

## Quality of life of blind people's carers

Łukasz Lewandowski<sup>1,A</sup>✉, Iwona Smotryś<sup>2</sup>, Angelika Puls<sup>2</sup>, Anita Radziejewska<sup>2</sup>, Magdalena Płocharczyk<sup>2</sup>, Aldona Reczek-Chachulska<sup>2</sup>, Sylwia Wieder-Huszla<sup>3,B</sup>

<sup>1</sup> Pomeranian Medical University in Szczecin, Doctoral Studies of the Faculty of Health Sciences, Department of Special Nursing, Żołnierska 48, 71-210 Szczecin, Poland

<sup>2</sup> Pomeranian Medical University in Szczecin, Student Science Club, Department of Special Nursing, Żołnierska 48, 71-210 Szczecin, Poland

<sup>3</sup> Pomeranian Medical University in Szczecin, Department of Special Nursing, Żołnierska 48, 71-210 Szczecin, Poland

<sup>A</sup> ORCID: 0000-0002-4287-4625; <sup>B</sup> ORCID: 0000-0002-6084-5780

✉ lewandowski195@wp.pl

### ABSTRACT

**Introduction:** Quality of life is a multidimensional concept and a subjective value that depends on many factors. Disability caused by sight loss induces changes for both patients and their carers. The function of a blind person's carer is usually performed by family members, whose limited knowledge limits their ability to help effectively and satisfactorily. This, in turn, may lead to their reduced sense of the quality of life. The aim of this study was to assess the quality of life of blind people's carers.

**Materials and methods:** The study was conducted September–October 2016 and involved 130 blind peoples' carers using a diagnostic poll. Short Form Survey SF-36 and a specially designed questionnaire were used. The majority of participants were

women (69.23%), married couples (63.1%), with high school education (40.77%).

**Results:** Wellbeing self-assessment indicated that 36.15% of carers considered their mental condition to have worsened, while 43.08% remained at the same level when compared to 1 year earlier. Analysis of quality of life showed that carers very highly rated their physical functioning 59.46 ±26.35; social functioning 57.4 ±26.12; vitality 55.48 ±23.27; and emotional functioning 54.81 ±29.24.

**Conclusions:** Quality of life tends to gradually deteriorate as the carers grow older. The carer's educational background and the professional activity of the disabled person influence the assessment of the carer's quality of life.

**Keywords:** quality of life; carers; blind people.

### INTRODUCTION

Concern for patient health has been a part of mankind since the beginnings of medicine. Undoubtedly, in modern times the basic aim of healthcare is to prolong the life of the sick. Along with technological and medical progress, increases in the number of chronic patients have created growing demands for constant care. Despite focusing mainly on treatment for the illness itself, medical personnel are increasingly noticing a need for improvement in the quality of life of both the sick and the carers.

While discussing the matter of quality of life, one cannot omit the significance of the ability to cope with deteriorating living conditions once the illness has been diagnosed. The assessment of well-being by chronic patients is subjective and depends on their condition as well as trouble caused by the illness. Level of life satisfaction and a sense of fulfillment in occupying social roles is another important factor in the quality of life assessment [1, 2].

According to literature, a carer is a person who permanently and regularly provides physical and emotional support for the disabled or the elderly in a weakened condition [3]. In modern health care, carers are the ones that play a key role in delivering care to disabled or chronically ill patients, for example the blind, who are unable to perform domestic duties unaided. Disability caused by sight loss causes changes in the life of family members who have to take care of a blind relative. The process of adaptation to new circumstances depends on how the carers

handle the situation, housing and financial conditions, set of beliefs, family relations, health, education, and personality.

Sight loss afflicting a close relative is unquestionably a problematic situation. During the rehabilitation of blind people, carers are faced with a set of problems concerning health as well as social, emotional, and everyday functioning [4]. A family faced with the necessity to look after a blind relative gradually reduces their social activity. The increasing cost of living caused by additional expense such as rehabilitation, house adjustments or buying computer equipment for the blind, often makes a family exceed the household budget.

