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Factors Determining the Assessment of Quality of Life Made by Patients Who Have Had a Stroke

Czynniki determinujące ocenę jakości życia dokonaną przez pacjentów, którzy przebyli udar mózgu

Aleksandra Stelmach[1], **Regina Lorencowicz**[2], **Józef Jasik**[2], **Krzysztof Turowski**[2]

[1]Student Medical University of Lublin, Poland
[2]Department of Neurological Nursing, Medical University of Lublin, Poland

Abstract

Introduction. Increasingly, studies relating to the consequences of chronic neurological diseases depart from the principle of exclusively biological evaluation of human health and a more holistic point of view is adopted, in which particural attention is drawn to the emotional experience of patients, their well-being and ability to function in daily life.
Aim. This work aims at analysing the factors determining the assessment of the quality of life made by patients who have had a stroke.
Materials and Methods. The study group consisted of 95 post-stroke patients. The research was carried out by means of: Ferrans & Powers Quality of Life Index — version III, evaluating the overall quality of life and the quality of life in terms of health and functional, socio-economic, psycho-spiritual as well as family aspects. The study also included the Acceptance of Ilness Scale (AIS) and Functional Indicator "Repty".
Results. The studies showed significant ($p=0.006$) differences in the level of acceptance of the disease by respondents with different degrees of functional capacity. As a necessary condition for fulfillment in life, 91.6% of respondents indicated the possibility of work continuing. For 84.20% of respondents good relationships with children were necessary for their fulfilment in life. 80% of the study population included health as an element of basic welfare. For 78.90% of respondents hapiness of their families was necessary to achieve their own happiness, and approximately three-quarters of respondents considered religious practices to be very important for their self-fulfilment (75.80%), health of immediate family (75.80%) and getting rid of chronic pain (74.70%).
Conclusions. 1) The ability to function independently favours the acceptance of the consequences of stroke. 2) The biggest problem with adjusting to the new reality of living with the disease referred to those respondents who were independent but in some activities had to rely on the assistance from others. 3) More than ninety per cent of respondents as a prerequisite for fulfillment in life pointed to the possibility to continue working. 4) The quality of life perceived is drastically reduced in patients who had a stroke within the period ranging from three months to a year before participation in the study. 5) The reduced sense of well-being of the respondents was mostly affected by the negative impact of the growing problems in performing basic activities of daily life, particularly in terms of health and functioning. 6) The functional capacity limited after the stroke and the problems with the acceptance of the disease do not disturb, according to patients' assessment, family relationships. **(JNNN 2016;5(4):136–143)**
Key Words: stroke, quality of life, functional capacity, acceptance of the disease

Streszczenie

Wstęp. Coraz częściej w badaniach dotyczących konsekwencji przewlekłych chorób neurologicznych odchodzi się od zasady wyłącznie biologicznego oceniania zdrowia człowieka, a przyjmuje się bardziej holistyczny punkt widzenia, w którym szczególną uwagę zwraca się na emocjonalne doznania pacjenta, jego samopoczucie i możliwości funkcjonowania w codziennym życiu.
Cel. Celem niniejszej dysertacji jest analiza czynników determinujących ocenę jakości życia dokonaną przez pacjentów, którzy przebyli udar mózgu.

