


# BMJ Open Human responses in adolescents with oncological disease: a scoping review protocol

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## ABSTRACT

**Introduction** The classification of human responses to health conditions or life processes, assuming that human responses are the way that a person responds, referring to the individual's experiences, feelings, perceptions, behaviours and physical reactions, can be an exercise that, although challenging, is central to nursing diagnoses and, consequently, to nursing practice. It is necessary to gather and organise the existing knowledge about the human responses in adolescents with cancer, starting from the moment of diagnosis, due to the specificities inherent to this stage of human development. A scoping review is an appropriate method to use in order to map the existing knowledge on human responses in adolescents with oncological diseases experienced since the diagnosis.

**Inclusion criteria** Will encompass all types of studies, including 'grey literature' that centres on human responses related to adolescents aged 10–19 years with oncological diseases. There will be no restrictions based on the type of cancer, disease stage or other contextual factors, whether in home or healthcare settings.

**Methods and analysis** The review will be conducted following the guidelines outlined by the Joanna Briggs Institute for scoping reviews. The search will encompass the following databases: CINAHL Complete (EBSCOhost), Cochrane Database of Systematic Reviews (EBSCOhost), MEDLINE Complete (EBSCOhost), Nursing and Allied Health Collection: Comprehensive (EBSCOhost), Cochrane Clinical Answers (EBSCOhost Answers), Latin American and Caribbean Literature on Health Sciences (LILACS) and 'grey literature' sources accessible through the Scientific Open Access Repositories of Portugal (RCAAP). A three-step search strategy will be implemented. Titles and abstracts will undergo analysis by two independent reviewers. Articles selected for a full-text review will be organised. The results will be presented in tables and narratively summarised.

**Ethics and dissemination** Ethics approval and patient consent for publication are not necessary. Findings will be disseminated through publication in scientific journals and through conference presentations.

**Review registration number** EXUB4. Registration was made in the Open Science Framework (OSF).

## INTRODUCTION

Childhood cancer represents a significant public health challenge, defined as a group

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This will be the inaugural scoping review dedicated to identifying and mapping the human responses of adolescents with oncological diseases.
- ⇒ It has the potential to initiate an investigative journey towards understanding the common experiences shared by adolescents with cancer from the moment of diagnosis.
- ⇒ The review will be conducted by experienced researchers with a background in providing nursing care to adolescents with cancer.
- ⇒ The study's inclusion criteria are comprehensive, encompassing all adolescents aged 10–19 with oncological diseases.
- ⇒ A limitation is that the review will not involve a quality assessment or grading of evidence, as this is not part of the chosen methodology.

of malignancies occurring between the ages of 0 and 19. Unlike cancer in adults, the vast majority of cases have no known aetiology and are not amenable to prevention.<sup>1</sup> This form of cancer is considered the primary cause of mortality due to disease in children above the age of 1.<sup>1</sup> Annually, it is estimated that 400 000 children (aged 0–19) receive a diagnosis of cancer worldwide, and an additional 40%–45% of cases in children with cancer go undiagnosed or unrecorded.<sup>1–3</sup> In the context of the adolescent population, defined as individuals between the ages of 10 and 19, cancer incidence has been steadily increasing by 0.8% per year since 1975.<sup>4–6</sup> In this population, cancer is a significant cause of mortality, with a 5-year survival rate of 86%.<sup>4–6</sup>

Oncological disease affects both adolescents and their families.<sup>7</sup> Throughout this experience, adolescents and their families encounter numerous crises and stress-inducing situations, along with losses, as well as the upheaval of daily routines, diminished independence and disruptions in family



dynamics, all of which profoundly impact the lives of both the adolescent and their family members.<sup>8</sup>

Oncological disease during adolescence, a transitional phase between childhood and adulthood, coincides with a period of rapid physical, social, emotional and cognitive maturation.<sup>5</sup> This can be seen as a journey marked by uncertainties due to the intricate and unpredictable nature of treatment responses, potential side effects, the invasive procedures to which patients are subjected, the inherent risks associated with development and the looming threat to life.<sup>5,9</sup> Research pertaining to adolescents with cancer, their caregivers and family members holds significant relevance, especially within this transitional age bracket. This is underscored by the limitations in health services that fail to provide optimal care for adolescents, largely due to a lack of dedicated, precise research that is vital for enhancing healthcare provision for individuals within this age group.<sup>4</sup>

In this review, given the importance of identifying human responses among the adolescent age group, we define the adolescent age range as encompassing individuals aged from 10 to 19 years.

