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Moral conflicts and ethical perspectives in dementia care

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Moral conflicts and ethical perspectives in dementia care

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Editorial: Moral conflicts and ethical perspectives in dementia care

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Editorial on the Research Topic
Moral conflicts and ethical perspectives in dementia care

Dementia can be caused by a heterogeneous group of disorders and is characterized by a progressive deterioration of cognitive function and a concomitant loss of independence. Due to population aging, the syndrome is becoming more prevalent and receiving increasing attention in many contemporary aging societies. According to the World Health Organization (1), more than 55 million individuals worldwide are currently living with dementia, with nearly 10 million new cases diagnosed each year.

In addition to the clinical challenges associated with treatment, prevention, and care, dementia raises complex ethical concerns that warrant in-depth examination. The increasing cognitive impairments of those affected challenge common standards and procedures of autonomous decision-making and informed consent in medical ethics. The extensive and sophisticated requirements of good dementia care can put a strain on family carers as well as professional caregivers. Many societies are still pervaded by negative images of dementia that link the condition to social stigma and discrimination.

This Research Topic is dedicated to exploring these multifaceted ethical dimensions. The contributions tackle a variety of moral aspects and challenges of dementia care. They range from the significance of prominent ethical concepts like dignity, autonomy, or privacy in the context of dementia to moral conflicts arising in family or migrant live-in care arrangements to the use of new instruments, such as advance research directives or assistive technologies. The authors approach their topics from the perspectives of ethical analysis and empirical social research.

Buhr and Schweda explore the moral significance of privacy in the care of people with dementia. They argue that traditional concepts of privacy, which are primarily based on autonomy, may not be entirely appropriate in the ethical context of dementia care—particularly during the advanced stages of the disorder. Instead, they advocate for a more nuanced approach that considers remaining personal preferences, objective criteria of dignity and well-being, and the importance of maintaining meaningful relationships.

Barth's ethnographic study explores the ethical dilemmas associated with managing challenging and aggressive behaviors of individuals with dementia. He critically examines the common practice of attributing such behaviors solely to pathological conditions rather than the patient's free will. While this approach can protect patients by removing moral responsibility—thus preventing blame and preserving empathy and compassion—it may simultaneously compromise the dignity of individuals with dementia by denying their capacity for autonomous action and overlooking the underlying emotional and social needs. Barth proposes a balanced strategy that recognizes the disease's influence on behavior while addressing the patient's emotions, experiences, and desires.

Dogan et al. examine whether it is legitimate—or constitutes undue pressure—for an uninvolved daughter to assume caregiving responsibilities for her mother in situations where formal support is lacking. Their analysis interrogates the moral obligations that adult children may have toward their parents while also underscoring the ethical issues associated with involving previously uninvolved family members in caregiving. Moreover, they highlight the deeply political nature of this dilemma, noting that the scarcity of formal resources often forces professionals into making ethically problematic choices to alleviate the burden of dementia care.

von Kutzleben et al. investigate the dilemmas faced by migrant caregivers living in the homes of individuals with extensive support needs, often due to dementia. Their article offers a conceptual ethical framework for analyzing moral conflicts within the caregiver–patient–family triad. Specifically, the study discusses how tensions between the norms, values, and expectations of migrant caregivers, family members, and service recipients—operating across different social levels—can give rise to moral conflicts. This multidimensional approach facilitates a deeper understanding of the moral complexities involved in close care provided by migrant caregivers. It aims to inform policy improvements while offering targeted advice and support.

Furthermore, Ulitsa et al. explore the intricacies of triadic care arrangements involving dementia patients, foreign caregivers, and family members. By qualitatively analyzing interviews with 24 experts from Germany and Israel, the study examines six dimensions of vulnerability—namely, physical, psychological, relational/interpersonal, moral, socio-cultural-political-economic, and existential-spiritual. The findings indicate that all parties involved in care experience complex, interconnected vulnerabilities. Additionally, the study reveals similarities and differences in the experiences of experts from Germany and Israel, reflecting the influence of unique social and legal contexts on caregiving practices.

The third area of inquiry focuses on ethical issues related to advance directives. Vulliermet and Kenis offer a critical perspective on advance directives. They argue that discussions surrounding advance directives are sometimes framed in language that portrays dementia as "monstrous" or as an "enemy." Such a portrayal not only perpetuates bias and stigmatization but also establishes a problematic dichotomy between the suffering of the "then self" and that of the "now self." In response, they advocate for a more nuanced approach to advance directives that accounts for the needs and identity of the contemporary self of the individual with dementia.

Gieselmann et al. investigate the perceptions of individuals with mild cognitive impairment and their families regarding the benefits and challenges associated with advance research directives. Their findings indicate that participants recognize several advantages—most notably, the capacity of advance research directives to alleviate the decision-making burden on family members and uphold personal autonomy. However, the study also reveals significant challenges, including the potential for conflicts between current preferences and the instructions documented in these directives.

Finally, two articles address the ethical dilemmas associated with the use of assistive technologies and robotics in dementia care. Deusdad's review examines the integration of technologies—including social and companion robots—into dementia care. It addresses the technical, psychological, and sociocultural dimensions of human-robot interaction among older adults with dementia, highlighting ethical concerns regarding robots' capacity to interpret human needs, issues of informed consent, increased dependency, and difficulties distinguishing reality from simulation. The review also discusses the potential ethical impact of reducing human caregivers' roles.

Welsch and Schicktanz conducted interviews with experts to examine the conditions that both promote and hinder the deployment of intelligent assistive technologies in this context. Their findings reveal a complex interplay of accelerating and inhibiting factors operating at three distinct levels: societal, political-regulatory-economic, and technological. These results underscore the need to enhance facilitators and mitigate barriers across all three domains.

Author contributions

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That was just your life: rethinking dementia for advance directives

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Over the past decades, literature in dementia ethics has extensively looked at moral questions revolving around the care of older people living with dementia. Particularly prevalent are autonomy-related concerns regarding topics such as advance directives. In this paper, we argue that these discussions are crucially premised on how dementia is understood and represented. Despite the multiplicity of dementia presentations in people, the dominant discourse predominantly frames dementia as 'monstrous,' an 'enemy,' a destructive experience in need of eradication. We contend that such a monolithic approach, from a moral standpoint, is problematic in several respects. Indeed, framing heavily influences the way dementia is understood and experienced, leading to stigmatization, bias, and distress. Not only does it influence decisions and discussions on advance directives, but we argue that this flawed understanding of dementia is rooted in and contributes to epistemic harm. In the first section, we introduce the ethics of advance directives. More specifically, we introduce the view developed by Dworkin who has largely influenced the debate by making the case for advance directives by grounding them in the principles of autonomy and beneficence. In the second section, we show how dementia is still mostly framed monolithically as a 'destructive experience.' We then show that this framing is problematic because it oversteps the different pathologies dementia implies, which leads to an inaccurate representation of the condition. In the third section, we present possible alternative framings: dementia as normal aging, a person-centered care framework, and an embodied view. In the fourth section, drawing on recent developments in the epistemic injustice literature, we explore how maintaining and utilizing flawed understandings of dementia may lead to distinct moral-epistemic harms for those living with dementia and inform ongoing discussions on advance directives. Finally, in the concluding section, we return to the case of advance directives and what the implications of rethinking dementia are.

KEYWORDS

dementia, Alzheimer's disease, epistemic injustice, contributory injustice, advance directives, representations

Introduction

In *Still Alice* (1), Alice (portrayed by Julianne Moore), a linguistics professor, is diagnosed with early-onset familial Alzheimer's disease. Aware of her declining state, Alice battles to delay the effects of dementia as much as possible. Nevertheless, as her decline becomes ineluctable, she formulates advance directives in the form of a recorded video addressed to her 'future self,' instructing her to take sleeping pills with a dosage that would implicitly lead to her death. Later in the movie, Alice stumbles upon the video her 'then self' had recorded without any recollection of its whole meaning or consequences. While she is following the instructions, she is interrupted by the arrival of her caregiver. Unable to remember what she was doing, Alice never takes the pills. The spectator may be appalled by Alice being unable to fulfill her wish to take her own life after reaching a stage her 'then self' had deemed unbearable. Nevertheless, a second reading conflicts with this interpretation, and the spectator should maybe rather rejoice that the attempt to take the pills failed. When she discovers the recording, Alice just had a video call with her younger daughter to help her rehearse a play while cooking simultaneously. Her 'now self' seems quite happy with her life and still engages in meaningful activities and exchanges. Looking again, one cannot then help but wonder if 'then Alice' would not have committed an irreparable wrong to 'now Alice' by instructing her to take her own life.

Dementia – as a clinical syndrome present in a variety of medical conditions and pathologies with distinct etiologies, such as Alzheimer's disease (AD) – describes the decline in cognitive abilities to perform everyday activities (2). From a public health perspective, this decline, increasing with age, coupled with an extended life expectancy, affects a growing number of people. More colloquially, dementia is sometimes referred to as a 'silver tsunami' (3, 4). The challenges of dementia are numerous: while it has become a growing concern from a medical perspective, the rise in dementia cases equally presents economic, political, and ethical challenges (5, 6).

Over the past decades, literature in dementia ethics has extensively looked at moral questions revolving around the care of older people living with dementia. Particularly prevalent are autonomy-related concerns regarding topics such as advance directives or managing feeding needs (7, 8). As we argue throughout this article, these discussions are crucially premised on how dementia is understood and represented. Despite the multiplicity of dementia presentations in people, the dominant discourse predominantly frames dementia as 'monstrous,' an 'enemy,' a destructive experience in need of eradication (4).

In this paper, we contend that while such a monolithic approach may be relevant from a curative perspective, from a moral standpoint, this framing is problematic in several respects. Indeed, such framing heavily influences the way dementia is understood *and* experienced, leading to stigmatization, bias, and distress. Not only does it influence decisions and discussions on advance directives, but this flawed understanding of dementia may also be a source of epistemic harm. We proceed as follows: in the first section, we introduce the ethics of advance directives. More specifically, we introduce the view developed by Dworkin who has largely influenced the debate by making the case for advance directives grounding them in the principles of autonomy and beneficence. In the second section, we come back to how dementia is still mostly framed monolithically as a 'destructive experience.' We then show that this framing is problematic because it oversteps the different pathologies dementia implies, which leads to an inaccurate representation of the condition. In the third section, we present possible alternative framings: dementia as normal aging, a person-centered care framework, and an embodied view. In the fourth section, drawing on recent developments in the epistemic injustice literature, we explore how maintaining and utilizing flawed understandings of dementia may lead to distinct moral-epistemic harms for those living with dementia and inform ongoing discussions on advance directives. Finally, in the concluding section, we return to the case of advance directives and address the implications of rethinking dementia.

The ethics of advance directives

The topic of dementia provides for a number of challenging moral quandaries and has, as such, been of primary concern to ethicists and legal scholars. Particularly pervasive are discussions on 'advance directives.' Advance directives are (generally) written statements stipulating instructions and preferences on future medical care in case of (expected) loss of decisional capacity (9). As a (legal) tool for surrogate decision-making, advance directives allow people to stipulate their wishes for future medical decisions. In general, advance directives are used as guidance for medical decision-making in the event the person is not able to express her will due to incapacitating circumstances such as cognitive impairments, being in a coma, after an accident, or because of illness.[1] Since dementia involves (at least) a partial loss of the cognitive capacities deemed necessary to exercise autonomous decision-making, people draft advance directives to stipulate the conditions and procedure for surrogate decision-makers. Advance directives are then conceived as a means to extend a person's autonomy to a 'future self' lacking this capacity.

Nevertheless, an important moral quandary arises when people with dementia express interests that run counter to their previously stipulated directives. If a person, prior to diagnosis, drafted a directive stipulating, for example, a 'do not resuscitate'-order but later does express a wish to receive treatment, it is unclear to healthcare workers and her relatives which wishes should be honored. The debate in dementia ethics, then, primarily concerns the moral authority of advance directives and has mostly been framed around the concept of autonomy.

One of the most influential stances[2] in this debate comes from Ronald Dworkin, who suggests that an advance directive reflects the

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[1] We should note here that the legislation and implementation of advance directives can vary greatly from one country to another. For instance, in 2021, only 15 countries in the European Union had developed specific legislation on advance directives (10).

[2] While we focus on the dominant view portrayed by Dworkin, we acknowledge other positions exist. Rebecca Dresser for instance has argued, against Dworkin, that the tenuous nature of advance directives fails to accurately capture how people's interests evolve over time (Choi, 2022).

individual's judgment of her own life and should, therefore, be viewed as morally authoritative. Dworkin, in what is now seen as the received view (9), offers two arguments for this stance: the argument from autonomy and the argument from beneficence. With regards to the first, Dworkins defense of the moral authority of advance directives is premised on a conception of autonomy grounded in the integrity of the 'then self,' which Dworkin stipulates as "people's general capacity to lead their lives out of a distinctive sense of their own character, a sense of what is important to and for them" (11, p. 224). Following Dworkin, people with dementia have lost this narrative capacity as they cannot reflect on their past or future (12). Therefore, in such cases, respecting the autonomy of the person entails respecting the preferences of the person before suffering from dementia, even over her current preferences. In practice, this makes an attractive case for advance directives, which evidently traces back to the (over)emphasized idea of rational autonomy present in Western bioethics (7) by allowing a person to take decisions over her 'future self.' This view culminated in the common (Western) bioethical assumption that extending a person's autonomy using advance directives was 'in principle correct' (12). This approach is morally correct for many since the 'then self' in full possession of its faculties has a higher moral status.

Nevertheless, even if autonomy is taken to be of prime importance in dementia care, the principles of non-maleficence and beneficence state that physicians should not inflict unnecessary harm[3] on patients and ensure their well-being, raising critical tensions regarding the effectuation of advance directives to stop treatment.[4] Indeed, even if people with dementia are found to lack the capacity to act upon their interests, caregivers and proxy decision-makers should still act out of their best interests. To mitigate these concerns, Dworkin introduces a distinction between experiential and critical interests (11). Whereas the former is comprised of the quality of our own experiences and mostly constitutes pleasure, the latter involves thicker evaluations of who we are and what we hold to be important. Since critical interests are fundamental as opposed to temporary, Dworkin considers only critical interests as essential to our well-being. Since, according to Dworkin, dementia introduces a decisive break in one's narrative self and therefore excludes the ability to have a temporally extended sense of self, people with dementia cannot engage with prior nor hold critical interests. Since the interests these people have are then 'merely' experiential – and when they conflict with the interests motivating the drafting of their advance directives – they fail to attain the moral weight that prior critical interests did.

Note, however, that the received view at several points relies on specific assumptions about what dementia is and how it is experienced. As Walsh suggests, the argument for autonomy "relies on us believing, like Dworkin does, that people with dementia in the moderate-late stage of the disease lack the mental capacities necessary to lead a life out of character" (9, p. 6). Indeed, we need to assume that the preferences people with dementia do evince, lack the stability and weight of those interests expressed prior to diagnosis or disease progression. Walsh continues that the argument from beneficence similarly relies on (i) the importance of 'critical' over other interests and (ii) the status of 'critical interests' being necessarily more stable and valid than any (relevant) interest expressed by the 'now self.'

Moreover, the communicative practice of assessing the interests and capacities of the person with dementia by family members, caregivers, and others may itself be liable to misunderstanding. As we will explore at length later, such misunderstandings open the door to specific moral-epistemic harms. As the literature on epistemic injustice – or the wrong done to someone in their capacity as a knower – informs us, assessing the reliability of a speaker does not occur in a vacuum but is influenced by structural factors such as pervasive stereotypes and the concepts we have available to make sense of specific experiences. Given the centrality of assessments of interests and capabilities, the enactments of advance directives can then be said to crucially rely on our societal understanding of dementia or, more precisely, on how its representation affects our understanding of dementia and our engagement with those living with dementia. Similar concerns apply to the drafting of an advance directive. Indeed, when one decides to draft an advance directive in view of the expected loss of capacities one deems vitally important, one relies on several assumptions of the disease trajectory, outcomes, and, more generally, what it is like to live with dementia. Here, too, people rely on dominant understandings of dementia as they exist in our social imaginary.

As such, both the philosophical discussions on the moral authority of advance directives, the enactment of advance directives in care contexts, and the individual decision to draft an advance directive critically depend on one's prior evaluation of the condition, which itself is deeply influenced by the dominant social representation of dementia. In the next section, we briefly sketch the dominant framing of dementia and suggest it relies on an impoverished clinical view of dementia, runs counter to the experiences of those living with dementia, and rests on a somewhat problematic philosophical understanding of identity.

Framing dementia

As we underlined in the introduction, the way dementia has been (predominantly) framed unilaterally emphasizes a negative valence; dementia is deemed a 'monster' to eradicate. The dominance of this particularly horrid understanding of dementia, overshadowing the multiplicity of expression encapsulated within the syndrome dementia, has resulted in its monolithic framing in most discourses. While dementia describes cognitive decline with a

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[3] While the concept of harm can be used nonnormatively (X's actions have adverse effects on Y), in the rest of the paper we will use harm normatively (if X harms Y, X also wrongs Y).

[4] The principle of non-maleficence entails that one ought to refrain from harming persons. The principle of beneficence on the other hand is more demanding and goes beyond the one of non-maleficence as it requires that someone actively takes positive steps to contribute to the welfare of others.

wide variety of pathologies affecting people in numerous ways, in popular representations, dementia often (exclusively) takes the face of its most severe instantiations. This monolithic framing is notably characterized by the predominance of AD in dementia discourses, which has been established both as a paragon and a vernacular term for dementia through the lobbying[5] of medical researchers and carers (13). This use has sedimented AD (and dementia) in the collective mind (or social imaginary) both amidst important segments of professional[6] and lay audiences so strongly and negatively that it has resulted in the 'idea' of dementia being one of the most terrifying illnesses (15).

The widely-held perception of dementia as 'terrifying' is, in important ways, related to the perceived threats it poses to an individual's capacities to exercise autonomy – a value critical to Western thinking and central to bioethics. Immanuel Kant, grounding morality in reason, contributed to the development of the Western notion of autonomy with the idea that being able to exercise full rational capacities would grant a higher moral status (7). Consequently, to be a 'full person' (in Western cultures) is linked to functions of rationality, memory,[7] and the autonomy that goes with them (16). While not universally lauded, autonomy has become (one of) the main principles in bioethics (17).[8] For instance, in some Asian countries, physicians do not fully disclose the medical condition to a patient when they believe it may harm them. There, the principle of beneficence trumps the one of autonomy. As dementia potentially deprives a person of her functions grounding autonomy, the issue has become core to dementia ethics.[9] As references to people with dementia as being 'mere vegetables' (18) or living a 'cabbage-like existence' (3) evince, people suffering from dementia are often taken to have lost partly or totally their autonomy.

The use of such terms, while explicitly undermining, is consistent with the idea that people with dementia are deprived of the functions that make them 'full persons.' This is anchored in the current framing of dementia and is the expression of a certain form of reductionism where a person would equate to her brain, which, when it does not work correctly, a person would be a lesser human. These discourses express a stark contrast between the person before and after suffering from dementia. Beyond autonomy, people with dementia can also show changes in their behaviors and personality, reemphasizing how 'terrifying' dementia can be by also robbing a person of her memories. In other words, reflecting upon dementia involves thinking about practical and philosophic problems linked to identity.

Philosophically, identity can be interpreted in two different ways: either as numerical or as psychological (narrative) (19). Dementia does not affect numerical identity; the person is still 'the same,' there is a continuation of a single body going through changes. It does, however, alter psychological identity (19). This identity refers to the conception a person has of herself, who she is, who she should be, and who she wants to be. This second understanding, prevalent in sociology and psychology, takes a person to be capable of having several identities throughout her life when she changes jobs, marries, etc. (19). This is the problem with dementia in this perspective: people may do things they do not remember, do not recognize people they were close to before, or have radical changes in their personalities. Here, the framing of dementia comes back into play, with strong and explicit formulations and metaphors saying that the person is 'gone,' for instance, inevitably emphasizing the destructive experience dementia is. After all, the first AD patient, Auguste Deter herself, would repeatedly say, "*I have lost myself*" (16). Knowing if a person with dementia is 'the same' from a psychological perspective is a thorny question. A dominant conception, developed by Locke and after him by Dawkins, grounds identity in psychological continuity. A person is 'the same' only insofar as she has conscious remembering, that she can recall her previous states and accredit them to herself (19). Simply said, memory is therefore crucial for this conception of identity, and losing memory when suffering from dementia is tantamount to losing identity.[10] Gerontological and dementia literature have then distinguished between the 'then self' that existed before the pathology and the 'now self' that lives in the present, with no or little recollection of the 'then self' (12).

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[5] In the 1960s' with the development of neurological research, AD was used as powerful articulation of concerns about ageing. Robert N. Butler, a leading gerontological physician, urged for instance to replace the ageist image of senility with AD, specifically with the purpose to obtain public funding on the ground that AD was separable from normal ageing processes (Katz & Leibing, 2023).

[6] As a recent review points out so-called 'Dementia Friendly Initiatives', combining insights from person-centered care and activist attempts to reframe dementia (cfr. later), are (increasingly) finding their way into care contexts promoting more inclusive, communal, and participatory dementia care models (14). Our concerns expressed here are, therefore, primarily addressed toward a lack of engagement with such alternative conceptions of dementia (care) in broader public and medical discourse. The failure of uptake of these initiatives expresses precisely the contributory injustice we discuss in section 3. We thank an anonymous reviewer for stressing this point.

[7] Memory, especially, is critical, as it allows a person to make sense of her life and shapes her interest. Not only does memory ground autonomy, it also allows one to exercise this autonomy.

[8] We need to stress here that if Kant was influential in the rise of autonomy as a central principle for biomedical ethics, his view was more stringent. For Kant, an agent has 'autonomy of the will' if and only if she acts in accordance with the categorical imperative. In biomedical ethics, autonomy, broadly construed, refers to that which makes judgments and actions one's own. Autonomy then requires a capacity for intentional action and an independence from controlling influences (Beauchamp & Childress, 2019).

[9] Mini Mental State Examination commonly used in these situations evaluates orientation, registration, attention and calculation, recall, and language.

[10] For an extended discussion of identity and dementia see (19–21).

Issues with this framing of dementia

In this section, we highlight some of the issues with the dominating framing of dementia. First, the monolithic framing oversteps the different pathologies dementia implies, which leads to an inaccurate (medical) representation of the condition. This results in a misleading portrayal of dementia with (potentially) significant consequences. Notably, it overlooks that people may experience dementia in different ways, not only from their personal perspective or their social condition but also from a strictly biomedical point of view. Disease onset and progression vary widely across persons. Some lose the capacity to speak and forget words (aphasia), while others forget most of their memories. The multiplicity of the clinical image of dementia, then, implies that the (clinical) needs of two persons with dementia can be radically different. Identifying the form of dementia then is crucial: not only may it suggest that the person's clinical needs will be different, but it also has clinical implications as rates of progression and prognosis are going to vary (22). This being said, recently and increasingly, even in the well-defined diagnostic category of AD, evidence suggests the need to recognize heterogeneity and the need to stratify people with dementia according to fine-grained disease characteristics. Nevertheless, further research and progress are still necessary here. Despite the need for a more granular biomedical view, Whitehouse himself still thinks in terms of a 'wide range of persons who have often 'similar needs' (our emphasis) regardless of specific diagnosis' (22). Indeed, while more granular diagnostic categories may function to improve dementia care and treatment, the issues identified transcend the clinical context and are, therefore, unlikely to be resolved within the biomedical purview.

Second, framing dementia solely as a 'destructive' experience is problematic because the ways people refer to dementia through words, stories, or discourses influence the way it is understood and experienced (4). This has implications from the perspective of the person receiving the diagnosis. Smedinga et al. (4) report that in lay contexts, a diagnosis of AD is often taken to amount to demolishing a person's life, 'bringing sadness and despair.' Unsurprisingly, as Post (1993) observed, such framing has sparked international debate over physician-assisted suicide as people increasingly started considering it as an option after receiving a diagnosis of AD. It also marked an increase in setting up advance directives (4). Furthermore, this framing also shapes how others and society treat people with dementia, notably how to communicate with them (23 More importantly, the framing of dementia also participates in the conception we have of the ones who suffer from it, leading to a moral stance with practical and ethical implications for how we treat them (3). As we showed previously, the framing allows for discourses undermining these people by comparing them to vegetables and being incapacitated.

Thirdly, even the ethical literature expounds on this 'defective" aspect, encouraging distinguishing between the person before dementia and after, especially to justify the relevance of advance directives.[11] We contend that this leads to another issue with how this particular framing is operationalized in the context of advance directives, namely that the distinction between the 'then-now' self is misleading. For one, as we saw, if we take identity in its numerical understanding, there is and will always be one person. Furthermore, even severely demented people retain some continuity between the 'now' and 'then self.' Even when such continuity may seem to be totally gone, it may simply be 'dormant.' Aquilina and Hughes recount the story of Mrs. G., who suffered from dementia and was mute and not interacting with her husband. After taking an anti-dementia drug, she showed tremendous improvements. Her case demonstrates that even when the self seems to have disintegrated, it actually may persist (15). The case of Mrs. G, which is not unique, leads us to believe that something of the 'self' remains even if dementia brings significant changes to a person's identity.

The monolithic framing of dementia is, therefore, problematic in several respects. First, it is erroneous within the frame of biomedicine since, as we have stated, dementia is a syndrome encompassing different conditions. Hence, it may lead to a misunderstanding of what dementia is among lay audiences. Notably, the fact that it does not affect everyone in a single unified way means that there are actually many unknowns in the prognosis (22). As we have shown, such thoughts are mistaken; they lack the granularity necessary to understand the variety of conditions dementia brings together, and it overlooks that predicting the exact extent of the cognitive decline after diagnosis is currently not possible. It is all the more problematic because misleading people has practical consequences starting already with the diagnosis, which itself can amplify the disability that could result from the pathology (3). This leads to the second aspect: the framing by being misleading may result in mistreatment and harming of people with dementia. Picturing an inevitable cognitive worsening akin to annihilating the person contributes to stigma and harming people with dementia (4). We need to highlight that what makes the framing especially problematic here is that the wrong done to them is insidious and pervasive. Pervasive because it is widespread and unavoidable: most stories, discourses, or diagnoses put an emphasis on the destructive aspects of the pathology. Insidious because this emphasis may lead to the viewing and defining of people with dementia primarily in defective terms, resulting in a malignant positioning leading relatives and carers to behave disrespectfully albeit unwittingly (24). Far from being an epiphenomenon, professional literature and lay public press is rife with malignant positioning.[12] Following Smedinga et al. (4), we advance (and will explore further) that current framings and jargon may be harmful and ought to be carefully used when communicating to lay audiences, media, or elsewhere. Because framings can steer people's understanding and be linked to moral appeals (4), it is a powerful tool to use, and reframing dementia can help us better understand and treat people suffering from it.

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[11] See discussion on advance directives in the previous section and, in particular, Dworkin's position.

[12] For exceptions, see footnote 6.

Reframing dementia

While, as stated previously, the negative framing of dementia is pervasive across lay and professional contexts, discursive spaces explicitly reframing dementia and offering important counternarratives exist.[13] For one, scholarship in dementia studies in dialogue with and supported by activist organizations such as the Young Dementia Network and DEEP have engaged in uprooting pervasive issues with problematic dementia narratives and advocated for different understandings of it (25). In this section, we highlight some of the ways in which reframing dementia would be possible. In the introduction, we characterized dementia as present in a broad range of pathologies and medical conditions characterized by a decline in cognitive abilities. The prospects of cognitive decline turn dementia into an often terrifying diagnosis. For many, losing personality, identity, or memories may register as a condition as fearsome as death (12). While we do not intend to underestimate the potentially severe implications of cognitive decline, we want to suggest that beyond these destructive aspects, cognitive decline is part of life and can be framed differently.

One alternative framing is to consider cognitive decline (and dementia) as part of 'normal aging.' Most will experience some form of cognitive decline over their lives, whether or not that decline meets the diagnostic thresholds of dementia. Researchers have suggested that the differences between age-associated decline in cognitive functioning and dementia are more quantitative than qualitative (26). Moreover, it has been suggested that distinguishing between 'normal,' age-related cognitive decline and 'cognitive decline' resulting from a neurocognitive condition at a neurobiological level is difficult (27). That is a reason why defining AD's boundaries precisely, for instance, is still complex because all of its individual features occur in normal aging to some extent (28). With aging, we generally become forgetful; people with dementia – according to this view – are 'just' more forgetful. Even if this position was recently reformulated, considering the memory difficulties and behavioral changes coming from dementia as related to normal aging is not new. This view was dominant in Western cultures until the 1970s (26). In fact, 'dementia-as-normal-aging' was once considered a fruitful explanatory model to understand dementia. However, it has since been partially abandoned due to its problematic implications for therapeutic contexts. In what could be called a 'social model of dementia,' stigma and suffering are explained mainly in reference to ageist social conditions. In societies where older people were respected and revered, people with dementia held similar esteem, whereas, in ageist societies, they suffered from dementia and were treated like other older people (although they arguably suffered more as they were more vulnerable and had less coping capacities) (26). A strictly social model of dementia, however, has difficulty recognizing the vulnerability and specific needs associated with the pathophysiology of dementia. Moreover, in terms of care, no special treatments or additional health resources were expected to be given to people with dementia over and above the ones for older people (26). Additionally, within a social model of dementia, it is difficult to account for harms (e.g., dizziness, sexual dysfunction, blood pressure, etc.) directly associated with dementia pathophysiology. For such reasons, this explanatory model was progressively abandoned and replaced by others, notably dementia as a neuropsychiatric condition that, despite its disparate etiology, is the result of underlying progressive brain disease. The framing we have been criticizing so far is grounded in this latter model of dementia, which is still dominant among professionals and lay audiences.

Nevertheless, this model has already been heavily criticized in the past for neglecting social and psychological factors. Moreover, for some, it was deemed too reductionist in its biological determinism and could not account for different facts about the social reality of dementia (26). Kitwood, notably, had significantly contributed to a change of perspectives advocating that 'the person comes first' (29). He proposed a new explanatory model by introducing the use of person-centered care (PCC) to distinguish a certain type of care approach from more medical and behavioral approaches to dementia (30). In this model, dementia is considered a dialectical interplay between neurological and social-psychological factors (31). Emphasizing the latter allows for a more comprehensive and less deterministic understanding of people with dementia. His view flourished and was impactful, notably through its influence on the biopsychosocial model of illness the WHO promoted (26).

As explanatory models have moved away from 'normal aging' to be more comprehensive and put the emphasis on the person and her needs to provide appropriate care, it may seem awry and counterintuitive to advocate for it. Nonetheless, we contend that this explanatory model still has value and can foster a better understanding of people with dementia. First, holding on to one explanatory model does not preclude excluding the others. Individuals or societies can hold several simultaneously or fluctuate between them (26). For this reason, we do not believe that a normal aging explanatory model necessarily entails not giving special treatments and care to people with dementia compared to other older people. On the contrary, we think that seeing dementia as inscribed in the process of normal aging can and ought to be compatible with models such as the one of Kitwood that highlights the need for interpersonal care aiming at the preservation and enhancement of the personhood (29, 31). With this mindset, the value of resorting to 'normal aging' lies in its potential to break down the barriers between 'us' and 'them.' Gubrium (32) argued that the attempts to establish distinctions at a neurobiological level were rather a social construction from the cognitive functioning ones to set them apart. Post (33) was going in the same direction when he observed a persistent bias against people with cognitive disabilities. If we want to include people with dementia and care for them, it requires us to deconstruct these barriers we have erected individually and collectively (23) and that a misleading framing of dementia perpetuates. Seeing dementia and the declines that go

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[13] By no means do we intend to undermine or underestimate the tragicness and seriousness dementia may encapsulate, nor the value of a biomedical framework. Receiving a diagnosis and living with dementia is generally challenging, both for the person and her surroundings. Nevertheless, as we argue further having a more nuanced understanding of what living with dementia entails may benefit patients, families, and care givers alike.

along with it as 'normal' rather than as 'defective and destructive' can emphasize our common humanity. Having this commonality in mind would allow us to relate to people with dementia in most respects with the same considerate and caring ways we relate to others (23).

While the PCC model represented a breakthrough in understanding and caring for people with dementia (amongst other conditions), substantial criticism has since emerged, emphasizing PCC's shortcomings, especially from the perspective of nursing staff and caregivers (34). In short, these critiques underline that neither Kitwood nor his contemporaries properly considered the resources and implications for caring staff and the structural changes required to treat people with dementia according to PCC principles (34). Although their concerns do not question the benefits of PCC, (Critical) Dementia Studies have moved to another stage, beyond a merely medical or social model of disability, as they engage in the shared project of 'de-centering' or revising notions of self and personhood and their associations with forms of power by grounding them in concepts such as relationality or embodiment (34). Embodiment in dementia, while maintaining personhood, eludes the reductionist account where a person would equate to her brain by looking at how dementia is expressed bodily and not strictly in cognitive ways. Fuchs, for instance, advances a conception of personhood rooted in the phenomenology of the body: selfhood is primarily vital and bodily (16). In short, for Fuchs, everything we do, consciously or not, has a bodily foundation that is never totally lost, even in the case of dementia. He justifies it by grounding the continuity of a person in body memory, the experiences sedimented in the body through life rather than in the repertoire of memories stored in the brain (16). Without expounding further on these views, resorting to concepts of embodied personhood can change how we view and treat people with dementia.

Rather than framing dementia on exclusively cognitivist accounts supporting views of autonomy, a relational embodied account stresses the importance and relevance of viewing people with dementia in their environmental and social contexts, in their own individual embodiment (16). Hence, although dementia remains a destructive experience, as without question, it deprives people of capacities such as reflective thought, which are crucial for one's own sense of identity, embodied approaches such as the one put forward by Fuchs emphasize that habits, sensory, and mentor memories remain, nonetheless. Even if Deter was saying 'she lost her-self,' she had to retain some sense of self to be able to state it, highlighting again that the 'self' was not simply totally gone and lost. So, while it does not discount destructive features of dementia, understanding selfhood as essentially bodily, we can arrive at a different perception of people with dementia: not just people who have lost their rationality and would be less than persons, but on the contrary as persons with bodily and intercorporeal personhood realized as long as they keep living in appropriate surroundings (16). Furthermore, adopting such a view and stressing the importance of the environment for the person with dementia allows us to advocate for the necessity to reconsider her and what appropriate biomedical care would be. In short, it comes down to rethinking whether it is the care networks that are not adapted rather than viewing the person with dementia as alienated (35).[14] (Body) memory is increasingly taken into consideration to understand dementia, with the purview to revise notions of personhood. More specifically, critical dementia studies have emphasized the need to rethink the 'category of people with dementia' to understand better the lived experience of these people (25, p. 5). We want to stress the critical importance of following this way, supporting initiatives and opportunities such as the one of Sandberg and Ward, who have encouraged people with dementia to write about their life experiences and openly share their perspectives using different (creative) forms such as photo reports.

Epistemic injustice and the framing of dementia

As stipulated previously, the predominance of a specific, negatively-laden monolithic framing of dementia may have significant implications regarding social stigma and the treatment of people with dementia. This seems particularly problematic since alternative resources rooted in dementia experience and subsequent academic engagement with those experiences suggest different, productive ways for treating (people with) dementia. In this section, we diagnose this tension and suggest it plays an important part in perpetuating the dominance of a reductionistic framing of dementia, which itself fosters distinct epistemic and practical harms. More explicitly, we contend that this unilateral, reductionist understanding of dementia is rooted in and propagates various forms of *epistemic* injustice. After a short introduction to Miranda Frickers' initial account of epistemic injustice, we suggest that the uniliteral framing of dementia is perpetuated by an active and persistent ignorance per the biomedical community.

It is precisely this contributory injustice that lies at the root of and exacerbates the testimonial and hermeneutical injustice people with dementia are vulnerable to.

Epistemic injustice

Miranda Fricker coined 'epistemic injustice' to stipulate the harm resulting from "(…) a wrong done to someone specifically in their capacity as a knower" (36, p.1). She argues that being wronged as an epistemic subject is to be wronged in a capacity essential to human value (36, p. 44). In addition to the primary harm of objectification, failing to express one's epistemic agency often involves particular practical harms as well. In the context of dementia, we will show how epistemic injustice may lead to

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[14] This point is critical as it could also lead to another injustice by overlooking the fact that the environment may have a predominant role in the willingness of the 'Now-Self' to end their life or not. A person with dementia living in a flourishing environment with appropriate care may well rethink her advance directives, while one living in a poor care structure may, on the contrary, may be more inclined to follow them through.

communicative issues impacting dementia care, as well as implicate discussions on advance directives.

Fricker distinguishes between two forms of epistemic injustice. Testimonial injustice concerns the prejudicial deflation of a speaker's credibility based on an identity-related stereotype. The prevalent dismissal of women's testimony on the grounds of it being overly emotional and subjective constitutes exactly the type of prejudicial credibility deficit Fricker captures in testimonial injustice. In addition to prejudicial credibility deflation, unjustified *in*flation of credibility can similarly result in testimonial injustice. Since credibility is a comparative good, the attribution of credibility to one person may result in a proportionate downgrade of another's credibility. An overestimation of an actor's epistemic authority can then result in a related testimonial injustice (37, 38). Hermeneutical injustice, the second form of epistemic injustice, occurs when an epistemic subject is hampered in understanding or communicating their experiences due to a hermeneutical gap in our collective repository of epistemic resources[15] owing to the structural exclusion of particular identities from meaning-making practices. Fricker provides the example of Carmita Wood, who, before the widespread availability and uptake of the term 'sexual harassment,' experienced distinct moral and practical harms due to an inability to understand and communicate her experiences of (workplace) sexual misconduct.

Subsequent literature has expanded significantly on Fricker's initial account to include a variety of other ways in which the epistemic agency – i.e., the ability to use, contribute to, and transform knowledge of subjects – can be thwarted (40). Drawing on this literature, in what follows, we argue that insistence on the conceptual framing of dementia as strictly detrimental and destructive despite the availability of other (complementary or even superior) ways to conceptualize dementia is rooted in a form of *actively and structurally maintained ignorance* (41). That is to say that, despite the availability of alternative means to understand dementia, societal and medical discourse largely (and structurally) ignores alternative contributions to the dementia imaginary. The recalcitrance of this flawed framing of dementia may be morally problematic since (i) it is based on a wrongful epistemic exclusion and persistent failure to engage with the understandings that arise from communities of people with dementia, and (ii) results in significant moral-epistemic and practical harms through depriving prospective people suffering from dementia the means to properly understand dementia and rendering the experiences of dementia unintelligible further deflating their credibility as interlocutors. It is important to note from the outset, then, that the epistemic harms associated with dementia are not merely the result of vicious caregivers or healthcare professionals – or *bad apples* – but rather have important structural origins and, therefore, require structural solutions.

Contributory injustice

As previously described, the framing of dementia, as it took hold in the social imaginary, seems to espouse a persistent yet unilateral and ultimately flawed understanding of the breadth of experiences of living with dementia, such as experiences of lucidity, adaptive interests, and expressions of personal growth. Moreover, despite the available alternative perspectives on dementia arising from people's experiences, activist groups, and patient organizations and validated by academic engagements in aging and dementia studies, the representations we draw upon in public debate, biomedical discourse, and popular culture still seem oblivious to such counternarratives. This persistent failure to engage with what are arguably more informed, better representations of dementia owes to what Kristie Dotson has labeled 'contributory injustice' (42).

Contributory injustice entails a dominant epistemic agent's or institution's willful and situated ignorance "in maintaining and utilizing structurally prejudiced [epistemic] resources that result in epistemic harm to the epistemic agency of the knower" (42, p. 9). Contra Fricker's treatment of 'collective epistemic resources,' Dotson suggests that marginalized groups often do develop an alternative set of epistemic resources that run counter to a dominant understanding. Indeed, in order to make sense of the specificities of experiences of oppression, typically not shared by dominant groups, marginalized knowers generally do or are even required to devise and share their own concepts, languages, and understandings. As such, while they, over time, collectively develop a linguistic sense of understanding of their experiences, a central issue to the perpetuation of epistemic injustices lies in that these resources often fail to garner uptake within dominant communities. We should, therefore, distinguish between *dominant* epistemic resources and *extant* resources arising in and through the experiences of marginalized people. It follows, then, that the issues related to hermeneutical injustice do not exist only in the unavailability but rather in a persistent neglect of these resources and the experiences they accompany in dominant knowers. Recall the example of 'sexual harassment' arising from shared workplace experiences of women. This concept first needed to find uptake beyond 'consciousness-raising groups' and, notably, with those in the position to affect (political) change (institutions, academic administrations, etc.) before the harms related to hermeneutical injustice could be mitigated. Despite the availability of epistemic resources sensitive to their experiences and oppression, marginalized groups are often impeded in *contributing* this knowledge to the conceptual repository operative within the relevant context, i.e., the set of dominant epistemic resources.

The aforementioned recalcitrance of a dominant view of dementia un- (or minimally) informed by more nuanced resources arising in patient, activist, and academic spaces patients is indicative of contributory injustice. While more nuanced resources do exist, are widely shared among dementia communities and patients, and find support in academic spaces and some healthcare professionals (see footnote 6), they generally fail to garner substantial uptake in broader societal dementia discourse. This is morally problematic for two reasons. First, it constitutes an injustice in itself since those in relevant meaning-making positions fail to show the necessary epistemic due diligence with regard to the resources available. Given that these alternative resources offer an important complementary understanding of the

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[15] Epistemic resources entail the concepts, language, and normative criteria we have available to make sense of our world and experiences (39).

phenomenon of interest, i.e., dementia, and are reasonably available, the burden of proof with regards to their irrelevance falls with those staying with the monolithic understanding offered above. Second, and importantly, the epistemic exclusion of these resources (and these epistemic communities more generally) in relevant meaning-making practices (i.e., institutions, clinical practice, and academic philosophy) may have important downstream consequences on the experiences of those living with dementia and dementia care alike. For example, while more nuanced resources to understand living with dementia exist, the resistance they encounter when transitioning to the wider conceptual repertoire may block (prospective) people with dementia's access to helpful, more nuanced tools to make sense of their own experiences. More generally, the unavailability of these – often more adequate – resources constitutes epistemic harm to the wider community to the extent that family members or caregivers are denied access to such tools, potentially hampering proper (self-) understanding (43). This might then contribute to, perpetuate, and even intensify hermeneutical and testimonial injustice.

Hermeneutical injustice

Recall that hermeneutical injustice concerns the harms that occur through the unavailability of epistemic resources necessary to make sense of or communicate one's social experiences owing to a structural exclusion from dominant meaning-making practices. As Kidd and Carel (2014), Kidd and Carel (44) have explored extensively, hermeneutical injustice is prevalent in clinical practice. Patients' experiences are not generally sought out, considered, or even wholly excluded from policy and research (45). Indeed, although there are some improvements in engaging patient representatives and organizations in biomedical research, clinical boards, and policy-making, historically, patients have rarely been consulted or asked to participate in the development of clinical epistemic resources (44). This may, in turn, introduce several difficulties for self-understanding and communicating illness experiences.

