

# **Open Access Repository**

www.ssoar.info

### Attitudes towards people with dementia in Germany

Weinhardt, Michael; Lärm, Astrid; Boos, Barbara; Tesch-Römer, Clemens

Veröffentlichungsversion / Published Version Arbeitspapier / working paper

#### **Empfohlene Zitierung / Suggested Citation:**

Weinhardt, M., Lärm, A., Boos, B., & Tesch-Römer, C. (2022). *Attitudes towards people with dementia in Germany.* (dza-aktuell: Deutscher Alterssurvey, 03/2022 - English Version). Berlin: Deutsches Zentrum für Altersfragen. <a href="https://nbn-resolving.org/urn:nbn:de:0168-ssoar-83408-7">https://nbn-resolving.org/urn:nbn:de:0168-ssoar-83408-7</a>

#### Nutzungsbedingungen:

Dieser Text wird unter einer CC BY-NC-SA Lizenz (Namensnennung-Nicht-kommerziell-Weitergebe unter gleichen Bedingungen) zur Verfügung gestellt. Nähere Auskünfte zu den CC-Lizenzen finden Sie hier:

https://creativecommons.org/licenses/by-nc-sa/4.0/deed.de

#### Terms of use:

This document is made available under a CC BY-NC-SA Licence (Attribution-NonCommercial-ShareAlike). For more Information see:

https://creativecommons.org/licenses/by-nc-sa/4.0





# DZA Aktuell German Ageing Survey

Issue 03/2022 - English Version

**Publisher:** 

**German Centre of Gerontology** 

# **Attitudes towards people with dementia in Germany**

Michael Weinhardt, Astrid Lärm, Barbara Boos, Clemens Tesch-Römer

## Attitudes towards people with dementia in Germany

Michael Weinhardt, Astrid Lärm, Barbara Boos, Clemens Tesch-Römer

Core statements	3
Introduction	4
Dementia - Information and background	5
Attitudes towards people with dementia - research to date	6
Data, indicators and method of analysis	8
Results	10
Discussion of results	16

#### Core statements

The German Ageing Survey (DEAS), conducted since 1996, is a representative cross-sectional and longitudinal survey of people in the second half of life. The most recent survey took place from 4 November 2020 to 1 March 2021; based on the survey, the life situation of people in the second half of life can be comprehensively represented. The present findings on attitudes towards people with dementia are based on information provided by 4,175 people aged 45 to 90.

- Many people are unfamiliar with dementia, while few are afraid of people with dementia. Almost half of respondents (45.5 per cent) say they are unfamiliar with dementia, while about one third of respondents (32.6 per cent) are familiar with dementia. Eight out of ten respondents (82.5 per cent) say they are not afraid of people with dementia. Only a very small proportion (4.0 per cent) report being afraid of people with dementia.
- There are no significant differences in attitudes between age groups or between men and women. Age and gender do not play a role in the extent to which people are familiar with dementia or willing to take care of those affected. All age groups, and both men and women, also feel a similar degree of fear of people with dementia and have similar perceptions of the possibilities to support those affected.
- People with a higher educational level show a higher familiarity with dementia. A total of 38.3 per cent of respondents with a high educational level say they are familiar with dementia. Around 30 per cent of people with lower levels of education report this.

- A higher household income is associated with less fear and more perceived support opportunities in relation to people with dementia.

  However, household income is not related to willingness to provide care. People with higher household incomes perceive more support options for people with dementia (78.3 per cent in the high-income group, compared to 71.5 per cent in the middle-income group and 67.5 per cent in the low-income group). However, willingness to provide care for people with dementia does not depend on income.
- Willingness to care for people with dementia is strongly related to familiarity with dementia. More than half of respondents (56.8 per cent) familiar with dementia are also willing to care for people with dementia; among respondents who are unfamiliar with dementia, this is only the case for approximately a third (35.2 per cent).

#### Introduction

People with dementia belong to long-life societies. As dementia affects all areas of a person's life, those affected and their relatives require support from very different areas of society. The design of the health and care system plays an important role in this, involving appropriate diagnosis, counselling, treatment, support and care for people with dementia, as well as support for their relatives. For the everyday lives of people with dementia and their relatives, a social environment that is sensitized to the disease and offers opportunities for social participation is of great importance. Improving the social integration and social participation of people with dementia is a challenge for society as a whole (Aihara, Kato, Sugiyama, Ishi, & Goto 2020; Alzheimer's Australia 2014).

Against this background, it is important to investigate attitudes among the general population towards people with dementia. Of particular interest is how familiar the general population is with the topic of dementia, as well as perceptions of the possible support for people with dementia. Equally relevant is the extent to which people avoid contact with people with dementia in everyday life or even encounter them with fear. If the social environment of people with dementia is not free of fear, it is unrealistic to maintain a largely normal everyday life beyond one's own household. Finally, demographic developments mean that questions related to care and nursing for people with dementia are becoming increasingly important; who takes responsibility for looking after them or who is willing to do so. This is important for realizing care and nursing potentials.

