

REVIEW

DIMENSIONS OF PERSONAL DIGNITY OF PATIENTS WITH MULTIPLE SCLEROSIS: A QUALITATIVE NARRATIVE REVIEW

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Abstract

Aim: The aim was to synthesize themes and influencing factors of personal dignity experienced among patients with multiple sclerosis (MS) in the context of health care. **Design:** A qualitative narrative review with regard to PRISMA statements was used as a study design. **Methods:** The CASP Qualitative checklist was chosen for critical appraisal and thematic synthesis for synthesis of findings was adopted. Narrative the electronic databases: Academic Search Complete; Health Source: Nursing/Academic Edition; Humanities International Complete; MEDLINE were used for search. 230 studies were retrieved. 4 studies met the reviewers' inclusion criteria and were included into the study. **Results:** Three synthesized themes – Ill body, changed healthy identity and personal integrity (8 subthemes); Fighting spirit and patient's factors (8 subthemes) and Social factors (8 subthemes) – seem to be relevant for dignity of patients with MS. Narrative review shows tendency that patients with MS are in the danger of loss of dignity. **Conclusion:** Focused on personal dignity of people with MS brings possibility to have non-psychiatric approach to patients' personality fully consistent with the patient-centred approach in the context of health care. Results will be used as a framework for ethical reflection, interventions focused on how to improve or maintain personal dignity of patients with MS. Based on the critical appraisal, researchers should pay more attention to reflexivity. According to study limitations, a systematic review is needed.

Keywords: multiple sclerosis; patient's dignity; patient's perspective; qualitative narrative review.

Introduction

Patient dignity is one of the most important phenomenon of health and social care (Matiti, Baillie, 2011; Jacobson, 2012) and it is fundamental to the well-being of every individual in every society (Matiti, Trorey, 2008). On the other hand, there is a strong scepticism related to dignity in care and bioethical discussions (Macklin, 2003; Čáp, Palenčár, Kurucová, 2016). However, the research evidence focused on dignity in care is grow in recent years (Gallagher et al., 2016). Dignity itself is a multidimensional concept (Enes, 2003). In the minimum, we can find two main ways how the concept of dignity is used in healthcare and bioethical discussion. The first meaning of dignity is intrinsic or "human dignity" and the second is extrinsic. Intrinsic dignity is the absolute one, it is essential nature of human beings which makes humans worthy. This kind of dignity is impossible to destroy,

but it is also immeasurable (Jacobson, 2012) because human beings are equal. Extrinsic dignity is based on individual, social and cultural factors (Heijkenskjöld, Ekstedt, Lindwall, 2010). Jacobson (2012) labels this kind of dignity as a Social Dignity. It consists of two subtypes: dignity of self and dignity in relation. This kind of dignity is scalable and contingent: it can be measured and compared, violated and promoted (Jacobson, 2012). Baillie, Gallagher, Wainwright (2008) define in this context dignity as concept concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being worth, in a way that is respectful of them as valued individuals. The perception of dignity can be also affected by the illness itself (Chochinov, 2012).

Multiple sclerosis is a chronic autoimmune, inflammatory neurological disease of central nervous system. The course of disease is highly varied and unpredictable. In most patients, the disease is characterized initially by episodes of reversible neurological deficits, which is often followed by progressive neurological deterioration over time.

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According to the course of disease, MS is grouped into four major categories based on the course of disease: relapsing-remitting, secondary progressive, primary progressive, progressive-relapsing (Goldenberg, 2012). It is the most prevalent chronic degenerative disease among young adults, occurring mostly between the age of 20 and 40 years (Korwin-Piotrowska, Korwin-Piotrowska, Sanochow, 2010; Tabuteau-Harrison, Haslam, Mewse, 2016) and major cause of the non-traumatic neurological disability in this age group that affects females more than males (Fazli, Shayesteh-Azar, 2013). The goals of therapy include shortening the duration of acute exacerbations, decreasing their frequency, and providing symptomatic relief for maintaining function and improve quality of life (Goldenberg, 2012). The prognosis of this disease is uncertain (Dehghani, Dehghan Nayeri, Ebadi, 2018).

