

Situation of people providing support and care to someone with dementia

Kelle, Nadiya; Ehrlich, Ulrike

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Nadiya Kelle & Ulrike Ehrlich

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Core statements

- **In Germany, 3.5 per cent of people in the second half of life provided support or care to someone with dementia in 2020/2021. 14 per cent of people in the second half of life provided support and care to someone without dementia.** Women provide support and care to people with dementia proportionately more often than men. Dementia support and care is provided in similar proportions by people of working age and people of retirement age, whereas support and care for someone without dementia is proportionately more often provided by people of working age.
- **Carers of people with dementia feel higher levels of burden than carers of people without dementia.** At the same time, carers of people with dementia have similar levels of subjective health, depressive symptoms and loneliness as carers of people without dementia and people who do not provide support or care.
- **People spend a similar amount of time caring for someone with dementia as for someone without dementia.** There are also no differences in the time spent by gender or age group. However, education seems to play a role; people with high education provide dementia support and care less time-intensively than those with low or medium education.

Introduction

Increasing numbers of people in Germany suffer from dementia (Glaeske 2020). Many of them require help, support and care; in most cases this is provided by family members or people close to them, often at home. Caring for people with dementia is often described by family members as burdensome and stressful and is associated with poorer physical and mental health (Bauer & Sousa-Poza, 2015; Bom et al. 2019; Riffin et al. 2017). Studies find higher levels of burden for family caregivers of people with dementia than for family members with other caregiving responsibilities - who already report higher levels of subjective burden and depressive symptoms than the population average (Karg, Graessel et al. 2018; Kim et al. 2012). However, providing support and care to people with dementia is not only associated with negative aspects. Positive experiences are also possible, such as the joy of being together, the feeling of emotional closeness to the person being cared for, the sharing of activities and a sense of belonging (Brodsky & Donkin, 2009; Laporte Uribe et al. 2017; Sanders, 2005; Spillman et al. 2014).

Support and care for people with dementia is characterised by a number of special features. While care in general often involves helping people cope with everyday life and restoring abilities, the care of people with dementia is often focused on tasks such as meeting needs for self-determination, recognition, security and safety (Bartholomeyczik & Halek 2017). In the case of progressive dementia, coping with daily care needs must be combined with maintaining autonomy while averting danger to oneself or others, a particular challenge for many carers (Bartholomeyczik & Halek 2017; Gaugler et al. 2003). Caregiver burden becomes particularly high when the cognitive abilities and the ability to cope with everyday tasks of the person in need of care are significantly limited, and when care must be provided in a time-intensive manner or over a long period of time (Zank & Schacke 2007; Thyrian et al. 2017). Overall, the care of people with dementia is associated with longer care histories and a higher use of professional care services than care that is unrelated to dementia (Schlenker et al. 2010).

Dementia - Background information

Prevalence of dementia in Germany

There are currently about 1.8 million people living with dementia in Germany (German Alzheimer Society 2022). The probability of developing dementia increases with age. As a result of demographic developments, the number of people with dementia in Germany is increasing. In the next 30 years this number could rise to about 2.7 million. The proportion of people with dementia in Germany would then grow from about 1.9 per cent at present to about 3.4 per cent in 2050. Similar developments are expected for most countries in Europe (Alzheimer Europe 2020, p. 43). While the proportion of people with dementia in the 60-64 age group is 0.9 per cent, this figure rises to 40.8 per cent in the 90+ age group (Alzheimer Europe 2020, p. 9). In older age, there are clear and increasing gender differences in the prevalence of dementia. While the prevalence for women and men is similarly low at the age of 60 to 64 (women 0.2 per cent, men 0.9 per cent), these values rise to 44.8 per cent for women over 90, but only 29.7 per cent for men.

