Public stigma towards informal caregiving in Germany: a descriptive study

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Abstract

Background. There is currently a gap in the research literature regarding the occurrence and magnitude of public stigma towards informal caregiving. However, the investigation of stigma towards informal care is highly relevant, given the negative consequences that stigmatization can have. Therefore, this study aims to investigate the public stigma towards informal caregiving for individuals older than 65 years in the German population. **Methods.** 1038 members of the adult population (18 years and older) living in Germany participated in an online-survey. They were sampled using a quota-system based on the German micro census data. To assess public stigma towards informal caregiving for individuals older than 65 years, the following three aspects of stigma were assessed: 1) emotional reactions (adapted version of the Emotional Reaction to Mental Illness Scale), 2) behavioral reactions (extended version of the Social Distance Scale), and 3) cognitive reactions (newly developed list of Cognitions regarding informal care). Exploratory and confirmatory factor analyses were conducted for the development and adaptation of the three instruments, and their composite reliability is provided. **Results.** Emotional reactions in terms of devaluing feelings and feelings of misery were low, while appreciative feelings were neither low nor high. Reported social distance was low. Agreement with cognitions towards informal care in terms of devaluing and accusative cognitions was on average low, but high regarding appreciative cognitions. **Conclusions.** The results show that there is stigma towards informal caregiving for older individuals (65 years and older) in terms of emotional reactions, cognitions and social distance, although the magnitude of this stigma seems to be small. Knowledge regarding the occurrence and magnitude of stigma, as well as the processes that underlie this, is needed to prevent stigmatization and its negative outcomes, or at the very least, to enable the development of support for the affected individuals.

Introduction

In Germany, like in many other industrial countries, a demographic change is occurring. There is a growing number of individuals in higher age groups and a decreasing number of individuals in mlower age groups (1). Due to this, the demand for care, especially for informal care, unpaid care provided by relatives and friends, is expected to increase. This can already be seen by current statistics showing an increase in the number of individuals needing care from 2015 to 2017, with the majority of these individuals being cared for at home, and the majority of this group receiving solely informal care (2). This is in part due to the population's preference for being cared for at home and by one's relatives (3, 4), and also in part due to the German government policy that prioritizes informal care (5). However, informal care can have detrimental consequences for caregivers, e.g., worse health outcomes (6, 7), and also for care recipients, e.g., reduced life satisfaction (8). Although many studies have investigated these consequences for informal caregivers and care recipients, very few studies have looked into the evaluation and treatment of informal caregivers by the population, in terms of stigmatization.

Stigma can be defined as a negatively perceived attribution of an individual, which leads to a change of the perception of the stigmatized person. Goffman describes it as the stigmatized person being perceived as tainted (p. 11, 9).

It should be noted that various forms of stigma exist. Stigma can be assessed from the perspective of the stigmatized, either as perceived stigma, that is the stigma as it is perceived by the stigmatized person, or as self-stigma, which is the internalization of the perceived stigma by the stigmatized person (10). It can also be assessed from the perspective of the person displaying this stigma towards stigmatized individuals, for example public stigma (11). Further differentiation is possible. We place our focus on public stigma, namely on the stigma as it is reported by those who have the capacity to stigmatize others.

Previous research on informal care has mainly focused on courtesy stigma. Courtesy stigma is a specific type of stigma that refers to the caregiver being stigmatized in the same way as the care recipient due to his or her association with the care recipient. In other words, the stigma towards the care recipient is transferred to the care recipient as well, due to their association. (9, 12). This stigma is usually assessed from the caregiver's perspective in terms of his or her perception of courtesy stigma. For example, Abojabel and Werner (13) investigated perceived courtesy stigma by questioning caregivers of individuals with Alzheimer's disease in their qualitative study. They found negative cognitions, emotions and social distance towards the caregivers, as well as some positive emotions. These results were extended by Kahn, Wishart (14) who reported a gender and generational difference, with women and adult children reporting higher perceived courtesy stigma than men and spouses, respectively. When investigating the internalized courtesy stigma of caregivers, Navab, Negarandeh (15) found negative emotions in their qualitative study as well.

Various studies have also investigated the stigma towards care recipients as perceived by the caregiver (16, 17). Detrimental outcomes for the caregiver, like increased caregiver burden, were reported (10, 17), with perceived public stigma towards the care recipient being reported as most relevant for caregivers (10). However, this concept differs from the public stigma we aim to investigate, since these studies assessed the stigma towards the care recipient and not towards the informal caregivers themselves.

Phelan and colleagues (18, 19) investigated the stigma towards informal caregivers of veterans. Their results indicate the occurrence of stigma towards informal caregivers and detrimental consequences of this form of stigma. They found perceived stigma towards caregivers and care recipients, with higher perceived discrimination towards the care recipient (19), and significant negative associations between stigma of informal caregivers, as well as health and social integration (18, 19).

Extending the knowledge of the negative consequences of stigma towards informal care, Weisman de Mamani, Weintraub (20) found increased critical behavior of caregivers towards care recipients when perceiving greater stigma.

In sum, qualitative and quantitative studies have found evidence of the occurrence of courtesy stigma towards informal caregivers (13–15). However, these studies investigated the perspective of the caregiver, namely, how the caregiver perceived stigma aimed from the public towards them (and their care recipients). However, perceived stigma, and public stigma that is actually displayed by society, might differ. Furthermore, these studies almost solely focused on informal care of individuals with Alzheimer's

disease (e.g.,13, 14, 15), with the exception of the studies from Phelan and colleagues. Due to this, the results cannot necessarily be generalized to all informal caregivers.

Thus, there is a gap in the research literature with respect to the occurrence and magnitude of public stigma towards informal caregiving. However, the investigation of stigma towards informal care is highly relevant, in view of the negative consequences of the stigmatization of informal caregivers that have been found. For example, increased depression, anxiety and loneliness in caregivers (18), and increased critical behavior of caregivers towards their care recipient (20) have been reported. Further negative consequences are possible, as indicated by the few studies conducted in this field. Stigma could discourage individuals from caregiving or could lead them to hide the size of their caregiver burden (19). It could also stop caregivers from looking for support (21), as has also been witnessed in other research fields on stigma (22). This can endanger the caregivers by worsening their situation. Given the expected increase in demand for informal care, stigma might endanger the availability and the capability of informal caregivers.

