



ARTICLE

A Case for Caregiver Testimony about the Cognitively Disabled

Sara Chan

University of Notre Dame, Notre Dame, IN, USA

Email: yychansara@gmail.com

(Received 13 August 2024; revised 26 November 2024; accepted 30 November 2024)

Abstract

It is common for caregivers of the cognitively disabled to speak on behalf of their charges who cannot speak for themselves. Their testimony, however, is often dismissed either because of doubt about their having relevant expertise or because of worries that they are blinded by love. This paper is positioned against such dismissals. I argue that good caregivers are uniquely positioned to offer reliable and often insightful testimony about the well-being of their charges and so ought to be taken more seriously. I argue first for the reliability of caregiver testimony via a phenomenological account, which reveals that accuracy is constitutive of good caregiving. I then argue further that caregiver testimony can be especially insightful because the love that is characteristic of good caregiving may be semi-transformative, facilitating insight into cognitively disabled lives in a way that cannot be achieved through more detached forms of engagement.

Keywords: Caregiver; testimony; cognitive disability; love; transformative

‘Nothing about us without us’. Thus goes one of the favourite slogans of the Disability Rights movement. It reflects a desire of disabled people to be included in decisions and evaluations made about themselves and their lives. More concretely, it is often heard in the context of disabled people who are frustrated at others judging their condition to be unfortunate or the quality of their lives to be lesser than that of abled people. These worries are especially acute because the distribution of healthcare resources is often informed by quality-of-life assessments.¹ Accordingly, the assumption that disability diminishes well-being has significant practical consequences in that a disabled individual is less likely to be prioritised for limited resources. Hence, the Disability Rights movement’s push for greater inclusion and the chance to advocate for themselves.

But not everyone is able to speak for themselves. In particular, some people with severe cognitive disabilities may be unable to communicate in words and hence unable to testify at all. Others may be able to communicate but unable to reliably advocate on their own behalf, perhaps because they lack concepts related to well-being or the ability

¹See Amundson (2005). For a defence of healthcare rationing, see Singer (2009). See also Campbell and Stramondo (2017), pp174–175.

to make reasonable decisions about their own care.² In such cases, it is common for their caregivers to speak on their behalf, and the practice is in good standing at least insofar as it aligns with the practice of having parents speak on behalf of their young children, which is standard in fields ranging from social science to medicine to law.³ Despite this, however, both empirical and anecdotal evidence suggests that there is a reluctance to accept caregiver testimony about the cognitively disabled, with many informal caregivers reporting frustration at not being taken seriously when advocating for their charge in healthcare settings. In the words of the parent of a child with severe learning disabilities,

*[I]n our experience, the professionals still operate out of a medical model, i.e., they know best and don't take parents', and indeed clients' views into account when planning services and/or interventions.*⁴

Similarly, a caregiver of an individual with dementia reports:

*[I]f you show a little bit of knowledge and stand up for the person [the charge], you immediately receive negative comments and questions: 'maybe you are a doctor, since you are asking all these questions?'*⁵

In this second quote, the caregiver identifies their 'show[ing] a little bit of knowledge' as a trigger for negative reactions. Perhaps this is because caregiving is not seen as skilled work in modern society. It is often undertaken by family members who do not have a 'real' job, who, in fact, may not be able to hold a real job because the time and effort caregiving requires is substantial. Accordingly, familial caregivers are often dependent on someone else for financial support, which tends to equate to a lower position in the capitalist social hierarchy.⁶ There are, of course, also professional caregivers, who are paid for their efforts, but even then, they tend to be poorly paid, and not particularly respected.⁷ As a result of this systematic devaluing of care and caregiving, caregivers' opinions are devalued as well. The interlocutor's sarcastic 'maybe you are a doctor' is an implicit dismissal; the subtext is that the caregiver lacks relevant expertise that would give them the right to be taken seriously.

Of course, the mere fact that dismissals of caregiver testimony are common does not itself call out for philosophical intervention. That bullying exists is regrettable, but it is a problem better addressed via practical intervention than a philosophical paper denouncing bullying. What does call out for philosophical intervention, however, is that unlike bullying, which is universally recognised to be wrong, there is not any strong

²This is not to say that every individual with a cognitive disability is unable to reliably testify on their own behalf. It is not uncommon for those with mild cognitive disabilities to report that they are happy, and it seems not implausible that such testimony might be reliable. That is, it seems the credibility deficits that cognitive disability generates shouldn't give you blanket reason to doubt everything a cognitively disabled person says – you might have reason to doubt their claims about nuclear physics, for example, but not to doubt their claims about something relatively easily understandable. And it is plausible that at least some judgements about one's own well-being are of the relatively easily understandable sort. The focus of this paper, however, is on those who are not able to speak for themselves.

