

ZQP-ANALYSE

Aggression, Violence and Elder Mistreatment in Informal Care

Study design

Quantitative population survey of caregiving relatives

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I. Background

Over three million people in Germany are in need of care according to the Social Security Code (Federal Ministry of Health, 2017, n.d.). As per the latest figures, 94% of them are 60 years or older (Federal Statistical Office, 2017, p. 9, own calculations), about three quarters are cared for at home (Federal Ministry of Health, 2017, own calculations). About 4.7 million caregiving relatives are involved in at-home care (Wetzstein et al., 2015). The percentage of people in need of long-term care in the overall population is expected to continue to grow considerably: By 2050, an increase of about two-thirds is expected due to demographic trends alone (Rothgang et al., 2016, p. 83-89).

It is, therefore, especially important to promote both the welfare of people in need of care and their carers. Conflicts, aggression and mistreatment, especially elder mistreatment or abuse, are major challenges in care settings. Although these are not exclusively care-related phenomena, problematic interpersonal relationships and the violation of protection standards deserve particular attention: Due to their often considerable health impairments people in need of care are usually very vulnerable. They depend on the carers, can hardly defend themselves in case of problems and can often not express themselves.

Elder mistreatment and violence in care settings usually presuppose intentional actions that do not necessarily need to mean harm. Therefore, negative effects of such actions for the persons affected often occur unintentionally. In general, elder mistreatment and violence show in different forms of which many are not punishable under criminal law. Research primarily distinguishes between physical forms and psychological, emotional and verbal forms of mistreatment and violence as well as the use of freedom-restraining measures, neglect, financial abuse/exploitation and sexual abuse (Schnapp, 2016; Suhr, 2015).

Elder mistreatment and violence may occur in different care constellations – for example by professional carers against those in need of care (for a summary see: Castle, 2015, p. 14-18; for Germany: Görgen, 2009; Rabold & Görgen, 2007) and also by people in need of care against professional carers (for a summary see: Edward et al., 2014; for Germany: Franz, 2010; Schablon, 2012) or between residents of in-patient facilities (for a summary see: Ferrah et al., 2015; Görgen, 2017a).

The present analysis addresses two other constellations: on the one hand, violence of people in need of care against their caregiving relatives. This includes disease-related violent behaviour, i.e. aggressive actions that occur in some people as a symptom of mental impairments such as dementia.

On the other hand, the study examines elder mistreatment by caregiving relatives against those in need of care. Relatives are defined as people from a patient's private environment who regularly look after a person in need of care, regardless of whether or not they are related to that person. The study focuses on manifestations of elder mistreatment that have also played a key role in previous research: physical abuse, verbal aggression, neglect and freedom-restraining measures against the will of the person concerned. The two latter forms of mistreatment are only examined with reference to cases where carers mistreat those in need of care, while the other two forms are also considered with regard to the use of violence by people in need of care.

Especially violence or disease-related violent behaviour of people in need of care against caregiving relatives has hardly been researched in Germany. There is only one study that quantifies this phenomenon. Görgen et al. (2009) surveyed 252 caregiving relatives between 2006 and 2008. Half of the sur-

veyed people classified the person they cared for as having dementia. Over three quarters of respondents lived in the same household as the person in need of care. In this sample, 17% of respondents reported physical and 33% verbal assaults by the person in need of care within the past 12 months. Yet these figures should be interpreted with caution: The authors do not claim representativeness for their study, and it must be assumed that the respondents did not report all violent incidents.

The reason for the latter aspect is the research topic itself: Questions about mistreatment and violence – especially about one’s own use of violence – are so-called “sensitive questions”, i.e. questions that “address personal circumstances which are more or less taboo” (Skarbek-Kozietulska et al., 2012, p. 5). It is known that such questions are often answered euphemistically (“socially desirable response behaviour”, for a summary see: Krumpal, 2013, Tourangeau & Yan, 2007). Moreover, respondents may have simply forgotten some incidents (on this phenomenon see: Skogan, 1986, p. 87-90). Both mechanisms lead to an underestimation of the frequency of occurrence.

When people in need of care are aggressive towards carers, this can promote aggressive feelings in the carers themselves. Pillemer and Suitor (1991) show that relatives who care for people with dementia and have not (yet) mistreated the person in need of care are more likely to report aggressive thoughts and feelings towards this person if he or she has been aggressive towards them. For Germany, results concerning aggressive feelings of caregiving relatives are available from the LEANDER study (Thoma et al., 2004). Caregiving relatives of people with dementia were interviewed for this study in 2002. Half of them reported having been “full of resentment at least once during the reference period (14 days) because of what my relative expects me to do” (48%) or “would have liked to shake the person in need of care with rage” (47%). The same study also reported figures on the mistreatment of caregiving relatives of those in need of care. 82% of respondents said they had become “loud” during the period considered; 48% reported derogatory remarks towards the person in need of care. 28% reported threats and intimidation. 39% of respondents said that they have sometimes have handled their relatives “a bit rough”, 25% said that they had used a freedom-restraining measure. Results on mistreatment of caregiving relatives of people in need of care are also available from the study by Görden et al. (2009). In this study, 48% of respondents reported actions over the past 12 months, which the researchers classified as psychological abuse. The corresponding figures were 19% for physical abuse, 5% for freedom-restraining measures, and 6% for caregiving neglect (Görden et al., 2009, p. 203). In summary, it can be stated that psychological forms of mistreatment were reported more often than physical ones.

When interpreting these numbers it is also important to keep in mind that the true values for the sample were probably underestimated because respondents did not want to report such unpleasant events or had forgotten about them. In addition, neither of these two studies claims to be representative. It is, therefore, not exactly known how often mistreatment or violence occurs in private care relationships in Germany. The results suggest, however, that this is a wide-spread phenomenon (Görden, 2017b; Schnapp, 2016; Suhr, 2015).

Beyond the description of proportional values, we must raise the question of risk factors for mistreatment or violence in care relationships. The present study defines a risk factor for a phenomenon X as a variable that has a *statistical correlation* with X, irrespective of whether it is a *causal* correlation or not (Moffitt, 2005, p. 534). International research has identified different risk factors related to elder mis-

treatment (regardless of the care dependency). Many of these risk factors have been addressed in the study by Grger et al. (2009) on mistreatment and violence in private care arrangements in Germany. Less is known about risk factors concerning violence used by people in need of care against carers. These are presented first below:

- General research on violence and research on elder mistreatment show that mistreatment and violence are more likely to occur against those who use violence themselves (Goldberg, 2005, p. 73-74, Pyrooz et al., 2014, Reingle & Maldonado-Molina, 2012; Reisig & Holtfreter, 2018). Research on people in need of care confirms this fact (Paveza et al., 1992; Grger et al., 2009; VandeWeerd et al, 2013). Accordingly, mistreatment by a carer can also be considered a risk factor for violence against the carer. This, however, describes only a statistical connection: The result does not mean that all those who experience violence or mistreatment have previously used violence themselves or vice versa.
- Carers who look after people with dementia are likely to be affected by aggressive behaviour by the person in need of care particularly often because dementia is sometimes accompanied by so-called "challenging behaviour". Some of the patients show dementia-related violent behaviour such as verbal attacks, pushing, spitting or kicking (Allen-Burge et al., 1999, p. 217; Kuhlmeier et al., 2010, p. 6). In the international literature, the estimated proportions of people with dementia showing such disease-related violent behaviour vary between 18% and 65% (for a summary see: Wharton & Ford, 2014, p. 464-465).

Research on risk factors for mistreatment of people in need of care provides additional information. Regarding the selected risk factors described above, it is useful to distinguish between the characteristics of the person in need of care, the characteristics of the carer and the characteristics of the care relationship.