Considering the potentially dangerous consequences of stigma on caregivers, research on the occurrence and magnitude of stigma and its consequences for informal caregivers of older individuals in need of care is highly relevant. Moreover, not only the public stigma that is perceived by caregivers but also the public stigma that is actually shown by the public should be investigated. Only by exploring both perspectives will it be possible to gain a comprehensive knowledge of the existence and magnitude of public stigma. This knowledge is needed for developing interventions to prevent or decrease stigma. Therefore, our study aims to investigate public stigma towards informal caregiving for older individuals within the German population.

Conceptual framework

Informal care in this study is defined as performing unpaid private care (e.g. relatives, friends or neighbors) for a person aged 65 years or older, with care including personal care, help with feeding, mobility, or household chores during the last six months at least once per week.

To define stigma, we refer to the definition by Goffman (9) and the theory on stigma from Link and colleagues (23, 24), which we apply to the caregiving context.

Stigma refers to a negatively perceived attribution of an individual (9). The development of stigma (23, 24) starts with labeling individuals with a specific characteristic or behavior, and distinguishing them from those without it. The labeled group is seen as separate from others and specific cognitions or stereotypes are associated with the label, which are in turn associated with emotional reactions. In consequence, these individuals are treated differently and discriminated against. Applying this theory to the caregiving context, we assume that individuals are labeled due to providing informal caregiving for older individuals. This label is associated with cognitions and emotional reactions, which in turn leads to discriminating behavioral responses, for example, by distancing themselves from these individuals.

As mentioned previously, various forms of stigma exist. This study focusses on the public stigma as it is demonstrated and perceived by the public. The reason for focusing on public stigma is that, by definition, stigma is based on social evaluation, and the public stigma influences other forms of stigma, like self-stigma. Due to this, we see public stigma as a central stigma concept.

Therefore, the *aim* of our study is to investigate if and to what extent public stigma towards informal caregiving exists in the German population.

Method

Design and Subjects

An Online-Survey was conducted with a computer assisted web interview (CAWI, approximate duration 10 minutes) among the adult population (18 years and older) living in Germany. Participants were recruited online (e.g., with social media networks, opt-in-mails, and co-registration) using a quota-system based on the German micro census data of 2016. The sample was quite representative with respect to regional distribution, women were only slightly underrepresented, and men slightly overrepresented. However, in the younger age group of 18 to 34 years of age, men in particular were underrepresented, while in the higher age group of 75 years and older, men were overrepresented and women quite underrepresented.

Recruitment and data assessment were conducted by USUMA in cooperation with Lightspeed GMI. USUMA is a market and social research institute (member of the Arbeitskreis Deutscher Marktforschungsinstitute e.V., ADM), which works in accordance with the guidelines of the ADM, the international ICC/ESOMAR Codex for market- and social research and in the DIN ISO 20252 “Markt- und Sozialforschungsdienstleistungen”, as well as all current laws regarding data protection.

The survey was completed by a sample of 1038 participants. Of the 2444 individuals responding to the invitation, 6.9 % drop-outs were registered. These mainly dropped out before starting the questionnaire, indicating a lack of interest in the research topic leading to the drop-out. Another 24 % were excluded because they finished the questionnaire below an established acceptable time limit. Due to the quota-based sampling 26.6% of individuals were excluded, leading to the final analytical sample of 1038 participants.

All participants were informed about the study conditions and data protection policy, and gave informed consent. We applied for an ethics vote at the ethics committee of the medical chamber of Hamburg (Ärztchamber Hamburg), who declared no ethics vote to be necessary.

The datasets generated and analyzed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

Instruments

Before the final data collection by USUMA, three pretests were conducted to test the plausibility, comprehensibility, and operability of the questionnaire. Pretest 1 (N = 8) and pretest 2 (N = 3) involved a convenience sample of academics and non-academics, respectively. The pretests were conducted during the final phase of questionnaire development by the research group. Participants were asked to comment on plausibility and comprehensibility of the questionnaire, and the questionnaire was adapted accordingly. Another technical and practical pretest, Pretest 3 (N = 66), was conducted by USUMA, with a sample assessed in the same way as the sample for the final data collection (see description above). During this pretest, participants had to answer to the preliminary CAWI questionnaire online. Operability, comprehensibility, duration and potential problems with the questionnaire were analyzed based on these results and the CAWI questionnaire was adapted accordingly.

Sociodemographic data. Participants were asked to give information on their age, gender, marital status (married, living together; married, living separately; divorced; widowed; single), highest educational degree (upper secondary school; qualification for applied upper secondary school; polytechnic secondary school; intermediate secondary school; lower secondary school; currently in school training; without school-leaving qualification) and highest vocational degree (university/university of applied science/school of engineering; college/technical school/ master school; vocational school/apprenticeship; without qualification). They were also asked about their employment status (employed, retired, not employed), if they were born in Germany, in which state in Germany they lived and how religious (0 = not religious to 100 = very religious) they are.

Previous experience with care. Furthermore, previous experience with informal care was assessed by asking if participants had been or are informal or professional caregivers, or—if participants were 65 years and older—if they were or are care recipients. Additionally, they were asked if they have friends or family, who were or are informal or professional caregivers, or care recipients aged 65 years or older.

Public stigma. Three questionnaires were implemented to assess public stigma towards informal caregiving for individuals aged 65 years or older in the German population in terms of emotional, behavioral and cognitive reactions. To cross-validate the instruments, the total sample was randomly split in two samples. An exploratory factor analysis was calculated for each instrument with sample 1 (N = 500), and a confirmatory factor analysis was conducted for each instrument with sample 2 (N = 538) (further information on the two samples available on request). Composite reliability was calculated for each factor.

