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How does beginning or ceasing of informal caregiving of individuals in poor health influence sleep quality? Findings from a nationally representative longitudinal study

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ABSTRACT

Background: Various cross-sectional studies exist examining the association between informal caregiving and sleep quality. However, there is a lack of longitudinal studies investigating whether beginning and ceasing of informal caregiving is associated with changes in sleep quality.

Aims: Investigating whether beginning and ceasing of informal caregiving of individuals in poor health is associated with changes in sleep quality in both sexes.

Methods: Data were taken from a nationally representative sample of individuals $\geq$ 40 years in Germany from 2008 to 2017. In our analytical sample, n equaled 22,910 observations. Based on the Pittsburgh Sleep Quality Index, the sleep quality was assessed by the difficulties falling asleep during the last month, difficulties with sleep because of waking up during the last month (in both cases: (from 1 = not during the last month to 4 = three or more times a week) and the overall assessment of sleep quality during the last month (from 1 = very good to 4 = very bad).

Results: Asymmetric fixed effects regressions showed that in men beginning to provide informal care was associated with decreased overall sleep quality (β=-.09 (95% CI: −.15 – −.03), $p<.01$) and an increased likelihood of difficulties because of waking up (OR: 1.54 (95% CI: 1.07–2.20), $p<.05$), whereas ceasing to provide informal care was not associated with the outcome measures (both, in women and in men).

Discussion: Starting informal caregiving had deleterious effects on sleep quality in men.

Conclusions: Efforts to assist men in maintaining sleep quality may be beneficial.

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KEYWORDS
Informal care; longitudinal; private care; sleep disorder; sleep disturbance; sleep quality; gender differences

Introduction

There is an ongoing demographic aging taking place in various industrialized countries. Since old age is associated with an increased need for care (Hajek, Bock, & König, 2017; Hajek, Luck, et al., 2017; Hajek, Brettschneider, et al., 2017), it is expected that the number of individuals in need for care will increase considerably. Most commonly, individuals in need for care prefer to stay in their homes as long as possible (Hajek, Lehnert, Wegener, Riedel-Heller, & König, 2017, 2018), for example to sustain familiar surroundings (Lehnert, Heuchert, Hussain, & König, 2019). Most often, informal care is provided by family members (Roloff, 2009).

While single longitudinal studies have shown that providing informal care can have beneficial consequences (e.g. for cognitive functioning (Zwar, König, & Hajek, 2018b)), various longitudinal studies have shown that providing informal care can have several detrimental consequences, e.g. decreased satisfaction with leisure time, decreased subjective well-being, increased depressive symptoms or decreased self-rated health (Hajek & König, 2016b, 2018, 2019; Zwar, König, & Hajek et al., 2018a). Furthermore, providing care is also associated with a decreased frequency of sporting activities (Hajek, Bock, et al., 2017; Stacey, Gill, Price, & Taylor, 2019) and can also lead to increases in body-mass-index (Hajek & König, 2017; Lacey, McMunn, & Webb, 2018). A recent systematic review showed that informal caregiving can reduce both mental and physical health (Bom, Bakx, Schut, & van Doorslaer, 2019).

However, to date, only a few, mostly cross-sectional studies (for example: (Al-Daken & Ahmad, 2018; Hoyt, Mazza, Ahmad, Darabos, & Applebaum, 2020; Koyanagi et al., 2018; Sittler & Wilz, 2019)), have examined the link between informal caregiving and sleep quality. They mainly found an association between providing informal care and lower sleep quality (Al-Daken & Ahmad, 2018; Hoyt et al., 2020; Koyanagi et al., 2018; Sittler & Wilz, 2019). This was also confirmed by a recent systematic review and meta-analysis (Gao, Chapagain, & Scullin, 2019).

In contrast, we are only aware of one recent longitudinal study (Sacco, Leineweber, & Platts, 2018) which examined the link between informal caregiving and sleep quality. Based on data from the Swedish Labour Force Survey (n = 12,253; waves 2010, 2012, 2014 and 2016; individuals in paid work aged 16 to 64 years), this study (Sacco et al., 2018) showed that providing informal care was associated with increased levels of sleep disturbance. Furthermore, using random-effects models, they showed that the end of caregiving was associated with reductions in sleep disturbance. In sensitivity analysis (using fixed effects regressions), only changes from not providing informal care to providing care $\geq$ 5 h per week were associated with higher levels of sleep disturbance.