For one, hermeneutical injustice may arise when the resources necessary to convey first-personal aspects of illness are not (sufficiently) available or acceptable in the clinical imaginary. Given that our extant epistemic resources on illness are primarily informed by a biomedical framework – focusing on biological dysfunction rather than illness experience – patients may encounter difficulties in conveying important social and phenomenological aspects of living with illness. Caregivers may, for example, fail to understand or see the significance of prevalent illness experiences such as feelings of loss, bodily betrayal, and social exclusion (44). Second, hermeneutical injustice may also occur through a lack of resources to understand *particular conditions*. People suffering from so-called contested conditions such as CFS/ME, fibromyalgia, and more recently Long Covid, or conditions that are unfamiliar to large swaths of healthcare professionals, such as endometriosis, often take years to arrive at a diagnosis (46–48).[16] This, too, constitutes a hermeneutical injustice since the exclusion of these resources is in part attributable to a prior marginalization of these patients in medical meaning-making. The wider unavailability of those resources to understand patient conditions hampers attempts to communicate their experiences to and with healthcare professionals.

Both forms of hermeneutical injustice have been described in the context of dementia as well. Given that dominant narratives on dementia characterize this experience as dominated by loss, suffering, and decline, it is clear that those living with dementia are vulnerable to hermeneutical injustice to the extent that other, more nuanced resources are unavailable, hampering (self-) understanding and communication. For one, framing dementia in the ways explored above may directly inform the communication opportunities of people with dementia. As Kitwood reminds us, malignant social processes, resulting in and perpetuating the infantilization and disempowerment of people with dementia, may lead others to be unperceptive to – i.e., lack the necessary resources to understand – the meanings of people with dementia being conveyed, and hence, deny the person with dementia's standing as a semiotic subject (Sabat and Harré, 1994). This may be particularly problematic for those living with dementia outside the frame of its societal representation. Dementia activist Helga Rohra recounts several instances of her and fellow activists' dementia status being cast in doubt due to a limited understanding of what dementia can be (Rohra, 2023). For one, she recalls a physician questioning the structured speech in which a fellow activist expressed herself. During the presentation of her own book, *Stepping out of the Shadows*, an audience member interjected that, surely, she had to be an actor; someone with dementia would never be this articulate (Rohra, 2023). Similar issues of communication and understanding are rife in the literature. Snyder (23) relates the story of a person suffering from AD who, during a support group meeting, expresses concerns about having less authentic exchanges because others treat them (patients with AD) with a 'you need help' attitude. These examples evoke how a limited understanding on the part of medical professionals and lay audiences may impact both how those living with dementia are treated in healthcare and society more generally. Compare this to cases of young onset dementia, where patients experience significant delays in attaining diagnosis due to physicians taking their concerns less seriously since they present as 'healthy' or 'still working' or prodromal symptoms (such as sleep disorders, behavioral alterations, or motor symptoms) of dementia not being registered as such, but rather as psychiatric conditions (O'Malley et al., 2021). In these cases, rather than strict communicative difficulties, it is a limited view of the clinical presentation of dementia that hinders healthcare professionals in proper diagnosis. Finally, the dominant framing of dementia as a deleterious and destructive experience also discounts the possibility

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[16] Note than that these issues do not merely arise in cases of 'missing or unsupported' diagnoses. Rather, conditions such as endometriosis have been adequately described, and clear diagnostic conditions are stipulated. The widely reported issues in arriving at a diagnosis relate to a lack of understanding of the condition within the biomedical community. As such, even if 'endometriosis' or similar conditions are known, individual physicians may lack the necessary resources to properly understand their breadth and extent in actual patients.

of understanding that dementia does not preclude positive appraisals of life and well-being. As Hertogh et al. emphasize, recently diagnosed AD patients tend to adapt to the new realities of their condition – resulting in pushing back or canceling earlier set advance directives. Akin to a 'disability paradox,' those living with dementia often transition towards a positive outlook on life (Hertogh et al., 2007).[17] These and similar experiences can be adequately understood as downstream effects of contributory injustices. Since those in positions that affect our wider understanding of dementia fail to engage with extant resources arising from those with relevant illness experience, hermeneutical gaps in our dominant frameworks persist, resulting in issues of understanding and communication of dementia experiences. This, moreover, has further downstream effects on how people with dementia are perceived by their interlocutors. Indeed, as José Medina notes, hermeneutical injustices may function to produce 'social forms of blindness and deafness' that impact communicative practices as well (37). Indeed, contributory and subsequent hermeneutical injustice may disadvantage people with dementia in communication by rendering their experiences unintelligible or nonsensical, reinforcing their vulnerability to testimonial injustice.

Testimonial injustice

Recall that testimonial injustice involves the prejudicial (preemptive or reactive) de- or inflation of a speaker's credibility based on identity-related stereotypes (36, 37). People living with dementia may be particularly vulnerable to this species of epistemic injustice. We suggest three reasons why this may be the case.

First, considering testimonial injustice in the case of dementia, we can straightforwardly advance that the current linguistic, cultural, and biomedical representations of dementia operationalize a variety of negative stereotypes that may function to deflate people with dementia's credibility, epistemic authority, and reliability. Constructions of dementia as 'identity-consuming,' 'hopeless,' and 'total and irrevocable' influence how people with dementia are perceived as persons but also as epistemic agents. This, however, is generally unfounded since these severe forms of cognitive dysfunction rarely arise, if only in severe cases of late-stage dementia (49). In addition to the total and global loss of cognitive reliability, Young and colleagues have identified a variety of stereotypes perpetuated in various contexts fueling defective ascriptions of people with dementia's credibility. Several metaphors prevalent in portrayals of dementia carry distinct epistemic valences. Portrayals of dementia as 'a return to childhood,' a 'mindless body,' or patients as 'empty shells' reinforce an understanding of patients as effectively unreliable, naive, or defective interlocutors. Finally, the expectation and anticipation of future loss have also been identified as effectively deflating people with dementia's credibility beyond reason (44, 50).

Second, as stipulated above, the dominant hermeneutical resources on which caregivers and others rely to understand dementia seem misaligned with the actual experiences of dementia. While this – as stated earlier – constitutes a potential hermeneutical injustice, it may also reinforce testimonial injustice. When patients rely on particular expressions or (non-propositional) ways of conveying experiences that seem to run counter to an established understanding of dementia, they might come across as nonsensical or confused, further deflating their credibility.

Thirdly, while dementia may, in general, increase one's vulnerability to testimonial injustice, people with late-stage dementia may be particularly susceptible to credibility discounting. Dementia progression is often accompanied by language impairments such as issues with phonology, syntax, or vocabulary (49) or even a complete loss of linguistic abilities. This results in the reliance on non-verbal communication, including pointing, pulling towards, pushing away, and facial and artistic expressions to convey basic needs, interests, or demands in exchanges with family members, friends, or caregivers. While the (partial) loss of linguistic abilities may hamper communication, it does not, in principle, inhibit those dependent on non-verbal communication from expressing epistemic agency as proverbial 'speakers.'

Spencer (49) argues that we do generally take gesture, movement, and other forms of non-verbal expressions as epistemically loaded - we do discern some sense of meaning from gestures and other bodily expressions. While a lack of linguistic capacity on the part of the 'speaker,' at face value, limits one's epistemic agency, the 'epistemic loadedness' of non-verbal communication and our general sensibilities to assess meaning in gestures, movements, and facial expressions means we can, in principle, extend attributions of epistemic agency to non-verbal knowers as well. If this is generally so, a failure to (selectively) extend these sensibilities to (non-verbal) people living with dementia, denying the epistemic-loadedness of their expressions, and therefore depriving them of their epistemic agency constitutes an additional form of (non-verbal) testimonial injustice.

Drawing upon recent empirical evidence, Spencer suggests that people with late-stage dementia are rarely allowed to exercise their epistemic agency. Even in care contexts, the non-verbal testimonies of dementia people rarely register as epistemically-loaded. They can, therefore, be subjected to a specific non-verbal form of testimonial injustice. This can occur pre-emptively when a hearer *a priori* decides not to engage with the person given an expectation of their lack of communicative capabilities – effectively silencing the person. On the other hand, a caregiver may engage with the person but register their non-verbal expressions as meaningless, delusional, or not epistemically charged (49).

While these concerns primarily track credibility *deficits* impacting how those living with dementia are treated as knowers, credibility excesses (37) of other actors might similarly implicate how those living with dementia are treated in epistemic practices. Consider the following case based on personal experiences: Mrs. M, an 89-year-old widow, was living alone in her house and suffered from early symptoms of dementia. One day, after falling, her condition worsened. She had difficulties moving around, showed

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[17] See also work on dementia as transformative experience for similar arguments (Boerstler, 2017; Walsh, 2020).

short-term amnesia, and had difficulties finding words to express herself. She had to go to a medical retirement home and was placed under judicial protection. Shortly after, a physician came to assess her state, declaring that Mrs. M could no longer express her will concerning her situation. As time passed, Mrs. M showed improvements, with good and bad days. On bad days, she would be exhausted, barely react to people around her, and seemed lost. On good days, she remembered a lot of her past life, recognized people, and could follow basic discussions. However, as the legal procedure followed its course, discussions, and decisions concerning Mrs. M were taken without consulting her based on the initial medical certificate issued by the physician. Rather than merely an instance of a prejudicial credibility deficit, the case of Mrs. M highlights the dynamics of excessive credibility attributions in dementia care. Although her relatives offered a more nuanced view of Mrs. M.'s cognitive state, and Mrs. M. herself was intermittently capable of expressing her will and interests, the (single) assessment of a healthcare professional (crystallized in a medical certificate) was granted authority over other testimonies – both in clinical and legal contexts. The point here is that those living with dementia are not merely liable to prejudicial ascriptions of a credibility deficit; their (and their relatives) testimony is often judged inferior to that of a clinician or other healthcare professional.

The analysis above suggests that those living with dementia may be particularly susceptible to a variety of epistemic injustices, increasing their vulnerabilities to moral-epistemic and practical harms (including improper care). Importantly, while these harms may arise due to epistemically vicious caregivers or interlocutors, our treatment of hermeneutical and contributory injustice suggests that these are better characterized as downstream consequences of structural issues in how dementia is framed and treated in dominant meaning-making practices. Crucial to the perpetuation of these harms is the persistence of a monolithic framing and resistance to marginalized resources in public debate, clinical practice, and popular culture. While these issues primarily affect dementia care, the operationalization of a dominant, impoverished understanding of dementia also informs both the practice of and discussions on advance directives. This will be our focus in the next section, where we argue that dementia ethics (i) has to contend with the pervasiveness of epistemic injustice in dementia and (ii) when continuing to draw on and forward a partial view of dementia, it risks perpetuating these injustices.

Return to advance directives

As stated, the decline in cognitive abilities associated with dementia represents several challenges and ethical dilemmas where autonomy and beneficence are in the balance in the perspective of the interests of the person with dementia. Advance directives have emerged over time as a powerful tool allowing a person to have her wishes respected in the event she would not be able to formulate them later on. Despite this promising prospect, advance directives often complexify decisions rather than simplifying them when the will and desires of the 'now self' of the person suffering from dementia conflict with the ones of her 'then self.' While this has sparked discussions and debates, the overall tendency is to honor the moral authority of advance directives, even in such conflicting cases. The position we defend in this paper is that this received view on advance directives may be more problematic than it appears and requires additional scrutiny.

The main reason we put forward is that advance directives are rooted in a framing of dementia, which is itself highly contentious. The dominating framing of dementia has drawn a stark contrast between the person before and after suffering from dementia. Discourses and representations conveyed amidst both clinical and lay audiences have cemented the idea that dementia constitutes a dramatic and destructive experience, a 'monster' that leaves nothing of the person you once were behind. Portrayals of dementia in popular culture, like in movies such as *Still Alice* or, more recently, *The Father*, end with their main characters totally lost and debilitated, as if they were mere shadows of their former self, and have also fostered the crystallization of the idea than the 'now self' is nothing in comparison to the 'then self.' Advance directives essentially appeal to the principle of autonomy, which is deeply rooted in Western bioethics and pervasive in this framing of dementia. As such, we have to highlight that resorting to them in this context and holding to them with high value makes sense because they are the formulation of the person's interests when she was fully capable.

Nevertheless, we reject this approach on the grounds that dementia ought to be, can, and, importantly, *is* being rethought across a variety of discursive spaces. As we have shown, this framing of dementia is problematic since it overlooks an important set of dementia experiences. It is misleading and potentially exacerbates susceptibility to harm, stigmatization, and injustice. Scholars, advocacy groups, and health professionals alike have raised concerns about how people with dementia are treated and advocated for a reconsideration of this framing. Stressing that different models need not be mutually exclusive, we have laid down three possible ways of seeing dementia. First, considering dementia as a part of normal aging, i.e., a form of cognitive decline experienced by most as we grow old. On the other hand, PCC models, rather than focusing on what is lost, stress the importance of care and aim at preserving and enhancing personhood. Finally, more recently, embodied perspectives oppose reductionist accounts equating personhood to the brain by emphasizing that selfhood is also and necessarily embodied. There is a body memory in which one's life experiences are sedimented and persistent, even in the case of dementia. While these different framings themselves are held up to critical scrutiny, they show that rethinking and reframing dementia is a distinct and fruitful endeavor.

Despite these available alternatives, advance directives remain anchored in a framework fostering different forms of epistemic injustice towards people with dementia. Considering these different forms of epistemic injustice (contributory, testimonial, hermeneutical), we advance that the entanglements between the unilateral framing of dementia and epistemic injustice raise several questions for the received view on advance directives.

For one, given the co-occurrence and the mutual reinforcement of communicative barriers and prejudicial dismissals of people with dementia's testimonies due to testimonial and hermeneutical injustice, we can question whether caregivers and healthcare professionals are currently sufficiently equipped to tackle and inquire into the interests of people living with dementia. If – as empirical evidence suggests – our communicative sensibilities are, in general, unattuned to the various alternative ways those living with dementia might express their interests and informed by persistent biases on the epistemic capabilities of those living with dementia, testimonial injustices might lead to a (pre-emptive) dismissal or hampered understanding of the wishes and interests of those living with dementia. Moreover, the overemphasis on advance directives' moral authority may amount to testimonial injustice. If, as Dworkin suggests, we take the interests expressed by people with dementia to be only experiential in nature (as opposed to critical), this may itself involve a preemptive and prejudicial failure to take seriously people with dementia as knowers and further inspire minimal engagement with those interests. The one-sided emphasis on the moral authority of advance directives may itself function to precisely confirm the credibility excess of clinical reports, health care professionals' assessment, and legal documents over the testimonies of those living with dementia and their caregivers.

Second, public (and often publicized) debates on advance directives and euthanasia in the context of dementia, as important instances of meaning-making, may constitute 'contributory injustice.' These discussions, when uninformed or preceded by a more thorough exploration of dementia, populate and reinforce an existing social understanding of dementia and inform the conditions under which people draft advance directives. In this sense, those involved (and often in positions of power or affecting policy) fail to perform their epistemic due diligence by neglecting extant resources and, in effect, build upon a narrow and ultimately flawed understanding of dementia. Importantly, these remarks in the specific context of dementia ethics echo longstanding concerns expressed in feminist bioethics with regard to the detached (and therefore partial) view dominant in principlist bioethics. Bioethical scholarship – notably that of dementia ethics - fails to engage with its own situatedness in that many of its 'arguments' are based on intuitions uninformed by a wide body of literature and experiences of those most critically affected by those debates. We advocate for wider engagement with the experiences and narratives of those engaging in life writing, academic dementia studies, and activist accounts of dementia experiences.

Finally, given that social imagination is colored by a flawed understanding of dementia, we can question whether those drafting advance directives can be considered appropriately informed. In the decision to write up specific advance directives, one draws on one's understanding and appreciation of one's future condition. If those views are dominated by the monolithic understanding of dementia expressed above, it is likely that (potential) people with dementia's decisions are informed by a particular framing of dementia.[18] The fact that something akin to the disability paradox is widely reported for dementia, and there is evidence that people with early-stage AD push back or alter their advance directives suggests that a new outlook on dementia – informed by experience – alters their appreciation of the condition and their assessment of well-being in the context of dementia [19].

Conclusion

In this paper, we suggested that the dominant framing of dementia as a 'monster' or a 'destructive experience' in clinical settings and lay audiences, in addition to stimulating bias and stigmatization towards people with dementia, similarly bears significantly on discussions of advance directives. The importance of the principle of autonomy anchoring the moral authority of advance directives and encouraging a distinction between the 'then self' and 'now self' suffering is, in important ways, indebted to a monolithic representation of dementia insensitive to the alternative epistemic resources arising from the experiences of people with dementia and scholarly engagement in dementia studies.

While the lack of engagement with such resources in dominant dementia meaning-making practices is problematic in and of itself, it raises three particularly thorny issues for the case of advance directives. First, the prejudicial dismissals of people with dementia's testimonies due to testimonial and hermeneutical injustice led us to question whether healthcare professionals (and even relatives) are sufficiently 'equipped' to take into consideration the wishes and interests of the 'now self,' the person with dementia. Second, debates on advance directives may themselves constitute a case of contributory injustice when they are uninformed and reinforce an understanding of dementia crystallized in our social imaginary, which in return also informs the conditions under which people draft advance directives. Finally, given that a flawed understanding of dementia colors the social imaginary, we can question whether those drafting advance directives can be considered appropriately informed.

To reiterate, the problem we perceive with advance directives does not lie in the tool itself but in the framing in which it is rooted and operationalized. Rather than discarding the very idea of advance directives and their use, we do emphasize their

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[18] See for example Cuadrado et al. (51). Here the authors show that presenting alternative framings using different representations of people with dementia led to a positive change in attitudes towards dementia. They contend that using such tools to develop policies targeting at communication of dementia can reduce the stigma associated with it.

[19] While substantial suggestions to this end are beyond the scope of the present text, the alternative framings of dementia as they arise from activism or academic engagements in critical dementia studies can also positively inform advance care planning. In a recent interview study on advance care planning with people living with dementia and their carers, Phenwan et al. (52) stress the co-construction of the needs and decisions of people living with dementia and their carers to initiate and revise advance directives. As such, they echo the importance of considering the relationality of dementia care and advance care planning of (critical) dementia studies against the strict moral authority of advance directives. Another way to conceive of advance directives from the purview of alternative, more nuanced understandings was discussed by Widdershoven and Berghmans (2005). They suggest that rather than being objective decisive statements about prior wishes, advance directives are hermeneutic tools for joint meaning-making. As such, they are not statements to follow when time has come, but tools to orient shared practices of care capable of furthering the autonomy of the person.

importance as tools to be used carefully in the context of dementia. In other words, advance directives should not be taken as measures stipulating exactly what must be done when the moment has come, but rather as instruments in need of interpretation symbolizing the critical interests and view of a good life of the person with dementia. We also put forward that this should be done with a reappraisal of the 'now self,' a self that still has meaningful experiences and interests and is not just the leftovers of a 'then self' deprived of autonomy. In considering advance directives, the 'now self' carries a heavy weight, and maybe a heavier one than the 'then self.'

Data availability statement

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

Author contributions

FV: Writing – original draft, Writing – review & editing. DK: Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Perspectives on advance research directives from individuals with mild cognitive impairment and family members: a qualitative interview study

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Background: Advance research directives (ARDs) provide a promising way to involve individuals with mild cognitive impairment (MCI) in research decisions before they lose the capacity to consent. At the same time, the views of people with MCI on ARDs are underexplored. This study assesses the perceptions of people with MCI and family members on the benefits and challenges associated with ARDs.

Aims: The aim of this study was to investigate the perspectives of individuals with MCI and family members of individuals with MCI on ARDs. We focus specifically on willingness to participate in nontherapeutic research, understanding of ARDs and the ethical considerations involved.

Methods: Thirteen open-ended, face-to-face interviews were conducted using a semi-structured format. Seven interviews were conducted with individuals with MCI, and six with family members of individuals with MCI. The narratives were transcribed verbatim and qualitative content analysis was carried out.

Results: Research participation and ARDs were viewed positively, largely based on altruistic motives and the desire to contribute to society. The participants recognized the potential advantages of ARDs in reducing the decision-making burden on family members and maintaining personal autonomy. They also highlighted challenges in comprehending ARDs and navigating the complexities surrounding potential conflicts between current preferences versus preferences described in an ARD.

Conclusions: ARDs were predominantly seen as valuable instruments that enable individuals with MCI to participate in research. This study provides insights into the reasons why affected individuals are interested in drafting ARDs. These insights can guide the development of supportive interventions that are tailored to assist individuals with MCI and their families in navigating ARD processes.

KEYWORDS

research ethics, dementia, vulnerability, mental capacity, substitute decision making, altruism, qualitative interviews

1 Introduction

The prevalence of dementia is expected to rise dramatically as the global population ages. This development underscores the urgent need for advanced diagnostic and therapeutic options for cognitive impairments, notably, Alzheimer's disease (1). Currently, there is a significant lack of effective treatments for Alzheimer´s disease, which makes research in this context and the development of therapeutic options even more important. Advance research directives (ARDs) have emerged as legal instruments that allow competent individuals to specify how research decisions should be made in the event that they lose the capacity to consent in the future. They have been proposed as a proactive approach for individuals who anticipate cognitive decline, such as those in the early stages of dementia, to prospectively consent to research participation (2).

Despite their potential benefits, ARDs are not yet commonly used in practice. Although several countries have established regulations governing their use, their adoption continues to be relatively low. A study from the US, for example, found that only 11% of the adult inpatients admitted to the NIH Clinical Center during the study period had completed an ARD, although nearly half of the participants were open to research that carried minimal risk without benefit (3). This discrepancy raises questions about the factors hindering the widespread adoption of ARDs, which may include a lack of awareness (4) or a preference to delegate such decisions to proxies (5).

ARDs are considered an extension of patient autonomy into future incapacity. Proponents of advance directives in the treatment context maintain that their ethical foundation lies in upholding the principle of respecting an individual's precedent autonomy (6). In the research context, ARDs are viewed as a way to promote self-determination and express altruism (7).

Concerns have been raised, however, about the ability of ARDs to replace current informed consent. Furthermore, practical challenges related to ARDs, such as difficulties in predicting future research scenarios and ensuring that ARDs are specific enough to be applicable yet flexible enough to cover unforeseen research opportunities, have previously been discussed in the literature (8). ARDs have specifically been discussed as a means to preserve autonomy in the case of dementia and cognitive impairment (9). However, there is a concern that the use of ARDs in dementia research may lead researchers to overlook emotional expressions of participants who, due to their condition, may not be able to communicate effectively. This issue arises when an ARD contradicts current preferences (10).

Despite these challenges, researchers are willing to offer ARDs for various research protocols, indicating a potential shift towards their broader implementation (11). A recent qualitative study from the UK showed that stakeholders, including researchers, practitioners, and members of the public, generally support the concept of ARDs (12). At the same time, the effectiveness and acceptance of ARDs can vary significantly across different cultural and legal landscapes, which can impact perceptions and uptake (13). Empirical research to date has focused primarily on healthy research participants, neglecting the perspectives of those directly affected by mild cognitive impairment (MCI) and their families (14, 15). For this reason, it is crucial to gain a deeper understanding of how individuals with MCI perceive ARDs.

To our knowledge, only three studies have explored the perspectives on ARDs of individuals with MCI or family members. A randomized controlled trial by Stocking et al. (2007) involved 149 dyads and evaluated the utility of an ARD among persons with dementia and their proxies. The findings indicated no significant difference between the groups in terms of enrollment rates, decision-making ease, or proxy comfort (16). A study by Bravo et al. (2016) described an intervention that significantly increased the documentation of research preferences among elderly participants. In their randomized controlled trial conducted in Canada, 80% of participants in the intervention group completed an ARD, a much higher rate compared to those who did not receive the intervention (17).

These results suggest that while ARDs may be feasible, their practical impact on decision-making in dementia research remains uncertain. This underscores the need for further investigation into how individuals with MCI and their families perceive ARDs. In addition to that, it seems important to evaluate the perspectives of persons with MCI also using other methodologies, such as qualitative methodology, and in different geographical areas.

To date, only one study was set in Germany and used similar methodology (18). Jongsma et al. (2020) have addressed the motivations and concerns of individuals with MCI regarding ARDs. This study involved semi-structured interviews with 24 participants who expressed a predominantly positive view towards ARDs. Participants highlighted the importance of drafting ARDs at an early stage. Building upon these findings, our study explores how individuals with MCI and their family members evaluate the use of ARDs, especially in terms of their willingness to participate in nontherapeutic research. While Jongsma et al. (2020) found a generally positive attitude toward ARDs among participants, our study aimed to verify these views, further investigate ethical considerations and extend the focus to include the perspectives of family members.

2 Method

This study used qualitative, semi-structured interviews to investigate the motivations and perceptions of individuals with MCI and their family members towards ARDs. The objective was to comprehend their willingness to participate in research, their understanding of ARDs, and views on the ethical and practical issues surrounding ARD implementation. Thirteen participants, seven persons diagnosed with MCI and six family members of persons with MCI, were interviewed. Some of the interviews were conducted jointly and the rest independently by A.G. and M.Schmi.

The majority of the participants with MCI and family members were identified and recruited through collaboration with a resident in psychiatry (M.Q.) at the University Hospital of Psychiatry in Frankfurt, Germany. This approach ensured access to persons who met our inclusion criteria which was having a confirmed MCI diagnosis. In addition, we recruited two participants, one person with MCI and a family member through a facilitated self-support group for individuals with dementia and their caregivers. The aim was to incorporate views from individuals who are actively seeking community support. This recruitment channel facilitated the inclusion of additional perspectives in our study.

Demographic and professional background details were collected from each participant, including age, gender, nationality and previous profession, in order to assemble a diverse sample. We included three female and four male individuals with an MCI diagnosis, ranging in age from 62 to 85 years. Four of the participants were related. One dyad consisted of a married couple, while the other comprised a mother and her daughter. The remaining participants were not related to each other. The family members consisted of four females and two males, aged between 55 and 78 years. Participants were informed about the study's scope and process before participating. Written informed consent was obtained from all participants. None of them were familiar with the concept of ARDs before their involvement in the study.

Data was collected through semi-structured interviews conducted in Frankfurt between January and August 2019. The interviews followed a topic guide that was developed based on a review of relevant literature and ongoing ethical and political discussions surrounding ARDs. The guide sparked discussions on critical topics, including the aims of biomedical research, distinctions between therapeutic and nontherapeutic research, the concept of "minimal risk" in nontherapeutic research, comprehension of ARDs, and the potential benefits and risks associated with ARDs.

To familiarize participants with the concept of ARDs, they were briefed on Germany's legal framework governing ARDs at the beginning of the interview. In Germany, the Fourth Amendment to the German Medicinal Products Act (*Arzneimittelgesetz*), adopted on November 11, 2016, allows nontherapeutic biomedical research with individuals who are unable to give consent under conditions specified in EU Regulation No. 536/2014. In addition to these conditions, the Fourth Amendment to the German Medicinal Products Act introduced ARDs as an additional safeguard, requiring individuals to explicitly declare their willingness to participate in nontherapeutic research (19, 20).

The interview guide allowed for spontaneous follow-up questions to ensure rich and in-depth data collection. Supported decision-making tools in the form of cards featuring key terms related to the study's themes were used to enhance the comprehension of ARDs and facilitate discussion. Interviews were conducted in settings convenient for the participants, either at the hospital or in their homes. All interview sessions were audio-recorded and transcribed verbatim. The interviews varied in duration, with the shortest being 21 minutes and the longest 47 minutes, while the average duration was 32 minutes.

The data was subjected to a systematic analysis employing thematic analysis methodology, as outlined by Braun and Clarke (21). Initially, deductive coding was employed using an initial coding framework based on the existing literature. This initial phase facilitated the structuring of the analysis around specific, anticipated themes, including the perception of ARDs, the ethical considerations in research, and the understanding of non-therapeutic research involvement. Subsequently, inductive coding was employed to identify additional themes. The coding process was iterative, with codes being continuously reorganized as new data were analyzed. All interview transcripts were coded by A.G. and the resulting code structure was discussed in team meetings with J.G. and M.Scho.

The research protocol, including the recruitment strategy, informed consent process and data handling procedures, was approved by the Research Ethics Committee of the Ruhr-University Bochum (No. 17-6145-BR).

3 Results

The socio-demographic characteristics of the participants are presented in Table 1. A pivotal finding of this study was the predominantly positive attitudes of participants towards research

TABLE 1 Socio-demographic characteristics of people with MCI and family members.

Characteristics	People with MCI	Family members
Number of participants	7	6
Gender		
Male	4	2
Female	3	4
Age		
50-59	0	2
60-69	2	2
70-79	2	2
80-89	3	0

participation as such and the potential of ARDs in their own lives. It is noteworthy that the participants were unfamiliar with the concept of ARDs prior to their involvement in this study, and many participants faced challenges in understanding the complexities of ARDs. The following sections will delineate the nine central themes identified through detailed analysis of the narratives of people with MCI and their family members. Each theme will be illustrated with exemplifying quotes.

3.1 Positive outlook on research participation

Our findings revealed that most participants held positive attitudes towards research and the idea of contributing to it. Participants articulated several motivations for engaging in research, with the desire to contribute to the broader societal good being the most compelling driver. This altruistic inclination was characterized by their desire to help researchers gain "*new insights*" (Person with MCI 5), thus, supporting the advancement of medical science. Furthermore, some people with MCI expressed optimism that their involvement in research could eventually lead to the discovery of a cure for their condition.

3.2 Altruistic motivations for research participation

A significant emphasis in our study was placed on understanding participants' attitudes towards nontherapeutic research, which aims to benefit society as a whole rather than the individual participant. When the distinction between therapeutic and nontherapeutic research was clarified, especially in instances where participants did not initially mention the potential for personal benefit, the altruistic motive for participating in research emerged prominently in the discussions. Most participants expressed their willingness to engage in research if it meant the possibility of aiding others. One participant stated, "*If I can help others by doing it, I'm happy to do it*" (Person with MCI 4). This highlights a prevalent willingness to contribute to the welfare of others beyond personal gain.

This theme extended to a more familial and generational perspective, with participants acknowledging the significance of research in its potential to safeguard the future health of their family members and descendants. One participant, for example, reflected on the hereditary aspects of MCI and expressed a proactive stance towards contributing to research with the hope of contributing to advancements that could benefit their children and grandchildren. The participant stated, "*For me, it is logical that one tries to get the best out of research for oneself, and for others, of course, I have children, I have grandchildren, I want them to be well, and especially if I think about dementia, it might be hereditary, at least from what I've heard, so I'm glad, if research at some point would be able to treat the illness*" (Person with MCI 7).

3.3 Acceptable interventions in nontherapeutic research

In our investigation we inquired about the willingness of participants to engage in nontherapeutic research and their comfort levels with various research interventions, particularly those classified as carrying minimal risk and burden. These interventions typically involve questionnaires, interviews, physical measurements (e.g. of weight and height), blood draws and noninvasive diagnostic measures, such as an electrocardiogram or electroencephalogram.

Most persons with MCI assessed questionnaires, interviews and physical measurements as relatively nonintrusive and noninvasive methods carrying minimal risk and burden. These interventions were generally perceived as neither problematic nor burdensome. A family member stated, "*counting, measuring and weighing: It doesn't hurt me. If you need it, please, you are welcome to have it*" (Family member 2).

This perspective was further supported by a family member who argued that individuals with MCI who can participate in an interview can discontinue research participation if they choose, highlighting the nonintrusive nature of such methods.

Opinions were divided regarding procedures involving blood draws and imaging techniques, with some participants not perceiving them as particularly burdensome, while others expressed reservations. One person with MCI explicitly stated their opposition to blood draws, saying, "*no, for research I wouldn't let someone draw blood from me*" (Person with MCI 4). This difference in opinions highlights the participants' varied understanding of what are considered acceptable burdens and risks in the context of nontherapeutic research.

3.4 Grasping the concept of an ARD

Participants first became familiar with the concept of ARDs during the interviews. Despite their familiarity with advance directives for health care – a concept many had not only heard of but had also had concrete experience with – participants encountered significant challenges in understanding the nuances of ARDs, such as the idea of planning for hypothetical research participation. The concept of ARDs was entirely new to all interviewees prior to their participation in the study. One person with MCI stated: "*actually, I never thought about this before*" (Person with MCI 1).

The difficulty in understanding ARDs was not equally distributed across participants. Family members of individuals with MCI generally exhibited a clearer grasp of the concept, while people diagnosed with MCI themselves faced more challenges, such as understanding complex ideas like "informed consent". This highlights the cognitive demands involved in conceptualizing ARDs, particularly for those directly affected by cognitive impairments.

3.5 Advantages of ARDs

The discussion on the benefits and drawbacks of implementing ARDs surfaced several key points. Persons with MCI and their family members identified potential advantages, with a principal benefit of ARDs being the reduction of decision-making burdens on family members. One individual with MCI stated, "*I don't want that they, yes, for the family members it is relatively hard to decide, yes, and if I decide beforehand, when I decide beforehand myself that I don't want this or that, then it will be easier for them*" (Person with MCI 2).

The aspect of maintaining control over personal decisions, specifically in the absence of decision-making capacity, was another critical advantage underscored by participants. A representative quote from the discussions illuminates this: "*The advantage is that I decide about my, about my life, and I think that's okay*" (Person with MCI 2). This perspective underlines the importance of ARDs in preserving self-determination.

Moreover, participants identified ARDs as a vital tool to enable research that otherwise might not be possible due to the difficulty in obtaining current informed consent, particularly in later stages of conditions such as Alzheimer's disease. A family member observed, "*because I do see that in case of a patient with Alzheimer disease in a late stage, research could not be done otherwise, if he wouldn't have given his informed consent, so this is an aspect that I do think is important, yes*" (Family member 5).

3.6 Potential disadvantages of ARDs and concerns about research participation

Although participants mostly emphasized the advantages of ARDs, some expressed concerns that shed light on potential disadvantages. The refusal to participate in research by means of an ARD was often linked to a general fear of participating in research. A woman with MCI, for example, expressed this by stating, "*I don't want to say anything in advance, that later I can't stand by*" (Person with MCI 4).

Participants also expressed concerns about the possibility of changing their minds in the future, highlighting the difficulties around deciding well in advance of a study's start. A family member stated: "*Yes, whether that really still is the will in that situation is very questionable. Because my will would probably change then too. You often say in theory that if this or that happens, then I definitely want to die. And many people then say: Oh no, I actually don't want to. I always say, it's theory and practice. You have to experience it first before you can really give your judgment on it. It's very, very difficult.*" (Family member 1). Additionally, worries about possible future regret were prominent.

The discourse highlighted the challenges that ARDs may pose for family members, particularly when their views diverge from the directives. One family member expressed concern about the potential conflict this could cause: "*If I would judge the situation differently in that moment, then it wouldn't be helpful, and then, then maybe it would put me under pressure, he wanted it differently, but I think it's not good for him anymore, that could put me in a dilemma […] that could be a disadvantage then*" (Family member 1).

Another layer of complexity is introduced when considering the impact of an ARD decision on caregivers. A family member put herself in the situation of being diagnosed with MCI herself and commented, "*If I would agree to that, then I would indirectly also compel the person who takes care of me to carry the burden of participation*" (Family member 5). This comment underscores the ripple effect of an ARD decision, extending its impact beyond the individual to those tasked with their care.

3.7 Trust in family members regarding decision-making

A significant and unprompted theme emerged during our discussions regarding the trust affected individuals place in their family members to make decisions on their behalf. Many participants expressed a preference for familial decision-making over documenting their own choices in an ARD. One participant stated that he trusted his wife's judgment more than his own due to potential changes in personality over time: "*as I might have written it ten years ago, then I would have been a completely different person, and now, now I am an old person, I might have a lot of experience, and my wife knows my experience, then I, then I need the experience or the decision of my wife*" (Person with MCI 6).

Similarly, another participant placed her confidence in her daughter's professional judgment, attributing to her the responsibility to make the best decisions in the event of any health-related issues: "*My daughter is a doctor, and if something happens to me, then she will find the right way. I leave it to the children to decide what should be done*" (Person with MCI 4).

3.8 Importance of information and communication during ARD development

During the interviews, participants discussed crucial factors in drafting an ARD. The need for professional guidance was emphasized, with many participants expressing a desire for, or even considering it essential to have, a consultation with a physician during the ARD drafting process. This preference underscores the importance of expert advice when dealing with the complexities of ARDs and making informed decisions.

The specificity of ARD content was also a topic of discussion. Participants varied in their views, but there was a consensus on the need for precision in the directives, while also considering the limitations of laypeople in understanding the specifics of research protocols. A family member expressed this by highlighting the need for clarity and guidance: "*That should be relatively precise, but for me, who is not a researcher, I wouldn't know how to formulate that in detail […] the researcher would have to know that […] then I would be presented the catalogue and I could say I want this, but I don't want that*" (Family member 2).

3.9 Navigating conflicts between ARDs and current preferences

The interviews ended with a discussion on scenarios where conflicts arise between the preferences described in an ARD and the current preferences of a person with MCI. This conversation was sparked by a hypothetical case in which a person with MCI who had previously consented to research participation by means of an ARD subsequently exhibited reluctance when approached for a study procedure.

Participants demonstrated a nuanced understanding of the conflict presented, despite initial difficulties with the concept of ARDs. The consensus leaned towards respecting the affected individual's present dissent, emphasizing the ethical principle of autonomy. This stance was expressed by an individual with MCI: "*I think, pulling the arm away and then taking blood, I don't like that*" (Person with MCI 2). Another participant with MCI argued: "*First, one would have to speak with her, with the person, you can't do anything with force there*" (Person with MCI 5).

Participants emphasized the importance of respecting the current preferences of individuals who lack decision-making capacity by highlighting their vulnerability and argued for exclusion from research if individuals are not able to articulate preferences anymore. One person with MCI stated, "*He basically can't speak anymore, and, therefore, can't justify himself, I would say, and that's why one is not allowed to do that*" (Person with MCI 1). Another family member suggested that the research could proceed with other participants to minimize the need to enforce participation against an individual's current preferences.

The conversation also addressed the fact that people in advanced stages of dementia retain their preferences, which may evolve over time. One family member argued, "*a person with severe dementia has a will, too, is not without a will but maybe with a different will than the one he had declared two, three, four years ago*" (Family member 5).

At the same time, a recurring theme was the possibility of reengaging with the individual at a later time, acknowledging the fluctuating cognitive abilities associated with dementia. This approach demonstrates the need for a balance between honoring immediate expressions of preferences and recognizing the potential for change over time.

4 Discussion

Research involving individuals who are deemed incapable of giving consent remains a highly debated and challenging issue. ARDs have been suggested as a way to resolve this ethical dilemma. The participants in this study frequently expressed positive attitudes towards research participation, which confirms previous research findings (18, 22). Many of the participants' responses suggest that altruism and a desire to contribute to societal good are motivating factors. Based on the views expressed by participants, ARDs may offer a way to maintain personal autonomy and could potentially reduce decision-making burdens on family members. Some of the participants also perceived these directives as potentially facilitating important research.

Within the ethical and political discourse surrounding ARDs, policy-makers, dementia researchers and ethicists have made assumptions about the perspectives of people with MCI towards ARDs. Our findings support some of these presuppositions. Previous research (7, 18, 23) has suggested that individuals may be motivated to participate in nontherapeutic research out of altruism or the hope that such research could benefit future generations. Consistent with these findings, many interviewees in our study expressed a desire to contribute to the well-being of others through research participation. Furthermore, some participants hoped that their involvement could potentially benefit their descendants, who may be at an increased risk of developing dementia. A distinctive insight from our study is the prioritization of altruistic motivations over the principle of self-determination in the drafting of ARDs by affected individuals. While theoretical discussions on ARDs (24) value these instruments primarily because they enhance patient autonomy and self-determination, these concepts were found to be of secondary importance to the participants in our study.

However, it is important to question whether all forms of participation driven by a desire to contribute to the well-being of others truly qualify as altruistic (25). Participants may perceive personal indirect benefits, such as a sense of purpose or emotional satisfaction from believing that their actions could benefit future generations. This introduces a potential overlap between altruistic motivations and self-interest, suggesting that what might initially appear as altruism could also partly serve the participants' psychological or social needs.

Another finding of our study is the apparent reluctance among some participants with MCI to commit to decisions via ARDs which they might not be able to uphold in the future. This observation appears to diverge from literature on advance care planning (ACP) for treatment decisions, which documents a generally favorable disposition towards ACP among service users and professionals alike (26). This discrepancy may be attributed to differences between advance care planning for research and advance care planning for health care. ARDs in the context of research involve decisions about participation in future studies that might be unfamiliar at the time of decision-making, in contrast to ACP, which often concerns more immediate medical treatments.

The discourse on the benefits and drawbacks of ARDs revealed varied perspectives among participants on the delegation of decisions about research participation. A significant theme that emerged was the consideration of an alternative to ARDs, where a family member or legal authorized representative makes decisions regarding research involvement. Some argued that ARDs can alleviate the decision-making burden on family members, positing that ARDs serve as a solution that could simplify difficult decisions. Others believed that family members may be better equipped to make decisions about research participation than the individuals themselves at the time of drafting the directive. The theme of trust in proxy decision-makers aligns with prior research that found a general trust in the decision-making abilities of family members on behalf of affected individuals (27). Research also indicates, however, that proxies may not always accurately predict the preferences of the individuals they represent (28, 29). This raises concerns about the reliability of family members or legally authorized representatives in making decisions that align with the affected individual's wishes. While the preference to delegate decision-making to family members exists, an ARD may, therefore, offer a more precise reflection of the individual's preferences. This precision underscores the potential value of ARDs in ensuring that research participation decisions are more closely aligned with the affected individual's autonomous choices.

The definition of "minimal risk" and "minimal burden" is a controversial topic in research ethics (30). This issue is also crucial in Germany, where nontherapeutic research in noncompetent populations is only allowed under these conditions and prior consent in an ARD (19, 20). German legislation, however, does not provide a clear definition of these terms, which creates a significant gap in guidance for researchers, counselors and participants. Participants in this study considered activities such as completing questionnaires, participating in interviews and basic physical measurements as carrying minimal risk and burden. More invasive or intrusive procedures, such as blood draws and the use of imaging technologies, elicited varied responses, highlighting the subjective nature of perceived risk and burden among individuals. Furthermore, the results indicate a clear preference among some potential research participants towards avoiding procedures deemed to exceed minimal risk and burden. Our findings, thus, support previous recommendations that a well-designed ARD should provide a detailed account of various research activities that refine a person's preferences and risk tolerances (31).

