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Intervention programs for children, adolescent and parents experiencing parental cancer: a scoping review[a]

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

Programas de intervención para niños, adolescentes y padres que experimentan cáncer en sus padres: scoping review

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ABSTRACT

Objectives: to map intervention programs for children, adolescents and parents, or binomial (oncology patients and children) experiencing parental cancer. **Method:** this scoping review was carried out according to the methodology recommended by Joanna Briggs Institute (JBI) and the Preferred Reporting Items for Systematic Reviews - Scoping Reviews (PRISMA-ScR). **Results:** a total of 29 intervention programs were identified: 13 directed to the binomial, 11 to children and adolescents and 5 to parents. Of all the identified programs, 10 do not specify the typology of proposed interventions, 9 refer to psychoeducational interventions, 7 refer to educational interventions and 3 refer to psychosocial type interventions. **Conclusion and implications for practice:** it was verified that most of the programs identified are directed to children/adolescents and parents. The characteristics of programs and interventions differ between studies; however, the psychoeducational interventions are the most prevalent. The mapping of intervention programs and promotion of adaptation to parental cancer contributes to the synthesis of existing evidence on this theme, knowledge about interventions developed and the obtained results, raising awareness among health professionals, namely nurses, and decision makers in the health area for relevance of its implementation in clinical practice, considering the quality of nursing care provided to these families.

Keywords: Neoplasms, Parents, Child, Adolescent, Health Programs and Plans.

RESUMO

Objetivos: mapear programas de intervenção para crianças, adolescentes e pais, ou díade (doentes oncológicos e filhos) a vivenciar o cancro parental. **Método:** scoping review, segundo a metodologia recomendada pelo Joanna Briggs Institute (JBI) e o Preferred Reporting Items for Systematic Reviews - Scoping Reviews (PRISMA-ScR). **Resultados:** foram identificados 29 programas de intervenção: 13 dirigidos à díade, 11 a crianças e adolescentes e 5 dirigidos aos pais. Dos programas identificados, 10 não especificam a tipologia das intervenções propostas, 9 referenciam intervenções psicoeducacionais, 7 referenciam intervenções educacionais e 3 referenciam intervenções do tipo psicossocial. **Conclusão e Implicações para a prática:** verificou-se que a maioria dos programas identificados se dirige à díade crianças/adolescentes e pais. As caraterísticas dos programas e das intervenções diferem entre estudos, no entanto as intervenções psicoeducacionais são as mais prevalentes. O mapeamento de programas de intervenção e promoção da adaptação ao cancro parental contribui para a síntese da evidência existente sobre esta temática, conhecimento sobre as intervenções desenvolvidas e resultados obtidos, consciencializando os profissionais de saúde, nomeadamente enfermeiros, e decisores da área da saúde para a relevância da sua implementação na prática clínica, tendo em vista a qualidade dos cuidados de enfermagem prestados a essas famílias.

Palavras-chave: Neoplasias, Pais, Criança, Adolescente, Planos e Programas de Saúde.

RESUMEN

Objetivos: mapear programas de intervención para niños, adolescentes y padres, o díada (pacientes oncológicos y niños) que padecen cáncer paternal. **Método**: scoping review según la metodología recomendada por Joanna Briggs Institute (JBI) y el Preferred Reporting Items for Systematic Reviews - Scoping Reviews (PRISMA-ScR). **Resultados**: de identificaron 29 programas de intervención: 13 dirigidos a díada, 11 a niños y adolescentes y 5 a padres. De los programas identificados, 10 no especifican tipología de intervenciones propuestas, 9 refieren intervenciones psicoeducativas, 7 intervenciones educativas y 3 intervenciones psicosocial. **Conclusión e implicaciones para la práctica:** se ha verificado que la mayoría de los programas identificados están dirigidos a díada niños/adolescentes y padres. Las características de los programas y las intervenciones difieren entre los estudios, sin embargo, las intervenciones psicoeducativas son más frecuentes. El mapeo de programas de intervención y promoción de la adaptación al cáncer parental contribuye a la síntesis de evidencia existente sobre este tema, el conocimiento sobre intervenciones desarrolladas y resultados obtenidos, sensibilizando profesionales de salud, a saber, enfermeros y tomadores de decisiones en el área de la salud por relevancia de su implementación en la práctica clínica, dada la calidad de los cuidados de enfermería prestados a estas familias.

Palabras clave: Neoplasias, Padres, Niño, Adolescente, Planes y Programas de Salud.

INTRODUCTION

The incidence of cancer in younger age groups has increased considerably in recent decades. It is estimated that internationally 15% of people with cancer are between 20 and 50 years old[1]. Cancer diagnosis in this age group has different implications from those found in older people, as many still work or study and are parents of children under 18 years[2].

Parental cancer comprises the experience of cancer at an early age of adulthood, in people with dependent children, representing a significant stressor for patients and children, due to the disease and the potential threat of death, which may cause changes in parent-child interaction[3,4].

