

Epistemic Arrogance, Moral Harm, and Dementia

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Bottenberg F. (2022) Epistemic Arrogance, Moral Harm, and Dementia. Journal of Philosophy of Disability 2: 185-208.



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<https://doi.org/10.5840/jpd20226916>

Abstract:

When it comes to supporting the well-being of a person living with dementia, remaining sensitive to that person's interests can be challenging, given the impairments that typically define the condition particularly in its later stages. Epistemic arrogance, an attitude regularly adopted by people not living with dementia towards those who are, further impedes this task. In this case, epistemic arrogance amounts to the assumption that one sufficiently knows or can imagine what it is like to live with dementia to make decisions in matters concerning the care and well-being of someone with dementia, without appropriately consulting their views and preferences. Drawing on three fictional scenarios, I describe common pathways for epistemic arrogance in dementia-support contexts and the ways in which these cause moral harm, linking them to central issues in dementia studies and medical ethics, including person-centered care, the "best interests" principle and the prescriptive reach of advance directives.

Keywords: dementia studies | epistemic arrogance | virtue epistemology | person-centered care | medical decision-making | advance directives | tragedy discourse

Article:

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Epistemic Arrogance, Moral Harm, and Dementia

Frances Bottenberg

ABSTRACT: When it comes to supporting the well-being of a person living with dementia, remaining sensitive to that person's interests can be challenging, especially given the impairments that typically define the condition particularly in its later stages. Epistemic arrogance, an attitude regularly adopted by people not living with dementia towards those who are, further impedes this task. In this case, epistemic arrogance amounts to the assumption that one sufficiently knows or can imagine what it is like to live with dementia to make decisions in matters concerning the care and well-being of someone with dementia, without appropriately consulting their views and preferences. Drawing on three fictional scenarios, I describe common pathways for epistemic arrogance in dementia-support contexts and the ways in which these cause moral harm, linking them to central issues in dementia studies and medical ethics, including person-centered care, the “best interests” principle and the prescriptive reach of advance directives.

KEYWORDS: Dementia Studies, Epistemic Arrogance, Virtue Epistemology, Person-Centered Care, Medical Decision-Making, Advance Directives, Tragedy Discourse

1. Introduction

When a person's views and interests are ignored by others whose charge it is to see to their well-being, a moral harm has occurred. Fundamentally, such action is morally harmful because it violates a tenet of what it means to belong in the moral community: as agents, we have a duty to be sensitive to others' views and interests when we make choices whose consequences we can be reasonably certain will affect them. That sensitivity should amount to being receptive to learning

about their views and interests and allowing these to factor appropriately into decision-making and other potentially shared epistemic activities. Accordingly, if we are placed in a position to see to another's well-being, and we are reasonably sure that decisions we make while acting in that capacity will affect that person, we ought not ignore their views or interests, but rather find ways to remain sensitive to them.¹

People living with dementia hold views and interests, but given the physical, cognitive and communicative impairments that develop as dementia progresses to the moderate and late stages, it is more difficult for others to confidently identify what those are and to act upon them in appropriate ways.² As I aim to show in what follows, this difficulty is compounded by the adoption of *epistemic arrogance*, an epistemic disposition that has yet to be expressly thematized in the literature on dementia. Briefly, epistemic arrogance involves being swayed by the presumed authority of one's own beliefs, or more broadly, one's worldview, in a way that hinders relevantly different beliefs or worldviews from appropriately informing one's actions. In the case of being sensitive to the views and interests of people with dementia, epistemic arrogance comes into play when people not living with dementia *think they know what it is like*, or would be like, to have progressive dementia, remain unreceptive to new or contrasting information, and on the authority of their presumed knowledge define the scope of knowledge and interests that individuals with dementia can or ought lay claim to, or be understood to express. Insofar as the above conditions are met, epistemic arrogance with respect to life with dementia can affect anyone—caregivers, proxy decision-makers, family and friends, health providers, community members, lawmakers, those imagining their own future with dementia and even diagnosed patients.

In what follows, I first consider how the concept of epistemic arrogance has been developed in the literature on virtue epistemology, refining its use for the special domain being examined here. Drawing on three fictional cases, I then demonstrate ways in which epistemic arrogance can impede sensitivity to the views and

¹The appropriate degree to which we ought to weigh such persons' interests against our own or against broader corporate interests is no small point of debate. For instance, Peter Singer's (2011) equal consideration of interests principle proposes we ought to weigh all like interests of those affected equally to determine the rightness of an action. This principle has in turn been criticized for downplaying the diversity of interests (Zuolo 2017) and the importance of moral status for establishing equality (see, for instance, Carter 2011). I will not engage this debate here. My focus rather is on the ways that epistemic arrogance (an epistemic vice) can from the outset impede our ability to acknowledge and appreciate the views and interests of those living with dementia.

²The arguments I make in this paper pertain more acutely to the moderate and late stages of dementia, since it is in these later stages of dementia that one typically experiences more severe challenges with verbal communication and short-term memory. On the classification and symptoms of Alzheimer's Disease and related dementias into "early," "moderate" and "late," see Alzheimer's Association (2021, 8).

interests of a person living with dementia across a variety of care-giving contexts, enabling the moral harming of that person. Next, I offer suggestions as to how epistemic arrogance might be countered through the mindful use of both interpersonal and systemic strategies. In concluding, I respond to objections concerning the relevance and meaningfulness of this project, given common skepticism regarding whether people living with dementia, particularly in its later stages, still have views and interests regarding their well-being that should not be ignored.