Materiał i metody. Grupę badawczą stanowiło 95 chorych po przebytym udarze mózgu Badania zostały przeprowadzone przy pomocy: Indeksu Jakości Życia Ferrans & Powers — wersja III, oceniającego ogólną jakość życia oraz jakość życia w aspekcie zdrowotno-funkcjonalnym, socjo-ekonomicznym, psychologiczno-duchowym i rodzinnym. W badaniach wykorzystano także skalę Akceptacji Choroby (AIS) oraz Wskaźnik Funkcjonalny „Repty".
Wyniki. Przeprowadzone badania wykazały istotne (p=0,006) różnice w poziomie akceptacji choroby przez osoby z różnym stopniem wydolności funkcjonalnej. Jako konieczny warunek spełnienia w życiu 91,6% badanych wskazało możliwość kontynuacji pracy. Dla 84,20% ankietowanych niezbędne dla spełnienia wżyciu były dobre relacje z dziećmi. 80% badanej populacji do podstawowych cech dobrostanu zaliczyło zdrowie. Dla 78,90% respondentów konieczne dla osiągnięcia szczęścia było szczęście rodziny, a około trzy czwarte ankietowanych za bardzo ważne w samorealizacji uznało, praktyki religijne (75,80%), zdrowie najbliższej rodziny (75,80%) oraz pozbycie się przewlekłego bólu (74,70%).
Wnioski. 1) Zdolność do samodzielnego funkcjonowania sprzyja akceptacji skutków przebytego udaru mózgu. 2) Największy problem z przystosowaniem się do nowej rzeczywistości życia z chorobą mieli respondenci, którzy byli samodzielni lecz w niektórych czynnościach musieli korzystać z pomocy innych. 3) Ponad dziewięćdziesiąt procent badanych jako konieczny warunek spełnienia w życiu wskazało możliwość kontynuacji pracy. 4) Odczuwana jakość życia ulega drastycznemu obniżeniu u pacjentów, którzy przeszli udar między trzecim miesiącem a rokiem przed udziałem w badaniu. 5) Do obniżonego poczucia dobrostanu badanych w największej mierze przyczynił się negatywny wpływ narastających problemów w wykonywaniu podstawowych czynnościach dnia codziennego, szczególnie w aspekcie zdrowie i funkcjonowanie. 6) Ograniczona po przebyciu udaru mózgu wydolność funkcjonalna oraz problemy z akceptacją choroby nie zakłócają w ocenie pacjentów relacji z rodziną. **(PNN 2016;5(4):136–143)**
Słowa kluczowe: udar mózgu, jakość życia, wydolność funkcjonalna, akceptacja choroby

Introduction

Recent decades have brought a radical change in the approach to the assessment of treatment outcomes and anticipation of the future condition of health in diseases of the neurological background. Increasingly, in studies relating to the consequences of chronic neurological diseases there has been a departure from the principle of exclusively biological evaluation of human health and a more holistic point of view is being adoped, in which particular attention is drawn to the emotional experience of the patient's well-being and ability to function in daily life. Assessing the results of treatment based on biological criteria has become insufficient. Interest in medical science has moved beyond traditional, purely medical area of acting, focusing on the activity of patients in various areas of life [1,2]. The physical capacity is defined as the efficient or functional activity. This concept can be associated with the ability to be independent from others in the fulfillment of basic activities of daily living such as moving, nutrition, maintaining personal hygiene or controlling physiological needs [3].

Cerebrovascular disease is the largest section of neurology. The most common effect of this group of diseases is a long-term decrease in functional capacity [4,5]. Strokes are one of the leading reasons for disability in the modern society, and the cost of treating this disease is one of the largest [6]. The coefficient of the incidence of stroke in Poland is comparable to the rates in other European countries and amounts to a total of 125/100 000 in women and 175/100 000 in men [7,8].

Limited functional capacity following a stroke confronts the patient with new challenges in all aspects of life. Coping with difficulties in everyday functioning, dramatic reduction in living standards, the loss of existing social status, lack of support in the family and helplessness in the face of fundamental existential problems as well as isolation from the external world and limitation of social interaction are just a few of the problems facing the patient after a brain stroke [9].

Assessment of the quality of life made by patients who have experienced stroke depends not only on a limited functional capacity. A sense of well-being of the patient with a history of vascular brain damage is also conditioned on intellectual, cognitive disorders, state of awareness, and above all on the personality of patients and their attitude to the new reality following the stroke.

The aim of this work is to analyse the factors determining the assessment of the quality of life made by patients who have suffered from a stroke.

Material and Methods

The study was conducted in the period ranging from April to May 2016 in Prof. M. Kaczynski Neuropsychiatric Hospital in Lublin, in the Public Health Care Centre in Pulawy, in the "Iwonicz Health Resort" in Iwonicz Zdroj, and in "Kalina" Social Welfare Home for the Physically Disabled in Lublin. The study involved 95 randomly selected post-stroke patients.

Gender distribution in the studied population was almost equal with a slight female predominance (51.6%). The age of the respondents ranged 65.5±12.4 years. Almost a half (48.4%) of the respondents were married. 10.5% of the surveyed were not married, 31.6% widowed, and 9.5% of the respondents were divorced. The vast majority (62.1%) of those surveyed lived in the city. In 78.9% of cases respondents' income came from annuity or pension. The ischemic incident was diagnosed in 80% of patients. The largest group (31.6%) included respondents in the early period not exceeding 3 months after the stroke, 28.4% of the patients suffered from the stroke within the period ranging from 3 months to 1 year prior to the survey, 26.3% of respondents experienced the stroke not later than a year and not earlier than 5 years before the survey, whereas 13.7% of respondents underwent a stroke earlier than 5 years before completing the questionnaire.

