

Discourse through Photovoice: “Lived experience” of epilepsy

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Abstract. The purpose of this article is to help medical students during the interaction of people with epilepsy, to learn more about “lived experience”, and find out more about patients’ voices. People with epilepsy sometimes disincline to talk about their problems because of stigmatization. Stigmatization of epilepsy determines diminished self-esteem, depression, anxiety for the future and low quality of life [1]. **Methodology**—photovoice is a qualitative method that combines pictures and narratives in exploring “lived experience” of people with epilepsy, patients’ and students’ voices. Photovoice project was conducted in processing steps considering Luo (2016). The research members included people with epilepsy and medical students who were divided into 8 groups. The duration of the project was 6 weeks and after the project exhibition was arranged. **Results.** Voices of patients with epilepsy allow students to understand the discourse between insiders and outsiders, the differences between professional language and conversation among professionals.

Key words: photovoice, discourse, epilepsy.

1 Introduction

System of medical education is generally understood as training of professionals at an educational institution and practical classes. Different environment, people, and health problems allow medical students to gain practical experience. Students employ their theoretical background and professionals’ help to find the solution in real practical workplace. Historically, doctors had been teachers for many years, but they had little knowledge how to teach students. Erlich and Shayghnessy (2014) distinguish two key elements of success. First, interleaving sessions devoted to didactic educational principles where practical teaching experience with actual students in a real course, and second, direct faculty guidance in developing knowledge, skills, and attitudes of teaching. Peer teaching is one of the suggested methods in accordance with this concept. Currently students’ teaching models, such as peer teaching, are very effective because “...they use accessible language to describe concepts and relate to the feeling of being novice”. Peer teacher personnel from similar social groups, somebody who is not a professional teacher helps others to learn and learn themselves by teaching [2]. Through the teaching process experiences of people with epilepsy remain unknown because the teacher observes students only during sessions and the teacher uses professional language which could be evaluated. People with epilepsy often have cognitive limitations and special needs and a doctor has to transform people’s language into the professional language. How do students transform nonprofessional language? What is the impact of voices of people with epilepsy on students’ professional language?

Photovoice is one of the methods allowing hearing the voice of people with epilepsy. Through photos and stories community members can identify important issues and acquire knowledge of what is meaningful for the community, but not for teachers [3, 4]. Photovoice often is used to draw attention to society otherwise the following method can change opinion of the community members and environment. Yamani et al. (2016) described that application of active teaching strategy, meaningful learning and integration of conceptual and practical knowledge are the core of curriculum. In this context the core curriculum is understood as a focal point for training teachers and as the basis for describing specific objectives. Practical knowledge of problems of people with epilepsy was explained by the teacher, but about the symptoms of the illness and arising social problems students heard from people with epilepsy. Students indicated the project as an innovative teaching method, without having previous experience. Innovations at all levels of medical education allow developing a curriculum and doing revisions in medical education [5]. It is important to remember that innovations could be evolutionary and revolutionary. Students noted that this project enabled them to change their opinion and they started to think more critically. Innovative education maintains learners' autonomy, self-efficacy, critical thinking and creativity [6]. Hjelm (2013) described learning through discourse analysis like directing a critical gaze at learning with discourse analysis process itself [7].

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2 The Photovoice method

Photovoice is a community-based participatory research method which enables combining visuals and narrative to disclose what is meaningful for the community [8]. The project members included people with epilepsy and medical students who were divided into 8 groups. Project members decided to demonstrate "lived experience" of epilepsy. It was all members' decision to expose that epilepsy is not an illness but life with it. 5 workshops were organized during the project. The project was conducted in processing steps considering Luo (2016): determining the problem to be explored (1), identifying the community members to participate in the project (2), introductory meeting (3), training (4), photo taking (5), facilitated discussion (6), analysis (7), exhibition (8), and debrief (9). The first step in this project was to identify the problem and to focus only on the problems concerning epilepsy.

Each project member had to present his / her opinion on the idea of the project and to plan next workshops. Project members named the project "I Am as You Are". It is very important that not only people with epilepsy, but each student could talk and express themselves. Discussions were organized after each workshop and project members prepared reflections in written form. The project members combined visuals and stories to show social aspects of epilepsy, stigmatization problems, epilepsy and work, need of social assistance. The duration of the project took 6 weeks and after the project an exhibition was arranged.

3 Data collection procedures

All of the project members decided to choose 3 photos and to write stories. Peer work was divided into two stages: individual and group work. At first, students were outsiders and tried

to discover the difference between professional language and conversation among people with epilepsy.