2. Epistemic Arrogance and Disrespect

The concept of epistemic arrogance first appears in work on virtue epistemology, particularly in reference to public discourse and unfair silencing practices (Darwall 2006; Roberts and Wood 2007; Tanesini 2016; Tollefsen 2017; Lynch 2018).³ Epistemic arrogance can vary both in degree and in scope: one can be arrogant across a range of related beliefs (a “worldview”) or in respect to isolated beliefs, and one can be committed to a relevant view’s correctness with differing levels of fervency. Lynch defines epistemic arrogance as “an unwillingness to learn from others arising from a distorted relationship with truth—a kind of bad faith” (2018, 284-285). This unwillingness to adapt one’s views stems from a commitment to the idea, deployed in one’s practical and theoretical reasoning, that “some or more aspects of [one’s] worldview will not be epistemically improved by the evidence or experience of others” (Lynch 2018, 286-287). This amounts to an *epistemic* variety of arrogance because what is being dismissed or ignored is the potential relevance of others’ knowledge and interests to enriching or checking one’s view. As a result, one is likely to overestimate the rightness or completeness of one’s understanding of a situation (*ibid.*).

Lynch surmises that epistemic arrogance ultimately stems from a commitment to protect one’s self-esteem; the epistemically arrogant “are under the delusion, to varying degrees, that their worldview is correct, just because it is their worldview” (*ibid.*). This psychological explanation may apply best in cases where the knower seeks most of all to preserve their self-image as a knower. An alternative, if complimentary, explanation is that epistemic arrogance pairs with systemic forms of epistemic injustice, for instance testimonial injustice, i.e., the wrongful attribution of low credibility to someone on the basis of their membership in a negatively stereotyped social group (Fricker 2007). Seen in this light, epistemic arrogance seems related to what Hookway (2010) identifies as systemic “participatory and informational prejudices.” In the case of participatory prejudice, someone’s perspective and participation are automatically assumed irrelevant to a conversation; with informational prejudice, their ability to offer relevant information is prematurely discounted. Hookway’s

³Referenced as “intellectual arrogance” in Roberts and Wood 2007; Tanesini 2016.

point is that, coupled with negative stereotyping, these prejudices exclude people from participation in shared epistemic activities even before interaction has been initiated.

Regardless of whether we choose a psychological or a socio-systemic explanation (or argue that the two are linked), epistemic arrogance can be construed as a kind of dogmatism in respect to the rightness, accuracy or completeness of one's own epistemic activity. Furthermore, as it is explored in the extant literature, epistemic arrogance is linked to pernicious effects on social interaction: it disrespects and silences interlocutors in what should be constructive and fair discursive contexts. Tanesini distinguishes two ways in which this disrespect manifests: first, in an "evaluative sense" that discounts another's intellect and rational capacity to participate meaningfully, and, second, in a "recognition sense" that discounts another's agency in terms of their stakeholder status in a deliberative context or, more broadly, their status as a participant in social discourse (2016, 76).

This distinction offers a conceptual in-road to the case of dementia, as it helps parse out two means by which people living with dementia are often excluded from deliberative or other discursive contexts, namely, on the one hand, by means of a dismissive judgment regarding their intellects and, on the other hand, a dismissive judgment regarding their agency.⁴ The next section will examine these two forms of dismissal in the context of dementia.

3. Epistemic Arrogance and Dementia

To begin, given the cognitive impairments people with later-stage dementia typically face, intellect-discounting might seem comparatively appropriate, that is, not inherently morally problematic or epistemically unwarranted. At least to some degree, the established use of surrogates to speak on behalf of persons with later-stage dementia suggests that intellect-discounting is the eventual result of progressive cognitive impairment and its effects on decision-making capacity (Dildy and Largent 2021, 81).⁵ Of course we must be careful when drawing support for a moral judgment

⁴Some take fully autonomous agency, or even a certain feature of agency, to be necessary for personhood. This is not a debate I directly engage in this paper, though I later defend the claim that some degree of agency is retained even into later stages of dementia. This contextualizes my use of the term "person" over "patient" throughout the paper. Further, I endorse the conclusions of Higgs and Gilleard (2016) that the concept of personhood, given its diverse philosophical and practical meanings, is of no practical use for setting models and standards of care for people with dementia. What matters most is that we support people's capabilities and interests.

⁵Models for decision-making with respect to patients fall into three categories: "by, with and for," which are expressed in autonomous, supported and surrogate decision-making (Wright 2020; Dildy and Largent 2021). Surrogate decision-making can be further divided into substituted judgment, best interests, and substituted interests approaches (Tsou and Karlawish 2014).

from established practice; not long ago, dementia was thought to be caused by the low moral fiber of the person suffering from the illness, which helped rationalize placing people with dementia in mental asylums (cf. Ballenger 2006; Powell 2009). Assuming, though, that proxy decision-making practices do not reflect inherently disrespectful silencings, morally acceptable instances of intellect-discounting will depend on a clinician's, family member's or proxy's ability to reliably and accurately identify losses in decision-making capacity, i.e., someone's general decisional abilities (Tsou and Karlawish 2014, 138). Accurately identifying lost capacity or competence must also be sensitive to the fact that the loss may be temporary (as in the case of sundowning) or permanent (if caused by a stroke, for instance). Since people living with earlier-stage dementia report being excluded from decision-making and social discourse leads them to feel dehumanized (Reed, Carson, and Gibb 2017), what matters is that a proxy not step in too soon or too comprehensively, ignoring the possibility of autonomous or supported autonomous decision-making in the interim (for instance, see Peterson, Karlawish, and Largent 2020). As Dildy and Largent explain:

