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Reintegration into school of childhood brain tumor survivors : a qualitative study using the International Classification of Functioning, Disability and Health – Children and Youth framework

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### Implications for rehabilitation

- The International Classification of Functioning, Disability and Health – Children and Youth framework is a useful instrument to describe experiences regarding school life of childhood brain tumor survivors and key figures in their environment.
- The ICF-CY model can be combined with a standardized assessment of neurocognition or performance to achieve a comprehensive view of the child's participation at school, by exploring both personal and environmental factors.
- Childhood brain tumor survivors mostly show impairments in acquiring and applying knowledge, executive functioning and social life, which may require increased support at school and professional aftercare.
- A positive attitude of school staff, high parental involvement in school life and adequate collaboration between parents, education and healthcare are important to prioritize in the context of reintegration into school of childhood brain tumor survivors.

## Abstract

**Purpose:** The purpose of this study was to describe experiences of childhood brain tumor survivors and key figures in their environment after returning to school, using the International Classification of Functioning, Disability and Health – Children and Youth framework. **Method:** We conducted semi-structured interviews with 5 children, 9 parents, 28 teachers and 14 health professionals at three predetermined times over a two-year period. A qualitative content analysis was performed by linking meaningful units from transcribed interviews to ICF codes. **Results:** Children experienced diverse body dysfunctions that could impede school participation, mostly related to knowledge acquisition and application, executive functioning and social life. Support at school and professional aftercare were essential to alleviate the child's difficulties. The teacher's attitude, parental involvement and practices of collaboration belonging to the child's supportive network further influenced the reintegration process. Also, child-specific factors including emotional reactions to illness, age and balance between school life and leisure time were considered to affect school readjustment.

**Conclusions:** The International Classification of Functioning, Disability and Health framework is a useful instrument to systematically describe experiences of childhood brain tumor survivors and key figures regarding school life, providing a common language to communicate for stakeholders in education and healthcare following the child's return.

**Keywords:** Childhood brain tumor survivors; experiences; International Classification of Functioning, Disability and Health – Children and Youth framework; key figures; school life; semi-structured interviews

## Introduction

For childhood brain tumor survivors (CBTS), returning to school after a period of illness and medical treatment is a milestone. Reintegration into school following the return, can be defined as renewing or restoring wholeness of an individual who has been segregated or excluded from the educational community [1]. This transition is an important stage in the child's rehabilitation, as it contributes to a sense of normalization and enables experiences of learning and success. Children who survived a brain tumor look forward to attending school again, because they associate school participation with a disease-free life [2,3]. Unfortunately, many of them face a less successful reintegration into school because of various disadvantages [4]. Children may experience problems with reconnecting with peers and social participation, possibly leading to adverse outcomes including exclusion, withdrawal and bullying [5]. They often show low(er) levels of emotional wellbeing, demonstrated by indications for psychological distress, negative self-image and reduced health-related quality of life [6,7]. In addition, CBTS frequently miss school days because of their condition and develop learning difficulties due to disease-related effects [8]. These children encounter impairments in basic areas needed for school performance, such as concentration, executive functioning and memory [9,10]. As a result, they are more likely to rely on special educational services and to repeat a grade, as well as complete their education more slowly compared to peers who have not survived a brain tumor [11].

Major differences among CBTS in terms of onset, nature and severity of such disadvantages complicate generalization of reintegration processes or prediction about further development. At the same time, they emphasize the importance of individual follow-up of the child's school career by stakeholders in education and healthcare, together with parents. Unfortunately, follow-up is often hampered by barriers at school, less inclusive evaluation by those responsible for health supervision, and inadequate communication between stakeholders.

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3 School staff working closely with the child are expected to detect and assess difficulties that  
4 emerge after the return [12]. Unfortunately, teachers are not always prepared to deal with pupils  
5 with medical needs such as CBTS, particularly in mainstream education [13,14]. They understand the  
6 importance of their own attitude for the child's further development and recognize the greater effort  
7 required in future school years compared to peers [15]. Nevertheless, teachers may feel incompetent  
8 to provide appropriate support and ask for additional information, training and assistance [16,17].

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16 Well-informed school staff who are assisted feel more confident, recognize needs in their pupils  
17 easier and approach difficulties more effectively, possibly after referral for professional care [18,19].  
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21 Although international guidelines on follow-up in pediatric neuro-oncology suggest a  
22 comprehensive neuropsychological evaluation [20], this is not a normalized practice. Assessment  
23 tools mainly focus on neurocognitive skills and insufficiently on personal outcomes such as wellbeing  
24 and participation [21,22]. However, a perspective on the child's participation opportunities and  
25 restrictions offers insights into achieving milestones in life. Examples include gaining independence,  
26 building up peer relationships and reaching academic goals [23]. By exploring personal experiences,  
27 knowledge about these and other subjective aspects of the child's functioning can be gathered.  
28 Standardized tools, by contrast, only provide quantitative information about performance.  
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40 Additionally, numerous stakeholders in education and healthcare display shortcomings while  
41 working together [24]. Reasons include negative attitudes among school personnel towards  
42 exchange of information [25], inadequate knowledge of health professionals about the educational  
43 system [12], and ambivalence about roles and responsibilities in both areas [26]. Consequently, CBTS  
44 do not receive specialized help (on time) when they experience difficulties, parents are expected to  
45 fulfill a supervising role in monitoring the child's progress, and/or meetings for consultation are not  
46 organized [12,27].  
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3 Knowledge about experiences of CBTS and those closely involved in their reintegration at school, is  
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5 scarce. That is why research into school life of CBTS after their return is needed and more specifically,  
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7 into experiences regarding school life of CBTS and key figures in their environment. We need to gain  
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9 more insight into their functioning at school, as viewed from the child's perspective and from  
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11 perspectives of those involved. Questioning all these viewpoints about main themes inherent to a  
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13 school setting - i.e., academic, health-related and psychosocial functioning - is an appropriate  
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15 approach to obtain such insights. Stakeholders in education and healthcare can use this knowledge  
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17 when they work with CBTS and their environment: school staff are informed about the various  
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19 difficulties that CBTS may encounter and can adjust their approach, while health professionals know  
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21 the health-related areas that need attention in addition to neurocognition to optimize their  
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23 aftercare.  
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29 Therefore, the objective of the present study is to describe experiences of CBTS and key  
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31 figures in their environment regarding school life during the period of reintegration. We aim to  
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33 question both parents, teachers and health professionals as key figures to know the different role-  
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35 specific perspectives on their shared concern. Because reintegration into school is a prolonged  
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37 process, a longitudinal design of two years is chosen. This well-defined time frame allows to gather  
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39 sufficient experiences over time and follow the child's phase of inclusion as long as possible.  
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41 Concerning the stage of education, we will focus on primary education because of our interest in the  
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43 fundamental (e.g., neurocognitive, physical, psychosocial) changes that typically take place here,  
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45 both in CBTS and non-CBTS. To describe the experiences of these different participants, we want to  
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47 use a science-based framework. It is our belief that applying such a structure brings clarity to  
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49 heterogeneous findings, as can be expected from experiences reported from different perspectives.  
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55 Consequently, the research question of this study can be formulated as follows: what are the  
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57 experiences of CBTS and key figures in their environment regarding school life after returning, and  
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59 can these experiences be described according to an existing classification system?  
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## Method