In 1980, the American Nurses Association articulated nursing as ‘the diagnosis and treatment of human responses to actual and potential health problems’ in their Declaration of Social Policy.<sup>10</sup> It is essential to delve into the concept of human responses to health conditions or life processes, which are intricate and profoundly influenced by the social, cultural, economic and political contexts at the micro, meso and macro levels in which individuals exist, forming the core of nursing care.<sup>11,12</sup>

Given the uniqueness, complexity and continuous development of each human being, the classification of human responses, whether they be physical, psychological, emotional, spiritual or social, constitutes an arduous yet central exercise within the practice of nursing care.<sup>13,14</sup>

NANDA International (the taxonomy of nursing diagnoses) further refines the concept of nursing diagnosis, having approved its definition in 2009 as ‘the clinical judgement of human, family or community responses/experiences to real or potential vital problems/processes. Nursing diagnoses form the foundation for the selection of nursing interventions aimed at achieving outcomes for which nurses are responsible.’<sup>13</sup> Accordingly, human responses can be understood as the way an individual reacts to a potential or actual health problem or process, encompassing their experiences, emotions, perceptions, behaviours and physical reactions.<sup>15,16</sup>

We can characterise the clinical judgement of nurses not only as an identification of health promotion opportunities but also as an identification of human responses. Therefore, it is imperative that, once we have identified human responses in adolescents with cancer, we proceed to identify nursing diagnoses associated with them. A precise understanding of human responses and the subsequent formulation of nursing diagnoses for both individuals and their families can lead to more appropriate intervention choices and positive outcomes.<sup>17</sup>

The exploration of human responses in adolescents with oncological diseases is a crucial area of investigation, presenting a unique challenge for healthcare professionals due to the inherent complexities of this stage of human development.<sup>4,5</sup> Professionals, particularly nurses, should be well-informed and discerning regarding the transformations in the lives of adolescents following a cancer diagnosis, as they play a pivotal role in nursing care, addressing the multifaceted changes affecting the entirety of the individual.<sup>9</sup>

In November 2022, we conducted an initial search across three databases (JBI Evidence Synthesis, CINAHL Complete via EBSCOhost, and MEDLINE Complete via EBSCOhost). While we did uncover some scientific articles that addressed specific human responses experienced by children and adolescents with cancer, we did not identify any published or ongoing primary studies, scoping reviews or systematic reviews specifically focusing on human responses in adolescents with oncological diseases.

Furthermore, we performed a search in the PROSPERO (International Prospective Register of Systematic Reviews) database in November 2022. Although we found a literature review that addressed fatigue in adolescents with cancer,<sup>18</sup> we did not find any literature specifically examining human responses in adolescents with cancer. From this initial search, it is evident that there is a compelling need for further research in this area.

Given the inherent complexity of this subject matter and the need to comprehensively map the existing knowledge pertaining to human responses in adolescents with oncological diseases, particularly since the time of diagnosis, we have concluded that a scoping review using the methodology of the Joanna Briggs Institute is the most suitable approach to address our research questions.<sup>19,20</sup>

## Review questions

These questions serve as a guide, directing the formulation of specific inclusion criteria and should incorporate the key elements of the patient, concept and context (PCC) framework.<sup>21</sup>

1. What are the human responses exhibited by adolescents with oncological diseases?
2. Which nursing diagnoses, in accordance with the NANDA International taxonomy, are correlated with the human responses observed in adolescents with oncological diseases?
3. What research methodologies have been employed in the examination of human responses in adolescents with oncological diseases?