Capacity can be thought of as a binary: an individual has the capacity to grant informed consent in a particular instance, or he does not. Yet, this binary should not obscure the fact that the components of capacity—understanding, appreciation, reasoning, and choice—are assessed along a continuum. Persons who lack capacity may nonetheless maintain one or more of these abilities to a meaningful extent. The ethical consequences of this are significant. (2021, 80)

To feel devalued as a person gets at the second form of dismissal identified by Tanesini (2016) as at work in epistemic arrogance, namely agency-discounting. What counts as “agency” in reference to personhood, however, is contested to a degree that “intellect” in reference to decision-making is not. Many cases of discounting the agency of someone living with dementia will count as wrongful if it can be shown that a degree of agency can be retained and acknowledged even into the late stages of dementia. Autonomous living and self-care may no longer be possible, and yet agency may still be apparent in terms of the emotional capacity to care (Jaworska 2017), for instance, or in the expression of stable (or changing) values and preferences (Dresser 2018), or in embodied selfhood and pre-reflective intentionality (Kontos 2005). The interest to be taken as a someone—a someone who cares, who matters and who can act based in some measure on subjective psychological motivations—is a vital form of human agency that must not be hastily or prejudicially denied to a person or group of people (Kitwood 1997; Jaworska 1999). This interest can remain robust despite the severe cognitive and communicative impairments that the later stages of dementia brings with them (Fazio and Mitchell 2009; Davis, Maclagan, and Cook 2013).

To discount the agency of someone simply because of a dementia diagnosis is obviously misguided, as would be the attribution of agency to a comatose person. The question then becomes whether any absolute cut-offs exist for agency in respect to one's participation in shared epistemic activities, especially where matters concerning one's own well-being are on the table.

That said, my intention in this paper is not to directly engage with debates surrounding the nature of agency or personhood in dementia. My aim is rather to present and defend the case that epistemic arrogance regularly occurs in relation to what it is like to live with dementia and that this epistemic vice brings pernicious epistemic and moral effects with it. The next section will develop these claims further—first, by exploring three fictional scenarios where, I will argue, epistemic arrogance impedes respectful and receptive communication with someone living with dementia.

The Case of Jack and Jill: "Remember Who You Were"

Let's imagine the following case:

Jack has moderate-stage frontotemporal dementia. He can still handle activities of daily living such as bathing and dressing himself on his own, but has difficulty speaking, sustaining a train of thought and recalling his personal history. Jill cares deeply for her brother Jack and visits him twice a week. She sees it as her special duty to try to remind Jack of his life prior to dementia: his career achievements, his hobbies and his values. She does this by setting photo albums in his lap, talking about her memories of him, and bringing materials that relate to his hobbies. Jack is often confused by these interventions and on occasion becomes visibly irritated. Jill in turn becomes frustrated by Jack's behavior and sometimes storms off angry or in tears, which further upsets Jack. At those times, Jill wonders: Why won't he at least *try*?

This fictional vignette bears careful analysis, given that most of us will at some time find ourselves in Jill or Jack's position—sharing a familial bond and a bond of love with someone living with dementia. To begin, Jill *thinks* she knows that what is best for Jack, and indeed what Jack himself wants—or should want, or would want, if he could—is to stay connected to his biographical self prior to dementia-related impairments, to remain identifiable to his family and friends as the same person. What Jill can't know, but also doesn't seem to be thinking about, is what it is like to be Jack now. Jill is frustrated by her perception that Jack isn't trying. Not trying to do what? we can ask. Trying to recall who he was in earlier times? Trying to please Jill, who cares for him? Trying to "get better" at the cognitive tasks he's progressively in-

ept at? The open-endedness of Jill's question: Why won't he at least try? does not seem exaggerated or untrue to real life expressions of frustration toward people living with dementia. It reveals a form of epistemic arrogance in which the question-asker is comfortable launching an ambiguous critique of a person's failure to achieve supposedly appropriate epistemic goals, revealing a problematic "know-it-all" or "knows-best" attitude on the critic's part.

In this case, it is precisely Jill's confidence in or loyalty to what she thinks she knows, but doesn't really, that impedes her from grasping the limits of her receptive awareness of present-Jack's interests concerning his own well-being, which may have shifted from earlier times. Notions of "staying true to who he was," "pleasing Jill" or even "maintaining" may or may not now bear meaning to his every day, possibly even to his overall sense of contentment. Exploring this scenario in light of an occurrence of epistemic arrogance on Jill's part helps explain and situate the siblings' mutual frustration when Jack demonstrates confusion at Jill's promptings. It also reveals that a person may be epistemically arrogant without being arrogant in the more conventional use of the term—Jill isn't acting haughtily or self-importantly in this scenario, rather the opposite: she cares deeply about Jack's well-being and wants to be at his service. Yet her choices reflect set beliefs concerning what that service must amount to and may be sourced in what Jack asked of her in the past or what a clinician or social worker advised her to do.⁶ To the extent that such practices prioritize a version of Jack that no longer exists, at the expense of being receptive to new facets of Jack's personality and preferences, they allow Jill's set beliefs about what it is like to live with dementia to dictate the way she interacts with Jack in the present, which in effect may hinder the siblings from coming together to have constructive, even joyful, new experiences together, which is one of the true tragedies of the situation.

