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Trends of Problems with Functioning in Everyday Life for Children Post Brain Tumor Treatment: As Documented in Professional Records

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ABSTRACT

Background: Children who complete brain tumor treatment encounter ongoing problems with functioning that fluctuate over time. Previous studies shows that health care and schools tend to focus more on the child's cancer-related body symptoms, rather than on existing problems to participate and manage everyday life activities, or moreover of environmental barriers they face. Few studies address how the child's problems to function on body, activity and participation levels co-occur and are presented over time. Therefore, this study ´s purpose is to describe how documented problems with functioning, vary over time in children who have completed brain tumor treatment.
Methods: Medical and school records from seven children were reviewed for up to 5 years after treatment completion, to identify problems and link these to International Classification of Functioning, Disability and Health (ICF) code domains. The coded data were divided into six-month blocks over a 4-year time period, analyzed statistically and illustrated graphically. Code variations on group-levels and patterns of body, activity and environmental codes that tentatively co-occurred with participation were exemplified in a child-case, using a collaborative problem-solving (CPS) approach.
Results: Based on median (Md) number of codes within participation, activity, body and environment, the children exhibited ongoing problems with body function over time (Md 11–18). Activity-related problems were most noticeable about 1-year post-treatment completion (Md 6), and participation problems (Md 1–2) persisted throughout the follow-up period. Documentation of environmental problems was limited but increased after 3 years (Md 3). In the child-case example, participation problems with self-care, schooling and peer-relations continued across the years, with plausible explanations related to

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problems with communication and fine-hand function (activity), fatigue (body function) and with surrounding supportive systems (environment).

Conclusion: Over time, professionals' documentation predominantly focused on problems with the child's body function, while functioning in everyday life and environmental barriers affecting participation, was often neglected. By using the ICF and CPS, service professionals, including nurses, are provided with guidance for comprehensive and systematic approach of addressing patterns of co-occurring problems with functioning, which could lead to improved support to optimize the child's participation in everyday life.

Introduction

After a child has completed treatment for a brain tumor, everyday life continues. However, their body, cognitive and social functioning in everyday life can be affected by the tumor and treatments received (Turner et al., 2009). Participation in vital everyday activities such as schooling (Lönnerblad et al., 2017) and peer-relational activities (Tamboli et al., 2024) can be particularly affected. Participation in everyday activities is fundamental for children's health and well-being (World Health Organization, 2001) and varies with chronological age, developmental stage and societal expectations (Halfon & Forrest, 2018). Therefore, it is crucial to conduct systematic comprehensive evaluations of the child's ability to function and participate in everyday life over time, and how problems with participation, activity performance and body functions are inter-related. Moreover, assessments must be followed by adapting the environment around the child to mitigate identified problems with functioning and participation (Batorowicz et al., 2016), keeping in mind that adaptations might need to change as the child matures and encounters new developmental tasks (Bollen & Curran, 2006).

When implementing comprehensive evaluations of a child's functioning and participation in everyday life, and when identifying modifiable environmental influences, the International Classification of Functioning, Disability and Health (ICF) framework can be used (World Health Organization, 2001). This bio-psychosocial framework emphasizes a broader view of individuals' functioning, e.g. social and educational issues beyond focusing on medical labels (Simeonsson et al., 2003). Through the ICF's common language of body, activity, participation and environmental codes, a person's physical, psychological and social function can be profiled and the capacity to perform and engage in everyday activities can be estimated. Furthermore, environmental hindrances that limit the person's participation in real-life situations can be identified and worked on (World Health Organization, 2001).

Previous studies have used the ICF to follow changes in health and discover functional limitations in the health trajectories among children treated for cancer and have reported individual variations (Darcy et al., 2015). In children treated for brain tumors, previous studies using the ICF stress the possibility of capturing rehabilitative concerns in follow-up care (Pletschko et al., 2017), considering the child's experience when being re-integrated into school (Vanclooster et al., 2021) or identifying what support the child requires to perform everyday life activities (Aalykkja et al., 2024). However, these findings report how the situation is for the child at a specific time point rather than trends of co-occurring problems in everyday life and how these evolve over time. Identification of co-occurring problems with participation, activity and the body alongside influential modifiable environmental characteristics can inform future interventions to optimize function and thus improve participation in everyday life (Almqvist et al., 2006; Darcy et al., 2015; Rusk et al., 2018).

One option to help in identifying existing problems and their co-occurrence when developing interventions, is the collaborative problem-solving model (CPS) (Björck-Åkesson, 2018). In this model, the person's self-expressed problems with participation are first identified. Second, explanations related to body, activity and environment that could plausibly cause problems with participation are identified. Furthermore, one problem with participation is prioritized to work on. Third, a goal is set for solving that problem. Finally, strategies based on the tentative problem explanations are developed and implemented for goal achievement (Björck-Åkesson, 2018). Earlier studies employing problem-solving techniques in collaboration with children found positive improvements in training daily life skills in children with acquired brain injuries (Chan & Fong, 2011), improved behavior in children with emotional challenges (Heath et al., 2020) and enhanced psychosocial well-being and family adaptation in children with long-term health conditions (Zhou et al., 2024).

In Sweden, parents of children treated for cancer report a lack of social and educational support for their child's needs in care received post-treatment completion (Swedish Childhood Cancer Foundation, 2022). Hospital aftercare for children who have completed cancer treatment traditionally focuses on follow-up screening for physical and psychological cancer late effects, as recommended by the national guidelines (Regionala Cancer Centrum, 2022). A focus on body-related functions is supported in previous studies when reviewing professional documentation regarding the child´s everyday problems from medical records (Backman et al., 2019; Björklund et al., 2021). Rehabilitation of the child's cancer late effects is in Sweden organized either by hospitals, or by the habilitation services, if the child remains affected to function in everyday life. School support with learning and developmental milestones according to the educational goals. However, few studies comprehensively address trends of co-occurring problems with functioning in children treated for brain tumors from a bio-psychosocial perspective. We hypothesize that problems expressed may vary with development and changes in life-role expectations. Therefore, this study's purpose is to describe how documented problems with functioning vary over time.

