

Ilona Kuźmicz^{1,2}, Marta Szeliga^{3,2}, Iwona Repka⁴, Ewa Kawalec-Kajstura¹, Joanna Sułkowska⁵

¹ Department of Internal Medicine and Community Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College (JU MC), Krakow

² St. Lazarus Hospice, The Society of Friends to People in Disease, Krakow

³ Department of Medical Education, Faculty of Medicine, Jagiellonian University Medical College (JU MC), Krakow

⁴ Department of Clinical Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College (JU MC), Krakow

⁵ Department of Internal Medicine and Community Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College (JU MC), Krakow – PhD student

ASSESSMENT OF THE MULTIDEMENTIONAL BURDEN AMONG INFORMAL CAREGIVERS OF HOSPICE CARE PATIENTS

Ocena obciążenia nieformalnych opiekunów pacjentów objętych opieką hospicyjną

Streszczenie

Wstęp

Sprawowanie opieki przez opiekunów nieformalnych nad osobą bliską u kresu życia może powodować wystąpienie negatywnych konsekwencji, w tym symptomów obciążenia manifestujących się na różnych płaszczyznach.

Cel

Ocena poziomu obciążenia w grupie opiekunów nieformalnych.

Materiał i metody

Badaną grupę stanowiło 30 opiekunów nieformalnych, których bliscy byli objęci opieką hospicyjną. W badaniu wykorzystano polską wersję Caregiver Burden Scale.

Wyniki

Najwyższy poziom obciążenia stwierdzono w podskali *Wysiłek ogólny* (Mean=2.71) oraz *Rozczarowanie* (Mean=2.48), a najniższy w podskali *Zaangażowanie emocjonalne* (Mean=1.78). Wykazano istotny statystycznie związek pomiędzy wynikiem całkowitym ($p=0.009$), poziomem obciążenia dla podskali *Izolacja społeczna* ($p=0.012$) oraz *Otoczenie* ($p=0.026$) a okresem sprawowanej opieki.

Wnioski

Jakkolwiek, w badanej populacji opiekunów odnotowano średni poziom obciążenia dla wszystkich podskal z wyjątkiem podskali *Zaangażowanie emocjonalne*, to analiza przypadków wykazała wysoki poziom obciążenia w różnych podskalach u niektórych badanych.

Słowa kluczowe: obciążenie, opiekun nieformalny, hospicjum

Abstract

Introduction

Taking care of a close relative who is coming to the end of their life may lead to negative consequences for their caregivers including the symptoms of multidimensional burden.

Aim of the study

The aim of the study was the assessment of the burden in a group of informal caregivers.

Material and methods

The study was conducted in a group of 30 informal caregivers whose close relatives were taken into hospice care. A Polish version of Caregiver Burden Scale was applied in the study.

Results

The highest level of burden was observed on the *General strain* (Mean=2.71) and *Disappointment* (Mean=2.48) subscales, whereas the lowest level on the *Emotional involvement* subscale (Mean=1.78). A statistically significant correlation was found between the total score ($p=0.009$), the level of burden on the *Isolation* ($p=0.012$) and *Environment* ($p=0.026$) subscales and the period of time during which care was provided.

Conclusions

Although in the examined group of caregivers a moderate level of burden was observed on all the subscales except the *Emotional involvement* one, an analysis of particular cases showed a high level of burden on various subscales in some respondents.

Key words: burden, informal caregiver, hospice

Introduction

According to World Health Organization the global cancer burden is estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018 [www1]. Similarly, an analysis of the data from the National Cancer Register also shows that the cancer burden in Poland is growing, reaching over 160,000 new cases in 2016 [www2]. An increase in the number of patients is accompanied by a growing number of caregivers who take on the burden of looking after their ill relatives [Gawlik et al., 2015]. In the case of hospice care, they are an essential part of an interdisciplinary team taking care of patients [de Graaf et al., 2016]. Although scientific publications frequently emphasize the role of caregivers looking after chronic patients in home environment, there is still little information on the care provided to patients who are coming to the end of their life [Janowicz, 2014]. According to study findings, most patients prefer to die at home [de Graaf et al., 2016], in which case the main burden of care is shouldered by their caregivers.

