SYSTEMATIC REVIEW PROTOCOL

Experience of hope in adult patients with advanced chronic disease and their informal caregivers: a qualitative systematic review protocol

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ABSTRACT

Objective: This systematic review will evaluate the experience of hope in adult patients with advanced chronic diseases other than cancer, transitioning toward end-of-life. The review will also evaluate the experience of hope in informal caregivers caring for adult patients with advanced chronic diseases other than cancer as they transition toward end-of-life.

Introduction: Hope is an important resource that assists patients and informal caregivers to deal with difficult and complex situations, such as living with advanced chronic disease.

Inclusion criteria: The review will include studies written in English, French, and Portuguese exploring hope. Qualitative studies focusing on adult patients with advanced chronic diseases other than cancer and/or informal caregivers will be considered. Studies with children as patients or parents as caregivers will be excluded.

Methods: The review will search Embase, MEDLINE, CINAHL, PsycINFO, Web of Science, ProQuest Dissertations and Theses, DART-Europe E-theses Portal, and Google Scholar. The search will be conducted without date restrictions. Articles will be assessed against the inclusion criteria by two independent reviewers. Data will be extracted using a standard tool. The extracted findings will be synthesized using the meta-aggregation approach through assembling and categorizing data.

Systematic review registration number: PROSPERO CRD42021266487

Keywords: adult patient; advanced chronic diseases; hope; informal caregiver; palliative care

JBI Evid Synth 2022; 20(8):2025–2031.

Introduction

Hope has been described as essential for life, health, and death.[1] Hope is "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant."[1(p.380)] Hope is an important resource that assists patients and families to deal with difficult and complex situations, such as living with advanced chronic disease.[2,3] Hope also plays an important role in comfort and quality of life (QoL), and is associated with psychospiritual well-being.[3] Conversely, hopelessness is associated with anxiety, spiritual suffering, depression, suicidal ideation, and past experience of loss.[3-5]

According to the Australian Institute of Health and Welfare, "[c]hronic diseases are long lasting conditions with persistent effects. Their social and

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The authors declare no conflict of interest.

DOI: 10.11124/JBIES-21-00364

economic consequences can impact on peoples' quality of life."[6(para.1)] Chronic disease progresses over time to become advanced chronic disease. When symptom burden increases and QoL decreases, palliative care becomes more prevalent for patients and informal caregivers. Palliative care is an approach intended to improve QoL of patients and their families who are experiencing difficulties related to life-threatening illness. This approach, when included early in the illness trajectory, relieves or prevents suffering through optimal assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.[7] Patients suffering from advanced chronic disease are frequently in transition from palliative care to end-of-life (EoL) care. This means they may be living the last year of their life and in need of additional supportive care.[8] End-of-life care is defined as "a type of palliative care for people in the final months of life and is considered when the person's condition deteriorates and active treatment does not control the disease."[9(p.731)]

In the context of palliative care, the concept of hope has been widely studied, but mostly with patients suffering from cancer.[4,10] The experience of hope may differ according to age, type of disease, and illness trajectory.[2] For patients with cancer, hope is mostly viewed in terms of prolonged life when there is no further possibility of cure, whereas patients with advanced chronic disease tend to see hope as the possibility of a positive outcome, even without guarantee that this outcome will be possible, albeit necessary for survival.[11,12] A 2021 qualitative study on the emotions experienced by people with motor neuron disease and their caregivers reported that, despite having to face many losses, finding hope and positivity (among other factors) were helpful strategies for emotional well-being.[13] For some, an attitude of not giving up on life was understood as hope for a cure or striving for alternative therapies.[13] A study describing the experiences and care goals of patients with end-stage heart failure and chronic obstructive pulmonary disease showed that patients hoped that their illnesses would remain stable, even if specific experiences made them think their health status might be deteriorating.[14] Notably, for patients at EoL, hope can be seen as more than expectation of a cure (eg, hope for a peaceful and pain-free death).[15]

