The Carenet Project:

A Roadmap to Continuous Improvement

Second Preliminary Report

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Executive Summary

The Carenet Project intends to provide an overall picture of CCI members community, giving visibility to the actions of CCI members around the world. One of the main actions that we have been carrying out until the present moment encompasses a scoping review of literature reviews with the aim of mapping the research describing psychosocial interventions in childhood oncology contexts. As such, the following tasks regarding the 1st Part of the Literature Review, which are further described in this report, have been developed: i) Development and definition of a literature search strategy; ii) Development of the eligibility criteria of the articles; iii) Screening and study selection; iv) Data extraction from the articles; v) Writing of the article. A total of 5 literature reviews were included, which comprehend 116 primary articles regarding psychosocial interventions in the childhood oncologic disease context. We are now in the process of reviewing the article for journal submission. The 2nd Part of the Literature Review encompasses the gathering and analysis of CCI documents. About this action, the following tasks have been completed: i) Preparation of the document analysis grid; ii) Gathering of documentation online through the CCI partners' websites. The next steps are i) the gathering of documentation through specific requests via e-mail and ii) the subsequent document analysis. The next immediate planned action of the project concerns the focus groups preparation, which is included in the stage of the methodological development of The Carenet Project. Specifically, we will i) develop a script for the focus groups, ii) train the interviewer(s), (iii) define the structure of the groups (number of focus groups to be carried out, number of participants *per* group, languages in which the focus groups will be carried out) and iv) carry out the fieldwork (focus groups implementation).

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1. Introduction

Every year, more than 400 000 children and adolescents below 20 are diagnosed with cancer. Under these circumstances, the rate of survival varies between 80% in most high-income countries, and 20% in low-and middle-income countries (https://www.childhoodcancerinternational.org). At the present time, cancer is the leading non-communicable cause of childhood deaths in high- and middle-income countries.

The consequences of the oncologic disease are enormous for children and adolescents, who have to endure such a debilitating disease at an early age. However, this health condition is also a burden for the survivors: 62.3% suffer from at least one chronic health condition, 29% reported moderate to severe pain, 27.5% have a severe or life-threatening condition, and 95% will have a significant health-related issue by the time they are 45 years of age (Oeffinger et al., 2006; Hudson et al., 2013; Karlson et al., 2020). The families, and in particular the primary caregivers (which are often the parents), are also immensely affected by this disease, namely through its psychosocial consequences, which we will further elaborate on.

Childhood Cancer International (CCI), as an umbrella organization of childhood cancer grassroots and national parent organizations, is the largest patient support organization for childhood cancer, building and enhancing the capacity of parent organizations. As such, CCI felt the need to develop a global diagnostic study with the purpose of listening to the main stakeholders of the CCI - key actors in each of the countries. To this end, the CCI Carenet Project aims to provide an accurate picture of the actions of the member organizations at a global level, identifying good practices that can serve as standards for all associates and identify priority intervention areas that can guide the design of new projects. Such project is currently being undertaken by the Iscte research team.

By conducting a scoping review of literature reviews, we summarize and critically analyze the current state-of-the art of psychosocial interventions in childhood cancer aimed at patients, survivors and their families and informal caregivers.

We chose to perform a scoping review of literature review of reviews partially due to the existence of a vast literature on psychosocial interventions concerning childhood cancer. As such, this was the most practical and encompassing way of collecting a great amount of information on the topic, having into consideration the quantity of articles included.

According to the WHO (2020), psychosocial interventions can be defined as "interpersonal or informational activities, techniques, or strategies that target biological, behavioral, cognitive, emotional, interpersonal, social, or environmental factors with the aim of improving health functioning and well-being" (England, Butler & Gonzalez, 2015). Psychosocial interventions use a psychological, behavioral or social approach, or a combination of these, to improve psychosocial well-being and reduce the risk of poor mental health outcomes (England, Butler & Gonzalez, 2015). Such interventions include programs targeting children/adolescents individually or in groups, or their caregivers and families. Interventions could be centered in the school, community (including in humanitarian contexts such as refugee camps), health center or home. They could also be online, digital or combinations of all the above. A range of individuals such as teachers, health and non-health professionals, community workers, lay workers and peers can deliver the interventions. This is the definition that we had in mind while writing this report and that we will consider throughout the development of the CCI Carenet Project. In our scoping review, we map the literature describing psychosocial interventions approaches in the childhood oncologic disease context, specifically aiming children with cancer, their families and childhood cancer survivors.

2. Methods

This study is a scoping review of literature reviews. Scoping studies are a popular approach for the review of health research evidence, being particularly useful when one intends to clarify a complex concept and refine subsequent research inquiries (Davis, Drey & Gould, 2009). Additionally, scoping reviews are used to examine a broad topic, mapping in a systematic and comprehensive way the published literature. Even though scoping reviews don't require an assessment of study's quality, it is considered a rigorous and methodological approach, analyzing the research activity regarding a specific field.

For this scoping review of reviews, we considered the most recent guidelines of the Joanna Briggs Institute (JBI) approach for scoping reviews (Santos, Secoli & Püschel, 2018), which were built upon previous guidelines of Arksey and O'Malley's (Arksey and O'Malley, 2005) and Levac et al.'s (Levac et al., 2010), which we now briefly explain. The PCC (Population

(or participants)/Concept/Context) framework is recommended by the JBI to identify the main concepts in the primary review questions. This framework then informs the succeeding search strategy. Breaking down the research question in this way allows the researcher to check for any potentially missed inclusion and exclusion criteria for the review protocol (Santos, Secoli & Püschel, 2018).

Arksey & O'Malley (2005) methodological Framework for scoping reviews encompasses five distinct stages, namely: (1) Identifying the research question; (2) Identifying relevant studies; (3) Study selection; (4) Charting the data; and (5) Collating, summarizing, and reporting the results. This analysis allows the identification of gaps in the evidence base and therefore the synthesis and dissemination of the research findings. Having the results presented in a comprehensible and user-friendly format, policy makers, practitioners and consumers are better able to make efficient use of the findings (Arksey & Lisa O'Malley, 2005).

Levac et al (2010) include the following recommendations for clarifying and enhance the scoping review methodology: clarifying and linking the purpose and research question; balancing feasibility with breadth and comprehensiveness of the scoping process; using an iterative team approach to selecting studies and extracting data; incorporating a numerical summary and qualitative thematic analysis; identifying the implications of the study findings for policy, practice, or research; and adopting consultation as a required com- ponent of scoping study methodology.

2.1. Search strategy

We developed a search strategy to frame the idea of interventions in the childhood oncologic disease context. The following electronic databases were used: PubMed, APA PsycInfo, Sage Journals, Scopus, WebofScience (Table 1). Our goal was to identify interventions targeting children with cancer, their families and childhood cancer survivors. The results of the search were retrieved and then the duplicates were identified and removed. Afterwards, a first screening of the articles took place, which was done through the assessment of title and abstract. The complete search strategy can be found in Appendix A.

Table 1

Key search strategy concepts.

Concept	Search String	Database
Psychosocial interventions	(Psychosocial interventions OR Health Promotion Interventions OR Psychosocial Support OR Supportive Care OR Non-pharmacological Interventions OR Psychological Interventions OR Psychoeducation)	PubMed, Apa PsycInfo, Sage Journals, Scopus, WebofScience
Childhood Cancer	AND (Childhood Cancer OR Pediatric Cancer OR Childhood Oncologic Disease OR Pediatric Oncologic Disease)	
Family	AND (Primary Caregivers OR Parents OR Siblings OR Families OR Children)	
Survivors	AND (Childhood Cancer Survivors OR Childhood Cancer Survivorship OR Oncology Cancer Survivors OR Oncology Cancer Survivorship OR Pediatric Cancer Survivors OR Pediatric Oncology Survivors)	
Type of Review	Meta-analysis OR meta-synthesis OR scoping review OR scoping study OR rapid review OR critical review	

2.2. Eligibility criteria

The inclusion and exclusion criteria for the scoping review of reviews are listed in Table 2. We considered that a period of one decade would be broad enough to include the most recent advances in the area, but at the same time, not too narrow, preventing important literature from being excluded. As such, we decided to analyze the last ten years of childhood cancer psychosocial intervention literature to gain a broad enough understanding of recent advances.

Table 2

Eligibility for inclusion.

Inclusion criteria	Exclusion criteria
Human subjects in any country. Published in English Date range 2012 – 2022 Research targeting children with cancer, their families and childhood cancer survivors. Methods describe a systematic review, meta-analysis, meta-synthesis, integrative analysis, rapid review, or a systematic approach to data collection. The articles must reflect psychosocial interventions.	Interventions that, although may be included in the childhood oncologic disease context, are not aimed at children with cancer, their families and/or at childhood cancer survivors. Articles that didn't report a rigorous methodology (e.g., book reviews, opinion articles, commentaries or editorial reviews). Research focusing on theories or concepts that support policy development, but do not report psychosocial outcomes regarding psychosocial interventions. Research that is focused on study design (e.g., methodology or protocol papers).

