**Selected social aspects in the life of patients with multiple sclerosis**

Anna Ovšonková *, Edita Hlinková, Michaela Miertová, Katarína Žiaková

Comenius University in Bratislava, Jessenius Faculty of Medicine in Martin, Department of Nursing, Martin, Slovak Republic

**Abstract**

**Aim:** To describe and interpret the impact of multiple sclerosis (MS) on selected social aspects of life, on the family and working life.

**Design:** A qualitative cross-sectional study.

**Methods:** The group consisted of 14 probands with MS, with an average age of 44.7 years (± 9.8) and average disease duration of 9.93 years (± 5.97). To collect empirical data, we used a semi-structured interview according to a pre-prepared protocol of our own design, in the period between January–October 2018. The interviews were analysed via an Interpretative Phenomenological Analysis.

**Results:** Due to the disease symptoms, the probands experienced limitations when performing daily activities. They also experienced fear of losing self-sufficiency and were worried about the future. With the progression of the disease, there were also limitations in their working life which affected the quality of their lives. For most of them, MS also had an impact on the quality of family relationships including relations with their partners. Although the partners and children of probands were a source of social support, these people needed some time to accept MS and live with it.

**Conclusions:** Knowledge of selected aspects of life in individuals with MS can contribute to knowing their problems, and makes it possible to provide specific help within complex care provision.

**Keywords:** Disability; Employment; Family; Multiple sclerosis; Social aspects

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**Introduction**

Due to its chronic and progressive character, multiple sclerosis (MS) is the most debilitating inflammatory neurological disease of the central nervous system (CNS), which leads to disability (Ambler, 2011; Mazaheri et al., 2011). It is included in the demyelinating diseases of CNS with a large variability of neurological symptoms (Petrleničová, 2016). MS is usually diagnosed in the age between 25 and 45 years (Vijayasingham and Mairami, 2018). In all populations, it occurs in a higher number of women than men, with the ratio of 4 : 3 up to 3 : 2, which may be explained by genetic pre-disposition (Browne et al., 2014).

The clinical picture shows visible movement disorders and so-called invisible signs such as weakness, fatigue, impaired attention and memory; which are negatively perceived and experienced by patients. Psychic symptoms include changes in affectivity, depression syndrome, and euphoria (Bogosian et al., 2010). Due to its occurrence in early and middle adulthood, the disease affects the personal, family and working life of patients. Being diagnosed with MS as an incurable disease is a big shock for the patients and their families, which raises social questions caused by physical, mental and social problems (Compston and Coles, 2008; Costa et al., 2013; Van Capelle et al., 2015). The negative impact of MS on families includes emotional anxiety, the breakdown of relationships, economical problems and feelings of loneliness (Bjorgvinsdottir and Halldorsdottir, 2014; Glantz et al., 2009; McPheters and Sandberg, 2010; O’Connor et al., 2008). Individuals with MS may suffer from social isolation due to chronic fatigue, sexual dysfunction (leading to rejection in intimate relationships), fear of incontinence and wearing absorption aids when going out, and a feeling of helplessness when losing control over their body (Guo et al., 2012).

The most common course of the disease sees it shifting between attacks/relapses and remissions (relapsing-remitting form). Relapse is a source of insecurity and fear for a patient and his/her family, it disrupts the family life and makes family members re-arrange their activities and adapt to the changes accompanying the progression of MS (Boström and Nilsagård, 2016; Halper, 2007; Nilsagård and Boström, 2015). Due to this, family members may feel negative emotions such as anger, sadness, fear and anxiety, and children can become confused and emotionally unstable. As the disease progresses, the patients may have problems with their role at work and in the family due to an increasing dependence on others. They start losing hope, dreams, desires, feelings of safety and security (Buhse, 2008; Guo et al., 2012).

