Research Article **GJON (2020) 3:17**

Global Journal of Nursing

(ISSN:2637-4994)

Effects of factors of informal care on the utilization of social care insurance benefits: A cross-sectional study

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ABSTRACT

Background: Presently in Germany, as there is a shortage of nursing staff, informal caregivers have become highly relevant. Because they often deal with care related burden, legislation was passed to improve caregivers' situations by offering more supports. Nonetheless, a considerable percentage of caregivers do not utilize it.

Methods: Data was collected in Saxony (Germany) from November 2019 to December 2019 by using an online survey and a postal survey (cross-sectional study design; n= 1,716). For analysis bivariate logistic regression (forward method LR, $\alpha \leq 0.05$) was performed.

Results: The average age of the sample was 61.9 years, 52.9% were female and 45.7% male. Results indicate a medium utilization of care insurance services. Considerable associations were time spent on care and utilization of care allowance (OR: 1.77), such as duration of care degree and utilization of residential care services (OR: 1.88) and substitute care (OR: 1.81).

Conclusions: Informal caregivers putting intensive effort into care do tend to utilize services. The resulting questions of why newer informal caregivers do not tend to utilize services and why there is a medium utilization among all caregivers implies that people need to gain better access to services independently of care factors.

Keywords: Informal care; Care Insurance; Services utilization

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How to cite this article:
Jenny Rueffer, Silke Geithner, Goetz Schneiderat, Tom Schaal. Effects of factors of informal care on the utilization of social care insurance benefits: A cross-sectional study. Global Journal of Nursing , 2020; 3:17.

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Website: https://escipub.com/

Study highlights

German legislature has passed two laws to strengthen the frequently burdensome situation of informal caregivers, but still there is low utilization of support services. In addition to already confirmed impacts for low utilization this study identified four care characteristics that affect utilization. Services need to be delivered more efficiently to the individual caregiver.

Background

When individuals in Germany take out social health insurance, they are automatically socially care insured. By paying regular insurance fees people receive support from social care insurance when they are in need of care. The most frequently utilized care insurance services among Germans are care allowance for self-organised care, care in in-patient facilities, combination of non-cash benefit and care allowance, substitute care for home-cared insured, and non-cash benefits (Federal Ministry of Health, 2018). Examples of non-cash benefits include, a nurse, looking after measures, and additional housekeeping support. If an informal caregiver becomes ill or needs a holiday, care insurance will pay a substitute care person for substitute care for up to six weeks annually. According to the degree of decline in independence and skills a care degree ranging from one to five is calculated by using a standardised assessment instrument. The financial value of support services and claims relates to their calculated care degree (SGB XI, 2020).

Altogether there are 72.75 Million of socially care insured people in Germany. More than 3 million people receive care insurance services, of these 2.9 million are out-patients (Federal Ministry of Health, 2020). Approximately 13,300 out-patient care providers employ 356,000 nurses to provide the care services for people in their homes according to SGB XI. 13,600 nursing homes care for an average of 63 people in need of care (Federal Statistical Office, 2017). Clearly there is a higher need of care than personnel resources in the country. Considering this conflict and the topic of demographic change informal caregivers who nurse their elderly, relatives and friends in their homes has gained more significance.

About 4.7 million adults care regularly for individuals needing care and one third of these caregivers provide at least two hours of care per day (Wetzstein, Rommel & Lange, 2015). Studies have shown a range of average ages among informal caregivers internationally, with age averages in the middle and older adulthood most common (Lüdecke, Mnich & Kofahl, 2012; Metzelthin, Verbakel & Veenstra et al., 2017). This leads to the assumption that they are often employed. Hielscher et al. (2017) confirmed that among informal caregivers more than 50% work either part-time or full-time. Nationally of the total of informal caregivers more than 19% work part-time whereas Germanys fit for employment population shows only 14%, therefore a correlation between work and time spent on informal care can be assumed (Geyer & Schulz, 2014). Consequently, people who provide care might more often have an unstable financial situation or even be in debt. Results of a German study show that providing care often leads to financial worries and furthermore to a neglect in personal needs such as marriage, family life, free time and hobbies (Continentale health insurance a.G., 2016). Those who provide extensive care frequently experience psychological and social isolation and more often feel unhealthy than people who do not provide care (Wetzstein et al., 2015). A Dutch study has confirmed that there is a direct correlation between the subjective well-being of informal caregivers and their burden and hours of informal caregiving (Verbakel, Metzelthin & Kempen, 2016). People providing informal care experience more burden and reduced well-being (Pinquart & Sörensen, 2003).

