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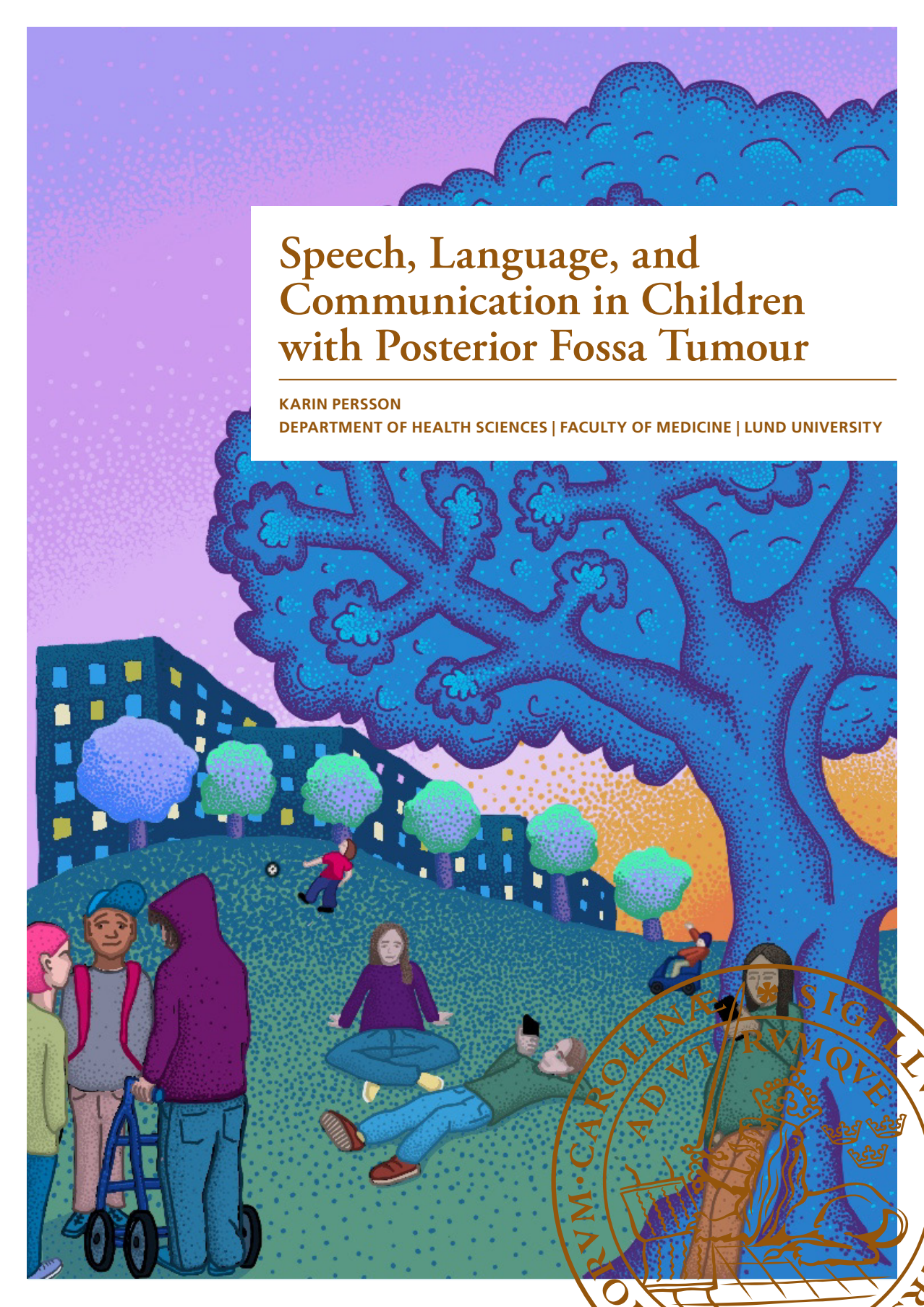
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Speech, Language, and Communication in Children with Posterior Fossa Tumour

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DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



Speech, Language, and Communication in Children with Posterior Fossa Tumour

Speech, Language, and Communication in Children with Posterior Fossa Tumour

Karin Persson



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DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Medicine at Lund University to be publicly defended on 11 September 2026 at 09.00 in Utblicken, Forum Medicum, Sölvegatan 19, Lund.

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Title and subtitle: Speech, Language, and Communication in Children with Posterior Fossa Tumour

Abstract:

Children diagnosed with brain tumours often have tumours located in the posterior fossa, a region containing the cerebellum, brainstem, and fourth ventricle. Posterior fossa tumours (PFT) and their treatment may affect speech, language, and communication, which need to be considered in relation to the child's activity and participation in everyday life. Previous research has mainly focused on postoperative outcomes and children who develop posterior fossa syndrome (PFS), while knowledge remains limited regarding preoperative language abilities, detailed language profiles, variation between children, and children's own experiences of communication.

This thesis aimed to investigate word-finding ability and narrative macrostructure and microstructure before and after surgery in children with PFT, and to describe children's experiences of communication in everyday life following PFT surgery.

Word finding was investigated using the Wordrace test in 148 children before surgery and in 184 children before and/or after surgery, with Swedish age-specific norms used in subanalyses. Narrative macrostructure and microstructure were investigated using the Fish Story task from the Expression, Reception and Recall of Narrative Instrument (ERRNI) in 44 Swedish children with PFT and 118 children with typical development (TD). Interviews were conducted with 10 Swedish-speaking children treated for PFT.

Word-finding and narrative difficulties were observed both before and after surgery. Word-finding difficulties mainly reflected slower naming speed rather than incorrect responses. Compared with peers with TD, children with PFT demonstrated difficulties in narrative macrostructure and microstructure, including fewer central story elements, shorter utterances, more grammatical errors, and a slower speech rate. Among those with both pre- and postoperative assessments, changes in word-finding and narrative ability varied between individuals, with no consistent group-level change. Participants described how small communicative situations could create a sense of belonging, while other experiences involved exclusion and not being heard. Communication was also described as important for managing changed circumstances, setting boundaries, and maintaining a sense of self and normality.

Language difficulties in children with PFT may involve word finding and narrative production. Assessment and follow-up should consider language functions, activity, and participation, incorporating children's experiences of everyday communication.

Key words: children; posterior fossa tumour; language; word-finding ability; narrative ability; communication; participation; everyday life

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Speech, Language, and Communication in Children with Posterior Fossa Tumour

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MADE IN SWEDEN 

*“To all the children I have met along the way, for the words,
silences, and stories you have shared”*

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Preface

“It is simply this: do not tire, never lose interest, never grow indifferent – lose your invaluable curiosity and you let yourself die. It’s as simple as that.”

Tove Jansson, *Fair Play* (1, p. 83)

In my clinical work, I meet children and adolescents whose speech, language, and communication abilities have changed. They may no longer be able to understand language, produce speech, find the right words, put them together, or communicate with others in the way they did before. These changes can evoke fear, sadness, anger, frustration, and grief, both in the child and in those around them. In such situations, I often find myself close to these powerful emotions, while also being driven by a need to understand what has happened and how speech, language, and communication can be supported. One encounter has stayed with me in particular: the first time I met a child with what was then described to me as posterior fossa syndrome. There was little to guide our understanding of the condition, and the presence of mutism felt like a genuine mystery. Why had this happened? What had been affected? What could be expected in terms of recovery? It was through this experience that my own curiosity, reflected in Jansson’s words, began to grow.

The questions raised by that first encounter stayed with me for many years. In 2014, they found a new direction when I became involved in the Nordic-European CMS study, initially through discussions about the language assessments and later through the analysis of the Swedish recordings. This involvement gradually developed into the research presented in this thesis.

This thesis has grown out of my clinical work with children and their families. It is also shaped by the hope that we can become better at recognising difficulties with speech, language, and communication; that speech and language therapists will have a clearer role throughout the care pathway; and that children will receive support that makes communication, participation, and everyday life easier.

I am deeply grateful to the children and families I have met, and to all the people and circumstances that have shaped this work: the conversations, discussions, arguments, reading, writing, and the continuing rollercoaster of emotions. This thesis has brought tears of both frustration and joy, and I am proud of the work it represents.

Karin Persson, July 2026

Abstract

Children diagnosed with brain tumours often have tumours located in the posterior fossa, a region containing the cerebellum, brainstem, and fourth ventricle. Posterior fossa tumours (PFT) and their treatment may affect speech, language, and communication, which need to be considered in relation to the child's activity and participation in everyday life. Previous research has mainly focused on postoperative outcomes and children who develop posterior fossa syndrome (PFS), while knowledge remains limited regarding preoperative language abilities, detailed language profiles, variation between children, and children's own experiences of communication.

This thesis aimed to investigate word-finding ability and narrative macrostructure and microstructure before and after surgery in children with PFT, and to describe children's experiences of communication in everyday life following PFT surgery.

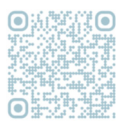
Word finding was investigated using the Wordrace test in 148 children before surgery and in 184 children before and/or after surgery, with Swedish age-specific norms used in subanalyses. Narrative macrostructure and microstructure were investigated using the Fish Story task from the Expression, Reception and Recall of Narrative Instrument (ERRNI) in 44 Swedish children with PFT and 118 children with typical development (TD). Interviews were conducted with 10 Swedish-speaking children treated for PFT.

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Language difficulties in children with PFT may involve word finding and narrative production. Assessment and follow-up should consider language functions, activity, and participation, incorporating children's experiences of everyday communication.

List of Papers

Paper 1



Persson, K., Boeg Thomsen, D., Fyrberg, Å., Castor, C., Aasved Hjort, M., Andreozzi, B., Grillner, P., Grønæk, J. K., Jakus, J., Juhler, M., Mallucci, C., Mathiasen, R., Molinari, E., Pizer, B., Sehested, A., Troks-Berzinskiene, A., van Baarsen, K., Tiberg, I., & The CMS study group. (2024). Preoperative word-finding difficulties in children with posterior fossa tumours: a European cross-sectional study. *Child's Nervous System*, 40, 87–97. <https://doi.org/10.1007/s00381-023-06119-4>

Paper 2



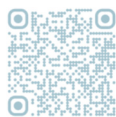
Persson, K., Grønæk, J., Tiberg, I., Fyrberg, Å., Castor, C., Andreozzi, B., Frič, R., Hauser, P., Kiudeliene, R., Mallucci, C., Mathiasen, R., Nyman, P., Pizer, B., Sehested, A., Boeg Thomsen, D., & The CMS study group. (2025). Postoperative word-finding difficulties in children with posterior fossa tumours: a crosslinguistic European cohort study. *Child's Nervous System*, 41, 128. <https://doi.org/10.1007/s00381-025-06787-4>

Paper 3



Persson, K., Boeg Thomsen, D., Andersson, K., Tiberg, I., Castor, C., Grønæk, J., Mathiasen, R., & Fyrberg, Å. (2026). Narrative Ability in Swedish Children Treated for Posterior Fossa Tumours: Macro- and Microstructural Performance Before and 1–4 Weeks After Surgery. *International Journal of Language & Communication Disorders*, 61, e70248. <https://doi.org/10.1111/1460-6984.70248>

Paper 4



Persson, K., Tiberg, I., Boeg Thomsen, D., Fyrberg, Å., & Castor, C. (2026). Children's Experiences of Communication in Everyday Life Following Posterior Fossa Tumour Surgery—A Sense of Belonging While Navigating Reality. *International Journal of Language & Communication Disorders*, 61, e70174. <https://doi.org/10.1111/1460-6984.70174>

Author's contribution to the papers

Paper 1

The author contributed to the development of the scientific question and study design. The author prepared the data for analysis, carried out the statistical analyses under the guidance of a statistician, and interpreted the word-finding results together with the co-authors. The first draft was prepared by the author and revised in dialogue with the co-authors. The author responded to reviewer comments, prepared the final version together with them, and was responsible for correspondence with the journal.

Paper 2

The author contributed to the development of the scientific question and study design. The author prepared the data, carried out the statistical analyses under the guidance of a statistician, and interpreted the results together with the co-authors. The first draft was prepared by the author and revised in dialogue with the co-authors. The author responded to reviewer comments, prepared the final version together with them, and was responsible for correspondence with the journal.

Paper 3

The scientific question and study design were developed by the author in collaboration with the co-authors. The author was responsible for the ethics application for the collection of data from children with TD. These data were collected under the responsibility of the author and a co-author, in collaboration with speech and language therapy students. The author prepared and analysed the narrative data, including transcription, coding, and the generation of narrative outcome measures, carried out the statistical analyses, and interpreted the results in collaboration with the co-authors. The manuscript was written by the author and revised in dialogue with the co-authors. The author prepared its final version and was responsible for correspondence with the journal.

Paper 4

The scientific question and study design were developed by the author in collaboration with the co-authors. The author was responsible for the ethics application for the interview study, conducted the interviews, transcribed the interview material, and led the qualitative analysis in collaboration with the co-authors. The manuscript was written by the author and revised in dialogue with the co-authors. The author responded to reviewer comments, prepared the final version together with them, and was responsible for correspondence with the journal.

Abbreviations

AAC	Augmentative and Alternative Communication
ABI	Acquired Brain Injury
CI	Confidence Interval
CMS	Cerebellar Mutism Syndrome
CNS	Central Nervous System
cWPM	Correct Words Per Minute
DLD	Developmental Language Disorder
ERRNI	Expression, Reception and Recall of Narrative Instrument
GY	Grammaticality
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disability, and Health
MATTR	Moving Average Type-Token Ratio
MLUw	Mean Length of Utterance in words
MSD	Motor Speech Disorder
PFS	Posterior Fossa Syndrome
PFT	Posterior Fossa Tumour
SALT	Systematic Analysis of Language Transcripts
SD	Standard Deviation
SI	Subordination Index
TD	Typical Development
WPM	Words Per Minute

Papers at a glance

	Paper 1	Paper 2	Paper 3	Paper 4
Aim	To investigate preoperative word-finding difficulties, associated characteristics, and error types	To investigate postoperative word-finding difficulties, changes, and associated factors	To investigate narrative macrostructure and microstructure, pre- to postoperative changes, and associations with PFS and MSD	To describe children's experiences of communication in everyday life following PFT surgery
Design	Cross-sectional observational study	Prospective observational cohort study	Prospective observational cohort study	Qualitative interview study
Participants	148 children with PFT	184 children with PFT	44 children with PFT and 118 children with TD	10 children following PFT surgery
Data collection	Wordrace picture-naming task; clinician-reported study forms	Wordrace picture-naming task; clinician-reported study forms	Fish Story narrative task; clinician-reported study forms	Semi-structured interviews; background questionnaire
Main findings	Frequent preoperative word-finding difficulties, mainly slowed speed; non-responses and semantic substitutions most frequent; higher risk associated with tumours in the right hemisphere or brainstem	Postoperative word-finding speed below age-specific norms; no group-level change but individual variability; fourth-ventricle tumour location associated with postoperative decline	Lower story content, shorter utterances, more grammatical errors, and slower speech rate compared to children with TD; no group-level change; postoperative decline was associated with MSD	Children described communication in relation to inclusion and exclusion, expressing needs, setting boundaries, managing energy, and maintaining a sense of self

PFT: posterior fossa tumour; TD: typical development; PFS: posterior fossa syndrome; MSD: motor speech disorder.

BACKGROUND

“Words is oh such a twitch-tickling problem to me all my life. So, you must simply try to be patient and stop squibbling. As I am telling you before, I know exactly what words I am wanting to say, but somehow or other they is always getting squiff-squiddled around.”

Roald Dahl (2, p. 46)

Words can be precise, playful, and persuasive. They can build relationships, shape identity, and make thoughts shareable. Yet, as described by Roald Dahl’s Big Friendly Giant (BFG), words can also be difficult to find and express. For children diagnosed with and treated for posterior fossa tumour (PFT), “*the wording*”, speech and language, can be disrupted (3, 4). However, detailed knowledge remains limited regarding speech and language abilities in children with PFT, how outcomes vary between children, and how communication is experienced in everyday life. These are the questions addressed in the studies included in this thesis.

Considering speech, language, and communication in children with PFT requires moving between several points of entry. The background chapter begins by introducing children diagnosed with PFT before turning to the cerebellum and cerebellar networks as one basis for understanding why these functions may be vulnerable. It then addresses speech, language, and communication development, followed by what is currently known about speech, language, and communication difficulties in children with PFT. Finally, the International Classification of Functioning, Disability, and Health (ICF) framework is introduced as a way of considering the linguistic and communicative findings in relation to body functions, activity, participation, environmental factors, and personal factors, thereby placing them within a broader functional context (5).

Children with posterior fossa tumour

Last week, Adam was supposed to start preschool. Instead, he lies in a hospital bed after surgery for a posterior fossa tumour. Only days earlier, he was looking forward to football, the schoolyard, and playing with his friends. Now that world seems far away. Sitting up takes support. Moving from his bed to a chair requires help. His balance is poor, his movements shaky, and even a small gesture, a thumbs-up for yes or a thumbs-down for no, may be too difficult. He tries to speak, but no words come out. He cannot ask for help, say no, explain that something hurts, or tell others what he wants. A look, a sign, tears, laughter, anger, or withdrawal may be the only expressions available, and they may be difficult to interpret.

Adam's case illustrates one possible early postoperative situation for a child following PFT surgery. It does not represent all children with this diagnosis, but shows a severe postoperative condition in which speech, language, and communication are affected. This thesis addresses specific language and communication abilities in children with PFT, including word-finding and narrative abilities before and after surgery, as well as children's experiences of communication after surgery.

Posterior fossa tumour in childhood

To place the vignette and the studies included in this thesis in context, it is first necessary to introduce children diagnosed with PFT. Among children diagnosed with brain tumours, the posterior fossa is one of the most common tumour locations. This region is located in the infratentorial compartment of the skull and contains the cerebellum, brainstem, and fourth ventricle (Figure 1). The cerebellum consists of two hemispheres connected by the vermis.

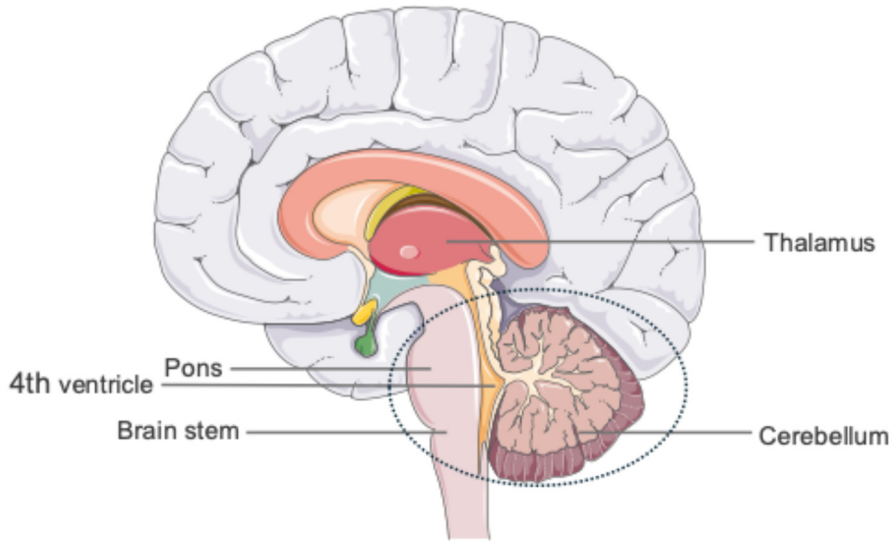


Figure 1. Illustration of the brain. The illustration shows the anatomical relationship between the cerebellum, pons, fourth ventricle, and thalamus. The dotted oval indicates the approximate posterior fossa region. Image(s) provided by Servier Medical Art (<https://smart.servier.com>), licensed under CC BY 4.0 (<https://creativecommons.org/licenses/by/4.0/>). Labels modified by the author.

Children diagnosed with central nervous system (CNS) tumours represent one of the major groups in paediatric oncology. In the Nordic countries, several other European countries, Australia, and the United States, between 3.9 and 5.7 children per 100,000 are reported to be diagnosed with CNS tumours each year, compared with a global incidence of 2.8 per 100,000 children per year (6, 7). Population-based data from Sweden show that nearly half of childhood CNS tumours are located in the posterior fossa region, in line with previous reports showing that this is one of the most common tumour locations among children with CNS tumours (7, 8).

Children with PFT are treated with surgical resection, sometimes combined with radiotherapy and/or chemotherapy. Prognosis varies between children depending on tumour characteristics, disease extent, and treatment response (8). Advances in diagnostics, treatment, supportive care, and follow-up have been associated with improved survival. In Sweden, five-year overall survival for children with CNS tumours increased from 75% to 82% between 1984 and 2021 (7). However, PFT remains a serious diagnosis. Mortality still occurs, and many children experience neurological, cognitive, physical, and speech-, language-, and communication-related consequences of the tumour and its treatment (9-11).

For the child and family, diagnosis and treatment may mean an abrupt shift from everyday routines to hospitalisation, surgery, oncological treatment, rehabilitation, and uncertainty about survival, recovery, and future treatment. For the child, this

period may involve pain, nausea, eating difficulties, fatigue, reduced physical capacity, and dependence on adults for everyday activities. It may also involve fear and uncertainty related to living with a serious illness, including worries about progression or recurrence and what renewed treatment or uncertain outcomes might mean for the family (12, 13). These worries and experiences are situated within the child's family context, where parents and siblings are also affected by the diagnosis, hospitalisation, changed routines, and emotional strain. Siblings may experience worry, loneliness, changes in family attention, and disruptions across home, hospital, and school contexts (14).

Treatment and recovery may involve extended hospitalisation and substantial school absence. Returning to everyday life can be complicated by fatigue, cognitive and executive difficulties, social challenges, and participation restrictions, affecting school life, family routines, peer relationships, and leisure activities (15, 16). Meanwhile, childhood continues: classmates continue going to school, relationships continue to develop, and language and communication abilities continue to expand through everyday learning, interaction, and play. Within this ongoing childhood context, children with PFT may experience speech and language difficulties (3, 4). Yet current knowledge remains limited regarding these difficulties and children's communication in everyday life.

In this thesis, the term children with PFT is used to refer to children diagnosed with posterior fossa tumour, regardless of treatment stage. This wording is used because the included studies involve children assessed before and/or after surgery. When the postoperative phase is specifically intended, the phrase following PFT surgery is used.

Posterior fossa syndrome

The early postoperative course described in the opening vignette illustrates one severe complication that may follow surgery for PFT: posterior fossa syndrome (PFS), also known as cerebellar mutism syndrome (CMS). Although surgery is central to treatment and recovery, it also carries a risk of postoperative complications for the child, and PFS is among the most severe. Reported incidence varies considerably across studies, from approximately 8% to 39%, depending on study design, population, and diagnostic criteria. Large prospective studies suggest that around one quarter of children develop PFS-related symptoms after surgery (17-19). According to the consensus definition of postoperative paediatric CMS, the syndrome is characterised by delayed-onset mutism or markedly reduced speech, accompanied by emotional lability, following surgery for tumours of the cerebellum or fourth ventricle in children (20). Additional common features include hypotonia and oropharyngeal dysfunction or dysphagia, and the syndrome may also involve cerebellar motor signs, cognitive-affective features, and brainstem dysfunction (20). Children may initially be able to speak after surgery, before mutism or severely

reduced speech emerges. A systematic review reported onset from immediately after surgery to 15 days postoperatively, although onset was generally within the first postoperative week (21). The period of mutism or severely reduced speech also varied considerably, with a median duration of 25.5 days and reported durations ranging from 1 to 912.5 days (21).

Speech usually returns gradually, but recovery may be prolonged. After speech is regained, many children continue to have speech and language difficulties (3, 4), as well as cognitive (22, 23), affective (9), motor (24), or other neurological difficulties (9, 25), which may persist for months or years after surgery and have implications for quality of life (26). For the child, persistent difficulties after PFS may continue to make communication demanding in everyday situations, even when speech has returned. Long-term challenges after PFS have also been described from the perspective of those affected, including challenges related to communication, social and educational rehabilitation, and support in structuring everyday life (27).

The terminology used for PFS and CMS has been inconsistent. Different terms have been used to describe different parts of the clinical picture, including speech, behaviour, motor symptoms, cognitive-affective features, and broader neurological difficulties, rather than one clearly defined condition (20, 28). To address this variability, a consensus definition of cerebellar mutism syndrome (CMS) was developed through a Delphi process led by the Posterior Fossa Society, an international multidisciplinary group of clinicians and researchers working with children with PFS/CMS (20). Although this definition has contributed to a more standardised description of the syndrome, variation in how CMS is defined and applied across studies remains (29). Terminology was further discussed at the 3rd Global Meeting on Posterior Fossa Syndrome, held in Copenhagen in April 2026 (30). The meeting was held within the context of the Posterior Fossa Society. Following these discussions, it was agreed that posterior fossa syndrome (PFS) should be used to refer to the postoperative condition, including neurological, cognitive, behavioural, and language difficulties. A new Delphi process has also been initiated to develop an updated consensus definition. In this thesis, PFS is therefore used to refer to this postoperative condition, whereas CMS is retained in the individual papers, where it reflects the terminology used at the time.

Beyond PFS, a broader question remains: why may speech, language, and communication be vulnerable in children with tumours in the posterior fossa? The next section therefore introduces the cerebellum and cerebellar networks as one basis for considering this vulnerability.

Cerebellum and cerebellar networks

The cerebellum has historically been associated with motor coordination. However, evidence from anatomical connectivity studies (31, 32), neuroimaging studies (33, 34), and clinical studies in children with cerebellar lesions and posterior fossa tumours (9, 23) has shown that the cerebellum is also involved in cognitive and language functions (35). The cerebellum has been proposed to contribute to functions related to timing (36), prediction and preparation (37), and modulation of motor, cognitive, and language-related processes (38). In the motor domain, cerebellar dysfunction may affect the scaling and coordination of movement, a disturbance referred to as dysmetria (35). Building on this concept, Schmahmann proposed that similar principles may extend beyond motor control, suggesting that the speed, capacity, consistency, and appropriateness of mental and cognitive processes may also be affected, a phenomenon described as dysmetria of thought (35).

Cerebro-cerebellar networks

Communication between the cerebellum and cerebral cortical regions occurs through reciprocal cerebro-cerebellar circuits, with descending pathways from the cerebral cortex to the cerebellum and ascending pathways from the cerebellum back to cortical regions (32, 39). These circuits provide a structural basis for interaction between cortical and cerebellar regions and include pathways associated with language-related networks (40).

The main descending pathway is the cortico-ponto-cerebellar pathway (CPC), through which signals are transmitted from cerebral cortical regions to the cerebellum via the pons and middle cerebellar peduncle. The main ascending pathway is the dentato-thalamo-cortical pathway (DTCP), which carries signals from the cerebellum back to cerebral cortical regions. Together, these pathways form part of a language-related cerebro-cerebellar network proposed to support language processes (39, 40).

These cerebro-cerebellar circuits are organised topographically, meaning that distinct functions are associated with specific cerebellar regions. Functional imaging studies show that motor, cognitive, and language-related tasks engage partly distinct cerebellar regions (33, 34). The organisation is predominantly contralateral, meaning that the right cerebellar hemisphere is linked to left-hemisphere cortical regions involved in language processing (39, 40). This organisation is relevant for considering why PFT and its treatment may affect language-related functions in children.

Cerebro-cerebellar networks in children

Evidence from lesion, neuroimaging, and connectivity studies has demonstrated cerebellar involvement in language processing and related cognitive functions (41, 42). Similar evidence has also implicated the posterior cerebellum in social cognition, including mentalising and the understanding of others' actions and mental states (43). However, much of this evidence derives from studies in adults. In children, cerebro-cerebellar networks are still developing and undergoing organisation and specialisation. Diffusion imaging studies have shown that cerebello-cerebral structural connections can be identified during the preterm-to-term period and show signs of maturation during this early phase of development (44). Resting-state fMRI studies further suggest that functional cerebro-cerebellar connectivity is present in infancy, mainly within sensorimotor networks, and becomes broader during childhood, involving sensorimotor, executive control, and default mode networks (45).

At the same time, the development of language-related cerebro-cerebellar networks during childhood remains less well understood. This is important when considering children with PFT, because cerebellar disruption may occur before these networks are fully mature. In children who develop PFS, incomplete maturation of cerebellar pathways has been suggested to increase vulnerability to the effects of cerebellar disruption (46). Thus, speech, language, and communication difficulties in children with PFT need to be considered in relation to ongoing development and the vulnerability of developing cerebro-cerebellar networks.

The cerebellum and its networks provide a neurobiological basis for understanding why speech, language, and communication may be affected in children with PFT. The following section considers speech, language, and communication from a developmental perspective and in relation to current knowledge about these abilities in children with PFT.

Speech, language, and communication in children with PFT: development and difficulties

Speech, language, and communication develop across childhood, adolescence, and adulthood (47, 48). Speech refers to the motor processes involved in producing spoken language through the coordinated control of respiration, phonation, resonance, articulation, and prosody (49). Language comprises interrelated abilities including phonology, morphology, syntax, semantics, and pragmatics (48). Communication involves both understanding and expression and enables children to share meaning, participate in everyday situations, and develop social relationships (50-52). Speech, language, and communication develop in interaction

with other people and within the contexts in which children participate in everyday life (50, 51).

In children with PFT, these abilities may be affected before and after surgery. Previous research has primarily focused on children who develop PFS, but speech and language difficulties may also occur in children who do not develop PFS, and outcomes vary between children (23, 53). From a speech-language therapist's perspective, detailed knowledge is still limited regarding how different speech, language, and communication abilities are affected and to what extent. Although language difficulties have been reported, findings are often based on neuropsychological assessments rather than detailed analyses of language. Language abilities at the time of diagnosis remain poorly described, as most studies focus on outcomes after surgery. Consequently, patterns of perioperative change are still not well understood. In addition, most research has focused on clinical or test-based outcomes, while children's own perspectives on communication have received less attention.

Speech

Speech development involves increasing coordination of the motor processes required for intelligible speech production. Across childhood, children gradually refine respiratory, laryngeal, velopharyngeal, and articulatory control, supporting clearer speech, more stable speech rate, and more precise articulation (54). In children with PFT, these processes are relevant because the tumour and surgery may affect the planning, programming, control, or execution of movements required for speech production.

In this thesis, speech is primarily considered in relation to motor speech difficulties, which mainly relate to body functions. In acquired neurological conditions, these difficulties include dysarthria and apraxia of speech. Dysarthria results from disturbances in neuromuscular control and is characterised by abnormalities in strength, speed, range, steadiness, tone, or accuracy of speech movements. These disturbances may affect articulation, rate, prosody, and voice quality (49). Apraxia of speech reflects impaired speech motor planning and programming and is characterised by disrupted sequencing and inconsistent speech errors in the absence of primary neuromuscular weakness (49, 55). Speech and language are analytically distinct but interact in spoken production. Although separable at a diagnostic level, speech and language disorders frequently co-occur and may both influence spoken language performance (56). The interaction between motor speech and language processes is complex, and observable characteristics of production may reflect contributions from both.

Motor speech disorders have been reported in children following PFT surgery, including reduced speech rate, ataxic features, monotony, and dysarthric

characteristics (4, 57). Motor speech difficulties may persist beyond the acute postoperative phase and are commonly classified as dysarthria. Apraxia of speech has also been reported following PFT surgery; however, it remains less investigated and more sparsely described in the literature (58). Clinically, distinguishing between dysarthria and apraxia of speech requires a dynamic motor speech assessment. Such assessment typically includes tasks examining oral motor function, respiration, phonation, resonance, articulation, prosody, speech rate, consistency of errors, sequencing of syllables and words, and the child's response to cueing and repeated practice (59).

Language

Language development involves the gradual expansion and organisation of linguistic knowledge across childhood and adolescence, including lexical, grammatical, and discourse-level abilities (47, 48). When difficulties in the acquisition or use of language are persistent and interfere with communication and participation, they may be described as a language disorder. According to the CATALISE consensus, the term language disorder is used when language difficulties are severe, persistent, and associated with functional impairment and a poor prognosis (60). When persistent language difficulties occur in the absence of a known biomedical condition, the recommended term is developmental language disorder (DLD). DLD reflects atypical developmental progression and may involve difficulties across multiple language abilities (60). Language disorders may also arise following a period of typical development as a consequence of injury to the CNS. In such cases, language impairment emerges after previously typical language acquisition and is described as an acquired language disorder or childhood-acquired aphasia. In childhood, such disorders may occur in association with a range of neurological conditions, including traumatic brain injury, stroke, brain tumours, and other neurological conditions. The nature and severity of language difficulties may vary depending on lesion characteristics and the child's developmental stage at the time of injury (61-64).

In children with PFT, language may be affected in different ways before and after surgery. In this thesis, language is examined specifically through word-finding and narrative abilities, including both narrative microstructure and macrostructure.

Lexicon and word finding

Lexical development begins early through children's participation in shared communicative situations, where words gradually become linked to objects, actions, and experiences through interaction with others (48). When hearing a novel word, the child must infer what the word refers to, and over time, word meanings become more differentiated and organised (65). With the onset of schooling, literacy further supports lexical growth, and vocabulary development becomes closely associated

with reading comprehension (66). Lexical development involves not only learning more words, but also becoming faster and more precise in finding and using words during communication. Word finding refers to the ability to access and produce the intended word from the mental lexicon accurately and efficiently during speech (67). As lexical representations become more specified and systematically organised, word access becomes more efficient, supporting more stable and precise word finding (65, 67). In this way, lexical development includes both vocabulary growth and increasingly efficient word finding. These lexical abilities mainly relate to body functions.

In this thesis, lexical aspects of language are considered through lexical diversity and word finding. Lexical diversity captures the range of different word types used within a language sample and provides one way of describing vocabulary use in narrative production (68). In assessment, word finding can be examined through tasks that require children to name familiar pictured objects, such as *apple*, *cow*, or *cake*. The speed and accuracy of naming in such tasks may provide information about how efficiently words can be accessed. Word finding is relevant beyond naming tasks. In children with word-finding difficulties, these challenges may have a clear and direct impact on everyday communication. When persistent, they may influence self-esteem, relationship building, educational attainment, and wider life chances (69).

Difficulties related to lexicon and word finding have been reported in children with PFT, although methods and findings vary across studies (3, 9, 11, 22, 23, 53, 70-72). Much of the evidence comes from neuropsychological assessments, where lexical abilities have been examined through naming, receptive or expressive vocabulary, and word generation (11, 70-72). In studies that included naming, this was often assessed with accuracy-based measures, for example the Boston Naming Test or similar confrontation-naming or picture-naming tasks (11, 23, 71-73), which may relate more closely to word knowledge than to word-finding ability and do not capture naming speed. This distinction is important because word finding involves both retrieving the correct word and doing so efficiently. Performance on naming tasks may reflect several underlying demands, including semantic and phonological processing, motor planning, motor execution, and general processing speed (58, 67, 74-76).

Reported findings have differed across studies. Some studies have reported difficulties on measures of naming, expressive vocabulary, verbal fluency, or related lexical tasks (11, 23, 71-73). Other studies have reported naming or language performance comparable to controls or norms, or only minor differences (77, 78). The variation across studies may reflect not only differences between children, but also differences in design, comparison groups, timing of assessment, tumour type, treatment history, and how specifically lexical outcomes were analysed.

More detailed neurolinguistic studies have added information about the nature of lexical difficulties after PFT surgery. A neurolinguistic study analysing spontaneous language in children after cerebellar tumour surgery reported reduced lexical diversity in some children at long-term follow-up, indicating a more restricted range of vocabulary in spontaneous language (3). Ahmed et al. (2026) examined word finding in a cohort partly overlapping with the children included in Studies 1 and 2 of this thesis. They found significantly slower word-finding performance after surgery while naming accuracy remained stable. Their analysis further showed that different target-word properties were related to different aspects of performance. Naming speed was associated with a lexical-semantic component, comprising word frequency and the number of semantic features, suggesting that lexical and semantic resources contributed to how efficiently words were retrieved. Naming accuracy was associated with a lexical component, comprising word frequency, familiarity, and age of acquisition, indicating that words that are more frequent, more familiar, and acquired earlier were more likely to be retrieved correctly. However, the findings should be interpreted cautiously, as the study did not include a control group or normative data against which performance could be compared (79).

Taken together, previous studies indicate that lexical and word-finding difficulties occur in children with PFT, and more recent neurolinguistic work has begun to clarify what these difficulties may involve. However, the available evidence still leaves several central questions unresolved. Because many earlier studies used accuracy-based naming or broader neuropsychological language measures, less is known about word-finding speed and about children who may retrieve the correct word but do so slowly. Because most studies have focused on postoperative or long-term outcomes, word-finding ability before surgery and, consequently, the possible contribution of the tumour itself remain insufficiently understood. Furthermore, limited evidence is available on how speed and accuracy relate to age-specific expectations, how word-finding performance changes from before to after surgery, and how such difficulties relate to factors such as age, sex, PFS, dysarthria, hydrocephalus, and tumour characteristics. Such knowledge is needed to support the identification and follow-up of children with word-finding difficulties, as these difficulties may affect their everyday communication, participation, and ability to express themselves in interactions with others (69).

Narrative microstructure

Narrative microstructure concerns the linguistic form of narrative production, including utterance length, grammatical structure, syntactic complexity, and grammatical accuracy. As children begin to combine words into multiword utterances, sensitivity to grammatical structure gradually develops (48). During the preschool years, children increasingly acquire and integrate the inflectional systems of their language, including tense, agreement, and plurality. Overgeneralisations such as *goed* instead of *went* are common and decrease as regular and irregular

forms become differentiated. With increasing linguistic experience, children begin to combine clauses using conjunctions such as *because* and *when*, supporting more precise expression of temporal and causal relations (48, 80). Throughout the school years, utterances become longer and clause structures more complex (47). This development is reflected in increased utterance length, greater use of subordination and more complex clause structures, as well as higher grammatical accuracy. In narrative analysis, these aspects are commonly examined as components of narrative microstructure (81). In this thesis, narrative microstructure mainly relates to body functions and is examined through language use in narrative production. Expressive grammatical difficulties may be relevant for communication in everyday life. In young children with presumed DLD, better expressive grammatical skills have been associated with better communicative participation, which in turn was related to higher social-emotional functioning and quality of life (82).

Difficulties related to grammatical production and narrative microstructure have been described in children following PFT surgery. Riva and Giorgi included MLU derived from a visually supported story and reported reduced MLU relative to normative expectations in some children after PFT surgery (70). They also clinically described telegraphic language with omitted grammatical elements and uninflected verbs, resembling agrammatism, in children whose postoperative mutism evolved into language disorders. These findings suggest that grammatical production and sentence formulation may be affected after PFT surgery, but the described grammatical features were not analysed in detail or compared with a control group. Docking et al. examined narrative microstructure in children treated for brain tumours, including mean length of utterance and grammatical accuracy, although not specifically in children with PFT (83). While no significant group differences were found compared with age-matched peers, variability was observed within the tumour group, and several children performed below the comparison group on these measures.

More recent neurolinguistic work has provided more detailed insight into morphosyntactic aspects of language after PFT surgery. Svaldi et al. analysed spontaneous language at long-term follow-up after PFT surgery (3). Relevant to morphosyntax, their analyses included MLU, grammatical accuracy, finite verb use, verb transitivity, and verb regularity. Morphosyntactic difficulties were reported in several patients, including reduced grammatical accuracy and shorter utterances, reflected in lower MLU. Among children with PFS, the clearest difficulties concerned grammatical accuracy and MLU. Building on this work, Svaldi et al. conducted an error analysis of the same participant group (53). They analysed morphosyntactic errors, including noun morphology errors, verb inflection errors, sentence structure errors, and errors in function words. Verb inflection errors were the most common morphosyntactic error type, particularly in the PFS group. These errors concerned how verbs were grammatically formed, for example in tense, agreement, or conjugation.

Despite these findings, several questions remain. The available findings are mainly based on postoperative or long-term follow-up data, small samples, studies not specific to PFT, or broader clinical descriptions without detailed linguistic analysis. It therefore remains unclear how narrative microstructure presents in children with PFT before and after surgery, including whether utterance length, grammatical accuracy, and syntactic complexity are affected in relation to children with TD. It is also unclear whether the morphosyntactic patterns described in previous studies apply to Swedish-speaking children with PFT. This is important because morphosyntactic structures and areas of vulnerability differ between languages, and findings from one language cannot be assumed to apply in the same way to children speaking another language (84, 85). Detailed analysis of narrative microstructure in Swedish-speaking children with PFT is therefore needed to examine utterance length, grammatical accuracy, and syntactic complexity in relation to children with TD assessed in the same language, and to describe how performance varies between children and across the perioperative phase.

Narrative macrostructure

Narrative macrostructure concerns the organisation of story content, including how events, goals, problems, attempts, and outcomes are included and connected (47, 48). Beyond producing words and sentences, children gradually learn to connect events into coherent discourse. Whereas early language use often focuses on naming objects or describing single events, narrative requires the integration of events across time and the coordination of grammatical and lexical resources to create coherence (48). In early preschool narratives, children often describe events as loosely connected actions, with limited marking of causal or motivational relations (48). For example, a child may recount parts of a story as: *The boy feeds the fish. His mum gives him money. He goes to the shop*, without marking why these events are related. As children gain greater linguistic experience, they increasingly connect events through temporal and causal relations. Instead of listing actions, they may say: *His mum gives him money so he can buy a new fish*, linking events through goals and consequences.

Over time, narratives become more coherent and organised around causal chains, problems, and resolutions, with more stable reference and more consistent use of connectors such as *because*, *when*, and *so* (48, 86). During later childhood and adolescence, children also develop more advanced discourse abilities requiring explicit reasoning, justification, and increasingly complex syntactic and lexical structures. Narrative discourse involves the coordination of multiple language and cognitive processes and plays a central role in how children organise experiences, share meaning with others, and participate in academic and social interaction (87-89). Within narrative analysis, these aspects are considered components of narrative macrostructure. They primarily relate to activity, as they concern how children organise and convey meaning in a narrative task.

Narrative discourse has not been examined in children with PFT specifically, and existing evidence is limited to children treated for brain tumours (83). Docking and colleagues found no significant group differences between children treated for brain tumours and age- and sex-matched peers on overall narrative macrostructure scores. However, individual-level comparisons showed variability within the tumour group: approximately half of the children treated for brain tumours had lower total macrostructure scores than their matched controls (83). These findings suggest that group-level comparisons may obscure individual differences and that children treated for brain tumours should not be considered a homogeneous group. Therefore, little is known about narrative discourse specifically in children with PFT. This knowledge gap is clinically relevant because narrative abilities are used frequently in everyday situations, both in social interactions and in school, where children are expected to retell events, explain experiences, and get their point across to others. Difficulties with narrative macrostructure may therefore have implications beyond the narrative task itself, as they may affect how children communicate experiences and participate in academic and social contexts (89, 90).