Causes and clinical picture

The term 'dementia' refers to a typical pattern of symptoms associated with certain diseases of the brain in which mental abilities are progressively lost as the disease progresses. Symptoms of dementia include disturbances in memory, attention and thinking skills. As the disease progresses, people with dementia also develop increasing difficulties in orienting themselves and independently managing their daily lives. Language and motor skills are also affected (Jessen 2018). As a result of these limitations, people with dementia need increasing support from others to live well with the disease. Most people with dementia continue to live at home; care and support are usually provided by family members or close friends, with increasing support from professional carers as the disease progresses (Brijoux & Zank 2022; von Kutzleben, Köhler, Dreyer, Holle, & Roes 2017).

The most common form of dementia is Alzheimer's disease; the second most common is vascular dementia, caused by circulatory problems in the brain. Most forms of dementia are currently not curable (Bienko, Burhanullah, & Munro 2019). However, a small percentage of all dementias are triggered by treatable diseases, such as metabolic diseases or alcoholism (cf. Wallesch & Förstl 2017). Under certain circumstances, the occurrence of dementia symptoms can be delayed by preventive measures (Livingston et al. 2020). Preventive measures include sufficient exercise, good social contacts and abstaining from tobacco and alcohol consumption (World Health Organization 2019). Early diagnosis can also improve the quality of life of people with dementia. Early diagnosis enables people with dementia to make timely decisions about their life with dementia. Ideas and wishes regarding medical and nursing care can be discussed and implemented, and those affected can develop strategies that help them to live independently with dementia for as long as possible (cf. Ding-Greiner 2010; Schröder & Pantel 2011).

In the context of the Corona pandemic, current research indicates that the situation for family caregivers of people with dementia has worsened compared to pre-pandemic times (Budnick et al. 2021; Eggert et al. 2020; Thyrian et al. 2020). The Corona pandemic temporarily led to a loss of support and respite services, such as day and short-term care (Bundesministerium für Gesundheit, 2021a, 2021b). These services play a crucial role for family caregivers of people with dementia as they are usually a prerequisite for providing care at home (Thyrian et al. 2017). Due to their condition, people with dementia also often have difficulties assessing the dangers of the pandemic and protecting themselves from infection. For family caregivers of people with dementia, this resulted in special challenges and conflicting situations (Fischer & Geyer 2020).

Research on the care of people with dementia emphasises both the danger of physical and psychological overload of caregivers and the high importance of people ensuring care. Nevertheless, there is comparatively little research on support and care for people with dementia in Germany that is based on representative population surveys. In addition, previous studies in the German context have often focused on the burdens of family carers within the group of carers (also specifically carers of people with dementia) (e.g. Eggert et al. 2020, Laporte Uribe et al. 2017, Seidel et al. 2019). In many cases, no comparison to the situation of other carers or non-carers is possible. It has not yet been possible to reliably determine the proportion of caregivers of people with dementia in the general population or across different socio-demographic groups. Also, there has not yet been a systematic investigation comparing the well-being of people supporting and caring for people with dementia with people who do not support or care for people with dementia and people who do not provide care or support.

With the data of the German Ageing Survey (DEAS) from the 2020/2021 telephone

survey, it is now possible to analyse the situation of providers of support and care to people with dementia using representative data of the resident population in Germany aged 46 and older. Comparisons with other carers and non-carers are possible. The DEAS covers a broad spectrum of support and caregiving ranging from regular help to care and nursing. Furthermore, in addition to privately provided support and care, assistance that takes place within the framework of voluntary work are also considered (Klaus & Ehrlich 2021).

Data collection took place between November 2020 and March 2021 during the second wave of the Corona pandemic so that the results for the well-being (subjective health, depressive symptoms and loneliness) and caregiver burden could reflect the special situation during the pandemic. However, since the information on support and care for people with dementia was collected for the first time in 2020/2021, no comparison with the situation before the pandemic is possible on the basis of the DEAS data. However, Ehrlich and Kelle (2022) showed that after deteriorating in the first pandemic wave, the situation and well-being of *all* supporters and carers returned to the pre-pandemic level (2017) in the second pandemic wave.

The following questions are examined:

- a) What proportion of people in the second half of life provide support and care to someone with dementia? How does this proportion differ according to age, gender and education?
- b) What is the average time commitment of people providing support and care to someone with dementia? How does the average time spent on care differ by age, gender and education? How does the average time spent providing dementia support and care differ from the time spent by people providing support and care to someone without dementia?

