

## ORIGINAL PAPER

## DIGNITY OF PATIENTS WITH MULTIPLE SCLEROSIS: A QUALITATIVE DESCRIPTIVE STUDY

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## Abstract

**Aim:** The aim of the study was to identify the impact of multiple sclerosis (MS) on the dignity of patients. **Design:** A qualitative descriptive design. **Methods:** Semi-structured interviews with eight participants were used to collect empirical data. The mean age of participants was 50 years. On average, participants were 21.9 years after diagnosis. A thematic analysis was used to analyze the data. **Results:** 21 sub-themes emerged from thematic analysis, which were grouped into four interconnected themes: Identity change and coping; Quality of social interaction and relationships; Living with the symptoms of the disease; and Violation of a fully-fledged life. The results indicate that MS can undermine patients' dignity and identity. Living with the symptoms of the disease impairs their quality of social interaction and relationships, their lives become restricted, and they must cope with a changed identity. Acceptance of the illness, a spirit of resistance to its effects, and a sense that they can still be of use help patients maintain dignity. **Conclusion:** Knowing and understanding the themes that patients with MS associate with dignity, can significantly help healthcare professionals to maintain and promote it in nursing care.

**Keywords:** dignity, interview, multiple sclerosis, patient perspective, thematic analysis.

## Introduction

Although dignity is a central concept in nursing care (Edlund et al., 2013), it can be difficult to define precisely (Čáp et al., 2016). Nevertheless, it is possible to identify two basic types of dignity: intrinsic and extrinsic dignity. Intrinsic dignity is understood as “an internal and essential characteristic of a human being, and thus... an inherent “property” of every human by virtue of being human” (Čáp et al., 2016). It is present within each individual, in equal measure, in all circumstances, throughout their lives (Nordenfelt, 2009). In contrast, extrinsic dignity is an external, acquired, and dynamic quality, and there are a number of ways in which it can be violated and lost (Čáp et al., 2016).

Sufferers of chronic and progressive neurological diseases, such as multiple sclerosis (MS), may be at risk of losing a sense of their own worth (Lohne et al., 2010). MS is a neurodegenerative disorder of the central nervous system, with significant somatic and psychosocial consequences affecting all aspects of patients' lives, including self-perception, dignity, and quality of life over a long-term period (Hartung et al., 2004; Hoskovcová et al., 2008).

People whose dignity has been seriously violated experience feelings of worthlessness and cease to perceive themselves as complete beings. Such feelings, together with the prospect of the further progress of the illness, may lead patients to conclude that their lives have become meaningless (Chochinov et al., 2002).

For this reason, it is important to understand how patients with MS perceive their own dignity, to be aware of factors that may diminish patient dignity, and, also to be aware of the ways patient dignity can be supported and maintained in nursing care. However, research in this area has been underestimated (Lohne et al., 2010; Sharifi et al., 2016).

## Aim

The aim of the qualitative study was to identify how patients with MS perceive the impact of the illness on their dignity.

## Methods

## Design

The study has a descriptive qualitative design (Doyle et al., 2020). Semi-structured (face-to-face) interviews were used to collect empirical data, and thematic analysis was adopted to analyze the data.

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## Sample

The method of purposive sampling was used in the study. The participants were recruited from the *Slovak Multiple Sclerosis Association* (SMSA) (Miovský, 2006). Eleven local associations of the SMSA were contacted (by telephone), two of whom were interested in participating in the study. We addressed 22 members at meetings of the SMSA. Inclusion criteria were MS sufferer and membership

of the SMSA, while the exclusion criterion was unwillingness to participate in the research (reasons not investigated). The authors were not involved in providing healthcare to the participants. Eventually, eight participants, with an average age of 50 years and average duration of disease of 21.9 years, took part in the study. The research sample represented 36.4% of the total number of patients approached. A detailed description of the demographic data is given in Table 1.