This first case reveals the importance of qualitative research and accounts offered by people living with dementia in respect to their experiences and valuings, since these establish evidence of the diversity of knowledge, interests and experiences of those living with dementia (cf. Reed and Bluethmann 2008; Nowell, Thornton, and Simpson 2013; Bryden 2016; Reed, Carson, and Gibb 2017; Saunders 2017; Mitchell 2018). Walsh (2020) argues that dementia may well be a transformative experience in the sense developed by Paul—an experience that can "teach us things we cannot know about from any other source but the experience itself" (2016, 3). Walsh proposes that dementia can be thought of as a *cognitive transformative experience*, which she defines as an experience "which alters a person's cognitive capacities in such a way that may change the way the person thinks about their preferences, values and lifestyle" (2020, 59). Walsh is in part responding to accounts such as offered by

⁶Lifebooks, or life story books, and other practices surrounding the collection of stories and artifacts from someone's past continue to be a commonly endorsed therapeutic intervention in narrative gerontology (Randall et al 2011).

Dworkin (1993), who argues that precedent values and preferences should generally trump any presently emerging interests and values of the person with dementia. As Walsh notes, this argument relies on a generalization regarding what life with dementia is like, that one is untethered from a past and a future, incapable of sustaining critical interests or projects. To generalize in this way about what it is like to live with dementia is problematic, for one thing, because it doesn't track with empirical reality: cognitive impairments brought on by dementia range greatly in terms of onset time and severity (Alzheimer's Association 2021). But if Walsh is right, it is also problematic because it de-legitimizes and discounts the very essence of what it means to undergo the cognitive transformative experience of dementia. This experience places one in an epistemically privileged position in relation to knowing what it is like to live with dementia, a position that it is not possible to inhabit from the outside. Preference changes that occur after onset of dementia symptoms may reflect the result of undergoing that transformative experience or they may be the result of a degradation of one's capacities and thus one's epistemic credibility. If we concede this fundamental ambiguity, then, as Walsh concludes, those who stand outside the experience of dementia lack epistemic access to relevant knowledge and "we ought to take seriously the preference changes a dementia patient experiences throughout the course of their illness and give them due moral weight" (2020, 58).

Thinking about Jack and Jill through the lens of transformative experience offers another read on the value of their ongoing relationship: to be a sister (or daughter, son, etc.) to someone with dementia can also lead to a transformative experience of one's sisterhood (or daughterhood, sonhood, etc.). But epistemic arrogance in relation to what it is like to live with dementia will impede that experience and reinforce a constrained and mutually frustrating model of relationship. It is worth noting in this context that the "memory work" that Jill attempts with her brother Jack in the fictional case above is not just about or for Jack—it is an important act of re-affirming his selfhood for Jill. As Margalit contends, memory work is about the creation and maintenance of "shared memory . . . is the cement that holds thick relations together" (2002, 7). Relationship-centered alternatives to memory work do exist, though; some build on the bonding power of spontaneous and joy-focused creative encounter (cf. Strauss 2002; Basting 2020; Holzman, Fridley, and Massad 2021). It is possible to sustain and even deepen social bonds without relying on the rehearsal of biographical details.

The Case of Peter, Paul and Mary: "It's for His Own Good"

Let's now move to the second fictional case:

Peter has late-stage Alzheimer's disease. He has lost the ability to speak intelligibly, and he can no longer dress, walk, eat, or handle matters of

personal hygiene without assistance. Paul works as a Personal Support Worker (PSW) in the long term care facility where Peter now lives. Having experienced Peter become very agitated on numerous occasions when other residents move past his open door—to the point where it seems Peter might fall out of his wheelchair and risk physical harm—Paul decides to start closing Peter’s door or keeping it only slightly ajar, and advises his co-workers to do the same. One of them, Mary, speaks up against this intervention, arguing that this closes Peter off from contact with other people even more than he already is, effectively placing him in a situation not wholly unlike solitary confinement. Who would want *that* for themselves? she asks.

Let us imagine that Peter, prior to this time, set no advance directive in place in respect to this kind of scenario. Co-workers Paul and Mary both apparently stake claims on behalf of Peter’s best interests, claims that are based on behavioral observation, policy directives and general sentiment but not direct communicative interaction with Peter. Let us imagine that Paul’s stake is grounded in concern for Peter’s physical safety more than his psychological well-being, and Mary’s in Peter’s emotional or psychological well-being more than his physical safety. Paul thinks he knows it’s in Peter’s best interest to sit behind a closed door rather than an open one, while Mary thinks it’s in his best interest to maintain as much contact with other people as his limited capabilities permit him to. Since promoting the physical safety and psychological well-being of a resident are both prime directives of all competent institutionalized care-giving, it is hard to know whose “best interests” claim should win the day in a scenario where they conflict.

As suggested by the scenario, determining what is best for someone living with later-stage dementia, when conflicting best interests claims crop up and no precedent wishes have been recorded, is no simple matter. The vagueness of the best interests standard does not shield decision-makers from epistemic arrogance and might even encourage its adoption as a way to pre-weight certain options, making decision-making easier in care scenarios where time and focus are pressured. Presumably, both Paul and Mary propose their solutions because they *think* they know what Peter wants for himself or what anyone would want were they in Peter’s situation. They may also simply be following a professional mandate to offer responsible care to residents. Regardless, neither Paul nor Mary interacts with Peter directly in the hypothetical scenario, making no effort to gauge Peter’s own knowledge and interests in the matter of an open door policy to his room. In other words, what Paul and Mary *don’t know and don’t think to find out* is whether Peter wants a say in the matter, how he might express this and what that say might be. To be sure, Peter may no longer be capable of making any of these things intelligible to Mary and Paul, and he may have

no interest in the matter either way. Then again, he may still be capable of expressing a preference, especially if the care workers competently employ an array of communicative strategies to give Peter opportunity to express his motives and interests in the matter.

