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# Attending school after treatment for a brain tumor: Experiences of children and key figures

Stephanie Vanclooster<sup>1</sup>, Johan Bilsen<sup>1</sup>, Lieve Peremans<sup>1,2</sup>, Jutte Van der Werff Ten Bosch<sup>3</sup>, Geneviève Laureys<sup>4</sup>, Elsie Willems<sup>4</sup>, Sophie Genin<sup>5</sup>, Patrick Van Bogaert<sup>6</sup>, Philippe Paquier<sup>7,8,9</sup> and Anna Jansen<sup>1,10</sup>

<sup>1</sup>Mental Health and Wellbeing Research Group, Vrije Universiteit Brussel, Brussels, Belgium

<sup>2</sup>Department of Primary and Interdisciplinary Care, University of Antwerp, Antwerp, Belgium

<sup>3</sup>Department of Pediatric Hematology Oncology, UZ Brussel, Brussels, Belgium

<sup>4</sup>Department of Pediatric Hematology, Oncology and Stem Cell Transplantation, Ghent University Hospital, Ghent, Belgium

<sup>5</sup>Department of Neuropsychology, Hôpital Erasme, Université Libre de Bruxelles, Brussels, Belgium

<sup>6</sup>Department of Pediatric Neurology, Hôpital Erasme, Université Libre de Bruxelles, Brussels, Belgium

<sup>7</sup>Department of Neurology, Hôpital Erasme, Université Libre de Bruxelles, Brussels, Belgium

<sup>8</sup>Unit of Clinical and Experimental Neurolinguistics, Center for Linguistics, Vrije Universiteit Brussel, Brussels, Belgium

<sup>9</sup>Unit of Translational Neurosciences, School of Medicine and Health Sciences, Universiteit Antwerpen, Antwerp, Belgium

<sup>10</sup>Pediatric Neurology Unit, Department of Pediatrics, UZ Brussel, Brussels, Belgium

Corresponding author:

Stephanie Vanclooster, Mental Health and Wellbeing Research Group, Department of Public Health, Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Laarbeeklaan 103, 1090 Brussels, Belgium

Email: [stephanie.vanclooster@vub.ac.be](mailto:stephanie.vanclooster@vub.ac.be)

## Abstract

Reintegration into school is a milestone for childhood brain tumor survivors, as well as for their parents, teachers and healthcare providers. We explored their experiences following the school re-entry by conducting semi-structured interviews. Thematic analysis resulted in four main themes: “school performance,” “psychosocial wellbeing,” “support and approach” and “communication and collaboration”. Children were pleased to return to school despite confrontation with adverse outcomes. Parents, teachers and healthcare providers identified current and future concerns and challenges, as well as opportunities for academic and personal development. Their experiences highlight the importance of coordinated and systematic follow-up in close collaboration with healthcare providers.

## **Keywords**

brain tumor, children, key figures, reintegration into school, semi-structured interviews

## **Background**

Childhood brain tumor survivors (CBTS) can experience numerous negative changes upon their return to school. Due to illness, treatment and/or long absence from school, CBTS frequently face learning difficulties resulting from deficits including attenuated executive skills, poor concentration and cognitive decline (de Ruiter et al., 2013; Upton and Eiser, 2006). They may also encounter psychosocial problems such as reduced self-confidence and social isolation (Salley et al., 2015; Wakefield et al., 2010). Moreover, brain damage often becomes apparent only after a considerable time because of cerebral maturation and higher learning objectives. This well-known concept is called “growing into deficit” (Arsen et al., 2006). Such consequences may disrupt the learning process and personality development in CBTS sooner or later, leading to diverse disadvantages compared to peers. In addition to physical limitations, these survivors show lower rates for educational attainment, sociodemographic outcomes and mental health at various stages in life (Armstrong et al., 2009; Gunn et al., 2016).

Both short- and long-term consequences of cancer treatment on neurocognition in CBTS have been the focus of earlier research (Barrera et al., 2005; Holland et al., 2014; Turner et al., 2009). However, questions related to the experiences of parents, school staff and healthcare providers involved in the child’s school life after treatment require further study. Since the child’s reintegration and development at school can be considered as a common concern of these key figures, their perspectives should be studied together.

Furthermore, the young survivor's own viewpoint needs to be examined as well, when it comes to rediscovering the school routine and feeling supported.

