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**I could have used a lot more help than I had: A qualitative systematic review and synthesis of families' experiences of pediatric brain tumor and schooling**

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### Abstract

Brain tumors are the most common and fatal of all solid tumors for children and adolescents. The effects of the tumor and treatment (chemotherapy, radiation, and/or surgery) results in significant disruptions to childhood development and large amounts of missed schooling. Among other challenges for families, this produces obstacles for children and adolescents to achieve and maintain academic performance and experience positive schooling encounters. We thus aimed to systematically identify and synthesize qualitative evidence on how families experience pediatric brain tumor from diagnosis and beyond with regards to their schooling and education to identify gaps in service delivery, research, and policy. Searches were conducted in Medline, CINAHL, PsycInfo, Embase, and Web of Science, and yielded 22 eligible papers (representing 17 studies). Data were extracted into NVivo12 and analyzed by qualitative description. We formed the following domain summaries: academic (perceived failure to keep up with peers and finding success where one could, the importance of encouragement for diagnosed children), social (the importance of friendships and the harm of bullying), and support (the defining factor in overall return-to-school experience, often not enough received from educational professionals and clinicians). Our review highlights the need for more comprehensive, individualized, and integrated support for diagnosed children to return to educational institutions, and for the need to address their social experiences, particularly with regards to bullying, potentially through a school-wide social and emotional learning approach. Funding support, evidence-based guidelines, staff skill development, and clear communication structures across families, healthcare facilities, schools, and educational departments are essential to achieving this.

*Keywords:* brain neoplasms, oncology, pediatrics, schools, return to school, policy.

### **Educational Impact and Implications Statement**

Brain tumours are the most common and fatal of all solid tumours for children and adolescents; the effects of tumour and treatment disrupt childhood development and large amounts of schooling are typically missed. These children and adolescents, and their families, have diverse academic, social, and supportive care experiences and needs that educators, clinicians, and policy makers must address.

**I could have used a lot more help than I had: A qualitative systematic review and synthesis of families' experiences of pediatric brain tumor and schooling**

Brain tumors are the most common and fatal of all solid tumors for children and adolescents (Aldape et al., 2019; Steliarova-Foucher et al., 2017). Both malignant and non-malignant brain tumors, and their treatment (chemotherapy, radiation, and/or surgery), cause significant disruption to childhood development with ongoing intellectual, physical, and social ramifications into adulthood for both the diagnosed child and their family (Long et al., 2011; Turner et al., 2009). Examples of late effects include impaired memory, partial paralysis, and depression; these can reduce survivors' subsequent social and economic participation in society. Compared to their counterparts, survivors of childhood brain tumors are 2.6 times more likely to have negative cognitive and socioeconomic effects (Ris et al., 2019).

The effects of the tumor and treatment results in large amounts of missed schooling; this produces significant challenges for children and adolescents to achieve and maintain academic performance and experience positive schooling encounters (Thompson et al., 2015). Challenges may arise upon first commencing school, when reintegrating back into school after treatment completion, or several years later—depending on the age the child is diagnosed, location of the tumor, and the treatment received. Across 11 high income countries, Saatci et al. (2020), reported childhood brain cancer survivors to be less likely to progress past non-compulsory schooling, and more likely to require special education needs. Such findings suggest few survivors receive adequate educational support, despite it having been identified as a key standard of care in pediatric oncology (Thompson et al., 2015). In Australia, for example, of 80 families surveyed in one state health district, 62% reported their child faced additional educational difficulties (e.g., attention, mobility, hearing) but only 9% reported receiving funding support upon return to school (Donnan et al., 2015). There are few established school re-entry support programs for those living with childhood cancer and little associated evidence of their effectiveness (Burns et al., 2021). Healthcare to address late

effects broadly is also lacking: a recent international review across 18 countries reported once childhood cancer survivors transition to adulthood, few are supported by a healthcare provider versed in the late effects of cancer and its treatment (Tonorezos et al., 2018). Family caregivers of those diagnosed with childhood brain tumor—particularly mothers—shoulder the burden of this absence (Nicklin et al., 2019; Woodgate et al., 2016).

To understand how to support children's academic performance and to foster positive schooling experiences for children and their families, we must consider their experiences and needs from their own perspectives. Qualitative methods are used to investigate experience and meaning from the perspective of those who experience a phenomenon of interest (Hammarberg et al., 2016). Through the summary and interpretation of people's experiences, systematic reviews of qualitative research can highlight areas of improvement for health policy and interventions to address gaps in service needs (Munn et al., 2018). The only previous qualitative review to consider family experiences of childhood brain tumor focused only on survivorship (Woodgate et al., 2016), and another mixed-methods review for brain cancer (but not tumor) in survivorship only (Nicklin et al., 2019); neither included a focus on schooling and education experiences.

We thus aimed to systematically identify and synthesize qualitative evidence on how families experience pediatric brain tumor from diagnosis and beyond with regards to their schooling and education to identify gaps in service delivery, research, and policy.