A differentiated picture of attitudes towards people with dementia is required in order to investigate whether different social groups (people of different age, gender, education or income) have similar attitudes towards people with dementia. If certain social groups are still very unfamiliar with dementia, public-relations work and education can be more strongly directed towards the corresponding target groups. Likewise, groups can be identified in which anxieties can be reduced and the willingness to care for people with dementia can be strengthened.

#### **Dementia - Information and background**

#### Prevalence of dementia in Germany

There are currently about 1.6 million people living with dementia in Germany. 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 the population of 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 stands at 40.8 per cent in the 90+ age group (Alzheimer Europe 2020, p. 9). In older age groups, there are clear and larger gender differences in the prevalence of dementia. While at the age of 60 to 64 the prevalence for women and men is similarly low (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

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 cognitive skills. People with dementia also develop increasing difficulties in orienting themselves and managing their daily lives independently as the disease progresses. Language and motor skills are also affected (Jessen 2018). As a result of these limitations, people with dementia require increasing support 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, followed by vascular dementia caused by circulatory problems in the brain. Most forms of dementia are currently incurable (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), such as 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: Choices regarding medical and nursing care can be discussed and implemented. Those affected can also develop strategies to help them to live independently with dementia for as long as possible (cf. Ding-Greiner 2010; Schröder & Pantel 2011).

#### Attitudes towards people with dementia - research to date

In many countries, knowledge and understanding of dementia remains low (Cahill, Pierce, Werner, Darley, & Bobersky 2015). For Germany, comparatively little is known about general attitudes towards dementia. Dementia generally has a negative connotation: 41.1 per cent of the German population say they are worried about dementia, or worried about being affected by it one day (Bowen, Kessler, & Segler 2019). For this reason, among others, researchers assume that dementia is associated with a negative stigma (Jolley & Benbow 2000; Werner & Heinik 2008). While older people overall are viewed as less competent than younger people (Kite, Stockdale, Whitley, & Johnson 2005), older adults with disabilities and illnesses are perceived particularly negatively (Kahana et al. 1996; Stone 2003). In some cases, dementia is even seen as a shaming disease (Umegaki, Suzuki, Ohnishi, & Iguchi 2009). Negative attitudes and prejudices towards people with dementia can lead to a range of derogatory behaviours and even discrimination. There is often inadequate support and treatment for people with dementia. For example, caregivers in homes have been found to have more negative

attitudes towards people with dementia than other groups of people (Brodaty, Draper, & Low 2003; Kahana et al. 1996).

Attitudes towards older people are influenced by a variety of factors, including the extent of contact with older people, the degree of knowledge about the ageing process (O'Connor & McFadden 2010) and people's own state of health (Gekoski & Knox 1990). The factors influencing the formation of positive or negative attitudes towards people with dementia have not been conclusively clarified (O'Connor & McFadden 2010). Some studies suggest that higher education, older age, residence in an urban area and experience of interacting with or caring for people with dementia are related to greater awareness of dementia. Studies show that people with more frequent contact and experience with people with dementia have more positive attitudes than people who have less frequent contact (O'Connor & McFadden 2010). Information and education can help to reduce prejudices and stereotypes. Even the provision of a small amount of information about dementia can help to reduce the stigma of dementia (Cheng et al. 2011).

#### Research questions

There has been relatively little research on the attitudes of the general population towards people with dementia (Peng, Moor, & Schelling 2012). Empirical findings on the prevalence of attitudes towards dementia in German-speaking countries are only available for Switzerland. These studies suggest that the Swiss population tends to have a positive and friendly attitude towards people with dementia, and is comparatively well informed about dementia diseases (Huber & Seifert 2021). For Germany, there have not yet been any populationrepresentative studies on the prevalence of attitudes towards people with dementia and the causes of these attitudes. Against this background, various research questions on

attitudes towards people with dementia need to be answered.

In the first step, we examine the status quo in Germany: To what extent is the population in the second half of life familiar with dementia as a topic? How is the potential for improving the living conditions of people with dementia perceived? Are there obstacles to dealing with people with dementia? How high is the willingness to care for people with dementia?

In the second step, we look at different social groups in which differences in attitudes towards people with dementia could potentially be expected; how do attitudes towards people with dementia depend on factors such as age, gender, education and income? Differences between men and women may exist, as women are affected by dementia at a different frequency (see grey box on dementia) and more often take on the care of relatives with dementia. Age differences are to be expected for similar reasons; the chance of being affected by dementia or experiencing it in one's personal environment increases considerably with age. Caregiving activities are also unequally distributed across age groups. Higher education is expected to be associated with greater familiarity with dementia. The financial situation of a household could also play a role in the willingness to care for a person with dementia. Relatives with a low income are more likely to provide care themselves; the personal contribution is a greater hurdle than claiming care services. At the same time, for relatives caring for people with dementia, care is often accompanied by a reduction in their own employment. The care allowance is therefore more attractive for relatives with a low income than for those with a high income (cf. Keck 2012). Opportunities for finding care support for people with dementia could also be influenced by income, since the implementation of support options can also be associated with financial costs.