For the needs of this work the method of a diagnostic survey was applied. In order to assess the quality of life of respondents Ferrans and Powers Standardised Questionnaire Index of the Quality of Life version Ferrans and Powers was used [10–12]. The acceptance of health condition was verified by means of the Acceptance of Illness Scale — (AIS) [13,14]. For the evaluation of the functional status of the respondents the Repty Functional Index (WFR) was applied [15–18].

The relationship between quantitative variables was verified by the Pearson r coefficient. The differences between the groups compared were tested by non-parametric tests. The Mann–Whitney test was used to compare two groups of variables, whereas by the Kruskal–Wallis U test more than two groups of variables were compared.

Results

The first intention of the authors was to verify whether and to what extent the stroke has reduced functional capacity of the patients included in the research. The WFR index in the study population stayed at the level of 79.06±23.38 (87.00 M), therefore the disease slightly disturbed the basic daily activities of the respondents. Detailed analysis has shown that more than a half (53.7%) of respondents enjoy full independence, and only a minor group (7.4%) requires full assistance in almost all activities (Figure 1).

The analysis showed that the ability to function independently favours the acceptance of the consequences of stroke. The average index of the disease acceptance in the studied population was 23.92 (SD=8.17). There were identified significant (p=0.006) differences in the level of acceptance of the disease by patients with varying degrees of functional capacity. The vast majority (71.6%) of respondents to greater or lesser extent, accept limitations in daily functioning resulting from the illness. Further analysis has shown that the biggest problem in adjusting to the new reality of life condition (M=19.95 ±8.904) referred to the respondents, who were independent but in some activities had to use the assistance from caregivers (Figure 2).

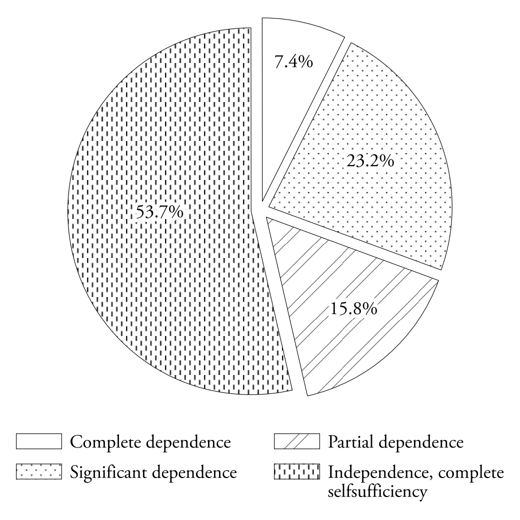

Figure 1. Functional capacity of the study group according to the Repty Functional Index

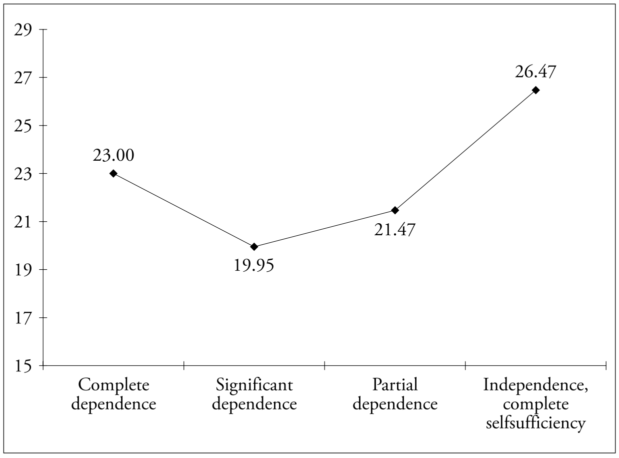

Figure 2. Average acceptance of the disease, including the degree of functional capacity

The quality of life is considerably affected by the significance of its individual aspects and the degree of their deprivation. Therefore, the respondents were asked to assess some selected aspects of everyday existence. The research analysis has shown that people with a history of stroke derive most satisfaction from: religious practices (94.70%), work (92.70%), the relationship with their offspring (91.60%), experienced health care as well as from various aspects of family and social life. Joy of life after stroke is disturbed, according to the respondents, by persistent pain (80.10%), stress in everyday functioning (75.80%), and sexual dysfunction (54.70%).

