

STRUGGLING FOR THE DIGNITY OF WOMEN WITH RELAPSING-REMITTING MULTIPLE SCLEROSIS: AN INTERPRETATIVE PHENOMENOLOGICAL SINGLE CASE STUDY ANALYSIS

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Abstract

This paper reports the findings of a study based on interpretative phenomenological analysis that aimed to explore the meaning of dignity for woman (Olivia) with relapsing-remitting multiple sclerosis. Olivia's dignity was related to five core themes: Fulfilling life; Unfair judging; To be dependent on others; Healthcare professionals – disregard and ignoring; Healthcare professionals – respect and support. Her sense of dignity interfered with physical dependence, help from others, loss of control and independency. Her dignity was violated by disregard and indifference in interactions. To understand individual experience is important for a comprehensive person-centred care.

Keywords: dignity, woman with multiple sclerosis, single case study, interpretative phenomenological analysis.

Resumo

Lutar pela dignidade de mulheres com Esclerose Múltipla Recidivante Remitente: estudo fenomenológico interpretativo de um só caso

Neste artigo, descrevem-se os resultados de um estudo baseado numa análise fenomenológica interpretativa cujo objetivo foi explorar o significado da dignidade de uma mulher (Olívia) com esclerose múltipla recidivante remitente. A dignidade de Olívia estava relacionada com cinco temas principais: satisfação com a vida; ajuizamentos injustos; ser dependente de outros; profissionais de saúde – indiferença e ignorância; profissionais de saúde – respeito e apoio. A sensação de falta de dignidade interferia com a sua dependência física, ajuda dos outros, perda de controlo e independência. A sua dignidade era violada pelo desrespeito e a indiferença nas interações.

Palavras-chave: dignidade, mulher com esclerose múltipla, estudo de caso único, análise fenomenológica interpretativa.

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Resumen

Luchando por la dignidad de las mujeres con Esclerosis Múltiple Recurrente-Remitente: estudio fenomenológico interpretativo de un solo caso

Este artículo informa sobre los resultados de un estudio basado en un análisis fenomenológico interpretativo con el objetivo de explorar el significado de la dignidad de una mujer (Olivia) con esclerosis múltiple recurrente-remitente. La dignidad de Olivia fue relacionada con cinco temas principales: satisfacción con la vida; juicios injustos; ser dependiente de otros; profesionales de la salud – desconsiderar a ignorar; profesionales de la salud – respecto e apoyo. Su sentido de dignidad interfería con su dependencia física, ayuda de los otros, pérdida del control e independencia. Para proporcionar una adecuada atención dirigida a la persona, es importante comprender la experiencia individual.

Palabras clave: dignidad, mujer con esclerosis múltiple, caso único, análisis interpretativo fenomenológico.

Introduction

Multiple sclerosis (MS) is an inflammatory progressive chronic disease of the central nervous system and the most common neurological cause of disability in adults (Rosiak and Zagożdż 2017). Neurologists agree that people with MS may be divided into four major categories or different subtypes, based on the course of disease: first, relapsing-remitting (RR); second, secondary progressive (SP); third, primary progressive (PP); and finally, progressive relapsing (PR). «The most common subtype of MS (85-90%) is the RR subtype, which is higher among women» (Kheradmand *et al.* 2019, 33; Goldenberg 2012, 175). About 3 million individuals suffer from MS worldwide (Coggan *et al.* 2015, 21217). People aged between 20 and 40 years are mainly affected. Women with MS are diagnosed at an earlier age than men (Harbo, Gold, and Tintoré 2013, 237). A higher incidence of MS is observed in women, who suffer this disease twice as often as men (Huang, Chen, and Zhang 2017). In Europe, MS affects more than 450,000 women (Charles River Association 2017). MS prevalence ratio of women to men has increased markedly during the last decades (2.3-3.5:1), which indicates a true increase in MS among women but not men. It is a phenomenon shared with several other autoimmune diseases. This has led to extensive studies of differences in the immune system or nervous system between women and men, which might be caused by the effects of gonadal hormones, genetic differences, different environmental exposures and modern lifestyle in women and men (Harbo, Gold, and Tintoré 2013, 237). In women with RR-MS, there is an evidence of the reduction of relapses during pregnancy and the increase in relapses in the postpartum period (Harbo, Gold, and Tintoré 2013, 241). Living with a chronic illness and uncertainty regarding the prognosis of MS leads to extensive changes in the daily life (Sharifi, Borhani, and Abbaszadeh 2016).