MS is typically associated with life-long adjustment to wide-ranging and changeable neurological symptoms and psychological disruption (Tabuteau-Harrison, Haslam, Mewse, 2016). Symptoms of MS and related psychosocial problems can result in functional limitations, disability, and reduced quality of life (Bašić Kes et al., 2013; Salehpour, Rezaei, Hosseini, 2014). Walking impairment is estimated to affect 60–90 % patient and can be progressive, resulting in worsening disability and profound effect on an activities daily living (Yildiz, 2014). Cognitive impairment in particular as well as depression, fatigue, and motor function resulting from MS have been shown to contribute to lowered work performance, increased unemployment rates, reduced social activities, long-term disability, and mental health (Alosaimi et al., 2017). Patients have low self-esteem, decreased self-acceptance and the illness is characterized by resignation, despair and apprehension (Korwin-Piotrowska, Korwin-Piotrowska, Sanochow, 2010). The complex of symptoms often creates problems and complications in the daily life of patients, as well as in social and family life (Masoudi et al., 2015). Anxiety, fear and uncertainty can lead to the hopelessness, depression and feelings of abandonment. Perception of stress, fear and uncertainty exert a negative impact on a patient's meaningful activities and interaction (Soundy et al., 2016). The disease can strongly influence daily performance, functional independence and individual planning for future (Dehghani, Dehghan Nayeri, Ebadi, 2018). Negative experience of losing independence has a negative impact on self-efficacy (low self-efficacy) (Jongen et al., 2014). Patients with progressive MS are considered vulnerable in the society. Apart from disease progression, functional (body) limitations and other

complications such as unemployment, separation, divorce, dependence on others, and continuity of care from a human orientation to an illness orientation can potentially threat patient's dignity (Masoudi et al., 2015; Sharifi, Borhani, Abbaszadeh, 2016). Some form of acceptance or related variant of acknowledgement, positive embracement, or resignation (chronic sorrow) likely protects patients against succumbing to the effects of the illness (Soundy et al., 2016).

Aim

The aim of this narrative review was to identify, analyse and synthesize themes and the influencing factors of personal dignity experienced among patients with MS in the context of health care. The review question was as follows: How patients with MS experienced own dignity in the context of health care?

Methods

Design

A qualitative narrative review focused on narrative thematic analysis and synthesis (Grant, Booth, 2009) was used with regard to PRISMA statements to enhance transparency of reporting the synthesis of qualitative health research (Liberati et al., 2009). Critical Appraisal Skills Programme (CASP) – Qualitative checklist was used for assessment of methodological quality of studies (Critical Appraisal Skills Programme, 2018). Narrative review (literature review) provide examination of recent or current literature, involves process for identifying materials for potential inclusion, formal literature searches for selecting included materials, process for synthesizing them in textual, tabular or graphical form and process for making some analysis of their contribution or value (Grant, Booth, 2009).

Eligibility criteria

The search was limited to articles in English language published in peer-reviewed journal with no time limit. Qualitative studies of any design focused on personal dignity of adult patients with MS (regardless gender or state of disease) from their own perspective in the context of health care were included. We did not include studies focused on patient dignity from healthcare provider or family members' perspective, and other publication types (abstracts, review articles, conference presentations, editorials, book chapters, or dissertations).

Sources

A search of literature was done in September 2017 via EBSCOhost using Academic Search Complete; Health Source: Nursing/Academic Edition; Humanities International Complete; MEDLINE.

Search

The search terms were: patient experience, lived experience, perception, view, interpretation, opinion, understanding, dignity, personal dignity, social dignity, identity, self-esteem, self-worth, self-image, self-respect, autonomy, multiple sclerosis, MS, nursing, health care. Boolean operators “OR” and “AND” were used.

Study selection

There were 230 studies retrieved. 107 duplicates were removed. Total of 123 studies was examined against exclusion/inclusion criteria by two authors independently. Based on this 102 articles were excluded. 4 studies were included in critical appraisal and were examined by authors independently to evaluate methodological quality, using the CASP – Qualitative checklist. All 4 studies met the reviewers’ inclusion criteria of appraisal scores 8 from 10 possible “yes” answers on the CASP Qualitative checklist questions. Any disagreements between the two exterminators in every phase of retrieval process were resolved through discussion or a third author and fourth were involved into the process. The retrieval process is depicted in PRISMA literature review flowchart (Figure 1).