³For example, see Raviv *et al.* (2021).

⁴Kenny and McGilloway (2007), p225.

⁵Kontrimiene *et al.* (2021), p7. See also Schulz and Eden (2016), *Families Caring for an Aging America*, a 2016 report by the National Academies of Sciences, which found similarly that family caregivers (in elder care more generally) are often marginalised and ignored, pp241–242.

⁶Kittay (1999), p41.

⁷Dodds (2013), p195.

sense that not taking caregiver testimony seriously is a problem – not even (or perhaps especially not) among philosophers. In fact, there may even be a sense that the attachment between the caregiver and the charge may compromise the objectivity of such testimony. Following a debate with Peter Singer and Jeff McMahan at a Stony Brook conference on cognitive disability and philosophy at which McMahan explicitly noted that he and Singer ‘engage in a fair amount of voluntary self-censorship’ in order not to hurt anybody’s feelings, Eva Kittay (herself a caregiver to her severely cognitively disabled daughter, Sessa) reports feeling frustrated:

*the discussion is hijacked, in a sense. It is turned away from the genuine point of contention to a cloaked and patronizing apology for hurting the feelings of a mother.*⁸

Instead of being treated as a source of valuable insight, Kittay’s relationship with her daughter and her experiences caring for her are treated as a potential impediment to Kittay’s ability to engage rationally with issues concerning the cognitively disabled.

This paper seeks to show that such dismissals are a loss for our collective pool of knowledge: the testimony of good caregivers ought to be taken seriously because they are in a unique position to offer reliable and often insightful testimony about the well-being of their charges and the good that is accessible to them. Section 1 begins arguing for the reliability of caregiver testimony via a close examination of what caregiving entails, which reveals that accuracy is constitutive of good caregiving. Section 2 then argues further that caregiver testimony can even be especially insightful because the love that is characteristic of good caregiving may be semi-transformative, facilitating insight into cognitively disabled lives in a way that cannot be achieved through more detached forms of engagement.

1. From a phenomenological account of caregiving to the reliability of caregiver testimony

The inquiry in this section is ‘phenomenological’ in that it involves really attending to the activity of caregiving, to its practices, its demands, and how it is experienced in order to draw out the implications for the epistemic status of caregiver testimony.⁹ In characterising caregiving, I will draw on philosophical accounts of what care is and what it should be but also personal reports describing the experiences of caregivers actually involved in the care of the cognitively disabled. With this in mind, I will examine what is implied about what the good caregiver would do and then what specifically epistemic demands care makes on the caregiver. Finally, I will discuss cases that deviate from the ideal of good caregiving and how they bear on the conversation surrounding the reliability of caregiver testimony. Ultimately, I will argue that because caregiving success requires a high level of sensitivity and accuracy with respect to how one’s charge is faring, testimony from good caregivers about the well-being of their charge can be counted on to be especially reliable.

Much of the philosophical work on the concept of care has, perhaps unsurprisingly, been in the field of care ethics, which takes as its starting point the mother–child

⁸Kittay (2009), p622. Transcript of the conference proceedings, available at https://podcast.ic.sunysb.edu/blojsom_resources/meta/phicdc/36-KITTAY%3AMcMAHAN_Q%26A.mp4.

⁹In doing so, I am following in the footsteps of Stroud (2006, pp500–503), who is in turn following Stoker (1976). Both Stoker and Stroud move from intuitions about what a good friend would do, to holding such behaviour to be constitutive of friendship, and hence to an account of the (moral or epistemic) demands that friendship makes on people who are friends.

relationship and the moral salience of caring for and meeting the needs of particular others.¹⁰ Notably, what is almost universally emphasised by theorists working on care is the equal importance of care as both an attitude and an activity – it is labour, but crucially, it is a labour of love.¹¹ The next section will return to caregiving as paradigmatically loving and how love affects the epistemic status of caregiver testimony. For now, let us focus on care as labour.

Caregiving is work that ‘enhances the power and activity of another; it is work that caters to the needs of another’.¹² In other words, to be a caregiver is to be committed to maintaining and enhancing the well-being of another, that is, to enable them to flourish. Successful caregiving minimally requires that a caregiver’s efforts do in fact sustain and benefit their charge. In order to do so, the good caregiver needs to be incredibly attuned to their charge, to discern their needs in order to then meet them. This work is hard, and it is harder the more vulnerable and dependent the charge is. The cognitively disabled may not be able to articulate or even understand their own needs, so their caregivers need to be especially vigilant. As participants in a study into the personal experiences of caregivers of dementia patients report:

*You have to listen all the time. Always be on standby.
The nights were probably the hardest.*¹³

These caregivers report the need not just for close attention but for that attention to be consistent and sustained, sometimes even through the night. This is a highly demanding level of attention that demands to be sustained even against the caregiver’s own interests (such as their need for sleep). As a result of such demandingness, Eva Kittay has even defined the idea of a transparent self, a self through whom the needs of another are discerned, as the regulative ideal of the caregiver.¹⁴ This is a self that, when it looks to gauge its own needs, sees first the needs of another. It is a self for whom the well-being and needs of that other are consistently paramount. Such a high level of attention to the well-being and needs of another is rarely, if ever, matched by a disinterested observer.