Finally, in the third step, we investigate whether familiarity with dementia is related to fear of people with dementia, the willingness to provide care, and the assessment of support possibilities. A stronger familiarity with dementia may be linked to a lower expression of fear, a higher willingness to provide care, and greater optimism regarding possibilities for change.

#### Data, indicators and method of analysis

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. Women and men have been regularly surveyed for more than two decades as they move into old age (1996, 2002, 2008, 2011, 2014, 2017, 2020/21). This long observation period of more than two decades enables a comprehensive view of ageing and the life situations of people in the second half of life. In addition, the cohort-sequential design of the study enables the examination of ageing in 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. Participants in the study are 40 years and older at the time of their first participation. 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 is therefore representative of the population of Germany living in private households in the second half of life. The German Ageing Survey can also provide insights into life situations in times of crisis - as is currently being experienced with the COVID-19 pandemic.

The most recent survey took place between 4 November 2020 and 1 March 2021. This survey focused on questions about respondents' current life situation, such as social relationships, well-being and employment. 5,402 people aged 46 and older took part in the survey. All respondents had participated in the study at least once before. Due to the COVID-19 pandemic, participants were interviewed by telephone (instead of in a personal interview as before). Following the telephone interview, the respondents were sent another questionnaire, which was answered by 4,419 people in writing or online.

In the analyses, weighted proportion values are presented using methods that take stratified sampling into account. Group differences or differences between survey waves were tested for statistical significance. A significance level of p < 0.05 was used. If a finding is statistically significant, it can be assumed with at least 95% probability that a detected difference not only exists in the sample but also in the population as a whole. If a finding is not statistically significant, it is possible that observed differences in the sample only occurred 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.deutscheralterssurvey.de. The analysis used data from the DEAS collected in winter 2020/2021 (basic information on the implementation of the German Ageing Survey can be found in the grey box above). Due to the COVID-19 pandemic prevalent at that time, the main DEAS survey was conducted by telephone. Attitudes towards dementia were collected in an additional paper questionnaire that expanded the survey spectrum and was sent to respondents by post following the telephone interview. This 'drop-off' questionnaire could be completed online or in writing by post. The data comes from 4,175 people aged between 46 and 90. The analyses are largely descriptive; the underlying data was cross-sectionally weighted for this purpose to take into account the sampling design and ensure the best possible fit to the population. When conducting significance tests, the complex sampling design of the DEAS was also considered. While many areas of life were significantly influenced by the COVID-19 pandemic, a direct influence on population attitudes towards people with dementia cannot be expected directly. However, such influences cannot be absolutely ruled out either: these external conditions should therefore be considered when interpreting the results.

The basis of the analyses is a battery of items on attitudes towards people with dementia, based on a Swiss translation of the Dementia Attitude Scale (DAS, O'Connor and McFadden (2010)) into German (Peng et al. 2012). The questions surveyed everyday beliefs regarding the perceived quality of life of people with dementia, and behavioural tendencies in dealing with people with dementia. The respondents could indicate whether they agreed or disagreed with individual statements based on a five-point response scale ("do not agree at all", "tend to disagree", "partly agree", "tend to agree", "completely agree"). The questions

included indicators on four items: (1) familiarity with dementia ("I am not very familiar with dementia"); (2) an assessment of support options regarding the quality of life of people with dementia ("There are many things we can do to improve the lives of people with dementia"); (3) discomfort in contact ("I am afraid of people with dementia"); (4) willingness to get personally involved ("I cannot imagine taking care of someone with dementia"). For the analyses, the agreeing answers ("completely agree" and "tend to agree") and the disagreeing answers ("don't agree at all" and "tend to agree") were each combined into a common category, so that the final indicators each had three categories (agree, undecided, disagree).

We examined how attitudes towards people with dementia are distributed in the German population, and the extent to which these attitudes differ by age group, between men and women, according to different educational backgrounds, and household income. Three age groups were distinguished: 46 to 65 (n = 761; 18.2)per cent), 66 to 75 (n = 2,016; 48.3 per cent) and 76 and older (n = 1,398; 33.5 per cent), with the oldest person in the analysis sample being 90 years old. Gender was used as another distinction; men (n = 2,041; 48.9 per cent) and women (n = 2,134; 51.1 per cent) wereapproximately equally represented in the sample. Education was recorded in three categories that combine school and vocational education levels (cf. Engstler & Hameister 2020: 25): the first category ("low to medium") included people who have completed at most vocational training or (technical) college entrance qualification (n = 2,096, 50.2 per cent); the second category ("advanced") included people with more advanced educational qualifications such as a technical or master school (n = 615, 14.7 per cent); the third category ("high") included persons

with a degree from at least one university of applied sciences (n = 1,464, 35.1 per cent). To form income groups, the respondents' disposable household income was weighted by the number of persons in the household (net equivalent