While providing care to a disabled blind person, carers tend to become too supportive in contrast to the actual needs of the patient [5]. Excessive protection, in turn, leads not only to the carer's burnout, but also makes a patient completely dependent on them. On the other hand, insufficient attention given to a patient reveals the carer's lack of acceptance of the patient along with their role as a carer [6, 7]. Care problems that blind people's families come across frequently result from a lack of knowledge or skills and insufficient social support [8].

The aim of this study was to assess the quality of life of blind people's carers.

### MATERIALS AND METHODS

The study was conducted September–October 2016 and involved 130 blind persons' carers registered at the Polish Association

of the Blind, West Pomeranian District. The study was based on a diagnostic poll method. The following research tools were used: a specially designed questionnaire concerning sociodemographic data, and Short Form Survey SF-36 regarding gender, age, place of residence, marital status, education, source of income, professional work, type of work, nature of work, financial situation, received social support, assessment of the independence of a blind person, the period of care for a blind person, sense of fatigue. The majority of participants (69.23%) were women. Approximately 44% of all participants were aged 41–60. Approximately 65% of all participants lived in cities with 10–100 thousand inhabitants. Nearly 63% of all participants were married couples. Approximately 40% of all participants held a secondary education degree. The research did not require approval from the Bioethics Committee and the participation was voluntary. All statistical analyses were performed using the statistical computer program PQStat ver. 1.4.2.324. Mann–Whitney U tests and Kruskal–Wallis tests were used. Differences at  $p < 0.05$  were considered statistically significant and at  $p < 0.01$  were considered highly statistically significant. A Kruskal–Wallis test was used to assess the quality of life of caregivers depending on age and level of education (SF-36). A Mann–Whitney test was used to assess the quality of life of caregivers depending on age and level of professional activity (SF-36).

## RESULTS

The vast majority of carers (43.08%) declared their well-being had remained at the same level compared to 1 year earlier, whereas 36.15% of them assessed it as somewhat worse (Tab. 1).

TABLE 1. Assessment of carers' well-being compared to 1 year earlier

Carer's well-being	n	%
Much worse now than 1 year ago	18	13.85
Somewhat worse now than 1 year ago	47	36.15
About the same	56	43.08
Somewhat better now than 1 year ago	5	3.85
Much better now than 1 year ago	4	3.08

According to the analysis of carers' quality of life, higher scores were achieved in 4 domains: physical functioning, social functioning, vitality, and role emotional. Lower scores were achieved in General Health, Role Physical, Bodily Pain, and Mental Health (Tab. 2).

The analysis revealed statistically significant differences ( $p < 0.05$ ) depending on the carers' age in the following domains: role physical, bodily pain, vitality, social functioning, role emotional, and mental health. To sum up, quality of life in the above-mentioned domains worsens along with age (Tab. 3).

Statistically high significant differences ( $p < 0.01$ ) depending on the carers' educational background were observed in physical functioning; role physical, role emotional, whereas statistically significant differences ( $p < 0.05$ ) in General Health and Social Functioning. Scores of carers with elementary education

TABLE 2. Assessment of carers' quality of life (SF-36)

Domain	Descriptive statistics			
	M ±SD	min.–max.	median	Q1–Q3
Physical functioning	59.46 ±26.35	5.0–100.0	60.0	35.0–80.0
Role physical	50.86 ±28.36	0.0–100.0	50.0	31.25–68.75
Bodily pain	50.03 ±24.71	0.0–90.0	42.0	31.0–72.0
General health	51.80 ±17.73	10.0–100.0	51.0	40.0–62.0
Vitality	55.48 ±23.27	0.0–100.0	56.25	43.75–68.75
Social functioning	57.40 ±26.12	0.0–100.0	50.0	37.5–75.0
Role emotional	54.81 ±29.24	0.0–100.0	50.0	41.67–75.0
Mental health	52.81 ±21.12	0.0–100.0	50.0	40.0–60.0

M ±SD – mean and standard deviation

were much lower compared to scores achieved by those with secondary school, vocational school or university graduate education (Tab. 4).

As far as carers' quality of life depending on patient's employment status is concerned, no statistically significant differences were found ( $p > 0.05$ ) only in 2 domains, physical functioning and role physical. As to the other domains, significant differences ( $p < 0.05$ ) and highly significant differences ( $p < 0.01$ ) were observed. Scores were lower among patients remaining unemployed (Tab. 5).