The research questions were

How do functioning across body, activity, participation and environment domains vary over time in health care and school documentation?

Do documented problems with functioning with activity, body function and environment co-occur with participation problems over time?

Materials and methods

Design

This study represents a longitudinal, retrospective design with multiple methods used for a secondary analysis of primary ICF linked problems generated in findings from Björklund et al. (2021).

Participants

A purposeful sampling was used to identify children diagnosed with varied brain tumors, who had successfully completed treatment within the previous 4 years. Inclusion criteria were as follows: (1) children aged 5–15 years at diagnosis, (2) having completed a neuropsychological examination 1 year following treatment completion and (3) followed by three services (hospital, habilitation and school). Documentation from seven children was included in the present study.

Settings

Two childhood cancer departments in mid-Sweden, with collaborating municipal hospitals, habilitation services and schools, were involved in the study. Yearly, the cancer departments collaborate to organize treatment and follow-up of about 50 children diagnosed with a brain tumor. Follow-up care includes radiological screening for tumor recurrence and dealing with complications related to the tumor and treatment. Neurocognitive assessments are recommended within 2 and 5 years from treatment completion. Broader multi-professional evaluations are executed depending on the child´s needs (Regionala Cancer Centrum, 2024). The results of these evaluations are shared with school professionals involved in the child's care, with referral to the habilitation service if the child has acquired a condition that needs continuous support for functioning and participation in everyday life. The children are expected, by law, to fully engage in schooling to the extent possible, irrespective of their medical history or future prospects (SFS, 2010).

Data collection

Documentation, from health care, habilitation and school records, was reviewed regarding the child's problems with everyday life. Problems, defined as a perceived discrepancy between the child's current and ideal state of functioning (Björck-Åkesson et al., 1997), were identified and collected from the records and linked to ICF codes within body function, activity, participation and environmental components by the main author with cross-check executed by a co-author with ICF expertise, see Björklund et al. (2021). ICF components and domains of codes are presented in Table 1. To exemplify, if the written text in records contained information of the child having a disturbed balance, that text section with the problem was extracted and linked to the most suitable ICF component (body function), ICF domain (b7 neuromusculoskeletal and movement-related functions) and ICF code (b755 involuntary movement reaction functions).

Data analysis

To examine how the ICF codes were distributed over time for each of the seven children, the codes were grouped into the ICF components of participation, activity, body function and environment and domains/chapters within the components. The codes were then divided into eight 6-month time periods (T1-T8). If different codes appeared within the same 6-month period, they were termed as "co-occurring." The amount of data varied from 2.7 years (5 time periods) up to 10.4 years (20 time periods) which posed a challenge, especially when comparing

Table 1. ICF component and domain definitions and code descriptions.

Component	Domain
Participation *Involvement in life situations*	p5 self-care p6 domestic life p7 interpersonal interactions and relationships p8 major life areas p9 community, social and civic life
Activity *Execution of a task or activity*	a1 learning and applying knowledge a2 general tasks and demands a3 communication a4 mobility
Body function *Physiological and psychological functions of body systems*	b1 mental functions b2 sensory functions and pain b3 voice and speech functions b4 functions of the cardiovascular, hematological, immunological and respiratory functions b5 functions of the digestive, metabolic and endocrine system b6 genitourinary and reproductive functions b7 neuromusculoskeletal and movement-related functions b8 functions of the skin and related structures
Environment *The physical, social and attitudinal environment in which people live*	e1 products and technology e2 natural environment and human-made changes to the environment e3 support and relationships e4 attitudes e5 service, systems and policies

data graphically. However, eight time periods covered nearly all children except child III and child V (see Table 2). Participant III dropped out after T5, due to a relapse in a secondary disease. Participant V had documentation available from T1-T4 because the extended four-year follow-up since the first cognitive assessment had not yet been completed. Reducing the series to six time periods would sacrifice valuable information for five participants, while adding two more time periods could result in the loss of two additional children (IV & VI). Therefore, using eight time periods provided an optimal balance when conducting the statistical and graphical analysis. The number of codes at each time period equals the number of different problems identified. The coding indicates that problem exists; severity is not considered.

The identified ICF code domains within components from T1-T8 were entered into Excel and SPSS. Descriptive statistics and comparisons were conducted at the component level, while in-depth analyses focused on the domains. By examining the number of codes

Table 2. Participant treatment data, school grades and follow-up time.

Participant	Treatment RT=radiotherapy	School grade at diagnosis	School grade at last data collection	Time in follow-up* (yrs.)
I	Surgery + RT + Chemotherapy	Pre-school	8th grade	6.7
II	Surgery + RT + Chemotherapy	Pre-school	7th grade	6.5
III	Surgery + RT + Chemotherapy	Pre-school	4th grade	2.7
IV	Surgery + RT + Chemotherapy	5th grade	1st yr. College	4.7
V	Surgery + RT + chemo	5th grade	9th grade	3
VI	Surgery + RT	Pre-school	4th grade	4.4
VII	Surgery + Chemotherapy	Pre-school	1st yr. College	10.4

*Since the first cognitive assessment.

within the four ICF components, the central tendencies (median = md), the lowest and highest values (range) and the percentage of codes at each time period for the seven children were identified.

To illustrate the pattern of problems over time related to problems with participation and co-occurring activity, body function and environmental codes, one detailed case “Douglas” (participant II), was provided for in-depth analysis with the use of CPS strategies described in Björck-Åkesson (2018). In this analysis, the two initial steps in the CPS were employed. First, participation codes for “Douglas” were identified in each of the 6-month time periods. Codes within activity, body function and environment that appeared in the same time periods as a participation problem were applied as potential plausible explanations of the participation problems, with contextual descriptions included. “Douglas” exemplifies a child with a broad range of problems and with increases in the number of problems during time periods T6 and T7, when the other study children showed a decrease in their patterns of problems (see Child II in Figures 1–7).