Characteristics of the person in need of care

- *Aggressive behaviour*: Since mistreatment by the carer can be named as a risk factor for violence against the carer, the use of violence by the person in need of care is also a risk factor for mistreatment by the carer (Grger et al., 2009; Paveza et al., 1992; VandeWeerd et al, 2013).¹
- *Dementia*: People in need of care who have dementia and show violent behaviour, even when it is disease-related, are probably themselves affected by mistreatment more often than those without dementia. In addition, even challenging, non-violent forms of behaviour can be highly frustrating for the carer and cause aggressive behaviour. Examples include constant seemingly unmotivated shouting at the person in need of care or the refusal of nursing actions. Accordingly, people with dementia are disproportionately affected by domestic violence (for a summary see: McCausland et al., 2016). This is confirmed by a related study on violence or mistreatment in private care settings in Germany (Grger et al., 2009, p. 205).
- *Physical impairments*: Elderly people with substantial physical impairments are mistreated more often than people without such impairments (for a summary see: Dong, 2016, p. 1227; Pillemer et

¹ Against this backdrop it can be assumed that there is a spiral of violence and mistreatment in some care relationships in which one person's aggression causes the other person's aggression and vice versa (Paveza et al., 1992, VandeWeerd et al, 2013, p. 5; Wharton & Ford, 2014, p. 464) although previous studies are not detailed enough to trace such dynamics. This also applies to this study.

al., 2016, p. S198-S199; Lachs & Pillemer, 2015, p. 1950). G6rger et al. (2009) conclude people with a very high need of care are mistreated particularly often.

- *Age*: Overall, research suggests that mistreatment of younger elderly people occurs more often than that of the older ones; the available data are, however, not conclusive (for a summary see: Dong, 2016, p. 1226-1227; Pillemer et al., 2016, p. S199). The data of G6rger et al. (2009) show only an insignificant difference.
- *Gender*: A meta-analysis on elder mistreatment of persons who do not live in residential institutions shows no significant gender difference (Yon et al., 2017, p. E152). The data of G6rger et al. (2009) show a small difference in that abuse against women in need of care occurs somewhat more often.

Characteristics of the carer

- *Aggressive thoughts and feelings*: Aggressive thoughts and feelings make aggressive behaviour more likely (Allen & Anderson, 2017; Anderson & Bushman, 2002). Therefore, a strong correlation between aggressive thoughts and feelings of the carer towards the person in need of care and aggressive behaviour towards this person is to be expected. Moreover, this connection is to be expected because aggressive behaviour towards the person in need of care may entail aggressive thoughts towards this person. After all, in retrospect people tend to find reasons that justify their behaviour (for a summary see: Kunda, 1990; Epley & Gilovich, 2016).
- *Time pressure and perceptions of stress*: Research confirms the view that elder mistreatment mainly happens through those who experience particular stress (for a summary see: Lachs & Pillemer, 2015, p. 1950). Data from Germany show that about one third of relatives feel that caring is a strong burden (Nowossadeck et al., 2016). The study by G6rger et al. (2009) shows a slight correlation between mistreatment and the feeling that care is a heavy burden. Accordingly, it could be assumed that people who have practical caregiving experience from their working life are less likely to be abusive because they may be better able to cope with the burden of care.
- *Mental health*: International studies have shown that people with low levels of mental health are more likely to mistreat elderly people (for a summary see: Pillemer et al., 2016, p. 199). In this context it is notable that people who care for a person for several hours a day are of poorer health than those people who do not care for anyone. This applies to both physical and mental health (Wetzstein et al., 2015).
- *Gender*: General research on violence repeatedly shows that men use physical violence more often than women (for a summary see: Archer, 2004; Daly & Wilson, 1997, p. 69-72; Eisner, 2003, p. 109-112; Gottfredson & Hirschi, 1990, p. 144-149). International research on elder mistreatment suggests that men are more likely to use serious physical violence; which, however, rarely occurs in care settings. The findings concerning other forms of mistreatment are less conclusive (for a summary see: Sethi et al., 2011, p. 32). G6rger et al. (2009) show that women are more likely to mistreat those in need of care. Overall, research findings so far suggest that there are no major gender differences.

Characteristics of the relationship

- *Status of the relationship:* International research on elder mistreatment shows that adult children and partners are more likely to abuse elderly people than others (for a summary see: Lachs & Pillemer, 2015, p. 1950). Only the first of these two findings is confirmed by Görden et al. (2009, p. 205).
- *Social isolation of the care relationship:* Elderly people with few social contacts are affected more often by mistreatment (Sethi et al., 2011, p. 34-35). This could be attributed to the fact that there are only few people who could prevent mistreatment of the person in need of care in such cases. Accordingly, Sethi et al. (2011, p. 34) assume that elderly people face a particular risk if they do not have social contacts except with the person who mistreats them.

The Centre for Quality in Care (Zentrum für Qualität in der Pflege, ZQP) – a non-profit foundation focussing on patient safety and the prevention of elder mistreatment and violence in the field of care and nursing – wants to contribute to the knowledge about the phenomenon of elder mistreatment and violence in care. The study analyses how often mistreatment and violence occur in informal care relationships. It also examines whether the risk factors described above can be confirmed by the present sample.

II. Authors in Alphabetical Order

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III. Methodology and Approach

For the preparation of the questionnaire, existing instruments were reviewed (Görge, 2009; Görge et al., 2009; Thoma et al., 2004; Zank & Schacke, n.d. a, b, c), but the scales were not adopted completely. When formulating the questions on mistreatment and violence, particular attention was given to ensure that behaviour which neither intended injury nor was perceived as such was not included. If this principle is disregarded, the number of violent events may be significantly overestimated (Oberwittler, 1999, p. 19).

In order to increase the willingness of the respondents to honestly answer sensitive questions, various principles were taken into account. First, by using a written questionnaire a mode was chosen where the problem of socially desirable response behaviour occurs less frequently than in telephone or personal interviews (for a summary see: Krumpal, 2013, p. 2034; Skarbek-Kozietulska et al., 2012 p. 6; Tourangeau & Yan, 2007, p. 863). Second, the groups of questions were arranged in such a way that they first addressed violence of the person in need of care against the carer and only then aggressive thoughts and feelings of the carer as well as mistreatment by the carer. Previous research has suggested that this results in more honest statements about one's own violence (Cowan et al., 1978; Simon et al., 2001). Third, so-called "forgiving phrases" were chosen to introduce sensitive questions - especially those in which it was truthfully stated that in other studies, many respondents have stated that they had been mistreating. Research findings on this topic are inconsistent but generally suggest that such formulations tend to increase the willingness to be honest (Acquisti et al., 2012, study 1; Catania et al., 1996; Holtgraves et al., 1997; Näher & Krumpal, 2012; Peter & Valkenburg, 2011). Fourth, the individual questions within the blocks were sorted in such a way that sensitive questions had to be answered at the beginning of a block rather than at the end. Acquisti et al. (2012, study 2) show that this optimizes respondents' willingness to report problematic behaviour. Fifth, instead of yes/no-questions, four verbal frequency descriptions were offered to record prevalence: *never - rarely - sometimes - often*. Methodological research suggests that this leads to a higher willingness to admit problematic behaviour (Peytchev & Hill, 2010; Schwarz et al., 1985). For the analysis, "rarely", "sometimes", and "often" were combined as "yes" and "never" was translated into "no".

The three variables used here were created by combining several output variables. They describe the carer's negative/aggressive thoughts and feelings towards the person in need of care, a lack of time

and symptoms typical of depression. The construction of these variables is described in detail in the methodological appendix.

The statistical population of this analysis is made up of people in Germany between the age of 40 and 80 who have cared for a person in their private surroundings for at least six months and at least once a week; the person in need of care has to meet the following criteria: (i) age 60 years or older, (ii) in need of care as defined by the German Social Security Code, i.e. the person has an official care grade (Pflegegrad) and (iii) is cared for at home (i.e. does not live in a residential institution). The sample of $n = 1,006$ people was drawn from a panel of approximately 80,000 German-speaking people. Only those who belonged to the statistical population were able to participate. The online survey was conducted between 20 April and 14 May 2018. The sample was re-weighted according to combinations of age, gender and formal education to approximate the ideal of a representative sample as closely as possible. Re-weighting was based on the German Aging Survey 2014, a representative survey of people between 40 and 85 who live in private households in Germany (Klaus & Engstler, 2016). It is based on the sub-sample of those participants who look after or care for a person who regularly receives benefits from long-term care insurance or who regularly provides help to such a person. A special analysis of the distribution of combinations of age, gender and formal education in this group was kindly provided by the German Centre for Gerontology (Deutsches Zentrum für Altersfragen). The highest weighting factor is 2.28. The margin of error of the study in the total sample is +/- 3% points.