## DISCUSSION

The function of a blind person's carer is usually performed by family members, whose limited knowledge is unable for them to deliver care in an effective and satisfactory way. This, in turn, may lead to a decline in their quality of life. According to this study, blind people usually received care from female carers (69.23%) who were mothers, daughters, or were unrelated. A study conducted by Zysnarska et al. also indicates that women most often become carers of chronically ill patients [9]. The research carried out by Kim et al. and Kim and Spillers among cancer caregivers shows that non-professional care is provided by persons aged 18–90 (55 on average), mainly female (65%) [10, 11].

Our study showed a correlation between the carers' age and a gradual decline in their quality of life. While performing daily activities, participants experienced limitations due to physical health and pain. In addition, social functioning and emotional functioning changed considerably. A study among long-term home carers by Kosińska et al. showed that carers over 61-years-old felt health problems due to care delivery [12]. Our study also indicated that blind people's carers with secondary or university education assessed their quality of life higher than those lesser educated. The same conclusion had been reached by Bobkowicz-Lewartowska in a study on the correlation between

TABLE 3. Assessment of carers' quality of life depending on age (SF-36)

Domain	Carers' age	Descriptive statistics				Kruskal-Wallis test
		M $\pm$ SD	min.-max.	median	Q1-Q3	
Physical functioning	21-40	63.46 $\pm$ 32.46	15.0-100.0	65.00	30.00-100.0	H = 2.26 $\rho$ = 0.3230
	41-60	61.21 $\pm$ 25.71	5.0-100.0	60.00	40.00-80.00	
	60+	55.00 $\pm$ 23.12	5.0-95.0	57.50	35.00-75.00	
Role physical	21-40	61.06 $\pm$ 31.69	6.25-100.0	62.50	31.25-93.75	<b>H = 7.35</b> <b>*<math>\rho</math> = 0.0253</b>
	41-60	53.45 $\pm$ 26.39	0.0-100.0	53.13	37.50-68.75	
	60+	41.85 $\pm$ 26.71	0.0-93.75	40.63	25.00-62.50	
Bodily pain	21-40	60.85 $\pm$ 24.63	22.0-90.0	62.50	41.00-90.00	<b>H = 9.30</b> <b>*<math>\rho</math> = 0.0096</b>
	41-60	51.31 $\pm$ 26.34	0.0-90.0	51.00	31.00-74.00	
	60+	42.30 $\pm$ 20.10	0.0-90.0	41.00	31.00-52.00	
General health	21-40	59.19 $\pm$ 22.37	15.0-100.0	53.50	45.00-82.00	H = 3.85 $\rho$ = 0.1457
	41-60	50.52 $\pm$ 17.18	10.0-87.0	52.00	40.00-62.00	
	60+	49.24 $\pm$ 14.44	10.0-85.0	47.00	40.00-57.00	
Vitality	21-40	65.87 $\pm$ 23.53	25.0-100.0	68.75	50.00-87.50	<b>H = 10.71</b> <b>*<math>\rho</math> = 0.0047</b>
	41-60	56.03 $\pm$ 24.02	0.0-100.0	56.25	43.75-68.75	
	60+	48.91 $\pm$ 20.17	0.0-93.75	50.00	37.50-62.50	
Social functioning	21-40	69.23 $\pm$ 24.81	25.0-100.0	68.75	50.00-100.0	<b>H = 8.29</b> <b>*<math>\rho</math> = 0.0158</b>
	41-60	56.47 $\pm$ 26.10	0.0-100.0	62.50	37.50-75.00	
	60+	51.90 $\pm$ 25.27	0.0-100.0	50.00	37.50-62.50	
Role emotional	21-40	68.91 $\pm$ 28.34	25.0-100.0	66.67	50.00-100.0	<b>H = 11.70</b> <b>*<math>\rho</math> = 0.0029</b>
	41-60	56.75 $\pm$ 25.58	0.0-100.0	50.00	50.00-75.00	
	60+	44.38 $\pm$ 30.73	0.0-100.0	50.00	25.00-58.33	
Mental health	21-40	62.50 $\pm$ 18.77	35.0-100.0	60.00	50.00-70.00	<b>H = 10.20</b> <b>*<math>\rho</math> = 0.0061</b>
	41-60	52.76 $\pm$ 22.40	0.0-100.0	50.00	40.00-65.00	
	60+	47.39 $\pm$ 19.05	0.0-100.0	47.50	35.00-55.00	