Next, apart from being highly attentive in order to discern their charge’s needs, the successful caregiver also needs to be able to accurately evaluate how to meet those needs and further promote their charge’s flourishing. In the following quote, a caregiver describes how she manages her charge’s medication:

*She [the charge] was prescribed sticking patches [for pain management]. These had some effect, but she developed spasms [. . .], so I decided to discontinue the treatment and removed the patch. Maybe there was an overlap of medicines? [. . .] later, they prescribed morphine. Once her pain had subsided, she no longer needed the morphine, so I stopped giving it to her. [. . .] for Parkinson’s [. . .] she takes two kinds of medicine – two tablets in the morning and two in the evening. On days when I notice that she is not trembling, I reduce her intake by one tablet. Then, I give her pills for dementia, for her confusion, which I cut in half [regulates the dose].*¹⁵

¹⁰Held (2006), p10.

¹¹Kittay (2001), p560. See also Held (2006), p9. Although Held speaks only of care and not of love, she too stresses that it is both an activity and an attitude.

¹²Kittay (1999), p39.

¹³Kontrimiene *et al.* (2021), p5. The need for constant vigilance from familial caregivers in general has also been noted by Schulz and Eden (2016), p82.

¹⁴Kittay (1999), p59.

¹⁵Kontrimiene *et al.* (2021), p4.

This caregiver's attention is characterised by active watchfulness, evaluation, and calibration. She does not merely passively follow the doctor's prescription; she is actively tracking how it affects her charge from day to day and evaluating how the various medications should be adjusted accordingly. Her actions are based on an intimate knowledge of how her own particular charge is faring, rather than abstract generalisations of how much of a dose is typically recommended. In doing so, she demonstrates the space for a domain of knowledge distinct from medical expertise. This is knowledge about her charge specifically from the day to day and how different interventions suit or do not suit her. In other words, it is knowledge pertinent to understanding her charge's well-being in particular and how that well-being is affected by different factors. This is not medical knowledge. Although caregivers may accrue some medical knowledge and self-report highly valuing input from medical professionals, caregiving does not magically confer medical expertise.¹⁶ The point is that caregivers bring something unique to the table, knowledge that is complementary to medical expertise, rather than a rival to it.

Here concludes our phenomenological account of caregiving. Notice that many of the skills that are constitutive of good caregiving – sensitivity, attentiveness, and consistent observation – are epistemic skills conducing to accuracy with respect to how their charge is faring. This is precisely because accurate knowledge in this domain is necessary for reliably successful caregiving. Being optimistically deluded about the well-being of one's charge is detrimental to caregiving. A caregiver who mistakenly thinks that their charge is doing well, when they in fact are not, will not be in a position to carry out appropriate interventions. The charge of such a caregiver will very likely further deteriorate to the point where the deterioration cannot be denied even by the most optimistic.

What this implies is that knowing that a caregiver is succeeding at caregiving should reassure us that their assessment of their charge's well-being is not outrageously divorced from reality. This in turn provides a kind of safeguard against false beliefs, thus making caregiver assessments more likely to be accurate than the average person's opinion, which has no such safeguard.

Of course, reliable testimony requires not just accuracy of belief but also sincerity in reporting, and nothing about the nature of caregiving guarantees the latter. In fact, since the well-being of one's charge reflects on one's ability as a caregiver, one might worry that a caregiver might deliberately inflate reports of their charge's well-being in order to boost others' esteem of their abilities. In response to this cynical worry, I would point out that in many other contexts, we often trust people's reports even when they stand to gain from them. That is, we do not think that someone's having an interest in something automatically disqualifies their testimony as a source of information. For example, we are not automatically suspicious of parents' positive reports of their (non-cognitively disabled) children, even though the interest they have in their child is similar to that a caregiver has in their charge. If such practices are in good standing, it seems plausible to hold that trust in others' sincerity is warranted, even when they have a (non-epistemic) interest in their testimony being believed – as long as one does not have evidence that they are, in fact, unscrupulous and willing to compromise on epistemic integrity for the sake of achieving that interest. And since there does not seem to be any reason to think that caregivers are more unscrupulous than the general population, their increased accuracy should translate to more reliable testimony.

Up till this point, we have been focusing on a particular kind of caregiving, namely, good caregiving, and it is obviously possible for caregiving to deviate from this mould.

