Chapter 2

Assessment of selected types of support and their importance for the quality of life of carers of people after ischemic stroke

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Abstract
Introduction: Informal carers of people who have had an ischemic stroke constitute one of the pillars of the state's welfare system. Individual social support can help solve carers' health problems and improve their quality of life. The aim of the presented research was to assess selected social services and indicate the importance of this support for self-assessment of their quality of life.
Material and methods: Research material included the results a diagnostic survey obtained from 39 informal caregivers of people who had suffered an ischemic stroke. The Berlin Social Support Scales and the WHOQOL-Bref quality of life questionnaire were used. The statistical analysis was carried out with the use of SPSS Statistics 24.0 software.
Results: When better support is perceived by the guardian, this correlates with higher quality of life in the social (r = 0.31) and environmental (r = 0.32) spheres. Better currently received support correlates with higher quality of life in the psychological (r = 0.32) and environmental (r = 0.36) spheres.
Conclusions: 1. Social support is important for carers' perceived satisfaction with their quality of life; 2. Satisfaction with personal functioning facilitates essential activities for providing competent care.
Key words: informal care, stroke, social support, quality of life

Introduction

Family carers are the main pillar of the state's welfare system [37]. The advantages of the care they provide pertain to the close relationship between them and their patients, which is normally characterized by mutual trust and a high level of involvement in the procedures and day-to-day life of the patients. What is also important is the closeness of caregivers, their availability, and the on-going possibility to identify needs or evaluate actions undertaken for their patients. On the other hand, this type of care is a difficult physical and emotional experience for the caregiver. The lack of interdisciplinary support staff that would enable more effective caregiving at home may be the cause of negative psychophysical experiences among this group of people. Caregiver Stress Syndrome (CSS) has been known for a long time; its symptomatology is varied and relates to the emotional and mental situation (Figure 1).
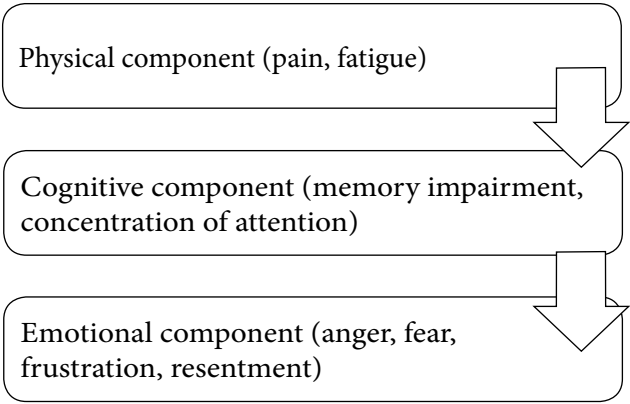
Physical component (pain, fatigue)

Cognitive component (memory impairment, concentration of attention)

Emotional component (anger, fear, frustration, resentment)

Figure 1. Components of a Caregiver's Stress Team [38]

English-language literature defines family caregivers as *"forgotten patients"* due to the fact that the health status and quality of life of the caregiver negatively changes in response to their duties [39]. So, how do you counteract the difficulties that arise in the life of the caregiver of a chronically ill person? How to reduce the risk of health problems and

poor quality of life? It seems that one answer to these questions may be social support. This is defined as a kind of social interaction undertaken by one or many participants in a problematic, difficult or critical situation. Emotions, information, instruments of action and material goods are transferred or exchanged in the course of this interaction. Support itself does not have a positive meaning if it is not adapted to the needs and expectations of the people who should benefit from it. There is evidence that constant support can shape an attitude of dependence and learned helplessness which limits the carer's adaptability and can even make them feel unwell [40].

Aim

The aim of the presented research was to assess selected aspects of social support received by carers of people after an ischemic stroke, and to indicate the importance of this support for self-assessment of their quality of life.