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* Author for correspondence: Anna Ovšonková, Comenius University in Bratislava, Jessenius Faculty of Medicine in Martin, Department of Nursing, Malá Hora 5, 036 01 Martin, Slovak Republic; e-mail: anna.ovsonkova@uniba.sk

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Patients with MS leave their job earlier than individuals without the disease, and their unemployment rate increases linearly with a longer duration of the disease. Up to 60–80% of patients with MS lose their job within 15 years of the diagnosis (Kozierska et al., 2018; Zwibel, 2009). The unemployment rate for patients doing manual work reached the range between 24% and 80%, mainly depending on disability level, progression of the disease, age and education level (Busche et al., 2003; Chiu et al., 2013; DeLuca and Nocentini, 2011; Krause et al., 2018; VanDenand, 2006). Working life significantly impacts the quality of life of the patients. Employed patients report a higher quality of life than the unemployed or patients who have retired due to disability and at the same time they are less dependent on social security, manage the disease in a better way, have a better social status and healthy self-confidence (Costa et al., 2013; Francová, 2005). Moore et al. (2013) state lower disability level (as a determining factor for leaving a job), shorter disease duration and higher education level to be the strongest predictive factors for maintaining employment. The most significant factor regarding reducing working hours or changing a job position is fatigue. Other factors negatively influencing employment are MS progression, higher age, lower education level, manual work, employment in the private sector, and the problem of commuting to and from work (Busche et al., 2003; Chiu et al., 2013; DeLuca and Nocentini, 2011; VanDenand, 2006). Johansson et al. (2016) state that MS symptoms and work limitations, as well as the social restrictions resulting from these issues, lead to feelings of depression, mood swings, feelings of sadness, dissatisfaction, irritation and loss of interest. Symptoms of depression occur in 26% to 42% of patients who verbalise feelings of worthlessness, doubt their abilities and complain about lack of empathy from others (Isaksson et al., 2007).

By focusing on all aspects of life (including family and work) it is possible to identify potential factors endangering the dignity of patients with MS, which helps professionals to better understand given problems and allows them to take measures to support a more dignified life for patients (Sharifi et al., 2016).

The aim of our study was to describe and interpret the life experience of patients with MS in the context of family and social life.

Materials and methods

The study has a qualitative cross-sectional design and uses the concept of Interpretative Phenomenological Analysis (IPA). 80 probands were addressed in written form, all of which were treated in the Centre for Diagnostics and Treatment of multiple sclerosis in the Neurological Clinic of University Hospital in Martin. The probands mostly originated from Central Slovakia. The research group consisted of 14 of probands (8 female and 6 male) who agreed to provide an interview about the problem. 15 probands is considered a sufficient number for IPA studies, given the fact that IPA uses the idiographic approach (Pietkiewicz and Smith, 2012). The criteria for acceptance into the research study were: age over 18, duration of the disease at a minimum of 1 year, willingness to cooperate (written informed consent to participate in the study). The criteria for exclusion included: presence of cognitive disorders, mental problems (treatment ≤3 months), age lower than 18, and unwillingness to cooperate in the research study. The current health condition of each proband, including cognitive diseases and mental problems, was objectified and documented by a neurologist through a medical check during their visit to the centre. Researchers verified the presence of problems and disorders via analysis of probands’ health records.

Empirical data were collected by a semi-structured interview according to a pre-prepared protocol of our own design. The content of the protocol consisted of open questions about the problem of dignity and consultation with experts in the given area (clinical expert – neurologist, clinical psychologist, cognitive-behavioural therapist, philosopher, nurses – academic workers). The collection of empirical data was preceded by a pilot testing that included 2 probands. Two trained research workers performed the data collection between January and October 2018.

For better objectification of the obtained data, the interviews were analysed by four research workers via IPA using the ATLAS.ti 8 program. The process of analysis took six steps that followed one another: (1) Reading and rereading of the text; (2) Initial noting; (3) Suggestion of initial themes; (4) Searching for connections across the themes; (5) Moving on to the next case, (6) Looking for patterns across cases (Smith et al., 2009).

The analysis was focused on problems of social aspects which affect the family and working life of patients.

Results and discussion

The average age of the probands was 44.7 years (± 9.8). Average duration of the disease was 9.93 years (± 5.97). The group included 8 married probands, 6 single probands and 2 divorced, 6 employed and 8 disability pensioners (more detailed characteristics of the group can be seen in Table 1).