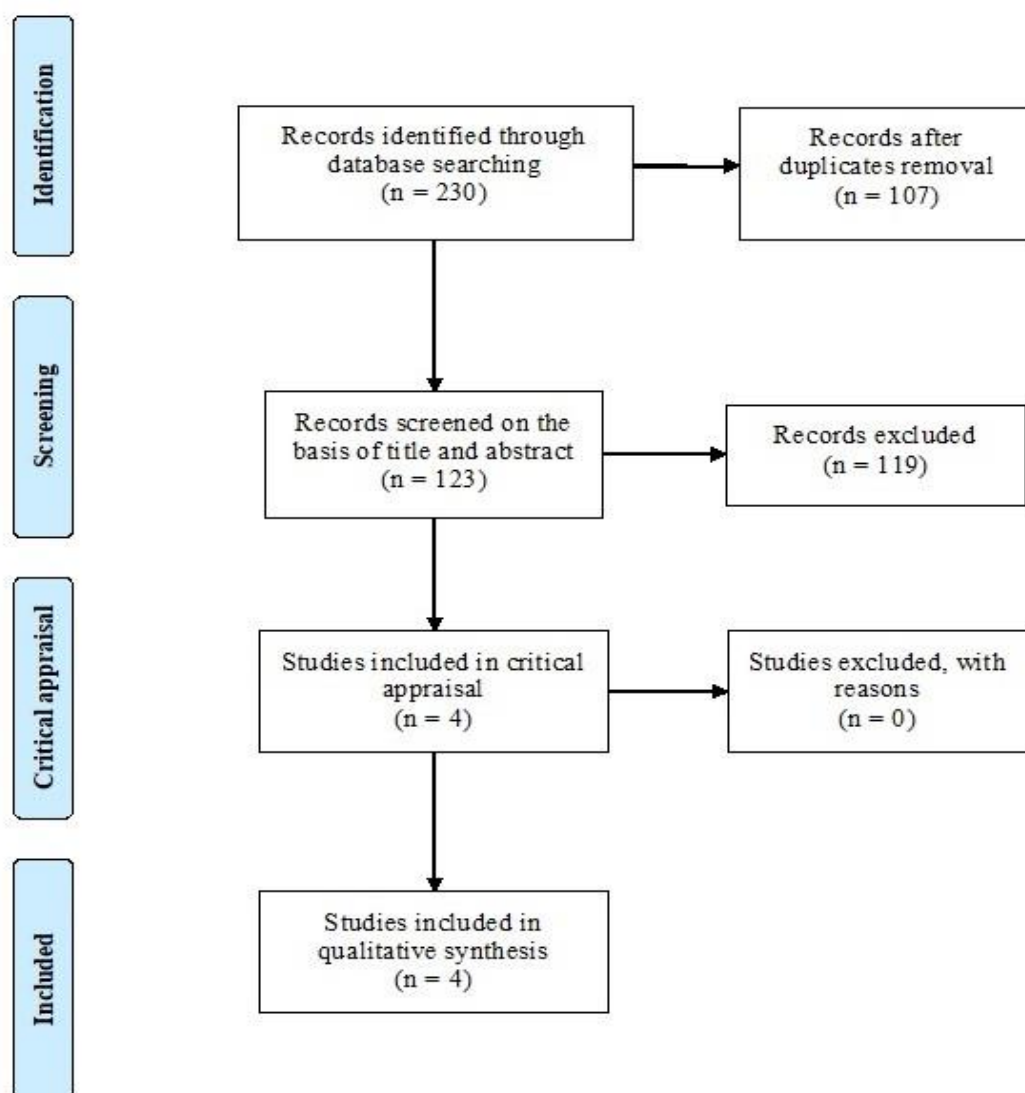


Figure 1 Literature review flowchart (PRISMA)

Data analysis

Two included studies were culturally located in Sweden (Olsson, Lexell, Söderberg, 2005; Isaksson, Gunnarsson, Ahlström, 2007) one was done in Norway (Lohne et al., 2010) and one study came from Iran (Sharifi, Borhani, Abbaszadeh, 2016). Two studies used phenomenological hermeneutic design (Olsson, Lexell, Söderberg, 2005; Lohne et al., 2010). Two studies used qualitative descriptive design in nature (Isaksson, Gunnarsson, Ahlström, 2007; Lohne et al., 2010; Sharifi, Borhani, Abbaszadeh, 2016). For data collection 3 studies

(Isaksson, Gunnarsson, Ahlström, 2007; Sharifi, Borhani, Abbaszadeh, 2010) used semi-structured interview and one (Olsson, Lexell, Söderberg, 2005) adopted narrative interview. In case of two studies (Isaksson, Gunnarsson, Ahlström, 2007; Sharifi Borhani, Abbaszadeh, 2016) data were analysed by content analysis. One study used hermeneutic analysis (Lohne et al., 2010) and one (Olsson, Lexell, Söderberg, 2005) phenomenological hermeneutic interpretation. See Table 1 for more details.