2.3. Screening and study selection

The studies included in the review were selected through a screening process with two stages. Firstly, the titles and abstracts were assessed by two independent reviewers in order to determine suitability for inclusion. Whenever uncertain, the articles were retained for additional analysis and the final decision was reached by

consensus. Then, the second stage consisted in the full-text analysis of the remaining articles to determine their eligibility, which was also done independently by two reviewers. To resolve discrepancies, besides the existing discussion among the research team, the interjudge agreement was calculated, assuring the rigor of the process. The interjudge agreement, that was calculated having into consideration that two independent reviewers analyzed the articles, has a % of agreement of 96.88% (Cohen's k: 0.91), which means an almost perfect agreement. As such, it is considered that the mentioned methodology was followed with rigor and that the quality of the process of the screening and selection of articles was ensured.

2.4. Data extraction

Data was extracted from the review papers included in the scoping review by two independent reviewers using a data extraction tool developed by our research team. The involvement of at least two reviewers in the process of data extraction reduces the chance of errors and bias, thus ensuring its rigor (Peters et al., 2020). In order to define the extraction method, the PRISMA guidelines were followed and then some specific dimensions were added so that we could properly meet the review question specifications. The extracted data includes specific details about the participants, concept, context, study methods and key findings relevant to the review question, particularly to map the literature describing psychosocial interventions approaches in the childhood oncologic disease context, aiming specifically children with cancer, their families and childhood cancer survivors. Being psychosocial interventions "interpersonal or informational activities, techniques, or strategies that target biological, behavioral, cognitive, emotional, interpersonal, social, or environmental factors with the aim of improving health functioning and well-being" (England, Butler & Gonzalez, 2015), the specific goals of the interventions were mentioned and detailed. Other important addition to the data extraction form entails the suggested guidelines of the review authors for future Interventions aimed at children with oncologic disease, their families and/or childhood cancer survivors. Additionally, the TIDieR checklist (Hoffmann et al., 2014) was also considered – some criteria were added (Why; When and how much; and Tailoring).

As such, the extracted data comprised the succeeding elements:

1. Review identifiers (authors, year of publication, place of publication, language of the article, and periodical – simplified by the use of the bibliographic reference);
2. Type of review – review type and number of studies in the review;
3. Review aim or goal – specifying what the review intends to achieve;
4. Inclusion/ exclusion criteria for the inclusion of the interventions in the reviews;
5. Setting and population (physical or geographical location of the intervention, age groups or ethnicities of the population; specifying if the interventions are intended for children with cancer, their families and/or pediatric oncologic disease survivors);
6. Outcome variables – what are the expected results of the interventions.
7. Determinant variables – biological, behavioral, cognitive, emotional, interpersonal, social, or environmental (it is expected, since we are approaching psychosocial interventions, that few or any biological determinants will be identified). Also, determinant variables might comprise an inclusion criteria of the identified reviews, otherwise that information might not be available in the studies and, if so, we might not be able to retrieve it.
8. Mechanisms of change - considering the different levels of analysis of the socio-ecological model.
9. Description of the goal of the interventions (and the psychosocial concern(s) addressed by the interventions);
10. Why – description of the rationale, theory or goal of the elements essential to the intervention(s) with children with cancer, families or childhood cancer survivors;
11. Structure and methods of the interventions (tools, scales, or surveys used to assess changes regarding psychosocial concerns about the target population);
12. When and how much – description of the number of times that the interventions were delivered and over what period of time (for example: number of sessions, schedule, duration, intensity and/or dose);
13. Tailoring – if the interventions intended to be personalized or adapted it should be specified how, what, why and when;
14. Results or key findings relevant to the review question. In this study we consider that results are the response to the review question, meaning that what we are referring

to as results are the answers to the main research questions or the effects of the interventions;

15. Limitations and biases of the reviews appointed by the authors;
16. Suggested guidelines by the authors of the reviews for future Interventions aimed at children with oncologic disease, their families and/or childhood cancer survivors.

The data extraction form is provided (and it can be consulted in Appendix B), along with the extracted information itself. It is worth observing that the scoping review methodology is a broad one and so is our research question. Therefore, the data extraction tool was modified and revised as necessary during the process of extracting data from each included evidence source. One significant modification in the scoping review concerns the fact that not all criteria from the TIDieR checklist (Hoffmann et al., 2014) were considered. In order to make that decision, we tried to apply all of the criteria to the two most recent articles included in our scoping review and we then realized that not all could be answered solely through the consultation of the reviews. As such, we decided to apply only the criteria that could be answered with the information comprised in the reviews and not in the primary sources. That decision was made considering the fact that scoping reviews of reviews don't intend to consult original articles, but should be limited to reviews. Any disagreements that arose between the researchers were resolved through discussion, or with an additional researcher(s). Indeed, data extraction in scoping reviews often is an iterative process, usually entailing several enhancements to be able to best meet the objectives and research question(s) of the scoping review (Peters et al., 2020).

3. Results

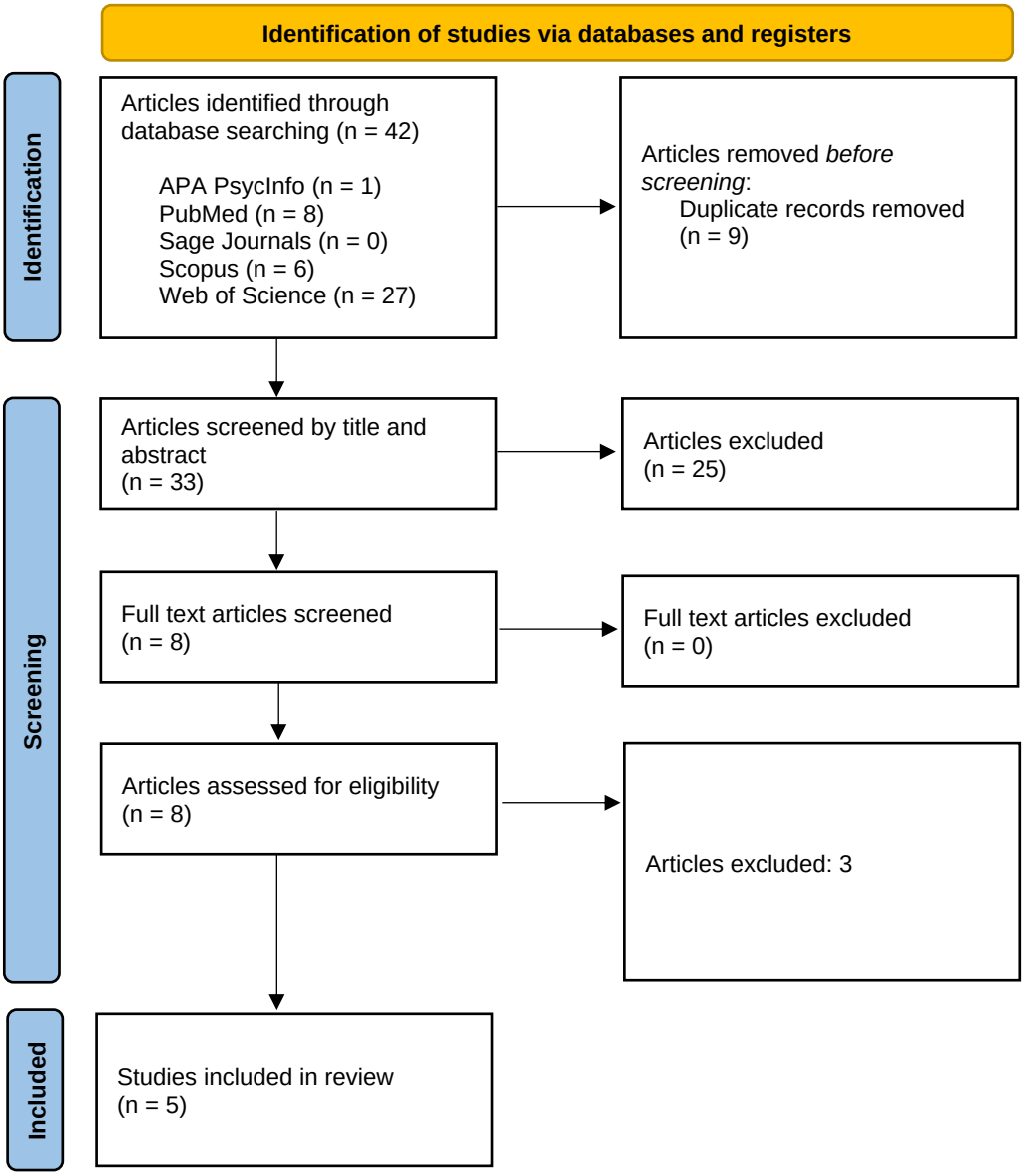

Fig. 1. PRISMA flow diagram describing the results of the literature search and study selection.

Table 3

Overview of the included studies - Interventions for children with cancer, their families and childhood cancer survivors.