The process of analysis included 14 interviews regarding the researched problem, identifying 11 themes of family life and 8 themes of working life (Table 2).

The probands realize the disease and its symptoms significantly affect their family life. They are prevented from having a usual family life by dizziness, throbbing sensations, tingling, burning in upper/lower limbs (perceived painfully), fatigue, weakness, insecurity when walking, balance disorders, clumsiness, weakness and trembling of hands (Ambler, 2011). Probands experience feelings of guilt and failure due to the inability to participate in family activities and their increasing dependence.

Proband 2 states she is limited by MS symptoms in performing daily-life activities in her household i.e. shopping, cooking, vacuuming and working in the garden. She learned not to hurry or stress around and "listen to her body more". Her family also had to get used to the disease, which took some time because: "[before] I was able to do everything 100%, but now I depend on their help in some activities."

Families and people around the individuals with MS often start to see them as persons who have changed and are different, which may result in feelings of fear and insecurity in the patients. Inside, however, the patients all feel the same (Olsson et al., 2010). Our probands revealed a similar experience. The biggest problems are fear of losing self-sufficiency and concerns about the future. They wonder: "How long will this condition be bearable when I compare myself with other MS patients?" When confronted with other patients with MS they are even more aware of the importance of their own self-sufficiency. Well-functioning feet and muscles and proper mobility guarantee self-sufficiency in daily activities at home as well as the ability to work. The patients try to be creative, move regularly, do physical exercise and follow recommendations.
### Table 1. Characteristics of the research group

<table>
<thead>
<tr>
<th>Probands</th>
<th>Gender</th>
<th>Age (in years)</th>
<th>Education</th>
<th>Disease duration (in years)</th>
<th>Marital status</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>male</td>
<td>43</td>
<td>UD</td>
<td>14</td>
<td>married</td>
<td>employed</td>
</tr>
<tr>
<td>2</td>
<td>female</td>
<td>51</td>
<td>SS</td>
<td>5</td>
<td>married</td>
<td>employed</td>
</tr>
<tr>
<td>3</td>
<td>male</td>
<td>34</td>
<td>UD</td>
<td>4</td>
<td>single</td>
<td>employed</td>
</tr>
<tr>
<td>4</td>
<td>female</td>
<td>25</td>
<td>UD</td>
<td>4</td>
<td>single</td>
<td>employed</td>
</tr>
<tr>
<td>5</td>
<td>female</td>
<td>44</td>
<td>SS</td>
<td>4</td>
<td>divorced</td>
<td>employed</td>
</tr>
<tr>
<td>6</td>
<td>female</td>
<td>48</td>
<td>SS</td>
<td>22</td>
<td>married</td>
<td>DP</td>
</tr>
<tr>
<td>7</td>
<td>male</td>
<td>56</td>
<td>SS</td>
<td>13</td>
<td>married</td>
<td>DP</td>
</tr>
<tr>
<td>8</td>
<td>female</td>
<td>34</td>
<td>SS</td>
<td>13</td>
<td>single</td>
<td>DP</td>
</tr>
<tr>
<td>9</td>
<td>male</td>
<td>61</td>
<td>UD</td>
<td>6</td>
<td>married</td>
<td>employed</td>
</tr>
<tr>
<td>10</td>
<td>male</td>
<td>42</td>
<td>SS</td>
<td>6</td>
<td>single</td>
<td>DP</td>
</tr>
<tr>
<td>11</td>
<td>male</td>
<td>42</td>
<td>SS</td>
<td>6</td>
<td>single</td>
<td>DP</td>
</tr>
<tr>
<td>12</td>
<td>female</td>
<td>41</td>
<td>SS</td>
<td>16</td>
<td>divorced</td>
<td>DP</td>
</tr>
<tr>
<td>13</td>
<td>female</td>
<td>49</td>
<td>SS</td>
<td>18</td>
<td>married</td>
<td>DP</td>
</tr>
<tr>
<td>14</td>
<td>female</td>
<td>56</td>
<td>UD</td>
<td>8</td>
<td>single</td>
<td>DP</td>
</tr>
</tbody>
</table>

Key: SS, secondary school; UD, university degree; DP, disability pensioner.

