



EFFECT OF SPIRITUALITY INTEGRATED INTERVENTIONS ON CAREGIVERS OF PEOPLE WITH TERMINAL ILLNESS: A SYSTEMATIC REVIEW OF QUANTITATIVE OUTCOMES

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BE KNOWN

- Who was/is a caregiver to a person with terminal illness?
- Who is a clinician works with a caregiver to a person with terminal illness?
- Who is interested in developing some clinical skills to work with a caregiver?



WHY DO WE DO WHAT WE DO?

- Caregiver
- Terminal illness
- Spirituality



CAREGIVER

- Approximately 39.8 million caregivers provide care to adults (aged 18+) with a disability or illness.
- About 15.7 million adult family caregivers care for someone who has Alzheimer's disease or other dementia.
 - (Coughlin, 2010; Alzheimer's Association, 2015)



CAREGIVER

- On average, caregivers spend 24.4 hours a week providing care to their loved one. Nearly one-quarter provide 41 or more hours of care a week (23%). Caregiving is particularly time-intensive for those caring for a spouse/partner (44.6 hours a week).
- (The National Alliance for Caregiving, 2015)



CAREGIVER

- Upwards of 75% of all caregivers are female, and may spend as much as 50% more time providing care than males.
 - (Institute on Aging, 2016)



CAREGIVER BURDEN

- Caregivers were found to experience greater psychological distress (Sklenarova et al., 2015). It is also evident that caregiver psychological distresses can lead to severe consequences, including impaired physical health such like fatigue or sleep impairment (Song et al., 2012); elevated symptoms of depression and anxiety (Oechsle, Goerth, Bokemeyer, & Mehnert, 2013); worsen health-related quality of life (Kim et al., 2015); greater perceived caregiving burden (Payne, 2010) etc.



TERMINAL ILLNESS

- Terminal illness impacts human functioning on all domains, especially, it can trigger issues of identity, autonomy, purpose and meaning, etc. Simultaneously, terminal illness can also lead to changes in family roles, dynamics, communication, and its everyday functioning.



SPIRITUALITY

- As death impending, addressing spiritual distress/needs emerges naturally.
- While coping with medical, practical, psychosocial, and spiritual uncertainty in preparing for patient's death and bereavement, caregivers were observed to have spiritual needs similar to, in certain times even higher than, those of patients (Bowman, Rose, Radziewicz, O'Toole, & Berila, 2009; Ross & Austin, 2015; Taylor, 2003).



SPIRITUAL DISTRESS

- Research has revealed substantial consequences when the spiritual needs were not met appropriately, including decreased quality of life (Cohen, Mount, Tomas, & Mount, 1996); increased level of anxiety and depression (McCoubrie & Davies, 2006; Wilson et al., 2007); suicidal ideation or loss of the will to live (Chochinov et al., 2005); more fear of the loss of dignity (Chochinov et al., 2002); more feelings of being a burden to others and hopelessness (Wilson et al., 2007); or resulting in a hindered or delayed grief resolution process and lead to higher risk of prolonged grief among caregivers (Lai et al., 2014).



RESEARCH GAP

- Despite the prevalence and significance of spiritual distress and needs in the context of advanced disease, they were often neglected and spiritual care was reportedly lacking.
- Over the past two decades, much has published related to spiritually integrated interventions. However, multiple recent systematic review or meta-analysis have revealed that current publications are either patient or care recipient focused (Brandstätter, 2014; Chen, Lin, Yan, Wu, & Hu, 2018; Kruizinga et al., 2016; Maltoni et al., 2012;) or not in the field of terminal illness (Gonçalves, Lucchetti, Menezes, & Vallada, 2015). There are few studies evaluating the available spiritual integrated interventions targeting caregivers, little is known about the efficacy of these interventions.



HOW DO WE DO IT?

- Systematic Review



METHODOLOGY

- Search Strategy
 - Electronic databases: Academic Search Premier, Ageline, Scopus, CINAHL, MEDLINE, Psychology and Behavioral Science Collection, PsycINFO, Sociological Collection, and TOPIC Search.
 - (spirituality OR spiritual care OR religious care OR pastoral care OR spiritual intervention OR spiritual therapy) AND (terminal illness OR terminal disease OR palliative care OR end-of-life care) AND (caregiver OR family caregiver OR informal caregiver)



METHODOLOGY

- Inclusion Criteria
- The intervention was focused on caregivers of people who are terminally ill or facing a life-threatening condition (i.e., advanced disease, end-stage disease, incurable chronic conditions such like AIDS or dementia) or in palliative care settings. Caregivers were aged 18 years or over and provided informal, unpaid care to a person with terminal illness. No restriction was put on age, sex, or ethnicity of and the patients. The intervention was also eligible if it was implemented on patients and caregivers simultaneously.
- The interventions was to address caregivers spiritual well-being or have a spiritual aspect in it.
- Eligible study was a randomized controlled trial or used random assignment of allocating participants to intervention and control groups.
- The study reported caregiver outcomes using quantitative self-reported measures.
- The study was published in a peer reviewed journal in English between January 1st of 2004 and October 15th of 2019.