Ethical considerations

Following approval from the Ethical Review Board in Linköping (Dnr 2017/475–31) written informed consent to access the child´s school, habilitation and medical records was obtained from parents and participating youths above the age of 15 years at study entry. All participants were informed about confidentiality and the possibility to withdraw at any time without explanation in accordance with Swedish and International guidelines (World Medical Association, 2024).

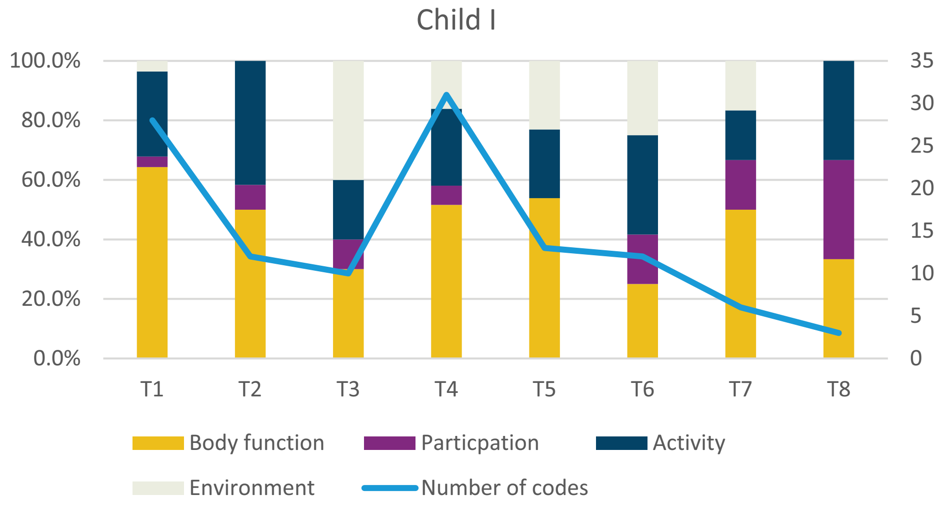

Figure 1. Proportion (bars) and frequency (curve) of ICF codes in child I.

Results

The sample included seven children (four boys, three girls). Their treatment modalities, school grades and time in follow-up are presented in Table 2. The mean follow-up time 1-year post-treatment to the last documentation in records (endpoint of data collection) was 5.4 years.

The variation of children's functioning across ICF domains and time in health care and school documents

The findings (see Table 3) reveal that there are variations over time in how documented problems with functioning are distributed, on median group levels. Problems related to participation were relatively low at T1 and evenly distributed throughout the eight time periods (md = 1–2) with individual variations displayed (range 2–12). Problems related to the activity component were highest at T1 (md = 6) and tended to decrease over time. The median distribution of problems related to body function varied between 9 and 18 codes, where the highest median was found at T1. No distinct decrease over time was visible. Finally, the highest distribution of problems related to environmental codes occurred at T6 and T7 (md = 3). The median distribution of codes related to each ICF component per time point is presented in Table 3.

To further illustrate variations between children's problem patterns over time (during the 6-month time periods), Figures 1–7 are provided. The Y axis to the left displays the proportion of different codes within components, and the right-side Y axis displays the code frequency with the line across the staples and shows the number of codes within the 6-month periods. The individual cases vary in the proportion of codes within the different components over time, with some children exhibiting larger variations, especially in activity and environmental codes (see left-hand side Y-axis). The children's number of codes varied over time, with four children displaying a decreasing trend of codes (child I, III, V, VII), whereas three children (Child II, IV, VI) had a variable code pattern with no explicit trend.

Figures 1–7. Proportion of ICF-linked bars and number of codes (curve) per time period and per child.

The co-occurrence of documented problems with activity, body and environmental domains over time – for case "Douglas"

Child II (Figure 2) who we have named Douglas was diagnosed with a malignant cerebellar brain tumor as a preschooler and underwent treatment with surgery, chemotherapy and

Table 3. Median code distribution within ICF components in 6-month periods on group levels.

ICF Component	Participation		Activity		Body function		Environment		Nr of children
Time periods	*Md*	*Range*	*Md*	*Range*	*Md*	*Range*	*Md*	*Range*	
1	2	12	6	8	18	16	2	6	7
2	1	2	3	6	11	20	2	10	7
3	2	5	2	8	10	18	1	5	7
4	2	4	4	7	11	21	1	6	7
5	2	7	3	8	9	23	2	2	7
6	2	6	2	13	11	25	3	9	6
7	2	6	5	17	12	19	3	9	5
8	1	2	1	3	11	24	1	6	5

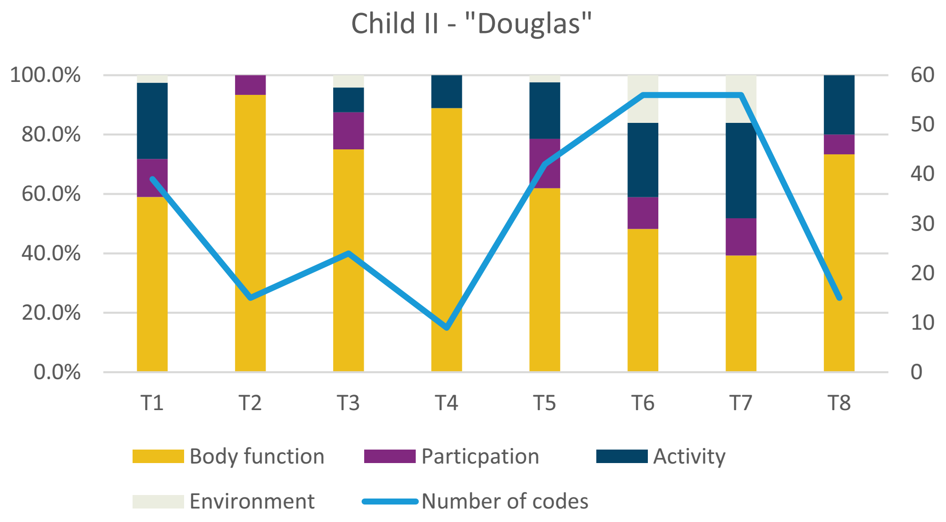

Figure 2. Proportion (bars) and frequency (curve) of ICF codes in child II.