Then the respondents were asked which aspects contribute to a sense of well-being and fulfillment in life. Almost everyone involved in the study agreed that all the statements in the questionnaire had a minor or significant effect on the sense of well-being. Only a little more than one-fifth (21.10%) of respondents felt that sexual intercourse had no effect on the quality of life. As a necessary condition for the fulfillment in life, 91.6% of respondents indicated the ability to continue working. For 84.20% of respondents good relationships with children were necessary for self-fulfillment. 80% of the study population include health as the basic feature of their welfare. For 78.90% of respondents happy family life was necessary for the achievement of happiness, and approximately three-quarters of respondents considered religious practices as very important in self-fulfillment (75.80%), health of the immediate family (75.80%) and getting rid of chronic pain (74.70%).

Following statistical analysis it was found that the overall quality of life (QLI) in this population of patients is 19.72±4.13 (M=20.08). The highest level of quality of life is declared by the respondents in terms of family (FAM) — 23.98±6.23, F=26.40), whereas the lowest assessment refers to their health as well as to independent functioning (HF) — 17.12±4.59 (M=17.62) (Figure 3).

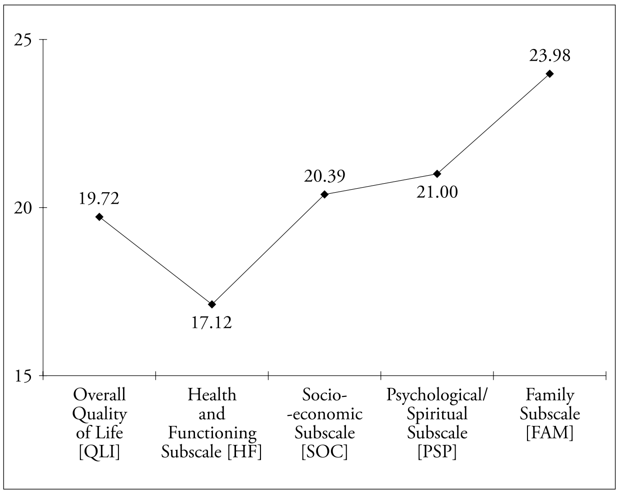

Figure 3. Overall Quality of Life Assessment on each subscale (QLI)

The next objective of the considerations taken was to determine the impact of demographic factors on the quality of life experienced by patients after the stroke. Statistical analysis included also an assessment of each component of the quality of life. The studies have shown that the quality of life perceived is drastically reduced (QLI drop of 3.42, p=0.006) in patients who had experienced a stroke within the period ranging from three months to a year preceding their participation in the study. This decline was the largest (4.86, p=0.009) on the Family subscale.

A similar significant difference in the evaluation of welfare (approximately 2.74, p=0.06) was found between respondents with vocational education and those with secondary one. In this case the largest difference (approximately 3.11, p=0.05) was observed in the evaluation of the quality of life in terms of Health and Functioning. The assessment of welfare in the study group was also significantly affected by the type of stroke. Those who experienced an ischemic stroke significantly better assessed the quality of life (approximately 2.34 p=0.023) than the patients after a hemorrhagic stroke. The biggest difference (about 3.35, p=0.009) was observed in the evaluation of welfare in the aspect of socio-economic quality of life.

A slightly smaller difference (of 1.3, p=0.061) in the assessment of well-being was observed between the respondents, who were married and those living alone. Respondents struggling with the disease who are married significantly better (by 3.04, p=0.039) evaluated the quality of life in terms of the Family than research participants struggling with adversities alone. The remaining demographic factors had no statistically significant effect on the assessment of the quality of life made by the respondents (Table 1).

Table 1. The average quality of life in general dimension and on each of the subscales in relation to the demographic characteristics of the study population

Demographic characteristics	Overall Quality of Life (QLI)		Health and Functional Subscale		Socio--demographic Subscale		Psychological and Spiritual Subscale		Family Subscale	
	M	SD	M	SD	M	SD	M	SD	M	SD
1	2	3	4	5	6	7	8	9	10	11
Gender										
Women	20.10	3.87	17.49	4.06	20.62	4.78	21.39	4.71	24.65	5.69
Men	19.32	4.39	16.71	5.11	20.14	4.98	20.59	6.13	23.27	6.74
Age										
Under 60 years	19.64	4.18	1.52	4.4	20.14	4.75	20.17	5.1	24.12	5.87
60–70 years	19.77	4.45	17.02	5.05	20.74	4.92	21.08	6.16	23.54	6.94
Over 70 years	19.74	3.8	16.88	4.29	20.18	5.02	21.63	4.82	24.39	5.77
Marital status										
Single	19.09	4.06	16.83	4.01	19.42	5.28	20.82	5.31	22.51	7.12
Married	20.39	4.14	17.42	5.16	21.42	4.19	21.19	5.6	25.55	4.7