### **Method**

The current paper formed part of a larger review of families' experiences of child and adolescent brain tumor. Due to the amount of data generated and the relevance of findings to different stakeholders, findings relating to the individual experiences of family members and those specific to healthcare are published separately in Young et al. (2021). Our review method is described in detail in Young et al. (2021), and summarized in Table 1 for reader convenience. A protocol for the review was registered with PROSPERO (ID: CRD42020177165).

[Insert Table 1 about here.]

## Results

The findings for the larger review are depicted in Figure 1; the current paper presents only those pertaining to schooling and education. Of the 40 papers (representing 33 studies) identified in the larger review, 22 (representing 17 studies) are included in this sub-analysis and are described in Table 2. All but one of these papers was conducted in high-income Anglo-Saxon countries, with more (N=8) from Canada. The majority (N=21, 95%) considered both malignant and non-malignant tumors. More papers (N=14) included the perspectives of parents, particularly mothers where identified, than survivors (N=8) or children and adolescent patients (N=6). Most papers (N=17, 77%) were focused on survivorship.

[Insert Figure 1 about here.]

[Insert Table 2 about here.]

In terms of methodological quality, most papers demonstrated a fit between the use of qualitative methods, the research question, and data collection methods; and had conclusions that flowed from the data (Table 3). About half of all papers did not describe a data analysis process consistent with the epistemological and ontological foundations of the qualitative methodology, and approximately three quarters did not adequately evidence participant voice. Only one paper included a statement that located the researchers, and most did not address the potential influence of the researchers on their research conduct and reported findings. This is despite author affiliations suggesting many were clinicians at the facility in which the research was conducted.

[Insert Table 3 about here.]

We use the term 'diagnosed children' when describing all those who have been diagnosed with childhood brain tumor including children, adolescents, and adult survivors. When using the phrase 'children and adolescents' throughout the findings, we are referring to survivors unless

otherwise stated; this reflects that most papers focused on survivors' return to school. We were guided by individual papers' definition of 'survivor' (which could include children, adolescents, or young adults for the purposes of this review); these varied substantially from 3 months to at least 2 years since last treatment, and for some, at least five years since diagnosis.

### **Overview**

Overall, children and adolescents' experiences of returning to school varied considerably in terms of both academic and social domains. During treatment, some families indicated that it was important to them that, when possible, their child attend school (Bruce et al., 2008; Russell et al., 2016). Attending school gave the diagnosed child the comfort of the familiar (Russell et al., 2016) and a chance to socialize outside of the hospital (Bruce et al., 2008). Both diagnosed children and parents stated concern for falling behind in their schoolwork if they could not physically attend school and were not supported to complete work outside of physically being at school (Bruce et al., 2008; Shortman et al., 2013; Soanes et al., 2009).

After treatment completion, parents often reported that the transition back to school took place over a period of time with their child initially returning for part days due to sickness and fatigue (Macartney et al., 2014; Norberg & Steneby, 2009), ongoing appointments (Macartney et al., 2014), and other symptoms or late effects (e.g., seizures; Lucas et al., 2014; Macartney et al., 2014). Some diagnosed children and their families were eager to go back to school as it was a sign of 'normality' returning (Vanclooster, Bilsen, et al., 2019a; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019), and an opportunity to be reunited with friends and make new ones (Boydell et al., 2008; Vanclooster, Bilsen, et al., 2019a). Children and adolescents, however, reported worry about whether they would be on time (Macartney et al., 2014), how they would physically adapt (Vanclooster, Bilsen, et al., 2019a; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019), how they would socially adapt (Boydell et al., 2008; Macartney et al., 2014), and whether they could keep up with the school work (Boydell et al., 2008; Norberg & Steneby, 2009;



Vanclouster, Bilsen, et al., 2019a): *I'm looking forward but right now, it's the transition. . . . I'm scared. I don't know how it's going to work out* (Boydell et al., 2008).

Cataudella & Zelcer (2012) and Zelcer et al (2010)—two papers from one study—briefly discussed the role of school at children's end of life. Parents were clear that school was important for some children at this stage, with attending or completing a grade giving them a sense of pride and accomplishment. Some parents reported their school as discouraging their child from attending:

*The school felt he should be at home waiting to die in his mother's arms. But an 8-year-old boy doesn't want to be with his mother that much ... where are his wishes?*

(Cataudella & Zelcer, 2012)

### **Academic**

Children and adolescents, and to a lesser extent their parents, often reported feeling frustrated and disheartened at how hard they had to work to keep up with their peers (Boydell et al., 2008; Carlson-Green, 2009; Forinder & Norberg, 2010; Vanclouster, Bilsen, et al., 2019a; Vanclouster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019): *It's not fair that I have to practice and study more, just because I have been sick* (Vanclouster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019). Memory problems, usually with short term memory, were commonly described as affecting children's schoolwork and class participation (Bruce et al., 2008; Gunn et al., 2016; Macartney et al., 2014; Vance et al., 2004; Vanclouster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019); specifically, their ability to focus and concentrate, and to physically navigate around the school (Macartney et al., 2014). Some children, adolescents, and parents reported having to give up all extra-curricular activities to manage their limited energy (Carlson-Green, 2009; Macartney et al., 2014). A few adolescents did not want to go to school or continue their education as they did not think they could keep up with their peers and/or were provided with little assistance to do so (Boydell et al., 2008; Carlson-Green, 2009; Vance et al., 2004): *I would have no idea about what to do. I would just hide from the teacher ... After a while, I couldn't take it anymore and I*

wanted to drop out (Boydell et al., 2008). Boydell et al. (2008) reported some adolescents to have moved to different schools or become home-schooled due to academic difficulties.