- c) How does the assessment of well-being (subjective health, depressive symptoms and loneliness) and burden by people providing dementia support and care differ from people providing support and care to someone without dementia and people not providing support or care?

Data and methods

The German Ageing Survey (DEAS)

The German Ageing Survey (DEAS) is a representative cross-sectional and longitudinal survey of people in the second half of life. As part of the study, women and men have been regularly surveyed for more than two decades (in 1996, 2002, 2008, 2011, 2014, 2017, 2020 and 2020/21) as they move into old age. This long observation period of more than two decades allows a comprehensive insight into ageing and the life situations of people in the second half of life. In addition, the cohort-sequential design of the study makes it possible to examine ageing in the context of social change. The German Ageing Survey is therefore the central study on age and ageing in Germany. More than 20,000 people have participated in the study so far. People who are 40 years and older at the time of their first participation are surveyed. The participants are selected on the basis of a sample of residents' registration offices stratified by age, gender and region. The data of the German Ageing Survey are therefore representative of the resident population of Germany living in private households in the second half of life. The German Ageing Survey can also provide insights and a better understanding of life situations in times of crisis - as we are currently experiencing due to the Corona pandemic.

Telephone interviews took place in winter 2020/21 (4 November 2020 to 1 March 2021) with 5,402 people aged 46. Directly after the telephone interview in winter 2020/21, the respondents were sent another questionnaire, answered by 4,419 people in writing or online. The surveys focused on questions about aspects of the respondents' current life situations, such as social relationships, well-being and employment.

In the analyses, weighted proportion values and weighted arithmetic means are presented using methods that take stratified sampling into account. Group differences or differences between survey waves are tested for statistical significance. A significance level of $p < 0.05$ is used. If a finding is statistically significant, it can be assumed with at least 95 per cent probability that a detected difference exists, not only in the sample but also in the population living in private households in Germany. If a finding is not statistically significant, it is possible that observed differences in the sample occurred only by chance.

The German Ageing Survey (DEAS) is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ).

Further information on the German Ageing Survey (DEAS) can be found at www.deutscher-alterssurvey.de.

Data from the German Ageing Survey (DEAS) 2020/21 was analysed. People aged between 46 and 90 years were included. The sample comprises 5,341 persons. In the present report, we present weighted proportional values on the provision of support and care, the extent of the burden and subjective well-being (subjective health, depressive symptoms and loneliness) as well as weighted arithmetic mean values on the temporal extent of support and care.

The reported contents were collected:

Providing support and care overall and specifically for people with dementia: In the DEAS, caregivers were identified by the following question: "In the last 12 months, have you provided private or voluntary care or regular assistance to people due to their poor health?" Respondents who answered "yes" to this question are considered as caregivers. Providers of support and care to people with dementia were identified through the following question: "Does the/at least one of the person(s) you support has dementia?". Due to the sequence and wording of the questions in the DEAS, providers of support and care to people with dementia identified by us may have additionally taken on support and care tasks for people without dementia. Respondents who answered "No" to the question whether the/at least one of the person(s) they support has dementia, on the other hand, only provide support or care to people without dementia.

Time spent on support and care: Identified caregivers were then asked: "How much time do you spend per week helping the person(s) you support? Please indicate the weekly average number of hours". All information on the time spent per week on support and care that exceeds the upper limit of more than 80 hours per week was set to the value 80.

Age, gender and education: The proportion of providers of support and care to people with and without dementia in the population is additionally presented within the following

socio-demographic groups: People of working age (46-64 years; n=2,037) and people of retirement age (65 years and older; n=3,365); women (n=2,746) and men (n=2,656); people with low or medium education (n=2,776) and people with high education (n=2,625). The indicators are based on self-reports or were already known due to respondents' previous participation in the DEAS.

