in this scoping review (see, Appendix II). Studies published or available in English will be included with no restrictions on the date of publication.

Study/Source of Evidence selection

Following the search, the identified studies will be exported into EndNote 20.2 and duplicates removed prior to exporting the studies into a cloud-based review application (Rayyan for abstract review and Covidence for full-text review). The titles and abstracts of the identified studies will be screened by two independent reviewers for assessment against the inclusion criteria for the review. Pilot testing using the inclusion criteria will be used by the two reviewers to assess clarity of the inclusion criteria and edited, if needed. After screening the identified studies and upon agreement between the two reviewers, the full text of selected citations will be assessed. Reasons for exclusion of the selected full text will be recorded and reported in the scoping review. Disagreements between the reviewers at each stage of the selection process will be resolved through discussion or by a third reviewer, if necessary. The results of the full text searches will be recorded and reported in full in the final scoping review and presented using the PRISMA-ScR flow diagram.

Data Extraction

A data extraction form (see, Appendix III) will be completed by at least two independent reviewers. The draft data extraction tool will be piloted with ten qualitative papers and revised as necessary. A survey tool available in Covidence will be used for data extraction purposes. Modifications to the data extraction form after the initial review of titles and abstracts will be indicated in the scoping review. The data extracted will include specific details about the study location, participants, concept, diseases or conditions, study methods, measures, and key findings relevant to the review. Disagreements between the reviewers will be resolved through discussion or by an additional reviewer, if needed. Conceptual mapping of the phenomena of spiritual, religious, and existential distress will be included following data extraction.

Data Analysis and Presentation

Once the data has been collected using the data extraction tool, it will be exported and displayed in tabular and visual formats followed by a narrative summary. This may also include separating different disease conditions (e.g., cardiovascular disease, oncology) to determine if there are different measures used with specific conditions. Data will be presented quantitatively (e.g., percent including specific concepts) and qualitatively (e.g., specific details from observed themes in how concepts are used or contextualized). Concept mapping will be used to present a

comprehensive visual display of the sub concepts identified in the literature that define and relate to spiritual distress for preventative chronic conditions (Alias & Suradi, 2008; Trochim & McLinden, 2017). This procedure will use the extracted summary data (definitions of spiritual distress, sub-concepts suggested by measures). Using Microsoft Visio, the research team will create a concept map using all studies included in the database (iteratively developed). The comprehensive map will be further reviewed for potential consolidation to create a single parsimonious presentation of core concepts identified in the literature.

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Conflicts of interest

There is no conflict of interest in this project.

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Appendices

Appendix I: Inclusion & Exclusion Criteria

Inclusion Criteria				
Study types	Experimental, quasi-experimental, observational, and mixed methods studies with at least 1 quantitative survey with a SRE measure			
Time frame	Any			
Language	English or available in English			
Population	Adults (18 years or older)			
SRE Measure	Includes Spiritual, Religious, or Existential Distress measure or description			
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Heart/Vascular

Heart/Vascular	Diabetes/Renal	Respiratory	Cancer/s	Liver
 Cardiovascular Disease Congestive Heart Failure Myocardial infarction Ischemic heart disease Coronary artery disease Coronary artery disease Coronary artery disease Coronary artery Sease Transient Ischemic Stroke Transient Ischemic Stroke Hypertension Dyslipidemia 	 Type 2 Diabetes Chronic Renal Disease Prediabetic Diabetic Ulcers (e.g., foot ulcers) 	 Chronic obstructive pulmonary disease Pulmonary Hypertension Emphysema Chronic Bronchitis Asthma 	 Esophageal Colorectal Hepatic 	 Liver Disease (e.g., fatty liver disease) Cirrhosis

Exclusion Criteria					
Not Patient Focused	Non-Adults	Terminal of life-limiting Disease	Communicable / Congenital Disease	Complementary / Alternative Medicine; religious behaviors	Paper Types

