



QUALITY OF LIFE AMONGST CARE GIVERS FOR PATIENTS WITH PARKINSON'S DISEASE

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Abstract

Parkinson's disease (PD) is a neurodegenerative disease. Due to a constantly growing rate of incidence and the lowering age of PD patients it is becoming a more serious social problem. The aim of this study is to assess the quality of life amongst care givers for people suffering from Parkinson's disease. The work includes research on the influence of physical rehabilitation of PD patients on the quality of life of their care givers. The research covered care givers (n=50) of PD patients diagnosed with third stage PD according to the Hoehn and Yahr classification. The diagnostics survey with a questionnaire addressed to care givers looking after PD patients was used. The questionnaire was created by the authors of this paper. The survey consisted of two parts, in which the first was to obtain basic information on the present status of the care giver, while the other was to verify life satisfaction level, using Jurczynski's Scale of Life Satisfaction. Statistical analysis showed significant differences in all analyzed statements between groups. Better effects were observed in the group participating in rehabilitation. Care for people suffering from PD affects the quality of life of caregivers. Participation in the process of rehabilitation of patients with PD improves the quality of life of caregivers.

Key words: Parkinson's disease, quality of life, caregivers, life satisfaction.

Introduction

Recently, there have been an increasing number of studies concerning life quality, which is a multi-dimensional concept. It reflects a subjective evaluation of a person's satisfaction and concerns in various domains of life [1, 9, 11].

This issue of life quality is becoming particularly important with the lengthening of human life expectancy. Moreover, it involves an increasing number of people reaching old age and suffering from diseases associated with it. Currently, it is estimated that nearly 600 million people aged 60 years and over live in the world, and the number is expected to double in 2025 [22]. In the aging body, many degenerative changes, including those of the nervous system take place [8, 21].

One of the most common diseases of the nervous system is Parkinson's disease (PD). According to current data, in Poland there are

approximately 80000 people suffering from Parkinson's disease, and every year about 4-8 thousand new cases are diagnosed. On a global scale it is estimated that the disease affects approx. 0.1-0.2% of the population. The disease mainly affects people over the age of 55; therefore, due to an aging population, it is becoming an increasingly important social problem [9,12].

The inevitable progress of the disease causes the patient great difficulties, challenges and fatigue, particularly as it develops into its more advanced stages. Parkinson's disease is progressive, so patients need a greater availability of care givers, assistance and psychological support [14, 16]. It happens that the help of one person is not enough and should involve all of his or her family and friends. This has a significant influence on the family, who must redefine and share their responsibilities. Another phenomenon associated with caring for

a PD patient at home is that the care giver must resign from their full time employment in order to take care of patients. Chronic stress resulting from the challenge of caring also has negative consequences in the area of mental and somatic health. Care givers are among the group of people facing developing anxiety disturbances, depression, sleep disorders, and cognitive efficiency degradation [2, 3, 17, 20].

Quality of life is an important evaluation tool concerning the actual abilities of carrying out long-term care. A high quality of life amongst care givers has a positive influence on the health condition of the patient, increases the standard of care, and reduces the risk of institutionalization of the patient. The study of quality of life and health conditions amongst health attendants aims at assessing their performance efficiency in the provision of care, identifying their needs, and finally on this basis, working out a plan and creating adequate support systems. Improving quality of life can be an important goal of treatment, providing optimal patient care in home conditions [4, 10, 11]. The aim of this study is to assess the quality of life of care attendants of people suffering from Parkinson's disease. The work includes research on the influence of physical rehabilitation of PD patients on the quality of life of their care givers.

The following questions have been raised in the work:

1. Does taking care of a person suffering from Parkinson's disease affect the quality of life of their care givers?
2. Is there any difference in terms of quality of life amongst those care givers whose patients participate in rehabilitation and amongst those who don't?
3. What is the satisfactory level of life amongst care givers whose patients participate or do not participate in rehabilitation?

Material and methods

A diagnostics survey with questionnaire addressed to care givers looking after PD patients was used. The questionnaire was worked out by the authors of this paper and then verified with regard to accuracy and reliability on the basis of piloted research. The survey consisted of two parts, in which the first was to

obtain basic information concerning the present status of the care giver while the other was supposed to verify their level of life satisfaction, using the Scale of Life Satisfaction - SWLS by Jurczynski [23].

The research covered care givers of PD patients who were members of the Silesian Society for People Suffering from PD and was approved of by Bioethics Committee at the University of Physical Education in Katowice. The examinations included 50 care givers out of whom 66% were women (33 people) and 34% men (17 people). The age distribution was as follows: 10% - under 35 years of age, 22% - 11 people between 35-54, 28% - 14 people between 55 - 64, 30% -15 people between 65-75 and 10% - 5 people over 75. 54% of givers live in towns, while 46% live in the country. 28% had university education, 36% - high school, 2%8 - vocational education and 8% - elementary school.