Title of the Articles	Review/ Interventions aims	Target Population	Results	Relevant Key Findings
Complex behavioral interventions targeting physical activity and dietary behaviors in pediatric oncology: A scoping review (Demers et al., 2021).	To review complex behavioral interventions (CBI) targeting physical activity and/or dietary behaviors in pediatric oncology.	Children with cancer and childhood cancer survivors	14 studies included	The interventions typically focused on PA, had a short duration (<6 months) and were conducted during the survivorship phase. There is preliminary evidence that CBI are feasible and potentially beneficial for children with cancer and survivors to improve their health behaviors and outcomes. Addressing parenting practices and offering psychosocial support or training to families may be beneficial for both parents and children with cancer.
School and educational support programmes for paediatric oncology patients and survivors: A systematic review of evidence and recommendations for future research and practice (Burns et al., 2021).	To identify peer-reviewed education support programs and compared them against the PSSC education standards.	Children with cancer and childhood cancer survivors	24 peer-reviewed articles included	Three school re-entry programs met all evaluation criteria, and their components were timed according to the child's position on the cancer trajectory (e.g., diagnosis and treatment, school re-entry, and follow up throughout schooling). These interventions appear to enhance students' education experiences and improve outcomes, which provides a promising structure for future education support programs.
Non-pharmacological interventions for pediatric cancer patients: A comparative review and	To summarize the evidence-based psychological interventions in childhood cancer	Children with cancer	28 intervention studies on children with cancer were	The benefit of intervention has been mostly seen in anxiety and distress. Aspects of behavior (internalizing, social competence) and trauma have also been shown to improve significantly. Neurocognitive benefits have been reported for variables like attention, memory, intelligence,

emerging needs in India (Satapathy et al., 2018).	and address the gap between intervention studies worldwide and India.		included (one from India)	vigilance and learning with cognitive remediation programs.
Psychosocial interventions for rehabilitation and reintegration into daily life of pediatric cancer survivors and their families: A systematic review (Peikert et al., 2018).	To provide an overview of psychosocial interventions for childhood cancer survivors and their families in the first years after the end of cancer treatment.	Childhood Cancer Survivors and their families	33 articles included	Most of the studies reported a significant psychosocial benefit of the interventions. Overall, the investigated interventions helped families to improve their mental well-being and enhance social skills.
Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: current state of the literature (Brinkman et al., 2018).	To review empirically supported interventions for psychological symptoms, for social functioning and for risky health behaviors in survivors of childhood cancer.	Childhood Cancer Survivors	17 articles included	This review states that many interventions suggest potential efficacy and should begin to be incorporated and disseminated as part of standard clinical care.

3.1. Description of the main key findings

In this scoping review of literature reviews, we map the literature describing psychosocial interventions in childhood oncologic disease contexts, specifically aiming at children with cancer, their families and informal caregivers and childhood cancer survivors.

As described in the PRISMA flow diagram (Figure 1), a total number of 5 literature reviews were included. These 5 articles encompass a total of 116 primary articles regarding psychosocial interventions in the childhood oncologic disease context. We start by exploring each review article and their particularities individually, stating the aims and the types of interventions approached. For clarification, we also provide further definitions of the distinct interventions that were carried out. Afterwards, a general discussion is presented. Ultimately, we proceed with presenting suggested guidelines for future psychosocial interventions and research with the mentioned population and primary conclusions. In table 3 we provide an overview of the included studies. A more detailed analysis can be found in Appendix B.

Demers et al. (2021), in their scoping review regarding the use and effects of complex behavioral interventions (CBI) targeting physical activity and/or dietary behaviors in pediatric oncology, emphasize how CBI can potentially make a positive impact on children with cancer, childhood cancer survivors, their families, and the health care system, improving health behaviors and patient outcomes such as physical and psychological health. The authors also mention that there is a lack of studies in the area, particularly for younger children and patients still undergoing cancer treatment. They suggest that future research is vital in identifying and defining the most efficient methods to implement CBI. In this review were included fourteen quantitative studies which, overall, demonstrated that it is feasible to implement CBI. Nonetheless, due to a paucity of studies and the heterogeneity of the studies included in the review, it was not possible to identify conclusive evidence favoring specific interventions.

A systematic review of evidence and recommendations for future research and practice, by Burns et al. (2021), approaches school and educational support programs for pediatric oncology patients and survivors. The authors identified 20 education support programs in pediatric oncology, including peer programs (n = 3), teacher programs (n = 5), and school re-entry programs (SRPs n = 12). Of these, only 3 met with the evaluation criteria as specified by the PSSC (Psychosocial Standards of Care) education standards. Regarding the limitations, Burns et al. (2021) point that there is a lack of theoretical underpinnings and

negligible evidence of programs' effectiveness. As such, they also compiled a set of recommendations for clinical practice and research, namely: 1) Ensure education support services are available to all cancer patients; 2) Provide details about program content, timing, and materials to enhance implementation; 3) Ground programs in appropriate theory and modelled outcomes and utilize rigorous methods of evaluation; 4) Adapt programs to local contexts to support implementation.

Satapathy et al. (2018) undertook a Comparative Review concerning non-pharmacological interventions for pediatric cancer patients, approaching the emerging needs in India. As such, 28 intervention studies on children with cancer were included (one study from India): 18 were conducted on children under treatment, 7 on survivors, 2 on off-treatment patients and 1 on mixed sample. There were distinct types of interventions: psychosocial (7), physical (7), cognitive behavioural (4), cognitive (3), music-art therapy and play therapy (4), mindfulness mediation (1), digital storytelling (1) and mixed physical and psychosocial intervention (1). Regarding the therapeutic outcomes, the authors reported that there were benefits mostly in anxiety and distress. Furthermore, they also reported significant improvements in some aspects of behavior (internalizing, social competence) and trauma. The authors also mentioned that some of the challenges that the research in pediatric psycho-oncology in India faces are related with the affordability of care, provision of adequate health personnel and environmental and sociocultural barriers to cancer control.

Peikert et al. (2018), in their systematic review concerning psychosocial interventions for rehabilitation and reintegration into daily life of pediatric cancer survivors and their families, aimed to provide an overview of psychosocial interventions for childhood cancer survivors diagnosed before the age of 21 and their family members in the first years after the end of acute cancer treatment. The authors included 33 articles in the qualitative synthesis: 15 studies described interventions for the cancer survivor; 9 studies regarding interventions for the whole family; 2 studies interventions for siblings. The interventions mainly take place in an outpatient group setting (n = 15). They mentioned that most of the studies reported a significant psychosocial benefit of the interventions; nevertheless, the quality of the included studies was limited. There were diverse aims of the interventions in the studies: reduction of psychological burden (n = 9); reduction of physical and psychological burden (n = 9); improvement of social skills (n = 8); increase of social support (n = 6); psychoeducation (n = 2). Peikert et al. (2018) also stated that social support appears to be a protective factor in

siblings of childhood cancer patients, meaning that psychosocial interventions focusing on social support could prevent long-term negative psychosocial consequences. As such, they recommend psychosocial support for the family as a whole.

Brinkman et al. (2018) reviewed the literature concerning psychosocial outcomes for survivors of childhood cancer, emphasizing the risk factors for adverse outcomes and highlighting potentially efficacious interventions to improve psychosocial outcomes for survivors. The authors reviewed empirically supported interventions for psychological symptoms in survivors of childhood cancer (N=4); empirically supported interventions for social functioning in survivors of childhood cancer (N=4); and empirically supported interventions for risky health behaviors among survivors of childhood cancer (N=9). It is worth noting that the authors refer that although most intervention efforts to date have been small, many suggest potential efficacy and should begin to be incorporated and disseminated as part of standard clinical care. They also mention that an important area of future research centers on the identification of potential genetic predispositions related to psychosocial outcomes among survivors of childhood cancer.

3.2. Aims, Types and Definitions of the Interventions

Demers et al. (2021) reviewed complex behavioral interventions (CBI) targeting physical activity and/or dietary behaviors in pediatric oncology. Studies could also include other health behaviors such as smoking, alcohol consumption, sun protection, health accountability, and self-examination. The included studies in this review evaluated a combination of modalities including educational interventions, individualized or group PA interventions, counseling, psychosocial support or training, reward system (i.e., healthy goods and services), and adventure-based activities. Programs included between two and three different modalities. Five studies were conducted in a hospital or clinic, four were delivered using various technologies (i.e., emails, text messages, online platforms) or telephone, two were home-based, and three were community based.

Complex Behavioral Interventions (CBI) are defined as broad interventions that are built from several interacting components, using multiple modalities to change one or more health behaviors. As such, a complex behavioral intervention will comprise a minimum of two different modalities (education, face-to-face intervention, self-management tools, among

others), propelling the modification of actions that individuals take regarding their health (Craig et al., 2008; Cutler, 2004; Demers et al., 2021).

Burns et al. (2021) identified peer-reviewed education support programs and compared them against the PSSC education standards. Their systematic review included 24 peer-reviewed articles, reporting on 20 education support programs, which consisted of 3 peer programs, 5 teacher programs, and 12 SRPs (school re-entry programs).

