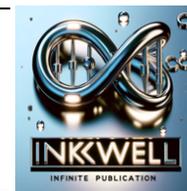




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Original Article

Information Needs and Preferences on Cancer-Related Symptoms Among Children with Cancer and Their Parents: A Systematic Review

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Abstract

Objective: This study aimed to explore information needs and preferences of children with cancer and their parents about cancer-related symptoms. **Methods:** A systematic review of the literature was conducted using five databases and citation searches. The quality of eligible studies was assessed with the Mixed Methods Appraisal Tool. **Results:** Thirty studies were included (N=256 children and N=1778 parents/guardians). Children's perspectives on their information needs were under examined and different from their parents. Both children and parents required more information about symptoms and late effects. Associations between participants' characteristics and their information needs about symptoms and late effects were inconclusive. Parents preferred to receive information from doctors, in verbal and written formats, more than from online sources. **Conclusions:** Children with cancer and their parents need more tailored information about symptoms and late effects. Further research is required to identify how best to support individualised information needs and delivery preferences of children with cancer and their parents.

Keywords: Paediatrics, Oncology, Information needs, Quantitative methods, Qualitative methods, Mixed methods.

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Introduction

Advances in treatment have increased the survival rates for paediatric cancers in high-income countries (Lam et al., 2019). However, cancer and its treatments result in distressing symptoms for 28-76% of children (Hooke & Linder, 2019; Linder &

Hooke, 2019), with severe symptoms persisting in 87% of adult survivors of childhood cancer (Huang et al., 2013). A symptom is a perception or sensation of change related to health function, in this case due to cancer and its treatments, and can occur throughout the cancer trajectory (Cleeland et

al., 2010). Sometimes cancer-related symptoms are referred to as side effects if they occur during cancer treatment or late effects if they develop after the treatment has been completed (Cleeland et al., 2010; Stein et al., 2008). The most bothersome symptoms for children with cancer are pain, fatigue, nausea, vomiting, sleep disturbance and sadness (Hooke & Linder, 2019). As symptom burden adversely affects the quality of life and daily activities of childhood cancer patients and survivors (Huang et al., 2013; Kestler & LoBiondo-Wood, 2012), high-quality care for cancer patients should include communication about symptom care throughout the cancer trajectory (Mooney et al., 2017).

Information about cancer symptoms and symptom management is an important educational topic for children with cancer and their parents (Kelly & Porock, 2005; Rodgers et al., 2016). Seeking and obtaining information about cancer and its treatment facilitates paediatric cancer patients and their parents to cope with the effects of cancer and its treatment (Pyke-Grimm et al., 1999; Walker et al., 1993). While children who had sufficient discussion on symptoms tended to perceive their current quality of life as “excellent” and predict their health to be better in one year (Levine et al., 2019); children aged 10-18 years reported that the restricted information received from their parents and/or healthcare providers was one of the barriers to symptom communication with healthcare providers (McLaughlin et al., 2019). Furthermore, unmet information needs of parents as well as adolescents and young adults with cancer are associated with distress (Dyson et al., 2012; McCarthy et al., 2018). A recent systematic review found that relatives of children with cancer had unmet information needs about cancer-related consequences, including symptoms (Sievers et al., 2024). However, information needs of children with

cancer and their parents regarding cancer-related symptoms, including how to manage symptoms and what factors are associated with their information needs, remain insufficiently understood. Understanding and meeting the information needs of children with cancer and their parents is an essential component of supportive cancer care (Fitch, 2008).

This systematic review aimed to explore the information needs of children with cancer and their parents regarding cancer-related symptoms. In addition, this review compared the information needs of children with their parents and identified when and how they prefer to receive the desired information. Understanding the scope of information needs and preferences on cancer-related symptoms reported in the literature is central to developing tailored educational resources and programs that strengthen family-centred communication and improve quality of life among children with cancer.

Methods

Protocol and Registration

The review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) under the registration number: CRD42020187583. This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021).

Eligibility Criteria

Studies were included if the sample involved children diagnosed with cancer and aged ≤ 19 years when they participated in the study or their parents/guardians, children were undergoing curative cancer treatment or had completed treatment, studies assessed information needs and/or preferences about symptoms, side effects or late effects from either the

child's or their parent's perspective, studies were empirical research with any study design, and studies were published in English.

Studies were excluded during the screening process for the following reasons if they included adolescents and young adults without reporting separate findings of adolescents group aged ≤ 19 years or included only adult survivors of childhood cancer, explored healthcare providers' perspectives on information needs, assessed information needs about cancer screening, prevention, prognosis, decision making, end of life, bereaved parents, or palliative care, and were reviews or conference abstracts.

Information Sources and Search Strategy

Five electronic bibliographic databases, i.e., CINAHL (EBSCOhost), Embase (OvidSP), MEDLINE (Ovid), PsycINFO (Ovid) and Web of Science (Core Collection), were searched from inception to March 2020. The search was re-run on 07 June 2021. The searches were conducted without restrictions. In consultation with two research librarians, search key terms were derived from the review aims, i.e., information needs and preferences, cancer, children, fatigue, and symptom management. Information need refers to wanted or desired information from professionals through proper communication resources (Timmins, 2006). In addition, information preferences refer to the wanted time and sources to receive information, such as delivery method and relevant individuals. Finally, symptoms refer to any cancer-related or treatment-related symptomology, e.g., pain, fatigue, and other physical or psychological side effects or late effects of cancer and its treatments.

A broad range of keywords was used. Search terms were adapted for use with each database, and subject headings were used where applicable. Backward and forward citation chaining of the included studies were searched using Scopus database. Databases and citations searches were conducted by the first author

(QMA). Furthermore, EndNote software (Clarivate, version 20, Philadelphia, USA) was used for reference management, and Covidence software (Veritas Health Innovation, version 2021, Melbourne, Australia) was used for screening processes.

Data selection, extraction, and quality assessment

The initial databases search yielded a total of 20244 publications. After removing duplicates by the first author (QMA), titles and abstracts of 14658 studies were screened independently by two reviewers to identify eligible studies. The full texts of 145 studies were then obtained and independently assessed for eligibility by two reviewers. Four authors were involved in the screening processes (QMA, JN, ED, CL). Consensus between reviewers was achieved through discussion without the need for a third reviewer. For the citation search, screening processes were conducted by the first author (QMA), and the eligibility of 30 citations was assessed by the senior author (ED). In total, thirty studies met the eligibility criteria and were included in this review (Figure 1).

Two reviewers independently extracted data from the same included studies (QMA and ED). The extracted data focused on results pertaining to information on symptoms and late effects, i.e., information needs, preferences, information received, associated factors with information needs, and any other relevant results. Relevant data for characteristics of the included studies and for quality assessment were also obtained. The extracted data were compared for consistency (QMA), and any disagreements about data extraction were resolved through discussion (QMA, ED). Finally, authors of four potentially eligible studies were contacted to request missing or additional data. Two authors did not respond; therefore, their studies were excluded (Arpaci et al., 2018; Darcy et al., 2016).

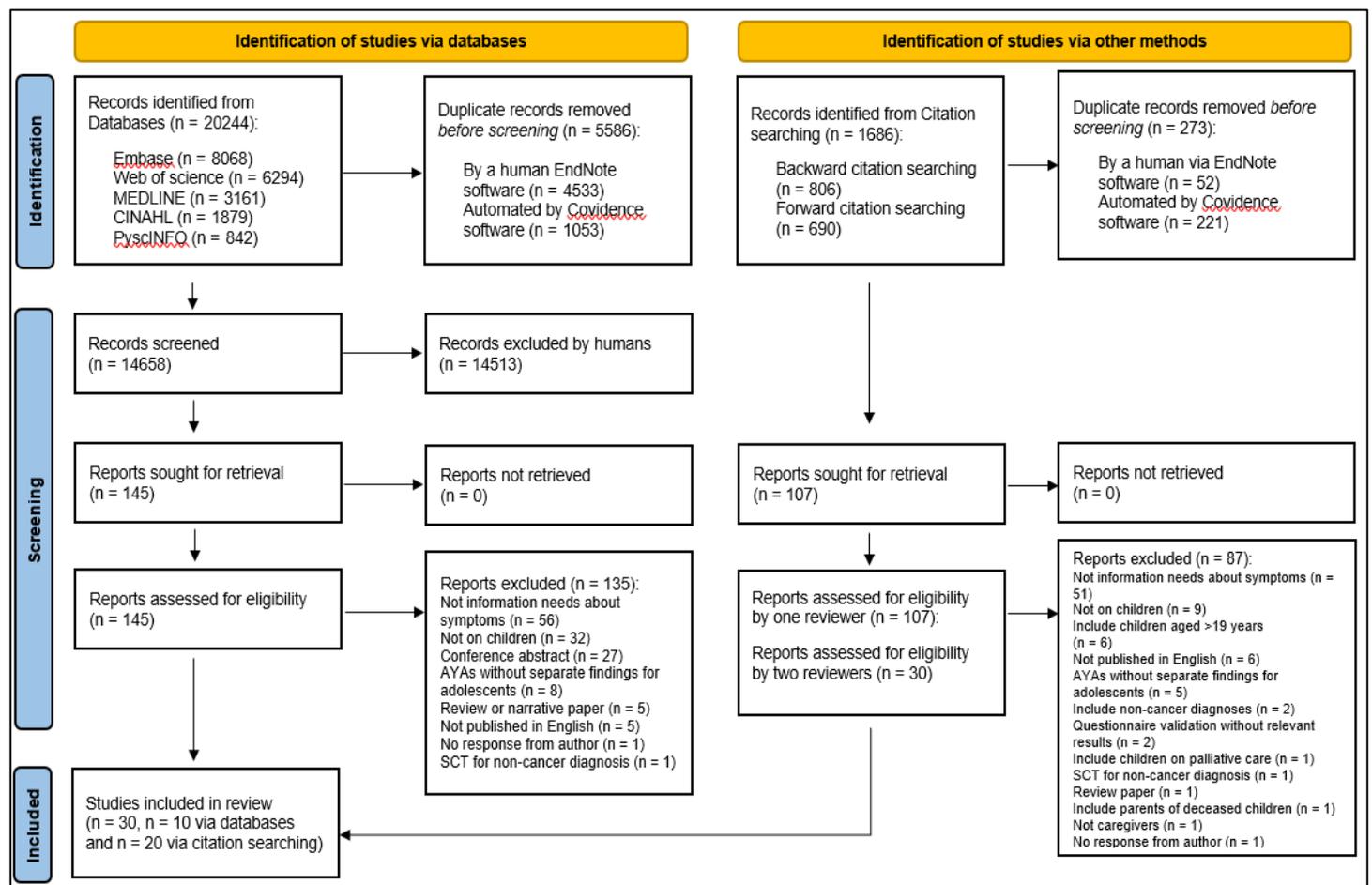
For quality assessment, the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was used independently by two reviewers per study (QMA and ED