M  $\pm$ SD – mean and standard deviation

\*p – statistical significance

life satisfaction and educational level of mothers taking care of children with Down syndrome [13]. Other researchers support the conclusions [14]. The results obtained by Kim et al. indicate that the unfulfilled needs of the caregivers depend on the age, gender, education, and even on the ethnic origin of the caregiver. In the research, the authors showed that younger female caregivers had greater unsatisfied psychosocial needs than older male caregivers. Persons with higher education reported unsatisfied psychosocial needs and daily life needs [15]. Our research and research done by others indicate that the daily efforts of caregivers providing non-professional care, their unsatisfied needs, lack of support and assistance, lead to a deterioration in their quality of life. Buchanan and Huang observed that older caregivers displayed worse health-related quality of life (HRQOL) results in the physical area, which is similar to the outcome of our research based on Short Form Health Survey SF-36 [16].

Providing care for a blind person does not have to inevitably contribute to a decline in quality of life. In accordance with Straś-Romanowska, people can lead a satisfactory life despite adverse circumstances [17]. Dębicka in her study pointed to a correlation between blind people and carers' sense of a high quality of life [18].

Care delivered by family members is usually a source of satisfaction. More than half of the participants taking part in this research did not experience emotional fatigue due to providing care and accepted the role of a carer. The participants did not express the feeling of being restricted when it came to the fulfillment of their needs. The majority of them were retired or drew a pension, which might suggest that the time spent together with the blind relative was mutually beneficial in terms of social relations. The blind constitute a specific group among the disabled, and in most cases do not require much help with personal care. Hence, providing care does not have to be highly demanding.

In contrast, numerous studies conducted among carers looking after people with disabilities other than blindness show that the emotional strain is greater. Carers express physical and mental fatigue leading to exhaustion and ignoring their own needs [9, 19, 20, 21]. The research done by Stenberg et al. showed that the most frequent problems encountered by caregivers providing care to their relatives were physical problems such as sleeping disorders and fatigue [22]. The problems burdening caregivers vary, depending on their experience in providing non-professional care, the intensity and nature

