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Selected factors burdening the caregiver of a chronically ill person on the example of multiple sclerosis

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Abstract: Introduction: The burden on caregivers of chronically ill patients is a subject of concern for many specialists. The course of multiple sclerosis and the associated change in the patient's functional ability, as well as the resources available to the caregiver, are related to the burden felt by the caregiver. It is extremely important in relation to the care provided to assess the factors that may determine the burden on caregivers. The aim of this study was to identify selected determinants of burden on caregivers of multiple sclerosis patients.
Material and Methods: A diagnostic survey was conducted among 107 caregivers of multiple sclerosis patients using the CBS Caregiver Burden Scale, Guy's Neurological Disability Scale (GNDS), Berlin Social Support Scale (BSSS), Antonovsky's SOC-29 Life Orientation Questionnaire, and the author's own questionnaire. The collected survey data were entered into a Microsoft Excel spreadsheet and then analyzed using Statistica 13 software. The level of statistical significance was adopted as $\alpha = 0.05$.
Results: The burden on caregivers was high in all subscales. Life orientation and social support were associated with the burden on caregivers. Low life orientation, decreasing perceived available support and currently provided support, as well as a shortage of currently received support and increased search for support resulted in a higher overall burden among caregivers. In addition, deteriorating functioning of patients exacerbated the caregivers' feelings of social isolation, disappointment, and emotional involvement.
Conclusions: Caregivers experienced burdens in various dimensions related to the functional ability of patients and their own resources, such as social support and life orientation.

Keywords: caregiver, burden, multiple sclerosis.

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Introduction

Chronic diseases are considered the most severe health problem, which is a challenge not only for people experiencing the disease, healthcare professionals, but also for people who decide to be their caregivers [1]. Unfortunately, the available assistance and support systems do not always fully meet the expectations of caregivers [2, 3]. Taking on the role of a caregiver for various reasons is a challenge [4], usually associated with providing free care [5], which carries a long-term burden. Due to the type of chronic disease and the previous functioning of the patient and their caregiver, the factors causing caregiver burden can arise at different stages of the disease.

The subject of subjective and objective burden on caregivers of chronically ill people [6–9] still needs to be explored in more depth — especially in the area of causative factors and measures taken to minimize the burden. Unfortunately, it is not possible to prevent the caregiver from experiencing burden in terms of their physical, mental and social functioning, which is why health care professionals should also pay attention to factors related to the accumulation of caregiver burden during each meeting with the patient and their family.

These factors include sociodemographic variables such as old age, female gender, being a wife [10], professional activity and economic status [11, 5], lack of higher education [12, 10]. The literature also points to the belief [13] that being an adult child living with an ill person [13] or being a mother and the associated responsibility or being a parent of children with special needs who attend educational centers irregularly [12]. Unfortunately, caregivers also experience stigmatization due to the disease of a family member [6–8].

The factors that focus on the disease and the patient are also specified, i.e. age of the patient [13], cost of care [14], total duration of care and length of care per day [15], course of the disease and the degree of dependence on the caregiver, the patient's fitness [4, 5, 16], cognitive functions, personality changes, behavioral disorders [13], presence of other chronic diseases [12], the patient's perception of the disease [13], as well as the process of adaptation and acceptance of the disease [4, 17].

Research also confirms the importance of the caregiver's mental health [18], prevalence of depressive disorders [13] and sleep disorders, fatigue, low sense of efficacy [19], experience of stress [16], doubts about the ability to provide proper care and a sense of loss of control over life [13], coping in a difficult situation [6–8], self-assessment of health [20] and a sense of coherence. A high sense of coherence in this area includes a sense of purpose and optimism in the role taken on and finding meaning. Knowledge about the disease, effective communication, experience in caregiving, resource utilization and commitment, giving meaning to human relationships can appropriately shape the components of coherence such as comprehensibility, resourcefulness and meaningfulness [21]. Caregivers with a less mature personality type who prefer a withdrawn and avoidant coping mechanism are at greater risk of burden [22]. The caregiver's burden is also related to a feeling of lack of support [23, 24, 10], which is compared to attachment, social integration, and social bonds in terms of human needs such as acceptance, security, and belonging [25]. The burden may be related to unrealistic expectations of the caregiver towards the environment and

the lack of skills in setting boundaries in contact with others [26], as well as setting tasks for oneself that exceed the ability to perform them [27].

Another area that generates a burden on the caregiver relates to social life resulting from the limitation or even isolation from relatives and/or friends, lack of free time and deprivation of intimacy [13]. The nature of the caregiving role, the interpersonal relationship between the caregiver and the patient [14], including the desire to pass on care, shame and growing tension in the family [13] and responsibility [13]. It should be noted that the experience of disease is always individual, which is why closeness and bonds between the patient and the caregiver are so important [4, 17].

