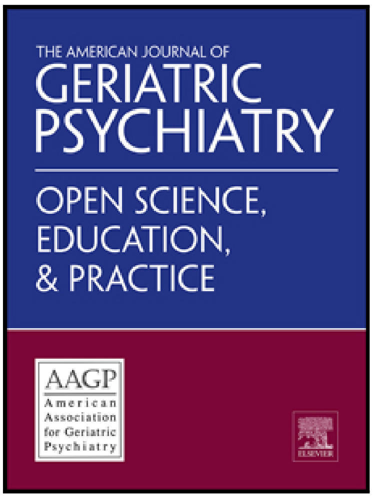

Exploring the sense of dignity among informal caregivers of individuals with dementia in a psychiatric hospital: a qualitative study

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Highlights

1) ***What is the primary question addressed by this study?***
How can the sense of dignity among informal caregivers of persons with dementia be described during the person with dementia’s treatment in a psychiatric hospital and by whom as well as which factors is it enhanced or violated?
2) ***What is the main finding of this study?***
This qualitative research identifies four relevant sources (1. the informal caregiver whose dignity is being affected, 2. the person with dementia, 3. the caregiver’s social environment and 4. supporting facilities, both while in hospital and in the community), who can either reinforce or violate the caregivers’ sense of dignity. Thereby, we specifically identified 21 contributing factors enhancing or violating the sense of dignity for each of the four sources, which all affected the caregivers’ sense of dignity in varying extends.
3) ***What is the meaning of the finding?***
The results of this dignity-research offer novel and specific insights on how informal caregivers in a psychiatric hospital are experiencing dignity, show that compared to other evidence, the caregivers’ dignity seems not to be violated by a dependence on supporting facilities and underline the main influence of the person with dementia on the participants’ sense of dignity.

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Exploring the sense of dignity among informal caregivers of individuals with dementia in a psychiatric hospital: a qualitative study

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Declarations:

Informed consent was obtained from all individual participants included in the study. The study protocol was designed in accordance with the Declaration of Helsinki and was approved by the joint Ethics Committee of the medical faculty at the Ludwig-Maximilians-University (LMU) Munich and the Medical Faculty of the University Augsburg (Reference Number: 22-0430).

Keywords: informal caregivers – relatives of persons with dementia – dignity – psychiatric hospital

Abstract:

Objective: Informal caregivers of hospitalized persons with dementia in psychiatric hospitals can be considered a vulnerable population. Alongside psychological burden, potential violations of their sense of dignity (SoD) may arise, even though the inviolability of human dignity is enshrined in German Basic Law. This research aims to explore the individual SoD of informal caregivers by specifically defining how and by whom their sense of dignity is enhanced or violated.

Design: The collected data were analyzed using qualitative content analysis.

Setting: Informal caregivers were recruited for a qualitative study on their SoD in a German psychiatric hospital.

Participants: 20 individual, semi-structured interviews with informal caregivers were conducted.

Results: When describing the SoD of informal caregivers, there were the following four relevant sources: 1. the informal caregiver whose dignity is being affected, 2. the person with dementia, 3. the caregiver's social environment and 4. supporting facilities, both while in hospital and in the community. Each source included SoD-contributing factors that can either reinforce or violate the SoD. In total, 21 contributing factors were extracted and evaluated (11 reinforcing and 10 violating a caregiver's sense of dignity).

Conclusions: The caregivers themselves and primarily the relationship between the caregiver and the person with dementia appear to have the most significant impact on their sense of dignity. Nevertheless, healthcare institutions play a crucial role which can either reinforce or violate the caregivers' sense of dignity. Therefore, psychiatric hospitals need to train the staff accordingly to support and preserve dignity in psychiatric hospitals.

Introduction:

The prevalence of adults aged over 67 years has been rising over the past decades in western countries[1]. As a result, the likelihood of being diagnosed with a neurodegenerative illness is steadily increasing, leading to a higher number of persons with dementia in (psychiatric) hospitals[2–5]. Nearly every person with dementia in psychiatric hospitals has relatives, who mostly act as their informal caregivers (further mentioned as "caregiver")[6]. Informal caregivers in general but especially of a hospitalized person with dementia show susceptibility for depressive symptoms and burden, mainly due to the acute stress response triggered by the hospitalization of a close relative[7]. These burdens of caregivers can also be caused by a variety of factors related to the person with dementia or the characteristics of the caregiver, as evidence shows, that informal caring for a person with dementia is more challenging than for persons with other diseases [8,9]. Thus, being an informal caregiver can lead to reduced quality of life, anxiety, and burn-out[10–12]. Evidence also suggests that both persons with dementia and caregivers face a high risk of dignity violations[13–16]. However, research exploring dignity among informal caregivers in a psychiatric hospital remains limited.

Now, when evaluating the concept of dignity, one needs to be aware of the first article of the Basic Law for the Federal Republic of Germany, which reads as follows: "(1) Human dignity shall be inviolable. To respect and protect it shall be the duty of all state authority"[17]. The constitution was based on the definition of dignity by Immanuel Kant calling it an *inner value* [18]. Furthermore, dignity always goes along with respect for each other as well as self-respect[19]. With regard to older adults, Jacelon et al. define dignity as reciprocal as it is influenced by the self and by others. Thereby, the treatment received from others (persons or institutions) has a major influence on the perceived dignity in geriatric settings[20]. However, dignity is characterized by high subjectivity and thus can be defined individually by each human[21]. To make the concept of dignity more accessible, the evolution of the actual sense of dignity (SoD) can be explored independently of its subjectivity.

Based on this, when looking at how one's sense of dignity changes, the treatment received from a counterpart is crucial, as Sabine Pleschberger defines an intrapersonal and a relational SoD[22,23]. Intrapersonal implies the dignity which is granted to every person solely by virtue of their existence[23]. Relational dignity develops in social interactions with human or institutional sources[20,23]. Therefore, there are different sources that can actively enhance or violate the individual's relational SoD[23]. Considering inherent dignity, every individual is also a source for how their own dignity is experienced[23].

Finally, when considering the first article of the German constitution (but also, e.g., the tenth article of the Constitutional Law of South Africa) and the aforementioned circumstances of informal caregivers, one confronts the question of how the health system and psychiatric hospitals in particular can contribute to a protection of their SoD[17,24]. In this context this qualitative research aims to describe sources and contributing factors to an enhanced or violated SoD among informal caregivers in a psychiatric hospital.

Methods:

Between August 2nd, 2022, and May 5th, 2023, 216 informal caregivers in three geriatric psychiatry wards of a Bavarian hospital (for a detailed description of the institution please refer to supplement

1) were initially invited (by phone or in person during visiting hours) to participate in a qualitative study. If interest was expressed, the informal caregivers were asked if they are informal caregivers of a person with dementia or informal caregivers of patients with other psychiatric diseases. Forty-four informal caregivers were caregivers of a person with dementia and agreed to participate. Participants were then scheduled while ensuring adequate heterogeneity regarding age, gender, and relationship status. The final N=20 came about after informal caregivers had withdrawn their consent, had not been available for re-contact or the treated person had not been diagnosed with dementia after all. The informed consent contained a description of the research project and, in detail, the background of the study, potential risks, and explanation of anonymized data processing. The interviewees did not receive any compensation for their participation. Exclusion criteria were not being an caregiver of a person with dementia, inability to consent due to a severe illness, or holding legal guardianship. The procedures were approved by the Ethics Committee of the Medical faculty at the Ludwig-Maximilians University Munich and the Medical Faculty of the University Augsburg (Ref. 22-0430).