As the child's main representatives, parents play a central role in his or her school career, since they are best positioned to recognize personal needs and obstacles with an influence on school participation. Many find it important to stay informed about their child's school life, being concerned about how the child performs or feels (Hutchinson et al., 2009; Long and Marsland, 2011) or about the school's approach to changes or difficulties (Bruce et al., 2008). So, although parents are relieved that the child has returned to school following an intense period of illness and treatment, they might also be worried because of possible (e.g. learning, psychosocial) challenges (Eaton Russell et al., 2016; Norberg and Steneby, 2009). At school, a close monitoring of the child by the teacher(s) is crucial in order to intervene when difficulties arise. Unfortunately, many teachers are not aware of or informed about the post-treatment vulnerabilities in CBTS (Bruce et al., 2008; Thompson et al., 2015). Often, they lack the knowledge or time to assist and are insecure about being capable of meeting individual needs, considering their low familiarity with childhood cancer (Moore et al., 2009; Nabors et al., 2008). Healthcare providers from diverse disciplines who supervise the aftercare of CBTS, contribute (in)directly to the process of reintegration as well (Aukema et al., 2011; Eiser, 2007). For instance, in addition to follow-up of the child's health, they assess neurocognitive abilities needed in the classroom and offer advice for dealing with post-treatment changes to others in the child's life.

The central research question addressed in this study was formulated as follows: how do CBTS, their parents, teachers and healthcare providers experience the reintegration into school? The use of a qualitative research design allows each key figure to disclose

experiences in its own way, so patterns inherent to each perspective may informally emerge. We expect that increased knowledge about the various stakeholders' experiences lead to different points of attention that can be used to improve short- and long-term opportunities for CBTS in education.

## Methods

### Study design

This multiple case study consists of semi-structured interviews with CBTS and key figures in their environment after having returned to school. The use of semi-structured interviews enabled us to obtain a profound view on the experiences of the participants. Additionally, we consulted medical records and school documents to understand the child's health and school performance.

The following inclusion criteria for case selection were applied. Children had to be between 6 and 12 years old and attended the same mainstream school as before their illness. The child had to live at home and had returned to school for longer than 6 months, so the school routine was sufficiently re-established. According to the treating physician, the primary treatment was completed and the child had a good prognosis. To prevent memory bias, children who had returned to school more than 3 years ago were excluded. The type of brain tumor or medical treatment was not a criterion for exclusion, since we did not focus on diagnosis and neurocognitive sequelae. CBTS with a genetic syndrome were excluded to avoid bias due to additional medical factors that could affect their school career.

We intended to study a limited but varied sample of cases with the purpose of in-depth exploration of experiences. Our aim was to select cases illustrative of the school trajectories of CBTS in Flanders (Belgium), but also defined by diversity to capture common patterns in this study population. Characteristics in the sample such as age, medical trajectory and time since having returned to school reflect this variety (see Table 1). Our combined sampling of typical cases and maximum variation (Patton, 2002) led to the inclusion of five children treated in the university hospitals UZ Brussel and UZ Gent. Table 1

shows the cases and the interviews with parents, teachers and healthcare providers. We mainly addressed classroom teachers, but also teachers with a background in special education who provided additional support. Participating healthcare providers included treating physicians and different rehabilitation therapists responsible for professional (after)care.

**Table 1.** Case description

Characteristics	Case 1	Case 2	Case 3	Case 4	Case 5
Gender	F	M	M	M	F
Age	10	10	10	7	8
Diagnosis	Pilocytic astrocytoma	Anaplastic ependymoma	Medulloblastoma	Low-grade glioma	Medulloblastoma
Treatment	Surgery	Surgery Radiotherapy	Surgery Radiotherapy Chemotherapy	Surgery Chemotherapy	Surgery Radiotherapy Chemotherapy
Time since return in months	7	28	12	21	6
Interviews	1 child 2 parents 3 teachers 2 healthcare providers	1 child 2 parents 3 teachers 2 healthcare providers	1 child 2 parents 3 teachers 2 healthcare providers	1 child 1 parent 2 teachers 5 healthcare providers	1 child 2 parents 2 teachers 2 healthcare providers

## Data collection

Between October 2014 and June 2015, we conducted interviews with 5 children, 9 parents, 13 teachers and 13 healthcare providers. Topic lists based on the literature (e.g. Aukema et al., 2011; Boonen and Petry, 2012; Harris, 2009) and pre-interviews with healthcare providers and experts in education were used. Each participant was interviewed in the corresponding environment, i.e. at home, at school or in a healthcare setting. Given their relatively young age, some children had difficulties with describing their experiences in depth. In these cases, the interviewer made use of toys to stimulate the child to engage in telling stories by which their experiences could be evaluated. All the participants provided written informed consent for participation in the study. The research protocol was approved by the ethical committees of the UZ Brussel and the UZ Gent.