The burden on the caregiver is also due to the level of knowledge [11] and the lack of preparation for caregiving [23, 24], lack of support and indifference from medical personnel, lack of understanding for their situation [13], lack of knowledge about support programs and services [5], difficulties in obtaining information about the functioning of aid institutions, available benefits and rights [3] and the style of care provided [6–8].

It is worth keeping in mind that caregivers also feel burdened even though their loved ones are being cared for in professional facilities [28].

Objective

The aim of this study was to identify selected determinants of the burden on caregivers of people with multiple sclerosis.

Material and Methods

The study group consisted of 107 caregivers. The research was conducted at the Helpful Hand Foundation in Cracow, the Department of Neurological Rehabilitation with the Sub-Department of Systemic Rehabilitation of the L. Rydygier Specialist Hospital in Cracow and the Department of Neurology with the Sub-Department of Stroke of the John Paul II Provincial Hospital of the Subcarpathian Region in Krosno. The Bioethics Committee granted its approval for the study (no. 176/KBL/OIL/2018).

A diagnostic survey method was applied using the Caregiver Burden Scale — CBS (evaluation of the burden in subscales: general burden/general effort, social isolation, disappointment, emotional involvement and environment in terms of the level of burden [29], Guy's Neurological Disability Scale GNDS (determination of the disability level and level of functioning of a person suffering from multiple sclerosis in various aspects supplemented by an interview [30], Berlin Social Support Scales BSSS (survey of support in various aspects) [31]. Antonovsky's SOC-29 Life Orientation Questionnaire (measuring the general sense of coherence and its components: sense of comprehensibility, manageability and meaningfulness) [25] and the author's questionnaire survey (socio-demographic data of the caregiver, problems in the relationship with the person under care, need for support and those characterizing the course of MS in a relative).

General characteristics of the study group

The survey was conducted among 107 caregivers of people with multiple sclerosis. 51.4% (N = 55) of the participants were women and 48.6% (N = 52) were men. Caregivers aged 60 and over accounted for 44.9% of the total number of respondents, while 22.4% of the respondents

were aged 40–49 and 17.8% were aged 50–59. The smallest group were respondents under 40 (14.9%). The majority of them were city dwellers (60.7%). The surveyed group was dominated by people in a marriage/partnership relationship (66.4%). People with secondary education dominated among the group of caregivers (47.7%). More than half of the caregivers (63.6%) did not work. In the opinion of 78.5%, the income they had was insufficient. Most of the caregivers lived with the person with MS and other family members in a shared household. The duration of the disease varied: over 20 years (62.6%), between 11 and 20 years (26.2%), and less than 10 years (11.2%). The average duration of the disease was 23.86 years. The duration of caring for the ill person ranged from 5 to 45 years. 66.4% of the respondents confirmed that they had been providing care for more than 15 years. The average duration of care provided by the surveyed caregivers was 18.28 years. The vast majority of caregivers provided care for relatives who were not independent (88.8%). Secondary progressive MS was diagnosed in 56.1% of the individuals, while primary progressive MS was diagnosed in 29.9%. A relapsing-remitting course was confirmed in 14.0%.

The study showed that the greatest difficulties for caregivers in providing care were related to the clinical picture of MS in their loved ones: difficulty walking (93.5%), spasticity and tremor (86.0%), sensory disturbances (84.1%) and sphincter disturbances (84.1%). Other reasons include a lack of self-care (82.2%) and the patient's fear of a deterioration in their quality of life (79.4%). The caregivers admitted that they experience difficulties in accessing rehabilitation and health resort treatment for MS patients (40.2%).

In the surveyed group, 91.6% of caregivers admitted that they felt burdened by caregiving, and their subjective sense of burden increased with the progression of disease (94.4%). Caring for a sick person contributed to a reduced ability to take care of own health (35.5%), a deterioration of the relationship with other family members (20.6%), a lack of active leisure and relaxation (15.9%) and the inability to take up gainful employment (11.2%). The caregivers also admitted to experiencing biological problems (96.3%): fatigue, deterioration of physical condition, insufficient amount of sleep, social problems (77.6%): loss of ties with other family members and social contacts, restrictions on the use of cultural goods, and psychological problems (73.8%): apathy, depressed mood, and difficulties in maintaining mental hygiene. 86.9% of caregivers expressed the need for support. The respondents expected help from a medical professional/disability assistant (69.2%), a spiritual advisor/volunteers (46.7%), and a psychologist (39.3%). The respondents also found the following to be helpful: physicians/rehabilitators, nurses (86.9%), friends/neighbors (69.2%), and family (18.7%). The caregivers expected better availability of rehabilitation for the sick (88.8%) and drew attention to the need for nursing and care services guaranteed as a part of primary health care (37.4%), the need to improve access to treatment (19.6%) and instrumental support (96.3%), information (90.7%) and material (75.7%) support from local government institutions.