In the last 20 years there has been an increase in studies on the impact of parental cancer on children and adolescents, the results indicating an increased risk of suffering from developmental disorders, psychological, emotional, behavioral and psychosocial problems, including anxiety, isolation, sadness, anger, depression, school/play difficulties, changes in family dynamics and post-traumatic stress[2,5,6].

Despite the relevance of the phenomenon and the impact on the parent-child binomial, there are no specific guidelines for health professionals regarding families who experience this situation[2,7]. However, some authors mention the need to develop standardized interventions for children/adolescents and parents[2,4,8].

In order to verify the existence of previous secondary studies, we carried out a search for reviews in MEDLINE (via PubMed), CINAHL Complete (via EBSCO), Cochrane Database of Systematic Reviews and JBI CONNECT+, finding four literature reviews [2,4,6,8] referring to intervention programs for children, adolescents and parents who experience parental cancer that did not respond, as a whole, to the formulated review question: “What programs exist, aimed at children, adolescents and parents experiencing parental cancer?”, and the sub-questions: What interventions are developed in intervention programs aimed at children, adolescents and parents experiencing parental cancer? What is the typology of interventions developed by different health professionals in intervention programs aimed at children, adolescents and parents experiencing parental cancer?

This scoping review differs from previous systematic reviews, as it aims to map intervention programs to children, adolescents and parents, or binomial (cancer patients and their children) experiencing parental cancer; identify the typology of interventions proposed in the programs; and identify and describe the intervention programs that are developed by different health professionals, such as nurses.

METHOD

This scoping review was carried out in accordance with the methodology recommended by the JBI and the Preferred Reporting Items for Systematic Reviews - Scoping Reviews (PRISMA-ScR)[9].

The eligibility criteria to select the studies were defined based on the PCC mnemonic (Population, Concept and Context). The study population includes children and adolescents, up to 19 years old, with at least one of the parents diagnosed with cancer, regardless of type and stage of cancer, the parents (oncology patients), and the binomial. Concept includes intervention programs for the study population, regardless of type of interventions implemented (educational, psychoeducational and psychosocial), developed by health professionals (doctors, nurses, psychologists), social workers, teachers, volunteers and/or others. Intervention programs should aim to promote children’s and adolescents’ adjustment to parental cancer and meet the needs of parents (oncology patients), enabling them throughout the course of the disease to perform their parental skills and concomitantly in the experience of oncological disease[4,10]. All intervention contexts were considered, without any limitation: health institutions (general or oncology hospitals, health centers), foundations, homes and recreational environments (vacation camps). This review included qualitative, quantitative or mixed studies (descriptive-exploratory, randomized and non-randomized clinical trials, intervention studies observational), of any level of evidence, literature reviews and gray literature. Studies in English, Portuguese and Spanish and without time limit were considered.

Research strategy and identification of studies

To identify the studies, we used the 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 databases. To identify unpublished studies, a search was carried out in the Open Access Scientific Repositories of Portugal (RCAAP), OpenGrey and Dart-Europe. The research was carried out in March 2021, in three stages. The first consisted of a search in the MEDLINE (via PubMed) and CINAHL Complete (via EBSCO) databases, to identify the keywords used in the titles and abstracts, as well as indexing terms. In the second stage, the natural words and listed keywords were combined to form the search expression, which was adapted to the specificities of each database or repository. The search expression used was: [(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 family*[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 “parents with cancer”[Title/Abstract] OR “relatives with cancer”[Title/Abstract] OR “parent diagnosed with cancer”[Title/Abstract] OR “parent developing cancer”[Title/Abstract] OR “family cancer”[Title/Abstract])].

In the last step, the bibliographic references of all selected articles and studies were analyzed in order to identify other studies that could be included in the review. The search results in the different databases were exported to the Mendeley Desktop reference manager (version 1.19.4), through which duplicate records were identified and removed. Subsequently, the screening of studies was carried out through analysis of titles and abstracts, in order to verify document eligibility. This process was developed by three independent reviewers (AFS, JFR, MJD), using a fourth element to clarify differences in the article selection process. When necessary, the authors of primary studies were contacted with a view to obtaining further information and/or clarification on the results. The documents that met the outlined eligibility criteria went on to the next stage of full-text analysis.

RESULTS

The database search identified 786 records. An additional 27 studies were identified from other sources. The selection process resulted in the inclusion of 16 studies in this review. The results obtained from the screening process are presented according to the PRISMA Extension for Scoping Reviews[11] recommendations, according to Figure 1.

The 16 studies (S) selected were carried out between 1992 and 2020 in eight different countries: United States of America (4), Australia (3), England (2), Ireland (2), Canada (1), Taiwan (1), Norway (1), and Germany (1) (Table 1).

