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Spiritual and religious interventions for adults with cancer and their carers: an overview of systematic reviews (Protocol)

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[Overview of Reviews Protocol]

Spiritual and religious interventions for adults with cancer and their carers: an overview of systematic reviews

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ABSTRACT

Objectives

This is a protocol for a Cochrane Review (overview). The objectives are as follows:

We aim to provide a comprehensive overview of systematic reviews pertaining to spiritual interventions, with or without religious interventions, for adults with cancer and their carers. We also plan to assess the benefits and harms of these interventions.

BACKGROUND

Description of the condition

Cancer incidence and deaths are increasing rapidly worldwide; there were approximately 18.1 million new cancer cases and 9.6 million deaths from cancer in 2018 (Bray 2018). Lung cancer is the most common type of cancer, constituting 11.6% of all cancer diagnoses and 18.4% of deaths from cancer. The next most common in terms of incidence are female breast cancer (11.6%), prostate cancer (7.1%), and colorectal cancer (6.1%); and in terms of mortality are colorectal cancer (9.2%), stomach cancer (8.2%), and liver cancer (8.2%) (Bray 2018). Emerging technological developments, such as advanced surgical devices and screening techniques, continue to improve clinical outcomes for people with cancer (Uchida 2015; Viswanath 2016). However, a recent study revealed that more than 80% of people with cancer reported low quality of life, which was affected by a range of symptoms (Nayak 2017). Previous studies have shown that quality of life includes multiple physical, psychosocial, and spiritual factors, which can interact with each other (Levine 2002).

Burdensome physical symptoms including pain, fatigue, and sleep problems have a negative impact on life and daily functioning in people with cancer (Levine 2002). A cancer diagnosis is stressful for the person, their family members and carers, and evidence has shown that a substantial number of people report the experience as traumatic (Cordova 2017). Effective coping mechanisms, and availability of support systems, are essential in maintaining the mental health of people with cancer whilst combating the disease and its related symptoms. Following a cancer diagnosis, people usually face life-changing treatment decisions. Living with uncertainty related to one's future, and having to cope with the possibility of a recurrence or metastasis (or both), can be frightening.

Generally, cancer is perceived with fear in most cultures. A degree of suffering is common towards the end of the disease and is sometimes unbearable in patients with advanced cancer (Ruijs 2009). It is a natural human response to ask questions such as 'why' or 'why me'. Spirituality can offer some relief from suffering evoked by ill health and fear. Levine's study, which included 191 women with breast or metastatic cancer, showed that spiritual factors were correlated with functional well-being, as the women's spiritual scores contributed to 40% of the variance in their functional well-being levels (Levine 2002). Thus, spirituality and spiritual well-being were shown to play important roles in both physical and functional well-being. Moreover, as confirmed by the findings of two meta-analyses on the topic of spirituality and cancer conditions, spirituality was associated with better self-reported physical health, mental health, and decision-making satisfaction among people with cancer (Jim 2015; Salsman 2015). In addition, cancer can trigger one’s contemplation on existential issues and spirituality by posing the threat to life and even pending death at an advanced stage. Death anxiety and anticipatory grief may be part of complex experiences for people with cancer.

Description of the interventions

Religion and spirituality will be two overarching terms in our overview. According to a review by Pargament 2013, spirituality is defined as "the search for the sacred"; meanwhile, religion is "the search for significance that occurs within the context of established institutions that are designed to facilitate spirituality". These broad definitions share similarities, as they both focus on fear beyond normal daily experiences. Both religion and spirituality have the potential to have a profound impact on human life, especially in the suffering experienced when facing death. They can incorporate personal or collective beliefs, practices, relationships, and spiritual experiences. Importantly, we recognize the distinctiveness of religion and spirituality considering the context and their functions.

The term 'religion' has a longer history than the term 'spirituality'. Religions, in practice, influence multiple aspects of human societies, such as community, education, science, financial, political activities, and individual behaviours (Pargament 2013). Meanwhile, one may be spiritual without following a religion, or vice versa. For instance, a self-labelled religious person could lose connection with their own spiritual pursuit, despite performing rituals. In addition, popular terms used in modern positive psychology for example, hope and meaning, can fall either within the realms of 'spirituality/religion' or more generally, where only the former would be considered as part of our review scope. Diverse usage of spirituality/religion-related terms should be expected from the literature.