Any success, such as graduating high school when they were told by authority figures that they never would, gave children and adolescents much encouragement and pride (Boydell et al., 2008; Bruce et al., 2008; Vance et al., 2004). Children, but particularly adolescents, attributed improvements in their performance to their own hard work, and to support received from parents and teachers (Norberg & Steneby, 2009; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019):

*Because I practiced so much at home and at school, I became better in things like spelling and reading. I don't think you will improve if you don't do anything about it.*

(Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019)

Conversely, not improving despite working hard was disheartening for children and adolescents (Cheung et al., 2019; Vance et al., 2004; Vanclooster, Bilsen, et al., 2019b; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019): *I feel a significant decline in my learning capability, I always get poor results from the tests and examinations, which make me feel very disappointed and distressed* (Cheung et al., 2019). In Boydell et al. (2008), adolescents identified a need for extra encouragement and recognition of their work:

*I think I could have used more of that (encouragement). Like I would get assignments done and hand them in, but that was it. I didn't get a good job or anything.*

Parents in Vance et al. (2004) also spoke of the importance of encouraging and celebrating children when they excelled in non-traditional academic areas, such as arts-based subjects.

## **Social**

Diagnosed children and parents often described difficulty for the child in forming and maintaining friendships. They attributed this to a range of factors including not having their brain

tumor experience recognized or understood by others (Bruce et al., 2008; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019), being misunderstood or judged by their peers and teachers (Bruce et al., 2008), feeling afraid of how people would react to them having a brain tumor (Bruce et al., 2008), jealousy among peers of 'special' attention the child received (Bruce et al., 2008), having difficulty managing unwanted attention or questions (Soanes et al., 2009), and because of late effects such as prosopagnosia (the inability to recognize people's faces) (D'Agostino & Edelstein, 2013; Lucas et al., 2014; Vance et al., 2004):

*When I came back, they behaved differently towards me. They didn't ask me things or listen to me, I felt like, alone a lot. (Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019)*

*When she sees somebody ... it doesn't register that she knows them. ... I think this is one of the biggest problems that other people, teacher and her friends, I think need to be really aware of ... just because they're looking at her doesn't mean to say she recognizes them. (Vance et al., 2004)*

Some children thought others knowing of their diagnosis helped them socially (Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019), while adolescents wondered if they just pitied them or thought it made things worse (Bruce et al., 2008; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019).

Many parents—and, to a lesser extent, children and adolescents—reported the child as having experienced bullying and social difficulties due to the effects of the tumor and treatment (Bruce et al., 2008; Hobbie et al., 2016; Macartney et al., 2014; Vance et al., 2004). Bullying usually involved name calling or teasing, not wanting to touch or be near the diagnosed child, and socially excluding them. It was largely triggered by the child's changed physical appearance (e.g., thinning hair or balding, increased weight), an inability to communicate at the same level as their peers, and a lack of understanding by their peers of their experience and the effects on their body:

*Those kids that would pick on me every once in a while. Like, "Oh my God, she is bald." ... when I was scheduled to go to my Wish to Disney World. . . . He said, "Oh, why give it to her? She is just going to die anyhow." And that was really hard. (Bruce et al., 2008)*

Parents and diagnosed children often pre-empted bullying and worried about it worsening in the future (Vance et al., 2004; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019; Zwiers et al., 2015):

*Going back to school so soon—like—I felt like a monster with my head shaven and a big scar there. ... all these kids are going to be like, "Oh he's a monster!" like I'm always going to be known as the kid with the brain tumor kind of thing. (Zwiers et al., 2015)*

*I think she might find she does get picked on. I think she'll find she will get bullied ... that's another worry of big school is how the other children are going to be. (Vance et al., 2004)*

A few parents reported moving their child to a different school or to home schooling due to bullying (Bruce et al., 2008; Vance et al., 2004).

Conversely, some children and parents reported their classmates as being supportive (Bruce et al., 2008; Shortman et al., 2013; Vance et al., 2004; Vanclooster, Bilsen, et al., 2019a). Parents in Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al. (2019), for example, reported classmates of younger children as regularly giving their child compliments about their successes and helping them with tasks like cleaning their desks, and in Bruce et al. (2008), that friends and siblings helped with schoolwork and provided encouragement:

*My brother helped me a lot. And my friends helped me too ... If I was stuck on a math problem, I remember some of the students would come and help me.*

In this same paper, having a strong friendship was described by children and adolescents as the most influential factor for their ability to manage schooling after brain tumor diagnosis.

For tertiary education, some parents and survivors were optimistic that bullying would be less of an issue due to peers being more mature (Boydell et al., 2008; Vance et al., 2004), them being less defined by their cancer (Carlson-Green, 2009), and that they may not stand out as much among more people (Boydell et al., 2008). Some did not want to go on to tertiary education for fear of bullying continuing or, if it did continue, did not complete their course (Carlson-Green, 2009; Vance et al., 2004).