METHODOLOGY

- Study Quality Evaluation
 - The Cochrane Collaboration's tool for assessing risk of bias in randomized trials was used to evaluate study rigor and quality.

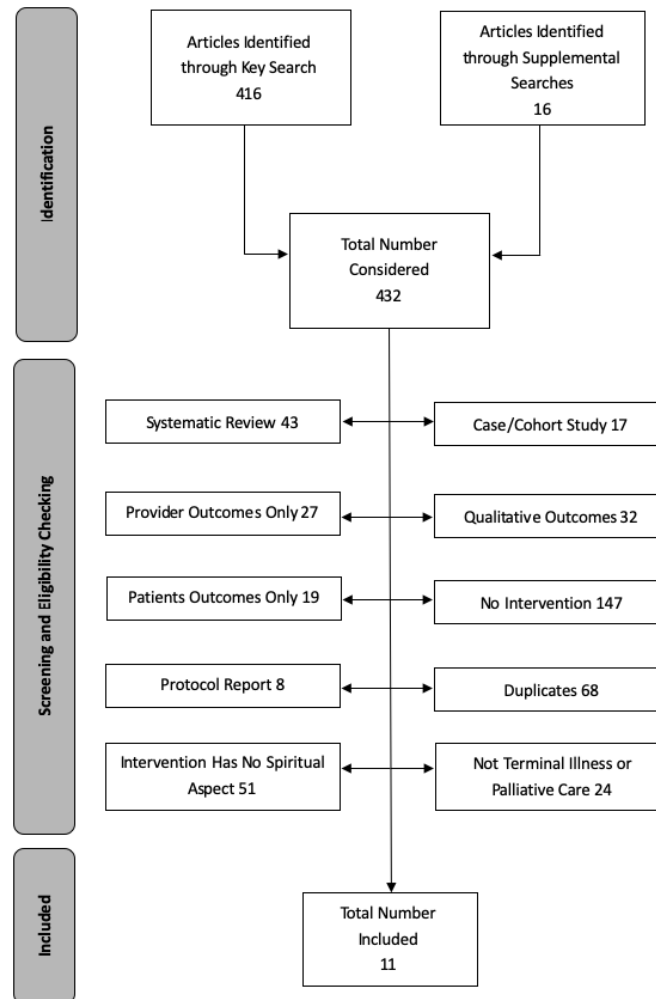


WHAT WE HAVE FOUND SO FAR?

- Study Inclusion
- Study Characteristics



STUDY INCLUSION



STUDY CHARACTERISTICS

- Patient Characteristics
- Caregiver Characteristics
- Intervention Characteristics
- Outcomes



PATIENT CHARACTERISTICS

- Cancer
- Glioma



CAREGIVER CHARACTERISTICS

- 42 caregivers
- 131 caregivers
- 10 patient and family caregiver dyads in South Korea
- 122 family caregivers
- 20 glioma patients and 20 caregivers
- 70 caregivers of patients undergoing hemodialysis in Iran
- 50 patients and caregivers dyads
- 81 caregivers in Germany
- 119 family caregivers in Sweden



INTERVENTION CHARACTERISTICS

- Self-administered web-based program, the Care for the Cancer Caregiver (CCC) Workshop (Meaning-Centered Psychotherapy)
- Structured multidisciplinary intervention session(Spirituality: grief, loss, hope, and blessings)
- A peer helping + coping skills intervention (Telephone-based)
- Music therapy
- Emotionally Focused Therapy (couple-based intervention, one session of the process of reviewing one's life; and existential issues that include meaning, value, and spirituality)
- ENABLE III(Educate, Nurture, Advise, Before Life Ends) telehealth intervention (caregiver self-care, addressing topics such as healthy eating and exercise, meditation, spirituality)
- Dyadic yoga (DY) intervention
- Family-based training program (prayer therapy)
- Telephone-based Acceptance and Commitment Therapy (Experiential practice of mindfulness; Identify personal values (e.g., being a loving partner, engaging in spiritual practices)
- Existential behavioral therapy (Death, bereavement and mindful, finding meaning, personal value)
- The psycho-educational intervention (Social worker/priest: existential issues)



OUTCOMES

- Spiritual well-being (The Functional Assessment of Chronic Illness Therapy (FACIT) Spiritual Well-Being Scale)
- Caregiver QOL (Caregiver Quality of Life Index-Cancer Scale (CQOLC); Linear Analogue Self-Assessment (LASA))
- Meaning(Life Attitude Profile-Revised (LAP-R19))
- Burden(The Caregiver Reaction Assessment)
- Anxiety & Depression (The Hospital Anxiety and Depression Scale),
- Benefit finding (The Benefit Finding Scale)
- Mood (Profile of Mood States-Brief (POMS-B))
- Intimacy between the patient and caregiver (The Family Intimacy Observation Scale)
- Marital functioning (The Revised Dyadic Adjustment Scale)
- Caregiver Grief (The Prigerson Inventory of Complicated Grief-Short Form (PGI3))



IMPLICATIONS

- What do you think about caregivers' spirituality?
- What types of spiritual care you would like to provide to your clients/families?
- How do you see that interventions in this systematic review could be applicable for your practice?



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