



Integrative review of school integration support following pediatric cancer

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Abstract

Purpose This study aims to understand parents' experiences of school integration support for their child's transition to K-12 schooling during or after cancer treatment.

Methods This integrative literature review used PubMed, CINAHL, PsycINFO, and Embase databases and included articles from January 2000 to July 2022 describing parent experiences with support from healthcare providers, school faculty/systems, and school integration programs. This review was guided by an adapted School Re-Entry Model and used constant comparison to identify common themes and guide synthesis. The Johns Hopkins Evidence and Quality Guide was used to appraise article quality and level of evidence.

Results Thirty-five articles were included in the final review: seventeen qualitative, fourteen quantitative, and four mixed or multi-method designs. Parents reported experiences receiving support from healthcare providers, school faculty/systems, school integration programs, and "other" sources. Parents reported both facilitators and barriers to communication, knowledge, and the process of receiving school integration support.

Conclusions Parents found neuro/psychologists highly supportive but reported limited support from other healthcare providers. Most parents reported mixed experiences with school faculty and reported many barriers to school system support. Parents reported positive experiences with school integration programs; however, limited programs were available.

Implications for Cancer Survivors Future programs and research should focus on addressing identified barriers and facilitators of school integration support. Further work is also needed to understand a wider range of parent experiences during school integration.

Keywords Cancer survivors · Parents · Return to school · Schools · Systematic review

Introduction

With advancements in research and treatment of pediatric cancer, more children are surviving than ever before [1]. Despite improved survival rates, there remain many long-term effects of cancer treatment that can begin during or after treatment and reduce a child's quality of life [2]. Neurocognitive late effects include impaired working memory, concentration, processing speed, intelligence, and attention [3–7]. Neurocognitive late effects can also affect a child's learning abilities, school achievement, and future employment opportunities [8]. It is estimated that over 90% of pediatric brain tumor survivors experience cognitive impairment post-treatment [9]. Additionally, 80% of adolescents from a combined brain tumor/acute lymphoblastic leukemia sample experienced cognitive impairments [10]. Many survivors experience neurocognitive late effects post-treatment and may benefit from classroom accommodations and/or special education services in school

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following diagnosis to optimize academic outcomes and to keep up with their same-aged peers. However, the process of obtaining special education services and navigating the school system can be daunting. Parents must advocate for their child's eligibility and be aware of and knowledgeable about available supports and services [11]. Although many challenges accompany a child's return to school, we found no review of the literature specifically focused on parents' experiences of school integration support following their child's cancer diagnosis.

Previous reviews examined perspectives of stakeholders other than parents on the return to school, including healthcare providers, school faculty, and the child [12, 13]. Vanclooster et al. [13] examined parent perspectives along with other stakeholders during the process of returning to school, focusing on communication. In contrast, the aim of this integrative literature review was to focus solely on parent experiences of receiving school integration support during their child's transition to school during or after cancer treatment. The parent perspective was chosen because of the parent's critical role as an intermediary between the medical team and the school faculty and as an advocate for their child. The review examined the following questions: (1) what experiences do parents have in receiving support from healthcare providers, school faculty, and school integration programs during their child's post cancer diagnosis attendance at school? And (2) what are the parent perceived barriers and facilitators for receiving school integration support?

Methods

This review was guided by an adaptation of the School Re-Entry Model [11]. The School Re-Entry Model was created using a grounded theory approach based on the qualitative experiences of parents during their child's re-entry to school after cancer [11]. This model was chosen because it outlines specific constructs that are key to the parent experience of school integration support. These constructs include communication across the medical team, education system, and family unit; stakeholder knowledge; and the process of school re-entry [11]. Our update, or the Adapted Parent Experiences of School Integration Support Model, includes these key constructs of communication, knowledge, and process (Fig. 1). The parent experience of communication and knowledge during the school entry process is influenced by their interactions with healthcare providers, school faculty/system, and school integration programs and their perceptions of how these groups interact with one another [11]. School integration programs were added into the adapted model as these programs have been shown to be helpful for the school entry process [12]. The adaptation reflects explicit inclusion of children diagnosed before they are school-aged — hence the shift to language of attendance, entry, or integration as opposed to re-entry or reintegration.

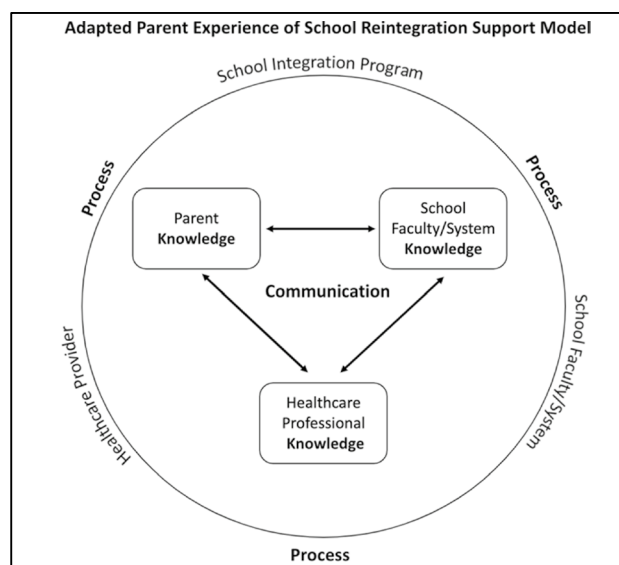


Fig. 1 Adapted Parent Experiences of School Integration Support Model. Model definitions: *communication*, interactions “occurring between individuals or institutions [11];” *knowledge*, “information residing in an individual or stakeholder [11];” *process*, logistics of the transition to school and access to services [11], as influenced by the timing of support, actions of involved stakeholders, and available resources; *healthcare professionals*, trained care providers working with the survivor or family including, but not limited to, oncologists, primary care providers, oncology nurses, and neuro/psychologists. Healthcare professionals may work within the hospital, outpatient, or school setting (i.e., school nurse); *school faculty*, the individual staff at the school, such as a general education teacher, special education teacher, school principal, tutor, or school counselor; *school system*, institution where the child receives education; *school integration program*, an intervention, program, or model of care developed and implemented to help parents and children with the transition to school during or after active cancer treatment. This includes, but is not limited to, school liaison programs and school integration research interventions

Search strategy

We examined four databases (PubMed, CINAHL, PsycINFO, and Embase) to identify papers that discussed parent experiences of school integration support during their child's attendance at school post cancer diagnosis. We used the following keywords and medical subject headings in our search: neoplasms, adolescent, child, parents, guardian, family, and schools. Please see supplemental information for full search terms used for each database. The reference lists of each article were reviewed for additional studies to be included.