After a comprehensive analysis of the selected studies, 29 intervention programs were identified, 13 of which were aimed at the binomial, 11 at children and adolescents, and 5 at parents. Of the 29 programs identified, 10 do not specify the typology of proposed interventions, 9 refer to psychoeducational interventions, 7 are educational interventions and 3 are psychosocial interventions (Table 2).

It was found that only four of the programs identified were health professionals in the team: nurses (P11 and P14), psychologists (P1), and psychologists and doctors (P3). The selected studies do not discriminate which interventions are developed by each of these professionals. Table 3 presents the intervention programs identified in the included studies, naming the target population, objectives, moderators and structure (periodicity, duration and typology of the sessions).

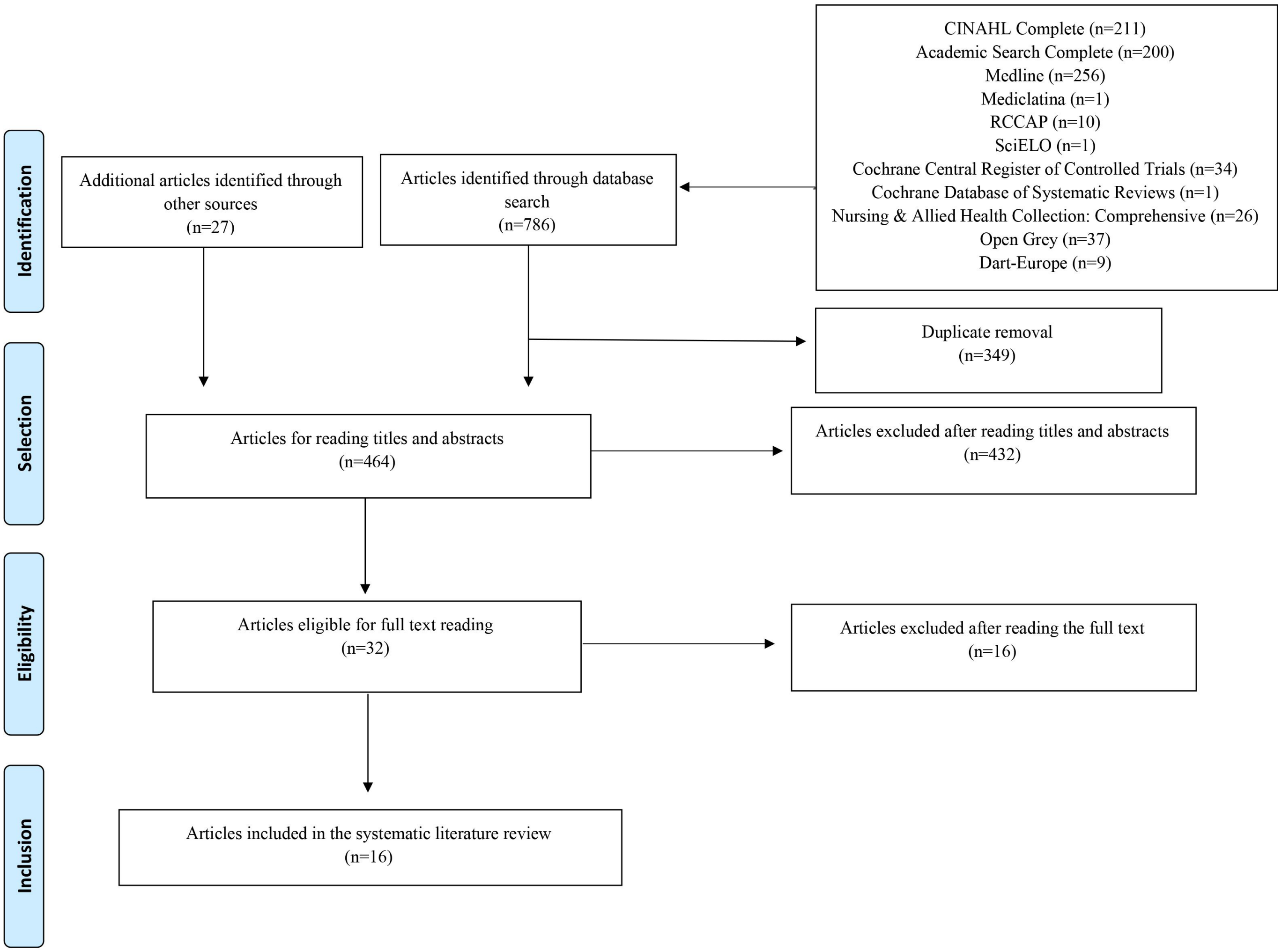

Figure 1- PRISMA Extension for Scoping Reviews flowchart.

Table 1. Studies included in this scoping review.

