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The Issue of Burnout for Lay Caregivers of Patients with Dementia in Easter Slovakia

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Abstract- In our work we focused on the issue of burden of lay caregivers, who care for their relatives with dementia. The aim of the work was to map the degree of nursing burden in families providing care for an ill relative suffering from dementia. The survey was implemented in the territory of Prešov region. The survey sample consisted of 60 addressed respondents, who take care for a family member with dementia. The non-standardized questionnaire focused on basic identification data (age, sex, length of provided nursing care, and family relation of the caregiver to the patient) was complete with Instrumental Activities of Daily Living Scale (IADL), Activities of Daily Living (ADL), and Nursing Burden Test by Svanborg. It results from outcomes that burden of caregiver statistically significantly correlates with ADL ($p < .01$), IADL ($p < .05$), whereas, also statistically significant difference in burden of caregiver regarding their sex ($p < .01$) was confirmed. Nursing burden occurs most often in women than men. Statistical significance was not confirmed in our sample regarding age of caregiver, length of nursing care, and family relation to the care receiver.

Keywords- Dementia, Patient, Caring for a sick relative, Caregiver burden.

1. Introduction

Dementia includes a group of diseases in which occur because of the disease process of brain cognitive decline. Alzheimer's disease (AD) is the most common for dementia a neurologic disease characterized by loss of mental ability severe enough to inter free with normal activities of daily living, lasting at least six months, and not present from birth. AD usually occurs in old age, and was mark by a decline in cognitive functions such as remembering, reasoning, and planning. A person with AD usually has a gradual decline in mental functions, of ten beginning with slight memory loss, followed by losses in the ability to maintain employment, to plan and execute familiar asks, and to reason and a judgment (Klímová, Magurová et al., 2013, Šanta, Klímová et. al., 2007). Communication ability, mood and personality also may be affected. Most people who have AD die within eighty ear so their diagnosis, although the interval maybe as short as one year or as long as 20 years. AD is the fourth leading cause of death in adults after heart disease, cancer, and stroke. According to measure of disability patient depends at home to caregiver, usually to relative (Jirák et al., 2009, Kalvach et al., 2008). Lay caregiver is a person, who helps meet the needs of their family member – care receiver. They perform activities, which the care receivers would have done themselves, if they had enough strength, will power, or necessary knowledge. Without help of the caregiver, the care receiver could not stay in their home milieu in many cases (Tabáková, 2009). In our work, we focused on the issue of burden of lay care givers, who care for their relatives with dementia. The aim of the work was to map the degree of nursing burden in families providing care for an ill relative suffering from dementia (Magurová, Majerníková, 2009).

A home caregiver is a person who helps to satisfy the needs of his family member – cared person. Caregiver performs also the activities which the cared person would perform himself if he had enough strength, will or necessary knowledge. In the social chain and healthcare he has an important place. Without his help in many cases cared person could not stay in the home environment. The caregiver usually has the greatest responsibility and the burden of care. The role of family caregiver is very stressful because it has an impact not only on the physical area but also on the psychological well-being and socio-economic status. Often in the moment when it is a family member diagnosed dementia, we talk about so-called hidden or a second patient. Family members who look after the person suffering dementia, describe their feelings as permanent stress and frustration. It affects the relationship of the family to the patient and vice versa. Common notion for this phenomenon has become the notion - burden of caregiver (Klímová, Magurová et al., 2013, Křivohlavý, 2002, Hudáková, 2016).

1.2 Methods and Material

The survey was implement in the territory of Prešov´s region in months of February and March 2015. The survey sample consisted of 60 addressed respondents, who take care for a family member with dementia. The non-standardized questionnaire focused on basic identification data (age, sex, length of provided nursing care, and family relation of the caregiver to the patient) was complete with Instrumental Activities of Daily Living Scale (IADL), Activities of Daily Living (ADL), and Nursing Burden Test by Svanborg (Staňková, 2001). To analyzed acquired results, we used descriptive statistics, like arithmetic average, standard deviation, and methodology of inductive statistics – Pearson correlation coefficient and analysis of variance test (ANOVA) with significance level $p < .05$.

1.3 Results

The survey sample consisted of 8 men and 52 women. The average age of respondents was 52.3 years; the average length of nursing care for the relative was 4.2 years. The survey has confirmed that 39% of respondents is highly dependent on others, 33% were medium-dependent. Other 25% of respondents were moderately dependent on others, and only 3% of the ill were totally independent (see Table 1 and 2).