Subjective health: Self-assessed health is understood as a global health measure that includes many factors, such as physical and mental health and health behaviour (Spuling, Cengia, & Wettstein, 2019). Respondents were asked to rate their current health status on a five-point scale from (1) "very good" to (5) "very poor". People with scores of 1 and 2 were grouped and reported as having good to very good health.

Depressive symptoms: Depressive symptoms were recorded on the basis of 15 statements (e.g. "In the last week I thought my life was one big failure"; "In the last week everything was exhausting for me") of an established survey instrument (CES-D short form according to Hautzinger/Bailer 1998). The interviewees could indicate how often the symptoms mentioned in each case had occurred in the last week on four-point scale, ranging from (0) "rarely or none of the time (for less than 1 day)" to (3) "most or all of the time (for 5 to 7 days)". A sum score was computed per person over all items between 0 and 45. Respondents with a score above the value of 18 show pronounced depressive symptoms (Lehr, Hillert, Schmitz, & Sosnowsky 2008) and are shown below as persons with depressive symptoms.

Perception of loneliness: Loneliness was assessed with a loneliness scale (de Jong Gierveld, & van Tilburg 2006). The scale contains three positive statements (e.g. "I know a lot of people I can really rely on") and three negative statements (e.g. "I often feel abandoned."). Respondents can agree or disagree with these statements on a four-point scale from 1 (strongly agree) to 4 (strongly disagree), from which an individual

mean score (range 1-4) is computed. Respondents with an individual mean of 2.5 or more are considered as lonely (Huxhold & Engstler, 2019) and are classified accordingly in the analyses.

Caregiver burden: Respondents who provided care to people suffering from poor health answered the following question in

2017 and in the winter of 2020/21: “If you look at this support or care overall, how much of a burden does it place on you?” Respondents had the following response options: (1) none at all, (2) fairly little, (3) fairly heavy or (4) very heavy. Respondents with values 3 and 4 were grouped together as persons experiencing a fairly heavy or very heavy burden.

Findings

Women provide support and care to people with dementia proportionately more often than men

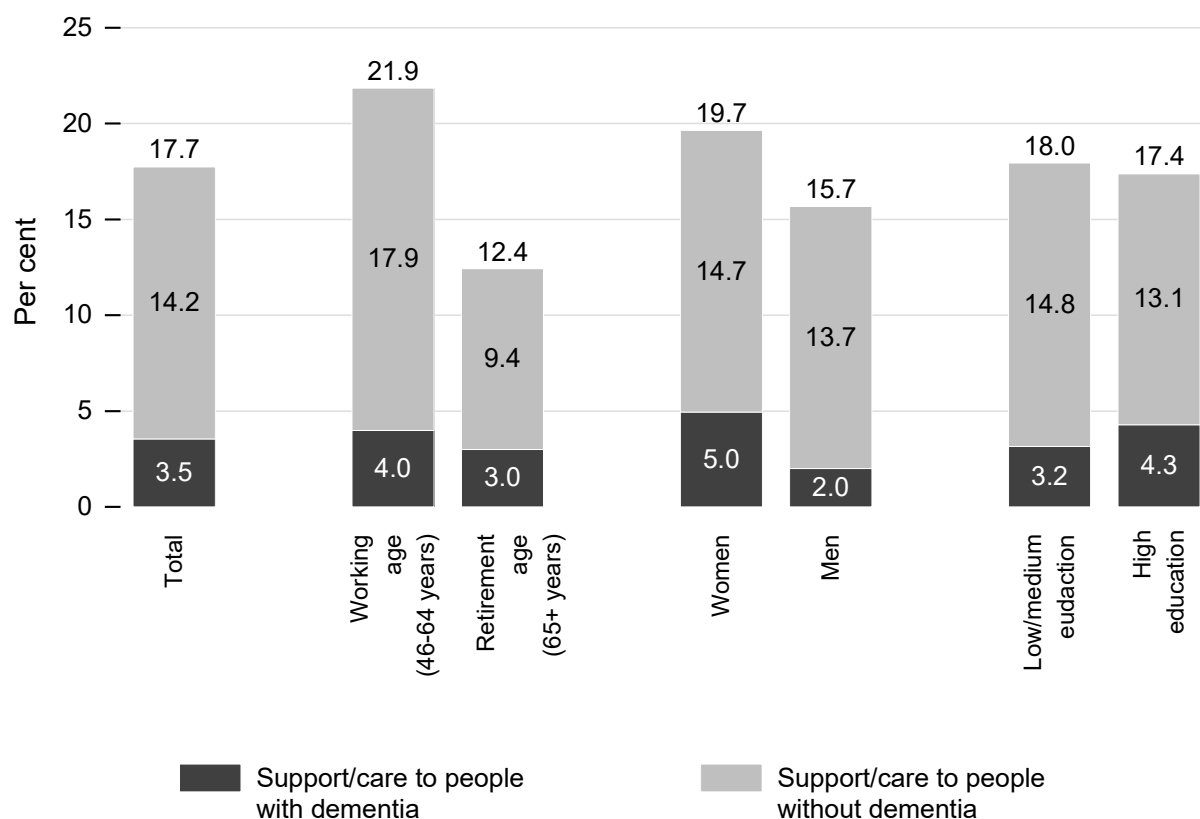
In 2020/21, 3.5 per cent of the population aged 46 and older in Germany provided support and care to people with dementia. 14.2 per cent of the population of this age provided support and care to people who do not have dementia (Figure 1). A total of 17.7 per cent of people in the second half of life provided support and care to people with and without dementia.