¹⁶Kontrimiene *et al.* (2021), p5.

The remainder of this section will discuss how the existence of poor caregiving bears on the argument for the reliability of caregiver testimony.

First, consider the less-than-competent caregiver. Many people in caregiver roles find themselves thrust suddenly into those roles without formal training and report bewilderment and worry that they might be doing something wrong.¹⁷ Additionally, as has been stressed multiple times already, caregiving is hard, and caring for the cognitively disabled is perhaps especially so. It is therefore entirely possible that many who find themselves in the role of caregiver lack the requisite knowledge and skills and surely one ought not to treat a caregiver's testimony as reliable when they themselves are doubtful and unsure of it.

As a matter of fact, although caregivers do express worries about the deficiencies in their caregiving skills, they also report increasing understanding of the care process as they gain more experience in caregiving, so bewilderment and unsurety tend to decrease over time.¹⁸ Perhaps more worrying than the case of the less-than-competent caregiver (who often grows more competent fairly quickly) are the cases of the unmotivated, or even ill-motivated, caregiver. Unfortunately, because of how demanding caregiving is, it is not uncommon for caregivers to feel as if their own lives and careers have been sacrificed to maintain their caregiving role, leading to feelings of social isolation and resentment.¹⁹ These negative feelings may cause a caregiver not to be as attentive or proactive as they ideally might be or even drive them to abuse. Indeed, despite caregiver abuse being both understudied and underreported even when studied, the rate of abuse among those caring for individuals with dementia has been reported to be as high as 11.9%.²⁰ In such a context, one might think, it is reasonable to be at least somewhat suspicious of caregiver testimony – being a caregiver is no guarantee of attentiveness or goodwill, which in turn undermines caregiving's link with reliability.

I accept this. The claim of this paper is not that every caregiver's testimony is always reliable: not every caregiver is a good caregiver, and even good caregivers are not infallible. Rather, the claim is that to the extent that one is a good caregiver, one's testimony is likely to be more reliable since the epistemic skills that conduce to good caregiving also conduce to accurate knowledge about the well-being of the charge. We can recognise this just as we recognise that the existence of ill-intentioned (pseudo-) scientists does not undermine the fact that scientists who do conscientiously follow the scientific method are epistemically authoritative in their fields. Despite being consistent with the main argument from good caregiving to reliable testimony in theory, however, the case of poor caregiving poses a practical problem: one ought to trust good caregiver testimony because it is reliable, but since not all caregivers are good caregivers, one first needs to discriminate between the good and the bad. How ought one to do so? A natural thought is that one might look at how well their charge is faring, relative to medical

¹⁷Kontrimiene *et al.* (2021), p4; Schultz and Eden (2016), p90.

¹⁸Kontrimiene *et al.* (2021), p5. See also Reinhard, Levine, and Samis (2012) who found that more than 60% of familial caregivers of elders reported developing a competency in medicine management over time, p6.

¹⁹Kontrimiene *et al.* (2021), p6; Kenny and McGilloway (2007), pp223–224. Reinhard, Levine, and Samis (2012), p8. Other factors contributing to caregiver burnout include feeling like one's work is not respected and having one's attempts to advocate for their one's routinely dismissed. Of course, this does not mean we ought to believe false testimony from poor caregivers because failure to do so might add to their frustration and exacerbate the risk of abuse. It is merely to flag that in addition to the epistemic costs to our collective hermeneutical resources, there is also a moral cost to overt suspicion being the default attitude to caregiver testimony.

²⁰Kohn and Verhoek-Oftedahl (2011), p2.

expectations.²¹ But then we have a dilemma: on the one hand, if we are able to make such an assessment for ourselves, the case that caregivers are in a unique position to make such assessments seems to be undermined. On the other hand, however, if we need to rely on caregiver testimony about their charge's well-being in order to determine if they are a good caregiver, and hence to determine whether their testimony about their charge is reliable, the explanatory circle seems to be getting rather too closed.

My solution to this dilemma will take a multi-pronged approach. Ultimately, I will suggest that we will at different times have to impale ourselves on one horn or the other, but luckily, neither horn is as bad as it seems: we can make some assessments for ourselves without undermining the special position of caregivers, and even when we cannot make such assessments, there are other non-circular indicators of good caregiving we can rely on.

Let us begin with the first horn of the dilemma, which I expect will apply to a majority of cases since the average person is likely to have at least some ability to assess whether an individual with a cognitive disability is faring well or poorly. Although there is some philosophical disagreement over what elements of a good life are accessible to those with varying levels of cognitive disability, most – if not all – of the elements that make life with cognitive disability good, when they are present, are the same familiar elements (health, loving relationships, etc.) that make non-disabled lives good. Similarly, many bad-making elements (such as pain, loneliness, etc.) are recognisable from non-disabled lives as well. Accordingly, most people do not find the well-being of individuals with cognitive disability to be completely opaque. Notably, although it is common to hear people express worry about the prevalence of poor caregiving, it is not at all common to hear people worry that they cannot tell the difference between good and bad caregiving when they see it. We can often rely on our own ability to discriminate between good and bad caregivers when deciding whose testimony to take seriously.