Inclusion and exclusion criteria

Articles published between January 2000 and July 2022 were included. Older studies were excluded given the lower 5-year survival rate for pediatric cancer during this time [1, 14],

and research prior to 2000 tended to focus on contemporary treatment strategies with more homogenous toxicity profiles. Studies were included if they described parent experiences and perspectives on the support that they received during their child's attendance at school post cancer diagnosis. Attendance in school was defined as attending in-person K-12 schooling after a cancer diagnosis, during active cancer treatment, or in partial or complete remission. All malignant pediatric cancer types were included. Parent experience with school integration support was defined as any qualitative or quantitative report of support received from a healthcare provider, school faculty, or school integration program.

Studies were excluded from review if they were not retrievable in English or were gray literature. Studies were excluded if they focused primarily on a serious illness other than pediatric cancer or nonmalignant conditions. Studies that described perspectives of parents with children who had not begun attending school or perspectives from other stakeholders were also excluded. Both EP and CMP independently reviewed the titles/abstracts and full texts and met to reach consensus on article inclusion.

Critical appraisal

The Johns Hopkins Evidence and Quality Guide was used to critically appraise the level of evidence and quality of the articles included [15]. Each article was first reviewed for its level of evidence and subsequently reviewed for its quality as a qualitative, quantitative, or mixed/multi-methods design.

Article synthesis

Articles were synthesized using the constant comparison method to identify emerging themes and patterns according to the iterative process outlined by Miles and Huberman [16, 17]. EP and CMP used the constant comparison method to compare results across articles and synthesize themes across the constructs of the Adapted Parent Experiences of School Integration Support Model.

Results

A total of 4576 results were produced from the database search. After screening by title/abstract, 80 full-text articles were reviewed resulting in 35 eligible studies (Fig. 2), including seventeen qualitative, fourteen quantitative, and four mixed or multi-method study designs, summarized in Table 1. In most studies, the term “parent” was an overarching term, which included biological parents or other caregivers. The studies were conducted in 11 different countries with parents of children with a variety of types of cancers. Only ten of the studies reported the race and ethnicity of the child or the parent. Results were categorized following the Adapted Parent Experiences of School Integration Support Model [11].

Healthcare providers

Sixteen of the included studies discussed parent experiences with communication, knowledge, and process of receiving support from healthcare providers.

Communication

Studies reported parent–healthcare professional communication about child neurocognitive needs. There was limited communication from the oncology team on the child's neurocognitive needs. Many parents reported that they did not receive communication about future treatment-related neurocognitive challenges from their oncology team [11, 46]. Thornton et al. found that fewer than half of parents (49%) had conversations regarding the neurocognitive effects of therapy with primary care providers at every visit, and 12% reported never having these conversations [52]. However, parents did report receiving communication from neuro/psychologists, if referred for these services by the oncology team. Parents described written reports from the neuro/psychologist as a method of clear communication about their child's neurocognitive needs. Parents in both qualitative and quantitative studies found that the reports were written in easily understandable language that included “laymen's terms” and clear explanations of complex terminology [21, 38].

Knowledge

The neuropsychological report increased parent knowledge of available supports, such as specific assistance and accommodation strategies, as well as general knowledge about their child's needs [11, 38]. In contrast, parents reported receiving limited information from the oncology team. Parents did not feel the oncology team fully comprehended or divulged the non-health aspects of school integration challenges, such as legal rights to educational access or additional resources to address learning difficulties [11, 46, 52]. Ruble et al. [46] reported that parents desired additional information on non-health aspects of school integration from their child's oncology team but were rarely provided with this information.

Process

Parents frequently described their experience with neuropsychology evaluations [21–47] and found it to be an effective resource during the transition to school [21, 38]. Parents in a qualitative study completed in the USA reported that the neuropsychological reports lent authority to and helped establish validity for their requests for additional academic support [11]. Parents also described meetings with

