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SYSTEMATIC REVIEW ARTICLE &

Intervention programs for children, adolescents, and parents experiencing parental cancer: A scoping review protocol

Programas de intervenção para crianças, adolescentes e pais a vivenciar cancro parental: Protocolo de scoping review

Programas de intervención para niños, adolescentes y padres que experimentan cáncer parental: Protocolo de scoping review

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Abstract

Background: Parental cancer affects children, adolescents, and the family unit. The implementation of intervention programs leads to the development of parental skills and positive outcomes for children in terms of understanding their parents' cancer, developing coping mechanisms, improving parent-child communication and relationships, and empowering the family to cope with cancer.

Objective: To map the available intervention programs for children, adolescents, and parents experiencing parental cancer (patients with cancer).

Review method: Scoping review methodology proposed by the Joanna Briggs Institute. The process of data analysis, extraction, and synthesis will be performed by independent reviewers.

Presentation and interpretation of results: Mapping the programs will allow identifying the interventions developed by health professionals for children, adolescents, and parents experiencing parental cancer. **Conclusion:** The review resulting from this protocol will allow selecting the best interventions for designing a nursing intervention program for adolescents and parents experiencing parental cancer.

Keywords: parental cancer; intervention; children; adolescents; nursing

Resumo

Contexto: O cancro parental tem impacto nas crianças, adolescentes e unidade familiar. A aplicação de programas de intervenção resulta no desenvolvimento de habilidades parentais e produz resultados positivos nos filhos ao nível da compreensão do cancro dos pais, desenvolvimento de mecanismos de *coping*, melhoria da comunicação e relacionamento pais-filhos, permitindo empoderar a família para enfrentar o cancro.

Objetivo: Mapear programas de intervenção existentes dirigidos a crianças, adolescentes e pais a vivenciar o cancro parental (doentes oncológicos).

Método de revisão: Metodologia de *scoping review* proposta pelo *Joanna Briggs Institute.* O processo de análise, extração e síntese dos dados será desenvolvido por revisores independentes.

Apresentação e interpretação dos resultados: O mapeamento dos programas permitirá identificar as intervenções desenvolvidas por profissionais de saúde, dirigidas a crianças, adolescentes e pais a vivenciar o cancro parental.

Conclusão: A revisão resultante do protocolo elaborado permitirá selecionar intervenções adequadas para o desenho de um programa de intervenção de enfermagem dirigido a adolescentes e pais que vivenciam a experiência do cancro parental.

Palavras-chave: cancro parental; intervenção; crianças; adolescentes; enfermagem

Resumer

Contexto: El cáncer parental tiene un impacto en los niños, los adolescentes y la unidad familiar. La aplicación de los programas de intervención permite desarrollar las habilidades parentales y genera resultados positivos en los niños a nivel de comprensión del cáncer de los padres, desarrollo de mecanismos de afrontamiento (*coping*), mejora de la comunicación y de la relación padres-hijos, lo que permite empoderar a la familia para afrontar el cáncer.

Objetivo: Mapear los programas de intervención existentes dirigidos a los niños, adolescentes y padres que experimentan el cáncer parental (pacientes oncológicos).

Método de revisión: Metodología de revisión sistemática exploratoria (*scoping review*) propuesta por el Joanna Briggs Institute. El proceso de análisis, extracción y síntesis de datos será desarrollado por revisores independientes.

Presentación e interpretación de los resultados: El mapeo de los programas permitirá identificar las intervenciones desarrolladas por los profesionales de la salud, dirigidas a los niños, adolescentes y padres que experimentan el cáncer parental.

Conclusión: La revisión resultante del protocolo elaborado permitirá seleccionar las intervenciones apropiadas para el diseño de un programa de intervención de enfermería dirigido a adolescentes y padres que experimentan el cáncer parental.