Emotional Reactions to Informal Care. The first instrument aimed to assess the emotional reaction towards informal care. So far, no research on emotional reactions towards informal caregiving for older people has been conducted. Therefore we used an adapted version of the Emotional Reaction to Mental Illness Scale (ERMI) (25). Participants had to rate the emotions on a 5-point Likert Scale (0 = “not applicable at all” to 4 = “totally applicable”). However, the ERMI has been developed for research on stigma towards mental illness, thus, the assessed emotions are primarily relevant for this context. Due to this, we adapted the instrument to assess all basic emotions by adding further items in accordance with

one of the leading theories on emotion, the theory of basic emotions from Ekman (26, 27). The following emotions were added: sadness, disgust, guilt, shame, embarrassment, happiness, rejoicing, wonder, surprise, envy, pride, relief, contempt, excitement, and schadenfreude. In discussion with two native English speakers we translated rejoicing into admiration. Compassion was added, despite not being defined as a basic emotion, because compassion is of central relevance and often expressed towards stigmatized groups (28). Based on the pretests we excluded some of the emotions: Ecstasy was described as inappropriate emotion in this context; one item from the ERMI assessing anger and two items assessing fear were found to be redundant and therefore excluded. Due to low variance ($<.40$) three items were excluded after data assessment (Item 3 amusement; Item 9 disgust; Item 21 schadenfreude).

An exploratory factor analysis (EFA) using principal factor analysis and oblique oblimin rotation was conducted on the final instrument. The Kaiser-Meyer-Olkin measure ($KMO = .862$) and the KMO values for all items of the final model were well above .50, and the Bartlett test of sphericity was significant ($\chi^2 (153) = 3048.708$; $p < .001$). Thus, sufficient correlation between the items existed. The Kaiser criterion (eigenvalue > 1) and the scree plot indicated a three factor solution. Two items were excluded because they loaded below .40 (29). The repeated EFA without these two items found a three factor solution again (Factor 1: Devaluing feelings; Factor 2: Appreciative feelings; Factor 3: Feelings of misery). Factor loadings after the rotation can be found in Table A1 in the appendix. Factor 1 and Factor 2 were negatively correlated ($r = -.11$), Factor 2 and 3 were positively correlated ($r = .07$) and so were Factor 1 and 3 ($r = .05$).

Confirmatory factor analysis (CFA) with a bootstrapped standard error (1000 replications), was conducted on the three-factor-model we found with the EFA. The fit indices show that the initial model (model 1, $\chi^2 (132) = 771.277$, $p < .001$) was not a good fit (Table 1, model 1). Based on the modification indices item 18 was excluded, which improved the fit indices of the modified model ($\chi^2 (116) = 590.964$, $p < .001$) (Table 1, model 2). Further modification of the specification did not improve the model. The final model (coefficients and bootstrapped standard errors are given in Appendix B Table B1) is an acceptable one ($RMSEA = .088$, $SRMR = .094$, $TLI = .786$, $CFI = .818$). Composite reliability was calculated for each factor (Factor 1: $r = .80$; Factor 2: $r = .79$; Factor 3: $r = .64$), ranging from questionable to good reliability.

In accordance with the results from the factor analyses, a mean score was built for each of the three factors, based on the items that loaded highly on these factors (Factor 1 Devaluing feelings: items 6, 7, 10, 11, 13, 14, 19, 22; Factor 2 Appreciative feelings: items 4, 5, 8, 15, 17, 20; Factor 3 Feelings of misery: items 1, 2, 12).

[Table 1 about here]

Social distance. The second instrument for the assessment of the behavioral reaction was the social distance scale (SD), which had originally been developed by Bogardus (30, 31) and has since been adjusted for use in various contexts (32, 33). Its results should give indications towards possible consequences of the stigmatization process, namely, the desire for distance from the stigmatized group.

We used the German translation of the modified version from Link, Cullen (34). The SD has good validity and reliability (Cronbach's $\alpha = .75-.90$) and is regularly used to assess stigma (24). Based on the results of our pretests we adjusted the item formulation to be closer to the original questionnaire, by changing the items back to statements and added two items. Results from the pretest suggested this change in wording to improve the comprehensibility of the items. The 9 items had to be rated on a 5-point Likert scale (0 = "do not agree"—4 "totally agree").

An EFA using principal factor analyses was performed after the tests of the assumptions showed that the KMO measure (KMO = .939) and values were well above .50 and Bartlett's test of sphericity was significant ($\chi^2 (36) = 2916.336$; $p < .001$). The factor analysis revealed a one-dimensional structure of the instrument (Appendix A, Table A2).

This model was tested with a CFA with bootstrapped standard errors (replications 1000) with results for the model ($\chi^2 (27) = 162.546$; $p < .001$) showing RMSEA = 0.097 [0.083; 0.111], SRMR = 0.036, CFI = 0.959, and TLI = 0.946. Despite RMSEA being above the recommended cut-off of .08 for a reasonably close fit, SRMR is well below the cut-off of .05 or .08 and CFI is above the recommended cutoff of .90 or .95, as well as TLI achieving the cutoff of .95. Thus, the model is accepted as a good fit (coefficients and bootstrapped standard errors are given in Appendix B Table B2). A composite reliability of .92 was found, indicating excellent reliability.

Based on this result a mean score was built from the 9 items, with higher scores indicating less social distance.

Cognitions regarding informal care. The third instrument was used to assess the cognitive reaction and included a list of possible statements (referred to as cognitions) regarding informal care for older people (65 years and older), for example, "Carers provide care because they want to feel needed". Subjects had to rate these cognitions on a 5-point-Likert scale (0 = "not applicable at all" to 4 = "totally applicable"). The list was developed for this study based on mostly qualitative research in scientific databases, as well as reports in public media on stereotypes voiced about caregiving for older people in general. In addition, experts in professional care gave advice and the item generation was discussed extensively within the research team. Furthermore, three pretests were conducted to test the plausibility and comprehensibility of the list. Due to low variance (≤ 40) two items were dropped (Item 7: "Carers are nauseating", and Item 10: "Carers provide care because they are too lazy to do real work") after data assessment.

