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ORIGINAL RESEARCH

Burden of caring for people with dementia – comparing family caregivers and professional caregivers. A descriptive study

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Purpose: Caring for people with dementia is known to be accompanied by burden for the caregiver. This study aims at describing family caregivers' and professional caregivers' burden immediately after hospitalization of the person with dementia.

Materials and methods: Twenty-five family caregivers and twenty-five professional caregivers of the locked gerontopsychiatric ward of a hospital in Northern Germany completed a questionnaire (BIZA-D-PV), which was evaluated in matched samples. The distribution of frequencies, differences in mean values and correlations were determined. Furthermore, family caregivers were categorized into risk groups.

Results: Family caregivers perceived a higher burden due to cognitive impairment as well as aggressive and disoriented behavior of the person with dementia compared to professional caregivers. Differences with regard to care tasks were not detected. Female family caregivers rated a higher burden compared to male family caregivers, whereas in the sample of professional caregivers males perceived a higher burden. Correlations between several dimensions of burden and caregivers' age, severity of dementia as well as physical symptoms were described. Categorizing family caregivers into risk groups showed high risks for depression of the caregiver, violence against the person with dementia and institutionalization of the person with dementia within the next months in 44–72% of cases.

Conclusion: Our findings emphasize the importance of acquiring knowledge about caregivers' burden in the course of time in order to develop targeting interventions to decrease caregivers' burden and to prevent hospital admissions of people with dementia due to a crisis of home caring.

Keywords: care of older people, informal care, formal care, nursing care, gerontopsychiatric hospital, cross-sectional study

Introduction

Currently, about 1.7 million people with dementia live in Germany. According to forecasts, this number will increase within the next decades due to demographic change.[1,2] Dementia affects several areas of life including memory, learning capacity, thinking, orientation, calculation, judgment, behavior and activities of daily life.[1] Therefore, people with dementia are in need of comprehensive support depending on the stage of the disease. The majority of people with dementia cared for at home are supported by their relatives.[3–5] Most commonly, these caregivers are spouses or life partners, followed by children and children-in-law, in majority women.[4,5] Caregiving is known to be accompanied by burden for the caregiver.[6–10] The concept of caregiving burden can be understood as a duty or responsibility to care for the relative with

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dementia which is hard to bear for the caregiver. It has been shown that caring for a person with dementia is even more burdensome compared to caring for an adult not affected by dementia.[9,10] Dementia caregiving is associated with several dimensions of burden.[4,11–16] Objective burden results from the dependency of the person with dementia and behavioral problems in particular. Subjective burden is associated with the appraisal of physical and emotional impact of caregiving and also caregivers' resources.[4] In a German study, the Berlin inventory on relatives' burden of patients with dementia (Berliner Inventar zur Angehörigenbelastung–Demenz, BIZA-D) was developed to assess the burden on caregivers of people with dementia. It evaluates objective burden due to caring such as care tasks, subjective burden such as burden due to behavior change and perceived conflicts between needs and responsibilities and also role conflicts.[11–13] In the last years, numerous studies were conducted to identify caregiver burden also in other pathologies, for example, in people caring for a relative after hip fracture.[17] Many interventions have been applied to improve caregivers' well-being and consequently delay hospitalization or rather institutionalization.[18–20] Nevertheless, in many cases people with dementia are treated in a hospital, particularly in the advanced stages of the disease and mostly induced by behavioral and psychological symptoms of dementia such as screaming, physical aggression and resistance to help, wandering, depression and sleep disturbances.[21–23] In these cases, professional caregivers are involved. A caregiving profession is associated with special education in caring for a person who suffers from a disease, with further training in continued work and being paid for caregiving. Regarding the burden of professional caregivers in nursing homes, several dimensions have been identified including physical strain, neuropsychiatric symptoms of the people with dementia, patient-related complexity of care due to multimorbidity, limited time resources, expanded need for documentation and conflicts with colleagues or relatives.[24–29] These dimensions can be categorized into the following three main sources of burden: firstly, subjective sources of burden including personality structure, attitude towards persons with dementia and current life situation; secondly, objective sources of burden including neuropsychiatric symptoms of the people with dementia and thirdly, structural sources of burden that are related to work conditions.[30] Emotional burden of the professional caregivers correlates with neuropsychiatric symptoms of the people with dementia, particularly agitation and aggressive behavior.[31,32] The differences in emotional burden between informal and professional caregivers have been examined in a few studies.[33,34] Family caregivers rated higher scores in depression and caregiving burden scales compared to professional caregivers and professional caregivers scored lower than a control group regarding the quality of life.[34] Whereas many studies focused on burden of professional caregivers in nursing homes, there is lack of data with regard to caregiving burden of nurses in locked wards of gerontopsychiatric hospitals. Aim of this study is to assess the burden of family caregivers immediately after hospitalization of the person with dementia. Thus, the following research questions were analyzed: (1) what caregiving burden do family caregivers experience after a crisis admission of their relatives to a gerontopsychiatric hospital; (2) what sociodemographic parameters are associated with family caregivers' burden; (3) what specific risks could be associated with family caregivers' burden; (4) what caregiving burden do matched professional caregivers experience.