or CL). The MMAT appraises the methodological quality of empirical studies in systematic mixed methods reviews. It includes five methodological quality criteria for each category of research design (i.e., qualitative, quantitative, and mixed methods studies). Each criterion can be scored with “Yes”, “No”, or “Can’t tell” if a study does not report clear information related to the criterion or appropriate information to respond by “Yes” or “No”. Additionally, methodological criteria for quantitative descriptive studies were used for quantitative studies (Hong et al., 2018). Discrepancies between the reviewers over the quality appraisal for

each study were resolved by discussion, with involvement of a third reviewer as necessary (ED or CL). According to the Hong et al. guide, studies were not scored or excluded based on their quality assessment (Hong et al., 2018).

Ethical statement

Ethics approval was not applicable. This systematic review does not report on or involve the use of any human or animal data or tissue.



Abbreviations: AYAs: Adolescents and Young Adults, SCT: Stem Cell Transplant

Figure 1. PRISMA 2020 Flow Diagram.

A narrative synthesis was conducted due to methodological heterogeneity between included studies and limited relevant findings reported by eligible studies. Extracted data were synthesised

Data Synthesis

based on the topic of information needed (i.e., symptoms, symptom management and late effects) as well as the focus of information (i.e., needs for information, fulfilment of information needs, importance of information needs, associated factors with information needs including information received, barriers to seeking and delivery of information, and information preferences). However, findings could not be synthesised according to the child's cancer diagnosis (i.e., tumour type, age at diagnosis or time since diagnosis) or their treatment received (i.e., treatment status, type of treatment, duration of treatment or time since completion of treatment) due to diversity of relevant findings. To address the aims of this systematic review, synthesised findings were grouped into three themes: (i) children's information needs, (ii) information needs and preferences of parents, and (iii) children's perspective on their information needs compared with their parents' perspective. Quantitative and qualitative findings were simultaneously summarised for each theme, compared against each other, and integrated if adequate data were available. Data were synthesised by the first and the senior authors (QMA and ED), and the synthesis of results was confirmed by all authors to ensure validity of the findings.

Results

Description of included studies

Thirty studies were included in this review (Table 1), with a total of 256 children and 1778 parents/guardians included across all studies. Children's perspectives were not included in 80% (N = 24) of studies.

All studies were descriptive, cross-sectional designs. Sixteen studies (53%) used quantitative methods (Arabi & Altamimi, 2013; Gunawan et al., 2016; Gunawan et al., 2014; Hooker, 1997; Ji et al., 2018; Levine et al., 2019; Ljungman et al., 1999; Ljungman et al., 2003; Mercer & Ritchie, 1997a; Motlagh et al., 2019; Mueller et al., 2018; Nagel et al., 2002; Pyke-Grimm et al., 1999; Rao et al., 2021; Vetsch et al., 2015; Wells et al., 1990). Nine studies (30%) were qualitative research using interviews (Çavusoglu, 2000; Kilicarslan-Toruner & Akgun-Citak, 2013; Kin-Fong Cheng, 2009; Koohkan et al., 2019; Loades et al., 2020; Lyu et al., 2019; McGrath et al., 2007; Mercer & Ritchie, 1997b) or both focus groups and interviews (Ringnér et al., 2011). Three studies (10%) used a mixed methods design with a combination of questionnaires and interviews (Kerr et al., 2007; Vetsch et al., 2017; Wakefield et al., 2012). Finally, two studies (7%) had a multiple-methods design, i.e., they collected data using quantitative and qualitative methods but did not involve data integration (Hobbie et al., 2010; Park et al., 2021).

Table 1. Characteristics of included studies.

The first author (year), country of origin	Study objective(s) ^a and whether information needs was a primary or secondary outcome	Focus of information ^a	Data collection method ^a and qualitative analysis ^a	Sample size and response rate ^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received
Quantitative studies								
Arabiat (2013), Jordan	To evaluate (1) priority of caring needs for parents of children with cancer, (2) meeting of these needs, and (3) needs for further information (primary outcome)	Symptoms: importance and fulfilment of information needs, and information needs	Family Inventory of Needs–Pediatric II (Arabic) questionnaire	98 parents <u>Response rate</u> : 92%	<u>Children</u> : 52.1% M: 45.9% F <u>Parents</u> : 19.4% M: 80.6% F	<u>Children</u> : $\bar{x} = 7.24 \pm 4.45$ years Range: 1-16 years <u>Parents</u> : ≥ 21 years	ALL/AML: 51.1%, solid tumours: 47.9%	100% on treatment <u>Treatment received</u> : Cx:73.4%, Rx: 2.1%, Cx + Rx: 5.1%, Sx: 5.1%, BMT: 14.3%
Gunawan (2014), Indonesia	To compare health beliefs about chemotherapy-related side-effects between parents, doctors, and nurses (secondary outcome)	Symptoms: information received, information needs and barriers to information delivery	A developed questionnaire	40 caregivers: parents, grandmothers and sisters <u>Response rate</u> : 98%	<u>Children</u> : 52% M: 48% F <u>Caregivers</u> : 13% M: 87% F	<u>Children</u> : $\bar{x} = 7.0 \pm 3.3$ years Range: 1-13 years <u>Caregivers</u> : N/R	ALL: 86%, solid tumours: 10%, other haematological tumours: 4%	95% on and 5% completed treatment <u>Time since completion of treatment</u> : N/R <u>Treatment received</u> : N/R
Gunawan (2016), Indonesia	To understand parents' and children's needs about chemotherapy-induced alopecia (secondary outcome)	Alopecia: sources of information received, information needs and barriers to information delivery	A developed questionnaire	50 caregivers: parents and grandmothers <u>Response rate</u> : 82%	<u>Children</u> : 54% M: 46% F <u>Caregivers</u> : 26% M: 72% F M+F: 2%	<u>Children</u> : < 15 years <u>Parents</u> : N/R	ALL: 70%, Wilm's tumour: 12%, retinoblastoma: 6%, AML: 4%, non-Hodgkin lymphoma: 4%, rhabdomyosarcoma: 2%, chronic myeloid leukemia: 2%	50% on and 50% completed treatment <u>Time since completion of treatment</u> : N/R <u>Treatment received</u> : N/R
Hooker (1997), UK	(1) To design, develop and pilot a research tool to ascertain the information priorities of teenagers with cancer, and (2) to describe the information priorities of teenagers with cancer (primary outcome)	Symptoms: priority of information needs	A card-sort method according to the paired comparison method scaling model	Seven children <u>Response rate</u> : N/R	<u>Children</u> : 57.14% M: 42.86% F	<u>Children</u> : 13 to 17 years	N/R	71.43% on and 28.57% off treatment <u>Time since completion of treatment</u> : ≤ 12 months <u>Treatment received</u> : N/R
Ji (2018), China	(1) To translate the Cancer Patient Needs Questionnaire into Mandarin, and (2) to test the reliability and stability of the factorial structure on parents of children with cancer (secondary outcome)	Symptoms: information needs	A revised translated version of the Cancer Patient Needs Questionnaire	112 parents of 112 children <u>Response rate</u> : 90%	<u>Children</u> : 42.9% M: 57.1% F <u>Parents</u> : 37.5% M: 61.9% F	<u>Children</u> : $\bar{x} = 7.35 \pm 5.11$ years <u>Parents</u> : $\bar{x} = 29.64 \pm 3.18$ years	N/R	48.9% just started treatment, 24.4% halfway through treatment, and 26.7% almost completed treatment <u>Treatment received</u> : Cx: 72.8%, BMT: 16.5%, Cx + BMT: 10.7%, N/R: 8%
The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received