Between January 26th and June 12th, 2023, a research assistant with experience in qualitative research (EW) performed a total of 20 semi-structured individual interviews (N=20). Basic socio-demographic data were collected (Table 1). For a complete overview of the content and theoretical framework of the interview guide, please refer to Table 2. During the interviews, the term "dignity" was not explicitly mentioned in order to minimize bias. Data were concurrently analyzed in a preliminary manner after each interview, and the recruitment process stopped when theoretical saturation was reached[25]. The interviews lasted 31.27 minutes (±8.13) on average. By summarizing the key contents following each interview, member checking was performed with the participants[26]. All participants received the transcript of the interview if they wished and were able to make requests for corrections. The transcripts were then analyzed following the rules for deductive/inductive qualitative structuring content analysis, according to Kuckartz[27]. First, based on the research question, the goal of the categories as well as the degree and level of abstraction of the categories were defined. Then, the text passages were allocated to a deductive code system. "Deductive" here refers to predefined codes based on existing SoD-related theories, which were used to create the initial category system. The main codes initially were based on Harvey Chochinov`s dignity theory, while also considering the approach by Sabine Pleschberger [namely: Illness-related concerns that influence dignity (both inherent and relational dignity), dignity -conserving repertoire (primary inherent dignity) as well as social dignity inventory (relational dignity)]. In a structured and standardized procedure, the entire transcripts were then analyzed by assigning all relevant content to newly created codes. These newly constructed codes were developed "inductively". Results evolved from multiple ("inductive") analysis and rearranging loops through which a novel, complete and holistic code system and theory was adapted specifically to understand the caregivers' SoD[26,2726]. Finally, code systems were designed with a hierarchical structure including main codes, subcodes, and sublevels of subcodes[27]. Four novel main codes were defined as **sources** who can affect the SoD. There is (1) **the informal caregiver whose dignity is being affected**, as well as three counterparts of the caregiver who have an influence on the study population:(2) **the person with dementia**, (3) **the caregiver's social environment**, and (4) **supporting facilities, both while in hospital and in the community**. In a second step, as subcodes to each main code, all sources were divided into the two segments, either **reinforcing** or **violating** the SoD. We observed 21 specific contributing factors to the SoD (11 SoD -reinforcing and 10 -violating). To view the coding system at a glance, please refer to Figure 1. Analyses were conducted using the software MAXQDA Plus (release 2020.4.2). Following the procedure of "intercoder agreement" , two members of the research team (EW and TH) independently coded all transcripts based on the principle of consensual coding[26,27].

Results:

All defined sources were mentioned in the 20 interviews, as summarized in Table 3, in Figures 2 and 3. An illustration of how the defined sources interact within the caregivers' SoD and the frequency with which they were mentioned can be found in Figure 4. We described all sources as follows:

1) The informal caregiver whose dignity is being affected:

"And I'm like, we stumble, but then it's not about staying down; you have to get up; you have to keep going. So, you have to make the best of every situation."

(Example "Resilience" from caregiver *01)*

This domain referred to the intrapersonal SoD. It describes the caregiver as an individual who could affect their own SoD, independently of any interactions with other relational sources (249 of 1005 code counts / 24.78%). The caregivers were able to reinforce their own SoD by the following three SoD-contributing factors: a) **self-care**, b) **resilience**, and c) **role continuity**. **Self-care** was mentioned by all caregivers and was described as a foundation of a positive SoD. In addition to dignity-preserving actions such as physical exercise or wellness, caregivers took proactive steps to seek support. Also, the participants described "me-time" and thereby relaxing activities completely on their own (e.g. watching soccer on TV alone) as well as enough privacy as mandatory. Another essential SoD-contributing factor reported by caregivers was **resilience**. Caregivers felt capable of managing the challenge of serving as the informal caregiver and reported feeling proud of their achievements in their new role. Here, despite the caregiving-duties, the caregivers did not describe an increase of health-damaging habits like smoking or bad nutrition. The SoD-contributing factor of

role continuity was mentioned least frequently and was defined by the caregivers as staying the same independent person with interests of their own and resources despite being the informal caregiver. When role continuity was present, participants were not solely feeling as an informal caregiver but also, e.g. still as a mother, as a father or as a professional in their job life.

"My wife and I haven't been on vacation for six years."
(Example "missing self-care" from caregiver *11)*

Caregivers also could diminish their own SoD, although these SoD-contributing factors were less frequently mentioned. The SoD was perceived to be violated by a) **missing self-care** and b) a **lack of "manageability"**. **Missing self-care** was associated with the inability to set boundaries and with the development of poor habits. Participants further mentioned that missing self-care led to a feeling of inherent pressure and the inability to relax. A **lack of "manageability"** referred to having problems in (emotionally) dealing with dementia and when feeling overwhelmed[28]. This SoD-contributing factor partially led to denying the situation and to withdrawing into oneself.

2) The person with dementia:

"And then there is her sense of humor. She always used to and still does tell jokes. Those are the moments you cherish - when you can still laugh together."
(Example "Valuable interactions with the person with dementia*" from* caregiver *01)*

Considering the frequency of specific codes, it appears that the person with dementia had the most influence on the caregiver's experience of dignity (442 of 1005 code counts / 43.98%). Person with dementia -related SoD-contributing factors were those that derived from the person with dementia as a person and/or were related to the person's illness itself. The person with dementia could reinforce or violate the caregivers´ SoD. In engaging with the person with dementia, the caregiver mentioned the SoD-contributing factors a) **valuable interactions with the person with dementia**, b) **hopes and perspectives**, and c) **psychoeducation** as SoD-reinforcing. **Valuable interactions with the person with dementia** were the reinforcing SoD-contributing factor that was mentioned the most by caregivers. Examples included lasting mutual respect or quality time spent together (e.g. walks in nature or laughing together). Some caregivers even described the development a closer relationship with the loved one, despite or maybe even because of the dementia diagnosis. Another important dignity-preserving SoD-contributing factor regarding the person with dementia was **hopes and perspectives**, which implied that the caregivers still had hopes for their own as well as for their loved one's future. Also, participants were optimistic that the treatment of the person with dementia in a psychiatric hospital might lead to symptomatic improvement, leading to things getting "back to normal". Moreover, several interviews illustrated **psychoeducation** as a fundamental stress-reducing SoD-contributing factor and an enhancement to the caregiver's SoD. Caregivers felt that they could handle their role as informal caregivers better due to understanding the diagnosis. Psychoeducation was defined as professional knowledge transfer mainly about the dementia diagnosis itself but also options of professional and structural support. Inter alia, knowledge about care level resources and applications, the power of attorney, and resilience-enhancing factors was imparted.

"I really felt like I didn't like my mother anymore. Yes, I literally hated her."