S*	Title	Country/year	Study design
S1[12]	The "Bear Essentials" Program: Helping Young Children and Their Families Cope When a Parent Has Cancer	USA, 1992	Cohort longitudinal
S2[13]	Kids Can Cope: A Group Intervention for Children Whose Parents Have Cancer	Canada, 1993	Cohort longitudinal
S3[14]	Evaluation of a Focused Short-term Preventive Counselling Project for Families with a Parent with Cancer	England, 2006	Quasi-experimental
S4[4]	Children's Adjustment to Parental Cancer: A Theoretical Model Development	Taiwan, 2007	Descriptive-exploratory
S5[15]	On Belay: Providing Connection, Support, and Empowerment to Children Who Have a Parent With Cancer	England, 2013	Cohort longitudinal
S6[16]	A study protocol for Truce: a pragmatic controlled trial of a seven-week acceptance and commitment therapy program for young people who have a parent with cancer	Australia, 2015	Randomized controlled
S7[17]	Optimizing Social Network Support to Families Living With Parental Cancer: Research Protocol for the Cancer-PEPSONE Study	Norway, 2015	Randomized controlled
S8[18]	Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer	USA, 2016	Cross-sectional
S9[8]	Psychosocial Interventions for Families with Parental Cancer and Barriers and Facilitators to Implementation and Use – A Systematic Review	Germany, 2016	Systematic literature review
S10[6]	Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions	Australia, 2016	Systematic literature review
S11[19]	The Enhancing Connections-Telephone study: a pilot feasibility test of a cancer parenting program	USA, 2017	Experimental
S12[20]	Children of Parents with Cancer: An evaluation of a psychosocial intervention	Ireland, 2018	Qualitative
S13[1]	Children Navigating Parental Cancer: Outcomes of a Psychosocial Intervention	Ireland, 2019	Qualitative
S14[21]	Web-based counseling for families with parental cancer: Baseline findings and lessons learned	Switzerland, 2019	Randomized controlled
S15[2]	A systematic review of the current interventions available to support children living with parental cancer	Australia, 2019	Systematic literature review
S16[22]	Upping my game as a parent: Attributed gains in participating in a cancer parenting program for child-rearing parents with advanced cancer	USA, 2020	Qualitative

*S- Study

The description of the interventions developed by health professionals is identified in 3 of the programs aimed at the binomial and in 1 of the programs aimed at children and adolescents (Table 4).

DISCUSSION

The analysis of results was organized into four emerging categories: *Intervention programs*; *Typology of interventions*; *Intervention programs that integrate nurses into the team*; *Theoretical model underlying intervention programs*.

Intervention programs

A significant part (13) of the selected programs is directed to the binomial. Living with parental cancer affects parents and children, being extremely stressful for the patient and family because it changes family functioning and intra-family relationships[2], causing emotional and physical exhaustion in cancer patients

Table 2. Identification of intervention programs aimed at children, adolescents and parents experiencing parental cancer.

P*	Program name	Studies	Typology of intervention	Intervention description
Intervention programs aimed at the binomial/families (n=8 studies and n=13 programs)				
P1	"Cancer-Psycho-Educational Program for the Social network (PEPSONE)"	S7, S15	Psychoeducational	Yes
P2	"Children of Somatically Ill Parents (COSIP)"	S3, S9, S15	Psychoeducational	No
P3	"Family online counseling for families with parental cancer (FAMOCA)"	S14	Psychosocial	Yes
P4	"Culturally adapted family intervention"	S9, S10	Does not specify	No
P5	"Family Focused Grief Therapy"	S9	Does not specify	No
P6	"Family Matters (including Kids I and II and Turtles programs)"	S10	Psychoeducational	No
P7	"Getting well together"	S9, S10	Educational	No
P8	"Parent Guidance Intervention"	S10	Does not specify	Yes
P9	"Short-term psycho-educational intervention"	S9	Does not specify	No
P10	"Struggle for Life trial"	S9, S10	Does not specify	No
P11	"The Bear Essentials Program"	S1, S4, S9, S10	Psychoeducational	Yes
P12	"The Children´s Summer Programme"	S10	Psychosocial	Yes
P13	"The Family Support Program (Family Talks in Cancer Care)"	S9, S10	Does not specify	No
Intervention programs for children and adolescents (n=9 studies and n=11 programs)				
P14	"Kids Can Kope"	S2, S9, S10	Psychoeducational	Yes
P15	"A Supportive-educative Program"	S15	Educational	No
P16	"Children's Lives Include Moments of Bravery (CLIMB)"	S9, S10, S12, S15	Psychoeducational	Yes
P17	"For Kids Only"	S4, S9	Educational	Yes
P18	"On Belay"	S5, S9	Does not specify	Yes
P19	"Quest"	S4, S9, S10	Psychoeducational	Yes
P20	"School-based Groups"	S4	Educational	Yes
P21	"The Kids Connection"	S4	Educational	Yes
P22	"The Komen Kids"	S4	Educational	Yes
P23	"The Truce Program"	S6	Psychoeducational	Yes
P24	"Wonders & Worries"	S8	Psychosocial	Sim
Intervention programs for parents (n=5 studies and n=5 programs)				
P25	"Art-therapy program for parents"	S9	Does not specify	No
P26	"Being a parent and coping with cancer"	S9	Does not specify	No
P27	"Enhancing Connections Program (EC)"	S9, S10, S11, S15	Educational	Yes
P28	"Enhancing Connections Program in Palliative Care"	S16	Psychoeducational	Yes
P29	"Preventive Intervention for Bereaved Children"	S9, S10	Does not specify	No

* P: Program

Table 3. Description of intervention programs for children, adolescents and parents experiencing parental cancer.