The necessity of mandatory counseling prior to the drafting of an ARD has emerged as a significant concern in the discourse surrounding ARDs (20). Our interviews indicate a strong preference among participants for information disclosure provided by physicians. Furthermore, our findings reveal that individuals with MCI find the concept of ARDs and the deliberation about their research participation preferences to be particularly challenging. Consequently, these insights indicate that information disclosure is essential, for both practical and ethical reasons, to ensure that individuals are fully informed and able to make decisions that accurately reflect their wishes and interests. Our findings also suggest that potential research subjects would accept a practical disclosure standard which has been proposed for ARDs (20, 32). In order to inform potential research participants about studies, researchers could describe types of research studies that pose minimal risk and burden, rather than providing information about specific studies (33). This would include information about potential research studies that have not been designed yet.

A longstanding ethical dilemma discussed in existing literature regarding the use of advance directives, particularly in case of dementia, involves the tension between the preference described in an advance directive and an individual's current preferences (10, 34). When the German legislation concerning ARDs was drafted, lawmakers explicitly stated that the current preferences of the individual should always take precedence. A pressing and unresolved practical question, however, is how to interpret and apply this principle in everyday research contexts. Specifically, it remains unclear what types of expressions from a research participant who lacks decision-making capacity should be interpreted as refusal to participate in research or as a withdrawal of consent given previously (35). Our study reveals that affected individuals and their family members have concerns about the potential for research participation to proceed contrary to a person's current wishes. These concerns align with the attitudes of researchers. Researchers in a previous study agreed strongly that current dissent of a research participant should take precedence over their previous consent as stated in an ARD (11). Our results also underscore the need for a minimal threshold for expressing dissent. This means that even nonverbal cues indicating an individual's reluctance or withdrawal should be respected.

Another important aspect to consider is the potential for regret, which is associated with all forms of advance directives. There remains the possibility that individuals may feel differently about decisions they made in an ARD at a later point. It is therefore important to establish mechanisms that allow for reviews and revision of ARDs over time.

The findings of our study are subject to certain limitations. Given the complexity of the concept of ARDs and the inherent challenges it posed to affected individuals and their family members, we used supported decision-making tools (36), including cards featuring key terms, to facilitate understanding. While these aids improved participants' comprehension of the questions, they may have introduced a bias and influenced their responses.

In addition to that, the small sample size of thirteen participants limits the generalizability of our findings.

The selection of participants may have introduced bias as well. The sample was predominantly recruited from a single urban hospital in Frankfurt, Germany. The urban setting of the study may influence the participants´ experiences, as urban populations often have better healthcare access and more progressive views than people in rural areas. In addition to that, individuals who are willing to discuss their preferences for decision-making around research participation might have more defined views on the subject, which could steer the findings towards those with stronger opinions or more positive attitudes toward ARDs. Moreover, the inclusion of dyads (a married couple and a mother and her daughter) likely influenced the discussions about ARDs, as these participants may have shared mutual expectations about each other´s preferences and values.

The temporal gap between data collection and the current date limits the relevance of our findings for the parliamentary discussion around ARDs in Germany, as the Fourth Amendment to the German Medicinal Products Act, which includes legal provisions for ARDs, was passed in parliament in 2016. At the same time, implementation of ARDs has since progressed slowly, and it is unlikely that the fundamental ethical issues surrounding ARDs and the attitudes of stakeholders towards these issues have changed significantly in the meantime. The findings thus remain relevant. Moreover, many jurisdictions worldwide do not have legal provisions for ARDs. The findings from this study can hence inform policy-making in these jurisdictions.

5 Conclusion

ARDs represent a potentially valuable mechanism for ethically facilitating the participation of individuals with MCI in research. At the same time, the deployment of ARDs raises ethical challenges. Our investigation shows that both individuals with MCI and their family members recognize the significance of dementia research and are willing to participate in research by means of ARDs. Although the concept of ARDs was new to participants, they recognized their potential to maintain personal autonomy, reduce decision-making burdens on family members and facilitate crucial research in dementia.

However, our study also highlights the challenges and ethical issues surrounding ARDs, such as the difficulty comprehending their concept, the possibility of changing preferences and the importance of clear communication. The necessity of professional guidance was emphasized by individuals with MCI and their family members alike. Our findings, therefore, support previous recommendations to develop training and educational resources for researchers, ethics committees and organizations to enhance their readiness to involve people with MCI in research (37).

Counseling could play an essential role in this context. Experience from advance directives for healthcare underline the importance of communication and support in the decision-making process. This can be applied to ARDs as well. In addition to physicians, other healthcare professionals and trained counselors could be responsible for counseling.

In order to minimize the challenges and barriers of ARD utilization, our study highlights the need for targeted interventions aimed at facilitating clear communication to ensure that individuals fully understand ARDs. Standardized templates, which have been suggested previously (18), could help address concerns about the complexity of drafting ARDs. By addressing these needs, it is possible to enhance the ethical quality of dementia research and ensure that the voices of those most affected are heard and respected.

Data availability statement

Due to the specifics of the informed consent obtained from participants, the interview transcripts are not available for sharing in their entirety. Participants consented only to the use of anonymized quotes from their interviews in the publication. Selected, anonymized excerpts can be provided upon reasonable request where they do not violate the terms of consent. Requests to access the datasets should be directed to astrid.gieselmann@charite.de.

Ethics statement

The studies involving humans were approved by Research Ethics Committee of the Medical Faculty of the Ruhr University Bochum. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

AG: Conceptualization, Data curation, Formal Analysis, Methodology, Writing – original draft, Writing – review & editing. JG: Conceptualization, Formal Analysis, Writing – review & editing. MSchmi: Investigation, Writing – review & editing. MQ: Writing – review & editing. JV: Writing – review & editing. MScho: Formal Analysis, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1419701/full#supplementary-material

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Ethical implications in using robots among older adults living with dementia

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The aging of the world's population due to accelerating demographic shift on all continents is causing increasing pressure worldwide, giving rise to a "crisis of care" or "care wave." The increase in longevity is resulting in an increase in chronic diseases (such as dementia), an increase in care needs to perform the activities of daily living, and situations of isolation and profound loneliness among older adults. These circumstances are opening the debate on the need to use technology, such as robots, to improve the wellbeing of older adults and their caregivers. The aim of this paper is to address the ethical questions in using social and companion robots for people with dementia, such as concerning consent, the replacement of human care, the potential for increased dependency, and the burden on caregivers. Involving older adults and other stakeholders offers the potential to pursue robotics to support older people while also ensuring a strong ethical commitment. The study is a review of high-impact articles on the topic of the use of social and companion robots with older people with dementia.

KEYWORDS

robots, older adults, dementia, ethics, formal caregivers, informal caregivers, co-creation, welfare technology

1 Introduction

The concept of "social robots" emerged within academic discourse during the early 21st century, with scholars primarily defining them based on their form, functions, and technical autonomy (1). These robots are characterized by their ability to interact with humans and generate expected behaviors during engagement (2–4)."Companion robots," on the other hand, refer to "pet-type robots" that accompany patients, particularly those living with dementia, alleviating their discomfort, improving mood, and mitigating loneliness and isolation (5, 6). However, there is no unified use of the terms. While some researchers emphasize emotional relationships and attachment, focusing on robots like PARO (7), others include cognitive tools with emotional and social focuses, such as MARIO (6). Throughout the article, I refer to both social and companion robots, designating social robots as those focusing on cognitive activities and companion robots as those focusing on emotional and attachment relationships. Both types of robots have demonstrated positive impacts on loneliness and isolation.

However, the debate is open regarding the ethical implications of their use in caring for vulnerable populations such as older people with dementia. In general, there is no clear position but opinions that fluctuate from 'gerotechnological optimism' (8, 9), which sees the utility of robots in avoiding isolation and loneliness, to warnings of the risk of greater segregation and exclusion of older adults and the replacement of human care by machines (10, 11). From an engineering and psychological perspective some aspects have already been identified. However, further research from an anthropological and sociological standpoint is still needed to better understand the ethical implications and the long-term perspective of older adults and their informal caregivers while taking into account the social and cultural implications and how these interact within the groups. The aim of this paper is to contribute to the debate on the use of social and companion robots for caring for older people with dementia while highlighting the ethical implications of their use and the importance of involving all stakeholders to enable a more informed assessment of the benefits and risks and avoid an ageist approach.

The demographic shift cannot be the only justification for using robots with vulnerable populations on account of the "crisis of care" (12) or "care wave" (Horizon Europe project: BB-Future. GA ID: 101093849), which will primarily affect Western societies (13). The demographic transition is progressing more rapidly in South America and Africa than in Europe or areas such as Japan and North America (14). The ethical implications for vulnerable populations are addressed from the engineering and psychological disciplines with the sole aim or justification of improving wellbeing. However, personal, social and cultural consequences must also be reconsidered and analyzed from a broad and interdisciplinary perspective, while the individual's wishes and decisions must also be taken into account. Despite the demographic transition and the dramatic figures – an estimated 46.8 million people worldwide currently live with dementia, and this figure is projected to double every 20 years to reach 131.5 million by 2050 (15) – the use of robots is not justified unconditionally and requires greater reflection on its ethical implications.

The ethical debate has identified ethical issues associated with using robotics and IA with people with dementia. The need for an ethical approach starting from the technology's ideation phase has been highlighted. Engineering students, for example, learn ethical concepts and have an interdisciplinary approach to technology so as to raise awareness of 'embedded ethics', i.e. the integration of ethics into the whole process from design and development to deployment (16). This is related to the involvement of all stakeholders in the robots' co-design process. However, in the case of people with dementia this participation is seen as an impediment because of their cognitive problems (17). Fortunately, research is already being conducted to find an inclusive mechanism that enables older adults technological illiterate or with cognitive problems to use new technologies and engage in participative processes by means of a buddy or facilitator (18). Despite these improvements in technology with a human-centric approach, using technological tools such as robots with vulnerable populations is raising doubts and dilemmas. Concerns are appearing regarding the capacity for robots to understand human pain and human needs when this understanding is already difficult for doctors (19).

Among older adults suffering from dementia, individual use of robots has been highlighted as a cognitive tool to act preventively, alleviate loneliness, and improve quality of life (4). Robots have been particularly beneficial in the socio-emotional sphere (20, 21) with significant socio-affective features (22) and the potential to improve engagement (23). While robots are recognized as valuable tools for people with dementia, further comparative studies are warranted (7, 24). Projects like MARIO, part of the European Horizon 2020 program, have illustrated how companion robots can mitigate loneliness and social isolation among older people with dementia (25), while a protocol for the use of PARO has been introduced for older adults with dementia (26). All current high-impact research must obtain approval for implementation from ethical committees to ensure adherence to ethical requirements and data protection standards. However, follow-up studies on the ethical consequences of these studies have not been carried out post-project and deeper analyses of the ethical consequences in the long run need to be addressed.

Other areas of debate relate to the need for the following aspects: transparency, which means understanding the process used by IA tools and communicating well; trust, in the sense that a reliable relationship with the healthcare professional makes the AI tool more acceptable; accountability, with users able to discuss their use; confidentiality, which is problematic because the integration of the healthcare system makes this difficult; autonomy, to avoid paternalistic attitudes and preserve human dignity; and informed consent. Another ethical issue relates to algorithmic bias, especially with regard to gender and race, where, for example, errors in diagnosis have been made and ageist attitudes have been perceived. Finally, fairness is not guaranteed either because economic difficulties mean that access to this technology is not assured (16). Moreover, there are two sides to robotics: although the existence of cheap robots may make them accessible to the population as a whole, those with more financial resources will be able to choose between technocare and human care whereas those with fewer resources will not.

This paper is a review of high-impact articles, mostly in the Web of Sciences and IEEE Xplore databases, that address the use of social robots and companion robots with older people with dementia: in other words, with the vulnerable population. Most papers analyzed are from an engineering or psychological perspective. The search focused on how their ethical implications, dilemmas or challenges have been addressed, what aspects have been highlighted in the research conducted so far, what their limitations are, and what aspects need to be questioned.

In later sections, I outline the characteristics and implications of using social and companion robots with people living with dementia. First, I identify the ethical implications in three interconnected approaches to human-robot interaction (HRI) with older adults with dementia, i.e., the technical, the psychological, and the social. Second, I address the fundamental ethical concepts, issues and problems that have been discussed and those that may arise when social robots and companion robots are used in research with older adults with dementia and also analyze the implications for the various social levels and stakeholders involved in care (older adults, formal caregivers and informal caregivers). Third, I identify research gaps associated with HRI with older adults with dementia and the possibilities for future research. Fourth, I discuss the ethical challenges in implementing robots in social interventions with older adults. Finally, I present the main conclusions of this review.

2 Ethical implications in using robots among older adults living with dementia

2.1 The ethics of human-robot interaction among older adults: psychological, technical, and sociocultural approaches

During the 1980s and 1990s, robots were mostly a figment of the collective imagination rather than something found in real life. Films commonly depicted robots as agents of the destruction of civilization, while also using the figure of the robot to question the essence, nature, and identity of humankind. By the end of the 20th century, robots were increasingly depicted as humanized entities, grappling with existential questions and striving for autonomy, as depicted in classic films such as *Blade Runner*, *AI*, and *The Matrix*.

Furthermore, the proliferation of robots from industrial services to social functions and companionship has spurred the production of science fiction literature (27–32), with each realm mutually influencing the others. This literature often explores the connections between robotics and ethics, delving into the essence of humanity. For instance, in 2003, Carnegie-Mellon University inaugurated the Robot Hall of Fame, inducting four robots—real or fictional—every two years, an example that underscores the enduring fascination with these objects.

Much of the research on HRI has been conducted from a psychological perspective (20, 33, 34), emphasizing emotional bonds and attachment, particularly evident in interactions with pet robots among older adults or children (35–37). Psychological perspectives regard robotics as therapeutic tools, aiming to enhance cognitive abilities, to engage with people with dementia, and improve quality of life for both patients and caregivers (23, 25, 26, 38, 39). Robots have proven beneficial in the socio-emotional realm, contributing to overall wellbeing (20, 21, 40). Consequently, robots have been viewed positively and are increasingly used to enhance abilities and interactions between individuals with dementia (7, 22). The ethical approach has been based on a substantive rationality following Weberian concepts in which the final aim is to improve the well-being of older adults with dementia by enabling them to communicate with someone or something.

Turning to technical approaches, the field of engineering tends to have machine-centric perspectives on HRI, prioritizing machine viewpoints and focusing on health-related improvements, albeit with less consideration for human outcomes (22). Breazeal (3) characterized social robots from a machine-oriented perspective, emphasizing their social participatory nature and internal motivations: ”Sociable robots are socially participative ‘creatures’ with their own internal goals and motivations. They pro-actively engage people in a social manner not only to benefit the person (e.g., to help perform a task, to facilitate interaction with the robot, etc.), but also to benefit itself (e.g., to promote its survival, to improve its own performance, to learn from the human, etc.)” (p. 169).

Ontological considerations are also pertinent, with robots—particularly anthropomorphic or zoomorphic ones—eliciting expectations regarding their behavior (41, 42). Because of robots' lifelike features, people—and even animals—expect them to perform value-based or instrumental “social actions” (43) when they interact with us. However, this machine-centric or robotic-centric approach often overlooks clear ethical questions regarding the effects of robotics on human beings, especially vulnerable populations. There is a pressing need for research on how robot implementation can enhance the wellbeing of older adults and their formal and informal caregivers. Technology development is increasingly geared toward addressing the care needs and cognitive improvement of older adults suffering from dementia, epitomized by initiatives such as the CLOHTILDE ERC project (GA ID: 741930) (see: https://clothilde.iri.upc.edu/).

Turning to a sociocultural perspective, in anthropology and sociology the focus shifts toward the individual as embedded in the group, with ethical consequences of the use of robotics with vulnerable populations taking precedence. Robots' social embeddedness and lifelike traits are analyzed from a sociocultural point of view. Robots prompt contemplation of what it means to be human and the relationships humans have with other living and non-living entities (44–46). This perspective is crucial because—in an expression of ageism—older adults are often viewed as a homogenous category rather than as persons who inhabit a range of cultures, possess different thoughts and beliefs (47), hold preferences, and have the capacity to decide for themselves what type of care they prefer from the options available. This ethical dimension involves ensuring or reinforcing anti-ageist practices.

Furthermore, the exploration of how humans engage with these new virtual beings outside laboratory settings invites an ontological and posthumanist examination of what it means to have relationships with “other-than-human” entities and to extend “sociality beyond the human” (46, 48, 49): What characteristics do we attribute to these virtual beings, and what sort of animisms and ontologies do they inspire? Where is the line between reality and imagination? Analyzing the social embeddedness of robots from a sociocultural perspective allows us to challenge human centrality and superiority. Robots contribute to overcoming anthropocentrism by challenging the dominion of humans over machines and nature, fostering a more egalitarian positioning within the ecosystem, and promoting new attributions based on techno-animism and a posthumanistic approach (44–46).

Finally, little has been said about HRI from an anthropological, sociological or social work perspective in terms of changes in social relationships such as those within families, kinship networks, communities or peer groups. Recent research underscores these gaps in our understanding of cultural differences and introduces this dimension (50, 51). of cultural differences and introduces this dimension. Fundamental ethical concepts, issues, and problems when using robots with older adults with dementia.

Using social and companion robots in the care of older adults with dementia raises several important issues that have been explored in the social sciences and humanities, particularly from phenomenological and anthropological viewpoints. From a social standpoint, studies of dementia often revolve around concepts of personhood and personal identity, questioning whether individuals with dementia continue to be the same persons they were before being affected by the illness, or even if they continue to be persons at all (52). As Stephen Ames (53) notes, understanding "what happens to the person with dementia" depends "on how the person without dementia is understood." Indeed, definitions of "person" and "personal identity" do not derive directly from empirical reality—and in that sense, they are not "natural"—but rather emerge from historically contingent values and philosophical positions, including brain-based elaborations that were developed in European thought in the late seventeenth century. These perspectives, which present themselves as "scientific," have come to be defining traits of modernity (54). They emphasize the continuity of memory and self-awareness as criteria of personhood and personal identity (disregarding other criteria, such as embodiment, culture, and intersubjectivity). From this biomedical perspective, dementia is treated as a "death in life or life in death" and the loss of human qualities (55). It is understood as a pathology rather than as another way of living. Research from an anthropological ontological perspective (56) has pointed out that people with dementia are often stigmatized even before the manifestation of severe dementia symptoms, impacting their family and social relationships. Dementia necessitates a readaptation to social life and social relationships. In this sense, both robots and dementia put a mirror before us, leading us to challenge our notions of personhood, humanity, and even life itself.

As Steven Sabat and Alison Warren (57) point out, the emphasis on "memory loss" in describing dementia "connotes an inability to form new memories and participate in meaningful social interactions" (p. 1819), contributing to a diminished sense of self and personhood. As Tom Kitwood and Kathleen Bredin (58) have long argued, "The key psychological task in dementia care is that of keeping the sufferer's personhood in being," and this requires seeing personhood in social rather than individual terms. C. Hughes (59), writing on questions of personal identity, personhood and selfhood, states that we aim for "memory to encompass a broader view which emphasizes instead the ability of people to continue to construct their life-worlds through their persisting meaningful relationships" (p. 283). Personhood or a meaningful sense of being, when cognitive capacities are being affected by dementia, can be perceived by the relationship with other beings or objects that can become meaningful or pleasant to us. On a practical level, robots can help older adults participate in social life and in this sense help them, paradoxically, to be a person. At the same time, robots can facilitate interconnection with informal and formal caregivers, thereby becoming a nexus for or creating or improving relationships. This social dimension of robots, which has been explored less, can be positive. However, it can also raise new ethical dilemmas about their use with individuals who cannot provide clear, informed consent or this may be relegated to tutors or other healthcare professionals.

There is a shared optimism regarding the potential of technology to mitigate the limitations caused by the disease, alleviate isolation, and assist in performing the activities of daily living, thereby aiding informal caregivers in managing the care burden. The optimism and hope for positive outcomes are also evident in educational initiatives associated with innovative practices before their implementation. Concerning dementia, the concept of "gerotechnological optimism" is intertwined with values and aspirations but can be tinged with fantasies or wishful thinking. While technology can ameliorate and even help prevent decline and fragility in individuals with dementia (8), it can also be viewed as an illusion, a phenomenon termed "cruel optimism" (9). At the same time, technological optimism is balanced by a techno-pessimistic view and resistance when technology is imposed in caring professions (8, 60, 61).

Despite advances in research, ethical issues persist, necessitating a careful examination of the fundamentally relational processes of HRI and ethical considerations, including social relationships and positionality (62), as well as the "fragility" inherent in the interactions and communication of persons with dementia (63), and the ethnographer's involvement (or lack thereof) in their interlocutors' experience (64). Further issues implied in the use of robots concern individuals' right to decide whether to use the technology, the dynamics of negotiation with end-users, the imperative not to pressure them, the possible reinforcement of ageist attitudes, and unequal access due to illiteracy and unaffordability.

Table 1 describes some ethical concerns that must be addressed prior to using social robots and companion robots' for people with dementia, either for empirical research or social interventions.

These issues should be considered from the perspective of patient-centered care when conducting research and healthcare interventions with robots so as to avoid ageist practices. The use of robotics and AI needs to be legally regulated to ensure ethical compliance, mitigate risks, and safeguard the rights of all stakeholders.

2.2 Ethics in artificial intelligence and robotics at the macrolevel

Institutions have the responsibility to regulate the use of AI and robotics in order to preserve an ethical and beneficial use for citizens and, particularly, to respect the rights of the most vulnerable. The European Union (EU) is at the forefront when it comes to the ethical regulation of AI. Aware of the need for public-private partnership (65), it holds a prominent global position in robotics (66). The EU is also at the leading edge of ethical legislation on trustworthy artificial intelligence (AI), with the first legislation on AI being approved by the European Parliament on 13th March 2024 (see https://digital-strategy.ec.europa.eu/en/policies/regulatory-framework-ai) and amendments to regulations (EC) No 300/2008, (EU) No 167/2013, (EU) No 168/2013, (EU) 2018/858, (EU) 2018/1139 and (EU) 2019/2144, and Directives 2014/90/

TABLE 1 Ethical concerns in the use of social robots and companion robots for older adults with dementia.

QUESTIONS TO BE ADRESSED	ETHICAL CONCERNS
1. What are the benefits of social and companion robots for older adults with dementia and for formal and informal carers?	Increase in dependence
	Increase in care work
	Stress and/or rejection of robots
2. How can robots help to address the social and care needs of older adults with dementia in different sociocultural and economic contexts?	Unaffordability of robots
	Rejection of technocare
3. How will older adults with dementia have agency in the decision to use social and companion robots?	Older adults' right to decide
	Advance directives
4. What is the added value of the introduction of social robots and companion robots in nursing homes and long-term care environments?	Lack of privacy
	Older adults' loss of control/ external imposition
5. How can this technology ameliorate older adults' loneliness and improve their wellbeing?	Lack of control of their own data
6. What are the cultural and social drivers to be robots' accepted for being incorporated into the social lives of older adults?	Stereotypes about age, culture, class, and gender
7. What kinds of relationships do older adults and other stakeholders develop with these "other-than-humans'?	Difficulties in distinguishing reality from imagination
	Disappointment or even frunstration
8. What are the social roles attributed to social and companion robots, if any, and the systemic implications in different kinship systems?	Difficulties in choosing from robots than human caregivers or having the possibility to complement one with the other
9. What sort of animism and ontologies are developed surrounding social and companion robots?	Difficulties in distinguishing reality from imagination
	Disappointment

EU, (EU) 2016/797 and (EU) 2020/1828 (Artificial Intelligence Regulation) (see https://www.europarl.europa.eu/doceo/document/TA-9-2024-0138_EN.pdf). Earlier, a white paper on artificial intelligence (67) (see https://digital-strategy.ec.europa.eu/en/library/ethics-guidelines-trustworthy-ai) encompassed robotics and other related technologies. Significant strides have been made in terms of data use and protection, notably with the introduction of the General Data Protection Regulation in 2018 by the EC. Despite these advances, implementing ethics in new technologies is challenging due to different legal structures, technological capacities, and production interests (68).

Efforts are underway to address these challenges through the development of the AI Act, which adopts a risk-based approach to ethical issues from the technology's initial development phase, emphasizing high levels of robustness, security and accuracy (https://digital-strategy.ec.europa.eu/en/policies/regulatory-framework-ai). Unacceptable risks, such as cognitive manipulation of individuals—especially from vulnerable groups—and the use of personal characteristics for profiling, have been identified. Recognizing the importance of ensuring safety and liability implications in AI, the EP and EC advocate for human oversight and coordinated European commitment and legislation, rooted in a human-centered, ethical, and sustainable approach to AI implementation, robotics, and related technologies (66, 67) aimed at "ensuring AI technologies work for people" (p. 2).

The EU is proactively proposing legislation to regulate both the potential risks and opportunities that robotics and AI imply, including job creation and progress toward the sustainable goals of the European Green Deal (66). For instance, there is a need to explore the potential mental health risks associated with engaging with humanoid robots (67). However, regulations often lag behind the development and deployment of technology (68, 69), necessitating ongoing efforts to ensure safety and trust (70). Addressing ethical concerns during the robot design process (71) through co-ideation and co-validation phases can enhance the acceptability of the final product.

2.3 The ethics of care in relation to the use of robots with older adults with dementia

As the use of robots is scaled up to organizational and societal levels, ethical considerations become even more crucial. For example, we must understand how the introduction of robots can affect existing care workers, how affordability may affect access to robots, and how the presence of robots may influence access to and choice of care (72).

According to Alasdair MacIntyre (73), the ethics of care involves interdependence, as people require support from each other at various stages of life. In alignment with this view, Judith Butler (74) describes vulnerability as a "proper condition" of the human being, framing it as a bodily ontology and a "relational social ontology" (75) that operates both at the individual level and as an epistemic framework. This critical perspective sheds light on the violence perpetuated by institutions and underscores how vulnerability is experienced individually yet distributed unequally according to social factors. By acknowledging each other's vulnerability, the ethical dimension of the concept is also developed. Vulnerability is understood as universal and intrinsic to human existence (76, 77), but it is socially produced and therefore has to be addressed collectively.

Butler's framework on vulnerability, particularly from a gender perspective, can be structurally adapted to provide a lens through which to illuminate older adults' specific vulnerabilities, particularly in the face of social actions, new generational dynamics, and technological advancements. From a biomedical perspective, fragility is often linked to bodily health conditions, which in turn influence social vulnerability. In this sense, vulnerability is both biological and social. This underscores, from a social perspective, that human bodies are inherently relational and dependent on each other, rather than autonomous.

Because care is an intrinsic need for all human beings, the provision of care becomes a human right, too. In *Caring Democracy*, Joan Tronto (78) claims that care is a public concern.

Both Tronto (78) and Carol Gilligan (79) highlight that there is no justice in democracy without care. The ethics of care necessitates flexibility and adaptability in different contexts, prompting consideration of whether and how to introduce personal robots. Equity and the ethics of care are particularly relevant for low-income countries, where care is crucial to economic development and work opportunities for women.

Previous research has identified several ethical implications: the loss of privacy and safety if robots malfunction, an increase in workload for caregivers tasked with overseeing robot functions, an increase in long-term care costs, and the possible replacement of human care (10, 11). There is growing apprehension that the use of robots could lead to a decline in human interaction for older adults and a consequent increase in dependency (34, 80–82).

Several studies have thoroughly examined these ethical implications. Allaban, Wang, and Padir (10) synthesize these concerns in six general ethical issues: 1) reduced human contact, 2) loss of control, 3) loss of privacy, 4) restriction of liberty, 5) deception and infantilization, and 6) accountability if something goes wrong (p. 11). In the case of older adults with dementia, to implement a Dementia Centered Care techniques, so as to observe whether the use of robots is something pleasant and positive for them or not is an ethical approach to it. There is apprehension about the potential infantilization of older adults, particularly when pet robots are used for older adults with dementia, with men seemingly encountering more difficulties than women who are accustomed to caregiving activities (83). Robots can also be inserted in a group rather than with individuals as a tool to help generate interaction between older adults and their formal and informal caregivers. Not all end-users are necessarily pleased with the use of social or companion robots. Their reactions should therefore be taken into the account when deciding whether robots should or should not be used in each case. A non-ageist approach means not making assumptions and not imposing this technology even on older adults who are living with dementia.

The ethical implications of using social and companion robots among older adults are greater than in the case of using robots in industrial settings (31, 84). The acceptance of robots is another ethical controversy underlined by scholars (31, 85, 86). This issue warrants further analysis to determine under which conditions robots can be ethically employed. It prompts us to ponder whether their use is legitimate given the imperative to address "the crisis of care," especially for vulnerable populations such as older adults with dementia. There is an ethical concern over the threat to human dignity when technocare is used with frail and vulnerable older adults with dementia, especially when there is no clear informed consent or preference regarding its use.

Both barriers and facilitators have been identified. Privacy concerns appear to be less prominent since no private data is utilized, especially in the case of companion robots. However, other ethical issues arise: for instance, a user's potential inability to distinguish between reality and imagination or between a machine and an animal, which can cause disappointment when the machine has fewer functions than expected. The replacement of human caregivers by robots is another complex issue that necessitates examination to determine the conditions under which it can be accepted. Additionally, social justice considerations, such as equitable access to this technology, warrant highlighting (72).

The use of social and companion robots seems more questionable than that of assistive robots, which fulfill specific care needs or provide physical help. Not surprisingly, there is worldwide cultural variation in how people accept the use of technology for activities traditionally associated with love and care (86). Research shows it to be controversial in Europe (87).

Robots highlight ethical questions about our care values, the allocation of resources, and the pursuit of collective wellbeing. In this sense, they have implications for substantial rationality or formal rationality following Weberian terms (43). The final aim and the values surrounding it are important elements to take into account to ensure an ethical approach. Likewise, Aristotelian virtues, which are placed in the social and community life and individual framework of human beings (73), are discovered in the inherent goodness of each being. The telos, or final aim, serves as the yardstick for ethical deliberations concerning robots and object relations, intertwined with human rationality. From a psychological and biomedical standpoint, implementing robots for older adults with dementia may prioritize cognitive enhancement as the end goal, potentially overlooking other consequential factors, ontological considerations, or even the patient's wishes.

From a social perspective, significant ethical dilemmas emerge regarding the consequences of integrating robots into care practices, following Weberian substantial rationality. This entails considering a blend of values concerning the nature of care and how it is provided. In this sense, stances toward technology are ambivalent: it is both a sign of progress in society and a harbinger of a dystopian future. An initial epistemological question arises regarding the implied obligation to use disruptive technology simply because it has been developed. This underscores the necessity of an ethical approach from the inception of the research process, weighing the appropriateness of adopting such technology for development while ensuring alignment with people's needs (88). Furthermore, ethical issues arise concerning the implementation of robotic technology as substitutes for human caregivers of vulnerable patients, particularly in the absence of clear consent by the end-user. The attribution of agency to these virtual beings by older adults with dementia, for whom the boundary between reality and imagination is blurred, can generate confusion and stress. This aspect requires careful consideration in deciding how to use this technology, among which end-users, and under which conditions.

2.4 The acceptance of social and companion robots among older adults

The acceptance of robots presents an ethical issue that requires careful consideration, particularly in the context of older adults with dementia. Research has indicated a clear lack of acceptance of social and companion robots among older adults without care needs. This reluctance stems from concern about the robots' lack of authenticity, fears of losing independence and being replaced by machines, or the inability to maintain control over the situation (89–91). Interestingly, even older adults with higher education levels who do not have care needs exhibit similar hesitancy toward robot acceptance (92, 93). However, robots seem to be more accepted when they have a specific purpose and task. Factors such as their functionality and appearance have been identified as crucial contributors to their acceptance among older adults (90). Nonetheless, further research on the social implications of robots and their acceptance is still needed (51, 86, 91).

The robots' appearance, as noted by Savery (94) is significant in their acceptance, but perhaps even more crucial is the range of care needs they can address, which appears to strongly influence acceptance among older adults (34, 95, 96). Additionally, technological literacy plays a vital role in improving understanding of and trust in robots (97, 98).

Among older adults, there is a preference for social robots that offer services rather than merely providing companionship. Consequently, humanoid or anthropomorphic forms are more likely to be rejected, especially if they are programmed to simulate a particular person, because of their lack of authenticity (89, 90). Some recent studies also identify gender differences, with women showing more interest in pet-type robots, while men tended to prefer humanoid forms (99).

The acceptance of social and companion robots among older adults with dementia has not been sufficiently addressed in the existing literature. Most studies draw conclusions as if acceptance were taken for granted simply because these robots are seen as disruptive technology (100). Acceptance is often viewed through the lens of the tool's adequacy in addressing cognitive impairment and social isolation from a psychological perspective (6, 25, 38), the perceived benefits in enhancing quality of life (5, 23, 34, 72), or the recognition of the robots' attributes (39). Although the attitude of end-users when interacting with robots is considered, the research tends to take for granted that users will accept the robots and focus instead on personal preferences in how to use them.

It must be stressed that obtaining informed consent can be challenging in the case of older adults with dementia, requiring a guardian to act on their behalf. However, advance directives could potentially address this issue. Currently, non-verbal indicators of users' attitudes toward the robots are used to judge whether consent has been given. This awareness can extend to a broader understanding of the ethical dilemmas surrounding the attitudes of patients who are displeased with the use of robots. Some patients may express indifference or lack of understanding toward robots, perceiving them as meaningless or failing to see their purpose. While this may not necessarily indicate clear disapproval or rejection, it casts doubt on their acceptance of the technology.

2.5 Robots' relationship with informal and formal caregivers

The near-future scenario of the "crisis of care" (101) or "care wave" is characterized by an escalation in the care burden, exerting significant pressure on informal caregivers, particularly women, and increasingly younger people who must take on the role of informal caregivers of their parents and/or grandparents. The crisis of care has multifaceted consequences, impacting the labor market, quality of life, and the health and wellbeing of both formal and informal caregivers. It necessitates a substantial increase in care service provision from both the public and private sectors to address the growing demand for care, placing immense pressure on the welfare state (102, 103). Assistive robots with rehabilitation functions or cognitive tools are seen as a way to relieve the care burden on informal caregivers who care for older adults with dementia. Social robots, on the other hand, have been used for remote control and entertainment (104), while the function of companion robots as pets to provide entertainment and play or give caregivers a rest, lies in the emotive and caring dimension itself.

Some caregivers are optimistic about new technology (105), viewing companion robots as a tool to alleviate caregiving responsibilities, increase caregivers' usefulness (106), and potentially increase the happiness of end-users (39), while also easing the burden of care work. However, it is important to note that in the case of pet-type robots, caregivers are cognizant that some end-users with dementia may reject the robot, experience stress, or simply not take to it (7). This reluctance may sometimes be attributed to individuals not liking animals, rather than the robot itself (72). Regardless, the use of robots for caregiving activities requires adequate training (106). Furthermore, it is crucial to consider the interests of caregivers, particularly informal caregivers, in the design and functionality of robots (107), as they are integral participants in the caregiving process and the care relationship.

The use of robots in nursing homes introduces changes in work organization and creates new tasks, posing certain barriers (108). The high cost of robots means that discussions should take place about robot-sharing (72), which in turn necessitates conversations about how to prevent infections as robots move from patient to patient (83). There are both advantages and disadvantages for formal caregivers, with benefits such as entertainment and cognitive improvement countered by the need for constant supervision and technical assistance, leading to additional work for already busy care workers and therapists (72, 105). (In this sense companion robots such as PARO could be a good option because of their ease of use). Moreover, the costs of technology present a significant barrier to implementation, as robots may not be affordable for all nursing homes, although lower-cost options are available on the market (72).

Despite these barriers and the burnout experienced by many residential staff and care workers, there is a tendency for care workers and healthcare professionals to be more receptive to collective staff activities than individual ones. In this sense, they may be willing to share their experiences with colleagues and, in doing so, innovate with new technological approaches. They also show a willingness to engage in partnerships with professionals outside their institutions (36), facilitating the exchange of views and practices and enhancing their professional relevance as a collective (see https://www.socatel.eu/wp-content/uploads/2021/06/D5.2.pdf).

In addition to the aforementioned considerations, concerns regarding safety in the use of robots have been raised, as their use may pose risks to users (39, 109, 110), and there is potential for problem behaviors. For example, some robots may make it possible for end-users to access gambling platforms. These new ethical dilemmas surrounding the use of robots by patients present challenges for both formal and informal caregivers (107). Despite some negative aspects identified by healthcare workers, such as the infantilization of patients (especially those without cognitive impairments), robots are also seen as a tool for supporting everyday care. Considering the specific factors of each nursing home context is increasingly important to face organizational needs, limitations and drivers. This approach is essential for the social acceptance of this emerging disruptive technology. Involving formal caregivers from the beginning of the co-design phase is crucial (71, 72, 110). As familiarity with the robots grows, so does their acceptance among formal caregivers.

The use of robots for care raises concerns about the potential reduction of human contact, prompting caregivers to reconsider the nature of their roles and how they fulfill them (111). Furthermore, this type of technical care can be perceived as a replacement for human caregivers, potentially leading to the dehumanization of care (72) and the loss of care jobs. The use of robots could be seen as a way of "entertaining" patients, without requiring constant support from caregivers and necessitating only minor supervision.

From an ontological perspective, employing robots with vulnerable populations also challenges the fundamental meaning of care and raises questions about what constitutes optimal care. Can we equate "human care" and "technocare"? Can robots be used effectively for caring for older adults with dementia? Can they substitute human caregivers? Should end-users have a choice in the matter? These are complex issues that society and individuals must confront, and responses may vary across different social contexts and cultural perspectives.

3 Research gaps and future research on the ethics of using social robots and companion robots among older adults with dementia

Studies in gerotechnology and science and technology have underlined the need for extensive research in the intersection of aging studies and technology across various disciplines in the social and health sciences (112). Despite positive outcomes in research using social and companion robots (34, 72, 95), some voices have expressed concerns regarding the excessive orientation toward technological solutions in care for older adults and argue that ethical dilemmas have not been solved, for instance in the use of pet-type robots (72).

Interdisciplinary cross-cultural research is essential to maximize the benefits and reduce the risks (113). Critical perspectives argue against the use of robots to care for people with dementia, drawing parallels with the rejection of using robots to care for children, regardless of the reasons (87). However, examining the issue from a cross-cultural standpoint reveals variations in attitudes and practices. For instance, low-cost robots *have* been used to care for children, for example in Korean preschools. Likewise, in Japan there seems to be less resistance to the deployment of social robots (113, 114). Large-scale comparative studies are essential, especially ones that test robots in real-world settings, rather than laboratory environments (50, 115). Sociocultural backgrounds also seem to play a role in the acceptance of robots, although research on cross-cultural aspects and HRI remains limited (50, 51, 116). Existing comparative analyses have primarily focused on reactions to design features, particularly among students and children, rather than adopting a gerotechnological approach that emphasizes the role of such technology in welfare or care.

The current focus of research remains predominantly centered on cognitive therapeutic interventions (117), such as the implementation of psychological protocols (26), rather than adopting a holistic and social approach that considers social and family relationships, as well as kinship implications in the use of social and companion robots. Further investigation into the social and cultural implications of using these robots is still necessary, with impact extending beyond academia to the broader society. It is imperative to consider the effect of social robots on older adults with dementia in various global contexts, while also assessing environmental trade-offs in terms of energy consumption and waste management (118), as well as cloud connectivity, where applicable. Additionally, there is a need to address country and regional differences and inequalities in access.

Most research on the ethics of robot deployment has predominantly focused on the service provided, neglecting to explore the social functionalities of robots and the dynamics of human interaction and relationships with them. Often, robots are viewed solely in their capacity as "assistive technology" or "welfare technology" (this last term used particularly in Nordic countries) (50, 119), disregarding their potential social and community-transformative roles in fostering kinship, friendships, and community relationships. The anthropomorphism of robots and the ontological phenomenology and animism attributed to these new virtual beings raise ethical concerns (120), as such attributions can make humans act differently. In particular, older adults with dementia may develop expectations and attachments that may result in disappointment if continuity is not ensured. Additionally, it is essential to consider the infantilization effect and the gender perspective, examining how the utilization of robots and their acceptance vary among older women and older men affected by dementia (83). Furthermore, there persists an ageist attitude toward older adults with dementia (which also applies to older adults in general), leading them to be treated as a homogeneous category without considering differences in gender, culture, age and educational background from an intersectional perspective.

Studies based on short periods of exposure to robots highlight the need to investigate prolonged use of robots among older adults (7, 121). Such research should aim to better understand the outcomes following these initial encounters with robots: the routinization—in the Weberian sense—of living with robots; in other words, becoming accustomed to them. Additionally, a new question arises regarding the possibility of expanding access to this technology beyond technologically advanced societies in the West and Asia, including the testing and assessment of robotics in Africa and Latin America. The global population should not be hindered from deploying robots and providing feedback, allowing researchers to adopt a more egalitarian approach and avoid biases in robot design. Moreover, the use of social robots should be a matter of choice and not be imposed, directly or indirectly, due to socioeconomic reasons or any other factors.

There is a notable lack of inclusion of older adults—particularly those living with dementia—in the design, development and implementation phases of social and companion robots (50). Utilizing participatory methods and co-creation and co-development techniques is essential to ensure a more effective deployment that is age-friendly and dementia-friendly, thus making robots a more familiar tool while addressing the needs and wishes of end-users and both formal and informal caregivers. Innovation in co-design necessitates the participation of people with dementia in all phases, including the analysis of data and interpretation of results (122). Including people with dementia in social research with older adults is not common. While it may be desirable to include individuals with dementia as a target population to reflect the variety among older adults' typologies and conditions, this is often avoided due to ethical complexities. The necessity of including such individuals must be well argued. Meeting all ethical requirements can be challenging for researchers, necessitating careful consideration to avoid substantial complications.

Participatory methods and community involvement serve a dual purpose: addressing the needs and desires of individuals while also enhancing robots' age-friendliness and dementia-friendliness. Additionally, these approaches facilitate the social inclusion of people with dementia within a community-based care framework. Inclusion also extends to both formal and informal careers, practitioners, and family members, who should participate in all research phases, including discussions about ethics and the promotion of sustainable engagement (72).

4 Ethical dilemmas in the implementation and assessment of robots among older adults with dementia

When it comes to implementing services for older adults with dementia, there is an emphasis on offering cognitive-oriented activities that present minimal disruption and cost. Proven effectiveness has been considered a sufficient justification to proceed with implementation, a premise that raises ethical questions and needs further analysis, as I have outlined throughout this article. Setting aside for now the issue of whether robots *should* be implemented in care for older adults living with dementia, I turn to issues that must be resolved if implementation were to proceed.

A distinction has been made between the biomedical approach, which tends to control and isolate the patient, and a more social, community-based approach that adopts a holistic, dementia-friendly view of personhood, based on selfhood and the individuality of each patient. From a biomedical standpoint, individuals with dementia are often viewed as unable to produce research knowledge, and there is a noticeable disparity between pre-diagnosis and post-diagnosis phases. The term "dementia" carries stigma, leading some to prefer the term "memory problems." However, consistency in terminology is crucial for accuracy in publication, which itself has ethical implications (123). The contrast between biomedical approaches and community-based care is evident. While biomedical diagnosis can inadvertently act as a self-fulfilling prophecy, exacerbating the severity of the disease by shaping the social construction of the illness and influencing family and social relationships, community-based care—which is person centered—emphasizes attention to non-verbal communication of older adults with dementia, uses empathy and inclusion, and fosters autonomy. This approach embraces flexibility or "going with the flow" to adapt to the day-to-day situation (56).