Results

Burden on caregivers

High levels of caregiver burden were observed in all subscales. Caregiver burden was high (Table 1).

Table 1. Caregiver burden according to the CB Scale.

Subscale	RESULTS OF THE CAREGIVER BURDEN SCALE							
	N	x	SD	Me	Min	Max	Q1	Q3
Overall burden	107	3.38	0.67	3.50	1.25	4.00	3.25	3.88
Disappointment	107	3.47	0.74	3.80	1	4.00	3.40	4
Emotional involvement	107	3.2	0.97	3.67	1	4.00	2.67	4.0
Environment	107	3.46	0.74	3.67	1	4.00	3.33	4.0
Social isolation	107	3.38	0.87	3.67	1	4.00	3.00	4.0

Legend: N — number of observations; x — arithmetic mean; SD — standard deviation; Me — median; Min. — minimum; Max. — maximum; Q1 — lower quartile; Q3 — upper quartile.

Functioning of people with multiple sclerosis and caregiver burden in relationship to caregiving

A statistically significant correlation was found between the functioning of MS patients and the burden on caregivers in the subscales: social isolation (R = 0.27; p = 0.0043), disappointment (R = 0.22; p = 0.0256) and emotional involvement (R = 0.28; p = 0.0030). The patients' deteriorating functioning deepened their sense of social isolation, disappointment and emotional involvement (Table 2).

Table 2. Functioning of patients with MS and caregiver burden.

	Scale	Subscale	N	R	t(N-2)	p
Guy's scale Total	CB — Scale	Overall burden	10	0.15	1.56149	0.1214
		Social isolation	107	0	2.91764	**0.0043**
		Disappointment	107	0.22	2.26429	0.0256
		Emotional involvement	107	0	3.03879	**0.0030**
		Environment	107	0.10	1.08153	0.28

Legend: Guy Scale — Guy Hospital Neurological Disability Scale; CB–Scale — Caregiver Burden Scale; N — number of observations; R — Pearson's correlation coefficient; t(N-2) — significance test; p — statistical significance.

A statistically significant relationship (p <0.05) was found between the patients' speech and communication problems and the caregivers' burden in the social isolation (R = 0.225; p = 0.020) and disappointment (R = 0.199; p = 0.040) subscales. The burden in these dimensions was greater the more the symptoms intensified. A difference was also shown between the emotional involvement of the caregiver and the swallowing problems of the patients (R = 0.192; p = 0.047) — increasing swallowing problems increased the burden on caregivers in this respect. A statistically significant correlation occurred between the subscales: general burden (R = 0.206; p = 0.034), social isolation (R = 0.230; p = 0.017), emotional involvement (R = 0.246; p = 0.011) and environment (R = 0.212; p = 0.028) and the functioning of the patients' upper limbs. The progression of

this disability was related to an increase in the overall burden and, in the subscales, social isolation, emotional involvement and environment. The progression of the patients' lower limb disability caused an increase in the burden on caregivers in the areas of social isolation (R = 0.244; p = 0.011) and emotional involvement (R = 0.258; p = 0.007); its aggravation increased the above-mentioned dimensions of caregiver burden. More frequent bladder problems in patients reduced the overall burden (R = –0.228; p = 0.018) and the environmental dimension (R = –0.236; p = 0.014). In contrast, intensifying intestinal problems increased the burden on caregivers in terms of social isolation (R = 0.229; p = 0.018), emotional involvement (R = 0.243; p = 0.012) and the environment (R = 0.212; p = 0.028) (Table 3).

Table 3. Functioning of patients with multiple sclerosis according to the Guy Scale and caregiver burden according to the CB Scale.