## Inclusion criteria

### Participants

This review aims to comprehensively survey the existing knowledge regarding human responses that emerge when adolescents, aged between 10 and 19 years, receive a diagnosis of oncological disease at any stage of diagnosis

**Table 1** Search strategy search conducted March 2023 in Medline (EBSCOhost)

Search	Query	Records retrieved
#1	AB adolescence OR AB teen OR AB teenager OR AB teenagers OR AB teens OR AB adolescents OR MH adolescent	2 281 693
#2	MH 'oncology nursing' OR AB 'Cancer Nursing' OR AB 'Nursing, Oncologic' OR AB 'Oncologic Nursing' OR AB 'Oncological Nursing' OR MH 'nursing care' OR AB 'Care, Nursing' OR AB 'Management, Nursing Care' OR AB 'Nursing Care Management' OR MH 'Nursing Diagnosis' OR AB 'Diagnosis, Nursing' OR AB 'home care' OR Medical Oncology	61 302
#3	MH 'Self-Report' OR TX signs OR TX symptom OR TX symptoms OR TX sequels OR TX 'associated conditions' OR AB Feelings OR 'Human Responses'	3 218 053
#4	#1 AND #2 AND #3	457
Limited to: English language, Portuguese language and Castilian language; full text		190

or treatment. All studies that include adolescents in this 'population' will be taken into consideration.

### Concept (interesting phenomenon)

This review does not focus on a specific concept but rather seeks to investigate a phenomenon, namely, the various manifestations of human responses in adolescents aged 10–19 years. Therefore, all studies related to human responses in this age group will be included in the review.

### Context

The context to be considered in this review, pertaining to human responses in adolescents, encompasses those experienced within the context of oncological disease, whether in a home or healthcare setting (eg, primary or secondary care). Studies examining human responses in adolescents related to this disease situation will be included in the review.

### Types of sources

This scoping review will encompass qualitative and quantitative studies of any methodological design. It will also encompass 'grey literature', defined as literature that addresses at least the first investigation's research question.

## METHODS AND ANALYSIS

The scoping review was selected as the preferred methodology, enabling the synthesis and comprehensive mapping of existing knowledge associated with a specific topic, field, concept or research question. This approach can illuminate and identify essential characteristics and factors relevant to the chosen investigative methodology.<sup>19</sup>

### Search strategy

The search strategy is designed to encompass both published and unpublished primary studies, reviews, text and opinion papers and other scientific publications.

The research involves three phases. Initially, a limited search was conducted in JBI Evidence Synthesis, CINAHL Complete via EBSCOhost and MEDLINE Complete via EBSCOhost to identify relevant articles on the chosen topic. Text words found in the titles and abstracts of these articles, as well as the index terms used to describe them, were used to develop a comprehensive search strategy. This step was taken once we reached saturation in index terms for relevant articles. The full search strategy, incorporating all identified keywords and index terms, will be adapted for each information source included in the review.

In the case of Medline via EBSCOhost, Medical Subject Headings (MeSH) were used, as exemplified in the search strategy provided (table 1). The only descriptor not belonging to MeSH, 'human responses', was included due to its relevance for this search. Full-text scientific articles in Portuguese, English and Castilian will be considered. No restrictions will be imposed on publication dates, as the intention is to comprehensively map all existing knowledge on the topic. If an extensive initial sample is found, a time constraint may be applied, initially spanning the last 10 years and if needed, the last 5 years, to capture the latest evidence.

The information sources to be fully searched encompass CINAHL Complete (EBSCOhost), Cochrane Database of Systematic Reviews (EBSCOhost), MEDLINE Complete (EBSCOhost), Nursing and Allied Health Collection: Comprehensive (EBSCOhost), Cochrane Clinical Answers (EBSCOhost) and Literature Latino-Americana and Caribbean in Health Sciences. For 'grey literature', a search will be conducted using the Scientific Open Access Repositories of Portugal (RCAAP). Given that RCAAP is a Portuguese source, the search terms will be specified in Portuguese, using the words 'adolescente' and 'cancro'.