Among all providers of support and care, people of working age (21.9 per cent) take on these activities in higher proportions than people of retirement age (12.4 per cent). Dementia support and care is provided in similar proportions by people of working age and retirement age (4 to 3 per cent), while support and care for people without dementia is proportionately more often provided by people of working age (17.9 to 9.4 per cent).

Furthermore, women provide support and care proportionately more often (19.6 per cent) than men (15.7 per cent), although this difference does not prove to be statistically significant. However, there is a significant gender difference in the support and care of people with dementia; while 5 per cent of women provide this type of support and care, the figure for men is 2 per cent.

Support and care as a whole took place independently of the level of education (low/medium education: 18.0 per cent; high education: 17.4 per cent). This also applies specifically to support and care for people with dementia; the difference between people with low/medium education (3.2 per cent) and high education (4.3 per cent) is not statistically significant.

Figure 1: Proportions of people providing support and care to people with and without dementia by age, gender and education (in per cent)



Source: DEAS 2020/21 (n = 5,341), weighted analyses, rounded figures. Statistically significant (p<.05): Women/men: difference between carers of people with dementia to carers of people without dementia. Working age/retirement age: difference between age groups for carers of people without dementia.

Support and care for people with dementia is time-consuming

Providing support and care is time-consuming. On average, more than 13 hours per week are spent providing support and care to people with dementia, while people who care for someone without dementia spend somewhat under 11 hours per week (Figure 2). However, this difference is not statistically significant. Age-, gender- and education group-specific differences in the time intensity of support and care for people with and without dementia are also not statistically significant.

Furthermore, there are apparent differences within the group of supporters and

caregivers of people with dementia and within the group of supporters and caregivers of people without dementia. For example, people of retirement age spend a higher number of hours per week on dementia support and care than people of working age (18.5 to 10.7 hours per week), and people with low/medium education spend a higher number of hours per week than people with high education (16.3 to 8.1 hours per week). There are also apparent differences in the support and care of people without dementia. However, all differences are not statistically significant¹, with the

¹ The fact that some apparent differences are not statistically significant may be due to relatively small numbers of cases among providers of support and care to