In order to obtain full information on care givers, degree of kinship was established and this revealed that 56% were spouses and 30% were their children, and the remaining 14% were grandchildren, neighbors and distant family.

Employment status was considered an important aspect of research and it showed that 28% were employed on a full time basis, 16 % - part time, 46% were retired and pensioners, 4%-unemployed and 6% had decided to quit their jobs to look after the patients.

Duration of the care period was also examined and it revealed that 2% had worked for less than 1 year, 14% - from 1 year up to 3, 18% - from 3 to 5 years, 36% - from 5 to 10 years and 30% - longer than 10 years.

In order to define the stage of the disease of patients, the 5 degree Hoehn-Yahra [21] scale was used where "0" means no symptoms, and "5" means total disability. All examined patients were classified as third degree, of whom there were 19 women aged 65,33+/-6,21 with a disease duration of 5,64+/-2.65 and 31 men, aged 64,23+/-4,97 with a duration of 6,10+/-5,02. As far as participation in rehabilitation exercises was concerned, 26 patients (56%) declared twice weekly participation for 60 min. and the remaining 24 people (48%) did not participate.

Analysis of results

Obtained results were statistically analyzed both for care givers of PD patients participating in rehabilitation (group A) and those not participating (group B). Basic statistical measures were taken and the Komogorow-Smirnow test was used to examine the distribution of data, and finally data obtained were compared using the Chi Square test.

The analysis showed that time devoted to care of PD patients in groups A and B differed statistically significantly ($p=0.001$). In group A, 54% of examined care givers declared that the time of care was less than 6 hours daily and only 2% of them declared more than 12 hours. In group B, only 22% spent less than 6 hours daily with patients, but 25% stated that they had to be with patients more than 12 hours a day.

Care givers' quality of life substantially depends on the duties they have to face when helping PD patients, and the extent to which a patient can manage themselves has a considerable influence on the well-being of relatives. Help in the simplest of activities is not required because the patient is able to cope with everyday tasks quite well. The care attendants were asked in what fields their patients needed help and the answers in both groups were similar: in cleaning, running the house and financial matters. However, a significant difference between both groups was found as group A patients more seldom required help in everyday duties (fig.1).

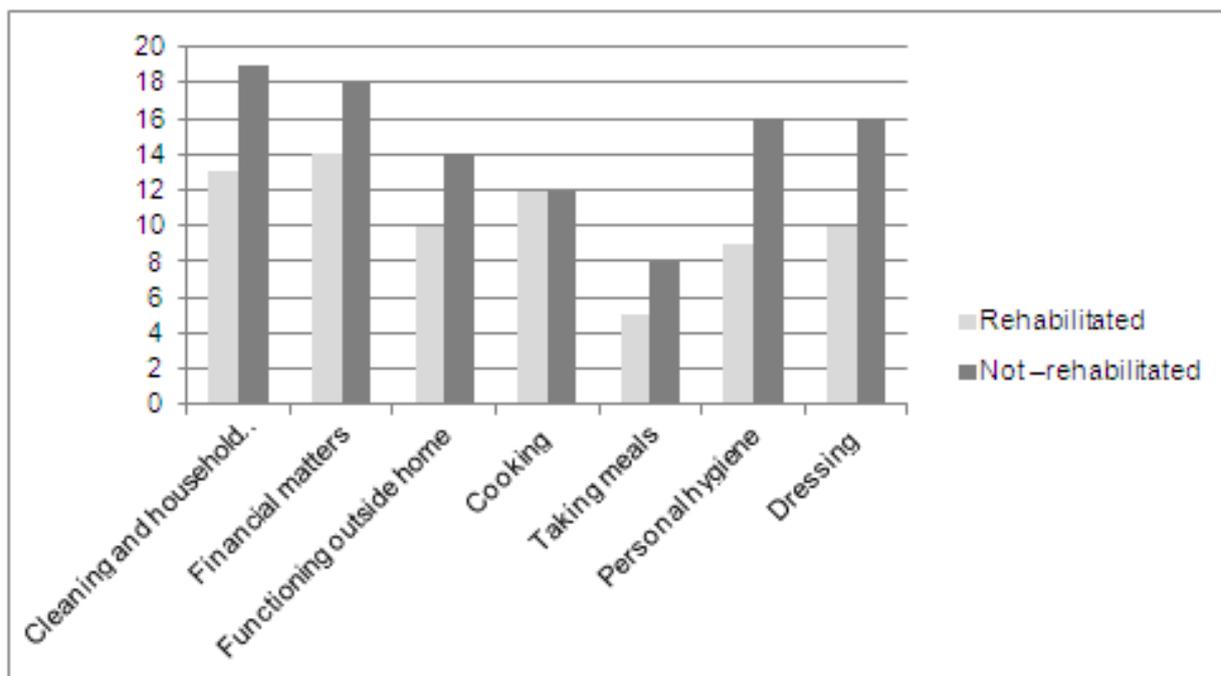


Fig.1. Forms of assistance provided to PD patients by care givers.