According to Family Caregiver Alliance National Centre of Caregiving, a family (informal) caregiver is “any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary care givers and live with, or separately from, the person receiving care” [www3].

Therefore, in various stages of disease, the patient and their family should be a focal point of concern in hospice care. Informative, instrumental and emotional support that caregivers may provide makes it possible for them to look after patients in the home environment as well as participate safely in stationary hospice care. However, active participation in providing care to chronic patients may, in consequence, result in the incidence of symptoms of multidimensional burden in caregivers’ functioning.

The aim of the study was to assess the burden among family caregivers looking after their relatives taken into hospice care.

Material and methods

The study was conducted in a group of 30 informal caregivers whose relatives were in hospice care provided by St. Lazarus Hospice, The Society of Friends to People in Disease in Krakow. These caregivers gave their informed consent to participate in the study, they took an active part in patients’ care and they were over 18 years old. The caregivers whose relatives were in agonal stage were excluded from the study.

The study received an approval from Bioethics Committee of Jagiellonian University nb. 122.6120.219.2015.

The study made use of a Polish version of Caregiver Burden Scale (CBS) consisting of 22 questions which belong to 5 subscales such as *General strain* (8 questions), *Isolation* (3 questions), *Disappointment* (5 questions), *Emotional involvement* (3 questions) and *Environment* (3 questions). Particular questions were scored according to a 4-point scale, on which 1 means never, 2 – rarely, 3 – sometimes and 4 – frequently. The higher the score, the higher the level of burden [Grabowska-Fudała and Jaracz, 2006].

The findings of the study were analysed with the application of R 3.3.1 program. The results were presented in the form of the mean and standard deviation as well as median, minimum and maximum. Depending on the type of variables, distribution calculations were conducted with the application of the following tests: U Mann-Whitney test, T-Student test, ANOVA or Kruskal-Wallis ANOVA test. The level of significance was assumed at $\alpha = 0.05$.

Results

Characteristics of the examined group: the examined group consisted of 30 family caregivers (18 women and 12 men). The average age of respondents was 63.5 ± 10.82 years old. The average period of caregiving was 17.7 ± 13.59 months.

Table 1. Level of burden according to Caregiver Burden Scale – descriptive statistics
Tabela 1. Poziom obciążenia według Caregiver Burden Scale – statystyki opisowe

CBS	M	SD	Me	Min	Max
Total score	2,39	0,59	2,45	1,23	3,45
General strain	2,71	0,55	2,69	1,63	3,75
Isolation	2,28	0,98	2,67	1,00	3,67
Disappointment	2,48	0,69	2,70	1,00	3,60
Emotional involvement	1,78	0,93	1,33	1,00	3,67
Environment	2,10	0,92	2,00	1,00	3,67

Legend: M – arithmetic mean, SD – standard deviation, Me – median, Min – minimum, Max – maximum

Source materials: Study based on the authors' own research.

The highest value of the average level of burden was observed on the *General strain* (Mean= 2.71 ± 0.55) and *Disappointment* (Mean= 2.48 ± 0.69) subscales, whereas the lowest level on the *Emotional involvement* subscale (Mean= 1.78 ± 0.69); Table 1.

The highest number of respondents reported a low level of burden on *Emotional involvement* (n=21; 70.0%) and *Environment* (n=14; 46.6%) subscales. On the other hand, a moderate level of burden was observed in the highest number of respondents on *General strain* (n=17; 56.6%) and *Disappointment* (n=16; 53.3%) subscales. About 1/3 of the caregivers reported a high level of burden on *General strain* (n=10; 33.3%), *Isolation* (n=11; 36.6%) and *Disappointment* (n=9; 30.0%) subscales; Figure 1.