IV. Results

Summary

Relationships in private care settings can lead to conflicts, aggression and mistreatment, especially elder mistreatment or abuse. The present study uses a survey of caregiving relatives (n = 1,006) to investigate the frequency of violence or mistreatment between them and the persons they care for. Relatives were able to participate in the survey if they have been providing care in their home environment for at least six months and at least once in a typical week to someone who meets the following criteria: (i) at least 60 years of age, (ii) requiring care as defined by the Social Security Code, i.e. the person has been assigned an official grade of care and (iii) is cared for at home and does not live in a residential institution. Respondents provided information about themselves, the person in need of care and the care situation. The central topic was violence and mistreatment. They were asked about violence and disease-related violent behaviour by the person in need of care against the carer as well as mistreatment the other way around. The results for the two constellations are not comparable with each other; this means that this study yields no information as to whether the mistreatment or violence as a whole or of a certain kind occurs more often through carers against the person in need of care or vice versa. The main results are:

- Many respondents report burdens and stress symptoms as well as negative thoughts and feelings towards the person in need of care. For example, more than a third (36%) feel depressed and more than a quarter (29%) say they have often been angry or irritated. In the past six months over half of respondents (52%) had the impression at least once that the person in need of care did not appreciate their help, a quarter (25%) would have occasionally, sometimes, or even often liked to “shake the person in need of care with rage” and over a quarter (29%) stated they have been at least temporarily disgusted by the person in need of care.
- 45% of the respondents report that they have been subjected to psychological violence by the person they care for within the past six months; 11% report physical violence. Relatives of people with dementia are more likely to be affected by violence or disease-related violent behaviour by the person in need of care than the other respondents.
- 32% of the respondents report that they have psychologically mistreated the person in need of care during the respective period; 11% report neglect and 12% physical abuse. 6% state that they showed a behaviour that must be considered a freedom-restraining measure.
- In relation to risk factors for mistreatment in care situations, the study also confirms that people with dementia who are in need of care are more often mistreated and more often by carers who complain about mental stress and a lack of time (for themselves or others).

1. People in need of care, carers and the care situation

- Nearly half of the people in need of care (44%), who are cared for by a respondent, live alone.
- 43% of people in need of care, who are cared for by the respondents, are between 80 and 89 years old and 22% are 90 years and older.
- Nearly two in five respondents look after the person in need of care on a daily basis.
- About one fifth of the respondents are neither supported by an outpatient care service nor by any other private person.
- 69% of the surveyed relatives are the main carers from the private environment.

Nearly one third (32%) of the people in need of care, who are cared for by a relative, are male. 35% are between 60 and 79 years old, 43% are between 80 and 89 years and 22% are older than 89. The people in need of care represent the entire spectrum from mild to severe cases. About a third (34%) were diagnosed with dementia.

Figure 1 shows the distribution of care grades.²

What is the current care grade of the person you care for?

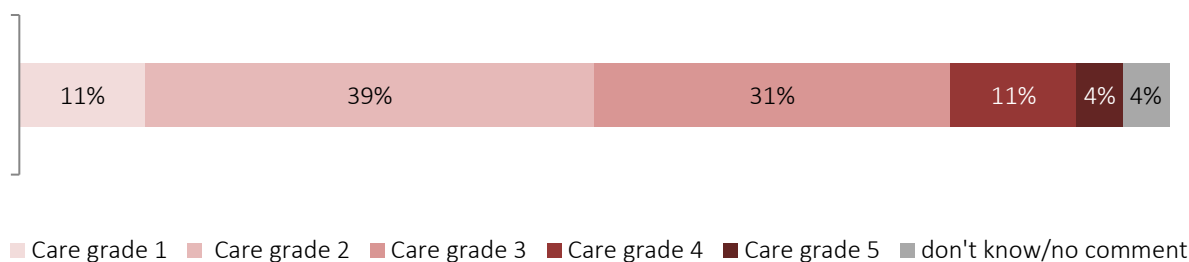


Figure 1: ZQP Survey Caregiving Relatives, n = 1,006

40% of respondents are male. 38% are between 40 and 54 years, 41% are between 55 and 69 years and the remaining 21% are between 70 and 85 years. The majority of the respondents balance care and work. 39% are employed and work 30 or more hours per week, 15% work less than 30 hours. 38% of respondents are retired and 2% are registered as unemployed. 6% are not registered as unem-

² Overall, the distribution is similar to that in the group of those requiring care at home aged 60 years and older in Germany. An exact correspondence is not to be expected, because the present study strives for representativeness with regard to the caregiving relatives (and not those in need of care). There is also no one-to-one correspondence between caregiving relatives and those in need of care: Although some people are cared for by exactly one relative, there are many who are cared for by several relatives – or by none (Schmidt & Schneekloth, 2011, p. 26). For comparison, however: In Germany, 39% of those in need of care at home (of all age groups) are male, and 31% of them showed a considerably limited ability to go about their daily lives (Federal Statistical Office, 2017, table 1.1, own calculations, as of: 31 Dec. 2015). This “occurs when, due to dementia-related disabilities, mental disabilities or mental illnesses, people are permanently severely restricted in their everyday life skills.” (Federal Statistical Office, 2017, p. 32), i.e. there is no one-to-one correspondence to a dementia diagnosis. 39% of those in need of care aged 60 and older are in the age group 60-79 and 45% in the age group 80-89; the remaining 16% are older (Federal Statistical Office, 2017, table 1.2, own calculations, as of 31 Dec. 2015). Nursing care data are available for those in need of care at home who are covered by statutory insurance. According to these figures, 3% of the insured cared for at home on 31 Dec. 2017 had care grade 1, 55% care grade 2, 27% care grade 3, 11% care grade 4 and 4% care grade 5 (Federal Ministry of Health, n.d., own calculations, as of 31 Dec. 2017).

ployed but also do not work (e.g. housewives). 15% of respondents gained nursing experience in their working life. They are or have been “in a nursing, medical or therapeutic profession through which they were/have been in contact with the ‘need for care’”.

The respondents differ considerably in how much time they spend caring for the person. Figure 2 shows the respective answers. Nearly two in five of the respondents look after the person in need of care on a daily basis.

How much time do you usually spend on looking after the person in need of care in a typical week?

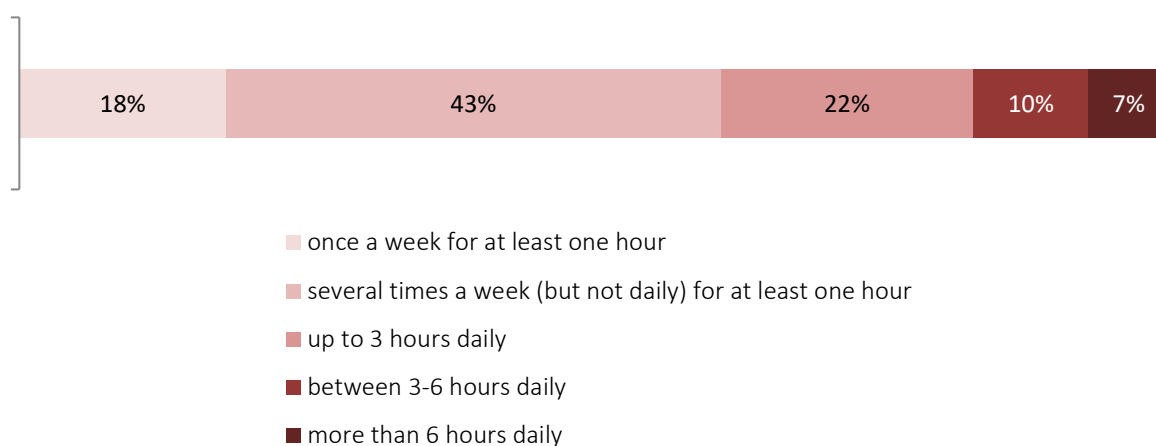


Figure 2: ZQP Survey Caregiving Relatives, n = 1,006

More than half of respondents (53%) care for a parent, another 14% for their mother-in-law or father-in-law. 15% care for their spouse or partner. Only in some cases the people they care for are their friends, neighbours, or acquaintances (8%), grandparents (1%) or other relatives (6%).