Table 1 Summary of included studies

Study	Aim	Sample	Methodology	Data collection	Data analysis	Credibility	CASP
Isaksson, Gunnarsson, Ahlström	Explore the presence and meaning of chronic sorrow in persons with MS	38	Descriptive cross-sectional mixed-methods design Qualitative part: Descriptive cross-sectional qualitative study	Semi-structured interview guide, patient version, developed by Burke et al. (1992)	Content analysis (Graneheim and Lundman)	Triangulation of researcher	9
Lohne, et al.	How persons suffering from multiple sclerosis experience and understand dignity and violation in the context of a rehabilitation ward	14	Phenomenological-hermeneutic approach Descriptive and explorative design	Semi-structured interview	Hermeneutic analysis (Ricoeur)	Researcher reflexivity	9
Olsson, Lexell, Söderberg	To describe the meaning of women's experiences of living with MS	10	Phenomenological hermeneutic approach	Interviews were conducted using a narrative approach	Phenomenological hermeneutic interpretation (Lindseth and Norberg; Ricoeur)	Researcher reflexivity	9
Sharifi, Borhani, Abbaszadeh	To investigate factors affecting dignity of Iranian patients with MS in the society	13	Qualitative conventional content analysis	Semi-structured interview	Inductive content analysis	Triangulation of data, peer debriefing	9

Data extraction and qualitative synthesis

Findings of studies were extracted and synthesized by two independent reviewers. Every extracted finding (primary subthemes) was explicitly or implicitly connected with phenomenon of the personal dignity. Each original theme or subtheme from the primary studies was extracted with illustrations and pooled using the Atlas.ti 8.0. Findings were analysed and combined into synthesized themes based on similarities in meaning. Finally, 24 primary study's findings were extracted and combined into 3 synthesized themes. Any disagreements between the authors were resolved through authors' discussion. Third and fourth author checked the process and results of synthesis for adequacy. After discussion, their comments were incorporated into final version of synthesis.

Results

The 24 findings (primary subthemes) from primary studies were extracted and grouped into three main

synthesized themes describing the experience with personal dignity from the patients with MS perspective: Ill body, changed healthy identity and personal integrity, Fighting spirit and patient's factors and Social relationships (Table 2).

Results of narrative review are presented according to our synthesized themes. The goal of result presentation is to offer a closer view on personal dignity and influencing factors from the perspective of patients with MS.

Ill body, changed healthy identity and personal integrity

MS symptoms, mainly fatigue, exhaustion or problems with mobility significantly affect daily life of patients (Olsson, Lexell, Söderberg, 2005; Isaksson, Gunnarsson, Ahlström, 2007; Lohne et al., 2010) Lohne et al. (2010) state that MS is an insidious disease which gradually (even before it is diagnosed) steals energy, balance and physical strength. This experience is a real start point to understand a vulnerable need of dignity among

Table 2 Synthesized themes and primary subthemes describing personal dignity and influences factors from the patients with MS perspective

Synthesized themes	Ill body, changed healthy identity and personal integrity		Fighting spirit and patient's factors		Social relationship	
Primary subthemes	A feeling of being perceived as different	Olsson, Lexell, Söderberg	Fighters' law: one who does not ask will not receive	Lohne et al.	Having the will but finding it troublesome to perform	Olsson, Lexell, Söderberg
	Loss of a healthy identity	Isaksson, Gunnarsson, Ahlström	Having the strength to fight	Olsson, Lexell, Söderberg	Sympathy	Sharifi, Borhani, Abbaszadeh
	Dignity is humanity	Lohne et al.	Seeing possibilities in life	Olsson, Lexell, Söderberg	Psychological harassment	Sharifi, Borhani, Abbaszadeh
	Loss of integrity and dignity	Isaksson, Gunnarsson, Ahlström	Patient's resources	Sharifi, Borhani, Abbaszadeh	Abuse	Sharifi, Borhani, Abbaszadeh
	Invisibly captured in fatigue	Lohne et al.	Patient's communication	Sharifi, Borhani, Abbaszadeh	Social values and beliefs	Sharifi, Borhani, Abbaszadeh
	Being directed by the ill body	Olsson, Lexell, Söderberg	Seeking answers to unpredictability	Olsson, Lexell, Söderberg	Loss of social relations	Isaksson, Gunnarsson, Ahlström
	Loss of control over the body	Isaksson, Gunnarsson, Ahlström	Patient's knowledge	Sharifi, Borhani, Abbaszadeh	Social knowledge	Sharifi, Borhani, Abbaszadeh
	Loss of freedom	Isaksson, Gunnarsson, Ahlström	Patient's values and beliefs	Sharifi, Borhani, Abbaszadeh	Social resources	Sharifi, Borhani, Abbaszadeh

people suffering from “invisibility” and physical as well as emotional fatigue.