**TABLE 4.** Assessment of carers' quality of life depending on educational background (SF-36)

Domain	Education	Descriptive statistics				Kruskal–Wallis test
		M ±SD	min.–max.	median	Q1–Q3	
Physical functioning	primary	38.04 ±24.01	5.0–85.0	40.00	20.00–60.00	<b>H = 18.07</b> <b>*p = 0.0004</b>
	vocational	61.58 ±26.71	10.0–100.0	65.00	40.00–85.00	
	secondary	64.15 ±22.05	20.0–100.0	65.00	50.00–80.00	
	university	69.69 ±27.84	30.0–100.0	72.50	35.00–100.0	
Role physical	primary	32.07 ±17.61	0.0–62.5	31.25	25.00–50.00	<b>H = 17.42</b> <b>*p = 0.0006</b>
	vocational	51.15 ±32.13	0.0–100.0	50.00	31.25–75.00	
	secondary	54.60 ±24.37	0.0–100.0	56.25	37.50–68.75	
	university	64.84 ±32.51	0.0–100.0	68.75	50.00–93.75	
Bodily pain	primary	48.30 ±27.23	0.0–90.0	41.00	31.00–60.00	H = 1.60 p = 0.6600
	vocational	48.87 ±24.20	12.0–90.0	41.00	31.00–64.00	
	secondary	49.38 ±24.59	0.0–90.0	51.00	31.00–72.00	
	university	57.44 ±23.54	22.0–90.0	56.00	41.00–82.00	
General health	primary	42.65 ±10.19	15.0–57.0	45.00	35.00–50.00	<b>H = 10.67</b> <b>*p = 0.0136</b>
	vocational	52.68 ±19.80	15.0–92.0	52.00	40.00–65.00	
	secondary	52.43 ±17.25	10.0–87.0	52.00	40.00–62.00	
	university	60.75 ±18.30	40.0–100.0	53.50	50.00–74.50	
Vitality	primary	55.16 ±25.26	0.0–100.0	50.00	43.75–87.50	H = 3.18 p = 0.3646
	vocational	55.59 ±24.18	6.25–100.0	59.38	43.75–68.75	
	secondary	52.83 ±21.81	0.0–100.0	50.00	43.75–62.50	
	university	64.45 ±22.79	25.0–93.75	68.75	46.88–84.38	
Social functioning	primary	47.28 ±23.52	0.0–87.5	50.00	37.50–62.50	<b>H = 10.20</b> <b>*p = 0.0169</b>
	vocational	58.55 ±28.04	0.0–100.0	62.50	37.50–75.00	
	secondary	55.90 ±23.97	0.0–100.0	50.00	37.50–75.00	
	university	74.22 ±25.60	25.0–100.0	87.50	56.25–93.75	
Role emotional	primary	35.87 ±22.95	0.0–75.0	41.67	25.00–50.00	<b>H = 14.18</b> <b>*p = 0.0027</b>
	vocational	56.36 ±33.08	0.0–100.0	54.17	41.67–75.00	
	secondary	57.70 ±24.78	0.0–100.0	50.00	41.67–66.67	
	university	68.75 ±30.96	16.6–100.0	79.17	50.00–100.0	
Mental health	primary	49.13 ±16.76	0.0–80.0	50.00	40.00–60.00	H = 2.88 p = 0.4102
	vocational	55.79 ±21.89	20.0–100.0	50.00	40.00–70.00	
	secondary	49.81 ±21.24	0.0–100.0	50.00	35.00–55.00	
	university	60.94 ±23.11	30.0–95.0	55.00	45.00–85.00	

M ±SD – mean and standard deviation  
\*p – statistical significance

of the tasks involved in such care. The presented research and other reports show that there is no objective or subjective research evaluating the caregivers' burdens and quality of life. The research helps better understand the needs and aspects of care related to the biopsychosocial condition of the caregivers [23].

According to this study, carers achieved the highest score in following domains: physical functioning, social functioning, vitality, and role emotional. Lower results were achieved in General Health, Role Physical, and Mental Health.

It is possible for a blind person to achieve self-sufficiency. According to a report released in 2010 by the Polish Association of the Blind, the number of employed blind people amounted

to 5990, which was only 18% of the general working age population of the blind (33009) [24].

Help in the learning and vocational training of a child or retraining of an adult may be a source of joy for carers. Most often, however, due to passive behavior, or fear of losing a disability pension, along with overprotectiveness from relatives, blind people are excluded from the labour market. Scholars are unanimous that the economic inactivity of the blind leads to seclusion, marginalization, low self-esteem, which consequently causes a decline of the quality of life of blind people and their carers [25, 26]. Our study revealed that scores achieved in most of the SF-36 domains are lower among carers of economically inactive blind people. The lowest scores were achieved in social functioning and vitality.

TABLE 5. Assessment of carers' quality of life depending on patient's employment status (SF-36)