Person-centered approaches to dementia care are naturally a step in the right direction, to the extent that they prioritize communication and relationship over the medical and behavioral management of dementia (cf. Kitwood 1993; Nolan 2001; Brooker 2003, 215). Even someone living with late-stage dementia can retain some capacity to express themselves in meaningful ways, that is, by communicating an intention through non-verbal communication, such as bodily re-positioning, facial expression, gesture and vocalized emotion (Davis, Maclagan, and Cook 2013; Strøm, Šaltyté Benth, and Engedal 2018). They may also notice when their social cues are ignored and respond with frustration (Walmsley and McCormack 2017). Speech is not the only communicative form that allows for sharing meaning across multiple conversants. As Frantik argues, equating speech capacity with thought capacity “risks implying that people with dementia who are unable to speak cannot do any thinking at all” (2021, 21). Being receptive and responsive to other kinds of communicative signals “can enable a more comprehensive understanding of the grounds for various claims” (ibid, 27), can be used as resources for participants to work together to construct meaning (Lindholm 2014), can improve shared decision-making in care contexts (Miller, Whitlatch, and Lyons 2016), and can inject a deeper sense of communion and shared concern into the interpersonal context (Clifford 2012). Insofar as Paul and Mary permit their assumed knowledge of Peter’s preferences and interests to exclusively guide their care decision, perhaps folded in with ambiguous “best-interests” policies, they seem pre-emptively trapped by epistemic arrogance.

The Case of Present and Future Alice: “I Don’t Want My Life to End that Way”

Here is a third fictional case, which in some respects is quite different from the first two: Alice is in her thirties and experienced her grandmother struggle with Parkinson’s and Lewy body dementia. She decides to take action against her family ever having to experience her decline in such a fashion, and also wants to spare them the burden of taking care of her at such a time. Alice drafts an advance directive that states: “I do not wish to live to a point I find to be demeaning and undignified, nor do I wish to become a burden to my loved ones. Should I ever reach a point at which I can no longer read, write, or speak intelligibly, I hereby not only authorize, but I require of my proxy that any and all life-sustaining medical interventions be rejected on my behalf, including, but not limited to,

antibiotics to treat infections, blood pressure medications, insulin to combat diabetes, and nourishment via hand- or tube-feeding.” After all, Alice thinks, life without the ability to communicate is bound to be a waking nightmare, an intolerable indignity. She would never want *that* for herself!

This third fictional scenario aims to show how epistemic arrogance can readily occur in situations involving only one person, namely oneself, as it can in cases involving two (as in Jack and Jill’s case) or more than two (as in the Peter, Paul and Mary case). Though I can legitimately refer to both my present existing self and my future not-yet-existing self using the pronoun “I,” we remain two distinct selves for practical intents and purposes, in at least two senses: they can’t exist simultaneously, nor can they exist in the same way, materially or experientially. It is plausible to claim, then, that my present self can cause moral harm to my future self *qua* “other” self, insofar as my present self, being charged with and invested in tending to the well-being of my future self, discounts or fails to be sensitive to that future self’s possible interests and perspective. Recalling the argument of Walsh (2020), this point is even more relevant given the possibility of cognitive transformative experience.

Given this, despite initially seeming quite distinct of the other two cases, Alice’s case offers a scenario in which one self (Alice’s present self) thinks she knows what’s best for another self (Alice’s future self)—the epistemic failing being that Alice has her present self’s interests in mind (as well as what she guesses her family would prefer) and not what relevant knowledge and perspective she may be missing. The injustice in this case is caused by present-Alice’s allowing her interests and knowledge to straightforwardly (that is, with self-authorizing weight) overrule a future self with dementia’s say in matters concerning well-being. Regardless of how much Alice *thinks* she knows about what it’s like to live with progressive dementia based on her second-hand experience with her grandmother, what she fails to acknowledge is that she *cannot possibly know* what it would be like for her future self to live with progressive dementia, in an unknown future care-context. Were she to acknowledge this epistemic deficiency and access problem, she might then search out ways to enrich her conception of what it might be like to live with such cognitive changes—or, as Walsh (2020, 63) suggests, be more careful about the advance directive she writes—instead of adopting a rigid vision constructed on the basis of limited experience.

Recall that the moral justification Alice offers in support of her directive is that, in her present view, to live post-verbally would be an intolerable indignity. To envision such a life—an aphasic life, particularly—as undignified, just “a waking nightmare,” is short-sighted, revealing more about Alice’s ableist and “hypercognitivist” assumptions (cf. Post 2000) than about what it is or can be like to live with aphasia, particularly in a person-centered and aphasia-friendly community (Alzheimer’s Disease International 2016). Granted, it is not possible to conclusively know what one’s

future self will want; the point remains that epistemic humility, not arrogance, is called for in the face of such ignorance. Alice's unchecked confidence in her present judgment leads to an action that will have a potentially harmful effect on her future self's epistemic status as a credible knower and self with interests, which in turn may affect her well-being. Instead of protecting her loved ones in the future, her advance directive may cause them additional pain and struggle having to reconcile a rigid legal directive with what they credit as future-Alice's expressed knowledge preferences and interests (Walsh 2020, 56).

Most worrisome is what Alice's epistemic arrogance leads her to decide, practically speaking, about ending the life of her future self living with dementia: when future-Alice can no longer read, write or talk intelligibly, life-sustaining care-interventions are to be stopped. In the fictionalized advance directive, there is no clause added to the effect that "These directions are to be followed, regardless of what I may at that time express in terms of preferences." Rather, the weight of precedent autonomy is taken to make such a clause meddlesome.