During the study the caregivers had also a chance to describe their life circumstances. Selected comments are presented below:

I'm a single mother and we live separately, I have a small child but my father is already an elderly man and he cannot cope on his own (daughter, aged 43, period of caregiving: 5 months).

I suffer from diabetes and because of diabetic neuropathy my fingers are numb. I'm 76 years old. I have to travel a long way and there's a problem with our dog, which has been living with us for 17 years (husband, period of caregiving: 4 months).

My social life came to an end when my wife got ill. I have been with her for 55 years and she's my companion. I have no plans. It's impossible to escape your fate (husband, aged 76, period of caregiving: 12 months).

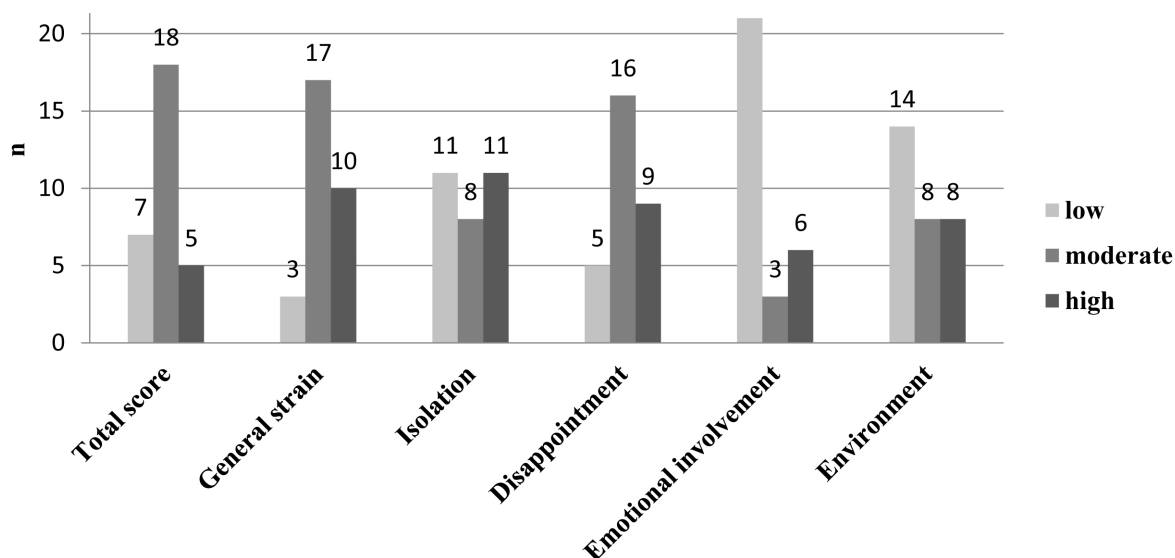


Figure 1. Distribution of the level of burden in particular subscales according to Caregiver Burden Scale

Rycina 1. Rozkład poziomu obciążenia w poszczególnych podskalach według Caregiver Burden Scale

Source materials: Study based on the authors' own research.

A correlation between the level of burden on particular subscales and sociodemographic variables was analysed as well. The analysis did not show a statistically significant correlation between the burden and the respondents' age ($p>0.05$), gender ($p>0.05$), education ($p>0.05$) or place of residence ($p>0.05$). However, a statistically significant correlation was observed between the total CBS score, the level of burden on *Isolation* and *Environment* subscales and the period of caregiving. The caregivers who have been involved in looking after their relatives for less than 6 months obtained a statistically significantly ($p=0.009$) lower total score (Mean=2.03) than people providing such care for over 12 months (Mean=2.75); Figure 2.