The diagnosis and the disease itself influence the dignity of people with MS; both have many devastating consequences in personal and social life, e.g. dependence on others in performing daily life activities, functional limitations, depression, speech problems, unemployment, social isolation (Dehghnani, Dehghnan Nayeri, and Ebadi 2017, 2018; Bašić Kes *et al.* 2013). Progression of the MS illness and the resultant decline in body function have a negative impact on the quality of life (Olsson, Skär, and Söderberg 2010) and can lead to decreasing dignity (Nordenfelt 2009). Women talk about uncertainty, discrimination, economic difficulties, and problems to access public places; these are factors that engendered a constant struggle (Olsson, Skär, and Söderberg 2010). In this way, MS disorder threatens dignity, personal autonomy, independence, life planning and can potentially limit the achievement of life goals (Costello, and Kalb 2019). People with MS have low self-esteem and low self-confidence, they have feelings of guilt and uselessness, and feel stigmatization and rejection in social relations (Sharifi, Borhani, and Abbaszadeh 2016; Lohne *et al.* 2010). Matiti and Baillie (2011, 21) stated that everyone has a unique and dynamic concept of dignity. This kind of dignity is experienced through the thoughts and feelings of the individual human being, involves a self-regarding and other-regarding value and can be maintained or violated (Gallaher 2004). Based on this, dignity in our study can be understood as a relative (Edlund *et al.* 2013) or subjective (Gallaher 2004) or social (Jacobson 2012) phenomenon rather than inborn human dignity, also known as *Menschenwürde* (Nordenfelt 2009) which refers to a kind of dignity that all people have in virtue of being human and cannot be taken from human beings as long as they are alive.

Aim

The aim of our single case study was to identify and interpret dignity from the perspective of a woman with relapsing-remitting type of multiple sclerosis (RR-MS).

The Case

This single case study included a 25-years-old woman, Olivia, with RR-MS disorder that has lasted for four years. She has higher education, university degree. In that time, Olivia had a boyfriend and she was employed. The RR-MS disease was in remission, the woman had gait abnormalities. Olivia was adherent to the treatment regimen and showed compliance with prescribed pharmacotherapy.

Methods

An interpretative phenomenological analysis (IPA) was used as a research strategy in this case study (Smith, Flowers, and Larkin 2009; Pietkiewicz, and Smith 2012). A semi-structured interview (according to the interview protocol) was used for data collection and field notes were also completed to provide a source of evidence. Research questions focused on the meaning of dignity and on the influence of MS and the effect of social interactions on participant's dignity. The interview took place in a calm atmosphere in a daily medical centre of the University hospital in Martin, Slovakia, in January 2018. The interview was audio-recorded and transcribed verbatim. In the field notes, the place and atmosphere of the interview, participant behaviour and the role of the researcher in the interview was reflected. The data were analysed using an IPA method in ATLAS.ti 8 programme. All processes of IPA: reading/rereading; initial noting with descriptive, linguistic and conceptual comments; developing themes and searching for connections across themes (Smith *et al.* 2009) were done by two independent authors. Final analysis and interpretation were made by a consensus of the 1st and 2nd author and by peer debriefing of the 3rd author to ensure the trustworthiness of this qualitative single exploratory case study (Yin 2003). This single case study is based on one selected interview from the larger research project focused on the dignity of people with a chronic neurodegenerative disease and with regard to idiographic approach of IPA (Smith *et al.* 2009).