Materials and Methods

The study group consisted of 39 people who directly looked after ischemic stroke patients. The study was cross-sectional and self-descriptive. The diagnostic survey method and the estimation method were used. The main research tools were standardized, including the WHO QOL-Bref Questionnaire and the Berlin Social Support Scales (BSSS).

The World Health Organization Questionnaire – The World Health Organization Quality of Life-BREFF (WHOQOL-BREFF) is a universal tool for assessing the quality of life of healthy and sick people for cognitive and clinical purposes. It contains 26 questions which analyze four areas of life: physical, psychological, social, and environmental. The questionnaire also includes two questions that are analyzed separately: a question about the carer's general perception of their quality of life, and a question about

their perception of their own health. Question scoring is in the range from 1 to 5 and has a positive direction: the higher the number of points, the better the quality of life [41]. The Polish version of the Berlin Social Support Scale (BSS Berlin Social Support Scale) consists of 8 items, to which the respondent responds on a 4-point Likert scale. The higher the score, the higher the level of social support [42]. For the purposes of the research objective, the results obtained in the following BSSS subscales were statistically analyzed:

1. perceived available support (assessment of the availability of assistance from other people),
2. demand for support (the need to use support in a difficult situation),
3. seeking support (frequency or extent of seeking help from others),
4. currently received support (perceived assistance provided by others for persons receiving support).

In addition, the survey used its own questionnaire regarding subjective opinions on support; a socio-demographic data sheet was also used.

Statistical analysis

Statistical analysis of the results was carried out using SPSS Statistics 24.0. The following descriptive statistics were calculated for the examined variables: average (M), standard deviation (SD), minimum value (Min.) and maximum value (Max.). Normal distribution of results was confirmed by the Shapiro-Wilk test. The correlation between the variables was evaluated using Pearson correlation(r) and Kendall's tau-b. The significance of the results was assumed at the level of $\alpha = 0.05$.

Results

Characteristics of the studied group

The respondents were aged 22–78 (M = 52.31; SD = 15.11): women (71.8%), married persons (84.4%), higher education (41%), resident of

a large city (74.4%) in the Lesser Poland voivodship (76.9%) and working full time (53.8%).

Table 1. Socio-demographic characteristics of the study group

Feature	Answer	n	%
Sex	Female	28	71.8%
	Male	11	28.2%
Marital status	Married	33	84.6%
	Single	3	7.7%
	Widowed	1	2.6%
	Informal relations	2	5.1%
	Divorced	0	0.0%
Education	Primary	1	2.6%
	Vocational	8	20.5%
	Secondary education	14	35.9%
	Higher	16	41.0%
Inhabitancy	Small city (up to 100,000 citizens)	6	15.4%
	Large city (over 100,000 citizens)	29	74.4%
	Rural area	4	10.2%
Voivodship	Lesser Poland	30	76.9%
	No data	9	23.1%
Profession	Full time	21	53.8%
	Part time	3	7.7%
	Contract	1	2.6%
	Pension	1	2.6%
	Retired	12	30.8%
	Others	1	2.6%

Experiences related to caring for a sick person

Guardians most often looked after a spouse (33.3%) or a parent (25.6%); care was less often provided for a child (17.9%) or another family member (17.9%), i.e. siblings, mother-in-law, niece, grandson. The vast majority of the carers (92.3%) had no previous experience in caring for a person after a stroke. Caregivers, due to the current health condition of a loved one, most often felt slight (48.7%) or strong fear (30.8%) of suffering from a stroke (Table 2).