Despite the increasing recognition of ethical concerns surrounding how to protect older adults living with dementia, there remains a disparity in focus between health sciences and social sciences. The importance of involving caregivers in research and incorporating their views is gaining prominence in both medical and social research, particularly considering the emotional implications and bonds formed with individuals living with dementia. This blurs the lines between the roles of researcher and caregiver in this humanistic and participatory approach. The researcher may assume a caregiver-like role due to this ethical involvement (124). Furthermore, the boundary between formal caregivers and researcher is often blurred, because interacting with older adults as a researcher often requires having some degree of care training. This situation raises post-project ethical implications, such as what happens after a short-term intervention with robots in a nursing home, in which people with dementia may have created bonds with these animated virtual beings and the researchers. As described above, research has indicated that older adults prefer social robots that provide services rather than only companionship (89, 90), and women prefer pet-type robots, while men prefer humanoid robots (99). However, before rollout, such generalizations would require testing across different sociocultural contexts, considering diachronic changes in gender values. Limitations in older adults' technological literacy—and their awareness of stereotypes about it—may produce embarrassment and anxiety when using robots, necessitating open dialogue and the development of user-centered experiences (125), particularly when the target users have dementia.

The implementation of robots would also need to navigate collective fears and uncertainties surrounding disruptive and unfamiliar technology. While it is crucial to consider age and cognitive abilities when designing social and companion robots, it is perhaps even more important to consider the sociocultural context in which they will be used (10). Additionally, multiple barriers exist at the organizational level, as mentioned above, which need to be addressed during implementation (108).

In the context of COVID-19, while other types of robots, such as telepresence robots, saw increased use, serving to facilitate exercise and enhance technology utilization overall—a silver lining in the pandemic (126)—the utilization of social and companion robots for people with dementia decreased. This decline can be attributed to the overwhelming situation faced by staff and the fact that robots are best suited for use in the early stages of dementia (127). The potential use of these robots in family settings has yet to be fully investigated. There may be reluctance stemming from the fact that so far, the use of robots is in an experimental phase.

One region of the world where robot implementation has begun to take place is the Nordic countries, through various municipal programs that align with the goal of welfare technology development (110, 128). Political discourse supporting welfare technology has encouraged care workers to embrace care robots that align with their professional values and that are deemed useful, for instance in dispensing medication (110), as a means to cope with increasing care needs.

As robots transition from laboratory settings to societal implementation, it is crucial to consider the wishes of older adults with dementia and to discuss the ethics of robotics in their care (72). One tool may be the use of advance directives in which an older person's wishes are recorded. Moreover, older adults with dementia should be included in the design and deployment phases of interventions, which can be aided by trained facilitators (18).

5 Discussion and conclusions

Despite considerable advancements and pioneering research on the utilization of social and companion robots for older adults with dementia (5, 6, 40), there is a pressing need for comprehensive analysis from a social sciences perspective regarding the ethical implications and repercussions of HRI in this context. This analysis should prioritize ethical awareness, while assessing the appropriateness of employing such technology to confront the impending "crisis of care" and the loneliness and isolation experienced by older adults with dementia.

From a gerotechnology perspective, ethical concerns persist regarding the use of robots with vulnerable populations. One key issue is the right of each individual to decide whether to use this technology, with decisions being negotiated rather than imposed. We must ensure that the use of robotics in care, particularly for vulnerable populations, such as older adults with dementia, is accepted and potentially included in advance directives. Additionally, there is the risk of reinforcing ageist attitudes by treating older adults as a homogeneous group. Barriers such as illiteracy and unaffordability and difficulties in distinguishing between reality and imagination can question the wisdom of incorporating such technology. We need to decide whether to use technocare tools and determine their role and importance in fulfilling care needs. Issues such as the replacement of human caregivers and the impact on employment opportunities also need to be considered.

There is also a need for greater involvement of formal and informal caregivers, older adults, and older adults with dementia from the inception of the research process, including the co-design phase. This approach aims to address real needs and avoid possible risks in the use of robots for older adults with dementia, ensuring their utility. It is important to anticipate all possible ethical implications from the initial design of the research and to follow up on any ethical concerns that arise during and after the research project. For example, removing robots after a successful but limited period without providing alternatives can pose significant ethical challenges. Also, older adults should be incorporated from the technology co-ideation and co-design phase in order to introduce a human-centric approach.

Ethics must be at the core of research and social interventions, addressed from the very beginning of the design of the research and followed throughout the entire process. Ethical debate should be open and should include the participation of all stakeholders involved in care. Currently, there are no specific guidelines with a practical focus on ethical research that promote a personhood-holistic approach and involve citizens. This approach should aim to raise awareness of ageist and stereotypical misconceptions that lead to the exclusion of people with dementia from research due to cognitive challenges (120). Empirical research is needed to better test and understand the use of social and companion robots with this population. A human-centric approach to technology that involves the participation of all stakeholders throughout the process—from co-ideation, co-design and co-development through to deployment—can ensure that an ethical perspective is applied to a more respectful, age-friendly and dementia-friendly approach to robotics. Dementia-centered care must also be included to ensure personalized enjoyment and acceptance of robotics while testing and/or using social and companion robots with older people with dementia.

Numerous experiments have used social and companion robots with people living with dementia in Western societies (6, 7, 26, 72) from therapeutic and psychological perspectives. However, there is a lack of research on the social implications, including potential biases and stereotypes related to gender, culture, age, and education. Major comparative studies are needed to consider social and cultural diversity in research involving robots. Additionally, there should be more international exchange of knowledge and experiences to improve implementation and share best practices.

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BD: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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On dementia, duties, and daughters. An ethical analysis of healthcare professionals being confronted with conflicts regarding filial duties in informal dementia care

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Background: Existing literature on moral conflicts that healthcare professionals encounter in dementia care has explored, amongst others, issues related to autonomy, decision-making capacity, privacy, and more. Notably, conflicts related to healthcare professionals who support informal dementia caregiving and who are confronted with family members being overburdened with their care responsibly remains an underexplored topic in the current literature, particularly in the context of Low-and Middle-Income Countries. The present paper introduces such an encounter, presenting an ethical case analysis of a conflict that occurred during a larger research project conducted in North Macedonia.

Case to be studied: Due to the absence of formal care services that could have relieved an overburdened family caregiver, healthcare professionals felt compelled to reach out to the uninvolved adult daughters, requesting them to participate in their parents' care. Wondering about whether their reaching out to the daughters might count as an attempt of pressure and undue interference, professionals conflicted over the appropriateness of their action. This paper follows up on their concern, ethically assessing the professionals' action. To answer the question on whether the healthcare professionals acted appropriately or not, and to what extent, theories of filial duties are applied, embedding their action in the larger context of dementia care in North Macedonia.

Results and conclusion: It is argued that the lack of formal care services in North Macedonia is of utmost relevance to the conflict. Thus, the conclusion is that the ethical inappropriateness of the case is to be located not so much with the action

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of the healthcare professionals but with the state because of its failure to provide professional care services that allow healthcare professionals to take ethically sound actions to counteract overarching burdens that family members face when providing informal dementia care

KEYWORDS

dementia, informal caregiving, filial duties, ethical conflict, healthcare professionals, North Macedonia, caring democracy

1 Introduction

In parallel to the ongoing scholarly and political discourse on how care responsibilities are to be distributed between the family and the state (1–5), in most countries, dementia care is provided mainly by female family members (6–9). While performing informal dementia care may be experienced positively, it frequently comes with negative effects for family caregivers (10–13). They often experience significant physical, emotional, and financial burden due to providing informal care (6, 14–16). Also, they often face social isolation as the demands of caregiving limit their ability to engage in social activities (17, 18). Lack of sufficient formal support services is known to exacerbate stress, depression, and other negative effects experienced by informal family caregivers (13, 19–21).

In North Macedonia, dementia care is also mainly provided by female family members, such as daughters (8). Located in the central Balkans region, it is a middle-income country with a population of nearly two million. Ethnic Macedonians make up 60% of the population, followed by ethnic Albanians (21%) (22). Around 17% of the population is over 65 years of age (22). Currently, about 28,279 people live with dementia, with an expected increase of 166% by 2050 (23). In North Macedonia, stigma and negative attitudes towards dementia prevail. Dementia is still referred to as ‘sclerosis’, a term often used as an offense. The stigma arises from perceiving persons living with dementia as deviations from the norm (24). Dementia is not recognized as national policy priority and the formal dementia care system in North Macedonia faces significant deficits in professional care provision (25, 26). The latest statistical review of social care users in 2020 stated that only about 1,500 adults (of all ages and conditions) are in institutional care (27). Most persons living with dementia are cared for by their family members at home. As the availability of formal care services is limited, family members, often adult daughters (8), are forced to provide dementia care without professional support (25, 27, 28). This negatively affects their quality of life (25, 28). Insufficient provision of formal care services has been pinpointed as the most significant predictor for reduced quality of life among informal dementia caregivers in North Macedonia, closely followed by elevated burdens and depression levels (28).

The NOMAD (*North Macedonia Interprofessional Dementia Care*) project was developed against the backdrop of inadequate dementia care structures in North Macedonia. The overall objective was to implement an interprofessional model of dementia care and to evaluate the potency of the model to improve the living conditions for families affected by dementia (8). The dementia care model employed interprofessional teams each comprised of one social worker and one nurse, referred to as ‘mobile memory teams’ (MTs). The MTs conducted home visits to individuals living with dementia and their family caregivers, residing in Skopje and surrounding rural areas. During the home visits, the MTs assessed their living conditions and identified their needs in domains such as physical health, mobility, environment, and psychosocial well-being. MTs were associated with general practitioners with whom they developed and implemented a comprehensive care plan that focused on non-pharmacological measures. Care plans and measures aimed at improving the living situation of both the individual living with dementia and their family caregiver(s). Packages included, amongst others, home safety suggestions to mitigate potential hazards and risks in the home environment, guidance on self-care practices for informal caregivers, anti-stigma education, assistance for financial aid and care allowances applications, guidance for managing challenging behaviors and communication difficulties, as well as support for adapting to changes in the individual’s abilities. The model’s effectiveness was evaluated through a cluster-randomized control study involving a total of 120 families (60 per trial arm). Various questionnaires were administered to collect differences in outcomes between both groups – to the end of evaluating the effectiveness of the intervention. The detailed study results were published. They showed the effectiveness of the intervention in improving the living condition of both the person living with dementia and their family caregivers (8).

During the NOMAD project, one MT encountered a conflict. The conflict arose as a result of missing formal care provision equipped to unburden an overburdened family caregiver. It was an older husband caring for his wife diagnosed with dementia. The informal caregiver was frail himself and experienced poor health. Their living conditions were poor, and he struggled to cope with his wife’s advancing dementia. Due to the absence of professional care services that could have relieved the overburdened informal caregiver, MT members contacted the adult daughters, who had not been involved in their parents’ care. The MT aimed at getting the daughters to step in to help. Wondering about whether their reaching out to the daughters might count as an attempt of pressure and undue interference, one MT member conflicted over the appropriateness of their action. Eventually they decided to proceed.

This paper follows up on the concern of the MT member. To address the question on *whether the MT acted appropriately or not, and to what extent*, MT's action is discussed in light of ethical theories on filial duties. Filial duties refer to obligations and responsibilities that adult children are expected to have towards their parents according to certain moral principles rooted in cultural and societal norms (29). In everyday moral concepts filial duties, as in the present case the claimed duty to care for one's older parents, are most often accepted uncritically. A sense of reciprocity for the care and support provided by parents throughout one's life is suggested (2, 30, 31). This also applies to North Macedonia. Here, caring for parents in advanced age is considered the natural, expected, and moral order of things (32). Not fulfilling this filial duty can result in feelings of guilt, shame, and public humiliation, referred in Balkan countries as 'loss of face' – the erosion of one's public image and status (32). The impact of these societal expectations is substantial. Surveys show that almost 80% of respondents in the Balkans felt pressured to provide informal care, even at the expense of their careers (33). Given gendered expectations, especially daughters are perceived as 'natural caregivers' (33, 34).

The MT's conflict is operationalized as a moral conflict in which the MT had to choose between either leaving the father as an overburdened caregiver on his own or imposing the burden of informal caregiving on the daughters who were not involved in the mother's dementia care until then. Moral conflicts may be conceptualized as situations "involving a clash of moral values within the practitioner, among practitioners, and/or between practitioners and patients, concerning what was the morally right action to take" (35). The literature shows that such conflicts are commonly encountered by professionals across the whole dementia trajectory. They are influenced by the condition's complexities as well as by cultural and religious beliefs (36, 37). Often such conflicts are accompanied respectively caused by scarcity of resources, such as staff and time, and could be avoided under more resourced circumstances (36, 38). Scholars have studied moral conflicts using the concept of moral distress. This may be defined as a phenomenon that combines "[1] the experience of a moral event, [2] the experience of 'psychological distress', and [3] a direct causal relation between [1] and [2]" (39). The recent literature debates about what it means to experience moral distress (40–42). Many authors stress that the frequency and severity of moral distress are high and a serious problem. They are working on effective interventions to mitigate moral distress (43, 44). Others, however, also point to positive effects of moral distress. They argue that it can draw the attention of professionals to systemic issues and deficiencies within the healthcare system and motivate them to advocate for better care standards and policies. This advocacy can lead to improvements in care provision that benefit both healthcare professionals and those in need of care and support (45–47).

The ethical case analysis aims to contribute to the literature that deals with moral conflicts in dementia care experienced by healthcare professionals. To the best of current knowledge, conflicts that healthcare professionals who support informal dementia caregiving (as carried out by the NOMAD MTs) encounter when being confronted with overburdened family members remain an underexplored topic in the current literature. Engaging with the ethics of filial duties, the assessment of the MT's action hinges on whether filial duties warrant requesting adult daughters to care for their parents or whether it is ethically problematic to call upon adult children to provide unpaid informal care for their parents. By integrating the ethics of filial duties with the literature on moral conflicts and moral distress in dementia care, a connection is established to the debate on caregiving responsibilities and informal caregiving burden. The present analysis will hold systemic deficiencies accountable for moral conflicts, illustrating the inherent political nature of this ethical quandary and many others. In what follows, an overview of how the conflict that this paper departs from came to attention is provided, before delving into the conflict's ethical quandary.

2 Identifying the conflict at hand

To gain deeper insights into the implementation of the care model introduced by the NOMAD project, semi-structured interviews were conducted with all MT members after the delivery of the intervention was completed. The interviews with the MTs were undertaken with the purpose of gathering insights crucial to the real-world application of the care model, fostering its integration within healthcare practices. All six team members (three social workers and three nurses), five of which were females, were interviewed. Their average age was 40 years old and they had an average working experience of 18 years. Individual interviews were conducted online in autumn 2023, with each session lasting approximately one hour. MT members were invited to share their experiences with the intervention and to review, from their professional perspectives, the care model that they pioneered implementing. They were asked to describe the care packages they developed in collaboration with the GPs, to elaborate on the measures they implemented or recommended to family caregivers, and to report on their collaboration with the GPs. Furthermore, MT members were invited to share their perspectives on what they consider to be the greatest challenges in dementia care in North Macedonia, and how the care model may contribute to address these problems.

The interviews were conducted in Macedonian, the native language of the MTs, by one of the first authors of this paper, Taneska, M., who, too, is a native speaker. Considering recommendations on cross-language qualitative research (48), the interviews were transcribed in original language and afterwards translated into English. This was done to make the interview data accessible to the research team members from Germany who do not have a command of the Macedonian language. Taneska, M., who is also proficient in English, translated the transcripts.

All MT members consented to being interviewed. The whole NOMAD study was approved by the Ethical Committee of the Medical Faculty at the University Ss Cyril and Methodius in Skopje, North Macedonia (Ref Number:03-1260/5). The study was conducted in compliance with European data protection guidelines.

When familiarizing with the data, a situation described by members of one MT caught attention. It is crucial to clarify that the original research objectives did not encompass an examination of ethical concerns. However, as this unanticipated issue surfaced, it seemed worthy of closer analysis. In the following, the situation is described, using quotes from the interviews to strengthen the transparency of the work. The case was not identified by applying qualitative research methodology on data analysis. The case to be presented stood out because of the difference in between the accounts of the healthcare professionals involved in the situation.

One MT was assigned to a married older couple. The wife, who was living with dementia, was cared for by her husband. Together, they were living in a rural area near Skopje, in a family house that was in substandard condition. The wife was severely impacted by cognitive decline, which had manifested over the past few years. Her cognitive abilities had deteriorated to the point where she experienced significant memory loss. Her speech was slurred and barely intelligible. Physically, she was frail, emaciated, and required assistance with activities of daily living, including personal hygiene. The wife also exhibited wandering behavior, posing safety risks. Her condition had rendered her incapable of engaging in activities she previously enjoyed, such as reading, writing, or using a phone. Her progressive decline resulted in her becoming almost entirely dependent on her husband.

The husband was primarily responsible for the care of his wife. He was struggling significantly with this role. MT members described him as worn out, confused, anxious, and overwhelmed by the situation. His health was also impaired, adding to the difficulty of providing care. He was worried about the family's situation and seemed to be under immense stress.

Given that the care needs of the wife were not met by the husband who was found to be heavily overburdened with his caring responsibility, the MT regarded support for the couple to be urgently needed. Faced with a lack of formal dementia care options, the MT members reached out to the couple's three adult daughters, who had previously not been involved in the care of their mother. Contact was made by telephone. During the telephone conversation with one of the daughters, the MT emphasized the need for additional help in caring for both parents. In subsequent visits, one of the daughters was always present and actively participated in the program, providing much-needed support to both the patient and her husband.

> *Well, we had one specific case where the patient lived with her husband. They had three [adult] daughters, and the living conditions weren't really … it was untidy, the daughters rarely visited. Apart from the problems of the wife [meaning the person living with dementia], the health of her husband who was her caregiver wasn't good. So, simply, he also met the criteria of someone who needed help. So, there we intervened, and we called the daughters and there was a positive outcome, so with each consecutive visit, although we weren't precise, the home was tidy. The patient looked neat, so…* (Translated quote from the nurse who was a member of the MT)

As explained in the introduction, the MTs were given authorization to implement non-pharmacological measures as part of the NOMAD intervention, which, in their professional opinion, were equipped to help improve the living situation of the families. In the specific case, the MT members gained consent from the family caregiver (meaning the husband of the woman living with dementia and the father to the daughters) to contact his adult children. They did not explicitly obtain consent from the daughters to be contacted, nor were the daughters listed as emergency contacts.

While accounting for the case, one MT member started wondering about the appropriateness of their interference with the daughters.

> *I don't know if they [meaning the adult daughters] experienced it as a threat … maybe they thought … but anyway, someone was going into the home and asking about their condition, and the daughters were more involved.* (Translated quote from the nurse who was a member of the MT 1)

While both MT members felt relieve because of witnessing that the living situation of the couple had improved due to the involvement of the adult daughters, only one MT member also felt discomfort because of reaching out the daughters to impose the burden of informal caregiving on the daughters who were not involved in the mother's dementia care until then. Her team partner showed no discomfort during the interviews.

> *From the daughters who were somehow aside because they were really busy, afterwards they were really involved in all of that, in their mother's care. And we explained to them that their dad is unwell and what would happen if God forbid and that it's better for them to be there than not call him at all and his health to get worse and etc.* (Translated quote from the social worker who was a member of the MT 1, talking about the same case)

That one MT member problematized their interference with the adult daughters and the other did not shows that a situation can be perceived as both a conflict and no conflict at the same time – which calls for a closer examination of the case as to whether the MT did or did not act ethically appropriate by reaching out to the uninvolved daughters to get them involved in the care of their parents.

3 Discussing the conflict at hand

The crucial question to be addressed is about the appropriateness of the MT's reaching out to uninvolved adult daughters and requesting them to participate in their mother's care. It is to be acknowledged that the outcome of the MT's intervention, as observed by the MT, was effective in that sense that the mother received better care and the overburdened father as caregiver received support and relief. Authors have argued that actions may be considered morally right that prove efficacious in practice (49). From this point of view, the MT acted morally right by involving the uninvolved adult daughters. However, this line of arguing dismisses the interests of the daughters too quickly and fails to problematize the absence of formal care provision that caused the conflict in the first place.

The case described reveals a triadic conflict of interests and rights as also observed in other care constellations (50). Referring to their job assignment and work ethos, the MT members have an inherent interest in the best possible care for the individual living with dementia, in this case the woman living with advanced dementia. Complementarily, the woman living with dementia herself has a fundamental right to receive a form of care that at least prevents further harm and ideally supports well-being according to her condition. The third party, here the husband as well as the daughters, supposedly have an interest in the best possible care for the wife/mother due to their relationship, but also have the right to physical integrity and self-determination including (partial or full) detachment from the care responsibilities. Especially when personal dignity is compromised, such conflicts can hardly be resolved by individually balancing the conflicting interests and rights. Due to the complexity of care settings, it is neither possible to justify asymmetric duties, including filial obligations, nor can their validity be claimed beyond the individual case. The moral conflict surfaced in the study fundamentally highlights the precarity of care situations in private households. It also illustrates that both, the well-being of those in need of care and the well-being of informal caregivers, are exposed to considerable (health) risks. Against this backdrop, it can be argued that facing such fundamental ethical and practical quandary, the state is constitutionally obliged to take responsibility in form of providing professional care services and considering the needs of all involved parties (51, 52). There are states that are fulfilling their responsibility, providing professional care services such as respite care, memory clinics, day care centers, telemedicine services, companionship services for both the individual living with dementia and their family caregivers, and/or mobile care services that offer assistance with activities of daily living, such as helping with bathing, dressing, grooming, eating, and toileting (53–64). In most states, however, professional care services are not or only insufficiently available (65), such as North Macedonia.

The lack of formal care services in North Macedonia is of utmost relevance to the conflict faced by the MT. As described in the introduction, dementia care in North Macedonia is characterized by significant deficits (23, 26–28). The failure to provide appropriate formal dementia care services is directly related to the exploitation of family members as unpaid caregivers – a phenomenon common not only in low- and middle-income countries, such as North Macedonia, but also in high-income countries, such as Germany (66). The lack of formal care services and the exploitation of family caregivers is linked to political debates that are premised on functional understandings of family members as caregivers whose right to partial or full detachment from care responsibilities carries little weight (67, 68). Such debates often apply conceptions of filial duties to discuss "how responsibility for the care of the aged should be divided between the family and the state" (2). Conceptualizations of filial duties, as explained in the introduction, depart from suggesting obligations and responsibilities of adult children towards their parents, including the duty to care for one's parents (29). Filial duties, hence, are often used as a counterargument to the state's responsibility to provide care, framing care as a family matter (69). Applying this argument to the present case, one could claim that the conflict is unrelated to the failure of the North Macedonian state to provide professional care structures as the daughters would have been obliged to care for their parents anyway. In the following, this claim is challenged. By drawing on different accounts of theories that try to substantiate filial duties, a basis is provided to ethically assess whether the MT acted appropriately or not, and to what extent. Contrary to what might be expected, this analysis will show that by closer examination theories on filial duties do not contribute to releasing the state of its responsibility to provide care but does the opposite.

3.1 Applying theories on filial duties to the present case

The so-called *debt theory* is, to the current knowledge, the oldest attempt that tries to establish and substantiate filial duties, dating back to Aristotle. According to debt theory, adult children are viewed as debtors of their parents and are morally obliged to settle the debts incurred through their upbringing (29, 70). This includes intensive care, financial sacrifices, adjustments to career plans, and giving up time-consuming hobbies (71). However, this theory faces widespread criticism, mainly for two reasons (2, 72, 73). Firstly, the theory fails due to the misconception of a contract between parents and children. A debt relationship must be preceded by a type of contract in which the future debtor (in this case children) voluntarily agrees to become a debtor. If applied, this would mean that children would get into debt by being born and by being cared for as minors. However, unborn children do not voluntarily agree to a contract to be born and minor children do neither voluntarily agree to a contract to be cared for (72, 73). Secondly, the theory is not equipped to solve the problem of the non-existent possibility to quantify filial debts. The concept of debt involves a clear obligation to repay a specific fixed amount of certain goods. Without a fixed amount, a debt can never be settled. Most goods that adult children are said to owe their parents are, however, defined by an unquantifiable nature (72, 73). Emotional support – as one example for a good that parents (are expected to) provide for their children throughout childhood – cannot be easily measured and repaid. Ultimately, dept theory turns out to be of no help for this analysis as the theory has been largely disapproved by the scholarly literature in that the concept of debt cannot be used to substantiate filial duties.

A second theoretical lens through which filial duties are often considered is the so-called *gratitude theory*. Gratitude theory posits that children are obligated to be grateful to their parents because of past parental achievements. This perspective suggests that filial duties arise from a sense of gratitude for past services (74–77). This theory, however, is being criticized, too. Numerous authors argue against understanding filial duties solely as duties of gratitude (2, 31, 78). They contend that not everyone feels comfortable receiving reciprocal acts, as intrinsic motivation drives such actions, done to benefit someone rather than to receive something in return. Consequently, the initial benevolence becomes doubtful, and expressing the depth of gratitude becomes challenging, as children may always feel inadequate towards their parents (2). Furthermore, the extent of duties of gratitude depends on the discomfort, exertion, and sacrifice involved in raising the child, factors that are challenging to measure (2). What is more, the theory faces criticism for its complexity, as basic duties are considered universal, but authors argue that obligations only apply if parents were proficient in parenting in the past (78, 79). According to a widely shared understanding, it is the parental duty to provide their children with appropriate goods (31). Conversely, if there is nothing for the offspring to be grateful for due to insufficient care in the past, the theory can't be applied accordingly. This raises the question of how being raised well is defined and by whom. It remains unclear why children would owe parents gratitude for the fulfillment of parental duties. Consequently, only children whose parents provided extraordinary services would be obliged to have duties emerging from gratitude. The lack of clarity on what constitutes extraordinary services and who determines the circumstances contributes to the problematic nature of this theory (31). Moreover, parental care does not constitute an advance performance, as a child has not demanded this performance. Conversely, what a child has given to its parents does not generate any obligation for gratitude on their part either (78). Although parents and children can be grateful to each other, gratitude is not the subject of a duty but rather a piety (79, 80). In sum, it appears that gratitude theory, if at all, only succeeds in establishing filial duties for those cases in which parents provide extraordinary parental care as defined by their children.

A third theory - known as *the friendship theory* - bases filial duties on love and affection between parents and adult children (72). In contrast to gratitude theory that addresses the relationship between children and their parents during childhood, this model seeks to substantiate filial duties with regard to the present relationship between parents and their adult children (2). Dixon (1995) explains that the relationship between parents and adult children gives rise to the duties among friends and is analogous to friendships in terms of moral dimensions (81). Critics of the theory problematize that characterizing parent-child relationships as friendships seems forced (31). They criticize that the parent-child relationship is unique and not comparable to conventional friendships. Also, it is not possible to choose one's parents. Children are stuck with their obligations towards their parents in a way that can't be transferable to duties of friendships, as those are based on different factors (e.g., simultaneous interests) (2). Proponents of the theory, however, stress the theory's advantages over debt and gratitude theory. For instance, the friendship model of filial duties can explain why duties do not differ depending on parental sacrifice and why reciprocal performance can never be discharged (2).

So far, it appears that substantiating filial duties requires an understanding of the unique parent-child relationship, making it a complex and context-dependent issue. It turns out that the question of duties depends centrally on the perspective of the adult children, on whether they acknowledge their parents' parental care as extraordinary (resulting in filial duties due to reciprocity) or on whether they view their parents as friends (resulting in filial duties due to the present relationship rather than to the past relationship during childhood). This means that through the lens of gratitude theory as well as through the lens of friendship theory, the answer to the question on whether the MT (by reaching out to the daughters) acted appropriately or not depends on the perspective of the daughters. The present data does not allow us to sufficiently explain why the daughters initially did not participate in their parents' care and then did so at the request of the MT. No legit conclusions can be drawn about their agency, that is about their power to turn down the MT's request. However, the introduction, outlines the societal expectations regarding the moral obligation to care for one's family members that prevail in North Macedonia, putting the daughters under pressure to comply to such expectations. What is more, dementia stigma remains a major issue in North Macedonia, as also pointed out in the introduction. Embarrassment, thus, could be another reason contributing to why the daughters got involved. Taking these contextual factors into account, it is to be emphasized that the taking up of care responsibilities by the daughters must not necessarily be interpreted as an acknowledgement in that sense that they agree to have filial duties towards their parents.

A fourth theory is known as *special goods theory* (2). Special goods theory emphasizes the uniqueness of family relationships, introducing the concept of special goods that only parents and children can exchange. This school suggests that the value lies in the affirmation of the relationship through unique goods, which is why those can't be delegated to third parties (e.g., nurses). The so-called generic goods can be provided by anyone and not merely the parents or children. Special goods, on the other hand, are explained to be more profound, as parents often share common traits with their offspring and can identify with them, leading to a special understanding. The sense of continuity due to getting along with the whole life development is of value (2). For example, the care for the parent can be outsourced, but the joy of a visit from the children cannot. Special goods theory thus suggests that by reaching out to the daughters the MT did not act appropriately as the MT did not ask the daughters to provide a special good but to get involved in hands-on dementia care – which is not considered to be a filial duty according to the theory. This assessment is, however, of little insight given the theory's shortcoming. The theory grossly ignores the context within which families live. The conflict unfolded in a situation with no instance existent to which the task of caregiving could have been delegated to other than to the daughters. The MT had to choose between either leaving the father as an overburdened caregiver on his own or imposing the burden of informal caregiving on the daughters who were not involved in the mother's dementia care until then. Operating in a vacuum that overlooks the systemic embeddedness of care responsibilities, the theory is not equipped to contribute to answering the question on whether the MT acted appropriately or not as the theory does not allow to take into account that no alternative formal care structures were in place that the MT could have delegated the task of caregiving to.

Taken together, theories on filial duties are not equipped to establish that adult children may be demanded to care for their parents. Filial duties can only be established on a case-by-case basis; they do not justify the state's failure to provide adequate formal care provision that allow adult children to partially or fully detach themselves from care responsibilities.

That adult children are not to be exploited as unpaid informal care workers to compensate for inadequate professional care structures counts as an insight that needs to be spread among healthcare professionals. As described, one MT member problematized their interference with the adult daughters, whereas the other member took no offense and did not show any sign indicating that she experienced the situation as morally distressing, illustrating that the same situation can be perceived differently by different individuals. This highlights individual differences in perceiving and reacting to moral conflicts and leads to the crucial insight that the absence of moral distress in healthcare professionals does not equate to ethical soundness; neither does its absence mean that the healthcare environment is free from systemic deficiencies. It is important that healthcare professionals become more conscious towards the problematic nature of exploiting family caregivers as only then they might experience relevant situations as moral distress – which, as explained in the introduction, might motivate them to become politically active, advocating improvements in systemic dementia care provision (45–47).

Being thrown into the conflict of having to choose between either leaving the father as an overburdened caregiver on his own or imposing the burden of informal caregiving on the daughters who were not involved in the mother's dementia care until then, the MT followed a pragmatic approach that was necessary in view of the mother's lack of care and the excessive demands on the father as caregiver. Such approaches are common in North Macedonia and other Balkan countries. Here, healthcare professionals are used to seek alternative solutions to accomplish tasks, making informal institutions, networks, and practices common for service provision in the Balkan region. Such informality is about the attempt to 'getting a job done', about recognizing the necessity of utilizing informal practices amidst the shortcomings of public institutions, particularly in health and social care (82). However, because of its effectiveness, informality contributes to systemic deficiencies being concealed, as it supposedly looks as if no systemic change is needed at all as solutions are being found. In the particular instance of the present case, the action of the MT was morally sound, but only because they had no other choice. This reveals a dual nature to their action: while morally sound, it remains ethically problematic as it is not generally appropriate to involve uninvolved adult children in their parents' care. Consequently, the moral conflict at hand as well as other moral conflicts caused by scarcity of resources (36, 38) underscore the deeper political nature of the issue. This insight must be taken into account by those who are committed to mitigate moral distress (43, 44) - so that they do not mitigate the political potential in the process.

3.2 Limitations

While this paper offers a comprehensive examination of a moral conflict experienced by a professional supporting a family affected by dementia from a cultural, moral, and sociopolitical perspective, it does have certain limitations.

This analysis draws on a case accounted for by the healthcare professionals involved in the conflict. It misses the perspectives of the individual living with dementia, of the informal caregiver, and their daughters. Incorporating their viewpoints would have provided a more comprehensive understanding of the situation and the perceived adequacy of the MT's action.

The present paper focused on a single scenario encountered during the implementation of an intervention as part of a larger research project. Obviously, no statements on the frequency of the conflict in practice can be derived. This analysis aimed at integrating the ethics of filial duties with the literature on the burden of informal caregiving, with the debate on caring responsibilities, as well as with the works on the political potential of moral distress to improve care provision and the overall healthcare system. It succeeded in doing so, which is why departing from a single observation is not considered to be problematic that the analysis departed from a single observation.

4 Conclusion

This paper has delved into a conflict encountered by healthcare professionals supporting family caregivers providing informal dementia care, discussing a situation where professionals, due to the absence of formal care services that could have unburdened an overburdened informal caregiver, reached out to uninvolved adult daughters, requesting them to participate in their parent's care. The paper highlighted the complex interplay between familial obligations, professional responsibilities, and systemic inadequacies in dementia care provision. The present ethical case analysis assessed whether the healthcare professionals, by contacting the daughters, acted appropriately or not, and to what extent. It was determined that, given the absence of any alternative, the MT's action was not only appropriate but necessary. The conclusion is that the ethical issue lies not with the actions of the healthcare professionals, but with the state's failure to provide adequate formal care services. While informal dementia caregiving can be a rewarding experience, the demands on the family caregiver can also be overwhelming, leading in some cases to exploitation. To prevent such exploitation, formal dementia care services (such as nursing homes, memory clinics, day care centers, mobile care services that offer assistance with activities of daily living, respite care services, etc.) must be available as an alternative and to ease the caregiving burden. A state failure to provide such services forces professionals into ethically problematic situations as they attempt to mitigate overwhelming burdens of informal dementia care. In essence, the paper thus may not only contribute to the scholarly literature on ethical conflicts in dementia care but also serve as an argumentative instrument advocating for broader societal and political changes to fairer allocations of care responsibilities, in dementia care and beyond.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author VD. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

Author contributions

ViD: Formal analysis, Project administration, Writing – original draft. MT: Investigation, Resources, Writing – original draft. GN: Funding acquisition, Project administration, Supervision, Validation, Writing – review & editing. SI: Resources, Validation, Writing – review & editing. AN: Funding acquisition, Writing – review & editing. VeD: Writing – review & editing, Software. MM: Writing – review & editing, Resources. LN: Resources, Writing – review & editing. AW: Writing – review & editing, Validation. BJ: Writing – review & editing, Software. IC: Software, Writing – review & editing. SH: Writing – review & editing. AI: Writing – review & editing. TG: Writing – review & editing. JF: Conceptualization, Formal analysis, Funding acquisition, Methodology, Project administration, Supervision, Writing – original draft.

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In memoriam

This article is dedicated to the memory of Prof. Alexander Kurz, who died on 29 January 2023.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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"Challenging behavior" in dementia care: ethical complications of a well-intentioned concept

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Uncommon behaviours such as aggression, apathy or restlessness are described as challenging behaviours in dementia care. On the one hand, this concept describes a practical problem faced by care staff and, at the same time, defines normatively how care staff should deal with this problem. A frequent benchmark here is the dignity of the person in need of care, which caregivers should also respect in the case of challenging behaviour. However, little is known about the normative standards that are effective in practice in everyday care when dealing with challenging behaviour. Researching these can provide information on which standards are actually applied and encourage reflection on which standards should be applied. In view of the fact that challenging behaviour can also be associated with aggression and/or violence in particular, an ethically significant question arises as to what effects the practical handling of such behaviour has on the extent of the willingness to use violence. The aim of this article is therefore to present empirical findings from an ethnographic study that focuses on the interpretation and practical handling of aggressive behaviour of care recipients by the nursing staff. In essence, it will be shown that a professional approach to challenging behaviour helps to prevent people with dementia in need of care from committing violent acts. If this finding is analysed in terms of its ethical implications, the conclusion suggests itself that the exclusion of the possibility of using violence is to be welcomed, since the exercise of violence makes respect for the dignity of another person, if not impossible, at least more difficult. However, it is questionable whether, under such conditions, the renunciation of violence can still be attributed the freedom required to qualify it as ethically good behaviour.

KEYWORDS

challenging behaviour, violence, elderly care, ethnography, ethical issues, dementia, sociology of care

1 Introduction

When caring for people with dementia, those in need of care may display behaviours that carers find challenging. Such behaviours can include apathy, restlessness or aggression. It is important for nursing research to explain the emergence of such behaviours and to investigate which nursing interventions have either a changing effect on such behaviours or on their experience (1–3). An important aim of this nursing research is to increase the level of professionalization of nurses by recommending certain forms of interventions (4–7). The recommendations cannot be based solely on the effectiveness and nursing feasibility of such interventions, but must also be able to specify the purposes that these interventions are intended to serve. These purposes are based on evaluative standards that are often taken from nursing ethics.

A central ethical benchmark that is regularly used as an evaluative standard is the emphasis on human dignity (8–10). This usually refers to two things: firstly, care should be based on the principle of respect for the person. Secondly, carers should strengthen the autonomy of those in need of care. It is clear that, based on the generally defined duty to respect the person of people with dementia, specifics are required as to how such respect can be conceived and implemented. A particularly widespread approach to this is the concept of person-centred care (11, 12). While this concept is intended to be the standard for all care situations, specific care situations, such as those involving challenging behaviour, require specific concretisations that explain precisely what constitutes person-centred care that respects dignity (13).

However, as important as it is to standardise nursing practice on the basis of evaluative benchmarks and feasibility studies, such specifications say little about the actual interaction in such situations. Examining those is not only relevant for determining the extent to which the assumed standards are correctly implemented in nursing care, but can also provide information on the extent to which the assumed standards, if they are implemented, fulfil their purpose at all. Secondly, such studies can determine the extent to which - whether due to practical necessity or other reasons - other standards may apply, i.e. which evaluative standards are actually used by nursing staff to interpret such situations and derive practical consequences (14). Findings from such studies can in turn contribute to reviewing and, if necessary, correcting assumed ethical standards of nursing behaviour. The actual practice of dealing with challenging behaviour can be examined in different ways. Considering that challenging behaviour can also be associated with aggression and/or violence in particular, an ethically significant question arises as to what effects the practical handling of such behaviour has on the extent to which it leads to violence.

Studies that focus on the *interpretation* of aggressive behaviour of care recipients are not yet common (15–17) or are still in the planning stage (18). The interpretations have so far been recorded on the basis of interviews. Interaction studies based on participant observation have not yet been carried out with this focus. While it has been researched, for example, that nursing staff attribute aggressive behaviour of people in need of care to different causes, it remains unclear what consequences the nursing staff draw from these interpretations and what consequences this has for the normative order in care as a whole. However, for the ethical evaluation of the nursing approach to challenging behaviour, it is particularly important to include the consequences of dealing with the aggressive behaviour of people in need of care in the research.

To this end, the findings of an ethnographic study will be presented in which situations of challenging behaviour were observed and the resulting observation protocols and interview transcripts were evaluated in the style of Grounded Theory Methodology (19) (section 2). In essence, it will be shown that a professional approach to challenging behaviour helps to prevent people with dementia in need of care from committing violent acts (section 3). If this finding is analysed in terms of its ethical implications, the conclusion suggests itself that the exclusion of the possibility of using violence is to be welcomed, since the exercise of violence makes respect for the dignity of another person, if not impossible, at least more difficult. However, it is questionable whether, under such conditions, the renunciation of violence can still be attributed the freedom required to qualify it as ethically good behaviour (section 4).

2 Materials, methods and theory: ethnography, grounded theory and phenomenology

2.1 Social theory: a reflexive understanding of violence

If one examines interaction situations with regard to violence, one can ask, for example, how violence affects the course of interaction or, conversely, how a course of interaction can contribute to the emergence of violence. In both cases, however, it must be assumed on the part of the observer what is meant by violence and what is not. In addition, violence is usually framed normatively as undesirable on the basis of such a preconception. Two different strategies for defining violence are common in the social sciences, which cannot be linked to each other, but which are similar in the way they are used as described above. A narrow understanding of violence (20) emphasises the restriction of violence to the injury of another person's body. A broad understanding of violence, such as 'structural' (21) or 'symbolic' (22) violence, on the other hand, relies on forms of suffering that are analogous to violence. While studies on violence in the care sector have so far focused on these concepts of violence (23, 24), a different approach is necessary when analysing interaction situations in terms of how they determine what constitutes violence (or the absence of it) and how legitimate and illegitimate violence are distinguished. I propose a definition of violence as a 'reflexive' understanding of violence, which begins with the interpretative practices of those being analysed (25–30).

It is rooted in phenomenological thinking and based on the proposal to understand violence in connection with harming and suffering as an institutionalised context of order (31–35). The understanding of violence is based on the principle of mediated immediacy (36). Accordingly, violence is characterised by the direct experience of a lived body (German: *Leib*) in harming and suffering (25). The experience cannot yet be considered violence because it must first become recognisable as such. It does so insofar as it is always mediated symbolically and communicatively. This means that in addition to the dimension of the lived body, the discursive dimension of violence must also be included in the analysis. Drawing on the distinction between normative and cognitive expectations (37) violence is used to make normative claims insofar as the use of violence symbolically expresses that certain expectations are upheld even in the event of disappointment. Whether it is violence in a particular case, what distinguishes it in terms of content, whether it is legitimate or illegitimate, is not only dependent on the interpreter, but must also exist as a representation to third parties, insofar as only this reference ensures that the interpretation cannot be arbitrarily revised, but can be socially generalised, i.e. exist as an institution.

Thus, violence is present when actors are involved in an engaging antagonistic lived bodily interaction in the context of harming and suffering, this relationship is communicatively and symbolically interpreted as (il)legitimate violence, insofar as the validity of normative expectations is represented in the antagonistic interaction and this interpretation is claimed as valid with reference to the expected expectations of third parties (26).

Even if this understanding of violence also places the lived bodily dimensions of harming and suffering violence at the centre, this does not yet imply who can be the author or addressee of violence. In the sense of the ‘social undecidedness relation’ (38) a decision on this question is left open and made researchable with reference to violence, because violence - understood as a phenomenon in terms of mediated immediacy - is precisely a representation of who is its addressee and originator of violence in a specific situation. This is precisely why violence is coextensive with the expansion of the normative: Only those who are considered moral actors can exercise or suffer violence, and vice versa: only those who may exercise or suffer violence can be moral actors.