Education support programs were developed to address the needs to deliver education support for childhood cancer patients and survivors. Psychosocial Standards of Care (PSSC) for pediatric oncology details standards that relate specifically to education support. It postulates that all children should have continuous access to their education throughout treatment, and that all should have access to school re- entry support in the form of timely information provision to the child's school about the implications of diagnosis and treatment on education. The PSSC also recommends continued monitoring of neurocognitive late effects and yearly screening for adverse academic progress, for survivors of childhood cancer (Wiener et al., 2015; Burns et al., 2021)

Satapathy et al. (2018), in their review, intended to summarize the evidence-based psychological interventions in childhood cancer. There were various types of interventions: psychosocial, physical, cognitive behavioral, cognitive, music art therapy and play therapy. Generally, intervention settings were either hospital or home, and were designed to promote psychological well-being. The main outcome measure of interest was a change in the mental health profile of children with cancer (e.g. quality of life, behavior, sleep, fatigue, anxiety, depression, attention, academic achievement, resilience, distress etc.).

Psychological interventions cover a broad spectrum of behavioral and psychological problem areas, and can be classified as either coping-oriented or psychotherapeutic (i.e. mental health interventions) (Hendrieckx et al., 2021). As such, psycho-oncological interventions encompass a broad spectrum, and may include psychopharmacological treatments, relaxation and music-therapy and psychotherapy (de Vries & Stiefel, 2013). Satapathy et al. (2018) focused mainly on psychosocial, physical, cognitive behavioral, cognitive, music-art therapy and play therapy. Moreover, they also approached mindfulness mediation, digital storytelling and a mixed physical and psychosocial intervention (Satapathy et al., 2018). Cognitive Behavioral Interventions intend to reduce psychological distress and enhance adaptive coping by modifying maladaptive thoughts and behaviors, by raising

awareness of emotional states and their connection with thoughts and behaviors, and by providing new skills (Hollon and Beck, 2004). Bishop et al. (2004) propose a operational definition for mindfulness and state that it can be conceptualized as a clinical approach to foster an alternative method for responding to one's stress and emotional distress. By becoming more aware of thoughts and feelings, relating to them in a wider, decentered field of awareness, and purposefully opening fully to one's experience, clients can abandon dysfunctional change agendas and adopt more adaptive strategies.

Peikert et al. (2018) aimed to provide an overview of psychosocial interventions for childhood cancer survivors and their families in the first years after the end of cancer treatment. The studies cover a wide range of different intervention settings: 15 studies describe interventions in an outpatient group setting; Four different cancer camps were evaluated in the included studies; Five studies evaluated a family-oriented rehabilitation program; Three studies evaluated computer-based interventions; Four studies described outpatient individual interventions; One study assessed psychosocial outcomes in participants of a home-based intervention. The primary aims of the interventions also vary across the studies: Reduction of psychological burden (n = 9), reduction of physical and psychological burden (n = 9), improvement of social skills (n = 8), increase of social support (n = 6), and psychoeducation (n = 2).

Brinkman et al. (2018) reviewed empirically supported interventions for psychological symptoms in survivors of childhood cancer (N=4) (CBT, family therapy, coping skills training, internet-based individual CBT); empirically supported interventions for social functioning in survivors of childhood cancer (N=4) (peer-mediated group training, group social skills training); and empirically supported interventions for risky health behaviors among survivors of childhood cancer (N=9) (survivorship peer counseling, tailored and targeted written educational materials and free nicotine replacement therapy; Web-based intervention or print materials condition that included the provision of self-help materials; enhanced care/decision aid intervention psychoeducational modules, an educational CD-ROM, tailored substance use risk behavior counseling delivered by nurse practitioners and telephone boosters; multicomponent risk counseling intervention; 12-week Facebook-based intervention (FITNET) or a 12-week Facebook-based self-help condition; integrated adventure-based training and health education program; health behavior change intervention designed to increase sun safety practices).

3.3. Guidelines Suggestions for Future Psychosocial Interventions and Research

Demers et al. (2021) listed the following suggestions regarding complex behavioral interventions targeting physical activity and dietary behaviors in children with cancer and cancer survivors:

- Important elements that should be included or considered are self-efficacy, psychological variables and cognitive deficits.
- To enlist the support of parents or friends to provide additional social support to the CCS.
- To use targeted, individualized programs and age-appropriate approaches.
- The use of technology offers a feasible, relatively low-cost alternative to more in-person intensive interventions in this at-risk but sparse population because it can be distributed across time and geography. Nonetheless, personal contact also appeared to help compliance with protocol and follow-up. An online intervention is feasible and acceptable among young CCS.
- It may not be feasible to implement interventions during early treatment owing to the child's responses to the disease and treatment. For survivors, it was found that trying to recruit after treatment was difficult as families are often trying to forget their cancer and hospital experiences and, similarly, too long after (e.g., more than 3 years) was also difficult as families are likely to have created a new normal.

Demers et al. (2021) also mentioned that future research is vital in identifying and defining the most efficient methods to implement CBI. Specifically regarding the gaps that should be addressed in future studies, these authors mentioned that, in their review, no studies included families of children younger than 3 years of age or focused specifically on children with central nervous system or solid tumors. They also mentioned that intervening during early childhood is an opportunity to improve lifelong health outcomes since it is known that healthy behaviors such as a healthy diet established during childhood continue into adulthood. Finally, they also reported that data on race or ethnicity and socio-economic status were also not available for most studies, which could help identify and address health disparities.

Burns et al. (2021) compiled a set of recommendations for clinical practice and research regarding education support programmes for children with cancer, namely:

- Ensure education support services are available to all cancer patients.
- Provide details about programme content, timing, and materials to enhance implementation.
- Ground programmes in appropriate theory and modelled outcomes and utilize rigorous methods of evaluation.
- Adapt programmes to local contexts to support implementation.

For future non-pharmacological interventions for pediatric cancer patients, Satapathy et al. (2018) suggest the following:

- Researchers can focus on developing and testing culturally sensitive intervention modules for children with cancer that use feasible, cost-effective modes of delivery.
- Researchers may focus on developing problem-focused techniques for children with cancer in different phases of cancer trajectory.
- Studies should also report long-term follow up of the participants in intervention, due that childhood cancer is not only associated with apparent psychological symptoms during treatment but present themselves during post treatment in the form of neurocognitive deficits and trauma.
- Improvement of interventions for neurocognitive problems, combining them with treatments that target emotional and socio-behavioral components of functioning.

Regarding the implications for research and clinical practice concerning psychosocial interventions for childhood cancer survivors and their families in the first years after the end of cancer treatment., Peikert et al. (2018) leave the following suggestions:

- More high-quality studies investigating the efficacy of psychosocial interventions for childhood cancer survivors and their family members are necessary;
- More high quality randomized controlled trials should be conducted;
- Future studies should counteract the low reporting quality by following reporting guidelines

- Siblings and the family as a whole should be addressed in psychosocial interventions after the successful treatment of the patient
- Once the investigated interventions helped families to improve their mental well-being and enhance social skills, these results can be used to optimize health care services that help families with the re-entry into daily life
- Overall, more high quality studies are necessary to validate previous findings and to develop future comprehensive interventions.

Brinkman et al. (2018) compiled the following Psychosocial Standards of Care for Survivors of Childhood Cancer:

- Routine and systematic assessment of psychosocial needs
- Monitoring of neuropsychological deficits in survivors of brain tumor and other high-risk groups
- Annual psychosocial screening of long-term survivors for educational/vocational progress; social relationships; anxiety, depression, and distress symptoms; and risky health behaviors
- Access to psychosocial support and interventions
- Assessment of financial hardship with targeted referrals
- Education and anticipatory guidance related to late effects provided throughout the trajectory of cancer care
- Opportunities for social interaction
- School-reentry support that includes provision of information and recommendations to school personnel
- Open, respectful communication and collaboration among families and providers

4. Discussion

Although only 5 articles were included in this literature review of reviews, it is worth noting that we could encompass a broad spectrum of research, with a total number of 116 primary articles regarding psychosocial interventions in the childhood oncologic disease context. As such, these 5 literature reviews, although distinct in methodology and goals, also have some converging points, which we will following discuss.

Demers et al. (2021), in their scoping review, approached the use and effects of complex behavioral interventions (CBI) targeting physical activity and/or dietary behaviors in pediatric oncology. Burns et al. (2021), in a systematic review, identified education support programs in pediatric oncology patients and survivors. Satapathy et al. (2018) undertook a Comparative Review regarding non-pharmacological interventions for pediatric cancer patients, approaching the emerging needs in India. Peikert et al. (2018) systematically reviewed psychosocial interventions for rehabilitation and reintegration into daily life of pediatric cancer survivors and their families. Brinkman et al. (2018) reviewed the literature concerning psychosocial outcomes for survivors of childhood cancer, highlighting potentially efficacious interventions to improve psychosocial outcomes for survivors.

