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How do parents of a child with cancer perceive their psychosocial needs from cancer diagnosis to remission? A systematic review of qualitative data

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Résumé

Introduction : Le cancer pédiatrique a un impact important sur la santé mentale des parents. Pour améliorer les soins psychosociaux offert aux familles, il est impératif de comprendre les besoins des parents, en fonction de leurs propres opinions et expériences. **Objectifs :** Cette revue systématique de la littérature et synthèse thématique vise à : (1) identifier les différentes catégories de besoins psychosociaux rapportés par les parents (2) isoler les besoins non satisfaits des parents, et (3) analyser la relation entre les besoins rapportés et le moment de la trajectoire. **Méthodologie :** Nous avons sélectionné sur PUBMED, EMBASE, CINAHL et PsycINFO des études qualitatives et mixtes sur les besoins psychosociaux des parents en oncologie pédiatrique, à l'aide des critères méthodologiques issus de l'outil Consolidated criteria for reporting qualitative research - COREQ (Tong, Sainsbury, & Craig, 2007). **Résultats :** On a identifié 102 études éligibles, dont 18 ont été inclus dans la synthèse thématique dans Nvivo 11 avec une analyse ligne par ligne et une analyse thématique des résultats des études. Cette analyse a mis en évidence cinq catégories de besoins non-satisfaits : 1) social ; 2) relationnel ; 3) émotionnel ; 4) déplacement ; 5) informationnel. Les besoins non satisfaits des parents portaient sur 1) manque de soutien familial et social ; 2) relation difficile avec l'équipe de soins de santé ; 3) stratégies inefficaces de coping avec le cancer ; 4) communication inefficace autour du cancer ; 5) transition difficile entre hôpital et maison. Les besoins rapportés étaient présents tout au long de la trajectoire du cancer. Seul le besoin de soutien était spécifique au moment du retour à la maison après la fin du traitement. La synthèse thématique a aussi identifié les thèmes suivants de suggestions d'amélioration pour les soins psychosociaux tels que formulés par les parents : 1) renforcer les relations avec la famille et la communauté ; 2) améliorer la relation avec les parents ; 3) aider à gérer les émotions et les aspects pratiques de la maladie ; 4) aider à la transition vers la maison ; 5) donner des informations sur le cancer. **Conclusion :** Cette revue de la littérature montre des besoins psychosociaux non satisfaits des parents et leurs suggestions sur la façon dont les soins psychosociaux qu'ils reçoivent pourraient être améliorés. L'avis parental sur leurs besoins est fondamental pour la validation sociale des services psychosociaux.

Mots-clés: Des besoins psychosociaux non satisfaits des parents ; Synthèse thématique ; Soins psychosociaux.

Abstract

Introduction: To improve psychosocial care, it is imperative to focus on the needs of parents, based on their own opinions and experiences. **Objectives**: This systematic review of the literature and thematic synthesis aims to: (1) identify the different categories of psychosocial needs reported by parents (2) isolate the unmet needs of parents, and (3) analyze the relationship between reported needs and the moment of the trajectory. We selected qualitative and mixed studies on the psychosocial needs of parents in pediatric oncology in PUBMED, EMBASE, CINAHL and PsycINFO databases. To select studies and extract methodological data for the thematic synthesis, we used the Consolidated criteria for qualitative research - COREQ tool (Tong, Sainsbury, & Craig, 2007). **Results:** We identified 102 studies with these criteria, of which 18 were synthesized in Nvivo 11 with line-by-line coding and thematic analysis of study results. This analysis revealed five categories of unmet needs: 1) social; 2) relational; 3) emotional; 4) displacement; 5) informational. Parents' unmet needs related to 1) lack of family and social support; 2) difficult relationship with the healthcare team; 3) ineffective coping with cancer; 4) ineffective communication about cancer; 5) difficult transition from hospital to home. These reported needs were present at all stages of the cancer trajectory, except for the need for support during the return home after the end of treatment. The thematic synthesis also identified the following themes of improvement suggestions for psychosocial care based on parental opinion: 1) strengthening relationships with family and community; 2) investing in a positive relationship with parents; 3) helping manage emotions and the practical aspects of the disease; 4) helping with the transition to the home; 5) giving information about cancer. **Conclusion:** This systematic review presents parents' unmet psychosocial needs and their suggestions about how the psychosocial care they receive could be improved, based on their own unmet needs. Parental opinions about their care are the base for the social validity of psychosocial care.

Keywords: Parents' psychosocial unmet needs; Thematic synthesis; Psychosocial care.

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Liste des sigles

COREQ – Consolidated criteria for reporting qualitative research

APA – American Psychologycal Association

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta- Analyses

Liste des abréviations

DX – Diagnostic

TR – Treatment

ATR – After treatment

(n) – Sample number

M – Mothers

F – Fathers

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Cette dissertation est le produit matériel de deux années d'intense apprentissage, non seulement dans le plan académique, mais aussi dans le plan personnel. Ces deux domaines se sont entremêlés et avec mon souhait d'être meilleure ont propulsé une grande croissance personnelle. Pourtant, personne ne fait rien seul. On existe en relation.

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Avant-propos

Ce travail est une revue systématique d'études qualitatives et mixtes sur les besoins psychosociaux des parents ayant un enfant atteint d'un cancer pédiatrique. Des études qualitatives et mixtes sur ce sujet rassemblent des informations approfondies sur les expériences des familles touchées par le cancer pédiatrique, généralement avec un nombre limité de participants, vu les caractéristiques de la recherche qualitative. De cette façon, on trouve important de rassembler ces informations dans un document unique de façon à élaborer un inventaire des besoins parentaux, auto-rapportés. En conséquence, nous avons produit une synthèse thématique des données qualitatives de ces études.

J'ai choisi de présenter le travail sous la forme d'article scientifique afin de faciliter sa publication et sa diffusion. Dans l'article présenté ci-dessous, je décris de façon détaillée la méthode utilisée pour la sélection, l'évaluation et l'analyse des études. Ensuite, je présente un résumé de tous les besoins psychosociaux des parents identifiés dans toutes les études analysées. Par la suite, j'analyse la relation entre ces besoins et la trajectoire du cancer de leurs enfants. Et finalement, je présente les recommandations des parents sur l'amélioration des soins psychosociaux en oncologie pédiatrique et ses implications cliniques.

