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**SELECTED DETERMINANTS OF QUALITY
OF LIFE OF CAREGIVERS OF PEOPLE
WITH ALZHEIMER'S DISEASE**

Wybrane determinanty jakości życia opiekunów osób z chorobą Alzheimera

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A - Koncepcja i projekt badania, B - Gromadzenie i/lub zestawianie danych, C - Analiza i interpretacja danych, D - Napisanie artykułu, E - Krytyczne zrecenzowanie artykułu, F - Zatwierdzenie ostatecznej wersji artykułu

Abstract (in Polish):

Cel pracy

Choroba Alzheimera prowadzi do istotnych zmian w jakości życia bezpośrednich opiekunów chorych. Wraz z zaawansowaniem otępienia i deficytami funkcji poznawczych, pojawia się szereg nowych, trudnych sytuacji będących źródłem stresu zarówno dla chorego, jak i jego opiekunów. W efekcie zmianie podlega dotychczasowa jakość życia pacjenta i jego najbliższych. W pierwszym stadium rozwoju otępienia chory wymaga nieznacznej pomocy i kontroli ze strony opiekunów. Zmienia się to wraz z postępem zaburzeń

poznawczych. W rozwiniętej fazie choroby będzie to opieka 24-godzinna. Celem pracy jest analiza wybranych determinantów jakości życia opiekunów osób z chorobą Alzheimera.

Materiał i metody

W badaniach zastosowano: metodę sondażu diagnostycznego, metodę szacowania, technikę ankiety oraz technikę skali szacunkowej. Wykorzystano kwestionariusz WHOQOL-BREF oraz autorski kwestionariusz ankiety. Anonimowe badania zostały przeprowadzone wśród 100 opiekunów osób z chorobą Alzheimera.

Wyniki

Domeny jakości życia istotnie różnią się w zależności od wieku opiekunów (w sferze fizycznej, psychologicznej i środowiskowej).

Wnioski

Ocenę wszystkich domen jakości życia istotnie różnicowało wykształcenie opiekuna, jego sposób zamieszkania oraz stopień pokrewieństwa z chorym. Wyższej oceny jakości życia w zakresie domeny fizycznej i socjalnej istotnie częściej dokonywali opiekunowie osób w pierwszym stadium choroby Alzheimera. Choroba Alzheimera nieuchronnie prowadzi do obniżenia jakości życia pacjenta i jego bezpośrednich opiekunów. Niezbędne jest dokonywanie systematycznej oceny sprawności funkcjonalnej chorego, aby oszacować poziom zapotrzebowania na opiekę i stopień obciążenia opiekunów takimi działaniami.

Abstract (in English):

Aim

Alzheimer's disease leads to significant changes in the quality of life of its immediate caregivers. With the progression of dementia and cognitive deficits, many new challenging situations arise that are a source of stress for both the patient and their carers. The study aims to analyze selected determinants of the quality of life of caregivers of people with Alzheimer's disease.

Material and methods

The research used: the diagnostic survey method, the estimation method, the questionnaire technique and the estimation scale technique. The WHOQOL-BREF questionnaire and the original questionnaire were used. Anonymous studies have been conducted among 100 caregivers of people with Alzheimer's disease.

Results

The domains of quality of life differ significantly depending on the age of the caregivers (in the physical, psychological and environmental spheres).

Conclusions

The assessment of all domains of the quality of life was significantly differentiated by the caregiver's education, his way of living and the degree of kinship with the patient. A higher assessment of the quality of life in terms of the physical and social domains was significantly more often made by caregivers of people in the first stage of Alzheimer's disease. Alzheimer's disease inevitably leads to a reduced quality

of life for the patient and their immediate carers. It is essential to make systematic assessments of the patient's functional capacity to estimate the level of care needs and the burden of such activities on carers.

Keywords (in Polish): jakość życia, opiekun, choroba Alzheimera.