In 2015 the first German legislation was passed to first law to improve the national care situation to provide more services in terms of higher payments and increased care support funding for up to ten days if an acute care situation involves the informal caregiver greatly (Wetzstein et al., 2015). Additionally, legislation to achieve a better family-care-work balance was enacted to enable informal caregivers who nurse a close relative to have the opportunity to receive 24 months off work (Wetzstein et al., 2015).

Although the state tried to counteract problems in care context the EUROFAMCARE study shows a low utilization of care insurance services of only 60% among German relatives providing care and nursing for their elderly (Lüdecke et al., 2012). The main two reasons why people do not use these supporting services are that they either are not in need of them or do not know they exist (Hielscher et al., 2017). An identified access barrier is a lack of finances so a low utilization of support services by financially deprived households can be concluded (Hielscher et al., 2017). Further factors that affect different levels of service utilization are the gender of informal caregivers and their educational level, and also how they perceive their care-related burden (Lüdecke et al., 2012). Another common reason for low utilization is the lack of locally support services (Hielscher, et al., 2017).

To summarize most German informal caregivers do not have a comprehensive understanding of supports available from the state. Even though enormous effort is put in informal care and care-related burden several factors prevent the utilization of care insurance services.

Objective

The aim of this study was to analyse the situation of informal caregivers in Saxony (federal state of Germany) households. To describe the study sample sociodemographic data were collected. Besides portraying the utilization of care insurance services this paper pursues the aim investigating effects of several care characteristics (care receivers' care degree, duration of informal care in years, duration of the care receiver care degree, and time spent on informal care) on the utilization of social care insurance services.

Methods

Design and sample

Using a stratified sample, 62 Saxon registration authorities provided 25,576 resident data sets in September 2019. After methodical stratification according to the number of inhabitants, 24,018 registration data were available. Residents aged 40-85 were contacted. By sending them a postcard they were invited to voluntarily take part in a web-based questionnaire 'Survey on home care in Saxony' (cross-sectional study). Potential participants who preferred not to participate online were given the option to call for a paper-based questionnaire.

Data collection

Recruitment took place in two phases. On the 5th of November 2019 the first phase of recruitment started by sending postcards to invite potential participants. A second phase of sending postcards started on 12th of December 2019. The questionnaire was partially standardized and validated. The survey consisted of 67 items essentially about the participants' care situation at home, utilization of care insurance services and well-being in different life areas. Before starting the data collection, an online pre-test was performed. An adjustment was performed based on these results.

Measurements

To describe the sample background information about caregiver characteristics gender, age, marital status and educational level was collected. Furthermore, the variable 'informal care' was assessed, because informal caregivers were the focus of this study, and all analyses performed in this paper are related to the informal caring sample.

The objective of this paper is to assess the dependent variable 'utilization of care insurance services' utilizing ten sub-variables referring to the utilization of the following services: care allowance, non-cash benefits, semi-residential care, residential care services, financial relief benefits, short-term care, substitute care, nursing aids, improvement to residential environment and flat sharing allowance. Participants could decide between 'I know but do not utilize it.', 'I know and utilize it.', 'I know it but do not know whether it is utilized.' and 'unknown / we do not utilize it'.

Four predictor variables were of interest: care receivers' care degree, duration of informal care in years, duration of the care receivers' care degree, time spent on informal care. These were assessed in a part of the questionnaire that was directed at informal caregivers only. 'Degree of care' was measured using the following item: 'On which care level/ care degree is the person who you support?' ('one', 'two', 'three', 'four', 'five', 'I don't know.'). The two items 'How long do you already support the care receiver?' and 'How long has the person you support had their care degree?' were assessed on a five-point scale ('less than one year', 'one to three years', 'three to six years', 'six to nine years', 'nine years and more') and a seven-point scale ('less than one year', 'one to three years', 'three to six years', 'six to nine years', 'nine years or more', 'there is no care degree.', 'I do not know.'). The predictor variable 'time spent on informal care' was measured on a six-point scale: 'less than five hours', 'five to ten hours', 'ten to 20 hours', '20 to 30 hours', '30 to 40 hours', '40 hours or more'.

Analysis

1,716 questionnaires (1,301 completed the online survey and 415 participated using the postal sent survey) could be used for statistical analyses. The software package SPSS for Windows, version 25, was used. Sociodemographic characteristics were analysed using descriptive statistic and frequency tools. To analyse the effect of the predictor variables on the utilization of care insurance services bivariate logistic regression was performed. Therefore, the ten sub-variables according to care insurance services were dichotomised by calculating two groups based on utilization (0- non-utilization; 1- utilization). According to the different services bivariate logistic regression (forward method LR, $\alpha \leq 0.05$) was performed using the same predictors care receivers' care degree, duration of informal care in years, duration of the care receivers' care degree, time spent on care and ten different dependent variables for all regressions. To analyse the effect on ten different care insurance services ten regressions were performed.