Cet article discute également l'utilisation des outils d'évaluation et de présentation des procédures de recherche des études qualitatives en psychologie. Parmi ces stratégies, on renforce l'utilisation de mécanismes existants pour préserver la transparence et la systématicité des études qualitatives en psychologie.

Article

How do parents of a child with cancer perceive their psychosocial needs from cancer diagnosis to remission? A systematic review of qualitative data

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Abstract

Introduction: To improve psychosocial care, it is imperative to focus on the needs of parents, based on their own opinions and experiences. **Objectives**: This systematic review of the literature and thematic synthesis aims to: (1) identify the different categories of psychosocial needs reported by parents (2) isolate the unmet needs of parents, and (3) analyze the relationship between reported needs and the moment of the trajectory. We selected qualitative and mixed studies on the psychosocial needs of parents in pediatric oncology in PUBMED, EMBASE, CINAHL and PsycINFO databases. We used the Consolidated criteria for qualitative research - COREQ tool on data extraction (Tong, Sainsbury, & Craig, 2007). **Results:** We identified 102 studies, of which 18 were synthesized in Nvivo 11 with line-by-line coding and thematic analysis of studies results. Five categories of unmet needs emerged: 1) social; 2) relational; 3) emotional; 4) displacement; 5) informational. Parents' unmet needs were 1) lack of family and social support; 2) difficult relationship with the healthcare team; 3) ineffective coping with cancer; 4) ineffective communication about cancer; 5) difficult transition from hospital to home. These needs were present at all stages of the cancer trajectory, except for the need for support during the return home after the end of treatment. The thematic synthesis also identified themes of improvement suggestions for psychosocial care: 1) strengthening relationships with family and community; 2) investing in a positive relationship with parents; 3) helping manage emotions and the practical aspects of the disease; 4) helping with the transition to the home; 5) giving information about cancer. **Conclusion:** This systematic review presents parents' unmet psychosocial needs and their suggestions about how the psychosocial care they receive could be improved. These opinions can guide further interventions, increasing the social validity of psychosocial care.

Keywords: Parents' psychosocial unmet needs; Thematic synthesis; Psychosocial care.

1. Introduction

The impact of pediatric cancer on parents:

The childhood cancer diagnosis is among the most powerful, unsettling, and lasting events that parents could experience (Vrijmoet-Wiersma et al., 2008). While most parents have a good capacity to cope with cancer problems, some are more vulnerable and may develop psychological sequelae (Kazak et al., 1998). Caring for a child with cancer is associated with clinically relevant depressive symptoms among parents and mental health problems (Paul D. Creswell, Lauren E. Wisk, Kristin Litzelman, Adelyn Allchin, & Whitney P. Witt, 2014). Also, the severe characteristic of pediatric cancer qualifies it as a traumatic event of enough significance to lead to Acute Stress Disorder (ASD) or Posttraumatic Stress Disorder (PTSD) (Patino-Fernandez et al., 2008).

Multiple sources of cancer-related stressors affect parents' health. Some of them are cancer's uncertainty; maladaptive daily functioning; caregiving demands and communication problems (Rodriguez et al., 2012). Additionally, financial problems are a source of poor mental health and families with pediatric cancer patients are likely to experience financial constraints (P. D. Creswell, L. E. Wisk, K. Litzelman, A. Allchin, & W. P. Witt, 2014). These sources of distress can be categorized into disease-related factors, personal characteristics factors and family factors (Sultan, Leclair, Rondeau, Burns, & Abate, 2016). Some well-known risk factors are female gender, pre-existing psychological problems, high anxiety trait, reduced social support, financial constraints, child behavior problems and high caregiving demands (Vrijmoet-Wiersma et al., 2008). Not only mothers are at risk, but fathers also present similar types and pattern of stressors (Rodriguez et al., 2012).

Currently, there are manualized psychosocial interventions programs that target post-traumatic stress, emotional distress, uncertainty, emotional burden, loss of control, uncertainty, loneliness and lack of information about cancer (Ogez, 2018).

The importance of identifying parental distress and accessing parental needs:

Parental distress can reduce parents' coping skills which can trigger new psychosocial needs (Rabineau, Mabe, & Vega, 2008). Additionally, parents' psychological difficulties can negatively affect the child's treatment, being a constraint to the child's long-term resilience (Picoraro, Womer, Kazak, & Feudtner, 2014).

Therefore, it is important to identify families at risk of distress as soon as possible to propose them adequate treatment (Kearney, Salley, & Muriel, 2015; Sahler et al., 2005). In general, psychosocial care focuses on families with ongoing mental health difficulties (Kearney et al., 2015). However, studies have shown that efficient psychosocial care must focus on families' psychosocial needs (Kusch, Labouvie, Ladisch, Fleischhack, & Bode, 2000). Moreover, to meet parents' psychosocial needs, caregivers must identify discrepancies between parents' desired support and their actual or perceived support (Sultan et al., 2016).

Psychosocial needs are related to one's psychological necessities such as coping with illness and its consequences, personal control, self-esteem, sense of self-worth, self-competence, and self-significance (Fitch, 2015). Psychosocial needs are also related to one's family relationship, acceptance and involvement in a community (Fitch, 2015; Kerr, Harrison, Medves, & Tranmer, 2004).

To understand parental needs and to offer them better psychosocial care, it is essential to listen to family perspectives, choices, values, beliefs, cultural differences and experiences with pediatric cancer (Wiener & Pao, 2012). Parents' experiences, requests, and opinions must be gathered and studied. This effort to identify parents' needs based on their own speech allow us to: 1) provide desired and efficient

psychosocial support at the right moment of the cancer trajectory; 2) improve and develop psychosocial interventions targeting parents' perceived difficulties; 3) use efficiently financial and staff resources to respond to parents' most urgent needs.

Qualitative studies about self-reported parental needs of psychosocial support usually are based on small samples, mostly due to the specific goals and characteristics of qualitative research (Sandelowski, 1995). To increase generalizability, it is necessary to gather these pieces of evidence in a single document to develop an inventory of self-reported parental needs.

This systematic review aims to synthesize results of qualitative and mixed studies on parents' perception of their psychosocial needs during childhood cancer. We aim to (1) identify the different categories of psychosocial needs reported by parents, (2) isolate parents' unmet needs, and (3) analyze the relationship between needs reported and moment in the cancer trajectory to identify if needs vary across time.

Thus, this systematic review focuses on synthesizing information of how parents of a child with cancer perceive their met and unmet needs of psychosocial support during the cancer trajectory.