Table 1: Characteristics of the caregivers

Length of caring in years	*(M ± SD)*	4.2 ± 2.11
Occupation caregivers		
employed	31	51%
unemployed	13	22%
pensioner	16	27%
Sharing a common household with the patient		
yes	46	77%
not	14	23%

Table 2: Characteristics of the patients with AD

ADL	*n=60*	100%
highly dependent	23	39%
medium-dependent	20	33%
moderately dependent	15	25%
independent	2	3%
IADL		
dependent	32	66%
partially dependent	26	44%
independent	2	3%
Key: ADL- Barthel's Activities of Daily Living Scale, IADL- Instrumental Activities of Daily Living Scale.		

Even 72% of respondents/caregivers consider nursing care for their relative to be obvious, something what is expected from them, 18% care for them based upon the wish of the relative, 8% do so due to a lack of vacancies in social establishments, and 2% do so due to distrust in social and health care establishments. Only 3% of respondents provide home care for their relative alone, without support of other persons. Most of families providing nursing care share their common household with the ill (77%).

Based upon results, even 55% of relatives provide nursing care for the ill relative 24 hours a day, 35% of relatives are also employed, and 10% stated that they provide nursing care for half of a month, during weekends, or other time periods (see Figure 1).

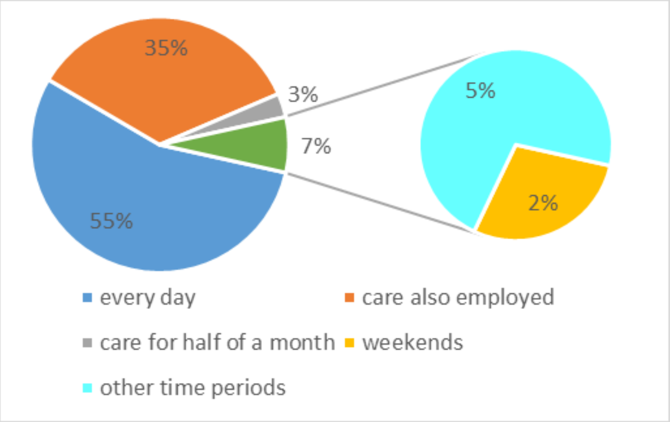

Figure 1 Providing care

In Table 3 we present the relation of burden of care giver regarding to selected, monitored variables (age, sex, length of nursing care, family relation to the chronically ill, level of self-sufficiency of the ill). It results from outcomes that burden of caregiver statistically significantly correlates with ADL (p < .01), IADL (p < .05), whereas, also statistically significant difference in burden of caregiver regarding their sex (p < .01) was confirmed.

Table 3: Statistical Analysis of Selected Monitored Variables

Selected Variables	r	p
Age	0.0485	0.589
Sex	0.3356**	0.0035**
length of nursing	-0.1834	0.658
family relation to the care receiver	-0.0424	0.745
ADL	-0.3041**	0.0047**
IADL	-0.3518*	0.0385*
Key to significance of statistical outcomes * p < .05; ** p < .01; *** p < .001		

Nursing burden occurs most often in women than men. Statistical significance was not confirm in our sample regarding age of caregiver, length of nursing care, and family relation to the care receiver.

As nursing care for the relative with dementia is a very difficult task and influences not only people suffering from it, but also other members in the family, we investigated if family members are interested in using services in social establishments or services of home care agencies.

Outcomes confirm that more than 50% of respondents are not interested in nursing services due to taking turns with other relatives when caring for the ill. 27 % of respondents are interested in services in morning hours. Regarding overall perception of burden, in 53% of cases relatives stated psychical burden and 44% of them physical burden resulting from nursing care for the relative (see Figure 2).