Progressing and unpredictable course of the illness gradually lead to increasing helplessness and replace safety and independence by crutches, diapers and wheelchairs. For the patients MS means a verdict: to become a cripple (Lohne et al., 2010). With the verdict comes chronic sorrow which by Isaksson, Gunnarsson, Ahlström (2007) can be described as loss of identity and dignity. The patients perceive their whole existence as limited. They miss lost abilities and activities they cannot participate in. Loss of physical or mental energy is a big problem that causes decreased capacity and chronic sadness due to loss of freedom and a life with restrictions (Isaksson, Gunnarsson, Ahlström, 2007). The illness basically takes its own course and a patient can only follow it (Olsson, Lexell, Söderberg, 2005).

Loss of an identity as a healthy person and personal integrity is accompanied by a certain ambivalence to retain the same identity as before the disease and before the attitude of those around changed. For example, Olsson, Lexell, Söderberg (2005) in their qualitative study found out that women with MS have to face the fact that other people treat them in a different way than before becoming sick. On the other hand, the women themselves claimed that their personal identity had not changed. In the attitude of the others prevails change in communication, avoiding contacts with patients, gradual reduction, even loss of social contacts, which all leads to feelings of disappointment, anger and frustration as well as in desire for somebody who would understand and treat them as if they were not sick, as if they were “normal”. Isaksson Gunnarsson, Ahlström (2007) point out that even if patients do not want to tell the others about their illness, the symptoms will betray them and they start feeling endangered. Some of them expressed their concerns about prejudice that makes them even more vulnerable. By Isaksson, Gunnarsson, Ahlström (2007) the comments about being vulnerable and exposed to the others illustrate the loss of identity. By Isaksson, Gunnarsson, Ahlström (2007) even patients with small syndromes claimed feeling useless regarding their work and social life. Lohne et al. (2010) find the way of communication important to retain their dignity. In health care provision the communication makes a central aspect to retain dignity. Communication should involve understanding, devoting time, high expertness, relevant competences and empathy (Lohne et al., 2010). Patients take dignity as an internal moral principle that should be perceived seriously by the others, is a part of integrity and cannot be taken away

from anybody. The core of dignity phenomenon is related to humanity (Lohne et al., 2010). Patients regarding this stated it was easier to speak about dignity disruption than its retaining. For instance, when they are not taken seriously and have to speak about personal matters, when they do not feel any empathy and are avoided openly, when the others take them for parasites or when they are treated as non-living things (Lohne et al., 2010). When the participants focused on dignity, they perceived it as synonym for respect. Patients also claim that another experience related to loss of dignity was loss of respect. Lack of empathy, misunderstandings and even cruel comments regarding decreased capacity were described to be received from families, colleagues and health-care professionals (Isaksson, Gunnarsson, Ahlström, 2007).

Fighting spirit and patient's factors

Patients with MS say they daily have to fight with situations where they are “invisible” or have an “invisible disease”. They do not get anything for free and if they do not say what they need, the others would never know. At the same time, they live between hope and despair or uncertainty, for example when they are worried about new attacks or getting to vegetative state. On the other hand, they hope they would not have to leave their home environment (Lohne et al., 2010). Olsson, Lexell, Söderberg (2005) describe in their study that lives lived by patients before the illness are currently their energy sources helping them to live with MS. Despite weakened bodies and overwhelming fatigue they try to stay at work as long as possible. Families (children) are considered for a strong source of help and motivation to fight with the illness. Sharing problems with other patients with MS, understanding and the feeling of not being different from the others can also bring relief. These meetings also result in realization of individual needs. To be understood by health-care professionals is important for life (Olsson, Lexell, Söderberg, 2005). Olsson, Lexell, Söderberg (2005) state that women with MS expressed hope that the disease will not get worse or even will alleviate. When these women do not feel significantly relieved, they turn to alternative treatment. They find it important to accept the illness and feel there is nothing else to do, but try to live with it. They are able to live with the illness when focused on things that are doable. Planning and organizing everyday life enabled them to dedicate to important things such as spending time with families and live their lives. Daily tasks were doable when done slowly, step by step. Asking others for help and using their help was perceived as re-participating in

life. The need and necessity for using assistance aids makes it possible to save strength and be able to manage everyday life (Olsson, Lexell, Söderberg, 2005). The will to get involved into daily life was linked to the usage of compensation aids which at the beginning caused some discomfort and embarrassment for the women (Olsson, Lexell, Söderberg, 2005).