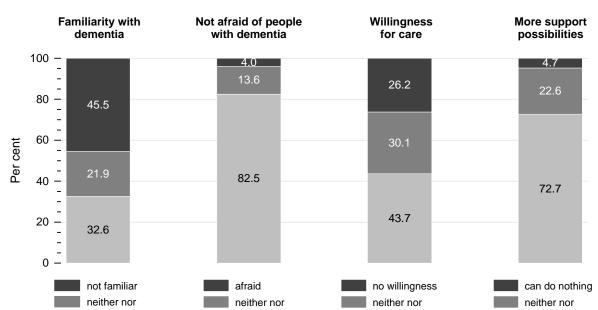
income) and divided into three roughly equal groups based on this: low (n = 1,329; 32.9 per cent), middle (n = 1,317; 32.6 per cent) and high income (n = 1,389; 34.4 per cent).

#### Results

#### Many people are unfamiliar with dementia, but few are afraid of people with dementia

Figure 1 shows an overview of the surveyed attitudes to dementia. About one third of the respondents (32.6 per cent) said they were familiar with dementia. Almost half (45.5 per

cent) said they were unfamiliar with dementia. Slightly more than one fifth (21.9 per cent) were undecided and chose the middle answer category.



not afraid

Figure 1: Attitudes towards people with dementia

Source: DEAS 2020/21, n = 4,175, weighted, rounded figures.

familiar

About eight out of ten respondents (82.5 per cent) reported not being afraid of people with dementia; only a very small proportion (4.0 per cent) reported feeling afraid of people with dementia. The middle answer category was chosen by 13.6 per cent of the respondents. A general willingness to care for people with dementia exists among about four out of ten respondents (43.7 per cent), but about a quarter (26.2 per cent) are not

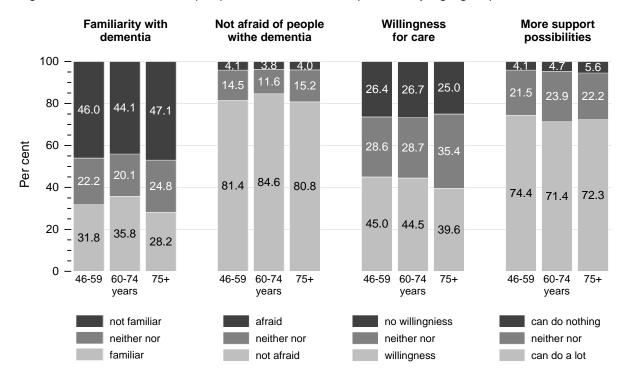
willing to do so. Another third was undecided in this respect (30.1 per cent). General potential for improving the quality of life of people with dementia was recognised by more than two thirds of the respondents (72.7 per cent). Only a small proportion considered no improvements possible (4.7 per cent). Just under a quarter of the respondents (22.6 per cent) were undecided on this question.

can do a lot

willingness

#### No significant age differences in attitudes towards people with dementia

Figure 2: Attitudes towards people with dementia, separated by age groups.



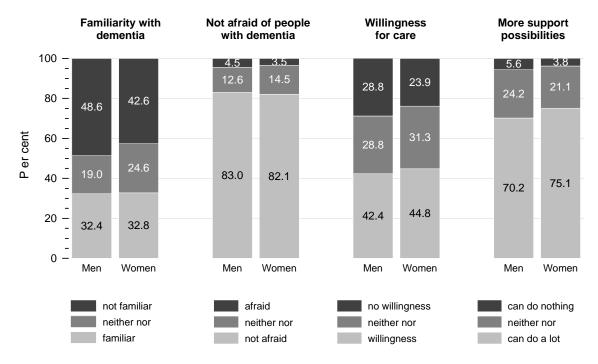
Source: DEAS 2020/21 (n = 4,175); weighted, rounded figures. Differences in percentages between age groups are not statistically significant (p < 0.05).

Figure 2 shows the relationship between attitudes towards people with dementia and the age of the respondents (comparing the three age groups: 46 to 65, 66 to 75, and 76 and older). Age might play an important role in attitudes towards people with dementia, as the risk of being affected by dementia itself increases significantly with age. It is also likely that with increasing age, cases of dementia occur in the respondents' circle of friends and acquaintances, and dementia and the

challenges that come with it become an issue. However, none of the comparisons between the age groups are statistically significant. The small differences between age groups shown in Figure 4 should be interpreted as random deviations. Neither the familiarity with dementia, the willingness to care for people with dementia, nor the fear of people with dementia or the assessment of support options are related to age.