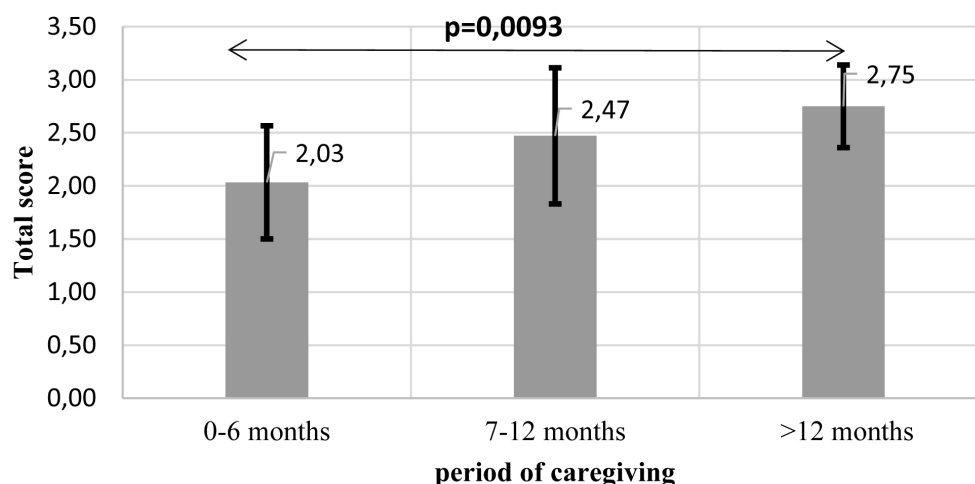


Figure 2. Correlation between the period of caregiving and the total CBS score

Rycina 2. Związek okresu sprawowanej opieki z wynikiem całkowitym CBS

Source materials: Study based on the authors' own research.

Corresponding results were observed also on *Isolation* subscale. The respondents who have been involved in caregiving for less than 6 months reported a statistically significantly ($p=0.012$) lower total score

(Mean=1.75) than those who have been looking after their relatives for more than 12 months (Mean=2.90); Figure 3.

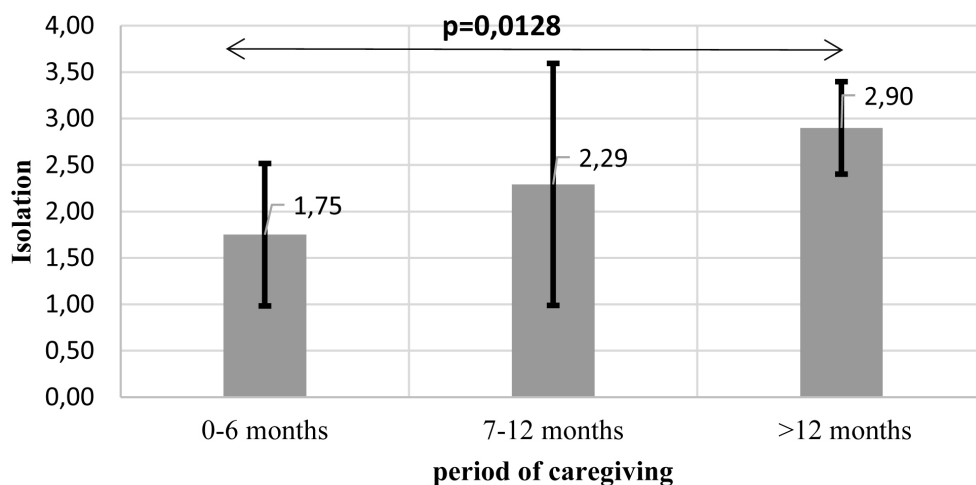


Figure 3. Correlation between the period of caregiving and the level of burden on Isolation subscale

Rycina 3. Związek okresu sprawowanej opieki z poziomem obciążenia w podskali Izolacja społeczna

Source materials: Study based on the authors' own research

On the other hand, the results obtained on *Environment* subscale showed statistically significant differences in the level of burden in the group of people who have been participating in caregiving for less than 6 months (Mean=1.47), for those who have been doing it for 7 to 12 months (Mean=2.67) and those who have been looking after their relatives for more than 12 months (Mean=2.40); Figure 4.

