

Hope in Adults With Inflammatory Diseases: Scoping Review Protocol*

A esperança em adultos com doenças inflamatórias: protocolo de scoping review

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Keywords

Adults, Hope, Inflammatory bowel disease

Abstract

Objective: This review seeks to map, analyse and describe in national and international literature the concept of hope in adults with inflammatory bowel disease to answer the following question: What do we know about hope in adults with inflammatory bowel disease?

Introduction: Inflammatory bowel disease (IBD) is a chronic, progressively evolving disease whose prevalence is increasing, which demonstrates the need for more and better interventions to prevent and control these diseases in order to promote a better quality of life and overall well-being for those affected by them. Promoting hope is a spiritual necessity and understanding this need is crucial for improving patient-centred care and for promoting appropriate supportive intervention.

Inclusion criteria: The review will include all the evidence identified that describes hope in adults (male and female, aged 18 or over) in outpatient, inpatient, or day hospital settings.

Methods: The databases where the search was conducted are Pubmed, CINAHL complete (by EBSCO); JBI Database of Systematic Reviews and Implementation Reports; Cochrane Library, including Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CENTRAL), Database of Abstracts of Reviews of Effects (DARE); PsycINFO and PROSPERO-International prospective register of systematic reviews, as at November 2024.

Palavras-chave

Adultos, Esperança, Doença inflamatória intestinal

Resumo

Objetivo: Esta revisão procura mapear, analisar e descrever na literatura nacional e internacional o conceito de esperança em adultos com doença inflamatória intestinal para responder à seguinte pergunta: O que sabemos sobre a esperança em adultos com doença inflamatória intestinal?

Introdução: A doença inflamatória intestinal (DII) é uma doença crónica que evolui progressivamente e cuja prevalência está a aumentar, o que demonstra a necessidade de mais e melhores intervenções para prevenir e controlar estas doenças, a fim de promover uma melhor qualidade de vida e bem-estar geral para estas pessoas. Promover a esperança é uma necessidade espiritual e compreender esta necessidade é crucial para melhorar os cuidados centrados no doente e promover intervenções de apoio adequadas.

Crítérios de inclusão: A revisão incluirá todas as evidências identificadas que descrevem a esperança em adultos (homens e mulheres, com 18 anos ou mais) em ambientes hospitalares, ambulatório ou de hospital-dia.

Métodos: As bases de dados onde a pesquisa foi realizada são Pubmed, CINAHL complete (por EBSCO); Base de dados JBI de revisões sistemáticas e relatórios; Biblioteca Cochrane, incluindo a Base de dados Cochrane de revisões sistemáticas (CDSR), o Registo Cochrane Central de Ensaio Controlados (CENTRAL), a Base de dados de resumos de revisões de efeitos (DARE); PsycINFO e PROSPERO – Registo internacional prospectivo de revisões sistemáticas, em novembro de 2024.

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Introduction

Inflammatory bowel disease (IBD) is a chronic disease that progressively leads to intestinal damage and disability. It can occur in all ages but is more prevalent in young people. Most patients present an inflammatory phenotype at the time of diagnosis, but, over time, complications (stenoses, fistulas, or abscesses) will develop in half of the patients, often resulting in surgery. The symptoms of the disease are intermittent and remitting, and have a major impact on patients' personal and professional lives.¹ The severity of the disease must take into account not only the inflammatory burden, evolution, cumulative complications, and surgical resections but also the disability produced by the disease, the extra-intestinal manifestations which can have a prevalence of between 20-50% and the effect of the disease on the person.^{2,3} IBD has a steadily increasing prevalence worldwide, which demonstrates the urgent need for more and better interventions to prevent and control these diseases in order to promote a better quality of life and well-being for these people. In 70% of the patients, the disease prevents them from living a normal life and interferes with the quality of their sleep. They also report reduced self-confidence and the frequent presence of negative feelings such as lack of motivation, anxiety, depression, anger, frustration and shame.^{4,5,6,7}

Promoting resilience in IBD patients mitigates the impact of perceived stress on subjective well-being, which contributes to a reduction in the intensity of symptoms in these patients.⁸ Since resilience is a protective factor of hope, what does the available evidence tell us about this concept in the inflammatory bowel disease population?