**Table 1.** Participants' characteristics

Participants	Age	Gender	Duration of disease (years)	Marital status	Number of children	Occupation
Participant 1	45	female	22	married	1	disability pension
Participant 2	34	male	10	single	-	disability pension
Participant 3	52	female	14	divorced	3	disability pension
Participant 4	44	male	19	divorced	1	disability pension
Participant 5	61	male	22	married	2	disability pension
Participant 6	51	female	15	married	-	disability pension
Participant 7	60	male	33	married	2	disability pension
Participant 8	53	female	40	married	1	sheltered workshop

## Data collection

The first author conducted semi-structured (face-to-face) interviews with all participants. The interviews were based on protocol and took place at SMSA meetings from September to October 2019. Only two local SMSAs agreed to cooperate with the study. The duration of the interviews ranged from 20 to 35 minutes. The questions were formulated on the basis of the following studies: Lohne et al. (2010), Matiti & Trorey (2004), Sharifi et al. (2016), van Gennip et al. (2013), and focused on the importance of dignity to participants, the identification of areas of patient dignity affected by MS, and how participants tried to preserve their dignity. The interviews were audio recorded and transcribed verbatim. Field notes were taken, reflecting on the interviews.

## Data analysis

Transcripts of the interviews were analyzed according to the method of thematic analysis introduced by Braun and Clark (2006), and Atlas.ti CLOUD was used to manage the data. Braun and Clark describe thematic analysis as a flexible method of identifying and analyzing patterns (themes) in data. It consists of six phases: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report (Braun & Clarke, 2006). After initial reading of the interviews, semantic patterns were identified in the data and were marked with separate codes. By merging codes based on similarities in meaning, specific subthemes were then

identified and subsequently grouped into higher order themes. Peer debriefing (Janesick, 2007) by the second author was realized to increase the trustworthiness of the study.