Table 1. Continued

1	2	3	4	5	6	7	8	9	10	11
Education										
Primary	19.61	3.55	16.49	3.51	19.40	5.23	22.25	4.57	24.90	5.55
Vocational	21.32	3.29	19.16	3.06	21.25	4.62	22.89	4.38	25.12	6.36
Secondary	18.59	4.68	16.05	5.49	19.66	5.29	19.29	5.71	22.80	6.28
Higher	19.10	4.25	15.90	4.95	21.49	3.50	19.56	6.52	23.30	6.57
Place of residence										
Country	19.32	3.81	16.35	4.81	20.06	3.98	20.47	4.60	24.68	4.76
City	19.97	4.33	17.59	4.43	20.59	5.35	21.33	5.89	23.55	6.98
Source of income										
Pension/Retirement	19.85	4.03	17.04	4.54	20.36	4.82	21.44	5.13	24.41	5.79
Other source of income	19.25	4.56	17.42	4.87	20.48	5.15	19.34	6.31	22.38	7.59
Type of stroke										
Ischemic	20.19	4.07	17.49	4.58	21.06	4.54	21.42	5.34	24.47	5.88
Hemorrhagic	17.85	3.91	15.60	4.43	17.71	5.31	19.32	5.58	22.03	7.32
Period following stroke incidence										
Under 3 months	21.58	3.76	18.47	4.19	22.37	4.63	23.26	4.71	26.75	4.21
From 3 months to 1 year	18.16	3.67	15.83	3.77	18.82	4.66	19.3	4.71	21.89	5.47
From 1 to 5 years	19.45	4.67	16.91	5.47	20.12	4.98	20.49	6.56	23.84	6.73
Over 5 years	19.21	3.48	17.07	4.84	19.6	4.53	20.31	4.79	22.21	8.54

The culmination of the deliberations undertaken in this thesis was to analyse the negative impact of the reduced functional capacity and problems with the acceptance of the disease on the assessment of the overall quality of life (QLI) and its individual aspects by the patients who had experienced a stroke. As expected, both the decline in the functional capacity as well as the problems with the acceptance of the disease contributed to a statistically significant ($p<0.05$) underestimation of the quality of life of respondents.

The negative impact of the growing problems in performing basic activities of daily living ($p<0.001$), particularly in terms of Health and Functioning ($p<0.001$) largely contributed to the reduced sense of well-being. The studies have shown that the functional capacity limited due to the stroke as well as problems with the acceptance of the disease do not interfere significantly, according to patients' assessment, with their family relations ($p>0.05$) (Table 2).

Table 2. The impact of the limited functional capacity and of problems with the acceptance of the disease on the assessment of the overall quality of life (QLI) and its each aspect by the patients who experienced a stroke

Quality of Life Index	R Pearson's			
	REPTY index		acceptance of illness scale AIS	
	Result	Significance	Result	Significance
Overall Quality of Life [QLI]	0.342	<0.001*	0.205	0.047*
Health and Functioning Subscale [HF]	0.555	<0.001*	0.213	0.038*
Socio-economic Subscale [SOC]	0.259	0.011*	0.148	0.151
Psychological/Spiritual Subscale [PSP]	0.236	0.021*	0.114	0.273
Family Subscale [FAM]	0.063	0.544	0.134	0.194

Discussion

The study has shown a reduced assessment of the quality of life (19.72, SD=4.13) by respondents after a stroke, particularly in terms of Health and Functioning (17.12±4.59, F=17.6). Similar assertions stem from the research carried out by Bejer and Kwolek. They argue that the assessment of the quality of life by patients who had experienced the incident of stroke is lower compared to the period prior to the disease and to the assessment made by healthy respondents from the study group [19].

It has been also stated that the disease slightly disturbed the performance of basic daily activities of the surveyed. Similar results have been obtained by Jucha, who has shown average reduction of efficiency due to prior ischemic stroke [20]. This is confirmed by Nalepa et al., who claim that 60.94% of stroke survivors function in the home environment using only a partial help from relatives [21]. Satisfactory functional capacity of patients is confirmed by T. Tasiemski et al., pointing to studies, in which they showed that more than a half of the patients after an incident of stroke had no problems with having meals independently, getting dressed and undressed, bathing, communication and walking (including climbing up and down stairs) [22].