(Example "Symptom-related burdens" from caregiver *19)*

On the other hand, caregivers reported felt that the person with dementia could also violate their dignity due to a) **symptom-related burdens**, b) **discontinuity in social roles**, and c) **concerns regarding adequate care**. In the most frequently mentioned contributing factor, caregivers reported **symptom-related burdens**, mainly behavioral and psychological symptoms of the dementia disease. For example, a caregiver's sense of dignity was violated by the person with dementia using hurtful language, by aggressive behavior, and by changes in the personality of the person with dementia and in the relationship to the loved one. Also, concerns about possible future emergencies or rapidly progressing symptoms were frequently reported. Additionally, the caregivers considered **social role changes** to be a SoD-violating contributing factor (e.g. feeling more like a formal caregiver than a daughter; less time for work or their own nuclear family). The person with dementia for example, now needed help, while the caregiver needed to take care of a person who in his/her prior family role used to take care of him/her. Furthermore, caregivers were affected by the need to make major decisions for someone else as well as feeling responsible for a loved one and the changes in their own social roles and identity. Mentioned with a similar frequency, managing adequate care and treatment (**concerns regarding adequate care**) for the person with dementia played an important role for many caregivers. Noted especially was the feeling of guilt for putting a relative in a nursing home, described as SoD-violating. Because the person with dementia was treated only temporally in a psychiatric hospital, the search for a hard- to- find follow-up care, such as a nursing home or outpatient care, was omnipresent for the caregiver and affected their sense of dignity.

3) The caregiver's social environment:

"My family is my rock."

(Example "family as resource" from caregiver *16)*

Aside from the individual with dementia, the social environment impacted a minority of caregivers (93 of 1005 code counts / 9.25%). As reinforcing SoD-contributing factors, the caregivers mentioned

a) **family as resource** and b) **the support from friends** as fundamental resources. With 80% and 56 over-all mentions, a majority of the respective interviewees underlined the importance of **family** in preserving their SoD. Mental support as well as support with the informal care work provided by other family members had a positive and relieving effect. Similarly, **friends** of caregivers served as a SoD-enhancing contributing factor (60% and 21 over all mentions), whether as a resource for supportive conversations or assistance with informal care work. The participants were thankful for exchange with peers having similar experiences and occasionally already were participating in group interventions for caregivers where they enjoyed group cohesion, acceptance, and support.

"Then I literally had to hear from my mother's siblings what kind of person I am and how I can have the audacity to go on vacation."
(Example "Negative external judgement" from caregiver *22)*

With 16 overall mentions, only a minority reported that the social environment was a contributing factor potentially damaging their dignity. Thus, the following SoD-contributing factors were mentioned rather infrequently: A) **negative external judgement** and b) **poor support in care work**. Negative external judgement specifically led to a violation of the SoD when it came from family or society. The caregiver felt as if they were doing the best they could, but still receiving criticism as microaggression (defined by Charles V. Willie et al.) from their private surroundings[29]. In addition, the caregivers considered the feeling of being the sole person responsible for all aspects of care (**poor support in care work**) to be a contributing factor violating the SoD, as they felt left alone by their peers. Especially, a sibling's feeling of doing all the informal care work for the parent alone led to a violation of the sense of dignity.

4) Supporting facilities, both while in hospital and in the community:

"Since I've been able to give away responsibility, I can sleep. "
(Example "Giving away responsibility" from caregiver *21)*

Supporting facilities were considered very helpful in enhancing the caregiver's sense of dignity (221 of 1005 code counts / 21.99%). As the setting of the study was a psychiatric hospital, this source mainly refers to the hospital but also includes nursing facilities or advisory centers with which the caregiver interacted. Examples included a) **support with care work**, b) **positive dependence**, and c) **giving away responsibility**. Particularly **support with care work** was most frequently reported. Caregivers described that their SoD was especially reinforced by a variety of formal care work support by the staff of the psychiatric hospital but also (before the hospitalization) by a nursing home or outpatient care services. Caregivers emphasized the importance of formal care work for the preservation of their SoD, leading to an endorsement of **positive dependence**. This factor implies that the caregiver's awareness of a dependency on supporting facilities did not lead to distress. Instead, the acceptance of help from supporting facilities was perceived as a relief from being the only one responsible for care. Participants were grateful for every help they could get and willing to accept it, regardless of dependency dynamics. Finally, some participants mentioned that their SoD was reinforced due to being able to **give away responsibility** to the psychiatric hospital. Caregivers described the moment of hospitalization as relieving, since they realized that they were no longer primarily responsible for their loved one. They felt less pressure and distress and thereby developed a sense of gratitude for the support of the staff.

> *"At first, from the medical side, there was this feeling of being left in the dark, because we didn't get any information - or the kind of information that was just incomprehensible. With the initial diagnosis, well, we were completely left on our own as family members. They just said, 'She has dementia.' No one took us by the hand, no one explained what we could do."*
> *(Example* "*Deficit in communication*" *from* caregiver *05)*

However, the caregivers also reported that supporting facilities could violate their sense of dignity. The three SoD-contributing factors mentioned were a) **administrative burdens**, b) **feeling left alone by the help system**, and c) a **deficit in communication**. Administrative burdens violated the caregiver experienced SoD due to the distress of being held responsible for care work support. The caregivers felt as if the overload of bureaucracy precluded their ability to process grief occasioned by having a loved one with dementia. The caregivers' fight for help was exhausting, leading to a general dissatisfaction with the German health system. Financial burdens also played an important role, as the caregivers felt like the upcoming financing of care facilities might lead to their personal bankruptcy. Furthermore, some caregivers mentioned that they felt left alone by the help system. The caregivers' experienced violation of their SoD was specifically caused by the feeling of having to do everything alone, as caregivers described a major deficit in the sharing of helpful contacts, e.g. to counseling opportunities for informal caregivers. Also, there occasionally was a dissatisfaction with the formal care work of the hospital staff, especially when no improvement was evident in the symptoms of the person with dementia. A **deficit in communication** of person with dementia - related information also led to a violation of their SoD, as they felt, like shared-decision-making was not practiced adequately. Thereby, the caregivers were not included into the treatment process of their loved one enough and experienced distress due to not knowing what was going on with their close one. Also, for some caregivers, participants, the diagnosis of the person with dementia was not communicated by the staff or solely in a way they were not able to comprehend. These deficits in communication by the staff of the psychiatric hospital felt like being ignored.

Discussion:

Research on how health system users and providers experience dignity is much needed as dignity is often endangered when individuals are admitted to psychiatric hospitals[30,31]. Dignity is crucial for strengthening an individual's health and ensures dignified treatment for those affected by illness and their loved ones[32]. It is the duty of the health system to prevent dignity violations regarding informal caregivers, to maintain their mental and physical health, as they are backbone of caregiving in western societies.[33] This is essential because without informal caregiving, a major number of persons with dementia would not receive the care they need.[1,33]

Furthermore, especially considering the required inviolability of dignity in the German constitution, all must be done, to act accordingly and protect the dignity of every individuum including caregivers[34]. However, to this day, the SoD of RDPs has not yet received adequate research, although available literature allows to assume that (e.g. due to "microaggressions" by the staff) caregivers face a high risk of experiencing dignity violations in psychiatric hospitals[13–16]. As the dignity of aging adults, especially in the context of neurodegenerative disorders, is impacted by the way they are treated by others, these psychiatric hospitals can and should actively contribute to a positively experienced SoD[20].Thus, we have sought in this study to contribute to a protection of the *inner value* of caregiver by acquiring a more profound understanding of sources and contributing factors impacting the actual SoD among caregivers in a psychiatric hospital based on their subjective experiences[18]. All of the here described 11 contributing factors to reinforce the SoD should be seen as requirement to protect the dignity, while all of the 10 SoD-violating factors should be minimized or prevented in order to honor the inviolability of the caregiver's dignity and *inner value*[18].