As such, both Demers et al. (2021) and Burns et al. (2021) focused on children with cancer and cancer survivors. The involvement of families and their own outcomes was also often mentioned in multiple reviews. Regarding CBI targeting the adoption of a healthy diet and frequent PA, Demers et al. (2021) refer that parental involvement should be considered throughout the continuum of care and regardless of the survivors' age, since addressing parenting practices and offering psychosocial support or training to families may be beneficial for both parents and children with cancer. Similarly, Satapathy et al. (2018) recommend to review studies on impact of parental interventions on child's psychosocial and behavioral functioning or on pain management due to the adverse impact of parental stress on pediatric survivors' emotional and somatic distress. Likewise, Burns et al. (2021) stated that their review was limited to programmes that predominantly reported outcomes for the child with cancer and their parents; however, they considered that siblings, peers, teachers, and healthcare professionals have distinct information and support needs in the process of delivering and advocating education support, which should be considered in future education support programmes. Interestingly, Peikert et al. (2018) focused not only on pediatric cancer survivors but also on their families, expressing that childhood cancer seems to be a family

challenge that goes far beyond cancer treatment. They also emphasized that social support seems to be a protective factor in siblings of childhood cancer patients and thus psychosocial interventions focusing on social support could prevent long-term negative psychosocial consequences (Peikert et al., 2018).

Satapathy et al. (2018) focused only on interventions for children with cancer and Brinkman et al. (2018) focused only on interventions for survivors of childhood cancer. Concerning psychosocial outcomes, Satapathy et al. (2018) mentioned that the psychosocial needs identification and analysis of intra-personal processes and interpersonal dynamics in adaptation have been overlooked, especially in India; as so, they consider that there are opportunities to further refine interventions for neurocognitive problems and to combine them with treatments that target emotional and socio-behavioral components of functioning. Similarly, and despite many pediatric oncology programs lacking the multidisciplinary teams necessary to implement the full set of standards, Brinkman et al. (2018) consider that psychosocial programming must be prioritized in pediatric oncology and survivorship settings as a means of promoting prosocial development and physical and mental health outcomes across the cancer continuum. Additionally, the incorporation of mental health and behavioral measures in established and new cohort studies will support research across a broader range of survivors and new cancer therapies and longitudinal studies will serve to enhance understanding of the time course of these outcomes as well as specific temporal causes Brinkman et al. (2018).

It was also possible to identify some particular needs. Satapathy et al. (2018) advocate that there is a need to develop and test culturally relevant intervention modules that use feasible, cost-effective modes of delivery. Brinkman et al. (2018) suggest that assessing psychiatric diagnoses and impairment because of psychological symptoms in outcomes research will significantly improve the understanding of survivors' mental health needs and help inform the development of intervention programs to meet those unique needs. An important area of future research centers on the identification of potential genetic predispositions related to psychosocial outcomes among survivors of childhood cancer (Brinkman et al., 2018).

There is a converging concern that arose in all of the reviews included in our study: methodological limitations. Demers et al. (2021) didn't identify conclusive evidence favoring specific interventions, although reporting preliminary evidence that CBI are feasible and

potentially beneficial for children with cancer and survivors to improve their health behaviors and outcomes. Burns et al (2021), likewise, pointed the limitation of lack of theoretical underpinnings and negligible evidence of programmes' effectiveness, identifying 20 education support programmes for children with cancer, but only 3 meeting their evaluation criteria. Additionally, Demers et al. (2021) mentioned that rigorous experimental methods should be applied to behavioral studies, and suggested that researchers could use the ORBIT model, which was developed to identify the most productive ways to implement durable behavioral studies. Satapathy et al. (2018) refer that it was not possible to make a definite recommendation on the most effective psychological intervention in pediatric cancer due to a lack of homogeneity in study design and intervention, which has limited the review to a qualitative analysis only. Although the variations in research designs and intervention outcomes provide insight into the wide range of techniques available, the limited number of studies employing each type of technique prevented further comprehensive analysis (Satapathy et al., 2018). Peikert et al. (2018) concluded that even though clinical efficacy could not be confirmed in all of their reviewed studies, for all settings at least some studies revealed a statistically significant benefit and therefore offer starting points for further research. Overall and similarly to the other reviews, the methodological quality of the included studies was poor (Peikert et al., 2018), being evident the necessity of more high-quality studies to validate prior findings. Also, due to the methodological heterogeneity of the studies, Peikert et al. (2018) could not conduct a quantitative synthesis of the study results.

5. Conclusion

A scoping review of reviews was carried out, in which we mapped the literature describing psychosocial interventions approaches in the childhood oncologic disease context, specifically aiming children with cancer, their families and childhood cancer survivors.

In order to ensure the rigor of the used methods, we had into consideration the Joanna Briggs Institute approach for systematic reviews (Santos, Secoli & Püschel, 2018), Arksey and O'Malley's scoping review methodology (Arksey and O'Malley, 2005) and also Levac et al.'s methodology advancement (Levac et al., 2010). Furthermore, a search strategy was developed to frame the idea of interventions in the childhood oncologic disease context. Then, the inclusion and exclusion criteria for the scoping review of reviews were listed and the studies were screened and selected. The interjudge agreement was calculated,

representing an almost perfect agreement. Then, we described the data extraction strategy that was developed and carried out.

Afterwards, we present the results of the scoping review of reviews, displaying the PRISMA diagram flow with the description of the results of the literature search and study selection, also presenting a table with an overview of the included studies regarding the interventions for children with cancer, their families and childhood cancer survivors. We then proceed to the description of the main key findings from the reviewed articles. After that, we state the aims and the types of interventions carried out in the reviews and further define the distinct interventions. Subsequently, we present guidelines suggestions for future psychosocial interventions and research.

Ultimately, there is preliminary evidence that CBI are feasible and potentially beneficial for children with cancer and survivors to improve their health behaviors and outcomes and that addressing parenting practices and offering psychosocial support or training to families may be beneficial for both parents and children with cancer. The school re-entry interventions appear to enhance students' education experiences and improve outcomes, providing a promising structure for future education support programs. The benefits of non-pharmacological interventions has been mostly seen in anxiety and distress. Regarding the rehabilitation and reintegration into daily life of childhood cancer survivors and their families, there was a significant psychosocial benefit of the interventions which, overall, helped families to improve their mental well-being and enhance social skills. Concerning interventions for psychological symptoms, social functioning and risky health behaviors, many interventions suggest potential efficacy and some authors suggest that they should be incorporated and disseminated as part of standard clinical care.

Overall, the existing literature on psychosocial interventions in the childhood cancer context reveals promising results on the improvement of psychosocial outcomes on children with cancer, survivors of childhood cancer, and their families. Despite this, more quality research is needed in order to confirm the interventions efficacy.

Appendix A. Search strategy

Search String	Database / N Articles	Other considerations
(((psychosocial interventions[Title/Abstract] OR Health promotion interventions[Title/Abstract] OR psychosocial support[Title/Abstract] OR supportive care[Title/Abstract] OR non-pharmacological interventions[Title/Abstract] OR psychological interventions[Title/Abstract] OR psychoeducation[Title/Abstract]) AND (childhood cancer[Title/Abstract] OR pediatric cancer[Title/Abstract] OR childhood oncologic disease[Title/Abstract] OR pediatric oncologic disease[Title/Abstract])) AND (primary caregivers[Title/Abstract] OR parents[Title/Abstract] OR sibling[Title/Abstract] OR families[Title/Abstract] OR children[Title/Abstract])) AND (childhood cancer survivors[Title/Abstract] OR childhood cancer survivorship[Title/Abstract] OR oncology cancer survivors[Title/Abstract] OR oncology cancer survivorship[Title/Abstract] OR pediatric cancer survivors[Title/Abstract] OR pediatric oncology survivors[Title/Abstract])	PubMed N = 8	Filters applied: Meta-Analysis, Review, Systematic Review, in the last 10 years, Humans, English. The Title/abstract was considered because the database didn't allow to consider only the abstract. Não foi possível obter acesso aos seguintes artigos: Weyl-Ben-Arush, M. (2017). The price of the successful treatment of pediatric malignancies. *Current Pediatric Reviews*, *13*(1), 4-7. Cahaney, C., Dhir, A., & Ghosh, T. (2022). Role of Precision Medicine in Pediatric Oncology. *Pediatric annals*, *51*(1), e8-e14.