2. Methods

2.1 Data Sources

We conducted a systematic review of the following databases: MEDLINE, EMBASE, CINAHL, and PsycINFO. We performed the search on all entries prior November 2017. The research concerned five components, the * is a Boolean search modifier to detect a root word in the databases: "parent*", "cancer", "pediatric", "psych* need*", "mixed and qualitative studies" (Search syntax in Table S1). All retrieved titles and abstracts were independently rated for relevance by two reviewers (RR DO). There was 100% agreement on the selected articles. We also examined reference lists of identified articles for additional hits.

Following the PRISMA recommendations, we completed this review by searching the grey literature on studies concerning parents' perception or experience of their own psychosocial needs (Moher, Liberati, Tetzlaff, Altman, & The, 2009). This research was also conducted on the Internet using the same keywords (search engine: Google, Google Scholar). We also performed a thorough investigation in the library of a Québec community support organization (Leucan, i.e. the largest French-speaking library in pediatric oncology for users) and sent a request via the listserv of the Society of Pediatric Psychology (APA div 54). We registered this systematic review on the Prospero platform on January 11th of 2018 (CRD42018084108).

2.2 Study selection and data extraction

Studies had to report data on parents' perception of their own psychosocial needs to be eligible. We included studies collecting perceptions at least partly qualitatively and focusing on various moments of the trajectory, such as diagnosis, active treatment, post-treatment, and survivorship, or cancer recurrence. The search

was limited to papers published in English because of resource availability. Exclusion criteria were: study not conducted in pediatric oncology and quantitative studies. After removing for duplicates, all hits were read by two raters (RR DO) to identify eligible articles. We screened titles and abstracts, and in case of disagreement, we read full texts to achieve a consensus between raters (Figure 1 - PRISMA 2009 Flow Diagram). To warrant transparency and systematicity to the data pool (Meyrick, 2006), we read 47 full texts of articles considered eligible and conducted an assessment using the COREQ - Consolidated criteria for reporting qualitative research (Tong et al., 2007).

COREQ is a comprehensive checklist to help researchers to report important components of qualitative research. This checklist covers 3 domains of qualitative research repporting: Research team and reflexivity; Study design; Data analysis and findings. We selected studies presenting enough information on two main domains of COREQ checklist: (1) a detailed description of study design (sampling method, sample size and characteristics; data analysis procedure and epistemological orientation; method of data collection; presentation of the interview guide, description of data collection context, audio or video recording) and (2) a detailed description of the analysis process and data report (clarity of major themes; presence of participants' quotations). These 2 domains of COREQ's assessment enable a clear audit trail for qualitative research (Onwuegbuzie & Leech, 2006). Studies that reported these COREQ criteria were retained. The non-observed domain didn't influence the studies' transparency, since researchers background and affiliations are already presented in the authors' section of every article.

2.3 Data analysis

We used the Results sections of selected studies as the primary verbal material to be analyzed by thematic analysis to identify and develop synthesized themes

(Thomas & Harden, 2008). We entered the studies in NVivo 11 (QSR International, Melbourne, Australia). We followed an inductive approach with a fixed classification system for coding (Swennen et al., 2013). First, we conducted (1) a word-frequency search using the terms "need*," "support*," “treat*” to identify general themes and create an initial set of descriptive themes. Then, we made an inductive analysis, thematically categorizing and interpreting the results parts of the studies by meaning. We achieved final descriptive themes by discussing their meaning with independent researchers with extensive experience and training in qualitative analysis. We then used a fixed system of coding, classifying all the verbatim by type of psychosocial need (objective 1) and whether needs were met or unmet (objective 2).

2.4 Data synthesis

The thematic synthesis method aims to analyze qualitative studies and to establish conceptual relationships between the results of each study (Swennen et al., 2013; Thomas & Harden, 2008). For the data synthesis, we initially compared the content of all descriptive themes. Then, all descriptive themes were thematically re analyzed and interpreted to develop a coherent portrait of parents’ needs, expressed in analytical themes. Subsequently, we developed analytical themes by comparing and interpreting all descriptive themes of all studies to present an outlook of all parents' needs (objective 1). These analytical themes allowed to distinguish parents’ met and unmet needs (objective 2), and to analyze the relationship between these needs and child cancer trajectory (objective 3).

3. Results

Following the PRISMA Guidelines (Moher et al., 2009), we identified 107 studies through electronic databases and 8 additional records from grey literature (Figure 1). These eight items were 7 unpublished thesis retrieved in APA and Research Gate databases and 1 dissertation obtained following a request email sent to the SPP listserv (div 54 APA). All the retained studies are presented in Table 1.

After removing duplicates, 102 independent hits remained. Then, we excluded 54 hits following the review of titles and abstracts. The excluded records did not observe the following criteria: full text with detailed results, pediatric cancer and parental psychosocial needs studies, English language articles; diagnosis, active treatment and post-treatment phases studies; primary studies. Within 47 records assessed for eligibility, 29 were excluded because they did not observe the selected items of the COREQ list (Tong et al., 2007). The studies characteristics presented in Table 1 were extracted by using COREQ guidelines, we followed Ponterotto's (2005) study to define studies' paradigms.

The final set is thus composed of 18 items, i.e. four thesis and 14 published articles. Among the selected items, most of them (10/18, 55%) were conducted in Canada and the US. Almost all studies were purely qualitative (16/18, 89%). Researchers interviewed a total of 407 parents – 67% mothers and 33% fathers, a median of 14 parents (Min-Max: 4-73); Most of them adopted post-positivist approaches (12/18, 66%) (Table 1).