2.2 Data & methods: ethnographic research & reconstructive analysis

The data used for this article is based on ethnographic field research (39), which I conducted over a period of approximately 6 months in 2016. During this time, I took part in professional dementia care as a participant observer in two different residential care facilities in Germany specialised in professional dementia care. The main reason I needed a second care facility was that I could better anonymize actors and their actions. An additional benefit resulted from using the second device for the investigation of contrasts (for the use of contrasts see below). I obtained informed consent for the field research from all participants. Participation enables researchers to ‘play along’ in the field and it promotes trust, which can be exchanged for further observation opportunities. The observation data in the form of handwritten notes made on site and repeatedly discussed with field participants were always digitised promptly and converted into ‘observation protocols’ with the lowest possible degree of interpretativity and the highest possible degree of descriptiveness. These observation protocols are the actual data for the analysis and are around 400 pages long. In the context of ethnographic research, further data sources can be tapped, and I have followed an opportunistic understanding of data (39): Data can be anything that appears useful in revealing the rules of a field. In addition to the observational data, I used data obtained from open guideline interviews, the aim of which was to make care-related experiences the starting point for episodic narratives. These were conducted in 2016/17 with 8 carers and 2 people in need of care and lasted between 45 and 120 minutes each (for this article, I have only used the data from the interviews with the carers). They were recruited on the basis of participant observation. This means that - as in the observation protocols - I spoke to the nursing staff on a first-name basis and to the people in need of care on a second-name basis. Accordingly, the nursing staff were pseudonymised with first names and the patients with surnames. The data was not made available to a repository and are held by the author. While the data were originally collected in German I translated them into English.

An important goal of ethnographic research is to reveal the rules of the field - its methodicity (40). The data obtained must therefore be analysed in such a way that the analysis leads to theoretically abstract statements about the field being researched. Establishing such a theory rooted in the object that is analysed is the declared aim of grounded theory methodology (19), which is why I have modelled myself on it. Its core features include:

1. It provides for a successively abstracting coding process that takes place via the constant comparison of formed concepts. However, the sequence of open, axial and selective coding is not a schematic process, because:
2. With the concept of theoretical sampling, data collection and data analysis basically follow an iterative-cyclical process (41). Data collection and data analysis are based on the principle of minimum and maximum contrast. This distinction replaces the distinction between verification and falsification in that the replicability and limits of concepts and categories are checked along minimal and maximal contrasts between different cases and so the theoretical integration of the data may advance. The sampling strategy therefore always includes the request to search for new minimum and maximum contrasts until no more are found (theoretical saturation). Following this line of reasoning, the amount of data is less relevant than its theoretical instructiveness in the research process. According to the task in finding and creating contrasts, the observations are to be validated by the participants even though the validation process did not follow a participatory design (42). My observations were validated (or even falsified) in three not clearly differentiating ways: a) Later observations of similar situations might have shown similar or contrasting outcomes b) As is usual for participant

observation, I was in constant communication with the participants, trying to validate my observations and thoughts. But these communications are nothing else then new observations c) I conducted interviews with participants and I observed them in 'natural' situations how they communicate with me or each other to let them show to me their own relevancies of how to interpret certain situations.

3. Like any other primarily inductive method, grounded theory methodology also provides for theory-guided coding, as long as the terms used fulfil the purpose of opening up material interpretatively and not assigning it to theoretical premises based on subsumption logic. To this end, they must be as empirically insubstantial as possible (43). The place for such theoretical premises in the grounded theory methodology is the coding paradigm, which can be changed depending on the requirements of the research. For this purpose, I used a coding paradigm specially developed for the sociological research of violence based on a reflexive understanding of violence (26), which combines the theoretical premises mentioned above with the demands of qualitative-reconstructive research.

While the research logic is inductive, the presentation of the results follows a more deductive logic: the aim is to present essential elements of a theory about the field, i.e. the key category and some subcategories, by substantiating central assertions with the material.

3 Results: Why persons with dementia may not act violently

Three findings are presented below. Firstly, the key category is presented. This is a pattern of interpretation[1] whose effect is that people with dementia hardly ever commit violence, but can easily suffer violence (3.1.). This pattern of interpretation contrasts with another pattern of interpretation according to which carers *ad hoc* assume that people with dementia are capable of and intend violence. On closer inspection, this is an action problem that carers have to solve so that they can continue their work (3.2). The problem of action consists of how carers can successfully prevent themselves from applying the latter pattern of interpretation. A number of strategies have been established in nursing care for this purpose, which therefore function as subcategories of the key category. One will be presented in this article: The administration of psychotropic drugs is intended to ensure that care recipients do not exhibit behaviour that they could interpret in terms of the undesired interpretation pattern (3.3).[1]

3.1 Why people with dementia cannot perpetrate violence, but can suffer it

The pattern of interpretation institutionalised in the inpatient care of people with dementia is characterised by a three-step logic: The starting point for activating this pattern of interpretation is the production of assaults by a person in need of care that are experienced by a caregiver, i.e. so-called challenging behaviour. This finding was obtained in the interpretation of reactions to a care situation presented to nursing staff that was taken from another care organisation:

> Mrs W. was mobilised to the edge of the bed in the morning as usual. Mrs W. hit, kicked and swore at the carer. The geriatric nurse (in the following GN) spoke to her slowly, gently, in short sentences and calmly. Despite her illness, the nurse tried to explain her actions as simply as possible. GN held her gently by the arms to prevent her from falling. Mrs W. was very active in this situation, stood up more often and was unsteady when walking. GN also tried to avoid further blows by holding her arms more tightly. […] The GN 's thoughts in this situation were to deal with the basic care as quickly and comfortably as possible. GN had sympathy for Mrs W. and was able to empathise with her situation. However, there was also the thought that basic care had to be provided (e.g. due to incontinence), even if the resident showed this defensive behaviour. The actions in the situation were that the nurse tried to work even faster, as well as to continue to avoid kicks and blows, to have a calming effect on Mrs W. and to talk to her about other topics such as the weather. After care, Ms W. was mobilised into a walker, in which she usually calms down and 'only' grumbles to herself. GN then takes Mrs W. to breakfast and lets her rest there.

The quality manager interviewed commented on this as follows:

> I would consider it a successful situation. #mhm# So the carer is right. Mrs W. shows that she did not want to be cared of. But that is the pathological change. To what extent Mrs W. would also have decided, if she had been clearly conscious and heavily soiled, not to let herself be helped to clean herself again #mhm# can be answered clearly in most cases: None of us walk around like that voluntarily. (Interview GN B).

This answer contains the first two phases of a three-step logic of interpretation:

1. The quality manager interprets Mrs W's behaviour 'that she did not want to be cared of'.

   A carer interprets this behaviour *ad hoc* as a communicatively meaningful action, the intention of which is not to want to be cared for. If this communicative expression were taken seriously, it could have been a violent act.

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[1] In the following, I use the word in the theoretically undemanding sense of a socially generalised interpretation of a situation.

2. However, this attribution of intention is immediately relativised: ‘But that is the pathological change.’

   The GN recognises that it is a person with dementia and attributes the assault to the dementia. This relativises the intention. The assault therefore appears to be involuntary. It can therefore no longer be violence that communicatively expresses normative expectations. The first intention is then replaced by a generalised intention of wanting to be cared for in any case, which would presumably be the case from the perspective of the GN if the person did not have dementia. However, as the person has dementia, she cannot introduce their intention into the flow of communication. The fact that this is non-communication and therefore automatically also non-violence is not interpreted arbitrarily, but requires reference to legitimising third parties.
3. At another point in the interview, the quality manager completes the three-step process:

> So action must be taken. The person must be helped, she must be cleaned up to prevent other damage, skin damage etc. #mhm#. These are things that are absolutely necessary. (Interview GN B).

The duty to provide care is derived from the relativisation of the initially understood intentions of the person in need of care. Acting contrary to this obligation as well as using violence that is not necessary for this purpose is considered illegitimate violence. The GN must present themselves to various third parties in such a way that there is no reason for this interpretation. The difference between interpretation step 1 and interpretation step 2 corresponds to a judgement about the actor status as well as about the commonality of interpretation steps 1 and 3: Someone whose external behaviour is denied intentionality due to a permanent illness cannot (any longer) be expected to be able to establish a consistent relationship between their own will and expression. Anyone who is unable to do this can no longer communicate and therefore cannot use violence. The fact that GN ‘s are under pressure for their behaviour to be interpreted as illegitimate violence is not least due to the fact that a) they expect that they are expected to establish a consistent relationship between expression and intention, and b) that in interpretation step 3 they put themselves in a situation in which, conversely, residents find themselves in interpretation step 1: as potential perpetrators of violence.

The intention of not wanting to be cared for is inferred from the initially observed physical behaviour. This intention is relativised and the behaviour is interpreted as the involuntary expression of a state of illness, whereby the behaviour must also be overcome by force in case of doubt, insofar as this is associated with the violation of the resident’s physical well-being. On the basis of this interpretation of physical behaviour, it is impossible for Ms W. to use violence. Nevertheless, the presentation of this sequence of interpretations fails to recognise the difficulties for care staff in applying this pattern of interpretation. The application of the interpretation pattern, which relativises the intention of violence on the part of the person in need of care, corresponds to the fact that the carers must take care not to allow themselves to be injured.

3.2 Opportunities and limits for carers to make themselves invulnerable

It is not at all the rule that all people with dementia regularly display behaviour that can be interpreted as violence. However, *if* it does occur, carers have to update their professional interpretation routine against other possible interpretations. To this end, they try to dethematise or play down violations of norms. In direct care, however, there are situations in which this strategy does not work. Based on their own direct experience of the situation, which they sometimes experience as a potential illegitimate experience of injury, they may use violence to represent the inappropriateness of the resident’s behaviour.

Caring for Mr Kaiser is a particular test. Carers usually provide care in pairs. They *expect* that they will have to be prepared to provide a difficult care for Mr Kaiser. They steel themselves internally, try to develop a specific attitude and are nevertheless caught up in a dynamic in which they develop and apply a pattern of interpretation that ascribes specific intentions of violence to Mr Kaiser. This puts them in the difficult position of having to put two competing patterns of interpretation into a practical relationship with each other, because completely different reactions are appropriate to violence than to forms of behaviour that only outwardly resemble violence but are in fact involuntary symptoms of illness.

The following is a description of a care situation with Mr Kaiser:

> The two of us go into his room. ‘Oooh,’ says Ruth. ‘I can’t stand it in this room.’ It really stinks terribly. She tells me she doesn’t know if I have to go in with her. I could also stand in the doorway. When I ask her, she confirms that the smell is just urine. ‘Good morning Hans,’ calls Ruth. She goes to him in the bathroom and wants to pour water into a plastic tub. It rattles loudly. I ask if everything is OK and open the door to the bathroom. She swears and tells me that the soap holder has fallen off the wall. Kristina comes in and asks who will do the body wash. Ruth suggests that they both wash at the same time. One on top, one on the bottom of the body. Kristina agrees. She throws back the blanket. ‘All full!’ she shouts. Ruth pulls off the duvet and throws both into a plastic tub. Turning to me, she says that’s not really the way to do it. ‘Eeeh’ shouts Kristina. Both GNs are visibly disgusted by what they find. ‘The diaper is dry,’ they exclaim. The urine is up to the shoulder. They are puzzled as to how Mr Kaiser has managed to keep the adult diaper dry while soiling a large area with urine. They refrain from answering.

> Mr Kaiser pinches and punches Ruth. Ruth shouts: ‘Hitting is bad.’ Ruth shouts that they just want to wash him. ‘No!’ he shouts. But this refusal is not taken up any further. Meanwhile, Kristina runs to the door and closes it. She doesn’t want the quality manager to come in and see her. Then she would quickly lose her job. She says this in a mixture of seriousness and an ironic undertone. She goes back to Mr Kaiser and dresses him

> while Ruth holds his arms. Ruth tells him not to be so 'angry'. If someone has a reason for violence, she can understand that. But with him it is 'pure malice.'
>
> Mr Kaiser is now sitting in the care chair. Kristina has shaved him. She then approaches him with a plastic cup and toothbrush. He knocks the cup out of her hand. The water in the cup splashes in all directions. 'Oh, you arseh…' shouts Kristina, but breaks off in mid-word. Together with Ruth, she realises that she actually would have wanted to shout: 'Oh, sheesh!' I have to laugh at that. I have the feeling that they are both overwhelmed by the situation. Ruth takes Mr Kaiser to the dining room and Kristina tidies up the room. I go to the dining room too.
>
> Kristina walks past me and tells me she hopes it wasn't too bad. I wonder for whom. I appease her and tell her that I've been to see Mr Kaiser before. Shortly afterwards, Ruth comes by and laughs at me, saying that Kristina is now walking all bent over because she is so unsteady.
>
> A few minutes later, I overhear a snippet of a conversation between Ruth and Dirk about Mr Kaiser. Ruth says: 'He's mean. He's really mean!'

It is not the case that all of Mr Kaiser's care is provided in this way or so drastically. In any case, it is the case that the carers are prepared for it to take place in this way.

Immediately after the care begins, the carers and Mr Kaiser enter into an antagonistic relationship, but this does not lead to the carers stopping the care. At least Kristina expects that the carers' behaviour could appear to be a case of illegitimate violence from the perspective of the quality management. In fact, it is not common for carers to close the door and thus exclude the presence of third parties. This indicates that the standards of legitimacy that the quality manager and Kristina apply are not the same in Kristina's eyes.

The nursing staff are not sure as to whether they should interpret Mr Kaiser's behaviour as illegitimate violence. For example, the nurse Kristina uses the interpretation pattern explained in 3.1 in relation to Mr Kaiser:

> 'Yes. Erm (sighs). (4) That's on the agenda. You come in, say good morning and sometimes instead of good morning you get slapped. Or you're brutally ignored by a resident. And the more active you become, the more you talk, the more the resident gets angry and can also become physically active - in terms of hitting and kicking. […].
>
> I can only say that perhaps you have noticed that Mr Kaiser also cries a lot and often? #mhm# It doesn't matter whether he's very sweet or aggressive, it has to do with his stroke. He probably can't control it any more. #mhm# I suppose this aggressive behaviour too, the clinging to us and hitting. Maybe that's why he can't control it either. That's what the doctor said about the crying, because we also presented the whole thing to the neurologist. Because we didn't know whether we were causing him pain or what. But I can imagine that he can no longer really control his behaviour, his aggressive behaviour.' (Interview GN A).

The case in the quoted observation is different: according to Ruth, Mr Kaiser is 'evil' and 'mean', which suggests that his actions are not involuntary and that he has intentions to hurt, for which Ruth cannot recognise any legitimising reasons. Kristina's spontaneous exclamation that Mr Kaiser is an 'arseh…' also speaks in favour of an *ad hoc* attribution of intentionality: An arsehole is always someone who decides in favour of a certain alternative course of action, knowing full well that other *possible* alternative courses of action do not cause this harm to other people. An arsehole therefore at least accepts the harm to other people, even if it is not clear whether they are doing this in order to gain a material advantage, for example, or whether they are doing it out of pleasure in the harm itself. The decisive factor is that arseholes would always have had alternative courses of action.

In the following scene, the interpretation that Mr Kaiser's behaviour is violent is supported by excluding alternative interpretations of violence: 'Ruth shouts that they just want to wash him.' This is a sentence that initially supports the above-mentioned interpretation that Mr Kaiser has no legitimate reasons for his behaviour. This becomes clear with the adverb 'only': Ruth anticipates the possibility of evaluative comments on her behaviour. The content of her behaviour consists of the intention to wash Mr Kaiser. With regard to this content, from her perspective - this is indicated by the 'only' - a negative evaluation is not to be expected. She thus doubts the possibility that the pinching and hitting constitutes such a statement and, accordingly, her behaviour does not appear to her as behaviour that is normatively criticised. Against the background of the assumption that there must be sound reasons for the use of violence, the 'only' excludes the possibility of such reasons. This also explains why Ruth does not respond to Mr Kaiser's exclamation 'No!': It is already established that Mr Kaiser cannot provide any acceptable reasons for the negative evaluation of Ruth's behaviour.

From the nursing staff's perspective, it is impossible for their care activities to constitute violations of norms for Mr Kaiser. Mr Kaiser's normative claim cannot be based on this. The care situation described above clearly shows that there is no need for this: The shout 'No!' towards Ruth and his assault allow in principle the interpretation that the nursing staff have committed norm violations towards Mr Kaiser - but they do not claim it. By attributing malice to Mr Kaiser, the normative claim made by Mr Kaiser is reduced to his self-assertive right to use violence whenever it is at his will.

Against the background of such an interpretation pattern, nursing staff are faced with a difficult situation: if they maintain this interpretation pattern, they evaluate the behaviour of the person in need of care, i.e. they have to decide, for example, whether Mr Kaiser is *allowed* to act in this way. As they are the ones who are directly affected by his actions, they are also the ones who have to demonstrate a negative evaluation of his behaviour to him in a communicative manner. In principle, there are different ways of presenting this behaviour. Kristina's exclamation: 'Oh, you arsehole…' is the beginning of the use of such a possibility - it is not only an interpretation of Mr Kaiser's behaviour as an act of violence, but also an evaluation of it: this shows that Mr Kaiser's behaviour violates norms and that Kristina is also affected by the disappointment of expectations.

However, if carers act as evaluators on the basis of such an interpretation of violence, they also present this evaluation to third parties. They must therefore also anticipate with regard to third parties whether the form of their evaluation can be expected to be judged as appropriate. One type of third parties is the second carer present. Kristina closes the door in order to exclude other third parties and thus competition from third party's different perspectives. Incidentally, this is a strategy that is not without risk because closing the door may still be visible to third parties: For example, if someone observes the closing process because noises can be heard from the room or because the presence light on the outside above the door is switched on. The fact that in this case the evaluation 'arsehole…' is nevertheless made in front of possibly competing third parties probably occurred to Kristina during the utterance, which is why she stopped it. It is unclear here whether the result of the consultation with Ruth, that she wanted to shout 'sheesh', applies to me as the observer present or, for example, serves to make amends for the shock about herself. Both together seem plausible, above all because Ruth's statement that Kristina is now walking 'all bent over' suggests that Kristina is obviously evaluating her own behaviour negatively, assuming how I would judge it.

This dynamic of spontaneously interpreting a behaviour as illegitimate violence and that the response is likely to be behaviour that falls under the same interpretation is confirmed and supplemented by another carer:

> So boundaries that should not be crossed are, um (3), um, unnecessary physical violence. # mhm# Um, the fact that you might have to hold tight a resident's hand or foot to avoid being kicked is still understandable for me. But if you suddenly feel the need to slap that person in the face or something like that, that would definitely be crossing the line. Erm. Is not okay at all. But unfortunately, from my point of view, you always work very, very close to it. Residents can be very, very provoking and you really have to be careful not to cross that line. Verbal abuse is another nasty thing but that needs to be interpreted a bit more generously. Um insults wouldn't necessarily be favourable or aren't favourable. But it has been shown that in some situations that have occurred, clear, loud words have led to success. #mhm# A kind of commanding tone, yes, that such things have actually led to success. […] So I think the verbal aspect has definitely reached its limit when you get into insulting behaviour, because I can't imagine that insults will probably lead to success. #mhm# Physically, if it turns into unnecessary violence and, uh, verbally, if it goes somewhere insulting, which makes no sense. #mhm# # (Interview with GN D).

'Residents can be very, very provoking and you really have to be careful not to cross that line.' The spontaneous tendency to interpret challenging resident behaviour as intentional and illegitimate is described here. This can lead to 'suddenly feel the need to slap this person in the face.' This need to punish presupposes the previous interpretation and activates the communicative representation of the validity of normative expectations. It is interesting that the interviewee now distinguishes unnecessary violence and insults from other forms of assault (holding hands and feet, tone of command). The demarcation criterion that she motivates is performance-related: Does the behaviour displayed lead to success? For example, the commanding tone can motivate a resident to co-operate. The holding of limbs serves to maintain care without the carer having to accept injuries. In order to be able to differentiate between unnecessary violence and legitimate coercion in this way, however, it is necessary to ensure that the resident's behaviour is no longer interpreted as illegitimate violence that needs to be evaluated, but rather, for example, as a disturbance that needs to be overcome or circumvented.

Against this background, steps must therefore be taken to switch to a pattern of interpretation that makes it unnecessary to act as an evaluator of violence at all. Strategies for this can start in two places. Firstly, carers can start with the way in which they directly experience the behaviour of those in need of care. In this sense, carers cultivate a habitus of invulnerability. Pain-avoiding postures and turning away from those parts of the body in relation to which the normative expectation of pain is particularly obvious help carers to avoid acting as evaluators of violence:

> '[W]ith time, you even develop postures. Somehow it develops that you can't be hurt quite so much. You watch how you present yourself. It's very important to protect the facial area #mhm#, whether you wear glasses or not. I find nothing worse than being hit in the face. But also: you really develop grips. Maybe that sounds really brutal now, but you develop grips, you develop a stance so that you don't hold on to the resident too tightly, but are a bit distanced from your body and can still work.' (Interview with GN A).

Secondly, however, the behaviour of people in need of care can also be used to stabilise the fact that they do not (or cannot) have any intention of harming others. For example, nursing staff attribute Mr Kaiser's behaviour to illness and thus eradicate the action character of his behaviour. However, this strategy only takes place ex post and thus continues to carry the uncertainty of other behavioural interpretations with it. One strategy to ensure that behaviour that could activate the first interpretation pattern does not occur in the first place is to administer psychotropic drugs. This is discussed in the following section.

3.3 Psychotropic drugs: ensuring non-violence in care

The use of psychotropic drugs in the care of people with dementia is often criticised. Depending on the form of dementia and the drug, it may be medically contraindicated (44, 45) or it may increase other risks, such as the risk of falls or other (46, 47). Accordingly, the guideline in Germany is to minimise their use as much as possible (48). This contrasts with findings of health care sciences that dementia patients are, at least in Germany, undersupplied with anti-dementia drugs and over-supplied with antipsychotics both in home and inpatient care (49). This is attributed, for example, to the use of on-demand medication (50) or to the decline in (other) measures involving deprivation of liberty, such as the use of bed rails (51).

It is therefore not surprising that the administration of psychotropic drugs is sometimes referred to as 'chemical violence' (52) or 'chemical restraint' (53). One *sociological* explanation for their use is that the administration of psychotropic drugs critically controls the potential for violence on the part of nursing staff by reducing the likelihood that the behaviour of a person in need of care will be interpreted as (illegitimate) violence in the first place. I would like to illustrate this with a case in which a person in need of care with dementia receives successively increased doses of the psychotropic drug Melperon, initially via the on-demand medication, but then also via the neurological prescription.

The case is about Mrs Pete, about whom care staff initially noted: 'Mrs Pete has settled in, approaches fellow residents and GN.' Eventually, however, they changed their minds:

> Telephone call to Löwith's practice, asked to be called back. Very noticeable behaviour since the weekend. She is tearful, caught up in her negative marital experiences, talks about them. She can't be distracted by anything, then gets angry, insults coresidents and misjudges situations. She irritates other residents with insults and intrusive behaviour, thereby endangering herself. (Observation protocols).

After about two months, which Mrs Pete had already spent at the residence, she apparently developed a behavioural disorder, which prompted the nursing staff to consult the neurologist and successfully request a change to the prescription for the on-demand medication. As a result, the long-term medication was extended to four doses of Melperon per day and the on-demand medication developed into continuous medication, which was medically sanctioned and finally supplemented with the neuroleptic Quetiapine. What happened?

The change in medication was a reaction to several events that had taken place since the weekend, according to the entry in the documentation. At least this is suggested by entries in the so-called handover book:

> Entries about Mrs Pete. She had refused food a few times. It now also says when she accepted food. She has often insulted people […] She has also threatened to hit them and last night she even hit Marion with her fist. Her legal trustee and partner visited her yesterday. Afterwards, she was 'even more angry'. (Observation logs).

The eating behaviour, insults, threats of beatings and the one-off beating of a carer provide initial indications of what might have made the medication change necessary from the carers' point of view. The following is a very abbreviated description of a situation in which Mrs Pete was involved and which subsequently triggered a series of reflections among the carers:

> I go into the nursing home and meet Mrs Pete and Mr König in the seating area between the staff room and the large dining room. I shake hands with both of them. As I shake Mrs Pete's hand, I notice that she is very upset. She was already in a bad mood last week. But today she seems to have hit rock bottom. She says she doesn't want to eat. She keeps getting up, standing in the passageway to the dining room or changing her seat in the aforementioned seating area. This consists of a corner bench and two leather-covered armchairs as well as a small round table. Passing GNs are drastically insulted: 'You fat bastard', 'arsehole' etc. She says about Anna, also a carer, that people say she's a beauty. But Mrs Pete is sure: 'She's wrong.' Shortly afterwards: 'I feel puke-sick!' The GNs ignore her or make eye contact with me instead. They raise their eyebrows or roll their eyes. There is no evidence that Mrs Pete changes her behaviour in response to the reaction she elicits from others […].
> Mrs Pete is a topic of conversation in the break room. Everyone agrees that Mrs Pete's mood has worsened since the beginning of last week. Heike opts to give her a tranquilliser because she can't find her way out of this aggression on her own. Anna agrees. I describe my impression that she is mixing up current events with things that happened a long time ago. Heike says she once learnt that dementia is like a shelf of books. Each book represents a year of life. With dementia, all the books fall over starting from the back. […] (observation protocols).

Mrs Pete's insults are interpreted as pathological. Maria answers my question about whether the strain on carers is always the same for mobile residents:

> No, for some people it's higher. Erm, Mrs Pete through her insults, but she probably can't help it, because she might say this insult against another person who is still in her head, a kind of Tourette. (Interview with GN D).

Nevertheless, these are also seen as a normative problem:

> Mona comes by and gets loud. She shouts that Mrs Pete can vent her bad mood in the entrance area. But that's not possible at this place because: 'We're a community here!' (Observation logs).

However, it is the task of this community to ensure that people are not excluded from it. Mona discusses this in an interview:

> Interviewer: I can remember, for example, that there were many discussions about this with Mrs Pete. #Yes# Um, whether to increase the medication, whether it was enough, whether she was well adjusted or not, whether to give her more time or not. #Mhm# Um, how did that go?

> Mona: Then you're exactly on point. Um, this woman certainly had needs and fears. #Mhm# Inside herself. And couldn't handle it any other way than the way she always reacted: With swearing, ranting, insults. Until some other resident was possibly no longer able to control it and would have endangered her. #Yes# And so we then discussed in the team, part of her reactions is certainly character-related, biography-related, um and perhaps with the help of the neurologist and medication the whole thing can be dampened down so that she no longer suffers from it and doesn't endanger herself by perhaps causing others to beat her. #Mhm# And the colleagues are always different in their um, in their ability to put up with it. Some clearly see what I said, that it's character-related. You can't change some things. Erm. And the others think that if I put something on top, then we'll have peace but that's not our approach. What, I can understand that too. It's not a job that can be taken lightly. #Mhm# (2) But you are exactly on the point of what I mean. The person who is then given medication should be fine. #Mhm# Not to flatten him and make him quiet, to make him compliant, but to make him well. #Mhm# And that has to be communicated to everyone involved. (Interview with GN C).

Mona confirms Heike's interpretation that Mrs Pete suffers from her own aggression and confirms the task of the nursing staff to eliminate this suffering with the help of medication by 'damping' it. Even if the existence of a pathological condition and the pressure of suffering are not sufficient to justify the change in medication, they are included in the justification as a purpose. Mona now adds further purposes to this: Mrs Pete's social identity, the benefit calculation of carers and the preservation of the normative order of her community. She fears that Ms Pete's behaviour is harming her in a completely different way than just the fact that the aggression itself is already causing psychological strain: Mona anticipates that Ms Pete's behaviour is a provocation for others and that these others could resort to violence in response to this provocation. The help that the GNs want to give Mrs Pete is therefore twofold: firstly, they free Mrs Pete from suffering from herself and, secondly, they prevent her behaviour from giving others an opportunity to use violence to demonstrate the validity of their disappointed expectations, so that Mrs Pete 'doesn't endanger herself by perhaps causing others to beat her'. Interestingly, Mona mentions this latter motive for help twice, but only refers to residents in the first case, leaving it open the second time. At least implicitly, Mona reveals an understanding of violence here that seems to assume that GNs could also be put in the situation of exercising violence. In this sense, the medication not only protects Mrs Pete from other residents, but possibly also from GNs. The medication can therefore not be seen separately from the local social order, its applicable or assumed norms.

4 Discussion: ethical issues concerning the impossibility of acting violently

The findings presented in this paper are merely indicative insofar as they cannot claim that the patterns found in the data are to be found in every dementia care facility. Nonetheless, the findings presented underline the fact that nursing staff in their professional role tend to pathologise aggressive behaviour of people with dementia in care facilities (54). However, the entire behaviour is not pathologised, but it is more precisely a question of casting doubt on whether the aggressive behaviour has come about of its own free will. With reference to the pathological condition of the people with dementia in question, it is denied that they harbour intentions to harm. However, it is not denied that they have any intentions at all - which would be the case with total pathologisation. This is related to the fact that a generalised intention wanting to be cared for is assumed here. This shall help the nursing staff to interpret the behaviour as an indication of unmet needs and to contribute to their satisfaction in accordance with their nursing skills.

Along the lines of everyday common sense, however, it seems *counterintuitive* to ask carers to adopt an interpretation according to which attacks on their own bodies should not be understood as illegitimate violence. In fact, it has been shown that carers do not readily attribute aggressive behaviour to dementia, but in some cases have great difficulty in distinguishing this pattern of interpretation from an interpretation according to which aggressive behaviour is due to intentions to injure. Insinuating those intentions is problematic from a professional theory point of view because such an interpretation changes the further care interaction in such a way that carers feel disappointed in their expectations and are therefore challenged to explain to the person with dementia which expectations should apply. They can do this, for example, by giving moralising speeches but even by using violence.

Precisely because it is sometimes a great challenge in everyday care to use the institutionally favoured pattern of interpretation, it makes sense to solve this problem in such a way that it does not yet arise. This is the case when people in need of care are prevented from displaying aggressive behaviour in the first place. Seen in this light, it is understandable why the administration of psychotropic drugs helps to prevent this behavioural problem from arising.

If one attempts to guide the professional handling of challenging behaviour ethically in such a way that the dignity of the person behaving in this way is preserved or even promoted, it is not surprising if the latter interpretation pattern is certified as not serving to respect the dignity of people with dementia. However, the institutionally favoured pattern of interpretation also raises at least three ethical remarks.

4.1 The dignity status of care staff

By declaring respect for the dignity of those in need of care, respect for the dignity of carers is pushed into the background. As respect for the dignity of those in need of care is a norm that care organisations use to control the behaviour of caregivers, this results in the fundamental problem that claims to autonomy are undermined if they are understood as prohibition of instrumentalization in the Kantian sense (55) but demanded heteronomously: They then become the prevailing morality. Whilst this problem cannot be solved completely, it is possible to deal with related practical problems: If carers experience the behaviour of people in need of care as violence, this can be accompanied by the fact that they feel their dignity has been violated. Insofar as this is not the institutionally preferred pattern of interpretation, this can lead to carers seeing their experience of such dignity violations devalued by care organisations.

4.2 The dignity status of those in need of care

Respect for a person's dignity involves recognising that person's freedom as a condition of the possibility of their moral actions. Organised doubt about intentions to harm can therefore possibly be reconstructed as a violation of the dignity of people in need of care insofar as their aggressiveness is not attributed to freedom and it is therefore questionable to what extent non-aggressive actions can be understood as actions that make use of autonomy. Should respect for the dignity of people in need of care therefore not also include the promotion of their autonomy insofar as it enables them to decide against aggressive behaviour of their own free will? This thought would be, on the one hand, in line with the concept of person-centred care (12) as it focuses on the recognition of the autonomy of the persons with dementia. But, on the other hand, this concept would have the tendency to judge this view as part of the so-called malignant social psychology insofar as it may be part of a 'dark' view on human personality, assuming human people willingly act violently. But – as Kitwood is arguing on the basis of recognition theory – the ethically more challenging question would be, if the concept of person-centred care bases then in parts of what Bedorf (56) calls "misjudging recognition": The problem that the actual recognition of a person (even in the way of person-centred care) would always overwrite what a person could possibly be and want.

4.3 The social reality status of dignity

From a sociological perspective, a person's autonomy and dignity – even in the Kantian sense of the *Menschenwürde* - are not inherent qualities. The sociality established and maintained in care relationships cannot simply be linked to the clinical picture of the person in need of care, but is essentially related to the specific dynamics of interaction. This therefore also applies to the form in which the dignity of those in need of care is asserted, as well as that of carers. This draws attention to the practical conditions for the recognition and institutionalisation of respect for the dignity of both people with dementia and carers and other groups of actors. The notorious vagueness of the concept of dignity is therefore not only a problem of philosophical ethics (57), but conversely, ethics as one actor among many contribute to a practically effective concretisation in everyday organisational life. In this context, it is a difficult question to answer to what extent the administration of psychotropic drugs harms or benefits the autonomy of people in need of care. On the one hand, this is due to the fact that it is administered partly because the subjectivity of those in need of care is considered to be damaged and the administration of psychotropic drugs is supposed to be able to help them to exhibit behaviour that is socially expected to be based on free will. On the other hand, it is assumed that the administration of psychotropic drugs can in turn damage the subjectivity of those in need of care in such a way that their autonomy can also be restricted. The corridor for the legitimate administration of psychotropic drugs is then correspondingly narrow and notoriously controversial.

Sociology cannot solve ethical problems. However, its empirical research may help at least to indicate such problems.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical approval was not required for the study involving humans in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' or their legal guardians/next of kin.

Author contributions

JB: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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A conceptual framework for the ethical analysis of moral conflicts in migrant live-in care

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In many industrialized countries, hiring a migrant live-in carer represents a promising solution to support families caring for an older person at home and to avoid institutionalization. Migrant live-in carers live in the household of the person in need of care and provide extensive care and social support. They usually come from geographic areas such as Eastern Europe or Southeast Asia. Due to often unclear legal regulations regarding labor and migration status, as well as contradicting expectations and entangled vulnerabilities within the triad of the person in need of care, the live-in carer, and the family, these live-in care arrangements are prone to a variety of moral conflicts that require ethical analysis. This article proposes a conceptual ethical framework for analyzing moral conflicts within live-in care arrangements. By recognizing and addressing these conflicts within the multi-level ethical framework, the ground for a triadic perspective is laid and the ethical discussion around live-in care for older people can be put on an empirical basis. This can help to inform counselling and support for these arrangements, as well as policy advice for ethical solutions and improved caregiving practices.

KEYWORDS

moral conflicts, ethical analysis, care ethics, norms & moral standards, values, family caregiving, live-in care, dementia

1 Introduction

Aging in place is a leading paradigm for later life around the globe (1) and most older people live at home. Usually, care responsibilities lie in the hands of relatives like spouses or children (2). Even if public support is offered, for example, by long-term care insurance schemes, everyday care and support needs may not be covered sufficiently. For example, families affected by dementia are confronted with extensive care requirements – often around the clock. In this situation, hiring a migrant live-in carer can appear as a promising solution to support families and to avoid institutionalization. These live-in carers usually come from abroad, for example, Eastern Europe or Southeast Asia, and live with the persons in need of care in their home. They provide extensive social and often also nursing care and are usually expected to be available 24 hours a day (3).

Migrant live-in care is a widespread model of care in many countries, but the arrangements are often shaped by structural disparities. The empirical body of evidence points to a considerable potential for problems related to the precarious social and legal situation of the live-in carers (4, 5). To a lesser extent, the perspectives of relatives (6–8) or of older persons with and without dementia have been taken into account (9–11). However, research to date has provided little insight into the complex triadic constellation of live-in carer, relatives, and care recipient. A triadic perspective is important to understand the complexity of moral issues in live-in care. Furthermore, the specific structure of moral conflicts that arise in this context deserve closer ethical examination (12, 13). Live-in care arrangements can be characterized by entangled vulnerabilities and often contradicting needs, wishes and expectations of the parties involved (14). For example, conflicts can be rooted in colliding with personal interests or moral orientations, in disagreements regarding the allocation of care responsibilities and matters of workplace organization, or different understandings of the care needs and good care of the person in need of care (4). They may be open conflicts that are explicitly discussed or implicit conflicts that are never expressed, but usually affect the quality of care as well as the satisfaction and well-being of people in need of care, family carers as well as live-in carers.

In this paper, we introduce a conceptual framework to identify and analyze moral conflicts in live-in care arrangements from an ethical perspective. In doing so, we follow an approach of empirically informed ethics that pursues a systematic combination of ethical analysis and social research (15). The proposed framework aims to facilitate a first ethical categorization of moral conflicts in this area and is therefore neither committed to a specific ethical theory, such as utilitarian ethics, deontological ethics, or care ethics, nor to specific cultural contexts or national framework conditions. We distinguish collisions between moral norms and values which can constitute different types of conflict occurring on different levels (see Table 1). In this way, we provide a heuristic tool for the empirical analysis and ethical evaluation of these conflicts. Using examples found in own empirical research and described in the work of colleagues, we illustrate how this tool to develop a more profound and differentiated understanding of concrete moral conflicts that occur in the context of live-in care.

2 Background

Live-in care is a common form of care in most Western industrialized countries, but also countries like Taiwan or Singapore rely on this model. All these countries have an aging population, but limited means to provide adequate long-term care structures and services. Yet, they differ regarding migration processes, employment regulations, and long-term care regimes (16). While some countries such as Israel (live-in carers mainly come from the Philippines as well as from India, Sri Lanka, Moldova or Uzbekistan) and the UK (live-in carers mainly from the Gulf States, but also from India, the Philippines and Indonesia) strictly regulate the length of

TABLE 1 Types of moral conflicts in migrant live-in care arrangements on different levels.

	Types of moral conflicts		
	Norms vs. norms	Values vs. values	Norms vs. values
1) Micro level			
Intra-individual	Live-in carer's respect for the care-dependent person's autonomy vs. protection and safety (e.g. when the person has dementia)	Working as a live-in carer as a trade-off decision: improving living standard of one's own family but leaving family members behind in the home country	Adequate fulfillment of the care-dependent person's needs (around the clock care) collides with live-in carer's (workers) rights
Inter-individual	Collision of cultural norms of care and understanding of ageing between the relatives and the live-in carer	Religious beliefs of the live-in carer collide with that of the person in need of care or family caregiver's values and life style (e.g. concerning sexuality)	Relatives' or care dependent person's expectations regarding caregiving behavior of the live-in carer (e.g. norms of care responsibility) may clash with the live- carer's interest in personal wellbeing (e.g. privacy, enjoying free time)
2) Meso level			
Individual vs. family/agency	The perceived role and expectations of family members regarding live-in care may be in conflict with the perceptions and expectations of the live-in carers or the agency	Values promoted by an agency (e.g., exchangeability of carers) may conflict with values of live-in carer (e.g. emotional bond with person in need of care or family)	Family values of unconditional care are at odds with the live-in carer's right to individual autonomy and privacy
3) Macro level			
Individual vs. state policy/law	National labor law regulations may collide with contractual agreements and familial expectations	State laws manifest values (e.g. regarding the weighing of individual autonomy and privacy) that are at odds with live-in carer's values (e.g. stronger emphasis on care and family relations)	Benefits from long-term care insurance are not sufficient to cover for a fair live-in care arrangement, which leads to a violation of family values and feelings of guilt

stay in the country, Canada (live-in carers mainly from the Philippines), offers a path for legal migration via the *Live-in Caregiver Program* and opens up the possibility to gain citizenship (17, 18). In Germany and Switzerland, live-in carers mainly come from Eastern European or Baltic countries and usually live in shuffle migration, travelling back and forth between the live-in arrangement and their home (18, 19). Both countries are lacking standardized pathways and clear legal frameworks. The regulations are hardly transparent for families and live-in carers and often live-in care takes place in a legal "grey area" or is actually illegal under labor or criminal law (20). In Austria (live-in carers mainly from Slovakia and other Eastern European countries), live-in care is legally covered under the *Constitutional Law on Care* and within the free movement directive of the European Union. However, regardless of specific national regulations, the live-in care model leads to problematic arrangements in terms of working hours and conditions (18).

In many countries, like Switzerland, Germany or the Netherlands, placement agencies play a crucial role and have a significant influence on the dynamics in live-in care arrangements (18, 21, 22). They are hiring live-in carers and are supposed to offer support for relatives to navigate legal questions and find the right live-in carer for the care recipient considering specific needs and support the live-in carer with the migration process. In some cases, they also provide training in care skills and knowledge and function as moderators in the case of conflicts or abuse (22, 23). However, in practice families report that communication and agreements with agencies are often unreliable and cause conflicts, insecurity and crises. For example, live-in carers do not always receive the information that the cared-for person has dementia, or families are falsely informed that the live-in carer is experienced in dementia care and speaks the local language. Especially in systems like Germany, where the live-in carers change on a regular basis, relatives as well as live-in carers face the challenge of coming to terms with each other and with the person in need of care, and both parties often feel betrayed. They feel left alone by "their" agency as they do not receive the expected or even promised supervision and guidance (8, 14, 24). Especially if the cared for person has dementia, the constant change of live-in cares and the associated uncertainties and discontinuities can be experienced as a permanent crisis (24).

Live-in care arrangements are often burdened by severe structural disparities and problems, regardless of the country or the mediation through a placement agency. Gender-sensitive migration research points out to the fact that the vast majority of live-in carers is female. They usually come from economically poorer countries and the live-in care migration provides an opportunity to support themselves and their families at home. The migrant live-in care model supports care chains and care drains where the care systems of the countries of origin are drained from their informal care resources (16, 25). Especially in countries where live-in care is part of the grey care market, the doors are open to exploitation, for example, when no regular social security is provided or when the contracts of the live-in carers include provisions and contractual penalties (26). Families and live-in carers are often left alone to negotiate working conditions, and both have few legal options when problems with payments or working hours occur (5, 8). Live-in carers report long working hours, sometimes no free time for weeks or months, and physical abuse from the person with dementia (21, 23). The employment relationship is entangled with a family relationship between the relatives, the live-in carer and the person in need of care, especially if the care arrangement lasts for a long time and the persons involved develop a close emotional relationship (27, 28). In consequence, professional and personal lines are blurred and families' expectations towards the live-in carer are often diffused or ambivalent (14). Although activities are usually defined by a contract, this is overlaid by "collateral contractual mechanisms" fostered by the informality of the domestic setting (8). All this can lead to issues of responsibilities, guilt, and power structures (21, 23, 27).

3 The development of a conceptual framework for ethical analysis of moral conflicts

While existing social research points to a high potential for, and broad variety of, serious grievances emerging in the context of live-in care, it usually does not provide any explicit theoretical account of their moral offensiveness and objectionability. What is missing is a perspective that can explain in a differentiated way what exactly is problematic about the respective phenomena and thus allows to specify and justify their critique or condemnation (12). In this contribution, we start from the assumption that many of these issues ultimately point to underlying moral conflicts in live-in care that call for a closer ethical analysis.