An EFA with principal-component factor analysis and oblique oblimin rotation was conducted. The KMO measure (KMO = .811) and the KMO values for all items of the final model all showed values well above .50 and the Bartlett's test was significant ($\chi^2 (78) = 1174.448$; $p < .001$). Item 2, 14, 17, 18 and 21 were dropped due to high loadings on two factors, and Item 1 and 22 were dropped since they were the only items loading on the fourth factor. The repeated EFA showed, based on the scree plot and Kaiser's criterion (eigenvalue > 1), a three-factor solution for the final model (Factor 1: Accusative cognitions; Factor 2: Devaluing cognitions; Factor 3: Appreciative cognitions), which explained 56% of the variance

(Appendix A, Table A3). Factors were correlated (Factor 1 and 2: $r = .28$, Factor 1 and 3: $r = -.18$, Factor 2 and 3: $r = -.14$)

A CFA was conducted with the second sample to cross validate the model found with the EFA (Appendix B, Table B2), with bootstrapped standard errors (replications 1000). Results for this model ($\chi^2(62) = 191.744$; $p < .001$) showed RMSEA = .063 [.053;.073] and SRMR = .057 were both well below .08; and CFI = .896 and TLI = .896 were close to .90. Thus, the model can be seen as a reasonably close fit (coefficients and standard errors are given in Appendix B Table B3). Composite reliability was calculated (Factor 1: $r = .70$; Factor 2: $r = .67$; Factor 3: $r = .66$), indicating questionable to acceptable reliability.

Based on the results from the factor analyses, a mean score was built for each of the three factors (Factor 1 Accusative cognitions: items 4, 6, 8, 11, 12, 13; Factor 2 Devaluing cognitions: items 3, 5, 16, 19; Factor 3 Appreciative cognitions: items 9, 15, 20).

Results

Sample

Details on the sample can be found in Table 2. The mean age of participants was 52 years ($SD = 16.63$, Range: 19–90) and there were marginally less female participants (48.94%). Regarding the marital status 60.40% were married and currently living together with their partner, and 21.19% reported being single. The majority had either an upper secondary school qualification (34.78%) or an intermediate secondary school qualification (31.89%), while only a small number of participants had no school training (0.19%) or were still in school training (0.39%). About half of the sample (52.12 %) had an apprenticeship or vocational school qualification, while about a third (27.17%) had a university degree as their highest vocational degree. The majority of the participants were employed (53.18%), with 14.35% being unemployed and 32.47% being retired. About 94% were born in Germany. The religiousness of participants was on average 32.14 ($SD = 31.88$, Range: 0–100). In general, the variables had very few missing values (between 0.10 and 0.39%, with the largest percentage of missing values found for religiousness: 2.7%) (more detailed information available on request).

[Table 2 about here]

Previous experience with informal care

The details on previous experience with informal care as reported by the participants can be found in Tables 3–5.

About a third (29%) of the sample had previous experience in *performing informal care* for an individual aged 65 years or older (Table 3). Of those, most had or still care for their parents or in-laws (62.13%), while 14.29 % cared or still care for their partner. The reason for the care recipient needing care were

mainly physical impairments (94.35%), although more than a third also named mental impairment as the reason for care (36.88%). All types of informal care we assessed were reported. Most frequently help with household chores was given (81.40%). Help with transport (75.08%), and help with eating (71.76%) were also named by a majority of participants, as well as help with medication intake (62.46%) and supervision (61.13%). Help with dressing (56.81%) and help with personal hygiene (55.48%) were also named by more than half of the participants.

[Table 3 about here]

A small group of participants aged 65 years or older (Table 4) reported having *experienced the receipt of informal care* (2.22% of the complete sample; 7.85% of the participants aged 65 years and older). Of these participants, the majority were cared for by their partner (47.83%) or children (26.09%). The majority reported physical impairments (91.30%), and 17.93% reported mental impairments as the reason for needing care. Most reported receiving help with household tasks (52.17%), help with transport (43.48%), and help with dressing (39.13%).

[Table 4 about here]

Regarding further experience with informal care (Table 5), about a third of the sample indicated they had friends or family who are informal caregivers (34.10%) and almost as many participants reported having friends or family who are recipients of informal care (29.58%). Furthermore, about 11% reported to deliver or to have delivered professional care, while 33.33% reported having friends or family who are professional caregivers.

[Tables 5 about here]

Public stigma towards informal care

Results regarding the *emotional reactions scale* are shown in Figure 1 and Table 6. Results show individuals to have, on average, low devaluing feelings (factor 1; $M = .41$; $SD = .54$). The highest mean value was found for feeling ashamed (Item 14, $M = .62$; $SD = .96$), while the lowest was found for feeling contempt (Item 19, $M = .22$; $SD = .69$). Feelings of misery towards informal care were on average 1.68 ($SD = .93$; factor 3), with feeling sorry for the caregiver showing the highest mean value (Item 2, $M = .2.15$; $SD = .1.26$) and being afraid of the caregiver (Item 1, $M = .1.07$; $SD = 1.20$) showing the lowest. Last, appreciative feelings were on average 2.58 ($SD = .83$; factor 2). Highest agreement was given to feeling admiration for the caregiver (Item 8, $M = 3.20$; $SD = .99$) and lowest agreement to being happy (Item 15, $M = 1.91$; $SD = 1.36$).

[Figure 1 and Table 6 about here]

Figure 2 and Table 7 show the results of the *social distance scale*. Individuals reported on average low social distance ($M = 3.08$; $SD = .76$). Highest agreement was given to accepting being comfortable with a

caregiver as a neighbor ($M = 3.39$; $SD = .80$). Lowest agreement was given to recommending the caregiver for a job position ($M = 2.92$; $SD = 1.07$).