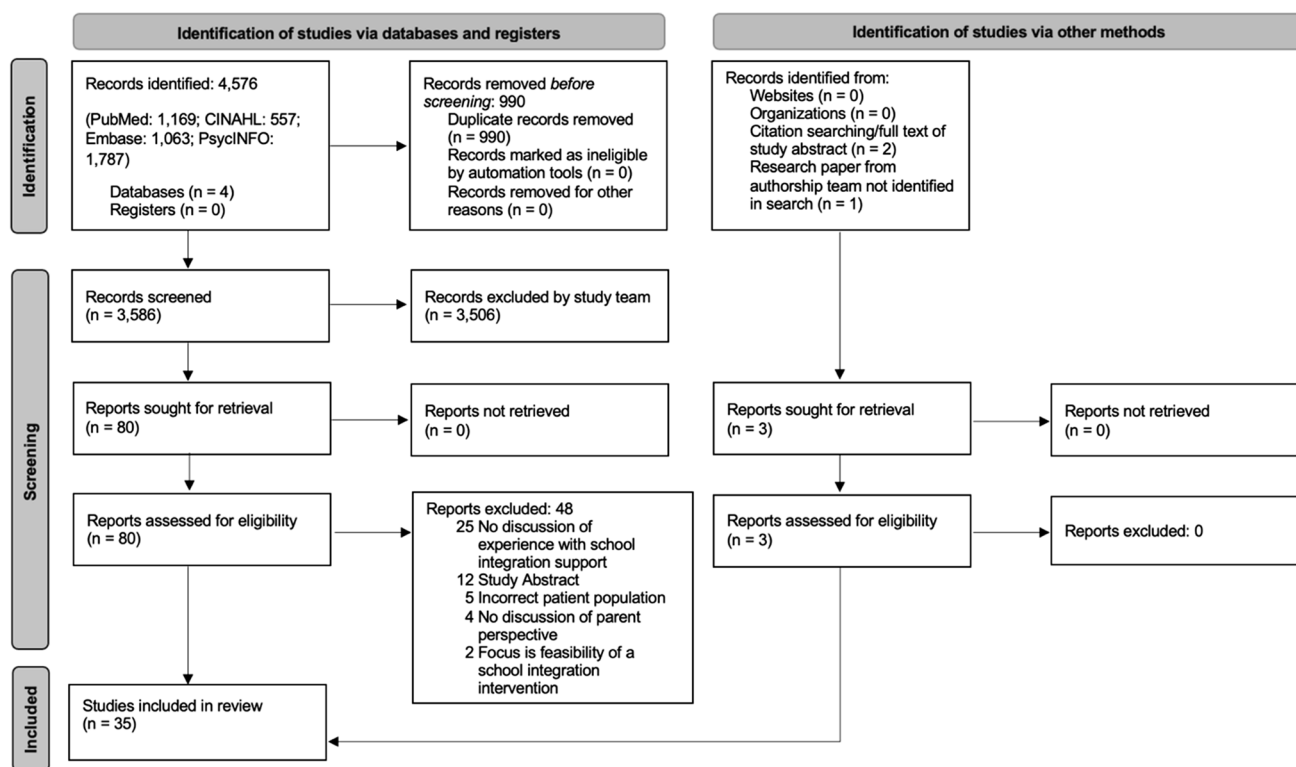


Fig. 2 PRISMA flow diagram. Source: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. <https://doi.org/10.1136/bmj.n71>

other healthcare professionals during their child's transition to school, including physical and occupational therapists [33, 41], speech therapists [41], and psychologists [47, 33]; however, it was not clear from these studies whether these meetings with other providers were beneficial for school integration.

Parents reported desiring support from healthcare providers during the transition to school [40, 29]. However, they tended to find support from healthcare providers unsatisfactory or completely lacking [38, 47, 29, 27]. Regarding the support that did exist, parents reported that psychologists needed to provide more psychosocial support and guidance to parents [47], referrals from other healthcare providers to neuro/psychologists were infrequent [38], they felt abandoned by the oncology team after the completion of treatment [29], and that the healthcare team should provide education to school faculty on their child's illness [40, 29]. Additionally, the timing of information received from healthcare providers was unhelpful — the information provided was too much all at once, and too early during the child's illness [46, 21].

School faculty and system

Twenty-five studies discussed parent experiences with school faculty or the school system, including communication with

school faculty, school faculty knowledge, and the process of receiving support from school faculty and accessing resources in the school system.

Communication

There was a range of both negative and positive experiences with parent–school faculty communication. Parents who described negative experiences felt burdened with the responsibility of monitoring their child's progress [11], reminding school faculty of their child's needs [21, 38, 19], and taking the initiative to educate school faculty on their child's illness [24]. Across studies, parents reported that teachers needed frequent reminders regarding their child's needs and ongoing communication to get the appropriate support in place for their child [11, 21, 38, 19, 23]. Unfortunately, parents also perceived that teachers may not take their child's needs seriously unless a healthcare provider communicated this information [25], which may be due to survivors not physically appearing to have a disability [19]. Some studies described fragmented communication. Many parents experienced the lack of a formal or systematic way for teachers to share information on their child's needs. Particularly, systematic communication was lacking between teachers associated with a change in the child's grade level