But then how can we maintain a privileged epistemic position for caregivers? An example might help. Consider a dog with bloodshot eyes, who is lethargic, panting heavily, and throwing up everything it eats. The average person should be able to tell that this dog is not doing well. Nevertheless, this is compatible with a veterinarian being in a privileged epistemic position with respect to how bad it is, what is the likely cause, and what is likely to improve it. Similarly, the average person is often likely to be able to tell in broad brush strokes if a cognitively disabled individual is doing well, and this broad assessment is sufficient to ground assessment of whether their caregiver is competent at their job while leaving room for the privileged epistemic position of the caregiver to make assessments of the same thing in a way that is both more substantive and finer grained.

Most cases, I believe, will be of the sort we have just discussed. That is, there will be cases where the average person is able to tell (broadly) how the cognitively disabled charge is doing and hence whether their caregiver is a good caregiver whose (more detailed) testimony ought to be taken seriously. There may, however, be some cases where severe disability renders the signs of flourishing much less recognisable. Kittay, for example, describes how she can tell that her severely cognitively disabled daughter Sesha is enjoying a particular piece of music by the glint in her eye, an indication that would likely be missed by anyone not similarly devoted to her care.²² In such cases, caregiver testimony might be necessary to come to an accurate picture of how the cognitively

²¹Taking medical expectations and the predicted trajectory of a condition into account is important because in some cases (e.g. when the charge suffers from a degenerative condition), the charge may objectively worsen over time despite excellent care.

²²Kittay (2001), p568.

disabled person is faring. This brings us to the second horn of the dilemma: when we cannot reliably assess the well-being of a caregiver's charge for ourselves, is any case for their being good caregivers, and hence reliable testifiers, doomed to be circular?

It will come as no surprise that my answer is no. Although caregiving success is most straightforwardly measured in terms of the charge's well-being, other factors can also be indicative of whether a particular caregiver is a good one. For instance, there may be 'objective' evidence available for certain aspects of physical care, such as biomarkers in blood tests that can confirm whether a charge is getting their medication. Additionally, attentiveness to one's charge, putting in effort to learn about treatment and management options, and speaking fondly of one's charge can all be markers suggestive of a well-intentioned, motivated caregiver. One can also look for the absence of signs indicating frustration and burnout in the caregiver, which are risk factors for abuse. Even the very act of giving testimony can be indicative since going out of one's way to advocate for a cognitively disabled charge in the face of sarcasm and dismissal is unlikely unless one cares about one's charge. (This also ought to be reassuring since it suggests that the risk of testimony from bad caregivers is smaller than what the depressing statistics on caregiver abuse and neglect might lead one to fear.) It is true that no piece of evidence is infallible – an abusive caregiver might fake affection so as not to get caught, for instance – but taken together, they can be evidence of someone's being a good caregiver which does not rely on their own testimony.²³ Moreover, unless there is positive evidence of poor care (e.g. biomarkers indicating negligence with medication), it seems like the burden of proof should be on the one who wishes to discredit someone as a bad caregiver, rather than the other way around.

In sum, the fact that poor caregivers exist is certainly a problem – but it is a problem because it means people are not getting adequate care and not because it undermines our ability to identify good caregivers and rely on their testimony. We can often recognise the indicators of well-being even in a cognitively disabled individual, and even in cases where these are less obvious, there are other markers of good caregiving that we can rely on.

2. The semi-transformative power of love

Because we as a family have been able to keep Sesha in our home and community, those who have made contact with her and have learned to see her as we who love her do have gained new perspectives on what it means to be a person.²⁴

This is a quote from the philosopher Eva Kittay's account of value and meaning in the lives of the cognitively disabled. Kittay frames her account by noting that it is an account born of love of her severely cognitively disabled daughter Sesha, which has given her 'new perspectives' she would not otherwise have seen. While the previous section argued merely that caregiver testimony is especially reliable because the labour of caregiving requires a high level of accurate knowledge, this section will argue further that caregiver

²³Indeed, even when a cognitively disabled individual's well-being is relatively accessible to the average person, one still ought to take these other indicators into account and make a holistic judgement when judging whether their caregiver is a good one. This is because there may be cases where good caregivers are 'unlucky' with charges who deteriorate despite good care and other cases where poor caregivers get 'lucky' with charges that happen to flourish despite poor care – although the latter is especially unlikely with severely disabled, non-communicative charges and the chance of it being sustainable over time even more unlikely.