Next, family relations and attendant-patient relations preceding the appearance of the disease were evaluated. In group A, 19% declared a clear worsening; 31% declared slight worsening; and 50% claimed there was no change. In group B, as many as 62% of examined patients declared apparent worsening of relations; 21% noticed some worsening; and 17% declared no change.

The following question asked concerned subjective feeling of fatigue resulting from taking care of the patient. In group A, the majority (31%) declared they were never tired; seldom – 19%; sometimes – 15%; often – 27%; and always – 7%. In group B, the answers “seldom” and “never” were never given; the answer “always” was given by 29% and “sometimes”- 17%.

The other part of the survey included SWLS Scale of Life Satisfaction, worked out by E.Diener, R.A Emmons, R.J Larson and S. Griffin with the adaptation of Zygfyrd Jurczynski [23]. The scale contained 5 statements, with which the participants could agree or disagree.

The given digits mean: 1-totally disagree, 2 disagree, 3 rather disagree, 4-neither agree nor disagree, 5-rather agree, 6-agree, 7-fully agree. Statistical results of obtained answers is presented in Tab. 1.

Tab.1. Statistical characteristics obtained in SKWL test.

SWLS scale	Arythmetic mean		Median		SD		Variance		Kurtosis		Chi square
	A	B	A	B	A	B	A	B	A	B	p
Question I	4,68	2,7	4	3	1,18	0,82	1,39	0,68	1,1	0,58	0,002
Question II	4,56	3,13	4	3	1	0,76	1,01	0,57	0,14	0,47	0,001
Question III	5,36	3,74	6	3	1,08	1,6	1,16	2,57	0,14	-0,09	0,005
Question IV	4,72	3,52	5	4	1,1	1,12	1,21	1,26	-0,79	-0,46	0,001
Question V	4,96	2,65	5	3	1,4	1,27	1,96	1,6	-1,26	-1,23	0,007

Question I- In many aspects my life is close to ideal

Question II – My life conditions are perfect

Question III – I am satisfied with my life

Question IV – In my life I have achieved what I wanted

Question V- If I were to live again, I would hardly change anything

Statistical analysis showed significant differences in all analyzed statements between groups.

Clear differences appeared in the first statement in both groups, as in group A the most frequent answers were “disagree” – 46% and “rather disagree” – 37.5%. In group B, the most frequent answers were “neither agree, nor disagree” – 35% and “agree” – 27%.

The second statement received the following answers in group A – “neither agree, nor disagree” – 38%, and “rather agree” – 35%. There were no answers like “totally disagree” or “disagree”. In group B, answers “neither agree, nor disagree” were given by 21% and “rather disagree” – 58%. No answers “agree” or “totally agree” were given.

The third statement was answered “agree” by 50% in group A, “rather agree” by 23% and there were no answers “totally disagree” and “disagree”. In group B, the most frequent answer was “rather disagree” – 37.5%, and “neither agree, nor disagree” – 17 %, and “disagree” – 12.5 %

The analysis of answers to the fourth question did not show such big differences

between groups as compared to previous questions. In group A, the answer “neither agree, nor disagree” – was given by 36%, and by 33% – in group B, the answer “rather disagree” – 26% – group A and 24% in group B. Despite those similarities, all differences in answers were statistically significant.

However, the biggest differences in answers between groups were found in the fifth statement as in group A there were no answers “totally disagree” or “disagree”, while in group B, nobody answered “agree” or “totally agree”. Further analysis showed that in the group 46% answers were “rather disagree” or “agree”. It is worth noticing that 15% declared that their life is ideal and would not like to change anything. In group B, 26% answered “totally disagree”, and “rather disagree” and 25% – “neither agree, nor disagree”. There were no answers “totally agree”.