50% of people in need of care who are cared for by the respondent are also regularly supported by an outpatient nursing service. Figure 3 shows the housing situation of the people in need of care. Almost half of them (44%) live alone.

Which of the following statements best describes the housing situation of the person in need of care?

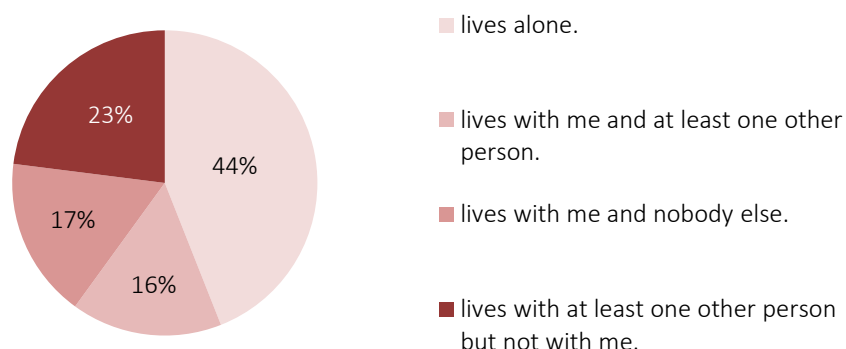


Figure 3: ZQP Survey Caregiving Relatives, n = 1,006

59% of respondents stated that at least one other person from their private environment looks after the same person in need of care. Of these respondents, 47% said that they themselves are the one who cares the most for the person in need of care.

Overall, 69% of survey participants can be considered the main carer from the private environment. 21% of respondents are completely alone with the care situation. They are neither supported by their private environment nor by an outpatient nursing service. In 10% of surveyed care relations, the respondent is the only person living together with the person in need of care and there is nobody else who also looks after that person.

2. Burdens and negative thoughts and feelings of the caregiving relative towards the person in need of care

- Over a third of the surveyed caregiving relatives (36%) often feel depressed, over a quarter (29%) are often angry or upset.
- Over half of the caregiving respondents (52%) had the impression at least once during the past six months that the person in need of care did not appreciate their help.
- More than a quarter (29%) stated that they were disgusted by the person in need of care at least once within the past six months.
- 25% of respondents stated that there was at least one situation within the past six months where they could have “shaken the person in need of care with rage”.

Caring for a relative can be accompanied by considerable burdens. The present study therefore asked about important forms of burden: lack of time (“too little time for oneself and to spend with others”), physical problems, frequent anger or irritation as well as symptoms that are typical for depression. The respondents were intentionally not asked to indicate only those feelings that they attributed to the care. Such an attribution would in most cases be very difficult. They were rather asked to indicate the extent to which they feel burdened. The results are shown in figure 4.

Please indicate to what extent each statement applies to you.

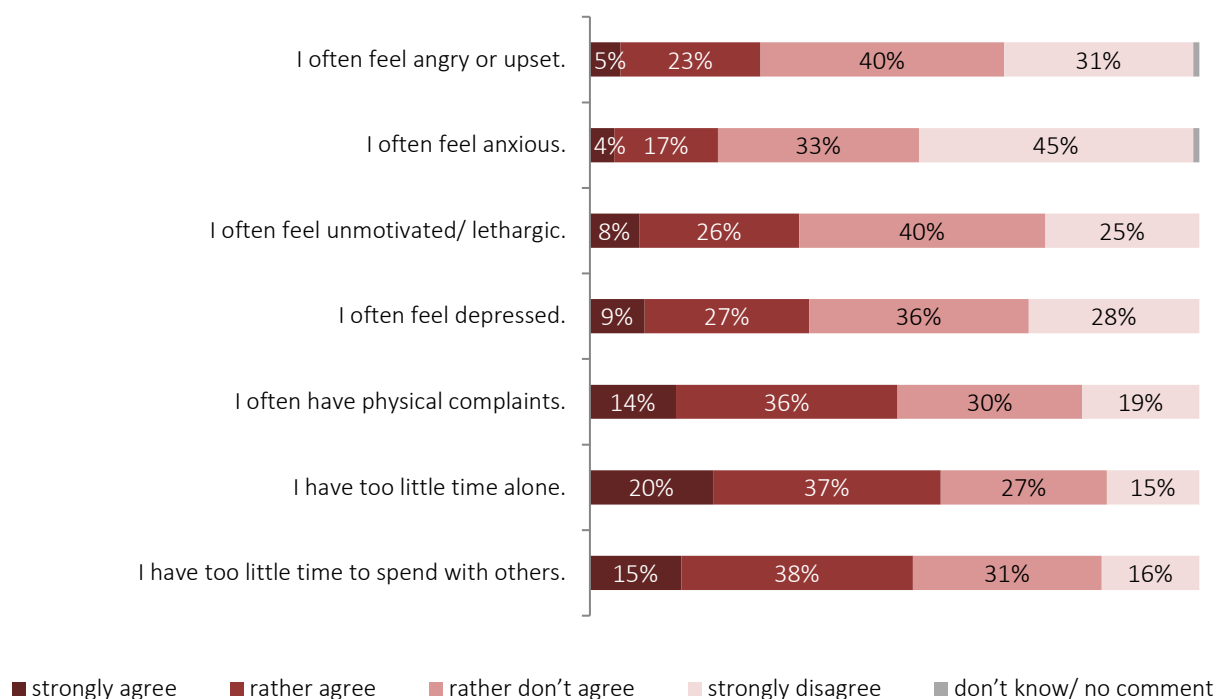


Figure 4: ZQP Survey Caregiving Relatives, n = 1,006

29% of respondents agree with the statement that they are often angry or upset. Regarding typical symptoms of depression, such as anxiety, lethargy and melancholy, 20-36% agreed that they had such feelings. 50% of respondents agree that they often have physical problems. 53-58% mentioned a lack of time (“too little time for oneself or to spend with others”).

Caring for relatives can be accompanied by negative feelings and thoughts towards the person in need of care. Figure 5 shows what the respondents answered with regard to such thoughts and feelings. In terms of the proportion of respondents who answered “rarely”, “sometimes”, or “often”, over half of them (52%) had the impression at least once in the past six months that the person in need of care did not appreciate their help, nearly two in five (38%) thought that the person deliberately made it difficult for them. 40% of respondents answered that at least once in the past six months they did not feel like doing something for the person in need of care that they actually should have done.

More than a quarter of respondents – around 29% – state that they are sometimes disgusted by the person in need of care. 25% of respondents say that they felt the urge to shake the person in need of care with rage, just under a tenth (8%) admit that they felt like “getting one over on the person in need of care because he or she caused so much work.”

Here are some thoughts and feelings you may sometimes have as a carer. Please tell us how many times you have felt or thought this way in the past 6 months – no matter how you actually behaved.