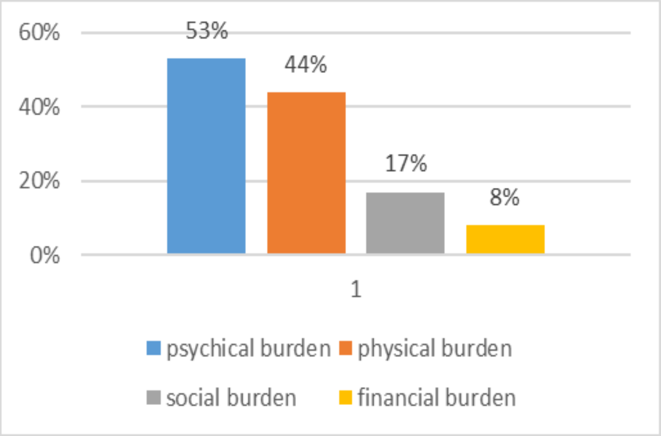

Figure 2 Overall perception of caregiver burden

2. Discussion

Long-term nursing care for a person, who is not self-sufficient, is in many cases burdensome. Caregiver feels burden in physical, psychical, leisure time, and financial area and feels it like obligation to their own family. Providing nursing care requires certain amount of knowledge, patience, and physical strength (Tošnerova, 2001).

In our survey, we focused on evaluation of burden of caregiver when taking care for the ill with dementia in home milieu, regarding age, sex, length of nursing care, family relation to the ill with dementia, and level of self-efficiency of the ill.

Rešetková states (2008) how the family can function during time when a family member is ill. It depends in a large extent on the quality of relations before the disease occurred and already applied ways of stress management. It is necessary to provide help for caregiver to avoid that nursing care be ultimate burden for them. It can be provided by means of social support, including family, friends, neighbors, co-workers, community, and professionals. It forms a system protecting people against harm influence of stress situations (Kebza and Šolcová, 2003).

Several studies point out to the influence of length of nursing care on relations in the family, financial and social aspects (Stoltz, 2004). In our study the relation between burden of caregiver and factors, like age, length of nursing care, family relation to the care receiver, has not confirmed. On the contrary, outcomes of our work show that burden of caregiver correlates with the level of self-efficiency of the care receiver.

This correlation was also confirm in the study by Topinková (2015). Šerfelová and Hladeková (2010) recorded in their work significant difference regarding family relation of caregiver to the chronically ill, whereas high level of burden was perceive mainly by a spouse.

Today in all developed countries gain ground an important and complex subject of an aging society, which is the result of demographic developments in last decades. To a population aging are contributing factors of current demographic trends such as the declining birth rate, increasing life expectancy and increasing group of very old people.

The active part of life does lengthen but old age and its extension is also associated with increasing disease peculiar to this period of life. Among these diseases belongs Alzheimer's disease. Reflecting the current requirements of modern society, the Faculty of health care of University of Presov was established Educational support center for relatives of patients with Alzheimer's disease, as a tool for improving the quality of education for students of nursing and physiotherapy in the role of educators led by lecturers. Establishment of the center we offer the general public the opportunity to increase the knowledge level of care of patients with Alzheimer's disease at home (Klímová, Magurová et al., 2013).

The topics of educational meetings focused on the establishment of the safe home environment, incentive programs, training memory functions, positioning and rehabilitation at home, peace elimination of psychological and physical stress, social support and innovative pharmacological and non-pharmacological methods of treatment, respite care, which preceded the theoretical basis of Alzheimer's disease. The benefit of the project has been active cooperation with devices that provide health and social care for seniors in the region of Presov.

Based on their requirements have been arranged an educational meetings right in social care facilities. Educated were also employees of these facilities. The output of the project is university textbook: Theory and Practice in the care of patients with Alzheimer's disease. Benefit of the project is the establishment of an educational center for the needs of professionals and the general public, improving the educational process with the possibility of linking theory and practice, priority in disciplines: psychiatric nursing, education in nursing, neurological nursing, applied psychology in nursing, professional ethics, communication in nursing, geriatric nursing, mental health nursing (Klímová, Magurová et al., 2013).

3. Conclusion

The goal was to map the level of nursing burdening families providing care for a sick relative with dementia. The investigation was carried out using non-standardized questionnaire for the local non-professional caregivers in number 60 respondents in the Presov´s region, which was supplemented by standardized questionnaires - Test instrumental daily activities - IADL, Activities daily living ADL, Test of nursing burden by Svanborg. The results from their search indicate the impact of burden on caregiver and on their psychological and physical aspects. Complex evaluation of both care receiver and care giver, making use of available evaluation tools and determination of correct nursing diagnosis may, in practice, help effectively solve the issue of burden of care giver when caring for the chronically ill.

