

# Caregiver Strain in Community Care

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Original Article

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Source: *Clinical Social Work and Health Intervention*  
Pages: 47 – 53

Volume: 13  
Cited references: 15

Issue: 3

## Reviewers:

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## Keywords:

Strain. Non-professional Caregiver. Caregiver Strain Index. Validation. Nursing Diagnosis.

## Publisher:

International Society of Applied Preventive Medicine i-gap

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CSWHI 2022; 13(3): 47 – 53; DOI: 10.22359/cswhi\_13\_3\_07 © Clinical Social Work and Health Intervention

## Abstract:

The paper focuses on the identification of areas of strain in caregivers who, on a non-professional basis, provide care to a person with a neurological disease in a community care-based setting. The aim of the survey was to validate the nursing diagnosis Caregiver Role Strain. Through a group of experts, we found out which determining features and related factors of the aforementioned nursing diagnosis occur most often in clinical practice while caring for patients with a neurological disease. Furthermore, for assessing caregivers we used the Modified Caregiver Strain Index to find out which neurological diseases cause the greatest strain for them, and which gender and age group of caregivers are most predisposed to strain. The survey took the form of online questionnaires from April 2021 to Sep-

tember 2021. Caregiver strain occurs most often in caregivers who care for neurological patients. By analyzing the data, we came to the conclusion that the experts in our survey identified fatigue as the most important determinant. The group of experts identified the most important related factor - inexperience in providing care. Due to the demanding position of the caregiver, it is important for care providers to correctly and quickly identify potential stressors, and thus relieve the caregivers from their difficult mission.

## Introduction

The basis of providing care in the community is to maintain family well-being and, at the same time, support the ability of family members to take care of the care receiver. We can understand providing home care by non-professional caregivers as a long-term, permanent and stressful commitment (Bruhn, 2016). However, providing care in the home environment not only affects the person to whom the care is provided, but also greatly affects family members. The longer the patient is dependent on the help of others, the more difficult the situation is for the family. Probably the most burdensome aspect of being a caregiver is the feeling of responsibility towards the cared-for person which represents a strain in the spiritual, social, mental and physical realms. The caregiver is often unaware of their overload which can lead to them becoming exhausted and eventually falling ill (Kolegarova *et al.*, 2011, Kozuchova, *et al.* 2014, Pathak, 2020).

**Survey:** Caregiver strain in community care is an issue that receives little attention. Caregivers undergo major changes in their lives and they often give up their work, activities, interests in exchange for helping their loved ones. Therefore, it is very necessary to address this issue.

**Aim:** The aim of the survey was to identify the defining characteristics and related factors in the nursing diagnosis Caregiver Role Strain in caregivers who provide care at home on an unprofessional basis to a cared-for person with a neurological disease.

## Work methodology and research methods

In order to obtain more reliable survey results, we decided to assess the caregiver through the Caregiver Strain Index. The assessment was carried out by expert nurses in the conditions of community care. To validate the nursing diagnosis we used quantitative methods to obtain the

necessary data. For data collection, we created a questionnaire-type evaluation tool which we distributed to nurses via online social networks. The questionnaire consisted of six parts.