Communication

Pragmatic development concerns how children learn to use language in social interaction (48, 51). With the onset of spoken language, children increasingly use language to influence others, regulate interaction, and share experiences. During the preschool years, pragmatic abilities develop alongside structural language growth, including the ability to maintain conversational turns, repair misunderstandings, and adapt utterances to the listener's knowledge and perspective (48). As communicative contexts expand, children must increasingly coordinate multiple speakers, interpret intentions, and adjust language to different settings, interlocutors, and communicative purposes (91). Pragmatic development thus reflects how children gradually coordinate linguistic knowledge and social understanding across communicative situations.

When difficulties affect how children understand, express, or use verbal and non-verbal communication in everyday situations, they may be described as communication disorders. In acquired neurological conditions, such difficulties may be related to underlying cognitive processes and are often described as cognitive-communication disorder (92, 93). Cognitive-communication disorder refers to communication difficulties arising from impairments in attention, memory, and executive functions rather than primary linguistic deficits (94, 95). These difficulties may affect both verbal and non-verbal communication and may be reflected in reduced coherence, difficulties with inference, and a reduced ability to adapt communication to different situations and listeners. As a result, communication may become less efficient, less informative, and more difficult to follow in everyday situations, which may affect social interaction and participation.

Pragmatic and communicative abilities following PFT surgery have received limited attention. Detailed analyses of pragmatic language use, including cohesion, reference, and listener-oriented organisation, have not been systematically examined in children treated for PFT. Pragmatic and communicative abilities may nevertheless be vulnerable following PFT surgery, particularly in children who develop PFS. Neuropsychological and neurobehavioural changes associated with PFS include difficulties with attention, executive functions, and regulation (9, 22, 23). Such difficulties may affect conversational participation, including the ability to initiate, maintain, and adapt language to different communicative contexts (96).

Communication difficulties also need to be understood in relation to the everyday situations in which children communicate. In everyday life, communication is used not only to exchange information, but also to express needs and wants, build social closeness, manage social situations, and take part in activities with others (50-52, 97). In children and adolescents with DLD, communication and language difficulties have been associated with social uncertainty, peer problems, bullying, social exclusion, and emotional difficulties (98-101). Studies including children's own perspectives further show that such difficulties may be described in relation to specific people, situations, and responses from others, rather than only as language symptoms (102, 103). Similar relational and contextual aspects have been described in young people with acquired brain injury (ABI), where communication changes have been linked to frustration, social withdrawal, efforts to rebuild confidence, identity, participation, and belonging (104, 105).

In children treated for brain tumours, social withdrawal, difficulties maintaining friendships, and challenges participating in group activities have also been reported (106, 107). Young adults who experienced PFS during childhood have described persistent social and communicative challenges, including losing friendships, struggling to form new ones, and feeling socially isolated, but these reports were retrospective and limited to individuals who had experienced PFS (27). Thus, although previous research indicates that speech, language, and communication difficulties may have consequences for social interaction and participation, children's own current descriptions of communication in everyday life following PFT surgery have not been described. Within the ICF framework, children's accounts can contribute to an understanding of communication in relation to activity, participation, and environmental and personal factors (5). The ICF framework is therefore introduced in the following section.

The International Classification of Functioning, Disability, and Health

The International Classification of Functioning, Disability, and Health (ICF) describes functioning and disability in relation to a health condition by considering interactions among its components, including body structures, body functions, activity, participation, and environmental and personal factors (5). Body structures refer to anatomical parts of the body, body functions refer to physiological and mental functions, activity refers to the execution of tasks and actions, and participation refers to involvement in life situations. Environmental factors refer to the physical, social, and attitudinal environment in which people live and conduct their lives, whereas personal factors refer to the particular background of an individual's life and living. These components are viewed as interrelated and as influencing one another, as illustrated in Figure 2. Everyday life has been defined as the mundane routines and contexts that are often taken for granted (108). In this thesis, children's everyday life is used to refer to the ordinary situations in which children communicate and participate, including home, school, leisure activities, and interactions with family, peers, and adults.

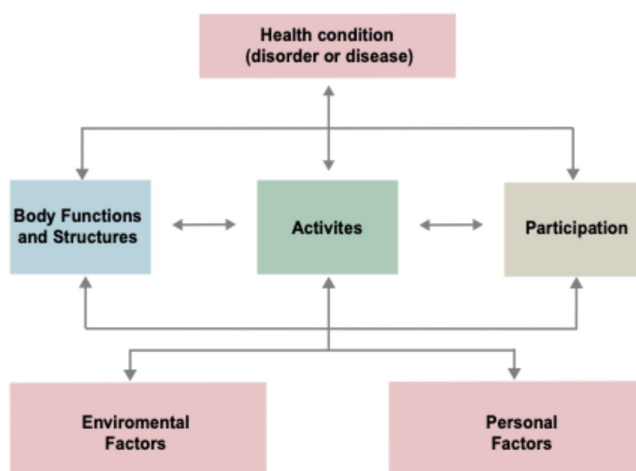


Figure 2. Illustration of the International Classification of Functioning, Disability, and Health (ICF). The model shows the interaction between body structures, body functions, activity, participation, environmental factors, personal factors, and health condition (5). Adapted with permission from the World Health Organization.

Within speech and language therapy, there has been increasing emphasis on applying this broader perspective to understand speech and language difficulties in relation to children's everyday functioning (5, 109-111). The ICF is an established

and useful framework in rehabilitation and habilitation services, where care often concerns how the consequences of illness or injury affect functioning in everyday life (112, 113). Studies have linked speech and language difficulties to children's social interaction, peer relationships, emotional well-being, and participation in school and everyday activities (98, 114-116). These associations should be understood as nonlinear and bidirectional (117). Difficulties with speech and language may restrict participation and relationships, while limited opportunities for interaction and language use may, in turn, affect the development or maintenance of speech and language functions. Environmental support, such as adapted communication, time to respond, and informed adults and peers, may therefore influence children's opportunities for participation, how speech, language, and communication abilities are used and supported, and the extent to which difficulties become visible in everyday life (117).

In children with PFT, previous research has often focused on body structures and body functions, while less attention has been given to activity, participation, and environmental and personal factors. The ICF is therefore used in this thesis as a conceptual framework for relating and discussing findings from the four studies. This allows speech and language difficulties to be considered not only as test outcomes, but also in relation to children's communicative functioning. Word finding and narrative microstructure are primarily considered in relation to body functions, as the ICF classifies language as a mental function involving the recognition and use of signs, symbols, and other components of language, and fluency and rhythm of speech as functions involving the flow, tempo, and speed of speech (5). Narrative macrostructure is considered in relation to activity because it concerns the child's execution of a communicative task, namely organising and conveying story content. Children's experiences of communication in everyday life are considered in relation to participation and environmental and personal factors because they concern involvement in everyday situations and the social, communicative, and personal conditions that shape such involvement. Although activity and participation are shown as separate components in the ICF model, they are closely related, and the distinction between them requires interpretation when the framework is applied (118). In the present work, activity refers to what the child does in communicative tasks, whereas participation refers to the child's involvement in everyday life. For children, communicative functioning must also be understood developmentally, because speech, language, and communication are still developing and are shaped through interaction with others and within the contexts where children participate and communicate (50).

Rationale

Despite increasing recognition that children with PFT may experience speech and language difficulties and challenges in everyday communication, important knowledge gaps remain. These concern language abilities before and after surgery, variation between children, and children's own experiences of communication. This is problematic because diagnosis, treatment, and recovery occur during childhood and adolescence, while speech, language, and communication are still developing. These abilities are essential for understanding information, expressing needs, telling others what has happened, and taking part in everyday contexts such as care, home, school, and peer relationships.

Research is therefore needed to describe language abilities in greater detail across the perioperative phase. This includes not only whether difficulties are present, but also which abilities are affected, how performance varies between children, and how findings before surgery relate to functioning after surgery. Such knowledge is important for understanding the range and nature of difficulties in this group, for identifying less pronounced difficulties that may otherwise be overlooked, and for interpreting postoperative performance in relation to the child's own preoperative level.

However, detailed assessment of language abilities alone cannot show how communication is used, supported, constrained, or experienced in everyday life, or how it relates to activity, participation, and environmental and personal factors. Children's own experiences of communication following PFT surgery therefore also need to be explored. Without this knowledge, there is a risk that support does not address the communicative situations that are most relevant to children themselves.

Together, these gaps indicate a need for knowledge that connects detailed analysis of language abilities before and after PFT surgery with children's everyday communication and participation. The present thesis addresses these gaps by investigating word-finding ability and narrative microstructure and macrostructure before and after PFT surgery, and by describing children's experiences of communication in everyday life.

“The question is,” said Alice, “whether you can make words mean so many different things.”

Lewis Carroll (119, p. 64)

Alice’s question addresses the complexity of words and their meaning. The studies included in this thesis concern how words are found, how narratives are produced, and how communication is experienced in everyday life by children with posterior fossa tumours. The overarching aims of this thesis were:

- 1) To investigate word-finding ability and narrative ability, including macro- and microstructural performance, before and 1–4 weeks after surgery in children with posterior fossa tumours.
- 2) To describe children’s experiences of communication in everyday life following posterior fossa tumour surgery.

Specific aims for each paper

Paper 1

- i. To investigate the occurrence of preoperative word-finding difficulties in children with posterior fossa tumours.
- ii. To investigate associations between preoperative word-finding difficulties and demographic and medical characteristics in children with posterior fossa tumours.
- iii. To investigate whether word-finding errors observed in children with posterior fossa tumours resembled or diverged from error types known from other child populations with word-finding difficulties and/or from typical development.

Paper 2

- i. To investigate whether children with posterior fossa tumours exhibit postoperative word-finding difficulties.

- ii. To investigate changes in word-finding performance from pre- to postoperative testing in children with posterior fossa tumours.
- iii. To investigate factors affecting postoperative word-finding ability in children with posterior fossa tumours.

Paper 3

- i. To investigate narrative macrostructure and microstructure in children with posterior fossa tumours, assessed pre- and postoperatively, compared with children with typical development.
- ii. To investigate change in narrative macrostructure and microstructure between pre- and postoperative assessments in children with posterior fossa tumours.
- iii. To investigate change in narrative macrostructure and microstructure between pre- and postoperative assessments in children with posterior fossa tumours in relation to the presence of posterior fossa syndrome or motor speech disorder.

Paper 4

- i. To describe children's experiences of communication in everyday life following posterior fossa tumour surgery.

METHODS

“When I use a word,” Humpty Dumpty said, “it means just what I choose it to mean, neither more nor less.”

Lewis Carroll (120, p. 127)

Humpty Dumpty’s remark reflects the complexity of meaning and how words may be understood differently depending on context and perspective. The four studies included in this thesis used different methodological designs to investigate language and communication in children with PFT from complementary perspectives. In Studies 1–3, children completed structured language tasks that captured performance-based measures of word finding and narrative ability. In Study 4, children participated in interviews where they described their experiences of communication in everyday life following surgery. Taken together, the studies describe children’s language and communication both through assessment-based performance measures and through children’s experience-based accounts. Table 1 presents an overview of the study design, study cohorts, settings, participants, timepoints, and data collection for Studies 1–4.

Table 1. Overview of the study design, study cohorts/samples, recruitment settings, participants, timepoints, and data collection for Studies 1–4.

	Study 1	Study 2	Study 3	Study 4
Design	Cross-sectional observational study	Prospective observational cohort study	Prospective observational cohort study	Qualitative interview study
Study cohort	Nordic-European CMS study, European group	Nordic-European CMS study, European group	Nordic-European CMS study, Swedish group; Swedish comparison group with TD	Swedish interview sample
Recruitment settings	European paediatric oncology centres	European paediatric oncology centres	Swedish paediatric oncology centres and educational settings	Swedish paediatric oncology centres
Participants	Children with PFT, 5–17 years; n = 148	Children with PFT, 5–17 years; n = 184	Children with PFT, 5–17 years, n = 44; children with TD, 5–17 years, n = 118	Children following PFT surgery, 6–18 years; n = 10
Timepoint	Preoperative	Preoperative and 1–4 weeks postoperative	Preoperative and 1–4 weeks postoperative	≥1 year postoperatively
Data collection	Clinician-reported study forms; audio recordings of Wordrace	Clinician-reported study forms; audio recordings of Wordrace	Clinician-reported study forms; audio recordings of Fish Story	Audio recordings of semi-structured interviews; background questionnaire

CMS: cerebellar mutism syndrome; PFT: posterior fossa tumour; TD: typical development.

Design

Study 1 was a cross-sectional observational study. In a subgroup analysis, the word-finding performance of Swedish-speaking children was compared with Swedish age-specific Wordrace norms. Studies 2 and 3 were prospective observational cohort studies (121). Study 2 included a comparison with Swedish age-specific Wordrace norms and a comparison between pre- and postoperative assessments within the PFT cohort. Study 3 included a comparison with children with TD and a comparison between pre- and postoperative assessments within the PFT cohort. Study 4 was a qualitative interview study (122).

Ethical approvals

Data collection for the Nordic-European CMS study, which provided the clinical study data used in Studies 1–3, was approved by the relevant ethical review authorities in each participating country. The Swedish part of the Nordic-European CMS study was approved by the Regional Ethical Review Board in Stockholm (Ref. no. 2014/1352-31). Separate approvals were obtained from the Swedish Ethical Review Authority for the collection of data from children with TD in Study 3 (Ref. no. 2024-05489-01) and for the qualitative interview study in Study 4 (Ref. no. 2022-02670-01).

Study cohorts and recruitment settings

Studies 1 and 2 were based on the European cohort within the Nordic-European CMS study, a prospective, multicentre observational study investigating the incidence and severity of PFT and associated risk factors in children undergoing PFT surgery (123).

The Nordic-European CMS study was initiated in 2014 and enrolls children younger than 18 years undergoing surgical resection or open biopsy for PFT at participating paediatric oncology and neurosurgical centres across several European countries. The study was initially designed with an enrolment target of 500 children, but recruitment has continued and the target has subsequently been expanded to 2,000 children. The papers included in this thesis are based on data extracted at different stages of the ongoing study and on study-specific samples, depending on language, assessment type, and data availability. As of July 2026, 15 countries and 37 centres were participating, with 1,015 children enrolled, and enrolment and follow-up were ongoing.

Study 3 was based on the Swedish group within the Nordic-European CMS study and included a Swedish comparison group of children with TD recruited from educational settings. Children with PFT were recruited through Swedish paediatric oncology centres participating in the Nordic-European CMS study, whereas the comparison group with TD was recruited from schools and preschools in Sweden.

Study 4 was based on a Swedish qualitative interview sample and was independent of the Nordic-European CMS study. Children treated for PFT were recruited through Swedish paediatric oncology centres, where they received ongoing care or follow-up after tumour treatment.

Participants

The participants in each study are described below. For Studies 1–3, final study samples differed according to study-specific inclusion and exclusion criteria, data availability, and the timing of data extraction from the ongoing Nordic-European CMS study. Figure 3 presents the recruitment settings, selection procedures, and participants included in the analyses in Studies 1–4.

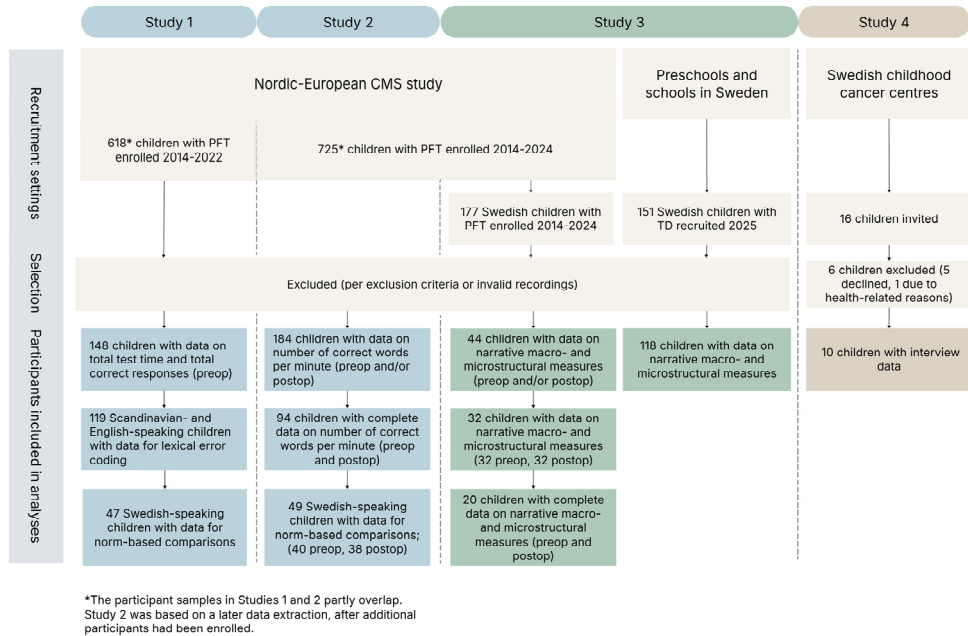


Figure 3. Overview of recruitment settings, selection, and participants included in the analyses in Studies 1–4. Preop, preoperative; postop, postoperative; PFT, posterior fossa tumour; TD, typical development.

Studies 1–2

Study 1 was based on children included in the Nordic-European CMS study between 2014 and 2022. Children aged 5 years or older with valid preoperative language data were eligible. To minimise potential confounding factors, multilingual children and children with additional neurological, speech, language, or developmental disorders, a history of tumour treatment, or previous tumour surgery were excluded. After applying these criteria, Study 1 comprised 148 children for the main analysis, with a median age of 9:8 years (Q1 7:2, Q3 12:9). The group included 70 girls (47%) and 78 boys (53%). The children spoke Swedish, Danish, Norwegian, English, Hungarian, Italian, Dutch, or Lithuanian. Additional analysis samples were used for

lexical error coding and norm-based comparisons, depending on language and data availability, as shown in Figure 3.

Study 2 included children with valid preoperative and/or postoperative language data. Because recruitment for the CMS study was ongoing, more children had been enrolled by the time data for Study 2 were extracted. Applying the same age and exclusion criteria, Study 2 comprised 184 children with a median age of 9:8 years (Q1 7:4, Q3 12:9), including 87 girls (47.3%) and 97 boys (52.7%). The children spoke Swedish, Danish, Norwegian, English, Hungarian, Italian, or Lithuanian.

In Studies 1 and 2, Swedish-speaking children were included in the norm-referenced subgroup because age-specific Wordrace norms were available only for Swedish. In Study 1, the lexical error analysis was restricted to Scandinavian languages and English, for which the researchers conducting the analysis had sufficient linguistic knowledge to classify alternative responses reliably.

Study 3

Study 3 included children from the Swedish part of the Nordic-European CMS study with valid narrative data preoperatively and/or postoperatively. Children aged 5 years or older were eligible. The same exclusion criteria as in Studies 1 and 2 were applied. Recordings with missing or invalid data due to procedural errors were excluded. After applying these criteria, the final PFT group comprised 44 children with a median age of 9:11 years (Q1 7:10, Q3 12:3), including 20 girls (45.5%) and 24 boys (54.5%).

The comparison group initially comprised 151 children aged 5 to 17 years, recruited between January and April 2025. Applying the same age and exclusion criteria, the final comparison group comprised 118 Swedish-speaking children with a median age of 9:11 years (Q1 8:1, Q3 12:1), including 67 girls (56.8%) and 51 boys (43.2%).

Study 4

Swedish-speaking children aged 5–18 years with speech, language, and/or communication difficulties who had undergone surgery for PFT were eligible for inclusion. At least one year had passed since the most recent surgery at the time of participation. This criterion was applied because the study concerned children's experiences of communication in everyday life after returning to school and other social contexts. Children relying exclusively on augmentative and alternative communication (AAC) were excluded, as were children with severe or profound intellectual disability. The latter was determined in accordance with the Nordic protocol for neuropsychological follow-up of children treated for brain tumour (124). Sixteen children were invited to participate in the study. Five declined to participate, and one child who had initially agreed was unable to take part due to health-related reasons. Ten children participated in the study, comprising eight girls and two boys. At the time of the interviews, the children were 6–18 years old, with

a median age of 13 years and 5 months. The time from surgery to interview ranged from one year and two months to ten years and two months, with a median of three years and six months, reflecting that Study 4 concerned everyday communication beyond the early postoperative period.

Data collection

Materials

Wordrace (Studies 1 and 2)

Word-finding ability was assessed using a picture-naming test called Wordrace. The test was designed for the Nordic-European CMS study by a Swedish speech-language therapist and a paediatrician specialising in neuro-oncology (125). The test material consisted of 25 coloured pictures, each representing a concrete noun. For each picture, a predefined target word was specified, together with accepted alternative responses. Performance was quantified based on total naming time in seconds and the number of correctly named items. Wordrace was normed only in Swedish, based on the performance of 299 Swedish children with TD, aged 5–15 years (126). In the normative sample, a negative correlation between age and naming speed was observed, such that older children completed the task faster, while most children produced no errors. Test-retest reliability, assessed using Spearman correlations, has been reported for both speed ($r = .894$) and accuracy ($r = .627$), although the accuracy measure showed limited variation due to ceiling effects (126).

Fish Story (Study 3)

Narrative ability was assessed using the Expression, Reception and Recall of Narrative Instrument (ERRNI), a standardised assessment of narrative ability (87). The ERRNI includes two picture-based stories and several assessment components. In Study 3, only the initial storytelling component of the Fish Story was used. The Fish Story consists of a sequence of 15 pictures from which the child independently generates a narrative. For the original British version, Bishop reported an internal consistency of $\alpha = .856$ for the Fish Story ideaspcore in initial storytelling (87). A Swedish version of the ERRNI was subsequently translated and evaluated in 87 Swedish-speaking six- and eight-year-old children with typical language development (127). The eight-year-old children obtained significantly higher scores than the six-year-old children on the ideaspcore for initial storytelling and MLUw.

Visual augmentative and alternative communication (AAC) materials (Study 4)

Visual AAC materials were used to support communication and participation during the interviews. The materials consisted of Wigit symbols (Wigit Symbols, Wigit Software Ltd, 2002–2025) presented on communication boards.

To support the children's understanding of their participation in the study and the interview situation, a visual information board was presented together with verbal information. The board conveyed key aspects of participation, including the voluntary nature of participation, what the interview would involve, how long it would last, that breaks could be taken, and that the interview could be stopped at any time. Information about audio recording, confidentiality, the option to use alternative ways of communicating, the absence of right or wrong answers, and the opportunity to ask questions was communicated using both visual symbols and spoken explanations. The same information board was used in all interviews.

The interview guide was supported by a separate overview board displaying the main interview topics. This visual overview helped the children understand what would be discussed and provided a shared structure that supported orientation and continuity throughout the interview. The overview board was identical across interviews.

Additional communication boards were available to support language and communication during the interviews. These included an emotion scale with symbols illustrating different degrees of positive and negative experiences, as well as theme-based and activity-based boards. The material was drawn from resources commonly used in paediatric habilitation and rehabilitation services in Region Skåne to support conversations about activity and participation in everyday life.

Procedure

For the children with PFT included in Studies 1–3, data were obtained from the prospective Nordic-European CMS study, in which clinical and medical information was registered in standardised study forms at predefined pre- and postoperative time points (123). Language assessments were administered at paediatric oncology centres by a physician, nurse, or speech-language therapist using written study instructions. The clinical and medical variables included age, sex, tumour location and histology, hydrocephalus, dysarthria, the presence of mutism and/or reduced speech, and, where present, their duration. Tumour location was reported as involvement of one or more posterior fossa sites, including the left cerebellar hemisphere, the right cerebellar hemisphere, the cerebellar vermis, the fourth ventricle, and/or the brainstem. Dysarthria was assessed and reported by clinicians in the study forms, but the assessment did not necessarily include a motor speech assessment by a speech-language therapist. Therefore, in this thesis, motor

speech disorder (MSD) is used as a broader term when referring to the children's motor speech difficulties, although Studies 1–3 refer specifically to dysarthria.

Language assessments were conducted before surgery and/or during the early postoperative period. Postoperative assessments were carried out 1–4 weeks after surgery, in accordance with the Nordic-European CMS study protocol, during postoperative hospital care. This interval captured the early postoperative phase, during which symptoms of PFS may emerge or begin to resolve, while allowing flexibility for clinical circumstances. Wordrace was used in Studies 1 and 2. During the word-finding assessments, pictures were presented one at a time either on screen or on paper, and the children were instructed to name the pictures as rapidly as possible. The examiner switched to the next picture once a picture was named, and no additional cues were provided if a child failed to name a picture. Fish Story was used in Study 3. In the narrative task, children were instructed to carefully examine the sequence of pictures before beginning their narrative. Minimal encouragement was provided by the examiner through neutral prompts such as *What happened next?* or *Tell me more*. All language assessments were audio-recorded, and the files were stored in the Nordic-European CMS database.

For the children with TD in Study 3, the Fish Story assessment was conducted in quiet rooms at the children's schools or preschools by a speech-language therapist or supervised speech-language therapy students. Demographic information about age, sex, multilingualism, and reported speech, language, or other diagnoses was collected through a parent- and/or child-reported questionnaire. The assessment followed the same written instructions as for the children with PFT. Children were instructed to carefully examine the sequence of pictures before beginning their narrative, and minimal encouragement was provided during the task through neutral prompts. All assessments were audio-recorded.

In Study 4, the children took part in a semi-structured interview conducted in person by the author either in the child's home or at the hospital, depending on the preferences of the child and family. The author was the first author of Paper 4 and a speech-language therapist with extensive clinical experience of working with children with speech, language, and/or communication difficulties. Demographic information was collected through a short questionnaire completed by the child and/or a parent. A pilot interview was conducted with one child to assess the clarity and appropriateness of the interview guide. The guide was judged to be suitable for the study and aligned with the study aims. The pilot interview was not included in the final analysis. Given the variation in the children's linguistic and communicative abilities, the interview guide was used flexibly and adapted to each child's communicative level within a child-centred approach (122). Interviews lasted between 25 and 78 minutes, with breaks offered as needed. Children were given the option to have a parent present during the interview. One adolescent chose to have a parent nearby, but the parent was not directly present in the interview situation and did not take part in the interview.

All children communicated verbally, but there was variation in how they expressed themselves during the interviews. The AAC materials described above were available throughout the interviews and were used flexibly by the interviewer, the child, or jointly. Children could combine spoken language with visual symbols, gestures, facial expressions, and signs to clarify, reinforce, or sometimes replace spoken language.

All interviews were audio-recorded. Observational field notes were taken in connection with the interviews to capture contextual and non-verbal aspects of communication. During transcription, extra-linguistic elements such as laughter, crying, and the use of signs or symbols were noted in the transcripts.

Analysis

Data preparation

Wordrace (Studies 1 and 2)

To identify word-finding difficulties, cut-off values for total test time and total correct responses were defined based on Swedish normative data from the Wordrace (126), previous studies, and clinical experience, as described in Paper 1. For word-finding speed, cut-offs were set at ≥ 70 seconds for children aged 5–9 years, ≥ 60 seconds for children aged 10–12 years, and ≥ 55 seconds for children aged 13–17 years. For accuracy, cut-offs were set at fewer than 23 correct responses for children aged 5–9 years and fewer than 24 correct responses for children aged 10–12 years and 13–17 years (Paper 1).

To reduce the influence of isolated self-corrections or incorrect responses on total naming time, a study-specific integrated outcome measure was derived (Paper 2). Correct words per minute (cWPM) was calculated as $(60 \times \text{number of correct words})$ divided by total test time in seconds. This measure was intended to combine naming speed and accuracy into a single rate-based score, analogous to words-correct-per-minute measures used in fluency assessment, but it has not been separately normed or validated for Wordrace. cWPM was used as the primary outcome in analyses of pre- to postoperative change. The original measures, total naming time and total number of correct responses, were retained for analyses based on Swedish age-specific norms, as no normative data were available for the integrated measure.

In addition to total test time and accuracy, lexical errors were analysed qualitatively in Study 1 to examine whether the word-finding errors seen in children with PFT resembled or diverged from error types known from other child populations with word-finding difficulties or from typical development. All responses deviating from the target word were classified into predefined error categories. Responses were first

coded as either no response, an aborted response, or an alternative response. Alternative responses were further categorised based on their lexical relationship to the target word, including semantically related substitutions and other non-target responses.

Fish Story (Study 3)

An initial rough transcription of the narrative recordings was generated using the automatic transcription software aTrain (128). All transcripts were then checked, corrected, and orthographically transcribed by the author in accordance with the Systematic Analysis of Language Transcripts (SALT) guidelines (81). The narratives were prepared and coded in three main steps: macrostructural manual coding, microstructural manual coding, and the generation of microstructural outcome measures using SALT.

Step 1: Macrostructural manual coding (story content)

The narratives were coded at the macrostructural level in accordance with the Swedish translation of the ERRNI material (127). The Fish Story task has a predefined story structure consisting of expected elements representing the core events and content of the narrative. Each narrative was evaluated with respect to 24 predefined story elements. For each story element, the child's production was scored on a three-point scale based on informational completeness. Two points were assigned when the story element was clearly and correctly expressed, one point when it was expressed partially or vaguely, and zero points when it was omitted or expressed incorrectly. For example, for the story element *The boy feeds the fish*, children received two points when they clearly conveyed the event, such as *The boy feeds the fish* or *He gives the fish food*. One point was assigned for a partial or vague account, such as *There is a boy with a fish*, in which feeding is not explicitly mentioned. Zero points were assigned when the event was omitted or expressed incorrectly. The scores were subsequently summed to form a total macrostructural score for each narrative, referred to as the ideaspcore.

Step 2: Microstructural manual coding

The narratives were coded at the microstructural level in accordance with the SALT manual (81). The coding included segmentation into communication units (C-units), identification of grammatical errors, and assessment of syntactic complexity.

- Segmentation into communication units (C-units)

The narratives were manually segmented into C-units defined as a main clause together with any associated subordinate clauses. Segmentation was guided by grammatical criteria rather than pauses or intonation, although prosodic cues were considered when relevant. Utterances containing coordinating conjunctions were segmented into separate C-units when each clause constituted an independent main

clause with an explicit subject, for example, *He went to the store. And he bought a fish.* In contrast, coordinated verbs sharing the same subject were treated as one C-unit, for example, *He went to the store and bought a fish.* Utterances containing subordinating conjunctions were treated as a single C-unit when the subordinate clause was grammatically dependent on the main clause, for example, *When he came home, he saw that there was a doll in the bag.* This segmentation established the analytical units on which all subsequent microstructural analyses were based.

- Coding of grammatical errors

Grammatical errors were manually coded at the word and utterance levels. Only errors that were not self-corrected by the child were coded. Word-level coding covered overgeneralised verb inflections, such as the application of a regular inflectional pattern to an irregular verb, for example, *goed* instead of *went*. Other word-level errors comprised errors in word choice and morphology, incorrect use of grammatical gender and prepositions, and words irrelevant to the context. A morphological error could, for example, involve the omission of a plural inflection, as in *two friend* instead of *two friends*. Pronominal errors concerned the use of an incorrect pronoun form, for example, *she* instead of *her*. At the utterance level, word-order errors were coded, including violations of the verb-second rule in Swedish, in which the finite verb did not occur in the second position following an initial constituent. As this construction is language-specific, the example is given in Swedish: *Sedan pojken köpte fisken* instead of *Sedan köpte pojken fisken*.

- Coding of syntactic complexity

Syntactic complexity was manually coded using the Subordination Index (SI), defined as the number of complete clauses per C-unit. Each C-unit contributed one complete clause for the main clause, with additional clauses counted when more than one complete clause was present within the same C-unit. C-units consisting of sentence fragments, abandoned utterances, or metacomments were coded as containing no complete clauses and therefore did not contribute to syntactic complexity.

Step 3: Generation of microstructural outcome measures in SALT

Once the manual coding had been completed, the microstructural outcome measures were generated by SALT from the coded transcripts. The following measures were extracted:

- **Mean Length of Utterance in Words (MLUw)**, calculated as the total number of words divided by the number of complete and intelligible C-units.
- **Grammaticality (GY)**, calculated as the proportion of C-units containing one or more grammatical errors, with higher values indicating lower grammatical accuracy.

- **Subordination Index (SI)**, calculated as the total number of clauses, including both main and subordinate clauses, divided by the total number of C-units.
- **Moving Average Type-Token Ratio (MATTR)**, used as a measure of lexical diversity. MATTR was calculated by computing the ratio between the number of different words (types) and the total number of words (tokens) within a series of consecutive, overlapping word windows of fixed length in each transcript, and then averaging these ratios. The window size was set to 21 tokens, corresponding to the length of the shortest narrative included in the analysis.
- **Words Per Minute (WPM)**, used as a measure of speech rate and calculated by dividing the total number of words produced by the duration of the narrative in minutes.

Interviews (Study 4)

An initial transcription of the interview recordings was generated using aTrain (128). All transcripts were then manually checked and transcribed verbatim by the author. Transcription included the spoken language and audible extra-linguistic elements relevant to the communicative situation, such as pauses, laughter, and crying. Non-verbal communicative expressions that were not always audible in the recordings, such as gestures, signs, body language, facial expressions, and the use of visual AAC, were added to the transcripts based on the field notes taken in connection with the interviews. The transcripts were checked against the audio recordings several times.

Agreement

Wordrace (Studies 1 and 2)

In Study 1, agreement was assessed for the lexical error coding. For the Scandinavian languages and English, alternative responses were independently categorised by two speech-language therapists with more than 15 years of clinical experience. The raters agreed on 86% of the 92 alternative responses. Cases of disagreement were discussed until consensus was reached.

Fish Story (Study 3)

In Study 3, inter-rater and intra-rater reliability were assessed for both the macrostructural and microstructural coding. Inter-rater reliability was evaluated on 10% of the narratives. For macrostructural coding (ideascoring), agreement between the first and last authors of Paper 3 was assessed using weighted Cohen's kappa, yielding a mean κ of .82. For the microstructural measures, agreement between the

first and third authors of Paper 3 was assessed using intraclass correlation coefficients (ICCs), resulting in a mean ICC of .86. Intra-rater reliability was also evaluated, as all narratives were coded by the author of this thesis. Ten percent of the narratives were randomly selected and re-coded following a three-week washout period to minimise recall bias. For the ideaspcore, intra-rater reliability yielded a mean weighted Cohen's κ of .91. For the microstructural measures, intra-rater reliability yielded a mean ICC of .97.

Statistical analysis

Table 2 provides an overview of the statistical analyses conducted in Studies 1–3 and the corresponding outcome measures.

Table 2. Overview of statistical analyses and corresponding outcome measures used in Studies 1–3.

Analysis	Outcome measure	Paper
Descriptive norm-referenced comparison (M, SD)	Total test time; total correct words	1, 2
Descriptive frequency analyses	Slow word finding; inaccurate word finding; combined slow and inaccurate word finding; lexical error categories	1
χ^2 / Fisher's exact tests	Slow word finding; inaccurate word finding; combined slow and inaccurate word finding	1
Odds ratios	Combined slow and inaccurate word finding	1
Paired t-test	cWPM	2
Linear mixed-effects models	cWPM	2
Linear regressions, comparison with the TD group	Ideaspcore; MLUw; GY; SI; MATTR; WPM	3
Linear regressions, change in relation to PFS and MSD	Ideaspcore; MLUw; GY; SI; MATTR; WPM	3
Linear mixed-effects models, within the PFT group	Ideaspcore; MLUw; GY; SI; MATTR; WPM	3

M: mean; SD: standard deviation; cWPM: correct words per minute; PFT: posterior fossa tumour; TD: typical development; PFS: posterior fossa syndrome; MSD: motor speech disorder; MLUw: mean length of utterance in words; GY: grammaticality; SI: subordination index; MATTR: moving average type-token ratio; WPM: words per minute.

Study 1

In Study 1, preoperative word-finding ability was analysed using total test time and total correct words. A Swedish-speaking subsample was analysed separately

because Swedish age-specific Wordrace norms were available for these measures. In this subanalysis, total test time and total correct words were compared descriptively with the corresponding Swedish normative values using means and standard deviations (SD). In the full crosslinguistic group, the age-specific predefined cut-off values for total test time and total correct words were used to classify the children as having slow word finding, inaccurate word finding, or both. Children who met both criteria were additionally classified as having combined slow and inaccurate word finding. The frequencies of slow word finding, inaccurate word finding, and combined slow and inaccurate word finding were described. Demographic and medical characteristics were compared between children without word-finding difficulties and children with each type of difficulty using χ^2 tests or Fisher's exact tests, as appropriate. For these comparisons, tumour location was recoded into five mutually exclusive categories. The left cerebellar hemisphere category comprised tumours involving the left cerebellar hemisphere alone or together with a maximum of one additional site: the vermis, the fourth ventricle, or the brainstem. The right cerebellar hemisphere category was defined analogously. The vermis category comprised tumours involving the vermis alone or together with either the fourth ventricle or the brainstem, and the brainstem category comprised tumours involving the brainstem alone or together with the fourth ventricle. The "other" category comprised tumours involving three or more sites and tumours reported only in the fourth ventricle. Odds ratios with 95% confidence intervals (CIs) were calculated for selected binary associations, following standard approaches for categorical data analysis (129). Lexical error categories were analysed descriptively by summarising the distribution of response types among alternative responses.

Study 2

In Study 2, word-finding ability in the Swedish-speaking subsample was compared with Swedish age-specific normative data both preoperatively and postoperatively. Total test time and total correct words were compared with normative reference values. Descriptive norm-based categories were used to indicate the extent of deviation from Swedish age-specific norms, with cut-offs set at 1 and 2 SDs, as commonly applied in clinical practice (130). For total test time, performance was described in relation to whether the children performed within the normative range, 1 SD above the normative mean, or 2 SD or more above the normative mean, as a longer test time indicates slower naming. For total correct words, performance was described in relation to whether the children performed within the normative range, 1 SD below the normative mean, or 2 SD or more below the normative mean.

Pre- to postoperative change in word-finding ability was analysed using a paired t-test in the children with both pre- and postoperative assessments. This analysis used cWPM as the outcome measure. Descriptive statistics were also used to describe individual change in relation to PFS and MSD.

Factors associated with postoperative word-finding ability were analysed using linear mixed-effects models, with cWPM as the outcome measure. Clinical and tumour-related factors were examined in interaction with timepoint (preoperative versus postoperative) to identify factors associated with postoperative change. Participant and language were included as random effects. Tumour location was analysed by examining each of the five possible locations separately as a binary variable indicating whether the location was involved or not: the left cerebellar hemisphere, the right cerebellar hemisphere, the vermis, the fourth ventricle, and the brainstem. The models were built in steps, exploring the effects of tumour location, tumour histology, hydrocephalus, sex, age, dysarthria, and test format. A backward selection approach was then applied to the model including multiple independent variables, starting from the maximal model. Models were compared using the Akaike Information Criterion (AIC), where lower values indicate a better model fit (131).

Study 3

In Study 3, narrative macrostructure and microstructure were analysed using ideaspcore, MLUw, GY, SI, MATTR, and WPM. To compare children with PFT with children with TD, separate linear regression models were fitted for each outcome measure. Group was included as the independent variable, with the TD group as the reference category. Because the TD group was not individually matched to the PFT group, age and sex were included as covariates in the regression models. Model estimates were reported as unstandardised regression coefficients (B) with 95% confidence intervals; standardised coefficients were also calculated to support the comparison of effect sizes across outcome measures.

To describe the extent of narrative difficulties at the individual level, the mean and SD for the TD group were calculated for each age group: 5–7, 8–12, and ≥ 13 years. Each observation from the PFT group was then classified in relation to the age-specific TD mean as within 1 SD, between 1 and 2 SD below, or more than 2 SD below. These categories were used as descriptive indicators of the extent of deviation from age-specific TD performance, in line with clinical assessment conventions where scores between 1 and 2 SD from the mean may indicate moderate weakness and scores more than 2 SD from the mean may indicate more pronounced difficulties (130). For GY, where higher values indicate poorer grammatical accuracy, deviations were defined in the opposite direction.

Pre- to postoperative change within the PFT group was analysed using linear mixed-effects models. Separate models were fitted for ideaspcore, MLUw, GY, SI, MATTR, and WPM. All available observations from children with PFT were included. Participant was included as a random intercept, while timepoint, age, and sex were included as fixed effects.

To analyse change in relation to PFS and MSD, analyses were restricted to children with complete pre- and postoperative data. Individual change scores were calculated for each outcome measure by subtracting the preoperative value from the postoperative value. Separate linear regression models were then fitted for PFS and MSD, with children without the respective condition serving as the reference group. All models were adjusted for age and sex.

In Paper 3, standardised coefficients were also calculated for selected regression models to quantify effect sizes in standard deviation units and facilitate comparison across outcomes with different measurement scales. In the present thesis summary table, narrative model estimates are reported as unstandardised regression coefficients (B) with 95% confidence intervals.

All statistical analyses were performed in R using RStudio. Different R and RStudio versions were used during the course of the project.

Inductive content analysis

Study 4

An inductive qualitative content analysis was conducted, following the methodological approach described by Graneheim and Lundman (132) and further elaborated by Lindgren et al. (133).

First, the interview transcripts were read repeatedly by the author and two senior co-researchers involved in Paper 4 to become familiar with the material and to form an overall understanding of its content. Second, meaning units related to communication were identified. These consisted of words, sentences, or longer passages that expressed one central meaning relevant to the study aim. At an early stage of the analysis, the author and the two senior co-researchers jointly read two interviews and identified meaning units related to communication in order to establish a shared analytical understanding and clarify analytical boundaries. Third, the meaning units were condensed, meaning that the text was shortened while the central meaning was retained. Fourth, each condensed meaning unit was labelled with a code that captured its main content. The meaning units from the two jointly read interviews were condensed and coded collaboratively. Fifth, the codes were compared across the interviews to identify similarities and differences. The initial categorisation was also carried out collaboratively, with the author and senior co-researchers arranging and rearranging codes to examine patterns, similarities, and differences in the material. Codes with related content were sorted into subcategories and then abstracted into broader categories representing the manifest content. Sixth, the categories were interpreted and synthesised into themes reflecting the latent content of the interviews. These themes captured underlying meanings and recurring patterns in the children's descriptions. Seventh, the

preliminary categories and themes were reviewed, refined, and discussed by the author and the senior co-researchers until a coherent interpretation was reached.

Analytical discussions were held with the senior co-researchers regarding meaning units, codes, categories, and emerging themes. This collaborative analytical process contributed to investigator triangulation by broadening analytical perspectives (134). It also supported credibility by allowing interpretations to be discussed, compared, and refined during the analysis (132). The analysis involved a continuous movement between the text as a whole and its parts, consistent with the iterative nature of qualitative content analysis (132, 133). Representative quotations were selected to illustrate the categories and to make the children's own experiences visible in the presentation of the results.