Caregivers can be understood as the pivot of their own dignity, affecting it while also interacting with the other three relational sources. Contrary to findings of previous research on dignity in vulnerable settings, it was possible to identify novel SoD-contributing factors such as the caregiver's description of being dependent on help as not SoD-violating[35,36]. Considering the results of other dignity research, the interviewees usually describe a dependency on help as a clear contributing factor to violate their SoD, due to needing support in physical care[16,35]. The results of this study revealed that caregivers are aware of their dependence but did not experience this circumstance as burdensome. In fact, the opposite was the case, as all caregivers were grateful for every help they were able to get, legitimating formal care work but also mandating a mission for supporting facilities to provide caregivers the help they need.

Moreover, while former evidence already described being an caregiver as potentially dignity-violating, the results of this study suggest that the person with dementia can be defined as the source with the most impact on the caregivers' SoD, since this source was mentioned by far the most[8,37,38]. In the dual relationship between caregivers and their loved ones, the SoD can be violated as well as reinforced, highlighting the contrasting effects of this interpersonal relationship. The behavioral and psychological symptoms of a dementia disease cannot be underestimated when looking at the SoD of caregiver. Similarly, disruptive actions are also described as the main reason for caregiver burden and depression in the review of Cheng et al.[39]. Furthermore, the loss of the relationship to a loved companion or significant personality changes in the person with dementia can lead to grief, which needs to be addressed in interventions for caregivers[40].

Moreover, caregivers' resilience and being aware of the need for appropriate self- care is a pillar of their SoD, which has previously been acknowledged in theories[35,41,42]. Consequently, psychiatric supporting facilities such as hospitals, but also nursing homes, need to provide adequate dignity-enhancing interventions such as the already existing "Dignity Therapy" (DT)[43,44]. This intervention that was first developed for palliative care settings provides a low-threshold, individualized psychotherapeutic intervention designed to address psychosocial and existential distress and thereby protect the individual's SoD[44]. Thus, further research should aim to adapt DT to the special needs of caregivers in the context of dementia.

What is more, most caregivers' expressed feelings of reduced stress when understanding dementia. As a result, psychoeducation can be considered a contributing factor to reinforce the SoD, and the health system can play a very important role by offering psychoeducational interventions with the aim of reducing the caregivers' susceptibility to depression or anxiety[10,11,45,46]. It appears that professionally moderated support groups for caregivers have the ability to combine the communication of content regarding the self-care (e.g. "what can I do for myself? "), resilience (e.g. "what resources do I have?") as well as psychoeducation (e.g. "what does the diagnosis of my loved one mean?") to the caregivers. There is a large body of evidence with varying but effective concepts for such group interventions, always adding to the positive impact of group cohesion[45,47–52]. Thus, all settings working with informal caregivers of people with dementia should implement such groups to standard care to protect their SoD.

Regarding violations related directly to the person with dementia, all participants emphasized that the symptoms associated with dementia and occasionally challenging behaviors have a crucial negative effect on the SoD. In addition, in most of the interviews, the caregivers saw themselves in a sudden dignity-violating role-discontinuity, while for a few caregivers, a preservation of dignity was evident when there was stability in certain aspects of life. This finding is in accordance with the concept of "continuity of self", which constitutes that the core of one's identity remains unchanged despite adverse circumstances[35].

Also, most of the interviewed caregivers had been facing challenges because of being responsible for an adequate care setting. Similarly, Ryan and Scullion show that informal caregivers fall into personal crisis when the person with dementia needs to move into a nursing home[53]. Thus, social workers in a psychiatric hospital can contribute significantly to enhancing the caregivers' SoD by providing support in social-medical issues.

During the interviews, the social environment of the caregivers was rarely mentioned. Nevertheless, our results demonstrate that social participation is essential to experiencing dignity as a caregiver. To experience dignity, caregivers need to know that they are not alone. Nonetheless, according to a previous study, two-thirds of caregivers experience loneliness[54,55].

Regarding help-institutional support, the caregivers reported that their SoD benefits from care work support. In addition, they reported the ability of ceding responsibility (to the psychiatric hospital) as SoD-enhancing. This aspect has also previously been reported by Beardon et al., who describe ceding caring responsibility as a relieving factor for some caregivers[56]. The administrative burdens, which were mentioned by more than half of the caregivers, play a significant role, which is reflected by Dang et al., stating that caring for someone with dementia, among other things, poses a "financial toll"[57].

Furthermore, every caregiver needs to be informed about the treatment of their relative by hospital professionals in accessible language as part of the shared-decision-making-process. Also, "microaggressions" from staff aimed at the caregiver need to be prevented by educating them about the major importance of adequate, respectful and detailed communication with the caregiver regarding the treatment process of their loved one. "Microaggressions" finally can be defined as subtle, routine, and seemingly harmless slights or demeaning comments (by the staff or social environment)[58]. This matter must be addressed in further research about dignity in similar study settings. The staff of psychiatric hospitals must know that to protect the dignity of caregivers, they need to listen deeply and non-judgmentally to their needs and burdens.

Limitations:

When interpreting the findings of our study, one needs to consider that all interviews were conducted in just one institution. The results are solely based on interviews with informal caregivers in a psychiatric hospital and may not always be clearly distinguishable from those in other formal care settings. The results reflect an accumulation of experiences the caregiver had with the help system, not solely with the psychiatric hospital.

Study eligibility was based on the caregiver's self-assessment as caring for a loved one with dementia. As a result, there is a risk of informal caregivers participating in the study whose relative did not actually have a confirmed diagnosis of dementia.

Finally, all results are the subjective insights of the recruited caregivers. Thus, the study cannot reach representativeness by means of statistically standardized research methods due to its qualitative approach.

Conclusions:

Existing dignity studies present a comprehensive foundation regarding aspects impacting the SoD in vulnerable settings[16,20,23,35,36,54,59]. With the results of this SoD research, we present novel and specific insights on how caregivers in a psychiatric hospital are experiencing dignity as well as how and by whom their SoD is reinforced or violated. The SoD of the caregivers can be composed of four SoD-affecting sources as detailed in figure 4. Next to ten contributing factors violating the SoD, we also identified 11 contributing factors reinforcing the SoD, which can function as guidelines for prospective dignity-enhancing interventions. Especially, our observation that the caregivers' SoD has not been violated by dependence on support seems to be a promising outcome as well as the finding that a main part of the caregivers' SoD arises in their interaction with a loved one having dementia and in the experience of the demented person's inherent dignity. Still, supporting facilities need to be aware of the significant role they can play in protecting but also violating the SoD of caregivers. Considering this, the concept of a "complexity of the obvious" is defined, meaning that although some SoD – contributing factors might seem trivial or obvious, they still must be practiced.