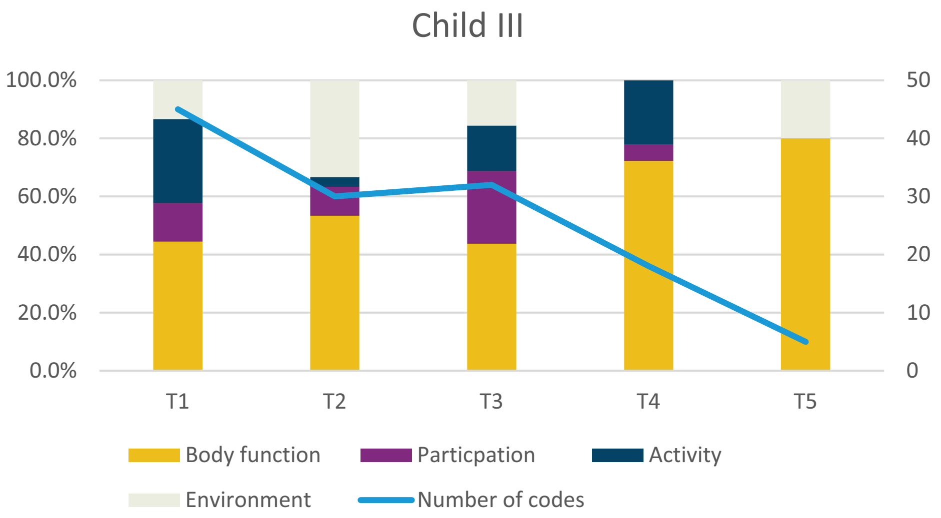

Figure 3. Proportion (bars) and frequency (curve) of ICF codes in child III.

radiotherapy. Documentation from hospital, habilitation and school records identified participation problems mainly within self-care, schooling and in peer relations.

By using the CPS an in-depth analysis of individual ICF codes within different components for “Douglas,” we have illustrated how problems with participation tentatively co-occur with activity, body function and environmental problems in the 6-month periods over the 4-year follow-up of professional records (T1-T8).

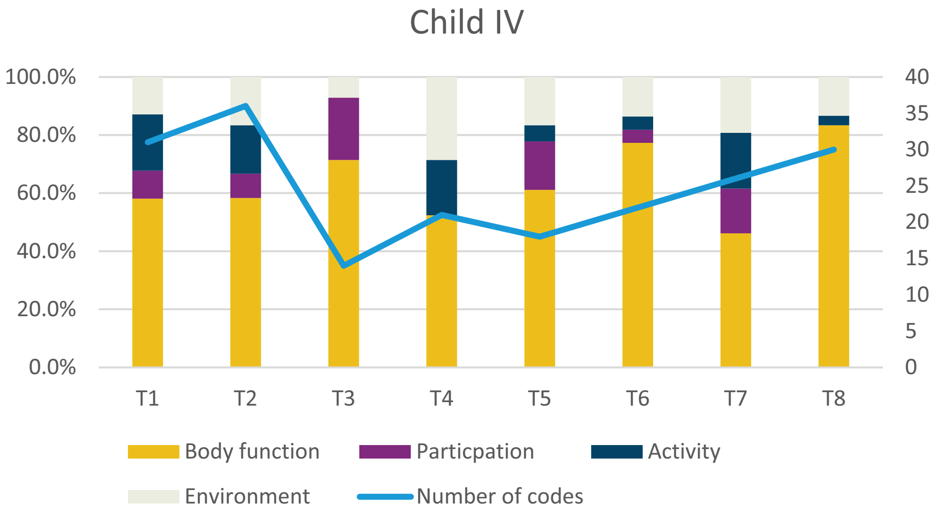

Figure 4. Proportion (bars) and frequency (curve) of ICF codes in child IV.

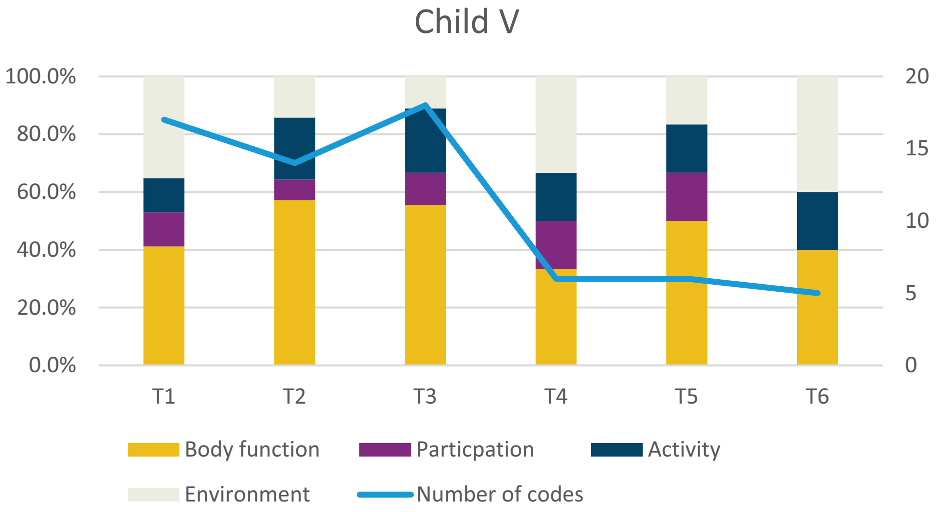

Figure 5. Proportion (bars) and frequency (curve) of ICF codes in child V.