## Data analysis

The aim of data analysis was to discover common themes in the experiences of the various participants (Miles et al., 2014). Therefore, we explored the data according to the principles of thematic analysis (Braun and Clarke, 2006). The analysis was carried out inductively to be connected as closely as possible with the data, while developing a codebook in an iterative way starting from the first interviews. The codebook was constantly adapted during the coding process, as new codes were added and existing codes were grouped into descriptive units. These successive adjustments resulted in a final framework of units, in which we could reveal several themes. Key themes were determined in relation to the diverse experiences of all the participants. During the analysis, we used NVivo 8 software for qualitative data management (QSR International, 2008) to store the interview transcripts, name the text



fragments using codes and link these extracts to preliminary insights. As a result, the ground for thematic analysis was provided, being the identification, review and interpretation of themes. By using a reflexive journal and organizing discussions with the team during the fieldwork and data analysis, the main researcher (SV) was constantly aware of her role.

## **Results**

Data analysis resulted in the identification of four main themes: “school performance”, “psychosocial wellbeing”, “support and approach” and “communication and collaboration”.

We present the experiences of CBTS, their parents, teachers and healthcare by reviewing the different themes in detail.

### **1. School performance**

After the return to school, most children encountered one or more changes in performance, for example lower test results and learning difficulties due to poor concentration. However, experiencing such a decline did not lower their motivation to perform well in class. Being aware of a learning delay or below average skills did not prevent them from working hard and accepting help, as observed by parents and teachers.

*“He works so hard, it’s a pleasure to help him. (...) I feel that he is grateful for what he gets. He is different from the others.”* [Simone, teacher]

Parents expressed concerns while discussing these adverse changes. Although most of them spoke positively about the child’s commitment, the parents realized that achieving educational goals had become more difficult than for peers. Others admitted to expect

learning problems because of the harmful impact of the tumor and/or treatment. Healthcare providers mentioned disease-related consequences on academic achievement as well, such as executive deficits and problems with processing information.

*“It’s good that she is trying, but it will be hard I’m afraid. She missed a lot and because of her limited opportunities to concentrate, she is behind the rest (classmates).”* [Julie, mother]

The same changes were discussed by teachers, but in a more objective way than parents did. For example, some of them described their pupils’ deficits in detail and explained how these could be understood as educational needs. A few teachers referred explicitly to obstacles that may arise during the child’s future school career. They were expecting challenges, pointing to the pupil’s present learning delay or to the increased teaching tempo and independent attitude required from pupils later on.

*“I’m afraid that she will have difficulties, since she is slower and has missed a lot the past two years. You have to work more independently and faster, so we must wait and see if she can manage.”* [Charlotte, teacher]

According to other teachers, the influence of external barriers on school performance should not be underestimated. Extracurricular activities such as hobbies and aftercare (e.g. physiotherapy) were considered essential to facilitate the child’s recovery, as long as they did not slow down the learning process.

*“I’m concerned that all the activities outside school are too much, she is already easily tired. Her progress should not be jeopardized.”* [Marlena, teacher]

At the same time, constructive elements or strengths in the children and their environment were reported. Even when the child demonstrated difficulties or had

developed special educational needs, protective factors for evolution at school were identified. Examples given by healthcare providers included the child's mental resilience and drive to reintegrate, multidisciplinary follow-up of the child's school career and parental involvement in the child's school life.

*"We may expect difficulties (at school), but she is young and strong with much energy. Also, there is strong network (of healthcare providers) besides her parents, always looking after her."* [Lisa, healthcare provider]

## 2. Psychosocial wellbeing

All the children were eager to return to school, although some admitted that it was hard to re-adapt given their confrontation with limitations (e.g. physical problems, learning difficulties). These feelings of contentment seemed to be related to the value of school participation, since they perceived going back as resuming normal life and being an ordinary pupil again. The reunion and relationships with peers appeared to be important motivations to re-attend school. Several children reported being reassured by the kindness and encouragement of classmates and teachers.

*"I loved seeing my friends again and do fun things, like playing on the playground and doing things in the classroom. No more hospital or staying at home, just great."* [Trixie, child]

*"Everyone at school was very kind to me after I returned. Just being in the classroom was nice, even when I could not pay attention."* [Michael, child]

The children's need for normality was reflected in their wish not to be viewed or approached differently. Most of them enjoyed the (temporary) attention without expecting any kind of privileged treatment.