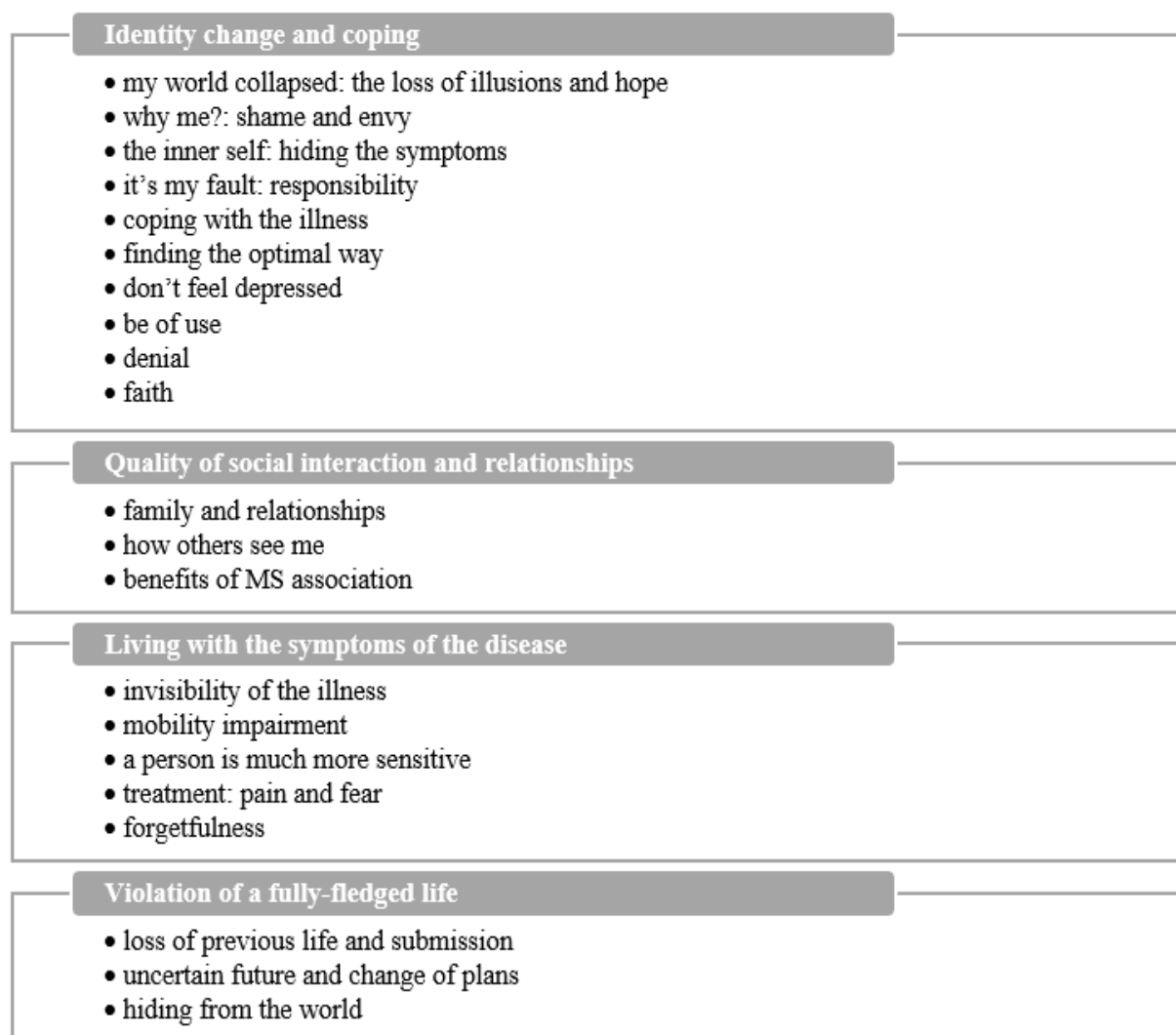
## Results

In the first phase of the thematic analysis, 78 codes were identified. Similar codes were merged into 21 subthemes, grouped into four superordinate themes based on interconnectedness and similarity in meaning: *Identity change and coping*; *Quality of social interaction and relationships*; *Living with the symptoms of the disease*; and *Violation of a fully-fledged life* (Figure 1).

### *Identity change and coping*

The theme of *Identity change and coping* was ambivalent, including subthemes reflecting both maintenance and violation of dignity. This theme was important to the participants since it was introduced in all interviews and was saturated with the largest number of subthemes.

Undergoing the diagnostic process was difficult for several participants, since the illness meant fundamental changes for them, with a negative impact on their dignity: “One does not know what to do ... you kind of lose your illusions about life” (Participant 8). As a result of the progression of the



**Figure 1** Dignity of patients with MS – results of thematic analysis

illness, they spoke of a complete loss of dignity, and even of a desire to die, suggesting that their worsening symptoms, with no hope of a better life, deprived them of all sense of their value as human beings: “My first reaction was: ‘is it curable?’, but it isn’t, and that ruins your life” (Participant 6).

Participants often hid how ill they felt in an effort to maintain their own identity: “In this way I protect what is mine, myself, my own personality” (Participant 8). Another participant described the ambivalence of this strategy of closing oneself off from others: “If you don’t suffer from it, you don’t understand it ..., for example, ... the family... They see me, know me, but ... my inner world is totally different from what I show, because I don’t want them to feel pity for me, although I need help, but ... I can’t feel down, so ... it’s such a double-edged sword ... I would like to [tell them], but I don’t want to” (Participant 1).

Several participants believed that they themselves had contributed to the change in their health condition, mainly due to noncompliance with a recommended treatment regimen, and an underestimation of warning signs and symptoms and doctors’ recommendations. The reason was that they had not known or believed that their condition could get any worse: “Maybe, if I had been more responsible, then ... I wouldn’t be like this now ... I think – I’m sure – some of my youthful recklessness is also to blame ...” (Participant 2). This self-blame negatively affected participants’ perception of their own dignity.