### **Support**

The support children and adolescents received to return and stay at school was a defining factor in families' experiences. It was crucial to parents—and to a lesser extent, children and adolescents—that the teacher/s and school support the diagnosed child (Boydell et al., 2008; Bruce et al., 2008; Gunn et al., 2016; Shortman et al., 2013; Vanclooster, Bilsen, et al., 2019b; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019). Families varied greatly in the support they wanted and received; Box 1 presents families' suggestions for optimal support. Some children, for example, benefited from considerations such as having more time to answer questions in exams while others required intense and ongoing learning assistance (Boydell et al., 2008; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019). In addition to academic support, the school had to cater for the child's physical accessibility needs, such as assisting with movement between classrooms in a limited timeframe and providing wheelchair access (Bruce et al., 2008).

[Insert Box 1 about here]

Most families reported receiving some support, resources and/or assistance for their child after treatment ended (Bruce et al., 2008; Shortman et al., 2013; Vanclooster, Bilsen, et al., 2019a; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019), but for many

it was deemed insufficient (Boydell et al., 2008; Bruce et al., 2008; Cheung et al., 2014; Vance et al., 2004; Vanclooster, Bilsen, et al., 2019b). In Bruce et al. (2008), some parents attributed this to a lack of funding and staffing, rather than to lack of recognition of the diagnosed child's needs:

*There was no money. There's a bigger need. We have too many kids. We have one resource teacher. ... oh we didn't get any resource done this week because there is, you know, no resource teacher ... so that she [daughter] would go weeks without any extra help.*

Parents reported little support in planning and conducting the initial reintroduction back to school after treatment had ended, with many going back to their child's original school with no awareness of all available options (Boydell et al., 2008; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019). Children appreciated support from their parents the most, but also valued that from their teachers, siblings, and friends (Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019). For parents, usually mothers, assistance with schoolwork and activities contributed greatly to their caring load; little support for them in this work was discussed (Bruce et al., 2008; see Young et al., 2021 for further related findings).

Some children and adolescents reported not knowing who could help them at school or if their teachers knew their circumstances when they returned (Bruce et al., 2008; Gunn et al., 2016), and some survivors reported frustration at not having a teacher who understood their experiences and needs (Boydell et al., 2008). Parents worried if teachers truly were equipped to meet their child's needs in survivorship (Bruce et al., 2008; Vanclooster, Bilsen, et al., 2019a):

*I wonder to what extent the school knows what difficulties still may appear. For them, it's over, while it's not for him or us. We have heard all the information at the hospital, but the school hasn't. (Vanclooster, Bilsen, et al., 2019a)*

Some parents volunteered at the school to support relationships with staff (Bruce et al., 2008), or made themselves available to school staff to answer any questions and to hear feedback (Bruce et al., 2008; Vanclooster, Bilsen, et al., 2019b). Despite parents' best efforts to communicate with the school and teachers, a few reported that neither demonstrated understanding of their child's needs (Bruce et al., 2008; Cheung et al., 2014; Vanclooster, Bilsen, et al., 2019a, 2019b). Parents and children, for example, wanted the child to have worked their way into the next grade; they did not value the practice of passing to the next grade if not merited (Bruce et al., 2008):

*Sometimes I just didn't want to be passed by because. . . I really shouldn't say this, because they felt sorry for me . . . I didn't want to get passed just because of that. I wanted to pass because I worked for it.*

Some children and adolescents, but to a greater extent parents, reported that because their child's needs were not visibly obvious after treatment ended, they were neglected by the school or had greater difficulty in being recognized (Boydell et al., 2008; Bruce et al., 2008; Vance et al., 2004):

*But I mean if we were to look at his brain, you would see that it is not the same as other kids because of the radiation treatment. ... And he slips through the cracks because ... He looks just like everybody else. So I have to keep reminding the school not to be hard on him in terms of . . . forgetting his schoolwork, being organized, short-term memory loss is a big problem. (Bruce et al., 2008)*

*I was just treated like everyone else. That was a good thing I think because ... I wasn't made to look any different than anyone else. But at the same time, I think I probably could have used a lot, a lot more help than I had. (Boydell et al., 2008)*

Some children spoke about appreciating support (Vanclooster, Bilsen, et al., 2019a), while other children and adolescents wanted to be treated like their peers or did not perceive that they

needed extra support (Boydell et al., 2008; Carlson-Green, 2009; Vanclooster, Bilsen, et al., 2019a; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019):

*She (specialized teacher) helps me to improve and get better grades, that's true, but ... She sits next to me or we have to go outside (the classroom) and then I just want to stay with the others and do the things they do. (Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019)*

*It's great that she (teacher) regularly takes the time to chat, just a moment between them. Others do not notice it and that's how it should be, because she wants to be like them. (Vanclooster, Bilsen, et al., 2019a)*

### **Discussion**

To the best of our knowledge, this is the first systematic review and synthesis of qualitative research examining families' experiences of pediatric brain tumor and schooling. Our review is limited by our inclusion of only studies published in English; the inclusion of additional stakeholder perspectives, such as teachers and educational psychologists, would also have enriched the findings. The methodological quality of the included papers was considerably low: few featured more than a summary of the data, evidenced statements in participant voice, or located the researchers within their research. Further, few studies captured the perspectives of school-aged children, with most including parents and older survivors only. Nevertheless, our synthesis revealed experiences, perspectives and concerns consistently reported over time.