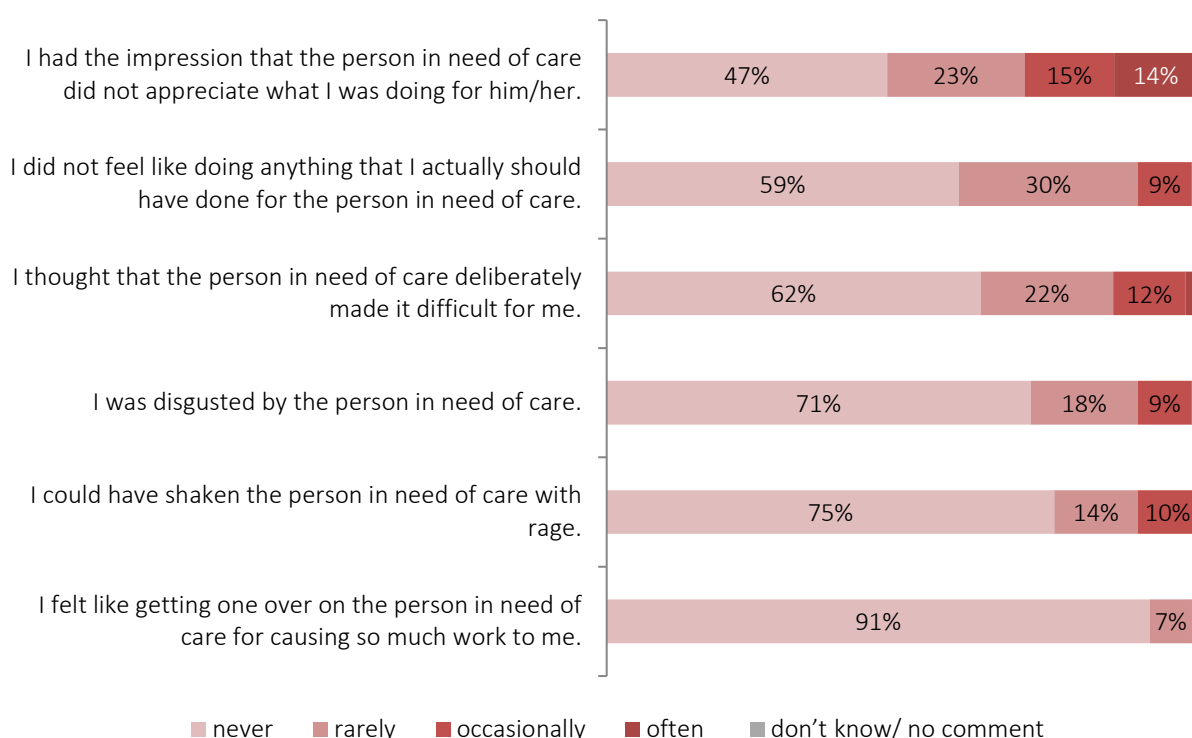


Figure 5: ZQP Survey Caregiving Relatives, n = 1,006

3. Violence or disease-related violent behaviour of people in need of care toward caregiving relatives

- 47% of surveyed caregiving relatives report that they have been affected by psychological and/or physical violence or disease-related violent behaviour by the person in need of care.
- 45% of respondents report that they have been affected by psychological violence or disease-related violent behaviour by the person in need of care.
- 11% reported that they have experienced physical violence or disease-related violent behaviour by the person in need of care.

Figure 6 shows how often the respondents – according to what they reported – have been subjected to violence or disease-related violent behaviour by the person in need of care in the past six months. Behaviour attributed to psychological violence is depicted in light red, forms of physical violence in dark red. It confirms a finding from previous research: Physical violence is mentioned considerably less

In the past six months, did the person in need of care ...

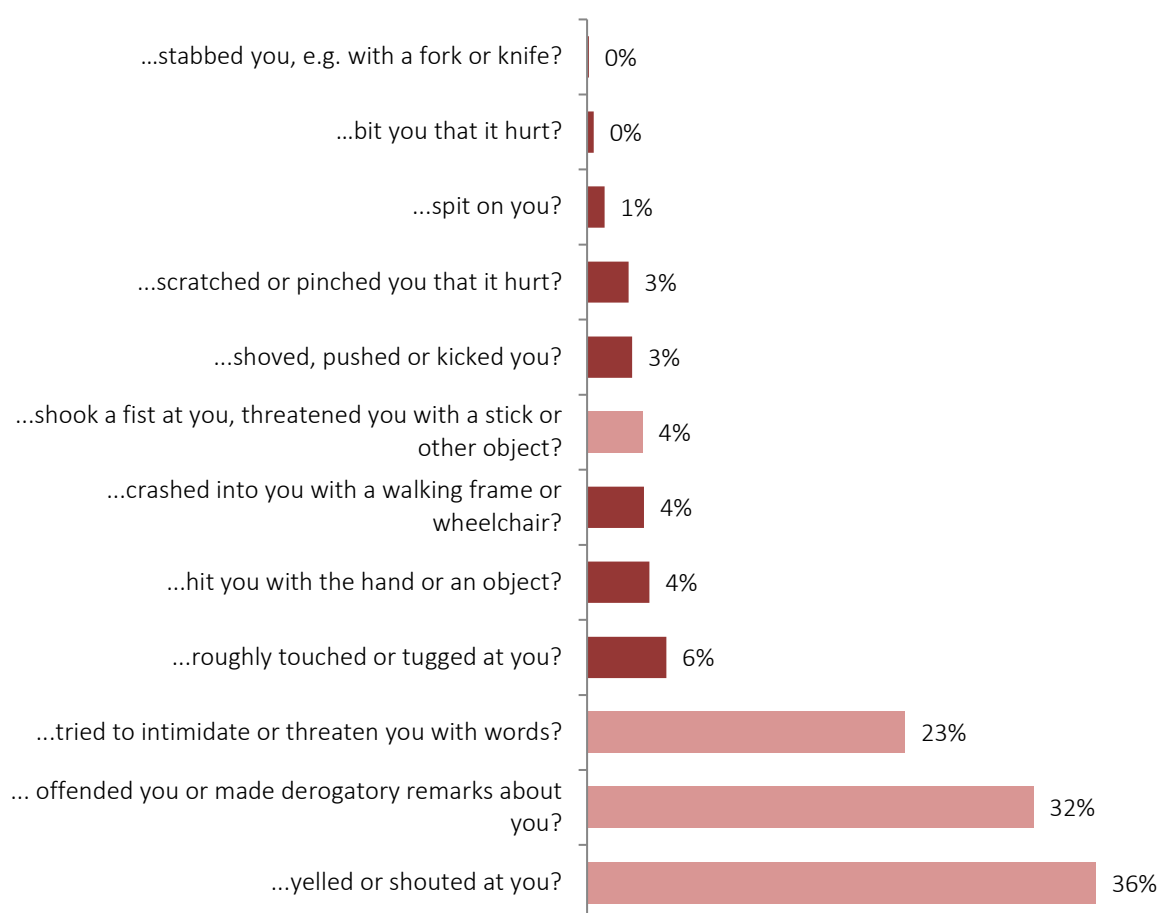


Figure 6: ZQP Survey Caregiving Relatives (n = 1,006). It presents the proportion of respondents who experienced a type of behaviour mentioned above by the person in need of care at least once within the past six months. Types of behaviour that are classified as psychological violence are displayed in light red and those that are classified as physical violence are displayed in dark red.

often than psychological violence. 23% of surveyed carers say that the person in need of care tried to intimidate or threaten them verbally.

In Figure 7, the individual behaviours are grouped into “psychological violence” and “physical violence”. The grey bars in the figure show how many of the respondents stated that the person in need of care acted against them in this way at least once during the past six months. Nearly half of the respondents state at least one incident that is considered psychological violence, over one tenth at least one form of physical violence. Looking at all manifestations together, we find that 47% of respondents state that they are affected by psychological and/or physical violence or the corresponding disease-related violent behaviour by the person in need of care. Relatives of people with dementia are more likely to be affected by psychological as well as physical forms of violence exerted by the person in need of care than other relatives.