#### No significant differences in attitudes between men and women

Figure 3: Attitudes towards people with dementia, separated by men and women.



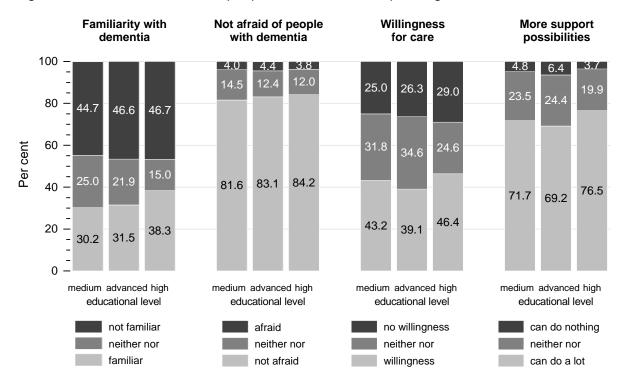
Source: DEAS 2020/21 (n = 4,175); weighted, rounded figures. Differences in percentages between men and women are not statistically significant (p < 0.05).

Figure 3 shows the same statements separately by gender. Gender could play a role; women are more often affected by dementia than men, and home care is generally provided more often by women than by men. Overall, however, the gender differences are not pronounced and are not statistically significant (p < 0.05). The

apparent gender difference in the assessment of support possibilities (women: 75.1 per cent, men: 70.2 per cent) is also not statistically significant. Gender therefore does not appear to be a category in which attitudes towards people with dementia differ significantly.

#### Higher educational level is associated with higher familiarity with dementia

Figure 2: Attitudes towards people with dementia, depending on the level of education



Source: DEAS 2020/21 (n = 4,175); weighted, rounded figures. Education groups differ statistically significantly (p < 0.05) in terms of familiarity with dementia between respondents with maximally medium education and those with high education.

Figure 4 illustrates the extent to which attitudes towards people with dementia differ by level of education. People with higher education may have more knowledge of dementia and this may have an impact on other attitudes. However, the only statistically significant difference in education is in familiarity with dementia; 38.3 per cent of respondents with high education said they

were familiar with dementia. In contrast, only 31.5 per cent of those with higher education and 30.2 per cent of those with low/medium education said they were familiar with dementia. Educational differences are not statistically significant regarding support options, fear of people with dementia and willingness to provide care.

# Higher income is associated with more perceived support options and less fear of people with dementia, but not with higher willingness to take on caregiving

Not afraid of people Familiarity with Willingness More support dementia with dementia for care possibilities 100 5.1 6.8 12.4 24.4 18.4 27.5 27.6 28.2 21.7 80 41.6 43.9 50.7 60 Per cent 31.8 27.1 29.4 19.4 30.4 85.9 82.5 16.6 79.2 78.3 71.5 67.5 45.3 43.8 43.1 20 36.8 32.7 28.0 0 middle middle high middle high hiah low middle hiah low low household income household income household income household income not familiar afraid no willingness can do nothing neither nor neither nor neither nor neither nor

Figure 3: Attitudes towards people with dementia, depending on household income

Source: DEAS 2020/21 (n = 4,035); weighted, rounded figures. Differences in percentages between age groups are not statistically significant (p < 0.05). The following differences are statistically significant (p < 0.05): Among respondents with high household incomes, a larger proportion of people report no fear of people with dementia and perceive more support options than people with low household incomes.

willingness

not afraid

Figure 5 shows attitudes in relation to household income. The material situation of the household could play a role in the willingness to provide care, which may involve financial costs in addition to personal commitment. People with higher incomes may also be able to contribute more materially or financially to improvements in the lives of people with dementia, as they are better able to cope with higher costs in the healthcare system.

familar

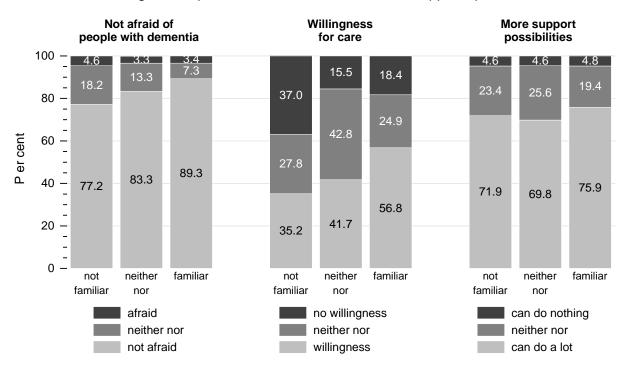
The relationship between household income and familiarity with dementia is complex; as income increases, so does the proportion of people who say they are familiar with dementia, as well as the proportion who say they are not. The proportion in the middle category decreases significantly with increasing income (from 30.4 per cent to 19.4 per cent to 16.6 per cent), i.e., as income increases, the proportion of those who are undecided on the question of familiarity decreases.