In our larger review of family experiences (Young et al., 2021), diagnosed children identified the adverse impact brain tumor had on their body image and mental health as being central to their experience. Many, but not all, found tumor and treatment-associated physical changes to cause them sadness or frustration in their bodies, and some reported experiencing



poor emotional wellbeing, depression, and/or anxiety for various reasons, including a pervading feeling of being inadequate compared to peers. These findings contextualize those of the current review with reports of bullying in school due to physical appearance and to the need to have the diagnosed child's schooling achievements recognized and celebrated. The psychosocial experience of school for diagnosed children is likely to have long-term effects. A recent systematic review of social attainment among pediatric central nervous system tumor survivors, for example, reported them to be more likely than the general population to have not completed secondary education, to not be married (other relationship statuses were not considered), and to be unemployed (Schulte et al., 2019). While there have been programs targeted at school-aged survivors to improve social skills and experiences, there is little evidence of associated improved outcomes (Schulte et al., 2019). A school-wide, evidence-based social and emotional learning (SEL) approach may be less likely to burden diagnosed children and their families, and to target underlying social constructions that inhibit the wellbeing of all children (Grove & Laletas, 2020; Mark et al., 2017). SEL approaches aim to teach the knowledge, attitudes and skills needed to enhance empathy and mental wellbeing management, and the development and sustainment of positive relationships (Joseph et al., 2011).

We also identified a strong theme of 'being as normal as possible' throughout families' general experiences (Young et al., 2021); this was particularly relevant to discussions of schooling in terms of both social experiences and wanting to receive educational support that did not single the diagnosed child out from peers. Adequate educational support was lacking for many families, though most studies were conducted prior to the 2015 establishment of school re-entry support as a standard of psychosocial care in pediatric oncology (Thompson et al., 2015). Our findings, however, are consistent with the most recent literature and policy review of school re-entry service for children diagnosed with cancer in Australia (Lum et al., 2017). No Australian school policy was found to address students' need for reintegration

services, despite it being the legal responsibility of the student's school to ensure educational opportunities are equitably provided to all regardless of illness and disability. Further, hospital-to-school communication is reported as lacking, as is training and support for teachers, and opportunities for quality home-based learning. This is likely consistent with the international picture, given the poor level of educational attainment for childhood cancer survivors in several high income countries (Saatci et al., 2020) and lack of evidence-based school support programs for childhood cancer patients and survivors (Burns et al., 2021). This lack of support inhibits the social and economic participation of not only the diagnosed child, but also those who provide the necessary caregiving—the bulk of which is shouldered by mothers—to compensate for its absence (Norberg, 2007; Young et al., 2021). A central liaison officer to manage communication between families, healthcare services, and schools has been a consistently proposed key factor to supporting families (Thompson et al., 2015); this could potentially be integrated within a nurse navigator model that supports families to access and use a range of supports services in their community (Spooner et al., 2019). In the United Kingdom, a comprehensive guide to support teachers addresses many of these issues and includes practical resources such as checklists and communication templates (Edwards et al., 2019). However, country-specific guidelines to ensure consistent support delivery for school re-entry, in addition to funding for public services to enact these, are needed (Lum et al., 2017).

### **Conclusion**

Children and adolescents diagnosed with brain tumor are at risk of experiencing lifelong physical, cognitive, and social impairments. As a society, we have an obligation to meet their needs, and that of their families, from diagnosis and beyond. Our review has highlighted the need for more comprehensive, individualized, and integrated support for diagnosed children to return to educational institutions, and for the need to address their social experiences, particularly with

regards to bullying, potentially through a school based SEL approach. Funding support, evidence-based guidelines, skill development, and clear communication structures across families, healthcare facilities, schools, and educational departments are essential to achieving this.

