

# How do narratives disclosed by patients with invisible and contested conditions in medical consultations help inclusivity?

Agnieszka Sowińska

Nicolaus Copernicus University, Institute of Linguistics; Universidad Católica del Norte, Facultad de Educación

Keywords: illness narratives, narrative of personal experience, invisible and contested conditions, medical consultations, inclusivity

The objective of this paper is to show how sharing experiences through narratives may help inclusivity, especially in the case of invisible, often contested and usually chronic, symptoms and mental conditions. Narrative has been shown to be one of our most powerful forms for making sense of and explaining illness experience (Labov and Fanshel 1977, Hydén and Bülow 2006, Mildorf et. al 2023). Invisible symptoms and conditions are usually difficult to describe, both in words and gestures, and explain in medical encounters (e.g. Bullo 2020, Sowińska and Boruta-Żywiczyńska 2020). Furthermore, since invisible symptoms are not as readily acceptable as physical symptoms in general practice, patients must struggle to demonstrate that they are “credibly ill” (Japp and Japp 2005). Narratives provide space for the voice of the patient, help to structure the patient’s illness experience and restore agency within a healthcare system (Sowińska 2018, 2019). Engaging in self-disclosure and sharing stories of personal experience in medical consultations allows the patients not only to explain symptoms and interpret causes of their current health problems, but also to manage accountability, establish legitimacy, and confront and cope with their painful experience and stigma (Sowińska 2024). The latter in particular will be illustrated by drawing on two datasets coming from two different projects: medical consultations with patients with medically unexplained symptoms (MUS) in a Polish primary care setting and medical consultations with students with invisible conditions conducted in a Chilean university health centre. To navigate the micro-analysis of narratives, I draw on the sociolinguistic and discourse-analytic approaches to narrative inquiry (Labov and Waletzky 1967, De Fina and Georgakopoulou 2011). I work on the assumption that mental health and stigma can be discursively constructed (Zayts-Spence et al. 2023). Finally, I consider doctor patient interviews as joint interactional accomplishments by the GP and the patient, and focus on the interactional context in which the narratives were embedded (De Fina 2009).

## Acknowledgment:

This study draws on the data collected in two research projects funded by the National Science Centre (DEC-2013/11/B/HS2/02449) and Agencia Nacional de Investigación y Desarrollo (Fondecyt 11191027).

## References:

- Bullo, Stella (2020), ‘I feel like I’m being stabbed by a thousand tiny men’: The challenges of communicating endometriosis pain, *Health*, 24(5), 476–492.
- De Fina, Anna (2009), Narratives in interview – The case of accounts. For an interactional approach to narrative genres, *Narrative Inquiry*, 19(2), 233–258.

De Fina, Anna, and Georgakopoulou, Alexandra (2011), *Analyzing Narrative: Discourse and Sociolinguistic Perspectives*, Cambridge University Press.

Japp, Phyllis M., and Japp, Debra K. (2005). Desperately seeking legitimacy: Narratives of a biomedically invisible disease, in L.M. Harter, P.M. Japp, and C.S. Beck (eds), (2005), *Narratives, Health and Healing: Communication Theory, Research and Practice*, Lawrence Erlbaum, 107-130.

Labov, William, and Fanshel, David (1977), *Therapeutic Discourse*, Academic Press.

Labov, William, and Waletzky, Joshua (1967), Narrative analysis: Oral versions of personal experience, *Journal of Narrative and Life History*, 7(1-4), 12-44.

Hydén, Lars Christer, and Bülow, Pia H. (2006), Medical discourse: Illness narrative, in K. Brown (ed), (2009), *Encyclopedia of Language and Linguistics*, 2nd ed., Elsevier, 697-703.

Mildorf, Jarmila, Punzi, Elisabeth, and Singer, Christoph (2023), Narratives and Mental Health. An Introduction, in J. Mildorf, E. Punzi, and C. Singer (eds), (2023), *Narratives and Mental Health. Reimagining Theory and Practice*, Oxford: Oxford University Press, 1-12.

Sowińska, Agnieszka (2024), Narratives of stressful and traumatic personal experiences disclosed by students with mental health conditions in medical consultations, *Narrative Inquiry*, 1-23, DOI:10.1075/ni.23042.sow.

Sowińska, Agnieszka (2019). Verbal and nonverbal communication of agency in illness narratives of patients suffering from medically unexplained symptoms (MUS). *Communication and Medicine*, 15(1), 77-89.

Sowińska, Agnieszka (2018). 'I didn't want to be Psycho no. 1': Identity struggles in narratives of patients presenting medically unexplained symptoms. *Discourse Studies*, 20(4), 506-522.

Sowińska, Agnieszka, and Boruta-Żywiczyńska, Monika (2020), Gestures in patients' presentation of medically unexplained symptoms (MUS), *Gesture* 19(1), 97-127.

Zayts-Spence, Olga, Edmonds, David, and Fortune, Zoe (2023), Mental health, discourse and stigma, *BMC Psychology*, 11(1): 180, 1-5.