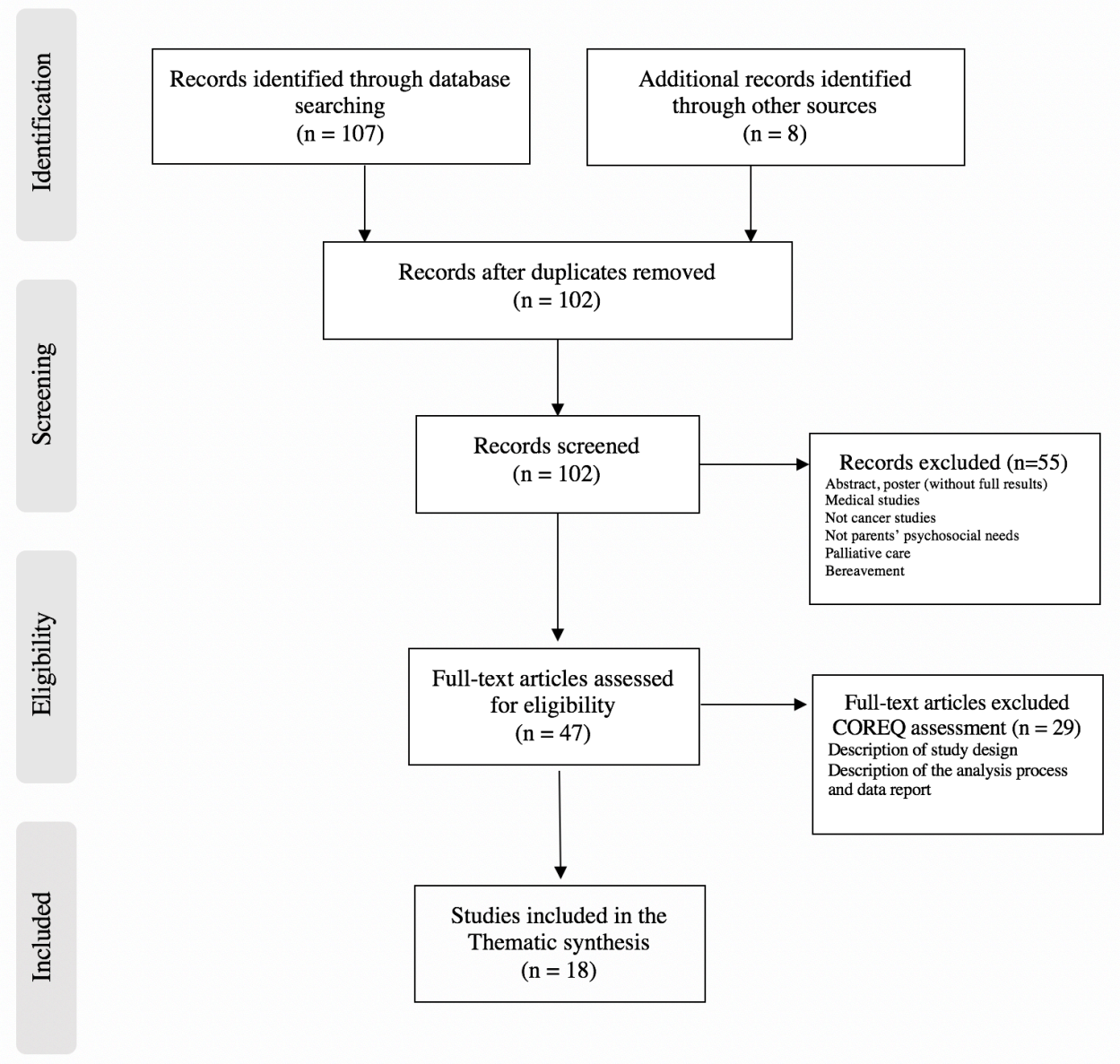

Figure 1 PRISMA 2009 Flow Diagram

Table 1 - Studies' description

STUDIES	TYPE OF STUDY	METHOD	EPISTEMOLOGY	ANALYSIS PROCEDURE	DATA COLLECTION METHOD	N (M/F) PARENTS	COUNTRY
1-(Zomerlei, 2015)	Thesis	Qualitative	Grounded Theory	Constant comparison	Semistructured interviews	16 (8/8)	Canada
2-(Gauthier-Frohlick, 2011)	Thesis	Qualitative	Action research	Listening guide	Individual interview, Focus groups, Photovoice	21 (12/9)	Canada
3-(Griffiths, 2009)	Thesis	Qualitative	Phenomenology	IPA	In-depth interviews	11 (9/2)	Australia
4-(Zogran, 2008)	Thesis	Qualitative	Grounded Theory	Constant comparison	Interviews, participant observations	15 (12/3)	United States
5-(Muskat et al., 2017	Article	Qualitative	Post-positivist	Interpretive description	Semistructured interview	17 (14/3)	Canada
6-(Maree, Parker, Kaplan & Oosthuizen, 2016)	Article	Qualitative	Phenomenology	Thematic analysis	In-depth interviews	13 (11/2)	South Africa
7-(Darcy, Knutsson, Huus & Enskar, 2014)	Article	Qualitative	Post-positivist	Content analysis	Semistructured interviews	23 (20/3)	Sweden
8-(Hocking et al., 2014)	Article	Mixed	Post-positivist	Content analysis	Focus group,	25 (20/5)	United States
9-(Rosenberg-Yunger et al., 2013)	Article	Qualitative	Constructive grounded theory	Constant comparison	Semistructured interviews	29 (24/5)	Canada
10-(Young et al., 2013)	Article	Qualitative	Post-positivist	Constant comparison	Semi-structured interviews, Recorded consultation	67 (40/27)	United Kingdom
11-(Arabiat, Alqaissi, & Hamdan-Mansour, 2011)	Article	Qualitative	Post-positivist	Content analysis	Semistructured interviews	51 (51/0)	Jordania
12-(Shepherd & Woodgate, 2011)	Article	Qualitative	Phenomenology	Thematic analysis	Semistructured, open-ended interview	5 (3/2)	Canada
13-(Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010)	Article	Qualitative	Post-positivist	Template analysis	Semistructured interviews	6 (4/2)	United Kingdom
14-(Rivero-Vergne, Berrios, & Romero, 2008)	Article	Qualitative	Phenomenology	Thematic analysis	In-depth interviews	7 (7/0)	Porto Rico
15-(Brody & Simmons, 2007)	Article	Qualitative	Post-positivist	Thematic analysis	Semistructured interviews	8 (0/8)	United States
16-(Duffey-Lind et al., 2006)	Article	Qualitative	Post-positivist	Content analysis	Focus groups, In-depth interviews	7 (7/0)	United States
17 - (Yin & Twinn, 2004)	Article	Qualitative	Ethnography	Thematic analysis	Semistructured interviews	13 (11/2)	Hong Kong
18-(Woodgate & Degner, 2003)	Article	Qualitative	Grounded theory	Constant comparison	Focus group interviews	73 (40/33)	United States

Table 1 Studies' description

M: mothers; F: fathers.

3.1 Thematic synthesis

Parents' opinions about their psychosocial needs have been identified and classified by major analytical themes. The same procedure guided the analysis of their met and unmet needs and the improvement suggestions of psychosocial support targeting this population. Figure 2 and Table 2 summarize the thematic synthesis procedures and its results.