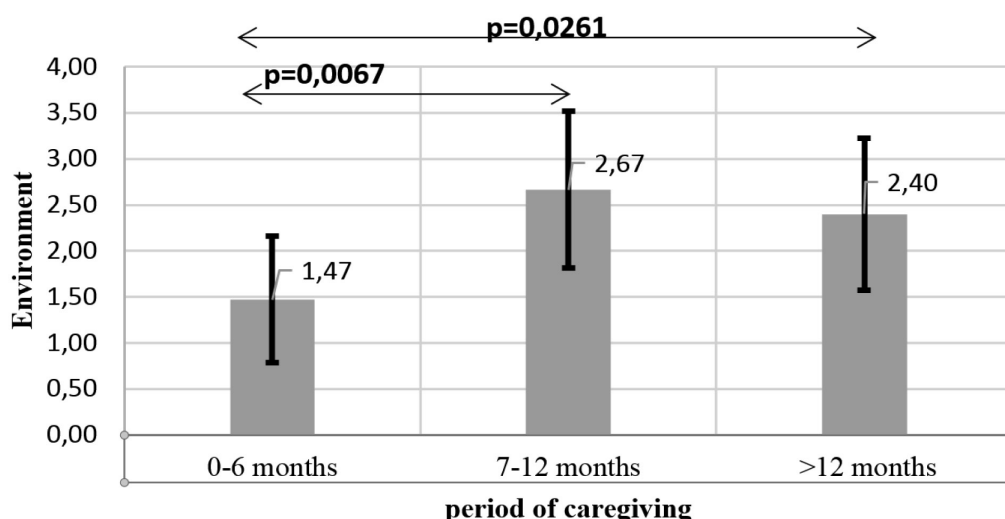


Figure 4. Correlation between the period of caregiving and the level of burden on Environment subscale

Rycina 4. Związek okresu sprawowanej opieki z poziomem obciążenia w podskali Otoczenie

Source materials: Study based on the authors' own research.

Discussion

Although informal family caregivers perceive their active participation in looking after their relatives as a natural activity, the fact of becoming such a caregiver is a random event [Velo and Tripodoro, 2016].

In our daily working routine, health practitioners deal with members of patients' families who are not prepared enough to become caregivers. Sometimes the problem is not only their lack of sufficient knowledge about the disease, its symptoms, planned treatment or potential sources of support, but also frequently they do not have sufficient skills to provide care safely their relatives.

The analyses that have been conducted so far confirm insufficient knowledge of caregivers and emphasize the need for their proper education [Docherty et al., 2008], which will allow them to satisfy patients needs in an optimal way [Farguhar et al., 2016]. Moreover, some relatives of hospice patients' also suffer from chronic diseases, including cancer and frequently the necessity to look after their loved ones results in exacerbation of their own health problems. Sometimes the person who decides to take on caregiving undergoes oncological treatment or grieves the loss of another close relative or friend. Other factors responsible for increasing caregivers' stress include lack of support from other family members, financial problems and the necessity to reorganize their personal, professional and family life.

Previous researches indicate a significant correlation between an active participation in caregiving and the incidence of burden in caregivers [Kinoshita et al., 2014; Sun et al., 2015; Velo and Tripodoro, 2016; Ponczek, Głowacka and Kośmider, 2017; Deluga et al., 2018; Szala and Potempkowski, 2018; Repka et al., 2019]. The burden experienced by caregivers includes physical, psychological and socio-economic problems [Velo and Tripodoro, 2016; Krug et al., 2016]. Caregivers have to cope with fear, helplessness or loss, and they may suffer from depression, tiredness or exhaustion [Krug et al., 2016]. Additionally, it has been proved that deterioration of patients' functioning has a negative influence on their caregivers' burden [Krug et al., 2016; Deluga et al., 2018], whereas the awareness of patients' preferences and needs might facilitate caregivers' care [Grądalski and Kochan, 2017].