Douglas problems with caring for his personal health over time and plausible explanations

Douglas had ongoing problems with executing personal health routines, including eating, dressing, toileting and toothbrushing over time (T1, T3, T5–T7). These self-care problems were plausibly explained by activity limitations related to fine-hand use (T1, T3, T5, T7), reaching the bathroom in time (T5–T6) and carrying out daily personal health routines (T1, T6). Bodily explanations for these self-care problems included obesity (T6), enuresis (T5–T6), having a slow tempo and muscle weakness (T1). Furthermore, fatigue and problems with planning for self-care tasks had

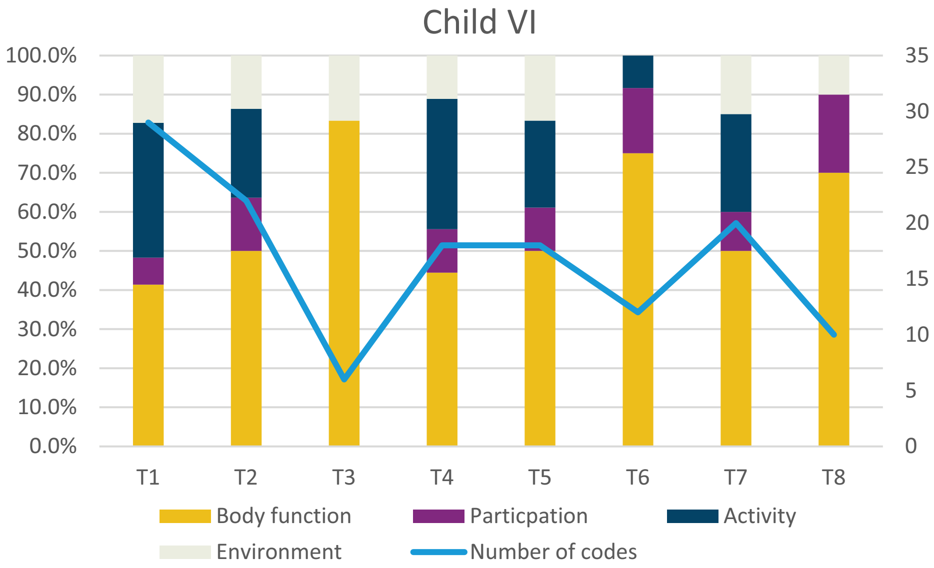

Figure 6. Proportion (bars) and frequency (curve) of ICF codes in child VI.

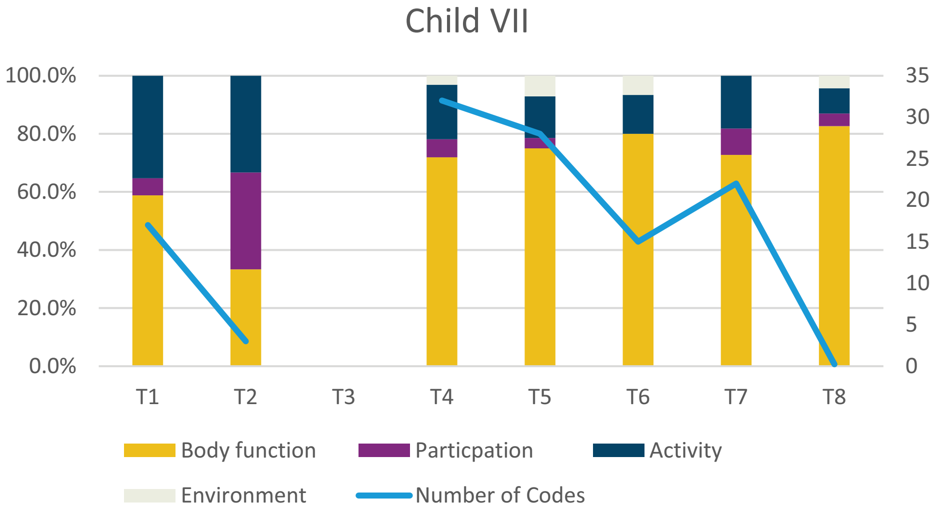

Figure 7. Proportion (bars) and frequency (curve) of ICF codes in child VII.

probably other body-related explanations (T7). Plausible environmental explanations to care for personal health included problems with unfolding a wheelchair (T3), lack of continuous support from others (parents and professionals), and of others' attitudes of expectations regarding the ability to manage personal health issues independently (T7).

Douglas problems with school participation over time and plausible explanations

Douglas' participation problems in school were related to school attendance, noted at multiple time points (T1, T2, T5–T7). This problem appeared to be plausibly explained by activity limitations such as with basic learning of reading and writing (T1, T5–T6), fulfilling daily academic requirements (T1–T2, T5–T7), remembering instructions and managing stress related to schoolwork (T6–T7). Plausible body function explanations contributing to the problems in school included fatigue (T1–T2, T5–T6), a slow working pace (T5–T6), motor impairments and headaches (T2). Environmentally, plausible scholastic problem contributors involved sensitivity to sound and light (T1, T5–T6), lack of teacher knowledge regarding support for a child with acquired brain injury (T6–T7), and insufficient adult support during the school day (T7). In addition, professionals also expected Douglas to manage school activities more independently along with aging.

Douglas problems with social relationships over time and plausible explanations

Douglas experienced ongoing participation problems in peer relationships, particularly in social interactions with friends (T1, T5–T8). These social relational problems were plausibly related to activity limitations involving verbal expression and difficulties understanding socially expected cues in peer conversations (T1, T5–T8). Bodily explanations included personal thoughts influencing interactions (T7), slow tempo and challenges with emotional regulation (T8). Environmental factors that plausibly contributed to the peer-related problems involved mutual attitudes between Douglas and his peers in how they responded to one another (T7).

Table 4 provides an example of how the documented problems with participation, tended to simultaneously occur with activity, body function and environmental problem domains over time.

Discussion

This study adds knowledge about longitudinal trends in problems with body functions, activity performance and environment in children who have ended brain tumor treatment, and how these problems occur and co-occur with problems with participation. The results build on a review of professional records from a bio-psycho-social perspective. The seven children in the study sample had documented problems with participation, activity, body function and environment that remained over time, both on individual and group levels. However, the number of problems varied between children. On a case level, problems with participation tended to co- and re-occur and were tentatively associated with activity limitations, body impairments and environmental barriers. Variations in functioning seemed to vary over time, which may be related to changes in role expectations from others (e.g. transportation to leisure activities) with increasing chronological age.

