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**CARER BURDEN WHEN PROVIDING CARE
FOR A PERSON WITH A CHRONIC DISEASE
ILLUSTRATED WITH THE EXAMPLE OF MULTIPLE
SCLEROSIS**

**Obciążenie opiekuna w trakcie świadczenia opieki nad osobą chorą
przewlekłą na przykładzie stwardnienia rozsianego**

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A - Research concept and design, B - Collection and/or assembly of data, C - Data analysis and interpretation, D - Writing the article, E - Critical revision of the article, F - Final approval of the article

Abstract (in Polish):

Wstęp: Stwardnienie rozsiane (SM) jako choroba przewlekła stanowi złożone doświadczenie i wpływa na różne sfery życia chorego i jego opiekuna. Decyzja o podjęciu roli opiekuna wiąże się ze świadomym przyjęciem nowych obowiązków, zmianą planów życiowych, a świadczenie stałej opieki nad osobą

chorą przewlekle może prowadzić do obciążenia, które oznacza problemy w wymiarze psychicznego, fizycznego lub społecznego funkcjonowania.

Cel: Celem pracy była charakterystyka wymiarów obciążenia opiekuna wynikającego z opieki nad osobą chorą na stwardnienie rozsiane.

Przeгляд: Obciążenie opiekuna określa się jako problemy osoby sprawującej opiekę nad chorym, mające swoje odzwierciedlenie w sferze fizycznej, psychicznej i społecznej. Opiekunowie doświadczają dolegliwości somatycznych, zaburzeń emocjonalnych, ograniczeń w życiu społecznym a także braku możliwości samorealizacji i realizacji planów.

Wnioski: Opieka nad chorym na stwardnienie rozsiane jako długotrwały i dynamicznie zmieniający się stresor prowadzi do obciążenia opiekuna. SM, jako choroba przewlekła charakteryzuje się okresami remisji i zaostrzeń, które wymagają w różnym stopniu zaangażowania opiekuna.

Abstract (in English):

Introduction: As a chronic disease, multiple sclerosis (MS) is a complex experience affecting various spheres of the patient's and carer's lives. The decision to take on the role of a carer involves a conscious assumption of new responsibilities, a change of life plans, and providing ongoing care for a chronically ill person can lead to a burden that implies problems in terms of mental, physical or social functioning.

Aim: The aim of this study was to characterise the dimensions of the burden of a carer resulting from caring for a person with multiple sclerosis.

Overview: Carer burden is defined as the problems of the carer reflected in the physical, mental and social spheres. Carers experience somatic complaints, emotional disturbances, limitations in social life and a lack of opportunities for self-realisation and plans.

Conclusions: Caring for a multiple sclerosis patient as a long-term and dynamically changing stressor leads to a carer burden. MS, as a chronic disease, is characterised by periods of remission and exacerbations that require varying degrees of carer involvement.

Keywords (in Polish): obciążenie, opiekun, stwardnienie rozsiane.

Keywords (in English): burden, carer, multiple sclerosis.

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Obciążenie opiekuna w trakcie opieki nad osobą chorą na SM

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Introduction

According to available data, multiple sclerosis (MS) is the most common demyelinating disease, affecting approximately 2.3 million people in the general population [1]. The course of the disease, with worsening neurological symptoms, cognitive impairment and the awareness of its incurability, is a traumatic experience for the patient and their carer [2]. Due to its consequences, a diagnosis of multiple sclerosis requires finding oneself in a new situation and changing life plans [3, 4]. As a chronic disease, it is a difficult experience and affects various spheres of the patient's and carer's life. People with MS require constant care, which often means their carers are under strain [1].

The decision to take on the role of carer is a difficult one. It means adapting to the many changes brought about by the disease while trying to normalise life within the family, relationships with relatives and the environment [5]. Acting as a carer requires consciously taking on additional new responsibilities, as well as changing personal, professional, and family plans [6, 7]. The failure of the patient to comply with medical and therapeutic recommendations can also be a carer burden [8].

Undertaking the day-to-day care of a multiple sclerosis patient by a carer fills in the gaps left by the healthcare system and, as a dynamic, long-term stressor, leads to the carer burden.

Aim

The aim of this study was to characterise the dimensions of the burden of a carer resulting from caring for a person with multiple sclerosis.

Overview

Chronic disease

Chronic disease, according to the WHO (World Health Organisation), is a disease with slow progression and a long duration. The definition adopted by the National Commission on Chronic Illness emphasises a long-term course with consequent disability, dysfunction or the need for specialised supervision, care or rehabilitation [9].