### Table 2. List of identified themes

<table>
<thead>
<tr>
<th>Family life</th>
<th>Working life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family background – help and support</td>
<td>Esteem, respect and help from colleagues</td>
</tr>
<tr>
<td>My wife and father know how to support me</td>
<td>I work as I am still capable</td>
</tr>
<tr>
<td>I am a strong person</td>
<td>I live a dignified life while working</td>
</tr>
<tr>
<td>Dignity – activity, creativity, independence</td>
<td>Fully-fledged life</td>
</tr>
<tr>
<td>Try to make the best of MS</td>
<td>Worries – attitudes of others at work</td>
</tr>
<tr>
<td>Meet other people and families</td>
<td>Job as an identity – be useful and help others</td>
</tr>
<tr>
<td>Being dependent – better not to think about it</td>
<td>Reassessment of priorities and values</td>
</tr>
<tr>
<td>Family provides me with a sense of meaning in life</td>
<td>Not giving up is important – stand up and start working</td>
</tr>
<tr>
<td>MS patient – Left out by others</td>
<td></td>
</tr>
<tr>
<td>Do common things like people without MS – I won’t manage</td>
<td></td>
</tr>
<tr>
<td>I am not saying I am ostracized, but I consider myself to be ostracized</td>
<td></td>
</tr>
</tbody>
</table>

Regarding this, proband 5 tries her best, as she herself says: “I do not know how long I will keep on doing well with this diagnosis, especially when I see all the others around me, but I am doing my best to be self-sufficient.” Proband 7 says: “I am trying to do all I am capable of by myself, although it is very demanding.”

MS has an impact on the life of all families and quality of relationships between family members. It can cause tension and stress affecting each family member and the overall behaviour of the family in terms of its functionality (Uccelli, 2014). One of the most negative impacts of MS is the breakdown of partner relationships resulting in the marriage finishing.

Communication between partners, demonstration of mutual respect, adoration and appreciation have a big effect on relationships (Liedstöm et al., 2010). If the partners only perceive problems, objections and limitations, their relationships will break up (Starks et al., 2010). Pfleger et al. (2010) state that 66% of relationships end, and this mainly affects women who are left by healthy partners. The critical age for split-up of partners is 35 years. By this time, children are already grown up and independent, so the men feel like they can leave (Glantz et al., 2009). In our group, 2 probands were divorced and 6 were married. Several of them went through a marriage crisis but later their relationships strengthened. Proband 12 said that after the crisis in her marriage she realised the importance of her family who will support and help her in the new situation (life with disease). It is important for her to have a family background, somebody to lean on and go through the hard moments with. Her family enlarged by grandchildren means security and source of values, especially after her husband’s infidelity. According to her, overcoming and withstanding the troubles had been worth it. The husband of proband 2 also needed time to understand and accept her restrictions and limitations. She finds it important to communicate with her partner, as he did not always understand her “invisible” troubles (fatigue), often did not believe her and “had to find some time to learn to respect me with my disease”. Similar results can also be found in other studies (Liedstöm et al., 2010; Starks et al., 2010), when, having handled the problems, partners express the feeling of success in managing the troubles related to MS.

The partners state that although their relationship to their spouse with MS did not change, they feel frustration, anger,
loneliness, isolation, all of which can lead to depression in individuals with MS, change the quality of the relationship and this may include its break-up (Björgvinsdóttir and Hall- dórsdóttir, 2014; Bogosian et al., 2009). The quality of relationship can be affected by MS symptoms such as sexual dysfunction or disorder of urinary sphincters (imperative urinating, retention, incontinence) (Ambler, 2011). As these are intimate problems, individuals with MS mostly do not speak about them. In our group only proband 1 openly said: “I have not had an erection for over a year, maybe a year and half, I cannot even tell... I am not capable of any sexual performance.” O’Connor et al. (2008) state that only one third of healthy individuals were satisfied with their sexual life in the relationship with their partner with MS.