Informal caregivers are a vital emotional, physical, and social support for patients with advanced chronic disease.[16] As a consequence, they may experience difficult moments when caring for their loved ones.[17] A qualitative meta-synthesis explored the experience of transition into palliative care for patients and their families. The results demonstrate that patients and informal caregivers experience transition differently.[17] Hope provided patients with a feeling of freedom, independence, and meaning in life, while, for informal caregivers, hope was an inner source of courage and strength.[17] Additionally, informal caregivers live with both uncertainty and stress in their daily lives as they have to adapt care.[18] In a study evaluating the association between hope and burden as reported by family caregivers, the lower the level of hope, the higher the risk of caregivers' burden.[19] In another study exploring if and how hope is experienced by dyads of patients with motor neuron disease and their informal caregivers, the results showed that hope was considered an "emotion-regulating coping mechanism"[(p.1)] essential to continue living with the consequences of the disease.[20] The authors highlighted that, by redefining and pursuing attainable objectives, positive emotions can be generated.[20] Although hope has been investigated in different contexts with different populations, the experience of hope in informal caregivers is poorly described in the context of advanced chronic diseases. In addition, as noted earlier in relation to palliative care, most of the literature focuses on hope in informal caregivers of patients with cancer.[2,19] Investigating dyadic perceptions in the context of advanced chronic diseases other than cancer in greater depth is important to increase our understanding of both patients' and informal caregivers' experience of hope.

Sustaining hope can have a positive impact on both QoL and depression in patients and their families,[21] even when patients are approaching death.[3] Yet, there are no clear guidelines on how to sustain and foster hope in patients and their informal caregivers, particularly for patients with advanced chronic disease.

The objective of this review is to critically appraise the available evidence on the experience of hope in adult patients with advanced chronic diseases other than cancer, and their informal caregivers as they transition toward EoL. A preliminary search of Embase, PROSPERO, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted in June 2021 to identify recent or ongoing systematic reviews on the topic. The search identified one recently published review on the effectiveness of hope-fostering interventions in palliative care.[22] This review focused on interventions delivered by any health care professional with the intention of increasing hope in palliative care patients, including those diagnosed with advanced, life-limiting, or life-threatening illness who are unlikely to be cured, recover, or stabilize (oncologic and advanced chronic disease patients confounded). A comprehensive understanding of patients' and informal caregivers' experiences of hope during an advanced chronic disease trajectory is essential for health care professionals to be able to define and adapt appropriate supportive care.

Review questions

i. What is the experience of hope in adult patients with advanced chronic diseases other than cancer?
ii. What is the experience of hope in informal caregivers caring for adult patients with advanced chronic diseases other than cancer?

Inclusion criteria

Participants

The review will consider qualitative studies on patients with advanced chronic diseases other than cancer and/or informal caregivers caring for adult patients with advanced chronic diseases other than cancer. Patients must be at least 18 years old and have one or more organ failure diseases according to the Gold Standards Framework Proactive Identification Guidance.[8] Specifically, heart disease (chronic heart failure, NYHA Stage 3 or 4), severe chronic obstructive pulmonary disease (MRC Grade 4/5, FEV1 $<30\%$ predicted long-term oxygen therapy criteria [$PaO_2 < 7.3kPa$]), chronic kidney disease (Stage 4 or 5), chronic liver disease (advanced cirrhosis), or general neurological diseases (Parkinson's disease, motor neuron disease, multiple sclerosis). Informal caregivers, family members, or significant others caring for patients with advanced chronic diseases other than cancer will be considered as those who are important and/or involved in care of the patients.

Studies with children as patients or parents as caregivers will be excluded. In addition, studies including only the experience of hope in patients with cancer or informal caregivers caring for patients with cancer will be excluded. Studies differentiating between patients with and without cancer will be included if considered relevant.

Phenomena of interest

This review will consider studies that explore the experience of hope in patients living with advanced chronic diseases other than cancer, and informal caregivers who accompany and support patients in those situations. For the purposes of this review, hope is defined as "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant."[1(p.380)]

Context

This review will consider studies conducted in all the settings, whether in hospital, hospice, or inpatient or outpatient care, without restriction on the country or culture in which the study was conducted.