Table 1 Study characteristics

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent Experiences of School Integration Support Model</i> (Fig. 1)
Qualitative study designs (17)									
Beeler et al. (2020) [18]	USA	Median age 14*	ALL, brain tumor, other	79.3% Caucasian 6.8% Black, 1.4% American Indian, Alaska Native 0.9% Asian, 0.9% Native Hawaiian and Pacific Islander 3.2% other, and 7.7% did not respond	Not reported	81	Qualitative description, secondary analysis	Level III, quality A	School faculty/system — knowledge
Bruce et al. (2008) [19]	Canada	7–20	Brain tumor	Not reported	Not reported	16	Qualitative description	Level III, quality A	Healthcare provider — communication School faculty/system — communication, knowledge, process
Bruce et al. (2012) [20]	Canada	5–18	Brain and spinal cord tumor	Not reported	Not reported	9 families	Qualitative description	Level III, quality A	School integration program — communication, knowledge, process
Cheung et al. (2014) [21]	Australia	0–16	Brain tumor	Not reported	Not reported	17	Qualitative description	Level III, quality B	Healthcare provider — communication, process School faculty/system — knowledge, process
Ellis et al. (2013) [22]	Australia	8–13	Leukemia, sarcoma, CNS tumor, aplastic anemia	Not reported	Not reported	8	Qualitative description	Level III, quality A	School integration program — process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent Experiences of School Integration Support Model</i> (Fig. 1)
Inhestern et al. (2020) [23]	Germany	0–17	Leukemia or CNS tumor	Not reported	Not reported	49	Qualitative description	Level III, quality A	School faculty/system — communication, process School integration program — process
Hen (2022) [24]	Israel	5–17	Specific cancer type not reported	Not reported	Not reported	15	Qualitative description	Level III, quality B	School faculty/system — communication, knowledge
McLoone et al. (2011) [25]	Australia	12–20	Leukemia (ALL, AML, CML), lymphoma, sarcoma (Ewing, osteo), other	Not reported	Not reported	36	Qualitative description	Level III, quality A	Healthcare provider — communication School faculty/system — communication, knowledge
McLoone et al. (2013) [26]	Australia	3–12	Leukemia (ALL, AML), Lymphoma, rhabdomyosarcoma, tumor (brain, liver, Wilms)	Not reported	Not reported	42	Qualitative description	Level III, quality A	School faculty/system — communication, process
Paré-Blagojev et al. (2019) [11]	USA	8–19	ALL, brain tumor	80% White 10% Black 10% Hispanic	Not reported	9	Grounded theory	Level III, quality A	Healthcare provider — communication, knowledge School faculty/system — communication, knowledge, process
Rivero-Vergne et al. (2010) [27]	Puerto Rico	6–17	ALL	Not reported	Not reported	7	Phenomenology	Level III, quality B	Healthcare provider — process School faculty/system — communication, knowledge, process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent School Integration Support Model</i> (Fig. 1)
Slater et al. (2020) [28]	Australia	0–19	Solid tumor, leukemia, lymphoma, nonmalignant hematology	Not reported	Not reported	25	Discovery interviews	Level III, quality A	School faculty/system — process
Tresman et al. (2016) [29]	UK	3–7	Brain tumor (medulloblastoma)	Not reported	Not reported	9	Qualitative description	Level III, quality B	Healthcare provider — communication, process
Tsimicalis et al. (2018) [30]	Australia	< 1–19	ALL, AML, lymphomas, CNS, and miscellaneous intracranial and intraspinal neoplasms, neuroblastoma, and other peripheral nervous cell tumors including retinoblastoma, renal tumors, malignant bone tumors, soft tissue, and other extraosseous sarcomas	Not reported	Not reported	66	Qualitative description	Level III, quality A	School faculty/system — communication, process
Vanclooster et al. (2018) [31]	Belgium	7–10	Brain tumor	Not reported	Not reported	9	Qualitative description	Level III, quality A	School faculty/system — communication, knowledge, process
Vanclooster et al. (2019) [32]	Belgium	7–10	Brain tumor	Not reported	Not reported	9	Qualitative description	Level III, quality A	Healthcare provider — communication School faculty/system — communication, knowledge, process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent Experiences of School Integration Support Model</i> (Fig. 1)
Vanloooster et al. (2020) [33]	Belgium	7–10	Brain tumor	Not reported	Not reported	9 (round 1 & 2) 7 (round 3)	Qualitative description	Level III, quality A	Healthcare provider — communication, process School faculty/system — communication, process
Quantitative study designs (14)									
Annett et al. (2009) [34]	USA	6–12	ALL	Not reported/ insufficient information	Not reported/ insufficient information	7 families	Observational, case series	Level III, quality B	School integration program — process
Bava et al. (2016) [35]	USA	5–18	ALL	6.1% White / Non-Hispanic 89.8% Latino 4.1% Asian Data reported as parent–child dyads	6.1% White/Non- Hispanic 89.8% Latino 4.1% Asian Data reported as parent–child dyads	49 parent–child dyads	Non-randomized prospective cohort study	Level III, quality B	School integration program — knowledge, process
Hauff et al. (2019) [36]	USA	11–21	Childhood cancers (ALL, solid tumor, Hodgkin and non-Hodgkin lymphomas) and CNS tumor	Not reported	Not reported	47	Cross-sectional	Level III, quality A	School faculty/system — knowledge
Hocking et al. (2017) [37]	USA	Pre-K to post-college*	Brain tumor, leukemia, lymphoma, non-CNS solid tumor	Not reported	Not reported	102 families	Cross-sectional	Level III, quality B	School faculty/system — communication, process
Jacobson et al. (2020) [38]	USA	4–18	Brain tumor, leukemia, lymphoma, and other non-CNS cancer	81.5% White 7.2% Black 4.6% Multiracial 1.0% Asian 1.5% Alaska Native or Hawaiian/ Pacific Islander 4.6% unknown race/ethnicity	Not reported	195	Cross-sectional	Level III, quality A	Healthcare provider — knowledge, process School faculty/system — communication, knowledge, process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent Experiences of School Integration Support Model</i> (Fig. 1)
Lee et al. (2019) [39]	South Korea	≥ 9	No type specified	Not reported	Not reported	210	Cross-sectional	Level III, quality B	School faculty/system — communication, knowledge, process
Moore et al. (2009) [40]	USA	6–19	ALL, non-Hodgkin lymphoma	Not reported	76.3% White Other not reported	59	Cross-sectional	Level III, quality A	Healthcare provider — communication, process School faculty/system — communication, knowledge, process
Northman et al. (2018) [41]	USA	5–17	Leukemia, lymphoma, brain tumor, other	97.8% White/ Caucasian in SLP group 2.2% non-White/ non-Caucasian Reported in aggregate with parents	97.8% White/ Caucasian in SLP group 2.2% non-White/ non-Caucasian Reported in aggregate with children	93	Quasi-experimental, non-equivalent control groups (post-test only)	Level II, quality B	Healthcare provider — process School integration program — communication, knowledge
Northman et al. (2015) [42]	USA	Elementary, middle, and high school*	Brain tumor, leukemia, Other	Not reported	Not reported	57	Cross-sectional	Level III, quality B	Healthcare provider — communication School faculty/system — process School integration program — communication, knowledge, process
Patel et al. (2014) [43]	USA	6–18	ALL, non-ALL, AML, non-Hodgkin's lymphoma/lymphoblastic lymphoma, other	Not reported	80% White (including Hispanic Americans and Anglo Americans)	21	RCT (pilot study)	Level I, quality A	School integration program — knowledge, process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the <i>Adapted Parent Experiences of School Integration Support Model</i> (Fig. 1)
Quillen et al. (2011) [44]	USA	7–19	Lymphoblastic leukemia, brain tumor, Wilms' tumor, non-Hodgkin's lymphoma, neuroblastoma, retinoblastoma	Not reported	Not reported	20	Cross-sectional	Level III, quality B	Healthcare provider — process School faculty/system — communication, process
Rubens et al. (2016) [45]	USA	5–17	Brain tumor, leukemia, neuroblastoma, neurofibromatosis, other, none reported	Not reported	87% Caucasian 2% non-Caucasian 4% Unknown	93	Cross-sectional	Level III, quality B	School integration program — knowledge, process
Ruble et al. (2019) [46]	USA	13 median age*	ALL, lymphoma, non-Hodgkin's lymphoma, brain tumor, AML, other	83.3% Caucasian 6.9% Black/ African American 3.0% Mixed racial background 3.5% Other 3.9% Hispanic ethnicity	Not reported	203	Cross-sectional	Level III, quality A	Healthcare provider — communication, knowledge
Van't Hoof et al. (2016) [47]	Sweden	0–17	Brain tumor	Not reported	Not reported	34	Cross-sectional	Level III, quality B	Healthcare provider — process School faculty/system — process School integration program — communication, process