Keywords (in English): quality of life, caregiver, Alzheimer's disease.

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Wybrane determinanty jakości życia opiekunów

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Authors (short)

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Introduction

Alzheimer's disease significantly alters the picture of the quality of life for the patient, but also their carers. This is because it inevitably leads to deficits in the patient's functional capacity, requiring more and more support in daily functioning from those closest to the patient, who devote more and more attention and assistance to the patient [1]. For this reason, it is necessary to systematically review the patient's independence in meeting his or her needs and to determine the extent to which carers' involvement will be necessary [2].

With the progression of dementia and cognitive deficits, many new challenging situations arise that are a source of stress for both the patient and their carers. As a result, the previous quality of life of the patient and his or her loved ones is altered [1]. In the first stage of dementia development, the patient requires little assistance and control from carers. This changes as the cognitive impairment progresses. In the developed stage of the disease, this will be 24-hour care [3,4].

Caring for a patient for many hours every day, for sometimes several years, is a difficult challenge. This is all the more so when the care is given to a person who is important and close to the carer. It can be both an inspiration for action and a source of satisfaction, but also of bad emotions and frustration [1,3]. Failure to provide care and be present with the patient inevitably leads to a reduced quality of life [5]. This situation is often compounded by material difficulties and a lack of opportunities to organise activities that stimulate cognitive functions and at the same time give pleasure to the patient [6].

In Poland, due to the lack of forms of institutional support for patients, the burden of care is shifted to the family. Usually, the caregiver is the spouse/life partner, who, like the patient, is usually elderly,

with chronic comorbidities and also expects support, and leisure [7]. The second most common group of caregivers are the adult children of patients, who usually also have families of their own and are professionally active. It is therefore extremely difficult for them to reconcile their piled-up responsibilities [4]. The round-the-clock care provided to a dementia patient promotes the carer's stress syndrome, which is the result of overload, and frustration resulting from not being able to cope with further responsibilities. On the other hand, fatigue and weariness of daily activities may even lead to aggressive behaviour toward the patient, which in turn is associated with remorse and the belief in poor care [8,9]. Equipping the caregiver with knowledge about the disease, the skills to implement effective care activities and ensuring that support from governmental and non-governmental institutions is available, can promote the optimisation of the quality of life of the patient and those undertaking care for the patient [10].

This study aimed to analyse selected determinants of quality of life for carers of people with Alzheimer's disease.

Material and methods

The study used a diagnostic survey and estimation method, a questionnaire technique and an estimation scale. The WHOQOL-BREF (The World Health Organization Quality of Life) questionnaire, an abridged version of the 2004 quality of life assessment questionnaire, and an original survey questionnaire were used. Approval for the use of the WHOQOL-BREF was obtained from Professor K. Jaracz, UM of Poznań. The study was conducted between November 2020 and January 2021 on the premises of the Hospital in Lipno, after obtaining the consent of the Bioethics Committee operating at the State Vocational University in Włocławek No. 31/20 and the President of the aforementioned healthcare institution. The statistical analysis used PASW Statistic18 and assumed a significance level of $p < 0.05$. Results were presented as the arithmetic mean (M), standard deviation (SD) and minimum (min) and maximum (max) values. The t-test for independent samples and one-way ANOVA of variance were used.