Discussion

The studies allow evaluation of the quality of life as well as satisfaction of people with PD. It is understood that long-term care may cause deterioration of life quality. Taking the two groups

into comparison: amongst caregivers of people with PD participating (group A) and not participating in the process of rehabilitation (group B), it was found that caregivers of people not involved in exercises spend more time caring, are frequently tired, and their relationships with loved ones are significantly worsened. The majority of them declared that they are always or very often tired of care. The results of the group of caregivers of people not involved in the rehabilitation process indicate a significant decline in the quality of life and satisfaction with it. Only 25% of all respondents in this group showed a minimal level of satisfaction with life. The remaining 75% have a negative attitude towards their situation. Whereas those dealing with patients suffering from PD, who participated in rehabilitation, have more free time for their own needs, they do not feel too tired to care as opposed to those from group B. Often, their relationships do not change. In group A, amongst caregivers of people involved in rehabilitation, 81 percent declared their satisfaction with life. This data show a significant influence of rehabilitation on the lives of people taking care of the patient. Improving motor skills and self-reliance ease the burden of care.

The research of O'Reilly et al. [15] is the confirmation of results obtained in the work on the impact of care for people with PD on the life quality of caregivers. In the studies the researchers presented the effects of care for patients with PD with regard to the mental and physical conditions of the examined person. The study was conducted in 1992-1994 on a selected representation of the population of the UK and Ireland. In this study, respondents were most often spouses living with a sick person, and the care of the patient was taken mainly by women. The results showed that an increase in the length of care caused both a decline in social contacts and the reduction of free time spent on visits, trips or meetings. The work often referred to variations between young people, who had just taken care of patients with PD and those who had been caring for many years. It has been shown that young caregivers who have just started are more resistant to depression and mental disorders. It was also observed that an

increase in length of care is followed by a five-fold increase in the risk of developing mental illnesses. The study did not reveal what reaction would be the most advantageous in order to improve the well-being of the caregivers.

Rivera-Navarro et al. Benito-Leon [16] who examined the caregivers of those with PD as well as those with multiple sclerosis, observed the progression of cognitive disorders, depression and tiredness in parallel with the length of the disease. According to the authors, men dealt better with caring for the sick. It was also observed that caregivers of patients with MS are not as mentally burdened as the caregivers of those with various types of dementia or Parkinson's disease. The result obtained was justified by a higher incidence of dementia amongst people with PD, which affects the emotional state of the family. According to the authors, a solid family structure is an important source of support for caregivers [6].

In 2008 McCabe et al. [11] conducted a study the purpose of which was to examine the effect of the disease on work and rest for both patient and caregiver. The study included patients with 4 types of neurological diseases. The observation was attended by 28 people with multiple sclerosis, 27 patients with motor neuron disease, 31 people with PD and 24 people with Huntington's disease. 57 patients admitted that the disease had forced them to give up their jobs, and the quality and efficiency of their work had dropped significantly. Despite resigning from their jobs, 13% of patients admitted that the new situation forced them to change their lifestyle and they perceived this change positively. On the other hand, the remaining patients presented a number of negative changes. Lack of work led to frustration, anxiety, depression and social isolation. They lost self-esteem due to lack of earnings and thus felt a great sense of guilt. This led to isolation, introversion and denial as well as reluctance to accept support. Social isolation was often caused by a lack of financial resources for social gatherings and a lack of confidence. It was observed that the majority of respondents did not continue their hobbies, became passive, reluctant and unwilling to take visits or trips. An aversion to public speaking was also revealed.

Fifteen of the surveyed caregivers declared that they had to abandon full employment in order to take care of the sick person. Some of them were forced to close their business. A significant number of caregivers reported reducing the number of working hours for the care of the sick or had to take over the household chores previously performed by the partner. 14% of the respondents did not experience any negative feelings in relation to the disease. They claimed that their relatives were happy with earlier retirement or dismissal. However, the vast majority experienced rather negative emotions. Only a few caregivers discerned the positive aspect of a new situation. They perceived the possibility of spending more time together as a positive side aspect.

The life quality of caregivers of people with PD has been evaluated by several researchers [13, 18]. In the research presented in the literature available, the participation of people with PD in the rehabilitation process was not taken into consideration. There is a common belief about the positive effects of exercises on the delay of the rate of progression of the

disease. It has been proven that physical activity of people with PD improves their physical performance and functional independence [5]. The slowdown in the rise of symptoms undoubtedly has the effect of extending patient autonomy. Maintaining motor skills of a patient suffering from PD slows down the beginning of necessary care for the sick, which undoubtedly influences the quality of life of caregivers [10, 19].

Conclusions

Based on the findings of this study, the following conclusions can be drawn:

1. Care for people suffering from PD affects the quality of life of caregivers.
2. Participation in the process of rehabilitation of patients with PD improves the quality of life of caregivers.
3. Caregivers of people with PD who are involved in the rehabilitation process are more satisfied with life in relation to caregivers of people with PD not involved in this process.

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