Figure 2 Thematic Synthesis Procedure

Table 2 - Thematic synthesis results – Parents' psychosocial needs

TYPE OF PSYCHOSOCIAL NEEDS	NEEDS		CANCER TRAJECTORY			IMPROVEMENT SUGGESTIONS
	MET	UNMET	Dx	TR	ATR	
Social 1, 2, 3, 4, 6, 8, 9, 12, 13, 15, 18	Effective support -Family 3, 4, 6, 9, 12, 13, 14, 15 -Social 1, 2, 3, 4, 9, 12, 13, 15, 18	Lack of support -Family 3, 14 -Social 1, 8, 13	8 13 18	1 3 6 9 13 15 18	1 2 3 4 12 13 18	Strengthening relationships: -With family 8, 14, 17 -With community 2, 4, 1, 8, 12
Relational 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 15, 16, 17, 18	The positive connexion with healthcare team 3, 4, 5, 6, 7, 9, 10, 12, 15, 16, 18	The negative connexion with healthcare team 1, 2, 3, 5, 6, 7, 10, 11, 12, 15, 16, 17	7 10 17 18	1 2 3 6 9 10 17 15 18	1 3 4 10 12 16 17 18	Investing in a positive relationship with parents 2, 3, 4, 1, 12, 17
Emotional 1, 3, 4, 5, 6, 7, 8, 9, 12, 13, 14, 15, 17, 18	Effective strategies 3, 4, 6, 9, 12, 13, 15, 18	Ineffective strategies -Treatment 1, 3, 6, 7, 8, 5, 12, 13, 14, 15, 17, 18 -Impact on family 3, 4, 1, 8, 6, 5, 17 -Psychological impact 6	7 8 13 17 18	1 3 6 9 13 15 17 18	1 3 4 13 14 12 17 18	Helping on managing -Emotions 3, 4, 8, 5, 14, 12 -Practical aspects of the illness 3, 8
Displacement 1, 3, 5, 7, 12, 14, 16	Constant moving 3, 5, 12, 14	Constant displacement: transitioning to home 3, 5, 7, 12, 16	1 7	2 3	3 5 7 12 16	Helping on transitioning to home 1, 2, 3, 16
Informational 2, 3, 4, 6, 11, 13, 15, 16, 17	Effective communication about cancer 2, 6, 15	Ineffective communication about cancer 3, 6, 11, 13, 15, 16, 17	13 17	3 6 11 13 15 17	3 4 12 13 16 17	Giving information about cancer 3, 4, 6, 12, 17

Table 2 Thematic synthesis results

The numbers represent the studies described on Table 1. Dx – Diagnosis; TR – treatment; ATR – after treatment.

3.2 Identifying the type of parents' psychosocial needs

We identified five types of psychosocial needs reported by parents: 1) social; 2) relational; 3) emotional; 4) displacement; 5) informational. Each type of psychosocial need was identified by analyzing parents' speech about the difficulties faced during their children's cancer. They were synthesized by theme and interpreted as types of psychosocial needs.

3.3 Distinguishing parents' met and unmet needs

Parents' needs were identified as met and unmet according to parents' opinions about their psychosocial support.

FAMILY AND SOCIAL SUPPORT

Effective support

We identified efficient family and social support in 10 studies (Brody & Simmons, 2007; Gauthier-Frohlick, 2011; Griffiths, 2009; Maree, Parker, Kaplan, & Oosthuizen, 2016; Rosenberg-Yunger et al., 2013; Shepherd & Woodgate, 2011; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010; Woodgate & Degner, 2003; Zogran, 2008; Zomerlei, 2015).

Concerning the family support, we observed that extended family members' help brought up a new dynamic grounded in closeness (Griffiths, 2009; Shepherd & Woodgate, 2011; Zogran, 2008). Paternal and maternal grandparents and great-grandparents played an essential role as strong supporting figures – during all phases of illness, enabling parents to focus on the ill child. Another study portrayed the importance of the unconditional support that husbands offered to their wives (Rivero-Vergne, Berrios, & Romero, 2008). These women felt understood and secured.

Parents from 6 studies reported social support as a met need (Brody & Simmons, 2007; Gauthier-Frohlick, 2011; Griffiths, 2009; Shepherd & Woodgate, 2011; Zomerlei, 2015). Friendship was an essential help, and community support was important during the treatment journey to increase resilience (Brody & Simmons, 2007; Rosenberg-Yunger et al., 2013; Woodgate & Degner, 2003). Families who had to travel for treatment and lived in small communities reported that they were impressed with the support received from their community back home (Gauthier-Frohlick, 2011; Shepherd & Woodgate, 2011). Their community sent help in different manners like taking care of parent's property or conducting fundraising events (Shepherd & Woodgate, 2011). Connecting with other parents at the cancer center was also described as very helpful. They described parents' support groups and meeting other parents from temporary residential resources as very beneficial for their mental health (Gauthier-Frohlick, 2011). These new friendships allowed them to share experiences and to feel with other parents who were going through the same process. They felt understood and able to get guidance from other parents' previous experiences. One family of Asian ethnicity described that the social support received from Caucasian Australian's enabled them to perceive themselves as equals, without considering their ethnicity in the foreground of their interaction, which improved their social inclusion perception (Griffiths, 2009).

Lack of support

Six studies reported lack of family and social support as an unmet psychosocial need (Griffiths, 2009; Hocking et al., 2014; Maree et al., 2016; Rivero-Vergne et al., 2008; Williamson et al., 2010; Zomerlei, 2015). One study reported the arousal of marital problems after the diagnosis (Rivero-Vergne et al., 2008). Some women expressed that their husbands were emotionally affected by the diagnosis. Besides having their husbands' support, these women said that they also felt responsible for taking care of them, which became an additional difficulty for them to manage. Two studies showed that in response to the diagnosis shock, men had a hard time to

communicate and expressed their feelings which could provoke a marital crisis (Maree et al., 2016; Rivero-Vergne et al., 2008). Mothers were also impacted by overwhelming and isolation, listed as women's unmet needs (Griffiths, 2009; Rivero-Vergne et al., 2008). Lack of family support was not their only concern. In 2 studies (Hocking et al., 2014; Zomerlei, 2015), parents expressed that no one truly understood their experience. They vented their need to connect with other parents of children with the same diagnoses to learn about it and discuss cancer-related topics, especially shortly after the diagnosis. Parents also felt frustrated when people did not know how to support them or how to deal with their kids' appearance (Williamson et al., 2010; Zomerlei, 2015).