Table 1 (continued)

Author and year	Country	Child age range at time of study (years)	Cancer type	Child race/ethnicity	Parent race/ethnicity	Parent sample size	Study design	Article quality	Relationship to the Adapted Parent School Integration Support Model (Fig. 1)
Mixed or multi-method study designs (4)									
Donnan et al. (2015) [48]	Australia	3–20 quantitative survey 4–20 qualitative focus groups	ALL, AML, osteosarcoma, neuroblastoma, brain tumor, Ewing's sarcoma, Hodgkin's disease or lymphoma, clear cell sarcoma, rhabdomyosarcoma, other	Not reported/ insufficient information (75% born in Australia 25% born in country other than Australia)	Not reported	80 quantitative survey 24 qualitative focus groups	Quantitative questionnaire followed by qualitative focus groups	Level III, quality B	School faculty/system — communication, knowledge, process
Patel et al. (2020) [49, 50]	USA	6–21 (phase 1) 5–12 (phase 2)	Leukemia	Not reported	100% Latino Race not reported	20 (phase 1) 10 (phase 2)	Pilot study with phase I: qualitative; phase II: non-experimental, one group (pre-test, post-test)	Level III, quality B	School integration program — knowledge, process
Soejima et al. (2015) [51]	Japan	9–18	Leukemia, lymphoma, osteosarcoma, other	Not reported	Not reported	36 (quant) 3 (qual)	Quantitative questionnaires followed by qualitative semi-structured interviews	Level III, quality B	School faculty/system — communication, knowledge
Thornton et al. (2022) [52]	USA	Not reported	ALL, lymphoma, brain tumor, AML, other non-CNS tumor	82.1% White 6.9% Black 3.5% Multiple 1.7% Alaskan/ Native American 1.2% Hawaiian/ Pacific Islander 4.6% Other	Not reported	174 (qualitative interviews with healthcare providers and not used for this study)	Explanatory mixed methods — quantitative survey followed by qualitative interviews	Level III, quality A	Healthcare provider — communication, knowledge School faculty/system — process

Key: ALL, acute lymphoblastic leukemia; AML, acute myelogenous leukemia; CNS, central nervous system; USA, United States of America; level I evidence, experimental study design/RCT; level II evidence, quasi-experimental study design; level III, non-experimental study design, qualitative study design; quality A/B, high or good quality

* Age range not reported

and with parents regarding their child's progress in school [11, 21, 33, 32–48].

Parents also reported positive experiences with teacher communication. One study reported frequent parent conversations with school faculty [37]. Other studies described that frequent communication and earlier identification of child needs may be facilitated through strong parent–teacher relationships [32, 26]. Positive experiences were also facilitated by communication and collaboration among teachers [27, 26]. In contrast to the barrier presented by fragmented communication, parents reported that it was helpful when teachers had a systematic method for identifying and sharing information about their child's school needs. McLoone et al. [26] discussed that parents in Australia found it helpful when teachers placed their child's photograph and a brief description of their school needs on the staff room notice board. Soejima et al. [51] reported positive experiences were further facilitated by teacher–child communication for parents in Japan; encouragement of the child by the teacher facilitated a positive experience for the child and in turn the parent [51].

School faculty–healthcare provider communication

Parents reported few instances of communication between school faculty and healthcare providers. Three studies found that parents appreciated when hospital outpatient clinics and nurse coordinators interacted with the school through in-person visits and establishing communication pathways [21, 19, 25]. Parents felt it was important for healthcare professionals to educate school faculty and student–peers about the child's disease and its consequences [21, 40, 29, 31]. Parents struggled when they had to act as communication intermediaries, as they did not always feel confident explaining their child's neurocognitive and other medical issues [11, 33, 31].

Knowledge

Parents reported lower confidence in teachers' knowledge about cancer and its impacts on schooling. Many parents described that their child's teachers lacked an understanding of long-term cancer treatment effects and how treatment may influence school performance [11, 19, 25, 32, 48, 18]. Teachers' understanding of long-term treatment effects on schoolwork was an important facilitator in parents receiving transition support in Japan [51]. Parents attributed low teacher understanding to a limited expertise in healthcare, lack of knowledge concerning treatment effects, and their child's absence of an outward appearance of being disabled [19, 25, 32]. In two studies, parents of survivors in the USA noted teachers appeared nervous or uncomfortable with having a survivor in the classroom due to a lack of understanding concerning their needs [11, 18].

Process

Parents reported experiences accessing resources during school integration. One resource was formal education support, to which parents reported limited access. Many parents struggled with obtaining and understanding the components of formal education support (Individualized Education Program or IEPs and 504 plans) and other accommodations within the classroom [11, 52, 38, 36]. Parents indicated that it would be helpful to have workshops or mandatory meetings on formal educational support, classroom accommodations, and planning for the child's future [47, 33, 36]. An additional resource affecting support was the school budget; limitations in school budgets led to shortages of trained faculty and assistive technology [40, 19]. The type of school was also viewed as a resource by parents in Australia. Parents reported that certain schools, such as private, Montessori, or Steiner schools, emphasized an individualized approach and were perceived to be supportive of the child's social, emotional, and academic needs [27, 26]. Another study revealed that parents felt educational support offered was school dependent [48]. Parents expressed the desire for a standardized approach to supporting families during integration across schools, such as a protocol or liaison [24, 48].