Levine (2019), USA	To assess children and their parents' perceptions of discussion regarding the physical and emotional impact of cancer and its treatment within the first year of cancer diagnosis (primary outcome)	Symptoms and their management: symptom discussion and information needs	Developed questionnaire s	258 participants (129 child/parent pairs) <u>Response rate</u> : 92%	<u>Children</u> : 53% M: 47% F <u>Parents</u> : 12% M: 88% F	<u>Children</u> : \bar{x} = 14.0 ± 2.2 years Range: 10-12 years (26%), 13-18 years (74%) <u>Parents</u> : Range: 26-65 years	Solid tumour: 32%, leukemia: 29%, lymphoma: 20%, brain tumour: 16%, other: 1%, unknown:2%	N/R
Ljungman (2003), Sweden	To evaluate support and information given to children and parents about pain (primary outcome)	Pain management: information received	Individual semi-structured interviews	55 children and 54 parents <u>Response rate</u> : 83%	<u>Children</u> : 51% M: 49% F <u>Parents</u> : N/R	<u>Children</u> : Median: 6.1 years Range: 0.8-19.2 years <u>Parents</u> : N/R	Leukemias: 58%, lymphomas: 18%, others:24%	On or completed treatment (percentages: N/R) <u>Time since completion of treatment</u> : ≤3 months <u>Treatment received</u> : N/R
Ljungman (2003), Canada	(1) To assess information needs of children and their families, and (2) to conduct an acceptability study of different ways to provide information, social support, and self-management therapy (primary outcome)	Symptoms and late effects: importance and meeting of information needs	Structured individual interviews using a developed questionnaire	56 families (56 parents and 13 adolescents) <u>Response rate</u> : 72%	<u>Children participated</u> : 31% M: 69% F <u>Children of participated parents</u> : 54% M: 46% F <u>Parents</u> : 25% M: 71% F, 4% N/R	<u>Children participated</u> : \bar{x} = 14.8 ± 2.8 years Range: >12 years <u>Children of participated parents</u> : \bar{x} = 8.9 ± 5.2 years Ranges: <6 years (43%), 6-12 years (25%), >12 years (32%) <u>Parents</u> : Ranges: 20->40 years	<u>Children participated</u> : Leukemia: 38.5%, solid tumour: 38.5%, CNS: 23% <u>Children of participated parents</u> : Solid tumour: 37%, leukemia: 36%, CNS: 27%	<u>Parents group</u> : 43% on and 57% completed treatment <u>Children group</u> : 31% on and 69% completed treatment <u>Time since completion of treatment</u> : ≤2 years <u>Treatment received</u> : N/R
Mercer (1997a), Canada	(1) To explore the parental needs, perceived importance of the needs, and whether the needs have been met during their children's cancer treatment, and (2) to identify differences in needs between parents whose children received all their care at the major tertiary centre (tertiary group) and parents whose children received at least some of their care in their local community (community group) (secondary outcome)	Symptoms: information needs	A modified version of the Caregiver Needs Scale questionnaire	58 parents of 37 children <u>Community group</u> : 40 parents from 26 families <u>Tertiary group</u> : 18 parents from 11 families <u>Response rate</u> : 50%	<u>Children</u> : N/R <u>Parents</u> : 44.83% M: 55.17% F	<u>Children</u> : \bar{x} = 6.4 years Range: 2-15.9 years <u>Parents</u> : N/R	Leukemia: 81.08%, solid tumours: 18.92%	82.8% ^c in remission [‡] , 10.3% ^c in relapse, and 5.2% ^c at the beginning of treatment <u>Time since completion of treatment</u> : N/R <u>Treatment received</u> : N/R
The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received

Motlagh (2019), Iran	To determine information needs of parents of children with leukemia (primary outcome)	Symptom management: information needs, and factors associated with information needs	A developed questionnaire	187 parents <u>Response rate</u> : N/R	<u>Children</u> : 52.9% M: 47.1% F <u>Parents</u> : 33.2% M: 66.8% F	<u>Children</u> : \bar{x} = 5.57 years Range: 1-10 years <u>Parents</u> : Range: 27-58 years	Leukemia: 100%	On or completed treatment (percentages: N/R) <u>Time since completion of treatment</u> : N/R <u>Treatment received</u> : N/R
Mueller (2018), USA	To understand the mobile technology desires and barriers by caregivers of children with cancer (secondary outcome)	Symptom management: mobile website/app use, needed, and factors associated with information needs	A developed questionnaire	121 caregivers <u>Response rate</u> : 31%	N/R	<u>Children</u> : \leq 18 years <u>Caregivers</u> : Range: 23-63 years	N/R	On or recently completed treatment (percentages: N/R) <u>Time since completion of treatment</u> : N/R <u>Treatment received</u> : N/R
Nagel (2002), Canada	To obtain input from the families of survivors of childhood cancer regarding their needs surrounding the "coming off treatment" period (primary outcome)	Symptoms and late effects: information needs and preferred sources	A developed questionnaire	41 parents <u>Response rate</u> : 100%	<u>Children</u> : N/R <u>Parents</u> : 37% M: 63% F	N/R	ALL/AML/lymphoma: 71%, other malignancies: 29%	100% completed treatment <u>Time since completion of treatment</u> : 0-2 years <u>Treatment received</u> : N/R
Pyke-Grimm (1999), Canada	To obtain (1) priority for information needs of parents, (2) if a relationship existed between treatment decision-making preferences and information needs, and (3) if sociodemographic, disease and treatment variables predicted information needs (primary outcome)	Symptoms: priority of information needs and factors associated with information needs	Thurstone's law of comparative judgement method and a developed questionnaire	58 parents of 38 children <u>Response rate</u> : 75%	<u>Children</u> : 34% M: 66% F <u>Parents</u> : 41% M: 59% F	<u>Children</u> : \bar{x} = 6 years Range: 2-12 years, <6 years (53%), \geq 6 years (47%) <u>Parents</u> : Range: 21-42 years	ALL: 26%, solid tumours: 74%	100% on treatment <u>Treatment received</u> : Cx: 100%, Sx: 40%, Rx: 29%
Rao (2021), India	To explore the unmet needs of caregivers of children with cancer to establish a paediatric caregiver support group (secondary outcome)	Symptoms: information needs	A developed questionnaire	17 caregivers: mothers (52.9%), fathers (41.2%), uncles (5.9%) <u>Response rate</u> : N/R	<u>Children</u> : N/R <u>Caregivers</u> : 37.9% M: 62.1% F	<u>Children</u> : Range: 3-15 years <u>Caregivers</u> : Range: 24-47 years	N/R	N/R
The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received

Vetsch (2015), Switzerland	To investigate (1) information received by parents and their information needs and (2) the association between information needs and parents' socio-demographic characteristics and clinical characteristics of the child's disease (primary outcome)	Late effects: received information, information needs, preferred information sources, and factors associated with information needs	A developed questionnaire	189 parents <u>Response rate:</u> 67%	<u>Children:</u> N/R <u>Parents:</u> 15.3% M: 84.7% F	<u>Children:</u> $\bar{x} = 14.7 \pm 1.8$ years Range: 10.7-18.0 years <u>Parents:</u> 33.5-59.5 years	Leukemia: 39.2%, CNS tumours: 18.0%, lymphomas: 8.5%, soft tissue sarcomas: 7.4%, neuroblastoma: 6.9%, retinoblastoma: 6.9%, renal tumours: 6.3%, others: 6.8%	100% completed treatment <u>Time since completion of treatment:</u> ≤ 5 years <u>Treatment received:</u> Cx: 63.1%, Sx: 16%, Rx: 16%, SCT: 4.9%
Wells (1990), USA	To describe information needs of parents of adolescents with cancer (primary outcome)	Symptoms: information needs	A developed questionnaire	26 parents <u>Response rate:</u> 43%	<u>Children:</u> N/R <u>Parents:</u> 42% M: 58% F	<u>Children:</u> N/R <u>Mothers:</u> $\bar{x} = 44$ years <u>Fathers:</u> $\bar{x} = 54$ years	N/R	35% on and 65% completed treatment <u>Time since completion of treatment:</u> N/R <u>Treatment received:</u> N/R
Qualitative studies								
Çavusoglu (2000), Turkey	To describe problems experienced by adolescents with leukemia related to their disease and treatment (primary outcome)	Symptoms: information received and information needs	Semi-structured individual interviews <u>Data analysis:</u> a content analysis	30 children	<u>Children:</u> 73.33% M: 26.67% F	<u>Children:</u> $\bar{x} = 14.4$ years Range: 13-18 years	Leukemia: 100%	73.33% on treatment and 26.67% in remission <u>Time since completion of treatment:</u> N/R <u>Treatment received:</u> N/R
Kilicarslan-Toruner (2013), Turkey	To explore the information-seeking behaviours and decision-making experiences of parents of children with cancer (primary outcome)	Symptoms: information needs	Semi-structured individual interviews <u>Data analysis:</u> an inductive content analysis	15 parents (2 fathers and 13 mothers)	<u>Children:</u> 60% M: 40% F <u>Parents:</u> 13.33% M: 86.67% F	<u>Children:</u> $\bar{x} = 8.07 \pm 5.91$ years Range: 2-18 years <u>Parents:</u> Range: 22-60 years	ALL: 60%, neuroblastoma: 26.6%, Wilms' tumour: 13.3%, non-Hodgkin lymphoma: 6.7%, chronic myelogenous leukaemia: 6.7%, rhabdomyosarcoma: 6.7%	100% hospitalised (on treatment) <u>Treatment received:</u> Cx: 53.3%, Cx + Sx: 33.3%, Cx + Rx: 6.7%, Cx + SCT: 6.7%
Kin-Fong Cheng (2009), Hong Kong	To explore children's and their parents' needs about oral mucositis during chemotherapy (secondary outcome)	Oral mucositis: information needs	Descriptive phenomenological design using individual semi-structured interviews <u>Data analysis:</u> an inductive content analysis	44 participants (22 child/parent pairs)	<u>Children:</u> 55% M: 45% F <u>Parents:</u> 5% M: 95% F	<u>Children:</u> $\bar{x} = 2.1 \pm 3.4$ years Range: 6-19 years <u>Parents:</u> Range: 27-57 years	ALL: 41%, osteosarcoma: 32%, lymphoma: 18%, others: 9%	100% on treatment <u>Treatment received:</u> Cx: 100%
The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received