Caregivers; Providers; Parents; Experts	Children; Adolescents; Pediatrics	End-of-Life; Advanced Disease; Palliative Care; Hospice	HIV/AIDS; Hepatitis; Cystic Fibrosis; Sickle Cell	Yoga, Meditation; Only religious behaviors; Fasting only; pilgrimages; Beliefs/behavior s about blood or tissue donations or transplants	Reviews; Opinions; Informative; Grey Literature; Background; Books; Book Reviews; Protocols; Program Development
					Development

Appendix II: Search strategy (Results from PubMed (Medline) preliminary literature search)

Search	Query	Records Retrieved from PubMed
#1 Spiritual distress	(("Humanism"[Mesh] OR "Existentialism"[Mesh] OR "Secularism"[Mesh] OR "Spirituality"[Mesh] OR Spiritual[tiab] OR Spiritualities[tiab] OR religious[tiab] OR 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 struggles[tiab] OR anguish[tiab]))	22,423
#2 Chronic disease	"Liver Disease"[tiab] OR "Liver Diseases"[Mesh] OR "Type 2 Diabetes"[tiab] OR "Kidney Disease"[tiab] OR "Chronic Renal Disease"[tiab] OR prediabetic[tiab] OR pre-diabetic[tiab] OR diabetic [tiab] OR prediabetic[tiab] OR pre-diabetic[tiab] OR diabetic [tiab] OR rediabetis 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 stroke[tiab] OR "Coronary artery disease"[tiab] OR "coronary arterial disease"[tiab] OR "Heart valve disease"[tiab] OR "coronary arterial disease"[tiab] OR "Heart valve disease"[tiab] OR "coronary arterial disease"[tiab] OR "Heart valve disease"[tiab] OR "coronary arterial disease"[tiab] OR TIA OR "Mini stroke"[tiab] OR "ransient Ischemic Stroke"[tiab] OR hypertension[tiab] OR "Transient Ischemic Stroke"[tiab] OR hypertension[tiab] OR "Ventricular Dysfunction"[MeSH Terms] OR "Myocardial stunning"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Ventricular Dysfunction"[MeSH Terms] OR "Myocardial Stunning"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Heart Valve Diseases"[MeSH Terms] OR "Meatabolic Syndrome"[MeSH Terms] OR "Ischemic Stroke"[MeSH Terms] OR "Heart Arrest"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Heart Arrest"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Heart Arrest"[MeSH Terms] OR "Cardiomyopathies"[MeSH Terms] OR "Heart Arrest"[MeSH Terms] OR "Schemic Stroke"[MeSH Terms] OR "Heart Arrest"[MeSH Terms] OR "Schemic Stroke"[MeSH Terms] OR "Heart Disease Risk Factors"[MeSH Terms] OR "Metabolic Syndrome"[MeSH Te	3,304,214
#3	#1 + #2	1,065

Appendix III: Data extraction instrument

	Information Field	Results		
G	Author/s	Copy/Paste		
	Year of publication	Copy/Paste		
en er	Journal name	Copy/Paste		
al St	Country (Sample Origin)	Copy/Paste		
ud y	Context	Copy/Paste		
Inf or m	Sample size	Copy/Paste		
ati	Aim of study	Copy/Paste		
on	Study design (including duration, if applicable)	e.g., randomized controlled trial, mixed methods, qualitative		
Co nt ex t	Setting	e.g., outpatient clinic, acute care hospital, hospice, multiple settings		
	Number of settings (if multiple)	Copy/Paste		
	Identified Disease/s	Copy/Paste		
S R	Definition of S/R/E Distress	Copy/Paste		
E Di	Measure/instrument for S/R/E distress	e.g., the Religious and Spiritual Struggles Scale, FACIT-SP, R-COPE		
str es s	Who is administering?	e.g., Nurse, Chaplain, Social Worker, Self (patient)		
Ot he r S/ R/ E M ea su re s	Specified religious affiliation	Copy/Paste (e.g., Protestant Christian, Hindu, Muslim, Jewish, Humanism, etc.)		
	Measures of religiosity, spirituality, or existentialism	Copy/Paste		