Generative artificial intelligence model

A subscription-based version of a generative artificial intelligence (AI) language model (ChatGPT; OpenAI) was used during the preparation of this thesis, in accordance with the Faculty of Medicine guidelines on the use of generative AI in PhD studies (135). The model was used as a discussion partner and sounding board to support the author in articulating and reflecting on her own reasoning. This included testing formulations, considering alternative ways of expressing ideas, examining how arguments and descriptions might be perceived by a reader, and clarifying wording and presentation, without introducing new content or perspectives.

In addition, the model was used for technical assistance related to programming, such as support with coding syntax and code structure in RStudio, based on specifications provided by the author regarding outcomes and analytical aims. All statistical models, analytical decisions, and interpretations were defined, implemented, and evaluated by the author. The AI model was also employed in a more restricted manner for language review, including checking grammar and syntax and suggesting alternative phrasings at the sentence level. This assistance was applied with caution, as the author remained responsible for ensuring terminological precision, methodological accuracy, and consistency with disciplinary conventions.

The AI model was not used to generate original scientific content, data, analyses, interpretations, or conclusions, and it did not influence study design, data collection, coding, statistical analysis, or qualitative interpretation. Responsibility for all scientific content, analytical decisions, interpretations, and conclusions rests solely with the author and co-authors.

FINDINGS

“Words are, in my not-so-humble opinion, our most inexhaustible source of magic.”

Albus Dumbledore (136)

Dumbledore, the headmaster of Hogwarts in *Harry Potter*, reminds us that words carry a particular kind of magic. In this thesis, that magic is not taken for granted, but explored in how words are found, how stories are told, and how communication is experienced in everyday life. The main findings from Studies 1–4 are presented in relation to the ICF components introduced in the background. Word finding and narrative microstructure are related to body functions because the ICF classifies language as a mental function involving the recognition and use of signs, symbols, and other components of language, and speech fluency and rhythm as functions involving the flow, tempo, and speed of speech. This makes body functions relevant for findings concerning word finding, utterance length, grammatical accuracy, lexical diversity, and speech rate. Narrative macrostructure is related to activity because it concerns the child’s execution of a communicative task, namely organising and conveying story content. Communication in everyday life is related to participation, environmental factors, and personal factors because it concerns children’s involvement in everyday communicative situations, how these situations were shaped by responses from others and available support, and how children managed energy, boundaries, and a sense of self (5).

Overall, word-finding and narrative difficulties were identified both preoperatively and postoperatively in children with PFT. Word-finding difficulties mainly concerned slower word finding, while narrative difficulties involved story content, utterance length, grammatical accuracy, and speech rate. Among children with both pre- and postoperative assessments, no consistent group-level postoperative decline was found, but individual variation was evident. Communication in everyday life following PFT surgery could support or undermine belonging. Children described situations of being included or left out, being heard or not heard, managing energy, setting boundaries, and maintaining a sense of self. Figure 4 gives an overview of the main findings in relation to body functions and structures, activity, participation, environmental factors, and personal factors (5).

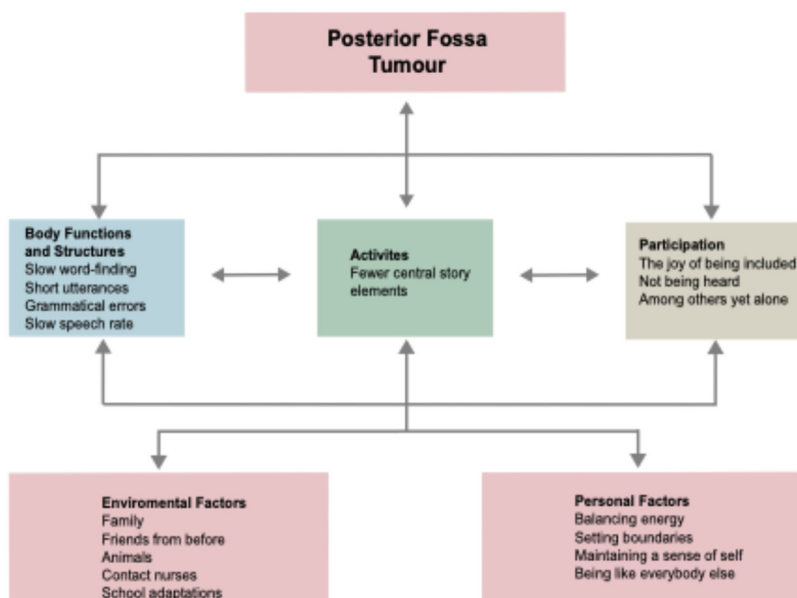


Figure 4. Overview of the main findings in relation to the International Classification of Functioning, Disability, and Health (ICF). The figure illustrates how the findings relate to body functions and structures, activity, participation, environmental factors, and personal factors in children with PFT. Adapted with permission from the World Health Organization.

Body functions and structures: word finding and narrative microstructure

Wordrace captured how quickly and accurately children retrieved target words in a constrained picture-naming task. Lexical diversity added information about lexical use in narrative production by describing the range of vocabulary used in the story. Regarding the temporal aspect of spoken production, WPM captured speech rate in a task that may involve linguistic formulation, pausing, self-monitoring, and motor speech demands. Together, these measures provided information about lexical access, vocabulary range, and the tempo of spoken production. Many children with PFT showed word-finding difficulties already before surgery (Paper 1). Among the 148 children included in Study 1, slow word finding was observed in 55 children (37%), while 35 children (24%) showed reduced naming accuracy and 23 children (16%) showed combined difficulties affecting both naming time and accuracy. For the Swedish-speaking children whose performance could be compared with Swedish age-specific Wordrace norms, mean total naming time was approximately twice the Swedish normative mean (Paper 1). The lexical error analysis added

further detail to these findings, showing that deviations from the target word occurred in only a small proportion of responses. These deviations mainly consisted of no responses, aborted responses, or alternative responses. Among the alternative responses, the most frequent type involved the use of a semantically related sideordinated word, for example *pear* for *apple*. In addition, there was no significant difference in lexical diversity between children with PFT and children with TD, indicating that children with PFT used a similar range of vocabulary as children with TD (Paper 3). Converging with the timing-related Wordrace findings, speech rate was also lower in the narrative task, where children with PFT had lower WPM than children with TD at the preoperative assessment (Paper 3).

Difficulties in narrative microstructure were also evident preoperatively. Compared with children with TD, children with PFT had lower MLUw, indicating shorter utterances, and higher grammatical error proportions, indicating lower grammatical accuracy. The individual comparisons showed the same pattern: for MLUw, 13 of the 32 children with preoperative narrative data scored more than 1 SD below the age-specific TD-group mean, including 5 children who scored more than 2 SD below the mean. For grammatical error proportions, 12 of the 32 children scored more than 1 SD above the age-specific TD-group mean, including 7 children who scored more than 2 SD above the mean, indicating more grammatical errors than in the TD group (Paper 3). The preoperative results are presented in Table 3.

Postoperatively, many children with PFT also showed word-finding difficulties (Paper 2). In the Swedish-speaking norm-based analysis, mean total test time was approximately twice the Swedish normative mean, and 36 of 38 children (95%) performed 2 SD or more above the Swedish normative mean. As in the preoperative findings, slow naming speed was the main concern, while deviations in naming accuracy were less pronounced (Paper 2). Lexical diversity also did not differ significantly between children with PFT and children with TD postoperatively, indicating a similar range of vocabulary use (Paper 3). Slower speech rate (WPM) was also observed in the postoperative narrative task (Paper 3). Difficulties in narrative microstructure were evident postoperatively, with lower MLUw and higher grammatical error proportions in children with PFT than in children with TD, indicating shorter utterances and lower grammatical accuracy. The individual comparisons also showed deviations from the TD-group mean for MLUw and grammatical error proportions (Paper 3). The postoperative results are presented in Table 3.

For children with both pre- and postoperative word-finding assessments, no overall group-level change in word-finding ability was identified when change was analysed using cWPM. However, individual change varied markedly, with 45 children improving, 46 declining, and 3 showing no change (Paper 2). For narrative microstructure, the analyses likewise showed no significant group-level change, although individual pre- to postoperative change varied across the microstructural

measures (Paper 3). The pre- to postoperative change results are presented in Table 3.

Together, these findings showed a recurring pattern across the pre- and postoperative assessments. The main timing-related finding was slower performance, reflected both in longer naming time and lower speech rate. Naming accuracy was less clearly affected, and lexical diversity did not differ significantly between children with PFT and children with TD. In narrative microstructure, the findings mainly concerned lower MLUw and higher grammatical error proportions, indicating shorter utterances and lower grammatical accuracy, whereas no clear group-level differences were found for syntactic complexity.

Activity: narrative macrostructure

Difficulties were also observed in narrative macrostructure (Paper 3). Compared with children with TD, children with PFT included fewer expected content elements in their narratives both before and after surgery. For individual children, deviations from the TD-group mean were observed, with children scoring 1–2 SD or more than 2 SD below the mean for ideaspcore. No significant group-level change in ideaspcore was identified from pre- to postoperative assessment, although individual change varied. The narrative macrostructure results are presented in Table 3. Together, these findings indicate that children with PFT showed difficulties not only in narrative microstructure, but also in narrative content, that is, in what they actually conveyed in the story.

Table 3. Main findings for word-finding and narrative ability before and after surgery. Word-finding columns show cut-off results and Swedish norm comparisons; narrative columns show PFT–TD group comparisons. The pre–post column shows within-group change.

Measure	Preop performance	Postop performance	Pre–post change	Paper
Word-finding				
Total test time	Slow: 55 (37%) (n = 148) Mean total test time ≈2× Swedish age- specific norm mean (n = 47)	Mean total test time ≈2× Swedish age- specific norm mean ≥2 SD above norm: 36 (95%) (n = 38)	–	1, 2
Total correct words	Inaccurate: 35 (24%) (n = 148) Mean total correct words ≈ Swedish age- specific norm mean (n = 47)	≥1 SD below norm: 6 (16%) of whom ≥2 SD below norm: 2 (5.3%) (n = 38)	–	1, 2
Total test time + total correct words	Slow and inaccurate: 23 (16%) (n = 148)	–	–	1
cWPM	–	–	No group-level change: 0.24 (–1.82 to 2.30), p = .819 Improved / declined / unchanged: 45 / 46 / 3 (n = 94)	2
Narrative				
Ideascore	–4.82 (–7.14 – –2.50), p < .001	–7.04 (–9.37 – –4.73), p < .001	–2.01 (–4.62 – 0.53), p = .133	3
MLUw	–0.82 (–1.50 – –0.14), p < .01	–1.55 (–2.22 – –0.87), p < .001	–0.68 (–1.42 – 0.05), p = .079	3
GY	0.06 (0.02 – 0.09), p < .01	0.04 (0.01 – 0.07), p < .05	–0.02 (–0.07 – 0.03), p = .411	3
SI	–0.06 (–0.24 – 0.13), p = .549	–0.10 (–0.29 – 0.12), p = .261	–0.05 (–0.18 – 0.08), p = .479	3
MATTR	0.00 (–0.03 – 0.01), p = .771	–0.01 (–0.04 – 0.00), p = .173	–0.01 (–0.04 – 0.01), p = .270	3
WPM	–20.7 (–34.69 – –6.58), p < .01	–18.3 (–32.39 – –4.32), p < .05	0.30 (–13.45 – 14.77), p = .966	3

Data are n (%) unless otherwise stated. cWPM values are mean pre–post differences with 95% CI; narrative values are unstandardised regression coefficients (B) with 95% CI. Higher total test time indicates slower performance; higher GY indicates more grammatical errors. Bold indicates p < .05. cWPM: correct words per minute; GY: grammaticality; MATTR: moving average type-token ratio; MLUw: mean length of utterance in words; SD: standard deviation; SI: subordination index; WPM: words per minute.

Factors associated with word-finding and narrative outcomes

Given the variability observed in pre- to postoperative change, with some children improving and others showing a decline, it is relevant to consider factors that may be related to this individual variation. Across the studies, factors were examined in different analyses and in relation to different aspects of word-finding and narrative performance. These factors can be considered in different ways within the ICF framework. Age may be regarded as a personal factor; tumour location relates to body structures; postoperative speech status, including MSD, concerns body functions involved in speech production; and PFS may be understood as a health condition.

Age-related patterns were evident in both word-finding and narrative ability. In the Swedish norm-based word-finding analyses, deviations from the normative mean for total test time were most pronounced in the 8–12-year and ≥ 13 -year age groups, both before and after surgery (Paper 2). For narrative macrostructure, deviations in ideaspcore were most evident in the 8–12-year and ≥ 13 -year age groups, where children more often scored more than 2 SD below the TD-group mean than in the youngest age group (Paper 3). For narrative microstructure, deviations in MLUw were particularly evident in the 8–12-year age group, while deviations in grammatical error proportions and speech rate were mainly observed in the 8–12-year and ≥ 13 -year age groups.

Tumour location was associated with word-finding outcomes, but the pattern differed between the preoperative and pre- to postoperative analyses. Preoperatively, right-hemisphere tumours and brainstem involvement were more frequent among children with combined slow and inaccurate word finding than among children without word-finding difficulties. Children with tumours in either of these locations had approximately three times the odds of combined word-finding difficulties compared with children with other tumour locations (odds ratio = 2.99, 95% CI 1.14–7.86; Paper 1). In the pre- to postoperative analysis in Paper 2, fourth ventricle involvement was associated with a pre- to postoperative decline in word-finding performance ($B = -4.09$, 95% CI -7.84 to -0.35 , $p < .05$).

PFS was examined in relation to pre- to postoperative change in word-finding and narrative outcomes. In Paper 2, 12 of the 94 children with complete pre- and postoperative word-finding data had PFS. Among these, eight children showed a decrease in cWPM after surgery. All four children who experienced mutism showed lower postoperative word-finding performance, although this association did not reach statistical significance ($p = .053$). In Paper 3, the corresponding narrative analyses were based on a very small group of children with PFS and complete pre- and postoperative narrative data ($n = 4$; one with mutism and three with reduced speech). Although the direction of change suggested decline across macrostructural and microstructural measures, no significant change in ideaspcore was found in relation to PFS, and none of the microstructural measures differed significantly

between children with and without PFS. These findings should be interpreted cautiously because the PFS subgroup was small.

MSD was associated with both word-finding and narrative outcomes. In Paper 2, postoperative MSD was associated with lower word-finding performance ($B = -4.07$, 95% CI -7.89 to -0.25 , $p < .05$). In Paper 3, postoperative MSD was associated with larger pre- to postoperative declines in narrative ability. Significant negative effects of postoperative MSD were observed for changes in ideaspcore, MLUw, SI, MATTR, and WPM, whereas change in grammatical error proportions did not differ significantly. These associations were interpreted as reflecting performance demands in narrative production, including the motor demands of speech production, rather than necessarily indicating underlying language deficits.

The findings presented so far concerned word-finding and narrative ability in structured assessment situations. The next section turns to children's experiences of communication in everyday life after PFT surgery. Within the ICF, these findings can mainly be understood in relation to participation, environmental factors, and personal factors.

Participation: A thin line between belonging and not belonging

Children described their experiences of communication in everyday life at least one year after PFT surgery, reflecting experiences at a later stage of recovery. Although all children ($n = 10$) had speech, language, and/or communication difficulties, these were not explicitly described as barriers. Difficulties were instead described in relational or contextual terms, such as who they were with, how they were treated, or what the situation demanded.

Children described a thin line between belonging and not belonging, where communicative moments could affirm or undermine a sense of inclusion. Experiences of belonging were reflected in everyday situations in which children felt included, recognised, or acknowledged through communication, often conveyed through small and subtle communicative acts, such as being invited, listened to, greeted, or included in shared moments. Even though these moments could be small, they were described as meaningful in creating a sense of belonging. This was described in relation to sitting together, talking, and doing puzzles during breaks:

“I have a room at school that I have access to. There I have puzzles. I LOVE doing puzzles. LOVE it. And... yes, my friends also like doing that(...) when she has time and a break, and when we do too, then she comes to us and do puzzles, and we can sit there during breaks sometimes”

Children also described digital communication and quiet presence as meaningful ways of participating and maintaining a sense of belonging, for example, being invited to join a group on social media such as Snapchat. A small Snapchat group was described as a way of staying in contact:

“I use Snapchat, yeah it’s mostly (...) I don’t have that many there, but we have a small group, we three, so we can talk and like if there’s something or if we’re gonna meet or something”

At the same time, children described experiences of not belonging, including being unheard, left out, alone, or overlooked in everyday situations, even when physically present with others, for example in situations where they were not addressed or were ignored in group interactions. Some children described being present together with others without being part of the communication, which could create a sense of being alone despite not being alone. This was described in relation to breaks at school, where others were physically present but not experienced as close or communicatively connected:

*“The others aren’t so keen to communicate with each other or to talk (...) we are spread out and not like have togetherness or what you should say, like we don’t have a short distance
[shows by putting hands together]”*

Children also described situations in which they tried to communicate but were not listened to or responded to, including not being taken seriously or having others speak on their behalf. Together, these accounts illustrated how belonging was not fixed but could shift across situations, communication partners, and moments.

Environmental and personal factors: Navigating reality towards normality

Children’s accounts also showed how communication was related to environmental and personal factors. Children described how communication was used to manage everyday life and to navigate changes following PFT surgery, such as expressing needs, setting boundaries, managing energy, and communicating limits in everyday situations, for example by saying no, withdrawing from activities or conversations,

or choosing when and with whom to communicate. This could involve balancing the wish to participate with the need to rest, and being able to tell friends when energy was no longer sufficient:

“Well, when you’re my age, maybe you want to go out and party and things like that, but I don’t have the energy for that, (...) I feel that I’ve become better at saying no, like ‘no, now I’m tired’, ‘now I have to rest’, because otherwise I know that if, let’s say, I were to go full speed the whole weekend, then I know that on Monday, then it just won’t work”

Communication was also described in relation to interactions with others, including family members, siblings, and trusted adults, where support could be conveyed through being listened to, understood, or simply having someone present. Some children also described situations where adults helped others understand what the child had been through. When the contact nurse informed the class, this was described as very important:

“But the others in my class got to hear it (...) so maybe they got a bit more insight into what I have been through like yeah and things like that (...) well they actually started talking to me a little more”

In addition, some children described communication with animals as offering closeness and comfort. Furthermore, some children described AI-based chatbots as a space where emotions could be released in ways that were not possible in communication with friends. The children’s accounts also included descriptions of efforts to be like others and to maintain a sense of normality, such as participating on similar terms as peers or avoiding drawing attention to difficulties. Their choices about what to talk about, when to speak, and what to keep private also reflected efforts to hold on to themselves, be recognised on their own terms, and decide what to share or withhold in communication.

DISCUSSION

*“It’s definitely best for little children to have a regular life,
especially if they can regulate it themselves.”*

Astrid Lindgren (137, chapter 9)

This line from *Pippi Longstocking* points to the importance of children having a say in matters that concern them. In children with PFT, this is particularly relevant, as speech, language, and communication may be affected, influencing how children express themselves. With this as a starting point, the discussion focuses on three issues: the pattern of word-finding and narrative difficulties, variation before and after surgery, and children’s experiences of communication, belonging, and participation. The discussion then considers methodological and ethical aspects of the thesis, before outlining clinical implications and directions for future research.

Interpretation of the main findings

A pattern of word-finding and narrative difficulties

For children to have a say in matters that concern them, they need to be able to express what they want, need, know, or feel. Children with PFT showed difficulties at the levels of body functions and activity (Papers 1–3). Together, the findings point to a pattern of slow word finding (Papers 1 and 2), low speech rate (Paper 3), short utterances with grammatical errors, and few central story elements in narratives (Paper 3).

The word-finding difficulties mainly concerned speed, as children with PFT were slower in naming while naming accuracy was less affected (Papers 1 and 2). This pattern is further supported by recent work on word finding in children with PFT (79). A time-related pattern was also seen in the narrative task, where children with PFT produced fewer words per minute than children with TD (Paper 3). Lexical diversity did not differ clearly between children with PFT and children with TD, indicating a similar range of vocabulary use in the narrative task (Paper 3). This differs from the findings of Svaldi et al., who reported reduced lexical diversity in some children at long-term follow-up after cerebellar tumour surgery compared

with controls (3). One possible explanation is methodological, as Svaldi et al. used type-token ratio, a measure sensitive to sample length and variation in the amount of produced language (68), whereas Study 3 used MATTR, which is less affected by sample length (Paper 3).

Grammatical difficulties were also observed. Children with PFT produced shorter utterances and more grammatical errors than children with TD (Paper 3). At the same time, syntactic complexity did not differ clearly between groups. This difference between grammatical accuracy and syntactic complexity is notable because both concern grammatical and syntactic aspects of narrative microstructure, but they showed different patterns. The findings therefore do not suggest a broad syntactic difficulty. Rather, they point to a more specific pattern, where utterance length and grammatical accuracy were affected, while syntactic complexity appeared relatively preserved. This differs from patterns often described in DLD, where grammatical accuracy is affected and difficulties with syntactic or clause complexity have also been reported (138, 139).

The pattern of difficulties also included reduced story content. Children with PFT included fewer central story elements in their narratives than children with TD (Paper 3). Narrative macrostructure concerns the organisation and conveyance of story content and therefore reflects the communicative activity of telling a story. Earlier work has also reported lower narrative macrostructure scores in children treated for brain tumours compared with children with TD, although the group differences were not statistically significant (83). In that study, assessments were conducted several years after treatment, the sample included both supratentorial and infratentorial tumours, and many children had received chemotherapy and radiotherapy in addition to surgery. Additional treatment burden and late effects may contribute to persisting or increased difficulties over time, whereas longer time since treatment may also allow for recovery and compensatory strategies, potentially increasing heterogeneity between children. In contrast, Study 3 showed difficulties in story content already in the perioperative phase in children with PFT, before additional oncological treatment had been given.

Taken together, these findings add new knowledge by bringing together the results of the included studies and identifying a pattern of difficulties in children with PFT. The significance of these findings lies in how they allow the results to be discussed in relation to activity and participation, rather than remaining only at the level of language functions. Slow word finding may make it harder to express a thought at the moment when it is needed; grammatical difficulties and shorter utterances may affect how clearly children formulate needs, explanations, or experiences; and reduced story content may affect how they convey what has happened in a way that others can follow. Word-finding difficulties have been described as relevant for everyday communication and may affect relationships, self-esteem, and education (69). Expressive grammatical skills have also been associated with communicative participation, social-emotional functioning, and quality of life in children with DLD

(82), and narrative abilities are relevant in everyday and school contexts where children need to retell events, explain experiences, and make these understandable to others (89, 90). Such language difficulties may affect peer relationships (140). Within an ICF-informed understanding of functioning, difficulties in language functions may therefore affect activity and participation, while reduced opportunities for activity and participation may in turn limit opportunities to use and practise language (5). Seen in this way, the findings from Studies 1–3 are relevant not only as findings concerning specific language functions, but also for considering how these abilities may be supported and promoted in functional and social contexts during illness and recovery in children with PFT. The next section considers the findings in relation to preoperative and postoperative functioning and individual variation in pre- to postoperative change.

Pre- to postoperative change and individual variation in word-finding and narrative difficulties

Across Studies 1–3, word-finding and narrative difficulties were identified before and after surgery, but Studies 2 and 3 did not show a consistent group-level deterioration from pre- to postoperative assessment (Papers 1–3). One might have expected children with PFT to show deterioration after surgery, and previous research has often focused on difficulties in the postoperative phase, particularly in relation to PFS or MSD (9, 18). Similar variation in patterns of change has also been described in previous studies, where language outcomes after cerebellar tumour treatment varied both in direction and extent between children (3, 71). A central contribution of this thesis is that it places preoperative assessment at the centre of interpretation, rather than treating postoperative findings as isolated outcomes. By showing that word-finding and narrative difficulties may already be present before surgery, and that postoperative change varies between individuals, the thesis supports a shift towards interpreting postoperative functioning in relation to preoperative functioning and individual change. This emphasis on relating preoperative language data to postoperative outcomes has also been taken up in subsequent work on children with PFT (79, 141).

Age-related differences were observed in word-finding and narrative ability, with larger deviations from children with TD in the older age groups (Papers 1–3). Because the studies were based on cross-sectional comparisons, these differences should not be interpreted as developmental change within individuals. Rather, they suggest that the pattern of difficulties may become more apparent in relation to increasing linguistic and communicative demands. This interpretation is consistent with research showing that language demands increase throughout childhood and adolescence, and that difficulties may become more visible when language is expected to support more complex communication and learning (47, 86). This pattern has also been described in children with other developmental and acquired

conditions associated with speech and language difficulties (95, 142-144). In children with PFT, this is important because the tumour and its treatment occur during a period when language and communication are still developing. The consequences may therefore be difficult to detect early but become more apparent as developmental demands increase.

Tumour location was examined in relation to word-finding ability before surgery and to pre- to postoperative change (Papers 1 and 2). Preoperatively, combined slow and inaccurate word finding was associated with right cerebellar hemisphere and brainstem involvement (Paper 1). In the pre- to postoperative analysis, fourth ventricle involvement was associated with a negative pre- to postoperative change in word-finding performance (Paper 2). Thus, the locations identified differed between the two analyses. This may reflect that word-finding performance before surgery and change after surgery are influenced by partly different conditions. Before surgery, the tumour itself may affect cerebro-cerebellar networks depending on its location, whereas after surgery, surgical impact on surrounding structures and connections may further influence these pathways. This interpretation is supported by previous research suggesting that disruption of cerebro-cerebellar networks, particularly involving the DTCP, is central in PFS (145-147), and by studies showing that PFS risk is related to locations such as the brainstem and structures around the fourth ventricle (9, 17, 18). Methodological differences between the studies, including differences in outcome measures, timing of postoperative assessment, and how tumour location was defined, may also have contributed to the different patterns. Overall, the findings may be interpreted in light of possible disruption of cerebro-cerebellar pathways involved in language functioning (39, 40), while recognising that the observed associations do not establish a specific mechanism.

PFS was examined in relation to pre- to postoperative change in word-finding and narrative outcomes (Papers 2 and 3). In the children who could be assessed, no clear group-level differences were found between children with and without PFS. This finding should be interpreted cautiously, as the groups were small and children with unresolved mutism could not complete the language assessments. In the word-finding study, all four children with previous mutism showed postoperative decline, although this was based on a very small subgroup (Paper 2). The findings therefore do not suggest that PFS is irrelevant for language outcome. Rather, they suggest that postoperative language difficulties cannot be understood through a simple distinction between children with and without PFS. This is consistent with previous research showing heterogeneous language profiles after PFT surgery, including in children without PFS (3, 53).

MSD was associated with word-finding performance in Paper 2 and with pre- to postoperative change in several narrative outcomes in Paper 3. As MSD is not a language disorder (49), these associations do not indicate differences in underlying language ability. Instead, they need to be understood in relation to the demands

involved in spoken language tasks. Constraints related to articulation, coordination, and voice may influence how utterances are produced, particularly in tasks that require word finding, grammatical formulation, and the organisation of content. In this way, both motor speech and language processes may contribute to the observed performance.

MSD and speech rate in the narratives are closely intertwined, as WPM is a speech-rate measure and rate abnormalities are a central feature of dysarthria (49). In Paper 3, postoperative MSD was associated with a negative pre- to postoperative change in WPM. However, lower speech rate was also observed at the group level when children with PFT were compared with children with TD. Because only a small number of children with PFT were identified as having postoperative MSD, the lower speech rate cannot be understood as reflecting MSD alone. The relative contribution of motor speech and other factors to reduced speech rate could not be determined within the scope of Paper 3.

Age, tumour location, PFS, and MSD were examined in different analyses and were related to different aspects of word-finding and narrative performance. The absence of a consistent group-level postoperative deterioration should therefore not be interpreted as an absence of difficulty. Rather, the group-level stability coexisted with substantial individual variation, which is important because children followed different trajectories. This highlights the importance of considering preoperative functioning, individual change, and different clinical and developmental factors when interpreting language difficulties before and after surgery.

Communication, belonging, and participation in everyday life

The children's accounts of communication in everyday life following PFT surgery add an important perspective to the findings of this thesis. Although all children in Study 4 had speech, language, and/or communication difficulties, these were not typically described as isolated barriers. This does not mean that speech, language, and communication difficulties were unimportant, but rather that children often described communicative challenges in relational or contextual terms, such as who they were with, how they were treated, or what the situation demanded. Communication thus emerged as closely intertwined with opportunities for participation and shaped by the contexts in which it took place. This relational and contextual understanding is important because it shows that these difficulties may not always be expressed through direct descriptions of speech, language, or communication problems, but through children's accounts of being included, recognised, listened to, overlooked, or left out in everyday life. Similar relational and contextual perspectives have been described in children and adolescents with DLD and persistent speech disorder, where language and speech difficulties have been associated with peer problems, bullying, victimisation, and social, emotional, and behavioural difficulties (100, 101).

Experiences of belonging were prominent in the children's accounts. The children described how small communicative moments, such as being spoken to, invited, greeted, listened to, or included in social contexts, could be highly significant for their sense of belonging and participation. These moments may appear small from an outside perspective, but in the children's accounts they could make a considerable difference. They could affirm a sense of being included, recognised, and part of what was happening with others. This emphasis differs somewhat from previous research on children with speech, language, and/or communication difficulties, where experiences of social exclusion have often been more prominent (148-150). Findings from young adults who experienced PFS during childhood also point to persistent social difficulties and challenges in peer relationships (27). One possible explanation for the prominence of belonging in Study 4 is that the interviews captured children's ongoing experiences after PFT surgery, rather than retrospective accounts many years later. Being closer in time to everyday situations may have made it possible for children to describe small communicative moments that felt important, whereas retrospective accounts may be more strongly shaped by overarching experiences of change, loss, or exclusion. A further explanation may be that children living with serious illness often describe their experiences in relation to life rather than illness, including activities, relationships, and meaningful participation (151).

However, the prominence of belonging does not mean that not belonging was absent. The children also described situations where silence, being left out, or having one's voice dismissed could undermine belonging, whether through passive absence or active disregard. This resonates with research on adolescents with ABI, where communication changes have been described in relation to identity, participation, and belonging, and where young people report frustration, social withdrawal, and efforts to rebuild confidence in everyday interactions (104, 105). In the present study, experiences of not belonging were described through being unheard, alone, and left out, and through situations where the child was physically present but not part of a shared communicative experience. These experiences show that not belonging was not necessarily tied to large or clearly visible events. It could also arise in ordinary situations when a response was absent, when the child was not addressed, or when their communicative attempts were not taken up by others. A similar situation could also carry different meanings for different children: being quiet among others could for one child feel like being part of something, and for another like being left out. The findings therefore show that belonging was not a fixed state, but something fragile that could shift across situations, communication partners, and moments. In this way, the line between belonging and not belonging could be thin in everyday communicative life after PFT surgery.

The findings also showed how children used communication to navigate everyday life after PFT surgery. Several children described a wish to be like everyone else and to participate without standing out, while at the same time expressing an

awareness that everyday life sometimes needed to be adapted to their circumstances. Communication was central in this negotiation, for example when children expressed needs, set boundaries, said no, withdrew from activities, or chose when and with whom to communicate. In this way, participation in everyday life involved balancing the wish to take part with the need to manage energy, limits, and changing circumstances. Similar experiences have previously been described among adolescents and young adults with ABI, where belonging, identity, and peer relationships have been reported to be influenced by altered abilities, everyday routines, and opportunities for adaptation (152-154). The present findings similarly suggest that everyday life following PFT surgery may involve continuous negotiation between taking part, adapting to changed circumstances, and maintaining a sense of self.

These experiences were also shaped by the everyday contexts in which children interacted with others and by environmental factors related to support. Communication with family members, siblings, trusted adults, peers, animals, and digital tools appeared to offer different forms of closeness, comfort, support, or opportunities to express oneself. Some children also described situations where adults helped others understand what the child had been through, for example, when the contact nurse informed the class. In the Swedish context, ongoing efforts to improve long-term follow-up and rehabilitation for children treated for brain tumours, including support for schools and families, may have contributed to some of the positive experiences described by the children (155, 156). However, support and follow-up still appear to vary, and speech, language, and communication needs following CNS tumour treatment may remain under-recognised in clinical practice (157). The findings therefore emphasise the importance of understanding children's opportunities for communication and participation in relation to everyday contexts and environmental factors.

By considering the assessment findings alongside the children's accounts, the discussion can move beyond whether speech, language, and communication difficulties were present towards how they mattered in children's everyday lives. Word-finding difficulties, grammatical difficulties, reduced speech rate, and narrative difficulties are important clinical findings, but their significance cannot be understood only from the tasks in which they were measured. In everyday life, such difficulties may matter in situations where children need to find words, formulate stories, explain what has happened, express needs, manage fatigue, take part with peers, or respond when others do or do not listen. The children's accounts suggest that communication after PFT surgery was shaped not only by the child's abilities, but also by communication partners, school and family contexts, opportunities for adaptation, and how others responded to the child's communication. This is where an ICF-informed understanding is particularly relevant. The findings from this thesis do not place speech, language, and communication in one component of functioning only. Rather, they suggest that body functions, activity, participation,

environmental factors, and personal factors need to be considered in relation to each other when interpreting communication after PFT surgery (5). This interpretation is consistent with ICF-informed work in speech and language pathology, where communication disorders are understood not only in relation to impairment, but also in relation to activity, participation, and environmental factors (111). It also aligns with recent work on paediatric cognitive-communication disorders after traumatic brain injury, where important outcomes were shown to span several ICF components and increasingly involved activity and participation with age (110). This broader view is important because functioning is shaped within family, school, and community contexts, as also emphasised in childhood disability and paediatric neurorehabilitation (112, 113).

The contribution of this thesis is to support a broader understanding of communication in children with PFT. Previous research has often focused on postoperative symptoms, clinical outcomes, and children with PFS. The present findings suggest that speech and language after PFT surgery also need to be understood in relation to children's everyday communicative functioning. To fully understand what communication, support, participation, and adaptation mean in everyday life, children themselves need to be asked about their experiences and listened to. Returning to Pippi Longstocking, this underlines the importance of children having a say in matters that concern them, including how communication and support are experienced and organised in their everyday lives.

Methodological considerations

Study design and participants

Studies 1–3 were based on observational multicentre data from children with PFT (123).

This design was essential because paediatric PFT is rare and because preoperative speech and language assessment is difficult to carry out systematically in this clinical context. Multicentre studies can facilitate recruitment of larger and more varied samples, but they also introduce methodological complexity. This includes clustering within centres and centre-related variation in recruitment, assessment routines, and clinical context (158). This complexity needs to be considered when interpreting the findings of Studies 1–3, as data were collected at several centres, with possible variation in clinical routines and between assessors. Studies 1 and 2 also included several countries and languages, adding further complexity. Given the rarity of paediatric PFT, the sample sizes in Studies 1–3 were determined by the data available within the ongoing Nordic-European CMS study rather than by a priori sample size calculations. Retrospective power calculations would not provide

a useful alternative, as they are largely determined by the observed p-value and add little information beyond estimates of precision (159). Uncertainty is therefore better communicated through the size of the available samples, subgroup sizes, effect size estimates, and confidence intervals (158), particularly in analyses involving small clinical groups such as children with PFS or MSD.

In the Nordic-European CMS Study, speech and language functions were assessed preoperatively and postoperatively (123). The early postoperative assessment was part of the overall study design aimed at identifying risk factors for PFS and was consistent with its clinical course, as mutism or reduced speech output typically emerges after surgery (20). The preoperative assessments were a central methodological strength of Studies 1–3. In Study 1, they allowed difficulties present before surgery to be identified. In Studies 2 and 3, they provided an individual baseline for interpreting postoperative performance and determining whether difficulties were already present or had emerged after surgery (121).

The postoperative assessments in Studies 2 and 3 were conducted 1–4 weeks after surgery, and the findings therefore reflect early postoperative functioning. During this period, fatigue, medical status, neurological symptoms, pain, and the hospital setting may have influenced task performance. The assessment window may also have affected which children could contribute spoken language data. Children who were still mute at the time of assessment could not complete the tasks, and those with severely reduced speech may have had difficulty doing so. The analysed postoperative samples may therefore not represent the full range of early postoperative speech and language functioning. This needs to be considered when interpreting the findings, as the children included in the analyses may differ from the target population (121). In the larger Nordic-European CMS cohort reported by Grønbaek et al., postoperative speech status was known for 376 children (18). Mutism was reported in 14% (53/376) and reduced speech in 16% (59/376). In Study 2, postoperative speech status was known for 173 children, of whom 12 had mutism and 25 had reduced speech. The overall proportion with postoperative mutism or reduced speech was therefore lower in Study 2 than in the larger cohort (21% vs 30%). This difference was mainly driven by the lower proportion of children with mutism. Children with more severe early postoperative speech difficulties may therefore have been underrepresented in Study 2, possibly because some had not recovered sufficiently to complete the spoken language tasks within the assessment window. The postoperative findings are thus based on children who were able to complete spoken language assessments during this early postoperative period and may underestimate the extent of speech and language difficulties in the wider PFT population.

In qualitative research, participants are selected to provide rich information about the phenomenon under study rather than to obtain a statistically representative sample (160). In Study 4, the children varied in age, sex, time since surgery, previous postoperative mutism, school adjustments, motor symptoms, MSD, and

communicative abilities. This variation made it possible to explore communication experiences among children at different developmental stages and with different health-related conditions, school situations, and communicative abilities. However, children who relied exclusively on AAC were not included. This may have limited the range of experiences captured, particularly those of children with more extensive communication support needs or who require other interview formats to express their views. Transferability was supported by detailed descriptions of the participating children, the interview context, and the communicative conditions under which the interviews were conducted, allowing readers to judge the applicability of the findings to other settings and populations (134).

Data collection, measures, and analyses

Wordrace and Fish Story were selected for use in the Nordic-European CMS study before data collection began (123) and shaped which aspects of speech and language could be examined in Studies 1–3 (121). As the first two time points were close to diagnosis and surgery, the tasks needed to be feasible to administer within clinical settings across participating centres and by different healthcare professionals, including physicians, nurses, and speech-language therapists. To ensure consistency across centres, the assessment procedures were specified in written instructions, administrations were audio-recorded, and the recordings were scored retrospectively by speech analysts with competence in the relevant language. This approach enabled perioperative speech and language data to be collected in a rare clinical population. The clinical assessment context should nevertheless be considered when interpreting the findings, as some variation in performance may reflect differences in assessment conditions and administration.

Data collection

Wordrace was a short, structured task that was clinically feasible to administer across centres in the perioperative setting. Its use enabled word-finding data to be collected before and shortly after surgery. Compared with less constrained word-generation tasks, such as verbal fluency, picture naming places fewer demands on generating search strategies, maintaining category rules, shifting between subcategories, and avoiding repetitions (161). A picture may elicit more than one acceptable label within the same language, such as *couch* or *sofa*, and a picture intended to elicit *mug* may also be interpreted as *cup*. Several alternative labels were therefore accepted as correct. The use of Wordrace in different languages raised specific questions about crosslinguistic comparability. The number and range of acceptable labels for each picture may differ between languages, which may affect naming accuracy. Other relevant factors include the familiarity and visual complexity of the depicted object and the frequency, familiarity, length, and phonological properties of the corresponding word (162, 163). These factors may

vary across languages and settings even when the same pictures are used. Differences in speed and accuracy may therefore partly reflect language-specific and item-specific factors rather than clinical differences alone. This reflects the broader methodological problem of bias and equivalence in cross-cultural score comparisons, where equivalence cannot be assumed simply because the same task format is used (164). These considerations shaped the analytical approaches in Papers 1 and 2, since decisions about outcome measurement and analysis affect which comparisons can be made and how findings can be interpreted (121). In both papers, comparisons with age-specific norms were restricted to Swedish-speaking children, for whom Wordrace norms were available. Data from the different language groups were included in the analyses of word-finding within the cohort. In Paper 1, results were presented by language in the descriptive analyses. In Paper 2, language was included as a random effect in the mixed-effects models. These choices allowed data from the different language groups to be included without treating the Wordrace versions as directly equivalent.

Fish Story was a picture-supported story-generation task. The picture sequence reduced memory demands compared with retelling tasks while still requiring the child to organise and formulate a coherent narrative. This was advantageous in the perioperative context, where fatigue, illness, and treatment-related factors could affect performance. However, the picture support may also have reduced demands on independent planning and content generation. This is particularly relevant for older children and adolescents, for whom more open discourse tasks, such as expository or argumentative discourse, place greater demands on linguistic formulation, reasoning, and organisation (165-167).

In contrast to Study 1 and 2, Study 3 was restricted to Swedish-speaking children. This was important because measures of grammaticality, syntactic complexity, and utterance length depend on the grammatical structure of the language being analysed. Crosslinguistic research on children with DLD has shown that grammatical profiles and areas of vulnerability differ across languages, including differences related to grammatical morphology, word order, and morphosyntactic structure (84, 85). Crosslinguistic narrative research has also shown that children may use different linguistic forms to express similar narrative content, depending on the structure of the language (168). These language-dependent measures cannot therefore be assumed to be directly comparable across languages (164). Restricting Study 3 to Swedish-speaking children strengthened the basis for interpreting these measures within one language and enabled comparison with children with TD assessed in Swedish.

Measures

Wordrace provided separate measures of naming accuracy and speed, capturing different aspects of word-finding performance. This distinction was important because word finding involves both accurate and efficient access to intended words

(67). Naming studies in children commonly examine accuracy, temporal aspects of performance, such as naming latency and naming speed, and error patterns, as these measures capture partially distinct components of lexical retrieval (169, 170). The two Wordrace measures had different interpretative limitations. In the Swedish normative data, accuracy showed limited variation and near-ceiling performance (126), which reduced its sensitivity as a separate outcome (Paper 1). Total test time captured speed, but did not indicate whether performance reflected slow lexical retrieval, additional time used for self-correction, rapid *I don't know* responses, or the early abandonment of an item. In Study 2, cWPM was therefore adopted as an analytical measure of correct naming rate, expressing the number of correctly named pictures relative to the time needed to complete the task. Because normative reference data were not available for cWPM, it could only be used for within-cohort analyses of change and associated factors, whereas norm-based interpretation of Wordrace performance remained limited to total correct words and total test time in the Swedish norm-based analyses.

Concerning speed in narrative production, WPM was used as a measure of speech rate in Study 3 (81). Because WPM is calculated from the number of words produced in relation to the duration of the narrative sample, it provided a comparable measure of speech rate across children and assessment points. However, WPM does not separate time spent producing words from time spent pausing, reformulating, self-correcting, or being affected by motor speech difficulties. These aspects were not coded separately in Study 3. The interpretation of WPM therefore required caution, because speech and language are analytically distinct but may interact in spoken production (56). WPM contributed to the interpretation of narrative performance, but could not identify whether reduced rate reflected linguistic formulation, pausing, self-monitoring, motor speech difficulties, or a combination of these factors.