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However, there is a lack of studies disentangling the potential different consequences beginning and ceasing informal caregiving can have for the sleep quality. Therefore, based on nationally representative data from community-dwelling individuals ≥ 40 years in Germany, the objective of this study was to examine whether beginning and ceasing of informal caregiving of individuals in poor health is associated with changes in sleep quality in both women and in men. This knowledge may help to develop appropriate strategies.

This is important because poor sleep quality is associated with lower cognitive functioning (Scullin & Bliwise, 2015). Ultimately, this may affect the relation between caregiver and care-recipient. For example, the caregiver may overlook new symptoms of the care-recipient or forget to manage medications of the recipient (De Vugt et al., 2006; Oken, Fonareva, & Wahbeh, 2011). Furthermore, a systematic review concluded that sleep problems can increase the own risk of cognitive impairment and developing Alzheimer's disease (Bubu et al., 2017).

As theoretical foundation, we used the caregiver stress model introduced by Pearlin et al. (Pearlin, Mullan, Semple, & Skaff, 1990). According to this model, caregiving can involve various stressors such as primary (e.g. functional impairment in the care-recipient) or secondary stressors (e.g. loss of self). These stressors can result in negative outcomes such as decreased physical or mental health (Pearlin et al., 1990)—as outlined above. Moreover, in accordance with the proposed stress-coping model, the characteristics of the caregiver are important for dealing with caregiving. The gender is such a main characteristic of the caregiver. It has been demonstrated that informal care is predominantly provided by women (Geyer & Schulz, 2014). Moreover, caregiver tasks often vary between women and men, with male caregivers receiving more support and more frequently delegating care tasks (Bertogg & Strauss, 2020). Most often, and conventionally, it is expected that women provide informal care (Cotter, 2018). Thus, it appears plausible that the caregiving situation differs between men and women. Additionally, it has been shown that coping strategies for stressful conditions vary between women and women (Brown & Chen, 2008; Tamres, Janicki, & Helgeson, 2002). In sum, we assume that the association between beginning and ceasing of informal caregiving and changes in sleep quality is more pronounced in women.

Methods

Sample

For our current study, we used data from a nationally representative sample exclusively focusing on inhabitants ≥ 40 years (second half of life) from Germany ("Deutscher Alterssurvey", DEAS). The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) funds the DEAS study. The DEAS study began in 1996 and has a cohort-sequential design. Individuals were selected based on a national probability sampling procedure. Various topics are included in the DEAS study (like grandchild care, occupational information, social ties, retirement or health).

For this study, we used data from the waves three (year 2008) to six (year 2017) due to data restrictions (i.e. sleep quality was only quantified from the third wave onwards). In our study, the analytical sample equaled 22,910 observations.

The time span between the single waves (from three to six) was three years. In total, 8,200 individuals were interviewed in the third wave (response rate: 38%; fourth wave: 4,855 individuals, response rate: 56% response rate; fifth wave: 10,355 individuals, 33% response rate; sixth wave: 6,626 individuals, response rate: 63%). The response rates are comparable to other surveys performed in Germany (Neller, 2005). While new samples were added in the third and fifth wave, the fourth and six wave are panel surveys (i.e. only including individuals who already took part in at least one former wave). Main reasons for lack of follow-up data were refusal and health reasons. Additional details are given by Klaus et al. (Klaus et al., 2017).

Dependent variables

Based on the Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989), the sleep quality was assessed by (i) difficulties falling asleep during the last month, (ii) difficulties with your sleep because of waking up during the last month (in both cases: (1 = not during the last month, 2 = less than once a week, 3 = once or twice a week and 4 = three or more times a week) and (iii) the overall assessment of sleep quality during the last month (1 = very good, 2 = good, 3 = fairly bad and 4 = very bad).

To ease the interpretability, we recoded the sleep quality variable (sleep quality: 1 = very bad to 4 = very good). Furthermore, we dichotomized the variables for 'problems with falling asleep' and 'problems with waking up' (1 = at least once a week; 0 otherwise).