CONNEXION WITH THE HEALTHCARE TEAM

Positive connexion

Parents' met needs to have a positive connexion with the healthcare team appeared in 11 studies (Brody & Simmons, 2007; Darcy, Knutsson, Huus, & Enskar, 2014; Duffey-Lind et al., 2006; Griffiths, 2009; Maree et al., 2016; Muskat et al., 2017; Shepherd & Woodgate, 2011; Woodgate & Degner, 2003; Young et al., 2013; Zogran, 2008). Collaborating and connecting with staff alleviated parental anxieties and helped them to establish a relationship of trust and accept the diagnosis (Rosenberg-Yunger et al., 2013; Shepherd & Woodgate, 2011; Zogran, 2008). They particularly appreciated when professionals took some time to connect with the child's school and to help them with administrative issues, allowing families to spend more time together (Darcy et al., 2014; Duffey-Lind et al., 2006). Parents mentioned that discussing the possibility of cure and talking about the treatment with the healthcare team reassured them, even when they talked about biomedical rather than emotional

issues (Brody & Simmons, 2007; Maree et al., 2016; Woodgate & Degner, 2003; Young et al., 2013). After the end of the treatment, parents felt supported and comforted by professionals' openness to keep in touch and to stay available for families' needs (Muskat et al., 2017). Additionally, local health care providers reassured parents when they were willing to learn about the child's diagnosis and treatment plan (Griffiths, 2009; Shepherd & Woodgate, 2011).

Negative connexion

In 10 studies parents pinpointed how some families did not develop a positive relationship with the healthcare team (Arabiat, Alqaissi, & Hamdan-Mansour, 2011; Brody & Simmons, 2007; Darcy et al., 2014; Gauthier-Frohlick, 2011; Griffiths, 2009; Maree et al., 2016; Muskat et al., 2017; Shepherd & Woodgate, 2011; Young et al., 2013). Some rural families were not comfortable taking their child to see their local health care provider during and after treatment due to lack of trust; others did not have any healthcare practitioner available in their region, having to travel to meet their family doctor (Gauthier-Frohlick, 2011; Shepherd & Woodgate, 2011). Notably, parents said that poor communication among staff and lack of continuity in care made them struggle to trust in the healthcare team (Darcy et al., 2014; Griffiths, 2009; Young et al., 2013).

Although this was infrequent, some parents complained about not being informed or consulted about treatment options. They felt they were not listened, which led to significant dissatisfaction with the staff (Maree et al., 2016). Some fathers felt ignored although they were the primary caretakers of their child (Brody & Simmons, 2007). After treatment, parents complained about the abrupt change of their relationship with the staff (Young et al., 2013). They felt disappointed with the lack of guidance, information, and support (Muskat et al., 2017). Fear of relapse and the need to readapt to a new routine kept parents insecure. They were also conflicted about reaching out the health care team with fear of overload the staff and prevent new families from getting the much-needed assistance (Muskat et al., 2017).

STRATEGIES TO FACE CANCER

This theme refers to the behaviors parents adopted to manage cancer-related difficulties. The analyzed studies do not name specific coping strategies; however, they describe parental behaviors and beliefs implemented to face cancer stressors.

Effective strategies

In 7 studies parents presented a positive and active attitude towards life, which helped them to cope with cancer (Brody & Simmons, 2007; Griffiths, 2009; Rosenberg-Yunger et al., 2013; Shepherd & Woodgate, 2011; Williamson et al., 2010; Woodgate & Degner, 2003; Zogran, 2008). Some parents counted their blessings and felt fortunate for having a healthy child after treatment. Others, emphasized the positive outcomes of the cancer experience, like living in the moment, appreciating each day, expressing love and showing their appreciation more frequently and used humor to reframe a distressing situation (Brody & Simmons, 2007; Griffiths, 2009; Williamson et al., 2010). Parents also mentioned their strategies to face fear: being in the present, being strong, maintaining hope/faith and making meaning out of the negative experience (Zogran, 2008). Reassessing life, values, happiness, and living without regrets were new attitudes that came with the traumatic experience.

In 2 studies, parents expressed attitudes that helped them to accept and cope with cancer and its difficulties (Griffiths, 2009; Maree et al., 2016). Developing a new routine assisted their adjustment. Investing their efforts in getting information about the treatment and developing a new schedule helped them to adapt faster, face reality, tame fear and stay emotionally available for their child. Additionally, parents mentioned how their spirituality enabled them to fight and cope with pediatric cancer and its life-changing consequences (Brody & Simmons, 2007; Maree et al., 2016; Shepherd & Woodgate, 2011).

Ineffective strategies

In 12 studies parents emphasized how they had difficulty to cope with cancer' psychological and family impact (Brody & Simmons, 2007; Darcy et al., 2014; Duffey-Lind et al., 2006; Griffiths, 2009; Hocking et al., 2014; Maree et al., 2016; Muskat et al., 2017; Shepherd & Woodgate, 2011; Williamson et al., 2010; Woodgate & Degner, 2003; Yin & Twinn, 2004).

Some parents described the psychological impact of the diagnosis as devastating, shocking and painful, causing fathers' social withdrawal (Maree et al., 2016; Williamson et al., 2010). Many felt mentally overloaded and struggled to continue with their child's cancer journey as it affected the whole family dynamic (Brody & Simmons, 2007; Shepherd & Woodgate, 2011). Parents struggled to talk about their feelings to their children (Yin & Twinn, 2004). The belief that children were too young to understand the illness, life, and death, ended by alienating siblings from parental care. Their reluctance to talk to their child about the disease may be related to their difficulty in coping with it (Yin & Twinn, 2004). As a result, families felt fragmented by the emotional constraints imposed by the treatment and by the fact that one parent was often away with the ill child (Griffiths, 2009).

The chemotherapy side effects produced feelings of anxiety, fear, and sadness(Maree et al., 2016). Parents implied feeling abused by the treatment and wished they be better prepared for its adverse effects and how to minimize this unwanted feeling (Darcy et al., 2014). They verbalized the unmet need to talk about the treatment and its impacts, but they needed to adapt to the diagnosis before being able to focus on their adjustment (Darcy et al., 2014; Hocking et al., 2014). After the treatment, parents felt relieved, grateful and happy, but anxious, fearful, uncertain and lost. This cocktail of emotions made them feel conflicted and shattered, having to rebuild a new healthy life marked by pediatric cancer (Muskat et al., 2017).