### *Study design*

The study design consists of a multiple case study [28] with longitudinal follow-up and a theoretical framework for data analysis. We conducted semi-structured interviews with CBTS who had returned to school and key figures (parents, teachers and health professionals) to collect their experiences regarding school life. We opted for this qualitative method, because it allows participants to disclose experiences from their own points of view and in their own words. The longitudinal design made it possible to obtain a comprehensive view of their experiences during the reintegration process. They were questioned at three predetermined times over a two-year period, at yearly intervals. In addition, we consulted medical records and school documents to gain more insight into the child's school performance, health and wellbeing. As a theoretical framework to apply to the data extracted from the interviews, the ICF-CY model was chosen.

### *Theoretical framework: the ICF-CY model*

The International Classification of Functioning, Disability and Health – Children and Youth framework [29] is an ideal frame of reference for this study for two main reasons. Firstly, the model makes it possible to investigate the topic of reintegration into school of CBTS in a systematic way, by linking experiences with a science-based classification system. Secondly, the framework provides stakeholders in education and healthcare a common terminology to discuss further development of CBTS in the main areas of life [30].

The ICF-CY framework is an adaptation of the ICF model, introduced by the World Health Organization (WHO) to cover developmental facets of functioning in children and adolescents. Similar to the version for adults, the ICF-CY is based on the biopsychosocial theory of health, functioning and disability to describe individual functioning on a continuum [31]. The framework

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3 consists of four interconnected domains: body functions, body structures, activities and  
4 participation, and environmental factors (Figure 1). Body functions refer to the physiological  
5 functions of body systems and to psychological functions. Body structures are anatomical parts of the  
6 body such as organs and limbs, as well as their components. Activities are defined as tasks or actions  
7 executed by an individual, while participation means involvement of a person in a life situation.  
8 Environmental factors make up the physical, social and attitudinal environment in which people live.  
9 In addition, the model includes personal factors specific to the individual but not part of the primary  
10 health condition, such as age, gender and personality. The ICF-CY has a hierarchical structure  
11 containing chapters on a first level and categories indicated with codes on a second, third and fourth  
12 level. For example, the following codes can be found in the body functions classification: sensory  
13 functions and pain (b2, first-level item), seeing functions (b210, second-level item), quality of vision  
14 (b2102, third-level item) and contrast sensitivity (b21022, fourth-level item). This structure makes it  
15 possible to link measures or descriptions of individuals to ICF codes, resulting in a general assessment  
16 of their functioning and health [32,33].

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38 [Insert Figure 1. here: Figure 1. The ICF framework. Reproduced with permission of the publisher  
39 from *International classification of functioning, disability and health: ICF* - © World Health  
40 Organization 2001.]  
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#### 48 *Study population*

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51 The following criteria for inclusion of cases were applied. Children between 6 and 12 years old had to  
52 attend the same school in mainstream education as before their illness, on a full-time basis. They had  
53 to have been back at school for longer than 6 months to ensure adequate readjustment to the school  
54 routine. Children who had returned to school more than 3 years ago were excluded to prevent  
55 memory bias. The cancer treatment had to be completed and the child had received a good  
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3 prognosis. The type of brain tumor or medical treatment was not a criterion for inclusion, as we did  
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5 not focus on diagnosis or disease-specific consequences.  
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8 We applied two strategies for purposeful sampling - typical case sampling and maximum  
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10 variation sampling - to select cases reflecting typicality and showing sufficient variation in criteria to  
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12 obtain a realistic view of the school life of CBTS in Flanders (Belgium). In Flanders, CBTS can attend  
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14 school in mainstream education where they follow the regular education program. However, they  
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16 may also need specialized education consisting of adapted curricula with daily support from teachers  
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18 and health professionals. The main dimensions by which diversity was established were age, medical  
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20 history, aftercare trajectory and time since returning to school. This sampling method **allowed** us to  
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22 study a number of cases in depth without requiring subsequent sampling until data saturation.  
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27 The academic hospitals UZ Brussel and UZ Gent participated in this study. Children and their  
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29 parents were invited to participate by their pediatric oncologist. If they were interested, they were  
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31 contacted by the main researcher (S.V.). Through the parents, we reached school staff and health  
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33 professionals. School staff included classroom teachers and teachers offering additional help, such as  
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35 school counsellors and specialized teachers. Health professionals had treated the child and/or  
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37 provided services of short- or long-term aftercare. Table 1 presents the participants' main  
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39 characteristics and the interviews that were conducted.  
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46 [Insert Table 1. Main characteristics of participants here]  
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#### 51 *Data collection*