Further research needs to address how the SoD among caregivers might vary depending on its study setting. Generally, more focus is needed on how definitions of dignity evolve over the lifespan, particularly in the context of heterogeneous and vulnerable life situations. Finally, this research aims to encourage focusing on the well-being of caregivers, especially given the increasing prevalence of dementia and the vital importance of informal caregiving.

Author contributions:

Conceptualization: EW/AH/MK/JH/GZ/PR; Interview guide development: EW/TH; Participant recruitment: EW; Data collection: EW; Data analyses: EW/TH; Writing - original draft: EW; Writing - review & editing: JH/TH/GZ/PR/MK/AH/EW; Funding acquisition: MK/AH; Supervision: JH.

The authors read and approved the final manuscript.

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All data-analysis and anonymized transcripts can be requested from the corresponding author via emanuel.wiese@med.uni-augsburg.de

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Supplement 1

Description of the institution

In Germany, psychiatric hospitals treat the full spectrum of psychiatric disorders within the ICD-10 F1X to F9X groups. Thus, a multidisciplinary team works with a heterogeneous patient population, whereas individuals are treated on specialized wards (e.g. for schizophrenia, for treatment-resistant depression or for behavioral disturbances in people living with dementia). When people living with dementia -whether at home, in somatic hospitals or in nursing facilities-are admitted to a psychiatric hospital, it is due to an acute psychiatric episode, such as Delirium, Psychosis, Depression or suicidal thoughts or a marked worsening of dementia-related symptoms like behavioral changes and challenging behavior in the context of nursing care procedures.

Participants of this study were recruited while their relatives (persons with dementia) were treated at the Department of Psychiatry, Psychotherapy, and Psychosomatics of the University of Augsburg (BKH Augsburg), which is a psychiatric hospital where the full spectrum of psychiatric diseases are treated. It is the largest psychiatric hospital in Bavarian Swabia, with 326 inpatient and 32 daypatient beds as well as a large outpatient clinic with more than 650 employees in total. The institution has three explicit geronto-psychiatric wards with a total of 66 beds. When looking at the length of stays in 2024, also depending on the complexity of the diagnosed disease, individuals were treated for an average of 30.3 days (±8.0 days). The initial admissions happen voluntarily or, if necessary, involuntarily and after the stay the recipients of care either return to their homes or are (re-) transferred to nursing facilities. caregivers often act as proxies due to their loved one's lack of capacity to consent.

Tables

Table 1

Sociodemographic characteristics of participants (N=20)

Sex (Female/Male/Diverse)	(12/8/0)
Age group	
40-60 years	15
61-80 years	4
81-100 years	1
Mean	56 years (±9)
Family relationship to person with dementia	
Daughter	10
Son	6
Spouse (Female/Male/Diverse)	(2/1/0)
Other familial relationship	1
Living together with the person with dementia	

(yes/no)	(4/16)
Setting of the interview (caregiver's home/hospital/online call)	(9/10/1)

Table 2

Interview guide used for semi-structured interviews

Main themes	Aim of the interview section / used literature	Used questions
Preliminary information	A calm atmosphere is created to feel comfortable and for mutual trust	- Greeting and introduction - Presentation of the interview topic - Guidelines for the procedure and duration of the interview - Information on data release and usage, anonymity
Topic Sect. 1.: Coping Strategies and Resilience Factors	Resilience often is part of dignity theories. Therefore, questions regarding the everyday life as an caregiver and how challenges are overcome are being asked[35,60].	- "What helps you to manage your daily (caregiving) responsibilities?" - "How do you cope with negative experiences?" - "How do you deal with stress? What strategies help you?" - "What do you do to find balance? Is there a resource from which you draw inner strength?" - "What role does your social environment (family + friends) play in coping with challenges?" - "Have you developed any 'negative' habits that contribute to relaxation? (e.g. lack of exercise, unbalanced diet, etc.)?"

Topic Sect. 2: The caregivers sense of dignity	Based on theories of dignity, open questions are asked about aspects such as privacy, experienced dependency, and changes[35,36,54,61].	- "What concerns and fears are currently on your mind?" - "How do you feel about accepting assistance from formal care-work institutions? (e.g., this psychiatric hospital)?" - "In what ways do you experience a negative dependence on formal care-work institutions?" - "How has the relationship with your relative changed since and due to the dementia diagnosis?" - "Do you have moments for yourself with enough privacy?" - "How do you communicate with your relative, and how does your relative communicate with you?" - "What do you and your relative need for ideal care?" - "How have you as an individual changed due to the dementia diagnosis of your family member?"
Positive closing questions	Questions to give the caregivers a positive feeling at the end of the interview as recommended in the literature[26].	- "What are positive qualities of your diseased family member?" - "What are positive qualities that you have discovered due to being the informal caregiver?" - "In a perfect world: What would your life look like in five years?"
Summary	With the help of the summary, the caregivers can confirm whether all content has been adequately summarized and open questions are being answered.	- Summary of the key statements by the interviewer - If needed, any relevant informational materials or flyers that may be useful to the participant are provided.

Note: The interview guideline was developed by the entire research team and by consideration of the review by Kalio et al. on developing a framework for a qualitative semi-structured interview guide[62]. Thereby, after conducting the first two interviews marginal changes were made (="pilot testing")[62]. The specific content of the interview guide was designed following the recommendation of Helfferich called "SPSS" (German: Sammeln-Prüfen-Sortieren-Subsumieren /English: Collecting-Checking-Sorting-Subsuming)[63]. Consequently, the interview guide was based on existing knowledge as well as resilience and dignity theories[62,63]. Here, the meta-analytic approach by Lee et al. was the basis for opening questions regarding resilience while publications by Chochinov, Klie, and Høy were used as orientation for SoD-content[35,36,54,60,61]. The mentioned research was used as a framework on which sources and specific SoD-contributing factors might be relevant (e.g., Klie with his focus on social environment or Chochinov with his focus on the importance of holistic formal care work or self-care)[35,54].