During the research ethnographic focus on examining what is insider or emic was used. Agar (2006) argues that culture is realized through language and a newcomer brings his/her own language culture [9]. This logic enquiry let us understand that every group member defines their situation during interactions [10]. Insiders' knowledge is unprofessional, and it depends on "lived experience", social constructs were made not only during insiders' interactions. Outsiders, professionals, joined the group and interacted with insiders: whole group tried to make notes and choose photos. During the discussions students clarified all the information they acquired from people with epilepsy and the amount of information they did not hear. The teacher was waiting for each answer as long as possible. Ingram et al. (2014) argues that extending the waiting time or not, is a part of toolkit for improving the quality of a dialogue. The teacher usually had to wait at least three seconds for an answer and it is not a productive strategy [11]. Language begins with the start of thinking, but sometimes people pronounce different words depending on the context. Language helps to construct social situations. This situation changed social construction of narrative stories. Outsiders used professional language within their group and tried to understand insiders' "lived experience" [10].

Reflective writing is one of the methods used for helping students to enhance self-awareness. It helps gaining an understanding of the perspectives of others. Reflection helps to explore experiences and these experiences help students to enhance their psychological well-being and their abilities to empathize with patients and themselves by enabling them to access and accept their feelings. Language changes could be the result in deepened critical thinking [12].

Language helps to translate internal thoughts and emotions to others and reflective writing could show us how students use language to construct their narratives and effective communication [12]. Lin et al. (2016) suggested that teachers enable students to see and hear what happens in the interactions of patients and their family members and interpreted the training purposes: "...medical students should be encouraged to enhance their empathetic understanding of the psychosocial issues in patients and illness by becoming aware of expressing their affective experience...". Common learning experience is essential for medical students to achieve clinical competencies [5]. These educational programs help students to analyze different psychological processes and this is challenging for all participants. Hjelm et al. (2013) explained that learning through discourse gives possibility for students and teachers to engage in critical reflection of the process while doing analysis. The discourse of classroom interaction constructs knowledge [7]. Students during this project obtained knowledge of themselves and of teamwork and group reflection. Medical students' learning process is individual and not only directed to knowledge about people with epilepsy.

Photovoice method enables students to see and hear what happens during interactions between them and patients. In order to construct epilepsy-narrative in a comprehensive way, which includes medical and non-medical understanding and experiencing of illness, it is essential to enhance their empathetic interaction and transform professional outsiders' language into understandable language for insiders (patients).

4 Findings

People with epilepsy and students discussed a range of challenges of living with epilepsy. Two key themes emerged from the analysis: coping with an illness strategies and portrait of a person with epilepsy.



Fig. 1. Everyone is similar and different.

4.1 Coping with illness strategies

People with epilepsy showed that self-realization, understanding of feelings and insight are the strategies in coping with an illness.

Self-Realization. People with epilepsy spoke of their purpose of life and their wishes to feel useful in community, but it is hard to control life because of unexpected seizure. People with epilepsy called these feelings “shadow of anxiety” because they feel unsafe and therefore it is hard to live and to do things in life, as the next excerpt illustrates:

- Aisté: I am sick. I go further to help other.
 Romualdas: I am sick. I’m taking care of my elderly mom.
 Neringa: I am sick. I bake muffin for my friends.
 Kasparas: I am sick. I do not forget my close friends.
 Povilas: I am sick. I am very active in social projects.

People with epilepsy fought with illness expressing themselves through the help to other people, participating in public life and realizing their abilities. Many people with epilepsy explained that the daily worries and intolerance of others – did not stop them achieving their goals. Emphasis is placed on self-realization for the purposes of life, regardless of public attitudes and veto (Fig. 1).

Photovoice, as peer teaching method, was experienced by medical students as innovative, creative and effective method which allowed students to understand epilepsy in biopsychosocial consequences [8]. Visual narratives enabled us to see how and what was learned about epilepsy by the project members. People act and interact, learn from each other in communities and students learned that patients were source of inspiration for them—they showed how to live a full life and not to give up. Acquaintance and communication with sick people can inspire healthy ones to achieve their goals, and help people with epilepsy to realize them.

Understanding of feelings and insight. Efforts, skills and help are needed to overcome emotional abundance and confusion (Fig. 2). The study revealed feelings of epilepsy and many persons with epilepsy mentioned that fear about unexpected seizure lead to tension, shame that makes them close up inside, and disengage from the outside world. Group members noticed that if persons with illness manage to ‘tease’ the disease, it does not necessarily make life easier and people with anxiety, distrust and unsafeness got help from other people with their interest, understanding, and listening, as the next excerpt illustrates:

We should encourage the people with epilepsy to share their feelings and difficulties. When people talk—the problem is reduced by half. In addition, those who do not suffer need to know about other people’s worries. There is only one way—to solve them together.