Analyses

The analyses in Studies 1–3 addressed different types of comparison, which affects how the findings should be interpreted. Some analyses examined performance related to age-specific norms or children with TD, whereas others examined task performance, pre- to postoperative change, or associations with clinical factors within the available study samples. Norm-based interpretation was only possible when relevant normative data were available, as in the Swedish Wordrace subanalyses. In Study 3, narrative performance was instead compared with that of Swedish children with TD. The findings should therefore be interpreted in relation to the specific measure, comparison, and analytical approach used in each study.

In Study 1, cut-off values were used to identify slow and/or inaccurate word finding. This was a pragmatic analytical choice in the absence of a psychometrically validated test suitable for crosslinguistic use and language-specific normative data for all included languages, and represented an initial approach to identifying

possible word-finding difficulties in this population. The cut-offs were based on Swedish normative data (126), developmental and normative studies of naming and word-finding-related performance in children (171-173), and clinical experience, but were applied to data characterised by variation in language, test format, assessor background, and clinical conditions. They should therefore not be understood as validated diagnostic thresholds or as providing exact estimates of word-finding difficulties in the cohort. The speed cut-offs were set cautiously, prioritising specificity: consequently, children classified as having slow word finding were likely to show clear deviations, whereas milder difficulties may not have been captured. Hence, not meeting the cut-offs should be interpreted cautiously, as milder word-finding difficulties may have gone undetected. A more robust approach would require age- and language-specific normative data and/or a formal evaluation of the cut-offs in relation to sensitivity and specificity (174). This limitation concerns the exact proportions reported in Study 1 and the classification of individual children in the multilingual sample. It therefore limits how precisely the proportion of children with slow and/or inaccurate word finding can be estimated. However, evidence of word-finding difficulties did not rely solely on the pragmatic cut-offs. In the Swedish norm-based analyses, word-finding performance was slower than expected according to age-specific norms in both Studies 1 and 2.

Linear mixed-effects models were used in Studies 2 and 3 to analyse repeated assessments. This approach was appropriate as observations from the same child are correlated, and mixed models allow this dependence to be incorporated into the analysis (131). The models made it possible to include children with available data at one or both assessment points, rather than restricting the analyses to complete cases only. This was crucial in the present clinical context, where not all children had both preoperative and postoperative assessments, and where missing data could occur for various clinical and practical reasons. However, this does not remove the methodological importance of considering missing data. Likelihood-based estimation in linear mixed-effects models relies on the assumption that outcome data are missing at random (MAR). This means that, after the observed information included in the model has been considered, the probability of an outcome being missing is assumed not to depend on the unobserved outcome itself (175). In the present studies, uncertainty regarding the MAR assumption mainly concerned the postoperative assessments, because some children with more severe early postoperative difficulties may have been unable to complete the spoken language tasks within the assessment window. If these children had poorer language performance than those represented in the analyses, the findings may provide an overly favourable picture of postoperative outcomes and underestimate deterioration in the full cohort (175). The postoperative findings should therefore not be interpreted as fully capturing the language outcomes of all children in the cohort, particularly those who were unable to complete the postoperative assessment. In Study 2, backward selection was used to reduce the full mixed-effects model, and candidate models were compared using the Akaike Information

Criterion (AIC). The AIC balances model fit against model complexity through a penalty for the number of estimated parameters, so that a lower AIC indicates a model with a better balance between fit and complexity among the candidate models (176). This was relevant because several clinical and methodological factors were considered in relation to postoperative word-finding performance. Starting from the full model also reduced the risk of omitting related factors too early when several candidate factors were considered (131). At the same time, AIC-based selection remains data-driven and does not remove the uncertainty introduced by model selection. The coefficient estimates, p-values, and CIs from the selected model should therefore be interpreted with caution, particularly in smaller samples, where model selection may be sensitive to small changes in the data (131). The final model in Study 2 should therefore be understood as an association model selected to balance model fit and complexity within the available data, rather than as a definitive explanatory model.

The analyses of clinical factors should be understood in relation to sample size, subgroup sizes, and model selection. Several analyses involved small subgroups, particularly those involving PFS, MSD, and complete pre- and postoperative data. Limited subgroup sizes reduce precision and increase the risk that true associations go undetected.

In Study 4, the qualitative analysis raised methodological considerations related to how children's communication experiences could be interpreted without losing proximity to their own accounts. The interview material was characterised by concrete descriptions of communication in everyday situations and by variation in how children expressed their experiences. Spoken language was often combined with facial expressions, gestures, signs, visual symbols, pauses, and other contextual or extra-linguistic expressions. This required attention not only to what was said, but also to how experiences were expressed in the interview situation. To make these expressions available for analysis, the interview material had to be documented in a way that preserved more than spoken words. Observational field notes were used to capture contextual and non-verbal aspects of the interview situation, and extra-linguistic elements such as laughter, crying, signs, and the use of symbols were noted in the transcripts. Together, these procedures supported confirmability by preserving contextual dimensions of the interviews and making it possible to trace how verbal, non-verbal, and contextual expressions informed the interpretations. Representative quotations further supported confirmability by allowing readers to assess the connection between the children's accounts and the categories and themes presented in the findings (134).

The concrete and multimodal nature of the material required the analysis to move beyond surface-level descriptions while remaining close to the children's own accounts and ways of expressing themselves. This movement between parts of the text and the material as a whole is central to qualitative content analysis, in which abstraction and interpretation are used to move from meaning units and codes

towards categories and themes (132, 133). To strengthen credibility, the author and senior co-researchers jointly identified meaning units in two interviews, which were then condensed and coded together. Thereafter, meaning units, codes, preliminary categories, and emerging themes were discussed repeatedly during the analytical process. The combination of clinical, qualitative, and child-health perspectives helped examine whether interpretations were sufficiently grounded in the data and whether the developing categories and themes were coherent and credible. Dependability was supported by documenting and revisiting analytical decisions throughout the process, which helped maintain consistency as the analysis progressed from meaning units and codes to categories and latent themes (134).

The author's background as a speech-language therapist was essential for conducting interviews with children with speech, language, and/or communication difficulties. This experience facilitated the adaptation of the interview situation to each child's communicative abilities, including attention to spoken responses, gestures, signs, pauses, visual support, and other ways in which children expressed meaning. Such communicative support was necessary to enable children to express their experiences, in line with the need to adapt research situations so that children with communication difficulties are not excluded from participation (177). However, the interviewer's clinical background and use of prompts, clarifications, and visual support could influence what was expressed, while the author's professional perspective could influence how the material was interpreted. Reflexivity was therefore required throughout both the interviews and the analysis to maintain a methodological balance between enabling the children's communication and remaining cautious about influencing the content and interpretation of their accounts (134).

Ethical considerations

Doing research with children raises important ethical questions, particularly when the children are living with illness, fatigue, and speech, language, or communication difficulties. In this thesis, the participating children were undergoing or recovering from treatment for posterior fossa tumours, often in situations marked by uncertainty, vulnerability, and dependence on adults. This made questions of voluntariness, understanding, assent, and communicative accessibility particularly important. At the same time, protecting children from burden or distress needed to be balanced against their right to participate in matters concerning their own lives and to have their voices heard, as stated in Article 12 of the United Nations Convention on the Rights of the Child (178). The need to balance protection from burden or distress with children's right to participate is consistent with the Declaration of Helsinki's emphasis on respect for autonomy, the protection of participants' rights and well-being, the minimisation of risks and burdens, and fair

inclusion in research (179). Ethical considerations in this thesis therefore concerned not only the protection of vulnerable children, but also how children's perspectives and rights could be acknowledged and respected throughout the research process.

The studies included in this thesis were conducted with approval from the relevant ethical review authorities. For the children with PFT included in Studies 1–3, informed consent procedures followed the requirements approved in each participating country. These requirements varied between countries, particularly regarding age thresholds and whether children's agreement was documented as assent or consent. For example, central age thresholds ranged from 12 to 16 years, while some countries placed greater emphasis on the child's competence, maturity, and understanding. Written informed consent was obtained from legal guardians and, where applicable, from the participating child or adolescent. Child assent was sought according to local ethical requirements and the procedures approved by the relevant ethical review authorities. The approved procedures generally aimed to provide children with age-appropriate information, involve them according to their capacity, and take account of any expressed unwillingness to participate. These procedures were consistent with the principles of the Declaration of Helsinki (179). Separate ethical approvals were obtained for the collection of normative data from children with TD and for the interview study exploring children's experiences of communication following posterior fossa tumour surgery. For these data collections, parents provided written consent for children under 15 years of age, while adolescents aged 15 years and older provided their own written consent. Younger children also provided verbal assent. Data for the children with PFT included in Studies 1–3 were entered into a central database at Karolinska Institutet by staff at each participating centre using password-protected accounts.

The anticipated benefits of the studies primarily concerned increased knowledge that could benefit children in the future, rather than direct benefits to the individual participants. These potential benefits needed to be weighed against the risks and burdens of participation. Although the assessments were non-invasive, participation required time and effort and could involve fatigue or frustration, particularly for children undergoing or recovering from treatment. For the children with TD in Study 3, the burden was lower but still included the time and effort required for participation. In Study 4, discussing personal experiences could also involve discomfort or emotional burden. These considerations were addressed by adapting participation to the individual child and remaining attentive to signs of fatigue, discomfort, or unwillingness to continue (179).

Respect for autonomy: voluntariness, understanding, and dependency

Children and families were informed that participation was voluntary and that they could withdraw from the study without affecting the child's care or follow-up. At the same time, respect for autonomy is complex in healthcare settings, where

children's participation is shaped by adults around them, including parents and healthcare professionals. Even when participation is presented as voluntary, it is therefore difficult to fully know whether children experience that they can decline or withdraw. Previous research on children's involvement in decisions about research participation suggests that assent is not only about receiving information or giving formal agreement. It also depends on whether children are actively involved, asked about their views and concerns, and made aware that they have a real possibility to decline participation (180). For children who may be tired, worried, or neurologically affected and who also have speech, language, or communication difficulties, assent therefore needs to be supported in ways that make it possible for the child to understand, respond, and express willingness or hesitation.

Although these considerations were relevant to all studies, they required particular attention in Study 4, where children were asked to devote time to an interview and share personal, potentially sensitive experiences. The children also differed in age, maturity, and speech, language, and communication needs. Particular attention was therefore given to supporting their understanding and assent, as well as their ability to express willingness or hesitation, throughout the research process. Written and verbal information was adapted to the child's communicative level through simplified language and visual AAC. The children could also influence practical aspects of participation, such as where the interview would take place and whether guardians should be present. Symbols representing "stop" and "pause" were visible on the table throughout the interviews to make it easier for children to express boundaries, uncertainty, or a wish to interrupt participation without having to verbalise it. This reflected an understanding of assent as something that needs to be supported throughout participation, not only obtained at the beginning. For children with speech, language, and communication difficulties, willingness, hesitation, discomfort, or refusal may be expressed in different ways during the research situation, and any expression of dissent should be respected (177, 179, 181). During several interviews, children chose to pause, avoid certain topics, or refrain from answering specific questions, demonstrating that they used the available opportunities to communicate boundaries during the interview situation.

The children with TD included in Study 3 were recruited through schools. Children were informed that participation was voluntary and that they could stop at any time. At the same time, because data collection took place in a school setting, it was important to consider whether children were given a real and safe space to indicate that they did not want to participate or continue (182). This made it important not only to provide information about voluntariness, but also to ask each child before each assessment whether they wanted to participate and to remain attentive to signs of hesitation or reluctance. Thus, even in a study involving low risk and short participation, questions regarding understanding and the possibility of expressing willingness or hesitation remained important to consider.

Justice, children's rights, and communicative accessibility

Children's rights and communicative accessibility were central ethical considerations in this thesis. Lundy argues that children must not only have opportunities to express their views, but also receive support to do so, be listened to, and have their views taken into account (182). If research primarily includes children who can express themselves verbally without difficulty, the experiences and perspectives of children with speech, language, and communication difficulties risk being overlooked. From the perspective of justice, the potential harms of excluding children with communication difficulties therefore need to be considered alongside the risks and burdens of inclusion, and appropriate communicative support is needed to enable their fair and responsible participation (179). Morris also argues that children with communication and/or cognitive impairments are often excluded when traditional research tools are used without adaptation (177). Communication therefore becomes not only a methodological issue, but also a question of participation, rights, and the possibility of being heard on one's own terms.

The children in Study 4 varied in their speech, language, and communication abilities and in the support they needed to express themselves. The interviews were therefore adapted to accommodate different forms of communicative expression. For children with speech, language, and communication difficulties, communicative accessibility requires attention to gestures, body language, facial expressions, use of AAC, pauses, silence, and other signals through which children may express views, uncertainty, boundaries, or experiences. The use of visual AAC support was intended not only to facilitate communication, but also to create opportunities for children to participate and express themselves in ways that were accessible to them. Morris emphasises that children should not be understood as having nothing to say because they do not communicate in expected ways (177). Rather, researchers need to assume that all children have something to communicate and find ways of understanding their views and experiences. The researcher's background as a speech-language therapist, together with long clinical experience of working with this group of children, was important in supporting communication and adapting the interviews to the children's communicative needs. At the same time, these supportive and responsive strategies carried a risk of influencing the children's expressions and responses. Balancing communicative support with openness to the children's own ways of expressing themselves was therefore an important ethical consideration throughout the interview process (177, 181). Communicative accessibility was not only a practical matter of data collection, but also an ethical condition for children's participation. Research situations needed to allow children to understand, respond, and express themselves in ways that were possible for them.

Clinical implications

The studies included in this thesis indicate that speech, language, and communication difficulties need to be considered throughout the care pathway for children with PFT, from the preoperative phase to follow-up and rehabilitation after surgery. The word-finding and narrative studies showed that several children had difficulties already before surgery. These findings underline the importance of early speech and language assessment, including before surgery, when clinically feasible. Preoperative assessment may provide an individual reference point for interpreting postoperative functioning. This reference point is important because a child may perform below age expectations after surgery but still show improvement compared with their own preoperative level. Conversely, low postoperative performance may reflect deterioration, persistence of preoperative difficulties, or partial recovery. Considering both normative comparisons and individual change may therefore help clinicians understand the child's communicative profile and plan support according to current communicative needs and the child's individual trajectory. If speech, language, or communication difficulties are identified before surgery, professionals can adapt information and interaction to the child's communicative needs. Some children may need adapted information, more time to respond, or alternative ways of expressing themselves. In this way, assessment before surgery is not only relevant for documenting speech and language function. It may also support the child's opportunity to understand, communicate, and participate in care from the outset.

Postoperative follow-up is also important. Word-finding and narrative difficulties were present after surgery in many children, including children without postoperative mutism or severely reduced speech. The absence of severe postoperative speech symptoms should therefore not be interpreted as an absence of speech, language, or communication difficulties. Children undergoing PFT surgery should be followed up with speech and language assessment, not only when severe postoperative speech symptoms have been observed. Postoperative assessment may help identify less visible difficulties and provide a basis for planning support according to the child's current communicative needs.

Assessment should include not only speech and language difficulties identified in testing, but also communication in the child's everyday life. This means considering body functions alongside activity and participation, including how the child communicates, takes part, and is supported in everyday situations. The children often described communication through concrete everyday situations rather than through explicit descriptions of speech or language difficulties. Professionals should therefore not rely only on test results or adult observations, but also invite children to describe their own experiences. Children's own descriptions may help identify participation needs and environmental factors that shape communication in everyday life.

Follow-up should be individualised and continue over time. Support should be based on the child's speech and language difficulties, how communication works between the child and others in everyday situations, and the child's own views on what works, what does not, where support is needed, and what is important to them. This requires coordination between health care, rehabilitation services, the child, family, and school, so that communication needs identified in assessment and everyday life can be translated into appropriate support. Previous work has described rehabilitation needs after PFS and long-term challenges related to communication, social and educational rehabilitation, support in structuring everyday life, and routine daily needs (27, 183, 184). The findings of this thesis add specificity to these recommendations by identifying word-finding and narrative abilities, communication in everyday life, and the child's own experiences and priorities as important areas for follow-up. The need for coordination with school is also consistent with research on school reintegration after childhood brain tumour treatment, which has emphasised support at school, professional aftercare, and collaboration within the child's supportive network (185). A structured approach to identifying these speech, language, and communication needs may support more targeted and coordinated planning of interventions in health care, rehabilitation, and school.

Future research

Further research is needed to increase understanding of how speech, language, and communication develop over time following PFT surgery in children. Although the present studies contribute knowledge regarding pre- and early postoperative language and communication, less is known about longer-term development and variability during later stages of recovery. Longitudinal studies following children over longer periods of time are therefore needed. Future studies may investigate developmental trajectories across childhood and adolescence, including how language and communication difficulties evolve in relation to increasing linguistic, cognitive, academic, and social demands over time.

There is also a need for continued research on narrative ability following PFT surgery, including both macrostructural and microstructural aspects of narratives. Narrative ability is closely related to academic performance, social interaction, and participation in everyday life, yet remains sparsely investigated in this group of children. Further research may therefore contribute to increased understanding of how narrative difficulties relate to school outcomes, participation, and quality of life following PFT surgery. Future studies may also include more demanding discourse tasks and investigate narrative and language abilities across larger and crosslinguistic samples. Future research should also include children with more diverse language backgrounds, such as multilingual children and children who do

not speak the majority language of the country in which they receive care. Although several European languages were included in the present studies, children whose language backgrounds did not match the assessment language were not represented.

The findings also indicate a need for further research on variability in outcomes following PFT surgery. Some children showed more pronounced difficulties, while others appeared less affected, and the factors related to these differences are still not fully understood. Further research may therefore contribute to increased understanding of why some children appear more affected than others and how difficulties develop over time following PFT surgery. Continued research may also contribute to increased understanding of neurobiological factors related to language and communication outcomes following PFT surgery.

Children's own experiences also need to be further explored. Future research may investigate how children experience support and rehabilitation following PFT surgery, including the use of AAC, school-based support, and communicative adaptations in everyday life. Further research may also explore how parents, teachers, and healthcare professionals perceive and respond to children's communication difficulties after PFT surgery. Studies exploring parents' experiences of information provided before and after surgery, including information regarding PFS and postoperative speech, language, and communication changes, would also be valuable. Such studies may contribute knowledge about how information and support are experienced by families and how information materials and communication practices could be further developed.

Further research in these areas may guide the development of assessment approaches, follow-up, and interventions that are responsive to children's speech, language, communication, and participation needs following PFT surgery.

CONCLUSIONS

Language difficulties were common in children with PFT, both before and after surgery. The difficulties were seen in word finding, where slowness was more prominent than incorrect responses, and in narrative ability, where children with PFT had more difficulty including central content, used shorter utterances, and made more grammatical errors than children with TD. At the same time, the results showed substantial variation between children. Some children improved after surgery; others deteriorated; and the difficulties were not limited to children with postoperative mutism or severely reduced speech. The findings therefore point to a pattern of difficulties in children with PFT, while also showing that the outcomes varied between children and did not follow a uniform pre- to postoperative trajectory.

The children's own descriptions added another dimension to this picture. Although the children did not explicitly describe their experiences as speech, language, or communication difficulties, their descriptions can be understood in relation to how communicative difficulties may shape everyday communication and participation. Small everyday communicative moments could strengthen or weaken the sense of belonging, and familiar friendships could provide continuity in a changed everyday life. The children also expressed needs, set boundaries, and tried to protect their identity while adapting to changed abilities and fatigue.

This thesis contributes to a more nuanced understanding of speech, language, and communication in children with PFT. The results concern not only language functions but also how communication is experienced and becomes meaningful in the child's everyday life. Assessment and follow-up therefore need to address not only word finding, narrative ability, and motor speech difficulties but also the child's participation, environment, and own experiences. To understand what support is needed, it is not enough to examine how the child performs on language tasks. The child also needs the opportunity to express how they experience communication in everyday life and what matters for their ability to participate, belong, and manage everyday communicative situations.

Sammanfattning på svenska

Hos barn är hjärntumörer ofta lokaliserade i den bakre skallgropen, posterior fossa, ett område som innehåller lillhjärnan, hjärnstammen och fjärde ventrikeln. För barnet och familjen innebär en posterior fossa-tumör (PFT) ofta oro och rädsla, med frågor om sjukdomen, behandlingen, överlevnaden, återhämtningen och framtiden. Utöver detta kan både tumören och den kirurgiska behandlingen påverka barnets tal, språk och kommunikation. Barnet kan få svårare att hitta ord, tala, berätta och delta i samtal med andra. Tidigare forskning har framför allt fokuserat på svårigheter efter operation och på barn som utvecklar posterior fossa syndrome (PFS), ett allvarligt postoperativt tillstånd som kan innebära mutism eller kraftigt nedsatt tal efter kirurgi. Kunskapen om tal, språk och kommunikation hos barn med PFT är fortfarande begränsad, särskilt när det gäller hur svårigheterna kan se ut redan före operation, hur olika språkliga förmågor påverkas och hur barn själva upplever kommunikation i vardagen efter PFT-kirurgi.

Avhandlingen består av fyra delstudier om barn med PFT och deras tal, språk och kommunikation. I de tre första studierna undersöktes barnens ordmobilisering och narrativa förmåga före och efter kirurgi. I den fjärde delstudien intervjuades barn om sina erfarenheter av kommunikation i vardagen efter PFT-kirurgi. Resultaten visade att många barn med PFT hade ordmobiliseringssvårigheter och narrativa svårigheter både före och efter operation. Svårigheterna syntes framför allt genom att barnen behövde längre tid för att hitta ord, talade långsammare, producerade kortare yttranden, hade fler grammatiska avvikelser och hade svårare att få med centralt innehåll i berättelser. Bland de barn som hade bedömts både före och efter operation sågs ingen tydlig försämring för gruppen som helhet. Däremot fanns stora skillnader mellan barnen: vissa förbättrades efter operation, medan andra fick större svårigheter. Svårigheterna sågs inte bara hos barn som utvecklade PFS, utan förekom även hos barn utan detta tillstånd. Barnen beskrev hur kommunikation i vardagen kunde stärka eller försvaga känslan av att höra till. Små kommunikativa situationer, som att bli tillfrågad, inbjuden, lyssnad på eller bara få vara med, kunde skapa en känsla av delaktighet och tillhörighet. Samtidigt beskrev barnen situationer där de inte blev tilltalade, inte blev lyssnade på eller var tillsammans med andra utan att känna sig delaktiga. Kommunikation beskrevs också som ett sätt att hantera vardagen, till exempel genom att uttrycka behov, sätta gränser, hantera trötthet och försöka bevara en känsla av normalitet och av att vara sig själv.

Sammantaget bidrar avhandlingen med en mer nyanserad förståelse av språk och kommunikation hos barn med PFT. Resultaten visar att språkliga svårigheter förekommer både före och efter operation, men också att kommunikation behöver förstås i relation till barnets vardag, delaktighet och egna erfarenheter. Bedömning och uppföljning behöver därför omfatta både språkliga funktioner och barnens egna upplevelser av vad som är viktigt för att höra till och vara delaktig.

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“Watch out for wild harpies and gray dwarfs and Borka robbers,” he said. “How will I know which are wild harpies and gray dwarfs and Borka robbers?” asked Ronia. “You’ll find out,” Matt said. “All right,” said Ronia.

“And watch out you don’t get lost in the forest,” said Matt. “What shall I do if I get lost in the forest?” Ronia asked. “Find the right path,” Matt said. “All right,” said Ronia.

“And watch out you don’t fall in the river,” Matt said. “What shall I do if I fall in the river?” Ronia asked. “Swim,” Matt said. “All right,” said Ronia. [...]

“Is there anything else?” “There certainly is,” said Matt. “But you’ll find out bit by bit. Go now!”

Astrid Lindgren (186, pp. 11-12)

Writing this thesis has, at times, felt like walking through Matt’s Forest. There have been things to watch out for, paths to find, rivers to cross, and much to learn bit by bit. The paths have certainly not been straight. They have turned back and forth, disappeared into thickets, and sometimes forced me to turn around and begin again. Some mountains have looked frightening from below. Others turned out to be green hills once I had climbed them. There have been moments when I was not sure which way to go. But there has always been a path. Sometimes I found it myself. More often, someone helped me find it.

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Paper I





Preoperative word-finding difficulties in children with posterior fossa tumours: a European cross-sectional study

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Abstract

Purpose Posterior fossa tumour surgery in children entails a high risk for severe speech and language impairments, but few studies have investigated the effect of the tumour on language prior to surgery. The current crosslinguistic study addresses this gap. We investigated the prevalence of preoperative word-finding difficulties, examined associations with medical and demographic characteristics, and analysed lexical errors.

Methods We included 148 children aged 5–17 years with a posterior fossa tumour. Word-finding ability was assessed by means of a picture-naming test, Wordrace, and difficulties in accuracy and speed were identified by cut-off values. A norm-based subanalysis evaluated performance in a Swedish subsample. We compared the demographic and medical characteristics of children with slow, inaccurate, or combined slow and inaccurate word finding to the characteristics of children without word-finding difficulties and conducted a lexical error analysis.

Results Thirty-seven percent ($n=55$) presented with slow word finding, 24% ($n=35$) with inaccurate word finding, and 16% ($n=23$) with both slow and inaccurate word finding. Children with posterior fossa tumours were twice as slow as children in the norming sample. Right-hemisphere and brainstem location posed a higher risk for preoperative word-finding difficulties, relative to left-hemisphere location, and difficulties were more prevalent in boys than in girls. The most frequent errors were lack of response and semantically related sideordinated words.

Conclusion Word-finding difficulties are frequent in children with posterior fossa tumours, especially in boys and in children with right-hemisphere and brainstem tumours. Errors resemble those observed in typical development and children with word-finding difficulties.

Keywords Cerebellar mutism syndrome · Child language · Language impairment · Nordic-European CMS study · Posterior fossa tumour · Word-finding difficulties

Introduction

Central nervous system (CNS) tumours are among the most common paediatric cancer diagnoses and account for 3.2 new cases per 100,000 children [1]. Around half of the CNS tumours are located in the posterior fossa [2]. Surgery is a key therapy for posterior fossa tumours, but it entails the risk of a severe complication, cerebellar mutism syndrome (CMS), with persisting impairments in both speech and language [3]. Most studies in children with CMS focus on postoperative impairment but knowledge about preoperative ability is essential to evaluate to which degree deviations

observed postoperatively were caused by surgery or were present before surgery. Preoperative language impairment, including word-finding difficulties, has been found to predict postoperative CMS [4, 5] but is still rarely investigated.

Word-finding ability is the ability to find the right word in the mental lexicon as we speak, quickly, and accurately [6]. In typical development, word-finding speed and accuracy increase with higher age [7–12] along with developments in children's vocabularies which continuously increase in breadth, depth, and interconnectedness [10]. Word-finding difficulties are seen in children with different diagnoses — e.g. developmental language disorders and dyslexia — and they are the primary impairment in children classified as children with word-finding difficulties (WFDs) [6]. Word

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finding may be compromised by impairment of semantic processes (retrieving words as units of meaning), phonological processes (retrieving words as structures of speech sounds), motor planning (planning articulation), or motor execution (articulation) as well as by impairment in general processing speed [6, 13, 14]. These different sources of word-finding difficulties are partly reflected in distinct error profiles [6, 15], and they require different types of intervention [16]. For children with posterior fossa tumours, it is therefore important to clarify whether their error profiles resemble error profiles known from other diagnoses and/or from typical development.

The exact role of the cerebellum in successful word finding is unclear, but for each of the subprocesses of word finding, there is evidence suggesting that it may be involved [17–19]. One reason why cerebellar damage may compromise word finding is that the cerebellum is reciprocally linked to the neocortical areas involved in linguistic processing [20–24]. For most people, principal language-processing areas are located in the left cerebral hemisphere, and as each cerebral hemisphere sends and receives information to and from the contralateral cerebellar hemisphere [25], damage to the right cerebellar hemisphere can be expected to affect language. Indeed, for adults, neuroimaging and lesion studies converge on right-hemisphere cerebellar involvement in linguistic tasks [24, 26, 27], and for lexical retrieval specifically, there is evidence that right-sided cerebellar lesions disrupt naming and verbal fluency [22]. For children with posterior fossa tumours, there is preliminary evidence for right-hemisphere location increasing the risk of linguistic impairment after surgery [28, 29].

Before surgery, one study found linguistic impairment in more than a quarter of children with posterior fossa tumours, and word-finding difficulties were significantly associated with brainstem involvement, invasion of the right dentate nuclei, and severe hydrocephalus [30]. Effects of right-hemisphere vs. left-hemisphere location were not investigated.

In the current study we ask:

1. How many children with posterior fossa tumours experience word-finding difficulties, defined as slow and/or inaccurate word finding, before surgery?
2. How are preoperative word-finding difficulties associated with demographic and medical characteristics in children with posterior fossa tumours? For location, we hypothesise that right-hemisphere and brainstem locations increase the risk of word-finding difficulties relative to left-hemisphere location. For the remaining parameters, the analysis is explorative.
3. Do the word-finding errors we see in children with posterior fossa tumours resemble or diverge from the types known from other child populations with word-finding difficulties and/or from typical development?

Methods

Study design and setting

This crosslinguistic, cross-sectional study is part of an observational cohort study, the Nordic-European CMS study, described in detail elsewhere [31, 32]. We included children aged 5–17 years with a tumour in the posterior fossa who were treated at centres between 2014 and 2022 in Sweden, Denmark, Norway, the UK, Hungary, Italy, the Netherlands, and Lithuania. The study was approved by regional and national ethics committees. The participants were approached with information about the study by the child's physician, and legal caregivers provided written informed consent for all children.

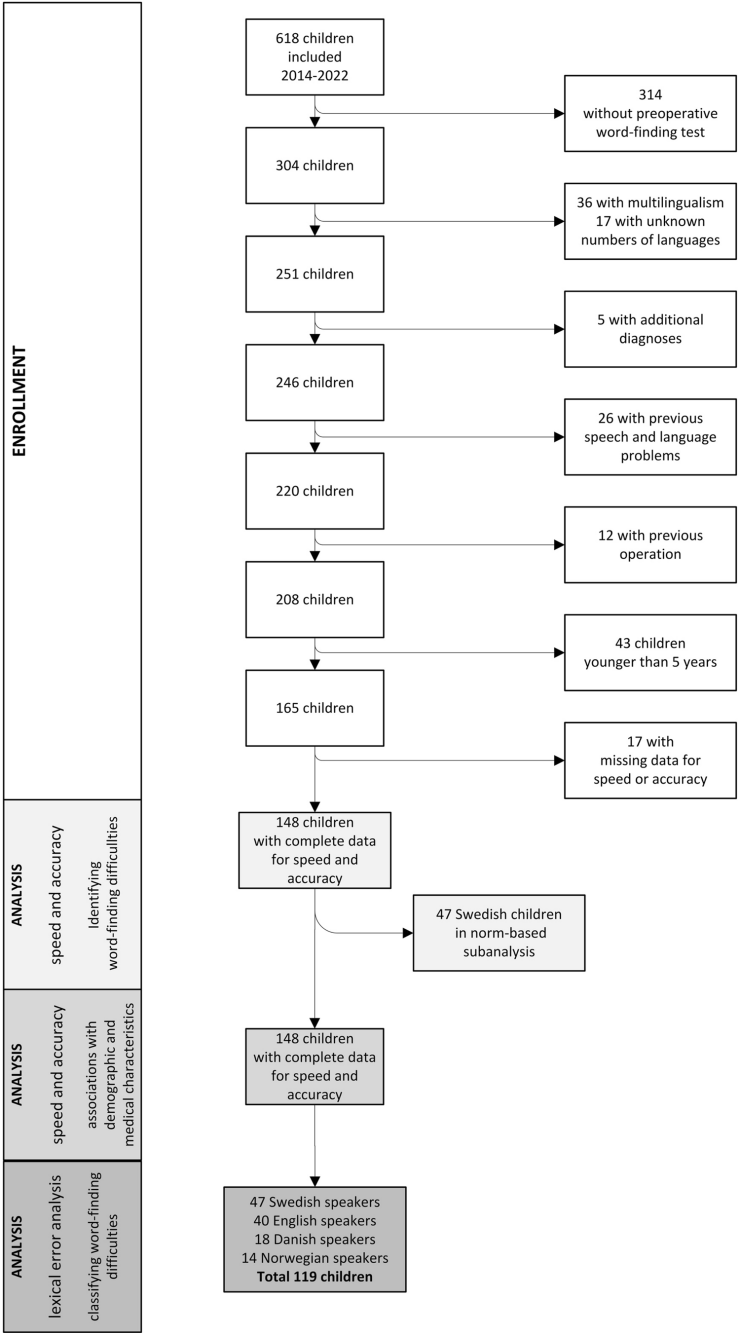
Participants

Between 2014 and 2022, 618 children younger than 18 years were included in the Nordic-European CMS study. We excluded multilingual children, children with additional diagnoses, previously reported speech and language disturbances and previous tumour surgery. Due to lack of norm data from children younger than five years for the assessment tool, we excluded children younger than 5 years old. We discarded data from children whose data for speed and/or accuracy were invalid due to experimenter error and included 148 children with complete data for both speed and accuracy. In a subanalysis utilising Swedish word-finding norms, 47 Swedish children were included. In a lexical error analysis, children from Sweden, Great Britain, Denmark, and Norway were included, in total 119 children. Figure 1 presents the inclusion process and the numbers of children included in each analysis.

Materials

To assess word-finding ability, we used the 25-item picture-naming test Wordrace which was designed for the Nordic-European CMS study as an instrument for assessing word-finding speed and accuracy [31, 33]. Details on Wordrace can be found in the online supplemental materials. Normative data is only available for Swedish, where a Master's thesis based on 299 typically developing children aged 5–15 years showed a negative correlation between age and speed in seconds (as children get older, they take fewer seconds to complete the task). Most of the children had no errors (named all items correctly). The Swedish norms are used in the Swedish subanalysis to evaluate word-finding performance in children with posterior fossa tumours.

Fig. 1 The inclusion process and the children included in each analysis



Data collection

Wordrace was administered at the hospitals by a physician, a nurse or a speech and language pathologist. Pictures were presented one at a time, on screen or on paper, and children were instructed to name the pictures as rapidly as possible. The test leader switched/browsed to the next picture as soon as a picture was named. If children failed to name a picture, they were not given any cues, and the next picture was shown after 5 s. The test procedure was audio recorded.

Preoperative demographic data on age, sex, dysarthria, hydrocephalus, oculomotor abnormalities, tumour location, and tumour histology were collected via study protocols by clinicians. Dysarthria was reported in four grading categories from normal to absent/unintelligible speech and oculomotor abnormalities were reported in four grading categories from normal to nystagmus. Hydrocephalus was reported as absent or present. Tumour location was reported postoperatively and could include more than one site in the posterior fossa: left hemisphere, right hemisphere, cerebellar vermis, fourth ventricle, and/or brainstem involvement. Tumour histology was reported as pilocytic or pilomyxoid astrocytoma (hereafter: pilocytic astrocytoma), medulloblastoma, ependymoma, atypical teratoid rhabdoid tumour, or other.

Analysis

Wordrace was scored by speech analysts in each country.¹ Two parameters were scored: speed (in seconds) and accuracy (number of correctly named pictures). Alternative responses were reported. We identified preoperative word-finding difficulties by means of cut-off values based on Swedish norms [8], results from other studies [7, 9, 10, 34] and clinical experience. Because the assessments were conducted in different formats (screen/paper), in different languages and by different professions, and because the sample included children with dysarthria, we set a generous cut-off for speed. This ensured specificity (i.e. only identifying children with genuinely slow word finding), but it compromised sensitivity (i.e. we cannot be sure that children *not* identified by our cut-off have normal word-finding speed). For speed, the cut-offs were ≥ 70 s for 5–9 years, ≥ 60 s for 10–12 years, and ≥ 55 s for 13–15 years. For accuracy, the cut-offs were ≥ 23 for 5–9 years and ≥ 24 for 10–17 years. A subanalysis was conducted comparing speed and accuracy with the Swedish norms.

For the Scandinavian languages and English a lexical error analysis was conducted, classifying alternative responses in 13 categories, in accordance with earlier research [11]. To examine interrater reliability, two speech

and language therapists with more than 15 years of clinical experience categorised the alternative responses independently with agreement on 86% of the 92 alternative responses. Cases with disagreement were discussed, and consensus reached.

Dysarthria and oculomotor abnormalities were classified as absent or present. For tumour type, we used the classification from the study protocol (see “Data collection” section), with the exception that atypical teratoid rhabdoid tumour ($n = 1$) was categorised as “other”.

Tumours were reported as being in numerous combinations of locations, and we grouped these in five categories:

1. Left cerebellar hemisphere (including max. one other location: vermis, fourth ventricle or brainstem)
2. Right cerebellar hemisphere (including max. one other location: vermis, fourth ventricle or brainstem)
3. Vermis (including max. one other location: fourth ventricle or brainstem)
4. Brainstem (including max. one other location: fourth ventricle)
5. Other (tumour extending into three or more locations, fourth ventricle)

These broad categories were used for statistical analysis, but for transparency, we specify subcategories of location in the tables.

Results

Demographics are shown in Table 1. Most children were speakers of a Scandinavian language (52%) or English (29%), and 6% had preoperative dysarthria.

Identification of preoperative word-finding impairment

Thirty-seven percent ($n = 55$) of the children were identified as having slow word-finding, defined as exceeding our cut-offs for speed (see Table 2). Four of them had dysarthria.

Twenty-four percent ($n = 35$) of the children were identified as having inaccurate word-finding, defined as naming fewer of the pictures correctly than required by our cut-offs for accuracy (see Table 2). Three of them had dysarthria.

Accuracy and speed could be independently impaired but 16% ($n = 23$) of the children had problems in both speed and accuracy, as illustrated by Fig. 2.

For the subset of Swedish children with posterior fossa tumours, we compared performance with norms from typically developing children (5–9 years: $n = 206$, 10–12 years: $n = 57$, 13–15 years: $n = 36$). As demonstrated in Fig. 3, there were radical differences in mean speed, with children with posterior fossa tumours taking approximately twice the

¹ With the exception of English, which was scored centrally.

Table 1 Demographic data

	Participants aged 5–17 (N = 148)
Age categories, years, <i>n</i> (%)	
(median, Q1,Q3)	9;8, 7;2, 12;9
5–9	77 (52)
10–12	35 (24)
13–17	36 (24)
Gender, <i>n</i> (%)	
Female	70 (47)
Male	78 (53)
Language, <i>n</i> (%)	
Swedish	47 (32)
English	40 (27)
Danish	18 (12)
Norwegian	14 (9)
Hungarian	12 (8)
Italian	6 (4)
Dutch	5 (3)
Lithuanian	6 (4)
Dysarthria, <i>n</i> (%)	
Present	8 (5)
Absent	120 (81)
Unknown	20 (14)
Tumour location, <i>n</i> (%)	
Left cerebellar hemisphere	25 (17)
LCH	17 (11)
LCH + VR/FV	6 (4)
LCH + BS	2 (1)
Right cerebellar hemisphere	34 (23)
RCH	22 (15)
RCH + VR/FV	8 (5)

Table 2 The distribution of children's performance in speed and accuracy based on cut-off values with language, test format and motor speech status specified

Speed	Accuracy			
	Fast word-finding	Slow word-finding	Accurate word-finding	Inaccurate word-finding
All	93 (63)	55 (37)	113 (76)	35 (24)
Language				
Swedish	27 (57)	20 (42)	36 (83)	11 (23)
English	27 (68)	13 (33)	27 (68)	13 (33)
Danish	16 (89)	2 (11)	14 (78)	4 (22)
Norwegian	9 (64)	5 (36)	13 (93)	1 (7)
Hungarian	5 (42)	7 (58)	5 (42)	7 (58)
Italian	5 (83)	1 (17)	6 (100)	0 (0)
Lithuanian	1 (17)	5 (83)	5 (83)	1 (17)
Dutch	3 (60)	2 (40)	5 (100)	0 (0)
Test format				
Paper	29 (49)	30 (61)	42 (71)	17 (29)
Screen	64 (72)	25 (28)	71 (80)	18 (20)
Dysarthria				
Yes	4 (50)	4 (50)	5 (63)	3 (38)
No	73 (61)	47 (39)	95 (79)	25 (21)
Unknown	16 (80)	4 (20)	13 (65)	7 (35)

The distribution is in *n* (%)

Table 1 (continued)

	Participants aged 5–17 (N = 148)
RCH + BS	4 (3)
Vermis	25 (17)
VR	16 (11)
VR + FV	6 (4)
VR + BS	3 (2)
Brainstem	17 (11)
BS	13 (9)
BS + FV	4 (3)
Other ^a	47 (32)
Tumour histology, <i>n</i> (%)	
Pilocytic astrocytoma	62 (42)
Medulloblastoma	47 (32)
Ependymoma	12 (8)
Other	14 (9)
Unknown	13 (9)
Hydrocephalus, <i>n</i> (%)	
Present	89 (60)
Absent	53 (36)
Unknown	6 (4)
Oculomotor abnormalities, <i>n</i> (%)	
Present	39 (26)
Absent	88 (59)
Unknown	21 (14)

The data are in *n* (%)
LCH left cerebellar hemisphere, *RCH* right cerebellar hemisphere, *BS* brainstem, *VR* vermis, *FV* fourth ventricle
^aOther: tumour extending into three or more locations and tumour located in only forth ventricle

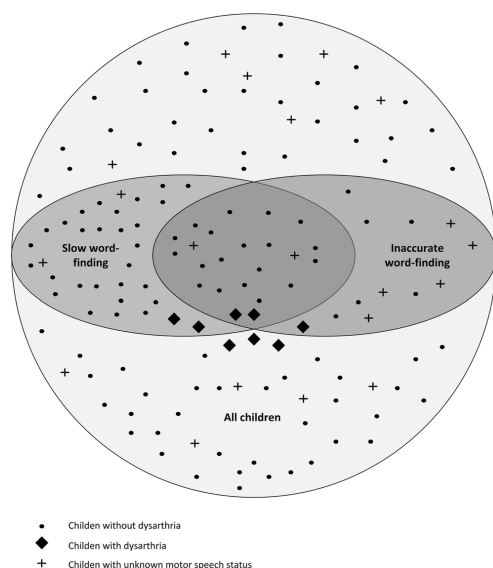


Fig. 2 Distribution of children with and without impairment in speed and/or accuracy. Motor-speech status is specified

time compared to typically developing children and even the oldest children with tumours being much slower than the youngest children in the norming sample. For accuracy, in contrast, the differences were negligible.