[Figure 2 and Table 7 about here]

Regarding *cognitions towards informal care* results are displayed in Figure 3 and Table 8. Descriptive analysis show that individuals reported on average low agreement to accusative cognitions towards informal care (Factor 1) ($M = 1.05$; $SD = .67$). Highest agreement was given to Item 12 “Carers provide care because they want to feel needed” ($M = 1.82$; $SD = 1.22$), while lowest agreement was given to Item 6 “Carers provide care because they can’t do anything else.” ($M = .59$; $SD = .98$). Participants also showed on average low agreement with devaluing cognitions (Factor 2) ($M = 1.22$; $SD = .74$). Agreement to these cognitions was very similar, with highest agreement being given to “Carers are often depressed.” (Item 5, $M = 1.50$; $SD = 1.11$). Appreciative cognitions were on average rated high (Factor 3) ($M = 3.32$; $SD = .70$). Highest agreement was given to “Carers provide a valuable service to society” (Item 9, $M = 3.53$; $SD = .81$); lowest agreement was given to Item 20 “People work as carers for the sake of their relatives.” ($M = 3.10$; $SD = .99$).

[Figure 3 and Table 8 about here]

Discussion

The aim of this study was to investigate the occurrence and the magnitude of public stigma towards informal caregiving for individuals aged 65 years and older in the German population.

As explained by the theory from Link and colleagues (23, 24), stigma is based on emotional reactions and cognitions or stereotypes, which express themselves in behavioral actions, like social distance. Our first instrument measured these emotional reactions with a three-dimensional instrument. Only a low level of devaluing feelings were reported. Feelings of misery were slightly higher than devaluing feelings, while an even higher degree of appreciative feelings were reported, which was still neither low nor high. This indicates that, while informal care does not seem to be associated strongly with negative emotional reactions, it is not associated with a high degree of positive emotions either.

The results are slightly different regarding cognitions. Here, a clear contrast could be found between deprecating cognitions (accusative and devaluing cognitions), which were ranked lower in agreement, and appreciative cognitions, which had rather high agreement. Social distance was also reported as rather low, indicating a low degree of stigmatizing behavior towards informal caregivers.

Thus, in general, stigma, as measured with the emotional, social distance and cognitions measure that we employed, did occur, but was rather low in the analyzed population.

Former quantitative studies, like Kahn, Wishart (14), also found stigma in the specific group of caregivers they analyzed. Further studies (15) reported internalized stigma towards informal care. Furthermore, qualitative studies like Abojabel and Werner (13) reported that caregivers perceived various negative and

positive emotions and behavior, as well as negative cognitions. However, many of the former studies used a qualitative study design. While qualitative studies can give important in-depth information and first evidence regarding a topic (35), their results are only representative for the group investigated. Moreover, they cannot quantify their results and thus give no indication regarding the magnitude of stigma. Therefore, the comparison of our results with former research is difficult.

Additionally, the difference in the type of stigma that has been analyzed has to be taken into consideration. While former studies investigated the perception of stigma by the caregivers, by asking them about stigmatizing emotions, cognitions or behaviors they had perceived in others, our study investigated the stigma as reported by the public. Internalized as well as perceived public stigma, as has been reported by previous research, might differ to the occurrence of public stigma. Both types of stigma can be biased by the perspective that was investigated. Therefore, information on both perspectives is necessary to gain a comprehensive understanding of the stigma.

Our results extend the findings of former studies on stigma as perceived by the caregivers, by showing that not only do caregivers report to perceive a stigma, a public stigma *is* expressed by the society as well. This is of high relevance in light of the significance that public stigma has for other forms of stigma (see Introduction). However, despite finding these emotions, cognitions and the behavior that indicate stigma occurs, in line with former research, our quantitative results indicate that the magnitude of stigma might be rather low in the analyzed population.

Another aspect that should be taken into consideration is that the perceived stigmatization of informal care recipients has been reported to be higher than the perceived stigmatization of the caregiver (21). However, although stigma towards the caregivers might be lower, it can still occur. Considering the consequences of stigma that have been shown by former research, like poorer mental health and increased critical behavior towards the care recipients (18, 36), the existence of even low stigma should not be ignored. Thus, future research is needed to form a better understanding of stigma towards informal caregiving.

Limitations, strengths and future research recommendations

The sample was drawn as an online sample, which restricts the representativeness of our sample, due to availability and capability of internet access (online affinity) likely influencing the sample selection. However, in online-surveys a social de-contextualization effect has been found (37), with individuals answering less frequently according to social norms. Thus, with a sensitive topic like stigma, we might have the advantage of reducing the social desirability bias linked to the assessment of sensitive topics, by using an online survey.

Our study uses instruments that have been adapted and developed for the assessment of stigma of informal caregiving and require further validation. Still, it should be noted that the Social Distance Scale

from Bogardus (30, 31) is a valid and reliable instrument, which has been widely implemented in different research contexts. As the results of the CFA for the modified SD scale show, the one-dimensional structure of the original instrument remained stable and the model indices indicated a good fit. Composite alpha was excellent, which suggests high reliability.

We also used the ERMI (25) which is a well-validated instrument regarding stigma of mental illness. We modified it to investigate the emotions relevant for informal-care related stigma and our model was the only acceptable fit. Since further modifications did not improve the model, we assume the assessment of further items might be necessary. This might also improve the composite reliability, especially for Factor 3 which consists of only three items. Thus, we recommend to include especially items relating to this factor to improve the model in future research.

Lastly, we could not find any instrument assessing specific cognitive reactions towards informal caregiving. Therefore, we had to develop a new instrument. The CFA showed the model was a reasonably close fit, although, the composite reliability for two factors was only moderate. As with the Emotional Reactions instrument, a possible explanation might be the low number of items assessing these two factors. We recommend the addition of more items relating to these two factors to improve the instrument in future research. In general, further research on the psychometric properties with a random sample is recommended for all our instruments.

Nevertheless, this study is the first in this new research field to investigate this topic. Only a few studies have been performed in this context yet. Therefore, instruments assessing the public stigma towards informal care specifically have not been available and the modification and development of our instruments was necessary to enable this research. Due to this, our study's results can give a first indication on the occurrence and magnitude of informal care-related stigma in Germany.

Conclusion

Stigma towards informal caregivers looking after older care recipients is a relatively new field of research. So far, only a small number of studies have investigated its occurrence and all have focused on stigma as perceived by the caregiver. However, to gain a comprehensive understanding of this stigma, not only the perceived stigma but also the occurrence and the magnitude of public stigma as shown by the society has to be analyzed. This study investigated public stigma towards informal caregivers, by assessing emotional, cognitive and behavioral responses to informal caregiving. Thereby, this study gives first evidence regarding the occurrence and magnitude of this type of stigma. The results show that stigma in terms of emotional reactions, cognitions and social distance occurs, although the magnitude of stigma towards informal caregiving seems to be low.