Materials and methods

Study design and participants

In this descriptive cross-sectional study, a sample of 25 family caregivers was examined. Recruitment was related to a crisis admission of the person with dementia into the locked gerontopsychiatric ward of a hospital in Greifswald, Northern Germany. The crisis made it impossible to continue home caring, for instance, due to aggressive behavior of the person with dementia, repeatedly running away from home or refusal of food. Additionally, 25 staff members of this ward were included in the study and matched with the respective family caregivers. They were asked to complete questionnaires. The inclusion criteria for the people with dementia were being formally diagnosed with dementia according to the International Classification of Diseases–10 (ICD–10) and being cared for at home, for the family caregivers being the main care person and for the professional caregivers being mainly involved in caring the respective person with dementia. Written informed consent was obtained from participating persons with dementia or their legal representative. The Ethics Committee of the University Medicine in Greifswald approved the study (registry number BB65/11a).

Materials

Dimensions of burden were assessed using the practice version of the Berlin inventory on relatives' burden in dementia (Berliner Inventar zur Angehörigenbelastung–Demenz–

Praxisversion, BIZA-D-PV). These dimensions are: the objective burden due to care tasks with 9 items, the subjective burden due to behavior change of the person with dementia (cognitive impairment with 4 items; aggression and disoriented behavior with 5 items) and the subjective burden due to perceived conflicts between needs and responsibilities (personal constraints with 5 items; missing social appreciation with 6 items). Furthermore, the individual acceptance of caring was evaluated with 4 items. We assessed information concerning age, sex, diagnosis according to ICD–10, stage of disease and nursing care level of the people with dementia. The stage of disease was classified using the German version of the Mini Mental State Examination (MMSE), which reflects the cognitive status of the person with dementia. A total score of 20–23 indicates mild cognitive impairment, of 10–19 moderate cognitive impairment and of 0–9 severe cognitive impairment. Informal and professional caregivers provided sociodemographic information such as age, sex, relationship to the person with dementia, duration of care, caregiving time per week, education, employment, use of public care services as well as nurses' participation in and satisfaction with advanced training courses. Moreover, data about chronic diseases and current physical symptoms of caregivers were assessed using a self-compiled questionnaire.

Statistical analysis

Descriptive statistics were used to characterize the samples of people with dementia, family caregivers and professional caregivers. Kolmogorov-Smirnov tests were applied to determine if the sample of values follows a normal distribution and Student's *t*-tests for matched samples to determine if the means of the two data sets are significantly different from each other. T-tests for one sample were applied to evaluate the sample of family caregivers in relation to a comparison sample of a German study with n=594 participants.[11,16] The correlation analysis was performed to assess the associations between caregiver's burden and other factors such as age, duration of care, indicating physical symptoms, stage of disease, use of public care services or nurses' participation in and satisfaction with advanced training courses by calculating Spearman's rank correlation coefficient. The level of significance was set at $p<0.05$ for all statistical tests. The statistical analysis was performed using SPSS (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY, USA).