Proportion of carers reporting disease-related violent behaviour by the person in need of care

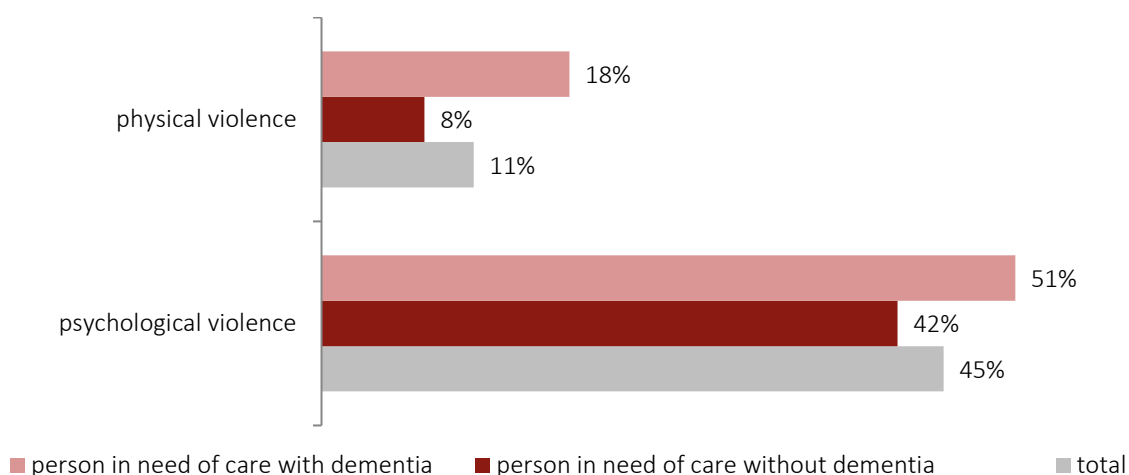


Figure 7: ZQP Survey Caregiving Relatives, n = 1,006 It presents the proportion of respondents who experienced a type of behaviour mentioned above by the person in need of care at least once within the past six months. The statements for the two forms of violence are summarized from answers given about concrete examples of how the people in need of care behaved (spitting, biting).

Carers who report that they have been subjected to violence or disease-related violent behaviour by the person in need of care are more likely to be depressed: 44% of respondents reporting such psychological violence agree with the statement, “I often feel depressed”; for those who did not experience such violence in the past six months, only 30% agree with this statement. Similar differences exist when it comes to physical violence: 44% of those affected report that they are depressed; for the non-affected group these are 35%.

4. Mistreatment by the caregiving relative of the person in need of care – proportionate values

- 40% of the surveyed caregiving relatives state that they showed at least one form of behaviour that can be classified as elder mistreatment.
- The respondents more often state that they have been psychologically abusive (32%) than they report physical abuse (12%), neglect (11%), or freedom-restraining measures (6%).
- 24% of respondents say that they shouted at or bullied the person in need of care, 16% say that they intimidated or threatened that person.

The surveyed relatives were not only asked to provide information on violence or disease-related violent behaviour that the people in need of care used against them, but also if they have mistreated the person in need of care. Although the specific forms of behaviour are similar on both sides in many cases, the results are not comparable in a meaningful way. First of all, socially desirable responses are more likely when the respondents report their own actions, and secondly the questions were formulated in such a way that they also asked for unintentional behaviour by the people in need of care but not for such behaviour by carers.

40% of respondents state that they deliberately engaged at least once in a form of behaviour in the past six months which is classified as elder mistreatment here. Figure 8 shows the summarized results on the four forms of mistreatment: “physical abuse”, “psychological abuse”, “freedom-restraining measures”, and “neglect”. It shows the proportion of respondents who answered that they showed at least one form of such behaviour at least once during the past six months. Freedom-restraining measures were stated by the respondents the least and psychological abuse the most often.

Proportion of respondents who report mistreatment of the person in need of care

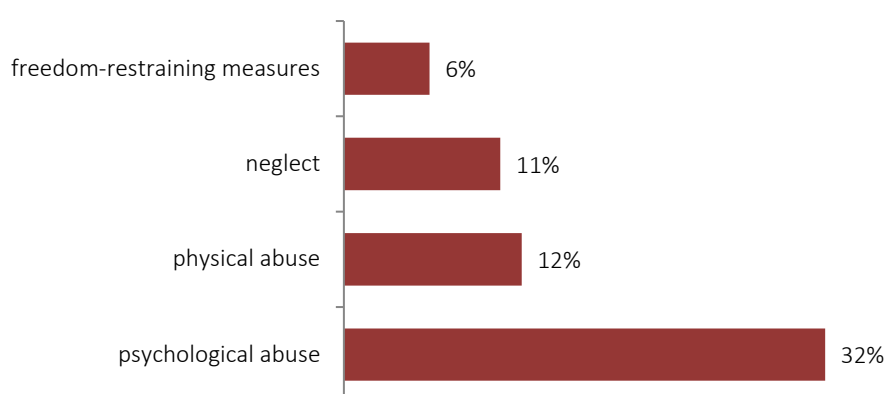


Figure 8: ZQP Survey Caregiving Relatives, n = 1,006. It presents the proportion of respondents who stated that they used a form of the mentioned behaviour at least once against the person in need of care in the past six months. Statements regarding the four forms of mistreatment are summarized from the answers to the questions that referred to concrete behaviour patterns (e.g. spitting, biting).

Figure 9 shows how often the respondents – according to their own statements – treated the person in need of care in a way that can be considered psychological or physical abuse. Once again, as in pre-

vious research, psychological abuse is reported more frequently than physical abuse. It is noticeable here as well how often intimidation and harassment are reported.

In the past six months, did you act in the following ways towards the person in need of care ...

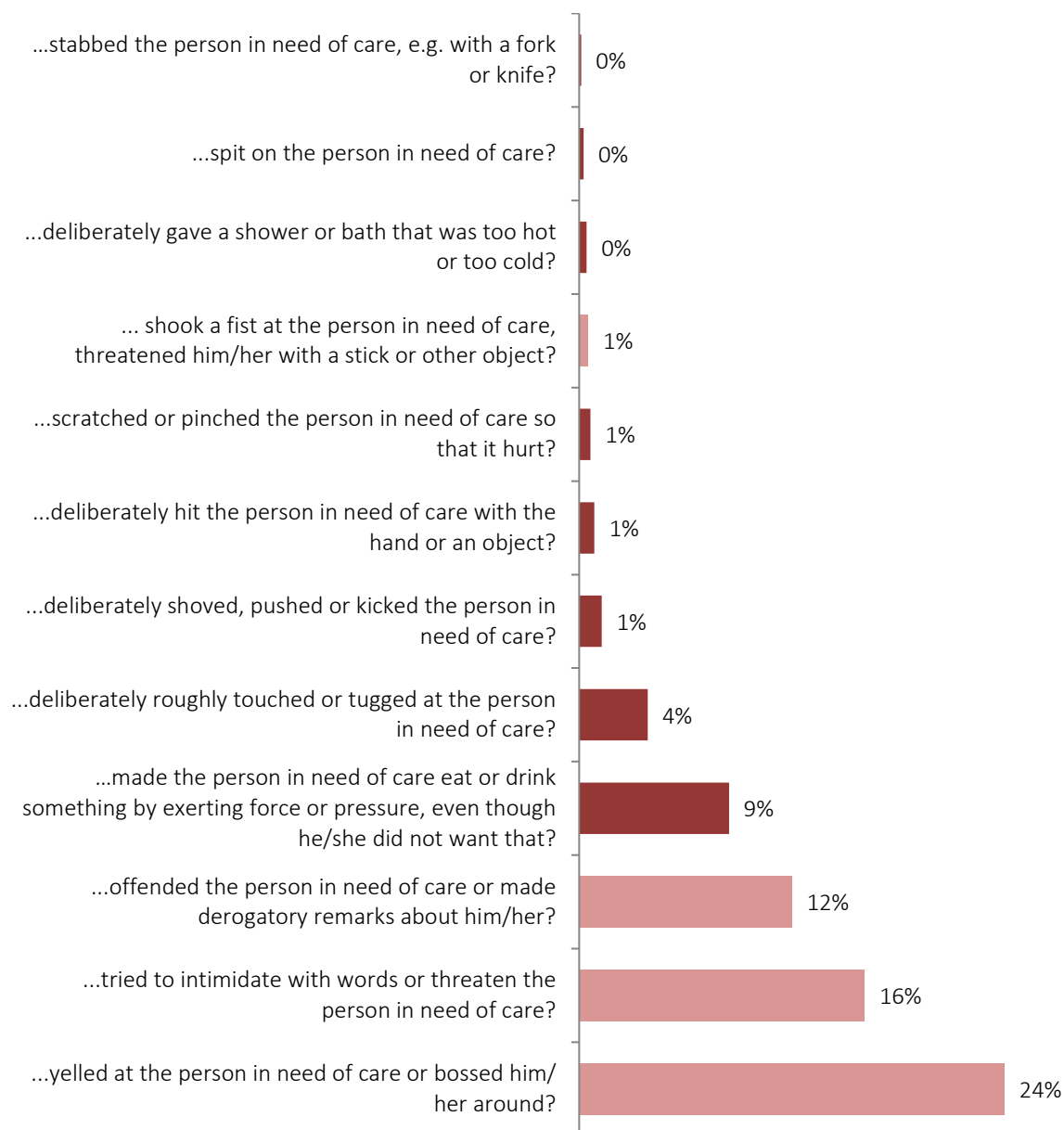


Figure 9: ZQP Survey Caregiving Relatives (n = 1,006). It presents the proportion of respondents who stated that they behaved in this way towards the person in need of care at least once within the past six months.