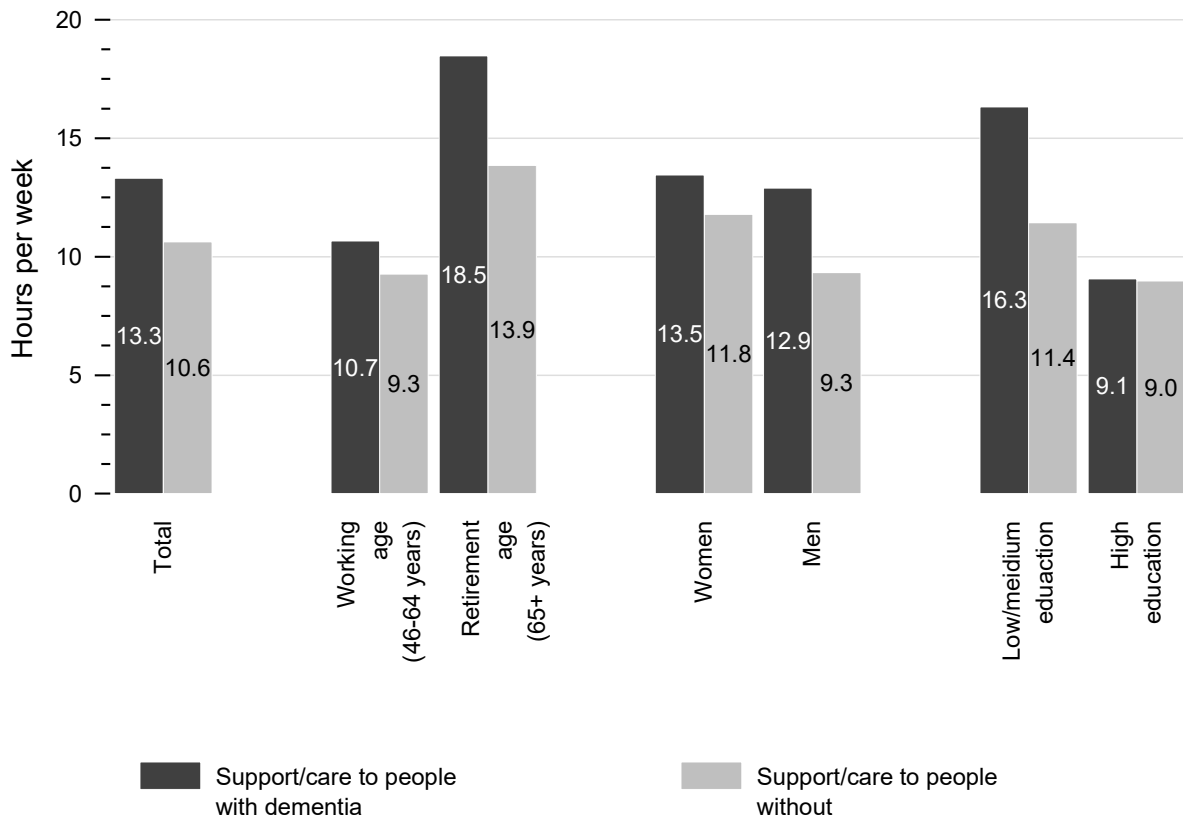
people with dementia. The lowest number of cases (n=65) is among men who provide support or care for someone with dementia.

exception of the difference between people with low/medium and high education in the weekly hours spent on dementia support and care.

The time spent on dementia support and care determined here is below the daily care effort of six to ten hours calculated by Schäufele et al. (2008). This can be attributed, among other things, to the broad

recording of support and care in the DEAS, which for example records weekly grocery shopping on the one hand and round-the-clock care on the other as support and care. In addition, the amount of care required also depends on the type of dementia and the respective stage (Frewer-Graumann, 2020) - information that was not recorded in more detail in the DEAS.

Figure 2: Average time spent providing support and care to people with and without dementia overall, and by age, gender and education (in hours per week)



Source: DEAS 2020/21 (n = 866), weighted analyses, rounded figures.
 Statistically significant (p<.05): Group of people providing dementia support and care: difference between education groups.

Supporters and carers of people with dementia show similar well-being compared to other groups, but feel more burdened

Figure 3 shows indicators of well-being: subjective health, depressive symptoms, loneliness and caregiver burden.