This omission doesn't seem far-off from real cases of advance directives being written without any reference to the interests or experiences of the future self with dementia. An example of this was shared by Cantor (2018), who argues that his wish to have life-sustaining treatment withheld from his possible future self with dementia should be legally respected. He shares an extract from his own advance directive, which reads:

I have witnessed the ravages that Alzheimer's disease and similar progressive dementias produce. I wish to be allowed to die upon reaching a degree of permanent mental dysfunction that I deem to be intolerably demeaning. For me, this means mental deterioration to a point when I can no longer read and understand written material such as a newspaper or financial records such as a checkbook. (ibid, 16)

In Alice's case, and perhaps in Cantor's, the problem concerns what epistemic arrogance hinders imagining: that one's future self may well have interests to keep living beyond the point at which specific impairments become manifest, and that these possible interests deserve sensitive consideration and factoring into one's present decisions concerning the care of one's future self, to the extent it's possible to do so. Such consideration may reveal valuable alternative conceptions of worthwhile experience and valuing. In the fictional case, Alice overlooks the rather obvious truth that verbal communication is only one form of interpersonal communication—and not even the most emotionally powerful form. Holding eye contact with a loved one, sharing a laugh with a friend, or using one's body's other expressive capacities to convey messages are other satisfying ways to "speak" with another, feel

close, and share meaning. Taylor (2008), Mehuron (2018), and Nilsson, Ekström, and Majlesi (2018), offer fascinating, detailed, and personal accounts of the interactive and vital relationships that evolved between their respective loved ones with dementia and themselves. Chronicles such as these reveal the ways in which persons living with even later-stage dementia may keep intact certain communicative conventions, such as pairing facial expressions with voice pitch modulations that express certain emotional states, even after becoming aphasic. Even with these communicative channels, there is still room for humor and enjoyed shared experiences (Person and Hansen 2015). These are valuable sources of communion.

All things considered, the advance directives drafted by Alice and Cantor send potentially legally binding missives into the future that impede a future proxy, caregiver or medical professional to pay attention to these sorts of considerations. These are cases of epistemic arrogance that enable the potential moral harming of vulnerable persons, even if those persons do not yet exist.

Summary Analysis of the Cases

I contend that the situations examined in the previous section, diverse as they are, all involve instances of epistemic arrogance that enable the moral harming of someone living with dementia. In all cases, someone's well-being is affected by another who makes choices based on what they think they know about what it is like to live with dementia and what someone in that state can or should want, rather than perceiving the situation in an epistemically humble way that would foreground the potential for interpersonal communication and knowledge sharing.

What's more, none of the decision-makers in the story attempt to consult the respective person living with dementia as to their present interests. It's true that in Alice's case this is not practically possible, since her future self with dementia does not yet (and may never) exist. However, present Alice makes decisions about future Alice's quality of life that exclude countervailing considerations—for instance that a life with aphasia can have dignity and be enjoyed, future-Alice may want to live beyond the loss of her writing and speaking abilities, or that she could conceivably find contentment in life, even in its post-verbal stage. In this sense, present-Alice, like the other fictional care-givers and proxies, prematurely discounts or discredits possible divergent yet relevant perspectives and knowledge. The moral damage caused, in reference back to Tanesini's distinction, is that each disrespects someone living with dementia, or life with dementia more broadly, by prejudicially discounting the latter's capacity to participate meaningfully in shared epistemic activities, or to count as a legitimate stakeholder or agent with views and interests in the first place.

Epistemic arrogance may be a regular factor in relation to perceptions of dementia that leads to the wrongful ignoring or discounting someone's interests and

preferences. To lessen its frequency, we must become aware of it and explore ways to weaken its impact in dementia care, policy and wider social contexts. What possible “de-arrogating strategies” are there? The next section turns to this question and offers initial suggestions.

4. Toward Epistemic Humility

If epistemic arrogance is the vice being critiqued, epistemic humility is the corresponding virtue we ought to embrace to correct vicious epistemic dispositions. What practices could disrupt the vice and foreground the virtue in question? I will suggest a few, grouped as *interpersonal* and *systemic* strategies respectively. At the interpersonal level, epistemic arrogance impedes communicative receptivity and relational awareness, so countering strategies should presumably aim to encourage these attitudes. At the societal or systemic level, epistemic arrogance reinforces biomedical reductionism or the tragedy narrative, a de-humanizing perspective that reduces someone with dementia to their diagnosis—deeming someone “lost,” even while they’re still alive (Reed, Carson, and Gibb 2017). Hence, countering strategies should presumably aim to champion alternative, (re)humanizing practices and narratives about life with dementia.

Interpersonal Strategies

Care-givers and proxies tend to know less than they could about the values and interests of those they care for (Arons et al. 2012), while healthcare discourse tends to focus more on the neurological aspects of dementia than its lived experience, which is how people with dementia tend to primarily know it (Petty et al. 2016). Paying attention to or learning more about the life story and earlier preferences of someone with dementia can create openings for interpreting expressions and behaviors in newly meaningful ways, as can attention paid to their present conditions and preferences. Dwelling in an attentive interpersonal space can keep de-personalizing or stereotyping impulses at bay, as Mehuron (2018) puts it, by creating “intersubjective freedom.” This sensed freedom is characterized by neither party being reduced to a static set of expectations by the other.