Spiritual interventions with or without religious interventions (S/R interventions) are usually characterized by the components of one's faith/religion, or existential factors including meaning, hope, and purpose in life. Worthington classifies such interventions as "religious accommodated interventions" (RAI) or "spiritual accommodated interventions" (SAI) (Worthington 2013). Some literature describes stand-alone specialized interventions, while others are embedded in psychological interventions, music or art therapy, or included in palliative care programmes.

More innovative programmes involving spiritual assessment in healthcare systems have emerged to incorporate the assessment of the participants' spiritual history, struggles, current beliefs, and S/R practices (Pearce 2013). Such interventions could include open prayers, offerings of S/R resources, support for spiritual inquiry or conversation, referrals to affiliated religious leaders, encouraging rituals, and discussions regarding peoples' beliefs in a psychotherapy format. These interventions could involve survivors, people with a diagnosis who are receiving treatment, people who have completed treatment, and those in the terminal stage. Interventions may also be targeted at families, caregivers, or healthcare professionals, especially when the person with cancer lacks or loses capacity/consciousness as part of the disease condition. The interventions are often implemented in facilities affiliated with medical institutions, research centres, and non-clinical environments including religious services or other community-based settings. For example, a new model of integrated palliative rehabilitation was designed in a randomized controlled trial (RCT) to offer flexibility to patients and families in the patient/caregiver training along with optional exercises and consultation. A hospital chaplain, as part of the multidisciplinary team, led one of the educational modules (named 'when life hurts') with a facilitating nurse. The aim was to assist people and their families with their existential issues, and overall the responses from participants were positive (Nottelmann 2019).

How the intervention might work

S/R interventions can be faith-based or existentially focused. S/R interventions accompany the development of modern healthcare

systems. For example, it is common to have a chaplain in palliative care. As reviewed by Worthington and colleagues in 2013, earlier religious accommodative interventions started to address both psychological goals (such as reducing anxiety and depression symptoms) and spiritual goals by integrating techniques like prayer, religious imagery, exposure, and cognitive behavioural therapy (Worthington 2013). Another way of categorizing such interventions consists of three types: pastoral counselling, spiritual direction, and spiritually integrated psychotherapy (Sperry 2013).

When facing increased life complexity alongside health-related issues, people with cancer and their families have their own needs to fulfil and this can include finding meanings for their challenging experiences. The literature supports the notion that spirituality/religiosity is part of clinical interactions, regardless of whether people acknowledge it (Pearce 2013). Efforts were made to advocate for the integration of S/R interventions into clinical practice in the fields of nursing, oncology, and end-of-life care. A pilot study was conducted on spiritual inquiries in oncology office visits among 118 adults with cancer, more than one month post diagnosis (the Oncologist to Assist Spiritual Intervention Study (OASIS) (Kristeller 2005). Their initial findings were encouraging: within three weeks, people reported enhanced quality of life and increased satisfaction with their care. It is important to note that the interventions lasted between five and seven minutes, and were semi-structured with a broad focus, because the OASIS volunteers were required to explore the spiritual concerns of the 118 people. Nevertheless, regardless of lack of structure, 76% of participants reported reductions in depressive mood when compared to their peers who did not have access to the brief S/R assistance provided in the study. In OASIS, the quality-of-life measurement, the Functional Assessment of Cancer Therapy - General (FACT-G), was applied repeatedly. At the third week of follow-up, compared to the usual care (control) group, the spiritual inquiry group exhibited higher overall quality of life scores and subscales of functional well-being and social/family well-being. However, there were no statistically significant findings in physical functioning and emotional well-being (Kristeller 2005).