Koohkan (2019), Iran	To identify health information needs of families in childhood cancer (primary outcome)	Symptoms: information needs	Semi-structured individual interviews <u>Data analysis:</u> a content analysis	35 parents	<u>Children:</u> 31.42% M: 68.6% F <u>Parents:</u> 25.8% M: 74.28% F	<u>Children:</u> N/R <u>Parents:</u> Range: 20-50 years	ALL: 42.8%, lymphoid tumour: 31.42%, brain tumour: 11.42%, osteosarcoma: 8.6%, Wilms' tumour: 5.8%	100% hospitalised (on treatment) <u>Treatment received:</u> N/R
Loades (2020), UK	To explore parental experiences of their adolescent's cancer-related fatigue and what they do to help (secondary outcome)	Fatigue: information received and information needs	Semi-structured individual interviews <u>Data analysis:</u> a reflexive thematic analysis	21 parents of 17 children	<u>Children:</u> 23.53% M: 76.47% F <u>Parents:</u> 28.57% M: 71.43% F	<u>Children:</u> 12-18 years <u>Parents:</u> N/R	Sarcoma: 23.53%, ALL: 17.65%, lymphomas: 17.65%, AML: 11.76%, brain tumour: 11.76%, germ cell cancer: 11.76%, thyroid cancer: 5.88%	58.82% on and 35.29% off treatment, 5.88% N/R their treatment status <u>Time since completion of treatment:</u> ≤12 months <u>Treatment received:</u> N/R
Lyu (2019), China	To explore the parental perceptions on unmet family needs related to healthcare services during their children's hospitalisation for cancer treatment (secondary outcome)	Symptoms: information needs	Semi-structured individual interviews <u>Data analysis:</u> a content analysis	19 parents of 19 children	<u>Children:</u> N/R <u>Parents:</u> 26.32% M: 73.68% F	<u>Children:</u> Range: 2-13 years <u>Parents:</u> Range: 30-42 years	ALL: 84.21%, lymphoma: 5.26%, rhabdomyoma: 5.26%, neuroblastoma: 5.26%	100% hospitalised (on treatment) <u>Treatment received:</u> Cx: 100%
McGrath (2007), Australia	To present parental perspectives on informational issues during treatment of paediatric ALL at the end of induction remission (primary outcome)	Symptoms: information needs	Semi-structured individual interviews <u>Data analysis:</u> a phenomenological approach	16 parents of 12 children	<u>Children:</u> 58.33% M: 41.67% F <u>Parents:</u> 25% M: 75% F	<u>Children:</u> Range: Nine months - 10 years <u>Parents:</u> Range: 28-44 years	ALL: 66.67%, ALL/T Cell Lymphoma: 16.67%, infant ALL: 8.33%, ALL/Philadelphia chromosome: 8.33%	100% during treatment <u>Treatment received:</u> N/R
Mercer (1997b), Canada	(1) To describe parents' experiences of necessary resources to meet their needs during their children's cancer treatment, and (2) to compare the resources needed by the parents whose children received all of their treatments at the tertiary centre (tertiary group) and parents whose children had received at least some of their care in their home community (community group) (secondary outcome)	Symptoms: information needs and barriers to seeking information	Semi-structured individual interviews <u>Data analysis:</u> a content analysis	20 parents of 17 children (a subset of Mercer and Ritchie (1997a) sample)	N/R	N/R	N/R	N/R
The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M: F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received

Ringnér (2011), Sweden	To describe parental experiences of acquiring and using information to create knowledge about their child's cancer during the illness (primary outcome)	Symptoms and late effects: information received, information needed and sources	Four focus group interviews and four individual interviews <u>Data analysis:</u> a content analysis	<u>Focus groups:</u> 14 parents of 11 children <u>Individual interviews:</u> Four parents (one parent from each focus group session)	<u>Focus groups:</u> 28.57% M: 71.43% F <u>Individual interviews:</u> N/R	<u>Focus groups:</u> Children: Range: 1-18 years <u>Parents:</u> Range: 26-53 years <u>Individual interviews:</u> N/R	<u>Focus groups:</u> Leukemia: 45.45%, solid tumours: 36.36%, brain tumour: 18.18% <u>Individual interviews:</u> N/R	<u>Focus groups:</u> 63.64% on and 36.36% finished treatment <u>Time since completion of treatment:</u> N/R <u>Treatment received:</u> N/R <u>Individual interviews:</u> N/R
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Mixed methods studies

Kerr (2007), Canada	To assess supportive care needs from the perspective of parents of children diagnosed with cancer (primary outcome)	Symptoms and late effects: information needs	A survey using a revised version of the Cancer Patient Needs Questionnaire and follow-up semi-structured individual interviews <u>Qualitative data analysis:</u> a content analysis	<u>Survey:</u> 15 parents <u>Response rate:</u> 75% <u>Interviews:</u> Three mothers	<u>Survey:</u> 60% M: 40% F <u>Parents:</u> 6.67% M: 93.33% F <u>Interviews:</u> N/R <u>Parents:</u> 0% M: 100% F	<u>Survey:</u> Children: \bar{x} = 10 years <u>Range:</u> 13-18 years (40%) <u>Parents:</u> >40 years <u>Interviews:</u> N/R	<u>Survey:</u> Leukemia/lymphoma: 40%, N/R: 21% rhabdomyosarcoma: 13%, hepatoblastoma: 13%, primitive neuroectodermal tumour: 13% <u>Interviews:</u> N/R	<u>Treatment status:</u> N/R <u>Treatment received:</u> Cx: 100%, Cx + Rx + Sx: 33.33%, Cx + Sx: 26.67% <u>Interviews:</u> N/R
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Vetsch (2017), Australia and New Zealand	(1) To assess information needs of childhood cancer survivors ^a and parents, (2) to investigate associations between unmet information needs and clinical and socio-demographic characteristics of survivors and parents (primary outcome)	Late effects: information received and information needs	A developed survey, then individual interview <u>Qualitative data analysis:</u> a content analysis	<u>Survey:</u> 163 parents <u>Response rate:</u> N/R <u>Interviews:</u> 31 parents	<u>Survey:</u> Children: 59.5% M: 40.5% F <u>Parents:</u> 14% M: 84% F <u>Interviews:</u> N/R	<u>Survey:</u> Children: \bar{x} = 12.9 ± 2.4 years <u>Range:</u> 7-19 years <u>Parents:</u> N/R <u>Interviews:</u> N/R	<u>Survey:</u> First cancer diagnoses: Leukemia: 46.6%, lymphoma: 8.6%, brain tumour: 4.3%, others: 39.9% <u>Interviews:</u> N/R	100% completed treatment <u>Time since completion of treatment:</u> N/R <u>Treatment received:</u> Cx: 92.6%, Sx: 51.3%, Rx: 27.6%, SCT: 19% <u>Interviews:</u> N/R
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Wakefield (2012), Australia	To determine unmet information needs and preferences for information delivery in the first year after treatment of young cancer survivors ^a their parents and siblings (primary outcome)	Symptoms of recurrence and post-cancer fatigue: information needs	Semi-structured interviews, including one structured scoring question <u>Qualitative data analysis:</u> an induction analysis with cross-tabulating and counting of emergent themes	78 parents from 45 families <u>Response rate:</u> 34%	<u>Children of participate d parents:</u> N/R <u>Parents:</u> 43.6% M: 56.4 % F	<u>Children of participated parents:</u> N/R <u>Parents:</u> 29-65 years	No separate data for children of participated parents	100% completed treatment <u>Time since completion of treatment:</u> 0.2–41.0 months <u>Treatment received:</u> N/R
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The first author (year), country of origin	Study objective(s)^a and whether information needs was a primary or secondary outcome	Focus of information^a	Data collection method^a and qualitative analysis^a	Sample size and response rate^b	Sex (M:F)	Current age (year)	Cancer types	Cancer treatment status, time since completion of treatment if applicable, and treatment received
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Multiple-methods studies