Types of studies

This review will consider qualitative studies, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Qualitative components of mixed-methods studies will also be integrated if it is possible to distinguish qualitative from quantitative findings.

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.[23] The review title has been registered in PROSPERO (CRD42021266487).

Search strategy

The search strategy will aim to locate both published and unpublished studies and will be conducted with the assistance of an expert librarian. An initial limited search of Embase and CINAHL was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and index terms used to describe the articles, were used to develop a full search strategy for Embase (see Appendix I). The search strategy combines keywords and index terms describing adults with advanced chronic disease, hope, and qualitative studies. This strategy will be adapted for each included information source. All the strategies will be peer-reviewed by another experienced librarian using the Peer Review of Electronic Search Strategies

(PRESS) checklist.[24] Backward and forward citation searching will be performed on all studies selected for critical appraisal. Studies published in English, French, or Portuguese will be included, reflecting the languages spoken by the systematic review team, but the search will remain inclusive of all possible studies. No date limit will be applied.

The databases to be searched include Embase, MEDLINE (Ovid), CINAHL (EBSCO), PsycINFO (Ovid), Web of Science Core Collection, ProQuest Dissertations & Theses A&I, and DART-Europe E-theses Portal. Google Scholar will be searched for published and unpublished studies.

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote v.20 (Clarivate Analytics, PA, USA), and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria. Potentially relevant studies will be retrieved in full, and their citation details imported into Rayyan (Qatar Computing Research Institute, Doha, Qatar). Two independent reviewers will assess the full text of selected citations in detail against the inclusion criteria. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at any stage of the selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.[25]

Assessment of methodological quality

Eligible studies will be critically appraised by two independent reviewers for methodological quality using the standard JBI critical appraisal checklist for qualitative research.[23] Authors of papers will be contacted to request missing or additional data, where required. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis, where possible. The results of critical appraisal will be reported in narrative format and in a table.

Data extraction

Data will be extracted from studies included in the review by two independent reviewers using the standardized JBI data extraction tool.[23] The data extracted will include specific details about the populations, context, culture, geographical location, study methods, and the phenomena of interest relevant to the review objective and review questions. The findings, and their illustrations, will be extracted and assigned a level of credibility (unequivocal, credible, or not supported). Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta-aggregation approach.[26] This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these on the basis of similarity in meaning. These categories will then be subjected to a synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative format.

Assessing confidence in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings (SoF).[27] The SoF will include the major elements of the review and detail how the ConQual score was developed. Included in the SoF will be the title, population, phenomena of interest, and context for the specific review. Each synthesized finding will then be presented, along with the type of research informing it, score for dependability and credibility, and the overall ConQual score.

Acknowledgments

This qualitative systematic review will fulfil part of the requirements for FB's doctoral studies in nursing science at the University of Lausanne, Switzerland.

Funding

The doctoral studies for FB are partially funded by the Institute of Higher Education and Research in Healthcare (IUFRS). The funders had no influence in developing the content of this review protocol.

Author contributions

FB was responsible for initiating, conceptualizing, and producing the initial draft of the review protocol. She is also the guarantor of the review. BP, CJ, GB, MR, SP, and PL also contributed to the conceptualization of this review protocol. BP provided expert guidance on qualitative research methods. CJ provided expert guidance on information sources and search strategies. GB contributed to the selection of inclusion and exclusion criteria. Additionally, all authors provided significant editorial comments on the protocol drafts and read and approved the final manuscript.