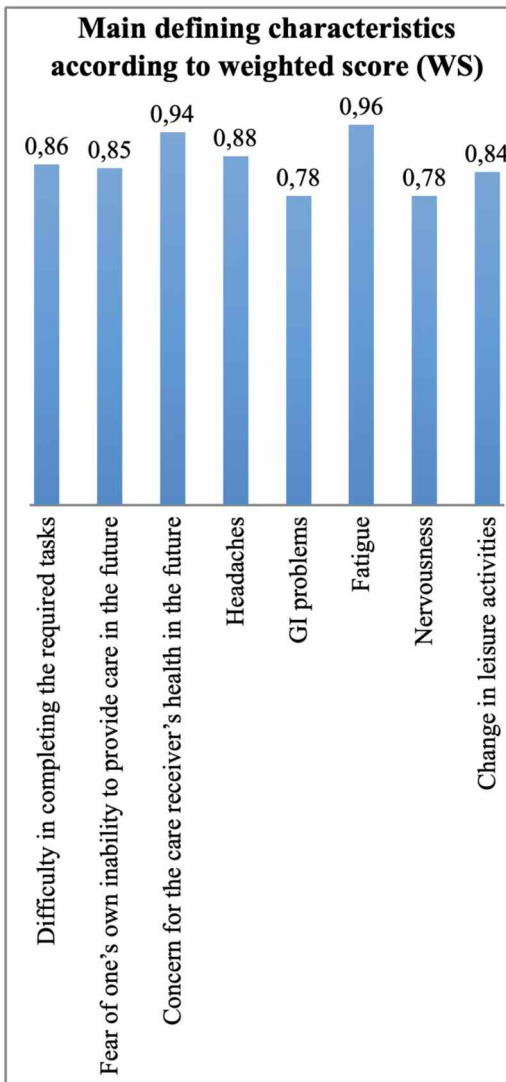
We selected the survey sample deliberately. The sample consisted of 85 nurses working in Slovakia in home nursing agencies, day hospitals, social service facilities or other facilities where they encounter caregivers who provide home care for a person with a neurological disease. Data collection took place from April 2021 to September 2021. Questionnaires were distributed online through social networks to nurses working in home nursing agencies, day hospitals, social service facilities or other facilities where they meet with caregivers who provide care in the home environment to a person with a primarily neurological disease.

## Interpretation of results and discussion

The aim of the survey was to use expert nurses to determine the level of caregivers' strain by identifying the most common defining characteristics and related factors of the nursing diagnosis Caregiver Role Strain. We set 5 sub-objectives.

**Sub-objective #1:** To find out which defining characteristics of the nursing diagnosis Caregiver Role Strain are the most common in clinical practice in the care of patients with neurological diseases.

**Graph 1** Main defining characteristics of nursing diagnosis Caregiver Role Strain



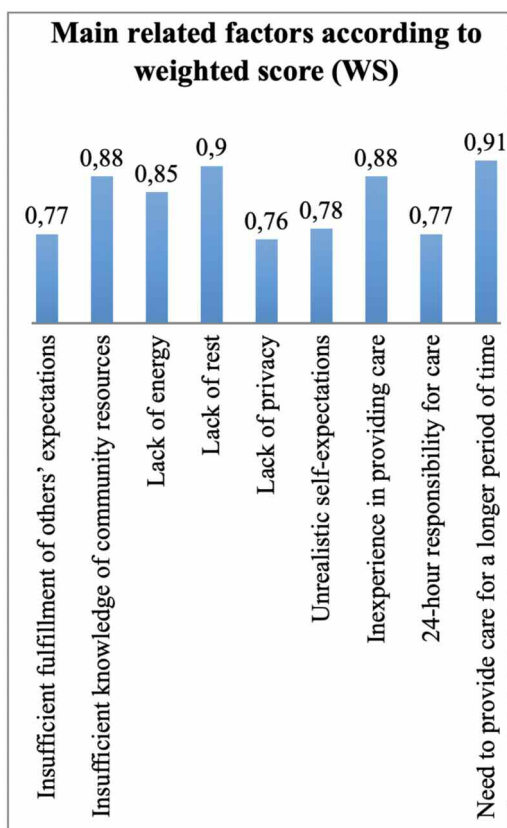
In care providers with an identified diagnosis Caregiver Role Strain in the care of a patient with a neurological disease, there is a significant difference in the occurrence of individual defining characteristics. Fatigue is the most common defining characteristic which was reported by the highest number of respondents at 88.24% and the

group of experts assigned it the highest frequency of occurrence (WS = 0.96). The group of experts assigned WS = 0.78 to the two main defining characteristics - the GI problems and nervousness which is the lowest value among all the main defining characteristics.

We recorded the same results for the first sub-objective as the results of the authors Slamkova, Polednikova & Pavelova (2020) in which Slovak and Czech experts identified fatigue as one of the main defining characteristics. We also observed the same results as in the research of the authors Tabakova, Zelenikova & Kolegarova (2011). In their research, authors present the results in which Slovak experts identified fatigue as one of the defining characteristics. We also find some agreement with the research of the Brazilian authors Monteiro *et al.* (2004), who state that the concern for the care receiver's health is one of the most common defining characteristics. Experts in our survey assigned to the defining characteristic mentioned above the second highest significance WS = 0.94.

