Condition of informal caregivers in long-term care of people with dementia

Roksana Malak1, Agnieszka Krawczyk-Wasielewska1, Katarzyna Głodowska2, Bartosz Grobelny3, Paweł Kleka4, Ewa Mojs3, Przemysław Keczmer1, Włodzimierz Samborski1

1 Department of Rheumatology and Rehabilitation, Poznan University of Medical Sciences, Orthopedic-Rehabilitation Clinical Hospital in Poznan, Poland
2 Department of Social Sciences, Poznan University of Medical Sciences, Poland
3 Department of Clinical Psychology, Poznan University of Medical Science, Poland
4 Adam Mickiewicz University, Institute of Psychology, Poznan, Poland

Abstract

Introduction. Caregivers of demented relatives devote their time and attention in order to help the beloved members of the family. Those who are informal caregivers require support in order to avoid being overburdened. Many such caregivers may suffer from chronic health problems, for instance, depression.

Objective. The aim was to assess the factors of depression in caregivers, and to discover the determinants of depression among informal family caregivers of demented individuals.

Materials and method. Forty-one caregivers in the research group were administered a questionnaire which included the caregivers’ demographics. Caregiver’s level of depression was measured by the scale of the Centre for Epidemiology Scale for Depression. The relationship between depression and demographic features was analyzed. Data were analyzed using STATISTICA 8.1 (StatSoft). Analysis of the results was performed using the Kolmogorov-Smirnov test of normality. Pearson correlation coefficient was also used.

Results. Referring to The Centre for Epidemiology Scale for Depression, the average score in the study group was 18 ± 7.49. There was no statistically significant relationship between the level of depression and such factors as caregiver’s age, time of care of demented relative, and type of kinship and pain.

Conclusions. Although there was no relationship between the level of depression and demographic features, the problem of quality of life, worries and grief which may appear, seemed to be sufficient reason for organizing the prevention of depression for all informal caregivers of persons with dementia.

Key words

depression, dementia, caregivers, psychiatry, family, pain

INTRODUCTION

People with dementia, a progressive neurodegenerative disorder [1], need long-term care. Although the symptoms are certainly heterogeneous, there are, however, some major groups of symptoms which are common to almost all those who suffer from dementia: problems with attention, memory, executive function, visual-spatial ability and language [2]. It is possible, but difficult, to provide appropriate long-term care for people with dementia, and it is especially difficult for an informal caregiver, such as member of the family of a demented person. This is primarily because dementia is a progressive illness, and sometimes a caregiver may not see effects of her or his work because of the relative developing a new stage of dementia. Additionally, the informal caregiver does not have to have medical knowledge about the disease and its typical symptoms which may be inconceivable in everyday life. The informal caregiver taking care of a demented relative is therefore exposed to caregiver burden.

This is the reason that the burden of a caregiver has been the subject of growing interest worldwide [3].

There are four main categories of symptoms characteristic for caregiver burden:

1) frequent mood swings – anger, sadness, irritability, discouragement, looking for magic solutions, inability to concentrate;
2) physical – posture failure (symptoms of fatigue), headaches, disturbed appetite and weight, sleeplessness, falling sick very often, neck pain, hyperhidrosis;
3) behavioral – problem in concentrating, increased use of drugs or alcohol, avoiding decisions, forgetfulness, boredom, over-reactiveness;
4) relationships – fewer contact with friends, loneliness, problems with marriage or children.

Anxiety and hostility could be other symptoms of caregiver burden [4]. Other factors may also increase caregiver burden, for instance, type of kinship of caregiver, gender of caregiver (female) may differ the symptoms of caregiver burden [4]. There are additionally some neuropsychological symptoms of caregiver burden, such as: delusions, hallucinations, restlessness, disinhibition, unusual motor behaviour, sleep disturbances and appetite alterations [5]. One of the most severe symptoms of burden is depression [4] which is associated with disturbance in the emotional, behavioural and social condition. Furthermore, caregivers who suffer from depression very often also report pain [6]. Depression may
develop following a trigger symptom, such as the appearance of dementia in beloved member of family as a stressful and unhappy life event. Sleep disturbance, which may appear as a result of taking care of a demented relative, can also cause depressive symptoms. The importance of detecting and treating such depression should be highlighted. If a caregiver develops depression she or he will not be effective in taking care of the member of the family with dementia. It is therefore predictable that the longer the time of caregiving, the higher the probability of burden.