In light of the growing importance and demand for informal care, especially in the German care system, these results are of significant importance. Despite the lack of research in this new field, there is evidence indicating detrimental outcomes of stigmatizing for the caregiver (18, 19), as well as for the care recipient (20). Thus, even though the magnitude of stigma we found is low, further research is needed to gain a

better understanding of the public stigma towards informal caregiving for older individuals, and the relevant aspects of influence. Knowledge regarding the occurrence and magnitude of stigma, as well as the underlying processes, will be able to help to prevent stigma and its negative outcomes, or at the very least enable the development of support for the affected individuals.

Declarations

Ethics approval and consent to participate: All participants were informed about the study conditions and data protection policy, and gave informed consent. We applied for an ethics vote at the ethics committee of the medical chamber of Hamburg (Ärztchamber Hamburg), who declared no ethics vote to be necessary.

Consent for publication: Not applicable.

Availability of data and material: The datasets generated and/or analysed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

Conflict of interest: None.

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Author's contributions: LZ made substantial contributions to conception and design of the study, the analysis and interpretation of data and drafted the manuscript. HM contributed to the statistical analysis of the data. MCA contributed to the conception and design of the study. SGRH contributed to the drafting of the manuscript. HHK and AH made substantial contributions to the analysis and interpretation of data and drafting of the manuscript and contributed to the conception and design of the study; these two authors contributed equally to the manuscript. All authors read and approved the final manuscript.

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Tables

Table 1

Fit indices for the confirmatory factor analysis of the Emotional Reactions towards informal care instrument

	Model 1	Model 2
RMSEA	0.091	0.088
- lower level	0.084	0.081
- upper level	0.098	0.095
SRMR	0.101	0.094
TLI	0.757	0.786
CFI	0.790	0.818
AIC	24636.767	23024.447
BIC	24880.321	23255.284

Note. Model 1 displays the fit indices for the initial model, model 2 displays the fit indices for the final model. RMSEA = Root mean squared error of approximation; SRMR = standardized root mean squared residual; TLI = Tucker-Lewis-Index; CFI = comparative fit index; AIC = Akaike's information criterion; BIC = Bayesian information criterion.

Table 2

Sociodemographic details and religiousness of the sample

Variable	N (%) / M (SD)
N	1038
Age (Range: 19-90)	52.361 (16.63)
Gender (female)	508 (48.94)
Education – highest educational degree	
· Upper secondary school	361 (34.78)
· Qualification for applied upper secondary school	115 (11.08)
· Polytechnic Secondary School	80 (7.71)
· Intermediate Secondary School	331 (31.89)
· Lower Secondary School	144 (13.87)
· Currently in school training/education	4 (0.39)
· Without school-leaving qualification	2 (0.19)
Education – highest vocational training degree	
· University/ University of applied science	282 (27.17)
· College / technical school / master school	140 (13.49)
· Vocational school/ apprenticeship	541 (52.12)
· Without qualification	73 (7.03)
Employment status	
· Employed	552 (53.18)
· Retired	337 (32.47)
· Unemployed	149 (14.35)
Marital status	
· Married, living together	627 (60.40)
· Married, living separately	41 (3.95)
· Divorced	102 (9.83)
· Widowed	48 (4.62)
· Single	220 (21.19)
Land of Birth	
· Germany	980 (94.41)

· Other	58 (5.59)
Religiousness (Range 0-100)	32.14 (31.88)

Note. Mean and standard deviation are given for continuous variables (age, religiousness), frequency and percent are given for categorical variables (gender, education, employment status, marital status, Land of Birth).

Table 3

Experience with providing informal care among former or current caregivers

<i>Previous experience with providing care</i>	N (%)
Care recipient	
· Husband/Wife/Partner	43 (14.29)
· Mother/Father/in-law	187 (62.13)
· Daughter/Son	7 (2.33)
· Acquaintances	35 (11.63)
· Other	52 (17.28)
Reason for Caregiving	
· Physical impairment	284 (94.35)
· Mental impairment	111 (36.88)
· Other	0
Type of informal care given	
· body care/personal hygiene (cleaning, bathing, toileting)	167 (55.48)
· (Un)dressing	171 (56.81)
· Eating	216 (71.76)
· Household	245 (81.40)
· Supervision	184 (61.13)
· Transport	226 (75.08)
· Medication intake	188 (62.46)
· Other	13 (4.32)

Note. Information on the informal caregiver and their care recipients is given only for those who reported to have experience with giving informal care (N=301; 29% of the complete sample).

Table 4

Experience with receiving informal care among former or current care recipients aged 65 years and older

<i>Previous experience with receiving care</i>	N (%)
Informal caregiver	
· Daughter/Son	6 (26.09)
· Husband/Wife/Partner	11 (47.83)
· Mother/Father/in-law	0
· Acquaintances	3 (13.04)
· Other	5 (21.74)
Reason for Care receipt	
· Physical impairment	21 (91.30)
· Mental impairment	4 (17.39)
· Other	0
Type of informal care received:	
· body care/personal hygiene (cleaning, bathing, toileting)	5 (21.74)
· (Un)dressing	9 (39.13)
· Eating	6 (26.09)
· Household	12 (52.17)
· Supervision	2 (8.70)
· Transport	10 (43.48)
· Medication intake	7 (30.43)
· Other	3 (13.04)

Note. Information on the informal care recipient and their caregivers is given only for those who reported to have experience with receiving informal care (N=23); only individuals aged 65 years and older were asked about their experience with care receipt with 7.85 % of the participants aged 65 years and older reporting to have experience with receiving care.