Domain	Employed	Descriptive statistics				Mann-Whitney U test
		M ±SD	min.–max.	median	Q1–Q3	
Physical functioning	no	60.05 ±25.98	5.0–100.0	60.00	40.00–80.00	Z = 0.48 p = 0.6284
	yes	56.43 ±28.69	15.0–100.0	65.00	20.00–75.00	
Role physical	no	48.74 ±28.18	0.0–100.0	50.00	31.25–62.50	Z = -1.65 p = 0.0981
	yes	61.90 ±27.31	25.0–100.0	62.50	31.25–87.50	
Bodily pain	no	47.34 ±24.10	0.0–90.0	42.00	31.00–62.00	<b>Z = -2.46</b> <b>*p = 0.0137</b>
	yes	64.00 ±23.60	30.0–90.0	61.00	41.00–90.00	
General health	no	50.05 ±17.30	10.0–92.0	50.00	40.00–62.00	<b>Z = -2.18</b> <b>*p = 0.0295</b>
	yes	60.90 ±17.52	40.0–100.0	55.00	45.00–82.00	
Vitality	no	51.89 ±22.53	0.0–100.0	50.00	43.75–62.50	<b>Z = -3.98</b> <b>*p = 0.0001</b>
	yes	74.11 ±17.82	37.5–100.0	81.25	62.50–87.50	
Social functioning	no	53.56 ±25.63	0.0–100.0	50.00	37.50–75.00	<b>Z = -3.92</b> <b>*p = 0.0001</b>
	yes	77.38 ±18.80	37.5–100.0	87.50	62.50–87.50	
Role emotional	no	52.29 ±29.48	0.0–100.0	50.00	33.33–75.00	<b>Z = -2.05</b> <b>*p = 0.0401</b>
	yes	67.86 ±24.62	25.0–100.0	66.67	50.00–91.67	
Mental health	no	50.46 ±21.20	0.0–100.0	50.00	40.00–55.00	<b>Z = -3.56</b> <b>*p = 0.0004</b>
	yes	65.00 ±16.28	30.0–100.0	60.00	55.00–80.00	

M ±SD – mean and standard deviation

\*p – statistical significance

According to our study, it is advisable to find “the virtuous mean”. This should be achieved through defining the scope of assistance and the necessary degree of independence that would ensure a blind person's safety without lowering their self-esteem. The role of carers in this demanding task is essential and invaluable, therefore, they should receive support from public institutions.

General practitioners, providing long-term healthcare, ensure continuous treatment and care meeting the needs of the patients and their caregivers. The demand for long-term care to persons with chronic illnesses and disabilities is very high and is on the increase. Family and caregivers play an important role in providing care to persons suffering a disease. They frequently come across numerous difficulties and hardships both in terms of their everyday life, emotions, social and professional lives. The problems encountered by family members result from insufficient knowledge and skills, as well as insufficient social support, and therefore it is the role of the family doctor and the entire interdisciplinary team of primary healthcare professionals to support those who provide care to patients with chronic diseases and disabilities.

## CONCLUSIONS

1. Quality of life tends to gradually deteriorate as the carers grow older.
2. Carer's educational background and the professional activity of the blind person influence the carers' assessment of the quality of life.

## REFERENCES

1. Stelcer B. Jakość życia i integracja psychiczna. In: Wołowicka L, editor. Jakość życia w naukach medycznych. Poznań: Dział Wydawnictw Uczelnianych Akademii Medycznej im. Karola Marcinkowskiego; 2002. p. 117-27.
2. Kowalik S. Pomiar jakości życia – kontrowersje teoretyczne. In: Bańka A, Derbis R, editors. Pomiar i poczucie jakości życia u aktywnych zawodowo oraz bezrobotnych. Poznań: Środkowoeuropejskie Centrum Ekonomii Działania Społecznego; 1995. p. 75-85.
3. Rosochacka-Gmitrzak M. Wsparcie opiekunów nieformalnych – w stronę równowagi społecznych oczekiwań i opiekuńczych możliwości rodzin. In: Raćław M, editor. Publiczna troska, prywatna opieka. Społeczności lokalne wobec osób starszych. Warszawa: Fundacja Instytut Spraw Publicznych; 2011. p. 140.
4. Kawczyńska-Butrym Z. Wyznania rodziny: zdrowie, choroba, niepełnosprawność, starość. Lublin: Wydawnictwo Makbet; 2008. p. 107-38.
5. Janocha W. Rodzina z osobą niepełnosprawną w społecznym systemie wsparcia. Niepełnosprawność, rodzina, wsparcie społeczne – wybrane zagadnienia. Kielce: Jedność; 2009. p. 20-5.
6. Kawczyńska-Butrym Z. Rodzina. koncepcje i przemiany rodziny. In: Majchrowska A, editor. Wybrane elementy socjologii. Lublin: Czelej; 2003. p. 163-90.
7. Kotowski S. Przewodnik po problematyce osób niewidomych i słabowidzących. Warszawa: Fundacja Polskich Niewidomych i Słabowidzących Trakt; 2008. p. 200-12.
8. Tracz M, Łukasik E, Oleksiak E, Brackenridge B, Rudnicka A. Edukacja niewidomych i słabowidzących chorych na cukrzycę. Warszawa: Katedra i Klinika Gastroenterologii i Chorób Przemiany Materii AM oraz Polski Związek Niewidomych; 1999. p. 21.
9. Zysnarska M, Wojnicz-Michera I, Taborowska M, KołECKI P, Maksymiuk T. Kobieta – opiekun osoby przewlekle chorej – wyznaczniki przeciążenia. Now Lek 2010;79(5):386-91.
10. Kim Y, Kashy DA, Kaw CK, Smith T, Spillers RL. Sampling in population-based cancer caregivers research. Qual Life Res 2009;18:981-9.
11. Kim Y, Spillers RL. Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. Psychooncology 2010;9(4):431-40.