Acceptance of the illness proved to be the most important step for those who were able to maintain their identity and sense of value, considering MS a fate to be accepted: “I don’t take MS as a tragedy, as I have come to terms with it – that it should be like this. Probably everything is as it should be” (Participant 4). According to some, it was necessary

to believe the disease would not progress. It was important not to give up, but to find the determination to fight: *“The most important thing about this illness is that you don’t let it get you down ... The worst is when a person starts to decline in spirit ... One must believe that it won’t get worse – in our case, it won’t get better, but it won’t get worse”* (Participant 5). Closely related to the dignity of participants is the desire to be useful to and needed by others. One female participant stated: *“Despite being [diagnosed] with MS, I raised a nice son ... an engineer already”*, and she spoke of her satisfaction with the fact that, despite the illness, she could be useful, and was proud of it: *“That I am the president of the association and I have such a duty or – how should I put it? ... I need to take care of my subjects (laughs) ... I have to take care of them and I want to take care of them. And they are satisfied, and I am satisfied that I am successful at it”* (Participant 1). Thus, the effort to be useful to society was an important factor in maintaining dignity in some participants.

Closely related to the acceptance of MS was coping with the fact that patients were unable to manage or engage in activities that they had been able to do before. Despite the limitations to which participants had had to adapt, it was important for them to consider their lives to be worthwhile. At the same time, it was important to accept the differences between themselves and healthy people. Patients with MS needed to be aware of their own limits, make compromises and rationally consider what they could manage and what they could not. The seventh participant stated: *“Although I can’t do what I could as a healthy person ... one has to ... lower these expectations ... I made ... compromises and now I know what I can and what I can’t do, and I live accordingly ... Sometimes one has to give up [those things] one would like to achieve. You have to reconcile yourself to [those things] you have and can live with it”*. Due to the fact that most of the participants had mobility problems, they also expressed opinions about mobility aids. Despite her initial negative reaction to her wheelchair, a female participant eventually realized that it enabled her to be part of society: *“When I got the first wheelchair and tried it out in the pharmacy, I started to cry ... I couldn’t imagine it. And then, when I found out that, actually, when I want to keep pace with those who walk only with crutches or don’t need support, then ... I found out that it’s good, because otherwise I couldn’t go anywhere with them ... Neither with anyone, nor anywhere. I would just have to be locked up at home. So, in fact, the wheelchair is my legs”* (Participant 6). The determination to find a way to

overcome constraints proved to be an effective dignity-promoting strategy.

#### *Quality of social interaction and relationships*

This theme reflects the ambivalent experiences of participants regarding the behavior of other people (family, partners, and friends).

All participants agreed that support from family and partners was an important factor helping them to cope with illness-related changes, and played an important role in maintaining their dignity. In their daily life, they needed someone to *“hold them”* and stand by them: *“The most important thing is that a person has somebody close to him or her, or kind of a support”* (Participant 5). Although the majority of participants had had positive experiences in this context, there were also some whose families had not provided the help and support they required, which undermined their dignity. Some of them lamented parental lack of interest, others the lack of support in relationships: *“My husband rejects any debate or multiple sclerosis society and so on. Absolutely not ... Many ... get divorced, and leave it at that, but since I am still functioning, my marriage is also functioning somehow, but ... it is obvious that ... it is different”* (Participant 1). Another participant felt that *“this diagnosis does not favor relationships”* (Participant 4).

The reactions of participants’ immediate social circle to the illness had a significant (and typically negative) impact on their sense of dignity: *“You know, I haven’t had a positive reaction yet, I mean in a wider [social] environment ... But, especially my mom... People’s reactions evoke my anger... and such ... such anger, just like ... hostility against them, totally.”* (Participant 8). Another participant encountered ambivalent reactions, influenced by the circumstances in which others saw her: *“[Some] consider me a poor woman, some take me for a malingerer, some see me as ... normal, it depends – it depends on when they see me, how they see me, whether I can walk fast, or I can do something. When I do something, they say: ‘look, she’s faking it because she can do that, but she doesn’t go to work”* (Participant 1). Participants’ greatest desire was to be regarded in the same way as they had been before their illness, without the sense of alienation or expressions of regret they received from people, which undermined their dignity. In this regard, the Slovak Multiple Sclerosis Association played an important role. Some participants described it as a space in which they could be themselves. The mutual understanding members shared had a significant positive effect on dignity. From the participants’ point of view, meetings of people with