Fig. 2. Diversity of feelings.



Fig. 3. Not everyone has the opportunity to go through the door.

The results of the study showed that understanding, expressing feelings and listening were helpful for community members, but it is an important condition for cohabitation and satisfaction with communion.

The walls do not stand by themselves. In society, ignorance, misunderstanding, and mystification of epilepsy prevail. People with epilepsy are often stigmatized. In this way, an “invisible wall” is created between people with epilepsy and other people (Fig. 3).

Analysis of research data revealed that it is not impossible to break down the borders that limit people’s with epilepsy ability to participate in society without public support, as the next excerpt illustrates:

We would like to emphasize that the unemployed should put more effort into integrating the people with epilepsy into community. First of all, educate members of the community about other members’ problems—reduce exclusion. Exclusion leads to ignorance and fear. In our opinion, everything depends on the approach to epilepsy.

The Photovoice method helped all group members to fight with the consequences of the disease.



Fig. 4. Posture of people with epilepsy.

4.2 Portrait of a person with epilepsy

Medical students and people with epilepsy expressed themselves differently, as the next excerpt illustrates:

The first photo, with a person who has raised his hands up, symbolizes a self-confident and resolute personality, who knows of the despair of the disease, but he keeps his hands up and strive for the heights of life or inner peace; the second photo shows how person is crushed, lowered hands and lost the meaning of life; also, part of the patients with epilepsy lock in, this situation is symbolized by the third photo; in the fourth picture we see a person who asks for help because he understands that there is a way out and may be better.

Many people with epilepsy and students said that posture is very important in relation to the disease which is revealed by overcoming the psychosocial consequences of the disease (Fig. 4).

People with epilepsy said that it is very important to be realistic and to ask help from others. Epilepsy seizures can be unpredictable and sometimes people with epilepsy need help after seizure.

Meaningfulness of disease. According to Franklin, “man is looking for meaning”. It was very important to see the meaning of suffering in the disease, as the next excerpt illustrates:

Just glance at it, it may seem that all the girls look alike, but looking closer, one can notice that one girl is distinguished by the fact that her hair is tied.

Maybe I wouldn't be who I was, maybe I wouldn't focus on selfishness and development, I wouldn't have time to spend with my daughter if I didn't get it.

The disease helped me to develop such qualities as patience, stubbornness to my goals, help and sensitivity to others. I think it's important, it strengthens self-esteem.

The disease gave significance to life for people with epilepsy, because they put effort into self-improvement, were devoted to their loved ones, developed self-esteem and sensitivity to other people.

5 Conclusion

Project members learned about people with epilepsy from live stories. Students acquired knowledge about discrimination, surrounding environment, insensibility for people with epilepsy. During the study process students learned about different types of epilepsy. Through working in groups like outsiders and after the project they broaden the understanding that each case is unique, different, and unpredictable. Students learned how to initiate the contact and how to maintain this close professional contact with people having epilepsy. People with epilepsy sometimes disincline to talk about their problems because of power balance. It is

very important for students to collaborate and to seek for the aim together. Photovoice method helped to work as a team and to seek aims of the people with epilepsy.

References

- [1] C. Soria, S. Escolano, S. El Sabbagh, S. Chmura, Ch. Bulteau, C. Chiron, G. Dellatolas, *Child Neuropsychol.* **18**(3), 209–227 (2012)
- [2] R. D. Erlich, F. A. Shayghnessy, *Medical Teacher* **36**, 322–332 (2014)
- [3] M. Teti, L. Johnson, D. Binson, *JERHRE* **7**(4), 34–43 (2012)
- [4] T. Heyns, G., Van Rensburg, T. Botma, I. Coetzee, *Gender and Behaviour* **14**(1), 7028–7039 (2016)
- [5] N. Yamani, M. Rahimi, *Res. Dev. Med. Education* **5**(2), 50–54 (2016)
- [6] P. Serdyukov, *JRIT&L* **1**(10), 4–33 (2017)
- [7] T. Hjelm, *Teaching in Higher Ed.* **8**(18), 871–882 (2013)
- [8] L. Luo. L. *Library Hi Tech.* **1**(35), 179–185 (2016)
- [9] M. Agar, *FQS* **7**(4), 36 (2006)
- [10] N. Markee, *The Handbook of Classroom Discourse and Interaction* (West Sussex: John Wiley & Sons Inc., 2015)
- [11] J. Ingram, V. Elliot, *Cambridge J. Ed.* **46**(1), 37–53 (2014)
- [12] Chi-Wei. Lin, M. Lin, C. Wen, S. Chu, *Med. Education* **21**, 29522 (2016)