²⁴Kittay (2001), p567.

testimony may even be especially insightful, particularly with respect to value in the life of the beloved, and it will do so by focusing on caregiving as paradigmatically loving and exploring what I will call the ‘semi-transformative’ power of love. This is not to suggest (implausibly) that every caregiver loves their charge, or indeed that they should, since love between a professional nurse and her patients would likely be too emotionally demanding, and moreover might be invasive and inappropriate. Nevertheless, for caregivers who stand in appropriate relationships with their charges and who do love them, love may make possible insights that are less accessible to the disinterested observer. After clarifying what I mean by ‘semi-transformative’, I will explore how love is semi-transformative, first in enabling epistemically virtuous habits towards the beloved and second in attuning the lover to value in the beloved’s life. Finally, I will discuss the worry that ‘love blinds’, that is, that the partial perspective of the lover is inimical to objective truth because it is distorted by love. As a note, I am using the word ‘lover’ broadly to refer to anyone who loves, rather than merely a partner in a romantic relationship.

What does it mean to say something is epistemically transformative? According to L.A. Paul, who coined the phrase, an experience is epistemically transformative when one gains knowledge of what something is like that would have been impossible without the experience, for instance, when one tries the infamous durian fruit for the first time.²⁵ Love may well be transformative in this sense, but it is not the sense with which we will be concerned in this paper. This is because a key feature of an epistemically transformative experience is that the knowledge gained by the individual who has undergone the transformative experience cannot be shared with others. Accordingly, it is not particularly useful for the sharing of knowledge through testimony, and very often, the aim of caregiver testimony is precisely to help others appreciate the value in the lives of their charges.

Rather than discussing love as transformative, therefore, the claim that I will develop in this section is that love is ‘semi-transformative’. With the additional prefix, I mean to pick out cases where an experience can make accessible knowledge that is normally very difficult – but not impossible – to achieve.²⁶ That is to say, the claim I want to defend is that a loving perspective offers a way of seeing value in the lives of the cognitively disabled that is otherwise far more difficult to appreciate.²⁷

The first way in which love is semi-transformative is in enabling and sustaining habits towards the beloved that are epistemically virtuous. Perhaps the most obvious of these is simply how love leads to paying more intense and sustained attention to the beloved.²⁸ As discussed in the previous section, caregiving as labour requires a highly demanding level of sustained attention that human beings rarely pay to one another. This would normally be very difficult to sustain, but love can make a big difference in enabling such attention.

²⁵Paul (2014), p14–15.

²⁶One upshot of dropping the ‘impossible’ criterion is that many intuitively banal changes in perspectives may qualify as ‘semi-transformative’. For example, growing 10 feet tall would render more accessible knowledge about what the world looks like from that elevated perspective. Such knowledge would normally be very difficult to achieve because learning how to walk on stilts is hard. Just as with transformative experiences where learning what parenthood is like is far more significant than learning what durian tastes like, some semi-transformative experiences are less interesting than others, precisely because the knowledge they make accessible is less significant.

²⁷As Barnes (2015, pp181–183) notes, sometimes a transformative experience occurs not in virtue of a newly acquired condition like a disability, but in virtue of seeing that condition in a new way. Seeing cognitive disability through the eyes of love might be transformative in this sense too.

²⁸Jollimore (2011), p46.

Next, love also motivates lovers to desire to know more about their beloved and to care more about getting things about them right. In turn, this often manifests in more patience and a willingness to put in the effort to seek a deeper understanding of the beloved. For example, consider a child throwing a tantrum for a seemingly small inconvenience. Although a disinterested stranger might be quick to judge the child as a spoiled brat, the child's parents are likely to be more patient with seeking an explanation: perhaps the child is particularly fretful because they are coming down with the flu or because something happened at school that day that they have not yet got over. Fairly often, the latter contextual reading of the situation is closer to the truth than the quick easy judgement, and it is precisely because the parent loves their child that they put in the extra effort to understand them.

All of these habits (intense and sustained attention; patience and effort) are generally recognised to be epistemically virtuous in that they are habits that tend to conduce to the truth. Accordingly, insofar as love naturally motivates such habits in the lover, love can be said to help the lover better understand the beloved in general.²⁹ There is, however, another more specific way in which love can be semi-transformative, namely, by attuning the lover specifically to value in the lives of the beloved, and it is to this phenomenon that we will now turn.