The anonymous study included 100 adult carers of patients with Alzheimer's disease who were subject to hospitalisation. The essential criterion for inclusion in the study was the daily care of the patient. The majority of respondents were female (61%; $n=61$), compared to 39% ($n=39$) male. The age of most caregivers ranged between 40 and 59 years (49%; $n=49$). The second largest group was between 60 and 74 years of age (29%; $n=29$). The youngest carers, i.e. those aged between 18 and 39, accounted for 17% of respondents ($n=17$). Respondents over 75 years of age were the least numerous group (5%; $n=5$). Carers most often had secondary education (33% of people; $n=33$) and vocational education (29% of people; $n=29$). The study group included 23% of people ($n=23$) with tertiary education. The fewest respondents had primary education (15%; $n=15$). More than half of the respondents (53% of people; $n=53$) lived in a rural area and 47% of people ($n=47$) lived in a city. Carers were most likely to be caring for a patient with stage II Alzheimer's disease (41% of people; $n=41$) and stage III (32% of people; $n=32$). In contrast, 27% of respondents ($n=27$) were caring for a patient in stage I of the disease. Respondents were a diverse group based on their relationship with the patient. The majority of carers (30% of people; $n=30$) were caring for a relative. In contrast, 28% of respondents ($n=28$) were a child of the patient. In contrast, 27% of respondents ($n=27$) were married to the patient or were the patient's life partner. The least frequent caregiver was a friend (15%; $n=15$). The majority of caregivers lived with their families (79% of people; $n=79$). Self-care was declared by 21% of respondents ($n=21$).

Results

Global quality of life scores ranged from 1 to 5 points in the study group, resulting in a mean of $M=3.11$ points with a standard deviation of 0.920 points. This means that the mean score for global quality of life was “neither good nor bad”. Respondents’ self-assessment of their health ranged from 1 to 5 points, resulting in a mean $M=2.92$ point, with a standard deviation of 0.950 points. ($n=100$). This means that respondents were ‘neither satisfied nor dissatisfied with their health.

Respondents in the individual domains of life could score between 0 and 100 points. The statistics show that in the physical sphere, patient carers scored between 14.3 points and 96.4 points, resulting in a mean score of $M=50.82$ with a standard deviation of $SD=18.221$ points. In the psychological sphere, respondents’ scores ranged from 12.5 points to 91.75 points with a mean score of $M=52.67$ with a standard deviation of $SD=15.742$. In the social sphere, scores oscillated between 0 and 100 points, resulting in a mean score of $M=52.67$ points with a standard deviation of $SD=22.656$ points. In the environmental sphere, on the other hand, scores oscillated between 0 and 84.4 points, resulting in a mean score of $M=38.56$ points with a standard deviation of $SD=17.950$ points. The data thus shows that the lowest quality of life concerned respondents within the environmental sphere assessment and the highest was related to the social, physical and psychological spheres.

In a further stage of the study, the influence of socio-demographic variables on the differences in the assessment of individual domains of quality of life of the respondents was verified.

Gender and place of residence of the respondents did not statistically significantly differentiate the assessment of their functioning in individual spheres of life ($p>0.05$; $n=100$).

The age of the patients’ caregivers significantly differentiated the assessment of their three domains of life: physical ($p=0.000$; $n=100$); psychological ($p=0.043$; $n=100$) and environmental ($p=0.001$; $n=100$). There were no statistically significant differences in functioning in the social sphere ($p=0.142$). The youngest subjects ($M=65.56$; $n=17$) and those aged between 40 and 59 years ($M=51.24$; $n=49$) rated the quality of life in the physical domain the highest, and those aged between 60 and 74 years ($M=42.61$; $n=29$) and over 75 years ($M=44.30$; $n=5$) the lowest. The rating of the psychological domain of life decreased with the advancing age of the respondents. The highest ratings of the psychological domain were made by the youngest ($M=63.74$; $n=17$), between 40 and 59 years of age ($M=55.87$; $n=49$) and between 60 and 74 years of age ($M=50.86$; $n=29$). The lowest ratings were made by the oldest respondents ($M=49.18$; $n=5$). The mean data shows that the rating of the environmental domain of quality of life decreased with age. The highest ratings of the environmental domain of quality of life were made by the youngest respondents ($M=52.94$; $n=17$). Lower ratings were given by respondents between 40 and 59 years of age ($M=38.14$; $n=49$) and between 60 and 74 years of age ($M=32.33$; $n=29$). The lowest ratings were given to the above sphere of functioning by the oldest aged carers over 75 ($M=30.00$; $n=5$).