A related interpersonal strategy involves paying attention to our communicative strategies and expanding them as appropriate. This can include co-developing new linguistic codes to express and share thoughts and feelings, which take into account lexical and mnemonic impairments (Walmsley and McCormack 2014). This strategy can also mean noticing and being responsive to non-verbal cues that may signal interpersonal communicative intent. Acknowledging and responding to such cues can have an immediate enriching effect on an interaction between people. As Frantík (2021, 32) notes, “Paying close attention to these sometimes very sub-

the communicative expressions can also encourage people with dementia to express themselves through the means of communication available to them.” In other words, expanding interpersonal communicative strategies may even empower someone with a severe speech deficit to make the first move, as it were, to open a conversation with the expectation that it can lead to meaningful exchange. Sensing an increased co-ownership of the conversation in turn may help inoculate against prejudicially assuming credibility deficits on the part of an interlocutor with dementia impairments. The threat of testimonial injustice is, as Kidd and Carel remind us, two-fold: the wrongfully discredited person experiences themselves as disrespected and may lose confidence in themselves as a credible participant, with the result being that, “a person or group suffering from such a situation will not expect what they say to be heard, and in time might not speak at all, as the constant assaults upon their testimonial practices gradually undermines their epistemic and social confidence” (2017, 177). In the case of dementia, this effect may be compounded by progressively severe cognitive impairment.

A third less well-researched and documented interpersonal strategy to disrupt epistemic arrogance in relation to dementia involves using augmented reality (AR) or virtual reality (VR) to stimulate interest and increase understanding among people without dementia in what it might be like to live with the condition. A growing number of virtual and augmented reality programs are being introduced as empathy and awareness-building tools for caregivers and health professionals, as well as the general public. These include *A Walk Through Dementia* (Alzheimer’s Research UK n.d.), the Dima and Beatriz Labs (Embodied Labs 2022), and the Virtual Dementia Tour (Second Wind Dreams n.d.). While there are limitations to what VR and AR can do to accurately or thoroughly reflect what it is like to live with dementia, when done thoughtfully such programs may allow someone to learn what it might be like to experience specific symptoms, or specific social stigma, associated with one or more stages or types of dementia. For instance, the experience of disorientation and feeling scattered when trying to complete a “simple” task such as recalling a list of items can be artificially induced in an AR environment that deploys sensory overstimulation and interference. Alternatively, a VR environment can be designed that invites the user to inhabit a scene from the first person point of view that elicits the feeling of frustration at being infantilized by the virtual protagonists in the story. As these technologies and approaches proliferate, philosophers of disability and bioethicists will undoubtedly pitch in to help define moral and epistemic parameters for such sensitization approaches.

Systemic Strategies

Epistemic arrogance is a prejudicial vice immanently expressed by an individual towards another, but it can be fed by laws, policies, methods and assumptions that structure or govern entire social systems, such as healthcare and news and social media. For instance, biomedical reductionism is prevalent in American healthcare practice and, as Kidd and Carel (2017, 178) emphasize, is supported by structural features such as time pressure, the routinization of tasks, and shift work. The claim is not that biomedical diagnosis, prognosis and treatment protocols aren't immensely effective in curing illness and prescribing appropriate therapies. It is rather that those protocols tend to overshadow sensitivity to the complexity of human perspective and feeling, if and when medical expertise involves little to no educational or institutional encouragement to practice medicine in relation to the whole human being. As implicitly defended earlier in the paper, the human sense of well-being is tied not only to the state of our physical bodies, but also to our sense of being treated respectfully, being sincerely listened to, and having interpersonal outlets for expressing difficult emotions and thoughts, for instance.

Accordingly, systemic strategies for mitigating occurrences or effects of epistemic arrogance should aim at humanizing the experience of living with dementia. Several such strategies come to mind, though they may be very difficult to implement. For one thing, the default task- or outcomes-organized nature of medical practice could be shifted to one which more strongly supports processes of relationship-building between healthcare providers and their patients. In the case of dementia support, this shift could affect not only what practical and clinical outcomes are encouraged but also the wider social perceptions of what it means to be living with dementia. For instance, in a 1984 study (Beckman and Frenkel 1984) mentioned by Kidd and Carel (2017), an average of 18 seconds was measured between when a patient begins to speak and when they were interrupted by their doctor. This statistic can be explained by the fact that the doctor-patient relationship in mainstream American healthcare is fraught with competing conceptions of what information counts as relevant in a conversation about health and well-being (Kidd and Carel 2017). Doctors grow impatient with what they view as medically irrelevant reporting from patients, while patients feel they are not being listened to by their doctors, resulting in "a difficult epistemic situation [. . .] in which neither group can engage in effective testimonial and hermeneutical relations with the other" (ibid, 173). People living with dementia in our society are especially vulnerable to these forms of silencing. A strongly relational model of care could help unsettle the socially dominant perception that life with dementia is life as a permanently medicalized subject with no epistemic credibility, since this model frontloads patient

credibility and authority (Nolan, Keady, and Aveyard 2001; Greenwood, Loewenthal, and Rose 2002; Dupuis et al. 2012).