Guy Scale	CB Scale	N	R	t(N-2)	p
Speech and communication problems	Overall burden	107	0.044	0.449	0.654
	Social isolation	107	0.225	2.368	**0.020**
	Disappointment	107	0.199	2.082	**0.040**
	Emotional involvement	107	0.186	1.937	0.055
	Environment	107	0.062	0.637	0.525
Swallowing problems	Overall burden	1	0.043	0.440	0.661
	Social isolation	107	0.186	1.945	0.054
	Disappointment	107	0.079	0.813	0.418
	Emotional involvement	107	0.192	2.008	**0.047**
	Environment	107	–0.047	–0.482	0.631
Upper limb disability	Overall burden	107	0.206	2.153	**0.03**
	Social isolation	107	0.230	2.419	**0.017**
	Disappointment	107	0.170	1.772	0.079
	Emotional involvement	107	0.246	2.601	0.011
	Environment	107	0.212	2.228	**0.028**
Lower limb disability	Overall burden	1	0.129	1.333	0.185
	Social isolation	107	0.244	2.580	**0.011**
	Disappointment	107	0.179	1.867	0.065
	Emotional involvement	107	0.258	2.740	**0.007**
	Environment	107	0.101	1.039	0.301
Bladder problems	Overall burden	1	–0.228	–2.399	**0.018**
	Social isolation	107	–0.127	–1.314	0.192
	Disappointment	107	–0.040	–0.413	0.681
	Emotional involvement	107	–0.133	–1.373	0
	Environment	107	–0.236	–2.491	**0.014**

Table 3. Cont.

Guy Scale	CB Scale	N	R	t(N-2)	p
Intestinal problems	Overall burden	107	0.177	1.841	0.068
	Social isolation	107	0.229	2.413	**0.018**
	Disappointment	107	0.090	0.921	0.359
	Emotional involvement	107	0.243	2.563	**0.012**
	Environment	107	0.212	2.228	**0.028**

Legend: Guy Scale — Guy Hospital Neurological Disability Scale ; N — number of observations; R — Pearson's correlation coefficient; t(N-2) — significance test; p — statistical significance.

Support for caregivers and their burden with regard to caregiving

The perceived decreasing availability of support contributed to an increase in the burden on caregivers in terms of general burden (R = –0.43; p = 0.0000), social isolation (R = –0.54; p = 0.0000), disappointment (R = –0.43; p = 0.0000), emotional involvement (R = –0.54; p = 0.0000) and environment (R = –0.19; p = 0.0498). The greater the caregivers' search for support, the greater the overall burden (R = 0.20; p = 0.0365), social isolation R = 0.35; p = 0.0003), disappointment (R = 0.29; p = 0.0021) and emotional involvement (R = 0.43; p = 0.0000). The current support provided correlated with the caregivers' burden in terms of general burden (R = –0.24; p = 0.0123), emotional involvement (R = –0.22; p = 0.0258) and environment (R = –0.19; p = 0.0460). An increase in the support currently provided resulted in lower burdens in the above areas. General burden on caregivers (R = –0.30; p = 0.0017), social isolation (R = –0.21; p = 0.0268), emotional involvement (R = –0.28; p = 0.0034) and environmental burden (R = –0.24; p = 0.0148) increased along with the decrease in the support currently received. The need for support and the need for buffering and protective support did not show statistical significance in terms of the burden on caregivers (Table 4).

Table 4. Caregivers' social support according to BSSS and burden according to CB Scale.

BSSS Scale	CB Scale	N	R	t(N-2)	p
Perceived available support	Overall burden	107	–0.43	–4.84951	0
	Social isolation	107	–0.54	–6.49438	0
	Disappointment	107	–0.43	–4.82051	0
	Emotional involvement	107	–0.54	–6.57693	0
	Environment	107	–0.19	–1.98501	0.049
Support requirement	Overall burden	1	0.07	0.69245	0.490
	Social isolation	107	0.02	0.22556	0.8220
	Disappointment	107	0.17	1.77773	0.0783
	Emotional involvement	107	0	0.86639	0.3883
	Environment	107	0.11	1.14658	0.2542

Table 4. Cont.

BSSS Scale	CB Scale	N	R	t(N-2)	p
Seeking support	Overall burden	1	0.20	2.11792	0.0365
	Social isolation	107	0.35	3.78543	0.0003
	Disappointment	107	0.29	3.15407	0.0021
	Emotional involvement	107	0.43	4.91431	0
	Environment	107	0.17	1.81116	0.0730
Current support	Overall burden	10	–0.24	–2.54835	0
	Social isolation	107	–0.12	–1.26184	0.209
	Disappointment	107	–0.13	–1.36232	0.1760
	Emotional involvement	107	–0.22	–2.26146	0.0258
	Environment	107	–0.19	–2.01948	0.0460
Current support received	Overall burden	107	—	–3.22293	0
	Social isolation	107	–0.21	–2.24583	0.026
	Disappointment	107	–0.17	–1.75772	0.0817
	Emotional involvement	107	–0.28	–2.99802	0
	Environment	107	–0.24	–2.47916	0.0148
Buffering and protective support	Overall burden	1	0.10	1.04078	0.300
	Social isolation	107	0	0.81605	0.4163
	Disappointment	107	0	1.07698	0.2840
	Emotional involvement	107	0	0.56002	0.5767
	Environment	107	0.01	0.12226	0.9029

Legend: BSSS — Berlin Social Support Scale; CB–Scale — Caregiver Burden Scale; N — number of observations; R — Pearson's correlation coefficient; t(N-2) — significance test; p — statistical significance.