the same diagnosis “*building their own community*” were positive and beneficial: “*We support each other because we understand each other, we know what is wrong with us. And ... creating our own community or rather... association is very good for both patients and society, because we don’t ... [hold anyone up], we don’t shut ourselves away at home ... and we don’t cry over each other. We cry, but we no longer cry on the outside*” (Participant 1).

#### *Living with the symptoms of the disease*

Participants described their everyday life with multiple sclerosis as unpredictable, since periods of remission could be suddenly reversed by a renewed attack of the disease: “*it’s like [being] on a see-saw*” (Participant 5). In addition, the disease is accompanied by many symptoms that are not visible at first glance, as one participant stated: “*I can’t urinate or... these ... little things. When I eat, I feel like I have food stuck in my throat, and these are, like, really imperceptible issues... Others don’t even notice what’s wrong with me. Or I can’t see far away, I can’t drive. My reflexes, reactions – they’re not... like [they should be]*” (Participant 1). As mentioned above, the biggest changes that multiple sclerosis brought to the lives of the participants were various problems with mobility. Some participants suffered from symptoms such as fatigue, reduced sleep, incontinence, or forgetfulness, which interfered with daily life and ordinary functioning: “*It was also a forgetfulness for me ... I work with numbers, so I have to concentrate and then, so many times, I completely zone out*” (Participant 8). Due to the nature of the disease, mental changes have to be considered, too. Moreover, some participants mentioned that they were much more sensitive than before as a result of MS: “*... In the case of this diagnosis, a person is much more sensitive... A little thing can touch you or even lead to tears...*” (Participant 7).

#### *Violation of a fully-fledged life*

Violation and loss of their previously fully-fledged life had a dramatic impact on the personal integrity and dignity of the participants. They often compared their former lives with their present situation and found vast differences. One of the participants spoke of a “*180 degree change in daily life*” and “*subordination to multiple sclerosis*” (Participant 1). The biggest change was felt by a participant suffering from a severe form of MS with rapid progression. In a short time, she had lost her independence, which fundamentally affected her sense of dignity: “*They found out that ... I also have these lesions in my*

*brain, but most of them are between the scapulae, that is, in the spinal cord, and thus I started to gradually become paralyzed. First ... the right foot, right hand, then the left foot, left hand. So, now I really cannot eat or walk on my own, so ... I am no longer independent*” (Participant 6). Almost all participants were eligible for a disability pension and reported a loss of their previous working life / career, resulting in fear of the future and disruption of their life plans: “*Depression is an everyday companion ... and actually, not [just] depression ... because I am unable to do what I would like to, but ... also [about] what will happen when I can no longer take care of myself, when my husband will have to change my diapers, feed me ... the full service – 100% care ... And [about] whether he would like to do it or how it will be, what will happen*” (Participant 1). Another participant said: “*I planned to travel around the world.*” He was diagnosed with MS at a young age, which had affected his personal life, with the result that he had given up on the idea of having a relationship: “*In fact, I meet hardly anyone ... I’ve probably rejected everyone or they’ve rejected me ... No social networks, nothing ... Or maybe I don’t want to or don’t have time, but it’s more that I don’t want to ... It all went wrong somehow*” (Participant 2).