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54 Between October 2014 and June 2017, semi-structured interviews were conducted with 5 CBTS, 9  
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56 parents, 28 schoolteachers and 14 health professionals. Children, parents and school staff were  
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58 interviewed three times, health professionals only once. The first interview took place when the child  
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3 had already returned to school for more than 6 months, with the second interview one year, and the  
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5 third interview two years later. We asked participants to talk about various topics associated with  
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7 reintegration into school of children with cancer or another severe illness. These topics included in  
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9 our interview guides were derived from the scientific literature, and from prior interviews with  
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11 experts in education and health professionals. We developed a guide for each interview which, in  
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13 addition to topics, contained case-specific details to ask very precise questions. Some children had  
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15 difficulties with describing their experiences in depth. In these cases, toys were used to encourage  
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17 the child to engage in telling stories by which their experiences could be evaluated. In Table 2,  
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19 examples of interview guides with the different perspectives can be found. During the first interview,  
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21 participants were questioned about the period following the return to school. During the second and  
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23 third interviews, we asked them to reflect on their current experiences, as well as on the past period.  
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25 Interviews lasted between 30 and 90 minutes and were audio-taped and transcribed verbatim with  
26  
27 permission. The ethical committees of UZ Brussel and UZ Gent had approved our study. The main  
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29 principles of research with children were strictly followed: respecting their informed consent and  
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31 autonomy, providing confidentiality as much as possible and taking their vulnerable nature into  
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33 account.  
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#### 44 *Data analysis*

45 Before performing a qualitative content analysis of data [34], the interview transcripts were inserted  
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47 into NVivo 8 software for qualitative data management [35]. Using this program, we could store the  
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49 texts and organize them to centralize case-specific data. A first exploration of the transcripts led to  
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51 extraction of text material with content relevant for further analysis. While reading the text  
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53 fragments, we looked for emerging themes that could be of interest for our research objective.  
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55 Fragments containing one or more interesting themes were converted to meaningful units, by  
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57 labeling them with a specific meaning. We then condensed these units, which implies a process of  
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3 abstraction to develop a broader concept [36]. Next, the condensed units were linked to the closest  
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5 ICF categories and to ICF codes at the second level [37]. Finally, the child's two-year trajectory was  
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7 reconstructed with an inventory of codes, providing a view of main events and associated  
8  
9 experiences. In Table 3, examples of ICF linkage can be found, demonstrating how statements from  
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11 participants are eventually linked to ICF codes. Themes that were discovered are not part of these  
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13 examples, because we merely used them in a preliminary stage of the linking process.  
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17 Several strategies were applied to establish rigor. Firstly, the research design was developed  
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19 by a team of members with different scientific backgrounds, who discussed aspects such as inclusion  
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21 criteria, sampling procedure and methodology. Also, the main researcher (S.V.) was supported by  
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23 this team (L.P., J.B., A.J.) while collecting, analyzing and reporting on the data. According to the  
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25 principle of member checking, participants received the opportunity to review their statements from  
26  
27 previous interviews for accuracy and resonance with their experiences. Furthermore, we pursued  
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29 data triangulation by gathering case-specific documentation as an objective source of information, in  
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31 addition to conducting interviews. These documents were primarily consulted to contextualize the  
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33 participants' experiences and to confirm what their narratives seemed to indicate. Additionally, the  
34  
35 encoded data were presented to an expert in child and youth healthcare familiar with the ICF-CY  
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37 framework (K.V.H.) for validation. Lastly, S.V. wrote her feelings, insights and biases down in a diary,  
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39 which made her aware of her role and perspective throughout the study.  
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48 [Insert Table 3. Examples of ICF linkage here]  
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## 53 **Results**

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56 The participants' experiences are organized in accordance with the ICF components. We do not  
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58 include the component body structures as a separate section, because discussing the child's  
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3 anatomical body parts is not directly relevant to our study aim. Moreover, impairments of these  
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5 structures are manifested as problems in or loss of body functions that are reviewed below. Also, we  
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7 add personal factors with a potential facilitating or impeding influence on the readjustment process,  
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9 which are not specified in the ICF framework.  
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16 *ICF component 1: Body functions (codes b110 – b899)*  
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18 Children showed various impairments in body functions, which were reported at an early point in  
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20 time or a considerable time after starting the follow-up. Most of these limitations gradually  
21  
22 decreased, but some continued to importantly impact the child's functioning and wellbeing at school.  
23  
24 Weak mental functions were often mentioned, such as memory problems or forgetfulness, fatigue  
25  
26 and intellectual or cognitive deficits. In terms of sensory dysfunctions, a number of children displayed  
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28 lower tolerance for noise and impaired (one-sided) hearing or vision in class. In a few cases, the  
29  
30 child's speech had changed, particularly the fluency and speed of speech. In addition, poor gross  
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32 motor skills were demonstrated by children who experienced difficulties with coordination, balance,  
33  
34 and muscular power, tone and endurance. These physical barriers were caused by the child's brain  
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36 tumor and/or medical treatment, as well as by other conditions including sleep problems, epilepsy,  
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38 developmental coordination disorder, cerebral visual impairment (CVI) and spastic hemiparesis.  
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43  
44 *"When she returned, she was often tired and could not remember what she had learned. This took a*  
45  
46 *while, because she had to repeat everything multiple times until it got better."* (case 1, classroom  
47  
48 teacher)  
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51 *"The chemotherapy had affected his balance and endurance, so not only his general health had*  
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53 *deteriorated, he also showed a slower motor development compared to peers."* (case 3, health  
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55 professional)  
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3 *ICF component 2: Activities and participation (codes d110 – d999)*  
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6 The child's participation at school could be hindered by problems with acquiring and applying  
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8 knowledge that affected further academic progress. Most cases presented short- or long-term  
9  
10 difficulties in directing and/or maintaining their attention in class. Furthermore, persistent problems  
11  
12 with spelling and reading were prominent in several children. For others, especially mathematics and  
13  
14 assignments requiring visuospatial skills proved to be challenging. Also, failing to complete tasks in  
15  
16 deliberate steps or respond to demands (on time) could influence the child's school participation  
17  
18 negatively. Learning processes were interrupted because the child was not able to internalize rules,  
19  
20 connect separate pieces of study material and/or make abstraction of the specific learning content.  
21  
22 Some cases struggled with working independently and developing an efficient schedule of tasks.  
23  
24 Moreover, organizational deficits were strengthened by the slow(er) work rate observed in most  
25  
26 children. These different barriers resulted in fluctuating or reduced school performance, along with  
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28 changing efforts to perform over time.  
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33 *"Mathematics in particular is difficult, because you have to internalize rules and reason in steps.*