Real or potential sources for the patients are education, profession, financial state and social status. For example, if the patients were employed before the illness and had to stop working because of it, it could have been a challenge for another work using their own sources. Patients' creativity, their past experience and family support help them to maintain dignity in the society (Sharifi, Borhani, Abbaszadeh, 2016). If, however, they did not have those sources, their dignity could be endangered because they might feel rejected and useless. Sharifi, Borhani, Abbaszadeh, 2016) state that patients' way of communication depends on how they perceive themselves (self-respect, self-esteem, self-regard, and self-trust) in the context of interaction with others. They point out that change of communication not only by the others, but also by the patients themselves, depends on how their personal dignity is changing. As an example they mention a patient with low self-trust who blames himself and perceives himself as incomplete and not healthy.

Women with MS claimed they had not accepted the danger brought by the illness and refused to let the disease control their own lives. They had an urgent need to know the findings and answers for questions about the course of disease but at the same time did not trust health-care professionals who did not confirm their experience (Olsson, Lexell, Söderberg, 2005).

Women with MS expected honesty and sincerity from the health-care professionals and the others, but often felt alone with unanswered questions and worries of unknown future and made their own searches due to lack of information. All of that resulted in anger and sadness, wondering about the reasons why from all the people it was only them hit by the illness (Olsson, Lexell, Söderberg, 2005). The knowledge (e.g. information found on the Internet) and cognitive abilities of the patients such as ability to solve problems, capability to face demanding circumstances, using previous experience in current situations and the ability to solve new problems creatively as described by Sharifi, Borhani, Abbaszadeh (2016) can decrease the progression of disease, delay progression of physical disorders, usage of aids and unemployment. Values and

believes of patients can also have a positive or negative role for maintaining their dignity. For example, believing that health is a gift from God which can be taken away anytime can help to maintain patient's dignity. Important goals in life can contribute to decreasing the threat to patients' dignity as they focus in something more important in their life, other than the illness (Sharifi, Borhani, Abbaszadeh, 2016).

Social relationships

The illness changes working abilities and patients with MS feel sad about losing the previous possibilities. Being dependent on the others contradicts with their desire to perform daily tasks independently. They feel like needing help from their family, yet find it difficult to ask for it (Olsson, Lexell, Söderberg, 2005). On the other hand, they do not want to be pitied by the others and getting help without asking for it might often have a negative effect. The help perceived this way can make them feel disabled or less than the others are or that they are "poor persons" (Sharifi, Borhani, Abbaszadeh, 2016). Not being able to involve in family activities can also lead to feeling guilty and failing. The women felt like their families were suffering and the families felt guilty for doing things the women could not participate in. Sharifi et al. (2016) describe changes in relations to families as mental abuse. Patients after being diagnosed sometimes experience abuse by the others due to their physical weakness or deepened religious belief. The authors of study state an example when deepened faith as response to the illness was abused by patient's family and friends in order to obtain financial means.

How the society views patients with MS (values and beliefs of society) is another factor that could be effective in maintenance dignity but could also be a threat to their dignity. The patients are blamed for repulsing possible partners of their siblings or cannot get married because they would become a burden (Sharifi, Borhani, Abbaszadeh, 2016). Isaksson, Gunnarsson, Ahlström (2007) claim that relations with friends can also be affected by lack of understanding of the illness. Patients lose their friends and do not take part in social life, which has negative consequences for forming new relationships. Loss of social contacts leads to feelings of loneliness. Awareness of society about the disease is related to benefits offered by the society to the patients, to overall knowledge possessed by the society, to the rules on education, work and legislation approved to support patients with MS (Sharifi, Borhani, Abbaszadeh, 2016). They are all sources dedicated for patients with MS, the sources provided to patients

by their families, friends, government or non-governmental organisations or volunteers (Sharifi, Borhani, Abbaszadeh, 2016).

Discussion

Results of narrative review supported the fact that MS threatens dignity and personal autonomy, independence and life planning and potentially limits the achievement of life goals (Costello et al., 2017). There is a variety of factors influencing dignity in this specific context, but based on analysis and synthesis we suggested 3 synthesised themes: *Ill body, changed healthy identity and personal integrity, Fighting spirit and patient's factors* and *Social relationships*. These themes are related to each other and cannot be understood independently.