Let us begin by recognising that emotions are not random psychological states untethered to the external world, but that they are directed at some object in reality (broadly construed so as to include diverse phenomena ranging from states of affairs to people to ideas), and that emotions can be apt for their object or not. In other words, it makes sense to ask whether it is fitting that one feels a certain emotion towards an object or not.³⁰ For example, feeling afraid in the face of an angry tiger is an appropriate emotion: an angry tiger really is a fearsome thing for a squishy human person. In contrast, feeling afraid of a daffodil is very rarely appropriate (unless, perhaps, one has a severe daffodil allergy). We can and do judge whether certain emotions are appropriate in certain situations, and if we accept this practice to be sensible, it seems we are committed to there being some natural or normative connection between particular emotions and particular objects. This in turn suggests that feeling a certain emotion towards an object is a *pro tanto* reason to think that object does indeed have the property that makes that emotion apt.

For example, consider anger as an emotion. Anger has recently been of particular interest to moral philosophers, especially those of a feminist slant, because of its association with injustice. Amia Srinivasan, for example, holds that what makes anger distinctive is that it indicates that the object it is directed at involves some moral violation, rather than simply a departure from how one wishes the world to be (a state of affairs that makes appropriate only disappointment).³¹ Anger, then, can be epistemologically valuable by helping one identify injustice and recognise the full extent of the wrong that has been done. Feeling angry is an indicator that injustice may have been done. Of course, one can feel angry mistakenly; that is, one's anger might be

²⁹Interestingly, hatred, which is the opposite of love, may also motivate similar habits of intense and sustained attention, inspired by a desire to see the hated individual fail to prosper. It is compatible with my argument that love is not the only emotion that can be epistemically semi-transformative in this way, but I would nevertheless caution against celebrating hatred for its potential to motivate epistemically virtuous habits. Apart from hatred being an emotion we simply should not seek to cultivate, there is also reason to doubt that a testifier would testify in good faith about someone they hate.

³⁰Zagzebski (2012), p76. Notably, Zagzebski holds that an emotion need not include a judgement or belief (i.e. one need not be to be a cognitivist about emotions) in order for emotions to be apt or not (p77).

³¹Srinivasan (2018), p128. See also Cherry (2021).

directed at something false because one has misunderstood the situation, or anger might not be the appropriate emotion after all. Anger's indication that injustice has been done is a defeasible reason that one ought to reflect on in order to consider whether it is truly appropriate. Nevertheless, it is still helpful in directing one's attention to the object of anger and considering whether that object is truly anger-apt.

I propose that in a manner similar to how righteous anger may help one identify injustice, so may proper love illuminate what is valuable and good in the life of the beloved. Of course, the analogy between anger and injustice is imperfect because whereas anger is the apt response to injustice, love is not the proper response to changes in well-being. Rather, it seems like the proper response to someone flourishing is to feel happy that they are, and the proper response to someone doing badly is to feel sad or sorry for them. Most of the time, however, we are not especially good at feeling these appropriate emotions. When we see a stranger doing badly, we might feel a little sorry, but we don't tend to dwell too long on it. And when we see a stranger doing well, we might be somewhat glad for them, but we might also feel jealous instead.

Here is where love comes in. If that person is someone we love, we are much more invested in whether they are doing well or poorly. Obviously desiring the well-being of the beloved is not all that love is, but it is definitely a component of it. Love is epistemically semi-transformative in that it enables us to feel joy or sadness at another's well-being, first more strongly and second more appropriately. This in turn facilitates the lover's being more attuned to the beloved's well-being in a way that does not boil down to the intense and sustained attention of mere care. Nothing about mere care entails the twinning of emotions involved in taking the beloved's joys and sorrows as one's own, which is so characteristic of love and which is precisely what makes apt sympathy come so easily to the lover.³²

Thus far, I have been focusing on love as semi-transformative in a way that conduces to truth in support of treating the testimony of loving caregivers as especially insightful. This is, however, far from an uncontroversial perspective on love. In fact, Kittay reports having received significant resistance in her advocacy of the cognitively disabled precisely because of the suspicion that her perspective is rendered unreliable because of her love for her daughter:

*It is easy enough to say that I am 'blinded by love', that because of my attachment to my daughter and to her friends I fail to see these folks as the sad specimens they are.*³³

The remainder of this paper will address the worry that love can lead to bias and delusion, thus undermining the reliability of caregiver testimony.

The idea that one can be blinded by love is of course far from confined to evaluations of caregiver testimony. The tendency of lovers to idealise their romantic partners has been documented extensively, and some research suggests that it may occur in non-romantic relationships as well.³⁴ Some theorists (notably Sarah Stroud and Tim Keller) have even argued that since part of what it is to love someone is to see them with special favour, love generates norms of belief and belief-formation that ensure the maintaining

³²In this the semi-transformative power of love also comes apart from that of hatred. Indeed, hatred – despite its ability to motivate intense and sustained attention – is likely to make it harder to feel this apt sympathy since the hater is likely to feel upset at the good fortune of the hated and to be pleased when they suffer. Whatever the epistemic worth of such emotions, they are hardly morally appropriate, which is perhaps why *schadenfreude* is often accompanied by a sneaking feeling of guilt.