Palabras clave: cáncer parental; intervención; niños; adolescentes; enfermería







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Introduction

According to the latest report of the World Health Organization (Organização Mundial da Saúde [OMS], 2018), in 2018, there were an estimated 18 million new cases of cancer worldwide, with Europe accounting for 23.4% of cases. In Portugal, the average of new cases is 260 per 100,000 inhabitants (Organisation for Economic Co-operation and Development [OECD], 2019).

In recent decades, there has been a marked increase in the incidence of cancer in younger age groups, with an international estimate that 15% of people with cancer are aged 15 to 50 years (O'Neill et al., 2019). In Portugal, cancer incidence data on these age groups are not available, but the types of cancer with the highest number of new cases (colorectal, breast, and prostate) are becoming increasingly common in young adults. The implications of a cancer diagnosis in these age groups differ from those found in older people, as many are still working or studying, and others are parents of children under the age of 18 (Alexander et al., 2019).

In recent decades, scientific advances have led to a holistic approach to the patient with cancer, both at the stage of diagnosis and throughout disease progression, being essential to integrate the family, particularly patients' children (children/adolescents).

Although there is no definition of parental cancer, it consists of the experience of cancer, at an early age in adult life, in people with dependent children (Barbosa, 2015). Cancer is a significant source of stress for patients and children due to the potential threat of death and may change the parent-child interaction (Su & Ryan-Wenger, 2007).

The number of studies on the impact of parental cancer on children and adolescents has increased in the last 20 years, and the results point to an increased risk of psychological and social problems in this population (O'Neill et al., 2019; Visser et al., 2004). Studies focus primarily on the adaptive problems of children and adolescents and the association between individual characteristics and the adaptation to parental cancer. However, a structured theoretical model is missing to support the development of intervention programs for children/adolescents and parents (Su & Ryan-Wenger, 2007).

According to Ellis et al. (2016), the interventions implemented in the programs should improve knowledge and understanding about the disease (cancer); facilitate family communication; reinforce the importance of peer support; normalize emotions and experiences; promote the development of coping mechanisms; prepare for the impending loss of a parent; and/or intervene in the grieving process.

Healthcare professionals working in hospitals specializing in adult care may have limited experience in caring for children and adolescents, which makes the teams insufficiently qualified to intervene with patients' children (Alexander et al., 2019). Given that the primary focus of healthcare professionals in these institutions is the cancer patient, the educational, social, and emo-

tional needs of their children are often disregarded, even though these families require professional guidance to improve the dyad's disease adjustment and well-being (Arber & Odelius, 2017; Philips & Prezio, 2016). Thus, the provision of care to cancer patients should include the assessment of the family, namely the internal structures, and identify the existence of children and/or adolescents in the household (Figueiredo & Martins, 2010; Su & Ryan-Wenger, 2007).

Studies on the effectiveness of intervention programs for adaptation to parental cancer have found significant improvements in children and adolescents, particularly in terms of post-traumatic stress and depression symptoms (Alexander et al., 2019), quality of life, development of coping mechanisms, and improvement of parent-child communication and relationships (Su & Ryan-Wenger, 2007), thus increasing the family's ability to cope with cancer.

Despite the relevance of the phenomenon of parental cancer and its impact on patients and their children, the authors found no programs with interventions aimed at the parent-child dyad in Portugal. In addition, there are few studies on this topic, and the interventions are scarce and not yet validated in clinical settings (Alexander et al., 2019). Some authors (Alexander et al., 2019; Inhestern et al., 2016; Su & Ryan-Wenger, 2007) recognize the need to develop standardized interventions for children/adolescents and parents experiencing parental cancer.

In view of this situation, a search for reviews was conducted in MEDLINE (via PubMed), CINAHL Complete (via EBSCO), and Cochrane Database of Systematic Reviews. Some literature reviews were found regarding intervention programs for children, adolescents, and parents experiencing parental cancer (Alexander et al., 2019; Ellis et al., 2016; Inhestern et al., 2016; Su & Ryan-Wenger, 2007).