People with high household incomes are more likely to say they are not afraid of people with dementia; 85.9 per cent for the high-income group compared with 82.5 per cent in the middle-income group and 79.2 per cent in the low-income group; the difference between income groups is statistically significant (p < 0.05). The willingness to care for people with dementia does not depend on income; financial resources do not play a significant role here. However, people with a higher household income see more opportunities for support for people with dementia; 78.3 per cent in the high-income group compared to 71.5 per cent in the middle-income group and 67.5 per cent in the low-income group; differences between income groups are statistically significant (p < 0.05). Optimism about improvements in the quality of life of people with dementia seems to increase with rising income.

can do a lot

# Willingness to care for people with dementia is strongly related to familiarity with dementia

Figure 4: Relationship of familiarity with dementia with fear of people with dementia, willingness to provide care, and assessment of support options



Source: DEAS 2020/21 (n = 4,175); weighted, rounded figures. The following differences are statistically significant (p < 0.05): The proportion of people with no fear of people with dementia is greater among people who report being familiar with dementia than people who report not being familiar. The proportion of people willing to care for people with dementia is greater among people who say they are familiar with dementia than people who say they are unfamiliar.

Figure 6 shows how familiarity with dementia is related to fear of people with dementia, willingness to care for people with dementia, and an optimistic view of support options: 89.3 per cent of respondents who say they are familiar with dementia also say they are not afraid of people with dementia. Among respondents who say they are not familiar with dementia, only 77.2 per cent say this. In the middle category, this proportion is 83.3 per cent. These differences are also statistically significant (p < 0.05).

The differences are most pronounced in the willingness to care for people with dementia. More than half of respondents (56.8 per cent) familiar with dementia indicate a

willingness to care; among respondents who are unfamiliar with dementia, this is only the case for about a third (35.2 per cent, differences statistically significant, p < 0.05). These results are a clear indication that familiarity with dementia reduces discomfort towards people with dementia and also increases willingness to care for them. There are also differences regarding support options (respondents familiar with dementia are more likely to perceive of support options than those unfamiliar with dementia; 75.9 per cent to 71.9 per cent); however, these differences are not statistically significant.

#### Discussion of the results

To educate the public and strengthen the social participation of people with dementia in Germany, information is needed about attitudes towards people with dementia. More detailed knowledge is also needed regarding the social groups in which negative attitudes towards people with dementia are particularly widespread, to be able to change them for the better. This article presents the first representative results regarding the attitudes of people in the second half of life in Germany towards people with dementia. In particular, we investigated how familiarity with dementia, fear of people with dementia, willingness to care for people with dementia, and the assessment of general potential for improvement are distributed in the general population aged 46 and over, and the extent to which age, gender, education and household income are related to such attitudes.

Familiarity with dementia is relevant to the social climate towards people with dementia and the general willingness of society to adapt to the needs of people with dementia. With greater familiarity with dementia, people show significantly less fear and are also significantly more willing to care for people with dementia. Against this background, it is alarming that just one third of people in the second half of life state that they are familiar with dementia, while almost half state that they are unfamiliar with dementia. There seems to be a substantial need for action here to strengthen this awareness in society. Highly-educated persons in particular report a greater familiarity with dementia. This could indicate that increased education and information can help to achieve greater awareness of dementia. Material situation, on the other hand, has no influence, nor does gender or age. Familiarity with dementia is approximately the same for women and men and does not differ in a statistically significant way between age groups. Overall, however, it should be considered that respondents can interpret 'familiarity'

differently. This could be understood as personal experience in dealing with people with dementia, as well as conversations among acquaintances or dealing with the topic through books or films. Different perceptions of familiarity with dementia among different groups of people should therefore also be the subject of further research.

Fear of people with dementia is only reported by a small minority of 4 per cent of the population; in contrast, over 80 per cent of the population in the second half of life say they do not fear people with dementia. Levels of fear are similar between women and men, between people of different ages, and between people with different levels of education. However, the results show a relevant connection with material situation. People with a higher household income are more likely to report not feeling fear of people with dementia. No conclusions can be made about the cause of this correlation on the basis of these evaluations; however, this should be the subject of future studies to identify possible influencing factors and effectively counter such fears (for example, with education, the communication of knowledge and the combating of stereotypes). Since people who are familiar with dementia are also significantly less afraid of people with dementia, strengthening this familiarity in the population could also be a suitable way to counteract fears of people with dementia.

As the number of people with dementia increases and more people wish to grow old in their own homes, the *willingness to care for people with dementia is* an important social resource. However, only 44 per cent of respondents can imagine taking care of people with dementia, while about 26 per cent cannot imagine doing so. These findings indicate that care and nursing by relatives, friends, or from within the community, cannot be guaranteed to a sufficient degree. Since about 30 per cent of the population aged 46 and older are still

undecided on this issue, there may be potential to strengthen the willingness to provide care. Counselling and relief offers, suitable forms of housing, and voluntary care for people with dementia should be promoted. However, measures that strengthen the general awareness of

dementia could also have a positive effect; the connection between the two attitudes proves to be very strong. At the same time, the willingness to care for people with dementia is practically independent of age, gender, education and the income situation of the respondents.