The synthesized theme *Ill body, changed healthy identity and personal integrity* highlight the interconnection of self-dignity with sexuality, identity and integrity of a human being. Patients with MS are confronted with a relatively drastic change in their body functioning, which causes changed healthy identity and disturbs their overall personal integrity. Patients with a serious illness generally live longer but often in a bad condition and have to face the hard reality of body damage and functional ability loss, depending on their families or the others (van Gennip et al., 2013). These conditions related to the illness can cause existential suffering and loss of personal dignity (Jacobson, 2007; Nordenfelt, 2009). A chronic illness accompanied by disability affects everyday life of a patient and undermines his or her self-identity. Losing physical abilities and performance, patients with MS cannot do all the duties they considered as standard in their lives (Charmaz, 1995). Boeijs et al. (2002) state that in interviews people often speak about their bodies: arm and leg impairments, immobility, swaying walk like a drunk, vision problems, difficulties to eat and drink independently and usage of assistive devices in the public. Soundy et al. (2016) point out that maintaining dignity and integrity of life is especially important for people with MS in progressive stages. As stated by Soundy et al. (2016) it was important for patients, especially at more advanced stages of MS, to feel respected as a person, as others (health care professionals, family, or friends) are required to have access to more private and personal aspects of the person's life.

Life situation of patients with MS is also strongly complicated by fatigue. Fatigue in MS is known as an invisible symptom (Courts, Buchanan, Werstein, 2004). It is so-called a hidden symptom or soft sign of this disease (Penner, 2016). In this disease it is the

most commonly reported symptom, and one of the most debilitating. Despite its high prevalence and significant impact, fatigue is still poorly understood and often underemphasized because of its complexity and subjective nature without a unified definition (Braley, Chervin, 2010). Fatigue is a subjective experience and it is different from normal fatigue (in common population or without the MS disease) due to its increased ability and severity to affect daily activities and social activities. It doesn't correlate with objective physical signs (Flensner, Ek, Söderhamn, 2003). Fatigue may be considered to influence the individual's goals of life and subjectively perceived health (Flensner et al., 2008).

As a part of change in personal integrity, patients with MS like they are losing freedom. Loss of freedom is strongly associated with the patient autonomy and control as a fundamental part of human dignity (Randers, Mattiasson, 2004; Chochinov, 2012; van Gennip et al., 2013). According to Barclay (2016) autonomy and control have dual importance to dignity. Firstly, they are in themselves personal attributes widely valued by most people, and a particular source of our status as equals. Secondly, autonomy and control are important factors that influence whether individuals can maintain the ability to continue to live according to their other standards and values. In the case of MS, personal dignity of patients is vulnerable by losing perceived possibilities of making choices about activities they wanted to perform. Their self-determination is often restricted. Patients are more dependent on planning activities in advance and also on help of other people, as a consequence of life limited by illness (Isaksson, Gunnarsson, Ahlström, 2007).

Fighting spirit and patient's factors is a dimension that positively supports personal dignity of patients with MS and can simply be described as a "do not give up" approach which motivates patients to overcome limitations related to the illness as well as a coping strategy with changed healthy identity and personal integrity. Other patient's factors, on the other hand, can contribute to low self-esteem feelings.

Soundy et al. (2016) state that meeting demands laid on families and patients requires for the patients to be brave, to struggle or fight against what happened, to be determined and persistent. This fighting spirit is according to the authors inevitable for the patients who want to keep doing meaningful activities and interactions. Study of Lode et al. (2007) highlights the need of sufficient quality information improving patient's knowledge. Providing information on the illness can not only decrease anxiety rate (Niino et

al., 2012) but also enables the patient to use the knowledge in decision process, solve problems and difficult life situations, use compensations aids, search for supporting resources, to be able to control his or her life, to positively assess his or her own situation and to cope better. The Iranian study of (Dehghani, Dehghan Nayeri, Ebadi, 2018) confirmed the importance of religious beliefs for support in coping and living with MS.

There is a considerable amount of evidence from literature reviews (Mohr, Cox, 2001; Dennison, Moss-Morris, Chalder, 2009) indicating a significant role of coping strategies, self-efficacy, social support in adjustment to MS. Psychological factors (such as stress appraisal and coping, social support, illness and symptoms cognitions, perceptions of control and self-efficacy) have been considered (Thomas et al., 2006; Dennison, Moss-Morris, Chalder, 2009) as a stronger predictor of individual differences in adjustment to MS than illness factors (extent of neurological disability, symptom severity, length of remission or illness). Certain emotion-focussed coping strategies (such as avoidance and wishful thinking) have been confirmed as significant predictors of worsened adjustment. High levels of uncertainty about MS (perceptions of ambiguity, complexity, deficiencies in information and unpredictability) and helplessness in relation to MS were also associated with worsened adjustment. On the other hand, positive reappraisal, seeking social support, higher self-efficacy for functional ability and managing MS and also satisfactory social support and positive interactions with significant others appeared to relate to better adjustment (Dennison, Moss-Morris, Chalder, 2009). These psychological factors are involved in reducing, increasing or maintaining of personal dignity of patients with MS.