In an integrative literature review, Su and Ryan-Wenger (2007) synthesized the existing evidence on the topic and developed a theoretical model to support intervention programs. The systematic literature review conducted by Ellis et al. (2016) excluded all types of literature reviews as well as intervention programs aimed only at parents (patients with cancer), given that their target population consisted of children and adolescents. In a systematic review, Inhestern et al. (2016) excluded studies whose programs did not include structured interventions, possibly excluding programs promoting adaptation to parental cancer. The systematic review by Alexander et al. (2019) included only studies with programs whose target population were children/adolescents with parents with cancer, excluding intervention programs directed to parents that aimed to address the dyad's needs.

This review differs from previous systematic reviews in this area because it maps the available intervention programs for children, adolescents, and parents (patients with cancer), or the dyad (patients with cancer and their children), and identifies the type of interventions implemented and the healthcare professionals implementing them to respond to the emerging needs of the target population.

Therefore, this scoping review aims to map the intervention programs for children, adolescents, and parents, or the dyad (patients with cancer and their children) experiencing parental cancer; identify the type of interventions proposed in the programs; and identify and describe the intervention programs developed by healthcare professionals, namely nurses. Thus, this study intends to answer the following review question: "Which programs are available to children, adolescents, and parents experiencing parental cancer?" and, consequently, the following sub-questions: "Which interventions are developed in the intervention programs for children, adolescents, and parents experiencing parental cancer?" and "What type of interventions are developed by the different healthcare professionals in the intervention programs for children, adolescents, and parents experiencing parental cancer?".

Review Method

This scoping review will follow the methodology recommended by the Joanna Briggs Institute (JBI; Peters et al., 2020) and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

Eligibility criteria will be established based on the Population, Concept, and Context (PCC) framework, according to the methodology proposed by JBI (Peters et al., 2020).

This scoping review will include studies whose population are children and adolescents, aged up to 19 years, with at least one parent diagnosed with cancer, regardless of the type of cancer and stage of the disease.

With regard to the concept, this review will include studies that address intervention programs for children, adolescents, and parents experiencing parental cancer, regardless of the type of interventions (psychoeducational and psychosocial) developed by healthcare professionals (physicians, nurses, psychologists), social workers, teachers, volunteers, and/or others.

The intervention programs aim to promote the child and adolescent's adjustment to parental cancer (Su & Ryan-Wenger, 2007) and meet parents' needs (patients with cancer), empowering them throughout the disease process in the performance of their parenting skills and, simultaneously, in the experience of the cancer disease (Hauken et al., 2019).

Concerning the context, all intervention contexts will be considered, without any restrictions: health institutions (general or oncology hospitals, health centers), foundations, patients' homes, and recreational settings (summer camps). Concerning study design, qualitative, quantitative, or mixed studies (descriptive-exploratory, randomized and non-randomized clinical trials, intervention and observational studies) of any level of evidence, literature reviews, and gray literature will be included. Studies in English, Portuguese, and Spanish will be included, without any time restrictions.

Study search and selection process

Based on the outlined study search and selection strategy, the following electronic databases will be used: MEDLINE (via PubMed), CINAHL Complete (via EBSCO), Academic Search Complete (via EBSCO), MedicLatina (via EBSCO), Nursing & Allied Health Collection (via EBSCO), SciELO, Cochrane Central Register of Controlled Trials, and Cochrane Database of Systematic Reviews. Unpublished studies will be searched for in the Open Access Scientific Repositories of Portugal, OpenGrey, and Dart-Europe.

The search is carried out in three stages. Initially, to identify the most frequently used keywords in titles and abstracts and the indexing terms used in the literature, a restricted search was performed in MEDLINE (via PubMed) and CINAHL Complete (via EBSCO; Table 1) databases.