Why it is important to do this overview

As reviewed by Pearce 2013, 41% to 94% of individuals would prefer their S/R needs to be addressed in a health care setting. However, their expectations are mostly left unmet (Best 2015; McCord 2004). One possible reason for this is that spiritual interventions are considered appropriate mainly when they are led by trained professionals (including psychotherapists and nurses) or religious representatives from traditional groups, such as chaplains (Candy 2012; Pearce 2013). It is reported that people's desire for spiritual discussion increases towards the end of life (McCord 2004). The key components, including spiritual needs, assessment, interventions, and important outcomes, should therefore be explored.

Though previous studies have demonstrated the importance of fulfilling peoples' spiritual needs, there are only a small number of reviews summarizing published research on spiritual care and interventions. The reviews conducted in this field have begun to accumulate gradually (Oh 2014; Wang 2017), and provide increasing evidence on the moderate effectiveness for spiritual well-being, meaning of life, depression, and anxiety. For instance, a recent systematic review and meta-analysis of 30 RCTs of existential interventions for 3511 adult cancer patients included dignity therapy, life review, narrative intervention, meaning-making intervention, hope intervention, and group or individual psychotherapy (Bauereiß 2018). The key conclusion included significant effects on existential well-being, quality of life, and self-efficacy at post treatment. The hope effect appeared significant both at post treatment and after six months. However, it reported no effects on other outcomes or time points (Bauereiß 2018). In addition, few studies have shown a relationship between S/R interventions and potential harm or effects on people with illnesses (Pearce 2013). Adverse effects are rarely reported, even though it is known that S/R interventions can have positive or negative effects (Pearce 2013). The literature reveals that rigid beliefs or interpretations of illness may lead to patients' burden of shame, guilt, or low self-esteem (Pearce 2013). Existing psychological literature has also found outcomes from negative religious coping, such as lower quality of life, worsening health, anxiety, depression, and greater two-year mortality in relation to S/R struggles, including disappointment in faith community (Pargament 2001). In this overview, we will explore more examples on the reasons for withdrawing from those interventions, in order to infer their potential harmful effects. We will maintain a neutral attitude towards S/R interventions during this overview process.

The field of oncology has recognized the need for further international synthesis of the evidence on this topic (Jim 2015). The S/R interventions cover more than the fields of healthcare, theology, and psychology. Candy and colleagues conducted a Cochrane Review in 2012 on spiritual and religious interventions for terminal-stage patients (Candy 2012).Their review, based on five RCTs (two of meditation and the rest palliative spiritual care), reported inconclusive findings. Based on the newly published evidence, further examination of the reviews on such interventions and their effectiveness could be worthwhile, regardless of the stage of disease or cancer sites. It is equally important to review the evidence with consideration of specific treatment purposes and cancer sites, as this could aid in the improvement of quality of life among people diagnosed with a certain type of cancer, and in curative treatment, palliative care, or end of life care. Our overview of systematic reviews will aim to provide a comprehensive knowledge base that could serve as a useful source of reference for those who wish to understand the outcomes of popular interventions related to the promotion of spiritual well-being and refer to existing empirical studies in which certain interventions were found to be effective.

OBJECTIVES

We aim to provide a comprehensive overview of systematic reviews pertaining to spiritual interventions, with or without religious interventions, for adults with cancer and their carers. We also plan to assess the benefits and harms of these interventions.

METHODS

Criteria for considering reviews for inclusion

Types of studies

We will include all systematic reviews or meta-analyses of randomized controlled trials (RCTs), quasi-randomized trials, or controlled clinical trials (CCTs).

Types of participants

Adults aged 18 years or older, who have been diagnosed with any stage of cancer or have survived cancer with or without treatment, will be eligible for inclusion. People with other medical complications comorbid with a cancer diagnosis will also be eligible for inclusion, as well as the adult carers who take responsibilities for people with cancer.

Types of interventions

We will expand the SAI-RAI classification from Worthington 2013 by including three groups: spiritually accommodated interventions (non-traditional); religious accommodated interventions (traditional and often with some religious affiliation); and other integrated intervention modalities with active spiritual components. There is a wide range of such interventions, in the format of the provision of general supportive care; specific individual counselling; life review; yoga/meditation; mind-body interventions; and other complementary/alternative therapies that aim to promote physical, emotional, social, spiritual, and holistic well-being. Individual, group, and family therapy interventions related to spirituality explicitly will also be eligible for inclusion. However, family therapy will be included only if family members and the person with cancer attend sessions together.