Binomial/family intervention programs				
P	**Target population**	**Program objectives**	**Program moderators**	**Periodicity/Duration/ Typology of sessions**
P1	Families (cancer in the last 5 years) with children aged 8 to 18*	Reinforce the importance of family network support	Psychologists	1 3-hour session, individual/ group
		Provide social support to families		
		Increase parents' health literacy		
P2	Families with children under the age of 18*	Increase parental skills	Psychotherapists	4 to 7 group sessions
		Prepare the grieving process		
P3	Families with children from 3 to 18 years*	Promote fit and family functioning	Psychologists Doctors	1 month, 4 online sessions
		Improve the emotional interaction of the couple and family		
P4	African families with school-age children, and parents with cancer stage I, II and III	Promote family communication and parent-child bonding	Not referred	Children: 3 sessions of 90 min. Families: 2 sessions of 120 min.
P5	Families with parents with terminal cancer, with children over 12 years old	Promote unity and family communication	Not referred	4-8 group sessions of 90 min.
		Manage personal/family conflicts		
		Provide support in the grieving process		
P6	Families with children from 5 to 11 years old*	Assist in the process of changing social roles	Not referred	Not referred
		Promote a safe environment to express emotions		
P7	Mothers with breast cancer and children	Support the family system	Not referred	Group sessions
		Minimize emotional problems in children		3 weeks
P8	Families with children from 7 to 17 years old*	Improve communication skills and family interaction	Not referred	6 individual sessions of 60-90 min, 12 months
P9	Families with children*	Promote the sharing of family concerns	Not referred	Group sessions
P10	Families with children from 8 to 17 years old*	Support family communication	Not referred	8 to 10 group sessions
		Promote psychosocial well-being of children and parents		
P11	Families with children from 4 to 8 years old*	Meet children's needs	Nurses	Monthly group meetings of 1/1:30h
		Increase parental skills	Priests	
			Social workers	
P12	Families with children under 18 years old*	Provide quality time for children	Not referred	Triweekly; 8 weeks
		Provide rest time to parents		Holiday camp

* 1- Families with at least one parent diagnosed with cancer

Table 3. Continued...

Binomial/family intervention programs				
P	**Target population**	**Program objectives**	**Program moderators**	**Periodicity/Duration/ Typology of sessions**
P13	Families with terminally ill parent and children aged 5 to 18 years	Prevent psychosocial problems Develop coping mechanisms Promote understanding of cancer	Not referred	5 weekly group sessions
Intervention programs for children and adolescents with at least one parent diagnosed with cancer				
P14	Children and adolescents from 5 to 18 years old	Teach about cancer, treatments and adverse effects Promote the expression and normalization of emotions Provide hospital visit	Volunteers Social workers Nurses	2 times a year, average of 6 weekly group sessions
P15	Adolescents	Improve adolescents' quality of life	Not referred	45-90 min sessions Individual/group
P16	Children from 6 to 11 years old	Clarify the concept of cancer Reduce the feeling of isolation Promote the normalization of emotions/experiences	Volunteers	1 weekly group session of 90 min, 6 weeks
P17	Children and adolescents with parents or significant person with cancer	Teach about cancer, treatments and adverse effects Refer children in need of differentiated intervention	Not referred	1-day group workshop
P18	Children and adolescents from 9 to 19 years old	Support the discovery of personal skills in the face of parental cancer	Volunteers	4 times/year, 1 day, group
P19	Children and adolescents with parents or grandparents with cancer	Teach about cancer, treatments and adverse effects Promote the normalization of emotions/experiences	Not referred	2-hour group semiannual sessions
P20	Children and adolescents from 6th to 12th grade, with terminally ill parents, or in mourning	Develop coping mechanisms Promote the normalization of emotions/experiences	Not referred	Weekly group session of 50/55 min. 10 weeks
P21	Children and adolescents from 5 to 15 years old	Teach about cancer, treatments and adverse effects Promote the normalization of emotions/experiences	Not referred	Monthly group session of 50 min.

* 1- Families with at least one parent diagnosed with cancer

Table 3. Continued...