Over time, irrespective of the 6-month time period, problems with body function were the most common problem among the children included in the present study. Various mental, gross motor and cognitive complaints are well-known cancer-related effects identified in earlier research among children who underwent treatment for brain tumors (Otth et al., 2022; Rey-Casserly & Diver, 2019). The high number of problems related to body

Table 4. A description of how the identified participation problems co-occur with problems regarding activity, body function and environment for "Douglas".

T1 3rd grade in school	
Identified problems with participation	Text descriptions of plausible explanations for participation problems (p5-p9) from activity (a1-a4), body function (b1-b7) and environmental (e1-e5) ICF domains (see table 1 for domain descriptions)
Problems with self-care (p5): Eating, Dressing	Douglas had problems with eating and dressing **(p5)** that could plausibly be explained by his difficulty with fine-hand function **(a4)**, performing daily routines **(a2)** and with being slow in processing speed **(b1)**.
Problem with social relationships (p7): Peer interactions	Douglas had social-relational problems **(p7)** that could plausibly be explained by his difficulty with communication i.e. expressing himself verbally and understanding overall conversation with others **(a3)**.
Problems with major life areas (p8): Education	Douglas had educational problems **(p8)** that could plausibly be explained by his difficulty with learning to read and write **(a1)**, executing tasks and switching from one activity to another **(a2)**, having fatigue **(b1)** and of being sensitive to sounds and bright lights **(b2)**.
T2	
Problem with major life areas (p8): School absence, refused Physical Education (PE) attendance	Douglas had school-related problems **(p8)** that entailed being absent from school and refused participation in PE activities, that could plausibly be explained by his increased exhaustion **(b1)**, headache in the mornings **(b2)**, sudden dizziness and heart palpitations **(b4)** and remaining balance disturbance as well as muscle weakness in the legs **(b7).**
T3 4th grade in school	
Problems with self-care (p5): Physical health	Douglas had problems with self-care that affected his ability to care for his physical health **(p5)**. This could plausibly be explained by his difficulty with fine-hand mobility **(a4)**, with muscle weakness **(b7)** and difficulty to unfold his wheelchair **(e1)**.
T4	
No participation codes	Douglas had problems with mobility, i.e. in riding a two-wheeled bike **(a4)** that could plausibly be explained by having pain in a foot **(a2)** and perceived dizziness **(b4)**.
T5 5th grade in school	
Problems with self-care (p5): Personal hygiene, cutting food	Douglas had continued problems with taking care of his personal hygiene and cutting food **(p5)** that could plausibly be explained by difficulty with fine-hand use **(a4)** and difficulty reaching the bathroom in time, causing "accidents" (**b6**).
Problems with social relationships (p7): Peer interactions	Douglas had problems with making friends since he had no-one to play with in school or after school **(p7)**. These could plausibly be explained by the difficulty expressing himself, responding in conversations and understanding social expected cues **(a3)**.
Problems with major life areas (p8): Education and school absence	Douglas had educational problems resulting from being absent from school and not keeping up with schoolwork **(p8)**. These could plausibly be explained by difficulty with following daily routines i.e. initiating and executing necessary school tasks **(a2)**, being slow in processing speed **(b1)**, writing letters and numbers **(a1)**, unfavorable pen-grip **(a4)**, extreme tiredness **(b1)** and with being sensitive to classroom noise **(e2)**.
T6	
Problems with self-care (p5): Personal hygiene, toileting	Douglas had problems with taking care of his personal hygiene i.e. toileting **(p5)**. These could plausibly be explained by his difficulty with following daily routines **(a2)**, with moving to the bathroom and using the bathtub **(a4)**, being obese **(b5)** and of upcoming enuresis **(b6).**

(*Continued*)

Table 4. (Continued).

Identified problems with participation	Text descriptions of plausible explanations for participation problems (p5-p9) from activity (a1-a4), body function (b1-b7) and environmental (e1-e5) ICF domains (see table 1 for domain descriptions)
T1 3rd grade in school	
Problems with social relationships (p7): Peer interactions	Douglas had problems with social relationships i.e. having no friends to play with **(p7)**. This could plausibly be explained by his difficulty with communicating both with children and adults **(a3).**
Problems with major life areas (p8): Education and school absence	Douglas had remaining educational problems resulting from refusing school attendance **(p8)** that could plausibly be explained by his difficulty handling stress from following daily routines **(a2)**, writing letters and numbers **(a1)**, concentrating and remembering instructions, having a slow working tempo and being fatigued **(b1)**. Furthermore, Douglas's school problems could plausibly be explained by difficulty with not taking his medications **(e1)**, being sensitive to classroom noise **(e2)** and the new teacher having difficulty keeping the classroom quiet and lacking knowledge on how to provide Douglas with relevant support **(e3)**.
T7 6th grade in school	
Problems with major life areas (p8): Education and school absence	Douglas's educational problems resulted from being absent from school **(p8)**. These could plausibly be explained by his difficulty with managing stress when not understanding how to execute tasks **(a2)**, with attention and remembering instructions, and handling emotions **(b1)**. Furthermore, Douglas's school problems could plausibly be explained by his continuous need for adult support **(e3)** and by teachers' lack of confidence in supporting a child with an acquired brain injury **(e4)**.
Problems with self-care (p5): Toothbrushing, buttoning clothes	Douglas had problems with self-care which resulted from problems with food intake, toothbrushing and buttoning clothes **(p5)**. These could plausibly be explained by his remaining difficulty with fine-hand use **(a4)**, with executive functions, slow processing speed and fatigue **(b1)**. Douglas's problems with self-care could plausibly be explained by his increased needs for parental and support from others **(e3)** and by attitudes of others related to performing expected daily activities independently **(e4)**.
Problems with social relationships (p7): Peer interactions	Douglas had problems with social interaction with peers **(p7)**. These could plausibly be explained by his difficulty with understanding messages in conversations **(a3)**, with psycho-motor and personal thoughts **(b1)**, as well as responding to peers **(e4).**
T8	
Problems with social relationships (p7): Peer interactions	Douglas had problems with social-relationships such as with peer-interactions **(p7)**. These could plausibly be explained by problems with communicating i.e. initiating and continuing a dialogue **(a3)**, having a slow processing speed and difficulty controlling emotions **(b1)**.

