

“I was fighting”:

A Co-Produced Account of Navigating Communication Disorder Post-ABI

Amy Endacott, Advanced Specialist Speech and Language Therapist, aendacott@rhn.org.uk
Brain Injury Service, Royal Hospital for Neurodisability, London UK

Background

The psychological impact of communication disorders are well documented in the literature, particularly the impact of aphasia (a language disorder) on social wellbeing, friendship maintenance and quality of life (1). Narrative therapy (personal story recounting), including that of communication experience, has previously been found to be beneficial to people with aphasia (2) both at linguistic and psychological level (3).

Method

These quotes are from over a period of 4 sessions between patient (Z) and her SLT (A.E). Z has severe aphasia following an ABI 18 months ago. A narrative-biographic approach (4) was used as a therapy intervention to target the macrostructures of communication. This was scaffolded using total communication principles. Conversation focused on lived experience of aphasia onset and identity renegotiation post aphasia. We discussed Z's communication journey, including barriers and facilitators, to tease out the themes of her experience and recommendations for those supporting people with aphasia (PwA).

Results

'To be asked'

'Talking to us'... 'Being with us'

'See the end of my problems'

'I could hear but I couldn't speak'.. 'I wasn't a person without this' (points to throat).. 'felt better once could talk'... 'I was fighting'

'you should be able to do good but you can't... but you have no choice'

Z talked **about the importance of being kept up to date and involved in day to day care decisions** even when communication may need extra support. She used the example of medication changes; these were either not being explained to patients or needed facilitation due to the complex language used.

Z called post brain injury life **a new world to navigate**. She appreciated staff engaging with her and sharing space with her to break down the staff and patient power imbalance. She believed **patients and staff should see themselves as friends**. She said this friendship contributed positively to her wellbeing.

Z reported she enjoyed speech and language therapy and found it helpful. She particularly benefitted from numerical outcomes **and receiving feedback which helped her to monitor progress**. She wanted therapists to frame **communication goals in relation to her personal long term / life goals** to situate them in context.

Z discussed the humanising aspect of communication and explained how communication was central to her previous job and therefore her **identity**. She explained the feeling of regaining communication as a **fight** with her pushing to get her voice out. She said **people treated her differently when she could talk**.

Z raised her fixation on **comparing to preinjury self**. She found aphasia education helpful in navigating her communication problems. She said staff should **understand patient's preinjury personality and not make assumptions** on what people may or may not want.

Discussion

These powerful and personal quotes remind us of likely common experiences of PwA following ABI. It highlights the importance of including patients as much as possible in care decisions, practising friendship with patients, the dehumanising experience that may arise from communication loss, the frustration of adjusting to a new way of being and the value of rehabilitation in relation to life goals. For people with communication needs, these needs should not be a barrier to standards of care. Healthcare organisations should remember that supportive communication partners are essential facilitators of best quality care and rehabilitation.

Acknowledgements

The upmost acknowledgement and thanks must go to Z for sharing her story with me. Without understanding the lived experience of those we work with we cannot develop our skills and practice.

References

- 1 Northcott S, Hilari K. (2011) Why do people lose their friends after a stroke? *International Journal of Language and Communication Disorders*. Sep-Oct;46(5):524-34
2. Corsten, S., Konradi, J., Schimpf, E. J., Hardering, F., & Keilmann, A. (2014). Improving quality of life in aphasia—Evidence for the effectiveness of the biographic-narrative approach. *Aphasiology*, 28(4), 440–452.
3. Dipper, L., & Cruice, M. (2018). Personal storytelling in aphasia: a single case study of LUNA therapy. *Aphasiology*, 32(sup1), 60–61.
4. Whitworth, A., Leitão, S., Cartwright, J., Webster, J., Hankey, G. J., Zach, J., ... Wolz, V. (2015). NARNIA: a new twist to an old tale. A pilot RCT to evaluate a multilevel approach to improving discourse in aphasia. *Aphasiology*, 29(11)