**Table 2** Data extraction instrument

Author/ authors	Publication year	Publication country	Journal designation	Study purpose	Study population	Study method	Human responses found (in the reviewed articles)
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Subsequently, the reference lists of all articles included in the review will be scrutinised to identify additional studies suitable for inclusion. If further information is required, the authors of the studies will be contacted.

### Study/source of evidence selection

After completing the search, all identified records, including 'grey literature', will be collected and uploaded into Rayyan (Qatar Computing Research Institute, Doha, Qatar). Here, records will be systematically organised, and any duplicate entries will be removed. Two independent reviewers with expertise in literature reviews and experience in caregiving for adolescents with oncological diseases will be engaged. Following a pilot test, these independent reviewers will meticulously screen the titles and abstracts of identified records against the inclusion criteria established for the review.

In the event of a disagreement over the relevance of specific papers, a third reviewer will be involved, serving as a mediator to facilitate the discussion between the two primary reviewers. If necessary, the third reviewer will make the final decision. Subsequently, potentially relevant papers will be retrieved in full and uploaded into Mendeley V.2.79.0 (Mendeley, Elsevier, Netherlands). Here, the full texts will undergo a detailed assessment by the same two reviewers, aligning with the established inclusion criteria.

Excluded articles, along with the reasons for their exclusion, will be documented in the final scoping review. In both phases, if discrepancies arise between the reviewers, they will be resolved through discussion or, if necessary, by the third reviewer. The results of the search will be comprehensively reported in the scoping review, in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews.<sup>22</sup>

### Data extraction

Data will be independently extracted from the articles included in the scoping review by two reviewers, using a data extraction tool developed by the authors of the review. A draft of the data extraction tool is provided in [table 2](#). The extracted information will encompass pertinent details such as the names of the article authors, the publication year, the publication's country of origin, the journal in which the article was published, the study's objective, the study population, the research methodology employed and the human responses identified within the reviewed articles.

Throughout the process, this data extraction tool may be subject to revision and modifications as deemed necessary. Any adjustments made will be comprehensively documented within the scoping review. In the event of disagreements between reviewers, resolutions will be reached through discussion or by the involvement of an additional reviewer. If required, we will make contact with the authors of the papers to request any missing or supplementary data.

### Data analysis and presentation

To comprehensively map the existing knowledge concerning human responses in adolescents with oncological diseases from the time of diagnosis, the extracted results will be systematically presented in tabular form, addressing the key research questions.

For the first question, a table will be constructed to categorise the identified human responses into distinct categories, including physical, psychological, social, emotional and spiritual aspects. Given the comprehensive nature of the population covered in this scoping review, if significant variations in human responses are observed based on age or gender, additional tables will be generated to present the identified human responses according to different age groups and/or genders within the adolescent cohort.

To address the second question, a table will be established to categorise and associate the identified human responses with the domains and nursing diagnoses as per the NANDA International Taxonomy. In response to the third question, a table will be developed to categorise the research methods employed in the reviewed articles.

These tables will be created, revised and adjusted as necessary by the reviewers during the data analysis phase. In the event of any disagreements, resolutions will be achieved through discussion or by involving another reviewer. Subsequently, a narrative summary will be crafted to contextualise the results and connect them with the overall objective of the scoping review, addressing the research questions. This scoping review has the potential to serve as the initial step in a research journey towards elucidating patterns of experiences encountered by adolescents with cancer from the moment of diagnosis.

### Patient and public involvement

None.

### Ethics and dissemination

We are committed to upholding the principles of research integrity throughout the scoping review process. This includes maintaining objectivity, avoiding bias and ensuring the accuracy and reliability of the findings. Since the scoping review methodology consists of reviewing and collecting data from publicly available materials, this study does not require ethics approval. Patient consent for publication is not needed since there are no patients involved in this review. The review findings will be disseminated via publication in a peer-reviewed journal, symposia and conference presentations.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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