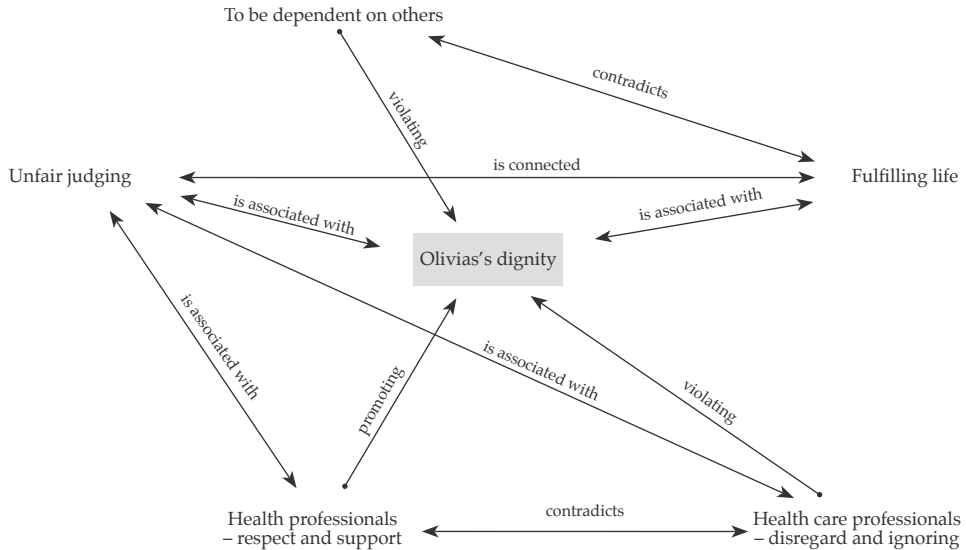
Ethical considerations

This study was approved by the Ethics Committee at Jessenius Faculty of Medicine, Comenius University in Martin No. EC 1828/2016. The name of the participant was changed to respect privacy and confidentiality. Firstly, the participant was informed about the aim of the study both in writing, and, immediately before the interview, verbally. She was also assured of confidentiality and anonymity. Moreover, the participant was informed about the possibility to stop the interview at any time.

Results and Interpretation

Olivia's dignity was related to five interconnected themes: fulfilling life; unfair judging; to be dependent on others; healthcare professionals – disregard and ignoring; healthcare professionals – respect and support. Identified themes and their relationships are illustrated in Scheme 1.

Scheme 1.
Olivia's dignity (Identified themes and their relationships)
Fulfilling life



According to Olivia, a fulfilling life can only be lived by a «full-fledged person» who can adjust to a common pace of everyday life. Olivia explains:

A full-fledged person in everyday life is how that person feels, what she/he can accomplish, as everybody compares herself/himself to everyone; so, compared to others, if she/he is able to keep up with such a pace, that is in today's society. I just try to function as best as I can, with such dignity; I try to be a full-fledged person as far as I can in that life and manage everything.

On the one side, women with a long-term illness generally can have difficulties reconciling their former identity with the new identity of being ill (Olsson, Lexell, and Söderberg 2005, 8). On the other side, women seem to cope with the illness better than men (Olsson, Skär, and Söderberg 2010). Regarding Olivia, we can say that she is a vital fighter (Lohne *et al.* 2010) who doesn't give up the fight with MS. In her fight, it is important to compare her life with the life of other people. If Olivia is able to be like «normal» others, then she feels valuable. It seems that the social dimension of dignity (dignity-in-relation) is dominant for Olivia. This tendency is also manifested in the following topic.

Unfair judging

Olivia sensitively perceived the dignity (expressed as fulfilling life) with the way how others see her. If others treat her unequally, she will consider it as undignified toward herself. In this theme, Olivia described how her dignity-in-relation (Jacobson 2012) was violated by unfair judging. Olivia gave an example of this/ such a situation from her study at university.