*"He just wanted to be treated like everyone else, although something had happened, obviously. He talked very openly about that, but wanted no different treatment and made that immediately clear."* [Karlene, teacher]

Parents were grateful that the child could return to school and expressed feelings of relief, because he or she looked forward to participating again. At the same time, some parents were concerned about their child's emotional state and/or friendships. They felt that despite the meaningful influence of the re-entry on the child's recovery, the past period and long absence at school continued to affect his or her wellbeing. Because of these concerns, some parents had become overprotective or anxious at times.

*"She has always been an outgoing girl, but now she is more hesitant towards others. (...) Her friendships became more superficial, because they had not seen each other for a long time."* [Lukas, father]

*"Yes, I'm worried because I know that he is struggling with what has changed (between him and classmates). Unfortunately, as a mother, you can't do everything."* [Ingrid, mother]

Likewise, concerns regarding the child's wellbeing were disclosed by various teachers. They spoke about personality traits and mentioned poor social skills, lack of emotional disclosure and fear of failure. In some children, it was difficult to distinguish between personality and condition-related consequences, when trying to understand specific responses or behavioral patterns in the classroom.

*“There must be consequences of her illness. It’s not all about her personality, right? Yes, I often wonder about the difference, but maybe that’s not even that important.”* [Helen, teacher]

Other teachers reported not to be worried, but did recognize that the child experienced psychosocial challenges following the return. The transition from individual tutoring at home to classroom teaching was challenging and even overwhelming for several children. In addition, re-adjusting to the school routine and the role as pupil among peers could be very demanding. Consequently, some children remained in the background while rediscovering their position in the class group.

*“His return didn’t go smoothly. The children patronised him and he didn’t know what to do, so he was even quieter and more restrained than before. (...) A few weeks later, it got better.”* [Simone, teacher]

### 3. Support and approach

Children received support to meet educational or psychosocial needs by means of small adaptations or assistance from classroom teachers, school counsellors and/or specialized teachers. Most children said to appreciate the help they received, although they did not always understand the benefits for their catching-up process and development.

*“Because my teacher helps me, I’m doing better. It’s good that she does, I’m bad at many things.”* [Thomas, child]

When teachers were asked how they experienced the re-entry, some talked about personal obstacles. Several teachers perceived the reunion with the child as confrontational

due to physical sequelae. As a result, they tended to react overprotectively by exempting him or her from certain tasks and activities. Other teachers emphasized difficulties with estimating and interpreting the child's capacities and wellbeing. For them, deciding how to approach the child in the best way was a recurring issue. Most teachers raised questions or doubts about the effectiveness of teaching methods and adjustments.

*"You have to start again, what is still possible and what is not anymore? (...) Slowly, you know, but you will ask those questions again and again."* [Kate, teacher]

Others mainly expressed positive experiences that made them feel strengthened while assisting the child. They spoke of increased self-confidence after attending a conference or meeting a healthcare provider to obtain health-related information. Experiences could also be related to the availability of a support network at school, consisting of sessions with colleagues. These teachers demonstrated an open attitude towards the child and emphasized the importance of their own commitment.

*"He is good at different things, even though it's not always visible to others. I believe that my job is to reinforce these strengths. (...) If everyone is motivated, then it should be fine."* [Tina, teacher]

On the whole, parents were satisfied with how teachers and schools responded to their child's return and condition. However, some questioned the approach at school, regardless of teachers' efforts to provide an optimal learning environment. They wondered if teachers were sufficiently alert and prepared for possible difficulties. An important reason behind this concern was the school's limited health-related knowledge or expertise.

*“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.”* [Irene, mother]

Parents had different expectations from the school in terms of follow-up. Some of them expected that teachers focused on the child’s feelings in addition to performance, in case of (suspected) emotional or social difficulties. On the other hand, others valued the teachers’ subtle attention for such difficulties, because it contributed to the child’s sense of normality.

*“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.”*

[Elisa, mother]

Irrespective of the support provided at that moment, most parents realized that the help of teachers would become less standardized in the future, particularly after finishing primary school. Assumptions about future assistance were sometimes accompanied by a level of concern and uncertainty, but also acceptance.