Parents also described that the actions of school faculty influenced support. Teacher receptiveness toward health plans was important; teachers who did not follow health plans or recommendations from the neuropsychology report were perceived as barriers to support [38, 44, 33, 40]. Timing and frequency of the support received further influenced parent experiences. Across studies, parents reported that teachers facilitated school integration support by providing both frequent academic and emotional support [33, 19, 25, 30, 26, 28]. Additionally, support was facilitated when conversations about the child's needs were held with school staff early in the integration process [32] and the school maintained continuous contact with the family during the child's absence [24]. In a study conducted in South Korea, many parents reported a formal school integration program would have been helpful when their child initially returned to school [39]. Parents who reported receiving home-based teaching services prior to and during school integration felt that these services highly benefitted their children [52, 30].

School integration program

Overview

Eleven studies included parent experiences with school integration programs. Four articles discussed the use of School Liaison Programs (SLPs) to facilitate school integration. In a SLP, a School Liaison (SL), who is either an experienced educator or clinician, promotes interdisciplinary

communication between healthcare providers, school faculty, and families; acts as an advocate for families; provides education on the child's needs to the school and family; and continuously reassesses the needs of the family and child [42, 41, 20, 45]. Two studies focused on parent advocacy training to help parents understand potential school related challenges and how to access resources [35, 34]. Other studies discussed programs that socially connected children with peers while in the hospital to facilitate school integration [23, 22]. Ellis et al. [22] implemented a program in which children connected with their peers at school through videoconferencing, while Inhestern et al. [23] described a family rehabilitation program where children were able to interact with other children with cancer while in the hospital. Parents in two studies received self-efficacy training on how to help their child succeed in school and access school and community resources [43, 49]. One study detailed a medical follow-up program for the child and family post-cancer treatment to ensure families received the support they needed and included medical, educational, psychosocial, and neurocognitive follow-up [47].

Communication

SLPs were described as positively affecting parent experiences with communication. SLPs acted as communication “bridges” across disciplines and allowed for engagement among parents, school faculty, and healthcare providers [42, 41, 20]. Parents also appreciated when educational, psychosocial, and neurocognitive information was communicated both verbally and in writing [47].

Knowledge

Six studies described programs designed to increase parent or school faculty knowledge. Programs included SLPs, meeting with a family advocate, and parent self-efficacy training to improve parent knowledge of available school resources, child school needs, and how to help their child in school [42, 41, 45, 35, 43, 49]. In one study describing a SLP, parents also reported increased school faculty knowledge of their child's academic needs [42]. Additionally, one study noted that parents reported better understanding in how to obtain school support services if they had greater exposure to SLP services (3 years versus less than 1 year) [45].

Process

School integration programs provided parents with support resources during the transition to school. Most school integration programs facilitated support and empowered parents with knowledge of their child's needs and how to advocate for their child [35, 34]. In Bava et al. [35], many

parents requested IEPs or 504 plans following the advocacy program. Parents perceived that both they and their child benefited from the programs they received during school integration [42, 41, 23, 20, 22–49]. However, in van't Hooft et al. [47], parents felt as though there was still a large burden on them to ensure follow-up for the child, especially as time progressed. Parents commented that they would have liked siblings to be included in the program as well [47].

The accessibility of these school integration program resources was also explored. In Annett et al. [34], the setting in which the program took place was important to parents; parents preferred the program to be completed in the hospital or clinic rather than their home. Accessibility of programs was also related to delivery method; in Ellis et al. [22], technological issues such as poor connection of the device became a barrier to receiving the program and its benefits.

Other formal and informal support

During article synthesis, we noticed trends in seven studies regarding formal and informal support systems that did not fit within the original model categories. Informal support systems tended to be friends and neighbors who provided information (*knowledge*), whereas formal support systems such as government programs provided procedural support (*process*).

Communication

Only one study commented on communication support from informal support systems. Parents discussed how neighbors from their community reached out to the school on their behalf as a form of support [24].

Knowledge

Parents relied on informal support systems for school integration, particularly their social network consisting of friends, neighbors, and chance meetings with other parents of children with cancer. Parents reported having friends with specific knowledge, including friends who were lawyers and could provide advice on available legal support and friends who happened to be school faculty or a parent of a child with special needs and could provide education system advice [18]. Parents in the USA reported that chance encounters with other parents of children with cancer were helpful in providing information about school integration [38].

Process

Formalized parent groups and government support were important sources of support for parents. Formalized parent groups were identified as an essential support for parents of

survivors in making resources available. For example, local parent associations helped connect parents with resources and information about school integration [23], and service groups took action to obtain assistive technology for transportation to school or in the classroom [19]. Studies from Germany and Puerto Rico reported that government support structures, such as availability of disability compensation and government-based at-home teaching services, were identified by parents as essential process supports for school integration [27, 23]. In addition to formalized support groups, parents in one study commented that neighbors and friends were sources of financial and logistical support during the integration process [24].

Discussion

This integrative review explored 35 research articles detailing parent experiences with and perspectives of school integration support from healthcare providers, school faculty/system, school integration programs, and other formal and informal sources of support. The review fills a gap in the literature in describing parent experiences with school integration support and synthesizes parent perceived barriers and facilitators (Table 2). Overall, the results across quantitative, qualitative, and mixed/multi-method studies were broadly consistent with each other.