Family caregivers can be categorized into risk groups on the basis of their sum scores in three dimensions of burden using BIZA-D-PV. This relation was described by Schacke and Zank in a longitudinal analysis.[16] Accordingly, they stated that higher scores in burden due to personal constraints are associated with the risk of depression within the next months, higher scores in burden due to aggressive and disoriented behavior with the risk of violence against the person with dementia and higher scores in burden due to cognitive impairment with the risk of institutionalization of the person with dementia. A high risk is described for a sum score which lies one standard deviation above the mean value of the average population in this dimension and an extremely high risk for a sum score which lies at least two standard deviations above. As an example, sum scores of 13–18 points in the dimension "Personal constraints" are associated with a high risk for depression, which means a risk of 45% for depression within the next nine months. We categorized the family caregivers of our study into these risk groups.

Results

Sociodemographic distribution

A detailed description of sociodemographic characteristics of the sample of people with dementia is given in Table 1.

88% of the family caregivers were female and the average age was 63.8 years (range 36–88 years). 52% of them

Table 1 Characteristics of the people with dementia

	People with dementia (n=25)
Sex (male/female)	60%/40%
Age (years)	m=79.4 SD=8.23 range=59–94
Diagnosis	
- Alzheimer's disease	48%
- Vascular dementia	12%
- Mixed dementia	32%
- Frontotemporal dementia	4%
- Dementia with Lewy bodies	4%
MMSE (score)	m=10.2 SD=7.10 range=0–21
Severity of dementia	
- Mild	16%
- Moderate	36%
- Severe	48%

Abbreviations: n, sample size; m, mean; SD, standard deviation; MMSE, Mini Mental State Examination.

were spouses or life partners of the persons with dementia, 40% daughters or sons and 8% daughters-in-law. 56% lived in a shared household with the person with dementia. Most of the family caregivers were unemployed or retirees (68%). 40% stated that their daily time for caregiving is 8 hrs or more. The average total time for caring this relative with dementia was 3.6 years (range 0.5–10 years). 44% of the family caregivers had to get up once or twice per night due to caregiving, 16% three times or more. 40% used public care services to support them, 24% used the help of relatives, friends or neighbors, 24% used both private and professional support, whereas 12% had no support in caregiving.

The average age of the professional caregivers was 36.3 years (range 20–60 years) and 68% of them were female. Most of the professional caregivers were nurses (76%), followed by geriatric nurse assistants (12%), geriatric nurses (8%) and nurse assistants (4%). They have been working in their profession for 4.8 years on average (range 0.3–15 years) and their current working time was 34.2 hrs per week on average.

Burden of caregiving groups

The family caregivers in our study rated on average the highest burden due to personal constraints, followed by cognitive impairment of the person with dementia and the lowest burden due to missing social appreciation and acceptance of caring. The professional caregivers perceived on average the highest burden due to personal constraints and care tasks, followed by missing social appreciation and the lowest burden due to cognitive impairment as well as aggressive and disoriented behavior of the person with dementia. Physical symptoms such as headaches, back pain and sleep disturbances were indicated more often among family caregivers compared to professionals.

Family caregivers caring for a male person with dementia perceived a higher burden due to all dimensions except for burden due to cognitive impairment compared to family caregivers caring for a female person with dementia. Female family caregivers rated a higher burden due to all dimensions except for burden due to aggressive and disoriented behavior of the person with dementia and noticed lower acceptance of caring compared to male family caregivers. Regarding the relationship to the person with dementia, the highest burden due to aggressive and disoriented behavior, personal constraints as well as missing social appreciation was perceived by daughters-in-law, whereas the highest burden due to care tasks was perceived by spouses and life partners.

Professional caregivers caring for a male person with dementia perceived a higher burden due to aggressive and disoriented behavior as well as care tasks compared to professional caregivers caring for a female person with dementia. In contrast to the family caregivers, the male professional caregivers rated a higher burden due to all dimensions except for burden due to missing social appreciation and also rated a lower acceptance of caring compared to female professional caregivers. Regarding the different professions, the highest burden due to care tasks and personal constraints was perceived by geriatric care assistants, but they rated also the highest acceptance of caring.