34 *Planning in advance and then executing and adjusting along the way, it's too much to ask."* (case 4,  
35  
36 school counsellor)  
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41 Some children were confronted with reduced mobility, as shown by problems with writing,  
42  
43 drawing and cutting during crafts activities in class. Other fine motor skills such as tying shoelaces,  
44  
45 closing zippers and changing clothing during gym classes could also be impaired. Several cases  
46  
47 experienced disruptions in gross motor skills, so they could not perform physical exercises, not  
48  
49 participate easily in games on the playground and not cycle to school.  
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52  
53 *"She cannot cycle to school independently, it's not safe. She hates it, she wants to join her friends, but*  
54  
55 *for now it cannot be otherwise."* (case 5, parent)  
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58 The children's social life had changed after their return to school. Sometimes changes were  
59  
60 already very noticeable directly following the return, particularly the challenge of reconnecting with

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3 peers. Other social issues only became apparent a considerable time after returning to school. For  
4  
5 example, children perceived a lack of relatedness to schoolmates as they regularly argued, felt  
6  
7 misunderstood or received unwanted attention. Many of these concerns lessened over time, while  
8  
9 the child was readapting to school life. Positive experiences regarding social participation were  
10  
11 associated with care and assistance from peers, as well as with peers' familiarity with the child's  
12  
13 condition. Classmates gave children compliments, offered practical support and made no comments  
14  
15 when they experienced difficulties or stress in class.  
16  
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18  
19 *"Everyone at school was very kind to me after I returned. Just being in the classroom was nice, even*  
20  
21 *when I could not pay attention."* (case 2, child)  
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27 *ICF component 3: Environmental factors (codes e110 – e599)*  
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30 At school, children with special needs were temporarily or permanently monitored or supported.  
31  
32 Some children experienced physical limitations for which they needed specific adjustments, for  
33  
34 example, sitting at a specially tailored desk to improve writing, using a headphone to enhance  
35  
36 concentration or having a permanent seat in front of the classroom for optimal hearing. Other  
37  
38 children were assisted by the classroom teacher, school counsellor and/or specialized teacher.  
39  
40 Educational arrangements were made for them to improve learning and performance including  
41  
42 ignoring certain errors on tests, receiving easier assignments than classmates and allowing more time  
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44 to complete tasks. In a few cases, teachers provided psychosocial support by offering the child the  
45  
46 opportunity to talk about personal issues outside teaching hours.  
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50  
51 *"He has been given a seat in front of the class, so he can easily pay attention. During the lessons, I sit*  
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53 *next to him to help individually and to correct errors as quickly as possible."* (case 4, specialized  
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55 teacher)  
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3 Increased support at school often proved to be inadequate and therefore, professional  
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5 aftercare was needed to alleviate the child's difficulties. A few children received speech therapy to  
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7 increase their level of reading and spelling, and to reinforce their motivation and performance  
8  
9 regarding particular subjects. In most cases, other types of aftercare were provided in the short or  
10  
11 long term to stimulate individual development, such as physiotherapy, occupational therapy and  
12  
13 psychological counselling. In addition to health professionals, School Health Services were mentioned  
14  
15 as potential sources of support. However, their supportive services as part of the child's reintegration  
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17 process varied across cases and seemed to be deficient in terms of working with schools and parents.  
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21 *"His teacher advised us to start speech therapy to improve his reading and spelling skills. (...) Then, we*  
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23 *also asked him to see a psychologist again, we thought it could be useful, but he refused."* (case 3,  
24  
25 parent)  
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29 A positive attitude of school staff was associated with being dependable, willing to help and  
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31 experienced in teaching pupils with special needs. Teachers who raised questions about the child's  
32  
33 inclusion were described as difficult to approach and not open to suggestions from others including  
34  
35 colleagues and parents. Furthermore, parents' involvement in homework or learning at home was  
36  
37 essential for every child. In several cases, parents acted proactively towards the school by asking for  
38  
39 exchange of information about school-related matters or informal meetings. These parents stressed  
40  
41 their need for regular consultations with teachers, while teachers primarily turned to their team at  
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43 school when questions or problems emerged. School staff and health professionals communicated  
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45 barely in a direct way, since parents usually acted as intermediaries and coordinated the child's  
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47 trajectory.  
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52 *"I feel that his follow-up is fragmented. He is monitored by the hospital, here in the rehabilitation*  
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54 *center and he is taught by a specialized teacher. His mother provides us information, but we need a*  
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56 *central contact person for everyone to speak to."* (case 4, health professional)  
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3 *ICF component 4: Personal factors (not specified)*  
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Overviewing the cases and their trajectories following the return, some child-specific factors can be assumed as influencing the readjustment process in a positive or negative way.

Firstly, parents and school staff reported diverse personal characteristics and emotional reactions when talking about the child's participation after returning to school. Negative features included little self-confidence, frustration, sadness, anxiety and sensitivity to stress. These attributes were discussed with regard to specific topics, such as performance, comparison with peers and confrontation with physical or educational changes. Positive features involved maturity, perseverance, pride, gratitude and sense of justice. Participants mentioned such characteristics while reflecting on the child's academic progress, future school career and interactions with others at school. Additional features that were frequently heard included the need for normality, shyness and conscientiousness.