**Sub-objective #2:** To find out which related factors of the nursing diagnosis Caregiver Role Strain are the most common in clinical practice in the care of patient with neurological diseases. The group of community nursing experts identified 9 out of 53 main factors. Using the Likert Scale, they assigned the highest frequency to the following main related factors: insufficient fulfillment of others' expectations; insufficient knowledge of community resources; lack of energy; lack of rest; lack of privacy; unrealistic self-expectations; inexperience in providing care; 24-hour responsibility for care; need to provide care for a longer period of time.

**Graph 2** Main related factors of the nursing diagnosis Caregiver Role Strain



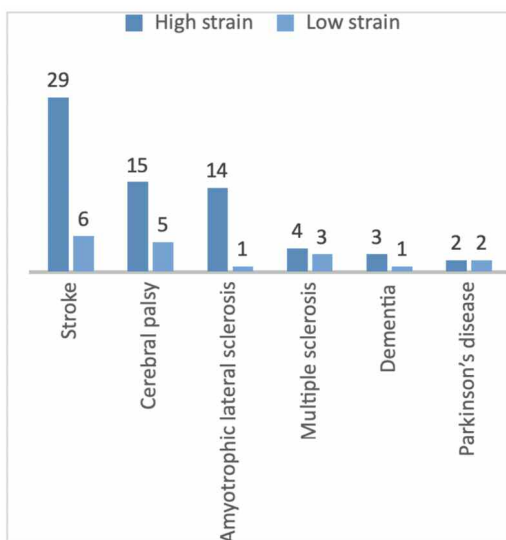
We found through statistical analysis of the data that care providers with an identified nursing diagnosis Caregiver Role Strain while caring for patients with neurological diseases show a significant difference in the occurrence of individual related factors. Inexperience in providing care is the most common of all the related factors, which

was confirmed by the highest significance of 83.53% of respondents. At the same time, a group of experts assigned the second highest frequency of WS = 0.88 to this related factor. The group of experts assigned the highest frequency of occurrence to the factor - providing care is needed for a longer period of time WS = 0.91. The lowest significance by a group of experts (WS = 0.76) was assigned to one of the main related factors - lack of privacy.

We can compare the results of the presented studies with the results of our most frequently related factors in the nursing diagnosis Caregiver Role Strain. With the findings of Reed *et al.* (2014) it is possible to compare the main related factors - lack of rest, lack of privacy and the need for care over a longer period of time. With the results of the study by Garlo *et al.* (2010) we can see agreement with related factors - inexperience in providing care and providing care is needed for a longer period of time. With the study by Bremault-Philips *et al.* (2016) it is possible to compare the related factor of inexperience in providing care. In the data resulting from the research of the authors Serfelova & Hladekova (2010) we can see the agreement with the related factor – providing care is needed for a longer period of time. We can therefore state that the results of our survey are partially or in some respects the same as the results of other authors.

**Sub-objective 3:** To find which neurological illness represents the biggest caregiver strain based on the caregiver’s assessment through the Caregiver Strain Index. The group of experts assessed the caregivers according to the Modified Caregiver Strain Index. Through the assessment, they identified the neurological disease that represents the greatest caregiver strain in providing care.

**Graph 3** Neurological diseases according to the Caregiver Strain Index



From the results of the experts, we identified the specific neurological disease that strains the care provider the most. It shows that 29 (43%) caregivers of the 67 highly strained caregivers provided care to a cared-for person who suffered a stroke. The remaining 15 highly strained caregivers cared for a person with cerebral palsy; 14 caregivers for a person with Amyotrophic Lateral Sclerosis; 4 caregivers for a person with Multiple Sclerosis; 3 caregivers cared for a person with dementia; 2 for a person with Parkinson’s disease.

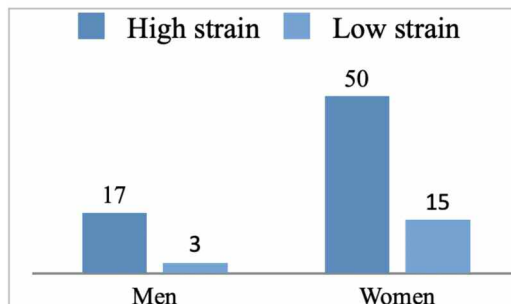
However, we concluded from the statistical analysis that neurological disease is not a predisposition to greater strain. Differences in strain with respect to neurological disease expressed in number or percentage are not significant.