Regarding the cancer impact on families' dynamics, parents felt conflicted about their new role. They expressed feeling frustration, inadequacy, constant worry

and powerlessness regarding the cancer treatment and how they should play their parental role (Brody & Simmons, 2007; Darcy et al., 2014). The way parents disciplined an ill child, comforted and protected them changed with the treatment constraints, and they had to quickly adjust to this new parental role (Duffey-Lind et al., 2006; Muskat et al., 2017). They realized that they were not able to always protect their child and felt these changes as a loss of their former identity (Griffiths, 2009).

DISPLACEMENT

This theme refers not only to the physical movement and dislocation which many families have to comply to receive specialized treatment, but it also refers to the emotional discomfort and feelings related to being away from home.

Constant moving

Frequent displacements marked families' trajectories, either going to the hospital or returning home. Two studies showed that parents were willing to go to the hospital and to comply with treatment routines to get the best care for their child (Griffiths, 2009; Shepherd & Woodgate, 2011). They also affirmed they felt secure at the hospital (Shepherd & Woodgate, 2011). Regarding their return to home, 3 studies showed that families received it with gratitude and they were committed to building a new normal, focusing on a simple life (Griffiths, 2009; Klassen, Gulati, & Dix, 2012; Muskat et al., 2017).

Constant displacement: transitioning to home

Four studies reported parents' struggle to return home (Darcy et al., 2014; Griffiths, 2009; Muskat et al., 2017; Shepherd & Woodgate, 2011). For many families leaving the hospital came with contradictory feelings. Parents worried about being away from the hospital. They felt ill-equipped and wished they have been prepared to go back home (Griffiths, 2009; Shepherd & Woodgate, 2011). Parents reported

difficulties readjusting to life at home (Griffiths, 2009). Despite having material support to care for their child at home, some families thought it was hard to adapt to the new routine and to meet the child's emotional need of reassurance and closeness (Darcy et al., 2014). In one hand, parents felt relieved for not having to go to the hospital in the other, they felt tied to the home care team and not free to plan their own time (Darcy et al., 2014). Some rural families from isolated areas could not count on the children's hospital as their local safety net (Shepherd & Woodgate, 2011). Returning to regular life was not easy (Griffiths, 2009). Parents experienced anxiety, uncertainty, hesitancy and fear of relapse (Muskat et al., 2017; Shepherd & Woodgate, 2011). They also felt lost and said it would have been useful to have some direction about transitioning to home (Muskat et al., 2017).

COMMUNICATING ABOUT CANCER

Effective communication

Two studies presented how receiving medical information eased their doubts(Maree et al., 2016). Also, getting adapted and personalized knowledge facilitated families' comprehension about the treatment and about what to expect from it. Parents said that written and specific information was very appreciated(Brody & Simmons, 2007; Maree et al., 2016).

Ineffective communication

In 7 studies families stated being unhappy with the communication about their child's health(Arabiat et al., 2011; Brody & Simmons, 2007; Duffey-Lind et al., 2006; Griffiths, 2009; Maree et al., 2016; Williamson et al., 2010; Yin & Twinn, 2004). They said they lacked knowledge about cancer and needed specific information about their child's type of cancer (Griffiths, 2009; Maree et al., 2016). This need of personalized information about cancer was constant from diagnosis to the end of the treatment. Parents asked for regular information about treatment evolution and its results (Brody & Simmons, 2007; Duffey-Lind et al., 2006; Maree et al., 2016). Information

about appearance changes was also scarce (Williamson et al., 2010). The scarcity of information about cancer induced fear of the disease in the families. At times, parents reported asking siblings not to talk about the diagnosis and even hid the diagnosis from others with fear of being stigmatized (Yin & Twinn, 2004). Some mothers were satisfied with the lack of openness with their children diagnosis, since they believed children are not equipped to deal with full disclosure (Arabiat et al., 2011). The belief that cancer was a terminal disease only for old people and the lack of information about the treatment and its procedures caused significant distress on families (Arabiat et al., 2011; Maree et al., 2016).

3.4 Relating parents' needs and child cancer trajectory

For aim 3, we compared three moments in the trajectory (diagnosis, treatment, and after treatment) to explore whether systematic specificities in reported needs could be identified over time. Six studies described parents' experiences during the diagnosis phase. Ten studies reported parents' needs during the treatment phase. Moreover, 14 studies presented data regarding the after-treatment phase. Table S2 summarizes the distribution of the studies in the cancer trajectory.

In our analysis since all categories of parental needs repeatedly appeared in all phases of the cancer trajectory, we could not identify a relation between parental needs and cancer trajectories for all psychosocial needs. Additionally, some studies reported parents' needs during the three phases without discriminating at which phase they were expressed. Still, the thematic synthesis allowed us to identify one

very distinctive theme related to parents' readiness to transition to home. In 5 studies transitioning to home was described as an unmet need after the end of the treatment.

4. Discussion

According to our study's aims, this systematic literature review identified five types of psychosocial needs reported by parents: 1) social; 2) relational; 3) emotional; 4) displacement; 5) informational. The main psychosocial needs were: reaching out for support, developing a good relationship with staff, adapting to cancer in life, traveling to the hospital and fearing to be back home, getting information about cancer. We also identified parents' most significant unmet needs. Lack of family and social support: men social withdraw due to the shock of diagnosis, women isolation. The negative connexion with the healthcare team: poor communication among staff, lack of cancer-related knowledge of local care providers, lack of continuous guidance and support. Difficulty in coping with cancer, its treatment and its psychological and family impacts: need to talk about their experiences, the shock of the diagnosis and the adverse effects of the cancer treatment. Need of support to disclose about cancer, to grieve their old parental identity and to manage conflicting emotions felt at the end of the treatment. Difficulty to adapt to their new life post-cancer. Need to learn how to talk about cancer to their children and need for curated information throughout the cancer journey. These family and social support needs have already been described as essential factors of adjustment to parents (Kupst & Schulman, 1988; Morrow, 2007; Patenaude & Kupst, 2005; Sloper, 2000).

This systematic review also identified particular subtopics of psychosocial needs - transcultural care and gender-related needs - that require further investigations.