The practice also calls for implementation of educational programs for caregivers, as in our conditions similar projects are absent. Therefore, some families have insufficient conditions for this demanding task of providing nursing care for the chronically ill in home milieu. The aim of such complex approach is to increase the quality of life of not only the chronically ill, but of all family providing home care, as these two are inseparable, and necessarily influence each other.

Currently, attention is paid mainly to the cared person and not to the caregiver who care provides. In many cases it is not a short-term care, but it can take several months, but it can also be lifelong care. The risk of a caregiver's burden is greater if care and full responsibility is given to only one person. Therefore, it is important to focus of interventions also on preventing caregivers' burden within the care provided.

References

Elmstahl, A. et al. (2005) Family Caregivers' subjective experiences of satisfaction in dementia care: a spects of burden, subjective health and sense of coherence. *Nordic Collegeof Caring Sciences*. 19:157-168.

Holmerová I., Janečková, H., Vaňková, H., Valeta, P. (2015) Nefarmakologické přístupy v terapii Alzheimerovy demence a praktické aspekty péče o postižené. In *Psychiatria pre prax.* 6(4):175-178.

Hudáková, A. et al. (2016) Geriatrické syndrómy ako prediktory ošetrovateľstva v geriatrii. Prešovská univerzita v Prešove, 192

Huňavá L., Koňošová, H. (2008) Špecifiká ošetrovateľskej starostlivosti o pacienta s Alzheimerovou chorobou. *Ošetrovateľský obzor*. 2008. 5(3): 84-88.

Jirák R., Holmerová I., Borzová C. et al. (2009) *Demence a jiné poruchy pamäti. Komunikace a každodenní péče.* Grada Publishing. Praha 2009. 164

Kalvach, Z., Zadák, Z., Jirák, R., Zavázalová, H., Holmerová I., Weber, P. et al. (2008) *Geriatrické syndromy a geriatrický pacient.* Grada Publishing, Praha. 336

Kebza V., Šolcová I. (2003) *Syndrom vyhoření*. 2. ed. Praha : Státní zdravotní ústav,123.

Klímová E., Magurová D. et al. (2013) *Teória a prax v starostlivosti o chorého s Alzheimerovou chorobou.* Prešovská univerzita v Prešove. Fakulta zdravotníckych odborov, Prešov, 235.

Křivohlavý J. (2002) *Psychologie nemoci.* Grada Publishing, Praha. 198 p.

Magurová D., Majerníková Ľ. (2009) *Edukácia a edukačný proces v ošetrovateľstve.* Osveta, Martin. 155.

Magurová D. et al. (2008) *Základy edukácie a jej využitie v ošetrovateľskej praxi.* Prešovská univerzita, Prešov. 116.

Rešetková D. (2008) Je úžasné niekam patriť. *Familia: kultúrno-spoločensk ý magazín pre rodiny.* 2008, XXIV(3):13.

Šanta M., Klímová, E. et al. (2007) *Neurológia a neurologické ošetrovateľstvo.* Prešovská univerzita v Prešove. Fakulta zdravotníctva, Prešov. 216 p.

Šerfelová, R. Hladeková, B. (2010) Záťaž opatrovateľa v procese starostlivosti o chronicky chorého. *Ošetřovatelství a porodníasistence.* 1(3):89 - 92.

Sheardová, K. (2011) Současné možnosti terapie demencí, význam nefarmakologických intervencii. In *Psychiatria pre prax.* XII(3):124-126.

Staňková, M. (2001) *Hodnocení a měřící techniky v ošetřovatelské praxi*. České ošetřovatelství 6. Brno: Institut pro další vzdělávání pracovníků ve zdravotnictví. 55

Stoltz, P. et al. (2004) Support for family carers who care for an elederly person at home – a systematic literature review. *Nordic Collegeof Caring.* 9:111-119.

Tabáková, M. (2008) Záťaž opatrovateľa v domácom prostredí. *Profese online.* 1(2): 77-88.

Topinková ,E. (2015) Péče o staré v rodine. Lze identifikovať rizikové rodiny s vysokou míroupečovatelskézáteže? *Praktický lékař.* (75)366-369.

Tošnerová, T. (2001) *Pocity a potřeby pečujících o starší rodinné príslušníky. Průvodce pro zdravotníky a profesionální pečovatele.* Praha: Ambulance pro poruchy paměti,. 68

Zormanová L. (2012) *Výukové metody v pedagogice.*
Grada Publishing, s.r.o., Praha. 155