From a philosophical point of view, a moral conflict describes a situation in which moral principles, obligations, and/or duties collide. The question to what extent decision-making and work situations of carers can cause moral issues has received considerable attention in nursing studies (29–35). However, the pertinent contributions usually subsume the respective issues under "moral distress" and leave their concrete moral structure and scope unexamined. Furthermore, the focus is often on professional nurses and care workers in a formal care setting and less on informal carers and informal domestic care settings. Expanding the focus beyond this domain is a necessary step to examine moral conflicts within live-in care arrangements.

In order to prepare the ground for a systematic ethical characterization and categorization of the different kinds of moral conflicts that can arise in a live-in care arrangement, we first need to distinguish different understandings of morality. In a general, descriptive sense, "morality" refers to judgments or standards regarding what intentions, actions, or institutional structures and processes are to be considered as good, right, or proper (36, 37). For a long time, moral philosophy and especially applied ethics was based on a rather narrow understanding of morality in terms of strict moral claims and obligations that individuals or groups have towards themselves or vis-a-vis each other, e.g., the claim to be treated with respect or the duty not to hurt others. This perspective can be called normative since it refers to moral norms, that is, general rules or standards of moral acceptability like the rule to respect others and avoid harm (37).

However, in more recent years, this narrow normative focus has been criticized since it neglects important moral questions regarding individual happiness, fulfilment and flourishing, e.g., what is desirable and important in life and gives our existence value and meaning

(38,39). This perspective can be called evaluative as it is not so much concerned with prescriptive norms of what is morally right or wrong but with eudemonistic standards of what is good, valuable and meaningful in life. It is important to note that both perspectives are not mutually exclusive but frequently closely entwined or even interdependent: On the one hand, values regarding a good life can be implemented through a set of general norms, for example, a catalogue of human rights recognizing basic needs and protecting individual wellbeing and self-fulfillment. On the other hand, individuals and communities can value moral norms such as justice to a degree that they become a personal or collective value for them.

In order not to exclude potentially relevant dimensions and kinds of moral conflicts right from the start, it appears generally advisable to start from a broad understanding of morality that comprises normative as well as evaluative aspects and factors: moral norms as well as values (39, 40). Especially in the field of migrant live-in care, where individuals from different cultural backgrounds share the deeply personal space of daily living and are entangled in value-laden practices and relationships of care, it seems plausible to assume that moral conflicts not only involve general rights or responsibilities, but also individual ideals and cultural orientations regarding wellbeing, home and family, as well as good care (24; Zriker et al., 2024; 41–43).

Furthermore, it is important to acknowledge that moral conflicts can arise on several societal levels. In the proposed framework we differentiate between three levels (see Table 1): The micro- the meso- and the macro-level. On the *micro-level*, individuals may struggle with reconciling different moral norms or values. This can be *intra-individual*, but also *inter-individual* if one person's moral norms and/or values clash with the moral norms and/or values of another person. At a *meso-level*, norms or values of institutions or organizations such as the family, the agency or a nursing service come into play and can cause conflicts in the live-in care arrangement. On a societal *macro-level*, moral conflicts in the live-in care arrangements can also involve norms and values which are connected to state policy and laws. In Table 1, we explain our conceptual framework along the two mentioned axes (1) Norm vs. norms; values vs. values; norms vs values and (2) Micro-, meso-, and macro-level and provide examples of possible moral conflicts (interlay between norms and values) on each level.

In the following, we illustrate paradigmatically how the proposed framework can help to develop a more profound and differentiated understanding of concrete moral conflicts that occur in the context of live-in care. We apply the framework's ethical perspectives to exemplary situations found in existing empirical research in order to analyze and interpret them with regard to moral norms and values involved on different levels and how their contradiction leads to moral conflicts.

3.1 Potential moral conflicts of live-in care on the micro level

3.1.1 Intra-individual conflict of norms

Many of the problematic issues of live-in care addressed in the literature apparently pertain to the micro-level of moral conflicts between members of the live-in triad. Thus, regularly reported cultural tensions between the live-in carer and the relatives can be interpreted in terms of moral conflicts between more individualistic and more paternalistic or collectivistic moral orientations. For example, family caregivers often expect live-in carers to respect their relative's autonomy while the live-in carer may tend to restrict personal autonomy and freedom for the sake of physical safety, or the overall wellbeing of the family. In live-in care arrangements for a person with dementia this could mean hindering the person from leaving the apartment or forcing her to eat and drink (6, 14). With regard to the live-in carer's inner conflict of norms concerning either autonomy or safety of the person they feel responsible for, this would be an intra-individual norm-conflict.

3.1.2 Intra-individual conflict of values

Conflicts of values on the micro-level can be identified when live-in carers have their own distinct values that are challenging to fulfill simultaneously. For instance, the decision to work as a live-in carer in a foreign country entails a complex trade-off. On the one hand, there is a desire to pursue a better life and provide a higher standard of living for oneself and one's family. On the other hand, it requires "sacrifice" – leaving one's family members behind, living far away, and missing the opportunity to raise one's own children or caring for one's own older family members (intra-individual value-conflict) (cf. Bruquetas-Callejo, 2019).

3.1.3 Intra-individual conflict of norms *vs*. values

Another type of moral conflict that can be retrieved from literature is a norm-value-conflict, which can arise when a person's values clash with recognized moral norms. For instance, someone may hire a live-in carer to fulfill the wish of a close relative to continue living at home. At the same time this can conflict with one's personal understanding – and acceptance of general norms – of fair working conditions. This situation is problematic as the relative or family exploits the live-in carers, neglecting their rights and disregarding established work laws as societal norms. Fulfilling the person's needs in this context perpetuates structural inequality (7).

3.1.4 Inter-individual conflict of norms

An inter-individual norm-conflict arises if the live-in carer and the relatives adhere to different (cultural) norms. For example, as described above for intra-individual conflict of norms, this can be regarding the weight given to individual autonomy of the person in need of care (8, 22).

3.1.5 Inter-individual conflict of values

Similarly, conflicts of values can occur between live-in carers, family caregivers, and the person in need of care regarding for example religious values clashing with sexual values. For example, a catholic belief of the live-in carer may collide with the person's with dementia, or the family caregiver's values, e.g., concerning sexuality when one of them defines themselves as gay or queer. Another case with a high potential for conflicts is described when migrant live-in caregivers are employed in faith-based societies like an ultra-orthodox Jewish family in Israel (44).

3.1.6 Inter-individual conflict of norms *vs*. values

An alternate combination of conflicts on the micro level that we have found in one of our own previous qualitative studies, is when a live-in carer may find that certain values held by family members violate moral norms, such as widely recognized and performed standards of due care and responsibility (14).

3.2 Potential moral conflicts of live-in care on the meso level

3.2.1 Conflict of norms

Other conflicts described in the literature pertain to the meso-level. These arise when institutional actors such as the family as a whole, placement agencies or other professional or profit-oriented stakeholders are involved. For example, the live-in carers can find themselves in the ambivalent role of quasi-family members. By placing the live-in carer in this role, families may feel comfortable making requests that go beyond what is stated in the contract. Live-in triads are therefore particularly prone to conflicts between familial norms of comprehensive care and responsibility for relatives on the one hand and contractual agreements between business partners, e.g. regarding free time and specified tasks on the other hand (23). Furthermore, the quality of the relationships within the triad is in danger if no balance between contradicting norms can be found.

3.2.2 Conflict of values

Certain values of placement agencies, like an uncomplicated fungibility of live-in carers from an efficient work force perspective may rather often conflict with values of live-in carers, for instance if they think that good live-in care involves an emotional bond (23).

3.2.3 Conflict of norms *vs*. values

A common conflict of norms vs. values on the meso-level is when family values of unconditional care are at odds with the live-in carer's right to individual autonomy and privacy. Especially the close relatives tend to lack awareness of the personal rights of the live-in carers (8, 45).

3.3 Potential moral conflicts of live-in care on the macro level

3.3.1 Conflict of norms

On the macro-level, political and societal structures as well as legal regulations and principles, e.g. the Aging in place policy of Western welfare states (1), are considered as a level for potential moral conflicts in our framework. At first glance, this level might seem "far away" from the conflicts arising from the everyday communications and negotiations within the triad in the micro-setting of the live-in care arrangement. However, empirical research points to the meaning of the framework conditions of the macro-level and how these come into conflict with familial expectations and contractual agreements regarding the tasks and the working hours of the live-in carer, which may violate national labor law regulations (14, 22). This conflict may arise from the desire for legal employment of a live-in carer, which is not feasible within the existing legal frameworks and in view of the actual care needs. This typical conflict is represented in a much-publicized court trial in Germany (46), in which a live-in carer sued successfully for recognition and remuneration of on-call times, particularly at night. Such a situation may lead to feelings of guilt in family caregivers towards the live-in carer accompanied by fear about potential personal consequences (7).

3.3.2 Conflict of values *vs*. values

Furthermore, state laws manifest values regarding for example the weighing of individual autonomy or privacy which can divert from the live-in carer's values in this matter. His or her values may rather emphasize the care needs or relation to other family members (7).

3.3.3 Conflict of norms *vs*. values

Another macro-level conflict arises from a disproportion between the extensive care needs that drive live-in arrangements and long-term care legislations, such as in Germany, that does not fully cover these needs. Families then find themselves in a situation where they cannot realize their desire for legal and fair employment with the (financial) resources provided by the system as this would require a two or three-shift live-in care arrangement with more than one live-in carer. However, national labor law still applies. This dilemma is ignored at the macro level, leaving families at the micro level with their feelings of guilt and a conflict of norms and values (8).

In summary, there is a large number of potential moral conflicts that can be enumerated along the indicated axles (level and type of moral conflict). We have only listed some of them and make no claim of the completeness of the table. However, the variations offer an insight into the myriad possible variations of moral conflicts that can arise in the context of live-in care. The framework presented in Table 1 demonstrates the interconnectivity of the moral conflicts between each societal level and therefore contributes to gaining a multi-perspective understanding of the moral conflicts in the field.

4 Discussion and conclusion

In this paper, we have introduced a conceptual framework for the ethical analysis of moral conflicts in migrant live-in care arrangements. We argue that moral conflicts in the context of live-in care can be analyzed as (1) *conflicts between norms*, (2) *conflicts between values*, and (3) *conflicts between norms and values*. All three types of conflicts may occur on the micro-level represented by the intra- and interindividual level of the triad, the meso-level in interactions between agencies and the triad as well as the macro-level with conflicts between legal regulations and policies and the triad. These levels are not independent but interrelated. Especially changes at the macro-level can have a ripple effect, influencing and impacting other levels of the framework.

Due to its rather broad ethical outline based on the fundamental meta-ethical distinction between values and norms, as well as on the differentiation of three societal levels (micro, meso, and macro), the proposed framework is able to accommodate a whole variety of ethical theories and cultural orientations. This is particularly important in a field like migrant live-in care that is located at the intersection of different social spheres and cultural contexts, each connected to specific paradigms of morality. Thus, the intricate web of moral roles and responsibilities that bind the members of a family calls for another ethical perspective and vocabulary than the general rights and obligations regulating interactions between individuals as contractual partners or equal citizens of a political community (14). Furthermore, more individualistic cultural views of morality, for example in the context of modern Western liberalism, prioritize other norms and values than more collectivistic stances that place greater weight on the family or on the community as a whole (44).

The examples provided illustrate the added value of a closer ethical analysis of moral conflicts arising in the live-in care setting. The framework proposed here allows a differentiated characterization and categorization of the concrete evaluative and normative aspects that are at stake in live-care arrangements. It opens moral conflicts arising in live-in care to a differentiated discussion and evaluation according to a whole range of complementary ethical theories and criteria. Especially in view of the triadic care setting, the perspectives of an ethics of care (47, 48) has proven fruitful for more in-depth analyses of the needs, vulnerabilities and asymmetrical relations between the parties involved (12, 23, 49). With regard to the role of the macro-level, human rights-based approaches, for example, regarding labor and migration laws, can highlight important structural perspectives (50, 51). Furthermore, with its different levels, the proposed framework leaves space for cultural differences of moral perspectives and particularly allows to categorize moral conflicts that can arise from the collision of more individualistic and more collectivistic values and norms (44).

Thus, the proposed multi-level framework ultimately demonstrates the complexity of moral conflicts in live-in care that usually involve several parties and their respective culturally embedded moral perspectives, which are located at different (intra- and inter-)individual, institutional, and societal levels. The framework lays the ground for a multi-perspective analysis and provides a heuristic tool to facilitate this in further studies. In doing so it highlights the importance of studying the migrant live-in care arrangement from a triadic perspective rather than an individual perspective. This is because moral conflicts usually are not limited to intra-individual experiences but rather encompass multiple stakeholders within the triad as well as outside of the triad (12, 52, 53). In this context, a central concern is including person in need of care, especially when they have dementia, in the research and ensuring his or her voice is heard. Future research will benefit from expanding the study of moral conflicts even further by extending our perspective beyond the triad to include additional network members. In addition, the study highlights the importance of incorporating the socio-cultural background of all members of the triad in the analysis of moral conflicts.

Although the proposed tool is complex and needs elaboration and discussion, its further development promises several benefits. First, we underline important yet neglected issues of ethics, norms, and values in the care provided to older people by their family members and by live-in carers. Pointing out these issues and bringing them to the attention of social workers, nurses, and other social and health care providers has the potential of assisting these professionals in their efforts to resolve conflicts within the triadic arrangement and to better understand the needs, norms, and values of each of these stakeholders. Moreover, by drawing attention to the different types of conflict that can emerge, we potentially set the ground for future innovative interventions that can be applied at different levels, depending on context and need, ranging from intraindividual to interpersonal, while taking into account institutional sources of stress.

Furthermore, with regard to its practical use, the framework could be applied as a heuristic tool for research and practice to identify the needs and wishes of the individuals in live-in care triads. The framework also can help to prioritize them, for example by highlighting moral questions such as when the care needs of the person with dementia are more important than the work regulations of the live-in carer and when it appears ethically suitable to evaluate the needs of the live-in migrant carer as higher. By supporting the identification and prioritization of problems, the framework can help to define areas of intervention, especially in grave conflicts when the safety of one or more persons involved is at risk.

On the micro-level, the framework could be adapted to be used in interventions and counselling to help actors of the triad to recognize and navigate conflicts of norms and values within themselves and with each other (micro-level). In an adapted version, the framework also has the potential to function as a didactical tool for nurses and social workers to sensitize them for potential conflicts they might observe when working in the context of live-in care arrangements. On the meso- and macro-level, practical application entails advocating for policy changes and legal reforms to align familial expectations and contractual agreements with labor law regulations. Ensuring fair working conditions and protection of live-in carers' rights can contribute to resolving moral conflicts and promoting ethically acceptable caregiving practices. Additionally, an adapted version of the framework could function as a foundation for ethical recommendations for individuals in the triad but also for agencies and policy makers to better address moral conflicts associated with live-in migrant home care. Finally, it could contribute to public debates, for example, in the media about the moral costs and the acceptability of live-in migrant care as a form of care in industrialized countries.

In sum, the practical application of our considerations involves promoting open communication, ethical reflection, and decision-making within different settings. By adapting and implementing the multi-level conceptual framework in practice, live-in carers, families, organizations, agencies, and policymakers can better understand, address, and resolve moral conflicts within live-in caregiving arrangements. It might facilitate ethical decision-making, policy reforms, and the promotion of fair and respectful caregiving practices.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

MK: Conceptualization, Methodology, Visualization, Writing – original draft, Writing – review & editing, Funding acquisition. MW: Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Funding acquisition. NU: Conceptualization, Methodology, Project administration, Writing – review & editing. A-EN: Conceptualization, Methodology, Project administration, Visualization, Writing – review & editing. LA: Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing. MS: Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

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Empowerment in structures. Practical-ethical considerations of the preconditions for technology-assisted dementia care in Germany based on an expert-interview study

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Background: Intelligent assistive technologies (IAT) have become more common in dementia care. Ethical reflection on technology-assisted dementia care (TADC) has focused so far mainly on individual and interpersonal implications (e.g., self-determination, (in)dependence, safety or privacy issues, caregivers' support and cost-efficiency). From an empowerment-sensitive perspective, however, the societal, political, economic and technological preconditions for TADC should be more deeply analyzed in terms of their accelerating or inhibiting effects on technology development, implementation and usage. Therefore, the aim of this study was to explore these preconditions in the German context and so to contribute to more empowerment-sensitive structures.

Methods: Semi-structured interviews were conducted with 20 German-speaking experts from health care, health policy and the fields contributing to IAT (e.g., computer science, engineering). Thematic content analysis was used to analyze the data.

Findings: The experts' assessments of the current preconditions for TADC in Germany were starkly ambivalent. In the field of „society", they identified digitalization, a change in mentality towards IAT and demographic change as accelerators, unequally distributed digital literacy, misleading perceptions and a lack of affinity as inhibitors. In the field "politics - regulation - economy", experts identified scarcity of public resources, growing private wealth and regulatory progress as accelerators and unclear financing options, an uncertain market, data protection and ethical challenges as inhibitors. In the field "technology", they identified progress in basic technical research and improved customizability and interconnectivity as accelerators, while deficient digital infrastructure, a lack of user participation, dementia-specific challenges and challenges regarding data collection and security were seen as inhibitors.

Conclusions: TADC promises an empowerment of persons with dementia, e.g. by enhancing their self-determination, increasing their independence from social control and by allowing more social participation. Yet its societal, political, economic and technological environments preconfigure the likelihood of successful empowerment as a socio-technical practice within TADC. Accelerators in the fields of society, politics-regulation-economy and technology need to be consolidated and strengthened. Inhibitors need to be mitigated, e.g. by with new educational, political and market economic policies. We make policy recommendations based on these conclusions.

KEYWORDS

empowerment, dementia, intelligent assistive technology, digitalization, exogenous preconditions, policy recommendations

1 Introduction

In recent decades, the normative concept of good ageing has changed fundamentally. Today, it focuses on sustained health and productivity, independence, self-determination and social participation for as long as possible. Good ageing means realizing these normative goals even if one is in need of care, for example due to late onset dementia. Moreover, since care is recognized as a continuum starting with informal care by relatives at home and extending to highly professionalized care in care facilities, this ideal holds in all phases of care (1–4).

Alongside to this normative change, care for ageing persons and persons with dementia is subject to ever more intensive technological development. As a result of advances in computer science and engineering, intelligent assistive technologies (IAT) are being used increasingly to maintain or improve individual functioning. "Intelligent" means that these technologies analyze their environment using sensors and (different forms of) artificial intelligence (AI) and, consequently, operate in a somewhat autonomous manner (5, 6). Examples of such IAT include smart GPS tacking systems that can learn the usual routes of their users and report deviations, smart home systems that use sensors to detect falls and call for help, and (humanoid) care robots that serve as interaction partners for their users (7).

In response to the typical symptoms of dementia — memory impairment, impairment of executive functions, attention, social skills and judgment abilities —, IAT are being implemented with increasing regularity and intensity in dementia care. Its use is intended to increase the safety and, thereby, independence of persons with dementia, to enable them to remain in their own homes longer and to participate more actively in social life (4, 7–9). Additionally, IAT is intended to relieve the physical and psychological burden of family and professional caregivers, to mitigate the shortage of skilled nursing staff and to increase the overall quality of dementia care (4).

Due to these normative goals, ethical reflection on technology-assisted dementia care (TADC) has so far focused primarily on individual and interpersonal implications and on the participation of users in technology development (10–14). With this focus, however, other crucial aspects of TADC are fading from view: TADC is a socio-technical practice of empowerment. As such, it is accelerated and inhibited by its social, political, economic and technological preconditions. Thus, a serious analysis of the actual potential for TADC to promote interpersonal empowerment means highlighting the significant impact of these exogenous preconditions for its likelihood of success.

By empowerment, we mean, first, the endeavor to reduce dependencies in asymmetrical interpersonal, social and political relationships and to support individuals' power of self-determination. Originally, its focus was solely on pre-existing power relations, i.e. on social and political structures that affect or limit the possibility of individuals and groups to practice self-determination, to be independent and to participate in social and political life. This includes social and political participation of members of marginalized groups (15–17). Secondly, we mean thereby the sum of different social and socio-technical practices: social practices utilizing technology with which these goals are pursued. Originally, empowerment started in community psychology, emancipatory pedagogy and social work, and addressed primarily marginalized socio-economic groups. However, in recent decades, it has become increasingly important in healthcare because of the need to transform asymmetric power-relations such as those between patients and professionals (17–19). Such goals formulated in the empowerment concept for health contexts are particularly relevant for areas of chronic illnesses and in long-term care (17). In a participatory study conducted by McConnell et al (20), people with dementia (PWD) defined empowerment as following: a "confidence building process whereby PWD are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources." In addition to this social practice of empowerment, IAT can be utilized to increase the independence, social participation and, hence, the self-determination of people with chronic conditions. Thereby, empowerment should be discussed nowadays as a socio-technical practice which utilizes technologies. In conclusion, the concept of empowerment provides more reflective potentiality than the traditional ethical principle of autonomy. It can be adapted in a particularly suitable way for a structure-sensitive reflection of socio-technical practices and their exogenous preconditions in society, politics, economy and technology development. Such preconditions preconfigure the possibility of fair access to TADC.

Against this backdrop, this study explores current preconditions for the development, implementation and usage of IAT in dementia care in Germany and discuss them from an empowerment-ethical perspective. A further aim is to contribute to more empowerment-sensitive structures by providing concrete policy recommendations.

To this end, we conducted a qualitative interview study with German experts to learn more about the structural preconditions and the opportunities and risks linked to TADC. In the following, we present the results of the expert study that relate to the preconditions for TADC. Findings on the opportunities and risks of TADC for people with dementia, their relatives and professional caregivers, as well as the care system, have been already published (21). In the discussion, we focus on four identified preconditions —digitalization, unequally distributed digital literacy, deficient digital infrastructure and unclear financing options— and their impact on TADC as a socio-technical practice of empowerment. We conclude with policy recommendations addressing relevant stakeholders in TADC.

2 Methods

We conducted a qualitative interview study with German-speaking experts. This design was particularly useful as the question of this study has not yet been adequately addressed in the scientific literature. Furthermore, the experts included have privileged access to the knowledge and debates of their professions and also can potentially influence public and political debates revolving around the preconditions investigated here.

2.1 Sample definition and participants

To be included in the study, participants had to belong to one of the following three groups (22, 23):

1. experts in the field of technology research or development related to IAT and/or people with dementia; or.
2. experts in a health care field such as health care policy, health care administration, long-term care insurance or patient organizations; or.
3. experts in the field of nursing profession policy.

Participants were identified based on their professional background as stated in job descriptions and academic profiles, their expertise in the field as evidenced by publications and professional activities and targeted internet research (Google and Google Scholar). Suitable experts were then invited by email to participate in the study. The experts contacted initially were asked to recommend other experts whom they considered relevant to the study. All invitation emails included a description of the research project, a data protection declaration and a declaration of consent for signing.

Of the 26 experts invited to participate in the study, 20 from a broad spectrum of relevant disciplines participated (Table 1). Three individuals did not react at all, two declined participation due to time constraints and one declined due to self-assessed lack of expertise.

2.2 Interview guide

Following the methods of qualitative research (24), we developed a semi-structured interview guide. The interview guide comprised 15 questions designed to elicit experts' perceptions and assessments of (1) the preconditions for the development and use of IAT in dementia care, (2) the opportunities and risks of using IAT for people with dementia, family and professional caregivers and (3) the technical and ethical criteria of good IAT in dementia care.

The guide was pre-tested with one participant to check the comprehensibility and factual appropriateness of the items. Following the pre-test, we made minor wording corrections and summarized the questions about opportunities and risks for the different user groups.

2.3 Procedure: interview setting and recording

The interviews were conducted from July 2020 to March 2021. After 20 interviews, thematic saturation was observed so no further attempts were undertaken to recruit more experts (cf. 25). Sixteen of the interviews were conducted using videoconferencing systems

TABLE 1 Groups of experts and related participants with professional background.

Group	Participants and professional background
1. Technology research and development	1. Expert 2, Engineer 2. Expert 6, Development of IAT 3. Expert 7, Computer Scientist 4. Expert 13, Computer Scientist 5. Expert 14, Engineer 6. Expert 16, Computer Scientist 7. Expert 18, Development of IAT 8. Expert 19, Computer Scientist 9. Expert 20, Engineer
2. Healthcare	1. Expert 1, Representative of a patient organization 2. Expert 5, Representative of a welfare agency 3. Expert 8, Representative of an association of private nursing care providers 4. Expert 9, Representative of federal healthcare politics 5. Expert 11, Representative of a welfare agency 6. Expert 12, Representative of a public long term care insurance 7. Expert 10, Representative of research funding 8. Expert 15, Representative of a private long term care insurance 9. Expert 17, Representative of the healthcare administration of a federal state
3. Nursing profession policy	1. Expert 3, Nursing Management Executive 2. Expert 4, Member of a Nursing Chamber

(Zoom, Microsoft Teams); three interviews were conducted by telephone; one interview was conducted face-to-face. The reason for all but one of the media-mediated interviews was COVID19-induced limitations, particularly social distancing and travel restrictions.

The interviews conducted online were recorded using the recording instruments of the videoconferencing systems and stored on an on-duty hard drive. The telephone and in-person interviews were recorded using a voice recorder. Subsequently, the audio recordings were transcribed verbatim in German; four interviews were transcribed by Johannes Welsch (anonymized for review), the rest by an external service provider who signed a confidentiality agreement.

2.4 Interview analysis

The analysis was conducted using the methods of Qualitative Content Analysis (26). For the purpose of qualitative content analysis, a German-language coding guide was developed by Johannes Welsch. To this end, the researchers familiarized themselves with the transcribed interviews by reading them several times and writing memos. In a second step, a preliminary coding guide was drafted with main categories corresponding to the items contained in the interview guide. The coding guide then included code names, rules for coding and anchor quotes. To ensure intercoder reliability, five transcribed and anonymized interviews were independently coded by Johannes Welsch) and the EIDEC project research assistant, Sabrina Krohm. After minor adjustments regarding the coding rules, intercoder reliability was established.

In the fourth step, all material was coded on the basis of the main categories. In the fifth step, all text passages coded with the same main category were compiled. In the sixth step, subcategories were formed for the respective main categories from the material thus compiled and structured. The complete material was then coded in the seventh step using the differentiated coding guide. In the eighth step, a final analysis of the data was carried out with the selection of anchor quotes.

The interview guide had defined three main themes for the qualitative analysis of the interviews: (1) preconditions for the development and use of IAT in dementia care; (2) opportunities and risks of the use of IAT in dementia care for affected persons, family and professional caregivers; (3) criteria of good IAT for dementia care. The preliminary analysis revealed that main theme 1 in particular is interesting from an ethical point of view as it reveals often-overseen structural aspects of technology-assisted dementia care. Main theme 2 covers the broader spectrum of empowerment-ethical implications of the implementation and usage of IAT in dementia care for individuals and interpersonal relations (self-determination, independence and social participation). With regard to the topic of this paper, we will focus on the main theme 1 in the following.

2.5 Translation

For the purpose of publication, the quotes from interviews were translated from German into English. Earlier, also the codes were translated from German into English for a cross-cultural publication on the opportunities and risks of TADC.

3 Results

The qualitative content analysis revealed that the interviewees mentioned both accelerating and inhibiting preconditions for the development, implementation and use of IAT in dementia care in response to the questions of main theme 1. We identified a total of eleven accelerating and thirteen inhibiting factors (Table 2). In the process of the qualitative analysis, we decided that these preconditions can be subsumed under three exogenous structural fields: (1) society, (2) politics - regulation - economy and (3) technology.

Results are presented below, structured by these three fields. A presentation of accelerators and inhibitors in each field shows ambivalence of TADC preconditions.

3.1 Society: digitalization without digital literacy?

In the exogenous structure field "society," we derived categories of societal developments and transformation procedures such as *digitalization*, the *COVID19 pandemic*, a *change in mentality* among the older generation regarding new technologies as well as need for care, *demographic change* and the *shortage of skilled nursing staff.* All of these were identified as societal preconditions accelerating the development and usage of IAT in dementia care. As societal preconditions, they are driven by explicit and often implicit socio-cultural developments that are not clearly governed politically or economically.

According to the experts, the most important precondition in this field is the digitalization, i.e. the digital transformation of (nearly) all individual and societal practices and realities. Various developments and factors mentioned by the experts can be subsumed under this term. For example, a participant from a welfare agency identified the "[…] *increasingly natural use of technology in everyday life* […]" as an accelerating factor (Expert 11). A health-system administrator recognized technology as an increasingly "[…] *fundamental part of the reality of life* […]" of most people (Expert 17). Overall, the affinity for technology is increasing in everyday life (Expert 5). Thus, the desire, especially among younger nurses, to use digital technologies in their professional practice is growing (Expert 9; Expert 8; Expert 1). Regarding the opportunities associated with technology use by people with cognitive and/or physical disabilities, a technology researcher emphasized:

TABLE 2 Accelerating and inhibiting preconditions for the development, implementation and usage of IAT in dementia care.

Exogenous structural field	Accelerators	Inhibitors
Society	1. Digitalization 2. Change in mentality 3. Demographic change 4. Shortage of skilled nursing staff 5. COVID19 pandemic	1. Unequally distributed digital literacy 2. Lack of affinity for technology/resentments 3. Misleading technology perception
Politics - Regulation - Economy	6. Growing private wealth 7. Scarcity of public resources 8. Enhanced funding policy 9. Regulative advances	4. Unclear financing options 5. High business risks 6. Uncertain market 7. Challenges regarding data protection and ethics 8. Short research funding periods
Technology	10. Advances in basic technical research 11. Enhanced customizability and interconnectivity	9. Deficient digital infrastructure 10. Lack of potential users' participation 11. Dementia-specific challenges in development and implementation 12. Focus on innovation 13. Challenges regarding data collection and security

> "Well, I guess we all use technology and benefit from it and see it as another opportunity for interaction. So there is no reason at all why people with impairments should not also benefit from digital technologies." (Expert 2).

Some experts from groups 2 and 3 noted that digitalization has been accelerated additionally by the *COVID19 pandemic*. The pandemic has triggered a "*boost*" (Expert 12; Expert 15) in overall technology use and in financial flexibility on the side of policymakers (Expert 17; Expert 3; Expert 9).

Another accelerating precondition was found to be a *change in mentality* among the older generation: Ageing people and those in need for care today have precise ideas about what their life in old age should look like (Expert 9). Here, the desire to remain in one's own home for as long as possible was identified as central (Expert 5; Expert 9; Expert 10; Expert 17; Expert 18).

Furthermore, the experts named the *demographic change* (ageing of the population) as an accelerating factor for the development and use of IAT in dementia care (Expert 1; Expert 7; Expert 14). This was linked to the ongoing *shortage of skilled nursing staff* and the *decreasing number of informal caregivers* (Expert 7).

According to the interviewed experts, these accelerating preconditions are counterbalanced by inhibiting factors in society. The experts identified a *lack of or unequally distributed digital literacy*, *unclear terms* and associated *misleading perceptions of technology* as well as a *lack of affinity for technology and resentments*, particularly among professional nurses, as inhibiting preconditions.

As a decisive inhibitor the experts identified the *lack of or unequally distributed digital literacy*. An expert stated:

> "There is very little knowledge about technology in the normal population." (Expert 14).

Another interviewee problematized the unequal distribution of the degree of digital literacy necessary for creative technology usage:

> "Of course, you need competencies. And these are very unequally distributed. There are people who happen to have a relative who is very tech-savvy and then it works, the relative shares his knowledge. And then there are others who just do not have such a relative and are then cut off from possibilities and opportunities." (Expert 2).

In addition, the challenge of lacking digital literacy and gaining competencies was mentioned with regard to professional caregivers:

> "Well, there are 1.2 million people working as professional nurses. Very few of them have profound digital literacy" (Expert 20).

Moreover, they simply lack the time to acquire these competencies (Expert 4).

Additionally, unclear terms and misleading perceptions of technology were identified as inhibiting factors in the field of society. A federal health care policymaker stated:

> "Many people do not know what is meant, but we still use simplifying buzzwords like robotics or digitalization […]." (Expert 9).

A third inhibiting factor was seen in the *lack of affinity and resentments*, especially among professional caregivers. This precondition was highlighted by interviewees from group 2 and 3:

> "Professional nurses do not usually have a strong affinity for technology." (Expert 15).

One expert saw the reason for this in the fact that "[…] *many people are still not clear about the role of technology and digitalization in relation to the profession and practical work.*" (Expert 12).

3.2 Politics - regulation - economy: who pays?

In the field "politics - regulation - economy," *scarcity of public resources*, *growing private wealth*, *regulative advances* and *enhanced funding policy* were identified as accelerating the development and usage of IAT in dementia care. This field addresses the close interrelation between soft and hard law as well as political-economic aspects that impact the regulation of access, offers and demands.

The representative of a patient organization named the *scarcity of public resources*, especially in the nursing sector, as an accelerator for the implementation of new technologies:

> "We have, of course, a scarcity of resources which could foster the use of such items" (Expert 1).

One technology expert differentiated this scarcity of resources regarding the dimensions of financial and human resources (Expert 18).

On the other hand, one expert from the healthcare administration of a federal state noted a general *growth of private wealth*. This makes it possible for private individuals to purchase modern assistive technologies:

> "[…] on the demand side, it is also the growing prosperity that makes such things possible, so that I say: I'll splurge on it […]." (Expert 17).

Additionally, some experts stated that the demand for IAT is strengthened by *enhanced funding policies* for individual investments as well as for research projects. A participant from a private long-term care insurance stated:

> "[…] today there are already funding programs via the KFW[1] to subsidize the corresponding renovation work in private apartments […]" (Expert 15).

In general, legal regulation in the area of digital healthcare "[…] *has picked up speed even more in recent years* […]" (Expert 12), for example through the Digital Health Care Act (Expert 10; Expert 12). In addition, the federal government funds research in the area of assistive technologies (Expert 10).

Nevertheless, several inhibitors were likewise identified in this structural field: *unclear financing options*, an *uncluttered market*, *high business risks*, *data protection and ethical challenges*, as well as *too short research funding periods*.

In clear contrast to accelerating developments such as growing private wealth, experts form all groups problematized the as yet *unclear financing options* of IAT and TADC for private individuals. One technology researcher outlined the fundamental problem: "*If technology changes care, then this changed form of care must somehow pay for itself*" (Expert 2). Another technology researcher stated:

> "It is, after all, always a question in care why many such interventions are not yet ready for the market or why they are not used, and then of course it would also be question of who ultimately bears the costs for expensive monitoring and assistive systems." (Expert 6).

According to the experts, this has been insufficiently clarified. In this context, a representative of a welfare agency criticized restraints on the long-term care insurance providers:

> "[…] that the insurance companies say, okay, we'll do a pilot project […], but on the other hand we are rather hesitant, for example, to expand the list of aids and to say that we think it's good that something like this is used, and we'll also finance it." (Expert 5).

At the same time, private willingness to invest is too low in relation to growing private wealth, according to a representative of a long-term care insurance:

> "One finding that we have taken away from our model program for the further development of new forms of housing is that, on the one hand, people are of course always grateful when apartment owner or housing cooperatives upgrade their apartments technically and digitally. The moment that this is then reflected in the rent and possibly associated with their own share, and perhaps with an increasing rent, then of course the willingness often drops." (Expert 12).

The inhibiting effect of unclear financing may be reinforced by the cluttered market that some experts identified:

> "It is not clear what is in the market, what is it actually good for." (Expert 8)

This, in turn, would mean high business risks for technology companies (Expert 4; Expert 7).

Additionally, *legal requirements regarding data protection* were identified as a (time-)relevant hurdle for companies and insurances:

> "Ensuring data protection and privacy for eighty million people is probably not an easy task" (Expert 12).

Legal requirements are an obstacle in this regard, especially in light of the quantity of data necessary for training algorithms (Expert 10). In addition, the application and approval procedures

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[1] KFW: Kreditanstalt für Wiederaufbau, is a German state-owned investment and development bank (https://kfw.de/kfw.de.html).

under the Medical Devices Act were seen as too extensive and time-consuming (Expert 8; Expert 10).

Moreover, *research funding periods* were criticized as *too short*. Due to the time limitations, the projects would often focus "[…] *technology development, technology design* […]" (Expert 2) and would not include "[…] *technology use, technology appropriation, changes of structures, processes* […]" (Ibid.). Hence, the research on the implementation of technologies are often neglected:

> "[…] we actually lack this transfer and diffusion area, where you really look a lot in practice and also on what happens after the technology was implemented" (Ibid.).

3.3 Technology: using IAT in the digital desert?

In this field, the experts named general *advances in basic technical research* as well as the *enhanced customizability and interconnectivity* of technical devices as accelerating preconditions. "Technology" as a field includes material, methodological and scientific developments that determine advancements in technology developments.

Participants from all expert groups identified a variety of advances in basic technical research as particularly accelerating the development and use of IAT in dementia care:

> "It starts with really very basic technological things, already starting with mechanical engineering up to AI technologies, especially in the field of image recognition, where it is about facial expression analysis, deep learning and so on […]." (Expert 7).

These advances would enable new applications and open up further fields of use for IAT (Expert 10; Expert 4; Expert 17).

The *enhanced customizability and interconnectivity* of devices, which enables flexible use of artifacts, is particularly accelerating. One technology researcher cited smartphones as an example:

> "So, if we just look at smartphones now, as a universal tool that I can adapt and expand as I want with apps, then we have an area here where we gain a lot of opportunities through the fact that technology becomes more networked, that it can be used more flexibly when I adapt it." (Expert 2).

In the field of technology, the experts identified a *deficient digital infrastructure*, a *lack of potential users' participation in technology development* and, thus, an *excessive focus on innovation*, as well as *dementia-specific challenges in development and implementation* and *challenges regarding data collection and data security* as inhibiting preconditions for IAT and TADC.

Deficient digital infrastructure was identified as a crucial inhibiting structural factor for IAT and TADC. For example, two participants from group 1 referred to a lack of "[…] *good and stable broadband network coverage* […]" (Expert 7; Expert 20). This challenge comes to a head in the context of nursing homes, as a technology researcher highlighted:

> "So, if we look at this digital gap, people who live in institutions […] are very much cut off from internet coverage, for example; thus, they are disadvantaged there" (Expert 2).

This assessment was confirmed by a participant from a welfare agency and referred to the insights of the COVID19 pandemic:

> "[…] the Corona pandemic also clearly showed that the nursing homes are not equipped with sufficient WLAN capacities […]" (Expert 11).

The lack of interoperability, i.e. the uniformity of data and technologies, is another major obstacle, as Expert 5 stated: "[…] *in some places fax machines are still in use* […]." One technology researcher was critical overall about the digital transformation in Germany, which "[…] *is so slowly and badly done* […]" (Expert 13).

Moreover, the lack of potential users' participation in technology development was stated as an inhibiting preconditions for IAT and TADC. This was especially highlighted regarding the group of professional caregivers:

> "I don't necessarily experience the willingness to do this in the field of nursing, which is understandable for me because what else am I supposed to do, now I'm also supposed to do ethics, now I'm also supposed to develop technologies […]." (Expert 4).

According to other participants, the unequal distribution of digital literacy, which was stated as an inhibiting factor in the field of society, also plays a decisive role in this regard because professional nurses in particular lack the time in their everyday lives to acquire the necessary competencies (Expert 20). At the same time, the lack of participation leads to an *excessive focus on innovation* and often result in a lack of suitability of the products for everyday use (Expert 19; Expert 20).

Another inhibiting factor identified was *dementia-specific challenges in development and implementation* of new technologies. In particular, competence limitations associated with dementia-related syndromes were named as an obstacle to both the participation of those affected and the measurement of outcomes of technology-assisted interventions in dementia care: especially communication problems of persons with dementia, the progression and variance of dementia-related syndromes and doubtful or fluctuating capacity to consent (Expert 1; Expert 2; Expert 12).

Mirroring the legal requirements regarding data protection, which were mentioned in the field of politics - regulation - economy, experts identified *technical challenges in the area of data collection and data security* as inhibiting factors in the field of technology. The former, according to a technology researcher, requires to "[…] *inflicting pain on people in a controlled setting in order to then gain the necessary data* […]" (Expert 10); this was described as both legally and ethically challenging and at the same time morally and psychologically stressful for the researchers (Ibid.; cf. Expert 13). In addition, there is a challenge of how to secure highly sensitive health-related data on a technical level: "*So, on the technical level* […] *it is clearly the issue of how can I actually guarantee privacy and security of the data in such systems* […]" (Expert 7); in this area, "[…] *there are currently dramatic shortcomings* […]" (Ibid.).

4 Discussion

In order to empower people who have dementia, to relieve the burden on caregivers and to improve the quality of care, IAT are being used increasingly in dementia care. As we stated in the introduction, successful and empowering TADC depends to a significant degree on exogenous preconditions. These are social, political, economic, legal and technological factors which accelerate or inhibit access to TADC. German experts from technology research and development, healthcare policy and administration, long term care insurances and professional nursing assessed these preconditions as highly ambivalent. In the three different exogenous structural fields that we identified, the experts identified as the most crucial preconditions: societal digitalization, unequally distributed digital literacy, deficient digital infrastructure and unclear refinancing options for IAT.

In sum, the results of our study indicate that the development, implementation and use of IAT in dementia care takes place in a highly complex structural framework, which to a large extent preconfigures the success of socio-technical empowerment. Thus, structures matter more than ever. For this reason, we will formulate practical-ethical recommendations following the discussion. Thereby, we also contribute to a more structure-aware medical and caregiving ethics.

4.1 Practical-ethical considerations of TADC with regard to empowerment by considering fair access

In all three structural fields — society, politics - regulation - economy and technology—, the interviewees identified accelerating as well as inhibiting preconditions. Notably, the factors identified are not only highly ambivalent (some accelerating and inhibiting preconditions within one structural field contradict or even undermine each other). For example, digitalization vs. unequally distributed digital literacy, growing private wealth vs. unclear financing options or enhanced customizability and interconnectivity vs. deficient digital infrastructure. Moreover, inhibiting preconditions can, at worst, reinforce each other and, thus, counteract the accelerating factors. We thus assume that there is an intersectionality of inhibiting preconditions for TADC. Other authors have identified these tensional connections, too. Sowa et al., for instance, highlighted the function of socioeconomic status for healthy and successful ageing. Higher social status, income and education do not only influence lifestyle choices but also "[…] increase options for dealing with ill health by better opportunities for the health care use and quality of care" (27).

In the following, we discuss four preconditions in detail which we think are crucial for fair access to IAT, and thus for the very possibility of socio-technical empowerment. In consequence, an empowerment-ethical reflection —i.e., a reflection of preconditions for and impacts on (socio-technical) practices on independence, participation and self-determination— of TADC must consider the exogenous structures and preconditions which either accelerate or inhibit fair access to TADC and to related opportunities to a significant extent.