Associations with demographic and medical characteristics

We compared the demographic and medical characteristics of children without word-finding difficulties, with slow word finding, with inaccurate word finding, and with both slow and inaccurate word finding (Table 3). For the hemispheric tumours central to our hypothesis, there was a clear lateralisation difference between the groups without word-finding problems and with combined slow and inaccurate word finding: for children without word-finding problems, 20% had the tumour located in the left hemisphere, 16% in the right, whereas for children with combined word-finding problems, 4% had the tumour located in the left hemisphere, and more than seven times as many, 30%, in the right. The distribution of hemispheric tumours differed significantly between these two groups (Fisher's exact: $p < 0.05$). Brainstem location also increased the risk for severe impairment relative to left-hemisphere location, with 17% brainstem tumours in the group with combined word-finding difficulties compared

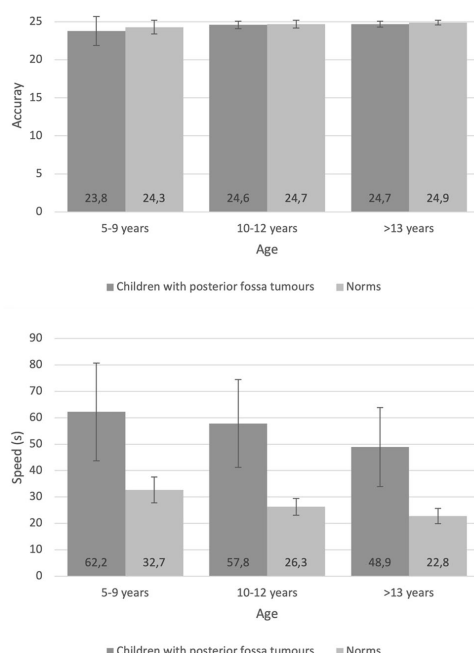


Fig. 3 Performance in speed and accuracy in Swedish children with posterior fossa tumours compared with the Swedish norms (means and standard deviations). Speed is in seconds and accuracy in number of correct responses

to 7% in the group without word-finding difficulties (Fisher's exact: $p < 0.05$). For children with a right-hemisphere or brainstem tumour, the odds of having combined word-finding difficulties were 2.99 times those of children with all other tumour locations (95% CI: 1.1383–7.8607, $p < 0.05$). Vermian tumours were frequent in children with combined difficulties (26%), but not significantly more than in children without difficulties (19%).

There was a significant difference between sex distribution in children with both slow and inaccurate word finding (70% males) and children without word-finding difficulties (46% males; $\chi^2 = 4.0897$, $p < 0.05$), and the odds of boys having combined difficulties were 2.72 times those of girls (95% CI: 1.0100–7.3149, $p < 0.05$). Oculomotor abnormalities were (non-significantly) more frequent in the group with slow and inaccurate word finding (45%) than in the group without word-finding difficulties (26%, $\chi^2 = 2.6244$, $p = 0.10523$). There were no significant effects of tumour histology, dysarthria or hydrocephalus.

Table 3 Demographic and medical characteristics of children with no difficulties, slow word finding, inaccurate word finding, and children with both slow and inaccurate word finding

Parameters	No word-finding difficulties	Slow word-finding	Inaccurate word-finding	Both slow and inaccurate word-finding
	81 children	55 children	35 children	23 children
Sex				
Male	37 (46)	29 (53)	21 (60)	16 (70)
Female	44 (54)	26 (47)	14 (40)	7 (30)
Age				
Mean	9:8	10:5	10:4	9:8
Median (range)	9:2 (5–17:9)	10:4 (5:3–17:9)	10:9 (5:3–16:1)	10:3 (5:8–16:1)
Tumour histology, <i>n</i> (%)				
Pilocytic astrocytoma	34 (48)	23 (43)	19 (58)	14 (61)
Medulloblastoma	26 (37)	17 (32)	9 (27)	6 (26)
Ependymoma	8 (11)	3 (6)	2 (6)	1 (4)
Other	3 (4)	10 (19)	3 (9)	2 (9)
Unknown	10	2	2	0
Tumour location, <i>n</i> (%)				
Left cerebellar hemisphere	16 (20)	8 (15)	2 (6)	1 (4)
LCH	11 (14)	5 (9)	2 (6)	1 (4)
LCH + VR/FV	3 (4)	3 (5)	0 (0)	0 (0)
LCH + BS	2 (2)	0 (0)	0 (0)	0 (0)
Right cerebellar hemisphere	13 (16)	18 (33)	10 (29)	7 (30)
RHC	12 (15)	8 (15)	4 (11)	2 (9)
RCH + VR/FV	1 (1)	7 (13)	3 (9)	3 (13)
RCH + BS	0 (0)	3 (5)	3 (9)	2 (9)
Vermis	15 (19)	8 (15)	8 (23)	6 (26)
VR	9 (11)	6 (11)	5 (14)	4 (17)
VR + FV	4 (5)	2 (4)	2 (6)	2 (9)
VR + BS	2 (2)	0 (0)	1 (3)	0 (0)
Brainstem	6 (7)	10 (18)	5 (14)	4 (17)
BS	4 (5)	8 (15)	5 (14)	4 (17)
BS + FV	2 (2)	2 (4)	0 (0)	0 (0)
Other ^a	31 (38)	11 (20)	10 (29)	5 (22)
Dysarthria, <i>n</i> (%)				
Present	3 (4)	4 (8)	3 (11)	2 (10)
Absent	67 (96)	47 (92)	25 (89)	19 (90)
Unknown	11	4	7	2
Hydrocephalus, <i>n</i> (%)				
Present	48 (62)	34 (65)	20 (57)	13 (57)
Absent	30 (38)	18 (35)	15 (43)	10 (43)
Unknown	3	3	0	0
Oculomotor abnormalities, <i>n</i> (%)				
Present	18 (26)	21 (42)	9 (32)	9 (45)
Absent	51 (74)	29 (58)	19 (68)	11 (55)
Unknown	12	5	7	3

The data are in *n* (%). The unknown data are not included in the percent calculations

LCH left cerebellar hemisphere, *RCH* right cerebellar hemisphere, *BS* brainstem, *VR* vermis, *FV* fourth ventricle

^aOther tumour extending into three or more locations and tumour reported as located in only fourth ventricle

Table 4 The frequency distribution of responses linguistically categorised in Wordrace

Total responses	2975		
In accordance with target word	2883		
Not in accordance with the target word	92		
Types of errors	Number of errors	Percentage of all errors	Percentage of all responses
No response/aborted response	41	45	1.4
Related sideordinated word ^a	28	30	1.0
Contextual association	6	7	0.2
Unrelated	7	8	0.2
Visual association	5	5	0.2
Subordinated word	1	1	0.0
Unrelated sideordinated word ^b	2	2	0.1
Superordinated word	1	1	0.0
Neologism	1	1	0.0

^aSemantically closely related^bSemantically in the same category but not closely related

Classification of word-finding errors

In 92 cases (3% of all responses), the child's response was not in accordance with the target word, and in 41 of these, the child did not produce any word ("no response/aborted response"). In the remaining 51 cases, the child produced an alternative response. Among a variety of alternative response types (see Table 4), choosing a sideordinated word, i.e. a semantically closely related word (e.g. "pear" for "apple"), was the most frequent type of lexical error ($n=28$).

Discussion

Word-finding difficulties are commonly reported after posterior fossa surgery, and this crosslinguistic study contributes new knowledge about the effect of posterior fossa tumours on word-finding abilities prior to surgery. Analysing word-finding performance in eight different languages, we found that 37% of the children were slower than expected for their age, 24% were less accurate, and 16% were both slower and less accurate. A subanalysis demonstrated that the subset of Swedish children was twice as slow as typically developing children. As predicted by functional cerebellar topography, right-hemisphere location posed a higher risk for preoperative word-finding difficulties than left-hemisphere location. Brainstem location was also associated with preoperative word-finding difficulties, as was male sex. The most frequent error types were lack of response and semantically related sideordinated words.

Preoperative word-finding difficulties: prevalence and factors

Our results replicate a previous finding by di Rocco and colleagues, who found that preoperative word-finding difficulties are frequent in children with posterior fossa tumours [30]. In their Italian sample, word-finding difficulties were present in 26.8%, i.e. a similar proportion to the 24% presenting inaccurate word finding in our crosslinguistic sample. We found a higher proportion of children with slow word finding (37%), but di Rocco and colleagues did not specify impairment in speed.

Based on evidence from adults [22, 26, 27] and children [28, 29], we hypothesised that tumour location in the right cerebellar hemisphere would increase the risk of word-finding difficulties relative to left-hemisphere location. Our results provided support for this hypothesis and thus support theories of functional cerebellar topography [26, 27] and cerebellar language lateralisation [24]. We also replicated a previous finding that brainstem involvement increases the risk of preoperative word-finding difficulties [30]. Our analyses of the remaining parameters were explorative, and we found no significant effects of tumour histology, dysarthria, or hydrocephalus. At first sight, it may be surprising that we found no differences between tumour types given that medulloblastoma is a known risk factor for postoperative cerebellar mutism [32]. In our preoperative sample, the share of children with medulloblastoma or ependymoma was slightly *lower* in children with both slow and inaccurate word finding, whereas the share of children with pilocytic

astrocytoma was slightly higher, but this difference was non-significant. Our results may indicate that the negative effect of medulloblastomas depends on events associated with their surgical removal, not on effects of the tumour itself. We did observe a significant effect of sex, with a higher prevalence of boys with both slow and inaccurate word finding, aligning with studies of other populations where the proportion of language-impaired males is typically also higher [35, 36].

Word-finding errors

Two types of errors accounted for most of the errors in our sample: (1) failure to produce any word and (2) semantically related sideordinated words (such as “swan” for “goose”). This pattern resembles the one seen in both typically developing children and children with WFDs [7, 11, 15]. The many semantically related errors reveal that the mental lexicons of children with posterior fossa tumours are still robustly organised in categories. There may be many explanations why children do not settle on the right word even when searching in the correct semantic category, for instance, underspecified representations of word meanings and/or slower processing speed [6]. The semantic errors indicate impairment at the level of semantic retrieval, and for individual children with many such errors, semantic intervention developed for children with WFDs may prove useful [16]. Errors involving failure to produce a word are more difficult to interpret, as they may arise from several reasons, including semantic, phonological, or speed-related difficulties, and may also reflect behavioural styles [11, 15].

Limitations and future directions

Wordrace lacks norms except for Swedish, so to identify word-finding difficulties, we created cut-off values, based on Swedish norms, other studies, and clinical experience. For speed, the cut-off values were generous, to ensure test specificity, but test sensitivity is likely to have been compromised, and we may not have identified all children with slow word-finding speed. We therefore consider this study a first step and hope that future studies will be able to identify word-finding impairment more precisely using age- and language-specific norms. We strongly encourage norming of Wordrace in more languages because it is a highly useful word-finding test, posing minimal demands on executive control and lexicon, contrary to other instruments, such as the Boston Naming Test (BNT) [37] and verbal fluency tests [38–40].

As for tumour location, the study protocol provided information in the sense of listing all areas encroached on by the tumour, but it did not provide information about *main* location or about how much the tumour infiltrated any of the locations listed. Such information would make

the analysis of associations between tumour location and word-finding difficulties more precise. Within the larger Nordic-European CMS study, MRI data have been collected, and they will provide the basis for future studies with more granular location information.

Our analysis of medical characteristics also revealed a potential source of error to be checked in future studies: oculomotor abnormalities were overrepresented in children with combined slow and inaccurate word finding. While the difference in distribution was non-significant, we cannot exclude that some children identified as having word-finding problems were in fact impeded by impaired visual processing of the visual test stimuli.

Assessing preoperative word-finding difficulties provides a baseline for evaluating postoperative word-finding difficulties, making it possible to examine to which degree these reflect exacerbation or improvement of word-finding abilities prior to surgery. A predictive relationship has been found between preoperative language impairment and postoperative CMS [4], and in future studies, it will also be important to investigate whether children with preoperative word-finding difficulties are at a higher risk of developing postoperative word-finding difficulties and CMS. For children whose preoperative word-finding difficulties do not resolve after tumour resection, future studies should investigate whether they will benefit from word-finding interventions developed for children with WFDs. Supporting children's word-finding ability is important, as word-finding difficulties affect well-being and participation in everyday life.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00381-023-06119-4>.

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Author contribution All co-authors took part in the collection of data. K. Persson, D. Boeg Thomsen, A. Troks-Berzinskiene, B. Andreozzi, and K. van Baarsen, J. Jakus contributed in analysing speech samples. K. Persson, D. Boeg Thomsen, Å. Fyrberg, C. Castor, and I. Tiberg contributed to data analysis and interpretation. K. Persson prepared the first draft of the manuscript. D. Boeg Thomsen, Å. Fyrberg, C. Castor, and I. Tiberg gave feedback on the manuscript. K. Persson and D. Boeg Thomsen prepared the final draft of the manuscript. All authors approved the final version of the manuscript.

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Data availability Due to ethical considerations, data associated with this paper cannot be accessed.

Declarations

Ethics approval This study was approved in Denmark by the Research Ethics Committees of the Capital Region (H-6–2014-002) and subsequently approved locally in all participating countries.

Conflict of interest The authors declare no financial, personal, or other conflict of interest.

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Paper II





Postoperative word-finding difficulties in children with posterior fossa tumours: a crosslinguistic European cohort study

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Abstract

Purpose Posterior fossa tumour (PFT) surgery carries a risk of mutism or severely reduced speech. As for higher-cognitive language functions, word-finding difficulties have been reported, but no study has compared pre- and postoperative word-finding speeds to identify impairment caused by surgery. The current study investigated changes in word-finding ability associated with PFT surgery and examined factors affecting postoperative ability.

Method We included 184 children aged 5:0–17:9 years undergoing PFT surgery and assessed word-finding ability before and after surgery using a speeded picture-naming test. We compared postoperative word-finding performance with both preoperative performance and age-specific norms and examined factors affecting word-finding ability.

Results We found no significant difference between pre- and postoperative performance, reflecting that some children exhibited better word-finding ability after surgery, others poorer. After surgery, 95% of the children performed two standard deviations above (slower than) age-specific norms. Tumour location in the fourth ventricle negatively affected postoperative word-finding ability ($B = -4.09$, $p < 0.05$).

Conclusion For some children, PFT surgery leads to postoperative word-finding difficulties, emphasizing the importance of postoperative language assessments and interventions. Fourth-ventricle tumour location emerged as a risk factor for poorer postoperative word-finding ability, likely reflecting surgical damage to the dentato-thalamo-cortical pathway (DTCP).

Keywords Cerebellar mutism syndrome · Child language · Language impairment · Postoperative speech impairment (POSI) · Posterior fossa tumour · Word-finding difficulties

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Introduction

Posterior fossa tumours comprise about half of all central nervous system tumours in children [1]. Surgical resection is essential, aiming to cure the patient and to alleviate the burden of acute symptoms, but carries a risk of complications, notably the development of cerebellar mutism syndrome (CMS) in approximately a quarter of affected children [2]. CMS is characterized by mutism or severely reduced speech, denoted as postoperative speech impairment (POSI) [3], emotional lability and other neurological deficits [4]. Symptoms typically have a delayed onset, emerging on average around 2 days post-surgery but can appear anywhere from the day of surgery up to 15 days later [5]. The condition can last weeks to months and can lead to persistent speech, language and/or communication impairments [4, 5]. POSI can evolve into a motor speech disorder, often described as dysarthria, with slow speech rate, monotonous tone and ataxic speech [6, 7]. Language impairments following POSI are still poorly understood with current studies suggesting that these impairments may involve both comprehension and production, affecting both morphosyntax and lexical semantics [8–10]. Even children who do not suffer from POSI may exhibit postoperative language impairments [10, 11]. The severity can vary, suggesting a continuum of postoperative language impairments [12, 13]. This study focuses on a specific lexical ability: word-finding ability. Word-finding ability refers to the capacity to quickly and accurately retrieve the appropriate word from the mental lexicon [14]. Word finding involves several processes: the semantic process (retrieving words as units of meaning), the phonological process (retrieving words as structures of speech sounds) and speech processes for planning and executing articulation [15, 16]. It further depends on general processing speed [17]. The cerebellum is suggested to be involved in each of these processes [18–20], and impairments in any or a combination of these may contribute to word-finding difficulties in children with posterior fossa tumour (PFT). PFTs have been shown to be associated with word-finding difficulties both pre- and postoperatively [8, 21, 22], with preoperative difficulties linked to the tumour itself and postoperative impairments primarily attributed to the effects of surgery. Di Rocco et al. (2011) reported that 12% of the children undergoing PFT surgery in their sample experienced postoperative word-finding difficulties [8]. However, the test they used for assessing word-finding abilities (Boston Naming Test) [23] only measured word-finding accuracy, not speed, which, as previously mentioned, is a crucial aspect of the word-finding process [15–17], and the actual prevalence of postoperative word-finding difficulties may thus be much higher. As

for lexical-semantic difficulties in general, the review by Svaldi et al. highlights that the quality of the current available evidence is low, and that there is no clear understanding of the nature or duration of impairments post-surgery. They conclude that postoperative difficulties are common, but the prevalence and severity vary across studies [24]. Children with tumours in the right cerebellar hemisphere or brainstem have been shown to be at higher risk of having preoperative word-finding difficulties [21, 22]. The finding of an effect of right cerebellar hemisphere location supports theories of functional cerebellar topography and cerebellar language lateralization, which propose the involvement of this hemisphere in linguistic processing, including word-finding tasks [25–28]. To our knowledge, only one study has investigated risk factors for postoperative word-finding difficulties [22]. As part of a larger study of neurological, neuropsychological and behavioral impairment in children undergoing PFT surgery, di Rocco et al. found that postoperative word-finding difficulties were associated with invasion of the brainstem and the right dentate nucleus. No association was found for tumour type, preoperative hydrocephalus or location (operationalized coarsely as midline vs. hemispheric) [22]. While the study carefully investigated both pre- and postoperative word-finding abilities, preoperative performance was not used as a baseline for analyzing postoperative change, and it is thus uncertain to which degree the factors associated with postoperative word-finding difficulties were related to surgery or had already caused poor word-finding abilities before surgery. Further, as this study too depended on the use of the Boston Naming Test for evaluating word-finding ability, factors potentially affecting word-finding speed could not be investigated. For language impairment more broadly, the review by Svaldi et al. found tumour location in the brainstem or in the fourth ventricle to be associated with a high risk of postoperative linguistic impairment, but as they stressed, this observation depended on a small sample size [24]. For POSI, tumours involving the right dentate nucleus, brainstem compression or infiltration, fourth ventricle tumours, diagnosis of medulloblastoma and younger age have been identified as significant risk factors [3, 29]. For medulloblastomas, molecular profiling has advanced classification beyond histology, identifying four subgroups: wingless (WNT), sonic hedgehog (SHH), group 3 and group 4. Group 3 and group 4 tumours, often midline and larger, carry a higher risk of CMS, while SHH tumours have the lowest risk [30]. For surgical approach, the evidence is mixed. The telovelar surgical approach has been suggested to carry a lower risk of CMS compared to the transvermian approach [31–35], but the largest studies of posterior fossa tumours in children did not identify an association between surgical approach and the risk of POSI [3, 36]. Furthermore, larger tumour volume

has been proposed as a risk factor, with more extensive lesions potentially requiring greater surgical manipulation and increasing the risk of CMS [36, 37]. Preoperative hydrocephalus is less well investigated [38] and may not directly cause POSI, but could exacerbate the severity of the condition [22, 39]. Word-finding difficulties might occur on a continuum with children suffering from POSI at one end of the continuum and children with mild word-finding difficulties at the other, and risk factors for more severe degrees of impairment need exploration. Understanding the continuum of difficulties affecting children postoperatively has potential to inform the development of targeted assessments and rehabilitation interventions.

In the current study, we aimed to:

- (1) Investigate if children with PFT exhibit postoperative word-finding difficulties. We hypothesized that children with PFT would exhibit significant impairments in word-finding abilities compared to age-specific norms.
- (2) Investigate changes in word-finding performance from pre- to postoperative testing in children with PFTs. We hypothesized that children would experience an impairment in word-finding ability postoperatively, with a worse degree associated with dysarthria and POSI.
- (3) Investigate factors affecting postoperative word-finding ability. We hypothesized that right-hemisphere, brain-stem and fourth ventricle involvement would be associated with an elevated risk of postoperative word-finding difficulties compared to other tumour locations. For the remaining factors (other tumour location, tumour histology, preoperative hydrocephalus, sex and age), the analysis was explorative.

Methods

Study design and settings

The present study is an observational cohort study conducted as part of the Nordic-European CMS study, which has been described elsewhere [40]. Children who underwent tumour surgery in the posterior fossa in Austria, Czech Republic, Denmark, Finland, Germany, Hungary, Italy, Lithuania, Norway, Sweden, The Netherlands and UK between 2014 and 2024 were included. Regional and national ethics committees approved the study.

Participants

Between August 2014 and January 2024, 725 children aged below 18 years were included in the Nordic-European CMS study. To minimize the influence of any confounding factors, we excluded those with additional diagnoses such as

neuropsychological disorders (e.g. autism, ADHD), previously reported speech and language disorders, previous tumour surgery, children younger than 5 years (due to lack of norm data), multilingual children and those from countries with fewer than 10 observations. Invalid data due to experimenter error were also discarded. The final sample included 184 children from Sweden, Denmark, Norway, Italy, Lithuania, UK and Hungary with valid word-finding data pre- and/or postoperatively. Of these, 49 Swedish children were included in a subanalysis using Swedish age-specific word-finding norms. Figure 1 presents the inclusion process, and the children included in each analysis.

Materials

The 25-item picture-naming test Wordrace was used to assess word-finding ability. The instrument was developed for the Nordic-European CMS study to measure word-finding ability, measured as *total number of correct words* and *total test time* [40, 41]. Details on Wordrace can be found in previously published online supplemental materials [21]. Currently, normative data for Wordrace is available for the Swedish language in a master's thesis involving 299 typically developing Swedish children aged 5–15 years. Results showed a negative correlation between total test time and age (i.e. older children name the items faster). Most children in the study completed the test without errors [42]. Given that language- and age-specific norms are only available for Swedish, we only include data from our Swedish participants in the subanalysis evaluating postoperative word-finding difficulties compared to norms.

Data collection

Wordrace was administered by a physician, nurse or speech and language pathologist at the pediatric oncology centres. Preoperative tests were conducted close to the surgery date and postoperative tests within 1–4 weeks after surgery. The 25 pictures were presented one at a time, either on a screen or on paper, and children were instructed to name them quickly. The test leader immediately switched to the next picture once a picture was named. If a child failed to name a picture, no additional cues were provided, and the next picture was displayed after 5 s. The test procedure was audio-recorded and stored in the Nordic-European CMS database. Demographic data, including birthdate, sex, presence of dysarthria, tumour location, histology, hydrocephalus and presence and duration of mutism and/or reduced speech, were collected by physicians and stored in the database. Dysarthria was reported on a four-point scale from normal to absent/unintelligible speech as judged by the physician, with separate reports for preoperative and postoperative dysarthria. Tumour location, reported by the surgeon after

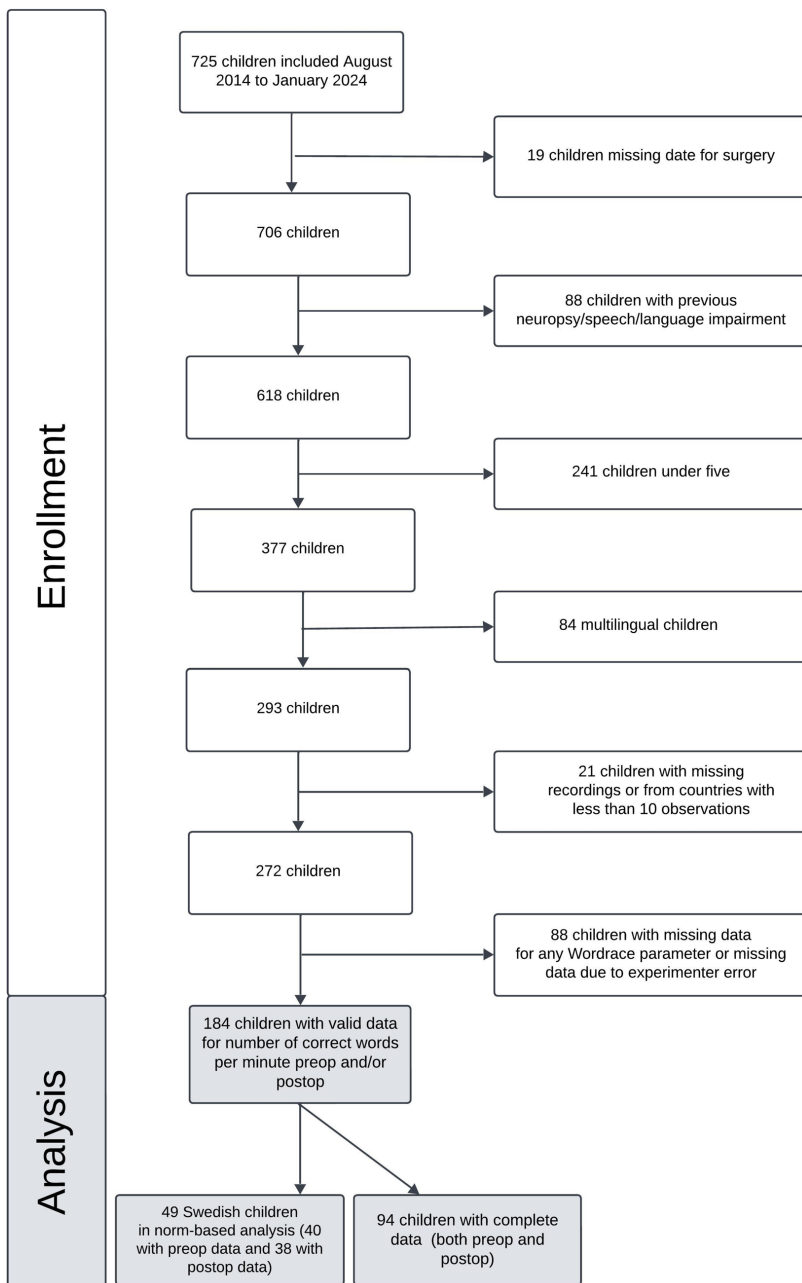


Fig. 1 The inclusion process and the children included in each analysis.

surgery, could include more than one site in the posterior fossa: left cerebellar hemisphere (LCH), right cerebellar hemisphere (RCH), cerebellar vermis (VR), fourth ventricle (FV) and/or brainstem involvement (BS). Tumour histology was categorized as pilocytic astrocytoma, medulloblastoma, ependymoma, atypical teratoid rhabdoid tumour or other. Data regarding subgroup of medulloblastoma was collected when available as part of standard of care. Hydrocephalus was reported as absent or present, with separate reports for preoperative and postoperative hydrocephalus. Mutism was defined as “absence of speech with no production of words or short sentences, but crying or whining can still be produced in some children”. Reduced speech was defined as “severely reduced speech production limited to single words or short sentences, which can only be elicited after vigorous stimulation”. The number of days of mutism or reduced speech was also reported.

Coding

Wordrace was scored by speech analysts in each country, with the exception of UK, which was scored centrally. Two parameters were scored separately: total correct words and total test time. This scoring approach entails the risk that children who self-correct may achieve a poorer outcome in total test time despite being linguistically superior to those producing incorrect responses. To avoid this error, the current study integrated the two measures and used the number of correct words per minute as the main outcome. Words per minute was calculated as: $(60 \times \text{number of correct words}) / \text{total test time in seconds}$. For example, if a child completes the test in 77 s and correctly names 22 words, their score would be approximately 17.14 words per minute. The original measures, total correct words and total test time, were used as outcomes in the analysis utilizing Swedish age-specific norms, as no norms for the integrated measure were available. In analyzing factors affecting postoperative word-finding ability, we investigated the influence of each of the five possible tumour locations separately, treating each location as a binary variable (location involved: yes/no). Tumour histology was classified into three categories: pilocytic astrocytoma, medulloblastoma and other. Molecular subgrouping data for medulloblastomas was not included due to substantial missing data, which rendered further analyses infeasible. Dysarthria was classified as absent or present. Age was calculated by determining the time between the child's birthdate and date of surgery.

Statistical analysis

We compared the total number of correct words and the total test time among the Swedish children in the cohort

with age-specific Swedish norms. We identified postoperative word-finding difficulties by using cut-off levels of 1 and 2 standard deviations below the Swedish norm. For the second analysis we used a paired t-test to determine a possible difference between the pre- and postoperative correct words per minute measure in children who underwent both pre- and post-op assessments. We used descriptive statistics to describe the relationship between the changes and POSI on the one hand and dysarthria on the other. To analyze factors affecting postoperative word-finding ability, we used linear mixed-effect models. These models incorporate words per minute as outcome, and all factors were examined in interaction with timepoint (pre vs. post) to detect the effect of surgery. Main effects apply to the entire dataset, both pre- and postoperative, and do not indicate the effect of surgery. All models included participants and language as random effects. Observations were excluded if they had missing values for any variables in the model, except for words per minute. The models include cases with only preoperative, only postoperative or both measurements. The models were built in steps, exploring the effects of tumour location, tumour histology, hydrocephalus, sex, age, dysarthria and test format. For the model with multiple independent variables, a backward selection approach was used, starting with the maximal model comprising all predictors. Models were compared using the Akaike Information Criterion (AIC), where lower values indicate a better fit [43]. Statistical analyses were conducted in RStudio (Copyright (C) 2022 by Posit Software, PBC, Version 2023.12.1+ 402). To account for different effects across age, we used a spline technique where we incorporated two knots at distinct age intervals at 7 and 12 years. The knots were chosen based on knowledge of lexical development, with substantial increase in vocabulary exposure in school and reorganization of children's vocabulary during the early school years and at puberty onset [44, 45].

Results

Most children were speakers of a Scandinavian language (54%) or English (21.3%). Out of the 184 children, 37 (20.1%) were reported to have had POSI. Among these, 25 had experienced reduced speech which persisted for 2 to 21 days (median 3 days), and 12 had suffered from mutism which lasted from 1 to 7 days (median 1.5 days). Of the children with POSI, 16 had postoperative dysarthria, equally divided between those with mutism (8) and those with reduced speech (8). Demographic data for all children, for the subset with complete data and for the Swedish subset are presented in Table 1.

Table 1 Demographic data for all children, all children with complete data and for all Swedish children

	All children <i>n</i> = 184	All children with complete data <i>n</i> = 94	All Swedish children <i>n</i> = 49
Age (median, Q1, Q3)	9.8, 7.4, 12.9	10.9, 8.0, 13.3	9.8, 7.5, 11.5
Sex, <i>n</i> (%)			
Girls	87 (47.3)	47 (50)	23 (46.9)
Boys	97 (52.7)	47 (50)	25 (53.1)
Language, <i>n</i> (%)			
Swedish	49 (26.6)	29 (30.6)	–
English	47 (25.5)	20 (21.3)	–
Danish	29 (15.8)	9 (9.6)	–
Norwegian	23 (12.5)	13 (13.8)	–
Hungarian	13 (7.1)	9 (9.6)	–
Lithuanian	12 (6.5)	8 (8.5)	–
Italian	11 (6.0)	6 (6.4)	–
POSI, <i>n</i> (%)			
Mute	12 (6.9)	4 (4.8)	4 (9.8)
Reduced speech	25 (14.4)	8 (9.5)	9 (22.0)
Habitual speech	136 (78.7)	72 (85.7)	28 (68.2)
Unknown	11	10	8
Tumour location, <i>n</i> (%)			
LCH (yes)	53 (30.1)	28 (31.1)	17 (36.1)
RCH (yes)	64 (36.4)	36 (40.0)	17 (36.1)
VR (yes)	73 (41.5)	31 (34.4)	22 (46.9)
FV (yes)	65 (36.9)	31 (34.4)	20 (42.6)
BS (yes)	33 (18.8)	17 (18.9)	9 (19.1)
Unknown	8	4	2
Tumour histology, <i>n</i> (%)			
Pilocytic astrocytoma	85 (51.8)	41 (48.2)	20 (48.8)
Medulloblastoma	51 (31.1)	27 (31.7)	14 (34.1)
Other	28 (17.1)	17 (20.0)	7 (17.1)
Unknown	20	9	8
Dysarthria, pre- postop, <i>n</i> (%)			
Present	7 (4.7), 23 (15.4)	4 (4.7), 12 (15.2)	0 (0), 6 (13.6)
Absent	144 (95.4), 126 (84.6)	82 (95.3), 67 (84.8)	44 (100), 38 (86.4)
Unknown	33, 35	8, 15	5, 5
Hydrocephalus, pre- postop, <i>n</i> (%)			
Present	121 (67.2), 13 (8.0)	63 (69.2), 3 (3.6)	32(65.3) 2 (5.1)
Absent	59 (32.8), 149 (91.9)	28 (30.8), 80 (96.4)	17(34.7) 37 (94.9)
Unknown	4, 22	3, 11	10, 10

POSI postoperative speech impairment, *LCH* left cerebellar hemisphere, *RCH* right cerebellar hemisphere, *BS* brainstem, *VR* vermis, *FV* fourth ventricle, *Other* ependymoma, *AT/RT* and other tumours

Postoperative word-finding difficulties

To identify word-finding difficulties, we compared patients' performance with norms from typical development, and as language- and age-specific norms for Wordrace are only available for Swedish, this norm-based analysis was conducted on the subset of Swedish children (*n* = 49). Of these, 40 had a preoperative assessment and 38 had a postoperative assessment. We compared both their preoperative and their

postoperative performance with norms from typically developing Swedish children (5–9 years: *n* = 206, 10–12 years: *n* = 57, 13–15 years: *n* = 38). As illustrated in Figure 2, children undergoing surgery for PFT exhibited a total test time approximately twice as long as the established norms, both before and after surgery. Postoperatively, 95% of the children (36 out of 38) had a total test time two standard deviations (SDs) or more above the norms (i.e. the children were substantially slower). Of these, one child had experienced

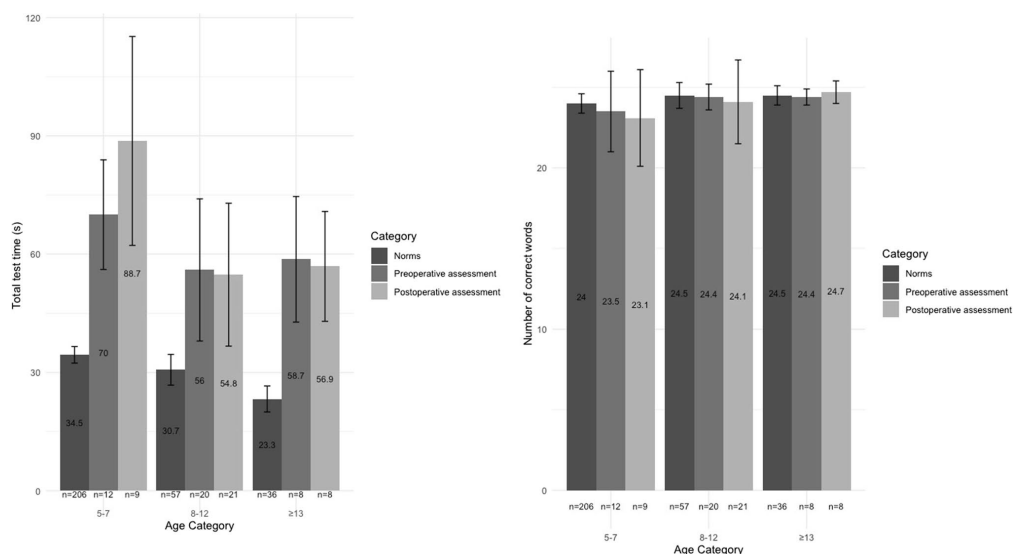


Fig. 2 Total test time (left panel) and total correct words (right panel) pre- and postoperatively in Swedish children undergoing tumour surgery in posterior fossa compared with Swedish norms (means and

SDs). Total test time is in seconds and total correct words in number of correct responses.

a period of mutism, six had experienced a phase of reduced speech and three had postoperative dysarthria (two had unknown motor speech status). When considering the total number of correct words, 16% (6 out of 38) performed one SD below the norms, whereof 5.3% (2 out of 38) exhibited serious impairment, obtaining scores two SDs below the norms. Of these children with serious impairment, none had experienced mutism or reduced speech and one had postoperative dysarthria. Thus, while no marked impairment in accuracy was observed at the group level, impairment was observed in individual children. The distribution of postoperative total test time and total correct words across age categories, differentiated by SDs from norms, are shown in Figure 3. This result indicates a high prevalence of impairments in word-finding speed both before and after surgery in all age groups.

As we see severe word-finding impairment also before surgery, it is interesting to inspect whether it is the same children who exhibit difficulties before and after surgery, which could indicate stable impairment unaffected by surgery, or whether we see changes in individual children's abilities, which would suggest effects of surgery. Figure 4 illustrates individual changes in total test time (speed, left panel) and number of correct words (accuracy, right panel) pre- and postoperatively. While the group means for both measures remain consistently slower (for speed) or lower

(for accuracy) compared to the norms, substantial variability is evident among individual children, and it is clear that for some children, performance is much poorer after surgery, while for others, it is much better. Thus, having difficulties before surgery does not necessarily entail more severe difficulties after surgery, and the variability in outcomes suggests that surgery has a negative effect on some children's word-finding abilities and a positive effect on others'.

Changes in word-finding ability

Changes in word-finding ability were analysed without relying on norms, allowing inclusion of the full dataset, encompassing all 94 children with complete preoperative and postoperative data. No statistically significant difference was observed (95% CI -1.82 to 2.30 , $p = 0.8191$) when comparing pre- and postoperative word-finding ability in terms of correct words per minute. About half of the children ($n = 45$) showed improved word-finding abilities postoperatively, and the other half ($n = 46$) showed a decline, as illustrated in Figure 5. A few ($n = 3$) had unchanged abilities (same number of correct words per minute before and after surgery).

Of the 94 children, 12 had had POSI. Among these, eight (four children with reduced speech and four children with previous mutism) showed a decrease in correct words per minute (mean -11.9 , SD 4.8 , range -18.1 to -5.7). There

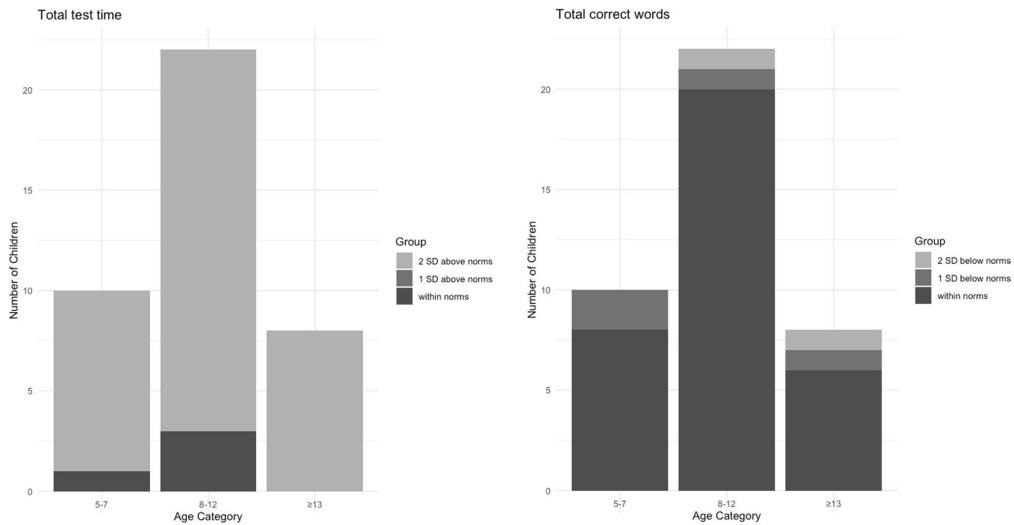


Fig. 3 Distribution of postoperative total test time (left panel) and total correct words (right panel) across age categories, differentiated by SDs from age-specific norms.

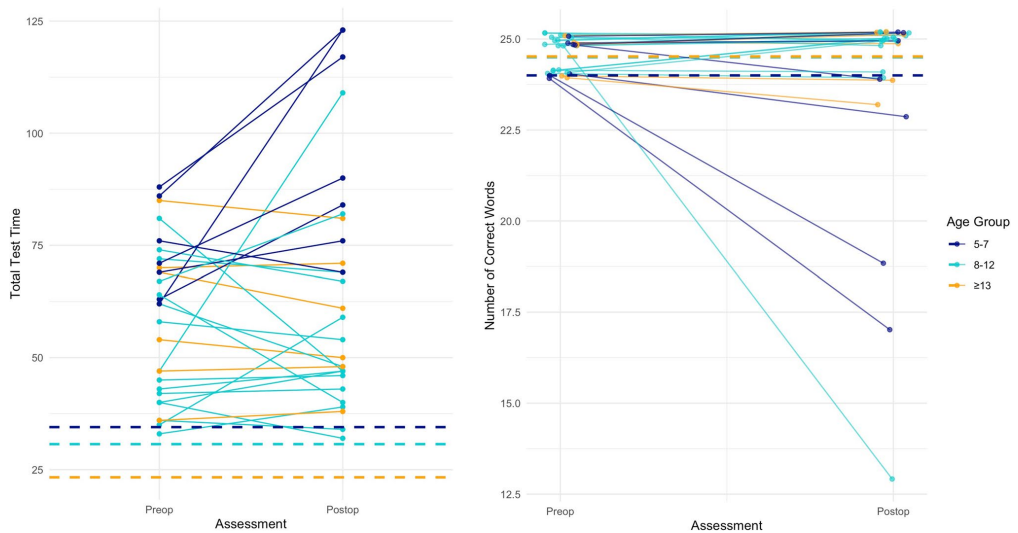


Fig. 4 Individual changes in total test time (left panel) and number of correct words (right panel) from pre- to postoperative assessment, compared to age-specific norms. Dashed lines indicate age-specific means, with colours representing the different age groups

was no significant association between the presence of POSI and postoperative decline (Fisher's exact $p > 0.05$). However, the four children with a period of mutism all showed a

postoperative decline (two of them with dysarthria) which was near significant (Fisher's exact $p = 0.053$). Of the 94 children, 12 had postoperative dysarthria (five with POSI).