*"He knows that he lacks certain skills, now even more than before. It influences how he looks at himself, his negative self-image, and I fear that this will only increase."* (case 3, parent)

Secondly, the child's age could have an (indirect) effect on reintegration into school with a higher age associated with a less smooth return. The older the children were, the more study material they had missed to keep up with peers and the more psychosocial issues seemed to prevail. Some of them experienced pressure to perform due to high learning objectives and upcoming study choices, in addition to the age-specific challenges of upcoming adolescence.

*"I know that I will have to work harder to succeed, it will become more difficult. We (parents and child) have already talked a lot about it, which study I will have to choose."* (case 2, child)

Thirdly, children diagnosed with a disorder such as developmental coordination disorder, dyslexia or cortical visual impairment faced both positive and negative consequences. On the one hand, such disorders hampered school performance and participation (even more) but on the other



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3 hand, they led to increased care through extra attention from school staff and formal educational  
4 arrangements. Whether there was a direct connection between the brain tumor and the disorder  
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6 could not always be clearly determined.  
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9  
10 *“She was entitled to additional support because of her developmental coordination disorder. This*  
11 *diagnosis certainly complicated the situation, but because of it, she received extra attention. In the*  
12 *end, we were quite happy with the increased monitoring at school.”* (case 1, parent)  
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18 Lastly, for some children, school life and leisure time seemed to be insufficiently balanced.  
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20 Most children had many hobbies from which they gained positive energy. However, it was not always  
21  
22 easy for them to optimally divide time between obligations for school and extracurricular interests.  
23  
24 Especially when the child also received professional aftercare, school commitment could be poor  
25  
26 with the risk of jeopardizing further academic growth.  
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29  
30 *“I’m concerned that all her extracurricular activities are too much for her, she is already easily tired.*  
31 *Her progress should not be jeopardized.”* (case 5, classroom teacher)  
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38 Table 4 presents the codes identified in the data and their higher-order chapters and components, as  
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40 well as the number of cases and interviews in which these codes were discovered.  
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46 [Insert Table 4. Results with ICF codes here]  
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51 Table 5 consists of themes and associated findings found across cases and over time, providing a  
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53 comprehensive view of the children’s reconstructed trajectories.  
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59 [Insert Table 5. Themes and findings per perspective]  
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## Discussion

This study demonstrates that the ICF-CY model is a useful framework to describe experiences of childhood brain tumor survivors and those of key figures regarding school life after returning. Their experiences can be organized according to the different ICF components and linked to the ICF codes. Our results reveal that children encounter various body dysfunctions with adverse effects on acquiring and applying knowledge, executive functioning and social life. Therefore, appropriate support at school and professional aftercare need to be provided to ensure optimal academic and personal growth.

### *Interplay of disease-related changes*

This study shows that CBTS may be confronted with various bodily dysfunctions resulting from their disease. Earlier studies have already extensively investigated such changes in CBTS, specifically regarding mental skills, sensory processing and motor performance [38,39]. Although physical impairments determine the children's participation in all areas of life, they primarily seem to affect school life [40]. Indeed, mental, sensory and motor functions are all required to participate optimally in class, during gymnastics and on the playground. Therefore, the impact of bodily changes on psychological wellbeing in CBTS should not be underestimated. They may develop a negative body image, become less self-confident and experience emotional distress, (in)directly related to their health condition and appearance [41,42].

Some children in our study with sensory deficits and concentration difficulties showed a discontinuous or delayed learning process. They were unable to acquire basic skills sufficiently, such as reading, writing and calculating. Academic progress could also be hampered by problems with organizing and executing tasks and higher-order thinking. Previous research has indicated that due to their neurological lesions, CBTS are prone to developing such neurocognitive and executive difficulties [43,44]. Fluctuating or below-average grades resulting from these problems are often

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3 observed in CBTS, which may have negative effects on school commitment, satisfaction with  
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5 performance and educational aspirations [3,45].  
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8 In this study, both positive and negative social changes in the children's lives were observed  
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10 following their return to school. Positive experiences were based on feelings of acceptance by peers  
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12 who took the child's changed needs into account, corresponding with previous findings [46].  
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14 Negative experiences included arguing regularly, feeling estranged from others and receiving  
15  
16 insufficient support, also demonstrated in other studies [4,47]. At school, children find themselves in  
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18 a well-known context but feel different because of their recent illness experience. They are urged to  
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20 make their survivor status fit in the familiar school setting, which implies an emotional challenge not  
21  
22 easily understood by peers [48]. Therefore, experiences of social connectivity and friendships are  
23  
24 necessary for CBTS to belong again, and to prepare the ground for satisfying relationships later in life  
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26 [49,50].  
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#### 34 *Support for individual needs*

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37 Our findings indicate that additional support is needed to alleviate disease-related consequences in  
38  
39 CBTS, organized at school or by aftercare services. The need for professional aftercare **proved** to be  
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41 higher for physical and (neuro)cognitive problems than for psychosocial concerns, as shown in  
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43 studies on care facilities in CBTS [51,52]. However, the importance of multidisciplinary aftercare with  
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45 special attention to psychosocial wellbeing is acknowledged, precisely because of CBTS' sensitivities  
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47 in this domain [53]. Regarding school life, support services easily accessible to both schools and  
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49 health professionals (e.g., School Health Services) are best positioned for monitoring pupils with a  
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51 medical background [54].  
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55 Teachers in this study were described as supportive, but other research points to attitudinal  
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57 barriers at school [17,25]. School staff who are reluctant to the child's inclusion might not prioritize  
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59 individual support, inform colleagues or external stakeholders about academic progress and/or  
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3 follow suggestions from parents or health professionals [12,55]. When parents perceive such  
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5 impediments, they act proactively towards the school by advocating for appropriate assistance and  
6  
7 deliver information about their child's condition to teachers themselves [4,47]. Clarity about each  
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9 other's responsibilities, available arrangements on working together and involvement of a  
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11 coordinating service all facilitate communication between stakeholders following the child's return to  
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13 school [56,57].  
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### 20 *Facilitators and barriers of reintegration*