*“Right now, formal assistance is organized in addition to classroom support, but it will be different when she attends high school. Probably, we have to make choices, the future will tell.”* [Victor, father]

#### 4. Communication and collaboration

Most parents reported to have positive relationships with teachers, as they felt involved and appreciated. They were reassured by the school’s staff willingness to make plans and adjustments and to communicate frequently. For instance, parents had been invited at

school to discuss the use of an individualized schedule or ways to inform classmates. Other parents brought up negative experiences characterized by misunderstanding, incomprehension and absence of commitment. They mentioned schools not showing a receptive attitude towards inclusion of the child, not communicating about difficulties on time or not assisting when professional support had to be organized.

*“They saw him as a troublesome pupil, I couldn’t expect any support. (...) On the contrary, they seemed to be working against me. I felt like I had to fight constantly, but gained nothing.”* [Ingrid, mother]

Parents expressed their ideas about how schools and families should interact. Exchanging information early during the reintegration followed by regular re-evaluation was considered crucial. This information included physical effects, psychosocial issues or organizational matters. A number of parents expected to be addressed directly when signs of problems were observed, since they wanted to reflect on solutions together with the school.

*“We have faith in his teacher and the school, but I am confident that we will be the first ones to detect difficulties, even when it’s about learning. In the end, we spend more time with him and know him best.”* [Benjamin, father]

Teachers stated to share parents’ viewpoints concerning the child’s (future) school career and valued their suggestions and help with practical or curriculum-related matters. Nevertheless, they also mentioned obstacles while working together. Examples included not receiving adequate key information about the child’s condition, experiencing too high expectations of involvement, and disagreement on the support to be organized. Teachers underlined the importance of making clear arrangements with parents, ideally just before or after the return. According to several teachers, their own responsibilities towards parents



involved keeping them up to date about the child's performance and explaining the school's attitude towards special educational needs. Conversely, they wanted to be informed about changes in the child's life that could influence school motivation and expected involvement when professional help (e.g. speech therapy) had to be organized.

*"After they return from the hospital, I always ask how it went. Perhaps they notice new things I should look out for. (...) If there is anything I should know, tell me. Then we can find the right way to help him."* [Tina, teacher]

In most cases, there was very little communication between schools and healthcare providers supervising the child's (after)care. Only a few teachers indicated to have received information about the child's specific condition-related consequences or therapy, or advice useful in a daily teaching context. However, some stressed the benefits of collective evaluation of the child's progress for their own teaching and of being informed about therapeutic techniques and evolution.

*"Our contact (with speech therapist) is rather informal, but I find it meaningful to be informed about the progress he has made and her approach. Then we know we think alike. Especially in the beginning, this was useful."* [Carmen, teacher]

On the other hand, healthcare providers said that schools often differed in approachability and acceptance of information, making constructive ways of working together difficult to achieve. Therefore, they considered parents as the key figures to address in case of questions related to the child's school career. In addition, a coordination service that would keep track of progress at school was suggested.

*"I feel that his follow-up is quite fragmented. He is monitored by the hospital and child rehabilitation centre, by us and he is even taught by a specialized teacher. His mother*

*informs us, but we need a central contact person for everyone to speak to.” [Elaine, healthcare provider]*

## **Discussion**

Our study shows that CBTS and key figures in their environment experience reintegration into school differently. Overall, children mostly recalled positive feelings, while parents, teachers and healthcare providers focused on concerns and challenges.

Children were pleased to re-attend school despite being confronted with various limitations. They longed for school life in order to participate in common activities and to reconnect with peers. During the phase of re-adjustment, a supportive environment strengthened their self-esteem and motivation to perform. Positive effects of social connectedness on wellbeing (at school) such as improved mental strength, sense of normalization and coping with stress, have previously been reported in CBTS (Decker, 2007; Tougas et al., 2016; Wakefield et al., 2010). Other studies mainly point at interpersonal difficulties they may encounter, for example social anxiety, exclusion and withdrawal (de Ruiter et al., 2016; Emond et al., 2016; Hardy et al., 2010). Such difficulties at a young age can predispose to numerous psychological and social problems including depression, somatization and loneliness later in life, making CBTS a vulnerable group in society (Howard et al., 2014; Zeltzer et al., 2009).

Parents expressed concerns regarding the child’s performance and wellbeing at school, and the school’s (future) response to needs or difficulties. Some concerns were child-specific, relating to learning difficulties or poor socialisation observed after the return. Other concerns proved to be rather contextual, since these were primarily associated with the

provision of support at present or for future years. Similar experiences of parents have been described in studies (McLoone et al., 2011; McLoone et al., 2013) and might be understood together with other family variables, determining their overall re-adjustment after the child's cancer treatment (Long and Marsland, 2011; Van Schoors et al., 2015). Parents also reported factors that had a positive influence on the progress of their child and which reassured them in case of concerns. Examples included the young survivor's eagerness to participate, increased attention of teaching staff and the school's question for involvement. Psycho-education or support for parents might refine their understanding of barriers to and facilitators of the child's academic and psychosocial development (Aukema et al., 2011; Norberg and Steneby, 2009).