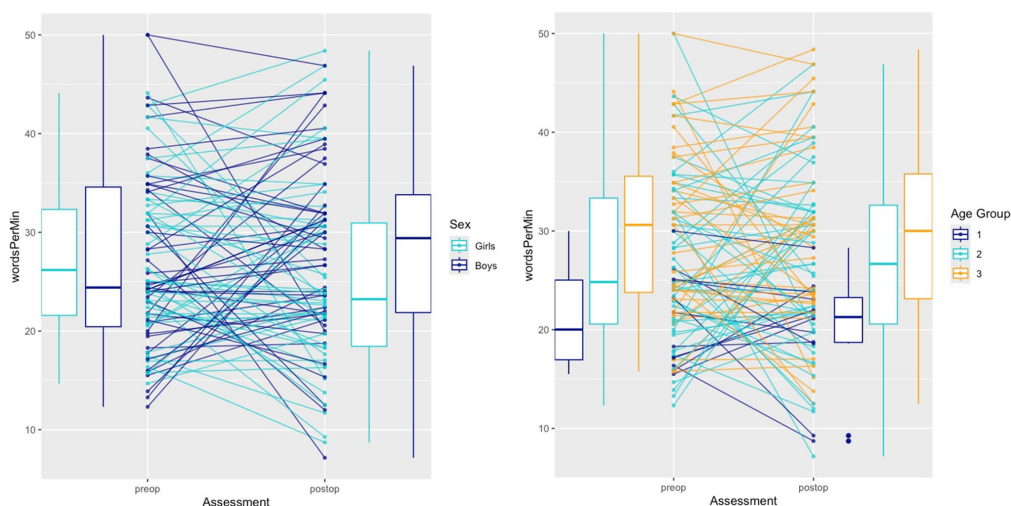


Fig. 5 Changes from pre- to postoperative correct words per minute stratified by sex and age groups. Each line represents a child ($n = 94$). The left panel shows changes stratified by sex (boys: dark blue, girls:

turquoise) and the right panel by age groups (1, 5–7 years; 2, 8–12 years; 3, ≥ 13 years). Boxplots summarize the distributions at each assessment point.

Among these, nine showed a decrease in correct words per minute (mean -7.6 , SD 7.5 , range -30.0 to -0.5). There was no significant association between the presence of dysarthria and postoperative decline ($\chi^2 = 2.64$, $p > 0.05$).

Given the extensive variability seen in postoperative outcomes, it is interesting to explore the potential factors underlying this variability, and to do so, the next section turns to regression analysis.

Factors affecting postoperative word-finding ability

Step 1: Null model

Initially, a null model was created including the dependent variable (correct words per minute; $M = 27.21$, max = 50, SD = 8.92) and the timepoint for assessment.

Step 2: Location of tumour model

To explore the effect of tumour location, the null model was compared with a model including tumour locations (LCH, RCH, BS, VR and FV) as fixed interaction effects with timepoint (pre vs. post). Significant negative impacts on postoperative performance were found for LCH: $B = -5.22$, SE = 1.95, 95% CI -9.06 to -1.38 , $p < 0.01$ and FV: $B = -5.17$, SE = 1.89, 95% CI -8.90 to -1.44 , $p < 0.01$. The AIC decreased from 1993.65 to 1441.49, indicating improved fit.

Step 3: Histology model

Adding tumour type (medulloblastoma, pilocytic astrocytoma, other) as an interaction effect with timepoint showed

no significant impact. The negative impact of tumour location remained significant: LCH: $B = -5.47$, SE = 2.11, 95% CI -9.62 , -1.31 , $p < 0.05$ and FV: $B = -4.94$, SE = 2.33, 95% CI -9.53 , -0.35 , $p < 0.05$. AIC increased to 1445.16.

Step 4: Preoperative hydrocephalus model

Introducing preoperative hydrocephalus as an interaction effect with timepoint showed no significant impact, with the tumour location impact remaining: LCH: $B = -5.36$, SE = 2.13, 95% CI -9.58 , -1.13 , $p < 0.05$ and FV: $B = -4.81$, SE = 2.38, 95% CI -9.50 , -0.11 , $p < 0.05$. AIC increased to 1445.16.

Step 5: Sex, age, dysarthria and test format, full model

Adding sex, age, dysarthria and test format reduced the AIC to 1420.36. The interaction of sex with timepoint showed a significant positive effect on postoperative outcomes, indicating that boys had an increase in correct words per minute compared to girls from pre- to postoperative performance ($B = 4.17$, SE = 1.98, 95% CI 0.27 to 8.28 , $p < 0.005$). Additionally, there was a significant main effect for test format, with paper format negatively impacting performance compared to screen format ($B = -5.52$, SE = 1.84, 95% CI -9.08 , -1.96 , $p < 0.001$). Age between 7 and 12 also had a significant positive impact, with children in this age range performing better than those younger or older ($B = 1.05$, SE = 0.63, 95% CI -9.16 to -1.89 , $p < 0.05$). Test format and age did not show an interaction with timepoint, indicating that their effects were consistent before and after the operation. This means that these factors had a stable

Table 2 Linear mixed model investigating factors affecting word-finding ability

	Step 2 Model with tumour location	Step 3 Model with tumour location and histology	Step 4 Model with tumour location, histology and preop. hydrocephalus	Step 5 Full model (as step 4 but sex, age, dysarthria and test format added)
	Estimates (95% CI) <i>p</i> -value (<i>n</i> = 176, 266 obs.)	Estimates (95% CI) <i>p</i> -value (<i>n</i> = 158, 240 obs.)	Estimates (95% CI) <i>p</i> -value (<i>n</i> = 156, 236 obs.)	Estimates (95% CI) <i>p</i> -value (<i>n</i> = 137, 200 obs.)
Postop (interaction effects)				
Location				
LCH	-5.22 (-9.06 to -1.38) <i>p</i> < 0.01	-5.47 (-9.62 to -1.31) <i>p</i> < 0.05	-5.36 (9.58 to -1.13) <i>p</i> < 0.05	-3.10 (-7.57 to 1.37) <i>p</i> 0.179
RCH	1.72 (-1.98 to 5.43) <i>p</i> 0.360	0.56 (-3.45 to 4.56) <i>p</i> 0.785	0.28 (-3.78 to 4.33) <i>p</i> 0.893	0.77 (-3.47 to 5.02) <i>p</i> 0.720
BS	-2.17 (-6.91 to 2.57) <i>p</i> 0.368	-2.50 (-7.82 to 2.83) <i>p</i> 0.357	-1.97 (-7.46 to 3.51) <i>p</i> 0.479	-0.86 (-6.53 to 4.81) <i>p</i> 0.764
VR	-2.09 (-5.83 to 1.66) <i>p</i> 0.273	-2.17 (-6.27 to 1.93) <i>p</i> 0.298	-1.78 (8-5.98 to 2.41) <i>p</i> 0.403	-1.01 (-5.39 to 3.37) <i>p</i> 0.649
FV	-5.17 (-8.90 to -1.44) <i>p</i> < 0.01	-4.94 (-9.53 to -0.35) <i>p</i> < 0.05	-4.81 (-9.50 to -0.11) <i>p</i> < 0.05	-2.57 (-7.47 to 2.33) <i>p</i> 0.302
Histology				
MB	—	-0.22 (-5.20 to 4.77) <i>p</i> 0.932	-0.06 (-5.13 to 5.01) <i>p</i> 0.982	-0.39 (-5.77 to 4.99) <i>p</i> 0.887
Other tumour	—	-0.43 (-5.92 to 5.06) <i>p</i> 0.879	-0.11 (8-5.64 to 5.42) <i>p</i> 0.968	1.24 (-4.57 to 7.05) <i>p</i> 0.674
Preop hydrocephalus; present	—	—	0.34 (-4.04 to 4.72) <i>p</i> 0.879	-0.20 (-4.61 to 4.21) <i>p</i> 0.928
Sex, boys	—	—	—	4.17 (0.27 to 8.28) <i>p</i> < 0.05
Pre- and postop (main effects)				
Age				
<7	—	—	—	1.31 (-3.83 to 6.46) <i>p</i> 0.615
7-12	—	—	—	1.05 (-0.19 to 2.29) <i>p</i> 0.095
>12	—	—	—	-0.13 (-1.62 to 1.36) <i>p</i> 0.868
Dysarthria; present	—	—	—	-0.04 (-7.12 to 7.03) <i>p</i> 0.991
Test format; paper	—	—	—	-5.52 (-9.16 to -1.89) <i>p</i> < 0.005

LCH left cerebellar hemisphere, RCH right cerebellar hemisphere, BS brainstem, VR vermis, FV fourth ventricle, PA pilocytic astrocytoma, MB medulloblastoma

impact on performance regardless of the surgical intervention. The models are presented in table 2.

A stepwise backward selection approach was then applied. Nonsignificant effects were removed one by one, ending with a final model including only significant effects. The final model showed a reduction in AIC (1391.5) compared to both the Step 4 model (AIC 1445.2) and the full model (AIC 1420.4), indicating a better fit.

Postoperatively, there was a significant negative effect of tumour location in the fourth ventricle ($B = -4.09$, $SE = 1.91$, 95% CI -7.84 , -0.35 , $p < 0.05$) and a significant positive

effect of male sex, with boys improving more after surgery than girls ($B = 3.90$, $SE = 1.75$, 95% CI 0.42 , 7.38 , $p < 0.05$). In addition, there were factors that had similar effects on the outcome before and after surgery. Dysarthria had a significant negative effect ($B = -4.07$, $SE = 1.94$, 95% CI -7.89 , -0.25 , $p < 0.05$), as did paper-based test format ($B = -5.70$, $SE = 1.34$, 95% CI -8.34 , -3.06 , $p < 0.001$). Additionally, age between 7 and 12 years had a significant positive effect compared to both higher and lower ages ($B = 1.43$, $SE = 0.29$, 95% CI 0.86 , 2.00 , $p < 0.001$). The final model is presented in Table 3.

Table 3 Linear mixed model investigating factors affecting word-finding ability. Final model including only significant effects

	Estimates	95% CI	p-value
Postop (interaction effects)			
Location: FV	−4.09	−7.84 to −0.35	<0.05
Sex: boys	3.90	0.42 to 7.38	<0.05
Pre- and postop (main effects)			
Age: 7–12 years	1.43	0.86 to 2.00	<0.001
Dysarthria: present	−4.07	−7.89 to −0.25	<0.005
Test format: paper	−5.70	−8.34 to −3.06	<0.001
Observations 221			

FV fourth ventricle

Discussion

Postoperative word-finding difficulties and changes in word-finding ability

Comparing postoperative performance with norms from typically developing children in the subset of Swedish children, we found that these children were approximately twice as slow after surgery compared with the established norms, with the majority of test times being two standard deviations above the Swedish norms (i.e. substantially slower). A previous study had indicated a relatively low incidence of word-finding difficulties after PFT surgery (12%), but the word-finding test used in this previous study did not measure speed and is thus likely to have underestimated the frequency of postoperative word-finding difficulties. Our current findings suggest that speed may represent a major concern, contributing significantly to postoperative word-finding difficulties.

Compared to norms from typical development, we also found severe word-finding difficulties before surgery, suggesting a negative impact of the tumour itself (cf. Persson et al. 2024). This opens the possibility that the postoperative word-finding difficulties we identified were present already before surgery, and indeed, when we directly compared performance before and after surgery in the full crosslinguistic sample, we found no significant group-level difference between pre- and postoperative word-finding abilities. While this lack of group-level difference could have reflected that children's poor word-finding abilities simply persisted after surgery, with no effect of surgery, close inspection of individual data, both in the Swedish subsample and in the full sample, reveals that the lack of group-level difference in fact reflects substantial variability in outcomes among individual children. Some children exhibited noticeably improved word-finding abilities and others showed marked decline after surgery. The finding that PFT surgery leads

to improved word-finding abilities for some children aligns with the results from di Rocco et al. [22]. Our study further replicates previous findings that even children without POSI after surgery for PFT may exhibit postoperative word-finding difficulties [10]. We found no significant association between the presence of POSI and postoperative decline in word-finding ability. For mutism, on the other hand, the results suggest an association, as all four children with a period of mutism showed a decline in word-finding ability. Such an association would support the idea of these difficulties varying along a continuum in severity, but note that this observation is based on only four children.

Factors affecting postoperative word-finding ability

The wide variability in postoperative outcomes, with some children exhibiting improved word-finding abilities after surgery and others experiencing deterioration, makes it important to examine the factors affecting these different outcomes. We did not find support for our hypothesis that the involvement of the right cerebellar hemisphere and brainstem increased the risk of postoperative word-finding difficulties, as seen preoperatively [21]. We did, however, find support for the hypothesis of a negative effect of tumour location in the fourth ventricle on postoperative word-finding ability compared with preoperative performance, indicating that the surgical removal of fourth-ventricle tumours leads to poorer word-finding ability. This aligns with the finding by Svaldi et al., who in their review of individual patient studies found that nearly 86% of children with fourth-ventricle tumours (12 out of 14) had postoperative language impairment [24]. The roof and walls of the fourth ventricle contain key elements of the dentato-thalamo-cortical pathway (DTCP), which is the main efferent pathway crucial to cerebellar involvement in higher cognitive functions, including language [26, 46]. Damage to this pathway, encompassing the superior cerebellar peduncle inserting on the brainstem, has also been associated with a higher risk of POSI [3, 29]. Di Rocco et al. also found that tumours involving the dentato-thalamo-cortical pathway (DCTP) contribute to postoperative language impairments, particularly through their role in disrupting cerebellar functions critical for language processing [8]. It is thus highly likely that the disruption of the DTCP contributes to postoperative word-finding difficulties. Surgical approach was not in focus in the current study, as our previous prospective multicenter cohort study of posterior fossa tumours in children (cf. Grønbaek et al. 2021), which represents the largest study to date, did not identify a significant association between surgical approach and POSI [3]. However, these associations remain debated with contradictory findings [3, 31–36]. We found an effect of sex, with boys performing better after surgery. In a previous study of preoperative word-finding difficulties, we found a

higher prevalence of boys with PFT experiencing word-finding difficulties [21]; therefore, one possible explanation for this sex-specific effect is that tumour removal has the potential to enhance word-finding abilities more in boys because the tumour in itself was causing more word-finding difficulties in boys. There were no differences in performance between sexes in the normative material [42]. Neither histology nor preoperative hydrocephalus were found to affect postoperative outcomes. Molecular profiling data, which distinguishes medulloblastomas into subgroups with differing biological profiles and risks, was not consistently available in our cohort due to variations in its implementation across centres. Consequently, molecular subgrouping was not included in this study. Given that wingless, group 3 and group 4 are associated with a higher risk of CMS, this data could have offered insights into whether subgroup-specific tumour biology plays a role in the severity or type of postoperative word-finding difficulties [30]. Children between 7 and 12 years of age were found to perform significantly better compared to both younger and older children, but this age effect was the same before and after surgery, i.e. it was not related to surgery. As expected, the presence of dysarthria and paper-based test format were also associated with poorer word-finding performance, but again, these effects were constant across pre- and postoperative performance.

Limitations and future directions

An important limitation is that our instrument for evaluating word-finding abilities, Wordrace, lacks norms for other languages than Swedish. Consequently, comparison with typical developmental trajectories is feasible only for the Swedish children. The present study only investigates word-finding abilities 1–4 weeks after surgery. To understand the long-term effects of surgery for PFT on language development and to identify factors that contribute to the persistence or improvement of word-finding difficulties over time, longitudinal studies would be highly valuable. The variability in the timing of postoperative assessments, conducted between 1 and 4 weeks after surgery, is another limitation. According to the original study design, speech recordings were ideally intended to be conducted within two weeks of surgery; however, in cases of logistical challenges or difficult patient scenarios, recordings were permitted up to four weeks after surgery. Differences in recovery phases, including the potential onset or improvement of cerebellar mutism during this period, could influence word-finding abilities and affect the consistency of the results.

The included participants are not fully representative, as children who remained mute beyond the 1–4-week postoperative assessment period were not included in the analysis. When comparing the included children with

those with missing speech data, we observe notable differences in the incidence of postoperative dysarthria and postoperative hydrocephalus. A higher proportion of children in the missing data group show postoperative dysarthria compared to the included children. The exclusions may have contributed to underestimation of postoperative word-finding difficulties in the study population. The lack of data on tumour volumes limits the evaluation of the influence of size on postoperative word-finding difficulties. Future studies with tumour volume measurements could clarify its potential impact. Furthermore, dysarthria was not assessed by speech-language pathologists, and therefore, the results should be interpreted with caution. Future studies are encouraged to focus on motor speech impairments with auditory-perceptual speech analysis. Additionally, the study protocol provided information about the areas encroached on by the tumour, but it did not specify the main location or the extent of tumour infiltration in each listed location. This lack of precise information limits the conclusions that can be drawn regarding associations between tumour location and word-finding difficulties.

Conclusions

This study contributes to our understanding of postoperative word-finding difficulties in children undergoing PFT surgery. The principal finding is that word-finding difficulties are prevalent in the postoperative phase, also without being preceded by POSI, with word-finding speed as the primary concern. Tumour location in the fourth ventricle had a significant negative effect on postoperative word-finding abilities, indicating that the surgical removal of fourth-ventricle tumours leads to poorer word-finding ability. The frequency of word-finding difficulties not preceded by POSI underscores the need for targeted assessments and interventions in the postoperative phase for children undergoing PFT surgery. Enhancing children's word-finding abilities is crucial, as difficulties in this area can affect their academic skills, social participation and overall well-being.

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Author contribution All co-authors took part in the collection of data. K.P., D.B.T. and B.A., contributed in analysing speech samples. K.P., J.G., D.B.T. contributed to data analysis and interpretation. K.P. prepared the first draft of the manuscript. All co-authors gave feedback on the manuscript. K.P, J.G and D.B.T. prepared the final draft of the manuscript. All authors approved the final version of the manuscript.

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Data availability Due to ethical considerations, data associated with this paper cannot be accessed.

Declarations

Ethics approval This study was approved in Denmark by the Research Ethics Committees of the Capital Region (H-6–2014-002) and subsequently approved locally in all participating countries.

Conflict of interest The authors declare no competing interests.

Disclaimer

The funding bodies had no role in the design of the study, analyses, interpretation of the data or decision to submit results.

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Paper III



RESEARCH REPORT OPEN ACCESS

Narrative Ability in Swedish Children Treated for Posterior Fossa Tumours: Macro- and Microstructural Performance Before and 1–4 Weeks After Surgery

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Keywords: cerebellar mutism syndrome (CMS) | narrative ability, macrostructure, microstructure | posterior fossa tumour (PFT) | speech, language and communication disorders

ABSTRACT

Background: Posterior fossa tumours (PFT), among the most common childhood brain tumours, place children at risk of speech, language, and communication difficulties, often described in relation to cerebellar mutism syndrome (CMS) but also seen in children without mutism. Narrative ability refers to the capacity to understand, create, and share stories. Narratives can be analysed at the macrostructural level, capturing structure and content, and the microstructural level, reflecting, for example, morphosyntax and lexicon. Narrative ability has not previously been investigated in children with PFT at both levels, including pre- and postoperative data, or in relation to CMS or dysarthria.

Aims: The aims were to investigate narrative ability at macrostructural and microstructural levels in children with PFT compared with typically developing (TD) peers, to investigate pre- to postoperative changes at both levels in children with PFT, and to examine relations between macro- and microstructure and the presence of CMS and dysarthria.

Methods: A story-generation task from the Expression, Reception and Recall of Narrative Instrument (ERRNI) was administered pre- and postoperatively, in the early postoperative phase (1–4 weeks after surgery). Macrostructure was analysed using ideaspore, and microstructure using mean length of utterance in words (MLUw), grammaticality (GY), subordination index (SI), lexical diversity (MATTR), and words per minute (WPM). Group comparisons and associations with CMS and dysarthria were analysed using linear regressions, and changes over time with mixed-effects models.

Results: Children with PFT scored significantly lower than TD peers on the macrostructural measure ideaspore and on several microstructural measures, including MLUw, GY, and WPM, both pre- and postoperatively (all $p < 0.05$). SI and MATTR did not differ between groups. Difficulties were most pronounced among older children. No significant pre- to postoperative changes were

Abbreviations: ABI, acquired brain injury; ADHD, attention-deficit/hyperactivity disorder; CI, confidence interval; CMS, cerebellar mutism syndrome; CNS, central nervous system; C-units, communication units; DLD, developmental language disorder; ERRNI, expression, reception and recall of narrative instrument; GY, grammaticality; ICC, intraclass correlation coefficient; IRR, inter-rater reliability; MATTR, moving average type-token ratio; MLUw, mean length of utterance in words; PFT, posterior fossa tumour; SALT, systematic analysis of language transcripts; SD, standard deviation; SI, subordination index; TD, typically developing; TTR, type-token ratio; WPM, words per minute.

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found, although individual variability was evident. The small group of children with CMS did not differ significantly from other children with PFT, while those with postoperative dysarthria showed a decline in both macro- and microstructure ($p < 0.05$).

Conclusions: Children with PFT showed pre- and postoperative difficulties at macro- and microstructural levels, producing narratives with fewer story elements, shorter utterances, and more grammatical errors compared with TD peers. The age-related differences suggest that narrative difficulties become more prominent as language and cognitive demands increase. The findings underline the clinical importance of including narrative tasks encompassing macro- and microstructural aspects, together with motor-speech evaluation, in assessment and follow-up of children treated for PFT to guide appropriate interventions.

WHAT THIS STUDY ADDS

What is already known on this subject

- Previous studies have described speech, language and/or communication difficulties following posterior fossa tumour surgery, particularly in association with cerebellar mutism syndrome (CMS). One aspect of language that may be affected is narrative ability, which can be analysed at two levels: the macrostructural level (content) and the microstructural level (form). Still, little is known about narrative ability in children with posterior fossa tumours (PFT), although a small study based on postoperative data has shown microstructural difficulties in children undergoing PFT surgery.

What this paper adds to existing knowledge

- Our study adds new knowledge about language profiles in children with PFT, showing that they have narrative difficulties at macro- as well as at microstructural levels, present both pre- and postoperatively. These difficulties are most evident among older children and show individual variability. We did not find more pronounced difficulties in the small group of children with CMS compared with the other children undergoing PFT surgery.

What are the potential or actual clinical implications of this work?

- The findings underline the importance of including narrative assessment in the evaluation and follow-up of children treated for PFT. Assessing macro- and microstructural aspects together with motor-speech evaluation can help identify children in need of interventions. Regular follow-up assessments are essential, as narrative difficulties may become more apparent as language and cognitive demands increase.

1 | Introduction

Narrative ability refers to the capacity to understand, create, and share stories, requiring the coordination of multiple language and cognitive processes (Bishop 2004). It plays a central role in the development of language comprehension and production and is a key predictor of academic performance, particularly literacy and reading achievement (Babayigit et al. 2021; Griffin et al. 2004; Reese et al. 2011). Beyond academics, narrative ability is essential for social interaction, sharing personal experiences, and engaging in humour, which form the foundation for social acceptance and group belonging (Berman 1988). Narrative ability develops throughout childhood and adolescence and continues to develop across the life span. After the age of five, development is largely characterised by refinement and increasing complexity: narratives become longer, more elaborated, and marked by advances in syntactic complexity, coherence, and the ability to adapt stories for a listener's understanding. Within this process, preschool narratives remain largely event-driven with limited coherence and minimal temporal or causal connections (Kupersmitt and Nicoladis 2021). As children enter middle childhood, they increasingly use story grammar elements, such as setting and causal sequencing, accompanied by gains in syntactic complexity (Nippold et al. 2014). By adolescence, narratives demonstrate greater coherence, abstraction, and perspective-taking, reflecting advances in language processing and higher-order cognitive functions (Kupersmitt and Nicoladis 2021) as well as narrative experience.

To capture this complexity, narratives can be analysed at two levels: macrostructural and microstructural level (Berman 1988). The macrostructural level refers to the global framework and organisation of a narrative, capturing how coherent and well-structured the story is. This level encompasses elements such as logical sequencing, thematic continuity, and the inclusion of components like setting, initiating events, and resolutions, which together reflect the overarching clarity and completeness of the narrative. Macrostructure can be evaluated through different approaches. One such approach is the measure ideaspcore, which reflects how effectively a child conveys the main ideas of a narrative (Bishop 2004). The microstructural level refers to the language details within the narrative, such as sentence structure, grammatical accuracy, and vocabulary use. This level can be evaluated using a range of microstructural language measures. Mean length of utterance in words (MLUw) provides an indicator of sentence length and is often used as a rough measure of syntactic complexity. However, utterance length alone is not a sufficient index of syntactic complexity, as longer utterances may simply reflect concatenation rather than more complex constructions (Frizelle et al. 2018). To capture syntactic complexity more precisely, measures of clause subordination are applied, as these indicate the child's ability to produce embedded structures. Grammaticality reflects morphosyntactic accuracy (Miller et al. 2016). Lexical diversity captures the range of vocabulary used within the narrative, indicating both the breadth and flexibility of the child's lexical repertoire (Malvern et al. 2004). Fluency-related

aspects such as pausing and speech rate reflect the ease of speech production (Berman 1988; Kapantzoglou et al. 2017).

Macro- and microstructural levels together provide a comprehensive view of narrative production, making narrative analysis a valuable approach for assessing both language and communicative abilities in children. Studies of children with developmental language disorder (DLD) report difficulties at both levels, including shorter and less coherent narratives, reduced grammatical accuracy, and fewer story grammar elements as well as limited use of internal state terms compared with typically developing (TD) peers (Andreou and Lemoni 2025; Reilly et al. 2004; Winters et al. 2022). Similar narrative difficulties have also been described in other paediatric groups, such as in children with autism spectrum disorder and foetal growth restriction (Partanen et al. 2020; Volden et al. 2017). Narrative analyses are also valuable for children with acquired brain injury, including those treated for brain tumours, since they enable examination of multiple language measures and can be carried out efficiently. In a study by Docking et al. (2016), narratives were analysed in children after brain tumour treatment. While no significant group differences were found compared with age- and gender-matched peers, many individual children performed below the comparison group on measures of lexical diversity, total number of utterances, mean length of utterance, grammatical accuracy, and overall narrative structure (Docking et al. 2016).

Tumours in the posterior fossa are the most common paediatric brain tumours, accounting for nearly half of all central nervous system (CNS) tumours in children (Ostrom et al. 2023). Surgical resection is essential and advances in treatment have improved survival rates for children with CNS tumours, but many survivors face neurological and functional complications (Cámara et al. 2020; Catsman-Berrevoets and Aarsen 2010; Di Rocco et al. 2010). Cerebellar mutism syndrome (CMS), one of the most severe complications, is characterised by mutism or severely reduced speech, along with emotional lability and other neurological deficits (Gudrunardottir et al. 2016; Grønbeek et al. 2021, 2023). While CMS often improves over time, many children experience persistent speech and language disorders that impact communication and academic performance (Catsman-Berrevoets and Aarsen 2010; Svaldi et al. 2023). The language disorders comprise both comprehension and production, with difficulties reported in morphosyntax and lexical semantics (Di Rocco et al. 2011; Svaldi et al. 2023; Riva and Giorgi 2000). While these findings provide valuable insights into language disorders in this population, many studies rely on standardized neuropsychological assessments, which do not capture the essential aspects of language (Di Rocco et al. 2010; Catsman-Berrevoets and Aarsen 2010; Cámara et al. 2020). A further uncertainty pertains to the role of the tumour versus the role of surgery in causing language disorders. The majority of studies only analyse postoperative data, making it impossible to separate the impact of tumour and surgery, but recent findings based on language assessments indicate that children with PFT already show word-finding difficulties before surgery (Persson et al. 2023), indicating a negative impact of the tumour itself. Moreover, postoperative language outcomes vary between individuals (Persson et al. 2025), indicating that surgery may have different effects on different children. One potential factor affecting individual language outcomes after surgery could be whether the child has experienced a phase of CMS. While

studies have often focused on the language disorders that may follow CMS, language disorders following posterior fossa tumour (PFT) surgery also sometimes occur in children without CMS, emphasising the broader impact of these tumours and their treatment on language outcomes (Cámara et al. 2020; De Smet et al. 2009). Moreover, a recent study by Svaldi et al. (2023) identified deficits at the microstructural level in spontaneous speech among children following PFT. These difficulties were evident in decreased lexical diversity, morphosyntactic deficits together with reduced MLUw and difficulties with verb transitivity. These deficits were observed in both children with and without CMS, although morphosyntactic and semantic difficulties appeared more prominent in the CMS group (Svaldi et al. 2023). Yet, this study was limited to postoperative data from a small sample and did not examine macrostructural narrative ability, and it remains unclear whether children with CMS exhibit a different or more pronounced pattern of narrative difficulties compared with those without CMS. Another potential factor affecting individual language outcomes after surgery is the presence or absence of dysarthria. Postoperatively, motor speech disorder is common, typically dysarthria, characterised by slow rate, monotonous tone, and ataxic speech (De Smet et al. 2007; Van Mourik et al. 1998). Dysarthria concerns the motor execution of speech and is not expected to directly affect language ability, but it may influence a child's language production since the increased effort required for speech can make it more difficult to produce coherent, long and fluent utterances.

Previous research on language deficits in children with PFT has mainly focused on the postoperative period (Catsman-Berrevoets and Aarsen 2010; Grønbeek et al. 2021). Without a preoperative assessment, it is difficult to determine whether difficulties observed after surgery reflect a deterioration associated with the surgical intervention or are attributable to the tumour itself. Furthermore, individual variability has been reported, with some children improving and others declining following surgery (Di Rocco et al. 2011; Persson et al. 2025). Given this heterogeneity, it is essential to include both pre- and postoperative assessments and to examine changes over time.

Therefore, in the current study, we aimed to:

1. Investigate narrative macrostructure and microstructure in children with posterior fossa tumours, assessed pre- and postoperatively, compared with typically developing peers.
2. Investigate change in narrative macrostructure and microstructure between pre- and postoperative assessment in children with posterior fossa tumours.
3. Investigate change in narrative macrostructure and microstructure between pre- and postoperative assessment in children with posterior fossa tumours in relation to the presence of cerebellar mutism syndrome or dysarthria.

2 | Methods

2.1 | Study Design and Setting

This was a prospective comparative observational cohort study including children undergoing PFT surgery and a comparison

group of typically developing (TD) children. Data for the PFT children were derived from the Swedish part of the Nordic-European CMS study, described elsewhere (Wibroe et al. 2017), which had collected these data at paediatric oncology centres in Sweden. A normative comparison group of typically developing (TD) children was recruited from educational settings in southern Sweden. The Swedish part of the Nordic-European CMS study was approved by the Swedish Ethical Review Board (reference 2014/3:8), and a separate ethical approval was obtained for the TD comparison group (reference 2024-05489-01).

2.2 | Participants

Between August 2014 and May 2024, 177 Swedish children under the age of 18 years were included in the Nordic-European CMS study. For the present study, children from this cohort were considered for inclusion if they had available audio-recorded narrative assessments pre- and/or postoperatively. To minimise the influence of potential confounding factors, the following exclusion criteria were applied for the present study: additional diagnoses such as neurodevelopmental disorders (e.g., autism and ADHD), previously reported speech and language disorders and previous tumour surgery. In some cases, information regarding earlier speech or language difficulties was reported only as the presence of prior difficulties, with further details provided in free-text fields. When such information indicated that the reported difficulties were tumour-related rather than developmental in nature, the children were retained in the study; otherwise, they were excluded. Children with a multilingual background were also excluded, as information on length and quality of exposure to the Swedish language was not available. Children younger than five years were also excluded, as narrative ability becomes more stable and structured from around the age of five. Recordings with missing or invalid data due to experimenter error were also discarded. The final sample included 44 children with valid narrative data either pre- and/or postoperatively. Of these, 32 had preoperative data, 32 postoperative data (comprising 64 narratives in total), and 20 had both pre- and postoperative data.

Children included for the collection of normative data were recruited from schools and preschools in southern Sweden between January and April 2024. Initially, 151 children aged between 5 and 17 years were enrolled. The same exclusion criteria were applied as for the tumour group: neurodevelopmental disorders (e.g., autism and ADHD), previously reported speech and language disorders, neurological conditions, or multilingualism. Recordings with missing or invalid data due to experimenter error were also discarded. The final control group comprised 118 children.

The distribution of age groups (5–7, 8–12, ≥ 13 years) did not differ significantly between children with PFT and TD peers ($\chi^2(2, n = 162) = 0.74, p = 0.69$), with the majority of children falling into the 8–12-year range. The sex ratio was balanced in the group of children with PFT, while girls were slightly more represented among the children with TD; however, the difference in sex distribution was not statistically significant ($\chi^2(1, n = 162) = 1.23, p = 0.27$). Figure 1 presents the inclusion process and the number of participants included in each analysis.

2.3 | Materials

To elicit narratives, the Expression, Reception, and Recall of Narrative Instrument (ERRNI) was used (Bishop 2004). The original British version of the ERRNI has demonstrated good interrater and test–retest reliability as well as construct and concurrent validity (Bishop 2004). The Swedish version of the ERRNI was developed and evaluated in a master thesis in 2009 (Gustafsson et al. 2009). In that study, interrater reliability was reported to be high, and children's performance on the Swedish ERRNI followed the same age-related patterns as those observed in the original British version, supporting its suitability for use with Swedish-speaking children. The assessment in this study involved the story generation part of the Fish Story task, which includes a set of 15 pictures. Using these sequential images, children were supported in generating an independent narrative.

2.4 | Data Collection

Demographic and medical data as well as audio-recorded narrative files for the children with PFT were obtained from the Nordic-European CMS study. The demographic and clinical information was reported prospectively via study forms completed by physicians. Dysarthria was reported using a four-point scale ranging from normal speech to absent/unintelligible speech. Tumour location, documented after surgery, could include multiple sites within the posterior fossa; left cerebellar hemisphere, right cerebellar hemisphere, cerebellar vermis, fourth ventricle, and/or brainstem involvement. Tumour histology was categorised as pilocytic astrocytoma, medulloblastoma, ependymoma, atypical teratoid rhabdoid tumour, or other. Hydrocephalus was reported as either absent or present in the study forms. Mutism was defined as “absence of speech with no production of words or short sentences, though crying or whining may still occur in some children.” Reduced speech was defined as “severely limited speech production, restricted to single words or short sentences, only elicited after vigorous stimulation.” The presence of mutism or reduced speech was documented, and when present, the duration (number of days) was noted. As children with unresolved mutism could not participate in the postoperative language assessment, no postoperative language samples are available for these cases. However, if mutism resolved within the 1–4-week postoperative window, the child was included once speech production was regained; children with reduced speech were included provided they were able to participate in the assessment.

Within the Nordic-European CMS study, the narrative assessment using Fish Story was administered in a quiet setting at the paediatric oncology centres by a physician, nurse, or speech-language therapist. The administration followed written instructions. Children were instructed to carefully examine the sequence of pictures before beginning their narrative. During the narrative task, minimal encouragement was provided by the examiner, who used neutral prompts such as “What happened next?” or “Tell me more”. Preoperative assessments were conducted as close as possible to the date of surgery, typically within the last few days before the procedure. Postoperative assessments were carried out 1–4 weeks after surgery, while the children were still hospitalised for postoperative care. The narrative assessments were audio-recorded, and the files were stored in the Nordic-European CMS database.

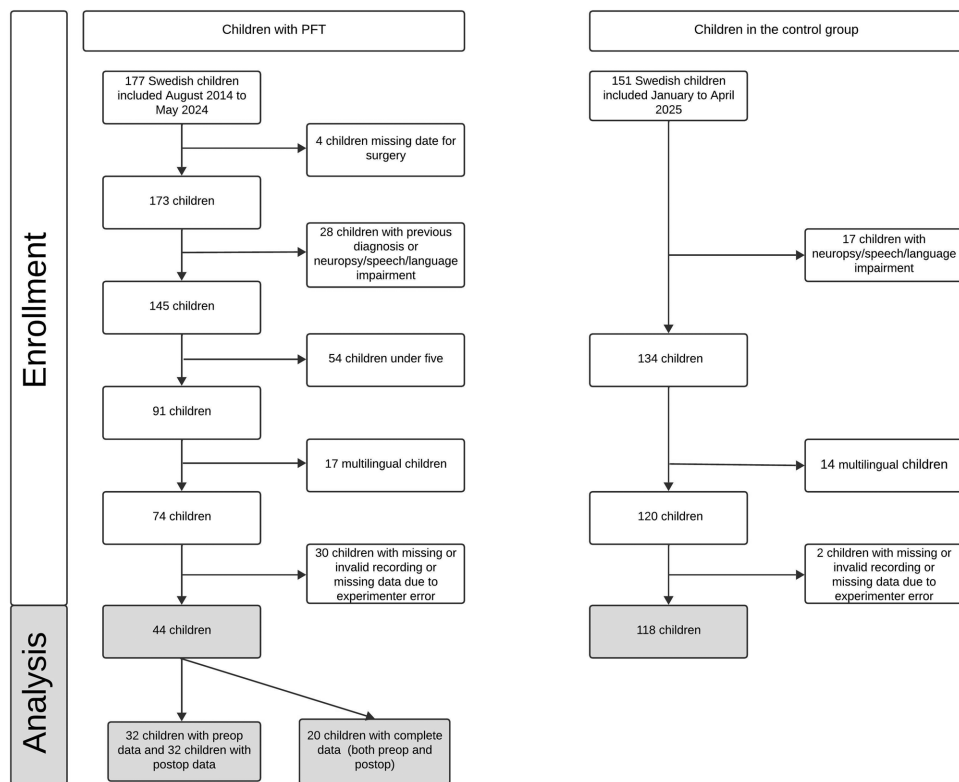


FIGURE 1 | The inclusion process and the children included in each analysis.

For the children with TD recruited for the current study as age-matched controls the demographic data, including birthdate, sex, language background, multilingualism, and any reported speech, language, or other diagnoses, were collected through parent-reported questionnaires. The narrative assessment using Fish Story was administered in a quiet setting at the children's schools by a speech-language therapist or supervised speech-language therapist students. The test administration followed the same written instructions as within the Nordic-European CMS study. The narrative assessments were audio-recorded and the files were stored.

The subsequent steps of transcription, assessment, and analysis, based on the audio files, were conducted by the first author and applied in the same way to data from both the PFT and the TD groups.

2.5 | Orthographic Transcription

The transcription process began with an initial rough transcription of the recordings using the @Train software (Haberl et al. 2024). The recordings were then transcribed orthographically

with the use of headphones, in a quiet environment. All narratives were transcribed by a single transcriber, the first author, to ensure consistency across the data.

2.6 | Assessment of Macrostructure

To assess the ideaspcore, all narratives were evaluated according to the ERRNI manual (Bishop 2004). Each of the 24 pre-determined story items was assigned a score ranging from 0 to 2 points: 2 points were awarded for a fully correct and detailed expression of the idea, 1 point for partial or vague information, and 0 points for omitted or incorrectly expressed items. The total ideaspcore was calculated by summing the scores for all items in each narrative.

2.7 | Assessment of Microstructure

The narratives were orthographically transcribed and coded following the Systematic Analysis of Language Transcripts (SALT) guidelines (Miller et al. 2016). Sentence length was measured using MLUw, calculated by dividing the total number of words by the total number of complete and intelligible communication

units (C-units; a main clause with all subordinate clauses). Grammaticality (GY) was calculated as the percentage of utterances containing grammatical errors, by dividing the number of incorrect C-units by the total number of C-units. Thus, higher values indicate lower grammatical accuracy. Syntactic complexity was represented by the subordination index (SI), calculated by dividing the total number of clauses, including both main and subordinate clauses, by the number of C-units; a higher index reflects more advanced syntactic complexity. Lexical diversity was assessed using the moving average type–token ratio (MATTR), which calculates the average type–token ratio from multiple consecutive subsamples of a transcript. In contrast to the traditional type–token ratio (TTR), MATTR is not sensitive to sample length, making it more suitable for comparing narratives of different lengths. The window size was set to 21 tokens, corresponding to the length of the shortest sample included (22 tokens). Fluency-related aspects were captured by speech rate, measured as words per minute (WPM), calculated by dividing the total number of words produced by the duration of the sample in minutes. All calculations were performed using SALT 2018 Research Version.

2.8 | Agreement

To ensure reliability of assessment, inter-rater reliability (IRR) was calculated for 10% of the narratives. Inter-rater reliability for macrostructural analysis was assessed by the first and last authors, yielding a mean Cohen's Kappa of 0.82, indicating a high level of agreement. Inter-rater reliability for microstructural analysis was assessed by the first and third authors, with reliability calculated using intraclass correlation coefficients (ICC). A mean ICC of 0.86 was obtained, demonstrating strong consistency between raters. Intra-rater reliability was evaluated for both the macrostructural (ideaspcore) and microstructural measures, as the same rater assessed all narratives. To achieve this, 10% of the narratives were randomly selected. Initially, 10 narratives were scored, followed by a washout period of 3 weeks to minimize recall bias. After this period, the same narratives were re-evaluated. Intra-rater reliability for the ideaspcore was assessed using Cohen's Kappa, with a mean value of 0.91, indicating excellent consistency. For the microstructural measures, intra-rater reliability was evaluated using the intraclass correlation coefficient (ICC), which resulted in a mean ICC of 0.97, demonstrating a very high level of agreement across repeated evaluations.

2.9 | Statistical Analysis

Demographic and clinical characteristics were presented descriptively. To compare pre- and postoperative macro- and microstructure in children with PFT to children with TD, linear regression models were fitted for each outcome. The dependent variables were ideaspcore, MLUw, GY, SI, MATTR, and WPM, and the independent variable was group (TD children, preoperative PFT assessments, and postoperative PFT assessments) with TD as the reference category. All models included age and sex as control variables. To complement the group-level findings, we examined the extent of the difficulties at the individual level. For each age group (5–7, 8–12, ≥13 years), the TD mean and standard deviation were calculated, and each PFT observation was classified as within one SD of the TD mean, 1–2 SD below, or more

than 2 SD below. For GY, where higher values indicate poorer accuracy, deviations were defined in the opposite direction. SDs are commonly applied in clinical assessment where scores 1–2 SD below the mean indicate moderate weakness and scores more than 2 SD below indicate severe difficulties (Semel et al. 2013).

To investigate change in macro- and microstructure between pre- and postoperative assessment in children with PFT, linear mixed-effects models were fitted with each outcome (ideaspcore, MLUw, GY, SI, MATTR, WPM) as the dependent variable. All available observations from children with PFT were included, with participant as a random intercept. Fixed effects were specified for timepoint (pre vs. post), with age and sex included as control variables.

To investigate change in macrostructure and microstructure in children with PFT in relation to the presence of cerebellar mutism syndrome (CMS) or dysarthria, analyses were restricted to children with complete pre- and postoperative data. For each outcome (ideaspcore, MLUw, GY, SI, MATTR, WPM), individual change scores (post—pre) were calculated. Children were classified according to the presence of postoperative cerebellar mutism syndrome (CMS) or dysarthria, which were analysed in separate models, with children without the respective condition serving as the reference group. Linear regression models were fitted with change for each outcome as the dependent variable, group as independent variable and all models adjusted for age and sex.