Table 3

Main codes, subcodes, sublevels of subcodes and two anchor examples for each sublevel of subcodes

Main codes	Subcodes	Sublevels of subcodes	Anchor examples
The informal caregiver whose dignity is being affected		Self-care	"At the moment, it's really like this-I'm happy when I come home from work and just, how do you say it these day - just chill out." (Example from caregiver 04) "Yes, yes, I actually try to go to the sauna once a week. I'm gone for about four hours and use the time to relax." (Example from caregiver 12)

	Contributing factors reinforcing the SoD	Role continuity	"Yes, exactly, that you still exist yourself that you don't get lost only in taking care of your partner." (Example from caregiver 08) "You have to try to think of yourself and find a way to keep living your life." (Example from caregiver 22)
		Resilience	"Yeah, I didn't even know I could manage so much at once. Because, normally, I'm a bit of an organizational mess. But when it comes to this, I think I've managed it pretty well." (Example from RDP 22) "Stress, well…you just have to find a way to get a handle on it with some good solutions." (Example from caregiver 04)
	Contributing factors violating the SoD	Missing self-care	"A constant restlessness, this feeling of never settling. Total restlessness, that's the right word. I just can't come down anymore." (Example from caregiver 22)"I'll just start smoking again-at least that way I won't be snacking as much." (Example from caregiver 07)
		Lack of "manageability"	"So, let's say, I was good at pushing things away or suppressing them." (Example from caregiver 13) "I thought I could handle it, at least for a while. But then… yeah. It didn't take long before those things started happening, when she started walking around and it became clear: I can't do this for long. I can't keep it up." (Example from caregiver 22)
The person with dementia		Psychoeducation	"And then it's already the case that the relationship, or this understanding of

	Contributing factors reinforcing the SoD		dementia, has simplified dealing with her nature or even saying, okay, she doesn't mean it that way now." (Example from caregiver 05) "You realize, okay, this is an illness. There's no bad intent or anything like that involved. It's simply an illness." Example from caregiver 21)
		Hopes and perspectives	"Considering the current situation, it would already be great if we could continue living like we are now for, let's say, an unlimited number of years." (Example from caregiver 12) "The perfect setup would be for all of us to live together in a *multigenerational home* — my father-in-law, my mother, that couple we are close with – all supporting each other, and having a lovely, peaceful time. And for me, it would mean knowing everything's okay — that things are just as they should be." (Example from RDP 18)
		Valuable interactions with the person with dementia	"So, I would now say, the affection of my husband towards me, has remained, that is stable." (Example from caregiver 08) "Like I said, he still has a joy for life. He can say, 'I'm happy.' He can start singing a song. Luckily, he hasn't lost that." (Example from caregiver 21)
		Multidimensional discontinuity	"I can't go on like this. We are in our golden years now. I feel like... yes, I don't want to spend the next ten years as my father's caregiver. I would actually like to go back to

	Contributing factors violating the SoD		the role of being the daughter who visits him." (Example from caregiver 21) "I noticed, when my son came to tell me something, I thought, I really don't want to hear this, tell someone else [...] I just cannot hear anyone else's worries anymore." (Example from caregiver 16)
		Concerns regarding an adequate care	"The only thing that weighs on me, or where I'm, how should I say, currently contemplating, is whether it's the right decision to put my mom in [a nursing home] whether there might be another option, because she is still quite young." (Example from caregiver 02) "I don't think it's going to work much longer— I don't think it can go on [the person with dementia returning home after treatment in the psychiatric hospital / note of the author]. And that's the point where I don't know when the right time is [to tell the loved one / note of the author], and especially, how do I explain that to him?" (Example from caregiver 15)
		Symptom-related burdens	"She makes it really, really hard for me personally. She gets spiteful with me. Some days, I'm in a good mood, and I can brush it off. But on other days, she hurts me. It really hurts." (Example from caregiver 01) "She would throw things around and insult us." (Example from caregiver 19)
The social		Family as	"Then there are also moments where you say,

environment	Contributing factors reinforcing the SoD	resource	okay, now we're doing something with the family, like a bike ride, and you enjoy these two, three hours, and you completely forget about the surroundings and can take a deep breath for once." (Example by caregiver 22) "The support of my family during these difficult times was absolutely essential." Example from caregiver 04)
		Supportive friends	"My friends are always there for me. My colleagues, my superiors, they know […about the patient's disease / note of the author]. Because in our company, everyone basically has a parent of the same age as mine, dealing with dementia and, well… so, you are supported." (Example from caregiver 19) "I did have support from friends who had been in a similar situation or who also have older parents. So, I didn't feel completely alone." (Example from caregiver 06)
	Contributing factors violating the SoD	External judgement	"For me, I don't like things being said behind my back. He should just tell me straight to my face if something's wrong or if something's not right." (Example from caregiver 01) "I always had the feeling that people were whispering about us, because we took care of our mother so often — like that wasn't seen as normal." (Example from caregiver 04)
		Poor support in care work	"I do have siblings but unfortunately neither of them look after her at all." (Example from caregiver 18) "Well, I had the bad luck of being an only

			child. And honestly, it'd be really helpful right now to have siblings to share all this with." (Example from caregiver 20)
Supporting facilities, both while in hospital and in the community	Contributing factors reinforcing the SoD	Giving away responsibility	"Since the legal guardianship has been settled, thankfully I've had a chance to recover." (Example from caregiver 17) "I'm truly grateful that there are people like that — professional caregivers in supportive facilities. I'm thankful and gladly accept their help. And, how should I put it... it's also a burden that's been lifted from us." (Example from caregiver 02)
		Positive dependence	"Yes, it's easy for me because we can't handle everything on our own. So, one has to allow oneself to seek help." (Example from caregiver 19) "It was a very positive kind of dependency. From the moment the medical doctor [name anonymized / note of the author] came and did the initial assessment, I saw it all in a very positive light." (Example from caregiver 04)
		Care work-support	"I have organized that and he [the person with dementia / note of the author] likes it, so that's okay. Yes, of course, there are good times and bad times. But this daycare is just great." (Example from caregiver 15) "I really think the care in that facility |the psychiatric hospital / note of the author] is good. The staff truly care. I honestly haven't noticed anything negative. They really have a very good relationship with the person with

			dementia." (Example from caregiver 17)
	Contributing factors violating the SoD	Administrative burdens	"As I said, the more burdensome part was rather the surrounding circumstances, all this paperwork and such, and not knowing where the places are to turn to for support. And then everything is so complicated with care allowance and care - what's the other thing called?" (Example from caregiver 05) "It's the administrative things, an overwhelming number of phone calls. You're constantly dealing with it... the topic just keeps circling around you." (Example from caregiver 21)
		Deficit in communication	"Because when the patient can't really tell you what is happening -he always told me something about what they do here but I didn't have real contact and didn't know what the doctor had ordered. It was difficult to reach the doctors. That has been a bit challenging. That's what I found difficult." (Example from caregiver 06) "But what's actually important is this lack of communication and information. Because while dementia seems to be on everyone's lips, in reality, it's still largely an unknown." (Example from caregiver 13)
		Feeling left alone by the helpsystem	"For me, what was difficult, or the burden, was that I had to organize so much and in the process was left alone by the places where you would expect support. That's a fact." (Example from caregiver 05) "At times, you feel like a lone fighter because,

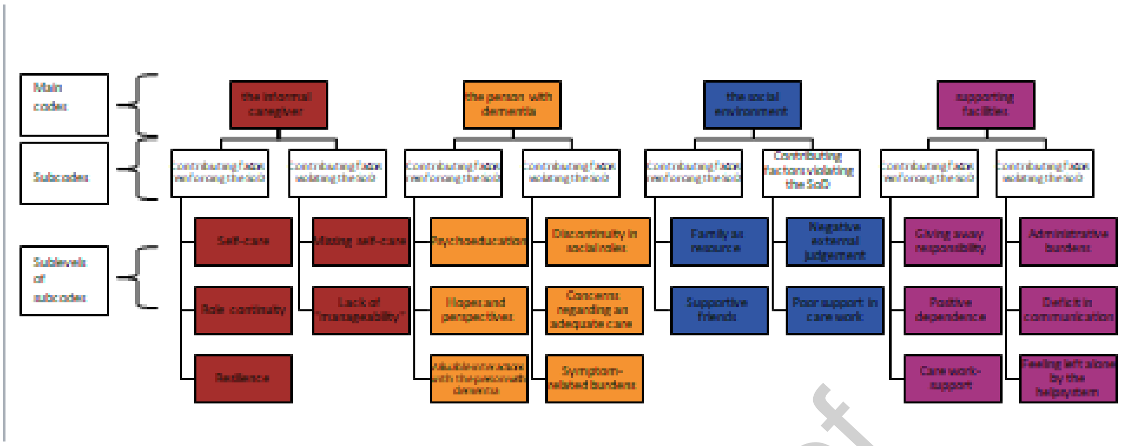
			well, you have to handle everything on your own." (Example from caregiver 06)