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**Table 1**

*Summary of review method in Young et al. (2021)*

<b>Review stage</b>	<b>Method</b>
1. Inclusion and exclusion criteria	<ul style="list-style-type: none"> <li>• Participants diagnosed with (malignant or non-malignant) brain tumor as a child or adolescent (&lt;25 years old), or their family caregivers or siblings.</li> <li>• Studies using qualitative methodologies published in peer-reviewed journals in English with all years included.</li> <li>• Excluded: studies focused on biological aspects of care only or childhood cancer where data relevant to brain tumor could not be extracted.</li> </ul>
2. Search strategy	<ul style="list-style-type: none"> <li>• Databases searched, April 2020: Medline, CINAHL, PsycInfo, Embase, Web of Sciences (Social Sciences Citations Index, Arts and Humanities Citations Index).</li> </ul>
3. Study selection	<ul style="list-style-type: none"> <li>• Titles and abstract imported into EndNote; duplicates removed.</li> <li>• Remaining articles imported into Covidence (<a href="http://www.covidence.org">www.covidence.org</a>).</li> <li>• Titles and abstracts reviewed by two authors; conflicts discussed and agreed upon by all authors.</li> <li>• Full text reviewed by two authors; conflicts discussed and agreed upon by all authors.</li> <li>• First author searched reference lists of all selected articles for further relevant papers; these were reviewed, discussed, and agreed upon by the whole research team.</li> </ul>
4. Quality assessment	<ul style="list-style-type: none"> <li>• Papers assessed by first author<sup>1</sup> using Joanna Briggs Institute Critical Appraisal Tool for qualitative research (The Joanna Briggs Institute, 2017).</li> <li>• All studies, regardless of methodological quality, underwent data extraction and synthesis.</li> </ul>
5. Data extraction	<ul style="list-style-type: none"> <li>• General descriptions of each paper collated into table in Microsoft Word (see Table 2).</li> <li>• Each paper uploaded into NVivo12 to assist with data extraction.</li> </ul>
6. Data synthesis	<ul style="list-style-type: none"> <li>• First stage: qualitative description using Miles and Huberman (1994) six analytic strategies.</li> <li>• Second stage – for only those data that enabled latent analysis<sup>2</sup>: six steps and framework of Braun and Clarke (2006) reflexive thematic analysis.<sup>3</sup></li> </ul>

*Note.* <sup>1</sup>Qualitative synthesis has the goals of transparency, rather than reproducibility, and with the review grounded in the subjective analysis of the reviewers, having additional members of the review team assessing quality or data would not make the outcomes ‘truer’ (Bearman & Dawson, 2013). <sup>2</sup>Where one can go beyond description to theorize underlying ideas and conceptualizations that shape the semantic content of the data (Braun & Clarke, 2006). <sup>3</sup>Findings from this stage are reported in Young et al. (2021).

**Table 2***Summary of reviewed papers*

<b>Paper, country</b>	<b>Aim</b>	<b>Participants</b>	<b>Data collection</b>	<b>Analysis</b>
Boydell et al. (2008) Canada	Explore survivors' experience of transition from adolescence to adulthood.  <i>Malignant only</i>	<u>14 survivors</u> : aged 17-29 years; 3 high school, 11 graduated high school. <u>22 family members (17 families)</u> : <i>no further information provided</i> . <u>Recruitment</u> : hospital database.	Focus groups, in-depth interviews	Diekelmann's 7-stage hermeneutical analysis
Bruce et al. (2008) Canada	Explore families' experiences of re-entry into school system after diagnosis and treatment.	<u>16 parents</u> : <i>no further information provided</i> . <u>14 children &amp; youth</u> : mean age = 12.8 years (range: 7-20); mean years since diagnosis = 6.4 (range: 2-13); 87.5% surgery, 81% chemotherapy, 75% radiation. <u>Recruitment</u> : hospital database.	Semi-structured interviews	Thematic analysis
Carlson-Green (2009) America	Hear survivors' concerns and experiences.	<u>11 survivors</u> : mean age = 28.4 years (range: 23-33). <u>Recruitment</u> : unclear.	Observations of informal focus group	None stated
Cataudella & Zelcer (2012) ♦ Canada	Explore psychological experiences of children at end of life.	<u>24 parents</u> : 9 male, 15 female; 8 30-39 years, 8 40-49 years, 9 50-59 years; 17 university educated; 21 Caucasian, 3 Native American; mean years since child's death = 5 (range: 3-11). <u>17 deceased children*</u> : 12 male, 5 female; age at death: 3 1-5 years, 3 8-11 years, 11 12-19 years. <u>Recruitment</u> : patient tumor registry.	Semi-structured interviews	Thematic analysis
Cheung et al. (2014) Australia	Explore parent and teacher understanding and use of neuropsychology reports.	<u>17 parents (15 families)</u> : 12 mothers, 5 fathers; mean age = 41.9 years (range: 32-54); 11 university degree. <u>15 patients*</u> : mean age = 10.7 years (range: 4-17); mean age at diagnosis = 8.7 years; 14 surgery, 2 shunt, 8 radiotherapy, 6 chemotherapy, 3 medication. <u>8 teachers</u> : <i>data not included in current review</i> . <u>Recruitment</u> : hospital database.	Semi-structured interviews	Unclear