4.2 Digitalization

The interviewees identified digitalization, i.e. the penetration of all areas of life with digital technologies, as a social phenomenon. It is seen as one of the most important accelerating preconditions for the development, implementation and use of IAT in dementia care. This transformative trend is made possible and fostered especially by two characteristics of new technologies: pervasiveness and ubiquity (9). The new technologies are characterized as pervasive as they are available everywhere, for everyone, and at all times (ibid.; cf. 28, p. 293). They are ubiquitous as they are present in an ever increasing invisible, interconnected and non-intrusive way (9, 29, 30).

On the one hand, these characteristics accelerate the use of new technologies and enable their seamless integration into everyday life. Hence, digitalization could be interpreted both as a means and manifestation of fair access to new technologies and the regarding opportunities. On the other hand, the subtle penetration of everyday life with digital technologies entails social and ethical risks. For instance, questions arise as to whether denial of the technologies is still possible at all and whether (possible) denial is associated with social disadvantages, e.g. exclusion and new or exacerbated inequalities (31).

From an empowerment-ethical perspective, it is to be stated that digitalization is fundamentally linked to ethical challenges. On the one hand, it opens up new windows of opportunity for a more independent and self-determined life and enables ever more persons to use digital technologies. On the other hand, self-determination is undermined when there is no possibility to opt-out, and social participation is challenged when it is no longer possible to engage in social life in a non-digital way.

4.3 Unequally distributed digital literacy

The digitalization is undermined by several other preconditions. One of the most influential of these is unequally distributed digital literacy. As Sowa and colleagues highlight, the educational status of a person exerts considerable impact on healthy and successful ageing (27). Furthermore, education is a crucial element of empowerment practices (32–34). Education enables persons to critical thinking and realization of their own interests (35–37). Thus, digital education and digital literacy is key for autonomous decisions regarding the use of IAT. Against this background, digital literacy can be defined in two ways: first, as the sum of competencies necessary to use digital technologies in a proper and critically reflected manner (38, 39); second and relatedly, as the (informal) educational status regarding digitalization in general and digital devices in particular.

In general, various interviewees described this status as very low in the general German population. In particular, some experts problematized a lack of digital literacy among professional caregivers which has also been considered by other authors (40–42). Furthermore, an expert from the field of technology development mentioned the fact that some older people and people in need for care have younger, digital literate relatives and some not; this means that the latter group has no opportunity to acquire digital competencies in a low-threshold and informal way, thus being disadvantaged in comparison to the first group. This challenge to fair access is even exacerbated by the before mentioned lack of digital literacy among professional caregivers as these are the only source of information about IAT and TADC for many older persons without young, digital literate relatives.

From an empowerment-ethical perspective, the unequal distribution of digital literacy must, hence, be characterized as a major obstacle to the self-determined use of IAT and to fair access to TADC in at least three dimensions. Firstly, this inequality is a symptom of unequal access to competencies. Second, lacking necessary digital literacy challenge the self-determination of persons in need for care as they cannot assess adequately the opportunities and risks related to IAT. Finally, a lack of digital literacy limits fair access to TADC: When not knowing about existing —and potentially useful— devices and systems, one cannot participate in their implementation and usage.

4.4 Deficient digital infrastructure

Another crucial inhibiting precondition is the deficient digital infrastructure in Germany. This refers in particular to lacking broadband internet coverages in rural areas and lacking access to WLAN in nursing institutions.

This challenge, is, however, not only prevalent in Germany but also in other countries. For instance, Vollmer Dahlke and Ort (43) have noted that 24 million US citizens are currently living in so-called digital deserts, i.e. areas without access to broadband internet. This access is, however, "[…] a prerequisite to telemedicine use" (44). Accordingly, Loccoh et al (40) identified a correlation of health care access and internet service availability in the United States: "health care deserts" —ie., areas with "[…] poor access to domains of pharmacies, hospital, hospital beds, trauma centers, primary care physicians, and low-cost health centers […]" (ibid., p. 1)— are often simultaneously digital deserts. They conclude that, when not accompanied by efforts to improve internet access, "[…] telemedicine expansions may have low effectiveness in counties where telemedicine is most needed […]" (ibid., p. 2). On the contrary, most probably such expansions would even reinforce rural-urban health disparities and the digital divide (9, 45).

It should be noted that deficient digital infrastructure fundamentally counteracts the trend of digitalization: Especially the disparities between rural and urban areas regarding fast and stable internet cause unequal opportunities to the usage of IAT and TADC. Even worse, already existing inequalities could even be reinforced. With a special focus on dementia care, this finding becomes even more tragic: Compared to metropolitan areas, the rural areas of Germany are not only digitally and health care-related disadvantaged but they also face the highest percentage of ageing persons and persons affected by dementia. Hence, these areas would benefit the most by TADC but are more and ever more disadvantaged due to lacking digital infrastructure.

4.5 Unclear and missing financing options

Alongside with digital illiteracy and deficient digital infrastructure, the interviewed experts identified unclear and missing financing options for IAT and TADC. As most IAT are or will be quite expensive (9, 46, 47), they stated that the acquisition is a challenge for both private users as well as institutional care facilities. Also internationally, the affordability and costs of IAT are considered in the discourse on IAT and TADC. The socioeconomic status is identified as a relevant exogenous precondition for the use of IAT and is linked with issues of fairness regarding persons with dementia and their relatives (9, 31, 48, 49). In several empirical studies on the implementation of assistive technologies, costs were identified as a major criterium of acceptability (48, 50). Accordingly, the most common reasons for persons with dementia and their caregivers not to use IAT was the high cost and the nonexistent refunding possibilities (7, 49). Remarkably, none of these studies cited concrete numbers that would prove the high costs.

Conversely, in our interview study experts from private insurances as well as from publicly funded care services and one from a welfare agency criticized private individuals for their unwillingness to invest private money in IAT. They stated, that for example people's willingness to purchase smart home systems themselves or to contribute to their implementation by paying higher rents is very low. In sum, it is not yet clarified who shall and who can bear the costs for IAT and TADC neither whether and to what extent public co-funding should be implemented.

Unclear and missing financing options bear the risks of exacerbating already existing disparities regarding long term care supply between upper and middle-to-lower class seniors (49). Middle-to-lower economic status of individuals is an (at least) threefold inhibitor for using IAT: first regarding the purchase for acquisition, second regarding maintenance-related costs and third, on an even more fundamental level, the socio-economic status of regions has significant impact on the supply with internet access. Vollmer Dahlke and Ort (43) elucidate that commercial internet providers try to avoid the economic risk of equipping rural areas with broadband internet associated with the probably non-usage by residents due to high costs.

With regard to this economic factor, the before mentioned intersectionality of exogenous preconditions becomes most evident: Individuals with restrained financial resources —regarding their own economic status and that of their relatives— are not free to decide whether or not to use IAT or participate in TADC and, thus are violated in their self-determination. Participation in the opportunities of TADC, hence, becomes a matter of economic class and not of evident-based need assessment.

5 Conclusions and policy recommendations

If TADC should be established as a socio-technical practice of empowerment for persons with dementia, the identified and discussed preconditions must not stay out of the focus of ethics and health policies. Health literacy as well as digital literacy, access to internet, and refinancing-based independence from the socioeconomic status are prerequisites for fair access to TADC.

In order to inform the scientific community and other relevant stakeholders and to equip them with normatively founded orientation, we propose some healthcare policy-related practical-ethical recommendations. Even if our discursive context is Germany with its special health care system, we try to formulate the recommendations in a more generalized manner as we think they are relevant for all high-industrialized, high-income and democratic contexts.

1. Digitalization seems to be a global transformative trend which entails many opportunities, but it has to be shaped by the society in the most participatory, democratic manner. The pervasiveness and ubiquity of new AI-based technologies and related autonomous systems must not undermine the self-determination of patients. It is important to ensure each single individual's choice whether or not to use these technologies or to participate digitally in social life. In order to guarantee this possibility of free choice, health care and long-term care policy should guarantee that existing human-human contact and opportunities to analogue social interaction are not being replaced by technology. The normative goal of fair access has to entail the possibility to veto or deny TADC on a case-by-case decision.
2. Residents of rural areas are often living in "digital deserts." They do not have equal access to digital technologies in comparison to residents of urban areas. Hence, relevant policy makers must maintain and strengthen initiatives to equip rural areas with broadband internet in order to establish fair access to modern health care.
3. With regard to residents of long-term care facilities, private and social welfare providers are called upon to apply adequate access to internet for their residents. The financing has to be solved efficiently and in favor of the yet disadvantaged residents. This must comprise public-private partnerships to ensure affordable access to stable and fast internet in the facilities. As this access is a fundamental precondition for modern health care, it has to be prioritized by policy makers.
4. The normative ideal of good ageing remains valid across the entire continuum of care and regardless of housing arrangements. In contrast, those living in rental properties often cannot decide autonomously about constructional adaptions to barrier-free living. They are dependent on the owners' consent for such measures. Therefore, relevant stakeholders and decision-makers in politics and long-term care insurances should consider facilitating the constructional adaption for the purpose of IAT-assisted living. Furthermore, public housing subsidies should generally accelerate the creation of barrier-free, IAT-adaptable residential units.
5. Digital literacy is particularly important for enabling the self-determined use of IAT and for achieving the goals of TADC. Therefore, various initiatives need to be taken to increase the digital literacy of persons with dementia, their relatives and professional caregivers. In our opinion, the necessary digital skills that need to be acquired include: knowledge about available devices and systems; knowledge about the costs of IAT and TADC; knowledge about the opportunities and risks associated with the usage of IAT; basic knowledge about the sort and amount of health data collected and processed; the ability to use the IAT devices properly; knowledge about how to withdraw consent in (aspects of) data processing in any phase of use; and knowledge about how to shut down a device as ultimate measure of self-determination. As digital literacy is key to self-determined, i.e. well informed and critically reflected, decisions about whether or not to use IAT, digital education for health contexts should be provided not only in old age, but already in school. With regard to the present older generation, educational measures and offers have to be installed in order to equip older persons with the necessary level of digital literacy. These offers have to be low-threshold, on site, and free or low-cost, e.g. in community colleges. In order to strengthen the users' capacity for digital decision-making in TADC, methods should be developed to visualize the sort and amount of collected and processed data during the entire use of IAT.
6. With regard to the lack of digital literacy among the group of professional caregivers, the professionals themselves as well as the policy makers need to be addressed: digital literacy and competencies must be recognized a part of healthcare professionalism. Professional associations of healthcare and long-term care personnel should promote this change in professionalism by supporting their members in acquiring necessary competencies by mandatory courses in professional trainings.

Data availability statement

Due to the data protection agreement with the participants and our ethics approval by University Center Göttingen, we cannot provide the raw data. Requests to access the datasets should be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Research ethics committee of the University Medical Center of Göttingen. in the context of the collective application "Ethical, social and socio-legal aspects in dementia care and dementia counseling: socio-empirical studies with experts" (application number 1/8/20). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JW: Data curation, Visualization, Writing – original draft, Writing – review & editing. SS: Conceptualization, Funding acquisition, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The value of privacy for people with dementia

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Introduction: The concept of privacy marks an astonishing gap in the discussion about care for people with dementia (PwD). In general, questions of privacy play an important role and attract much attention in the ethics of nursing care. Yet, when it comes to dementia care, there is hardly any systematic ethical debate on the topic at all. It almost seems as though PwD lost any plausible interest in privacy and no longer had a private sphere that needed to be considered or protected. However, this not only contradicts widespread moral intuitions but also ignores the views and needs of those affected.

Arguments: This conceptual analysis sets out to explore the value of privacy for PwD. We first outline the origins and dimensions of the concept of privacy itself and point out problems and limitations in the context of dementia. Especially the prevalent liberal conceptions' dependence on the idea of individual autonomy poses considerable challenges to an adequate understanding of the moral significance of privacy for PwD. Therefore, we subsequently examine alternative ways of conceptualizing the value of privacy in the context of dementia care.

Conclusion: We argue that autonomy-based concepts of privacy may still apply in the early stages of dementia. In the further course of the syndrome, however, the relevance of other normative aspects comes to the fore, especially respect for remaining personal preferences as well as objective criteria of dignity and well-being. Thus, we outline in a differentiated way how and to what extent privacy can be of normative importance even beyond the purview of autonomy and should consequently be considered in dementia care.

KEYWORDS

privacy, dementia care, well-being, dignity, nursing ethics

Introduction

In 2017, the daughter of a nursing home resident with dementia filed a complaint with the German Federal Constitutional Court. At the core of the case was the enforcement of her mother's fundamental rights and the constitutionally guaranteed inviolability of her home. "Are caregivers allowed to just tear open the door to the room?" asked the newspaper

WELT in a report on the case. “For six years, a daughter has been fighting for privacy for her mother” (1 [own translation]).

This example points to an astonishing gap in the ethical debate about the care of people with dementia (PwD). In general, the topic of “privacy” plays a significant role in the ethics of nursing care. Nursing is considered a sensitive activity that extends into deeply personal areas of other people’s lives. Particularly care involving close physical contacts directly affects the private or intimate sphere of the person being cared for and therefore requires special attentiveness and consideration (2). However, the comprehensive care for the well-being of a person in need of assistance also affects their privacy in many other ways. For example, the growing popularity of outpatient care raises the question of what impact the use of professional care services has on the privacy of the home of those receiving care and their family members (3). And in the setting of the “total institution” (4) nursing home, maintaining the privacy of residents takes on a particularly critical importance (5, 6). Indeed, respect for and protection of the privacy of those being cared for, as well as corresponding duties of restraint, secrecy, and confidentiality also play a significant role in professional ethics standards and codes of the nursing profession (7, 8). In the course of the development of new monitoring and assistance technologies for nursing, the entire topic is currently gaining renewed attention from the perspective of data protection (9, 10).

Remarkably, this intensive ethical discourse on privacy in nursing care seems to fall almost completely silent as soon as the care of PwD is concerned. In this context, only a few scattered comments on the topic can be found (11–13). These mainly address aspects of privacy of family members or professional caregivers that might be affected by ambulatory care in the home setting or by new monitoring technologies (14–18). In contrast, the meaning of privacy for PwD themselves is hardly discussed at all. It could almost appear as though privacy no longer played a significant role for them, as if they lost all comprehensible interest in privacy in the course of their disease and eventually no longer had any private space of their own that needed to be respected or protected in nursing care. Indeed, empirical research shows that the privacy of PwD is frequently violated in the context of care, for example by intrusive behavior or inappropriate familiarity on the part of caregivers (19). An analysis of health apps for this group concluded that more than half of these applications lacked a clear privacy policy (20). This situation is not only difficult to reconcile with the moral conviction that PwD should be recognized as persons to whom we owe respect and consideration (21). It also directly contradicts the views and preferences of those affected themselves as social research shows that PwD consider privacy as an important dimension of their quality of life (22).

Against this backdrop, the present article provides a conceptual analysis of privacy in the context of dementia. We examine to what extent the value, i.e. the moral meaning of privacy for PwD can be made comprehensible and plausible from an ethical point of view. To this end, we first outline the origin and the different dimensions of the concept itself and then demonstrate its difficulties and limitations in the context of dementia. As it turns out, prevailing liberal understandings of privacy have a strong focus on individual autonomy that can be a significant obstacle to an adequate conceptualization of the meaning of privacy for PwD. For this reason, we subsequently explore alternative ways of understanding the “value of privacy” (23) in this context, independent from its function as an expression of the right to individual self-determination (23). While autonomy-based conceptions of privacy may still hold in early stages of dementia, the relevance of recognizable personal preferences as well as objective conditions of dignity and well-being are becoming more important in the further course and advanced stages of the syndrome. In this way, we provide a differentiated analysis of the extent to which privacy is important for people with dementia and how it can be appropriately considered in nursing care across different stages of dementia.

The liberal notion of privacy and its limits in the context of dementia

Privacy plays an important role in medical and nursing ethics. Its special significance in health-related matters seems to be rooted in the physical closeness and intimacy of medical and nursing practice (24). However, in the form of medical privilege, the confidential handling of health-related information also constitutes a fundamental requirement of the relationship between doctor and patient, nurse and care recipient, as well as researcher and research subject (25).

Similar ideas also play a role in the concept of informational self-determination, which is becoming increasingly important in the wake of digitalization and the emergence of data-intensive medical research and healthcare (26). In the 1960s and 70s, the United States Supreme Court even justified the right of married couples to contraception or women’s right to abortion by recourse to privacy [Griswold v. Connecticut, 381 U.S. 479; 85 Sup. Ct. 1678 (1965), Roe v. Wade, 410 U.S. 113 (1973); 23, 24, 27)]. Although Roe v. Wade was recently revised, this still highlights the importance of privacy as a resource of normative justification. At all these levels, the notion of privacy is closely linked to the claim of non-interference by third parties in one’s bodily concerns and health-related matters and decisions.

The theoretical discourse surrounding the concept of privacy was originally shaped by jurisprudence (28). Here, privacy is traditionally understood as an individual’s right or interest that includes the actively and deliberately exercised control over matters concerning one’s own person (23). Psychological considerations underline that the central concept of control requires both informedness and intentionality (29).

From a moral philosophical point of view, a number of more detailed definitions and distinctions can be made with regard to the function and scope of privacy. The *function* refers to the “value of privacy,” i.e., the purpose that it serves in different areas of life. It provides clues as to why privacy is valued in specific contexts. In the prevailing liberal conceptions, privacy is usually either functionally oriented towards individual autonomy or presupposes a certain degree of autonomy (23, 30). For example, it is seen as a prerequisite for the formation of personal identity as well as for the protection of individual freedom or autonomy (23, 28, 31–33).

The *scope* of privacy indicates the areas of life to which the concept refers. In this context, objects and places as well as knowledge, decisions and actions can be private. Accordingly, privacy can be differentiated in terms of its *decisional*, *informational* and *physical-local* dimensions (23). *Decisional* privacy refers to the possibility of controlling access to one's personal matters, i.e. being able to decide who has a say in one's own decisions and actions and who does not (23, 28, 34). The *informational* dimension refers to control over access to information concerning oneself (23, 28, 35–37). *Physical-local* privacy describes control over others' access to one's own body, as well as the actively and deliberately exercised regulation of access to one's places and spaces of living (23, 24).

With regard to PwD, the prevailing liberal conceptions' focus on autonomy has far-reaching consequences. After all, dementia is accompanied by increasing neurocognitive impairments so that those affected gradually lose capacities usually associated with the ability for self-determination and thus for the active and deliberate exercise of control over their own affairs (38). Indeed, in advanced stages, they may no longer have the explicit notion of an own private sphere and may not even be able to consciously register any violations of this sphere at all.

Accordingly, the claim of PwD to decide on their own personal matters in the sense of *decisional privacy* also seems to be undermined in the course of the disease. In fact, in advanced stages of dementia, relevant decisions are usually taken out of their hands and crucial personal matters are regulated by others on their behalf, for example in the context of legal guardianship and proxy decision-making (39).

Similar observations can be made with regard to the dimension of *informational privacy*. The progressive impairments of short- and long-term memory that accompany dementia mean that those affected increasingly lose the overview of and control over knowledge that concerns their own person, right down to their name, identity and biography. In advanced stages, personal information is therefore usually managed and provided by close third parties (40). In the wake of the development of data-intensive tracking, monitoring, and assistance technologies for PwD, for instance in the field of Ambient Assisted Living, this problem is likely to become even more acute in the future (13, 41).

Finally, comparable trends can also be observed with regard to *physical-local privacy*. Due to their condition, PwD also lose the ability to orient themselves in space and hence to independently control their own living environment. In advanced stages, they can therefore usually neither determine their own place of residence nor provide or deny access to it. Instead, they are cared for at home by family members or professional caregivers, or are placed in nursing facilities (42).

Perspectives on the value of privacy for people with dementia

Due to changes in cognitive capacities of PwD, theoretical approaches that define privacy in terms of the active and deliberate exercise of control over one's own affairs are not readily applicable in the context of dementia. However, this does not necessarily mean that privacy is no longer of any moral significance for PwD. After all, the autonomy-based conception of privacy itself could prove to be limited and inadequate in this context. Indeed, PwD explicitly state in surveys that privacy has great significance for their quality of life (22). Values associated with privacy, such as intimacy, confidentiality, social relationships, absence of coercion, are also undoubtedly important in the life and care of PwD (43). Studies in nursing science suggest that even people in advanced stages of dementia do have a sense of privacy that is expressed in their behavior (44–48). Starting from such everyday perspectives and empirical findings, the moral significance of privacy for PwD will be further explored and ethically spelled out in the following sections. In doing so, it becomes apparent that each stage of dementia calls for different lines of argument. Especially with regard to advanced stages, it is crucial to examine to what extent privacy can be conceptualized without recourse to individual autonomy and thus might encompass more than only active and deliberate control over one's own affairs.

Early stages: reasserting active control over one's own affairs

At the beginning of dementia, privacy is of particularly great importance for those affected. In this stage, first memory and orientation problems occur and affect everyday life. Initially, however, this does not derogate the ability to lead a self-determined life. At the same time, knowledge of an increased risk of dementia and especially a diagnosis of dementia constitute highly sensitive personal information that give rise to a strong interest in *informational privacy* (49). In fact, social research indicates that the mere communication of a dementia diagnosis can already lead to increased paternalism and surveillance of those affected by their immediate social environment. For example, one's decisions are no longer simply accepted but increasingly questioned or even called into doubt. People diagnosed with dementia are no longer readily left to their own devices and find themselves under increased scrutiny and close supervision by others (50). This social reaction can place those affected in a vulnerable position regarding their decisional and physical-local privacy. In addition, the spread of information about someone's dementia diagnosis can lead to social stigma as well as discrimination, e.g., by employers or insurance companies (51).

Against this backdrop, it appears evident that people in the early stages of dementia have an increased interest in privacy. It is in line with the general autonomy-based reasoning that emphasizes the right to individual self-determination. As the diagnosis of dementia does not per se imply a loss of autonomy, those affected clearly have the right to determine for themselves to which extent they want to involve others in their personal decisions, disclose information about themselves, or allow third parties access to their personal living environment. They are usually also in a position to express and assert this interest in privacy themselves. In fact, studies show that the preservation of their privacy is of particular concern to PwD at these early stages and that its violation causes them distress (47). This could be due to the fact that those affected are often the first ones to notice dementia-related changes, struggle to integrate them into their own self-image, and experience shame and fear of stigma (49). Accordingly, the diagnosis itself, as well as early stages of dementia in general, are associated with various concerns that make the need for privacy immediately plausible. It is therefore particularly important to reassert the right of self-determination of people with beginning dementia as well as their corresponding claims to privacy. This also includes the repudiation of paternalistic tendencies (52).

Notwithstanding this understandable and prima facie undoubtedly justified interest in privacy, however, the diagnosis of (beginning) dementia may give rise to certain moral responsibilities of those affected vis-à-vis third parties. Thus, it could be argued that a diagnosis of dementia can also have far-reaching consequences for life partners or other close relatives that may give them a moral claim to be informed or to have a say (49). For instance, this may pertain to the explanation of changes in the condition and behavior of those affected which can significantly influence their day-to-day interactions with their relatives. If shared professional, financial, or legal interests and concerns will be affected in the future, there may also be a moral responsibility to inform partners or family members of a dementia diagnosis. In particular, the expectation that others will assume care responsibilities may be connected to a moral claim to be informed on the part of the respective individuals (49). However, all these justified interests of third parties do not fundamentally call into question that people with beginning dementia have a right to privacy and to the autonomous regulation of their own affairs. At most, they may correspond to moral responsibilities that must be weighed against this right in specific cases.

Middle stages: respect for personal identity and subjective preferences

As their condition advances, PwD become increasingly dependent on assistance. The progressive impairment of cognitive abilities affects executive functions and hence also activities of daily living, such as choosing suitable clothing or preparing meals. In particular, the impairment of language and judgment skills compromises the ability to process complex information and to make well-considered self-determined decisions. This can also lead to behavior that is dangerous to oneself or others, for example at home or in traffic. Despite this successive diminishment of autonomy, however, a sense of privacy and de facto preferences with regard to privacy can still be observed in PwD at this stage. This raises the question to what extent the moral meaning of privacy can be made explicit without reference to personal autonomy.

Social research shows that PwD continue to be concerned about privacy even as their condition becomes more severe. In fact, the very awareness of the progression of their dementia and the experience of the symptoms described seem to induce an increased desire for intimacy and familiarity, i.e. privacy (22). Apart from verbal statements, this interest in privacy can also become manifest in corresponding behavior. For example, PwD often show defensive reactions when doctors attempt to perform examinations without advance notice or consultation (46). The (non-verbal) rejection of unsolicited nursing measures and the feigning of sleep to avoid interactions with caregivers and other nursing home residents can also be regarded as expressions of a claim to decisional privacy. The ostentatious deviation from caregivers' suggestions may be interpreted as an attempt to assert a say in one's own daily schedule and thus also as a desire for decisional privacy. Furthermore, the possibility to have an undisturbed conversation and talk about intimate fears and concerns in familiar surroundings is a frequently expressed need of PwD that points to a desire for informational privacy (12). Finally, behaviors such as choosing a particular place to sit (46), furnishing one's room with personal items (45) and the "embodied memory" expressed this way (53), or the frequently described desire to "go home" (54) can also underscore a concern to maintain some form of *physical-local privacy* (22, 47). Especially for women with dementia, the importance of one's own handbag and the contents stored in it as "biographical objects" may serve as another example (55).

It may no longer be possible to interpret such privacy-related behaviors of people in the middle stage of dementia as expressions of personal autonomy in a sophisticated moral philosophical sense. Nevertheless, it would hardly appear acceptable to simply dismiss them as morally irrelevant or summarily disregard them without careful consideration. Eventually, they seem to represent physical and habitual expressions of deeply rooted personal priorities and preferences regarding one's own lifestyle and relationships with others. Acknowledging and respecting them can therefore be crucially important for the personal identity and subjective well-being of those affected. In this vein, it could be argued that privacy-related behaviors, even if not fully autonomous, still carry moral significance in the middle stages of dementia, particularly when they can be interpreted as expressions of fundamental or identity-relevant needs, wishes, or feelings. With regard to the aspect of personal identity, such behaviors may represent certain characteristic traits of the person concerned that deserve respect, especially if we accept the idea of an "embodied self" (56) of PwD that becomes apparent in their physical appearance and habitualized demeanor. With regard to subjective well-being, one could speak of "experiential interests" (57) of PwD regarding privacy. In contrast to so-called "critical interests," that is, well-considered judgments formed in light of personal values and life plans, "experiential interests" rather refer to immediate, momentary experiences in the present. Although people in the middle stage of dementia are sometimes no longer able to make decisions based on "critical interests," such "experiential interests" must still be respected and considered as far as possible because their violation would be detrimental to their well-being or even cause them harm.

Against this backdrop, respecting the privacy-related preferences of people in the middle stages of dementia would require the consideration of statements and behaviors of those affected that may no longer qualify as expressions of autonomous, informed and well-considered judgements.[1] Of course, such an approach raises considerable hermeneutic and moral-practical questions and poses challenges in the context of nursing care. Thus, the interpretation of erratic utterances or nonverbal behavior usually does not provide clear, unambiguous directives

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[1] Richard Dworkin and Rebecca Dresser discuss the scope of non-autonomous decisions. Cf. Dworkin (57); Dresser (58).

for concrete care provision. In many cases, it would probably remain ultimately indeterminable which statements and behaviors of PwD could be regarded as manifestations of a specific desire for privacy, at all. Furthermore, privacy-related behavior also does not provide any clues as to what moral relevance should be assigned to the desire for privacy vis-a-vis other preferences of the person concerned or requirements of their well-being, such as personal hygiene, safety and protection against self-harm. Therefore, the question of how to deal with verbally or non-verbally expressed privacy preferences in practice would eventually be hard to decide.

Advanced dementia: objective conditions of dignity and well-being

In late stages of dementia, preference-based arguments to explain the value of privacy for PwD also reach their limits. The progredient impairment of language increasingly restricts the possibility of communicating subjective preferences. In advanced stages, the behavior of those affected eventually also becomes more erratic and difficult to interpret. Ultimately, the condition affects the underlying cognitive categories and mental operations. As a consequence, the abstract concept of privacy, as well as the subjective awareness of one's own private sphere and its violations, may be lost. The diminishment of a sense of shame and social appropriateness, e.g., in connection with clothing, food intake, or excretion, could be interpreted in this vein (59).

Under these conditions, ethical approaches aiming to establish the moral significance of privacy for individuals with advanced dementia must ultimately rely on aspects other than the perspectives of those affected themselves. Such approaches could be termed objectivistic since they do not refer to the subjective views, attitudes, and evaluations of the individuals directly concerned. At first sight, this seems to be at odds with the normative principles of the modern liberal understanding of morality and its ethical reflection in categories of individual autonomy and self-determination (60). Nevertheless, there exist at least a number of argumentative precedents for such an objectivistic exploration of the value of privacy for people with advanced dementia.

A first starting point could be the concept of human dignity (61). In the Basic Law for the Federal Republic of Germany, respect for dignity is more fundamental than the individual right to self-determination and the free development of the personality. Accordingly, prominent court rulings derived and enforced the legal prohibition of self-deprecation through self-display or self-degradation, for example, in cases about peep shows or "dwarf tossing" (BVerwGE 64, 274; NVwZ 1993). Along the lines of this form of paternalism aimed at protecting human dignity, one could argue that the privacy of people in advanced stages of dementia should be protected in order to prevent them from self-deprecation. Such paternalistic protection of privacy may even appear more justifiable in this case as it refers to an involuntary self-deprecation and would not override an autonomous will. However, the concept of dignity is itself notoriously ambiguous and controversial. Approaches that see dignity as grounded in certain capacities, such as autonomy, reach their limits in the context of advanced dementia, just like corresponding autonomy-based understandings of privacy (62). Concepts of human dignity based on cosmological or theological considerations may be able to circumvent these difficulties but are based on particular religious or ideological presuppositions that are not generally shared in modern pluralistic societies (62). Moreover, the question arises as to whether protecting individuals with dementia from self-deprecation only aims to preserve their dignity or is actually more about upholding their esteem or remembrance in the eyes of third parties like partners or family members. These concerns are all the more serious as such protection from self-deprecation might require measures that could conflict with the current will and subjective well-being of PwD, for example, the prevention of physical intimacy in socially inadequate situations. For this reason, the importance of privacy in the context of dementia is sometimes relativized in the ethical discussion. As the historical development of the concept is entangled with "the repression of physicality by rational reason", privacy can appear to "be of secondary importance for the quality of life of people with advanced dementia […] (e.g., compared to social proximity)" (63 [own translation]).

Arguments that focus on the best interest of the persons concerned and thus ultimately on objective preconditions of their well-being could provide an alternative. In the sense of weak paternalism, one could argue that privacy is a necessary condition for the well-being of people with advanced dementia in certain respects and contexts, and therefore should be protected even if they themselves have lost any discernible subjective interest in it. In this sense, it could be argued that the careless disclosure of personal information may enable abuse or even criminal activities and pose serious risks to the physical well-being or financial security of the individuals concerned (13). Similarly, physical-local and informational privacy may constitute a necessary precondition for the development of personal care relationships that are fundamental to the well-being of those affected. If PwD benefit from the care of persons who feel close and connected to them and responsible for them (even if they themselves may no longer recognize these persons at all), then conditions that enable and strengthen such caring closeness, attachment, and responsibility should be protected (64). Finally, respect for the informational and physical-local privacy of people with advanced dementia may also provide protection against forms of objectification and instrumentalization that are detrimental to their well-being, such as public display and humiliation or sexual exploitation. Of course, such notions of trans-subjective preconditions of individual well-being ultimately presuppose an objective theory of the good life and hence also take on considerable theoretical burdens of justification. Moreover, some objective approaches such as Nussbaum's anthropologically grounded list of fundamental human capacities have been criticized for not granting persons with cognitive impairments the possibility of a life that can count as fully human (65). Finally, such approaches also touch upon the difficult problem of how to balance the protection of the objective well-being of those affected with their momentary subjective impulses or preferences in cases of conflict (66).

Conclusion

In contemporary ethical discussions about the central importance of privacy in nursing care, the perspective of PwD finds virtually no systematic consideration. It almost seems as if the principle no longer played any particular role in their lives and in their care. The fact that their privacy is actually often undermined in practice and has to be defended against various violations seems to confirm the power of such a view. It raises the question of the value of privacy for PwD, which becomes even more important in the face of the emergence of new data-intensive tracking, monitoring, and assistance technologies (67).

As argued here, this desideratum is probably not least related to the specific theoretical implications of prevailing liberal concepts of privacy. These concepts understand privacy primarily in terms of an active and deliberate control over one's own affairs and thus presuppose autonomy or are functionally oriented toward it. However, as their condition progresses, PwD lose the ability to take charge of their own affairs in an active and deliberate way. In order to make the meaning of privacy intelligible in this context, we therefore need a more encompassing understanding of the concept that is not exclusively based on autonomy.

By reference to the typical stages of dementia, we have explored possibilities for justifying the moral meaning and function of privacy for PwD. It has become apparent that each stage requires different lines of argument. In early stages, the liberal autonomy-based understanding of privacy is still relevant since those affected are generally capable of managing their own affairs in a self-determined manner. However, as cognitive abilities such as speech and judgment become more impaired in middle stages, the autonomy-based concept of privacy reaches its limits. Nevertheless, it is still possible to identify an interest of PwD in privacy based on a range of verbal and nonverbal behaviors. This interest should be recognized and protected in order to support their embodied sense of self and their subjective well-being. Of course, it becomes increasingly difficult for outsiders to assess the privacy preferences of those affected and to balance them against the increased need for care and protection. In advanced stages of dementia, we must therefore find other ways of substantiating the moral significance of privacy for PwD. One option are objectivist arguments that make the meaning of privacy for people with advanced dementia plausible without referring to the perspective of those affected themselves, for example, by recourse to ideas of dignity or human flourishing. The associated burdens of justification may be considerable. Yet, in the interest of the protection of privacy even in late stages of dementia, they should not be evaded. For example, objective notions of a good life postulating basic human capabilities could be used to defend privacy as the basis for the ability to maintain caring relationships that are beneficial to PwD.

Further conceptual, empirical and normative research is needed to better understand the meaning of privacy for PwD. First, the views of affected persons themselves should be considered in more detail and in a more differentiated manner in order to find out what needs, emotions, and moral concerns privacy comprises for them. Of course, prevailing theoretical conceptions of privacy seem hardly suitable for such a socio-empirical exploration, given their narrow focus on the idea of individual autonomy. Before we can explore the value of privacy for PwD in empirical studies, we therefore need to develop a more comprehensive understanding of the concept itself and its various implications, connotations, and references to related notions such as closeness, intimacy, or security. For this purpose, it is possible to draw on values and functions associated with privacy as well as on established criteria in the care of PwD. By interweaving this conceptual-philosophical analysis with empirical studies, for example in the form of qualitative social research with affected people and relatives, an empirically informed concept of privacy could be developed. Such a concept would have at least two advantages: First, it would provide a basis for making the meaning and value of privacy for PwD systematically plausible. This could help raise the awareness of caregivers for privacy-relevant behavior of PwD. Thus, even those who are no longer in a position to decide for themselves who they want to grant access to their own room, such as the nursing home resident mentioned at the beginning of this contribution, may well have an understandable and legitimate interest in protection, security, and familiar close relationships – in short, in privacy. Moreover, a perspective developed through empirically informed ethical discussions in the context of dementia could also help to overcome the narrow focus on the liberal principle of individual self-determination and expand the general academic debate about privacy as such. Eventually, this could contribute to the further illumination of the multifaceted and morally complex nature of privacy, even beyond the field of dementia care.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material. Further inquiries can be directed to the corresponding author.

Author contributions

EB: Writing – original draft, Writing – review & editing. MS: Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1437813/full#supplementary-material

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Vulnerabilities in migrant live-in care arrangements for people with dementia: a comparative analysis of experts' insights from Germany and Israel

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Background: The global rise in dementia among older adults has led to an increased reliance on migrant live-in caregivers, particularly in countries like Germany and Israel. This triadic care arrangement, involving persons with dementia, their families, and migrant live-in caregivers, presents unique challenges and vulnerabilities. These vulnerabilities, deeply intertwined with ethical concerns, are shaped by the socio-cultural and legal contexts of each country. This study aims to explore these vulnerabilities through a comparative analysis of expert experiences in Germany and Israel.

Method: A qualitative study was conducted using semi-structured interviews with 24 experts—14 from Israel and 10 from Germany—who have extensive experience in dementia care or migrant caregiving. The interviews were analyzed through qualitative content analysis, focusing on six dimensions of vulnerability: physical, psychological, relational/interpersonal, moral, socio-cultural-political-economic, and existential/spiritual.

Results: The analysis revealed that all parties in the care triad—persons with dementia, migrant live-in caregivers, and family members—experience distinct yet interconnected vulnerabilities. These vulnerabilities are deeply entangled, manifesting in complex, interrelated ways both within each party and between the different parties in this triadic arrangement. The study also highlighted both similarities and differences in expert experiences between Germany and Israel, reflecting the unique socio-cultural and legal contexts of each country.

Conclusions: The study underscores the multifaceted and interdependent nature of vulnerabilities in migrant live-in care arrangements for people with dementia. By comparing expert insights from Israel and Germany, the research highlights the critical role of national policies and cultural contexts in shaping these vulnerabilities, leading to distinct experiences and challenges in each country. Addressing these vulnerabilities is essential for improving the quality of care and the well-being of all parties involved in the triadic care arrangement.

KEYWORDS

vulnerability, dementia care, migrant caregivers, experts, triadic care arrangement

1 Introduction

The phenomenon of demographic aging is closely linked with an increasing number of older individuals living with dementia who require care services. Currently, more than 55 million people worldwide are living with dementia, with nearly 10 million new cases emerging each year (1). This growing burden is both significant and concerning. In many Western countries, including Germany and Israel, a majority of people with dementia reside within their communities, receiving care primarily from family members, often supplemented by migrant live-in carers (2, 3), thereby creating a triadic care arrangement. Providing dementia care with the assistance of migrant live-in carers entails a multifaceted set of difficulties, possible conflicts, and vulnerabilities (4–7). Vulnerability is closely tied to ethical issues in migrant live-in care for people with dementia due to several key factors, e.g. *protection of vulnerable groups* -ensuring the welfare, rights, and dignity of vulnerable populations, such as people with dementia and migrant caregivers, is a fundamental ethical concern; *risk of exploitation* - migrant caregivers face potential exploitation, and people with dementia risk neglect, highlighting the need for ethical vigilance and protective measures; *equity and justice* -the reliance on migrant caregivers reflects deeper societal inequalities, raising ethical questions about the fair distribution of care responsibilities and resources (8).

This research offers a comparative perspective on the complexities of this triadic care arrangement and explores vulnerabilities for all parties involved (persons with dementia, family members, and migrant live-in carers) based on the experiences of experts in migrant live-in dementia care in Israel and Germany.

In the following sections, we will provide a background on migrant live-in care in Israel and Germany, elaborate on the issue of vulnerabilities in aged care and home-based dementia care with migrant live-in carers, and explain the rationale and importance of the present study.

1.1 Migrant live-in care for people with dementia in Israel and Germany

Migrant live-in care for people with dementia plays a critical role in supporting older individuals in both Israel and Germany. Despite many similarities and common challenges across nations, notable differences are primarily influenced by each country's unique geographical and socio-cultural contexts and legal frameworks. In Israel, regulated by the Long-Term Care Insurance Program (LTIP) since 1988, the system promotes 'aging in place' through home-based care. Israel has over 73,633 migrant caregivers—59,254 documented and 14,379 undocumented—origating from countries like the Philippines, India, Sri Lanka, Uzbekistan, Moldova, and Ukraine (9). Recent reforms since 2018 have enhanced the flexibility of care options and facilitated the employment of migrant live-in carers (10, 11).

In contrast, Germany's care sector, which relies on about 500,000 Eastern European caregivers, operates within a less regulated 'grey' market (12, 13). German families often engage caregivers through agencies that navigate strict employment laws, facilitating frequent caregiver rotations. This practice, influenced by legal constraints and caregivers' preferences due to their geographical proximity to their home countries, allows for more flexible employment arrangements but leads to less stable care relationships compared to Israel's more regulated approach (6). These differences in regulatory frameworks and policies significantly impact the experiences and challenges faced by migrant live-in carers, people with dementia, and their families.

1.2 Vulnerabilities in migrant home-based dementia care

Migrant live-in care arrangements for people with dementia involve complex interactions between care recipients, migrant live-in carers, and family members, leading to various challenges, potential moral conflicts, and vulnerabilities (14–16). Building upon the initial exploration of challenges and vulnerabilities in migrant live-in dementia care, it is essential to delve deeper into the concept of vulnerability itself. Vulnerability, as analyzed in various studies, is a multifaceted concept that encompasses different types, definitions, and categories (17–20). Basic human vulnerability refers to the inherent condition affecting all individuals due to their human nature, characterized by the universal experience of 'human finitude' and susceptibility to harm and injury (21, 22). Various approaches to the concept of vulnerability agree that while we all share a common vulnerability, this vulnerability is distributed differently across individuals.

Universal vulnerability can become exacerbated in certain social, political, and other contexts (23). Specifically, situational vulnerability arises from specific external conditions—such as cultural, social, political, and economic factors—that render some individuals more susceptible to harm than others (24).

In the context of aged care, Sanchini and colleagues (25), based on the latest studies, proposed six dimensions of vulnerabilities for older people that characterize aged care. *Physical vulnerability* is observed in the bodily deterioration associated with aging, which can lead to conditions like frailty, illness, dementia, and disability. *Psychological vulnerability* encompasses mental health changes, diminishing intellectual functioning, and emotional factors such as the cumulative loss of loved ones and the absence of emotional support. *Relational/interpersonal* vulnerability highlights the impact of human interdependence and the potential for conflicts and miscommunications. *Moral vulnerability* concerns ethical dilemmas, respect for dignity, and the potential for infantilization and depersonalization of older adults. *Socio-cultural, political, and economic vulnerabilities* reflect discrimination, economic instability, and marginalization faced by older adults and their caregivers. Lastly, *existential/spiritual vulnerability* pertains to existential questions about identity, purpose, and finitude experienced more intensely by older adults. These dimensions also offer insights into the vulnerabilities of persons with dementia in home-based care. However, it is imperative to explore the vulnerabilities of all parties involved in the triadic care arrangement—persons with dementia, family members, and migrant live-in caregivers—to fully capture the scope of challenges they face. This comprehensive approach will provide a holistic understanding of the care arrangement and the dynamics within it.

1.3 Present study: rationale and research questions

This study focuses on the vulnerabilities in dementia home care with migrant live-in carers. Addressing these vulnerabilities is crucial for enhancing the well-being and safety of everyone in the care triad. These vulnerabilities can significantly impact the quality of care for persons with dementia. Understanding them, especially through experts' experiences, will help identify systemic inequities and gaps, leading to more effective support systems and policies that improve conditions for migrant live-in carers, persons with dementia, and their families.