#### The National Dementia Strategy (NDS)

The National Dementia Strategy (NDS) was adopted by the Federal Government of Germany in June 2020. It was developed with numerous partner institutions from politics, society and research. Containing 162 measures, the situation for people with dementia and their relatives in Germany is to be improved by 2026. A central goal is to strengthen knowledge about dementia in society. This should help to improve awareness 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.

Overall, socio-demographic characteristics have hardly any influence on the attitudes considered here. There are no statistically significant differences between men and women. This was not necessarily to be expected, since men and women are affected differently by dementia. There is a strong correlation between age and the occurrence of dementia, both among the persons affected and among their acquaintances, so it is also surprising that there is no statistically significant correlation between age and attitudes towards people with dementia. Through contacts in the family circle with parents, grandparents and great-grandparents, the topic of dementia also becomes relevant to younger population groups. Overall, this finding is a point for further research. One possibility is that if parents or grandparents have dementia, the topic can become relevant across generations early in life, levelling out potential age differences. However, the DEAS survey 2020/21 only includes people

over the age of 45 as a data basis. It may be that familiarity with dementia is lower at younger ages. Whether this is the case must be clarified in future studies.

Raising awareness of dementia and strengthening the public's understanding of prevention and risk reduction is a key objective of the German National Dementia Strategy (Federal Ministry for Family Affairs, Senior Citizens, Women and Youth & Federal Ministry of Health 2020) as well as most dementia strategies internationally (World Health Organization 2017). Such information campaigns can help to increase familiarity with the topic of dementia and raise awareness of how to deal with people with dementia. This article is a first step towards investigating attitudes towards people with dementia in Germany. In the future, it will be interesting to see how attitudes towards people with dementia develop over time. Furthermore, it is important to clarify which factors influence

the formation of attitudes towards people with dementia, as this will assist in the

development of promising intervention strategies.

#### Literature

- Aihara, Y., Kato, H., Sugiyama, T., Ishi, K., & Goto, Y. (2020). Public attitudes towards people living with dementia. A cross-sectional study in urban Japan (innovative practice). *Dementia*, *19*(2), 438-446. https://doi.org/10.1177/1471301216682118
- Alzheimer Europe (2020). Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe. Luxembourg: Alzheimer Europe.
- Alzheimer's Australia (2014). *Living with dementia in the community: Challenges & opportunities.*Canberra: Dementia-Friendly Community Program.
- Bienko, N., Burhanullah, M. H., & Munro, C. A. (2019). Dementia. In: D. Gu & M. E. Dupre (Eds.) *Encyclopedia of Gerontology and Population Aging* (pp. 1-9). Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-69892-2\_961-1
- Bundesministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ) & Bundesministerium für Gesundheit (BMG) (2020). *Nationale Demenzstrategie*. Berlin Bundesministerium für Familie, Senioren, Frauen und Jugend; Bundesministerium für Gesundheit. Online: https://www.nationale-demenzstrategie.de/die-strategie (Last retrieved 15.07.2022)
- Bowen, C. E., Kessler, E.-M., & Segler, J. (2019). Dementia worry in middle-aged and older adults in Germany: sociodemographic, health-related and psychological correlates. *European Journal of Ageing, 16*(1), 39-52. https://doi.org/10.1007/s10433-018-0462-7
- Brijoux, T., & Zank, S. (2022). Auswirkungen kognitiver Einschränkungen (Demenz) auf Lebensqualität und Versorgung [D80+ Kurzbericht 7]. Köln: ceres cologne center for ethics, rights, economics, and social sciences of health.
- Brodaty, H., Draper, B., & Low, L.-F. (2003). Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. *Journal of advanced nursing, 44*(6), 583-590. https://doi.org/10.1046/j.0309-2402.2003.02848.x
- Cheng, S.-T., Lam, L., Chan, L., Law, A., Fung, A., Chan, W.-C., Tam, C., & Chan, W.-m. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *International Psychogeriatrics*, 23, 1433-1441. https://doi.org/10.1017/s1041610211000834
- Ding-Greiner, C. (2010). Demenz vom Alzheimer-Typ. Grundlagen und Begleiterkrankungen. In: A. Kruse (Ed.) *Lebensqualität bei Demenz? Zum gesellschaftlichen und individuellen Umgang mit einer Grenzsituation im Alter* (pp. 281–296). Heidelberg: Akademische Verlagsgesellschaft AKA.
- Engstler, H., & Hameister, N. (2020). Deutscher Alterssurvey (DEAS): Kurzbeschreibung des Datensatzes SUF DEAS2017, Version 2.0. Berlin: Deutsches Zentrum für Altersfragen. Online:
  - https://www.dza.de/fileadmin/dza/Dokumente/Publikationen/DEAS2017\_V2.0\_Kurzbeschr eibung.pdf (Last retrieved 15.07.2022)