Teachers raised challenges and obstacles concerning the child's academic achievement and personal wellbeing, and ways of approaching and teaching the child. Nevertheless, none of the teachers expressed an active request for more information or support from other stakeholders, such as healthcare providers responsible for the child's aftercare. Apparently, discussions with parents and colleagues were sufficient for them in order to approach the situation appropriately and feel confident. Their low demand for expertise can be explained by poorly-established associations between schools and healthcare providers. However, offering school staff knowledge and training about (teaching) chronically ill children have clear benefits (Selekman, 2017; West et al., 2013). Informed teachers feel competent to recognize needs in such pupils while the pupil's difficulties are properly addressed, possibly after referral for additional support (Hinton and Kirk, 2015).

Both parents and teachers considered systematic communication and collaboration starting at the child's return to school as fundamental. Parents attached value to being addressed and informed by teachers, while teachers appreciated feedback and help from parents. Healthcare providers did not seem to be consistently part of the network of key figures, as their services to facilitate the child's reintegration and trajectory at school varied across cases. Consequently, teachers expressed few (uniform) experiences and expectations in terms of collaborating with healthcare providers. On the other hand, healthcare providers felt constrained by the inaccessibility of school teams and decentralized follow-up of the child's evolution at school. Studies on situations where teachers and healthcare professionals work together after a seriously ill child has returned to school report differing views (Bradley-Klug et al., 2010), uninformed school personnel (Canto et al., 2014) and confusion about roles and responsibilities (Mukherjee et al., 2002) as potential barriers. Still, maximal integration of the healthcare perspective into the child's school career is important due to the interplay between aftercare and other developmental areas, in particular psychosocial maturation and education (Grier and Bradley-Klug, 2011).

#### Implications for theory and practice

The present study confirms the protecting effect of a supportive environment with respect to the potential development of (psycho)social problems in CBTS (Castellano-Tejedor et al., 2016). Our findings also provide evidence for the well-known difficulties related to learning and performance in CBTS (Robinson et al., 2010), despite this not being the primary research focus. The study emphasizes the importance of constructive communication and collaboration following the child's return, as reported by school reintegration programs (e.g.

Bruce et al., 2012). In addition, the need for coordination or liaison throughout the child's school trajectory is highlighted (Bruce et al., 2008; Northman et al., 2015). Our results point to the variety in services of healthcare providers in the context of reintegration into school of CBTS (Moore et al., 2009). Further research should be conducted to question their viewpoints and suggestions on this point.

Our study indicates that multidisciplinary follow-up is crucial for the child's success, focusing on cognitive, learning and psychosocial variables. Ideally, this process starts with an overall assessment just before the return and continues with systematic evaluation until the end of the school career. An independent service such as the School Health Services (WHO, 2014) with combined expertise in education and healthcare might play a supervising role. Moreover, this coordinating service can contribute by listening to concerns and problems of parents and teachers, and by referring to professional aftercare if necessary. A network including those who play a role in the child's school trajectory should be installed at the return. Hereby, clarity about each other's expectations and ways of working must be pursued to avoid barriers preventing the child's progress and cooperation process. In order to enhance participation of healthcare providers, the introduction of a school liaison to formalize connections between schools and healthcare might be beneficial, as it releases parents from their role of constant intermediaries.

### Strengths and limitations

The present study is unique in integrating different perspectives of CBTS and key figures on reintegration into school, using a qualitative methodology. This research is relevant because

its findings demonstrate that the experiences of the various stakeholders require specific approaches to be incorporated into the school policy on CBTS.

The study has some limitations. The representation of the child's perspective in the results section is relatively limited. Because of their young age, most children found it hard to reflect on experiences in depth. Perspectives of healthcare providers are also less elaborated, since they were less involved in the child's school career compared to parents and teachers. Therefore, their experiences should be considered as additional to the other perspectives. Furthermore, the study explores findings concerning moments immediately following the return. A longitudinal design to investigate processes and changes throughout the school trajectory of CBTS might reveal further insights. Finally, our results cover experiences reported by participants, not observations in real life. Direct exploration by means of participant observation at school would provide complementary information.

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