Table 5

Experience with informal or professional care of participants themselves or of individuals close to them

<i>Further experiences with care</i>	N (%)
Being or having been a professional caregiver (yes)	114 (10.98)
Friends or family who are informal caregivers?	354 (34.10)
Friends or family who are recipients of informal care?	307 (29.58)
Friends or family who are professional caregivers?	346 (33.33)

Table 6

Detailed descriptive statistics for the factors and items of the *Emotional reactions* scale

	M (SD)
Factor 1 – devaluing feelings	.41 (.54)
6 She/he triggers incomprehension in me.	.52 (.90)
7 I am angry	.50 (.94)
10 I am disgusted by her/him	.22 (.64)
11 I feel envious	.31 (.70)
13 I feel guilty	.56 (.88)
14 I feel ashamed	.62 (.96)
19 I feel contempt for her/him	.22 (.69)
22 I am embarrassed	.37 (.75)
Factor 2 – appreciative feelings	2.58 (.83)
4 I feel sympathy for him/her	3.15 (.97)
5 I feel the desire to help her/him	2.28 (1.18)
8 I feel admiration for her/him	3.20 (.99)
15 I am happy	1.91 (1.36)
17 I feel proud for her/him	2.76 (1.16)
20 I feel enthusiastic	2.17 (1.26)
Factor 3 – feelings of misery	1.68 (.93)
1 He/she causes fear in me	1.07 (1.20)
2 I feel sorry for him/her	2.15 (1.26)
12 I feel sad	1.83 (1.28)

Note. Emotional reactions towards informal care - Range 0-4.

Table 7

Detailed descriptive statistics for the factors and items of the *Social distance* scale

	M (SD)
Social distance	3.08 (.76)
If you had an apartment or house that you could rent out, would you have such a person as a tenant?	3.22 (.89)
Would you accept such a person as a work colleague?	3.37 (.84)
Would you be comfortable having such a person as a neighbor?	3.39 (.80)
Would you trust such a person to watch over your children for a few hours?	3.00 (1.07)
Would you be happy for such a person to marry into your family?	3.12 (.93)
Would you introduce such a person to a friend?	3.15 (.92)
If an acquaintance of yours had a job position available, would you recommend such a person to your acquaintance?	2.92 (1.07)
Would you enter a romantic relationship with such a person?	2.33 (1.23)
Would you befriend such a person?	3.19 (.89)

Note. Emotional reactions towards informal care - Range 0-4.

Table 8

Detailed descriptive statistics for the factors and items of the *Cognitions regarding informal care* scale

		M (SD)
	Factor 1 – accusative cognitions	1.05 (.67)
4	Carers provide care because they have nothing/nobody important in their lives.	.65 (.97)
6	Carers provide care because they can't do anything else.	.59 (.98)
8	Carers provide care in order to gain recognition.	1.01 (1.04)
11	Carers provide care in order to have control over those they care for.	1.14 (1.13)
12	Carers provide care because they want to feel needed.	1.82 (1.22)
13	Carers would rather provide care to their relatives themselves in order to get the "care allowance".	1.11 (.97)
	Factor 2 – devaluing cognitions	1.22 (.74)
5	Carers are often depressed.	1.50 (1.11)
16	Carers are people who are easy to exploit.	1.37 (1.08)
3	Carers always complain.	.82 (.89)
19	Carers put themselves into a position where they become a victim.	1.18 (1.10)
	Factor 3 – appreciative cognitions	3.32 (.70)
9	Carers provide a valuable service to society.	3.53 (.81)
15	Carers are admirable.	3.32 (.92)
20	People work as carers for the sake of their relatives.	3.10 (.99)

Appendix A

Table A1

Results from the exploratory principal factor analysis with oblique oblmin rotation for instrument 1: *Emotional Reactions to informal care* (factor loadings, eigenvalues and common variance of each factor is given)

Item number	Items	Factor 1 – devaluing feelings	Factor 2 – appreciative feelings	Factor 3 – feelings of misery
6.	She/he triggers incomprehension in me.	0.55		
7.	I am angry	0.51		
10.	I am disgusted by her/him	0.70		
11.	I feel envious	0.61		
13.	I feel guilty	0.62		
14.	I feel ashamed	0.63		
19.	I feel contempt for her/him	0.67		
22.	I am embarrassed	0.70		
4.	I feel sympathy for him/her		0.67	
5.	I feel the desire to help her/him		0.53	
8.	I feel admiration for her/him		0.65	
15.	I am happy		0.67	
17.	I feel proud for her/him		0.72	
18.	I feel relieved		0.59	
20.	I feel enthusiastic		0.71	
1.	He/she causes fear in me			0.41
2.	I feel sorry for him/her			0.50
12.	I feel sad			0.56
	Eigenvalue	3.64	3.18	1.29
	% of common variance	0.50	0.44	0.18

Table A2

Results from the exploratory principal factor analysis model for instrument 2: *Social Distance* (factor loadings, eigenvalues and common variance of the factor is given)

Items	Factor 1
If you had an apartment or house that you could rent out, would you have such a person as a tenant?	0.77
Would you accept such a person as a work colleague?	0.83
Would you be comfortable having such a person as a neighbor?	0.86
Would you trust such a person to watch over your children for a few hours?	0.66
Would you be happy for such a person to marry into your family?	0.82
Would you introduce such a person to a friend?	0.80
If an acquaintance of yours had a job position available, would you recommend such a person to your acquaintance?	0.69
Would you enter a romantic relationship with such a person?	0.53
Would you befriend such a person?	0.83
Eigenvalue	5.24
% of common variance	102.30

Table A3

Results from the exploratory principal component factor analysis model with oblique oblimin rotation for instrument 3: *Cognitions regarding informal care* (factor loadings, eigenvalues and common variance of each factor are given)

Item number	Items	Factor 1 – accusative cognitions	Factor 2 – devaluing cognitions	Factor 3 – appreciative cognitions
4.	Carers provide care because they have nothing/nobody important in their lives.	0.74		
6.	Carers provide care because they can't do anything else.	0.58		
8.	Carers provide care in order to gain recognition.	0.74		
11.	Carers provide care in order to have control over those they care for.	0.60		
12.	Carers provide care because they want to feel needed.	0.65		
13.	Carers would rather provide care to their relatives themselves in order to get the "care allowance".	0.50		
3.	Carers always complain.		0.45	
5.	Carers are often depressed.		0.77	
16.	Carers are people who are easy to exploit.		0.63	
19.	Carers put themselves into a position where they become a victim.		0.81	
9.	Carers provide a valuable service to society.			0.80
15.	Carers are admirable.			0.77
20.	People work as carers for the sake of their relatives.			0.67
	Eigenvalue	2.91	2.30	2.02
	% of explained variance	0.22	0.18	0.16
	Explained variance (%)	.56		