Caregivers' sense of coherence and their burden with regard to caregiving

Statistically significant negative correlations were found between the sense of comprehensibility and the general burden (R = –0.43; p = 0.0000), social isolation (R = –0.31; p = 0.0012), disappointment (R = –0.29; p = 0.0025), emotional involvement (R = –0.33; p = 0.0005) and environment (R = –0.42; p = 0.0000). A decreasing sense of comprehensibility resulted in an increase in the burden on caregivers. The caregivers' reduced sense of controllability exacerbated their burden in the general area (R = –0.48; p = 0.0000), social isolation (R = –0.38; p = 0.0001), disappointment (R = –0.38; p = 0.0000), emotional involvement (R = –0.46; p = 0.0000) and environment (R = –0.42; p = 0.0000). A decreasing sense of meaningfulness increased the caregiver's burden in general (R = –0.33; p = 0.0005), social isolation (R = –0.22; p = 0.0201), disappointment (R = –0.31; p = 0.0010), emotional involvement (R = –0.21; p = 0.0314) and environment (R = –0.40; p = 0.0000) (Table 5).

Table 5. Life orientation of caregivers according to SOC-29 and burden according to CB Scale.

SOC-29 Subscale	CB Scale	N	R	t(N-2)	p
Comprehensibility	Overall burden	107	–0.43	–4.85765	0
	Social isolation	107	–0.31	–3.32294	0.0012
	Disappointment	107	–0.29	–3.09901	0.0025
	Emotional involvement	107	–0.33	–3.60447	0.0005
	Environment	107	–0.42	–4.78611	0
Controllability	Overall burden	107	–0.48	–5.53896	0
	Social isolation	107	–0.38	–4.19359	0.0001
	Disappointment	107	–0.38	–4.26223	0.0000
	Emotional involvement	107	–0.46	–5.31702	0
	Environment	107	–0.42	–4.73287	0
Relevance	Overall burden	107	–0.33	–3.57168	0.0005
	Social isolation	107	–0.22	–2.36099	0.0201
	Disappointment	107	–0.31	–3.38955	0.0010
	Emotional involvement	107	–0.21	–2.18177	0
	Environment	107	–0.40	–4.41831	0

Legend: SOC-29 — Life Orientation Questionnaire; CB-Scale — Caregiver Burden Scale; N — number of observations; R — Pearson's correlation coefficient; t(N-2) — significance test; p — statistical significance.

A lower life orientation exacerbated the overall burden (R = –0.45; p = 0.0000), social isolation (R = –0.36; p = 0.0001), disappointment (R = –0.38; p = 0.0000), emotional involvement (R = –0.39; p = 0.0000) and environment (R = –0.43; p = 0.0000) (Table 6).

Table 6. Overall result of caregivers' sense of coherence according to SOC-29 and burden according to CB Scale.

SOC-29	CB Scale	N	R	t(N-2)	p
Total	Overall burden	107	–0.45	–5.18106	**0.00**
	Social isolation	107	–0.36	–3.97833	**0.0001**
	Disappointment	107	–0.38	–4.23612	**0.00**
	Emotional involvement	107	–0.39	–4.28412	**0**
	Environment	107	–0.43	–4.86050	**0**

Legend: SOC-29 — Life Orientation Questionnaire; CB-Scale — Caregiver Burden Scale; N — number of observations; R — Pearson's correlation coefficient; t(N-2) — significance test; p — statistical significance.

Discussion

In the course of multiple sclerosis and progressive disability, it becomes necessary to provide the patient with constant care. Family members often take on the role of informal caregivers. Taking on the role of a caregiver is related to a deterioration of functioning in the bio-psycho-social dimension, and therefore the evaluation of factors conducive to this phenomenon should be a permanent part of the activities of professionals caring for a patient with MS in order to provide adequate support to caregivers.

Burden on caregivers of people with chronic diseases, including multiple sclerosis

Caring for a relative involves the carer in daily assistance, support and confrontation with the burden that arises [32, 33]. Studies confirm a significant correlation between the active care of chronically ill persons and the burden on caregivers [10, 34–39].