Figure 10 shows behaviour related to physical freedom-restraining measures. Figure 11 presents the behaviour that can be considered neglect.

In the past six months, did you...

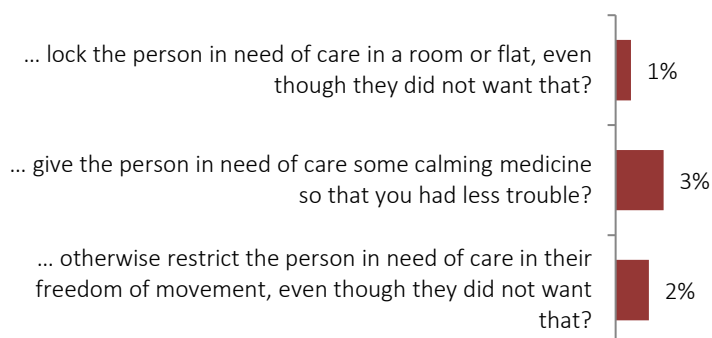


Figure 10: ZQP Survey Caregiving Relatives (n = 1,006). It presents the proportion of respondents who stated that they behaved in this way towards the person in need of care at least once within the past six months.

Compared to psychological abuse, restraining measures are rarely reported. It is striking that restraining a person with drugs is more common than locking them up.

This also applies to deliberate neglect which is significantly less often reported than psychological abuse. Deliberate neglect regarding oral and personal hygiene is reported relatively often.

In the past six months, did you ...

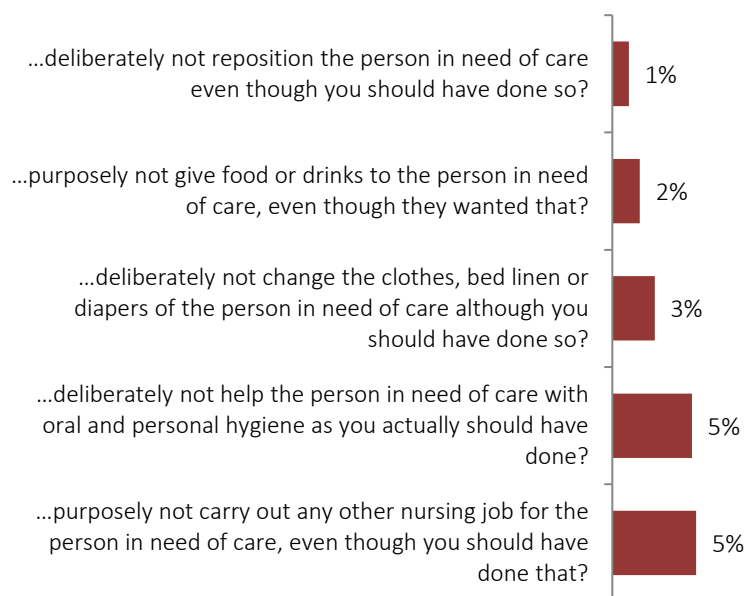


Figure 11: ZQP Survey Caregiving Relatives (n = 1,006). It presents the proportion of respondents who stated that they behaved in this way towards the person in need of care at least once within the past six months.

5. Mistreatment of caregiving relatives against people in need of care – risk factors

- The surveyed relatives who care for a person living with dementia state more often that they have been mistreating.
- The respondents who feel that they do not have enough time for themselves or for others state more often that they have mistreated the person in need of care. There is, however, no correlation between the carer's professional situation and mistreatment.
- Surveyed spouses and partners most often indicate that they were psychologically abusive. Regarding other forms of mistreatment, there are no significant differences between types of relationships.

It is also important to examine risk factors for elder mistreatment – i.e. those circumstances that are statistically related to the mistreatment by carers. As in the introduction, these are arranged according to the characteristics of the person requiring care, the carer and the relationship.

Characteristics of the person in need of care

- *Aggressive behaviour:* People in need of care who, according to their relatives, use psychological violence themselves are more often also affected by psychological abuse than those about whom relatives do not report such behaviour. In the first group these are 52% and in the second group 16%. It is less obvious that psychological abuse has a similar (although less significant) connection to physical abuse (18% vs. 7%), freedom-restraining measures (7% vs. 5%), and neglect (16% vs. 6%).
The data show that those people in need of care are more likely to be mistreated who, according to the respondents, use physical violence themselves. They are at greater risk of being affected by psychological abuse (59% vs. 29%). This is similar when it comes to physical abuse (41% vs. 8%), freedom-restraining measures (16% vs. 4%), and neglect (27 vs. 8%).
- *Dementia:* According to this study, people in need of care living with dementia are more likely to be subjected to mistreatment than those without dementia. This holds for psychological abuse (used against those with dementia: 38%, those without dementia: 30%), physical abuse (19% vs. 8%), freedom-restraining measures (12% vs. 2%), and neglect (15% vs. 8%).
- *Care grade:* The results of the survey show that people with higher grades of care are more likely to be subjected to mistreatment – although there is no linear correlation. The differences are particularly pronounced between care grades 4 and 5 on the one hand and care grades 1 to 3 on the other. Thus, 38% of people with a higher grade of care are affected by psychological abuse compared to 31% in the group of people with grades 1 to 3. The differences are more distinct when it comes to physical abuse (24% vs. 9%), freedom-restraining measures (12% vs. 4%), and neglect (18% vs. 9%).
- *Gender:* Based on the answers given by respondents, there are no noteworthy differences between men and women in need of care with regard to mistreatment.

Characteristics of the carer

- Aggressive thoughts and feelings:** In order to test whether aggressive thoughts and feelings of the carers are related to their behaviour towards the person in need of care, the answers to the six questions related to negative/aggressive thoughts and feelings were summarized in such a way as to create two groups of respondents of about the same size. One group is characterized by less intense and the other by intense negative thoughts and feelings (for details, see the methodological appendix). As would be expected, more carers in the latter group report psychological abuse of the person in need of care (54%) than in the first group (15%). The results are similar for physical abuse (20% vs. 6%), freedom-restraining measures (9% vs. 3%), and neglect (19% vs. 4%).
- Time pressure:** The professional situation of the surveyed caregiving relatives shows no systematic correlation with their statements made about mistreating. One might expect that respondents who spend more time supporting the person in need of care mistreat this person more often. This is confirmed in figure 12 although the connection is not monotonous in most cases. People who reported looking after the person in need of care for more than six hours every day are more likely to report mistreatment. When interpreting the answers it has to be taken into account, however, that the group only includes 75 people.

How much time do you usually spend on looking after the person in need of care in a typical week?