Notes: The main codes (sources) are (1) the informal caregiver whose dignity is being affected, (2) the person with dementia, (3) the social environment and (4) supporting facilities, both while in hospital and in the community. The recorded audio files were transcribed and anonymized by a transcription office not otherwise involved in this study. The statements quoted in this table were translated into English by the interviewer (EW).

Figures

Figure 1

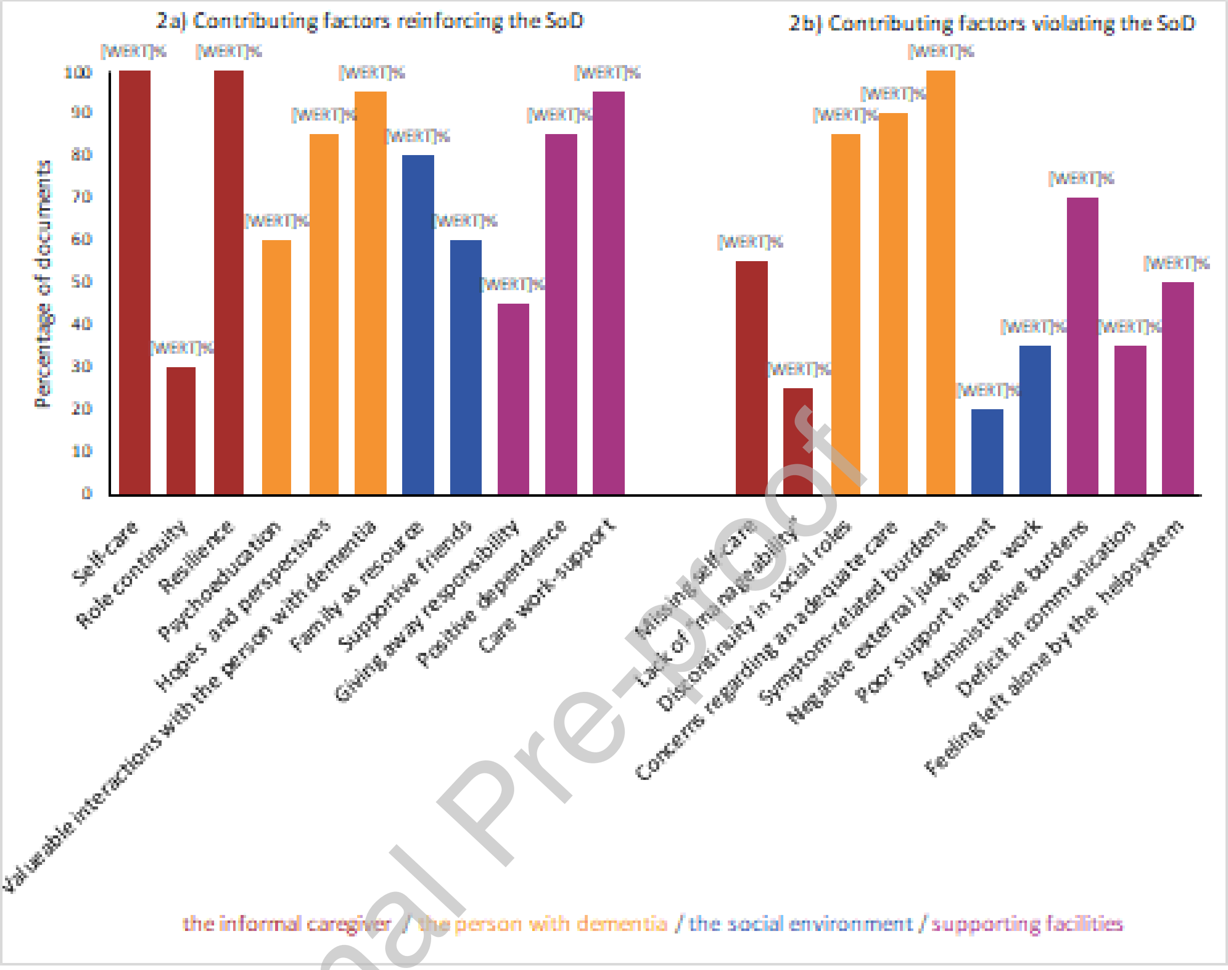
The final code-system



Note: The SoD among informal caregivers is evolving through four different sources who and which all can either practice a reinforcement or a violation of the SoD. There are 11 contributing factors reinforcing the SoD and 10 contributing factors violating the SoD.