This study conducted in a group of 30 caregivers actively looking after their hospice care relatives showed a moderate level of burden on all subscales except *Emotional involvement* (Mean 1.78 ± 0.93). Similar results were obtained by Grabowska-Fudała, whose findings showed a moderate level of burden on all subscales except *Emotional involvement* (1.75 ± 0.68) and *Environment* (1.83 ± 0.85). The aforementioned studies were conducted in a group of people looking after their relatives in the period of 6 months after their hospitalization following their first cryptogenic cerebral stroke [Grabowska-Fudała, Jaracz and Górna, 2012]. However, the studies carried out by Dulaga et al. [2018] in a group of 150 caregivers working with patients requiring long-time home nursing showed a higher level of burden accompanied by a positive experience of provided care. The caregivers' burden was assessed with the application of COPE Index [Deluga et al., 2018].

In the analysis of the results of this study, the authors did not observe a statistically significant correlation between the burden and the respondents' age ($p > 0.05$), gender ($p > 0.05$), education ($p > 0.05$) or place of residence ($p > 0.05$). Different results were obtained by Repka et al. [2019], who conducted a research in a group of 80 caregivers looking after children undergoing oncological treatment. Their study was based on Daily Life Fatigue Questionnaire. The authors showed that the level of physical fatigue was decreasing with the respondents' age, and women, as compared to men, reported a higher level of general physical and mental fatigue [Repka et al., 2019]. These differences may result not only from the size of the group but also from the fact that children cancer diagnosis and oncological treatment are extremely traumatic experiences for parents.

This study also shows that the respondents whose period of caregiving was the longest experienced higher burden as far as *Isolation* subscale was concerned. Moreover, the results obtained on *Environment* subscale showed that the caregivers who have been looking after their relatives for 7 to 12 months and those who have been doing it for more than 12 months experienced higher burden than the respondents with a shorter period of caregiving.

Conclusions

1. In the examined group of caregivers a moderate level of burden was observed on all the subscales except the *Emotional involvement* one.
2. The rewerescases of high level of burden on various subscales.
3. A higher level of burden was observed on *Isolation* subscale in the group of caregivers looking after their relatives for more than 12 months and on *Environment* subscale in the group of respondents with the period of care giving between 7 and 12 months.
4. It is essential to identify caregivers' problems and needs in order to provide them with optimal support.
5. Further studies in a bigger group of caregivers should be conducted in the future taking into account variables such as patients' functional capacity, intensity of disease symptoms, medical diagnosis, intercurrent diseases and also caregivers' quality of life.