Chronic diseases are not a stable condition, characterised by periods of remission and exacerbation. Exacerbation of symptoms results in partial or total dependence of the person on the carer. Chronic diseases require interventions from health care professionals, entire social communities and, above all, from people who experience the disease and their carers [10]. Chronic

diseases are characterised by incurability, but disease progression can be slowed, symptoms can be controlled and altered body functions can be compensated [9]. In addition to cancer, psychiatric, respiratory, cardiovascular or rheumatoid arthritis diseases, multiple sclerosis has been recognised as a chronic disease [11].

Styles of care for the chronically ill.

Carer burden and burnout in caring for a chronic patient with a diagnosis of MS.

In the case of multiple sclerosis, a chronic and progressive disease, sufferers require ongoing, comprehensive care that takes into account their physical, emotional and social needs. Carers must present a style of care that ensures an appropriate level of involvement and collaboration with the professionals of the healthcare team and results in the provision of holistic, appropriate support to the needs of the patient and a reduction in the level of burden on carers. Caring for a chronically ill person requires a range of skills and commitment from the carer, and style makes a big difference to the health of patients as well as their carers [12].

There are many different styles of care that can be used depending on the situation, needs and preferences of the carer [12]. The first style of care involves a good relationship with the client, involvement and collaboration with the professional healthcare team. The second one consists in providing sufficient care, but without regular contact with the medical team. The third one means providing care at a minimal level, without much involvement in outreach activities. Another style of care is characterised by the minimal provision of care and a reluctance to cooperate with health professionals. The fifth one is identified in a situation of neglect of caring responsibilities and exposure to the consequences associated with such neglect [12]. Over-involvement and inadequate assessment of the client's situation, insisting on one's vision of care, rejecting help, disagreeing with medical professionals and blaming the medical staff for possible failures characterise the sixth style of care. Still another style is characterised by abuse of the care situation, leading to subjugation of the person under one's care or gaining advantages from various forms of assistance, controlling the patient's contact with the environment, as well as aggression towards medical professionals and accusing them of lacking competence and due care. The last style refers to an inadvertent inability to provide assistance due to health or other reasons, e.g. financial [12].

Carer burden is defined as the problems of the carer reflected in the physical, mental and social spheres. Carers sacrifice time and financial costs, and experience the emotional distress of coping with the stressful situation of experiencing a loved one's illness and caring for a patient. Social problems manifest themselves in the decrease of the carer's active participation in the local community, reduced contact with other people, and lack of opportunities for self-realisation and professional plans [13].

Carer burden is a multidimensional phenomenon conditioned by the patient's illness, functional status and personality. Disease progression, disability and accompanying cognitive decline result in a change in the carer-patient relationship when a spouse is ill. Female carers, especially wives, have a significantly higher burden [14]. The care provided by the wife considered as a social norm is connected with the traditional division of responsibilities in the family and is the result of cultural conditioning [15]. Factors related to the socio-demographic characteristics of the carer, such as lower social status, low education, and old age lead to a greater carer burden [14]. In addition,

a higher risk of burden is found in carers manifesting a less mature personality type, preferring a withdrawal-avoidant coping mechanism for stress [15].

The burden of care has two dimensions: subjective and objective. The subjective burden is difficult to verify and is related to feelings of psychological discomfort and often stigmatisation due to the illness of a family member. It appears to be associated with styles of care, level of psychosocial support and individual styles of coping with a hard situation [16 - 18]. The objective burden is connected with objective indicators, measurable unfavourable, unsuccessful, unpleasant and disadvantageous changes in the functioning of the carer. The objective burden is expressed in family and social relationships, leisure time organisation, work activities, health disorders and changes concerning daily household activities [19].

Taking on the role of carer for a person with multiple sclerosis involves taking on additional responsibilities and changing plans in various areas of life [6, 7]. In the aftermath of a family member's illness, the carer's life situation changes and there is a reorganisation in the way the carer used to function [20, 21]. As a result of the progression of the disease and the loss of patient autonomy, the presence of a carer is required for an increasing amount of time [22, 23]. The family carer has a natural, supportive, caring and nurturing role towards the person with a disability and ill health [24, 25]. The care of an informal nature for MS patients is most often voluntary, driven by family relationships and cultural norms, and may be a consequence of a sense of obligation and, in extreme cases, guilt towards loved ones [26].