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23 Reflecting further on these findings, possible facilitators and barriers of the child's reintegration  
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25 process can be identified.  
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28 Most experiences reported in this study relate to the ICF components 'body functions' and  
29  
30 'activities and participation'. Physical - i.e., motor, sensor and mental - changes that impede  
31  
32 participation in school activities represent the greatest barriers. After all, body dysfunctions easily  
33  
34 bring about underdeveloped skills needed for numerous tasks and personal interactions.  
35  
36 Furthermore, experiences collected in this research demonstrate that the ICF component  
37  
38 'environmental factors' includes both facilitating and hindering factors. Individual support and high  
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40 parental involvement influence the child's reintegration positively, while attitudes of school staff and  
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42 practices of collaboration belonging to the child's network can have a positive or negative impact.  
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46 Additionally, some child-specific factors should be kept in mind when it comes to the  
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48 children's readjustment to school life. Firstly, emotional reactions to illness need to be considered  
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50 when trying to interpret the child's behavior at school. Mixed feelings such as relief and happiness to  
51  
52 return but also uncertainty and concern about the future were mentioned, also discussed in earlier  
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54 research into school experiences of pupils with cancer [42,46]. Secondly, our findings seem to  
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56 suggest that an older age is accompanied by more challenges during the reintegration process.  
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58 Changing cognitive and emotional skills, coping difficulties and increasing self-awareness typical for  
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3 the (upcoming) adolescence are plausible explanations for this difference, since these are less  
4 present in younger children [3,58]. Thirdly, time-consuming leisure activities or aftercare at the cost  
5 of schoolwork can lead to low school commitment and suboptimal readjustment. In the present  
6 study, this imbalance appeared to be a process of familiarization, while other studies provide  
7 indications for experiences of complaints, concern or stress in both children and key figures [59].  
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### 18 *Strengths, considerations and limitations*

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20 To our knowledge, this is the first longitudinal study describing the functioning of CBTS after  
21 returning to school, based on perspectives of children and key figures and using the ICF-CY  
22 framework. Their narratives were rich in content and generated a large amount of data on  
23 experiences suiting the study aim. We found the ICF-CY a useful instrument to present the study  
24 participants' views and provide a common language for communicating research findings.  
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32 Methodological considerations of this study should be mentioned. The complicated process  
33 of ICF linkage given the high degree of overlap between codes must be considered. For example,  
34 several mental functions as part of 'body dysfunctions' could similarly be approached as data needed  
35 for 'activities and participation'. In order to present clear and structured findings, the one or the  
36 other ICF component was chosen to describe them. Also, simply linking ICF codes to experiences of  
37 individuals is inevitably accompanied by loss of thickness from their narratives. Therefore, it is  
38 necessary to look at the codes in parallel with the components' descriptions representing the -  
39 already construed - perspectives of participants.  
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51 It is important to keep in mind that our results do not cover real observations. Unlike this  
52 study, research based on direct observation or neurocognitive assessment does provide information  
53 about objective parameters impacting the child's readjustment. Furthermore, health professionals  
54 were underrepresented as stakeholder group compared to stakeholders in education. This limitation  
55 is evident because of their lower involvement in the child's school life, but should be taken into  
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3 account. Another limitation is that different children had returned to school at different times upon  
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5 inclusion. This point in time may determine their overall school experience along with readjustment  
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7 to school life. However, this effect was largely minimized by conducting multiple interviews over  
8  
9 time.  
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### 11 12 13 14 15 *Implications for research and practice*

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18 Our narrow focus on school life clarifies the need for research into experiences of CBTS (and key  
19  
20 figures) regarding other life domains, such as body awareness, social activities and family life. The  
21  
22 ICF-CY framework can again be used to describe the child's functioning and participation. In addition,  
23  
24 relationships between the personal factors identified in this study and specific outcomes of  
25  
26 reintegration into school of CBTS should be examined in depth. A mixed methods study using both  
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28 questionnaires and individual interviews is highly appropriate for this research objective. Lastly,  
29  
30 studies focusing particularly on experiences of CBTS and key figures at times of transition at school  
31  
32 are required. For example, when children just started a new school year, changed schools or moved  
33  
34 to secondary school. We can expect certain aspects to be more decisive or prominent at such points  
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36 in time, for example, attitudes of new teachers, higher learning objectives in secondary education  
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38 and schoolmates unaware of the child's illness experience.  
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44 Our research indicates that the ICF-CY can be combined with standard tools (e.g., tests,  
45  
46 surveys) to describe the functioning of CBTS at school. Exploring the child's experiences and those of  
47  
48 key figures (e.g., parents, teachers, health professionals) regarding school life using this framework,  
49  
50 is a good starting point for follow-up meetings after the return. At such meetings, key figures should  
51  
52 discuss both child-specific and environmental factors affecting the child's participation at school.  
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54 School staff need to be attentive to difficulties typical for CBTS, remain positive about their pupil's  
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56 inclusion in class and remember that individual support is mostly inevitable. With regard to their  
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58 aftercare, health professionals should take personal areas other than physical health in CBTS into  
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3 consideration and strive for systematic follow-up, ideally in close collaboration with parents and  
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5 school staff.  
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### 10 11 **Acknowledgements** 12

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14 The authors thank the children and their families for participating in this study.  
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### 20 21 **Declaration of Interest** 22

23 The authors declare that they have no competing interests.  
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For Peer Review