Healthcare providers

There is a gap in the information provided to families by the oncology team during the transition to school. Information does not consistently include a discussion of health-related learning difficulties, child legal rights, or formal education support processes (i.e., obtaining an IEP/504 plan) [46]. However, many providers report they do not receive formalized training in post-treatment cognitive and school issues [53, 54]. Oncology providers should have a basic knowledge of the intersection of the neurocognitive impacts of therapy and educational supports, and additional formalized training should be provided to improve oncology provider knowledge and clinical confidence [53]. Parents also reported feeling abandoned by the oncology team after cancer treatment [29] and desired more long-term support. One possibility for longer-term support could be from primary care providers (PCPs). Although PCPs are potentially poised to fill this gap, previous research demonstrates that PCPs do not feel adequately prepared to address survivor needs due to a lack of training and knowledge in survivorship care [55, 56].

Neuropsychology reports were broadly reported to be very helpful in school integration. Parents appreciated clear, easy-to-understand language and reviewing the report with

the neuro/psychologist [11, 21, 38]. Referral for ongoing neuropsychological assessments is a standard of care for children who receive CNS-directed therapies [57], as they are essential for monitoring child health [58] and aid in providing support to parents during school integration [11, 21, 38]. However, studies have shown care is inconsistent with this standard. Jacobson et al. [38] reported low patient-reported referral rates by oncology providers and Ruble et al. [53] found that the majority of institutions do not have guidelines for neuropsychological assessment referral. Additionally, while neuropsychological assessments are typically covered by insurance (in the USA), these procedures are costly, and the individual co-insurance may still represent a barrier; thus, there is a dual concern that children who are eligible may not receive this recommended service and that the negative impact of being unable to benefit from such assessments could disproportionately affect families of more limited means [59, 60].

School faculty and system

Parents appreciated frequent parent–teacher communication to discuss child school needs [32, 37, 26, 39]. However, other parents experienced barriers to communication. Parents struggled with being a communication intermediary [11, 33, 31] and experienced fragmented communication among teachers and between healthcare professionals and school faculty [21, 38, 33, 32, 31]. Parents may benefit from more formalized methods of communication, such as the school reintegration protocol detailed in Tresman et al. [29]. The protocol detailed an individualized plan to educate and communicate child needs among school faculty, healthcare providers, and parents [29]. Strategies for implementing more formalized systems of sharing information should be assessed.

Parents reported that teachers had limited knowledge regarding working with survivors who have academic challenges [27, 19, 32]. Previous literature demonstrates that teachers feel they lack preparation in working with children who have chronic medical conditions [61]. Most children with academic difficulties, including those with chronic medical conditions, receive instruction in the general education setting as it is the least restrictive, most inclusive, environment [62]. Training programs preparing teachers may consider including specific strategies in helping children with medical complexities succeed in the classroom.

School integration programs

School integration programs were found to be helpful in facilitating support. Parents particularly appreciated SLPs and other programs in which they gained knowledge about how to help their child in school or advocate for their child

Table 2 Synthesized barriers and facilitators to school integration support identified by parents

Healthcare provider	School faculty and systems	School integration program	Other
<p>Communication</p> <p>(-) Insufficient communication between healthcare providers and school faculty/systems about potential consequences of cancer treatment, including neurocognitive effects, and sharing the neuropsychological report. <i>Quality A [n=5], Quality B [n=2]</i></p> <p>(+) Clearly written neuropsychology reports <i>Quality A [n=1], Quality B [n=1]</i></p> <p>(-) Inappropriately timed communication about neurocognitive effects from cancer treatment <i>Quality A [n=1], Quality B [n=1]</i></p>	<p>Healthcare providers and school faculty/systems acting as bridges of communication between school faculty, parents, and healthcare providers <i>Quality A [n=1], Quality B [n=2]</i></p> <p>(+) Frequent parent-teacher communication <i>Quality B [n=1]</i></p> <p>(+) Strong parent-teacher relationships <i>Quality A [n=2]</i></p> <p>(-) Fragmented communication among school faculty on child needs <i>Quality A [n=4], Quality B [n=2]</i></p> <p>(-) Burden of monitoring child academic progress falls on the parents rather than a collaborative effort with teachers <i>Quality A [n=3], Quality B [n=1]</i></p>	<p>(+) School Liaison Programs acting as bridges of communication between school faculty, parents, and healthcare providers <i>Quality A [n=1], Quality B [n=2]</i></p> <p>(+) Verbal and written summaries of educational and psychosocial recommendations <i>Quality B [n=1]</i></p>	<p>(+) Neighbors and community members reaching out to the school on behalf of the parents/child <i>Quality B [n=1]</i></p>
<p>Knowledge</p> <p>(+) Specific information about health-related learning difficulties and formal education support processes (IEP/504 plan) <i>Quality A [n=2]</i></p> <p>(-) Oncology team not fully comprehending or divulging non-health challenges of school reintegration such as legal rights or access to additional resources <i>Quality A [n=2]</i></p>	<p>(-) Limited knowledge of cancer treatment and its consequences for child school functioning <i>Quality A [n=5], Quality B [n=1]</i></p> <p>(-) Limited knowledge in working with children who have variable academic challenges resulting from complex medical conditions or treatment <i>Quality A [n=3]</i></p>	<p>(+) Programs that improved parent advocacy skills and knowledge of child school needs postcancer treatment <i>Quality A [n=1], Quality B [n=5]</i></p>	<p>(+) Provide opportunities for informal networking to exchange knowledge between parents of cancer survivors <i>Quality A [n=2]</i></p>
<p>Process</p> <p>(+) Continue providing child's neuropsychological evaluation and report to parents <i>Quality A [n=2], Quality B [n=1]</i></p> <p>(+) Improve parental access to other healthcare providers and specialists (physical, occupational, and speech therapists) as needed <i>Quality A [n=1], Quality B [n=2]</i></p> <p>(-) Discontinuation of oncology team and other healthcare provider involvement in care and support after cancer treatment <i>Quality A [n=2], Quality B [n=3]</i></p>	<p>(+) School approach to education is individualized to student needs <i>Quality A [n=1], Quality B [n=1]</i></p> <p>(+) Frequent teacher academic and emotional encouragement <i>Quality A [n=6]</i></p> <p>(-) Difficulty accessing information and navigating formal education support and accommodations (IEP/504 plan) <i>Quality A [n=4]</i></p> <p>(-) Limited school budget for child accommodations and trained faculty <i>Quality A [n=2]</i></p> <p>(-) Negative teacher attitudes toward health plans or recommendations <i>Quality A [n=3], Quality B [n=1]</i></p>	<p>(+) Delivery of the program in the clinic or hospital setting <i>Quality B [n=1]</i></p> <p>(-) Technological issues for delivering program via technology <i>Quality A [n=1]</i></p> <p>(-) Lack of sibling inclusion in the program <i>Quality B [n=1]</i></p> <p>(-) Lack of long-term follow-through as needs continue <i>Quality B [n=1]</i></p>	<p>(+) Identification of and connection to formal support structures, such as parent groups, government assistance, etc <i>Quality A [n=2], Quality B [n=1]</i></p>