function codes at T1 could be explained by frequent medical follow-ups in hospital following brain tumor treatment. This is a period where the risk of tumor recurrence is increased (Hill et al., 2020) and the child is examined clinically and with brain imaging about every third month. This strong focus on the child's body functions might somewhat explain the lack of attention given to supporting the child in solving psychosocial and educational needs, something noted by parents in cancer follow-up (Swedish Childhood Cancer Foundation, 2022). The lack of attention to social and scholastic issues in hospital follow-up is probably related to the national guideline recommendations, which mainly focus on screening for recurrent disease and cancer-related effects post-treatment completion (Regionala Cancer Centrum, 2022), with less consideration for everyday functioning. This prevailing focus on reporting individuals' cancer-related body effects is problematic. The re-occurring, relatively stable trajectories of body problems that are visible in child records, indicate that the child is not cured of these impairments; they rather become a chronic state (Pancaldi et al., 2023) that might have different effects at different time points when expectations from others change. Therefore, professionals should pay attention to how the chronic body symptoms impact on the child's ability to engage in everyday activities in different environments (home, school, leisure), not only at one time point but over time. This is important to consider, as it pertains to the context of day-to-day activities where children perceive health (Almqvist et al., 2006). This information is missing in the child record documentation presented in previous findings (Backman et al., 2019; Björklund et al., 2021). The use of ICF codes can help to give a comprehensive view of the child's functioning in everyday life, with the potential to identify barriers that could be worked on to enhance the child's adaptation to new life circumstances, which refer to Hubers definition of health (2011). The ICF's bio-psychosocial "mindset" and common language are available for interprofessional communication (World Health Organization, 2001). Such communication can reduce the gap in meeting the child's need for school and psychosocial support after ending brain tumor treatment, by identifying the need for adaptions in surrounding environments. All this can stimulate service collaboration and enhance child-directed support (Swedish Childhood Cancer Foundation, 2022; Vanclooster, Bilsen, Peremans, Van der Werff Ten Bosch, Laureys, Willems, et al., 2019).

The findings reveal that problems related to participation were sparsely documented at all the 6-month time periods over 4 years. The low occurrence of participation codes might partly be explained by participation-related problems being unrecognized in health-care follow-up, and thus in documentation. Schools may be aware of the problems without documenting all of them. In a previous study by Ståhl et al. (2013), school professionals tended to communicate child-sensitive psycho-social issues verbally instead of documenting them in records. Standard educational matrixes for educational goal achievement are used in schools, with no obligation to document temporary learning problems or adaptations according to what is stated in the Swedish school law (SFS, 2010). However, we know from earlier studies that children with a history of a brain tumor to a lesser extent graduate from school (Lönnerblad et al., 2020) and have fewer social peer connections compared to healthy children (Schulte et al., 2018; Willard et al., 2019). Furthermore, these children experience difficulties with independent self-care management (Hobbie et al., 2016) and with participating in home or school activities (Verwaaijen et al., 2021) that could negatively affect their life quality over time (Macartney et al., 2014). Again, with a bio-psychosocial approach such as with the ICF, it is possible to get an overview of the child's participation in everyday life and to identify barriers to participation (World Health Organization, 2001). Some of these participation barriers can be overcome by adapting the environment for the child, such as with organizing suitable aids or working with child's peers. The child's own opinion about being involved in life situations should be asked for and supplemented with parents' views, as children tend to avoid reporting embarrassing problems such as social exclusion (Srinath et al., 2019). However, a prior study reported that parents' and children often attempted to protect each other by avoiding open communication about their feelings, worries or needs during clinical follow-up visits (Bull et al., 2024). This highlights the importance of professionals building trustful relationships with stakeholders (parents, health care, school staff) so these issues can be raised naturally in follow-up.

Problems related to performing activities were evident in this study about a year after ending brain tumor treatment, with a decrease over time for the entire group. Given the recommended assessments in the child cancer follow-up-and rehabilitation programs (Regionala Cancer Centrum, 2024; Regionala Cancer Centrum, 2022), a multi-professional assessment could have been executed at T1, T4 and T5 (illustrated in Figures 1–7), impacting identified activity related problems.

The variations, not only in problems with activity performance, but also with participation, might indicate that the problems (at least on body level) are always there, but the consequences for performing activities and participation are not discussed. The first year after treatment completion is the time period when the child reenters into a more “typical” everyday life, which could also explain the increase of activity problems detected at this time point. At the multi-professional evaluations, the child´s cognitive levels (assessed by a neuropsychologist), skills in performing daily home activities (assessed by an occupational therapist) or school requirements (assessed by a special education teacher) are examined (Regionala Cancer Centrum, 2024). However, the abilities are often investigated and compared with age- and developmental-related norms rather than based on the person’s own or environmental preferences and functional problems. Prior studies have shown that children treated for a brain tumor display complex problem patterns such as difficulty acquiring basic learning skills in school and carrying out daily routines, as defined by the curriculum (Björklund et al., 2021; Lönnerblad et al., 2017; Vanclooster et al., 2021). Such basic skills are essential for future independence, and problems with these abilities could affect the possibility of meeting daily life requirements unless having an adapted environment, as pointed out by Demers et al. (2016). In this study, such issues can particularly be seen as the child matures, and the role expectations on the child are changing. To exemplify, this could entail the child taking responsibility for getting themselves to and from leisure activities, in order to participate. The sparsity of activity problems seen in documentation between T1-T4 and T5-T8 could hypothetically be explained by the activity problems being solved or that they are not recognized in health-care follow-up or in school.

