

Telling patient's stories online as a new territory in Health Psychology

Andrea Madarasová Gecková

University of Pavol Jozef Safarik in Kosice, Slovak Republic

Listening and telling stories is the most natural, powerful, and effective way of learning about the world. It is the way we build our memories, build our experience and transfer it. It is the way we make sense of our experience resulting in hurt or heal, trauma or growth. It is our story that we are telling when we are asked what happened to us if we became ill. The medical information, or rather the information mostly shared by the medical staff, is from a different point of view, it has a different purpose and different content compared to the information shared by patients. While in one universe the level of insulin is an issue, in that parallel one the love expressed in eating dinner cooked by a wife might be the issue. Being a patient means living in both universes and a health care professional should be familiar with both, should be able to navigate a patient in both of them.

Lisa Morrison and Katy Jo Stevens (Morrison & Stevens 2013) formulate the following three possible aims to share patient's stories: (1) to evoke strong emotion for lobbying or fundraising context, (2) to promote empathy and understanding of what might be helpful in supporting the culture shift and (3) to promote change that might be helpful in influencing the process or policy.

Twenty years ago Rita Charon from Columbia University published her essay in JAMA (Charon 2001) introducing narrative medicine as a model for respectful, empathic and nourishing medical

care. Narrative competence, understood as the ability to listen, acknowledge, interpret and respond to patient's stories is a core concept of this approach. So we might aim to share patient's stories to develop narrative competence as a part of medical education (Huang et al. 2021), and also acknowledge them as an essential part of medical profession expecting that physicians will be able to not only understand the disease and treat medical problems, but also to accompany patients through their illness.

Whether we intended it or not, sharing patients' experiences could affect health of those who listen. Sue Ziebland and Sally Wyke (Ziebland & Wyke, 2012) published a very comprehensive conceptual review of literature in social and health sciences on how sharing experiences on the internet might affect people's health and they identify following seven domains through which online patients' experiences could affect their health: (1) Finding information, (2) Feeling supported, (3) Maintaining relationships, (4) Experience with health services, (5) Learning to tell story, (6) Visualizing disease, (7) Affecting behaviour.

There is no doubt about the potential and power of telling patient's stories but we should be alert as there are resources promoting health endangering behaviour where full content is dangerous and also a vast amount of online content without validation, guaranty, regulation, which might have commercial purpose or result in unintentional undesirable side effects and be aware about both, potential for harm as well as benefit. Sharing patient's stories, if done well, might indeed have a huge impact on the quality of life of patients and

their relatives, might improve quality of health care and consequently also patient safety. Taking into account how much capacity, energy and time need to be invest in the development and implementation of the online resources enabling s patient's stories to reach the this goal, we should value a robust initiative with sufficient sustainability if there is any like that a lot. An example of good practice could be the Database of Individual Patients' Experiences. It was launched in July 2001, with a module on hypertension and prostate cancer, and this initiative lead by Dr. Ann McPherson and dr. Andrew Herxheimer aim to create a web portal portal where people could get verified, organized information on various topics from people who had a similar experience (Herxheimer et al. 2000, McPherson & Herxheimer 2001,2002). In present time the network includes 14 countries, covers nearly 200 health conditions, includes 8000 interviews and reaches million people each year. It is a robust repository of patients' experiences of high quality, allowing for comparisons across health conditions, facilitating comparison across countries and health systems, proving its sustainability over two decades, delivering validated patients' experience with professional guaranty, serving patients, caregivers, their beloved as well as community, but also medical students, health care professionals as a guide through living with particular health condition (for more information search on <https://dipexinternational.org/>).

This huge repository of patients' experience collected and processed with such high standards is a precious resource for science also, so I tried to find out how DIPEX contributed to body of research knowledge. There are around 700 000 hits for patient experience, narratives or perspective in Web of Science, from which only up to 600 are published in health psychology journals (e.g. Psychology Health, Health Psychology, Psychology Health Medicine, Health Psychology Report, Health Psychology Review, Health Psychology and

Behavioral Medicine, Health Psychology Open), which compose about 4% of its production (570 from 14 152) and none of them with the keyword DIPEX. Searching in Web of Science I found up to 70 research papers published, some of them introducing DIPEX methodology or evaluating the database of patients' experiences, some of them on utilization of this database in research, teaching or service improvement, but most of them contributing to our understanding of patients experience with illness.

Medicine needs to be based on people's experience, needs to be as close as possible to people and it could be. We, health psychologists, need to support health care workers as much as possible to develop and maintain narrative capacity. We owe it to the patients, our beloved, to all of us. Particularly in Central and Eastern Europe, there is a lot of work within medical education, a lot of work with regard to patient empowerment and support, and a lot of work in sensitisation of public discourse which should be done to improve chances for improving efficiency of health care system, improving benefit of patients from offered services and improving their and their relatives chances for quality of life. Being able to collect and use patients' stories might be a tool towards this change.

References

- Morrison L., Stevens K.J.: Training Patient and Family Storytellers and Patient and Family Faculty. *The Permanente Journal*, 2013,17(3):e142-145
- Charon R.: Narrative Medicine. A Model for Empathy, Reflection, Profession, and Trust. *JAMA*, 2001,286 (15):1897-1902
- Ziebland S., Wyke S.: Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health. *Milbank Quarterly*, 2012,90(2):219-249

Huang Ch. Jenq Ch., Liao K., Lii S., Huang Ch., Wang T.: How does narrative medicine impact medical trainees' learning of professionalism? A qualitative study. *BMC Medical Education* 2021,21:391

Herxheimer, A., McPherson, A., Miller, R., Shepperd, S., Yaphe, J., & Ziebland, S. (2000). Database of patients' experiences (DIPEX): a multi-media approach to sharing experiences and information. *The Lancet*, 2000,355(9214), 1540-1543.

McPherson, A. & Herxheimer, A.: Database of Individual Patients' Experiences – an update. *The British Journal of General Practice*, 2002,52(484):954.

McPherson, A. & Herxheimer, A.: DIPEX – A Database of Individual Patients' Experiences. *The British Journal of General Practice*, 2001, 51(470), 770.

**Andrea Madarasová Gecková**

Dpt. of Health Psychology and
Research Methodology, Medical
Faculty

University of Pavol Jozef Safarik in
Kosice, Slovak Republic

andrea.geckova@upjs.sk