Hobbie (2010), USA	(1) To determine the educational needs of parents as their children completed cancer treatment, and (2) to assess the feasibility of measuring parental educational needs, anxiety, and family management styles as treatment ends (primary outcome)	Symptoms and late effects: information needs and timing of information	Two focus group interviews and a pilot survey of 4 questionnaires, including Coming Off-Therapy needs survey (adapted from Nagel et al. (2002)) <u>Qualitative data analysis:</u> a content analysis	<u>Focus groups:</u> 10 parents <u>Feasibility of questionnaires:</u> 15 parents <u>Response rate:</u> 100%	<u>Focus groups:</u> 10 parents <u>Children:</u> N/R <u>Parents:</u> 30% M: 70% F <u>Feasibility of questionnaires:</u> N/R <u>Children:</u> N/R <u>Parents:</u> 7% M: 93% F	N/R	<u>Focus groups:</u> ALL, AML, Hodgkin disease, Ewing sarcoma, brain tumour, and osteosarcoma (percentages: N/R) <u>Feasibility of questionnaires:</u> ALL: 40%, Ewing sarcoma: 13%, rhabdomyosarcoma: 13%, AML: 7%, brain tumour: 7%, lymphoblastic lymphoma: 7%, osteosarcoma: 7%, N/R: 6%	100% completed treatment <u>Time since completion of treatment:</u> <u>Focus groups:</u> 11-15 months <u>Feasibility of questionnaires:</u> 3-6 months <u>Treatment received:</u> N/R
Park (2021), South Korea	(1) To explore the uncertainty level (ambiguity, lack of clarity, lack of information, and unpredictability) of parents according to each treatment phase of paediatric cancer (i.e., treatment initiation, ongoing treatment, and post-treatment), and (2) to identify parents' nursing needs for each treatment phase (primary outcome)	Symptoms and late effects: information needs based on treatment phase	Perception of Uncertainty Scale-Family Member questionnaire and open-ended questions about nursing needs <u>Qualitative data analysis:</u> a quantitative content analysis	119 parents: 39 in the treatment initiation group, 40 in the ongoing treatment group, and 40 in the post-treatment group <u>Response rate:</u> N/R	<u>Children:</u> 58.0% M: 42.0% F <u>Parents:</u> 11.8% M: 88.2% F	<u>Children:</u> $\bar{x} = 7.65 \pm 4.98$ years Range: ≤ 18 years <u>Parents:</u> Range: 23-55 years	Leukemias: 39.5%, brain tumours: 13.4%, non-Hodgkin lymphoma: 11.8%, neuroblastoma: 6.7%, osteosarcoma: 6.7%, retinoblastoma: 5.9%, rhabdomyosarcoma: 5.0%, germ cell tumour: 4.2%, Wilms tumour: 3.4%, Ewing sarcoma: 2.5%, hepatoblastoma: 0.8%	32.78% at treatment initiation, 33.61% ongoing treatment and 33.61% completed treatment <u>Time since completion of treatment:</u> <12 months (62.5%), 1-4 years (37.5%) <u>Treatment received:</u> Cx: 100%, Transplantation: 29.4%

Abbreviations: M: Male, F: Female, \bar{x} : mean of a sample, ALL: Acute Lymphoblastic Leukaemia, AML: Acute Myeloid Leukemia, Cx: Chemotherapy, Rx: Radiotherapy, Sx: Surgery, BMT: Bone Marrow Transplant, CNS: Central Nervous System, SCT: Stem Cell Transplant, N/R: Not reported

^a Reflects those that are pertinent to the objectives of this review

^b For quantitative methods

^c Percentage of parents, not their children

^d Unclear about what remission referred to as one of the inclusion criteria for that study was that the child was presently receiving treatments for cancer

^e No separate results for survivors aged ≤ 19 years

Children's information needs

Four studies (13%) reported relevant findings about children's information needs, all including only children aged ten years or older (Çavusoglu, 2000; Hooker,

1997; Levine et al., 2019; Ljungman et al., 2003). Children were included in another two studies, but Ljungman et al. (1999) combined the findings from the children and their parents, and Kin-Fong Cheng (2009)

did not report any relevant results from the children's perspective.

Children had information needs related to symptoms (Çavusoglu, 2000; Levine et al., 2019; Ljungman et al., 2003) and late effects of cancer treatment (Ljungman et al., 2003). Across the cancer trajectory from the time of diagnosis through to cure or recurrence, some children report information needs, particularly related to physical symptoms such as pain (Çavusoglu, 2000; Levine et al., 2019; Ljungman et al., 2003) (Table 2). Children rated the importance of information needs on symptoms and late effects as seven to eight out of a 10-point scale (Ljungman et al., 2003) (Table 3). In contrast, Hooker (1997) found that children ranked the priority of information on symptoms as seven out of 13 other cancer-related information topics.

Three studies investigated the information received by children (Çavusoglu, 2000; Levine et al., 2019;

Ljungman et al., 1999), although one of these studies did not report separate findings from the children's perspective (Ljungman et al., 1999). Before starting cancer treatment, children had less discussion about emotional symptoms compared with discussion about physical symptoms (Levine et al., 2019); (Table 3). During cancer recurrence and treatment phases, children reported that they had been given insufficient information about physical symptoms (Çavusoglu, 2000). In comparison to younger children (aged 10-15), older children (aged 16-18) reported having more discussion about physical and emotional symptoms with their doctors and/or parents (Levine et al., 2019). However, no studies have investigated the association between participant factors (such as age or gender) with the children's information needs or information presentation preferences. Moreover, there were no studies that compared between children's information needs during cancer treatment with their needs after treatment completion.

Table 2. Children's perspectives on their information needs compared to their parents.

	Children aged ≥10 years	Parents
Information needs (Levine et al., 2019)	Percentage of children who wanted information about managing: <ul style="list-style-type: none"> Emotional symptoms: 20.9% Physical symptoms: 24% Pain: 23.3% 	Percentage of parents wished their children to had given more information about managing: <ul style="list-style-type: none"> Emotional symptoms: 19.4% Physical symptoms: 7.8% (P < 0.001) Pain: 7% (P < 0.001)
Meeting information needs (Ljungman et al., 2003)	A mean value of the child's information needs with a "10" score referred to fully met information needs: <ul style="list-style-type: none"> Expected time for symptom recurrence: 6.3 Rating of meeting information needs of children had a similar pattern to parents, and the rating was generally lower than parents (the study only reported scores for statistically significant responses) 	A mean value of the parent's information needs with a "10" score referred to fully met information needs: <ul style="list-style-type: none"> Expected time for symptom recurrence: 8.4 (95% CI: 7.8 - 9.0), P = 0.046 Possible symptoms (8.7), physical symptoms (8.3), emotional symptoms (7.3), possible late effects (8.0), the likelihood of late effects (7.6)
Importance of information needs (Ljungman et al., 2003)	Mean values of the child's information needs out of a 10-point scale: <ul style="list-style-type: none"> Physical symptoms: 8.3 Emotional symptoms: 7.6 The likelihood of late effects: 7.4 Possible late effects: 8 	Mean values of the parent's information needs out of a 10-point scale: <ul style="list-style-type: none"> Physical symptoms: 9.6 (95% CI: 9.2 - 9.9), P = 0.038 Emotional symptoms: 9.5 (95% CI: 9.1 - 9.8), P = 0.004 The likelihood of late effects: 9.6 (95% CI: 9.2 - 9.9), P = 0.006 Possible late effects: 9.7 (95% CI: 9.5 - 10), P = 0.007

Abbreviation: CI: confidence interval

Table 3. Information received about symptoms and late effects.

Information received	Quantitative findings	Qualitative findings*
No information	<ul style="list-style-type: none"> Pain treatment: 31% of children and parents (Ljungman et al., 1999) Emotional symptoms: 20.9% of children, 6.2% of parents (Levine et al., 2019) Physical symptoms: 3.1% of children, 6.2% of parents (Levine et al., 2019) Late effects: 16.9% of parents (Vetsch et al., 2015) 	<ul style="list-style-type: none"> “We had no idea that the fatigue would be such an issue.” (Father of an 18-year-old female with thyroid cancer who was on treatment) (Loades et al., 2020, p. 1099) “I don’t know the side effects or when each one is injected.” (Koohkan et al., 2019, p. 4) “I didn’t know it would be that serious. We didn’t know what could be done.” (Kin-Fong Cheng, 2009, p. 834)
Some information	<ul style="list-style-type: none"> Pain treatment: 35% of children and parents (Ljungman et al., 1999) Emotional symptoms: 47.3% of children, 49.6% of parents (Levine et al., 2019) Physical symptoms: 38.8% of children, 29.5% of parents (Levine et al., 2019) Chemotherapy-related symptoms at diagnosis time: 90% of parents (Gunawan et al., 2014) 	“They explained some information about side effects of drugs.” (Koohkan et al., 2019, p. 4)
Enough information	<ul style="list-style-type: none"> Pain treatment: 29% of children and parents (Ljungman et al., 1999) Emotional symptoms: 31.8% of children, 43.4% of parents (Levine et al., 2019) Physical symptoms: 58.1% of children, 69.8% of parents (Levine et al., 2019) 	<ul style="list-style-type: none"> “I was prepared for the tiredness quite well through either the literature or through um the specialist nurses” (a mother of a 15-year-old female with acute lymphoblastic leukemia who was off treatment) (Loades et al., 2020, p. 1099) Parents were satisfied with limiting information by healthcare providers about symptoms and late effects during the initial treatment phases (Ringnér et al., 2011)
Format of information received/used*	<ul style="list-style-type: none"> Alopecia: 66% of parents received information from parents of other cancer patients, 14% from doctors, 6% from the internet, 4% from relatives, 4% from books, 2% from nurses, 2% from friends (Gunawan et al., 2016) Late effects: 74.6% of parents received verbal information, 19% written information (Vetsch et al., 2015) Symptom tracking/management applications regularly used on mobile phones: 12.4% of parents (Mueller et al., 2018) 	“I was prepared for the tiredness quite well through either the literature or through um the specialist nurses” (a mother of a 15-year-old female with acute lymphoblastic leukemia who was off treatment) (Loades et al., 2020, p. 1099)

* From studies that reported only parents’ perspectives

Information needs of parents

All included studies investigated parental information needs about their child’s symptoms (Table 1), except two studies (Çavusoglu, 2000; Hooker, 1997). Information needs about pain and fatigue were most frequently assessed in the included studies (Levine et al., 2019; Ljungman et al., 1999; Loades et al., 2020; Vetsch et al., 2017; Wakefield et al., 2012). Furthermore, parental information needs about symptom management specifically were reported in 23% (N = 7) of the studies (Gunawan et al., 2016;

Hobbie et al., 2010; Ji et al., 2018; Kerr et al., 2007; Levine et al., 2019; Motlagh et al., 2019; Mueller et al., 2018).