The results of the presented research and study partially agree with our results. A consensus can be seen in the study by Garlo *et al.* (2010), who claim that the caregiver strain should

be assessed regardless of the care receiver’s diagnosis. Bremault-Philips *et al.* (2016) recommend educating caregivers providing care for people with dementia so that they can be better prepared for care in the future. Papastavrou *et al.* (2007) also state that caring for a person with Alzheimer’s dementia put a heavy strain on more than half of the caregivers. However, our statistical survey showed that there is no significant dependence between the neurological disease and the level of strain. According to our survey the specific disease is not a predisposition to greater strain. We can only assume that the type of handicap, the degree of disability or dependency of the care receiver, or their age or polymorbidity, may be among the potential factors in the caregiver strain.

**Sub-objective 4:** To find out which gender has a greater predisposition to strain based on the caregiver assessment through the Caregiver Strain Index

**Graph 4** Gender of care providers according to the Caregiver Strain Index



The results of the assessment of care providers by a group of experts through the Caregiver Strain Index showed that out of 67 highly strained caregivers, 50 of them are female (75%). Of the total number of caregivers, 59% are highly strained women providing care. By analyzing the data, we found that the caregiver’s gender is not a predisposition to their greater strain.

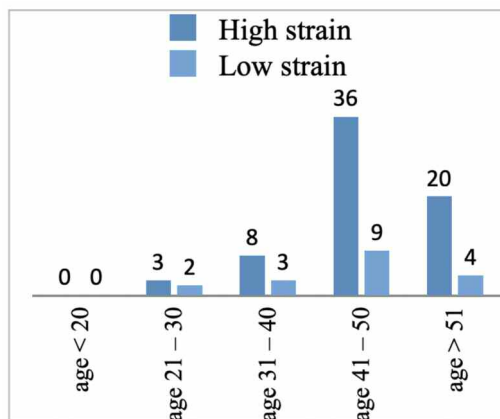
Based on the results of the assessment of care providers by a group of experts using the Caregiver Strain Index, we identified which gender of the care provider might be predisposed to strain. The obtained data showed that out of 67 highly strained caregivers, 50 of them are female (75%). Of the total number of caregivers, 59% are highly

strained female care providers. However, we found from a statistical analysis that there was no significant relationship between the Caregiver Strain Index and the gender of the caregiver. According to our survey, the gender of the caregiver is not a predisposition to a greater strain.

The results of the survey do not match the results of other authors who claim that the vast majority of caregivers are women. Some authors are of the opinion that the female gender is more strained in caring for the cared-for person. Our statistical analysis did not confirm this fact. We can state the agreement in the results of the study only with the author Hladekova (2010), whose survey results did not show significant differences in the degree of caregivers' strain with regard to their gender. At the same time, we agree with her view that the level of strain on women can be influenced by the division of tasks in the household.

**Sub-objective 5:** To find out which age group has a greater predisposition to strain based on the caregiver's assessment through the Caregiver Strain Index.

**Graph 5** Age group of care providers according to the Caregiver Strain Index



The analysis showed that caregiver age is not a predisposition to their greater strain. According to the results of the experts, we have identified the age group which, based on the care provider's assessment through the Caregiver Strain Index may be a predisposition to the care provider's strain. Of the 67 highly strained caregivers 36 were care providers aged 41 - 50. This represents

54% of the total number of highly strained caregivers and 42% of the total number of caregivers. We found from a statistical analysis that there is no significant relationship between the Caregiver Strain Index and the age group. Therefore, based on the information obtained, we can assume that age is not a predisposition to greater strain. We noticed the agreement with the results of the authors' study of Tabakova & Vaclavikova (2008), but also with the author Glodzakova (2019), who are of the opinion that there is no statistical significance between the age of the care provider and their strain.

## Conclusion

At present, we can consider family members' help, or having care providers for a chronically ill person, practically as a necessity. Help for caregivers is therefore a high priority, and it is important for professional care providers to correctly and timely identify the potential strain, and thus relieve family caregivers from their difficult mission at least partially.

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