P	Target population	Program objectives	Program moderators	Periodicity/Duration/ Typology of sessions
		Binomial/family intervention programs		
P22	Children and adolescents from 7 to 17 years old	Promote communication in the family system Promote the development of coping mechanisms	Not referred	24-hour hotline and monthly meeting
P23	Adolescents from 14 to 22 years old	Provide psychological support to adolescents	Volunteers (specific training)	Average of 7 weekly group sessions
P24	Children from 2 to 18 years old	Teach about cancer, treatments and adverse effects Promote a safe environment for the expression of emotions	Experts in pediatrics	6 weeks, 90-minute session, individual/group
		Intervention programs for parents		
P25	Patients with or without children	Develop a book to promote communication between parents and children	Not referred	22 group sessions, weekly, 90 min.
P26	Patients with children undergoing chemotherapy	Increase parental skills	Not referred	1-day group workshop
P27	Mothers with breast cancer at different stages, with children from 8 to 12 years old	Reduce feelings of distress Promote adaptation to changes caused by the mother's disease and management of emotions	Educator and/or other non-specific	5 telephone sessions, individual/group, 30-60 min, biweekly
P28	Terminally ill patients with children	Improve adaptation to the disease Increase parental skills	Educators	5 sessions of 30-60 min, biweekly
P29	End-stage cancer patients with children aged 7 to 17 years	Support parents to deal with suffering Promote well-being and continuity of family functioning	Not referred	6-8 90-minute individual sessions

* 1- Families with at least one parent diagnosed with cancer

and emotional suffering in children and adolescents[23]. These data reinforce the importance of targeting intervention programs not only to parents or children.

The age of children and adolescents targeted by the programs ranged between 2 and 22 years. Of the analyzed programs, 28 include adolescents, but only 2 (P15, P20) are exclusive for this age group, considering the World Health Organization classification, which defines adolescents as individuals between 10 and 19 years old[24]. A study on the impact of parental cancer disease on children concluded that the greater the children's development, the greater the impact of cancer on parents, given that older children have a greater ability to perceive the disease and its implications[25]. Adolescents are considered more vulnerable than children when faced with their parents' cancer disease, showing high levels of anxiety and depression[26-28]. The aptitude for abstract thinking and increased cognitive skills makes them more susceptible to anguish, because they have greater knowledge about the possible consequences, being more awake to the losses and physical and emotional pain of their parents. These results support the need for intervention and programs specifically aimed at this population. Some programs, despite having different age limits, refer to samples divided

Table 4. Intervention description in programs developed by health professionals.

P	Intervention description
	Binomial/family intervention programs
P1	Educational interventions on: pathology and its consequences in the family; reactions and needs of children and parents; coping strategies; importance of social support; importance of communication within the family. Provision of different types of social support.
P3	Online interventions organized in 4 modules: 1st - "Understand what is happening"; 2nd - "Deal with everyday family life"; 3rd - "Take care of me and others"; and 4th - "Plan for the future integrating the past." Teach families how to deal with emotions by promoting parental skills in relation to children's emotional responses.
P11	Children group: activities related to different topics (friends, feelings, new beginnings, family and hospital visit). The activities begin and end in the circle of friendship, with the teddy bears. Parents group: binomial presentation; sharing of current diagnosis/situation. The discussions begin with the theme chosen by children for each session.
	Intervention programs for children and adolescents with at least one parent diagnosed with cancer
P14	Educational interventions (teaching about cancer, treatments and adverse effects, feelings and fears about death and unstable nature of cancer). Visits to the hospital (radiotherapy and chemotherapy service).

into groups according to age, demonstrating the need to adapt interventions according to the age group of children and their level of development.

Of the 29 programs, 3 focus their interventions during the terminal phase of cancer patients (P13, P28 and P29), and only 1 (P20) integrates the terminal phase and the grieving process of children and adolescents. In terminal situations, children and adolescents may suffer from anticipatory grief, increased responsibilities and less social activity. In cases of loss of a parent, the emotional impact is greater and the suffering is prolonged, so it is necessary to intervene in the grieving process[6]. The remaining 25 programs do not specify the stage of the parents' illness; however, their objectives allow identifying interventions that are consistent with the stage of diagnosis and treatment. Children and adolescents, during the diagnosis and/or treatment phase of their parents, face fears, anxiety and changes in their routines, taking on additional responsibilities, and may receive less support and parental attention in school and recreational activities[6]. The results support the importance of differentiating the binomial interventions for each stage of cancer, since from the initial moment of diagnosis to the process of treatment, recovery, or palliative care, these families are faced with different emotions, commitments and information while trying to maintain a degree of normality in their lives[1]. Although no program contemplates interventions for the recovery phase, the consequences of living with parental cancer can be seen in the long term, namely post-traumatic stress, which highlights the need for intervention also in the follow-up[6].