Measured values for age, duration of caring and separate dimensions of burden were approximately normally distributed, as assessed by the Kolmogorov-Smirnov test with $p>0.05$ for each variable. The difference in the mean values between family caregivers and professional caregivers regarding age was obviously significant (t=9.69; $p<0.01$); regarding duration of caring, no statistically significant result was found (t=1.67; $p=0.109$). Compared to professionals, the family caregivers perceived a higher burden due to cognitive impairment (t=3.30; $p<0.01$) as well as aggressive and disoriented behavior (t=4.27; $p<0.01$), whereas differences in mean values of burden due to care tasks were not statistically significant (t=0.30; $p=0.767$). Statistical power assessed by calculating the effect size Cohen's d was moderate to strong for the differences in burden due to cognitive impairment (d=0.66) as well as aggressive and disoriented behavior (d=0.70). A description of the characteristics of caregiving groups and their perceived burden is given in Table 2.

With regard to family caregivers, we detected a negative correlation between caregiver's age and perceived burden due to missing social appreciation (r=−0.64; $p=0.001$). With regard to professional caregivers, we determined a positive correlation between caregiver's age and acceptance of caring (r=0.51; $p=0.010$). In both groups, there were positive correlations between the severity of dementia and caregiver's burden due to cognitive impairment (for family caregivers r=0.42; $p=0.038$ and for professional caregivers r=0.46; $p=0.020$) as well as aggressive and disoriented behavior (for family caregivers r=0.52; $p=0.007$ and for professional caregivers r=0.46; $p=0.021$). Furthermore, we detected some correlations between physical symptoms of caregivers and dimensions of burden. Regarding family caregivers, we found that current headaches were positively correlated with the burden due to missing social appreciation (r=0.46; $p=0.021$), back pain was

Table 2 Characteristics and burden of caregivers

	Family caregivers (n=25)	Professional caregivers (n=25)	Comparison sample (n=594)[a]	Family caregivers versus comparison sample	Family caregivers versus professional caregivers
Sex (male/female)	12%/88%	32%/68%	21%/79%	–	–
Age (years)	m=63.8 SD=12.18 range=36–88	m=36.3 SD=11.11 range=20–60	m=60.0 SD=11.40 range=28–91	t=1.54 *p*=0.136	t=9.69 *p*<0.01*
Duration of care (years)	m=3.6 SD=2.96 range=0.5–10 n=23	m=5.0 SD=3.98 range=0.3–15	m=3.5 SD=2.70	t=0.09 *p*=0.929	t=−1.67 *p*=0.109
Burden due to cognitive impairment (range 0–16)	m=8.12 SD=3.82	m=4.72 SD=3.68	m=9.11 SD=4.44	t=−1.30 *p*=0.208	t=3.30 *p*<0.01*
Burden due to aggressive and disoriented behavior (range 0–20)	m=8.84 SD=5.10	m=4.12 SD=3.93	m=7.93 SD=5.20	t=0.89 *p*=0.382	t=4.27 *p*<0.01*
Burden due to care tasks (range 0–36)	m=16.92 SD=10.68	m=16.20 SD=7.92	m=26.55 SD=9.20	t=−4.51 *p*<0.01*	t=0.30 *p*=0.767
Burden due to personal constraints (range 0–20)	m=11.04 SD=3.77	m=9.08 SD=3.88	m=12.21 SD=5.15	t=−1.55 *p*=0.134	–
Burden due to missing social appreciation (range 0–24)	m=7.64 SD=5.23	m=9.88 SD=4.39	m=10.58 SD=5.22	t=−2.81 *p*=0.010*	–
Acceptance of caring (range 0–16)[b]	m=10.68 SD=3.90	m=9.68 SD=3.87	m=11.91 SD=3.42	t=−1.58 *p*=0.128	–

Notes: [a]Sample of family caregivers described by Zank et al.[11,16] [b]Dimension is interpreted in a different way, the higher the score, the higher the positive outcome from caregiving. *Statistically significant *p*-value.
Abbreviations: n, sample size; m, mean; SD, standard deviation.

positively correlated with the burden due to personal constraints (r=0.52; *p*=0.008) and sleep disturbances were positively correlated with the burden due to cognitive impairment (r=0.40; *p*=0.045) and personal constraints (r=0.44; *p*=0.027). With regard to professional caregivers, sleep disturbances were positively correlated with the burden due to missing social appreciation (r=0.41; *p*=0.040). There were no correlations between family caregivers using public care services and dimensions of burden, between professional caregivers' participation in and satisfaction with advanced training courses and burden, as well as between duration of caring and dimensions of burden in both groups.