Table 1Search in MEDLINE and CINAHL databases on April 7, 2020

Database	Strategy	No. of records
MEDLINE (via PubMed)	Search (((((((program*[Title/Abstract] OR service*[Title/Abstract] OR intervention*[Title/Abstract] OR project*[Title/Abstract]))) OR (("Program Development"[Mesh])) OR "Program Evaluation"[Mesh]))) AND ((((child*[Title/Abstract] OR adolescent*[Title/Abstract] OR youth[Title/Abstract] OR teen*[Title/Abstract] OR Infant*[Title/Abstract] OR famil*[Title/Abstract] OR parent*[Title/Abstract] OR mother*[Title/Abstract] OR father*[Title/Abstract] OR spouses[Title/Abstract] OR offspring[Title/Abstract]))) OR (((("Infant"[Mesh]))) OR "Child"[Mesh])) OR "Adolescent"[Mesh])) OR "Parents"[Mesh]))) AND (("parental cancer"[Title/Abstract] OR "parent with cancer"[Title/Abstract] OR "parent with cancer"[Title/Abstract] OR "parent diagnosed with cancer"[Title/Abstract] OR "parent developing cancer"[Title/Abstract] OR "family cancer"[Title/Abstract]))	226
CINAHL Complete (via EBSCO)	(TI (program* OR service* OR intervention* OR project*) OR AB (program* OR service* OR intervention* OR project*) OR (MH "Program Development+") OR (MH "Program Evaluation")) AND (TI (child* OR adolescent* OR youth OR teen* OR Infant* OR famil* OR parent* OR mother* OR father* OR spouses OR offspring) OR AB (child* OR adolescent* OR youth OR teen* OR Infant* OR famil* OR parent* OR mother* OR father* OR spouses OR offspring) OR (MH "Infant+") OR (MH "Child+") OR (MH "Adolescence+") OR (MH "Parents+")) AND (TI ("parental cancer" OR "parent with cancer" OR "parents with cancer" OR "relatives with cancer" OR "parent diagnosed with cancer" OR "parents with cancer" OR "family cancer") OR AB ("parental cancer" OR "parent with cancer" OR "parent with cancer" OR "family cancer"))	197

In the second stage, the identified indexed terms and keywords will be combined to formulate a search expression that will be adapted to the specificities of each database or repository. In the third and final stage, the reference lists of all selected articles and studies will be analyzed to identify potential studies to be included in this scoping review.

The results of the search in several databases will be exported to Mendeley Desktop reference manager (version 1.19.4), through which duplicate records will be identified and removed. Then, titles and abstracts will be screened to verify the eligibility of the studies. This process will be carried out by three independent reviewers (AFS, JFR, MJD), with the involvement of a fourth

reviewer to clarify any disagreements in the study selection process. If necessary, study authors will be contacted to clarify any doubts or provide additional information. The documents that meet the eligibility criteria will move on to the next stage, the full-text review. The results from the screening process will be presented based on the recommendations of the PRISMA-ScR (Tricco et al., 2018).

Data extraction

Three independent reviewers (AFS, JFR, MJD) will extract the data using tools developed by the reviewers for this review (Table 2 and 3), which may change after the analysis of the data obtained from the selected articles.

 Table 2

 Data extraction tool developed by the reviewers: study characteristics

DATA EXT	RACTION	TOOL						
Review title	e	Intervention programs for children, adolescents, and parents experiencing parental cancer: A scopi protocol						
Review que	estions	"Which programs are available to children, adolescents, and parents experiencing parental cancer?" "Which interventions are developed in the intervention programs for children, adolescents, and paren experiencing parental cancer?" "What type of interventions are developed by the different healthcare professionals in the intervention grams for children, adolescents, and parents experiencing parental cancer?".						d parents
Population: Children and adolescents aged up to 19 years, with at regardless of the type of cancer and stage of the disease. Concept: Intervention programs for children, adolescents, and par less of the type of interventions (psychoeducational and psychosoc (doctors, nurses, psychologists), social workers, teachers, volunteers. Context: All intervention contexts, without any restrictions: health pitals, health centers), foundations, patients' homes, and recreation					arents experie cial) develope ers, and/or oth th institution	encing parental ca ed by healthcare hers. s (general or onc	ancer, regard- professionals cological hos-	
STUDY CI	HARACTE	RISTICS						
Article	Title	Authors	Publication year	Country of origin	Study design	Objective	Participants	Context