Table 1. Main characteristics of participants

Characteristics	Case 1	Case 2	Case 3	Case 4	Case 5
<b>Gender</b>	F	M	M	M	F
<b>Age at inclusion</b>	10	10	10	7	8
<b>Cancer diagnosis</b>	Pilocytic astrocytoma	Anaplastic ependymoma	Medulloblastoma	Low-grade glioma	Medulloblastoma
<b>Medical treatment</b>	Surgery	Surgery, radiotherapy	Surgery, radiotherapy, chemotherapy	Surgery, chemotherapy	Surgery, radiotherapy, chemotherapy
<b>Additional diagnosis</b>	DCD, epilepsy	Dyslexia, epilepsy		Cerebral visual impairment, spastic hemiparesis	
<b>Months since return upon inclusion</b>	7	28	12	21	6
<b>School grade at first interview</b>	5 <sup>th</sup>	5 <sup>th</sup>	4 <sup>th</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>
<b>School grade at second interview</b>	6 <sup>th</sup>	6 <sup>th</sup>	5 <sup>th</sup>	3 <sup>rd</sup>	4 <sup>th</sup>
<b>School grade at last interview</b>	7 <sup>th</sup>	7 <sup>th</sup>	6 <sup>th</sup>	4 <sup>th</sup>	5 <sup>th</sup>
<b>First round interviews</b>	1 child, 2 parents, 3 teachers, 2 health professionals	1 child, 2 parents, 3 teachers, 2 health professionals	1 child, 2 parents, 3 teachers, 2 health professionals	1 child, 1 parent, 2 teachers, 5 health professionals	1 child, 2 parents, 2 teachers, 2 health professionals
<b>Second round interviews</b>	1 child, 2 parents, 3 teachers, 1 health professional	1 child, 2 parents, 2 teachers	1 child, 2 parents, 1 teacher	1 child, 1 parent, 1 teacher	1 child, 2 parents, 1 teacher
<b>Third round interviews</b>	1 child, 2 parents, 1 teacher	1 child, 2 parents, 1 teacher	1 child, 1 parent, 2 teachers	1 child, 1 parent, 1 teacher	1 child, 1 parent, 2 teachers
<b>Aftercare or professional therapy</b>	Physiotherapy, speech therapy	Speech therapy	Physiotherapy, speech therapy	Physiotherapy, occupational therapy, speech therapy	Physiotherapy, occupational therapy, psychological counselling

Table 3. Examples of ICF linkage

Meaningful units	Condensed meaningful units	ICF categories	ICF codes second level
<i>'Because of his impaired hearing, it is difficult for him to concentrate in class. I expected, however, that it will improve.'</i> (health professional)	Concentration difficulties	Specific mental functions	b140
	Impaired hearing	Hearing and vestibular functions	b230 d115
		Purposeful sensory experiences	d160
		Applying knowledge	d161
<i>'He works slower and performing a task in sequential steps is not easy. As a result, unfortunately, his motivation has dropped.'</i> (classroom teacher)	Slower work rate	Global mental functions	b130
	Disrupted task execution	Specific mental functions	b147
	Less motivation	Basic learning	b164 d155
			d210
<i>'I don't want them to see me as someone who is different or not normal because I was ill. I think about that from time to time.'</i> (child)	Personal feelings and thoughts	Global mental functions	b125
	Negative treatment by peers due to illness	Specific mental functions	b152
		General interpersonal interactions	d720 e425
<i>"I wonder to what extent the school knows what difficulties may still appear. We have heard all the information at the hospital, but the school hasn't."</i> (parent)	Knowledge at school about CBTS-related difficulties	Education	d820 e430 e585

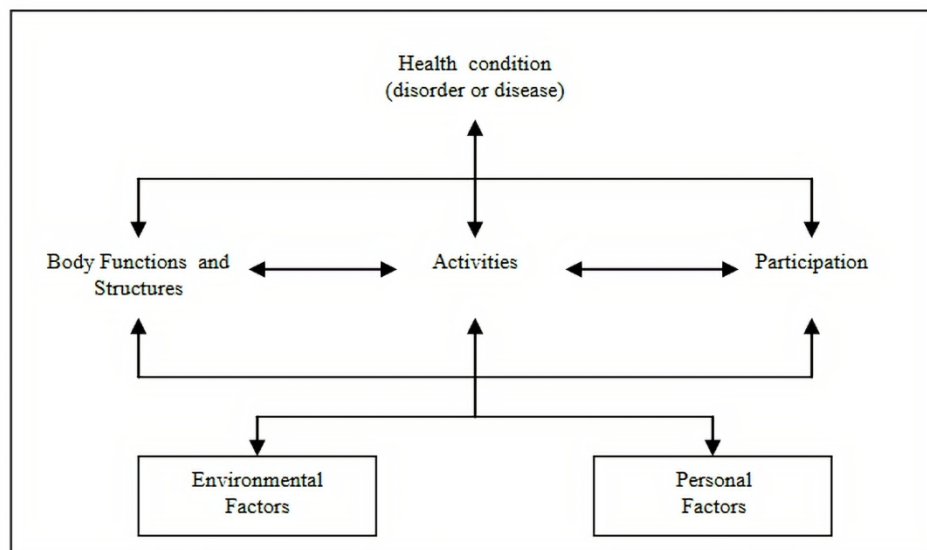


Figure 1. The ICF framework. Reproduced with permission of the publisher from International classification of functioning, disability and health: ICF - © World Health Organization 2001.