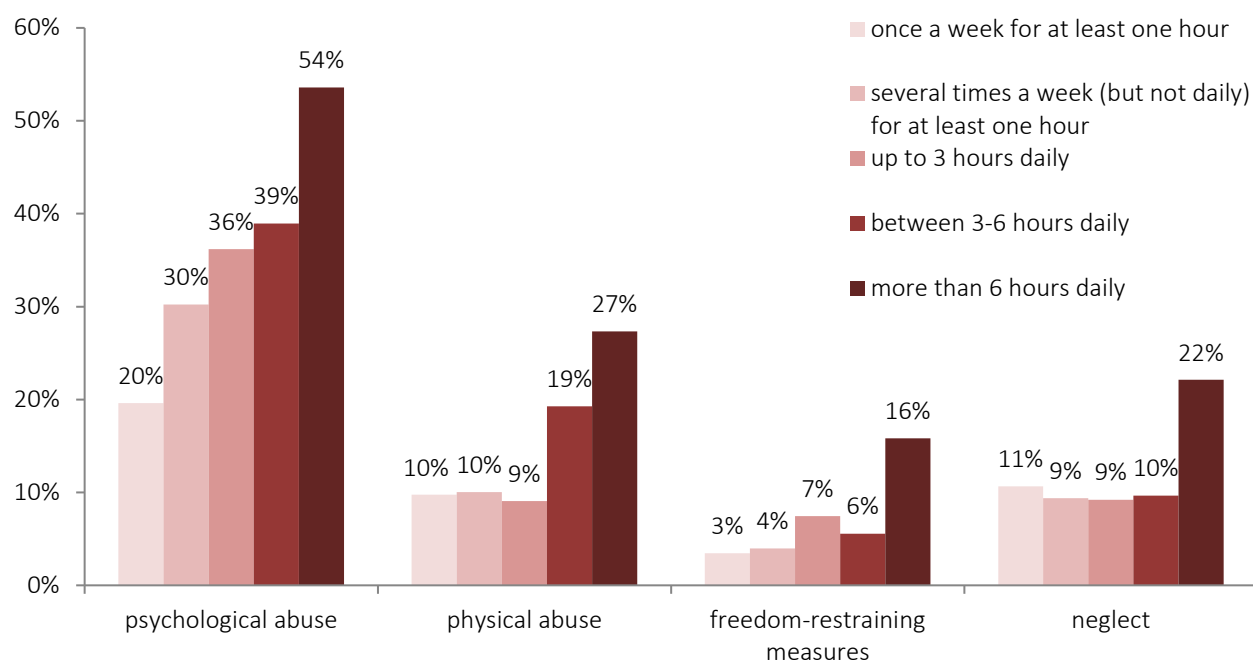


Figure 12: ZQP Survey Caregiving Relatives (n = 1.006). It presents the proportion of respondents who stated that they have mistreated the person in need of care in the way mentioned above at least once in the past six months. The statements regarding the two forms of mistreatment are summarized from the answers to the questions that referred to concrete behaviour patterns (e.g. spitting, biting).

The results are clearer when it comes to the subjectively reported lack of time. The answers to the two questions about lack of time (“too little time for oneself or for others”) show a high statistical correlation. They are combined and again two groups are formed, which are approximately the same size (for details, see methodological appendix). It shows the expected relationship: Respondents with a pronounced subjective lack of time (“too little time for oneself or for others”) report psychological abuse against those in need of care (40%) more often than those with a less pronounced lack of time (26%). The same holds for physical abuse (16% vs. 8%), restraining measures (8% vs. 3%) and neglect (13% vs. 8%).

- *Physical problems:* Respondents who agree with the statement “I often have physical problems” state that they are more often psychologically abusive against the person they care for than those respondents who disagree (38% vs. 27%). For the other forms of mistreatment, differences point in the same direction, but they are not as pronounced: physical abuse 10% vs. 14%, freedom-restraining measures 6% vs. 5% and neglect 13 vs. 8%.
- *Nursing experience:* It can be assumed that people with experience in professional care and nursing are better able to care for a relative and therefore mistreat less. The study, however, does not confirm this – there are no major or systematic differences.
- *Mental health:* Three variables were used to measure symptoms typical of depression: melancholy, lethargy and anxiety. Empirically, the survey data show a close correlation between the three variables. Therefore, they are summarized as well (for details, see the methodological appendix). The findings indicate that respondents with more pronounced symptoms are more likely to abuse psychologically (39%) than those with less severe symptoms (27%). This pattern repeats in physical abuse (15% vs. 10%), restraining measures (8% vs. 4%) and neglect (14% vs. 8%).
- *Anger and irritation:* The respondents who agree with the statement that they often feel angry or irritated are also more likely to report psychological abuse against those who need care (48%) than respondents who disagree (26%). This pattern is also visible for physical abuse (14% vs. 11%), restraining measures (7% vs. 5%) and neglect (15% vs. 9%) – though it should be noted that the differences are not large, especially for restraining measures.
- *Gender:* There are no noteworthy differences in statements regarding mistreatment between the surveyed male and female caregiving relatives.

Characteristics of the relationship

- *Relationship:* The surveyed carers commit psychological abuse significantly more often against the person in need of care when it is their spouse or partner (46%) than when it is a parent (in-law) (33%). Psychological abuse in other constellations is even significantly rarer (18%). This pattern cannot be observed, however, for other forms of mistreatment – there are hardly any noticeable differences.
- *Social isolation:* Using various survey results, it was examined whether there is a connection between mistreatment and the degree of social isolation of the care relationship. This is confirmed for psychological abuse: 35% of respondents, who are the only caregiving person in the immediate environment of the person in need of care, report that they have been psychologically abusive; in the other group these are 31%. The surveyed carers reportedly were psychologically abusive in the past six months against 34% of people in need of care who are not regularly cared for by an outpatient service; of those who are regularly cared for by an outpatient service these were 31%. Looking at the two aspects together creates a clearer picture: In 39% of cases where neither an outpa-

tient service nor any other person in the immediate environment looks after the person in need of care, respondents report actions of psychological abuse; in the other group 31%. 45% of respondents living alone with the person in need of care state that they have been psychologically abusive; the corresponding values are 38% if at least one other person lives in the household and 28% if the person in need of care does not live with the respondent. Finally, one can look at care relationships in which the respondent is the only person living with the person in need of care and nobody else looks after that person. 46% of these respondents report that they have been psychologically abusive; for all others, 31% reported such mistreatment. These findings only hold for psychological abuse: no clear patterns can be identified for the other three types of mistreatment.

When interpreting this study, it has to be recalled that it only records mistreatment against the person in need of care when used by the respondent. Our figures show, for example, that those in need of care who are not supported by an outpatient service are more likely to be subjected to psychological abuse by the respondent. It is, however, possible that people who are cared for by an outpatient service generally experience higher levels of psychological abuse – for example, by the staff of the outpatient service. Our study does not address this question.

Methodological Appendix:

Composition of the combined variables regarding negative/aggressive thoughts and feelings, lack of time and depressive symptoms

Negative/aggressive thoughts and feelings

This variable was established in several steps:

(i) Conversion of the six variables on negative feelings into metric variables. The conversion values were taken from Rohrmann (1978); for this purpose, the arithmetic mean weighted by the respective sample size was calculated from the three samples. This resulted in the conversion values (1 = 1.04918033), (2 = 2.83196721), (3 = 4.54754098), (4 = 7.13770492) and (missing value = missing value). A principal component analysis of the resulting variables results in a single factor solution according to the Kaiser-Guttman criterion. The component explains 48% of the variance. All variables load above 0.6 on this component.

(ii) From the six metric variables, a new variable was calculated as the arithmetic mean value; inclusion criterion: valid values on at least 4 of the output variables ($n = 1.002$).

(iii) The median of this variable was calculated. A median split was made. The resulting dummy variable has the values “negative thoughts/feelings low” (56% of respondents with valid values) and “negative thoughts/feelings high” (44%). The groups are not the same size due to the clustering of the cases at the median (1.643443).

Lack of time

The variables have a high correlation ($r = 0.75$) and similar mean values and standard deviations (too little time for myself: $m = 2.4$, $sd = 0.97$; too little time for others: $m = 2.5$, $sd = 0.93$).

The arithmetic mean of the variables was calculated; inclusion criterion: valid values on both variables ($n = 1.001$).

The median of this variable was calculated. A median split was made. The resulting variable has the values “no significant lack of time” (53% of respondents with valid values) and “significant lack of time” (47%). The groups are not the same size due to the clustering of variables at the median (2.5).

Depressive Symptoms

The principal component analysis of this variable results in a single factor solution according to the Kaiser-Guttman criterion. The component explains 75% of the variance. All variables load above 0.8 of this component.

The median of this variable was calculated. A median split was made. First, the average was calculated for respondents who have valid values on all output variables ($n = 993$). Then, the median of this variable was calculated. Due to the fact that 18% of cases fall on the median (3.0), the groups are of a very different size. The cases of doubt were attributed to the group “no strong symptoms”, which is therefore significantly larger (59%) than the group “strong symptoms” (41%).

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