For an individual with MS, a partner is a source of social support. For example, proband 1 talks about his wife in the best terms, stating that she is welcoming and helping “in all matters”, and he is extremely grateful for that. “I cannot imagine how many hats I would need to put on and take off at once. She perceives my disease and knows how to support me.” Proband 9 talked about his wife in a similar way – she was a supportive person, standing by him since he was diagnosed. He admits that under the influence of the disease he started to be “irritated, responding in an annoying way”, which could be confirmed by his wife as a witness of this behaviour. “Many times, she has to draw back, which is why I think my wife is in a worse situation than myself.” Other family members are also helpful – “yes, they support me a lot”.

Another source of mental and social support, security and help for individuals with MS are their parents. Proband 1 feels his father’s respect in the form of interest in his disease and treatment: “He calls me and wants to know.” They also talk about other things, which “makes me forget for a while that something like MS ever existed”. Socially isolated probands, like proband 7, realise it is the family who can always support and help them. “Now when I have limited possibilities due to the disease, my mother and children are the only ones I have left.” However, they can also feel like a burden to their families, and somebody who “makes their lives complicated”. This is perceived very intensively by younger probands who rely on the help of their parents (often seniors), who help them with mobility problems (i.e. drive them to medical checks). The probands realise it is them who should be helping the parents, not the other way around. This fact might by an obstacle for setting up their own family. “If I married and had a family, I would be a burden to my wife” (proband 3). Proband 14 taught her father to cook, as she was not capable of maintaining the household anymore. “I simply showed him how to do this and that and now he cooks quite well. He did not even know how to make tea before.” The older probands assessed their situation more positively than the younger ones. “I already have a family, and at least I can be sure they will take care of me when the time for a wheelchair comes... But what about the youngsters? Who will take care of them? Their parents? They will be 90-years-old. And now they have to push a 60-year-old in a wheelchair?” (proband 9).

For individuals with MS, their children provide a source of personal value and meaning of life. The consequences of the disease are worse perceived in young individuals who establish a family and have children, than in MS patients diagnosed in a higher age. Proband 12 stated she had been diagnosed at the age of 30, when her children were little. “It looked like I was going to end up in a wheelchair quickly, as I went so down mentally.” She needed almost 2 years to cope with the disease mentally, but her strong will helped, even when she had to deal with a marital crisis (her husband’s infidelity). “I thought we were going to divorce, but then I focussed on my children and slowly things got better and better until I managed to overcome all the bad.”

The probands in our study did not see themselves in the role of a parent. Proband 1 said he “did not want to bother my children with the disease and related problems”. If parents decide not to talk about the disease, children might be hesitant to ask. Communication barriers begin to build up, information is understood wrongly and assumptions, anxiety and fear start to appear (Nilsgård and Boström, 2015). Due to this, several studies confirm the importance of communication between single family members (Arden-Close et al., 2010; Ondrejkovič and Majerčiková, 2006). In their study, Faliokosta et al. (2009) stated that a lack of information about their parents’ disease led to mental problems, anxiety and emotional instability in children. Children can take the role of a caregiver, stay at home and look after the parent. The range of their care however should not affect their relationships with friends and peers and they should be able to perform activities relevant to their age. In our study, probands with adult children found the meaning of life in their grandchildren.

Single probands found friends in pets. Proband 4 said: “I got myself a dog, as besides health-care personnel, I will need somebody to stay with me. The best prescription is to have a dog. Mine has a cleft lip, so I say we match [laughter]... we make such a good team...” Social support is a significant factor that positively impacts on quality of life of the patients (Majerníková et al., 2019).

Several probands from our study left a “message” to other patients that they should not cry, swear and complain, because if they do they can lose their family and friends’ support and will “slowly fade away” (proband 6). Persistent bothering of those around by the disease can lead to the situation when a patient stays lonely. Proband 6 recommends a different view on the disease, seeing some positive things that come out of it, such as new friends, new patient family and health-care personnel. “In the hospital we are like one big family, we know each other and are connected by MS.”