Appendix B

Table B1

Results from the confirmatory factor analysis for *Emotional reactions to informal care* (standardized factor loadings β and unstandardized factor loadings B)

Item number	Items	β	SEb	B	SEb	Factor
10.	I am disgusted by her/him	.77	.0512	1		Factor 1 – devaluing feelings
6.	She/he triggers incomprehension in me.	.54	.046	1.02	.107	Factor 1 – devaluing feelings
7.	I am angry	.47	.056	.92	.139	Factor 1 – devaluing feelings
11.	I feel envious	.65	.051	.91	.073	Factor 1 – devaluing feelings
13.	I feel guilty	.48	.048	.92	.112	Factor 1 – devaluing feelings
14.	I feel ashamed	.51	.052	1.01	.145	Factor 1 – devaluing feelings
19.	I feel contempt for her/him	.68	.060	1.02	.083	Factor 1 – devaluing feelings
22.	I am embarrassed	.65	.054	1.03	.144	Factor 1 – devaluing feelings
4.	I feel sympathy for him/her	.76	.038	1		Factor 2 – appreciative feelings
20.	I feel enthusiastic	.61	.040	1.02	.107	Factor 2 – appreciative feelings
5.	I feel the desire to help her/him	.55	.040	.90	.101	Factor 2 – appreciative feelings
8.	I feel admiration for her/him	.71	.037	.94	.061	Factor 2 – appreciative feelings
15.	I am happy	.45	.048	.82	.118	Factor 2 – appreciative feelings
17.	I feel proud for her/him	.72	.037	1.10	.098	Factor 2 – appreciative feelings
12.	I feel sad	.80	.053	1		Factor 3 – feelings of misery
1.	He/she causes fear in me	.46	.058	.55	.096	Factor 3 – feelings of misery
2.	I feel sorry for him/her	.55	.045	.70	.081	Factor 3 – feelings of misery

Note. β = standardized factor loadings; unstandardized factor loadings = B; SEb = bootstrapped standard error (1000 repetitions).

Table B2

Results from the confirmatory factor analysis for *Social Distance* (standardized factor loadings β and unstandardized factor loadings B)

Items	β	SEb	B	SEb
Would you be comfortable having such a person as a neighbor?	.86	.018	1	
If you had an apartment or house that you could rent out, would you have such a person as a tenant?	.82	.025	1.07	.047
Would you accept such a person as a work colleague?	.81	.028	1.00	.040
Would you trust such a person to watch over your children for a few hours?	.72	.025	1.07	.066
Would you be happy for such a person to marry into your family?	.81	.020	1.07	.051
Would you introduce such a person to a friend?	.83	.021	1.09	.049
If an acquaintance of yours had a job position available, would you recommend such a person to your acquaintance?	.68	.029	1.04	.061
Would you enter a romantic relationship with such a person?	.61	.031	1.08	.083
Would you befriend such a person?	.84	.019	1.09	.049

Note. β = standardized factor loadings; unstandardized factor loadings = B; SEb = bootstrapped standard error (1000 repetitions).

Table B3

Results from the confirmatory factor analysis for *Cognitions regarding informal care* (standardized factor loadings β and unstandardized factor loadings B)

Item number	Items	β	SEb	B	SEb	Factor
8	Carers provide care in order to gain recognition.	.66	.036	1		Factor 1 – accusative cognitions
4	Carers provide care because they have nothing/nobody important in their lives.	.57	.049	.79	.079	Factor 1 – accusative cognitions
6	Carers provide care because they can't do anything else.	.43	.053	.62	.089	Factor 1 – accusative cognitions
11	Carers provide care in order to have control over those they care for.	.48	.045	.82	.083	Factor 1 – accusative cognitions
12	Carers provide care because they want to feel needed.	.46	.044	.83	.090	Factor 1 – accusative cognitions
13	Carers would rather provide care to their relatives themselves in order to get the "care allowance".	.60	.041	.87	.076	Factor 1 – accusative cognitions
19	Carers put themselves into a position where they become a victim.	.60	.049	1		Factor 2 – devaluing cognitions
3	Carers always complain.	.62	.052	.85	.126	Factor 2 – devaluing cognitions
5	Carers are often depressed.	.51	.053	.86	.091	Factor 2 – devaluing cognitions
16	Carers are people who are easy to exploit.	.54	.049	.87	.093	Factor 2 – devaluing cognitions
9	Carers provide a valuable service to society.	.68	.059	1		Factor 3 – appreciative cognitions
15	Carers are admirable.	.68	.061	1.14	.164	Factor 3 – appreciative cognitions
20	People work as carers for the sake of their relatives.	.53	.054	.92	.132	Factor 3 – appreciative cognitions

Note. β = standardized factor loadings; unstandardized factor loadings = B; SEb = bootstrapped standard error (1000 repetitions).

Figures

Figure 1

Descriptive results for the three factors of the Emotional Reactions scale with median, lower (25%) and upper (75%) percentile represented with the box, whiskers representing the largest and smallest value within 1.5 interquartile range (IQR), and outliers outside this 1.5 IQR are shown with dots (Range: 0-4).

Figure 2

Descriptive results for the Social Distance scale with median, lower (25%) and upper (75%) percentile represented with the box, whiskers representing the largest and smallest value within 1.5 interquartile range (IQR), and outliers outside this 1.5 IQR are shown with dots (Range: 0-4).

Figure 3

Descriptive results for the three factors of the Cognitions regarding informal caregiving scale with median, lower (25%) and upper (75%) percentile represented with the box, whiskers representing the largest and smallest value within 1.5 interquartile range (IQR), and outliers outside this 1.5 IQR are shown with dots (Range: 0-4).