Ethical considerations

Every participant was informed that taking part in the study is on a voluntary and anonymous basis.

Results

Out of 1,716 participants, 311 provided informal care, and this 18.1% of the sample were subsequently the focus of the analysis (Table 1). The average age of the sample was 61.9 years, the average age of informal caregivers was 62.9 years. Of all the sample, 52.9% were female and 45.7% were male. Among informal caregivers the percentage of women (62.4%) was comparatively higher than men (35.4%). Gender diverse was only 0.4% participants and 0.6% informal caregivers. Most of the participants were married or lived with a partner (74%), whereas a smaller number was unmarried (8.3%), divorced/ separated (8.3%) or widowed (8.2%). A comparable distribution was shown by the figures of informal caregivers (76,8%; 7.4%; 5.8%; 8.4%). Of the total participants 51% were gainfully employed and 49% were not gainfully employed. This was very similar to informal caregivers of which 49.2% were gainfully employed and 48.9 were not gainfully employed.

255 caregivers reported that the person cared for has a care degree. The two most frequent care degrees were two (30.5%) and three (25.1%), degree four and one were common (12.5%; 8.4%), but degree five was rare (4.5%). The minority claimed that the supported person had a degree of care for six to nine years (5.8%) whereas duration less than one year (17.4%), one to three years (31.5%) and three to six years (19.6%) were common. 10% had a care degree for nine years and longer. There is missing data of 36 participants regarding duration of care degree. The duration of informal care often continued for three to six years (29.3%) or one to three years (27.3%). Support duration shorter than one year accounted for 16.7%, and longer than nine years 15.8%. One in ten caregivers had already supported for six to nine years. Three participants did not answer about this item. The time spent on care varied. Interestingly, 11.6% cared more than 40 hours a week. Supporting the person in need 30-40 hours per week was uncommon (6.4%) compared to 17.4% cared less than five hours, 31.5% cared five to ten hours, 21.2% cared ten to 20 hours and 11.9% cared 20-30 hours. The utilization of several care insurance services among informal caregivers varied strongly. Utilizing care allowance (64.3%), nursing aids (56.3%) and non-cash benefits (51.1%) were reasonably frequent. Less often informal caregivers received financial relief (28.0%), improvement to residential environment (24.8%), substitute care (22.8%) and short-term care (17.7%). Comparing these percentages, three services were rarely utilized, 9.6% utilized semi-residential care, 8.0% residential care services and flat sharing allowance was confronted with great ignorance (1.0%). No participant who provided informal care did not utilize one service at minimum.

For bivariate logistic regressions different sample sizes were included as a result of informal caregivers' different utilization of several care insurance services (care allowance n=247; residential care services n=223; amount for financial relief n=214; substitute care n=224; nursing aids n=243). An acceptable quality of the regression model was indicated by Nagelkerkes R^2 that showed 0.21 for care allowance and 0.25 for substitute care. Nagelkerkes R^2 for the dependent variables residential care services (0.15), nursing aids (0.07) and amount for financial relief (0.04) indicated comparatively lower model qualities (Table 2).

The figures have shown that the duration of the care receivers' care degree had a considerable effect on the utilization of several care insurance services. The longer the person was on a care degree the higher the chance that he/she utilized residential care services (OR: 1.88) or the caregiver utilized substitute care (OR: 1.81). Use of Nursing aids was also influenced by the duration (OR: 1.41). An increasing time spent on care implied a higher chance for the utilization of care allowance (OR: 1.77). On the other hand, the more time caregivers spent on informal care the smaller the likelihood of utilizing residential care services (OR: 0.57) and substitute care (OR: 0.79). Utilizing the amount for financial relief was affected by the duration of care in years (OR: 1.32). The probability of utilizing substitute care was affected by the care degree of the care receiver (OR: 1.72). Another small impact had the variable care degree on the utilization of nursing aids (OR: 1.03). The analysis did not identify an effect of these characteristics on non-cash benefits, semi-residential care, short-term care, improvement to residential environment and flat sharing allowance.