OBJECTIVE

The aim of the study was to assess the predictors of burden in caregivers and to discover the determinants of depression in family caregivers of demented individuals. The relationship between depression and demographic features was also analyzed.

MATERIALS AND METHOD

The necessary informed consent was obtained from all participants in the study which took place in 2014. All caregivers in the study group were administered a questionnaire which included caregivers’ demographics: age, gender, relationship with the patient, duration of the patient’s disease, and time (hours per week spent with the patient). Caregiver level of depression was measured by The Centre for Epidemiology Scale for Depression (CES-D) was used to identify individuals had depressive symptoms and the level of depression. The respondents were asked to rate the frequency during the past week from among 18 depressive symptoms by choosing response options ranging from ‘rarely or none of the time’ to ‘most or all of the time’, on a scale ranging from 0–54. The original recommended cut-off point for having depressive symptoms was 16 points (corresponding to the 80th centiles) by the founder of the CES-D in 1977 [7].

A sample of 41 members of families with a demented relative were interviewed to determine the influence of such factors as: finished graduation, caregiver’s age, family relationship to the care recipient, leisure time, and having the support of other family members, to discover the impact of the appearance the depression. There were 32 spouses, 8 people who were single, and one divorced person. The majority of respondents had finished secondary education (22%), higher education (39%), vocational education (5%), and basic education (2%). The average age of the study group was 61.7 years old (SD = 13.5; Me = 59). Respondents had taken care of their demented relative from 2–252 months (median, Me = 60 months, the most common being 35.6 months).

RESULTS

Referring to CES-D scale, the average score was 18±7.49. The scores ranged from 7–39 points. Analysis of the results obtained in the Kolmogorov-Smirnov test of normality lets us apply parametric tests for connection allows the application of parametric tests of individual variables with the level of depression (p = .152).

<table>
<thead>
<tr>
<th>Group</th>
<th>Group ‘yes’</th>
<th>Group ‘no’</th>
<th>t(df)</th>
<th>P</th>
<th>95%CI of difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>16.78</td>
<td>18.96</td>
<td>-0.94 (38)</td>
<td>0.354</td>
<td>-6.88, 2.52</td>
</tr>
<tr>
<td>Dementia Supervisor</td>
<td>17.81</td>
<td>18.60</td>
<td>-0.33 (20)</td>
<td>0.745</td>
<td>-5.82, 4.24</td>
</tr>
<tr>
<td>Relatives and Friends</td>
<td>18.56</td>
<td>17.84</td>
<td>0.26 (14)</td>
<td>0.800</td>
<td>-5.22, 6.64</td>
</tr>
<tr>
<td>Home services*</td>
<td>17.69</td>
<td>20.20</td>
<td>84.00</td>
<td>0.826</td>
<td>-16.78, 11.77</td>
</tr>
<tr>
<td>Day centre*</td>
<td>18.13</td>
<td>16.33</td>
<td>62.50</td>
<td>0.802</td>
<td>-11.48, 15.08</td>
</tr>
<tr>
<td>Selfhelp group*</td>
<td>18.50</td>
<td>11.67</td>
<td>89.50</td>
<td>0.108</td>
<td>2.12, 11.54</td>
</tr>
<tr>
<td>Local parish*</td>
<td>18.31</td>
<td>12.00</td>
<td>60.50</td>
<td>0.203</td>
<td>2.43, 10.19</td>
</tr>
</tbody>
</table>

* – the score of nonparametric test (Wilcoxon) because the small amount of caregivers were satisfied with received support (Home services: n=5, Day centre: n=3, Selfhelp group: n=3, Local parish: 2)

There was no statistically significant relationship between the level of depression and such factors as: caregiver’s age, time of care of demented relative, satisfaction of with social support (Tab. 1). Similarly, the type of kinship (spouse: n=18, adult child: n=12, other: n=11) had no influence on the level of depression (F [2, 38]=1.499; p=.236).