- Gekoski, W. L., & Knox, V. J. (1990). Ageism or Healthism?:Perceptions Based on Age and Health Status. *Journal of Aging and Health, 2*(1), 15-27. https://doi.org/10.1177/089826439000200102
- Huber, A., & Seifert, A. (2021). Einstellungen gegenüber Menschen mit Demenz. *Zeitschrift für Gerontologie und Geriatrie, 54*(7), 636-642. https://doi.org/10.1007/s00391-021-01867-x
- Jessen, F. (2018). *Handbuch Alzheimer-Krankheit: Grundlagen Diagnostik Therapie Versorgung Prävention.* Berlin: De Gruyter. https://doi.org/10.1515/9783110411003
- Jolley, D. J., & Benbow, S. M. (2000). Stigma and Alzheimer's disease: causes, consequences and a constructive approach. *The International Journal of Clinical Practice*, *54*(2), 117-119.
- Kahana, E., Kinney, J. M., Ercher, K., Kahana, B., Tinsley, V. V., King, C., Stuckey, J. C., & Ishler, K. J. (1996). Predictors of Attitudes toward Three Target Groups of Elderly Persons: The Well, the Physically III, and Patients with Alzheimer's Disease. *Journal of Aging and Health*, 8(1), 27-53. https://doi.org/10.1177/089826439600800102
- Keck, W. (2012). Die Vereinbarkeit von häuslicher Pflege und Beruf. Bern: Hogrefe.
- Kite, M. E., Stockdale, G. D., Whitley, B. E., & Johnson, B. T. (2005). Attitudes Toward Younger and Older Adults: An Updated Meta-Analytic Review. *Journal of Social Issues*, *61*, 241-266. https://doi.org/10.1111/J.1540-4560.2005.00404.X
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sampson, E. L., Samus, Q., Schneider, L. S., Selbæk, G., Teri, L., & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, *396*(10248), 413-446. https://doi.org/10.1016/S0140-6736(20)30367-6
- O'Connor, M. L., & McFadden, S. H. (2010). Development and Psychometric Validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease, 2010*, 454218. https://doi.org/10.4061/2010/454218
- Peng, A., Moor, C., & Schelling, H. (2012). Einstellungen zu Demenz. Übersetzung und Validierung eines Instruments zur Messung von Einstellungen gegenüber Demenz und demenzkranken Menschen. Zürich: Universität Zürich, Zentrum für Gerontologie.
- Schröder, J., & Pantel, J. (2011). *Die leichte kognitive Beeinträchtigung: Klinik, Diagnostik, Therapie und Prävention im Vorfeld der Alzheimer-Demenz; mit 25 Tabellen*: Schattauer Verlag.
- Stone, S. D. (2003). Disability, Dependence, and Old Age: Problematic Constructions. *Canadian Journal on Aging / La Revue canadienne du vieillissement, 22*(1), 59-67. https://doi.org/10.1017/s0714980800003731
- Umegaki, H., Suzuki, Y., Ohnishi, J., & Iguchi, A. (2009). Changes in the perception of dementia in Japan. *International Psychogeriatrics*, *21*(4), 793-795. https://doi.org/10.1017/s1041610209009132
- von Kutzleben, M., Köhler, K., Dreyer, J., Holle, B., & Roes, M. (2017). Stabilität von häuslichen Versorgungsarrangements für Menschen mit Demenz. *Zeitschrift für Gerontologie und Geriatrie*, *50*(3), 210-218. https://doi.org/10.1007/s00391-015-0990-0
- Wallesch, C.-W., & Förstl, H. (2017). *Demenzen* (3. Ed.). Stuttgart, New York, Delhi, Rio: Thieme Verlagsgruppe. https://doi.org/10.1055/b-0037-144448

- Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging and Mental Health*, 12(1), 92-99. https://doi.org/10.1080/13607860701616325.
- World Health Organization. (2019). *Risk reduction of cognitive decline and dementia: WHO guidelines*. Geneva: World Health Organization. Online: https://www.who.int/publications/i/item/9789241550543 (last accessed on 15.07.2022)
- World Health Organization. (2017). *Global action plan on the public health response to dementia* 2017–2025. Genf: World Health Organization

#### **Imprint**

Weinhardt, M., Lärm, A., Boos, B., & Tesch-Römer, C. (2022): Attitudes towards people with dementia in Germany [DZA Aktuell 03/2022 – English Version]. Berlin: German Centre of Gerontology.

Published in November 2022.

DZA Aktuell is a product of the German Centre of Gerontology (DZA), Berlin. The DZA is funded by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

www.dza.de