Thus, the overview will include any interventions that contain an active spiritual component in the treatment, which may be related to the following.

1. Traditional S/R care
2. Psychological therapies (including psycho-education to make sense of the illness)
3. Life-review interventions
4. Reminiscence interventions
5. Narrative therapy
6. Yoga and other mindfulness-based therapy
7. Palliative care including pain management at different stages

We do not have specific requirements for comparison groups, which may include, but are not limited to: usual care, alternative treatment, or waitlist groups.

Types of outcome measures

Primary outcomes

The primary outcomes for adults with cancer, survivors, and carers (as measured via standardized scales or self-report questionnaires) will include the following.

1. Quality of life/well-being. Popular measurements are the Functional Assessment of Cancer Therapy - General (FACT-G) and McGill Quality of Life Questionnaire.
2. Spirituality/religious-related, which may include post-traumatic growth, hope, meaning, purpose, and existential or spiritual well-being. The valid measurements, as reviewed by Hill 2013, can either be spiritually focused (e.g. the Spiritual Well Being Scale, SWBS) or general (e.g. quality of life or meaning/peace subscale of the Functional Assessment of the Chronic Illness Therapy, FACIT-Sp), with any explicit spiritual factor.
3. Any adverse events, as reported or discussed.

Secondary outcomes

The secondary outcomes for adults with cancer, survivors, and carers (as measured via clinical records, standardized scales, or self-report questionnaires) will include the following.

1. Symptoms (pain, anxiety, depression, breathlessness, fear, worry). Examples of outcomes measures include the MD Anderson Symptom Inventory (MDASI), Hospital Anxiety and Depression Scale (HADS), and Anticipatory Grief Scale (AGS).
2. Overall five-year survival rate (people with cancer only).
3. Existential suffering (tolerable or unbearable) that may include personal, relational, social, and environmental aspects, using measurements such as the State Of Suffering-Five (for five domains) (SOS-V).
4. Wish/desire for hastened death, as measured by the Schedule of Attitudes toward Hastened Death (SAHD).
5. Dignity. A valid reliable measure is the Patient Dignity Inventory (PDI).

Specific measurement details on validity and reliability will be added in our formal literature search as we expect to detect more in the process of conducting the overview.

Search methods for identification of reviews

Electronic searches

We will include the following databases in our search: MEDLINE, the Cochrane Central Register of Controlled Trials (CENTRAL), Embase, CINAHL, and PsycINFO. The MEDLINE search strategy is detailed in Appendix 1.

Searching other resources

We will search grey literature, including theses and conference proceedings, on the following websites.

1. Grey matters www.cadth.ca/resources/finding-evidence/grey-matters
2. Open grey www.opengrey.eu/

We will also perform manual searches and will contact experts for relevant reviews in order to minimize the likelihood of publication bias in this overview.

Data collection and analysis

Selection of reviews

Two authors (BY and XX) will screen the titles and abstracts of all the Cochrane systematic reviews and non-Cochrane systematic reviews from the listed databases independently, to identify relevant articles for inclusion and assign codes to them. We plan to retrieve the full text of selected reviews, and two authors (BY and XX) will screen the full text of the reviews independently, to assess fulfilment of the eligibility criteria. The reasons for excluding ineligible reviews will be documented. If any disagreements arise, consensus will be reached through discussion or the involvement of the third or fourth author (DC or CL, respectively).

To be included, reviews must be published in English. To be as inclusive as possible, we will place no restrictions in terms of the following.

1. The durations of interventions
2. The professional/non-professional roles in the interventions
3. Whether the interventions are general or specialized
4. Outcome measures
5. The timing of the targeted systematic reviews
6. Location

Data extraction and management

Two review authors (BY and XX) will extract the publications and data from original systematic reviews independently. If disagreement regarding study inclusion arises, consensus will be reached though discussion or the involvement of the third or fourth author (DC or CL, respectively). We have developed a data extraction form which we will use to extract the following details from included systematic reviews.

