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# Children’s experiences of communication after posterior fossa tumour (PFT) surgery

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“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

## Introduction

Communication is essential for children’s development and for forming social relationships. Children undergoing PFT surgery are at risk of speech and language difficulties that may affect communication.

**Little is known about how children themselves experience communication after PFT surgery.**

## Method

An inductive qualitative content analysis was conducted based on semi-structured interviews. Ten children (6–18 years) in Sweden with speech, language and communication difficulties following PFT surgery participated. Interviews were conducted a median of 3:6 years post-surgery (range 1:2–10:2). Augmentative and alternative communication (AAC) was used.

## Conclusion

- **Small everyday communicative moments can make a big difference for feeling included and being part of things.**
- **In communication with family, friends, and teachers, children expressed needs, set boundaries, and navigated their situation while wanting to be like others.**
- **Listening to children’s own accounts is key to understanding what works, what does not, and what matters to them, so support can be adapted to their needs.**

“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



## Results

Two themes emerged. Although all children had speech, language and/or communication difficulties, these were rarely described explicitly. Instead, children described experiences in relational and contextual terms.

### A thin line between belonging and not belonging

- Being included – invited, digital contact
- Among others yet alone – not spoken to, not included
- Not being heard – ignored, others speaking for oneself

### Navigating reality towards normality

- Facing reality – expressing needs, setting limits, support from others, animals, AI chatbots
- Holding on to oneself – not standing out, deciding what to tell

“Well, this thing I did (...) [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

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