The respondents who experienced a stroke generally accept the new situation in life. The authors indicate that it is interesting and surprising, that the patients who are completely dependent on the help from neighbours, show quite a large (M=23.00±10.279) degree of acceptance of the disease, especially that the fully independent patients accept their disease to a slightly greater extent (M=26.47±6.810). A similar result has been obtained by Kumasińska and Rojowska [13].

The negative impact of low functional capacity on the assessment of the quality of life in terms of health and functioning has been confirmed by Weber-Rajek et al [23]. On the other hand Vestling et al. see the reason for the low quality of life of patients after the incident of stroke in the difficulties related to their careers [24]. Brola and Węgrzyn however, claim that the problems of everyday life, giving up careers, loss of previous social status and helplessness in the face of limitations in functioning is often the reason for the isolation of a patient from social life and neglecting relationships with friends which results in a significant reduction of the patient's quality of life in this area [9].

Against the background of the overall quality of life assessment made by respondents, the evaluation of its psycho-spiritual aspects ranks at the average level (21.00; SD=5.43). A similar result has been obtained by Jaracz et al. [25], and Ratkowski et al. [12], who studied seniors with impaired locomotion.

The studies indicate a positive role of a successful marriage in assessing the welfare of those who have experienced a stroke. Similar is claimed by Tasiemski et al. [24], indicating that relationships with one's spouse and family received the highest assessment. Kim et al. [26] confirm that marriage and good relations between spouses contribute to a higher quality of life assessment. Analogous test results have been obtained by Bluvol and Ford-Gilboa [27] arguing that the post stroke patients who receive support from the family and partner better assess their quality of life and recover quicker.

The type of stroke significantly differentiates the quality of life. Patients with hemorrhagic brain stroke much worse assess their quality of life in all of its aspects. Similar results have been obtained by Jucha [20], who in his research, states that the type, location and severity of the stroke my considerably affect the assessment of the quality of life made by patients.

Patients in the early stages following a stroke better assessed the quality of life both in the general dimension and in its particular aspects. According to the authors to the decline of the sense of well-being three months following the stroke there may contribute both the fatigue caused by the proces of treatment and a long stay in hospital. One can also expect that the interpretation of test results should include the ability to assess the quality of life before the disease in the case of respondents surveyed immediately after the stroke. Similar assertions are derived from their research by Schuling et al. [28], indicating that the assessment of welfare made by patients after the incident of stroke did not change within the period ranging from the 8th to 26th week of the disease.

Conclusions

The analysis of the collected research material allowed to draw the following conclusions:

1. The ability to function independently promotes the acceptance of the consequences of the stroke experienced.
2. The largest problem with the adjustment to the new reality of life with the disease regarded those respondents, who were independent but in some activities had to rely on the help of others.
3. More than ninety per cent of respondents pointed to the possibility to continue working as a prerequisite for their fulfillment in life.
4. The quality of life perceived is drastically reduced in patients who experienced an incident of stroke within the period ranging from three months to a year prior to the participation in the study.
5. The reduced sense of well-being of respondents was largely affected by the negative impact of growing problems related to the performance of basic activities of daily life, particularly in terms of health and functioning.
6. Functional capacity limited as a cosequence of stroke as well as the problems with the acceptance of the disease do not disturb, according to the patients, family relations.

Implications for Nursing Practice

The problem of the reduced quality of life, discussed in this study, in the context of the acceptance of a limited functional capacity after stroke identified the areas which should be particularly considered in the care of patients with vascular disease of the brain. According to the authors, more care and attention should be paid to patients who having ended intensive treatment immediately following a stroke, slowly learn to function in the new reality. Studies have shown that the biggest problem with the acceptance of the disease referred to patients with a slight limitation of functional capacity, who needed help or assistance from a caretaker in the performance of some everyday activities. Lack of acceptance of the disease was reflected in a lower assessment of the quality of life among the respondents who completed the survey a few months after the incidence of stroke. It can be therefore recommended that the patients should be supported through conversations and provided discreet assistance in the arduous process of learning basic daily activities. The Authors' findings point to the obvious therapeutic benefits to the patient resulting from the support from nurses in the difficult path to independence following a long period of being immobilised in bed.

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Corresponding Author:
Regina Lorencowicz
Katedra i Zakład Pielęgniarstwa Neurologicznego
UM w Lublinie
ul. Jaczewskiego 8, 20-954 Lublin, Poland
e-mail: regina_lorencowicz@wp.pl

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