The studies conducted in this area included various variables, such as the duration and extent of care, relationship to the ill person, economic situation, course and knowledge of the disease, and the availability and quality of institutionalized care. The aspect of care duration proved to be diverse. Krawczyk-Wasilewska *et al.* showed that the average duration of care for people with dementia was between 5.8 and 3.6 years [38], and in the study by Niedorys *et al.*, care for the elderly lasted an average of 7.74 years [40]. Caregivers of patients in long-term home care provided care for an average of 8.4 years [39]. In comparison, the average duration of care for people diagnosed with malignant disease was between 14.6 and 10.5 months [41]. Algahtani *et al.* showed that care for multiple sclerosis patients lasted from 1 year to 30 years. [42], while caregivers of people with MS participating in the Petrikis study reported that the average duration of caregiving was 10.0–6.3 years [43]. The results of our own research showed that the average time of caring for the patients was 18.28 years.

In the presented study, most caregivers lived with the ill person and other family members, and the caregivers were mainly spouses or people in a relationship. In comparison, the caregivers in the study conducted by Algahtani *et al.* were mainly immediate family members (spouses — the most burdened, siblings, parent and child of the patient, or a second-degree relative). It is worth emphasizing that in Asian culture, family social support is more visible than in European countries [42].

Kosińska *et al.* drew attention to the economic factor affecting the burden on caregivers [44]. Similar conclusions regarding the deterioration or loss of material (financial) resources due to care were presented by Tobiasz-Adamczyk [45]. The research results of Garcia-Dominguez *et al.* conducted among caregivers of MS patients confirmed the impact of the economic factor on the caregiver burden [46]. Some studies have shown that free healthcare may not be sufficient and that caring for a patient can be difficult for financial reasons [42], and according to some, income level had no correlation with quality of life and caregiver burden [43]. Unfortunately, the results of our own research showed that the caregivers' income was insufficient and showed a trend in which admitting insufficient income was associated with higher emotional involvement. According to Stenberg *et al.* and Negri *et al.*, the burden on caregivers is related to the direct care of a chronically ill person, which includes: dressing, washing, feeding, grooming, providing support in coping with changing feelings and experiencing fear of a deterioration in the quality of life [47, 48]. The results also indicate a lack of knowledge about the nature of disease as a factor that may affect the

burden on caregivers of people with MS [49]. According to other studies, also among caregivers of people with multiple sclerosis, self-care deficits, spasticity and muscle tremors, walking difficulties, pain and anxiety of the patient due to the increasing deterioration of the quality of life, as well as sensory disturbances, caused difficulties in the provision of care [50]. Our own research has shown that the majority of patients were diagnosed with secondary progressive multiple sclerosis, characterized by widespread walking difficulties, spasticity, tremors, sensory and sphincter disorders, and self-care deficits, which made it difficult for caregivers to care for the patient. It was observed that caregivers of patients with relapsing-remitting multiple sclerosis were more burdened compared to caregivers of patients with other forms of MS. The results of our own research also confirmed that caregivers felt an increase in burden as the patient's multiple sclerosis progressed.

Recently, attention has been drawn to the psychological issues that caregivers [51] and people with multiple sclerosis [52, 53] may experience. Bisschop *et al.* have shown that the future of people suffering from MS and their caregivers is unpredictable and uncertain [54], and this feeling particularly affects caregivers of patients with relapsing-remitting multiple sclerosis [55]. The fears accompanying the caregivers make it difficult to implement short- and long-term plans [56, 57], and the feeling of anxiety increases their burden [51, 57]. According to Ocetkiewicz, caregivers forgot about their needs while devoting their time and energy to the ill person [58]. The results of study conducted by Petrikis *et al.* proved that increasing fatigue, stress and depression deteriorated the psychophysical condition of caregivers [43]. Moreover, other caregivers declared that they wanted to escape the situation they found themselves in or admitted to feeling defeated in terms of self-fulfillment or realizing their professional plans and failure in providing care, as well as to sleep disorders, fatigue, weakness and headaches [59]. In our own research, caregivers declared that they experienced biological, social and psychological problems while caring for a loved one. It should be emphasized that the problems of caregivers of people with MS, as well as caregivers of people with other chronic conditions, such as: stroke [60, 61], Parkinson's or Alzheimer's disease [62, 63], bipolar disorder, mental disorders such as schizophrenia [64] or Huntington's disease [39] are similar.