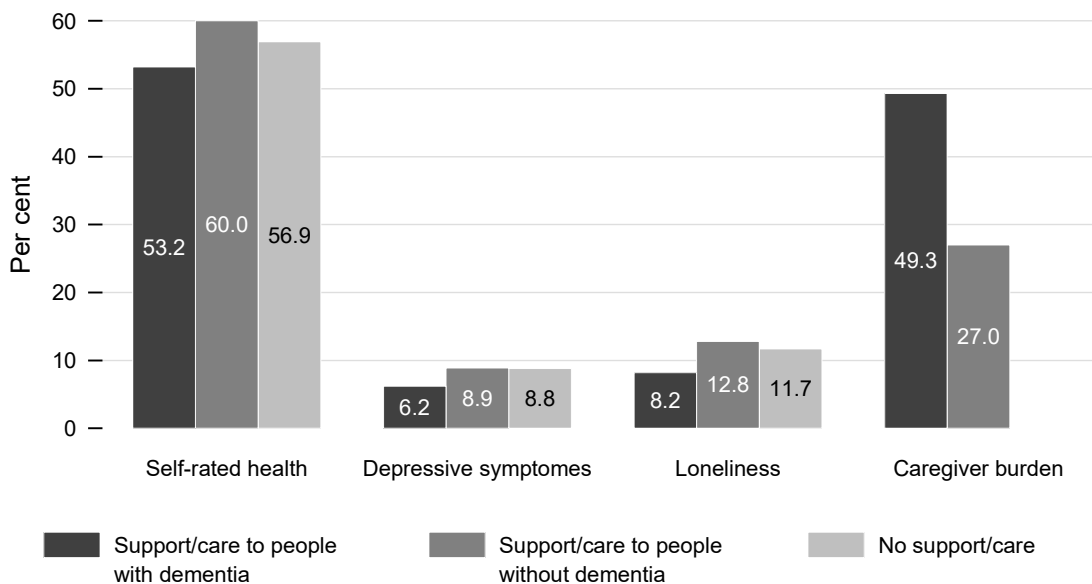
Comparing the groups of providers of support and care to people with dementia, without dementia and people providing no support or care, there is a tendency for people providing dementia support and care to proportionately assess their health less often as (very) good; they also proportionately show depressive symptoms and feel lonely less often (Figure 3). However, the differences are not statistically significant.

Statistically significant differences were determined for the perception of burden,

which is exclusively surveyed for providers of support and care. Almost half of all providers of support and care to people with dementia feel fairly heavily or very heavily burdened by the assistance and/or caregiving they provide, whereas among providers of support and care to people without dementia, the figure is 27 per cent (Figure 3).

We thus find group differences in caregiver burden, but not in self-assessed health, depressive symptoms or feeling of loneliness. This could be because caregiver burden refers specifically to the care situation, which places special demands for people supporting and caring for someone with dementia.

Figure 3: Well-being and caregiver burden of carers of someone with dementia, compared to carers of someone without dementia and people providing no support or care



Source: DEAS 2020/21 (n[well-being indicators]=4,355-5,339); (n[caregiver burden]=894), weighted analyses, rounded figures. Statistically significant (p<.05): Caregiver burden: Difference between carers of people with dementia and carers of people without dementia.

Summary and discussion

Due to the demographic ageing of the population, the proportion of people with dementia is expected to increase. Relatives,

friends and neighbours who provide support and care play a significant role in ensuring that people with dementia are well and can

remain in their own home environment for as long as possible. However, due to a lack of representative data, there is little knowledge about the proportions of people providing support and care to someone with dementia in the general population and across different socio-demographic groups. Furthermore, relatively little is known about the well-being of family carers of people with dementia compared to carers of people without dementia and to non-carers. This DZA Aktuell has undertaken a descriptive study with focus on carers of people with dementia.

In 2020/2021, 3.5 per cent of people aged 46 and older in Germany provided support and care to someone with dementia. 14 per cent of people in this age group provided support or care to someone without dementia. Women provided care and support to people with dementia proportionately more often than men. This result is consistent with previous findings (Riffin et al. 2017). In addition, working-age and retired people provided similar proportions of support and care to people with dementia, while working-age people were proportionately more likely to provide support and care to people without dementia. This indicates that the support and care tasks for people with dementia are taken on independently of the life stage.