Hope is felt uniquely and as the surrounding environment and personal experiences influence it, it plays a key role. It is a multidimensional phenomenon in human life. Since the 1960s, the concept of hope has been developed in healthcare-related literature. It is a concept that can be concrete or abstract, has a multidisciplinary perspective and has been investigated in the nursing discipline in the context of chronic illness care since the 1980s by Herth and Cutcliffe. In the same decade, qualitative studies emerged that demonstrated the importance of the specific dimensions of hope, identifying the interpersonal element, the focus on the future, and expectation as a goal and/or fulfilment of hope.⁹ In recent decades, there has been a growing theoretical evolution in terms of research and the transposition of hope-promoting interventions into practice.^{10,11,12,13}

The promotion of hope is a spiritual need described as a power or force that drives the person to transcend the current situation towards a new awareness and enrichment of being. Care is underpinned by the promotion of hope, spiritual well-being, and quality of life, which are highly relevant dimensions of nursing care. People need to find meaning in life, especially in crises, as dealing with illness and its existence or absence can influence the way they experience this phase.¹⁴

Promoting hope is more than just a professional responsibility, and it is also a fundamental moral and ethical obligation for all nursing care. A preliminary search was done for other existing literature reviews in some databases, namely the JBI Database of Systematic Reviews and Implementation Reports, the Cochrane Database of Systematic Reviews, MEDLINE, DARE, ACCESS, EPISTEMONIKOS, and PROSPERO. It was found that there were no systematic reviews or review protocols registered on this subject as of 15 May 2024. As no other reviews have been found that transcribe the best evidence on hope in adults with inflammatory bowel disease, it is pertinent to carry out this review, which will be drawn up in accordance with the recommendations of the JBI. This review aims to map, analyse and describe the concept of hope in adults with inflammatory bowel disease in national and international literature.

Review question

What do we know about hope in adults with inflammatory bowel disease?

Inclusion criteria

Participants

The review will include all the evidence identified that describes adults (male and female, aged 18 or over).

Concept

The concept of interest is hope.

Context

The context of interest is inflammatory bowel disease in an outpatient setting, hospitalised or being treated in a day hospital.

Types of sources

This scoping review will consider primary and secondary research, both experimental and quasi-experimental, including randomized controlled trials, non-randomized controlled trials, before and after studies, and interrupted time series studies. In addition, analytical observational studies will be considered for inclusion, including prospective and retrospective cohort studies, individual case reports, descriptive cross-sectional studies, and case-control studies, except for editorial reviews, letters to the editor, and commentaries. Qualitative studies will also be considered that focus on qualitative data, including but not limited to designs such as phenomenology, grounded theory, ethnography, qualitative description, action research, and feminist research. The review will also consider documents developed by services, institutions, organizations, patient associations, health groups, and committees. In addition, systematic reviews that meet the inclusion criteria will also be considered, depending on the research question.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews.

Search strategy

The search strategy will aim to locate both published and unpublished studies. A three-step search strategy will be utilized in this review. First, an initial limited search of MEDLINE (PubMed), CINAHL (EBSCO), JBI Database of Systematic Reviews and Implementation Reports, and PROSPERO – International Prospective Register of systematic reviews were undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a complete search strategy for reporting the name of the appropriate databases/information sources (see Appendix D).

The second phase of the search strategy will be a more extensive search carried out in each of the databases included in the protocol, using all the keywords and indexed terms identified. It will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies.

All studies published in English, Spanish, and Portuguese will be considered for inclusion in the review. No publication period restrictions will apply. To complement the research, unpublished studies and grey literature are to be searched, and websites of institutions, health organizations / patient associations / committees / groups will be searched for the concept of hope in adults with inflammatory bowel disease. The search for unpublished studies will be carried out in RCAAP – Open Access Scientific Repository of Portugal; Banco de Teses & Dissertações – CAPES (Brazil); OpenThesis: Upload and Search Theses and Dissertations; OpenGrey: System for Information on Grey Literature, and Google Scholar.