Risk groups

By categorizing the family caregivers of our study into risk groups described by Schacke and Zank, we determined a high risk for depression in 44%, a high and extremely high risk for violence against the person with dementia in 64% and a high and extremely high risk for institutionalization of the person with dementia within the next months in 72%.[16] A detailed description of the categorization is given in Table 3.

Discussion

Study population

Alzheimer's disease is the most common type of dementia with an estimated proportion of about 60%, followed by mixed and vascular dementia.[2,36] Mixed dementia is an often diagnosed type among older people with dementia. The estimated proportion of mixed dementia varies between 10% and 20% in literature.[35,36] Accordingly, the proportion of people with Alzheimer's disease (48%) is underrepresented and of people with mixed dementia (32%) somewhat overrepresented in our study. The sample

Table 3 Categorizing family caregivers into risk groups[a]

Dimensions of burden	Risk groups	Results of our study (percentage of family caregivers with this sum score)	Calculated risk within the next 9 months[b]
Burden due to personal constraints • score of 13–18 • score of 19–20	Depression of the caregiver • high risk • extremely high risk	 • 44% • 0%	 • 45% • 63%
Burden due to aggressive and disoriented behavior • score of 9–14 • score of 15–20	Violence against the person with dementia • high risk • extremely high risk	 • 52% • 12%	 • 36% • 48%
Burden due to cognitive impairment • score of 6–14 • score of 15–16	Institutionalization of the person with dementia • high risk • extremely high risk	 • 64% • 8%	 • 13% • 21%

Notes: [a]By using the questionnaire BIZA-D-PV. [b]In a longitudinal study by Schacke and Zank.[16]

size of the two caregiving groups in the present study is small but sociodemographic characteristics, including age and sex of people with dementia, age and sex of family caregivers, relation to patient, employment of family caregivers and proportion of caregivers living with the person with dementia in a shared household, are similar to those in other studies with larger sample sizes.[11–13,16] Similar mean values of the family caregivers' sex, age and duration of care in the sample by Zank et al are listed in the column "Comparison sample" of Table 2.[11,16] Differences to a study by Thyrian et al were seen concerning the severity of dementia.[12] The average score of Mini Mental Status Examination was much lower in the present study compared to the study by Thyrian et al (score of 10.20 versus 21.27), which might be caused by the different study designs. Thyrian et al conducted their study in primary care collaborating with general practitioners and including a screening for dementia. Thus, also people with mild dementia who are not yet formally diagnosed were detected and their caregivers were asked to participate in the study. However, in our study, most of the people with dementia were in the moderate and severe stages of the disease because hospital admissions due to a crisis of home caring are more frequent in these stages compared to mild dementia. The frequency of stages of dementia in participants of our study is similar to those in the study by Zank et al.[11,16] In our sample, 36% of the people with dementia had moderate and 48% had severe cognitive impairments; in the sample by Zank et al, 42% had moderate and 56% had severe cognitive impairments.[11,16] There are no greater sociodemographic differences between the sample by Zank et al and our study. For this reason, the study by Zank et al seems suitable as a comparison sample. However, there are differences between the current study and the study by Zank et al regarding recruitment of test persons. In the study by Zank et al, test persons were recruited by a newspaper call while home caring and therefore another type of selection bias can be assumed compared to our study.[11,16] In our study, caregivers were asked to participate directly and not by newspaper advertisements. The personal contact might have influenced the decision whether to participate in the study. Takahashi et al compared family caregivers to professional caregivers with regard to burden, depression and quality of life, but in their study, samples were not matched. The age of the caregivers, the frequency of assistance from relatives and use of public care services were similar to those in the present study, whereas the average duration of caregiving regarding professionals was lower in their study (4.8 versus 1.6 years). They used the Zarit Burden Interview as a screening instrument for caregiver's burden and family caregivers scored higher.[34]