Experts provide comprehensive insights into these vulnerabilities, drawing on a broad spectrum of experiences and observations. This is especially valuable given the practical challenges of directly accessing the care triad, whose members may face barriers to participation due to privacy concerns, health issues, or legal constraints. Furthermore, as experts positioned within intermediate structures such as organizational, community, and policy frameworks (meso-level), they offer invaluable insights that bridge the micro-level of individual experiences and the macro-level of national policies.

In this study, we obtained information from interviews with experts in Israel and Germany. We focus on Germany and Israel due to their aging populations, high life expectancy, and increasing numbers of people with dementia. Both countries have national dementia plans (Israel, 2013; Germany, 2020) and a growing number of migrant caregivers (10, 26). Despite similarities as modern Western countries, they also differ culturally (e.g., Israel is more collectivistic, with closer family ties and greater reliance on groups (27) and geographically. These differences in socio-cultural and geographic settings impact the legal and practical aspects of migrant live-in care arrangements. For example, in Israel, migrant live-in caregivers reside with the person with dementia for extended periods, while in Germany, live-in caregivers typically stay for 2-3 months and are rotated. Focusing on experts' experiences in these two countries may help identify common and unique vulnerabilities and deepen our understanding of the influence of different socio-cultural and policy contexts on these vulnerabilities. In addition, the focus of most existing studies on single-country contexts (7, 28–30) constrains our comprehension of how diverse cultural and policy environments affect the nature and scope of these vulnerabilities. Our research seeks to bridge these gaps through a comparative analysis between countries, aiming to enhance our understanding of vulnerabilities in home-based care settings across different cultural and policy backgrounds.

In this study, we aimed to answer two research questions:

1. According to experts' experiences, what are the vulnerabilities of each party involved in triadic arrangements (person with dementia, migrant live-in caregiver, family member)?
2. What are the commonalities and differences in experts' experiences regarding vulnerabilities inherent in migrant live-in care arrangements for people with dementia between Israel and Germany?

2 Materials and methods

2.1 Study design

A qualitative methodology using semi-structured interviews was adopted to elicit experts' experiences regarding complexities and vulnerabilities in home-based migrant care arrangements for older people with dementia. The study protocol was approved by the Bar-Ilan University (062201, June 2022) and Carl von Ossietzky Universität Oldenburg Ethics Committees (2022–049).

2.2 Sample composition and recruitment

This study included 14 Israeli and 10 German participants. We defined "experts" as individuals meeting the following inclusion criteria: 1) holding a senior position in a governmental, political, or public setting; 2) having substantial knowledge and experience in the field of dementia care or migrant home care for older people/people with dementia, and 3) Being directly involved in the recruitment and monitoring of migrant caregivers, including representatives of placement agencies, care and welfare organizations, NGOs, human rights organizations, and governmental structures. For this study, we excluded individuals who: 1) do not have substantial experience in dementia care or migrant home care, and 2) hold positions that do not provide direct insight or influence in the field of dementia or migrant care. For more detailed information regarding the characteristics of the experts in Germany and Israel, see Table 1.

Purposive sampling was used in both countries. In Israel, experts were recruited via researchers' professional and personal connections. Additionally, targeted outreach was conducted through email to key persons in the field of dementia home-based migrant care to achieve diversity regarding their professional expertise and positions. In Germany, several strategies were used. Participants were primarily recruited through email, e.g., all directors of placement agencies. Some of the directors were chosen based on their agency's size and status. Politicians were contacted based on their importance in the field of aged care and on variance in their political orientation/party affiliation.

2.3 Procedure

All participants signed informed consent sheets prior to participating in the study. In Israel, 14 semi-structured interviews with experts were conducted using *Zoom* or video telephone call platforms from October 2022 to June 2023. In Germany, ten semi-structured interviews with experts were conducted using the video call platform *Big Blue Button* between August 2022 and January 2023.

The interviews were conducted following a semi-structured interview guideline, which was developed jointly by the research teams in both countries in English and later translated into Hebrew and German. Interviews started by asking the participants to describe their professional background and experience with migrant live-in care arrangements for people with dementia. This was followed by questions aimed at gaining the expert's views regarding dementia home-based care (e.g., "How do you perceive this form of care in comparison to other forms of care, for example, home? "). In this particular study, we focused on challenging situations, conflicts, and vulnerabilities, asking experts, for instance, the following questions: "Do you recognize problematic power structures within the arrangements? "; "Do you see potential conflicts in live-in care arrangements?"; "Can you describe vulnerabilities in live-in care arrangements?"; "In your opinion, is there a side that is more vulnerable in these triadic arrangements, and if so, which side?". Interviews lasted an average of 60 minutes both in Israel and Germany and were conducted by members of the research teams with experience in qualitative research.

TABLE 1 Characteristics of expert in Israel and Germany.

	Germany (n=10)	Israel (n=14)
Gender (% female)	40 %	86%
Professional background		
Representatives of Placement agencies for migrant live-in caregivers	5	0
Social Workers in a senior position in medical organizations/ Organizations for dementia care	1	2
Lawyers	1	2
Journalists (in the field of aging and old age)	0	1
NGO representatives	1	2
Politicians	2	0
Representatives from the Alzheimer's association	0	2
Heads of departments in governmental organizations	0	2
Public figures (representatives/heads of communities)	0	1

2.4 Data analysis

We employed a qualitative content analysis approach to ensure a thorough and nuanced examination of the expert interviews, following several steps outlined by Braun and Clark (31). The process began with verbatim transcription of the interviews, followed by multiple readings. Initially, guided by the study's questions, we applied deductive coding to analyze expert interviews concerning the vulnerabilities of people with dementia, using a predefined set of categories based on the six dimensions of vulnerabilities in aged care identified in prior studies [e.g (32, 33)] and elaborated by Sanchini et al. (2022) (25). These dimensions (as mentioned in the introduction section) include: 1) physical, 2) psychological, 3) relational/interpersonal, 4) moral, 5) socio-cultural-political-economic, and 6) existential/spiritual. We used these six categories as a basis because they offer a comprehensive and up-to-date literature review-based view of the vulnerabilities of older people in need of care, including those with dementia. We chose to employ Sanchini's and colleges' framework (25), tailored initially to describe the vulnerabilities of older people in need of care and adapt it to all members of the triad because, to the best of our knowledge, no existing concept or model in eldercare comprehensively considers the vulnerabilities of all parties involved. This approach allowed us to systematically capture the multifaceted nature of vulnerabilities experienced by persons with dementia, their family members, and migrant live-in carers, providing a holistic understanding of the triadic care dynamics. For instance, the physical dimension of vulnerabilities for a person with dementia encompasses issues such as physical illness, cognitive decline or advanced dementia stages, increased frailty, and disability. In contrast, this dimension for migrant live-in caregivers might be expressed in physical and mental strain from caregiving tasks, including orthopedic problems, sleep deprivation, and the risk of workplace injuries. As for family members, this dimension of vulnerabilities may involve health issues and potential neglect of their own physical well-being.

This framework, detailing vulnerability dimensions for each party, served as the main categories for discussion within and across research teams in both countries until a consensus on the coding structure was achieved. The final phase involved identifying quotes/ statements within the interview material that support these categories (dimensions of vulnerabilities) for each party involved in the care triad. Due to space constraints, we present a detailed description of each dimension of vulnerability for each party in the triadic home-based care arrangement in Table 2, and we provide examples of relevant quotes from the expert interviews in Israel and Germany in Table 3.

3 Results

In exploring the vulnerabilities within migrant live-in care arrangements for people with dementia across Israel and Germany based on experts' experiences, it becomes apparent that, according to them, all parties involved are vulnerable in different ways and that some of these vulnerabilities are interdependent.

In general, Israeli experts highlight the complex nature of vulnerability, suggesting that it is difficult to pinpoint the most vulnerable group within the care triad. While the person with dementia is often perceived in public opinion as the most vulnerable, Israeli experts acknowledged that each party in the triad—persons with dementia, migrant live-in carers, and family members (both spouses and children)—faces unique challenges that can amplify their respective vulnerabilities depending on the context and specific circumstances. In contrast, German experts focused more on the vulnerabilities of migrant live-in carers, drawing attention to their exposure to discrimination, excessive working hours, and challenging working conditions coupled with a lack of autonomy. Interestingly, the vulnerabilities of family members received relatively less attention in interviews with German experts, possibly reflecting their less extensive involvement in the caregiving process compared to their Israeli counterparts.

In the following, we present different dimensions of vulnerabilities that emerged from the analysis of interviews with experts in Israel and Germany, noting commonalities and specificities between the two countries.

3.1 Dimensions of vulnerabilities for persons with dementia, migrant caregivers, and family members

3.1.1 Physical vulnerabilities

We identified various types of physical vulnerabilities that arise from the specific situations of each party in the caregiving triad. Israeli and German experts acknowledged these vulnerabilities for persons with dementia and migrant live-in carers, while only Israeli experts recognized them for family members. These vulnerabilities are partly interdependent and context-specific.

For persons with dementia, cognitive impairment significantly limits their physical and cognitive abilities, leading to considerable dependence on others and a diminished level of autonomy. This dependency is a primary reason for employing a migrant caregiver.

Migrant live-in carers, as acknowledged by both Israeli and German experts, face physical vulnerabilities resulting from the nature of their work, which includes managing the physical and behavioral symptoms of dementia. This can lead to chronic sleep deprivation, strenuous physical labor, and potential trauma from aggressive behaviors exhibited by older individuals with dementia.

Family members, even without direct physical involvement, may experience indirect physical vulnerabilities due to the caregiving burden. The physical and cognitive condition of their loved ones, coupled with the responsibility of coordinating care, can result in neglecting their own health, thus manifesting in a vulnerable physical state. However, it was observed that only Israeli experts, and not their German counterparts, highlighted the physical dimension of vulnerabilities among family members.

TABLE 2 Dimensions of vulnerabilities in dementia home care for persons with dementia, migrant live-in carers and family members.

Dimension	Person with dementia	Migrant live-in-care	Family member
Physical	Illness, cognitive deterioration, increased frailty, and disability.	Physical and mental strain from caregiving tasks (e.g., orthopedic issues, sleep deprivation), potential for workplace injury.	Health issues, potential for neglect of own physical health.
Psychological	Emotional distress, depression, anxiety, feelings of confusion, loneliness, psychological discomfort (due to invasion in a private space).	Stress, burnout, loneliness, and isolation due to cultural and language barriers.	Anxiety, guilt, and emotional strain from caregiving responsibilities or decision-making.
Relational/ Interpersonal	Reduced social interactions, dependency on caregivers and family members, and potential isolation.	Challenges in establishing trusting relationships due to cultural differences and potential for professional isolation.	Altered family dynamics, increased dependency on migrant caregivers, loss of control/power.
Moral	Risk of being undervalued or stigmatized, infantilization, depersonalization, deprivation of personal dignity, and ethical considerations in care decisions.	Navigating ethical dilemmas in care, balancing professional duties with personal values, depersonalization (objectivization), and stigmatization.	Concerns over the quality and ethics of care provided and managing care decisions, moral conflicts, and moral distress.
Socio-Cultural-Political-Economic	Ageism, risk of marginalization, and reduced access to resources.	Legal vulnerabilities, discrimination, economic instability, and job insecurity; cross-cultural disparities, and language barriers,	Navigating healthcare systems, the financial burden of care, and societal expectations.
Existential/Spiritual	Facing existential questions about identity, purpose, and finitude.	Personal sacrifices, questioning life choices, and dealing with separation from own family.	Dealing with loss, grief, and existential concerns regarding the well-being of their loved one.

TABLE 3 Dimensions of vulnerabilities in triadic dementia home care arrangements accompanied by direct excerpts from experts' interviews in Israel and Germany.

Dimension of Vulnerability	Person with Dementia		Migrant caregivers		Family members	
	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany
Physical	"Dementia brings very negative consequences, greatly increasing the chance of negative outcomes in all areas of life, from health and functionality to cognitive decline, among others. (…) So yes, the older person is the weak link. In any case, I think the main victim is usually the older person with dementia because he is the weakest in this situation. I believe it's the older person who suffers the most because of this (dementia)."	"Or even months ago, so she had had a mild delirium and, according to her relatives, another severe episode of dementia. (...). The mother used to travel a lot. Since Corona, she's let many social contacts slide and no longer comes out of the house. He [the son of the Person with dementia] has now taken the car away because he has realized it's getting really risky. And now we're looking for a caregiver who has a driving license and who can clearly talk to the senior citizen and say, "Let's go shopping, let's go out and have a coffee" and get her going again".	"I think it's scandalous that most foreign workers today are working 24/7. It's not humane, and then we're terribly shocked to find there's abuse and all sorts of things like that."	"The caregiver had tears in her eyes, slid a piece of paper over and said: Here one and twelve o'clock 3:15h 3:33 4:15 where she had to get up and couldn't catch up on sleep during the day."	"Family members can harm themselves. They often neglect their own care, failing to visit doctors or address their health problems. This means there are associated risks with them being the main caregivers, including emotional, mental, physical, health-related, and financial risks." "If it is a spouse who is the main caregiver for a person with dementia from among the family - he is also in an old age and may not be healthy, then he becomes even more vulnerable because in addition to his own health problems he has to care for his spouse".	Not found
Psychological	"In the end, the introduction of a foreign caregiver into the home is an intrusion into the older person's private space by an outsider. This intrusion is often not easy, and we must also remember the position of the foreign caregiver, who also faces difficulties on their side." "One of the greatest anxieties of older persons, as soon as a foreign caregiver enters the home, is the disconnection from the family. "(family member): It's okay, now we've made a vee, there's someone watching, and I can back off." This anxiety (to be alone without family members) can cause a lot of conflicts	"No one wakes up in the morning and says to themselves, 'I'm glad that a foreign Eastern European is moving in with me'. That's the big compromise that families make in order to avoid this stationary hell."	"The vulnerability of the foreign caregiver arises often because they have to endure challenging behaviors from their care recipient, which is far from easy. I always remind myself, sitting in my chair as a social worker, telling her (the foreign caregiver), 'Don't take it personally, it's the disease speaking.' Yet, I constantly remember that there's a human being there, a person with feelings, with a heart, and someone who puts their all into their caregiving role, only to receive accusations like 'You stole from me,' 'You took from me,' 'Take your things and get out,' not to mention the instances of violence... Even if, five minutes later, the person with dementia settles down and stops making those accusations, it still	"She must then always, when the daughter comes or the son, is supposed to take herself back, officially, and act as if she is just working there and then sits in the kitchen and waits until they have drunk their coffee"	"Family members who are primary caregivers also represent a vulnerable population; they too are at risk because it becomes very difficult over time. Even if they are not directly involved in activities like bathing or cooking, they remain integral to the caregiving process. There's a constant sense of responsibility and obligation, which can be exhausting and wearing. This wear and tear, coupled with frustration and difficulty, can lead to a short path to causing harm." "Let's not ignore the underlying feeling, though it may be subtle, that here comes someone (live-in-care) who manages to take care of the mother, something	"When the children are on site and are on the verge of burnout, so to speak, they are already so over it, over the day, over the bike, so completely hysterical. And then they want to save themselves by getting someone. And then it's just hysteria, hysteria, so on the outside it's like that and then it's over and then I wouldn't call it conflict anymore, but terrorism. So that's how it is when you see some children who have given themselves up to look after their parents."

(Continued)

TABLE 3 Continued

Dimension of Vulnerability	Person with Dementia		Migrant caregivers		Family members	
	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany
	between the old man and the foreign caregiver”.		creates a significant vulnerability for the foreign caregiver."		that the three, four, or even seven of us (siblings) couldn't achieve."	
Relational/ interpersonal	"Because there is a shortage of foreign caregivers today, you often find foreign caregivers with the power in their hands. They decide where to work, and if they don't feel good, they decide to leave or move to a place where they are paid more. This creates a kind of situation where the family has to keep the worker so he doesn't run away. To 'please' him... a gift here, a gift there, all kinds of conveniences. So maybe, just maybe, the fact that there is a shortage of caregivers gives them a lot of power in their hands."	"(…) So, the problem was, she somehow didn't think about things at the time or beforehand. And that was the problem. It was about millions. Her children, when they realized that the mother was no longer quite sane, let's say casually, they took over everything. Somehow, she was not incapacitated, but somehow, she had a care order. And so on. Somehow, they took over so they could empty the accounts."	“The foreign caregiver arrives, and he is a foreign worker in Israel (...) he is a foreign worker, there is no Israeli family here, the power is in the hands of the family. It is very hard…” “There are family members who may, and not only may, but they also do abuse the foreign live-in carer. They see them as a servant, someone who should be at the service of the older person, but also at their service. I have already heard of quite a few situations where the family hired the same live-in-care to do all sorts of things for them, including cleaning and other tasks. This is exploitation, abuse, inappropriate treatment, and disrespectful treatment towards that live-in by the family.” “Let's say there is a woman with dementia who has a partner. I have heard of situations where the partner attempted to initiate something with the live-in-care and not only attempted but also touched and did all kinds of things. So, maybe I understand his frustrations and shortcomings, but the live-in carer is not supposed to satisfy his emotional or sexual needs.”	“(...) I don't place cleaning ladies, we place caregivers. The service is housekeeping to a certain extent and on the other hand, of course, basic care. But I'm not allowed to go overboard here and then, let's say, misuse the staff by having the son-in-law say: "Oh, it's easy. Dad only has mild dementia and can stay alone for five hours. I pay €3,000 a month. Why don't you come over? I live three streets away and mow the lawn, let's be clear. We go this far and no further again and again.” “The others are really rootless here. Like truck drivers. They sit in their chambers and wait until they have to go back to work.”	“Loss of control, a genuine lack of control over what happens inside the house where the parent and caregiver reside. That's the reason why you hear about the use of cameras and other such measures.” “If there is a spouse living at home and there is a foreign caregiver living at home, a caregiver, it could be explosive, it is very difficult to bring a stranger into the home who would be an angel from heaven. It's not easy at all. absolutely not. You have a stranger at home. Not a guest, not a family member and this may create situations of tension, of conflicts, of discomfort, of unpleasantness”.	“But of course you already have a big dilemma on your hands. The family is of course beside themselves. That's understandable, they want you to leave immediately. They just want the person out of the house immediately. And they just have to see how they can manage it so that they still treat and see the person as a fully-fledged human being. And then simply bring everything back in an orderly fashion and, above all, offer the person assistance and simply not leave them to their own devices”
Moral	Not Found	"(…)So, and I was just a disruptive factor because I made sure that the mother could think more clearly again,	"The general public has a built-in lack of trust in foreign caregivers. I know... in courses I teach, when I would come to the topic of abuse	“I believe some [live-in carers] also would like to go to church on Sundays, have kind of rituals, but don’t dare to say	Not found	“Yes, money is money again. It's always about money somehow. (…). And I have two or three siblings who have dollar signs in

(Continued)

TABLE 3 Continued

Dimension of Vulnerability	Person with Dementia		Migrant caregivers		Family members	
	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany
		because she had someone who took her seriously and who even started to talk to her about it, for example, to ask, somehow they made an order, because she was held like a convict. She somehow had no rights at all, she had fewer rights than anyone in any home, she was in a gilded cage but wasn't allowed out."	and ask people, 'Who abuses an older person the most?' many times, the answer was - migrant caregivers." This caregiver spoke on behalf of her friends, also migrant caregivers who often say that they feel like a "slave" because they (families) treat them like slaves". "They see her (a foreign caregiver) not as a human being, they sometimes see her as a caregiving tool that is inanimate, an inanimate tool ".	that, because of course people [main carer/employer] say 'But why, there is work'" "I have already experienced that a caregiver [live-in carer] called me and said: 'Well, he is sitting on the toilet, his face is limp, what should I do now?' I drove there and thought about calling the hospital on the way, but then I was only five minutes away and it was quite obvious that the customer had had a stroke and even the wife was standing next to him and said: 'No, don't call an ambulance, he doesn't want to go to hospital'"		their eyes, and one of them might say no, we promised Dad he'd stay in his house, and so on, and the others, no, go into a home and then you can sell the cottage."
Socio-cultural-political and economic	"Misunderstandings due to language and communication difficulties are common, especially since many older people might not speak English well, if at all. They may struggle to understand the caregiver, and the caregiver might not understand them. This can lead to conflicts, even resulting in inappropriate or incorrect treatment (care). It's often the small things, like not responding to the person's needs, that become problematic. Again, this is largely due to communication and language barriers."	"Because of the language barrier. Then you have to see it this way, so purely from the point of view of the dementia patient, it's not so easy, ummm suddenly having another person in the apartment and uh that's not understandable to a certain extent and is sometimes seen as a foreign body that you have to get rid of, so that power struggles or conflicts arise, um, which can then escalate due to a lack of language barriers. So that doesn't necessarily go well, that's one thing, um so with the person themselves who is to be cared for and then of course there are also the cultural differences not only language differences but also cultural differences in other countries you sometimes have a completely different	"One foreign worker worked for an old woman who was wonderful in that she took her abroad; she went to Spain, Germany, and other places. The foreign caregiver really saw the world with this woman. But in the end, she decided to leave her because the woman always screamed at her and yelled at her. For her (live-in-care), culturally, it was a terrible thing to be yelled at; you don't yell like that in her culture. So, she gave up the job. These are the intercultural gaps, which I think are paid less attention to and are terribly important. The intercultural gaps are present in food and in the perception of what a family should look like, how care should be, and how relationships should be between people. Many times, families make a mistake because they extrapolate directly from Israeli culture to the	"We sometimes have very nasty senior citizens, but they are simply very difficult for us to deal with, and we realize ourselves that we usually ask them very, very honestly in the questionnaires that the relatives answer and say that they are verbally aggressive or that we have a big problem with some hidden National Socialism, I would say, that still lies dormant in their people. It's like this, come from Poland, it's always a bit more dangerous. But you only realize that when there is actually a care worker there all the time. And we immediately terminate anything that involves any kind of racism and say it's not possible."	"This arrangement - (costs) is a lot of money. Many times, it is the family members who pay so it increases the vulnerability". "I feel that when the family needs a foreign caregiver, they spend a lot of time getting the permit, which is a very, very important thing. It takes time - all the paperwork and bureaucracy".	Not found

(Continued)

TABLE 3 Continued

Dimension of Vulnerability	Person with Dementia		Migrant caregivers		Family members	
	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany	Examples of quotations Israel	Examples of quotations Germany
		understanding of uh people with dementia and older people in general it depends very much on which culture the live ins come from, so the caregivers come from.”	relationship with the foreign caregiver, and they fail there because it is not the same. There is value in seeing the other culture. So, intercultural differences—this is one of the important things, starting with how her (foreign caregiver's) food smells. 'Ugh, disgusting,' is the reaction of the family. Stuff like that."			
Spiritual	Not Found	Not found	Not found	Not Found	Not Found	Not found

This discrepancy could be influenced by cultural and geographical differences: for example, in Germany, a country much larger country in area than Israel, children often reside at a significant distance from their parents, resulting in less active involvement in caregiving. This geographical distance means that family members in Germany might not face the same physical strains of hands-on caregiving, potentially reducing their physical vulnerabilities. However, this can lead to other forms of vulnerability, such as emotional stress and anxiety, due to their inability to be physically present. In contrast, Israeli family members, who are more likely to live closer to their aging parents, are more actively involved in caregiving, which increases their physical vulnerabilities due to the direct physical demands and stresses of caregiving.

3.1.2 Psychological vulnerabilities

Drawing from insights provided by experts in Israel and Germany, we identified several types of psychological vulnerabilities affecting all parties within the caregiving triad. Similar to the previous dimension, these vulnerabilities stem from the unique circumstances each party faces and are often interrelated.

For persons with dementia, experts from both Germany and Israel noted that the discomfort of welcoming a foreign caregiver into their home can lead to emotional stress and feelings of intrusion into their personal space, as well as an increased awareness of their dependency.

Migrant live-in-carers face psychological vulnerabilities resulting from being in a stranger's private space in a foreign country and adapting to an unfamiliar culture. They might experience additional emotional stress due to separation from their families and being out of their comfort zone. German and Israeli experts both highlighted the psychological harm migrant caregivers may suffer. For instance, Israeli experts noted unfounded accusations of theft or violence from the person with dementia they care for, while German experts observed feelings of being belittled due to their status.

Family members also experience psychological vulnerabilities. The psychological strain of caregiving was recognized by experts in both Germany and Israel. Additionally, Israeli experts pointed out the complex emotions family members might experience, such as guilt and jealousy, due to hiring foreign caregivers, reflecting on their perceived inadequacies in providing care.

3.1.3 Relational/interpersonal vulnerabilities

This dimension focuses on human interdependence, resulting in vulnerabilities. For individuals with dementia, their condition necessitates reliance on migrant caregivers and family members, who then overtly or covertly take up decision-making roles. Israeli experts have noted that due to a scarcity of migrant caregivers, these caregivers gain disproportionate power and may abruptly leave the person with dementia, possibly without notice, if they find better pay elsewhere. German experts emphasized the loss of autonomy and the dependence of a person with dementia on their adult children, who can sometimes abuse this power, leading to moral vulnerability, which will be described in the next section. This paternalism on the part of the children, which may stem from genuine concern or from a belief that a parent has lost the capacity to make decisions, can result in the denial of rights and a lack of consideration, turning the person into a "prisoner in their own house."

Concerning migrant live-in carers, their relational/interpersonal vulnerabilities are linked to complex relationships with family members who inherently hold more control and power, potential exploitation and even sexual abuse, and loneliness stemming from being in an unfamiliar environment. Both Israeli and German experts acknowledged these issues.

Regarding family members, both Israeli and German experts highlighted the loss of control that adult children experience over what happens inside the house. Israeli experts noted that this has led to the adoption of surveillance cameras to monitor caregiving, while German experts reported cases of migrant live-in carers engaging in inappropriate behaviors, such as excessive alcohol consumption, which initially went unnoticed by relatives. This situation places family members in a moral quandary, as they feel compelled to protect the rights of the live-in caregiver, despite any misconduct, rather than terminating their employment hastily. Additionally, Israeli experts pointed out spouses' discomfort with entrusting their homes to an "outsider," which can also be challenging for them. These observations reflect the complex dynamics of trust, control, and vulnerability that characterize the caregiving relationship.

3.1.4 Moral vulnerabilities

This dimension encompasses vulnerabilities within live-in care arrangements that are tied to overarching norms and values. These might be expressed as the risk of being stigmatized and undervalued for persons with dementia and migrant live-in carers, ethical dilemmas in care for migrant live-in carers, and family members' concerns over ethics and quality of care for their loved ones.

For migrant live-in carers, Israeli experts describe depersonalization and their treatment by family members not as human beings but as tools to achieve a goal—referred to as the "objectification" of live-in carers or treatment of them as "slaves." Furthermore, influenced by portrayals in public media regarding evidence of abuse of older people by migrant caregivers, live-in carers in Israel may experience public stigmatization and a built-in lack of trust from society, including family members and older persons- recipients of care. In Germany, experts highlight the moral dilemmas faced by live-in carers, who struggle to take time off due to the constant demands of their responsibilities, whether caring for a person with dementia or managing household tasks. In emergency situations, these caregivers must make rapid decisions about the health of the person with dementia, balancing not only the wishes of the individual but also those of the family members.

For persons with dementia, German experts point out specific moral vulnerabilities for them. They noted that cognitive decline and dependence of the person lead to their devaluation by family members, financial exploitation, deprivation of rights, and inability to take part in decisions regarding their own care.

For family members, German experts noted moral vulnerabilities that might arise when several siblings are involved. Financial disagreements between them may lead to ethical concerns and dilemmas about whether the parent's funds should be viewed as a potential inheritance for them (the children) or if they should be allocated toward care expenses, such as employing a migrant live-in carer.

Notably, Israeli experts did not mention these particular moral vulnerabilities concerning persons with dementia or their family members.

3.1.5 Socio-cultural, political, and economic vulnerabilities

These vulnerabilities refer to the risk of marginalization and reduced access to resources for persons with dementia; discrimination, economic instability, and job insecurity for migrant live-in carers; and the financial burden of care and societal expectations for family members. Both Israeli and German experts identified language barriers and cultural disparities between the person with dementia and the live-in carer as sources of clashes, misunderstandings, and conflicts that may lead to such vulnerabilities in the caregiving setting. Accounts range from persons with dementia feeling estranged in their own homes to the neglect of their needs and even power struggles that may escalate, leaving both parties feeling disregarded. The inability of persons with dementia to effectively communicate their needs and the inability of migrant live-in carers to understand and respond to these needs, coupled with existential interdependence, renders both parties vulnerable. Experts in both Israel and Germany also stressed that cultural differences contribute to these vulnerabilities. Live-in carers may feel unwelcome or even harassed due to these cultural differences. German experts specifically addressed covert racist attitudes toward Polish live-in carers from the care recipient's side.

Regarding family members, German experts, except for indirectly mentioning workload, do not explicitly address vulnerabilities. However, Israeli experts recognize the financial constraints and bureaucratic challenges faced by family members as significant vulnerabilities.

3.1.6 Spiritual vulnerabilities

This dimension remained unaddressed by experts in both countries in our study.

4 Discussion

This study aimed to comprehensively understand the vulnerabilities within the triad of dementia home-based care with migrant live-in caregivers, focusing on persons with dementia, live-in caregivers, and family members based on experts' experiences in Israel and Germany. The relationships in home care arrangements with migrant live-in caregivers are complex and characterized by significant interdependence; each member of this triad relies on the others for their well-being in crucial ways (34). The exploration of vulnerabilities within this triadic setting, based on interviews with experts from Israel and Germany, reveals the multifaceted nature of this caregiving environment and its dynamics.

The complexities of vulnerabilities within the care triad were widely acknowledged. Israeli experts emphasized the intricate nature of these vulnerabilities. Contrary to the popular opinion among the general public and professionals, which often views the person with dementia as the most vulnerable member of the triad due to their health and mental condition (35), Israeli experts did not identify any particular side of the triad as the most vulnerable. Instead, they noted that vulnerabilities are present in all parties involved, stemming from their unique situations. Each party faces distinct challenges that can increase their vulnerability in specific contexts, making these vulnerabilities inherent to the triadic care arrangement. This aligns with existing literature that acknowledges different conditions leading to vulnerabilities: asymmetrical power relations and the intersection of ethnicity, culture, class, and legal status for migrant care workers; the poor physical and cognitive condition of people with dementia; and the emotional and physical burden experienced by family members (28, 36–38). However, German experts placed significant emphasis on the vulnerability of migrant live-in caregivers, highlighting their susceptibility to discrimination, excessive working hours, and challenging conditions.

The relatively lesser focus on family members' vulnerabilities in Germany may be influenced by several socio-cultural factors, such as fewer children per family, greater geographic distance from parents, and more remote involvement in caregiving. These factors suggest a divergence in familial engagement between the two countries. However, it is important to note that these interpretations are derived from our analysis and were not explicitly probed during the interviews. Explicitly addressing this question with the experts could have provided deeper insights into these dynamics, and we recommend this for future research. Another explanation may be the different expectations in the two countries regarding family involvement in care, as Israel's more collectivistic culture involves closer family ties (27), leading to greater family involvement in care.

In general, five of the six dimensions, except for spiritual vulnerability, were acknowledged by Israeli and German experts as relevant to all parties involved in triadic dementia home care arrangements. However, these vulnerabilities differ for each party according to their specific situations. While physical and psychological vulnerabilities are universally recognized, the emphasis on relational and moral vulnerabilities varies. Israeli experts noted the power dynamics and potential exploitation of migrant caregivers within the caregiving arrangement. This observation aligns with recent studies highlighting how relationships within the care triad can sometimes be discriminatory, reflecting power imbalances and the vulnerability of migrant live-in caregivers (7, 10). In contrast, German experts highlighted the moral dilemmas and decision-making challenges faced by migrant caregivers, underscoring the ethical complexities inherent in caregiving. Interestingly, the moral vulnerability dimension for a person with dementia was acknowledged by German experts but not by Israeli experts, potentially indicating a greater awareness in Germany of preserving the autonomy of people with dementia and probably a lower level of public stigma surrounding the condition. Supporting this, a study found that only 4% of the German population over the age of 50 reported fear of people with dementia, while over 80% expressed no fear, indicating relatively low levels of stigma in Germany (39). This could also stem from the more autonomy-oriented orientation of German society (27, 40).

Our findings also indicate a gap in addressing existential and spiritual vulnerabilities, suggesting that these aspects are often overshadowed by more immediate practical and ethical concerns. This oversight points to a potential area for further research and intervention, recognizing that spiritual well-being significantly impacts the quality of life for all parties involved (41).

In a comparative view, our analysis also showed that home care arrangements for people with dementia, along with the complex vulnerabilities for all parties involved, are significantly influenced by the legal policies specific to each country. These policies distinctly shape the vulnerabilities experienced by each party. For example, in Israel, a shortage of caregivers allows them to switch families for better pay, leading to concerns about caregivers gaining disproportionate power and potentially leaving their positions abruptly. Conversely, in Germany, while family members may wish to quickly dismiss a live-in caregiver for inappropriate behavior or keep them longer, they are constrained by legal policies requiring caregivers to rotate every three months. Such differing policies highlight the variations in how care arrangements are managed across these countries, underlining the distinct vulnerabilities that arise in Israel and Germany.

4.1 Entangled vulnerabilities in dementia care triads

This study aimed to deepen our understanding of the various vulnerabilities present in home care arrangements for people with dementia involving migrant live-in caregivers. We introduced a theoretical framework that distinguishes between different dimensions of vulnerability to address the challenges faced by each side of the triadic care relationship. However, the complex reality of caregiving—where individuals with varying health conditions, economic and legal statuses, cultural backgrounds, and generational differences interact within intricate human relationships—often results in these vulnerabilities becoming entangled, complicated, and interrelated. While previous studies have acknowledged the existence of vulnerabilities within home care arrangements, they typically addressed these vulnerabilities in isolation for each party involved (5, 42–44). Based on our findings, we propose viewing these vulnerabilities as entangled, interconnected, and interdependent rather than separate, highlighting the need for a more holistic approach to understanding and addressing them.

Interrelations *within a single party* of the triad refer to how different dimensions of vulnerability intersect and reinforce each other. For instance, our findings indicate that the "relational/interpersonal dimension of vulnerability" for a person with dementia can intensify their moral vulnerability. As German experts highlighted, when a person with dementia becomes increasingly dependent on others, they may lose autonomy, leading to a sense of diminished dignity. Similarly, Israeli experts revealed that the psychological vulnerability of family members, burdened by the responsibilities of caring for a parent with dementia and managing the relationship with a foreign caregiver, can manifest in physical vulnerability, such as neglecting their own health due to caregiving stress.

The interrelations of vulnerabilities *between the parties* of the triad highlight the entangled dependencies within the caregiving arrangement. For example, the physical vulnerability of a person with dementia, exacerbated by rapid health deterioration, can lead to increased physical or psychological strain on migrant live-in caregivers. These caregivers may face more demanding physical care tasks or suffer from sleep deprivation due to nighttime caregiving, leading to stress and burnout. This situation, in turn, can heighten the vulnerabilities of family members, who may experience increased stress, greater dependency on the caregiver, and concerns over care decisions, such as whether to continue with live-in care or opt for institutional care. Moreover, the socio-cultural, political, and economic vulnerabilities of migrant caregivers—who often occupy a lower position in terms of resources and power—are intricately linked to the vulnerabilities of family members, who bear the financial burden of employing a migrant caregiver. Language barriers, a form of psychological vulnerability, further complicate communication between all parties, leading to misunderstandings that affect the quality of care. For example, when people with dementia struggle to express their needs due to language differences, the caregiver's ability to provide appropriate care is compromised, causing emotional stress and concerns over care quality among family members. In another example, the physical and cognitive decline of a person with dementia can create moral dilemmas for family members, who may face difficult decisions regarding care budgets and sibling relationships. These moral vulnerabilities can, in turn, influence the economic vulnerabilities of live-in caregivers, who might experience job insecurity based on the family's decisions.

5 Conclusions

In summarizing our study, we can conclude that our research revealed multifaceted and interrelated vulnerabilities in dementia care arrangements with migrant live-in caregivers, illustrating the depth and complexity of the challenges faced by all parties involved in the triadic care arrangement. Furthermore, our findings emphasize the significant role of meso- and macro-level factors in shaping these vulnerabilities. By adopting a comparative research perspective, we have been able to identify how different socio-cultural and legal contexts influence the dynamics of these vulnerabilities.

For example, at the meso-level, the organizational structures within the care systems of Israel and Germany play a critical role in shaping the experiences of vulnerability for each party. In Israel, where migrant live-in caregivers reside with care recipients on a permanent basis, the constant presence of the caregiver can lead to a blurring of professional and personal boundaries. This close proximity might increase the relational vulnerability for both the caregiver and the care recipient, as tensions may arise from continuous interaction without sufficient breaks. Additionally, this setup can exacerbate the psychological vulnerability of caregivers due to the potential for burnout from being on call 24/7, while care recipients might feel a loss of privacy and autonomy in their own homes. In Germany, the less regulated grey market of migrant caregiving, where many caregivers are hired through agencies that navigate strict employment laws, creates a different set of challenges. The frequent rotation of caregivers, as required by German policies, disrupts the continuity of care, exacerbating the psychological vulnerability of both the person with dementia and the family members, who may struggle to build trust with constantly changing caregivers. This rotation system, while intended to protect caregivers from exploitation, can inadvertently lead to a lack of stability in care, highlighting how macro-level legal frameworks directly influence the relational and psychological vulnerabilities within the triad.

At the macro-level, broader socio-cultural and legal factors also play a pivotal role. For instance, Israel's collectivistic culture, which emphasizes close family ties and a strong sense of responsibility toward older family members, often leads to higher involvement of family members in the caregiving process. This cultural expectation can heighten the physical and psychological vulnerabilities of family members, who may feel obligated to take on more significant caregiving responsibilities despite the presence of a live-in caregiver. In contrast, Germany's more individualistic culture, where families are often geographically dispersed, reduces direct family involvement in daily caregiving tasks. While this can lessen the physical strain on family members, it can increase their psychological and emotional vulnerabilities due to feelings of guilt or helplessness when they cannot be physically present to care for their loved ones. This geographical and cultural distance can also create a sense of isolation for the person with dementia, as their primary emotional support system is not immediately available, further complicating their psychological and relational vulnerabilities.

These examples demonstrate how the interplay between meso- and macro-level factors, including organizational structures, legal frameworks, and cultural contexts, profoundly shapes the vulnerabilities experienced by each party in the triadic care arrangement. Understanding these complexities is essential for developing targeted interventions and policies that address the specific needs of each party involved, ultimately leading to improved care strategies in diverse socio-political environments.

6 Study limitations and strengths

The present study is not without its limitations. Firstly, the number of participants was relatively small, and the composition of the sample differed between Israel and Germany. However, these differences reflect the distinct organization of live-in care arrangements in each country. The German sample predominantly consisted of directors of placement agencies, who play a significant role in the migrant home care framework, while the Israeli sample included many social workers responsible for monitoring live-in care arrangements, as the employment of migrant live-in caregivers in Israel often relies on care recipients or family members.

Additionally, while the study mentions the country of origin of migrant caregivers, future studies could examine how the caregivers' different cultural and socio-economic backgrounds influence the care dynamic, including vulnerabilities and resilience strategies within the triadic care arrangement.

Secondly, the findings of this study may not be generalizable to all settings or populations. Nevertheless, the comparative design allowed us to identify the influence of contextual factors, such as cultural and policy environments, on vulnerabilities in triadic care arrangements—insights that might not have emerged if the study had been conducted in only one country.

Thirdly, our study exclusively involved experts in the field, relying on their experiences as informants. While this is crucial for understanding the vulnerabilities of all parties from an intermediary perspective (between micro- and macro-levels), it is also a limitation. This choice was deliberate, as experts are uniquely positioned to synthesize diverse experiences and provide critical insights into systemic and policy-level complexities. To complement these findings, we have conducted interviews with individuals directly involved in triadic care arrangements across different countries. These interviews aim to provide a more direct and comprehensive perspective on vulnerabilities and care dynamics. We plan to publish these findings separately.

Despite its limitations, this study provides valuable insights into the complexities and vulnerabilities associated with migrant live-in care arrangements for people with dementia in Germany and Israel. Through comparative analysis, we identified both common and unique vulnerabilities within the caregiving triad, significantly shaped by the differing cultural and legal frameworks of the two countries. The proposed framework of vulnerability dimensions deepens our understanding of the challenges faced by each party, while the discussion of the interdependencies of these vulnerabilities' sheds light on their deeply entangled nature.

While vulnerability is an ontological or universal condition inherent in human beings (21, 23), we strive to reduce these conditions as much as possible. Therefore, understanding these vulnerabilities within migrant live-in care settings is crucial for developing effective interventions that improve the well-being of all parties involved. This study contributes to the broader discourse on dementia care ethics and offers actionable insights for policymakers, care practitioners, and families, paving the way for improved care strategies in diverse socio-political contexts.

Data availability statement

Due to ethical considerations and participant confidentiality, the datasets from this study are not publicly accessible. Access to anonymized data may be granted upon request, pending approval from the relevant ethics committee.

Ethics statement

The studies involving humans were approved by Bar-Ilan University, Israel (062201, June 2022); Carl von Ossietzky Universität Oldenburg, Germany (2022-049). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

NU: Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. AN: Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. LA: Conceptualization, Project administration, Supervision, Writing – review & editing. MV: Conceptualization, Data curation, Writing – review & editing. MS: Conceptualization, Data curation, Project administration, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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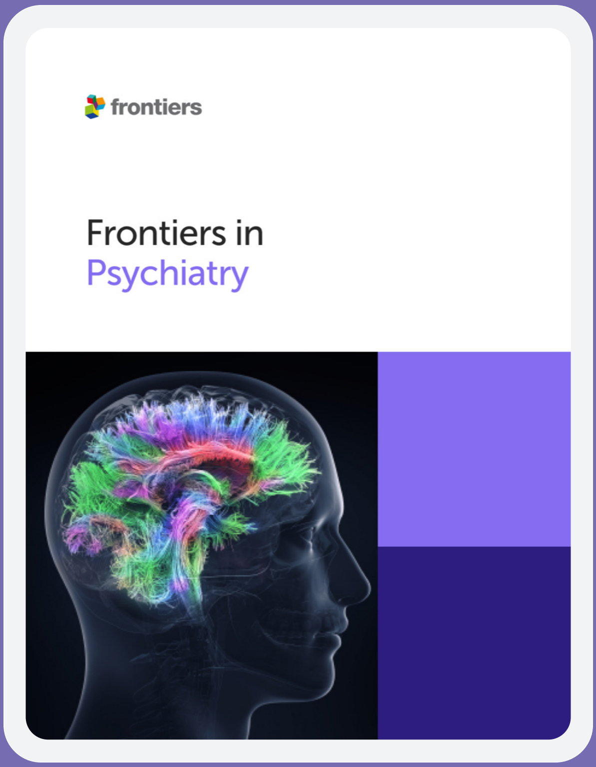

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