Respondent’s education significantly differentiated their assessment of their quality of life in the physical ($p=0.000$; $n=100$), psychological ($p=0.036$; $n=100$), social ($p=0.017$; $n=100$) and environmental domains of life ($p=0.000$; $n=100$). Ratings of the physical domain of life increased with the increasing education of patient carers. The lowest was for respondents with primary education ($M=37.62$; $n=15$) and vocational education ($M=45.08$; $n=29$). In contrast, respondents with tertiary education ($M=59.02$; $n=23$) and secondary education ($M=56.16$; $n=33$) rated the above life domain highest. The evaluation of the psychological domain of life was lowest in the group of people with primary education ($M=45.83$, $n=15$) and highest in respondents with higher education ($M=60.89$, $n=23$). Respondents with vocational and secondary education made similar assessments ($M=55.75$; $n=29$ and $M=55.68$, $n=33$, respectively). Ratings of the social domain of life increased with the educational level of Alzheimer’s caregivers. It

was lowest among those with primary education (M=40.00; n=15) and vocational education (M=50.00; n=29). The highest assessment was made by respondents with tertiary education (M=63.04; n=23) and secondary education (M=53.54; n=33). Similarly, the assessment of the environmental domain of quality of life increased with the educational level of Alzheimer's caregivers. The lowest assessment was for those with primary education (M=24.52; n=15) and vocational education (M=32.11; n=29), and the highest for respondents with tertiary education (M=50.95; n=23) and secondary education (M=41.57; n=33).

The mode of residence of caregivers of people with Alzheimer's disease statistically significantly differentiated the assessment of their physical (p=0.008 n=100) and environmental quality of life domains (p=0.016 n=100), and did not affect the assessment of the psychological and social domains (p>0.05, n=100). The physical domain of quality of life was rated higher by those living with family (M=53.30, n=79) than those living alone (M=41.51; n=21). Similarly, the environmental domain of quality of life was rated higher by those who lived with family (M=40.78, n=79) compared to respondents who lived alone (M=30.21; n=21).

The degree of kinship of the Alzheimer's caregiver statistically significantly differentiated the assessment of all spheres of life of the respondents (p>0.05; n=100). The lowest assessment of the physical sphere of quality of life was presented by the patients' spouses (M=41.66; n=27) and their children (son/daughter; M=44.14; n=28). On the other hand, the highest assessment was for caregivers who were friends of the patient (M=65.48; n=15) and relatives of the patient (M=57.98; n=30). The assessment of the psychological sphere of quality of life was lowest among the spouses of the sick person (M=48.30; n=27) and his children (M=48.06; n=28). In contrast, the highest was among the caregivers who were friends of the patient (M=68.03; n=15) and his/her relatives (M=62.36; n=30). The lowest assessment of the social sphere of life was presented by caregivers who were the patient's spouses (M=46.30; n=27) and their sons/daughters (M=44.05; n=28). Caregivers who were friends of the patient (M=67.22; n=15) and their relatives (M=59.17; n=30) rated the above sphere the highest. They rated the environmental sphere of life lowest for the spouses of the person with the illness (M=29.51; n=27) and their children (M=28.80; n=28). The highest ratings were given by carers who were friends of the patient (M=58.96; n=15) and their relatives (M=45.63; n=30).

The stage of severity of the client's dementia significantly differentiated the assessment of the physical (p=0.013; n=100) and social (p=0.013; n=100) quality of life of their carers. No statistically significant differences were found in the assessment of the psychological and environmental spheres of life (p>0.05; n=100). The physical domain of quality of life was rated highest by those caring for a patient in stage I Alzheimer's disease (M=59.53; n=27), and significantly lower by respondents caring for a patient in stage III (M=48.22; n=32) and stage II (M=47.12; n=41). Higher ratings of the environmental domain of quality of life were given by caregivers caring for a patient with stage I Alzheimer's disease (M=62.65; n=27). In contrast, respondents caring for a patient in stage III (M=52.34; n=32) and stage II (M=46.34; n=41) rated the above domain of quality of life lower.