Independent variables

The key independent variable was informal caregiving. It was measured using the question "Are there people you look after or care for regularly due to their poor state of health, either on a private or volunteer basis" (0 = no; 1 = yes). As socio-economic covariates, we included age, marital status (distinguishing between 'never married', 'widowed', 'divorced', 'married, living separated from spouse', and 'married, living together with spouse') and labor force participation (employed; retired; not employed). As health-related covariates, we included self-rated health (from 1 = very good to 5 = very bad), physical illnesses (e.g. diabetes, cardiac and circulatory disorders or cancer; ranging from 0 to 11) and physical functioning (subscale physical functioning of the SF-36 (Ware & Sherbourne, 1992); ranging from 0 (worst) to 100 (best)). The time-constant variable education was solely used for descriptive reasons (ISCED-97 (UNESCO, 2006), distinguishing between low (0–2), medium (3–4) and high (5–6) education). Low education refers to individuals without formal vocational qualification. Medium education refers to individuals with vocational training (at work/at school). This includes individuals with a higher general school certificate without professional training. High education refers to individuals with completed professional development training (professional, master or technical school, university of cooperative education, or academies) as well as individuals with completed

university studies. This includes universities of applied sciences and universities (UNESCO, 2006).

Statistical analysis

Similar to other studies which examined the consequences of informal care (Kaschowitz & Brandt, 2017; Oshio, 2014; Van den Berg, Fiebig, & Hall, 2014), fixed effects (FE) regressions were used to analyze the link between informal caregiving and sleep quality in our study. One of the key advantages of FE regressions is that it allows for an association between time-constant factors (observed and unobserved such as genetic components) and explanatory variables (Cameron & Trivedi, 2005). Even when such an association is present, FE strategies produce consistent estimates (when the strict exogeneity assumption holds) (Cameron & Trivedi, 2005). In contrast, other regression techniques such as random effects regressions produce inconsistent estimates when time-constant unobserved factors are associated with the explanatory variables (Cameron & Trivedi, 2005). A Hausman test with cluster-robust standard errors underlined our statistical choice (for example, with overall sleep quality as outcome measure and among men: Sargan-Hansen statistic = 163.3, $p<.001$). An important attribute of FE regressions is that they exclusively use individual variations in the observation period. For example, intraindividual changes in providing informal care. Time-constant factors such as sex or country of origin are implicitly controlled in FE regressions.

Conventional linear FE regressions presume that effects of variables are symmetric. This means that the effect of increasing an independent variable is the same as the effect of decreasing that variable (in the opposite direction) (Allison, 2019). However, as also stated by Allison (Allison, 2019), this appears to be implausible for many social and psychological phenomena. In our case, it may be more realistic to presume asymmetric effects. To investigate these asymmetric effects, Allison recently introduced the idea of asymmetric FE regressions (Allison, 2019). Like Uccheddu et al. (Uccheddu, Gauthier, Steverink, & Emery, 2019) and as one of the first studies, we also used asymmetric FE regressions to study our link of interest (i.e. the link between *beginning* and *ceasing* informal care and changes in sleep quality). This means that those who responded that they provided informal care (i.e. answering the question "Are there people you look after or care for regularly due to their poor state of health, either on a private or volunteer basis" with "yes") were coded as 1 (otherwise, they were coded as 0). Those whose code changed from 0 to 1 during the course of the four waves (2008 to 2017) were considered as having begun informal care. Contrary, those whose code changed from 1 to 0 during the course of the four waves were considered as having ceased informal care.

In our study, the significance level was set at $p < 0.05$. To perform statistical analysis, Stata 16.0 (StataCorp, College Station, Texas, USA) was used in this study.

Results

Sample characteristics

Sample characteristics (pooled) for our analytical sample are displayed in Table 1. In total, 49.9% were female, and 51.7% had a medium education. Average age was 64.8 years (SD: 11.2; from 40 to 97 years). The average sleep quality was 3.0 (SD: 0.8), 31.4% had 'problems with falling asleep' and 41.5% had 'problems with waking up'. Further details are given in Table 1.

In the observation period, 1,219 individuals started to provide informal care. In contrast, 1,198 individuals ceased to provide informal care.

Regression analysis

Findings of asymmetric FE regressions stratified by sex are displayed in Table 2. In column 2 and 3 overall sleep quality served as outcome measure (linear FE regressions). In columns 4 to 7, 'problems with falling asleep' and 'problems with waking up' served as outcome measures (conditional FE logistic regressions).

Asymmetric FE regressions showed that in men beginning of providing informal care was associated with decreased overall sleep quality (β=-.09 (95% CI: −.15 – −.03), $p<.01$) and an increased likelihood of difficulties because of waking up (OR: 1.54 (95% CI: 1.07–2.20), $p<.05$), whereas ceasing of providing informal care was not associated with the outcome measures (both, in women and in men).