MS also has a huge impact on working life. Compared with other chronic diseases (like diabetes mellitus – type II, arthritis, depression), in the group of patients with MS there is higher rate of those who are unemployed or who have a partial disability pension, which is also related to a lower income (Jennum et al., 2012; Vijayasingham and Mairami, 2018). Employment provides economical resources and feelings of personal and professional identity and social engagement and interaction. Work troubles and causes of unemployment result from the inability to cope with work requirements and stress, long working hours, inflexible work conditions and work life intensity (Jennum et al., 2012; Vijayasingham and Mairami, 2018).

Individuals with higher education level (and those who did not work manually) can find a job adjusted to their possibilities more easily. They possess real or potential resources like education, profession, and financial and social status. Patients with MS who were employed before being diagnosed and had to stop working due to the progression of the disease could see this as a challenge to search for another job using their resources. On the other hand, if they do not possess such resources, they could feel useless and rejected (Krause et al., 2018; Sharifi et al., 2016). In our study, more than one half of the probands (8 probands) were disability pensioners. Proband 13 says: “You have to have a job to be able to exist... you need money... I could not imagine what would happen to me and my little children. When the physician recommended I take full disability pension I thought I would not manage, I became unwell mentally and it was a difficult time, very difficult.” There is a 40% possibility that after
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15 years of being diagnosed the patients are not capable of independent walking, which is the most frequent reason for a decrease in productivity and loss of employment (Kantorová et al., 2012). For proband 10 the hardest impacts of MS are movement limitations and inability to work, but he still tries to be useful and helpful. As he stated: "I have always been like that, but now it has intensified and it comes from my inside. I can offer my experience after all those years." To be useful to others raises his self-esteem.

Sweetland et al. (2012) state that unemployment rate is not linearly conditioned by the level of disability or damage of patients. If they had to leave their jobs due to discrimination and negativity from their co-workers, they take it positively that they do not have to work and be exposed to all of that. Proband 6 stated: "... because I do not work, I do not worry about people scowling at me when I am not able to manage and my job having to be done by somebody else. It is good, because when I feel bad, I can lie down and when I feel well, I can do other activities."

On the other hand, the possibility to work after being diagnosed (along with a cooperative attitude from the employer) positively affects the situation. There are several possibilities of employment support for patients with MS. Proband 2 did not take the change of her work position negatively; she found it positive to have been able to reach a compromise and solve the situation. "I made a step forward and they did as well, so I can continue with my job. Of course, in a different position which I can manage, but it was possible to solve by a compromise from both sides." Employers can adjust a position or workload to the needs of employees with MS, such as making it a part-time job, flexible working hours, and working from home. Another possibility would be setting up a protected workplace or protected workplace by the employer. As proband 1 says: "I work in a sheltered workshop and I have to admit, they are really very helpful." Work conditions and job performance expectations in these workplaces are adjusted to the health conditions of workers (Act No. 5/2004 Coll., Paragraph 55 (1)). A protected workplace provides a feeling of usefulness, self-realisation, fellowship and a possibility to be part of a work team and make some money. Proband 14 appreciates that she can work whilst receiving disability pension "I work in insurance, which makes my life better. I am not as financially dependent on others as I would be if I did not work". Proband 2 relates the possibility of working with being around people and thinking about the disease less. "You do not sit alone at home and think. It is better to be surrounded by others."

Johnson et al. (2004) mention MS patient statements that describe the advantages and barriers to employment. For most of them, those that prevail are advantages related to the financial benefit of maintaining a job, the importance of work for personal identity, self-esteem, social contacts and the therapeutic effect of work. The barriers include changes in symptomatology, fluctuations of energy and cognitive functions during the day and stress. The employment itself but also the presence of losing the job and professional identity as well as risk of poverty, lack of health-care benefits, disability and pain are all stressful factors for the patients.