1. Review objectives
2. Participant/population characteristics
3. Methods/interventions
4. Comparisons, outcomes, and follow-up times, if any

In addition, where possible, we will record information on the GRADE assessment; methodological quality assessment; risk of bias assessment; heterogeneity; and subgroup analysis. We will follow the guidance in the *Cochrane Handbook for Systematic Reviews of Interventions* on conducting overviews of reviews (Higgins 2019; Pollock 2020).

We plan to contact the review authors, rather than the authors of the individual trials, for missing information that is required during the extraction process. We will input included reviews into Review Manager 5.4.

Assessment of methodological quality of included reviews

We have created a template 'Risk of bias' table to ensure inclusion of all the key domains of our assessments, which will be performed at the current protocol stage based on the AMSTAR 2 tool (Shea 2017). The table will be populated by two authors (BY and XX) during a later stage of the review. To allow evaluation of the items on the AMSTAR 2 checklist with missing or unreported information, we plan to contact the authors of the systematic reviews. If no supplementary information is available from the authors, we will assume that their review or meta-analysis does not meet the specific item requirements for the AMSTAR 2 checklist.

If heterogeneity is detected in our overview, we will report the existing statistics in a manner similar to that used to report in systematic reviews or meta-analyses. We will examine potential bias in the intervention trials in the existing systematic reviews, based on findings regarding selection bias, performance bias, detection bias, and attrition bias. We will report low, moderate, and high level of bias in our overview.

Data synthesis

We plan to conduct a narrative synthesis of the findings in our overview, rather than a meta-analysis, given the likely considerable variation in the included interventions in the targeted reviews. In the very unlikely event that only one study meets our criteria, we will provide a narrative description of the findings from that systematic review or meta-analysis alone. Moreover, if a number of systematic reviews meet our criteria, we will classify them according to the particular situation, for example, Cochrane or non-Cochrane systematic reviews, common intervention types (religiously accommodative interventions, spiritually accommodative interventions, integrated models), treatment purpose (curative care, palliative care, or end-of-life care), diagnosis, and key outcomes prior to synthesising the evidence from their GRADE assessments. It could be beneficial to the field practitioners, researchers, and possibly even healthcare policy makers in the future to have the category 'map' of the available evidence on the intervention effects (Pollock 2020).

Subgroup analysis

If there are sufficient systematic reviews or meta-analyses included, we will perform subgroup analysis based on classification of treatment purposes (curative care, palliative care, or end-of-life care). Subgroup analyses will be conducted in the narrative format in the planned overview. The variables of interest for adults with cancer in subgroup analyses are as follows.

1. Participants' age
2. Participants' sex
3. Participants' medical diagnosis and treatment
4. Participants' stage of illness
5. Participants' religiosity or spiritual beliefs

Summary of findings

Where possible, we will present a 'Summary of findings' table containing the key data extracted from the included reviews. The primary outcomes will be presented in the 'Summary of findings' table (quality of life, spirituality/religious, and adverse events). Two review authors (BY and XX) will rate the certainty of evidence in the included systematic reviews or meta-analyses independently, based on GRADE criteria, and the GRADE assessments of the certainty of evidence will be presented for outcomes in the included reviews, dependant on whether the extracted information enables assessment (Higgins 2019; Pollock 2020). Reviews that contain non-randomized trials will be reported separately. We will resolve any disagreements that arise between authors during review process. If necessary, the third or fourth author (DC or CL, respectively) will offer additional judgement. A template 'Summary of findings' table is included in Appendix 2.