Some authors point to the fact that parents' sex can influence the emotional, behavioral and somatic manifestations of their children, with these differences depending on whether the father or mother has cancer[29]. However, from the analysis of the results, only 2 programs (P7 and P27) discriminate the sick parent's sex, including only mothers. At the same time, of the 29 programs under analysis, 27 include patients with any type of cancer in the target population, e only 2 (P7 and P27) include women with breast cancer. This lack of differentiation in the programs regarding the type of cancer is justified by the lack of a relationship between the type of cancer in the parents and the impact on children and cancer patients[29]. Mothers and fathers who have cancer tend to have a decrease in parental skills, having a feeling of failure in the face of responsibilities to meet their children's needs[30]. Decrease in parental skills is due to the disease's emotional and physical strain characteristic and the difficulty in recognizing their children's needs, as well as in understanding their reactions to the disease[23]. The identified programs aim to improve the parents' adaptation to the disease, increasing their parenting skills, promoting the development of coping strategies and communication skills to minimize children's distress. Program interventions should focus not only on children's needs, but also those of the parents, as when the family is sure that a patient is receiving the best possible nursing care, their apprehension and anxiety decrease[12]. The frequency of sessions and programs analyzed varies between daily, weekly, biweekly, monthly, semiannual, or annual. Duration varies between 30 minutes and 3 hours, and the number of sessions, between 1 and 24. A program (P22), in addition to providing face-to-face sessions, also provides a 24-hour telephone support line; in another (P27), the sessions take place over the phone; and only in one program (P3) they are held exclusively in online format. The program sessions are developed individually and/or in groups within the binomial/family or in groups of parents and children. These results demonstrate the importance of adapting the sessions to different contexts, stage of cancer and the binomial's needs, and interventions should be tailored to the situation of each family[8]. The intervention context of the analyzed programs includes associations, foundations, schools, homes and recreational environments. None take place in health institutions, although some advocate hospital visits in their interventions as a way to reduce the fear associated with the hospital environment, professionals and procedures. However, some authors point to the importance of interventions being integrated into the institutional environment in which patients are monitored[8].

Typology of interventions

Of the analyzed programs, 10 do not refer to the typology of interventions they propose, nor do they categorize or describe them. The most named interventions (9 programs) are psychoeducational. This type of intervention integrates the psychological/emotional and educational component, aiming to provide social support to families, increase parenting skills in terms of emotional availability and communication skills, and improve children's understanding of cancer, minimizing anguish and fear. They also contribute to increasing parents' and children's health literacy, promoting the expression of emotions/experiences, assisting in the process of changing social roles and preparing a possible grieving process[2,6,8,10,14]. The results of effectiveness studies on psychoeducational intervention programs demonstrate the existence of significant improvements in children and adolescents, namely in terms of symptoms of post-traumatic stress and depression, quality of life, development of coping mechanisms, optimization of communication and parent-child relationship[2,4]. Interventions of educational typology (identified in 7 programs) are relevant for teaching about parental illness, promoting normalization of emotions/experiences, and developing coping mechanisms, favoring communication in the family system and in the referral of children and adolescents in need of differentiated intervention[4,8]. Psychoeducational and educational interventions were the majority (55.2%) identified in the analyzed programs. Psychosocial interventions, identified only in 3 programs, despite their benefits, as in the provision of services and support networks for families, also bear a set of barriers to their implementation, such as the difficulties of families in being present at the sessions[8]. The stigma of cancer and parental fear of their children's coping with the disease are emotional aspects identified as barriers. Simultaneously, the inexistence of interconnection with institutions was identified, justified by the time and effort required of professionals to build the networks necessary for the implementation of interventions[8]. In this sense, it emphasizes the need for interventions to be flexible and adapted to the contexts and family situation, integrated into the organizational environment and developed by motivated teams, with specific training and ability to reflect and assess the processes[8]. In short, the studies, in general, show that programs developed for children and adolescents should include three essential components in their structure: education (about parental cancer); normalization (creating a safe environment that allows them to express their feelings, providing support); and development of strengths (helping to recognize the ability to deal with stressful events that allow the development of coping mechanisms)[4].

Intervention programs that integrate nurses into the team

Of the programs identified in this scoping review, only 2 have nurses who provide care in oncology units in their team (P11 and P14). Studies referring to the development of these programs were published in 1992 and 1993, respectively, and do not specify which interventions were developed by nurses[12,13]. After a search in the MEDLINE (via PubMed) and CINAHL (via EBSCO) databases using the terms "parental cancer" and "nurse", it was found that, in about 30 years, only 17 nursing publications were identified in parental cancer, which indicates the little investment in the development of investigations on this theme. At the same time, it appears that nurses who work in cancer hospitals specialized in providing care to adults have limited experience with children and adolescents, which makes the teams insufficiently qualified to intervene with the clients' children[2]. In this way, the educational, social and emotional needs of children of cancer patients are often disregarded, although families need professional guidance that contributes to the adaptation to the disease and promotion of well-being[7,31]. The consequences of parental cancer in the family (patients and children) emphasize the need for nursing intervention[32]. Family assessment in terms of structure should be a priority for nurses who take care of cancer patients, to identify the presence of children and/or adolescents in the household[4,33] and the relationship between members. The relevance of this assessment allows meeting the binomial's needs, focusing care on the family, providing confidence and ensuring an efficient and motivated team that invests and is involved in the recovery process. The skills of nurses specialized in child and adolescent health care provide for interventions at the family assessment level, promoting adaptation to changes in health and family dynamics, with the existence of expert nurses in child health and pediatrics in the oncology unit teams directed at adults being essential[34].