Table 3Data extraction tool developed by the reviewers: extracted data

Article	Name of the program	Target population of the program	Objectives of the program	Structure of the program (Theoretical model, Frequency/Duration and Type of Sessions)	Interventions pro- posed in the program (Type and Description)	Healthcare pro- fessionals who implemented the program
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Data synthesis

Data will be presented in a narrative format, using tables where necessary, taking into consideration the purpose and focus of the scoping review. This process of synthesizing and presenting the results will be carried out independently by each of the three reviewers (AFS, JFR, MJD). Data synthesis tables were developed to answer the review questions set out. Table 4 on the intervention

programs for children/adolescents and parents experiencing parental cancer is divided into three sections according to the target population (dyad, children/adolescents, and parents). Table 5 aims to identify the type of interventions developed in the programs and identify and describe the programs developed by healthcare professionals (physicians, nurses, psychologists), specifying their intervention in the development and implementation.

Table 4

Tool for data synthesis: intervention programs for children/adolescents and parents experiencing parental cancer according to the target population.

4 7 7				** 11	Structure of the intervention program			
Author and publication year	Name of the larget popu- Objectives of		Theoretical model	Frequency/ Duration of the sessions	Type of ses- sions			
Intervention [programs for chil	dren and adolesce	nts (n= studies	and n= interventio		e of the intervention p	rogram	
Author and publication year	Name of the program	Target popu- lation	Objectives of the program	Healthcare pro- fessionals in the program	Theoretical model	Frequency/ Duration of the sessions	Type of ses- sions	
Intervention [programs for pare	ents (n= studies	and n= interes	ventions)				
Author and	Name of the Target po program lation			Healthcare pro-	Structure of the intervention program			
Author and bublication year		Target popu- lation	Objectives of the program	fessionals in the program	Theoretical model	Frequency/ Duration of the	Type of ses- sions	

Table 5

Tool for data synthesis: type of interventions developed by the healthcare professionals in the intervention programs for children, adolescents, and parents experiencing parental cancer

Author and publication year	Intervention program	Healthcare Professionals	Interventions		
Author and publication year			Туре	Description	

Presentation and interpretation of results

The mapping of the available intervention programs and the interventions implemented by healthcare professionals aimed at children, adolescents, and parents experiencing parental cancer can be used as an informative tool to support healthcare professionals' decision-making and clinical practice and contribute to the dissemination of available evidence on the topic.

Conclusion

The literature points to the need to direct and centralize the interventions available for children/adolescents and parents and develop validation studies that follow the appropriate methodological guidelines and involve children/adolescents and parents in the assessment process. Clinical practices are still not aligned with the available evidence, with intervention programs not being implemented in the target population.

The scoping review resulting from this protocol aims to meet the objectives set out by mapping the intervention programs for children/adolescents and parents experiencing parental cancer. In addition, it will identify the structure and the type of interventions used in the programs and examine which interventions are being developed by the several healthcare professionals.

Thus, this protocol is a starting point for further analysis and systematization of the best available evidence on this area.

The scoping review resulting from this protocol is expected to gather relevant information that will serve as a basis for the development of a nursing intervention program for adolescents and parents experiencing parental cancer, as well as to provide information that will support the analysis of current practices related to parental cancer.

Author contributions

Conceptualization: Sousa, A. F., Ferreira, M. M., Lomba, M. L.

Methodology: Cardoso, D. F., Sousa, A. F.

Validation: Ferreira, M. M., Lomba, M. L.

Writing – original draft: Sousa, A. F., Rodrigues, J. F., Dias, M. J.

Writing – review & editing: Sousa, A. F., Rodrigues, J. F., Dias, M. J.

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