Across the included studies, parents needed to know possible symptoms, detailed information about specific symptoms, symptoms of chemotherapy and new treatment, adolescent-specific information, expected time for symptom occurrence, reasons for symptom recurrence, symptom management, late effects, and symptoms of recurrence (Figure 2, Table

4). Overall, $\geq 70\%$ of parents needed information about symptoms and late effects (Figure 2). However, there was variability in parental information needs pertaining to pain, fatigue and symptom management (Figure 2). Information needs regarding symptoms (Arabiat & Altamimi, 2013; Ljungman et al., 2003) and late effects (Ljungman et al., 2003) were rated as highly important by parents, but only a medium priority when compared with other information needs (Pyke-Grimm et al., 1999).

The amount of information received by parents regarding symptoms, symptom management and late effects was variable (Table 3). Some parents did not receive information from healthcare providers but through less formal pathways such as other parents of childhood cancer patients or the internet. Barriers to both information-seeking and information delivery concerning symptoms were identified, including a history of unfulfilled information needs (Mercer & Ritchie, 1997b), as well as a lack of educational materials about symptoms and provision of information by junior medical staff only (Gunawan et al., 2016; Gunawan et al., 2014).

Five studies (17%) reported on factors related to parents' information needs relevant to symptoms and

late effects (Ljungman et al., 2003; Motlagh et al., 2019; Mueller et al., 2018; Pyke-Grimm et al., 1999; Vetsch et al., 2015), (Table 5). Parents' need for more information was significantly associated with having a small family size (Motlagh et al., 2019), parental involvement in follow-up care, having more concerns about cancer consequences, and not receiving any information about late effects (Vetsch et al., 2015). There were inconsistencies in the associations between parental information needs and their education or income, with Motlagh et al. (2019) reporting an increase in information needs for parents with low educational level or low economic status, but three other studies did not find significant associations with parental education level (Mueller et al., 2018; Pyke-Grimm et al., 1999; Vetsch et al., 2015) or their income (Mueller et al., 2018). Furthermore, there was no association between parental information needs and their child's cancer diagnosis (i.e., leukaemia/lymphoma, CNS tumour, or other tumours) (Vetsch et al., 2015), disease severity (i.e., low, intermediate, or high risk) (Pyke-Grimm et al., 1999), time since cancer diagnosis in months or years (Pyke-Grimm et al., 1999; Vetsch et al., 2015), treatment received (i.e., chemotherapy, surgery, radiotherapy, or SCT) (Pyke-Grimm et al., 1999; Vetsch et al., 2015) or treatment status (i.e., on vs. off treatment) (Ljungman et al., 2003).

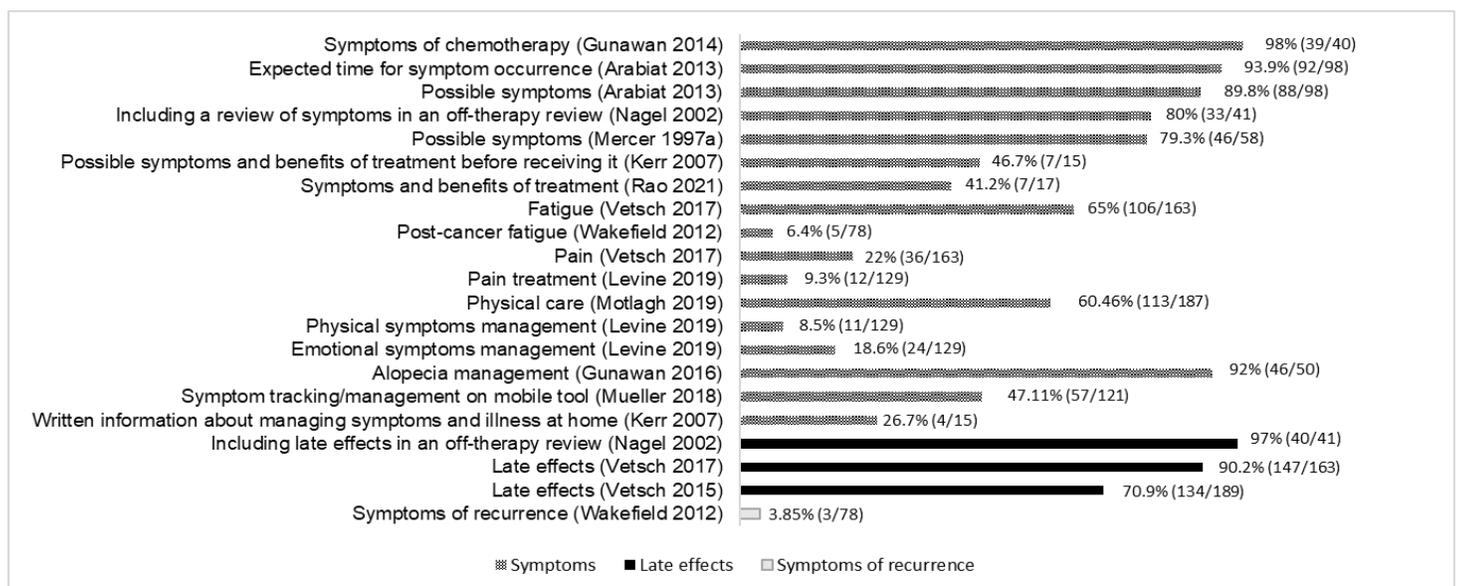


Figure 2. Proportion of parents who reported information needs about symptoms and late effects.

Table 4. Qualitative findings about parents' information needs.

Information needs	Relevant themes and subthemes	Exemplar quotes
Detailed information about certain symptoms that were specific to adolescents	Theme: "health care needs," subtheme: "education needs" (Kin-Fong Cheng, 2009, p. 834)	"I needed the doctor to explain to us what it's like to have [oral mucositis], the severity of it, and the extent of oral ulceration, how serious it was. It'd reassure me." (Kin-Fong Cheng, 2009, p. 834)
	Theme: "how do we manage?" subtheme: "seeking support from others" (Loades et al., 2020, pp. 1098, 1099)	"I definitely think there needs to be something that is very much adolescent age specific...they're not children...they've got very different needs" (Mother of an 18-year-old female with Ewing's sarcoma who was off treatment) (Loades et al., 2020, p. 1099)
Information about possible symptoms at admission to the hospital and during hospitalisation	Theme: "unmet need for adequate information" (Lyu et al., 2019, p. e69)	"We should be given some information at the beginning of the child's hospitalisation. The information should include why the child's behaviour is as it is, what kind of side effects may emerge during treatment, why the child becomes irritable and why some symptoms recur, and so on..." (Mother) (Lyu et al., 2019, p. e69)
	Overarching theme: "information needs," theme: "obtained information after diagnosis," subtheme: "therapy complications" (Kilicarlan-Toruner & Akgun-Citak, 2013, p. 179)	"... other parents of children with cancer said that chemotherapy affects children's psychology more. I try to learn the bad sides and the good sides of those medicines." (Kilicarlan-Toruner & Akgun-Citak, 2013, p. 180)
	Theme: "Information about cancer," subtheme: "medicine information (side effects, effectiveness, etc.)" (Koohkan et al., 2019, p. 4)	"I don't know the side effects or when each one is injected." (Koohkan et al., 2019, p. 4)
Information about symptoms of new treatment during treatment phase	Themes: "progress of treatment and medication" and "adverse effects of treatment and coping strategy" (Park et al., 2021, p. 9)	"When introducing a new treatment or drug, I would like an exact explanation of why it is used, its side effects, its intended effects, test results with detailed descriptions, and the exact treatment process." (Park et al., 2021, p. 10)
Information about late effects	Theme: "need for information," subtheme: "about long-term prognosis and side effects" (Kerr et al., 2007, p. 287)	"Concern of the long-term effects of getting these types of medications over such a long period of time." (Mother) (Kerr et al., 2007, p. 288)
	Theme: "unmet information needs" (Vetsch et al., 2017, p. 359)	"I think that information [about late effects] and knowledge is always useful; knowing when not to have to panic or being prepared if something does happen. You can say, well yeah I knew that might have been a risk. You're sort of almost prepared for it – forewarned and forearmed." (Parent of a 12-year-old male who was off treatment) (Vetsch et al., 2017, p. 359)

The timing of providing information for parents was outlined in four studies (13%) (Hobbie et al., 2010; Kilicarlan-Toruner & Akgun-Citak, 2013; Lyu et al., 2019; Ringnér et al., 2011). At times of significant events, for example, diagnosis (Kilicarlan-Toruner & Akgun-Citak, 2013), during treatment (Kilicarlan-Toruner & Akgun-Citak, 2013) and in the event of hospitalisation (Lyu et al., 2019), parents reported needing more information about symptoms. Parents also needed information about recognising possible symptoms at the end of the treatment (Hobbie et al.,

2010; Ringnér et al., 2011) and information about late effects to be delayed (Hobbie et al., 2010).