Theoretical model underlying intervention programs

Five programs (P1, P2, P23, P24 and P27) identify theoretical models as a structuring basis for the construction of the proposed interventions, content and structure of the sessions: Direct Effect Model, Stress-buffering Model, Quality of Life Theory and Bandura Learning Theory (P1); Family Therapy Theory (P2); Acceptance and Commitment Theory (P23); Model of Factors Influencing Children's Adjustment to Parental Cancer (P24); and Contextual Model of Paternity Development, Transactional Coping Model and Bandura Learning Theory (P27). The analysis allows us to identify that only 1 program (P24) is based on a model specifically related to parental cancer, Model of Factors Influencing Children's Adjustment to Parental Cancer, developed by Lewis *et al.* (1989, 1993)[18,35]. The model focuses on the family system, explaining the relationships between complex variables, proposing a framework that illustrates the interrelationships between child and family, family characteristics, family functioning, relationships, and children's well-being. This model seeks to conceptualize cancer as a family experience, stressing the need to address the impact that this experience can have on children's and adolescents' adaptation[18]. Although some of the programs structure their interventions based on theories, scientific evidence highlights the paucity of theoretical models that conceptualize how children and adolescents are affected by their parents' cancer diagnosis and that provide a theoretical framework for how to intervene in the binomial[2]. The existence of a theoretical model that aims to systematically analyze the process of dealing with parental cancer has implications for clinical practice, namely in interventions aimed at families experiencing parental cancer[4]. In this sense, Su and Ryan-Wenger[4] proposed the Children's Adjustment to Parental Cancer: A Theorical Model Development model, which is based on the principle that cancer diagnosis invariably leads to psychological and social stress in children and adolescents. The model emphasizes the importance of nursing interventions to promote children's and adolescents' adjustment to parental cancer. It appears that both the Model of Factors Influencing Children's Adjustment to Parental Cancer and the Theoretical Model of Children's and Adolescents' Adjustment to Parental Cancer are based on Hoke's classification[36], which identifies four dimensions of reactions of children and adolescents to their parents' cancer, which condition their adjustment, namely the emotional (mood and self-esteem changes), somatic, social (school performance) and interpersonal dimensions.

Despite scientific evidence identifying at least these two theoretical models, only 1 program (P24) was based on one of them. These models are considered a reference and conceptual basis for nursing intervention in the binomial, and can be used to guide nurses to develop programs aimed at these families.

CONCLUSIONS

This scoping review made it possible to map the intervention programs aimed at children, adolescents and parents experiencing parental cancer and identify the respective interventions. It was concluded that programs aimed at the binomial and with psychoeducational interventions are the most used, with those aimed at parents (oncology patients) being the least mentioned. The programs that integrate nurses into the team are scarce, highlighting the need for greater investment by this professional class in the area of parental cancer. Although some programs identify theoretical models underlying intervention programs, only 1 integrates a model related to parental cancer. The design of intervention programs should have at its conceptual basis a theoretical model that supports interventions aimed at the binomial. None of the programs were implemented in health institutions, suggesting future development of intervention programs in the hospital context. The implementation of programs in health institutions will contribute to demystifying the fear associated with cancer and neoadjuvant treatments, minimizing anguish through the expression of emotions, promoting the binomial's adaptation and well-being. Of the analyzed programs, none integrates the different stages of the oncological disease, referring only to specific periods, such as diagnosis, treatment, palliative and/or mourning. It is suggested that the programs' design consider nursing interventions taking into account the different stages of cancer, including follow-up.

The results of this scoping review synthesize knowledge about existing intervention programs, enabling its implementation in clinical practice for families who experience parental cancer, meeting the needs of children, adolescents and their parents.

This review highlights existing gaps in the area, suggesting the development of new studies, namely assessment of the effectiveness of intervention programs aimed at all stakeholders (parents and children).

Language restrictions (Portuguese, English and Spanish) stand out as a limitation in this study. However, it should be noted that the language of excellence in scientific publication was included (English language). Also, the fact that the assessment of the methodological quality of the included studies was not carried out, as it is not relevant for a scoping review, makes it difficult to assess the impact of the analyzed programs and interventions, so it is suggested that they be carried out in future, primary or systematic reviews.

AUTHOR'S CONTRIBUTIONS

Review study design. Ana Filipa Domingues Sousa. Maria Margarida da Silva Reis dos Santos Ferreira. Maria de Lurdes Lopes de Freitas Lomba

Literature search. Ana Filipa Domingues Sousa. Joana Filipa Cunha Rodrigues. Maria João Graça Silva Neves Dias.

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