Furthermore, carers of people with dementia invest a similar amount of time in support and care as carers of people without dementia do. This may be related to the fact that the intensity of care for people with dementia is highly dependent on the severity of the dementia (Riffin et al. 2017); however, we are not able to reflect this in the data used.

People with high education seem to invest less time in providing support and care to people with dementia than people who do not have high education. On average, people with high education occupy higher professional positions than others and earn higher incomes; unlike them, families with lower incomes might be more likely to rely

on care allowances and thus might not claim benefits in kind or might not be able to afford the co-payments for professional care services. In addition, the complexity of applying for assistance requires intensive engagement with the care system, and people with higher education are more able to act within these structures and obtain the necessary information (Möller et al. 2013). Another reason why the more highly educated invest less time in support and care could be that the potential loss of income from providing care would be comparatively high among the more highly educated and might therefore be avoided for (household) economic reasons. With regard to gender or age group, no differences are found between the time investments in the support and care of people with and without dementia.

Furthermore, we were able to show that with regard to self-assessed health, depressive symptoms and feelings of loneliness, carers of people with dementia do not differ from carers of people without dementia or people without support and care tasks. However, there are indications that carers of people with dementia feel more burdened in their specific care situation than carers of people without dementia. This corresponds with many other studies showing that caring for people with dementia is perceived as particularly burdensome (Cooper et al., 2007; Karg, Graessel et al. 2018; Kim et al. 2012; Pinguart & Sörensen, 2003; Zank & Schacke 2004). However, other studies also indicate poorer well-being for family caregivers compared to non-caregivers, as well as poorer well-being for caregivers of people with dementia compared to caregivers of people without dementia (for example, Bauer & Sousa-Poza, 2015; Bom et al. 2019; Pinguart & Sörensen, 2003; Yee & Schulz, 2000). The lack of significant differences in the caregiving-unspecific well-being indicators, both within the support and caregiver group, and between support and caregiver and non-caregiver group, may be due to the broad coverage of caregiving in the DEAS in terms of activities (support vs.

care), intensity (1 hour vs. around the clock) and temporal location (on one day vs. every day in the last 12 months). Accordingly, the support and care providers included in this study can vary greatly in terms of the amount of support and/or care provided, from support providers who help with housework or grocery shopping every second or third week or only on weekends to caregivers who provide intensive care for several hours every day. It is possible that due to this broad coverage of support and care, differences in well-being within the group of support and care providers are balanced out. Nevertheless, for the first time in the German context, our analysis is able to compare the situation of providers of support and care to people with dementia to that of providers of support and care to people without dementia and people without such support or care tasks. This is made possible by the thematic addition in the

DEAS 2020/21 on support and care for people with dementia.

Our findings indicate that people providing dementia support and care should receive even more support due to the high caregiver burden this activity entails, such as specialised services oriented towards the burdens, challenges and needs associated with caring for people with dementia. To this end, the measures developed within the framework of the National Dementia Strategy (Bundesministerium für Familie, Senioren, Frauen und Jugend & Bundesministerium für Gesundheit 2020), such as supporting relatives of people with dementia with specially developed counselling services by qualified care professionals (Dementia Care Managers) or improving access to psychological counselling for relatives, should be advanced.

The National Dementia Strategy (NDS)

The National Dementia Strategy (NDS) was adopted by the Federal Government in June 2020. It was developed together with numerous partner institutions from politics, society and research. The situation for people with dementia and their relatives in Germany is to be improved by 2026 with 162 measures. A central goal is to strengthen knowledge about dementia in society. This should improve understanding of the disease and break down barriers in dealing with people with dementia. With the help of initiatives and campaigns within the framework of the strategy, the public will be made more aware of the concerns of people with dementia.

The Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health were responsible for developing the National Dementia Strategy. The office of the National Dementia Strategy is located at the German Centre for Gerontology in Berlin. Further information on the National Dementia Strategy can be found at www.nationale-demenzstrategie.de.

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