The results of our own research confirmed that the burden on caregivers is high. By comparison, the burden on caregivers in one Turkish study also indicated a high level [65]. In contrast, one study in Saudi Arabia showed that more than half of the caregivers reported little or no burden in relation to the care provided [42]. A high level of burden in relation to caregiving was also present among caregivers of patients with Alzheimer's dementia [66]. Kuźmicz *et al.* showed a moderate level of burden among caregivers actively caring for their loved ones in hospice, in all subscales except for emotional involvement [67]. The results of studies by Bayen *et al.* and Santos *et al.* showed the burden on caregivers of independent MS patients, and caregivers reported anxiety, feeling overwhelmed from the moment of diagnosis, and expressed concern about the unpredictability of disease and prognosis [68, 69]. In our own studies, a greater burden was observed in the caregivers of independent patients.

Domaradzki drew attention to the difficulties associated with the availability and quality of medical care provided and the lack of support from medical or social organizations [39]. Other authors emphasized the need to create specialized medical centers with a multidisciplinary approach focused on the patient and caregiver, as well as the insufficient number of support groups for caregivers and patients [42]. Studies by Buchanan *et al.*, Roth *et al.*, and Bayen *et al.* have shown that support for caregivers cannot be limited to information about the causes and symptoms of MS. It is crucial to provide information about caregiving and care planning, rehabilitation,

assistance in reaching a specialist, finding effective strategies for coping with stress, and the ability to seek and accept support. It seems that directing caregivers to use temporary alternative care is the right approach [68–71]. The results of our own research showed that caregivers paid attention to the improvement in access to treatment and rehabilitation.

Functioning of people with chronic diseases, including multiple sclerosis, and caregiver burden

Multiple sclerosis causes loss of fitness and leads to disturbances in daily functioning, as confirmed by the research results conducted by Rybka *et al.* [72]. A study by Dymecka *et al.* showed that the main symptom in patients was fatigue, followed by problems with bladder and lower limb function as well as sexual function. Less common were problems regarding emotional state, upper limb disability, intestinal problems and cognitive functions. The least common were problems with swallowing, speech and vision [73]. According to Maguire *et al.*, the burden on caregivers increased with the severity of the patients' disabilities, the clinical symptoms of MS and the progression of disease. The burden on caregivers was higher among those caring for patients with secondary and primary progressive multiple sclerosis [74]. The results of studies conducted by Petrikis *et al.*, Bayen *et al.* and Katsavos *et al.* also showed an increase in the burden on caregivers with the progression of disability [43, 68, 75]. Studies by Fidecki *et al.* and Bartoszek *et al.* have shown that the burden on caregivers and lower satisfaction with care result from the deterioration of the mental and functional abilities of patients [76, 77]. In comparison, the participants in the study by Deluge *et al.* — caregivers of chronically ill people in long-term care — were more overburdened due to the deterioration of mental and functional capacity of the patients [78], and as presented by Niedorys *et al.*, the deteriorating functional capacity of the elderly significantly increased the burden on informal caregivers [40]. Grochowska reports that caregivers of chronically ill people with low levels of fitness were burdened [79]. Better mental fitness and higher functional fitness of the chronically ill patients translate into less burden on caregivers and better quality of their lives [80]. Own research has shown that the deteriorating functioning of patients caused burden on caregivers in the area of emotional involvement, disappointment and social isolation.

Caregivers' sense of coherence in caring for people with chronic diseases, including multiple sclerosis

Taking care of a chronically ill person contributes to long-term stress, burden, decreased self-efficacy [81] and a sense of life orientation [82]. A sense of coherence is a kind of buffer in the confrontation with a stress-inducing stimulus [81].

The level of sense of coherence and burden has also been the subject of research among professional caregivers. One study among nurses confirmed that a high sense of coherence facilitated engagement in care, use of effective coping strategies, seeking support, and reduced burden and stress [source]. Other studies, including among nurses, have confirmed the significant relationship between life orientation and a positive attitude towards work. An increase in the sense of coherence allowed the perception of work as less burdensome and more satisfying [83]. In comparison, among social workers, an increase in the sense of coherence improved job satisfaction and decreased burnout [84], and in the group of volunteers, an increase in the overall sense of coherence and higher values in the components of resourcefulness and meaningfulness strengthened

the sense of effectiveness in helping [81]. The results of our own research confirmed the low level of sense of coherence among caregivers. It was shown that as the caregivers' life orientation decreased, the general burden, social isolation, disappointment, emotional involvement and the environment increased. Perhaps the low life orientation resulted from the caregivers' belief in a permanent disability of their loved ones, the prospect of constant, long-term care, the stress experienced, and the negative emotions experienced by the patient. In comparison, Grabowska-Fudala *et al.* presented results showing a high level of coherence among caregivers of stroke patients, which reduced their level of burden experienced by them [85].