Caregivers' burden

Compared to a German study with n=594 participants, the family caregivers in our study rated a higher burden due to aggressive and disoriented behavior and a higher burden due to lower acceptance of caring, whereas in our sample the family caregivers indicated a lower burden due to all the other dimensions.[11,16] The differences in the mean values between our sample of family caregivers and the comparison

sample were statistically significant regarding the burden due to care tasks (t=−4.51; $p<0.01$) and missing social appreciation (t=−2.81; $p=0.010$). The differences in the mean values with regard to age and duration of caring were not statistically significant. The comparison is shown in Table 2. Detected differences could be explained by the different settings of the two studies. Zank et al assessed the burden of family caregivers while home caring. Family caregivers in our study perceived a lower burden due to care tasks and missing social appreciation, which might be related to relief by hospitalization of the person with dementia.

Thyrian et al assessed the burden of family caregivers in a quantitative in-depth analysis in the same region of Northern Germany, where the present study was conducted.[12] Data were collected in a cluster-randomized, controlled intervention trial. The perceived burden was low to moderate and lower in all dimensions compared to the present study. This might be caused by recruitment in primary care with a higher proportion of people with dementia in the earlier stages of the disease and with a considerably lower risk of selection bias due to the study design.

Laporte Uribe et al assessed the burden of family caregivers which were recruited in dementia care networks in Northern, Eastern and Western Germany.[13] Overall, the perceived burden was similar to the results in the present study. However, the subjective burden due to personal constraints was higher in our study. The reason for this might be the fact that test persons in our sample were not involved in specialized dementia care networks and therefore, family caregivers might have less professional support in caregiving. In our study, female family caregivers perceived a higher burden than male family caregivers in almost all dimensions confirming the results of the study by Laporte Uribe et al.[13] The perceived burden due to aggressive and disoriented behavior of the person with dementia was highest for the included daughters-in-law in our study. This finding is not supported by literature. Generally, spouses or life partners perceive a higher burden due to behavior change of the person with dementia compared to family caregivers not being a spouse or life partner.[4,15] The reason for this discrepancy might be the small sample size of our study which was not adjusted for statistical outliers.

In general, family caregivers perceived a moderate burden in our study, whereas professional caregivers perceived a low to moderate burden. Our findings indicate that being a family caregiver is more burdensome than being a professional caregiver regarding behavior change of the person with dementia, but equally burdensome regarding care tasks. Therefore, it should be emphasized how important it is to assess the burden of professional caregivers of persons with dementia as well, particularly in often challenging working environments, such as locked wards of gerontopsychiatric hospitals. However, the age differences and other differing variables between family caregivers and professional caregivers have to be considered when interpreting our findings. Moreover, chosen instruments have to be discussed. BIZA-D-PV is a standardized questionnaire for detecting burden of family caregivers of persons with dementia. It is not validated for detecting burden of professional caregivers. However, this questionnaire contains three modules, which record dimensions of burden that occur in both caregiving groups and refer additionally to the matched person with dementia. Only these were compared. In summary, it is obvious that they reflect merely a small proportion of professional caregivers' overall burden.

Limitations

To the best of our knowledge, this is the first study which aims at describing family caregivers' and professional caregivers' burden in matched samples after hospitalization of the people with dementia. Although we used the shorter practice version of the questionnaire to lower the inhibition threshold for participation, recruiting test persons was difficult. The representative nature is obviously limited with regard to the small sample size and selection bias in this study. Due to the cross-sectional design of the study, it is not possible to prove causality. Detected differences regarding the perceived burden of family caregivers measured while home caring and immediately after hospitalization of the person with dementia should be assessed in further studies with a lower risk of selection bias. The aim of further research should be to improve the early detection of an upcoming breakdown of home caring.

Conclusion

Surveying caregivers immediately after hospitalization of the people with dementia focuses on an important issue because the sources of burden may vary in the course of time. To acquire knowledge about caregivers' burden in the course of the disease is part of a necessary multidisciplinary approach of preventing the breakdown of caregiving for the person with dementia at home on the one

hand and of preventing caregivers from becoming patients themselves due to burden on the other hand.

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Disclosure

The authors report no conflicts of interest in this work.

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