Five studies (17%) reported results regarding the preferred sources of information for parents (Gunawan et al., 2016; Hobbie et al., 2010; Nagel et al., 2002; Ringnér et al., 2011; Vetsch et al., 2015), (Table 6). Overall, parents wanted to receive information about symptoms and late effects from doctors (Gunawan et al., 2016; Nagel et al., 2002). Additionally, parents requested a written overview or guide, including symptoms and how to manage them (Hobbie et al.,

2010; Ringnér et al., 2011). For late effects, written and verbal formats were more preferred over online information (Vetsch et al., 2015). Furthermore, parents

wanted a formal appointment or meeting to review information about coming off treatment (Nagel et al., 2002; Ringnér et al., 2011).

Table 5. Factors associated with parents' information needs about symptoms and late effects.

	Factors associated with information needs	No associations *
Symptoms	<p><u>Possible symptoms</u> (Pyke-Grimm et al., 1999) High importance of information needs in parents preferred:</p> <ul style="list-style-type: none"> active role (ranked first out of nine items) in treatment decision making followed by preferred collaborative (ranked fifth) then passive role (ranked seventh) <p><u>Management of physical symptoms</u> (Motlagh et al., 2019) More information needs associated with:</p> <ul style="list-style-type: none"> low education level (t test = 8.664, $P < 0.001$) low economic status (t test = 5.976, $P = 0.003$) less family size member (t test = 9.139, $P < 0.001$) 	<p>No association between information needs about symptoms and the following:</p> <ul style="list-style-type: none"> child's age (Pyke-Grimm et al., 1999) child's and parent's gender (Motlagh et al., 2019; Pyke-Grimm et al., 1999) parental age, their education level (Mueller et al., 2018; Pyke-Grimm et al., 1999) parental marital status (Pyke-Grimm et al., 1999) parental annual household income (Mueller et al., 2018) parental insurance (Motlagh et al., 2019) time since diagnosis in months, disease severity (i.e., low, intermediate, or high risk), treatment received (i.e., chemotherapy, surgery, or radiotherapy) (Pyke-Grimm et al., 1999) No association between the importance of information needs about symptoms and treatment status (i.e., on vs off treatment) (Ljungman et al., 2003)
Late effects	<p>Having information needs about late effects (Vetsch et al., 2015) associated with:</p> <ul style="list-style-type: none"> parental involvement in follow-up care (OR = 2.7, 95% CI: 1.29–5.77, $P = 0.009$) greater concerns about cancer consequences (medium concerns: OR = 2.11, 95% CI: 0.91–4.88, high concerns: OR = 3.06, 95% CI: 1.37–6.84; $P = 0.019$) not receiving any information (OR = 2.62, 95% CI: 0.95–7.24, $P = 0.045$) 	<p>No association between information needs about late effects (Vetsch et al., 2015) and the following:</p> <ul style="list-style-type: none"> parental gender, age, education level, migration background, language region, employment, parent-reported late effects, type of treating hospital, the child's age at diagnosis, time since diagnosis in years, treatment received (i.e., chemotherapy, surgery, radiotherapy, or SCT), and relapse <p>No association between the importance of information needs about late effects and treatment status (i.e., on vs off treatment) (Ljungman et al., 2003)</p>
Abbreviations: OR: Odd Ratio, CI: Confidence Interval		

Table 6. Needed/preferred sources of information for parents about symptoms and late effects.

Needed/preferred sources of information for parent		
	Who deliver information	How to receive information
Symptoms	<ul style="list-style-type: none"> Doctors to provide information about alopecia: 92% of parents (Gunawan et al., 2016) Healthcare providers reviewing coming off treatment review that included symptoms: doctors (90%), nurses (73%), child life specialist (63%), social workers (47%), nutritionist (40%), physiotherapist (37%), pharmacist (17%) (Nagel et al., 2002) 	<ul style="list-style-type: none"> A meeting and a written overview included possible symptoms at the end of treatment (Ringnér et al., 2011) A guide for off-therapy involved practical information about symptom management (Hobbie et al., 2010) A formal appointment for reviewing coming off treatment information involved symptoms (Nagel et al., 2002)

Late effects	<ul style="list-style-type: none"> Healthcare providers reviewing coming off treatment review that included late effects: doctors (90%), nurses (73%), child life specialist (63%), social workers (47%), nutritionist (40%), physiotherapist (37%), pharmacist (17%) (Nagel et al., 2002) 	<ul style="list-style-type: none"> Different formats: written general (~27%), verbal general (~25%), written personal (~21%), online (~12%) (Vetsch et al., 2015) A formal appointment for reviewing coming off treatment information involved late effects (Nagel et al., 2002)
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Children's perspective on their information needs compared with their parents' perspective

Two studies (7%) compared children and their parents' perspectives on information needs (Levine et al., 2019; Ljungman et al., 2003). Children needed more information about managing physical symptoms as well as managing pain than what their parents wished them to have ((Levine et al., 2019); Table 2). Children's information needs about symptom recurrence were met less than their parents ((Ljungman et al., 2003); Table 2). However, there was no statistical difference found between children's and parents' information needs regarding possible symptoms and late effects (Ljungman et al., 2003). For managing emotional symptoms, the percentage of children who needed more information was similar to the percentage of their parents who wanted them to have more information (Levine et al., 2019). Children reported a lower ranking of importance of information needs about symptoms and late effects than parents (Ljungman et al., 2003).

Two studies (7%) reported information received by children and their parents (Levine et al., 2019; Ljungman et al., 1999). When asked about information received before starting cancer treatment, children reported receiving less information about physical symptoms from their parents and or doctors than their parents ((Levine et al., 2019); Table 3). However, comparable percentages of children and parents received less information about emotional symptoms than physical symptoms (Levine et al., 2019). When findings from children and their parents were combined, more participants were likely to report they had received insufficient information on pain

management than sufficient information ((Ljungman et al., 1999); Table 3). However, the number/percentage of children and their parents reporting not receiving any information was not different based on the child's age group, i.e., <5 years vs ≥5 years (Ljungman et al., 1999). None of the included studies reported relevant findings comparing the associated factors with information needs between children and their parents, nor the difference between children and their parents' information preferences about symptoms.

Quality appraisal of included studies

Four studies (13%) met all methodological quality requirements (Arabiat & Altamimi, 2013; Kin-Fong Cheng, 2009; Loades et al., 2020; Lyu et al., 2019). For the remaining studies, methodological flaws were present (Table 7). For example, several qualitative and mixed methods studies did not report adequate quotes to support their interpretations; therefore, coherence between data collection, analysis and interpretation for those studies was not known. Half of the included studies did not report clear information about the sampling strategy for quantitative methods (Table 7). Quantitative and mixed/multiple methods studies had small sample sizes (ranging from 9 participants to 129 dyads), and all except one study (Arabiat & Altamimi, 2013) used non-validated tools to measure information needs. The risk of nonresponse bias also was high in six quantitative studies. In each mixed methods study, methodological reporting requirements for the quantitative component were met less frequently than for the qualitative component. Lastly, there was inadequate data integration in all mixed methods studies.

Table 7. Results of quality assessment of included studies using Mixed Methods Appraisal Tool.