Social support for caregivers of people with chronic illnesses, including multiple sclerosis

Social support has a positive effect on health and well-being, improves the ability to cope with difficult situations, reduces exposure to setbacks and acts as a buffer. For caregivers of chronically ill people, social support means closeness and help from others, providing a sense of security. In contrast, a lack of support and feelings of loneliness increase the risk of burden, burnout [86], depressive disorders or mood deterioration in caregivers [87]. Studies conducted by Cummings *et al.* and Sullivan *et al.* indicated the protective function of social support in maintaining mental and somatic health [88, 89] and emphasized that the burden on the caregiver results from the responsibilities assumed and mobilizes new resources, such as support [90]. According to Kobelt *et al.*, it is crucial to identify the type of social support that caregivers would like to receive in order to reduce their burden [91]. It turns out that one of the desired forms of social support is contact with people outside the family and medical staff [47]. Caregivers participating in the research of Kosińska *et al.* in a crisis situation, apart from qualified medical personnel, asked for and received support from friends and neighbors [44]. On the other hand, the results of the Mazurkiewicz *et al.* study showed that although support from friends is desirable and important, it is nevertheless insufficient and unsatisfactory for caregivers [92]. Basińska *et al.* showed that a higher level of social support reduced the fatigue of caregivers of people with Alzheimer's disease. The perceived and received social support allowed for a positive assessment of the experience of caring for a chronically ill person and compensated for the emotional costs of caregiving [93]. In comparison, caregivers of people with Parkinson's disease needed support in the form of access to a specialist physician, speech therapist, and physiotherapist [94]. The caregivers participating in the study also emphasized the support provided by the healthcare system (improved access to rehabilitation, nursing and care services, treatment programs and specialist care under the contract with the National Health Fund). Therefore, it seems reasonable for legislative, executive and local government bodies to take initiatives aimed at improving the system of care for people in need. Our own research has confirmed the burden on caregivers as a result of perceived decreasing availability of support and the support they currently receive. Consequently, it seems reasonable to create support groups for caregivers, facilitate access to information about institutionalized care, and raise public awareness of the role of family caregivers in the healthcare system.

Social support among people with MS can also be provided through information technology. Caregivers created online support groups where online interactions reduced their burden and sense of loneliness [95]. Support using social media can be particularly helpful for caregivers who, for various reasons, are physically isolated from their surroundings. An example of this are the circumstances resulting from the COVID-19 pandemic. It is highly likely that the experience of isolation has been a burden on caregivers [96]. The results of our own research confirmed the need

for support among the vast majority of caregivers and for assistance from the healthcare system in the form of improved access to rehabilitation for the patients. Respondents indicated the need for support from various professional groups, which was also noted by Domaradzki. The results of a survey of people caring for patients with Huntington's disease emphasize the role of social workers, disability assistants and psychologists [39]. Therefore, the postulate of Rachel *et al.* is justified, emphasizing the importance of psychological assistance for caregivers and understanding their needs in order to facilitate their care for the chronically ill [84].

Social support minimizes the experience of burnout or depression among caregivers of people with multiple sclerosis, as well as among caregivers of people with dementia, as confirmed by the studies of Dayapoglu *et al.* and Safavi *et al.* [90, 97].

Research has been and continues to be conducted on the burden of informal caregivers in the care of chronically ill patients, including those with MS [43, 65–67, 78]. This issue is still relevant and important, and the evaluation of the caregiver's burden should be a standard procedure for the therapeutic team when providing services to patients in order to ensure their care and support. The role of informal caregivers is crucial in filling the gaps left by the healthcare system [98–100].

Conclusions

1. Caregivers of people with multiple sclerosis presented a high level of burden in the areas of social isolation, disappointment and emotional involvement as a result of low life orientation and a reduction in the functional ability of the patients.
2. A decrease in perceived available support resulted in an increase in the burden on caregivers in terms of general burden, social isolation, disappointment, emotional involvement and environment. The greater the caregivers' search for support, the greater the general burden, social isolation, disappointment and emotional involvement. The current support provided caused stress in the caregivers in terms of general burden, emotional involvement and environment. The lack of support currently received did not affect the caregivers in the disappointment subscale.
3. The stress of caregivers of people with MS was determined by their low life orientation.

Contribution statement

Research design: E.S., A.G.; Analysis and writing the article: E.S., K.W., A.G.; Critical evaluation: E.S., A.S.; Literature research: E.S., K.W.; Statistical analysis: P.J.

Conflict of interest

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