Table 1: Descriptive statistics of sociodemographic factors

	Sample (n=1,716)	Missing data from sample	Informal caregivers (n=311)
Average age	61.9 (SD±11.9)	9 (0.5%)	62.9 (n=308; SD±10.9)
Gender		18 (1%)	
Male	784 (45.7%)		110 (35.4%)
Female	907 (52.9%)		194 (62.4%)
Diverse	7 (0.4%)		2 (0.6%)
Marital status		20 (1.2%)	
Unmarried	143 (8.3%)		23 (7.4%)
Married/Live with partner	1,270 (74.0%)		239 (76.8%)
Divorced/separated	143 (8.3%)		18 (5.8%)
Widowed	140 (8.2%)		26 (8.4%)
Employment			
Gainfully employed	844 (51%)		153 (49.2%)
Not gainfully employed	841 (49%)		152 (48.9%)

Table 2: Results from bivariate logistic regression ($p \leq 0.05$)

Dependent variable	**Independent variable**	**Odds Ratio (OR)**	**CI (95%)**
Care allowance	Time spent on care	1.77	1.33-2.35
Nagelkerke-R^2: 0.207 Hosmer Lemeshow: 0.068			
Residential care services	Duration of the care receivers' care degree	1.88	1.31-2.69
	Time spent on care	0.57	0.41-0.8
Nagelkerke-R^2: 0.154 Hosmer Lemeshow: 0.434			
Amount for financial relief	Duration of care in years	1.32	1.05-1.66
Nagelkerke-R^2: 0.037 Hosmer Lemeshow: 0.326			
Substitute care	Care degree	1.72	1.72-2.5
	Duration of the care receivers' care degree	1.81	1.35-2.42
	Time spent on care	0.79	0.63-0.99
Nagelkerke-R^2: 0.25 Hosmer Lemeshow: 0.571			
Nursing aids	Care degree	1.03	1.0-1.06
	Duration of the care receivers' care degree	1.41	1.1-1.81
Nagelkerke-R^2: 0.072 Hosmer Lemeshow: 0.662			

Discussion

Key results

Informal care is provided by 18.1% of the study sample. The most frequently utilized care insurance services among informal caregivers were care allowance, nursing aids and non-cash benefits. This study identified four care characteristics that have an impact on whether informal caregivers utilize several services: time spent on care, care degree, duration of the care receivers' care degree, duration of informal care. It is evident that care allowance and substitute care are considerably affected.

Discussion

The results of the logistic regression analyses identify that time spent on care and duration of the care receivers' care degree have considerable effects on the utilization of services, so it seems that the chance of use is higher if there is more time spent and longer effort on care. Since informal care often has a full-time character – the main caregiver supports 36.7 hours/week on average (Meyer, 2006) – substitute care is utilized by a minority of caregivers. Although, the results of this paper show that approximately half of all informal caregivers are gainfully employed. The more time that is spent on care then the less time there is available to be spent on employed work thus caring informally correlates with minor occupation and part-time jobs (Schneekloth & Müller, 2000). Consequently, the motivation to apply for care allowance could be a financial deficit. In addition to that, informal care often means burden or a reduced well-being for the caregiver (Continentale health insurance a.G., 2016; Metzelthin et al., 2017; Verbakel et al., 2016) so presumably people who spent more time on care need more time off. This might be the reason for a higher incidence of utilization of substitute care.

The longer a care receiver is on a care degree the higher the chance to utilize residential care services, as figures have shown. Studies have portayed high average ages of 80-90 years in nursing homes and high percentages of cognitive and mobility impairment among residentials (Telenius, Engedal & Bergland, 2013; Sverdrup, Bergh, Selbaek et al., 2018) these study results support the fact that care receivers tend to choose living in a nursing home later.

Regarding the results from the German sample of the EUROFAMCARE study that shows a weak impact of care characteristics on service utilization the results of this paper display a more considerable influence (Lüdecke et al., 2012). A possible cause for this could be an increasing political effort to strengthen care and informal care as a reaction to demographic change during recent years. Legislation passed in both 2015 and 2017 strengthened care in Germany to include more financial support for people in need of care, their relatives, formal and informal caregivers (Federal Ministry of Health, 2016). The number of people utilizing care insurance services has climbed since 1995 but did not conspicuously increase in every year (Federal Ministry of Health, 2018). A more frequent utilization could be a consequence of an ageing population. An explanation for the insignificant increases in 2015 and 2017 could be that although people receive more support, there is a lack of knowledge of supports available among Germans. This correlates with the results of this study that presents a minimal utilization of services. Hielscher et al. (2017) proposed one important reason care consultation and care insurance services are not utilized is educational disadvantage. Recognizing this, consultation offers need to be more accessible particularly to educationally disadvantaged informal caregivers to improve awareness of services. Advertising care insurance services in public places, integrating the topic of informal care already in school classes (for instance in social sciences or politics) and sending pamphlets about possible services and their benefits to informal caregivers who already have applied for one service could be the first steps to solve problems of ignorance. Additionally, informal caregivers should be able to be connected to enable them to exchange information about care insurance services. This aim is included in the 'care package Saxon' which was presented in May 2019 and is directed at the informal caregiver network to provide better exchange between informal caregivers, care consultation and support (Saxon State Ministry of Social Affairs and Consumer Protection, 2020). Through this network informal caregivers of all educational levels can be reached. Looking at these study results long caring people could pass on their experiences and utilization of several care insurance services.