AB (psychosocial interventions OR Health promotion interventions OR psychosocial support OR supportive care OR non-pharmacological interventions OR psychological interventions OR psychoeducation) AND AB (childhood cancer OR pediatric cancer OR childhood oncologic disease OR pediatric oncologic disease) AND AB (primary caregivers OR parents OR sibling OR families OR children) AND AB (childhood cancer survivors OR childhood cancer survivorship OR oncology cancer survivors OR oncology cancer survivorship OR pediatric cancer survivors OR pediatric oncology survivors) Ano de Publicação: 2012-2022; Idioma: English; Grupo Populacional: Human; Metodologia: LITERATURE REVIEW	Apa PsycInfo N = 1	Filter applied: Publication Years: 2012-2021 Idiom: English Populational group: Human Methodology: literature review
Abstract (psychosocial interventions OR Health promotion interventions OR psychosocial support OR supportive care OR non-pharmacological interventions OR psychological interventions OR psychoeducation) AND Abstract (childhood cancer OR pediatric cancer OR childhood oncologic disease OR pediatric oncologic disease) AND Abstract (primary caregivers OR parents OR sibling OR families OR children) AND Abstract (childhood cancer survivors OR childhood cancer survivorship OR oncology cancer survivors OR	Sage Journals N = 0	within review article, Since 2012

oncology cancer survivorship OR pediatric cancer survivors OR pediatric oncology survivors)		
ABS (*"psychosocial interventions"* OR *"Health promotion interventions"* OR *"psychosocial support"* OR *"supportive care"* OR *"non-pharmacological interventions"* OR *"psychological interventions"* OR *"psychoeducation"*) AND ABS (*"c hildhood cancer"* OR *"pediatric cancer"* OR *"childhood oncologic disease"* OR *"pediatric oncologic disease"*) AND ABS (*"primary caregivers"* OR *"parents"* OR *"sibling"* OR *"families "* OR *"children"*) AND ABS (*"childhood cancer survivors"* OR *"childhood cancer survivorship"* OR *"oncology cancer survivors"* OR *"oncology cancer survivorship"* OR *"pediatric cancer survivors"* OR *"pediatric oncology survivors"*) AND (LIMIT-TO (DOCTYPE , *"re"*)) AND (LIMIT-TO (PUBYEAR , *2022*) OR LIMIT-TO (PUBYEAR , *2021*) OR LIMIT-TO (PUBYEAR , *2020*) OR LIMIT-TO (PUBYEAR , *2019*) OR LIMIT-TO (PUBYEAR , *2018*) OR LIMIT-TO (PUBYEAR , *2017*) OR LIMIT-TO (PUBYEAR , *2016*) OR LIMIT-TO (PUBYEAR , *2015*) OR LIMIT-TO (PUBYEAR , *2014*) OR LIMIT-TO (PUBYEAR , *2013*) OR LIMIT-	Scopus N = 6	Language: English Doc Type: Review Não foi possível obter acesso ao(s) seguinte(s) artigo(s): Cahaney, C., Dhir, A., & Ghosh, T. (2022). Role of Precision Medicine in Pediatric Oncology. *Pediatric annals*, *51*(1), e8-e14.

TO (PUBYEAR , *2012*)) AND (LIMIT-TO (LANGUAGE , *"English"*))		
(((AB=(psychosocial interventions OR Health promotion interventions OR psychosocial support OR supportive care OR non-pharmacological interventions OR psychological interventions OR psychoeducation)) AND AB=(childhood cancer OR pediatric cancer OR childhood oncologic disease OR pediatric oncologic disease)) AND AB=(primary caregivers OR parents OR sibling OR families OR children)) AND AB=(childhood cancer survivors OR childhood cancer survivorship OR oncology cancer survivors OR oncology cancer survivorship OR pediatric cancer survivors OR pediatric oncology survivors)	Web of Science N = 27	Query link: https://www.webofscience.com/wos/woscc/summary/09531e9e-1885-49bd-83f0-25ac4c50df33-343ba305/relevance/1 Não foi possível obter acesso ao(s) seguinte(s) artigo(s): Weyl-Ben-Arush, M. (2017). The price of the successful treatment of pediatric malignancies. *Current Pediatric Reviews*, *13*(1), 4-7.

Appendix B

Interventions for children with cancer, their families and childhood cancer survivors.

Bibliographic Reference	Type of review	Review aim or goal	Inclusion / exclusion criteria of the review	Setting and population	Outcome variables	Determinant variables	Mechanisms of change	Description of the goal of the interventions	Why	Structure and methods of the interventions	When and how much	Tailoring	Results / relevant key findings	Limitations and biases of the reviews	Suggested guidelines for future Interventions
Demers, C., Brochu, A., Higgins, J., & Gélinas, I. (2021). Complex behavioral interventions targeting physical activity and dietary behaviors in pediatric oncology: A scoping review. *Pediatric Blood & Cancer*, *68*(8), e29090.	Scoping review	To report on the state of the evidence on the use and effects of complex behavioral interventions (CBI) targeting physical activity and/or dietary behaviors in pediatric oncology.	Studies were included for full-text review if they involved: (i) children with cancer or CCS who were diagnosed before the age of 21, (ii) CBI, and (iii) interventions targeting PA and/or dietary behaviors.	Studies included a total of 1000 participants, ranging from 1022 to 267 participants. The age of the participants ranged from 3 to 34 years old. Four studies targeted adolescents and/or young adults (11–34 years	Behavioral: PA (Physical Activity) was targeted in 13 studies and dietary behaviors in seven.	cancer and its treatment	complex behavioral interventions	The interventions included in this review were based on CBI (Complex behavioral Interventions) addressing PA (Physical activity) and/or dietary behavior in pediatric oncology.	For many cancer-related complications, behavioral modifications represent the primary method of risk modification available to children with cancer and survivors. To the authors' knowledge, no guidelines provide guid-ance on the	The studies evaluated a combination of modalities including educational interventions (n = 11), individualized or group PA interventions (n = 6), counseling (n = 5), psychosocial support or training (n = 6), reward system (i.e., healthy goods and ser-	The shortest intervention had a half-day duration, with the post-intervention assessment conducted 3 months following the intervention, whereas the longest proposed a 2.5-year program beginni	In Keats and Culos-Reed, 2008;Canada, "Individualized programming was essential for the overall success." Braam et al., 2018;Netherlands, stated that "targeted programs might be better than standard programs to increase the applicability, motivatio	14 studies were included in this scoping review. The interventions typically focused on PA alone or in combination with other health behaviors, the majority had a short duration (<6 months) and were conducted during the survivorship phase. CBI targeting the adoption of a healthy diet and frequent PA have huge potential to make a positive impact on children with cancer or CCS, their families, and the overburdened health care	This is a developing field of research, with the oldest article published in 1999 and with few studies using CBI to date. The high variability in intervention type and outcome measures across studies made comparison of results difficult. many of the included studies had small sample sizes and short follow-up duration. This review underlines the need for further well-designed trials using standardized outcome measures to be implemented in this population as well as addressing the gaps in the evidence base.	Supporting participants' self-efficacy. Psychological variables and cognitive deficits were deemed important to address. Positive social interactions and encouragement with the mentor was associated with greater adherence to healthy behaviors, therefore recommending to enlist the support of parents or friends to provide additional social support to the CCS. To use targeted, individualized programs and age-appropriate approaches. Researchers could use the ORBIT

				old), seven included children and adolescents (4–20 years old), and three were designed for the caregivers of younger children (3–13 years old). No studies included families of children younger than 3 years of age. In eight studies, the target of the interve					promotion of complex behavioral interventions (CBI) (i.e., the use of multiple modalities to change one or more health behaviors) in the pediatric oncology population.	vices) (n = 2), and adventure-based activities (n = 1). Programs included between two and three different modalities. Health behavior assessments included, but were not limited to, PA levels, dietary recalls, health behavior self-efficacy, and consumption of alcohol (Supplemental Table S2). The most frequent patient outcomes were physical fitness	ng after diagnosis and continuing through the end of treatment. Most interventions had a duration ranging between 6 and 12 weeks.	n, self-worth, and at the end the effects of the program". Moyer-Mileur et al., 2009;USA, refer "Individualization of exercise program recommended" Cox et al., 2018;USA, mention that "Different strategies for categories of patients may need to be considered" Berg et al., 2014;USA,	system. However, there is a lack of studies in this area, especially for younger children and patients still undergoing cancer treatment. No conclusive evidence favoring specific interventions were identified, although there is preliminary evidence that CBI are feasible and potentially beneficial for children with cancer and survivors to improve their health behaviors and outcomes. Addressing parenting practices and offering psychosocial support or training to families may be beneficial for both parents and children with cancer. Rigorous experimental methods should be applied to		model, which was developed to identify the most productive ways to implement durable behavioral studies. Monitoring devices such as accelerometers, pedometers, and heart rate monitors can be used to objectively measure PA and a measure of weight, BMI, or body composition change to evaluate the impact of change in behavior. Long-term follow-up may be needed to determine whether the downstream effects on the health outcome predicted by the change in behavior occurred or whether the short- term changes, such as the change in behavior, persisted. Collecting data over an extended period of time (e.g., more than

				ntions were the childre n with cancer or survivo rs thems elves, five studies were family oriente d, and one was design ed for parent s only. Partici pants in nine studies were survivo rs, where as the remain ing five studies recruit ed childre n underg oing treatm ent. Nine studies were						and quality of life (QOL).		mention that "Tailoring the messagin g specificall y for the needs of individual young adult cancer survivors would likely enhance message relevance and increase their engagem ent and satisfacti on with the content"; also "Using a commerc ial approach was a win-win situation for cancer survivors and business es". Huang et al., 2014;US	behavioral studies.		12 months after starting the intervention) would allow clinicians or researchers to evaluate the long-term effects and benefits of the interventions or program on outcomes such as QOL, which requires an extended period to respond to the intervention compared with other outcomes, for example levels of PA. According to the MRC Framework, process evaluation and qualitative research are essential to understanding the implementation of complex interventions and guide future efforts. Studies included in this review used outcome evaluation and quantitative data exclusively; underpinning the need for qualitative and mixed methods study in the field.