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APPENDICES

Appendix 1. MEDLINE search strategy

1. exp Spiritual Therapies/
2. exp Religion/
3. ((relig* or spirit* or pray* or prey* or pastoral* or belief* or believe* or heal or healing* or faith* or multifaith* or multi faith* yog*) adj5 (interven* or prog* or ritual* or car* or service* or plan* or resourc* or attitude* or need* or aspect* or nurs* or support* or therap* or help* or assist* or treat* or ceremon*)).mp.
4. (spiritual* or religio*).mp.
5. (deity or divinity or divine).mp.
6. (church* or cleric or clergy* or priest* or preacher* or vicar* or (minister* adj10 religi*) or (minister adj10 church)).mp.
7. (shamanism or mystic* or transcend*or esoteric).mp.
8. (existential or salutogenesis).mp.
9. (Buddhis* or Christian* or catholic* or jew* or muslim* or muslem* or moslem* or "eastern orthodoxy" or "Jehovah* witness*" or protestant* or Hindu* or Islam* or Judaism or Tao* or Sikh* or Rastafari* or theology).mp.
10. (confucianism or mystic* or "eastern philosophy").mp.
11. (God or "supreme being" or "higher being").mp.
12. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13. exp Neoplasms/
14. (neoplas* or cancer* or tumour* or tumor* or oncolog* or carcinoma* or adenocarcinoma* or malignan*).mp.
15. 13 or 14
16. exp Cancer Survivors/
17. exp Palliative Care/
18. (cancer* adj5 surviv*).mp.
19. (palliat* or comfort* or compassion* or terminal* or advanced disease* or end stage disease* or end stage illness*).mp.
20. exp Cancer Pain/
21. 16 or 17 or 18 or 19 or 20

22. 15 or 21
23. 12 and 22
24. Meta-Analysis as Topic/
25. meta analy$.tw.
26. metaanaly$.tw.
27. Meta-Analysis/
28. (systematic adj (review$1 or overview$1)).tw.
29. exp Review Literature as Topic/
30. 24 or 25 or 26 or 27 or 28 or 29
31. cochrane.ab.
32. embase.ab.
33. (psychlit or psyclit).ab.
34. (psychinfo or psycinfo).ab.
35. (cinahl or cinhal).ab.
36. science citation index.ab.
37. bids.ab.
38. cancerlit.ab.
39. 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38
40. reference list$.ab.
41. bibliograph$.ab.
42. hand-search$.ab.
43. relevant journals.ab.
44. manual search$.ab.
45. 40 or 41 or 42 or 43 or 44
46. selection criteria.ab.
47. data extraction.ab.
48. 46 or 47
49. Review/
50. 48 and 49
51. Comment/
52. Letter/
53. Editorial/
54. animal/
55. human/
56. 54 not (54 and 55)
57. 51 or 52 or 53 or 56
58. 30 or 39 or 45 or 50
59. 58 not 57
60. 23 and 59

key:

[mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]

Appendix 2. Template for 'Summary of findings'

Spiritual and religious interventions for adults with cancer and their carers						
Outcome	**Intervention and comparator intervention**	Illustrative comparative risks (95% CI)		**Relative effect (95% CI)**	**Number of participants (studies)**	**Quality of the evidence (GRADE)**	**Comments**
		Assumed risk	Corresponding risk				
		With comparator	**With intervention**				
Outcome #1: Quality of life							
	Intervention and comparator 1						
	[…]						
	Intervention and comparator X						
Outcome #2 Spirituality/religious-related							
	Intervention and comparator 1						
	[…]						
	Intervention and comparator X						
Outcome #3 Adverse events							
	Intervention and comparator 1						

Reference: Pollock M, Fernandes RM, Becker LA, Pieper D, Hartling L. Chapter V: Overviews of Reviews. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions.* Version 6.0 edition. London: Cochrane, updated March 2020. [Available from www.training.cochrane.org/handbook]

HISTORY

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CONTRIBUTIONS OF AUTHORS

BY as the primary author, initiated the preliminary search for the topic, registered the title, and led the development of the protocol draft and revision. BY will implement the search strategy with assistance from editors and information specialists. BY and XX will screen the reviews, extract the publications, and data from original systematic reviews. BY will lead the analysis, the write-up, and update the review. XX and DC have contributed to the background section and the process of protocol formulation. XX, DC, and CL will continue assisting in assessing eligibility, data analysis, writing and updating of the review.

DECLARATIONS OF INTEREST

Bo Yan: none known
Xinyi Xu: none known
Denise Shuk Ting Cheung: none known
Chia-Chin Lin: none known

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External sources

- No sources of support supplied