Table 2. Structure of experiences related to caring for a sick person

Experience	Answer	*n*	%
Relationship with the sick person	Husband/wife	13	33.3%
	Child	7	17.9%
	Sibling	2	5.1%
	Parent	10	25.6%
	Partner	1	2.6%
	Niece	1	2.6%
	Mother-in-law	2	5.1%
	Grandson	3	7.7%
Is it the first person in a family after a stroke to be taken care of?	Yes	36	92.3%
	No	3	7.7%
Do you feel a fear of a stroke associated with the illness of a loved one ?	Yes, to a large extent	12	30.8%
	Yes, to a small extent	19	48.7%
	No fear	8	20.5%

Sense of support of caregivers

According to the respondents, they received most support from their spouse (66.7%): this was mostly emotional support (53.8%), but what was most needed was actually informational support (69.2%). In their opinion, the support they provide is sufficient (71.8%) for those under their care (Table 3).

To interpret the results obtained in the study using the BSSS scale, descriptive statistics were calculated for each of them. Their analysis indicates that each of the specified types of support was rated highly, although the highest M value (median) was recorded in the currently received support subscale (M = 3.72) (Table 4).

Although self-assessment of the quality of life was not a fundamental goal in the presented material, descriptive statistics that measure this variable are presented in Table 5 for the analysis of the relationship between the quality of life and social support. The obtained values indicate that caregivers rate the social aspects of their quality of life the highest (M = 75.33).

Table 3. Structure of the sense of support of caregivers

Issue	Answer	n	%
Care received from	Husband/wife	26	66.7%
	Children	14	35.9%
	Sister/brother	7	17.9%
	Parents	3	7.7%
	Other relatives	3	7.7%
	Nurses	5	12.8%
	Doctors	4	10.3%
	Partner	0	0.0%
	Friends	1	2.6%
Type of support received	Emotional support	21	53.8%
	Informational support	19	48.7%
	Instrumental support	9	23.1%
	Material support	1	2.6%
	Spiritual support	8	20.5%
Support expected	Emotional support	17	43.6%
	Informational support	27	69.2%
	Instrumental support	13	33.3%
	Material support	5	12.8%
	Spiritual support	6	15.4%
Sufficiency of the support	Yes, and my loved one feels the same	28	71.8%
	Yes, although my loved one does not recognize it often	7	17.9%
	Yes, although I think I should get more	3	7.7%
	No, because whatever I do is not sufficient	1	2.6%

Table 4. Descriptive statistics of self-assessment of selected aspects of the sense of support

	Min	Max	M	SD
Perceived available support	1.00	4.00	3.21	0.61
Demand for support	2.00	4.00	3.21	0.56
Currently received support	2.38	4.00	3.72	0.39
Support sought	2.00	4.00	3.48	0.57

Min / Max – minimum / maximum; M – mean, SD – standard deviation

Table 5. Descriptive statistics of self-assessment of the quality of life of carers of sick people

	Min	Max	M	SD
Somatic domain	44	100	66.74	12.20
Psychological domain	31	94	65.15	15.53
Social domain	44	100	75.33	15.40
Environmental domain	44	94	70.31	11.65

Min / Max – minimum / maximum; M – mean, SD – standard deviation

The relationship between the sense of support and the standard of life of caregivers of ischemic stroke patients showed that a guardian's better perception of the support they receive correlates significantly with higher quality of life in the social (r = 0.31) and environmental (r = 0.32) domains. When better support is currently received, this correlates moderately but significantly with a higher standard of living in the psychological (r = 0.32) and environmental (r=0.36) domains (Table 6).

Table 6. Values of Pearson's correlation between the sense of support and quality of life of carers of ischemic stroke patients

Examined aspects of support	Examined aspects of quality of life			
	Somatic domain	Psychological domain	Social domain	Environmental domain
Perceived available support	0.12	0.25	0.31*	0.32*
Demand for support	-0.09	0.17	-0.07	0.07
Currently received support	0.17	0.32*	0.26	0.36*
Support sought	-0.21	-0.13	0.14	-0.01