For all change analyses, standardised regression coefficients (β_{std}) were additionally calculated to quantify effect size in standard deviation units, thereby facilitating comparison across outcomes with different measurement scales. All analyses were performed in RStudio (version 2025.09.0+387).

3 | Results

The sample consisted of 44 children with posterior fossa tumours and 118 typically developing (TD) peers. Among the children with PFT, 32 contributed preoperative data, 32 postoperative data, and 20 had complete data at both timepoints. Of the children with PFT, 12 developed postoperative CMS symptoms, three children developed mutism, aged 7;5, 11;0, and 12;5 years, and nine children had reduced speech, with ages ranging from 5;6 to 15;8 years. Duration data were available for one child with mutism, with a duration of 2 days, and for five of the nine children with reduced speech, with individual durations of 2–4 days. Dysarthria was documented in 3 children preoperatively and 5 children postoperatively. Demographic data for all children with PFT, for the subsets with preoperative, postoperative, and complete data, and for all TD children are presented in Table 1.

3.1 | Narrative Difficulties in Children With PFT Compared With TD Peers

On our measure of macrostructure, ideaspcore, children with PFT scored significantly lower than TD peers, both preoperatively ($\beta = -4.82$, 95% CI -7.14 to -2.50 , $p < 0.001$) and postoperatively ($\beta = -7.05$, 95% CI -9.37 to -4.73 , $p < 0.001$). For the microstructural outcomes, significant group differences were observed for MLUw,

TABLE 1 | Demographic and clinical characteristics of children with posterior fossa tumours (PFT) and typically developing (TD) peers.

	All children undergoing PFT surgery (<i>n</i> = 44)	Children with preoperative data (<i>n</i> = 32)	Children with postoperative data (<i>n</i> = 32)	Children with complete pre- and postoperative data (<i>n</i> = 20)	All children with typical development (<i>n</i> = 118)
Age (median, Q1, Q3)	9:11, 7:10, 12:3	10:7, 8:2, 12:3	9:11, 8:1, 12:3	11:0, 8:4, 12:11	9:11, 8:1, 12:1
Age group, <i>n</i> (%)					
5–7	12 (27.3)	8 (25)	8 (25)	4 (20)	26 (22)
8–12	24 (54.5)	18 (56.2)	17 (53.1)	11 (55)	73 (61.9)
≥13	8 (18)	6 (18.8)	7 (21.9)	5 (25)	19 (16.1)
Sex, <i>n</i> (%)					
Girls	20 (45.5)	15 (46.9)	16 (50)	11 (55)	67 (56.8)
Boys	24 (54.5)	17 (53.1)	16 (50)	9 (45)	51 (43.2)
CMS, <i>n</i> (%)					
Mute	3 (7.5)	3 (10.7)	1 (3.4)	1 (5.9)	—
Reduced speech	9 (22.5)	6 (21.4)	6 (20.7)	3 (17.6)	—
Habitual speech	28 (70)	19 (67.9)	22 (75.9)	13 (76.5)	—
Unknown	4	4	3	3	—
Tumour location, <i>n</i> (%)					
LCH	3 (7)	3 (9.7)	1 (3.1)	1 (5)	—
LCH + FV	2 (4.7)	1 (3.2)	1 (3.1)	—	—
RCH	5 (11.6)	2 (6.5)	5 (15.6)	2 (10)	—
RCH + LCH	2 (4.7)	2 (6.5)	2 (6.2)	2 (10)	—
RCH + VR	1 (2.3)	1 (3.2)	1 (3.1)	1 (5)	—
VR	6 (14)	3 (9.7)	5 (15.6)	2 (10)	—
VR + FV	2 (4.7)	2 (6.5)	1 (3.1)	1 (5)	—
BS	3 (7)	3 (9.1)	1 (3.1)	1 (5)	—
BS+FV/VR	2 (4.7)	2 (6.5)	2 (6.2)	2 (10)	—
FV	7 (16.3)	4 (12.9)	6 (18.8)	3 (15)	—
≥3 locations	10 (23.3)	8 (25.8)	7 (21.9)	5 (25)	—
Unknown	1	1	0	0	—
Tumour histology, <i>n</i> (%)					
Pilocytic astrocytoma	19 (50)	14 (51.9)	14 (48.3)	9 (50)	—
Medulloblastoma	14 (36.8)	11 (40.7)	10 (34.5)	7 (38.9)	—
Ependymoma	2 (5.3)	1 (3.7)	2 (6.9)	1 (5.6)	—
Other	3 (7.9)	1 (3.7)	3 (10—3)	1 (5.6)	—
Unknown	6	5	3	2	—
Dysarthria, pre- postop <i>n</i> (%)					
Present		2 (6.9)	4 (14.8)	1 (5.3), 3 (15.8)	—
Absent		27 (93.1)	23 (85.2)	18 (94.7), 16 (84.2)	—
Unknown		3	5	1	—
Hydrocephalus, pre- postop <i>n</i> (%)					
Present		14 (60.9)	1 (5)	12 (80), 1 (6.7)	—

(Continues)

TABLE 1 | (Continued)

	All children undergoing PFT surgery (n = 44)	Children with preoperative data (n = 32)	Children with postoperative data (n = 32)	Children with complete pre- and postoperative data (n = 20)	All children with typical development (n = 118)
Absent		9 (39.1)	19 (95)	3 (20), 14 (93.3)	—
Unknown		9	12	5.5	—

Note: Data are presented for all children with PFT, and for the subsets with preoperative, postoperative, and complete data, as well as for all TD children. Age is reported as median with first (Q1) and third quartiles (Q3).

Abbreviations: CMS, cerebellar mutism syndrome; LCH, left cerebellar hemisphere; RCH, right cerebellar hemisphere; BS, brainstem; VR, vermis; FV, fourth ventricle.

Other includes atypical teratoid rhabdoid tumour and other tumours.

GY, and WPM. Preoperatively, children with PFT produced shorter MLUw ($\beta = -0.82$, 95% CI -1.50 to -0.14 , $p < 0.01$), had more grammatical errors ($\beta = +0.06$, 95% CI 0.02 to 0.09 , $p < 0.01$), and fewer WPM ($\beta = -20.7$, 95% CI -34.69 to -6.58 , $p < 0.001$). Postoperatively, differences between children with PFT and TD peers were even larger for MLUw ($\beta = -1.55$, 95% CI -2.22 to -0.87 , $p < 0.001$), while the difference for GY ($\beta = +0.04$, 95% CI 0.01 to 0.07 , $p < 0.05$) and WPM ($\beta = -18.3$, 95% CI -32.39 to -4.32 , $p < 0.05$) was of similar magnitude. No significant group differences were found for SI or MATTR at either timepoint. The models are presented in Table 2

A visualisation of these group differences is provided in Figure 2. The boxplots show the distribution of scores for ideastore and all microstructural measures (MLUw, GY, SI, MATTR, WPM), complementing the model estimates. For GY, higher values indicate a greater proportion of grammatical errors.

To provide an indication of the clinical extent of difficulties we also explored the individual deviations from the TD mean pre- and postoperatively (Figure 3). For ideastore, deviations were already evident preoperatively, and these became more pronounced after surgery. The largest difficulties were observed among children aged 8–12 and ≥ 13 years, where several scored more than two SD below the TD mean. A similar pattern was found for MLUw, with deviations present before surgery and increasing afterwards, particularly in the 8–12 age group. For GY, most children in the youngest group (5–7 years) were within norms, while in the older groups a substantial proportion deviated, and several scored more than two SD above the TD mean both pre- and postoperatively. This deviation represents performance outside the range that includes approximately 95% of typically developing children. For WPM, difficulties were evident already preoperatively, and postoperative assessments showed a further increase in the number of children performing below the normative range, especially in the older age groups. For SI and MATTR, the majority of children in all age groups remained within the norms at both assessments, and only occasional deviations were observed.

3.2 | Narrative Changes in Children With PFT

We then analysed whether the PFT group showed an average change from pre- to postoperative assessment. No statis-

tically significant change was observed in either macro- or microstructure between pre- and postoperative assessment. For the macrostructural outcome ideastore, the scores declined from pre- to postoperative assessment, but the change was not statistically significant ($\beta = -2.01$, 95% CI -4.62 to 0.53 , $p = 0.133$).

For the microstructural outcomes, no statistically significant changes were observed between pre- and postoperative assessments. MLUw showed a tendency towards shorter utterances postoperatively ($\beta = -0.68$, 95% CI -1.42 to 0.05 , $p = 0.079$). There was an individual variation across both macro- and microstructural measures, where some children showed postoperative decline, others improved, and some remained relatively stable. Given this variability in postoperative outcomes, it is interesting to explore whether children who deteriorated were those with CMS or with motor speech disorder that is, postoperative dysarthria.

3.3 | Narrative Changes in Relation to CMS and Dysarthria in Children With PFT

The group of children who developed postoperative CMS and for whom both preoperative and postoperative narratives were available was small, consisting of four children (one who had experienced mutism, three who had experienced reduced speech). For the macrostructural outcome ideastore, no significant change was found in relation to postoperative CMS, and none of the microstructural measures differed significantly between children with and without CMS (Table 3).

In relation to postoperative dysarthria, significant differences were observed for several outcomes. A significant decline was found in ideastore ($\beta = -14.03$, 95% CI -19.93 to -8.12 , $p < 0.001$), MLUw ($\beta = -3.11$, 95% CI -5.50 to -0.71 , $p < 0.05$), SI ($\beta = -0.63$, 95% CI -1.00 to -0.26 , $p < 0.01$), MATTR ($\beta = -0.09$, 95% CI -0.16 to -0.03 , $p < 0.05$), and WPM ($\beta = -73.88$, 95% CI -104.12 to -43.65 , $p < 0.001$), while GY did not differ significantly between groups (Table 4).

Individual change scores for CMS and for dysarthria across macro- and microstructural measures are shown in Figure 4.

TABLE 2 | Linear model estimates comparing children with posterior fossa tumours (PFT; preoperative, postoperative) with typically developing (TD) peers for macrostructural (Ideascore) and microstructural (MLUw, GY, SI, MATTR, WPM) outcomes, adjusted for age and sex.

	B (95% CI)	p-value	Standardised β (95% CI)
Ideascore			
PFT preop	-4.82 (-7.14 – -2.50)	<0.001	-0.64 (-0.95 – -0.33)
PFT postop	-7.04 (-9.37 – -4.73)	<0.001	-0.94 (-1.25 – -0.63)
Age	1.11 (0.81 – 1.40)	<0.001	0.45 (0.33 – 0.56)
Sex: boys	-1.81 (-3.57 – -0.06)	<0.05	-0.24 (-0.48 – -0.01)
MLUw			
PFT preop	-0.82 (-1.50 – -0.14)	<0.01	-0.39 (-0.71 – -0.07)
PFT postop	-1.55 (-2.22 – -0.87)	<0.001	-0.73 (-1.05 – -0.41)
Age	0.35 (0.26 – 0.43)	<0.001	0.49 (0.37 – 0.62)
Sex: boys	-0.40 (-0.99 – 0.08)	0.099	-0.20 (-0.44 – 0.04)
GY			
PFT preop	0.06 (0.02 – 0.09)	<0.01	0.64 (0.26 – 1.02)
PFT postop	0.04 (0.01 – 0.07)	<0.05	0.40 (0.02 – 0.77)
Age	0.01 (-0.08 – 0.01)	0.148	-0.11 (-0.25 – 0.04)
Sex: boys	0.01 (-0.01 – 0.04)	0.192	0.19 (-0.10 – 0.48)
SI			
PFT preop	-0.06 (-0.24 – 0.13)	0.549	-0.12 (-0.50 – 0.27)
PFT postop	-0.10 (-0.29 – 0.12)	0.261	-0.22 (-0.60 – 0.17)
Age	0.04 (0.01 – 0.06)	<0.01	0.23 (0.09 – 0.38)
Sex: boys	-0.03 (-0.16 – 0.12)	0.712	-0.05 (-0.35 – 0.24)
MATTR			
PFT preop	0.00 (-0.03 – 0.01)	0.771	-0.05 (-0.42 – 0.31)
PFT postop	-0.01 (-0.04 – 0.00)	0.173	-0.25 (-0.61 – 0.11)
Age	0.005 (0.005 – 0.010)	<0.01	0.38 (0.25 – 0.52)
Sex: boys	0.00 (-0.02 – 0.01)	0.292	-0.15 (-0.42 – 0.13)
WPM			
PFT preop	-20.7 (-34.69 – -6.58)	<0.01	-0.53 (-0.88 – -0.17)
PFT postop	-18.3 (-32.39 – -4.32)	<0.05	-0.47 (-0.83 – -0.11)
Age	4.63 (2.86 – 6.40)	<0.001	0.35 (0.22 – 0.49)
Sex: boys	-3.63 (-14.28 – 7.00)	0.500	-0.09 (-0.36 – 0.18)

Note: Unstandardised (β) and standardised (β_{std}) coefficients with 95% confidence intervals (CI) are reported. Bold values indicate statistically significant effects ($p < .05$).

Ideascore is narrative macrostructure score.

Abbreviations: GY, grammaticality (higher values = poorer accuracy); MATTR, moving average type–token ratio; MLUw, mean length of utterance in words; SI, subordination index; WPM, words per minute.

4 | Discussion

To our knowledge, this is the first study to investigate narrative ability in children with PFT at both the macrostructural and microstructural levels, including pre- and postoperative assessments. The findings provide valuable new insight into how narrative ability may be affected in the perioperative phase, and we first discuss the key difficulties identified across the macrostructural and microstructural levels. The second aspect we discuss concerns how these difficulties varied with age, as

they were more pronounced in older children. Finally, we address the individual variation observed in postoperative outcome and note that children with CMS did not appear to experience a greater decline in narrative ability compared with others undergoing tumour surgery. Together, these findings deepen our understanding of the language consequences and variability in outcome following PFT surgery. They also highlight the clinical importance of conducting language assessments and follow-up in children treated for PFT, in order to identify those in need of interventions.

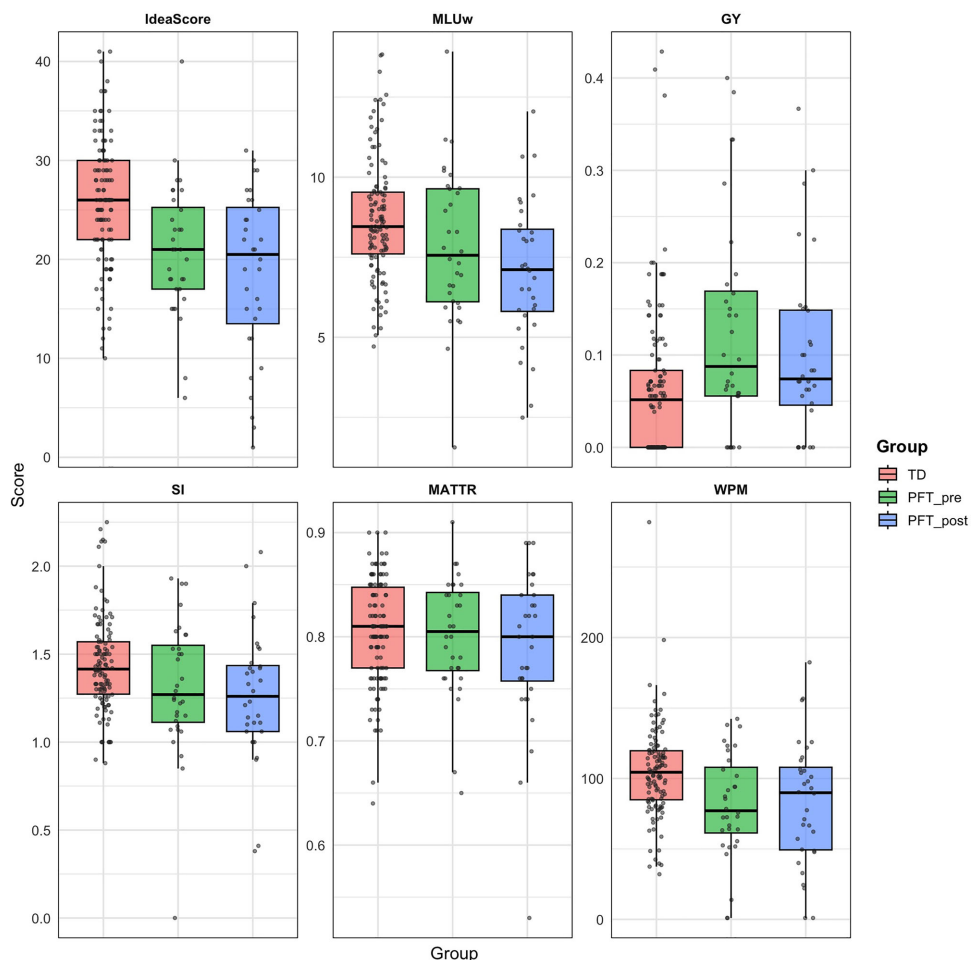


FIGURE 2 | Boxplots comparing narrative macrostructural (Ideascore) and microstructural (MLUw, GY, SI, MATTR, WPM) outcomes between TD children and children with PFT assessed pre- and postoperatively. Abbreviations: Ideascore = narrative macrostructure score; GY = grammaticality; MATTR = moving average type-token ratio; MLUw = mean length of utterance in words; SI = subordination index; WPM = words per minute.

4.1 | Narrative Difficulties in Children With PFT Compared With TD Peers

The comparison with TD peers revealed narrative difficulties in children with PFT, affecting both the content and form of their narratives. The children with PFT performed significantly below TD peers on Ideascore both pre- and postoperatively, showing difficulties with narrative macrostructure in the perioperative phase. This means that the children, for example, have failed to describe causal relationships between events and/or that essential components of the story are not included, resulting in

narratives that are less complete and less informative compared with those of TD peers. This result aligns with earlier findings. Docking et al. (2016) reported lower macrostructural scores in children treated for brain tumours (including PFTs) compared with TD peers. However, in that study, the assessments were conducted several years after treatment, which for many children included chemotherapy and radiotherapy in addition to surgery, and the sample comprised both supratentorial and infratentorial tumours, however with no significant differences between these groups (Docking et al. 2016). To our knowledge, no previous study has investigated narrative macrostructural ability specifically in

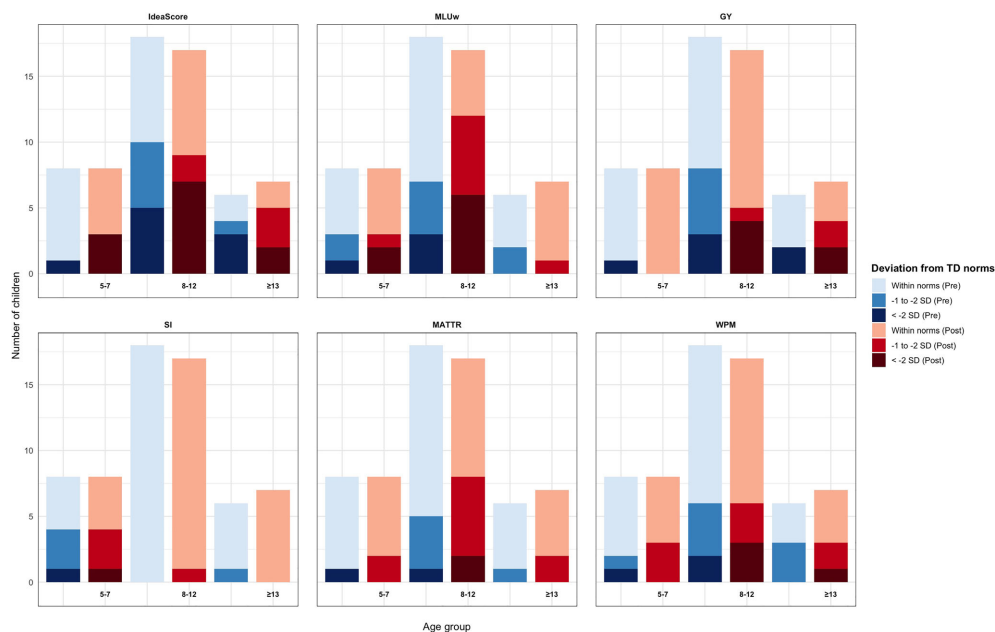


FIGURE 3 | Number of children with PFT classified in relation to the TD mean (within one SD, 1–2 SD below, or more than 2 SD below), shown separately for pre- and postoperative assessments and across age groups (5–7, 8–12, ≥13 years). For GY, higher values reflect poorer accuracy, and deviations are above the TD mean (+1–2 SD, >+2 SD). Abbreviations: Ideascore = narrative macrostructure score; GY = grammaticality; MATTR = moving average type–token ratio; MLUw = mean length of utterance in words; SI = subordination index; WPM = words per minute.

children with PFT, and our results showed that these difficulties were present both preoperatively and postoperatively and accordingly before additional treatment. These findings align with our previous reports of preoperative and postoperative word-finding difficulties in children with PFT (Persson et al. 2023; Persson et al. 2025), indicating that the tumour itself may influence language abilities prior to surgery. Whether these difficulties arise from tumour-related or surgical factors may not be of major clinical relevance in the perioperative phase, as children's communicative needs require similar interventions regardless of the underlying cause. However, understanding whether these difficulties are present before surgery is important for interpreting postoperative change, as it clarifies the relative contribution of tumour-related and surgery-related factors and helps relate such changes to the neurobiological mechanisms that may underlie the narrative difficulties observed in children undergoing treatment for PFT.

While difficulties in conveying narrative content were evident at the macrostructural level, additional differences were observed in language production at the microstructural level. In comparison with TD peers, the microstructural profile of children with PFT was characterised by shorter utterances, more errors in morphology and syntax, and reduced speech rate both pre- and postoperatively, while syntactic complexity and lexical diversity were preserved. This indicates that although children with PFT

were able to produce complex sentences, their productions contained more morphological and syntactic errors than those of TD peers. Our results correspond with those reported by Svaldi et al. (2023), who found difficulties in MLU, grammatical accuracy, and fluency in children several years after cerebellar tumour surgery, suggesting that these problems are present both perioperatively and at long-term follow-up (Svaldi et al. 2023). However, in contrast to our findings, Svaldi et al. (2023) also reported deficits in lexical diversity in spontaneous language. In their study, with smaller sample size, lexical diversity was measured using type–token ratio, which is highly sensitive to sample length and has been shown to have limited validity as an indicator of lexical diversity in children's language samples (Ratner et al. 2024). We used MATTR instead, which is less affected by variation in sample length. The nature of the task is also likely to play a role, as the structured ERRNI narrative provides an external framework and fewer opportunities for lexical variation compared with spontaneous conversation.

Our results are in line with previous studies showing that children with DLD produce shorter utterances and more errors in morphology and syntax compared with TD peers (Delage and Frauenfelder 2020; Leonard 2014; Moscati et al. 2020). However, contrary to our results from children with PFT, children with DLD have been reported to show lower SI, suggesting reduced

TABLE 3 | Linear models of change in narrative macrostructural (ideascore) and microstructural (MLUw, GY, SI, MATTR, WPM) outcomes from pre- to postoperative assessment in relation to the presence of postoperative cerebellar mutism syndrome (CMS). The reference group consists of children without CMS. Models are adjusted for age and sex.

		B (95% CI)	p-value	Standardised β (95% CI)
Ideascore	CMS	-6.09 (-14.22-2.05)	0.132	-0.89 (-2.07-0.30)
	Age	0.30 (-0.89-1.49)	0.603	0.12 (-0.37-0.61)
	Sex: boys	-4.62 (-11.15-1.92)	0.154	-0.67 (-1.62-0.28)
MLUw	CMS	-1.01 (-3.63-1.62)	0.427	-0.50 (-1.79-0.80)
	Age	0.11 (-0.28-0.49)	0.569	0.15 (-0.39-0.68)
	Sex: boys	-0.80 (-2.91-1.31)	0.433	-0.39 (-1.43-0.64)
GY	CMS	0.01 (-0.15-0.17)	0.893	0.08 (-1.24-1.40)
	Age	0.01 (-0.01-0.04)	0.504	0.24 (-0.30-0.78)
	Sex: boys	0.10 (-0.05-0.25)	0.176	0.36 (-0.70-1.43)
SI	CMS	-0.12 (-0.57-0.33)	0.585	-0.34 (-1.61-0.94)
	Age	0.03 (-0.04-0.10)	0.346	0.24 (-0.29-0.77)
	Sex: boys	-0.12 (-0.49-0.24)	0.479	-0.35 (-1.38-0.68)
MATTR	CMS	-0.06 (-0.13-0.02)	0.089	-0.91 (-1.98-0.15)
	Age	0.01 (0.00-0.02)	0.074	0.40 (-0.04-0.84)
	Sex: boys	-0.02 (-0.08-0.04)	0.453	-0.31 (-1.17-0.55)
WPM	CMS	-38.73 (-79.45-1.99)	0.061	-1.10 (-2.26-0.06)
	Age	0.22 (-5.73-6.18)	0.938	0.02 (-0.46-0.49)
	Sex: boys	-26.34 (-59.05-6.38)	0.107	-0.75 (-1.68-0.18)

Note: Unstandardised (β) and standardised (β_{std}) coefficients with 95% confidence intervals (CI) are reported.
Ideascore is narrative macrostructure score.
Abbreviations: CMS = Cerebellar Mutism Syndrome, MLUw = mean length of utterance in words; GY = grammaticality; SI = subordination index; MATTR = moving average type-token ratio; WPM = words per minute.

syntactic complexity (Araya et al. 2023; Delage and Frauenfelder 2020). Our findings indicate a specific language profile in this perioperative phase, characterised by difficulties in morphologic and syntactic accuracy, utterance length, and fluency, and a pattern that appears to differ from the difficulties observed in children with DLD.

Difficulties in both narrative form and content may affect children's communication, academic performance, and participation in social life (Berman 1988). Although the ideascore is derived from a structured, picture-supported task, it reflects the child's ability to convey the main ideas of a story, an ability that is equally important in everyday communication.

4.2 | Age-Related Differences in Narrative Ability

The results further revealed an effect of age, with increasing narrative difficulties with increasing age in the children with PFT. Interestingly, the youngest children with PFT (5–7 years) largely performed within the normal range compared with age-matched TD peers, both on the macrostructural measure ideascore and on several microstructural measures. In contrast, the largest deviations from TD norms were observed in the older age groups (8–12 and ≥ 13 years). This indicates that narrative difficulties, in both macro- and microstructure, were more pronounced among older children in our cohort. Similar age-related pat-

terns to those seen in our study have been reported in other paediatric groups (St John et al. 2019). In children with DLD, difficulties in narrative organisation and microstructure often become more evident with increasing linguistic and cognitive demands (Reilly et al. 2004; Isoaho et al. 2016; St John et al. 2019). Likewise, in children with acquired brain injury, language and communication difficulties often become more apparent as academic and communicative demands increase in school (MacDonald 2016). While our findings do not reflect developmental change per se, they suggest that the language differences between children with PFT and their TD peers become more pronounced as linguistic and cognitive demands increase with age. This pattern indicates that the age-related differences observed in our study are in line with previous findings. One might not have expected the Fish Story task to be sufficiently demanding to reveal such differences, as for the older children it represents a relatively low-demand task. More complex discourse contexts, such as expository or argumentative tasks, have been shown to elicit more complex syntactic and morphological forms in older children and adolescents, as these tasks place higher demands on language planning and reasoning (Berman and Verhoeven 2002; Nippold et al. 2008, 2007, 2014, 2017), and may therefore serve as more sensitive tools for examining narrative ability in this age group. The fact that the difficulties were most evident among the older children, despite the simplicity of the task, suggests that the difficulties described here are substantial. These findings underline the importance of attending to both

TABLE 4 | Linear models of change in narrative macrostructural (Ideascore) and microstructural (MLUw, GY, SI, MATTR, WPM) outcomes from pre- to postoperative assessment in relation to the presence of postoperative dysarthria.

		B (95% CI)	p-value	Standardised β (95% CI)
Ideascore	Postoperative dysarthria	-14.03 (-19.93 – -8.12)	<0.001	-2.04 (-2.90 – -1.18)
	Age	0.29 (-0.49–1.06)	0.443	0.12 (-0.20–0.44)
	Sex: male	-1.80 (-6.08–2.47)	0.385	-0.26 (-0.89–0.36)
MLUw	Postoperative dysarthria	-3.11 (-5.50 – -0.71)	<0.05	-1.53 (-2.70 – -0.35)
	Age	0.09 (-0.22–0.03)	0.553	0.12 (-0.31–0.56)
	Sex: male	-0.25 (-1.98–1.49)	0.766	-0.12 (-0.97–0.73)
GY	Postoperative dysarthria	0.05 (-0.13–0.22)	0.578	0.38 (-1.04–1.80)
	Age	0.01 (-0.02–0.03)	0.545	0.25 (-0.27–0.77)
	Sex: male	0.07 (-0.08–0.21)	0.334	0.31 (-0.72–1.33)
SI	Postoperative dysarthria	-0.63 (-1.00 – -0.26)	<0.01	-1.77 (-2.81 – -0.73)
	Age	0.02 (-0.02–0.07)	0.311	0.19 (-0.19–0.57)
	Sex: male	-0.03 (-0.05–0.05)	0.813	-0.09 (-0.84–0.67)
MATTR	Postoperative dysarthria	-0.09 (-0.16–0.03)	<0.05	-1.41 (-2.44 – -0.38)
	Age	0.01 (0.00–0.01)	<0.05	0.43 (0.05–0.81)
	Sex: male	0.00 (-0.05–0.05)	0.924	0.03 (-0.71–0.78)
WPM	Postoperative dysarthria	-73.88 (-104.12 – -43.65)	<0.001	-2.10 (-2.96 – -1.24)
	Age (years)	0.43 (-3.53–4.39)	0.820	0.03 (-0.28–0.35)
	Sex: male	-10.13 (-32.01–11.75)	0.341	-0.29 (-0.91–0.33)

Note: The reference group consists of children without dysarthria. Models are adjusted for age and sex. Unstandardised (β) and standardised (β_{std}) coefficients with 95% confidence intervals (CI) are reported.

Ideascore = narrative macrostructure score; MLUw = mean length of utterance in words; GY = grammaticality; SI = subordination index; MATTR = moving average type–token ratio; WPM = words per minute.

macro- and microstructural aspects of narrative ability in school-age children treated for PFT. Narrative difficulties may be less obvious than, for example, motor-speech problems, and risk being overlooked, yet they can have a marked effect in everyday life. Regular narrative follow-up assessments over time may help identify difficulties that can become more apparent as linguistic and cognitive demands increase, allowing for timely intervention.

4.3 | Postoperative Changes and Their Relations to CMS and Dysarthria

The substantial individual variation in narrative change profiles highlights the complexity of language outcomes after PFT and suggests that different factors may underlie postoperative trajectories. Our findings reflect the heterogeneity in postoperative language outcomes, with some children improving and others declining, a pattern also noted by Di Rocco et al. (Di Rocco et al. 2010) and consistent with previous reports (Persson et al. 2025; Svaldi et al. 2023). Although the present study did not examine underlying factors for the interindividual variation in postoperative change profiles, our previous work has shown that a tumour in the fourth ventricle was significantly associated with poorer word-finding abilities after surgery (Persson et al. 2025). A possible interpretation is that surgical removal of a tumour in this region may disrupt cerebello–cerebral networks important for language. However, language outcomes after posterior fossa tumour surgery are not uniform and likely reflect

multiple interacting factors (Stoodley and Schmahmann 2010; Schmahmann et al. 2019). Among the factors that may contribute to this variation are postoperative CMS, known to result in language disorders (Catsman-Berrevoets and Aarsen 2010; Svaldi et al. 2023), and dysarthria, which may secondarily affect speech production. Since we wanted to take preoperative level into account and therefore examined change, the analyses were based on a small subgroup of children with complete pre- and postoperative data. Children with postoperative CMS showed a general decline across both macrostructural and microstructural measures, although these changes did not reach statistical significance. The results may reflect the very small and heterogeneous CMS group, which included both children with total mutism and those with severely reduced speech. It is also important to note that, at the time of postoperative assessment (1–4 weeks after surgery), the children with CMS had recovered sufficiently to participate in the narrative task, which may indicate that they had a mild form of CMS. More prolonged or pronounced symptoms may be associated with greater subsequent language difficulties, and this should be considered when interpreting the findings for the CMS subgroup included in the present study. In our previous study of word-finding ability, we found a tendency towards a clearer postoperative decline among children with mutism (Persson et al. 2025). Our results indicate that among these few individuals, CMS may influence narrative ability to varying degrees, in line with our previous findings suggesting that postoperative outcomes in children with PFT are best understood as existing on a continuum of severity rather than

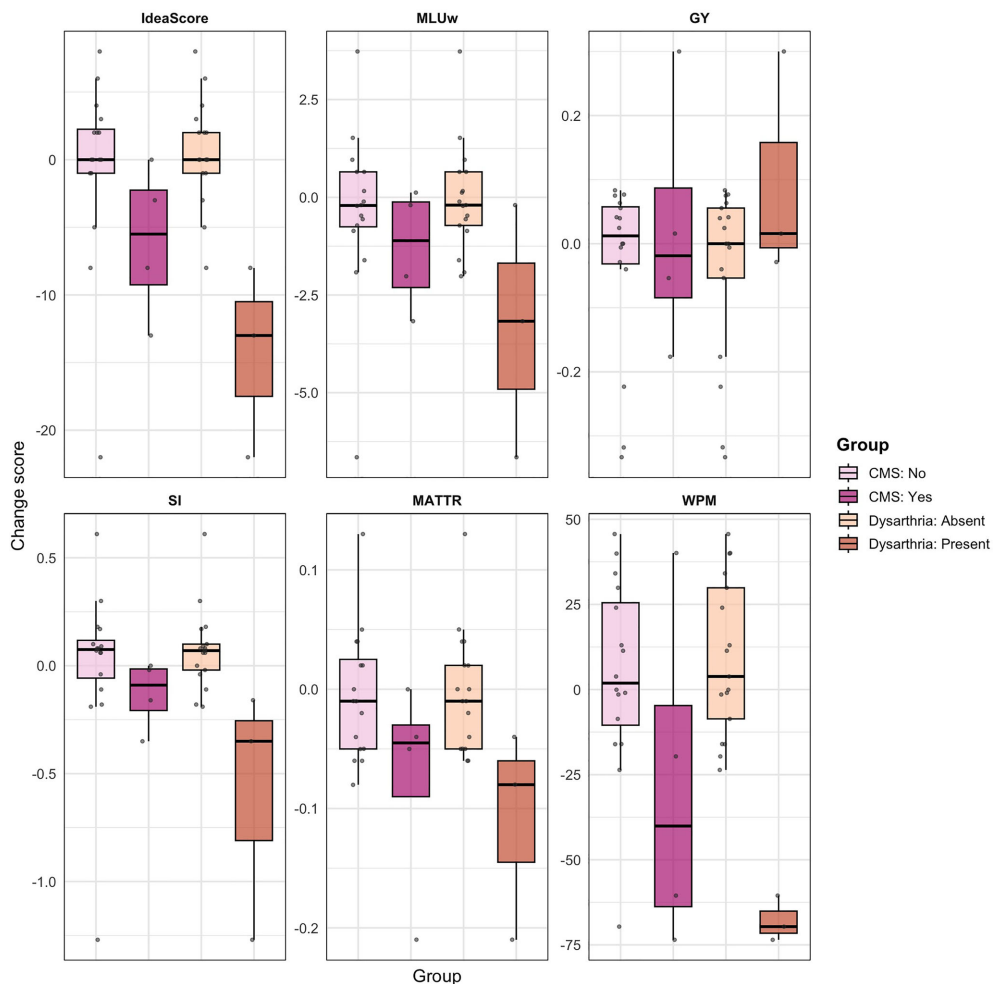


FIGURE 4 | Individual change scores (post – pre) for macrostructural (Ideascore) and microstructural (MLUw, GY, SI, MATTR, WPM) in relation to postoperative CMS and dysarthria.

Abbreviations: Ideascore = narrative macrostructure score; GY = grammaticality; MATTR = moving average type–token ratio; MLUw = mean length of utterance in words; SI = subordination index; WPM = words per minute.

as discrete categories (Persson et al. 2025). A similar direction of change was observed for children with postoperative dysarthria, who also showed a decline across both macrostructural and microstructural measures, indicating a relation between motor speech disorder and narrative performance. Dysarthria is not a language disorder, and we interpret this relation as a reflection of the performance demands involved in narrative production. The relation is likely to reflect constraints related to articulation, coordination, and voice, which make narrative production more demanding and may limit utterance length, syntactic complexity, lexical diversity, and fluency. We consider dysarthria to be

primarily related to the motor-executive aspects of language production rather than to underlying language deficits, while acknowledging that the interaction between motor speech and language processes is complex. Regarding the microstructural measure WPM, it is closely related to motor speech disorders, as rate abnormalities are one of the main features of dysarthria (Duffy 2016). However, in the present study this measure captures speech rate as words per minute and incorporates pauses related to formulation processes (such as word-finding and grammatical encoding), as well as revisions and self-corrections during narrative production. Although WPM was significantly associated

with postoperative dysarthria, the measure reflects both motor and language-related factors. Given that only a small number of children in the present study were reported to have postoperative dysarthria, we interpret reduced speech rate as reflecting not only motor constraints but also language difficulties, noting that disentangling these contributions requires other methodological approaches. Our findings emphasise the individual variability in language outcomes after PFT, indicating that several factors may contribute to this variability. Dysarthria may contribute to narrative difficulties by placing additional constraints on speech production. Clinically, it is important to assess both narrative ability and motor speech in order to capture the different disorders that may underlie narrative difficulties after PFT. This is essential, as these difficulties require distinctly different forms of intervention.

5 | Methodological Considerations

Several methodological aspects should be considered when interpreting the present findings. Although this is one of the largest studies including both pre- and postoperative narrative data in children with PFT, subgroup analyses, particularly those involving children with postoperative CMS or dysarthria, were based on small samples and should therefore be regarded as exploratory. The postoperative assessments were conducted 1–4 weeks after surgery, and variation in recovery and fatigue during this early phase may have influenced the results. Longer follow-up periods are needed to determine whether the observed patterns persist or change over time. Follow-up studies would also allow investigation of longer-term outcomes in children with more severe or prolonged CMS who were not represented at the short-term postoperative assessment in the present study. The structured ERRNI Fish Story task allowed for standardised data collection across centres and languages, which is a major strength in a multicentre study. However, the picture-supported format may have constrained children's narrative production, especially regarding lexical diversity and complex syntax. While the task was clearly sensitive enough to capture difficulties among the older children in this study, it can be assumed that more demanding tasks might have revealed additional or different types of difficulties. Future studies could include elicitation tasks that place higher demands on language planning and reasoning, such as expository or argumentative contexts, to capture a broader range of language and communication abilities. Variability in test administration across professionals (e.g., speech-language therapists, physicians, and nurses) cannot be excluded, although written instructions were followed in all settings.

6 | Clinical Implications and Future Directions

The present findings underline the clinical importance of including narrative assessment in the evaluation of children treated for PFT. Assessing narrative ability provides valuable information about both the content and form of children's language, helping to identify those who may benefit from interventions. Because postoperative outcomes vary between individuals, speech and language follow-up should be tailored to each child and include

both language and motor-speech assessments. Repeated assessment over time is also essential, as narrative difficulties may become more apparent when linguistic and cognitive demands increase with age and schooling.

Given the well-documented association between narrative ability and academic achievement, particularly literacy and reading outcomes (Babayigit et al. 2021; Griffin et al. 2004; Reese et al. 2011), future studies could link narrative outcomes in children with PFT to national educational register data to examine how narrative difficulties relate to school performance, including prior to tumour identification. Building on our previous work on pre- and postoperative language abilities in children with PFT and in those with CMS, future studies may also investigate how narrative abilities relate to the neurobiological underpinnings previously associated with language difficulties in these groups. Such work would allow for the development of more refined hypotheses about why some children experience narrative difficulties and how these difficulties evolve over time. A complementary line of enquiry concerns longitudinal follow-up, examining how narrative and related language abilities change beyond the perioperative phase and whether recovery or continued vulnerability can be observed over time. Extending this work to larger and cross-linguistic samples and combining narrative procedures with tasks that elicit more complex discourse, would make it possible to capture a broader range of developmental trajectories and deepen our understanding of how language difficulties evolve across childhood and adolescence. Such knowledge may also guide the development of future clinical approaches and intervention strategies aimed at supporting communication and participation in everyday life.

7 | Conclusion

Children undergoing PFT surgery showed preoperative and postoperative difficulties in narrative macrostructure and microstructure compared with TD peers. These difficulties were most evident among older children, suggesting that narrative challenges become more apparent as linguistic and cognitive demands increase. Postoperative outcomes varied considerably between individuals; while we did not identify significant differences between children with and without CMS, children with postoperative dysarthria showed a decline across both narrative levels, interpreted as reflecting the performance demands involved in narrative production. Our findings emphasise the variability in language outcomes after PFT and highlight the importance of individualised follow-up that includes assessments of both language and motor-speech abilities.

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Consent

Written informed consent was obtained from caregivers of all participants and by participants when appropriate.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Due to ethical considerations and data protection regulations, the datasets generated and analysed during the current study are not publicly available.

Ethics Statement

The study was approved by the Swedish Ethical Review Board (reference 2014/3:8) and (reference 2024-05489-01).

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Paper IV



RESEARCH REPORT OPEN ACCESS

Children's Experiences of Communication in Everyday Life Following Posterior Fossa Tumour Surgery—A Sense of Belonging While Navigating Reality

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Background: Posterior fossa tumours (PFT) are the most common childhood brain tumours, and children treated for these tumours are at increased risk of persistent speech, language and/or communication difficulties. Such difficulties have often been described in association with the postoperative complication cerebellar mutism syndrome (CMS), but can also occur in children without a period of mutism. Speech and language difficulties may affect communication, participation and social relationships. However, little is known about how children themselves experience communication in everyday life following PFT surgery.

Aim: This study aimed to describe children's experiences of communication in their everyday lives following PFT surgery.

Methods: An inductive qualitative content analysis was conducted based on semi-structured interviews with 10 children, aged 6 to 18 years at the time of the interview, carried out at least 1 year after PFT surgery. Interviews were adapted to the children's communicative abilities, using augmentative and alternative communication (AAC) when needed, and a flexible, child-centred approach was used to capture their experiences.

Results: Two overarching themes were identified: The theme *A thin line between belonging and not belonging* captured children's experiences of inclusion and exclusion through everyday communicative events; The theme *Navigating reality towards normality* captured how children expressed who they were and managed how they were perceived.

Conclusions: While speech, language and/or communication difficulties were not explicitly mentioned, the children's descriptions reflected how the consequences of such difficulties shaped everyday communication and participation. Small, everyday moments could affirm or undermine belonging, and familiar friendships provided continuity during a time of change. Children also expressed needs, set boundaries and protected their identity while adapting to new circumstances. The findings underline the importance of listening to children and planning support that is flexible, responsive and grounded in their perspectives.