Transcultural care is an emergent focus to psychosocial oncological care. Some authors already described the importance of a multicultural approach to family care

(Sahler et al., 2013; Sahler et al., 2005; Wiener & Pao, 2012). Our findings support the importance of healthcare practitioners to keep an open channel of communication not only by handling information in the language parents feel most comfortable with, but also maintaining openness to cultural differences that can be expressed in values, family roles, and interpersonal contact needs (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003; Brach & Fraserirector, 2000; A. F. Klassen, S. Gulati, L. Watt, et al., 2012; Stewart et al., 2006). Working with culturally-varied families require culturally competent healthcare practitioners. Parents may need help to manage immigration challenges as reduced social support, financial strains and the cognitive effort of decoding languages, social roles and navigating the healthcare system while facing the emotional burden of cancer (Gulati et al., 2012; A. F. Klassen, S. Gulati, L. Granek, et al., 2012; Watt et al., 2013). We strongly recommend more studies regarding this theme as a way to improve oncological psychosocial care in culturally-diversified societies.

Concerning gender-related needs, our review reinforces the discussion that fathers and mothers can have different necessities regarding how and at which moment they process the psychological impact of having a child with cancer. Men and women can have different reactions when talking about feelings and managing cancer-imposed constraints: as communicating with each other and with the healthcare team, needing to balance responsibilities and tensions between the couple and requiring different approaches to disclose and process strong emotions arisen with the illness (Barakat et al., 1997; Barrera et al., 2004; Brody & Simmons, 2007; Sahler et al., 2013; Wagner, Johns, Brown, Hanna, & Bigatti, 2016).

All these unmet needs occurred in all phases of the cancer trajectory. However, transitioning to home is a significant struggle after the end of the treatment phase. At this phase, parents have to manage identity changes and lifestyle adjustments that still require additional psychosocial support (McKenzie & Curle, 2012). Parents also have significant unmet needs regarding the information received during the post-treatment phase (Wakefield, Butow, Fleming, Daniel, & Cohn, 2012).

The thematic synthesis also revealed improvement suggestions of psychosocial care to parents' unmet needs that have clinical implications for psychosocial care. Previous manuals of recommendations of psychosocial care in pediatric cancer have already enlisted the general themes parents articulated (Kusch et al., 2000; Meyler, Guerin, Kiernan, & Breatnach, 2010; Steele, Mullins, Mullins, & Muriel, 2015; Wiener & Pao, 2012). We confirm that most available manualized psychosocial interventions do approach many parents' self-reported needs. However, the studies we reviewed suggest specific strategies to approach parents' unmet needs like gender-related psychosocial care, multicultural inclusiveness, transcultural care, creative methods of parental socialization with peers, fighting isolation, teaching communication strategies within couples, training family doctors, improving communication with healthcare practitioners, individualizing cancer-related information and implementing transitioning programs.

Potential limitations

We had limited access to unpublished studies. However, all available procedures were taken to gather these studies.

The use of COREQ checklist could be interpreted as a contributor to the modest inclusion rate 18/47. We also believe that the limited access to research documents lowered the inclusion rate of studies due to the limited space available to describe research procedures in journals. One alternative to increase studies' inclusion rate is to use open repositories platforms or to examine open data papers(Asendorpf, 2013). A similar strategy of Community-augmented meta-analysis (CAMA) has been proposed to synthesize quantitative research in psychology(Tsuji, Bergmann, & Cristia, 2014).

The use of COREQ guidelines to evaluate qualitative studies increased data validity and offered an overview of the application of qualitative research in pediatric oncology(Rathbone et al., 2017; Thomas & Harden, 2008; Tong et al., 2007). We are

aware that each paradigm assumption and methodology carry different validity procedures(Barker & Pistrang, 2005; Creswell & Miller, 2000; Morse, 2015). Still, despite the challenge of using one single tool for different qualitative studies, the evaluation allowed us to identify transparency and systematicity strategies adopted in these studies (Mays & Pope, 2000; Meyrick, 2006). Other guides to report qualitative research may be considered in future researches. For example, the SRQR – Standards for Reporting Qualitative Research (O'Brien, Harris, Beckman, Reed, & Cook, 2014) has broader guidelines, more adaptable to the wide range of qualitative approaches and methodologies. In brief, while assessing studies' strategies to report qualitative research, we observed that the field could benefit from future improvement in reporting research procedures (Mays & Pope, 2007; Yardley, 2000).

In conclusion, this systematic review allowed us to report parents' psychosocial needs based on parents' experiences and opinions. It also shows some parents' suggestions to improve psychosocial care. Since, the assessment of parents' perception about their psychosocial care is a necessary procedure for the social validation of ongoing treatments (Carter, 2009), we recommend more frequent in-depth studies about their evaluation of existing programs. According to this systematic review about parents' unmet needs, it is recommended to improve psychosocial support at the end of the treatment and the transition to home phases. Parents need more adapted information about cancer, its treatment and survivorship. They also need a closer relationship with the healthcare team, and culturally adapted psychosocial care about the impact of cancer on the whole family. Additionally, families still need more support at the end of the treatment to readjust to normal life and to face survivorship challenges, like the impact of cancer's sequelae.

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Supplementary table

Table S1 - Syntax of searches
Parent*, mother*, father*
Pediatric*, child*, adolescent*
Cancer, neoplasm, oncology, hematology
Psych* need*, necessity(ies)
Mixed, Qualitative stud*, method*

Supplementary table 1 Syntax of searches

Table S2 - Studies and cancer trajectory

Studies	Diagnosis	Active treatment	After treatment
1-(Zomerlei, 2015)		✓	✓
2-(Gauthier-Frohlick, 2011)			✓
3-(Griffiths, 2009)		✓	✓
4-(Zogran, 2008)			✓
5-(Muskat et al., 2017)			✓
6-(Maree et al., 2016)		✓	
7-(Darcy et al., 2014)	✓		
8-(Hocking et al., 2014)	✓		
9-(Rosenberg-Yunger et al., 2013)		✓	✓
10-(Young et al., 2013)	✓	✓	✓
11-(Arabiat, Alqaissi, & Hamdan-Mansour, 2011)		✓	
12-(Shepherd & Woodgate, 2011)			✓
13-(Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010)	✓	✓	✓
14-(Rivero-Vergne et al., 2008)			✓
15-(Brody & Simmons, 2007)		✓	✓
16-(Duffey-Lind et al., 2006)			✓
17-(Yin & Twinn, 2004)	✓	✓	✓
18-(Woodgate & Degner, 2003)	✓	✓	✓

Supplementary table 2 Studies and cancer trajectory