Limitations

Regarding interpreting the results of this study several limitations must be examined. Since 1,716 out of 24,018 participants completed this questionnaire the effects of a low response rate must be considered. An explanation for that could be the length of the survey (longer than 30 minutes) that correlates with low response rates but does not influence quality of response (Deutskens de Ruyter, Wetzels et al., 2004). Different reasons cause non-responding. An increasing tendency of refusing to participate correlates with ages (Kaldenberg, Koenig & Becker, 1994). Facing the age as a possible reason for non-response participants had the chance to call, put their questions to us and were then motivated to participate. 415 of 1,716 participants using the offered paper questionnaire instead of the online survey confirmed the offers' effectiveness. Using a combination of online and postal questionnaires made it possible to reach a huge social circle despite limited financial resources. There was an inconsiderable amount of missing data in variables of interest, so missing data were not replaced.

Apart from this the study sample might be representative as the sample collection was performed randomly in a large population (Levin, 2006). Considering the uniform framework legislation of Germanys' federal states, a transferability of the results can be assumed. Regarding several studies that confirmed low utilization of care insurance services (Hielscher et al., 2017; Lüdecke et al., 2012) achieving generalisability of this study could have be assumed. Informal caregivers' percentage of the whole sample was elevated compared to Germanys population (Geyer & Schulz, 2014) which could be caused by higher response rates among informal caregivers because of their connection to the surveys topic.

Finally, this was the first representative study about this topic revealing interesting aspects of informal care. Nonetheless, cross-sectional studies are limited to the fact that data was collected at one time so distinguishing in an association between exposure and outcome is impossible (Levin, 2006 & Mann, 2012). According to this an association between care effort and care insurance utilization is evident but a causality could not be inferred meaning further studies on this should be performed.

Conclusions

To conclude, among moderate utilization issues care characteristics can be associated with several services. At first, informal caregivers spending high and long-standing effort in nursing tend to utilize personal support (substitute care) and financial support (care allowance). The resulting question why informal caregivers who have recently started providing care or care less hours do not tend to utilize services leads to the assumption that the accessibility of information and services to beginning informal caregivers needs improvement. Apart from this, moderate service utilization has been established which requires more institutional effort, of politics and care insurances, on removing existing barriers and delivery of these services to the individual caregivers.

List of abbreviations

OR	Odds Ratio
CI	Confidence Interval
SD	Standard Deviation

Declarations

Ethics approval and consent to participate

In Germany, surveys relating to social health and care insurance and the associated quality of care can be carried out without obtaining an ethics vote. Sensitive data was not collected. Rather, informal caregivers were asked for their opinion. No human or animal substances and no sensitive disease data were included in the study. This follows from §92 and §137 of the Social Code Book V (Code of Social Law V, SGB V), in conjunction with §4 of the Quality management guideline (Quality management directive for panel doctors' supply, ÄQM-RL).

A cover letter informed the participants about the purpose of the survey and that participating in the study is on a voluntary and anonymous basis. At the beginning of the questionnaire, participants had to explicitly agree to their participation and anonymous data processing by ticking the consent to participate. Otherwise, editing was not possible online. Paper questionnaires without a declaration of consent were excluded from data analysis. By returning the questionnaire, they gave their consent to participate in the study. The survey was conducted in accordance with the ethical standards of the Declaration of Helsinki.

Consent for publication

Not applicable

Competing interests

The authors have declared that there are no competing interests.

Funding

This paper bases on the survey “home care in Saxony” which was performed in 2019 and co-financed by tax revenues from the budget that was decided by the parliament of Saxony.

Authors' contributions

TS and SG conceptualized the study. JR was the person in charge of data curation. The methodology of the study was drawn up by TS and GS. TS and JR analysed and interpreted the data regarding associations between informal caregivers and their utilization of social care insurance services. JR and TS were the major contributors in writing the manuscript. All authors read and approved the final manuscript.

Acknowledgements

The authors thank the participants and the resident registration offices who contributed to this study. We are very grateful to Carol van Dyk for linguistic assistance.

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