Cheung et al. (2019)	Assess impact of brain tumor on the well-being of Hong Kong Chinese survivors.	<u>16 survivors</u> : no further information provided. <u>Recruitment</u> : hospital database.	Semi-structured interviews	Colaizzi's method
Hong Kong				
D'Agostino & Edelstein (2013)	Identify psychosocial resource needs of young cancer survivors, and potential influence of age at diagnosis or brain tumor diagnosis.	<u>9 survivors</u> : 5 female, 4 male; mean age at diagnosis = 16 years (range: 7-27); mean age = 26 years (range: 20-32); 1 radiation, 2 surgery, 1 surgery + radiation, 2 surgery + radiation + chemo, 1 radiation + chemo + stem cell transplant. <u>Recruitment</u> : hospital database, purposive.	Focus groups	Thematic analysis
Canada				
Forinder & Norberg (2010) ♣	Explore existential issues expressed by parents.	<u>11 parents</u> : 7 mothers, 4 fathers; no further information provided. <u>7 survivors*</u> : 4 girls, 3 boys; aged 7-14 years. <u>Recruitment</u> : hospital database, purposive.	Semi-structured interviews	Thematic analysis
Sweden				
Gunn et al. (2016)	Evaluate survivors' quality of life.	<u>21 survivors</u> : 14 male, 7 female; median age = 24 years (range: 14-35); median years since diagnosis = 17 (range: 8.1-25.7); surgery = 21, chemotherapy = 8, irradiation = 17. <u>Recruitment</u> : National cancer registry and clinic records.	Semi-structured interviews	Thematic analysis
Finland				
Hobbie et al. (2016)	Describe how young survivors describe their physical, emotional, and social functioning.	<u>41 survivors</u> : 16 female, 25 male; mean age = 23 years (range: 15-36); 34 White, 4 African American, 3 other; mean years since diagnosis = 15 (range: 7-27); 11 resection only, 16 focal radiation +/- chemotherapy, 14 cranio spinal radiation +/- chemotherapy/stem cell rescue. <u>Recruitment</u> : secondary from larger study, purposive.	Semi-structured interviews	Directed content analysis
America				
Lucas et al. (2014)	Explore survivors' and mothers' expectations for survivor function and independence.	<u>40 mothers</u> : mean age = 52.18 years (range: 41-67), 28 some college or more. <u>40 survivors</u> : mean age = 23.38 years (range: 15-37), mean years since diagnosis = 15.26 (range: 7-27). <u>Recruitment</u> : hospital database, purposive recruitment.	Semi-structured interviews	Directed content analysis
America				
Macartney et al. (2014)	Explore children's symptom experience, coping strategies, and quality of life after treatment.	<u>12 children</u> : 6 girls, 6 boys; median age at diagnosis = 10.3 years (range: 2-15); median years since diagnosis = 3 (range: 1-14). <u>Recruitment</u> : hospital database, purposive.	Semi-structured interviews	Content analysis
Canada				
Norberg & Steneby (2009) ♣	Explore parents' perceptions of treatment influence.	<u>11 parents (7 families)</u> : 7 mothers, 4 fathers; no further information provided. <u>7 children*</u> : 4 girls, 3 boys; aged 7-	Semi-structured interviews	Thematic analysis

Sweden		14 years; off treatment for 20-38 months. <u>Recruitment</u> : hospital database, purposive.		
Russell et al. (2016)	Explore children's and parents' experiences.	<u>12 children</u> : 6 female, 6 male; mean age = 10.5 years (range: 7-14.5); mean months since diagnosis = 32.6; 12 chemo, 7 radiation, 10 surgery. <u>12 parents</u> : 2 East Indian, 1 Middle Eastern, 2 Canadian Aboriginal, 7 Canadian European; <i>no further information provided</i> . <u>Recruitment</u> : patients at hospital, purposive.	Semi-structured interviews	Constructivist grounded theory
Canada				
Shortman et al. (2013)	Explore mothers' experiences of caring for their child.	<u>6 mothers</u> : <i>no further information provided</i> . <u>6 children</u> *: 4 male, 2 female; median age = 10.5 years (range: 8-13); median months since diagnosis = 27 (range: 17-35); 6 surgery, 5 radiotherapy, 4 chemotherapy. <u>Recruitment</u> : secondary from larger study, purposive.	Semi-structured interviews	Unclear
United Kingdom				
Soanes et al. (2009)	Explore children's and families' experiences.	<u>10 children</u> : 5 male, 5 female; age range = 5-13 years, 7 White British, 1 Asian other, 2 unknown; 3 surgery and radiotherapy, 7 surgery + chemo + radio. <u>18 parents</u> : 9 mothers, 9 fathers; <i>no further information provided</i> . <u>Recruitment</u> : hospital database.	Poster making, draw and write technique, semi-structured interviews	Framework analysis
United Kingdom				
Vance et al. (2004)	Describe long-term impact of childhood brain tumors.	<u>8 parent-caregivers</u> : 5 mothers, 1 father, 2 mother-father pairs; <i>no further information provided</i> . <u>8 survivors</u> *: 5 female, 3 male; mean years at diagnosis = 5.53 (range: 0.69-9.51); mean years since diagnosis = 8.95 (range: 3.85-12.35); 7 radiotherapy, 6 chemotherapy. <u>Recruitment</u> : hospital database.	Semi-structured interviews	Interpretative phenomenological analysis
England				
Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al. (2019a)•	Explore survivors' experiences of school re-entry.	<u>5 children</u> : 3 male, 2 female; mean age = 9 years (range: 7-10); 1 surgery, 1 surgery + chemo, 1 surgery + radiation, 2 surgery + chemo + radiation. <u>9 parents</u> : <i>no further information provided</i> . <u>13 teachers &amp; 13 healthcare providers</u> : <i>data not included in current review</i> . <u>Recruitment</u> : Hospital database, purposive.	Semi-structured interviews	Thematic analysis
Belgium				
Vanclooster, Bilsen, et al. (2019b)•	Discover short-term changes in parents' and teachers' perspectives on school reintegration.	As above – parents and teachers only.	Semi-structured interviews, longitudinal	Thematic analysis