Life of patients with MS is affected by various *Social relationships* that have impact on personal dignity. Tabuteau-Harrison, Haslam, Mewse (2016) state that maintenance of pre-existing social roles and relationships was critical in providing a meaningful basis for integrating the old with new senses of self. Symptoms accompanying MS can affect activities of everyday life and the ability to fulfil family and social roles straight from the beginning. Work performance is significantly limited by physical difficulties (e.g. walking impairment) and fatigue. This may lead to loss of job including related work relations, and, as a consequence, social isolation of patients or threat of it occurring (Hakim et al., 2000; Lee, Dunn, 2013). Due to progressive character of the disease and loss of job the incomes of patients with MS are decreasing and expenses for treatment are increasing, which significantly degrades quality of

life (Dehghani, Dehghan Nayeri, Ebadi, 2018). Other considerable factors affecting dignity include values of the society and its view of MS. Dehghani, Dehghan Nayeri, Ebadi (2018) state that most of the participants suffered from lack of information of the community about the disease: “People are really uneducated. When they see us in the streets, they do not know how to treat us and do not understand our conditions”. Personal dignity is also influenced by valid legislation, financial and other sources (emotional, mental, and spiritual) including help from the government, professional organisations, non-governmental supportive groups and health-care professionals.

The stated factors together with sources of social support from families, life partners and other patients with MS contribute not only to maintaining dignity, but also to disease management and decrease of stress rate and improve their physical and psychological well-being. They can alleviate their symptoms and improve their adherence to treatment and life expectancy (Abolhassani et al., 2015; Dehghani, Dehghan Nayeri, Ebadi, 2018).

Communication proves to be important, even central component affecting maintaining dignity (Lohne et al., 2010). Patients very sensitively perceive the way of communication from family members, friends, co-workers and health-care professionals (Yorkston, Klasner, Swanson, 2001). Dignity is negatively affected by improper way of communication, refusal, lack of empathy, misunderstandings and offensive comments related to degrading functional capacity (Bowen, MacLehose, Beaumont, 2011). Personal dignity of patients is degraded by lack of information about management of symptoms accompanying the disease from health-care professionals and partly also by their inability to help patients (Bowen, MacLehose, Beaumont, 2011). Several studies highlight positive affect of quality and nature of meetings and overall communication with health-care professionals (Carter et al., 1998; Kralik, Brown, Koch, 2001). Basic communication competences of health-care professionals should involve interpretation of information and guiding in initial phases. They should establish cooperation with patients which would enable patients to make complete decisions about their health care and improve their knowledge and skills. Such communication models help overcome worries and support patients' self-confidence (Thorne et al., 2004).

Limitations of study

This narrative review is a result of initial stage of larger research project focused on the personal

dignity of patients with MS. The results supported the need for more attention on qualitative research in this area to support evidence based practice.

The search was limited on electronic scientific databases accessible from authors' institutions. Authors are aware that the processes of quality appraisal, data extraction, synthesis and interpretation of data were influenced by scientific, research and personal experience of authors. The first author (KŽ) is a nurse, second is a philosopher (JČ), third is a nurse (MM) and the last one is a nurse and cognitive-behavioural therapist (EG).

Conclusion

Findings shows tendency that patients with MS are in the danger of loss of dignity. Results will help with pre-understanding of the personal dignity of patients with MS. According to synthesis, three synthesized themes – *Ill body, changed healthy identity and personal integrity*; *Fighting spirit and patient's factors* and *Social relationships* – seem to be relevant for dignity of patients with MS. Synthesized themes will be used as a framework for recommendations and interventions focused on how to improve or maintain personal dignity of patients with MS in nursing practice and ethical reflection. Health care of people with MS focused on personal dignity brings to health-care professionals possibility to have approach to patient personality, which is fully consistent with the holistic and patient-centred approach.

Based on the results of critical appraisal, researchers should pay more attention to research reflexivity especially in case of the relationship between researcher and participants and more critically examine their own role, potential bias and influence during the whole research process.

According to study limitation, this narrative review also indicated a need to establish qualitative systematic review (meta-synthesis) focused on dignity of patient with MS.

Ethical aspects and conflict of interest

The study was approved by the Ethics Committee of the Jessenius Faculty of Medicine in Martin, Comenius University in Bratislava, Slovakia.

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Author contribution

Conception and design (KŽ, JČ, EG), data collection (KŽ, JČ), data analysis and interpretation (KŽ, JČ, MM, EG), manuscript draft (KŽ, JČ, MM), critical revision of the manuscript (EG), final approval of the manuscript (KŽ, JČ, MM).

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