With regard to covariates (for reasons of clarity: results not shown, but available upon request) decreases in overall sleep quality were associated with decreases in physical functioning, increasing age, increases in physical illnesses and worsening self-rated health in both sexes. In both sexes, increases in the likelihood of problems with falling asleep and waking up were consistently associated with increases in physical illnesses and worsening self-rated health (except for problems with falling asleep in women).

Discussion

Based on a large nationally representative sample of community-dwelling individuals 40 years and over, the current study aimed to analyze whether beginning and ceasing of informal caregiving of individuals in poor health is associated with changes in sleep quality in women and in men. Asymmetric FE regressions revealed that in men beginning of providing informal care was associated with decreased overall sleep quality and an increased likelihood of difficulties because of waking up, whereas ceasing of providing informal care was not associated with changes in the outcome measures (overall sleep quality, difficulties: falling asleep, and difficulties: waking up).

Our longitudinal study adds to the current knowledge on the link between informal caregiving and sleep quality based on cross-sectional studies. The only other longitudinal study examining this link focused on younger and middle-aged adults (16 to 64 years) in paid work in Sweden. This current study extends our knowledge by analyzing individuals ≥ 40 years and older in Germany.

We found that the end of providing informal care did not increase sleep quality. While caregivers may feel relieved that they do not have to provide care anymore which may decrease their burden, the end of private care is commonly associated with transitions to institutional care of the care-recipient or the loss of the care-recipient

Table 1. Characteristics of observations ($n = 22{,}910$) included in fixed effects regressions (waves 2008–2017, pooled).

Female: N (%)	11,425 (49.9%)
Education (ISCED-97): N (%)	
Low education	1,605 (7.0%)
Medium education	11,833 (51.7%)
High education	9,465 (41.3%)
Age (in years): Mean (SD); range	64.8 (SD: 11.2); 40–97
Employment status: N (%)	
Working	7,908 (34.5%)
Retired	12,850 (56.1%)
Other (not employed)	2,152 (9.4%)
Married, living together with spouse: N (%)	16,254 (71.0%)
Self-rated health (from 1 = very good to 5 = very bad): Mean (SD); range	2.5 (SD: 0.8); 1–5
Number of physical illnesses: Mean (SD); Range	2.5 (SD: 1.9); 0–11
Physical functioning: Mean (SD); range	82.4 (SD: 22.8); 0–100
Sleep quality	
Overall sleep quality (from 1 = very bad to 4 = very good): Mean (SD)	3.0 (SD: 0.8); 1–4
Presence of difficulties: Falling asleep: N (%)	7,158 (31.4%)
Presence of difficulties: Waking up: N (%)	9,472 (41.5%)

Comments:: The variables sex and education were not included in FE regressions as explanatory variables because they are time-invariant. This means that they do not vary within individuals.

Table 2. Determinants of sleep quality. Results of linear FE regressions (column 2 and 3) and conditional FE logistic regressions (columns 4 to 7)

	Overall sleep quality —men	Overall sleep quality—women	Difficulties: falling asleep—men	Difficulties: falling asleep—women	Difficulties: waking up—men	Difficulties: waking up—women
Potential confounders†	✓	✓	✓	✓	✓	✓
Beginning of informal caregiving	−0.09** (0.03)	0.001 (0.03)	1.23 (0.81–1.88)	0.91 (0.66–1.25)	1.54* (1.07–2.20)	1.01 (0.75–1.36)
End of informal caregiving	0.01 (0.03)	−0.04 (0.03)	0.96 (0.63–1.46)	1.28 (0.92–1.77)	1.01 (0.71–1.44)	1.05 (0.77–1.42)
Observations	11,485	11,425	2,418	3,112	3,374	3,472
Individuals	6,038	5,876	839	1,078	1,170	1,193
(Pseudo) R^2	0.03	0.03	0.05	0.03	0.05	0.03

Comments: Beta coefficients (for linear FE regressions) or odds ratios (for conditional FE logistic regressions) are displayed. Cluster-robust standard errors (for linear FE regressions) or 95% confidence intervals (for conditional FE logistic regressions) in parentheses.
***$p < 0.001$,
**$p < 0.01$,
*$p < 0.05$,
+$p < 0.10$.
†Potential confounders include age, marital status, employment status, physical functioning, self-rated health and chronic diseases.
Overall sleep quality: from 1 (very bad) to 4 (very good). Difficulties: falling asleep: 1 (at least once a week; 0 otherwise). Difficulties: waking up: 1 (at least once a week; 0 otherwise).

which may counterbalance the positive effects of ceasing to provide care.