Belgium				
Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al. (2019)•	Investigate survivors' perspectives on school reintegration over a 2 year period.	As above – children and parents only.	Semi-structured interviews, longitudinal	Thematic analysis
Belgium				
Zelcer et al. (2010)♦	Explore end-of-life experiences of children and their families.	<u>25 parents</u> : 16 female, 9 male; age range = 30-60+ years; 25 White. <u>17 deceased children*</u> : 12 male, 5 female; age range at death = 1-19 years; median years since child's death = 5.5 (range: 3-12). <u>Recruitment</u> : hospital database	Focus groups	Thematic analysis
Canada				
Zwiers et al. (2015) Canada	Explore meaning of the term survivor from the perspectives of young adults.	<u>Six survivors</u> : 4 male, 2 female; age range = 22-30 years; age at diagnosis range = 7-23 years; 1 medication, 4 surgery, 1 surgery + radiation; 2 university completed, 2 college. <u>Recruitment</u> : community sampling, purposive.	Semi-structured interviews, reflective journals	Constructivist grounded theory

Note. Symbols (♦♣•) indicate the same data source was used across one or more papers. \*Did not participate in study.

**Table 3***Quality assessment of reviewed papers*

Paper	Philosophical/methodology	Methodology/research question	Methodology/data collection	Methodology/data analysis	Methodology/results interpretation	Locate researcher	Address influence of researcher	Participant voice	Ethical	Conclusions flow from data
Boydell et al. (2008)	Y	Y	Y	Y	Y	N	N	Y	U	Y
Bruce et al. (2008)	U	Y	Y	Y	Y	N	N	Y	U	Y
Carlson-Green (2009)	U	U	N	N	N	N	N	N	Y	Y
Cataudella and Zelcer (2012)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Cheung et al. (2014)	U	Y	Y	Y	Y	N	N	N	Y	Y
Cheung et al. (2019)	U	Y	Y	N	Y	N	N	N	Y	Y
D'Agostino and Edelstein (2013)	U	Y	Y	N	Y	N	N	N	Y	Y
Forinder and Norberg (2010)	U	Y	Y	Y	Y	N	N	N	Y	Y
Gunn et al. (2016)	U	Y	Y	N	Y	N	N	N	Y	Y
Hobbie et al. (2016)	U	Y	Y	N	Y	N	N	N	Y	Y
Lucas et al. (2014)	U	Y	Y	N	N	N	N	N	Y	Y
Macartney et al. (2014)	U	Y	Y	N	N	N	N	N	Y	Y
Norberg and Steneby (2009)	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Russell et al. (2016)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Shortman et al. (2013)	U	Y	Y	U	Y	N	N	N	Y	Y
Soanes et al. (2009)	U	Y	Y	N	U	N	N	N	Y	Y
Vance et al. (2004)	U	Y	Y	Y	Y	N	N	Y	Y	Y
Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al. (2019a)	U	Y	Y	U	Y	N	U	N	Y	Y
Vanclooster, Bilsen, et al. (2019b)	U	Y	Y	U	Y	N	U	N	Y	Y
Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al. (2019)	U	Y	Y	U	Y	N	U	N	Y	Y
Zelcer et al. (2010)	U	Y	Y	N	Y	N	N	N	Y	Y
Zwiers et al. (2015)	Y	Y	Y	Y	Y	N	N	Y	Y	Y

**Box 1***Families' suggestions for schooling and educational support*

- Open, clear, and ongoing communication between family and school staff (principal and teachers) (Bruce et al., 2008; Cheung et al., 2014; Vanclooster, Bilsen, et al., 2019b)
- Make long-term plans for child's educational needs with school principal (Bruce et al., 2008)
- Work with the family to develop solutions to problems as they are identified (Bruce et al., 2008; Vanclooster, Bilsen, et al., 2019a, 2019b)
- Teacher/s take responsibility for child's needs and demonstrate concern for meeting these (Boydell et al., 2008; Bruce et al., 2008; Vanclooster, Bilsen, et al., 2019a; Vanclooster, Bilsen, Peremans, Van Der Werff Ten Bosch, et al., 2019)
- School must address child's physical needs e.g. be wheelchair accessible, have a teacher aid assist the child to move between classrooms, have required transport options (Bruce et al., 2008)
- Health professionals evidence their child's educational, social and physical needs to the school (Bruce et al., 2008; Cheung et al., 2014)
- Have a professional support organization come and speak with the teacher/s yearly about how they can best support the child (Bruce et al., 2008)
- Individual programs and support targeted to their child and their specific needs (Bruce et al., 2008)
- Give the child copies of notes (from the teacher or a carbon copy of a classmate's) so that they can concentrate (Bruce et al., 2008)
- Offer flexible testing arrangements e.g., testing alone outside of the classroom to support concentration, having a teacher aid assist in reading and interpreting questions or dictating their responses for them (Bruce et al., 2008)
- In high school, where there are multiple teachers, have one learning support person assigned to the adolescent (Cheung et al., 2014)

**Figure 1**

*Findings from the larger review reported in Young et al. (2021)*