The findings reveal that professionals seem to overlook the impact of environmental factors, according to few environmental problems documented over time and completely missing in documentation at some time points for some children. There was a slight increase in environmental codes about three to 4 years after treatment completion. The low occurrence of environmental codes could be associated with professionals’ inattention in medical follow-up as to how environmental aspects (family, school) affect the child’s functioning, which is not part of the national guideline recommendations (Regionala Cancer Centrum, 2022). However, awareness of family, school and peer-relational issues is part of the new rehabilitation program for children with cancer that was launched in Sweden in 2024 (Regionala Cancer Centrum, 2024). Screening for family, school and environmental supportive systems around the child, should be a natural part of the follow-up of children treated for brain tumors, as these systems are essential for the child’s development and health. Prior studies confirm the family as the primary and most important advocating system for the child (Hovén et al., 2017; Rosenbaum & Gorter, 2012). However, it is in school where formal learning and social interactions happen. A previous review pinpointed that it is important to build partnerships between home, school and health care to provide child-directed support through these collaborative systems (Plage et al., 2022). To build such relationships across systems, to overcome communication and collaboration barriers, a care coordinator (preferably a nurse) could bridge these systems and advocate for the child's interests when organizing support for the child's health in center (Jeon et al., 2025; Young et al., 2023).

Douglas, for whom multiple problems within each component were documented, illustrates recurring patterns of problems with participation, activity performance and body functions in 6-month periods and over time. His re-occurring problems with participation were related to the ICF domains of self-care, schooling and peer-relations. Daily self-care tasks, such as cutting food or getting dressed, are abilities usually attained before the child reaches school age. The plausible explanations for the problems were related to Douglas's reduced fine-hand mobility which affected execution of everyday routines, causing him to hold a slow tempo and a limited stress threshold. Prior studies confirm limitations in fine motor skills and the co-occurrence with cognitive impairments for children treated for brain tumors (Chipeeva et al., 2022; Gielis et al., 2022) that could affect daily activity performance and cause limitations in managing stress. Self-care problems need support from the immediate environment to be managed by the child, where parents are the natural compensators during the phase of the child's recovery. As the child grows, the expectation of autonomy in everyday activities at home, in school and with peer relations expands, which could be challenging for parents of children with brain tumors to handle (Aukema et al., 2011). To overcome this parental dependency, the study of DallÓglio et al. (Dall'oglio et al., 2021) suggests a focus shift from parents' guidance to engaging the child in self-care management via educational support, e.g. from professionals, which the CPS model supports.

Douglas's school-related problems with being absent from school or arriving late, co-occurred with learning problems in reading, writing and mathematics, which are well-known problems in previous research on children who underwent treatment for brain tumors (Lönnerblad et al., 2017). School-required duties increased his distress and could plausibly relate to his memory problems and the problems with organizing daily schedules. Such problems with executive functions are common and are often recognized in the regular cognitive assessments of children with brain tumors (Tonning Olsson et al., 2013). These problems may become more apparent not only when the child returns to school, but also with increasing curriculum demands. That is why school re-integration should be pre-organized with relevant assessments of everyday functioning, as suggested by Vanclooster et al. (2019), to find out what kind of support the child might need in school not only at one time point but over time. For some children, as in the case of Douglas, the school-related problems seem to persist over time. He underwent a multi-professional assessment about a year after ending treatment and at later time points (T6-T7) when more problems in school were noticed. This may illustrate the need for comprehensive follow-up of children's functioning among service professionals who work with children treated for brain tumors in different settings. If problems are identified in health care, they should be discussed with school staff within a school context, to further collaborate regarding relevant child assessments and of the support to be organized. In prior studies, service coordination and collaboration have been associated with greater academic success for the child (Lum et al., 2017).

The findings also reveal that Douglas had participation problems with peer-relations in school that co-occurred with problems of communicating properly and understanding social cues. Outside school he seemed to lack friends to play with. Challenges with social-behavioral integration have been recognized in previous studies of children with brain tumors (Hamidah et al., 2020; Schulte et al., 2018), which could lead to social exclusion (Fantozzi et al., 2024), such as for Douglas, especially in the age span where children usually develop peer relations. Peer-interactional problems affecting the child's social health are difficult to capture in health-care follow-up (Hollin et al., 2022) but should be part of the educational follow-up in school.

The CPS model could serve as a working model for repeated reviews (Björck-Åkesson, 2018). However, services seem to have difficulties in organizing such comprehensive assessments of the child's functioning and in organizing support according to the child's rehabilitation needs (Stensvold et al., 2020; Swedish Childhood Cancer Foundation, 2022). Involving the child as an expert when addressing what matters in their everyday life is essential when directing rehabilitative efforts (Nicklin et al., 2019; Socialdepartementet, 2021). To encourage the child to identify goals and co-produce meaningful activities to engage in has been shown in earlier studies to be beneficial for enhancing participation (Vänskä et al., 2022). Teaching the child strategies for solving their own problems with participation, e.g. by practicing collaborative problem-solving, means that over time they can develop the social and practical skills necessary to manage challenges in adult life. However, solving problems autonomously takes time to learn and requires repeated experiences of successful problem solving. It indicates that a life-course perspective should be employed (Ullenhag et al., 2024) in both child and adult follow-up after ending cancer treatment. Supporting interventions focusing on body aspects of functioning, e.g. directed toward the child's motor function, could improve specific body function abilities but may not impact the child's overall participation in everyday life (Wright et al., 2008). Future research should therefore explicitly investigate the translation of problems with body functions (impairments) into context-dependent problems in the child's everyday context and explore potential solutions.

Methodological considerations

Some methodological considerations can be highlighted in relation to this study. First, the sample size of seven children treated for brain tumors limits the generalizability of the findings. However, documentation from these children spanned several services and time periods. Second, the retrospective review of documentation in service records may not fully capture the children's actual problems in everyday life. Third, we are aware of that code occurrence within the 6-month time periods, can be quite a long time in clinical practice where several months can pass between documentation time points. Fourth, the ICF manual does not provide guidance about how to document changes over time. This study is one of the few that use ICF to examine the interplay between the components of child body function, activity performance, participation. In addition, to evaluate longitudinal variations in patterns of problems on group levels is difficult for this heterogeneous group of brain tumor-treated children, who display varying individual profiles. On the other hand, this “limitation” is a strength regarding displaying the child-centered focus required to organize individualized support, according to the child’s needs, across the life span.

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