Extreme fatigue is considered to be one of the main causes of functional disability, occurring in 75 to 90% of patients. In 50% of patients it is assessed as the most negative and debilitating symptom of MS (Forwell et al., 2008; Jakubiková and Klímová, 2010). Fatigue occurs immediately in the morning after waking up and gets worse during the day. Its presence affects mobility, physical activity, daily life at home and work, and can trigger other problems. Fatigue and overall health condition also affect work pace (Kos et al., 2008; Schwid et al., 2002). Proband 2 says: "I keep working because I can manage. I stay at work because I feel capable." Proband 4 adds: "If you can keep up with the usual pace of life, you are considered a fully-fledged person." She tries to be fully-fledged "while it is possible" and "to manage."

Proband 3 associates going to work with a dignified life. "Until now, going to work, being a part of a team, and the ability to have decent clothes, food and hygienic standard, all made my life meaningful." In his view, a satisfactory life standard means "to live in a decent way if one works". He mentions that "a working or employed person should live a normal lifestyle and should not have a problem with it". He says his life is meaningful when he feels part of a circle of people (work team), and that his current long-term unemployment has a negative effect on him.

The disease and its related limitations also affect the re-evaluation of one's own priorities and values. Proband 13 stated both she and her husband had worked too much, only cared about money, and did not pay attention to some problems. Only after being diagnosed with MS did she realise that money is not everything. Now she puts her health and children (family) first. She assigns the origin of the disease to the high pace of work and the effort to make money. "Before I only worked and worked and worked. I did not think about it, I just thought money is important, you need it to exist... only after I got ill I realised that health must come first and I changed my view of life." Based on her experience, she mentioned it is important to feel useful and be a part of society. Proband 13 says she was at home for 15 years, but it made her feel depressed and she found it worse. "I was at home for 15 years but my condition deteriorated, my mental condition got worse and I felt like my life was stagnating, not going forwards or even backwards. Then I started working for four hours and that started me up – meeting people, getting involved in working life, feeling a bit useful because staying at home was killing me." It is important to have meaning in your life, "for me, God comes in first place, then family and then my job, so that my life does not hit rock bottom."

Conclusions

Considering the lack of studies devoted to problems of both family and working life of patients with MS in Slovakia, the authors of this contribution tried to describe the life experience of these patients. Good family and work relations lead to the improvement of health and support the dignity of the patients. Thanks to this, patients do not focus so much on MS symptoms like fatigue, sadness, fear and anxiety (which they fight with every day), or on problems such as loneliness, anger, frustration, unworthiness and desperation that a life with disease brings. Understanding the factors related to the process of leaving and re-entering work improves the ability to act in favour of patients. Early job ending or reduction of work ability can cause economic, health and psychosocial difficulties. Current symptoms and limitations resulting from the disease should be taken into account to support employment for patients with MS. Within health care provision it is important to provide support and counselling to the patients as well as to their partners and children.

It would be useful to explore this topic in future research studies, so that we can point out its importance from a holistic view of a patient with MS.

Study limitations

The authors are aware of some limitations of this research study and therefore it would be useful to continue with the
research. The content and course of individual interviews were affected by the current health condition of probands and their individual perception. Due to sensitivity and perception of the situation, several of them refused to participate in the study, even though they had agreed to at the beginning.

Conflict of interests
The authors have no conflict of interests to declare.

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Vybrané sociálne aspekty života pacientov so sklerózou multiplex

Súhrn
Cieľ: Cieľom štúdie bola opisovať a interpretovať dopad sklerózy multiplex (SM) na vybrané sociálne aspekty života, na rodinu a právno slow život.

Design: Kvalitativná prierezová štúdia.

Metodika: Súbor tvorilo 14 probandov so SM, s priemerným vekom 44,7 rokov (± 9,8) a priemernou dlžkou ochorenia 9,93 roka (± 5,97). Na zber empirických údajov bol použitý polostruktúrovaný rozhovor podľa vopred pripraveného protokolu vlastnej konštrukcie v období január–október 2018. Rozhovory boli analyzované prostredníctvom interpretatívnej fenomenologickej analýzy.


Záver: Poznanie vybraných aspektov života u jednotlivcov so SM prispeje k poznaniu ich problémov a dáva možnosť konkrétnej pomoci v rámci zaistenia komplexnej starostlivosti.

Kľúčové slová: dizabilita; rodina; skleróza multiplex; sociálne aspekty; zamestnanie

References