$*p< 0.05$

Discussion

Quality of life is a so-called soft assessment indicator and is analyzed with increasing frequency among both the sick and the healthy. For the purposes of this work, quality of life is understood as subjectively felt satisfaction in the context of a person's needs and capabilities [43]. Many

factors determine the degree of this satisfaction: some of them are beyond our control (e.g., age, treatment, place of residence, etc.) or their impact is negligible, while others are can be influenced, for example with social support. Support for the quality of life of carers of ischemic stroke patients plays a protective role. Moreover, it can be identified as one of the important predictors of high quality of life [44]. According to many reports on the quality of life of caregivers of ischemic stroke patients, their quality of life worsens due to the fact that they are fulfilling this role [45]. The aim of the study was to assess the support provided for caregivers of people after ischemic stroke and to analyze the importance of this support for their perceived quality of life. The obtained results indicate that in the self-assessment of caregivers, support is important for their quality of life. A higher assessment of perceived support is significantly associated with better quality of life in the environmental (r = 0.31) and social (r = 0.32) dimensions. Therefore, the presence of people who can be counted on in difficult situations is important in order to satisfy interpersonal relationships, offer a sense of security, develop and implement life passions, and finally provide satisfaction with personal life. The results of a Polish national survey entitled Caregivers of Oncologically and Neurologically Ill Patients (2018) indicate that caregivers often have to consider giving up their life plans and passions (66% of respondents), and even activities such as work or studying (11.9%).

Better currently received support in the form of the presence of a loving person who shows acceptance and care and raises caregivers' self-esteem is crucial for experiencing less negative emotions, higher self-acceptance, and a feeling of meaning in their lives. Undoubtedly, this highly rated psychological aspect motivates further actions, creates new ways of solving problems, counteracts the process of caregiver burnout, and co-determines their emotional condition, which often is subjected to anxiety, sadness, low mood and even sometimes anger towards themselves or their mentees. In a multicenter study, Zysnarska et al. (2010) observed anxiety disorders of varying severity in more than 58% of respondents (caregivers of chronically ill people); depressive mood disorders were observed

in nearly 40% of respondents [46]. Moreover, the results of Cumming et al.'s (2008) study show that an increase in social support is associated with a lower level of anxiety, depression and internal irritability among carers of ischemic stroke patients [47]. There is evidence that a support group is an important tool when coping with home care. The participants of Cumming et al.'s study were diverse in terms of age, gender, social role, and the type and scope of care experience, which is why they become the optimal source of informational and emotional support for each other. Informational support is an exchange of information that aids a better understanding of the situation, the general life situation, and the problem itself. Emotional support is not only about providing positive emotions, it is also about experiencing community and belonging [40].

Condonet et al.'s (2019) study provides interesting information on key areas of interventions that are important for the well-being of the informal caregivers of stroke patients [48]. According to this study, some key interventions that can improve well-being are training to deal with difficult emotions, strategies for taking care of one's own health, or problem-solving skills. The other studied group (the caregivers) also indicates the importance of interventions which focus on their emotional condition, or identifying potential areas in which they need help to cope with the patient's care. Jaracz et al. (2012) adds that professional activities directed to dyads (ischemic stroke patients and their caregivers) should be two-way and aim to increase the patient's independence, while providing caregivers with strategies for coping with stress [49]. The results obtained in the aforementioned 2018 national survey indicate that – apart from informal support received from self-help groups – specialist support from medical staff such as doctors and nurses (47.9% respondents) and psychological support (33% respondents) are also important. [37]. This confirms that nurses are perceived by caregivers as being competent in providing support. The declared need for informational support that is so important in the field of patient care can and should be met by nursing staff because pre- and post-graduate education provides the necessary knowledge and skills. Therefore, using these skills in nursing practice is a way to meet the

reported needs and is a factor that builds nurses' authority and strengthens their position in an interdisciplinary team [50].

Conclusions

1. Adequate Social support for carers of ischemic stroke patients is important for their satisfaction with their quality of life.
2. Satisfaction experienced in the field of personal functioning makes it easier for carers to take actions that are relevant to competent care for the sick.