Study/Source of evidence selection

Following the search, all identified citations will be collated and uploaded into RAYYAN and duplicates will be removed. Following a pilot test, titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information.¹⁵ The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer/s. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA flow diagram.¹⁶


Data extraction

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the participants, concept, context, study methods and key findings relevant to the review question/s.

A draft extraction form is provided (Appendix II). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review. Any disagreements that arise between the reviewers

will be resolved through discussion, or with an additional reviewer/s. If appropriate, authors of papers will be contacted to request missing or additional data, where required.

Data analysis and presentation

The data extracted from relevant published and unpublished literature will be presented in a tabular form that is aligned with the objective of this scoping review. Data that are presented in tables will reflect the information collected using the data extraction tool (Appendix II). This will include i) the author and year of publication; ii) type of source; iv) target population; v) context; vi) concept; vii) objective(s) and outcome(s). A narrative summary will accompany the tabulated and/or charted results and will describe how the results are related and important to the review objective and question. 

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Declarations

The authors take on equity, diversity and inclusion to recognize authors working to improve diversity and inclusion in research and to encourage them to move forward.

Author contributions

Author ZC and JT had a specific involvement in the manuscript, in the analysis design phase, and authors MLC and JS contributed to data collection, analysis and writing of the manuscript.

Conflicts of interest

There is no conflict of interest in this project.

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Appendix I: Search strategy

The databases searched were: Pubmed, CINAHL complete (by EBSCO); Cochrane Library, including Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CENTRAL), PsycINFO and SCOPUS. ((Inflammatory Bowel Disease* (Topic) or “Idiopathic Proctocolitis” (All Fields) or Colitis* (All Fields) or Gastroenteriti* (All Fields) or Crohn Disease (All Fields) or “Gastrointestinal Disorders” (All Fields) or “Digestive System Diseases” (All Fields) or “Digestive System Disorders” (All Fields) or “Colon Disorders” (All Fields) or “Gastrointestinal Ulcers” (All Fields))) AND ((Adult (Topic) or Adults (All Fields) or Aged (All Fields) or Middle Age

(All Fields) or Elderly (All Fields) or Aded, 80 and over (All Fields) or Oldest Old (All Fields) or Centenarian (All Fields) or Nonagenarian (All Fields) or Octogenarian (All Fields) or Young Adult (All Fields) or Middle Aged (All Fields))) AND ((Hope* (Topic) or Optimism (All Fields) or “Positive Attitude” (All Fields) or “Positive Thinking” (All Fields) or Positivism (All Fields) or “Positive Emotions” (All Fields) or Expectations (All Fields) or Emotions (All Fields) or “Emotional states” (All Fields) or “Positive Psychology” (All Fields) or “Wishful thinking” (All Fields) or “Emotional responses” (All Fields) or “Emotional content” (All Fields) or “Affective valence” (All Fields) or “Emotional health” (All Fields) or “Emotional regulation” (All Fields)))
 Search conducted on November 2024.

Appendix II. Data extraction instrument

TITLE/AUTHORS	TYPE OF SOURCE/ /DATE	ABSTRACT	KEYWORDS	PCC/STUDY METHODS OBJECTIVES/ /OUTCOMES
				<p>P-</p> <p>C-</p> <p>C-</p> <p>STUDY METHODS -</p> <p>OBJECTIVES-</p> <p>OUTCOMES-</p>

Contributos dos autores | Author's roles

Contributo Role	Autor 1 Author 1	Autor 2 Author 2	Autor 3 Author 3	Autor 4 Author 4	Autor 5 Author 5
Conceptualização <i>Conceptualization</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Gestão dos dados <i>Data curation</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Análise dos dados <i>Formal Analysis</i>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Aquisição de financiamento <i>Funding acquisition</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Investigação <i>Investigation</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Metodologia <i>Methodology</i>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gestão do projeto <i>Project administration</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gestão de recursos <i>Resources</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Software	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supervisão <i>Supervision</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Validação <i>Validation</i>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Visualização <i>Visualization</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Escrita – 1.ª versão <i>Writing – original draft</i>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Escrita – revisão e edição <i>Writing – review & editing</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>