				conducted in the United States, two in Hong Kong, one in Canada, one in the Netherlands, and one in Taiwan. Five studies were conducted in a hospital or clinic, four were delivered using various technologies (i.e., emails, text messages, online platforms) or telephone, two								A, stated that "Tailored approach, as opposed to generic weight management intervention, may be helpful to youth who have survived leukemia".			

				were home-based, and three were community based.											
Burns, M. A., Fardell, J. E., Wakefield, C. E., Cohn, R. J., Marshall, G. M., Lum, A., ... & Lah, S. (2021). School and educational support programmes for paediatric oncology patients and survivors: A systematic review of evidence and recommendations for future research and practice. *Psycho-*	Systematic Review ("narrative literature overview with a systematic search according to Green et al.", with the intent of identifying peer-revi	The aims of this review are to (1) identify peer-reviewed education support programmes and compare them against the PSSC education standards, (2) summarize the structural features and limitations of the programmes that meet all PSSC education standards, and (3) provide practical recommendations for clinical practice	Inclusion criteria were: peer-reviewed articles, published in English, reporting on education support or school re- entry programmes for school aged cancer patients or survivors, parents, teachers, or peers. Exclusion criteria were: case studies, reviews, books, conferen	School-aged cancer patients and survivors. Also parents and teachers.	Not available	Not available	Psychosocial Standards of Care (PSSC) in paediatric oncology	Education support programes in alignment with the Psychosocial Standards of Care (PSSC).	The PSSC (Psychosocial Standards of Care) details standards that relate specifically to education support. It is unclear whether available education support programmes are meeting the PSSC standards. Providing support consistent with the PSSC education standards may be challengi	The main content is psychoeducation. Also: Initial consultation; Liaison communication; Classroom visits; Education planning; Ongoing consultation and advocacy; Tutoring.	Regarding the 3 programs that met all the criteria, they had an ongoing school liaison or had an ongoing multi-component.	Regarding the 3 programs that met all the criteria: Education planning; Ongoing consultation and advocacy; Parent and patient counselling.	This review included 24 peer-reviewed articles, reporting on 20 education support programmes in paediatric oncology, including peer programmes (n = 3), teacher programmes (n = 5), and school re-entry programmes (SRPs n = 12). Of the 20 education support programmes for children with cancer that were identified, only 3 met the evaluation criteria as specified by the PSSC education standards.	The analysis of peer-reviewed papers reporting on these programmes revealed major shortcomings., namely the lack of theoretical underpinnings and the negligible evidence of programmes' effectiveness.	Recommendation 1: Ensure education support services are available to all cancer patients Recommendation 2: Provide details about programme content, timing, and materials to enhance implementation Recommendation 3: Ground programmes in appropriate theory and modelled outcomes and utilise rigorous methods of evaluation: "Researchers may consider utilising existing theoretical models, such as the Eco-Triadic Model of Education Consultation for Children with Cancer (Eco-

Oncology, *30*(4), 431-443.	ewed programmes)	and future research.	ce abstracts, conference proceedings, and doctoral theses.						ng without explicit implementation guidance.						Triadic Model),58 or developing novel theory based on a social-ecological framework (SEF) to guide the development of their program." "Both outcomes and instruments must align with the programmes aims and be grounded in relevant theory, with preliminary research high-lighting the importance of psychological and academic outcomes." "research must employ rigorous research methodology when evaluating programme effectiveness." Recommendation 4: Adapt programmes to local contexts to support implementation
Satapathy, S., Kaushal, T., Bakhshi, S., & Chadda, R. K.	Comparative review	This review aims to summarize the evidence-based psychological	Inclusion: Studies published in peer-reviewed English language	pediatric cancer population intervention setting	Change in the mental health profil	Not available	Various types of key interventions were psychosocial, physical,	Various types of key interventions were psychosocial (7), physical	To address the wide gap that exists between intervention	Overall, most of the studies reviewed here targeted improvin	The number of sessions ranged from a minim	Most of the studies utilized individualized program and	28 intervention studies on children with cancer were included in current analysis (one study from India)	The limitations of this review include lack of studies in languages other than English, and non-availability of more full text	Researchers in future can focus on developing culturally sensitive intervention module for children with cancer. They may

(2018). Non-pharmacological interventions for pediatric cancer patients: A comparative review and emerging needs in India. *Indian Pediatrics*, *55*(3), 225-232.		interventions in childhood cancer over the two decades and addresses the wide gap that existed between intervention studies worldwide and India	journals pertaining to psychological management of children with cancer. Primarily a psychological/non-pharmacological intervention or focused on the holistic care along with the treatment of childhood cancer, children below 18 years' age; studies done over the past 20 years only. Exclusion: not with adults or parents or siblings	s were either hospital or home	e of children with cancer (e.g. quality of life, behavior, sleep, fatigue, anxiety, depression, attention, academic achievement, resilience, distress etc.)		cognitive behavioral, cognitive, music art therapy and play therapy.	(7), cognitive behavioural (4), cognitive (3), music-art therapy and play therapy (4) and other three types of intervention.	studies worldwide and India, and to highlight the need for research and appropriate services.	g social-emotional functioning. Some of the studies have also utilized various physical techniques like aerobics, adapted physical activity, yoga, and enhanced physical exercise to manage psychological components like anxiety, sleep, cognitive fatigue and quality of life. Studies demonstrating social skills interventions have targeted following social skills in	um of two sessions to twice daily for 24 days (48 sessions). Roughly, it took 8 sessions to complete the recovery program. The vast range of sessions depended upon the nature of intervention.	individual sessions as compared to group intervention for its participants.	The benefit of intervention has been mostly seen in anxiety and distress. Aspects of behavior (internalizing, social competence) and trauma have also been shown to improve significantly. Neurocognitive benefits have been reported for variables like attention, memory, intelligence, vigilance and learning with cognitive remediation programs.	articles. Lack of homogeneity in study design and intervention has limited the review to a qualitative analysis only. While the variations in research designs and intervention outcomes provide insight into the wide range of techniques available, the limited number of studies employing each type of technique prevented further comprehensive analysis. Hence, a definite recommendation on the most effective psychological intervention in pediatric cancer cannot be made.	focus on developing problem-focused techniques for children with cancer in different phases of cancer trajectory. Further, studies should also report long- term follow up of the participants in intervention.

			of children with cancer; articles reporting importance of psychological management or models of management.							order to decrease isolation and improve friendships. in this review, cognitive interventions [16,24,25,29] primarily focused on targeted cognitive dsyfunctioning/ impairment. Another set of interventions included music and art therapy					
Peikert, M. L., Inhestern, L., & Bergelt, C. (2018). Psychosocial interventions for rehabilitation and reintegration into	Systematic review (following the PRISMA Checklist;	This study aims to provide an overview of psychosocial interventions for childhood cancer survivors and their families in the first	The inclusion criteria for study characteristics were: (1) Language English or German, (2) full text accessibl	childhood cancer survivors diagnosed under the age of 21, their family members or	Social, emotional, behavioral,	psychosocial interventions for childhood cancer survivors and/or their	15 studies describe interventions in an outpatient group setting. Four different cancer camps were evaluated in the	The interventions had as primary aim: Reduction of psychological burden (n = 9), reduction of	The burden and needs of affected families change over time and depending on their current age, patients	Information not available in the review	Highly variable in the included interventions	Information not available in the review	Were included 33 articles in the qualitative synthesis. Most of the studies described interventions for the cancer survivor (n = 15). Nine studies investigated interventions for the whole	Most of the studies were conducted in North America and Europe, meaning that the results cannot be generalized to other parts and cultures of the world. Only studies in English or German were included. (studies	There is a necessity for high quality studies. The results may help to optimize health care services that support families with the re-entry into daily life. Siblings and the family as a whole should also be addressed in

daily life of pediatric cancer survivors and their families: A systematic review. *PLoS One*, *13*(4), e0196151.	research questions in concordance with the PICO criteria)	years after the end of cancer treatment. Research questions: 1. Which psychosocial interventions for rehabilitation and reintegration into daily life of pediatric cancer patients and their families after the end of acute cancer treatment were evaluated and published? 2. What are the effects of these interventions on psychosocial outcomes in the family members?	e, (3) no conference proceedings, (4) article published in a peer-reviewed journal, (5) primary research (no study protocols or intervention descriptions) and (6) not only qualitative research. The participants in the studies had to meet the following inclusion criteria: (1) Cancer patients and/or their family members, (2) the	the family as a whole		family members during the first five years after the end of cancer treatment.	included studies. Five studies evaluated a family oriented rehabilitation program. Three studies evaluated computer-based interventions. Four studies described outpatient individual interventions. Only one study assessed psychosocial outcomes in participants of a home-based intervention	physical and psychological burden (n = 9), improvement of social skills (n = 8), increase of social support (n = 6), and psychoeducation (n = 2).	face different challenges and may have specific developmental needs (e.g. keeping up in school, development of autonomy).				family, and two studies interventions for siblings. The interventions mainly take place in an outpatient group setting (n = 15). Most of the studies reported a significant psychosocial benefit of the interventions. The quality of the included studies was limited. Overall, the investigated interventions helped families to improve their mental well-being and enhance social skills.	in other languages might have been overlooked). Due to the methodological heterogeneity of the included studies, we could not conduct a quantitative synthesis of the study results. Lastly, we conducted the systematic database search in four data- bases that are relevant for this field of research and conducted additional hand searches. We had to add only few studies to the records identified through our database search. Neverthe- less, relevant studies published in peer-reviewed journals that are not covered by these data- bases, might have been missed.	psychosocial interventions after the successful treatment of the patient.

