"I will fight, but I am outsider" – dignity of man with multiple sclerosis: Interpretative phenomenological analysis

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1 Abstract / Introduction

Dignity is one of the most important phenomenon in healthcare practice (van Gennip et al., 2013; Jacobson, 2012). There are several theories like Jacobson (2012) or Nordenfeld (2009) describing patients’ dignity in context of healthcare. These theories show that dignity is not only moral value but also vital phenomenon of people lived experience connected with someone’s identity, integrity and social life. Jacobson (2012) in General theory of dignity distinguishes two basic dimensions of dignity: Human dignity and Social dignity. Human dignity is the abstract, universal value that belongs to every human being, does not matter on concrete condition and situation. Social dignity is divided to Dignity-of-self based on quality of self-respect or self-worth and identity and Dignity-in-relation based on ways in which respect and worth are conveyed through expression and recognition. Multiple sclerosis (MS) is unpredictable neurodegenerative diseases with dramatic impact on patient’s life. The presence of a wide range of symptoms and their deterioration causes the disability and a gradual dependence on help and care, which has also significant impact on dignity of the people with MS (Lohne et al., 2010). From this point of view, there is a necessity for health caregiver to realise how people with MS understand their own dignity.

2 Aim and design

Main aim of this case study is to explore how man with MS experiences own dignity. For this purpose, the Interpretative Phenomenological Analysis - IPA (Smith, Flowers, & Larkin, 2009) was adopted for a study design. IPA is based on phenomenology, hermeneutic and idiographic approach. The study presented partial result of larger research project focused on dignity of people with chronic neurodegenerative disease.

3 Participant

A purposive sampling was used to find male with desired lived experience in the line with IPA. Our participant (Oliver) was 43 years-old married man with higher education. He suffered from MS for 14 years. The authors have no previous relationship with participant. The name of participant was changed to protect confidentiality. The study was approved by the Ethics Committee of the Jessenius Faculty of Medicine in Martin, Comenius University in Bratislava, Slovakia (No. EC 1828/2016).
4 Methods

Semi-structured interview guided by protocol was conducted in daily centre of University hospital in Middle Slovakia in January 2018. After initial question followed research questions like: what does dignity mean for you, how does MS influence your sense of dignity. Interview was audio-taped and transcribed verbatim and was done by second author. Analysis followed the IPA process by Smith, Flowers, & Larkin (2009): Reading and rereading, Initial noting, Developing emergent themes, Searching for connections across emergent themes. Analytical process was done by first and second author separately. Final analysis and interpretation was created by consensus and peer debriefing with another two authors. These methodological strategies were used to increase and support rigor and trustworthiness of the study.

5 Results

Based on analysis, six themes seem to be essential for man participant’s sense of dignity: (1) I will fight; (2) I don't want to say: "I'm an outsider, but I am in a group of outsiders"; (3) Shame; (4) My wife and father knows how to support me; (5) Respect - help from colleagues; (6) Healthcare - "It was terrible" versus "I cannot say bad word". Oliver’s sense of dignity-of-self has been strongly affected by announcement of his diagnosis and he has never fully accepted the fact of being an ill person. On the one side, his reaction was that the previous "normal" life is totally lost and the future is "dark" and unpredictable. On the other side, he had started to fight, but still with the question: "Why me?". Oliver felt like "outsider" due to problems with mobility, sexuality, loss of sport activities, fatigue and urinary problems. Oliver’s sense of dignity-of-self and dignity-in-relation was strongly violated by shame because of his feeling that everyone sees his disabilities and he felt like "naked". Oliver’s dignity-in-relation was preserved and promoted by the fact that his family (especially his father and wife) offered him the support and also his colleagues respected him at work. The fact that Oliver was still employed was very positive, because he felt worthy and it maintained his sense of dignity-of-self. Oliver’s sense of dignity (dignity-in-relation) was promoted by the possibility of his participation in a local fishing organization (He was responsible for management of activities and education of children and adults). The ambiguity is seen in the relation with healthcare. On the one hand, his sense of dignity was violated by grouping him with people in worst conditions like he was in hospital. On the other hand, his sense of dignity was promoted by good quality of care and interaction with health caregiver (dignity-in-relation).

6 Conclusion

Oliver’s case explored how MS strongly affected his sense of dignity. The sense of dignity is dynamic phenomenon (van Gennip et al., 2015) with a variety of influencing factors. In his case, ambiguity between "fighter" and "outsider" was essential for sense of dignity. This ambiguity has grown up from the loss of previous life and from the need to cope with this fact. The case study also shown that deeper understanding of the unique lived experience of people with MS is crucial for person-centered care and also for tailored supportive interventions during provision of health care.

Keywords: Dignity, multiple sclerosis, interpretative phenomenological analysis, idiographic approach.
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References