References

1. de Graaf Everlien, Zweers Daniëlle, Valkenburg Anna C., Uyttewaal Allegonda, Teunissen Saskia C. 2016. Hospice assistat home: does the integration of hospice care in primary health care support patients to die in their preferred location – a retrospective cross-section aevaluation study. *Palliative medicine*. vol. 30, issue 6: 580-586.
2. Deluga Alina, Bartoszek Agnieszka, Ślusarska Barbara, Kocka Katarzyna, Nowicki Grzegorz, Piasecka Katarzyna, Kachaniuk Hanna 2018. Obciążenie opiekunów nieformalnych a sprawność funkcjonalna i umysłowa pacjentów objętych opieką domową. *Pomeranian Journal of Life Sciences*. vol. 64, issue 4: 79-83.
3. Docherty Andrea, Owens Alastair, Asadi-Lari Mohsen, Petchey Roland, Williams Jacky, Carter Yvonne H. 2008. Knowledge and information needs of informal caregivers in palliative care: a. *Palliative Medicine*. vol. 22, issue 2: 153-171.
4. Farquhar Morag, Penfold Clarissa, Walter Fiona M, Kuhn Isla, Benson John 2016. What are the key elements of educational interventions for laycarers of patients with advanced disease? A systematic literature search and narrative review of structural components, processes and modes of delivery. *Journal of pain and symptom management*. vol. 52, issue 1: 117-130.
5. Grabowska-Fudala Barbara, Jaracz Krystyna 2006. Obciążenie osób sprawujących opiekę nad chorymi po przebytych udarze mózgu. *Udar Mózgu*. vol. 8, issue 1: 42-47.
6. Grabowska-Fudala Barbara, Jaracz Krystyna, Górna Krystyna 2012. Obciążenie opiekunów chorych po udarze mózgu – wyniki wstępne oceny prospektywnej. *Nowiny Lekarskie*. vol. 81, issue 1: 3-9.
7. Grądalski Tomasz, Kochan Krystyna 2017. Oczekiwania głównych opiekunów chorych niezdolnych do wyrażenia woli u kresu życia. *Medycyna Paliatywna*. vol 9, issue 1: 21-29.
8. Gawlik Marta, Kurpas Donata 2015. Ocena jakości życia opiekunów domowych pacjentów z chorobą nowotworową z wykorzystaniem kwestionariusza Caregiver Quality of Life-Cancer. *Medycyna Paliatywna*. vol. 7, issue 1: 67-77.
9. Janowicz Anna 2014. Rola opiekunów nieformalnych w opiece u kresu życia. Przyczynek do badań w ramach projektu European Palliative Care Academy (EUPCA). *Pielęgniarstwo i zdrowie publiczne*. vol. 4, issue 2: 161-167.
10. Kinoshita Hiroya, Maeda Isseki, Morita Tatsuya, Miyashita Mitsunori, Yamagishi Akemi, Shirahige Yutaka, Takebayashi Toru, Yamaguchi Takuhiro, Igarashi Ayumi, Eguchi Kenji 2014. Place of death and the differences in patient quality of death and dying and care giver burden. *Journal of Clinical Oncology*. vol. 33, issue 4: 357-363.
11. Krug Katja, Miksch Antje, Peters-Klimm Frank, Engeser Peter, Szecsenyi Joachim 2016. Correlation between patient quality of life in palliative care and burden of their family caregivers: a prospective observation cohort study. *BMC palliative care*. vol. 5, issue 1: 4.

12. Ponczek Danuta, Głowacka Mariola, Kośmider Natalia 2017. Zespół wypalenia opiekuna wśród rodzin pacjentów przebywających w ośrodku opieki długoterminowej lub paliatywnej. *Pielęgniarstwo w Opiece Długoterminowej*. issue 1: 4-8.
13. Repka Iwona Barbara, Betka Patrycja, Kuźmich Ilona, Puto Grażyna, Zurzycka Patrycja 2019. Zmęczenie rodziców sprawujących opiekę nad dzieckiem z chorobą nowotworową. *Medycyna Paliatywna*. vol. 11, issue 2: 88-96.
14. Sun Virginia, Grant Marcia, Koczywas Marianna, Freeman Bonnie, Zachariah Finly, Fujinami Rebecca, del Ferraro Catherine, Uman Gwen, Ferrell Betty 2015. Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer*. vol. 121, issue 2: 3737-3745.
15. Szala Natalia, Potemkowski Andrzej 2018. Sytuacja polskich opiekunów rodzinnych osób z chorobą Alzheimera. *Polski Przegląd Neurologiczny*. vol. 14, issue 2: 75-80.
16. Veloso Verónica Inés, Tripodoro Vilma Adriana 2016. Caregivers burden in palliative care patients: a problem to tackle. *Current opinion in supportive and palliative care*. vol. 10, issue 4: 330-335.
17. www1: WHO. Retrieved from: <https://www.who.int/cancer/PRGlobocanFinal.pdf>; access on: 9 of November 2019.
18. www2: Wojciechowska Urszula, Czaderny Krzysztof, Ciuba Agata, Olasek Paweł, and Didkowska Joanna. Nowotwory złośliwe w Polsce w 2016 roku. Warszawa 2018. Retrieved from: <http://onkologia.org.pl/publikacje/>; access on: 9 of November 2019.
19. www3: Family Caregiver Alliance National Center of Caregiving, Definitions. Retrieved from: <https://www.caregiver.org/definitions-0>; access on: 9 of November 2019.