			patient was diagnosed with cancer before the age of 21 and (3) no primary focus on palliative cancer patients.												
Brinkman, T. M., Recklitis, C. J., Michel, G., Grootenhuis, M. A., & Klosky, J. L. (2018). Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: current state of the literature.	review of the literature, not specified	The primary objectives of this paper are to review research related to psychosocial outcomes for survivors of childhood cancer, with an emphasis on risk factors for adverse outcomes, and to highlight potentially efficacious interventions to improve psychosocial outcomes	Not available	Survivors of Childhood Cancer	Psychological symptoms, social outcomes, socioeconomic attainment (educational achievement, Vocational Attainment), health behaviors (Tobacco Use, Marij	Not available	individual CBT or standard of care; group CBT; family therapy; telephone-delivered coping skills training; internet-based individual CBT. peer-mediated group training; group social skills training; self-help condition or survivorship peer counseling, tailored	Primary Intervention Target(s in Empirically Supported Interventions for Psychological Symptoms in Survivors of Childhood Cancer): Behavior problems; Posttraumatic stress; uncertainty, anxiety, benefit finding, health	Not available	(same as mechanism of change)	Not available	Not available	Empirically Supported Interventions for Psychological Symptoms in Survivors of Childhood Cancer: Significant reduction in attention problems, internalizing problems, social problems, somatic complaints, withdrawn behaviors; significant improvement in social skills; Significant reduction in arousal symptoms; Small sample size precluded inferential statistics.	Not available	Psychosocial Standards of Care for Survivors of Childhood Cancer: Routine and systematic assessment of psychosocial needs; Monitoring of neuropsychological deficits in survivors of brain tumor and other high-risk groups; Annual psychosocial screening of long-term survivors for educational/vocational progress; social relationships; anxiety, depression, and distress symptoms; and risky health behaviors; Access to psychosocial support and interventions;

Journal of Clinical Oncology, *36*(21), 2190.		for survivors.			uana (Cannabis) and Illicit Drug Use, Alcohol Use, Diet, Nutrition, and Physical Activity, Sun Exposure, Risky Sexual Behavior)		and targeted written educational materials, and free nicotine replacement therapy; Web-based intervention or print materials condition that included the provision of self-help materials; enhanced care/decision aid intervention psychoeducational modules, an educational CD-ROM, tailored substance use risk behavior counseling delivered by nurse practitioners and	promotion; depression, fear of progression/relapse. Primary Intervention Target(s) in Empirically Supported Interventions for Social Functioning in Survivors of Childhood Cancer: Peer acceptance, social reputation; Social skills; Social problem solving, social behaviors. Primary Intervention Target(s) in Empirically Supporte					Authors suggest generally positive effects, particularly in benefit finding.; Significant reductions in symptoms of posttraumatic stress, anxiety, depression, and fear of progression/relapse. Empirically Supported Interventions for Social Functioning in Survivors of Childhood Cancer: No significant differences in social competence between survivors and peers. Intervention classrooms showed lower levels of social rejection and victimization; Significant improvements in self-control, social skills, and quality of life; Significant improvement in social skills in the intervention group;		Assessment of financial hardship with targeted referrals; Education and anticipatory guidance related to late effects provided throughout the trajectory of cancer care; Opportunities for social interaction; School-reentry support that includes provision of information and recommendations to school personnel; Open, respectful communication and collaboration among families and providers

							telephone boosters; multicomponent risk counseling intervention; 12-week Facebook-based intervention (FITNET) or a 12-week Facebook-based self-help condition; 4-day integrated adventure-based training and health education program or attention-only group; multiple health behavior change intervention designed to increase sun safety practices; UVP or education-only	d Interventions for Risky Health Behaviors Among Survivors of Childhood Cancer: Tobacco use, self-reported smoking cessation; llicit drug use, risk motivation; Diet nutrition, knowledge of disease and treatment, risk perceptions, protective/risky health behaviors; Physical activity, body mass index, body weight, Functional Assessment of					significant increase in social problems in untreated comparison group; Significant improvements in maintaining eye contact, social conversations with peers, and cooperative play; no observed change in social problem-solving. Empirically Supported Interventions for Risky Health Behaviors Among Survivors of Childhood Cancer: The quit rate was significantly higher in the peer counseling condition v the self-help condition at 8 (16.8% v 8.5%) and 12 (15% v 9%) months; Quit rates at long-term follow-up were significantly higher in the peer counseling condition v the		

							comparison.	Cancer Therapy–General Survey, physical well-being, social well-being, emotional well-being, functional well being; exercise behavior, levels of physical activity, self-efficacy, quality of life; Sun exposure, sun safety practices; Sun protection.					self-help condition (20.6% v 17.6%); Equivalent rates of cessation were reported for both groups (16%) at the 15-month follow-up.; At 6 months post intervention, there was a significant change in risk motivation for low risk takers.; In the intervention group, self-reported junk food consumption significantly decreased.; Over 12 weeks, increases in light physical activity were 135 min/wk greater in the FITNET group relative to the self-help condition, and the FITNET group reported significant weight loss over time (22.1 kg).; Those in the experimental group		

													reported significant differences in physical activity stages of change, higher levels of physical activity, and self-efficacy as compared with those in the control group. There were also statistically significant mean differences in physical activity levels, self-efficacy, and quality of life of participants in the experimental group from baseline to 9 months after starting the intervention.; Survivors in the intervention arm reported significantly more sun safety practices at 1 month post intervention than control participants.; UVP was found to be acceptable and not distressing to survivors. UVP resulted in significantly		

													improved sun protective behaviors (ie, reduced sun exposure, increased sunscreen use, and increased hat wearing).		

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Next on The Carenet Project

Some of the next planned actions for the global mapping project are as follows:

Literature Review

- The 116 interventions included in the literature reviews will be organized, categorized, and further analyzed.

Writing of the Preliminary Report

- The 3rd preliminary report, due on September 15th, will be written.

Instruments Development

- Two methodologic instruments will be developed: a quantitative survey and guidelines for the focus groups.

Interviewer training

- Afterwards, the training of the interviewer, for the focus group, will take place.

Field Work

- The focus group interviews will be carried out, followed by an analysis of the collected data and the development of the quantitative survey.

Scheduling and planning of events and tasks.

Graphic Representation of the Tasks to be Developed considering the Project Stages

Childhood Cancer International: The Carenet Project												
Tasks / Months	March	April	May	June	July	August	September	October	November	December	January	February
General Tasks												
1. Elaboration of the communication strategy by the Waves team												
2. Writing and delivery of reports		Preliminary report deadline - April 30th ✓			Preliminary report deadline - July 31st		Preliminary conference report deadline – September 15th	Conference – September 28th to October 1st				Final report deadline - February 28th
Stage 1: Model Elaboration												
3. Literature Review Part 1												
3.1. Development and definition of the search strategy	✓											
3.2. Development of the eligibility criteria of the articles	✓											
3.3. Screening and study selection		✓										
3.4. Data extraction												
3.4.1. Development of the data extraction instrument			✓									
3.4.2. Application of the instrument previously developed												
3.5. Development of the PRISMA diagram				✓								
3.6. Writing of the article					1st draft of the article deadline – July 31st			2nd version of the article				
4. Literature Review Part 2 – Gathering and analysis of documents												
4.1. Preparation of the document analysis grid						✓						
4.2. Gathering of documentation												

4.2.1. Gathering of documentation online through the CCI partners websites				✓								
4.2.2. Gathering of documentation through specific requests via e-mail												
4.3. Document Analysis												
4.3.1. Online Documents												
4.3.2. Requested Documents												
Stage 2: Methodological Development and Implementation												
5. Focus Groups												
5.1. Script development for the focus groups												
5.2. Preparation for the focus groups												
5.2.1. Training of the interviewer												
5.2.2. Constitution of the focal groups (how many and in which languages)												
5.3. Field Work (Focal Groups)												
6. Online Survey												
6.1. Development of the quantitative online survey												
6.2. Field Work (online survey)												
Stage 3: Final Diagnosis												
7. Statistical analysis of data												
8. Writing of the final report												

Labels:

✓ **Completed Tasks**

Planned Activities

Deadlines