Discussion

Caring for a patient with dementia involves many burdens for caregivers in physical, psychological, economic and social dimensions [4]. The pathomechanism of cognitive dysfunction, which assumes a gradual worsening of the patient's independence deficits, multiplies the number of daily responsibilities of their carer. It is assumed that 70% suffer from permanent stress and 50% experience depressive syndromes and depression. In addition, they feel exhausted and debilitated and limit their activities in social life. All of the above burdens, therefore, change the picture of carers' quality of life [4].

The burden on carers of patients with dementia has been the subject of numerous studies. As part of the Alzheimer Europe project, 1181 carers from 5 European countries were surveyed [11]. It also involved 201 caregivers in 9 Polish cities, who indicated that the vast majority of their patients were over 65 years of age, in the middle and advanced stages of the disease, and whom they care for more than 10 hours every day. The vast majority of the caregivers were women, who were usually the patient's spouse or adult child. Most of the caregivers were non-working [12].

In our study, carers presented an average global assessment of the quality of life and self-rated health. The assessment of the quality of life domains varied significantly by age of the respondents in terms of physical, psychological and environmental domains. The youngest carers gave the best assessment in these domains and those aged over 60 gave the worst assessment. The assessment of all domains of quality of life was significantly differentiated by the education of the carers. In the physical, psychological, social and environmental domains, the best assessment was presented by those with a university education and the lowest by those with primary education. Ratings in the physical and environmental domains of quality of life were significantly differentiated by the way respondents lived. Higher ratings in both domains were obtained by carers of patients living with their families than by those living alone. Ratings of all domains of quality of life were significantly differentiated by the degree of relationship of the respondents to the patient. Higher ratings of the physical, psychological, social and environmental domains were given by carers who were friends of the patient than by their spouses or children. Respondents' ratings of the physical and social quality of life domains were significantly differentiated by the stage of the patient's illness. Higher ratings of the physical and social domains of life were made by carers of patients in stage I of the disease than in stage III. Assessment of quality-of-life domains did not differ by gender or place of residence of respondents.

The results of several studies confirm that, in the subjective perception of carers of patients with dementia, the physical and psychological costs incurred are high [13]. Similar problems are faced by carers of people with other chronic diseases. The most important stressors include economic and time constraints, temporary deterioration of caregivers' health, and reduced work and social activities [14].

Our research indicates that the quality of life of a carer of a person with dementia is not always poor, especially in the initial phase of the disease. The advancement of the patient's disease is accompanied by a lower quality of life for their carers. The results of a study by Porzych et al [15] confirm the multifaceted negative consequences of dementia syndromes for patients' carers. The overall burden of care for patients with dementia was 25.46. Similar findings were presented by Szewczyk et al. where the level of caregiver burden was 25.5 [16]. In contrast, a lower sense of burden (18.6) was associated with respondents in the study by Ochudło et al [17]. In contrast, Schneider et al. in a study of 280 caregivers of people with Alzheimer's disease from 14 European countries showed that the level of caregiver burden associated with caregiving was similar across countries and reached a high value [18].

Conclusions

1. The assessment of the quality of life domains varies significantly by age among carers of Alzheimer's patients (physical, psychological and environmental domains).
2. The assessment of all quality of life domains was significantly differentiated by the education of the Alzheimer's patient's carer, their mode of residence and the degree of relationship to the patient.
3. Higher ratings of quality of life in the physical and social domains were significantly more frequent among caregivers of people in the first stage of Alzheimer's disease.

Recommendations for nursing practice

Alzheimer's disease inevitably leads to a reduced quality of life for the patient and their immediate carers. It is essential to make systematic assessments of the patient's functional capacity to estimate the level of care needs and the burden of such activities on carers.

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