I had an individual study plan... actually people... sometimes were envious of me because I missed some lessons... They didn't even realize that it was twice as hard for me, because I had to work harder, so I felt less dignified because of their point of view, not mine ... I tried to function as best as I could according to my health status, and actually... these people... it was and it is unpleasant.

Olivia had RR-MS characterized by episodes of acute worsening of function (attack, relapses) followed by partial or complete recovery (remissions) (Kheradmand *et al.* 2019, 38). When bodies functioned with some predictability in people with MS, and when they were able to manage and trust themselves, then they felt well (Dahlberg, Todres, and Galvin 2009). In the clinical picture, there are various symptoms in people with MS. In women with MS, the perceived «randomness» of MS symptoms is reported as most debilitating to women's daily lives. Also, common symptoms that MS women experience, such as fatigue, mobility issues, pain and sleep issues have impact on their ability to carry out household activities or stay fit as they do sports and exercise (Charles River Association 2017). Olivia had a negative experience in which people did not understand how a person-woman with MS feels, what are her experiences, and what the everyday living with this limiting disease means. Our research study results are similar to the conclusion of the Charles River Association (2017). There we can find that especially women suffering from MS feel misunderstood from the public because of visible as well as invisible (hidden) symptoms of the disease. There are efforts to improve awareness of MS in the general public, but many men and women patients report adverse reactions to the MS from their friends and co-workers, which can lead to feelings of exclusion and discrimination.

To be dependent on others

The theme «Fulfilling life» contradicts the theme «To be dependent on others'. Olivia's dignity was threatened by gait disability and functions limitation in performing daily life activities. The factor violating her dignity was to be dependent on others. Olivia tried not to think about MS because to get help means also to admit the «failure of controlling» her own disease. In this context, she labelled the

dignity as «flabby’. Because of the progression of the disease, she needed help and became more dependent on others.

At this moment, it is hard for me because I’m still dependent on others. When I need some help, it will be actually flabby dignity in this context. I will always need someone to be with me, and help me, including the health care system. It is a flabby dignity that I will not be able to work independently and, whatever happens, I will still need someone to help me.... I don’t know, it is a fact that I won’t change and I try not to think about it.

Mobility limitation (impairment), which affects the majority of people suffering MS, is frequently addressed by clinicians, as they are at the heart of patients’ (and families’) concerns at the time of diagnosis and throughout the course of the diagnosed disease (Bethoux, and Benett 2011a, 2). Among factors affecting quality of life, mobility was given the highest priority by patients suffering from MS (Bethoux, and Benett 2011b, 5), like Olivia in our research study. Gait problems «were also shown to be a significant predictor of patient independence, with slower speed, shorter stride length, and decreased distance walked identified as contributing factors to patients» perceptions of their ability to perform activities of daily living» (Bethoux, and Benett 2011a, 5). Physical dependence on others is experienced as a failure and a loss of control in people suffering from chronic disease (including MS). This can lead to the violation of human dignity (Jacobson 2012). It is very important for Olivia «not to think about» the physical dependence. This coping strategy is used to manage the life situations and it contributes to the maintenance of dignity, especially in reduction of functional capacity (Oosterveld-Vlug *et al.* 2014). Keeping MS illness in check is very important for women suffering from MS to feel well (Olsson, Skär, and Söderberg 2010).

Healthcare professionals – disregard and ignoring

Olivia had negative experiences with some healthcare professionals who did not take her problems seriously. She said:

It was a catastrophe there. They looked at me like a troublemaker. I said that I had had a problem but nothing was solved. It is like working with a paper, I could press Ctrl-C, Ctrl-V on the papers by myself, I can do this way too, and that is why I wouldn’t have to go for a check-up nor undergo any tests...