Key: (+), facilitator to school reintegration; (-), barrier to school reintegration. Quality A indicates a high-quality study, Quality B indicates a good-quality study

[42, 41, 35, 43, 49]. SLPs were also perceived as helpful in bridging communication between healthcare providers and school faculty [42, 41, 20]. Unfortunately, SLPs are typically non-reimbursable by medical insurance in the USA and therefore not widely available to parents [46]. Additionally, although these programs are perceived as helpful, future work is needed to establish the effectiveness in optimizing child academic and psychosocial outcomes [63], which in turn may help to create policies that make these programs more widely available to families.

Other formal and informal supports

Parents of survivors found additional support in their child's transition to school through informal social connections and formalized parent groups and government programs [38, 27, 19, 23, 18]. Surprisingly, access to online resources was not discussed in the included studies. A review of available parent-focused online resources about schooling after cancer suggests available tools are typically not comprehensive and are often written in a way that requires a fairly high education to be easily understood [64]. The current review demonstrates that parents seek additional support outside of the school and healthcare team, highlighting a need to create accessible online school integration resources that are comprehensive and readable across health literacy levels.

Strengths and limitations

A strength of this integrative review is its focus on parent experiences with school integration support, a previously under-studied group. In addition, this paper offers an adapted model of parent experiences with school integration that can be used by future researchers studying parent perspectives. One limitation of this review is the focus on school integration support in terms of parents' understanding and receiving academic resources. Although academic success is an essential component of education, another crucial factor is the child's social and emotional experience [65, 66]. Subsequent reviews should consider parent and child experiences of receiving social and emotional support. Another limitation of this review is that access to academic resources and programs may vary across countries. It is challenging to compare experiences of school integration resources and programs across countries whose healthcare and school systems have significant structural differences. However, all countries included in this review (Table 1) are classified as high income by the World Bank Classification of Income and have comparable economies [67]. Additionally, this review excluded literature that could not be found in English, limiting the international scope of this work.

Future directions

The identified barriers and facilitators provide a foundation for a model of care in delivering school integration support to parents. This review highlights the need for new communication platforms to be developed to support parents in their role as intermediary between the healthcare professionals and school faculty, for example, the use of school "passports" or protocols that share essential child medical information between the parents, school faculty, and healthcare professionals [29]. Another method to bridge this gap includes healthcare professionals meeting with parents and school faculty virtually to review the child's learning needs. Both healthcare professionals and school faculty developed new expertise in holding virtual Internet-mediated meetings during the COVID-19 pandemic that can be an asset in school integration planning moving ahead. Future studies should explore the interest and capacity of healthcare providers, school faculty, and parents to engage in school integration planning in new ways to address parent concerns revealed in this review.

Additionally, there were only two qualitative studies conducted in the USA. Further qualitative research with parents would be beneficial to understand experiences with support specific to the resources within the USA's healthcare and educational system. This review also highlights the need to understand experiences of school integration support from a more diverse parent population. Few studies examined and reported race and ethnicity. Of the 16 studies completed in the USA, only ten reported child or parent race and ethnicity. Additionally, the majority of the parents and children in these reported samples were White. It is essential to gain a diverse range of parent perspectives, as survivors from diverse racial and ethnic groups report more neurocognitive symptoms from cancer treatment [50] and are at risk for worse educational outcomes than their White peers [68, 69]. Future research should focus on reporting parent experiences with receiving school integration support while considering the influence of race/ethnicity as well as other social determinants of health [70]. Researchers may consider integrating our proposed model with others, such as Bronfenbrenner's social ecological approach and Kazak's social ecological model applied to child health [71], to understand parent experiences of school integration support within the context of social determinants of health. The majority of studies also did not distinguish between experiences of support among parents of elementary, middle school, and high school age children. The literature demonstrates that school integration support needs may vary across the lifespan. Younger children are at greater risk for developing neurocognitive late effects [72], and parents may benefit from receiving early, individualized support

to promote their child's development [73]; however, in adolescence, there is increased independence from parents, and social support may be an essential consideration in addition to academic support [73]. It will be imperative to explore how parent support needs differ across age groups and grade levels in future work.

Conclusions

This review synthesized parent-experienced barriers and facilitators to school integration support from healthcare providers, school faculty/systems, school integration programs, and other informal and formal sources. Parents found neuro/psychologists highly supportive; however, there was limited information on support from other healthcare providers. Parents reported both positive and negative experiences with teacher knowledge and communication. There were numerous reported barriers to navigating school system supports, particularly formal education support. Parents reported positive experiences with school integration programs; however, limited programs are available. School integration support is an important component of survivorship care and offers value to parents during school entry [57]. Hospitals should have school integration programs and resources more widely available to families, even if they are not reimbursable by a third-party payer. Further work is also needed to fully understand the experiences of a wider range of affected families and to address these identified barriers and facilitators to support parents and survivors during the transition to school.

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Data availability No datasets were generated for this manuscript.

Declarations

Ethics approval This integrative review does not include research with human or animal subjects and does not require ethical approval.

Consent to participate This integrative review does not include research with human subjects and does not require informed consent.

Consent for publication This integrative review does not include an individual person's data and does not require consent to publish.

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