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Appendix I: Search strategy

Embase

Search conducted on December 17, 2021

Search	Query	Records retrieved
#1	(‘palliative therapy’/exp OR ‘palliative nursing’/de OR ‘terminal care’/de OR ‘hospice care’/de OR ‘terminally ill patient’/exp OR ‘terminal disease’/de OR ‘chronic disease’/exp/mj OR (‘chronic disease’/exp AND (advanced OR end OR terminal*):ab,ti,kw) OR ‘chronic obstructive lung disease’/de OR ((‘heart failure’/de OR ‘cardiopulmonary insufficiency’/de OR ‘heart ventricle failure’/exp) AND (‘chronic disease’/exp OR (chronic OR advanced OR terminal):ab,ti,kw)) OR ‘chronic kidney failure’/exp OR ‘end stage renal disease’/de OR ‘chronic liver disease’/exp OR ‘chronic liver failure’/de OR ‘end stage liver disease’/de OR ((‘liver disease’/de OR ‘liver cirrhosis’/exp) AND (‘chronic disease’/exp OR (chronic OR advanced OR terminal):ab,ti,kw)) OR ‘chronic hepatitis’/exp OR ((‘neurologic disease’/de OR ‘neuromuscular disease’/de) AND (‘chronic disease’/exp OR (chronic OR advanced OR terminal):ab,ti,kw)) OR ‘myotonic dystrophy’/de OR ‘Duchenne muscular dystrophy’/de OR ‘motor neuron disease’/exp OR ‘Parkinson disease’/exp OR ‘multiple sclerosis’/de OR ‘cerebrovascular accident’/exp OR ‘stroke patient’/exp OR (chronic* NEXT/1 (disease* OR ill*)):ti OR (Palliative OR (terminal* NEAR/3 (patient* OR care OR ill* OR disease* OR stage*)) OR hospice OR (end NEAR/3 (life OR care OR stage* OR disease* OR illness*)) OR (incurable NEAR/3 (ill* OR disease*)) OR “life limiting” OR “life threatening” OR (advanced NEAR/3 (chronic OR disease* OR illness* OR condition*)) OR (Chronic NEXT/2 (airflow OR airway) NEXT/2 obstruct*) OR (Chronic NEAR/2 (obstruct*) NEAR/2 (bronchopulmonary OR lung OR pulmonary OR respiratory) NEAR/2 (disease* OR illness* OR disorder*)) OR COPD OR ((chronic OR advanced OR terminal) NEAR/3 (heart OR cardiac OR myocardial) NEAR/3 (failure OR insufficiency OR decompensation OR disease* OR illness* OR disorder* OR dysfunction)) OR ((chronic OR advanced OR terminal OR end) NEAR/3 (kidney OR renal) NEAR/3 (failure OR insufficiency OR disease* OR illness* OR disorder* OR dysfunction)) OR ((chronic OR advanced OR terminal OR end) NEAR/3 (liver) NEAR/3 (failure OR insufficiency OR disease* OR illness* OR disorder* OR dysfunction)) OR (advanced NEAR/3 cirrhosis) OR ((chronic OR advanced OR terminal OR end) NEAR/3 (neuro*) NEAR/3 (disease* OR illness* OR disorder*)) OR (parkinson NEXT/2 disease) OR ((motoneuron OR “motor neuron”) NEXT/1 (disease* OR illness* OR disorder*)) OR (Duchenne NEXT/3 (syndrome OR dystrophy)) OR (Steinert NEXT/3 (disease OR myopathy)) OR “myotonic dystrophy” OR “lateral sclerosis” OR (progressive NEAR/3 “muscular atrophy”) OR “multiple sclerosis” OR ((cerebrovascular OR “cerebro vascular”) NEAR/2 (accident* OR lesion*)) OR Stroke*):ab,ti,kw) AND (‘hope’/de OR ‘hopelessness’/de OR (hope* OR hoping OR despair*):ab,ti,kw) NOT ((‘juvenile’/exp OR ‘childhood disease’/exp) NOT ‘adult’/exp) AND (‘qualitative research’/exp OR ‘interview’/exp OR ‘narrative’/de OR qualitative OR (“mixed method*” OR “focus group*” OR ethnograph* OR ethnolog* OR ethnonursing OR fieldwork OR “field work” OR (field NEAR/1 (study OR studies OR research)) OR themes OR “thematic analysis” OR interview* OR ((semi-structured OR semistructured OR unstructured OR informal OR indepth OR “in depth” OR “face to face” OR structured OR guide) NEAR/3 (discussion* OR questionnaire*)) OR “key informant” OR phenomenolog* OR (grounded NEXT/1 (theor* OR study OR studies OR research OR analys?s)) OR “action research”):ab,ti,kw)	2017