Figure 2

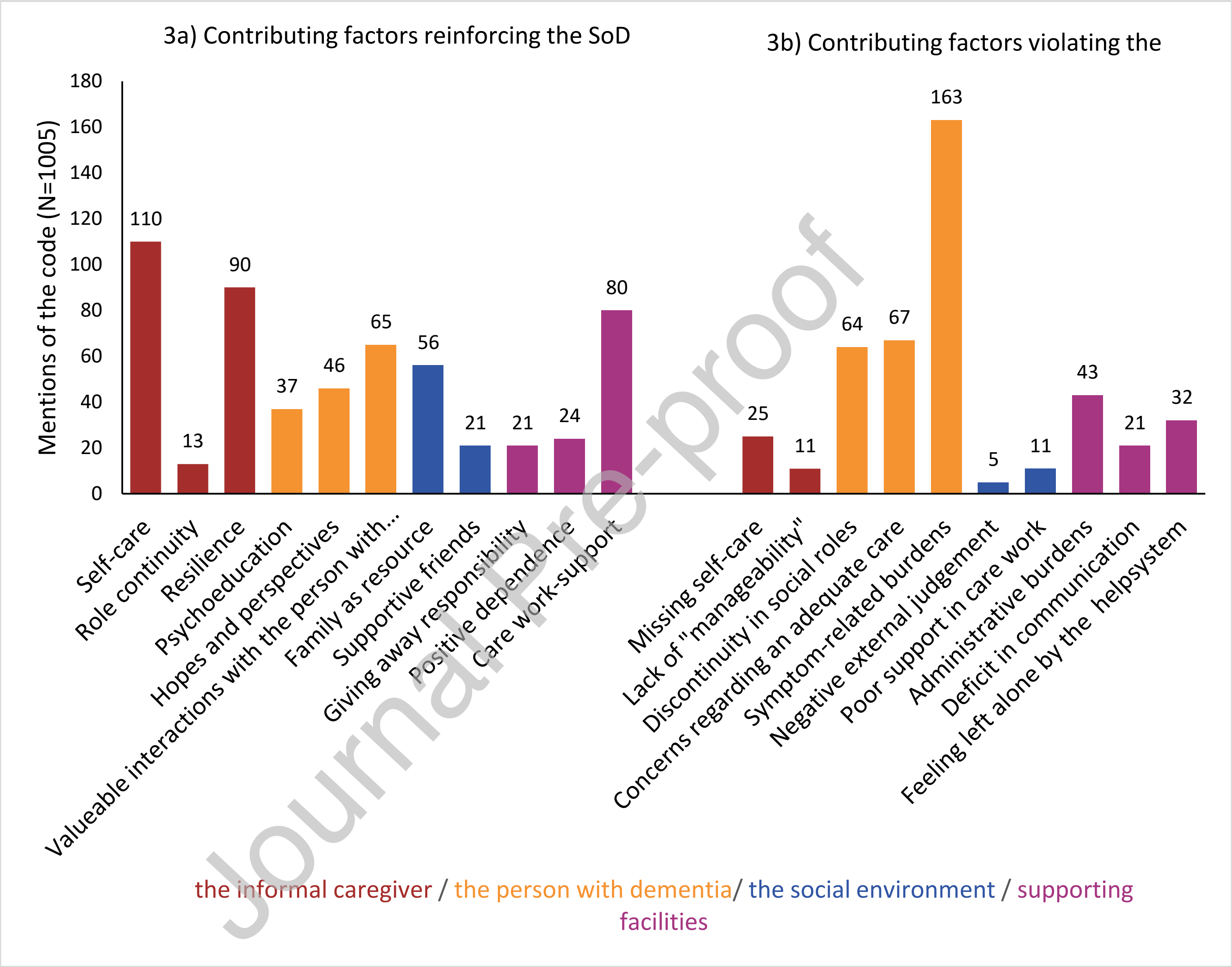
Percentage of documents with code (N=20)



Notes: Each source can strengthen or weaken the caregiver's sense of dignity. The y-axis presents the percentage of documents, in which the sublevel was mentioned. In total there are 20 interviews / documents (N=20). Each code varies in the percentage of documents being mentioned, as can be seen in the x-axis. The codes "Self-care", "Resilience" and "Symptom-related-burdens" were mentioned in every interview.

Figure 3

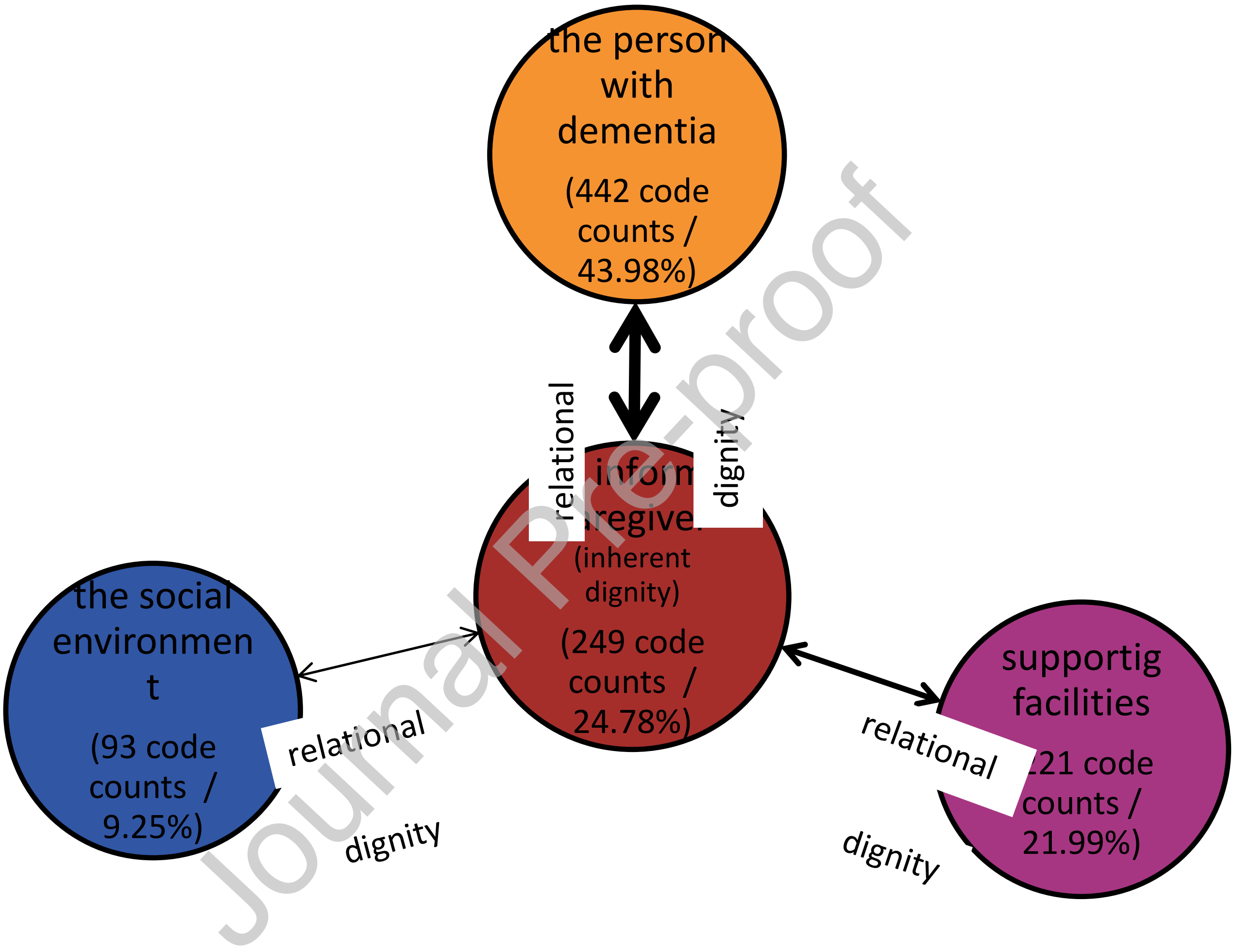
Frequency of mentions of the respective sublevels of subcodes



Notes: In total there are 1005 mentions of SoD-contributing factors (N=1005) (y-axis). Each factor varies in the number of being mentioned, as can be seen in the x-axis.

Figure 4

Illustration of how the caregivers' *sense of dignity can be described*



Notes: Each source can strengthen or weaken the caregivers' SoD while they might also interfere with each other. The different codes vary in the number of mentions (code counts). The person with dementia -source was mentioned the most, followed by the informal caregiver whose dignity is being affected and supporting facilities. The social environment was mentioned the least. The wider the arrow, the more it can be assumed, that the given source has an influence on the caregivers' SoD.

Declaration of interests

☐The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☒The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Alkomiet Hasan: editor of the German (DGPPN) schizophrenia treatment guidelines, first author of the WFSBP schizophrenia treatment guidelines; on advisory boards of and speaker fees from AbbVie (speaker fees only), Advanz (speaker fees only), Janssen-Cilag, Lundbeck, Recordati, Rovi, and Otsuka