In our study, the beginning of providing informal care was associated with deleterious consequences (in terms of poor sleep quality) among men. This is plausible because according to a recent systematic review and meta-analysis informal caregivers usually lose 2.4 to 3.5 h of sleep each week for reasons of difficulty falling asleep and sustaining sleep (Gao et al., 2019). In contrast to our findings, this recent meta-analysis found that the sleep quality of female caregivers is commonly more adversely affected compared to male caregivers (Gao et al., 2019). This is often explained by an increased burden and distress experienced in female caregivers (Hagedoorn, Sanderman, Buunk, & Wobbes, 2002). However, a recent longitudinal study showed that spousal caregiving only decreased mental health in men, but not in women (Hajek & König, 2016a). This may explain why we only observed deleterious consequences in men. Another explanation may be that male caregivers often provide care for their spouse (in the same household), whereas female caregivers often also provide care for their parents (Roloff, 2009) (outside the household). This missing geographic distance may heavily affect sleep quality.

Based on the theoretical foundation of the caregiver stress model introduced by Pearlin et al. (Pearlin et al., 1990), it may be the case that in men their own resources and their social network are insufficient to deal with the onset of informal caregiving (Zwar, König, & Hajek, 2020). In line with this, it has been demonstrated that male caregivers find it difficult to deal with household chores and basic care (Lopez–Anuarbe & Kohli, 2019; Russell, 2007).

Due to insufficient resources to deal with providing informal care, this may ultimately result in a decreased sleep quality. This is in accordance with a recent study showing that transitioning into informal caregiving leads to depressive symptoms and loneliness in men, but not in women (Zwar et al., 2020). However, future research is required to identify the underlying mechanisms.

Some strengths and limitations are worth emphasizing. One strength is that we used asymmetric FE regressions. By doing that, we were able to examine how beginning and ceasing of providing informal care were associated with changes in sleep quality (asymmetric effects). It should be noted that this is the first longitudinal study analyzing the link between beginning and ceasing of providing informal care and sleep quality. Longitudinal data from 2008 to 2017 (four waves) were taken from a nationally representative sample of inhabitants 40+ in Germany. The problem of unobserved heterogeneity was mitigated using FE regressions. The tool to assess sleep quality is based on the Pittsburgh Sleep Quality Index. While it captures main domains of sleep quality, future studies with more

sophisticated tools are required to confirm our findings. More precisely, the original Pittsburgh Sleep Quality Index can quantify insomnia caused by, among other things, depression, anxiety or non-psychotic factors. Moreover, it can quantify sleep disturbance caused by obstructive sleep apnea. However, the DEAS study is a large nationally representative sample covering several topics important for middle aged and older individuals. Due to these time constraints, only the presumably most important domains of sleep quality were covered in the DEAS study. Furthermore, a small sample selection bias has been identified in the DEAS study (Klaus et al., 2017). Therefore, it is most likely not a persuasive threat to the validity of our findings. Moreover, there are limitations regarding the nature of caregiving (e.g. quality of the relationship or the reason for beginning or ceasing of providing informal care) due to data availability. While it can be argued that the reason for beginning of providing informal care of individuals in poor health is quite obvious, future studies are particularly necessary to clarify the link between ceasing of providing informal care (e.g. due to death of the care recipient or due to admission to nursing home) and sleep quality. Due to the small number of waves and the quite large time span between the waves (e.g. compared to large household panels), we could not introduce anticipation and adaptation effects. Future research is required to clarify this issue (Gerlich & Wolbring, 2020).

Conclusion

Results showed that the beginning and the end of informal caregiving can have different consequences for sleep quality (in women and men). More precisely, data suggest that starting informal caregiving can have deleterious effects on sleep quality in men. Efforts to assist men in maintaining sleep quality may be beneficial. More generally, our data suggest that future studies should unravel the consequences of informal caregiving (transitioning in and out of caregiving) among women and men.

Disclosure statement

The authors declare that they have no conflicts of interest.

Ethics approval

An ethical statement for the DEAS study was not required, as the criteria for it were not fulfilled (e.g. risk for the respondents, examination of patients or the use of invasive methods).

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Data availability statement

The anonymized datasets of the DEAS study were retrieved from the Research Data Centre of the German Centre of Gerontology (https://www.dza.de/en/fdz/german-ageing-survey/access-to-deas-data.html), which is available to scientists at universities and research institutes for secondary analyses.

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