12. Kosińska M, Kułagowska E, Niebrój L, Stanisławczyk D. Obciążenia opiekunów osób zakwalifikowanych do długoterminowej opieki domowej. *Med Środow* 2013;16(2):1-10.
13. Bobkowicz-Lewartowska L. Wybrane uwarunkowania jakości życia rodziców dzieci i młodzieży z zespołem Downa. Warszawa: Difin; 2013. p. 34-9.
14. Nadler A, Lewinsein E, Rahav G. Acceptance of mental retardation and help-seeking-by mothers and fathers of children with mental retardation. *Ment Retard* 1999;29:17-23.
15. Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: 3 cohorts comparison. *Psychooncology* 2010;19(6):573-82.
16. Buchanan R, Huang C. Health-related quality of life among informal caregivers assisting people with multiple sclerosis. *Disabil Rehabil* 2011;33(2):113-21.
17. Straś-Romanowska M. Jakość życia: wielki temat w psychologii. Wrocław: Instytut Psychologii; 2003: Nieopublikowany wykład. Instytut Psychologii.
18. Dębicka U. Poczucie jakości życia osób niepełnosprawnych i ich opiekunów. Doniesienia z badań. In: Palak Z, Lewicka A, Bujnowska A, editors. *Jakość życia a niepełnosprawność*. Lublin: Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej; 2006. p. 109-21.
19. Mikołajewska E. Kierunki wsparcia opiekunów pacjentów po przebytym udarze mózgu w opiece domowej. *Udar Mózgu* 2011;13(1-2):12-7.
20. Chądzyńska M, Spiridonow K, Kasperek B, Meser J. Porównanie jakości życia osób chorych na schizofrenię i ich opiekunów. *Psychiatr Pol* 2003;37(6):1025-36.
21. Grabowska-Fudala B, Jaracz K. Obciążenie osób sprawujących opiekę nad chorymi po udarze mózgu. *Udar Mózgu* 2007;9(1):24-31.
22. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2010;19(10):1013-25.
23. Frambes D, Given B, Lehto R, Sikorskii A, Wyatt G. Informal caregivers of cancer patients: Review of interventions, care activities, and outcomes. *West J Nurs Res* 2017;40(7):1069-97.
24. Kik P. Raport o orzecznictwie i sytuacji osób niewidomych i niedowidzących na rynku pracy. Fundacja Widzialni/Fundacja Imago; 2012. [http://projekt.nowaperspektywa.org/container/dokumenty/analizy%20eksperckie/Raport%20o%20orzecznictwie%20i%20sytuacji%20osob%20niewidomych%20i%20niedowidzacych\\_etap%20I.pdf](http://projekt.nowaperspektywa.org/container/dokumenty/analizy%20eksperckie/Raport%20o%20orzecznictwie%20i%20sytuacji%20osob%20niewidomych%20i%20niedowidzacych_etap%20I.pdf) (11.04.2017).
25. Rydzewski P, Maciejewska R, Bielecka-Prus J, Szkoła A. Osoby niepełnosprawne na rynku pracy Lubelszczyzny. Lublin: WSPA; 2011. p. 11-263.
26. Żbikowski J, Dąbrowski D, Kuźmicki M, editors. *Problemy aktywności zawodowej osób z niepełnosprawnością zamieszkałych na obszarach wiejskich*. Biała Podlaska: Wydawnictwo PSW im. Papieża Jana Pawła II; 2012. p. 230-78.