Olivia felt undignified when healthcare professionals were unable to listen to her and they were unwilling to help her solve problems. Based on this negative experience, she changed healthcare providers. Underlying staff attitudes and

values are key to staff behaviour that promotes or violate dignity (Matiti and Baillie 2011, 69). Therefore, the role of healthcare professionals is twofold, first, not to cause indignity and, second, to minimize it whenever possible (Allmark 2002). Healthcare professionals need to understand that failure to deliver sensitive care that promotes dignity has important negative clinical outcomes for patients with MS (Tadd *et al.* 2011, 208). Olivia's case is an example of a situation when healthcare professionals treat the patients as a case or body part and then patients can lose their «personality» easier (Nordenfelt 2009, 74). The healthcare professional-patient interactions and communication are important features that impact on the lived experience with the illness, affecting individuals' sense of identity, feelings and attitudes. Experiences of communication with staff can also strongly influence patient's generalised hopes and mental well-being (Soundy *et al.* 2016, 188). Communication that can help patients to feel valued is mainly listening, which was missing for Olivia. Patients suffering from MS wanted further information in various areas, they have serious problems in everyday life and progression of MS (Soundy *et al.* 2016, 196). Finally, Olivia suffering from disregard and ignoring of health care professional that dramatically violated her dignity (Matiti and Baillie 2011, 70-71).

Healthcare professionals – respect and support

Help and support of healthcare professionals promoted Olivia's dignity. She perceived very sensitively their communication and approach to her, mood, and atmosphere in a healthcare setting. These were factors for maintaining dignity. She said:

Whatever I need, they will help me. When a person comes, nobody ever will look at you like you should feel bad or as if you were some kind of burden. There is a good atmosphere and mood. The nurses and physician are always smiling and in a good mood. They ask how you are. It is very pleasant for me. It is simply a different approach.... So, it is much better here (in a health-care facility); they help me with whatever I need...

According to help and support for people with MS, healthcare professionals can be divided into three types. First, emotional support, i.e. attention, understanding patient's emotions, promoting their self-esteem; second, informative support (equally important), i.e. an advice to help patients to understand their medical problems, aetiology; and, third, practical support and help, providing patients physical and financial help as well as help necessary for specific activities (Rosiak, and Zagożdż 2017). People with MS will perceive the healthcare professionals if their support is implemented through coordinated healthcare (during

diagnostics and treatment) and through multidisciplinary support. It is necessary to stress that people with MS make informed life decisions that manage the impact of MS on their future. Moreover, although there is support of families and healthcare professionals (e.g., a neurologist who ensures access to appropriate information, treatment and care while pregnancy planning, or a nurse who provides continuous information about dealing with family members and family relationships), this support could be improved (Charles River Association 2017). People with MS associate dignity in healthcare settings with respect, privacy, control, choice, humour, matter-of-factness as well as effective communication, maintenance of privacy and physical environment, protecting patients, providing adequate information and confidential conditions, staff's decency, preserving autonomy and sense of control, satisfying patients' needs, and taking into account patient's opinions (Manookian, Cheraghi, and Nasrabadi 2013; Lohne *et al.* 2010).

Conclusion

Olivia's case explored how a woman with MS experiences her dignity. Dignity is for her a highly sensitive topic. Crucial for Olivia's dignity was her independence in performing daily life activities. The sense of her dignity interfered with the getting help from others as well as with communication and interaction during healthcare provision. In Olivia's case, physical dependence was experienced as a failure as well as a loss of control and independency that lead to violation of dignity (Jacobson 2012). Also, if her problems were not taken seriously, Olivia would consider it undignified. In this context, her dignity was violated by disregard and indifference (Jacobson 2012). This individual single case study is an example that the factors influencing dignity are dynamic and subjective in nature (Manookian, Cheraghi, and Nasrabadi 2013). In the case of Olivia, identified themes are the core areas on which healthcare professionals had to focus to maintain her dignity. Moreover, in the context of dignity, it is important to understand the experience of the people suffering from this chronic disease from their perspective as well as achieve patient-centred healthcare (a patient-centred approach) as a comprehensive care approach to meet the needs of patients with MS (Halper 2008).

Authors are aware of difficulties of representativeness, generalization and the subjectivity of the researchers in case study research. They offer one of possible interpretations based on their own insight into data.

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