In caring for a family member with multiple sclerosis, carers experience a health burden, with back pain, varicose veins, hernias and lowering of the reproductive organs in women [27], as well as syncope, fainting and gastrointestinal disorders [19]. As a result of providing long-term care, their immune system is also weakened [6], resulting in a risk of increased morbidity and affecting their life expectancy [28]. 24-hour care over many years is associated with the possibility of carers developing heart disease, osteoarticular injuries, exacerbation of pain syndromes [6], headaches and leg pain, and arthritis [8, 29]. In addition, caring for a relative can result in a decrease in the family's living conditions [30], limit the possibility for active leisure and relaxation, which affects biological well-being [20, 21]. As a result of responding to the patient's health situation, the carer can develop an eating disorder manifested as a lack of appetite or, in extreme cases, cessation of eating [31].

Carers also experience emotional changes, including diagnoses of neurotic and depressive disorders [27], and the emotional state of the carer directly affects the quality of care provided [32]. Receiving little emotional support and perceiving caregiving as a negative experience significantly contribute to fatigue, depression and sleep disturbances [33 - 35]. Depression affects between 11% and 52% of carers of chronically ill people with a neurodegenerative disorder [36].

At the time of diagnosis of a chronic disease, a mechanism of denial, guilt associated with negative behaviours towards the patient and anger may be triggered [37]. The source of the crisis experienced by the carer becomes uncertainty about the course, development and successive appearance of the disease, as well as accompanying the suffering of a loved one [8]. The vision of the patient's death can cause the carer to feel a loss of meaning in life [37]. Carers acknowledge living in permanent fear, with the guiding emotional response being fear of disease progression, an unpredictable future and the physical disability of the person under their care [38]. Possible emotional reactions of a carer related to caring for a chronically ill person are: experiencing anger,

despair, mood swings, loss of emotional balance, feelings of loneliness, frustration, nervousness, feelings of hurt, loss or feelings of uselessness. Many carers experienced feelings of shock, panic, trauma and difficulty in seeing the positive aspects arising from the situation of their loved one's illness. In addition, the difficult situation is exacerbated by hiding the true feelings from the patient and presenting an attitude of optimism and calm. The accumulation of negative emotions leads to extreme mental fatigue, exhaustion, as well as impaired cognitive functioning (memory and attention disorders). Coping with the illness of a loved one is one of the difficult situations which are described as stress. The carer's experience of stress influences the occurrence of psychological disorders - guilt, emotional tension, panic attacks, depression, sleep disturbances, chronic fatigue, and feelings of social incompetence [39]. The illness, seen as a stressor, exacerbates the tendency of the carer to engage in anti-health behaviour such as smoking or increasing the frequency of alcohol use [31].

Caring for a chronically ill spouse also causes changes in sexual life. There is a loss of intimacy, a sense of loss of closeness, feelings of regret, decreased satisfaction with sexual life and a lack of communication in the area of sexual activity [8].

Caring for a multiple sclerosis patient is also reflected in social functioning. Both the lack of opportunities to pursue professional plans and opportunities for self-fulfilment significantly affect the withdrawal of the carer from active social life [20, 21]. Restriction of trips, contacts or meetings with other family members, friends and cessation of hobbies [27] results in feelings of social isolation, and loneliness [40].

Caring for a patient who requires long-term and intensive care depletes the carer's resources and ultimately leads to carer burnout syndrome [41]. It is worth noting that this is a state of gradually increasing symptoms such as insomnia, somatic complaints, decreased activity and mood, and irritability reminiscent of the effects of exhaustion. In addition, the carer experiences apathy, a sense of hopelessness about the situation, a lack of competence, and doubt in their ability to overcome everyday difficulties. The carer distances oneself from the patients and their needs, belittles their problems, neglects the carer's responsibilities, and may also blame family members or medical professionals for problems that arise. Progression of mental and physical exhaustion, deterioration of health, chronic fatigue, back and muscle pain, dizziness, and a negative self-image characterise the final phase of burnout. The feelings of loneliness, powerlessness, decreased self-esteem and self-worth [19], a tendency to blame oneself, increased self-criticism and a pessimistic attitude towards life accompany the carer. [42]. The resulting dissonance between caring for oneself and caring for the patient quite often manifests in carers a tendency to neglect themselves, their health and their needs [19]. Carer involvement, setting of tasks that exceed one's mental and physical capabilities, exhaustion, and sometimes suicidal thoughts are all related to loss of insight [43]. The issue of chronic diseases and their consequences is present in the literature and continues to be the subject of ongoing analysis and research.

Conclusions

The available studies and research findings confirm the phenomenon of carer burden over a person with MS and show the multidimensionality of this phenomenon. Caring for a multiple sclerosis patient as a long-term and dynamically changing stressor leads to a carer burden. As a chronic

disease, multiple sclerosis characterised by periods of remission and exacerbations that require varying degrees of carer involvement.

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