A second potential strategy to lessen the systemic reinforcement of epistemic arrogance in relation to what it is like to live with dementia involves a discursive change that disrupts the monopoly of the “panic-blame” and “tragedy” narratives that continue to dominate in news reporting and social media posts about dementia (Van Gorp and Vervuyse 2012; Peel 2014; Nair and Dubjevic 2021). These simplistic narratives both create and sustain the stigma associated with dementia (Batsch and Mittelman 2012). Devlin, MacAskill, and Stead (2007) propose guidelines for media campaigns that counter those negative, simplistic narratives, including using consumer research methods such as running focus groups to determine what prevalent perceptions about dementia exist in a given population and what its consequent informational needs are. The most effective awareness-raising campaigns will likely be mounted by advocacy groups by, for and with people living with dementia, an argument supported the advocacy work represented in Bryden (2016) and community coalitions and grassroots movements, such as the Dementia Action Alliance (daanow.org), Momentia (www.momentiasattle.org), and Reimaging Dementia: A Creative Coalition for Justice (Kontos et al. 2021). These efforts can not only inform and enrich the public imagination of what life with dementia is (or could be) like, they can also open up new visions of life with dementia beyond “patienthood” (biomedicine) or “clienthood” (social psychology), pushing for what Bartlett and O’Connor call *social citizenship* for people living with dementia. This they define as:

a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (Bartlett and O’Connor 2010, 37)

The interpersonal and systemic possibilities sketched out above are united by a fundamental purpose: to counter the prejudice that dementia is a “fringe experience” that stands opposed to and outside of “normal” life and that unequivocally repositions a person’s subjecthood and agency into a compromised and marginalized state, which calls for no particular adaptive epistemic response from those living “normal” lives. One may have cause to speak in such generalizations, but the critical lens employed in this paper should be kept in mind to ensure such views are not encouraging the prejudices that support epistemic arrogance.

5. Considering Skeptical Challenges

This paper has aimed to shed light on an underthematized phenomenon in the dementia-care literature that is well worth critical attention. Readers will be skeptical of the value of this project, however, if they hold either of the following assumptions regarding people living with dementia, particularly in its later stages: (1) Such persons no longer have interests regarding their own well-being, or (2) such persons may well have interests regarding their own well-being, but they are not rational interests and thus need not be taken seriously. I will briefly respond to each objection.

Regarding the first, in my view such a generalization is easily tempered by self-reports and interviews from people living with various stages of dementia that adamantly report the contrary. As has been explored in this paper, people without dementia tend to underestimate the degree to which people with dementia can or do still have interests and care about their well-being, in part because of the tragedy discourse that surrounds dementia, feeding the simplistic view that dementia robs people of access to their authentic selves and interests, deadens them to new experience, and ultimately makes them into zombie-like beings that are neither dead nor fully alive. Qualitative research countering the tragedy narrative suggests, however, that people living with dementia adapt better to their changing cognitive circumstances than often imagined by people without dementia (Kitwood and Bredin 1992; Reed and Bluethmann 2008). This finding correlates with “disability paradox” research that reveals a strong variance between how abled people rate the expected quality of life of disabled people and how people living with disabilities rate their own quality of life (Albrecht and Devlieger 1999; Ubel et al. 2005). In the case of dementia, a narrative less defined by the tragedy discourse should allow for a broader appreciation of the ways that life with dementia, even in later stages, can be a life directed by interests and knowledge.

The second skeptical concern is that people particularly with later-stage forms of dementia may well still have interests, but they are not rational interests and thus need not be taken seriously into account. It is worth recalling points made earlier regarding what distinguishes appropriate from inappropriate intellect-discounting of someone’s ability to contribute meaningfully to shared epistemic activities. Though decision-making capacity and competence decrease as dementia progresses into later stages, whether or not someone’s expressed interests are *rational* remains a live question throughout that calls for sustaining a permanently receptive stance, rather than a prejudicial and premature discounting of someone’s responsiveness to reasons or the intelligibility of their intentions. Obviously, what counts as “rational” will depend on the particular account adopted, and these vary in degree of stringency. To count an interest as “rational” may involve as little as holding in mind a reason or motive for doing or wanting *X* instead of *Y*, or it may involve having

“good” reasons for doing or wanting *X* instead of *Y*, where good-making criteria will be contextually, intersubjectively or even objectively derived. That said, as long as one doesn’t insist on a definition of rationality that bars all but the most cognitively nimble and verbally articulate human beings from participation in rational activity, earlier points regarding epistemic arrogance seem to stand: Epistemic arrogance is an epistemic failing insofar as it prematurely and pre-emptively presents a limited picture of life with dementia as the full picture, and fails to consider the knowledge and interests of people living with dementia as epistemically relevant to improving the accuracy of that picture. Morally speaking, epistemic arrogance can lead to unfairly silencing or ignoring those living with dementia and barring them from participating in decision-making or social discourse, which in turn may lead to their feeling devalued, disrespected and marginalized.

6. Conclusion

Violations of the moral rule considered in this paper—that it is wrong for someone charged to see to the well-being of another to ignore or be insensitive to that person’s views and interests regarding their own well-being—are more likely to occur in contexts of dementia care-giving if little attempt is made to understand the views and interests of the person living with dementia. Hence, careful attention should be paid to lessening, dismantling or finding ways around the obstacles that hinder the fulfillment of fair epistemic and moral standards in relation to people living with dementia.

This initial exploration of epistemic arrogance within the context of dementia suggests that it makes it easier to ignore or discount the views and interests of someone living with dementia in ways that are epistemically unjust and morally harmful. My aim has not been to argue against the fact that progressive dementia has eroding effects on a person’s epistemic reliability, autonomy and decision-making capacity or competence. Instead, I’ve argued here that epistemic arrogance in relation to living with dementia may arise in a variety of social contexts and can impede treating people with dementia with appropriate respect and with a sustained sensitivity to their expressions of knowledge and interests. The task of eliminating epistemic arrogance in these contexts seems daunting, given the deep social stigma linked with dementia, the functional communicative and cognitive challenges that may come with dementia onset, and a healthcare system that continues to privilege a neuropathological reading of what it means to live with dementia. I have suggested some interpersonal and systemic “de-arrogating” strategies that could help bring about a future where these factors form less of an obstacle to caring with and for those living with dementia.

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