## **Discussion**

The dominant theme of the interviews was *Identity change and coping*, including supporting subthemes and subthemes violating participant’s dignity. While some participants felt that their dignity remained intact and had not been affected by the illness, or that they had managed to regain it, others felt that it had been lost completely, and the incurability of the disease had caused them to lose all expectations of a better life (Isaksson et al., 2007). Their initial reactions to the diagnosis had been fear, shame, guilt, and envy. Patients may feel that suddenly they are different to others, undermining their self-image (Kalantari et al., 2018) and due to prejudice, they may become more vulnerable, and their integrity endangered (Isaksson et al., 2007). Over time, some participants, realizing the seriousness of their condition, had responded with a desire to fight it, rather than give way to it, and to thereby delay the progression of MS. Some had been driven by this spirit of resistance to push at their boundaries until they had found the optimal way of life available to them. Acceptance of their changed identity and adapting to their deteriorating state were important steps in restoring their sense of dignity. (Žiaková et al., 2020). In several studies, this “fighting spirit” is considered essential to patients’ struggle to reconcile

themselves to the coming changes, to fulfil their potential, to avoid the fall into depression, to restore satisfaction with life, and to maintain dignity (Lohne et al., 2010; Reynolds & Prior, 2003). In addition, the belief that, in spite of their illness, they can still be important to others helps MS patients preserve or regain their dignity (van Gennip et al., 2015).

Another theme influencing the level of dignity retained was *Quality of social interaction and relationships*. All participants agreed that family and partners were important factors helping them to cope with more difficult periods, and to keep the changes that MS caused under control (Lohne et al., 2010; Sharifi et al., 2016; Žiaková et al., 2020). Understanding and empathy from family and friends were often mentioned as invaluable factors for coping with the illness (Ghafari et al., 2015). In the context of social relationships, it is important to emphasize that stigmatization of people with MS negatively affects the process of acceptance of the illness and undermines patient dignity and identity (Barker et al., 2019).

Other factors affecting dignity emerged within the theme *Living with the symptoms of the disease*. An important problem was the “invisibility” of the illness, since some symptoms were “imperceptible” to others, such as tiredness, memory disorders, or incontinence. They interfered with everyday life and disrupted normal functioning. The invisibility of the illness is also identified as a major problem in the study by Lohne et al. (2010), who describes MS as an insidious illness gradually robbing the sufferer of energy, balance, and physical strength. An impaired ability to manage many tasks of everyday life is described in the study of Žiaková et al. (2020). Patients with MS feel as if they were trapped in a sick body that prevents them from manifesting their true identity, and they experience changes in behavior, such as increased sensitivity or emotional instability (van Gennip et al., 2013).

The final theme identified was *Violation of a fully-fledged life*. Comparison of their previous life with their present situation and patients’ worries about the future were closely connected with their awareness of the progressive nature of MS and with the decline in motor skills which would continue to worsen (Finlayson, 2004). Participants needed to be careful not to exhaust themselves, limiting the choices available to them. Consequently, violated dignity was caused by the loss of abilities and competencies which previously had given MS sufferers a sense of dignity (Žiaková et al., 2020). Courts et al. (2004) mention that the devastation caused by symptoms of MS force patients to fight in order to retain a certain

degree of “normality”. It was this normality that our participants understood as the fully-fledged life that they were losing or which they had already irretrievably lost.

### Limitation of study

There were several limitations to our study, one of which was the small number of participants willing to join the study. In addition, interviews with participants tended to be quite short, possibly due to the effects of the disease (tiredness, difficulty in expressing oneself). Finally, the study was the first qualitative research performed by the first author, which may have had an influence on the interviews and analysis.

### Conclusion

The dignity of patients with MS can be violated by their experiences of the radical life changes they are subjected to, depriving them of their previously fully-fledged lives. Acceptance of the illness, a “fighting spirit”, and a sense that they still could be useful, helped them to retain their dignity. Knowing and understanding the themes that patients with MS associate with dignity can significantly help the maintenance of their dignity and its promotion in nursing care.

### 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* (decision 42 / 2019). Written informed consent was obtained from participants. To maintain anonymity only interview numbers were used in the study. No conflict of interest has been declared by the authors.

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### Author contributions

The concept and study design (JČ, LP), data collection (LP), data analysis and interpretation (LP, JČ), processing the draft of the manuscript (LP), critical revision of the manuscript (JČ, LP), article finalization (LP, JČ).



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