Methodological quality criteria	First author and year	Qualitative related questions					Quantitative related questions					Mixed methods related questions				
		Q 1	Q 2	Q 3	Q 4	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10	Q 11	Q 12	Q 13	Q 14	Q 15
Qualitative related questions	Mercer (1997b)	Y	Y	Y	C/T	C/T	Not applicable					Not applicable				
Q1: Is the qualitative approach appropriate to answer the research question?	Çavusoglu (2000)	Y	Y	C/T	N	C/T										
Q2: Are the qualitative data collection methods adequate to address the research question?	McGrath (2007)	Y	Y	Y	Y	C/T										
Q3: Are the findings adequately derived from the data?	Kin-Fong Cheng (2009)	Y	Y	Y	Y	Y										
Q4: Is the interpretation of results sufficiently substantiated by data?	Ringér (2011)	Y	Y	Y	C/T	C/T										
Q5: Is there coherence between qualitative data sources, collection, analysis and interpretation?	Kilicarstan-Toruner (2013)	Y	Y	Y	Y	C/T										
	Koohkan (2019)	Y	Y	Y	C/T	C/T										
	Lyu (2019)	Y	Y	Y	Y	Y										
	Loades (2020)	Y	Y	Y	Y	Y										
Quantitative related questions	Wells (1990)	Not applicable					C/T	C/T	C/T	N	Y	Not applicable				
Q6: Is the sampling strategy relevant to address the research question?	Hooker (1997)						C/T	C/T	Y	C/T	Y					
Q7: Is the sample representative of the target population?	Mercer (1997a)						C/T	Y	C/T	N	Y					
Q8: Are the measurements appropriate?	Ljungman (1999)						C/T	Y	N	Y	Y					
Q9: Is the risk of nonresponse bias low?	Pyke-Grimm (1999)						C/T	Y	C/T	N	Y					
Q10: Is the statistical analysis appropriate to answer the research question?	Nagel (2002)						C/T	Y	N	Y	N					
	Ljungman (2003)						Y	Y	C/T	N	Y					
	Arabiat (2013)						Y	Y	Y	Y	Y					
Mixed methods related questions	Gunawan (2014)						Y	Y	C/T	Y	Y					
Q11: Is there an adequate rationale for using a mixed methods design to address the research question?	Vetsch (2015)						Y	Y	N	N	Y					
Q12: Are the different components of the study effectively integrated to answer the research question?	Gunawan (2016)						C/T	Y	C/T	Y	Y					
Q13: Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Ji (2018)						C/T	Y	C/T	Y	Y					
Q14: Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Mueller (2018)						Y	Y	N	N	Y					
Q15: Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Levine (2019)						C/T	Y	C/T	Y	C/T					
	Motlagh (2019)						C/T	Y	C/T	C/T	Y					
	Rao (2021)						C/T	C/T	C/T	Y	Y					
	Hobbie (2010)	Y	C/T	Y	N	C/T	C/T	N	C/T	Y	C/T	Not a mixed method design				
	Park (2021)	Y	C/T	Y	Y	C/T	Y	Y	Y	C/T	Y					
	Kerr (2007)	Y	C/T	Y	Y	C/T	C/T	Y	C/T	Y	Y	Y	C/T	N	C/T	C/T
	Wakefield (2012)	Y	Y	Y	Y	Y	Y	Y	C/T	C/T	Y	N	C/T	C/T	C/T	C/T
	Vetsch (2017)	Y	Y	Y	C/T	Y	C/T	Y	C/T	Y	Y	Y	C/T	C/T	C/T	C/T

Abbreviations: Q: Question, Y: Yes, N: No, C/T: Can't tell

Discussion

This systematic review aimed to explore the information needs and preferences of children with cancer and their parents about cancer/treatment-related symptoms during and after curative cancer treatment. This study revealed that children with cancer and their parents have unmet information needs, with some reporting they received no information about symptoms and late effects.

However, children's perspectives on their information needs differed from their parents. There is also limited evidence on associations with information needs as well as information preferences concerning symptoms and late effects. Differences in the information needs findings between studies may relate to the focus or aim of each study. For example, when asked generally about symptoms and late

effects, most parents reported having unmet information needs. However, when the research focused on specific symptoms, lower percentages of children and/or their parents reported information needs. Variability between studies may also be due to the variability in symptoms experienced by cancer patients, with some children experiencing more symptoms than others (Hedén et al., 2013; Miller et al., 2011), although this requires more investigation. Similarly, more research is required to determine the difference in perspectives on information needs between children and their parents, as parents often act as proxy reporters for their children in paediatric research.

The views of children on their information needs did not align with their parents' expectations of the child's needs. This finding aligns with research on symptoms related information needs involving children receiving palliative care for cancer (Ellis & Leventhal, 1993), suggesting that parents may not recognise their child's information needs. Furthermore, some children did not receive enough information about symptoms via their parents and/or doctors. Potentially, this finding may be due to information not always being passed on to them by their parents (Hokkanen et al., 2004). Adolescents, therefore, preferred leading communication with healthcare providers over their parents (Gibson et al., 2010). Parents tend to underestimate their children's understanding of cancer (Smith et al., 2019) or act as gatekeepers of information (Bahrami et al., 2017). It is recommended that children be addressed directly, provided with age-appropriate information, and involved with communication about symptoms. Furthermore, little research has accounted for children's perspectives on their information needs and preferences about symptoms, which might be due to difficulty in recruitment and in interviewing or surveying young children about their experiences with information. What, when and how children need to

know about symptoms during and after cancer treatment require further investigation, especially as they transition to young adult health services and survivorship.

Most parents reported significant information needs about symptoms and late effects in general, as has been found in adolescents and young adults with cancer (Karst et al., 2018; Keegan et al., 2012; McCarthy et al., 2018; Tsangaris et al., 2014). However, there was a lack of clarity about the factors that may be associated with parental information needs, with poor reporting in the included studies. Further research, therefore, is needed to explore the association between information needs on symptoms with important factors such as paediatric age groups, type and stage of tumour, type of treatment received and treatment status (i.e., on vs off treatment). Moreover, the form that information on symptoms is received is important to parents. Parents preferred information delivered by doctors, with more preference for written and verbal formats than online information, a preference which is supported in the previous studies on adolescents and young adults with cancer (Christen et al., 2019; Dyson et al., 2012; Karst et al., 2018; Rodgers et al., 2016; Tsangaris et al., 2014). When parents were asked generally about their information-seeking or preferences, they reported some barriers to accessing online information, such as the inability to trust mobile apps, unavailability of helpful websites or apps (Mueller et al., 2018), the risk of accessing inaccurate/out-of-date information, too much available data (Wakefield et al., 2012) and information deemed to be too threatening (McGrath et al., 2007). As technology changes, there is a need to understand children with cancer and their parents' interactions with technology regarding information needs and preferences about symptoms and symptom management.

While this systematic review utilised all available literature in the identified area, there are a number of limitations of the included studies that should be considered. Firstly, there was ambiguity in the terms around “symptoms” as well as “information needs” in the eligible studies. This review, therefore, had broad criteria for inclusion to avoid missing any relevant findings concerning information needed about symptoms. However, future research on defining terms such as symptom, side effect, and late effect of paediatric cancers and their treatments would assist in focusing the information needs literature. Secondly, integration of quantitative and qualitative data was planned. However, best practices for mixed methods data integration in systematic reviews could not be applied because of variability in tools and questions used to assess information needs (Stern et al., 2020). Many of the eligible studies found limited relevant results or reported inadequate quotes relevant to the review aims, which limited the integration of mixed methods findings into the results of this review. Thirdly, the majority of the included studies had methodological quality issues such as inadequate reporting of sampling strategy, lack of using standardised outcome measures for information needs, high risk of nonresponse bias, insufficient interpretation of some qualitative results, and inadequate data integration for mixed methods studies. Fourthly, sub-analysis investigating differences in information needs between children of different ages or types of cancer could not be made due to the sample sizes and different outcome measures used. This heterogeneity of cancer diagnoses and age groups is a frequent challenge in paediatric oncology research because childhood cancers are rare diseases (Ward et al., 2014). Lastly, exclusion of literature written in other languages than English and publication bias should be considered when interpreting the results of this review.

The findings from this review suggest a number of recommendations for clinical practice. There is a need for an individualised approach to meet the information needs of children and their parents/carers about symptoms and late effects. Tailored psycho-educational resources co-designed by healthcare professionals and families of children with other childhood diseases, such as congenital heart disease, have been successful in alleviating mental health of children and their families (Kasparian et al., 2016). However, sharing information in an open and honest approach was supported by healthcare professionals but not by all parents of children with cancer (Coyne et al., 2016). Healthcare providers, therefore, could regularly assess the information needs of children and their parents, including their interest in learning and their preferred source of information, to identify their priorities for information and how to meet their information needs. Moreover, there is a need to develop specific well-designed websites and smartphone applications to overcome parents’ perceived barriers to accessing online information. Other recommendations include: (a) developing an information checklist for topics that should be discussed with children and their parents, (b) encouraging parents and their children to prepare their checklist before meeting with the healthcare providers, (c) creating time and space specifically for discussion on information needs, (d) providing communication training for healthcare providers if needed, and (e) using age-appropriate information with understandable language to children directly and to their parents across multiple occasions throughout cancer journey. However, integrating multidisciplinary healthcare, including psycho-social support, as well as engagement with consumers and end-users, is critical to ensure that these recommendations are effective and can be implemented in clinical care. Lastly, there is a need for more targeted studies on children with cancer and

their parents' information needs and preferences about symptoms.

Conclusion

Children with cancer and their parents have considerable unmet information needs regarding cancer-related symptoms, but their perspectives differ. Moreover, children's preferences on delivery of information on their cancer-related symptoms are underexplored. Parents appear to rely mainly on doctors and written/verbal formats, reporting hesitations in online sources. This review highlights the need for individualized, family-centred communication strategies, including age-appropriate materials about cancer-related symptoms for children with cancer as well as structured, trustworthy educational resources for their parents. Future longitudinal and mixed-methods studies are warranted to clarify changes in information needs and preferences pertaining to symptom burden across the child's cancer trajectory in order to guide the development of targeted interventions that improve communication, support, and quality of life among this population.

Author Contributions

All authors significantly contributed to the work reported, including conception, study design, execution, data acquisition, analysis, and interpretation. They actively participated in drafting, revising, or critically reviewing the manuscript, provided final approval of the version to be published, agreed on the journal submission, and accepted accountabilities for all aspects of the work.

Data Availability Statement

The authors will transparently provide the primary data underpinning the findings or conclusions of this article, without any unjustified reluctance. If needed from editorial team.

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Conflicts of Interest

The authors declare no potential conflicts of interest related to the research, writing, or publication of this work.

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