It was also investigated whether support given for caregiver of demented relative was related to the level of depression. According to the estimation of received support (Support_GP) there was no statistically significant difference (t[38]=−0.94; p=0.354) between the level of depression (CES-D scale) in caregivers who received support (N=23) and those who did not receive support (N=18) (Tab. 2).

Although the Table 2 shows that there was no correlation between received support and level of depression, it should be noted that there was such a small amount of caregivers who were satisfied with given support.

Pain (SF result) was another dependent variable in the study. The difference between those who felt pain (N=33) and those who did not feel pain (N=8) was not statistically significant (t[41]=0.00; p=1.000). Similarly, there were no statistically significant differences between age (t[49]=−0.08; p=0.934) and the time of caregiving (W=121.50; p=0.931) and the level of depression of caregivers.

Analysis of the distribution of the number of people caring for demented relatives in relation to the perceived pain showed no significant correlation between the variables (chi²=4.11; p=0.128)

DISCUSSION

Caregivers play an important role in the management of individuals with dementia. Nowadays, it is well known that informal caregivers require support in order to avoid burden. Many informal caregivers may suffer from chronic health problems, for instance, depression, which should be diagnosed as early as possible, especially among family
Informal caregiver should know that they are at risk not only in reduced physical health, but also in their mental condition. Consequently, their quality of life may decreased. Having a family member with a chronic illness is associated with some spillover effects which may vary by the type of relationship with the ill family member [16]. There occur such feelings in caregiving as guilt, worry and depression; higher levels of guilt are associated with higher levels of depression. Higher levels of guilt among family member of demented relative, especially of a daughter, are related to a lower level of leisure activities [17]. Another spillover effect of caregiving associated with mental health, is feeling worried. In general, this is a significant predictor of sanity, especially in daughters. However, wives feel worried the most, while husbands worry the least [18]. Adult daughters, wives and husbands had comparable caregiver burden scores, but adult daughters had greater caregiver burden scores, compared to more distant relatives [19].

Some researchers have revealed that, similar to the presented study, there is no statistically significant difference between the different types of relationships and caregiver burden [20]. Similarly, the type of relationship to the demented person does not seem to differ the level of depression. Although there was no statistical significant correlation between the level of depression and type of kinship, the problem with quality of life, worries and grief which may appear, seem to be sufficient reason for organize psycho-education for all informal caregivers of persons with dementia. Psycho-educational group programmes may decrease behaviour problems in members of families with relatives with dementia [21]. The psychoeducational group may play a significant role in reducing the stress, tension and spillover of caring for a demented relative. It can also be a support, and broaden the knowledge about dementia, which may also have a positive influence on the family of the demented person.

It is obvious that pain may accompany serious illness: both the person suffering from dementia and those who take care of relative with a prolonged, serious illness. Pain is also associated with caregiver burden [22]. However, the pain may have few different meanings; for example, if a person can stand the pain, she or he may feel stronger, thereby increasing self-esteem, and depression will not even appear [21]. Perhaps this explains why there was no statistical significant correlation between pain and level of depression in this study [23]. However, many persons with dementia and their caregivers report physical, psychological, and dementia-specific symptoms, such as pain and depression at the same time [24].

CONCLUSIONS

The aim of national governments should be cope with the symptoms of depression, or even prevent the appearance of any symptoms of depression, especially in informal caregivers of demented persons. An illness such as depression leads to the exclusion of the sufferer from society, and is associated with additional costs for the State. Perhaps it would be worthwhile assigning a nurse and psychologist in order to help caregivers to identify their negative feelings and experiences about caregiving. It may help them reflect upon the coping strategies to find a balance in their situation [25].
Although there is no relationship between the level of depression and demographic features, the problem with quality of life, worries and grief which may appear, seem to be sufficient reason to organize the prevention of depression for all of informal caregivers of persons with dementia.

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REFERENCES