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Table 2. Examples of interview guides

Participant	Examples of topics	Examples of questions per interview rounds
Parents	1. School's approach and support	Round 1: <i>Does the school provide adjustments to meet your child's needs? If so, what can you tell about their adjusted approach?</i>
	2. Parental roles concerning school life	Round 2: <i>In the past year, have you stimulated your child's learning process at home? If so, in a way different than before?</i>
	3. Communication and collaboration with school staff	Round 3: <i>Regarding the period since your child's return, how would you describe your communication and collaboration with the school?</i>
Teachers	1. School climate and policy	Round 1: <i>Could you explain the school's point of view on teaching children with medical needs such as the child?</i>
	2. School performance	Round 2: <i>Have you noticed any changes in the child's school grades recently, compared to the period directly following the return?</i>
	3. Teaching approach and support	Round 3: <i>In the past two years, which teaching methods have been used by you and other teachers to support the child?</i>
Health professionals	1. Condition-related difficulties	Round 1: <i>Is the child experiencing difficulties as a result of his/her condition, and what kind of therapy or aftercare is being provided?</i>
	2. Expectations on physical and/or mental health	Round 1: <i>How do you see the child evolve physically and/or mentally in the coming years?</i>
	3. Involvement with school life	Round 1: <i>Do you have a view of the child's school life and how would you describe your involvement?</i>
Children	1. Return to school	Round 1: <i>What were you thinking and feeling when you first returned to school?</i>
	2. Social life at school	Round 2: <i>How do you feel when you are with your classmates and friends, and do you feel different with them than before?</i>
	3. Emotional wellbeing at school	Round 3: <i>Looking back on the past two years, what makes you feel good at school and what makes you feel bad?</i>



Table 4. Results with ICF codes

ICF component	ICF chapter	ICF code second level	Number of cases	Number of interviews	
1. Body functions	1. Mental functions	b117 Intellectual functions	3	23	
		b122 Global psychosocial functions	2	15	
		b125 Dispositions and intra-personal functions	2	9	
		b126 Temperament and personality functions	5	40	
		b130 Energy and drive functions	3	18	
		b140 Attention functions	4	31	
		b144 Memory functions	3	22	
		b147 Psychomotor functions	2	6	
		b152 Emotional functions	5	37	
		b163 Basic cognitive functions	2	3	
		b164 Higher-level cognitive functions	3	19	
		b172 Calculation functions	3	26	
		2. Sensory functions and pain	b210 Seeing functions	3	15
	b230 Hearing functions		2	8	
	3. Voice and speech functions		b330 Fluency and rhythm of speech functions	2	11
		7. Neuromusculoskeletal and movement-related functions	b730 Muscle power functions	3	13
			b735 Muscle tone functions	3	13
	b740 Muscle endurance functions		3	13	
	b760 Control of voluntary movement functions		3	11	
b770 Gait pattern functions	3		16		
b780 Sensations related to muscles and movement functions	3		9		
2. Body structures	<i>Not discussed in relation to study topic</i>		<i>Not discussed in relation to study topic</i>		
3. Activities and participation	1. Learning and applying knowledge	d110 Watching	3	15	
		d115 Listening	2	10	
		d137 Acquiring concepts	5	25	
		d140 Learning to read	3	17	
		d145 Learning to write	3	17	
		d150 Learning to calculate	4	19	
		d155 Acquiring skills	5	26	
		d160 Focusing attention	4	33	
		d161 Directing attention	4	33	
		d163 Thinking	5	24	
d166 Reading	4	29			
d170 Writing	4	29			

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2					
3		d172 Calculating	4	27	
4	2. General tasks and demands	d210 Undertaking a single task	2	12	
5		d220 Undertaking multiple tasks	3	13	
6		d230 Carrying out daily routine	2	23	
7		d240 Handling stress and other psychological demands	5	36	
8	4. Mobility	d440 Fine hand use	4	32	
9		d445 Hand and arm use	3	34	
10		d450 Walking	3	16	
11		d455 Moving around	3	16	
12	5. Self-care	d475 Driving	2	15	
13		d540 Dressing	2	11	
14	7. Interpersonal interactions and relationships	d710 Basic interpersonal interactions	5	36	
15		d720 Complex interpersonal interactions	5	36	
16		d750 Informal social relationships	5	31	
17	8. Major life areas	d810 Informal education	5	20	
18		d820 School education	5	44	
19		d835 School life and related activities	5	52	
20	4. Environmental factors	1. Products and technology	e130 Products and technology for education	5	37
21		2. Support and relationships	e310 Immediate family	5	42
22			e320 Friends	5	45
23			e325 Acquaintances, peers, colleagues, neighbours and community members	5	16
24			e330 People in positions of authority	5	43
25			e340 Personal care providers and personal assistants	5	12
26			e355 Health professionals	5	37
27		4. Attitudes	e410 Individual attitudes of immediate family members	5	42
28			e420 Individual attitudes of friends	5	45
29			e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	5	16
30			e430 Individual attitudes of people in positions of authority	5	43
31			e440 Individual attitudes of personal care providers and personal assistants	5	12
32			e450 Individual attitudes of health professionals	5	37
33		5. Services, systems and policies	e580 Health services, systems and policies	5	44
34			e585 Education and training services, systems and policies	5	47
35	5. Personal factors	<i>Not applicable</i>	<i>Not applicable</i>		

Table 5. Themes and findings per perspective

Perspective	Primary themes	General findings
Children	School life and participation Peer relations and friendships Performance and difficulties	School attendance is positively experienced by children, because of the presence of peers and the absence of disease and treatment. However, they also encounter feelings of incomprehension, frustration and/or sadness due to (neuro)cognitive or physical limitations, academic challenges, changes in relations or friendships, and required additional support from parents, teachers or health professionals.
Parents	Performance and difficulties Psychosocial functioning and wellbeing Attitude and approach at school Communication and collaboration	Parents recognize strengths in their child and resources in the school environment, but are particularly concerned about the child's performance, psychosocial wellbeing and future school career, as well as the teachers' approach. Consequently, they tend to adapt a proactive attitude towards the school and act as intermediaries between teachers and health professionals.
School staff	Performance and difficulties Psychosocial functioning and wellbeing Teaching and learning approach Communication and collaboration	Teachers mainly focus on assessing their pupil's learning potential and determining the most appropriate teaching method. This searching process is often difficult for them, as they are not prepared to deal with the child's condition. When questions concerning additional support arise, they primarily address the school team instead of parents or health professionals.
Health professionals	Current health status Expectations on health Communication and collaboration	Health professionals highlight illness-related effects on academic performance and maturation processes, given their attention to health parameters. They feel responsible to inform parents about their expectations regarding the child's further development. Health professionals experience schools as little accessible and express the need for coordination, when communicating with stakeholders in addition to parents.

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