WHAT THIS PAPER ADDS

What is already known on the subject

- Previous studies have described speech, language and/or communication difficulties following posterior fossa tumour surgery. In children with speech and language impairments, such difficulties have been linked to fewer peer interactions, social withdrawal and difficulties maintaining friendships and participating in group activities.

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What this paper adds to existing knowledge

- This study offers a unique insight into children's own experiences of communication after PFT surgery. These experiences have not previously been described from the children's perspective. The study captures how children experience everyday communication, showing how it can support or disrupt a sense of belonging depending on how communication unfolds in different contexts.

What are the potential or actual clinical implications of this work?

- The findings of this study have implications for healthcare providers, school health services and educational settings. Professionals should not rely solely on observation but actively invite children to share their experiences. Supporting pre-existing friendships and informing classmates may contribute to more understanding and positive responses.

1 | Introduction

Communication is essential for children's social, emotional, cognitive and not least, language development (Vygotsky and Cole 1978; Tomasello 2005; Bruner 1985). As a multifaceted process, communication may be verbal or nonverbal, intentional or unintentional, and involves both understanding and expression. Communication has been described as serving multiple purposes, including the expression of needs and wants, the transfer of information, the development of social closeness, the management of social etiquette, and communication with oneself or internal dialogue (Light 1988; Beukelman and Mirenda 1998). Forms of expression may include spoken language, gestures, facial expressions and various forms of augmentative and alternative communication (AAC), such as signs, pictures, symbols or voice output devices (Beukelman and Mirenda 2013). These various forms of communication enable children to engage with others, make sense of their experiences, and actively participate in their everyday life (Vygotsky and Cole 1978; Tomasello 2005; Bruner 1985). Participation refers to the children's involvement in everyday situations, where communication is not viewed as something that leads to participation, but as an integral part of it, mutually shaping and being shaped by participation, consistent with the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2013; Socialstyrelsen 2024). Everyday life has been defined as the mundane routines and contexts that are often taken for granted (Chandler and Munday 2011). Children's everyday lives refer to the ordinary contexts and routines where they spend time, such as home, school and leisure (Christensen and James 2008).

Difficulties in speech, language and/or communication can impact a child's ability to participate in everyday life (MacDonald 2016; Beitchman and Brownlie 2013). *Speech* involves the articulation, voice and fluency used to produce spoken language, i.e., motoric processes, while *language* refers to the symbolic system used for understanding and generating meaning (Beukelman and Mirenda 2013). In practice, these domains interact in a complex interplay. Spoken language production requires the coordination of linguistic and motor processes (Levelt et al. 1999), and impairments in one domain may limit or mask abilities in the other, which can affect communication (Smith and Goffman 2004). Previous studies show that children and adolescents with developmental language disorder (DLD) are at increased risk of social, emotional and behavioural difficulties (Durkin et al. 2017;

van den Bedem et al. 2018; Conti-Ramsden et al. 2019; Wren et al. 2023; Langbecker et al. 2020). Children and adolescents with DLD tend to show lower social confidence and greater social uncertainty in interactions (Durkin et al. 2017) and are also more likely to experience bullying and social exclusion than their typically developing peers (van den Bedem et al. 2018; Wren et al. 2023). Emotional and peer problems frequently co-occur and may persist into adolescence, with long-term implications for mental health, education and social well-being (Conti-Ramsden et al. 2019; Langbecker et al. 2020). Studies incorporating children's own perspectives further indicate that those with DLD often report greater social uncertainty, emotional difficulties and vulnerability to peer problems compared to their typically developing peers (Durkin et al. 2017; van den Bedem et al. 2018; Conti-Ramsden et al. 2019).

One group of children who, in addition to other late complications, are likely to develop speech, language and/or communication difficulties are children who have undergone surgery for a posterior fossa tumour (PFT) (Svaldi, Paquier et al. 2023; Persson et al. 2024, 2025; Di Rocco et al. 2010; De Smet et al. 2009; Catsman-Berrevoets and Aarsen 2010). PFTs comprise about half of all central nervous system tumours in children (Rickert and Paulus 2001). Surgical resection is essential, aiming to cure the patient and alleviate the burden of acute symptoms, but it carries a risk of complications, most notably cerebellar mutism syndrome (CMS), which affects around a quarter of children after PFT surgery (Mei and Morgan 2011). CMS is characterised by mutism or severely reduced speech, emotional lability and other neurological deficits (Gudrunardottir et al. 2016). The condition can last weeks to months and lead to persistent speech, language and/or communication disorder (Gudrunardottir et al. 2016) together with other neurological and cognitive consequences (Horne et al. 2026). Language disorders following posterior fossa tumour (PFT) surgery also occur in children without CMS, emphasising the broader impact of these tumours and their treatment on linguistic outcomes (De Smet et al. 2009; Cámara et al. 2020). Motor speech disorders, such as dysarthria or apraxia of speech, may affect prosody, fluency and articulatory control (De Witte et al. 2017; Catsman-Berrevoets et al. 1999, 1992; Cornwell et al. 2003; De Smet et al. 2012). While motor speech disorders are expected from a traditional view of cerebellar function, it is now well established that the cerebellum also contributes to language and other cognitive processes (Stoodley and Schmahmann 2010). Language disorders following CMS

are still poorly understood, with current studies suggesting that these impairments may involve both comprehension and production, affecting both morphosyntax and lexical semantics (Svaldi, Paquier et al. 2023; Persson et al. 2025; Di Rocco et al. 2011; Riva and Giorgi 2000). These difficulties may co-occur and interact (Gudrunardottir et al. 2016) in ways that constrain how children are able to understand others (Di Rocco et al. 2010; Catsman-Berrevoets and Aarsen 2010), express themselves and participate in communication (Catsman-Berrevoets and Aarsen 2010; Gudrunardottir et al. 2016; Suresh et al. 2024). Within the broader field of paediatric acquired brain injury (ABI), qualitative studies have shown that young people often describe communication changes as closely related to their sense of identity, participation and belonging. Adolescents with ABI report frustration, social withdrawal and efforts to rebuild confidence in everyday interactions (Buckridge et al. 2020; Lo et al. 2023). Similar aspects have also been highlighted among youths with motor speech disorders, where communication is described as essential for maintaining relationships and participation (Connaghan et al. 2022). These findings underline the importance of understanding communication from the child's own perspective, also when considering the broader social outcomes for children with brain tumours. In addition, questionnaire studies have found survivors of paediatric brain tumours in general to report social withdrawal, difficulties maintaining friendships, and challenges participating in group activities (Desjardins et al. 2022; Hocking et al. 2020; Fantozzi et al. 2024). While speech, language and/or communication difficulties may contribute to these challenges, research also highlights the role of late complications such as fatigue, executive dysfunction, neurocognitive impairments and social-cognitive difficulties in shaping brain tumour survivors' social communication and participation (Fantozzi et al. 2024; Pühr et al. 2021; Willard et al. 2017; Levitch et al. 2022). Despite the risk of extended consequences due to these difficulties, to our knowledge, only one qualitative study has described the long-term consequences of CMS from the perspective of those affected. In that study, young adults who were diagnosed with CMS during childhood described both early difficulties and persistent social and communicative challenges in their current lives, such as losing friendships, struggling to form new ones, and feeling socially isolated (Wibroe et al. 2021). While these findings provide valuable insights, they reflect adult perspectives, shaped by retrospective accounts many years after their childhood surgery, and only included participants who had experienced CMS. Children's own descriptions of communication in everyday life following PFT surgery have not been addressed. This points to a lack of knowledge about how communication is experienced and described by children currently living with the consequences of PFT and related treatment. Understanding how children experience communication is essential for developing support that is relevant to their everyday lives. To address this gap, this study aims to describe children's experiences of communication in their everyday lives following PFT surgery.

2 | Method

2.1 | Design

This qualitative study, based on semi-structured interviews, is reported in accordance with the Consolidated Criteria for

Reporting Qualitative Research (COREQ) (Tong et al. 2007). The study was conducted using qualitative content analysis with an inductive descriptive approach (Graneheim and Lundman 2004; Graneheim et al. 2017). This approach was chosen to describe variations in the children's experiences of communication while remaining close to their own expressions, without imposing predefined frameworks. The inductive analytic process was considered appropriate to ensure that the analysis remained grounded in the children's perspectives. Individual interviews were used to allow each child to describe their own experiences of communication without influence from others.

2.2 | Recruitment

The study was approved by the Swedish Ethical Review Authority (Dnr: 2022-02670-01). Recruitment was conducted through contact nurses at Sweden's six childhood cancer centres. These nurses, who were familiar with the children through clinical follow-up, identified potential participants based on their personal knowledge of the patients and by reviewing medical records. Indications of speech, language and/or communication difficulties originated from documentation in the medical records by clinicians involved in the child's care, such as speech-language therapists, neuropsychologists, physicians or nurses, based on clinical observations or results from routine follow-up assessments. Children aged 5–18 years who had undergone surgery for a posterior fossa tumour were eligible if at least 1 year had passed since the most recent surgery. In addition to surgery, the children could also have received adjuvant anti-tumour therapies such as radiotherapy and/or chemotherapy, depending on tumour type and treatment protocol. Children were eligible for inclusion if they were Swedish speaking and did not rely exclusively on AAC. In addition, children with a severe or worse intellectual disability were excluded, based on neuropsychological assessments conducted as part of routine clinical care, in accordance with the Nordic protocol for neuropsychological follow-up of children treated for brain tumour (Regional Cancer Centres in Sweden 2023). Eligible children and legal guardians received both verbal and written information about the study from the contact nurses. The information provided to the children was adapted using simplified language and text supported by symbols to ensure that it was age-appropriate and linguistically accessible, thereby supporting comprehension and informed participation. If interest in participation was expressed, the contact details of the legal guardian were forwarded to the first author, who provided additional information, answered any questions, and obtained written informed consent from the legal guardians for all participants under the age of 15. Participants aged 15 years and older provided their own written informed consent. In addition, informed assent was obtained from all children under 15 to ensure that their willingness to participate was acknowledged and respected. Both children and parents were informed that they could withdraw at any time without providing a reason and without any consequences. Since the legal guardian was the child's parent in all cases, the term 'parent' is used hereafter. To facilitate participation, interviews were scheduled at a time and location of the child's choosing, with the possibility to meet in person at home, school or hospital facilities, or to meet online if preferred. The children recruited from southern Sweden may have previously met the first author in a clinical setting, but no

TABLE 1 | Child- and parents reported demographic data in participating children.

	n (%)	Median	Range
Sex			
Boys	2 (20%)	—	—
Girls	8 (80%)	—	—
Age (years)	—	13:5	6:0–18:0
Age at first surgery (years)	—	5:5	1:5–15:0
Time from surgery to interview	—	3:6	1:2–10:2
Mutism Postop			
Yes	6 (60%)	—	—
No	4 (40%)	—	—
Mutism duration (weeks)	—	—	1–52
School adjustments			
Yes	8 (80%)	—	—
No	2 (20%)	—	—
Achieving academic goals			
Yes	6 (60%)	—	—
No	4 (40%)	—	—
Reoperation			
Yes	2 (20%)	—	—
No	8 (80%)	—	—
Age at second surgery (years) ^a	—	9:8	9:5–10:0

Note: Age and time are reported in years:months, and mutism duration in weeks. For children who underwent reoperation, the time since surgery refers to the most recent operation.

^aAge at second surgery is reported for the two children who underwent reoperation.

ongoing therapeutic relationships were in place at the time of the study.

2.3 | Participants

Sixteen children were invited to participate in the study. Five declined during recruitment, and one child who had initially agreed was unable to take part due to health-related issues. In total, 10 children, eight girls and two boys, from different parts of Sweden took part. At the time of the interviews, they were between 6 and 18 years old. Demographic data were reported by the children and/or their parents. Six of the children had experienced a period of postoperative mutism, whereas four had not. Most described receiving various school adjustments to manage their daily functioning, such as reduced hours, smaller group instruction or individualised support. In the Swedish school system, pupils work toward knowledge targets in the early years, with formal grading introduced from year 6 (approximately at age 12) and continuing through secondary school. Six children reported that they were achieving their academic goals, while four were not. For younger participants, this referred to progress in relation to curriculum-based knowledge targets; for older children, to receiving passing grades. All background characteristics are presented in Table 1. The following descriptions, based on the first author's observations during the interviews, are intended to provide a fuller picture of the participants. Eight of

the children had motor symptoms, and five used mobility aids, including walkers and wheelchairs. Seven of the children showed signs of motor speech impairment, for example, characterised by reduced prosody, imprecise articulation and/or a slow speech rate. According to the first author's clinical impressions during the interviews, most children also showed signs of word-finding difficulties and challenges in producing longer or more complex utterances. One child primarily had difficulties with interactional aspects of communication, such as taking turns, maintaining a topic or adjusting the amount of information shared.

2.4 | Data Collection

Demographic information was collected through a short questionnaire completed by the child and/or a parent. A pilot interview was conducted with one child to assess the clarity and appropriateness of the interview guide. The guide was judged to be suitable for the study and aligned well with the study's aims. Given the marked heterogeneity in participants' linguistic and communicative abilities, each interview required individual adaptation of the guide to meet the child's communicative level. The interview guide (available in [supplementary materials](#)) covered topics related to communication in school, leisure activities, peer relationships, class activities and the use of digital platforms such as social media and messaging apps. Although all children communicated verbally, there was

variation in how they expressed themselves during the interviews. Visual AAC materials were present during all interviews, placed visibly on the table throughout the session, and used either on the interviewer's initiative, the child's or jointly during the interview. The children often combined spoken language with gestures, facial expressions, and visual symbols, such as pointing to symbols representing happy, neutral or sad emotions or using thumbs up or down to express agreement or disagreement, to signal something as good or bad, or to convey other meanings in context. These visual expressions were used to clarify, reinforce or sometimes replace spoken language. Examples of the symbols and symbol boards used are available in [supplementary materials](#) (Widgit Symbols Widgit Software Ltd 2002–2025). The interviews were conducted by the first author, a speech-language therapist with extensive clinical experience working with children with speech, language and/or communication difficulties. Although online participation was available, all interviews were ultimately conducted in person, as this was preferred by all participants. Data collection took place between January 2023 and January 2025. Interviews lasted between 25 and 78 min ($M = 45$ min), with breaks offered to accommodate fatigue. Children were given the option to have a parent present during the interview. In one case, an adolescent wished to have a parent nearby and the parent remained seated at a distance to allow for autonomy. Each child was interviewed once; no follow-up interviews were conducted. All interviews were audio-recorded. Observational field notes were taken in connection with the interviews to capture contextual aspects and non-verbal communication. Interviews were conducted until the data were considered sufficiently rich and varied to reflect the breadth of the children's communication experiences. The interviews were first transcribed using @Train transcription software (Haberl et al. 2024) and subsequently manually checked and transcribed verbatim by the first author. Extra-linguistic elements such as laughter, crying and the use of signs or symbols were noted in the transcripts. No transcripts were returned to the children for comment or correction.

2.5 | Analysis

An inductive qualitative content analysis was used to describe the children's communication experiences, following the steps outlined by Graneheim and Lundman (2004) and further elaborated by Lindgren et al. (2020). In the first step, the interviews were read several times by the first, second and last authors to gain an overall understanding of the content. In the second step, meaning units related to communication, as defined in the introduction, were then identified in the text: segments of words, sentences or paragraphs that conveyed a single idea related to the study aim. In the third step, these meaning units were condensed to shorten the text while preserving its core meaning. In the fourth step, each condensed meaning unit was labelled with a code that captured its essential content in concise terms. In the fifth step, codes expressing related ideas were compared for similarities and differences, and then sorted into subcategories and abstracted into broader categories representing the manifest content of the data. In the sixth step, the categories were interpreted and synthesised to develop themes that reflected the latent content, capturing underlying meanings and recurring

patterns grounded in the children expressed experiences. Finally, in the seventh step, the preliminary categories and themes were reviewed, refined and discussed within the research team until consensus was reached, and a coherent interpretation of the material was achieved. Throughout this process, the analysis involved a continuous movement between the whole and the parts of the text, consistent with the iterative nature of qualitative content analysis, as further illustrated in Table 2, which provides an example of how meaning units were condensed, coded and abstracted into categories and themes.

To ensure credibility, the first, second and last authors jointly identified meaning units in two interviews, which were then condensed and coded together. This initial collaborative step provided a common ground for the analysis. Thereafter, the authors repeatedly discussed meaning units, codes and preliminary themes during all stages of the analysis. Representative quotations were selected to illustrate each category and to elucidate the children's voices in the results (Graneheim and Lundman 2004; Graneheim et al. 2017; Korstjens and Moser 2018).

3 | Results

Two overarching themes emerged from the interviews, each containing categories that reflected how children described their communication experiences following PFT surgery. The themes demonstrated how communicative moments could support or challenge children's feelings of belonging, and how participation was related to a sense of self and normality. An overview of the themes and categories is presented in Figure 1.

3.1 | A Thin Line Between Belonging and Not Belonging

This theme captures a range of experiences where communication shaped children's sense of inclusion or exclusion, encompassing moments of feeling included and recognised, as well as experiences of being unheard, alone and left out. Belonging was not a fixed state, but something that could be affirmed or undermined in everyday moments. A shared joke, an invitation or simply being spoken to could affirm a sense of inclusion. At the same time, silence, being left out or having one's voice dismissed could result in a sense of exclusion, whether through passive absence or active disregard. A similar situation, like sitting quietly among others, could for one child feel like being part of something, and for another like being left out. The children's experiences illustrated how fragile belonging could be and how much it mattered to be seen, listened to and included through communication.

3.1.1 | The Joy of Being Included

All the children described experiences of belonging and feeling part of a group, a setting or a shared moment. These experiences emerged through communication with friends, classmates, siblings, teachers and others, in school, during leisure time, within families or through digital platforms. Talking during

TABLE 2 | Example of the analytic process illustrating the abstraction from meaning units to codes, categories and themes.

Meaning units	Code	Category	Theme
I use Snapchat, yeah it's mostly (...) I don't have that many there but we have a small group, we three, so we can talk and like if there's something or if we're gonna meet or something	Small group on Snapchat where we talk	The joy of being included	A thin line between belonging and not belonging
the others aren't so keen to communicate with each other or to talk but like just this thing that it's spread out, that we are spread out and not like have togetherness or what you should say, like we don't have a short distance (shows by putting hands together)	Not keen to talk, spread out, no togetherness, we don't have a short distance (shows by putting hands together)	Among others yet alone	
I told them (the teachers) that 'I can't have it like this cause like the class doesn't want to . .no one wants to be with me and no one yeah wants to be with me or so' and I said several times, 'please let me change class'	Told the teachers several times and asked to change class.	Not being heard	
I feel that I have gotten better at speaking up I can now tell friends like 'no now I'm tired', 'now I have to rest' because otherwise I know that if we say I would go full on the whole weekend, then I know that on Monday it's just not gonna work	Can say no to friends to balance energy	Facing reality	Navigating reality towards normality
But it actually went like half a year before I told all classmates (about my condition) I actually had a Swedish presentation and then we should tell about things I've been through Yeah things I've gone through and then I talked about the Children's Cancer Foundation and then I got in there like 'I also have had cancer '	Waited to tell everyone in class about the condition	Holding on to oneself yet being like others	

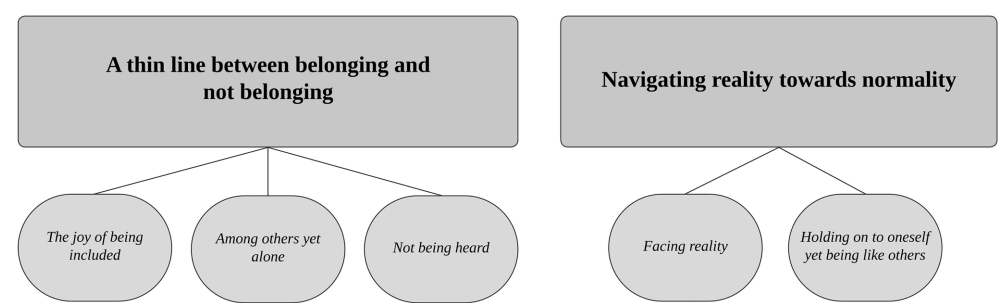


FIGURE 1 | Overview of the two overarching themes and associated categories describing children's experiences of communication in everyday life following posterior fossa tumour (PFT) surgery.

breaks, laughing together, being asked to join or simply being greeted were all described as communicative acts that contributed to a sense of inclusion. Everyday situations such as chatting in the cloakroom, playing in the schoolyard or being invited

to a birthday party were not only activities, but also ways in which communication confirmed belonging. Children described experiences of being invited to join and participate, expressed through simple communicative acts such as being asked or invited to take part:

I'm going to his birthday party on Friday... it's fun... I haven't been to much parties for a long time. I haven't got so many much invitations, so a few days ago I got one [smiles, eyes lighting up, shifts from lying back on the sofa to sitting upright]. (Participant 2, 8 years).

Digital communication also played an important role in experiences of inclusion. Children described staying in touch through apps like Snapchat, TikTok and Instagram. Messages, jokes, and short videos were exchanged, helping to maintain a sense of inclusion even when time at school was limited or when friends were in different places during the school day. These digital exchanges felt like important ways of maintaining communication:

And a friend from school made one of those edits [an edited short video, often shared via social media, combining pictures or clips set to music to express appreciation or friendship]. It's like one of those videos and then it's just me and her the whole video [showing the video including the message Best Friends Forever (BFF)]. It felt really good. (Participant 7, 17 years).

Friendships that existed before the PFT surgery, whether maintained over time or reconnected through digital communication or visits, were described as providing a sense of safety and familiarity. Communication within these established relationships was described as easier and more comfortable, as they did not require explanations about what had happened due to the condition. Children described how familiar relationships could support a sense of communicative ease:

We've known each other from before. It's actually kind of nice that we've known each other from before. Yeah, we went to the same preschool and then we also did scouts together and we sometimes hang out at break time. It's really fun. (Participant 8, 8 years)

In some cases, experiences of inclusion were described as emerging through more subtle forms of communication. Children spoke of being physically present without actively participating, for example, by just being there, observing, listening or scrolling on their phones. This quiet presence could still involve a communicative dimension and carry a sense of belonging, even when two-way verbal communication was limited. One child who had extensive difficulties with describing responded briefly and with support, yet still described moments that felt good, such as being together with a friend.

3.1.2 | Among Others Yet Alone

Children across all ages described how being with others in everyday settings did not necessarily involve communication that made them feel included. They described communicative experiences of exclusion, such as not being spoken to, not being asked to join or being left out of everyday moments like group chats on Snapchat. Some children described this exclusion in direct and explicit terms:

Me ... I'm left out ... Mm [points at 😞]. Yes me ... Mm... Me ... I do like this ... [points at 😞] Eeh ... Why don't friends ask me [points at 😞]. (Participant 3, 6 years).

Others described exclusion as more subtle and inconspicuous, such as being overlooked or not being addressed in conversation. They described situations where they were physically present with others, but communication was absent or minimal, leading to a sense of not being part of a shared experience:

Sometimes I'm by myself and sometimes someone else is there. But we usually don't talk... It's just like I'm by myself there and the other person is by themselves there. (Participant 6, 18 years)

This sense of not belonging was described in emotional terms by some children, while others highlighted how physical limitations affected their ability to take part in the communicative flow of play or group activities. Not being able to join, keep up or participate in shared situations often meant missing out on communication that might have supported a sense of inclusion.

While some friendships were maintained and experienced as easy and familiar, other relationships changed in the opposite direction, as communication with friends diminished or disappeared, and inclusion was no longer experienced. Children described how friendships that once offered comfort had faded, how group structures felt closed, and how classmates seemed to withdraw. These changes were described as the absence of communication, such as not being contacted, not being invited or no longer being included in everyday talk. It was not only about being physically alone, but about a lack of communicative connection that contributed to a deeper sense of emotional loneliness:

I felt really lonely after I got sick because almost all my friends from before I got sick, like, disappeared from my life (...). I had my family around me who tried to do fun things with me, tried to cheer me up and stuff, and yeah, my siblings, my two siblings (...) yeah, so I did have them but ME deep inside, like if you think here inside [points to heart] I felt lonely. It wasn't out here I felt lonely [shows hands a bit away from body], it was in here, deepest within [points to heart]. (Participant 1, 17 years).

3.1.3 | Not Being Heard

Children described situations where they tried to express themselves but felt that their communicative attempts were not acknowledged. They described how they were ignored in situations when they tried to make themselves heard:

I was SO ANGRY because the teachers didn't listen to me. (Participant 1, 17 years).

Emotional responses such as frustration and anger often followed when communicative efforts were left without response. In a play

situation during recess, one child described repeatedly calling out to get others to stop, but feeling that no one listened:

I said so much, 'stop! stop!' (shouts). Then my throat hurts. (Participant 3, 6 years)

Not being heard was not only about silence or lack of response. There were also instances where others, such as parents or relatives, spoke for the child, making the child's personal experiences public without their consent. These situations were described as experiences of exposure and of no longer being able to tell one's own story in one's own way. Together, these situations illustrated how efforts to communicate could be disregarded, leaving children feeling powerless and unheard.

3.2 | Navigating Reality Towards Normality

This theme reflects how children through communication manage challenges in everyday life. It shows how they expressed needs, set boundaries, and protected a sense of who they were in everyday life. Their accounts revealed a tension between adjusting to changes and maintaining a sense of normality and self. Through communicative actions, such as asking for help, saying no or setting limits, children created space for themselves in situations that might otherwise have been overwhelming. At the same time, they described a strong desire to be like others, act independently, and hold on to a feeling of normality.

3.2.1 | Facing Reality

Children described how they gradually came to understand their new situation and use communication to express what they needed from others in order to manage everyday life. Facing reality was not described as giving up, but as recognising what had changed and finding ways to live with it. Through communication in school and at home, with both adults and peers, children described how they expressed what helped, what was difficult, and what they needed in order to participate on their own terms. In school, communication about needs could lead to support that was practical, emotional, pedagogical or social. Some children described a moment when the contact nurse visited their class and communicated with classmates about their situation. This was described as an important communicative event that contributed to improved attitudes and positive reactions from classmates, making it easier to feel included. Children also described situations where support was lacking, and where it became necessary to explain or insist on what was needed. They spoke about what didn't work, such as being placed in environments where they couldn't participate or when their needs were overlooked or unmet. In some cases, they actively rejected inadequate arrangements and communicated a clear boundary that led to change.

Children also described how managing energy and setting limits were part of their everyday communication. They described the challenge of balancing participation with physical and mental exhaustion, and how they communicated both with themselves, through internal dialogue, and with others by expressing needs

and setting boundaries. Even when they wanted to be part of something, the body or mind sometimes refused. Saying no, leaving early or taking breaks became strategies that allowed them to stay involved without becoming overwhelmed. Communicating personal limits and protecting one's own boundaries was described as something they had to learn over time.

Children also described how support from others helped them face reality and manage emotional challenges in everyday life. Communication with family members, siblings or trusted adults was often central. This support could take place in ordinary situations such as going for a walk, picking flowers, playing a game or simply having someone nearby. Emotional reassurance came through closeness, being listened to and having someone who understood what was difficult without the need for many words. Animals were also mentioned as especially meaningful. They offered a sense of social closeness and comfort without requiring verbal communication, and were described as supportive in ways that felt calming and genuine:

I feel like, well, I got a friend [when my family got a puppy]. Yeah and then, you know, he barks loads [laughs and looks happy] and he's like, you know, like a whole welcome committee when you come home, he's always happy and always outside when the taxi comes and then he starts barking and then he knows it's me coming. (Participant 1, 17 years).

AI chatbots were also described as one example to release emotions and to explore the boundaries of what could be expressed or was allowed to be expressed:

You can do whatever you want with them [the AI chatbots]. You can't do that with your friends... You can take out all your aggression on them. (Participant 9, 11 years).

3.2.2 | Holding on to Oneself yet Being Like Others

Children described the importance of holding on to who they were, striving for independence, and at the same time wanting to be like others. They described how they expressed who they were, how they wished to be seen, and how they protected parts of their identity that felt important. Holding on to who they were was central in the children's experiences. They described the importance of being recognised for who they were, rather than being defined by their condition. This was exemplified in moments where they chose how to communicate with friends by speaking up, joking or simply being themselves in everyday situations, as well as in deciding what to communicate, or not, in order to be recognised for who they were:

Well, this thing I did when I started upper secondary school [not telling everyone about the diagnosis] I didn't want people to know, because I wanted them to see me and not the cancer. That was incredibly important to me (...) just because I've had cancer doesn't mean it defines

me as a person... I want them to see ME, not the cancer.
(Participant 10, 17 years)

Children also described striving for independence at different levels: physically, emotionally and socially. In their everyday lives, children expressed their independence through speaking for themselves, making decisions and doing things on their own without relying on others. As for emotional independence, children expressed a wish to manage situations on their own. This included wanting to handle everyday challenges without relying on others and to feel capable and strong. One child described how she communicated to her teacher about how peers should not be expected to assist:

I sat in there by myself and ate a sandwich. And this, they like, they didn't really get it, you know... so then they fixed it so someone would bring food from the canteen for me... It's completely mad. And at first, he [the teacher], like, he was going on about how my classmates should go get food for me. And I just said, 'no, they shouldn't be doing that I mean, that's where I draw the line. That's me.
(Participant 10, 17 years).

Being recognised on their own terms, rather than being spoken about or defined by others, was described as an essential part of reclaiming oneself. Children also described a wish to be like others and to participate in everyday life without standing out. This was reflected in how they communicated in social situations, by holding back, avoiding attention or choosing not to ask for help to avoid being seen as different. In doing so, they strived to maintain a sense of normality and to be seen as just like everyone else.

4 | Discussion

Child survivors of PFT surgery are at increased risk of postoperative speech, language and communication disorders (Svaldi, Paquier et al. 2023; Persson et al. 2024, 2025; Grønbaek et al. 2021; Svaldi et al. 2025; Svaldi, Ntemou et al. 2023), and this study provides insight into their experiences of communication in everyday life following PFT surgery. Although all children had speech, language and/or communication difficulties, few explicitly described these as barriers in their communication with peers and others. This finding differs from earlier studies where children with DLD explicitly described how diverse difficulties, such as problems with word-finding, sentence construction or pronunciation, affected their everyday communication and peer interaction (Ekström et al. 2023; Merrick and Roulstone 2011). At the same time, the children's experiences showed that they did not always view their current social or communicative challenges as primarily caused by their speech and language difficulties. Rather, they often described these challenges in relational or contextual terms, such as who they were with, how they were treated or what the situation demanded (Ekström et al. 2023; Merrick and Roulstone 2011), which corresponds with findings showing that the communicative difficulties of children with DLD are closely linked to relational and contextual factors, including peer interactions, social acceptance, and others' responses (Durkin et al. 2017; van den Bedem et al. 2018; Conti-

Ramsden et al. 2019; Wren et al. 2023). This relational and contextual way of describing difficulties is also evident in children with ABI. In previous studies, children have explained that communicative challenges are shaped by the social context and by interaction. They describe how difficulties often arise within group situations and depend on how others respond and adapt during communication (Buckeridge et al. 2020; Lo et al. 2023). In the present study, such relational and contextual perspectives appeared more prominent, while direct references to speech and language difficulties were absent. There may be several plausible explanations for this. One possibility is that the children did not view their current social or communicative challenges as primarily caused by their speech and language difficulties. Another explanation could be that longstanding difficulties had become internalised and normalised over time, as suggested by Ekström et al. (2023). It may also reflect what children considered relevant, permissible or safe to share in the interview context, also noted in earlier studies (Ekström et al. 2023; Merrick and Roulstone 2011). The fact that speech or language difficulties were not explicitly mentioned does not suggest that these had no influence on the children's everyday communication. Rather, this absence may be understood in light of the explanations discussed above and considered an important finding that warrants careful reflection.

The children in this study described experiences of belonging and of being invited to participate, often communicated in subtle or nonverbal ways. Through everyday communication, such as being included, addressed or simply being present with others, they conveyed how they felt part of a group, a setting or a shared moment. They also described communication with animals and different forms of digital communication, including chatbots, gaming and online communication, further illustrating that communication and participation can occur beyond face-to-face exchanges, through presence, play or brief digital contact. The children's accounts show how communication and participation were closely intertwined, consistent with the ICF (World Health Organization 2013; Socialstyrelsen 2024), where each continuously shapes the other in everyday life. Participation was experienced through different forms of communication, by being invited, addressed or simply present with others, while opportunities for participation also created possibilities for communication. However, these experiences of belonging stand in contrast to earlier research that has primarily highlighted experiences of social exclusion among children with speech, language and/or communication difficulties (Conti-Ramsden and Botting 2004; Wadman et al. 2011; Lindsay et al. 2008). In addition, Wibroe et al. (2021) described that young adults who had experienced CMS in childhood reported persistent social difficulties and challenges in maintaining peer relationships. While such challenges were also mentioned in this study, they were not dominant. Instead, the children's accounts illustrate how belonging could be created through small acts of communication and how inclusion was experienced in subtle, everyday ways. There may be several possible explanations for this. One possible explanation is that communicative support in the children's surroundings, for example, from peers, teachers or family members, may have adequately been able to facilitate experiences of inclusion. This interpretation is supported by Merrick and Roulstone (2011), who describe how participation can be enabled when others adapt, listen and include children

with communication needs in everyday activities. In the Swedish context, national efforts to improve long-term follow-up and rehabilitation for children treated for brain tumours, including support directed towards schools and families, may also have contributed to enabling participation in everyday life (Regionala Cancercentrum i Samverkan 2024, 2025). While such efforts vary across regions and remain in development, they may have supported some of the positive experiences described in this study. The environmental factors are also emphasised in the ICF framework, showing how participation and communication are co-constructed through supportive contexts and interactions in everyday life (World Health Organization 2013; Socialstyrelsen 2024). However, a recently defended Swedish dissertation on children's participation after CNS tumour treatment shows that speech or communication needs are rarely documented in clinical records (Björklund 2024), indicating that these aspects may still be under-recognised. Taken together, the present findings underscore the importance of not only providing structured follow-up but also ensuring that each child's support is individually adapted, grounded in their communicative needs, lived everyday experiences, and perspective on participation. In addition to contextual factors, individual explanations may also be relevant. One such possibility is that children downplayed their difficulties and instead emphasised the sense of belonging. Previous studies have shown that children often highlight positive experiences and describe themselves in capable terms, even when communication difficulties are present (Merrick and Roulstone 2011).

In addition, the timing of the interviews should be considered. Unlike the study based on retrospective accounts from young adults (Wibroe et al. 2021), the present study captured children's ongoing experiences. It is possible that negative aspects had not yet become prominent or that being closer in time to the events helped children notice and describe the small things that felt important, whereas memories of times that has passed tend to be dominated by more over-arching feelings.

An important aspect concerned how children following PFT surgery navigated the tension between adapting to changes and maintaining a sense of self. Through their communication with others, both in how and what they communicated, they expressed a strong wish to be like others and to be recognised beyond their condition. This was evident in how they communicated with others, wanting to participate without standing out, to act independently, and to be seen as 'the same' as before. Although struggles with belonging, identity and peer relationships are common developmental challenges for many children and adolescents (Bukowski et al. 2010), the experiences described here were shaped by additional layers of complexity. In addition to these common challenges, the children had to manage persistent fatigue and physical limitations, in combination with the impact on speech and language, which likely influenced their sense of not being like others and their longing to return to normality. However, they also demonstrated an awareness of being different through how they communicated with others, particularly when describing the adjustments they made or the limits they needed to set in everyday situations. Similar experiences have been described among adolescents and young adults with ABI, where belonging, identity and peer relationships were reported to be shaped by multiple interacting factors, including age, time since injury and opportunities to adapt to altered abilities and

everyday routines (Di Battista et al. 2014; Mealings et al. 2020; 2017; Roscigno and Liew 2008). These studies illustrate how identity and belonging after brain injury evolve over time and are influenced by a range of individual, developmental and contextual factors, which are also likely relevant in relation to the children's experiences of these challenges in the present study.

At the same time as they wanted to be like others, the children also demonstrated an awareness and acceptance of being different through how they communicated with others, particularly when they talked about the support they needed and wanted in school, the adjustments they made in relationships (such as saying no), and the limits they needed to set in everyday situations. However, some children expressed a wish to participate without standing out, which may be understood as an attempt to preserve a sense of identity and normality in situations where their differences risked becoming visible. Similar processes have been observed in children with speech, language and communication difficulties who describe efforts to protect their identity in interaction, for instance by choosing silence, avoiding support or withdrawing from situations where they feel different or less competent (Levitch et al. 2022; Wibroe et al. 2021). This tension between how the children communicated about wanting to be like others while also expressing their difference may have been shaped by the same individual, developmental and contextual factors that characterised their everyday experiences (Di Battista et al. 2014; Mealings et al. 2020; 2017; Roscigno and Liew 2008).

5 | Methodological Considerations

This study included the experiences of children with speech, language and/or communication difficulties following PFT surgery, a group whose voices, to our knowledge, have not previously been represented in research. To capture their experiences, a flexible semi-structured interview guide was used in combination with visual AAC materials. However, several methodological challenges were encountered.

First, the sample had an uneven sex distribution, with eight girls and two boys participating. It is possible that girls were more likely to express an interest in participating in a study involving reflection on communication experiences. This may relate to broader gender differences in emotional expression and socialisation, where girls have been found to express more internalising emotions and to engage more frequently in emotional communication than boys (Haberl et al. 2024). This imbalance in the sample may have shaped the content of the findings by amplifying certain experiences or ways of expressing them, while other perspectives may have been less visible in the material and may limit transferability. Although this study is context-specific, efforts were made to support transferability by providing detailed descriptions of the children, the interview process, and the context of the study (Korstjens and Moser 2018), allowing readers to judge the applicability of the findings to other settings.

Second, due to their speech, language and/or communication difficulties, as well as age in the younger children, their ways to express themselves were often concrete, a phenomenon previously highlighted in qualitative research with children (Graneheim et al. 2017). This required careful attention during the

analysis to move beyond surface-level descriptions without losing proximity to the children's own ways of expressing themselves. The goal was to stay close to the children's accounts while organising their descriptions into meaningful categories and latent themes.

Third, the variation in communicative modalities was an important feature of the data. To strengthen credibility and confirmability, the analysis was shaped through continuous discussions and joint reflection involving the first, second and last authors. These discussions combined complementary perspectives, with the second and last author bringing extensive experience in qualitative research. To enhance dependability, the analytic process was carefully documented and revisited throughout the study. Notes, coding logs and reflections were used to make visible how interpretations developed over time (Graneheim and Lundman 2004; Korfjens and Moser 2018).

Finally, the first author's professional background as a speech and language therapist was a necessary condition for conducting interviews with children with speech, language and/or communication difficulties. At the same time, this background required careful reflexivity throughout the research process. While an interpretative and supportive style is critical in clinical work to expand communication, there was a risk that such responsiveness could inadvertently influence the children's expression, for example, by prompting or shaping their responses. Maintaining methodological rigour in this study involved a conscious effort to balance providing necessary support for expression with minimising the researcher's influence on the content of the children's descriptions.

5.1 | Clinical Implications

The findings of this study have implications for both healthcare providers and school health services and educational settings. Firstly, the fact that children did not explicitly refer to speech, language or communication difficulties does not mean these aspects were unimportant or absent. Instead, many of the challenges they described may reflect the consequences of such difficulties in everyday life. Professionals in both healthcare and educational settings need to be attentive to this and create opportunities for children to share their experiences, for example, by asking them to describe specific situations and how they felt in those situations. Children may not frame their difficulties in diagnostic terms but instead express them in relational or contextual ways, such as who they were with, how they were treated or what the situation demanded.

Secondly, support planned and delivered in healthcare, school or home contexts should be based on children's own perspectives and communicative preferences, recognising that subtle, nonverbal or quiet behaviours may signal inclusion and connection. Children may experience seemingly similar situations in very different ways. What might appear to an outside observer as withdrawal or exclusion could, for the child, be a valued moment of inclusion and connection. For one participant, sitting quietly in the cloakroom among others was described as the best part of the school day. Listening to how children describe their experiences is

essential, as observational assessments alone may miss important dimensions of participation.

Thirdly, to ensure that the communication issues are identified and recognised, structured collaboration between hospital, rehabilitation teams and school health services is needed. Existing national guidelines for long-term follow-up after childhood cancer recommend multidisciplinary assessment including speech, language functions and communication (Regional Cancer Centres in Sweden 2024, 2025), but implementation varies regionally. Shared communication pathways between services can help ensure that difficulties are not overlooked.

Finally, children's wish to be like others and to be recognised beyond their condition should be taken seriously in both healthcare and educational support. In this study, children described how they managed everyday situations by adapting, setting limits or choosing when and how to communicate their needs. These strategies reflected an awareness of their difficulties and a desire to preserve a sense of normality and independence. Support should therefore be flexible and responsive, meaning that it adapts to each child's difficulties, preferences, level of independence and changing needs over time. This includes recognising when subtle or quiet participation already represents meaningful engagement and offering support that promotes participation while respecting the child's wish not to stand out.

6 | Conclusion

This study offers new insights into how children experience communication in everyday life following PFT surgery. While speech, language and/or communication difficulties were not explicitly mentioned by the children, their descriptions reflected how the consequences of such difficulties shaped everyday communication and participation. The findings show how small and seemingly ordinary communicative moments could affirm or undermine a sense of belonging, and how familiar friendships provided continuity during a time of change. Children also demonstrated agency in expressing needs, setting boundaries and protecting their identity in the face of altered abilities and fatigue. Taken together, the findings highlight the need to listen carefully to children's own accounts and to recognise the subtle, diverse and context-dependent ways in which communication is used to navigate relationships and everyday life. These insights underscore the importance of support that is flexible and responsive, adapting to difficulties, preferences, level of independence, and changing needs over time. Such an approach allows children to participate in ways that feel authentic, meaningful and sustainable to them.

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Ethics Statement

This study was approved by the Swedish Ethical Review Authority (Dnr 2021-01869).

Consent

Written informed consent was obtained from all participating children and their legal guardians.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Due to the sensitive nature of the qualitative data and ethical restrictions regarding participant confidentiality, data are not publicly available.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

About the author



Karin Persson is a speech and language therapist at a specialist paediatric rehabilitation clinic in Lund, Region Skåne, Sweden. She has more than 20 years of clinical experience working with children and adolescents with acquired brain injury, including many children treated for central nervous system tumours. Her research builds on this clinical experience.

This thesis investigates word-finding ability and narrative macro- and microstructure in children with posterior fossa tumours, both before and after surgery. It also describes the children's own experiences of communication in everyday life after treatment.