³³Kittay (2009), p619.

³⁴For example, see Jollimore (2011), p49.

of positive (or at least minimally negative) beliefs about the beloved, but which, crucially, deviate from epistemic norms.³⁵ This is the idea of epistemic or doxastic partiality. The issue, of course, is that deviating from epistemic norms opens the door to delusion, which would in turn render a lover's testimony unreliable.

On the one hand, it doesn't seem like epistemic partiality should extend to the well-being-related features of the beloved. Finding out that your loved one has developed a chronic illness, or has lost all their money, isn't – or shouldn't be – a reason to stop loving them in the way finding out that they are vicious, evil, or manipulative would be. The relevant sense of 'well' in the norm 'love involves thinking well of one's loved one' is a moral (or perhaps an aesthetic) sense. In contrast, the sense of 'well' relevant to caregiver testimony about their charges doing well is concerned with well-being.³⁶ So it seems like it ought to be orthogonal to the love-derived norm that grounds epistemic partiality.

On the other hand, however, the well-being of the cognitively disabled may be a special case. This is because when it comes to cognitive disability, what is in question is not just well-being but the individual's innate capacity for flourishing.³⁷ When a caregiver claims that their charge enjoys Beethoven, they are not merely making a point that music is adding happiness to their charge's life but also defending the claim that they are capable of appreciating music. Capacities may not be moral virtues but they may still be a legitimate subject of praise. At least, it is not uncommon to hear parents of young children bragging about how their toddler has learnt to walk at only so many months old. Accordingly, evaluations of a beloved's capacity for well-being, when that capacity is often doubted, might be something that could be susceptible to epistemic partiality.

Ultimately, I think that there are strong reasons to reject epistemic partiality. This is because love is not merely an affective feeling; at its core, it is inherently other-centred. The lover loves the *beloved*, and in order for that love to be truly directed at the beloved, the lover needs to see the object of love truly. If one's delusions are severe to the extent that one cannot even see the beloved, it is not love at all, but something like idolatry, which only superficially resembles it.³⁸ Moreover, the lover who cannot see their beloved's flaws cannot respond appropriately to them, which in turn blocks off opportunities for vulnerability, growth, and greater intimacy. One cannot, for instance, truly forgive one's beloved if one refuses to see that they have truly done wrong. Even if one claimed to do so, the forgiveness would be cheap without a true appreciation that the deed was truly wrong.³⁹

What this means is that accuracy is a good-making feature of love. Love shines brightest when it best respects epistemic norms because it is by respecting these norms that one comes to a true understanding of the beloved and hence how one is able to direct one's love to the beloved (rather than a false image of them). It is also how one is able to respond fittingly to them, thus allowing for true vulnerability and intimacy.⁴⁰ I take this truth-directedness to be a key feature of loving relationships in general, but it takes on particular importance in relationships in which one party is highly dependent

³⁵See Stroud (2006) p513; Keller (2004), p25. Proponents of doxastic partiality vary in how great the tension between love and epistemic norms is and how often love should supersede epistemic norms.

³⁶Cf. perfectionists about well-being who hold that well-being is at least partly constituted by virtue. See Haybron (2007) on why perfectionism about well-being is implausible.

³⁷For example, McMahan (2009), pp243–244.

³⁸Dormandy (2022), p11; Jollimore (2011), p47; Kawall (2013), p361.

³⁹Dormandy (2022), pp13–14.

⁴⁰Dormandy (2022), p3.

and the other is responsible for their care. In a loving caregiving relationship, the lover's impulse to benefit the beloved comes together with the caregiver's responsibility to promote their dependent charge's well-being, and as the last section shows, accuracy is required for good care.

This is all well and good, the cynic might say, but the fact that doxastic partiality is inappropriate does not mean that lovers are not still partial in this way – that the normative claim is false does not mean that the descriptive one is. That empirical research shows a positive bias in lovers' evaluations of those they love compared to disinterested individuals surely is cause for concern.

As a matter of fact, given what I have argued above about love's semi-transformative power particularly with respect to value in their beloved and in their lives, it would be surprising if there were no difference in their evaluations compared to the disinterested observer. The point I would push back on is the assumption that the disinterested observer's default perspective is the objective ideal for getting at the truth. As discussed earlier, love facilitates certain epistemically virtuous habits like attentiveness, patience, and effort. Consider two people attending a poetry recital at a cafe. One is a friend of the poet, whereas the other is a stranger. While the stranger listens half-heartedly, distracted by their annoyance at having mistakenly got a blueberry rather than a chocolate muffin, the friend gives the poem their full, sympathetic attention, actively seeking to appreciate its virtues.⁴¹ The friend is much more likely to have a positive impression of the poem, but that in itself does not mean the friend's appraisal is less likely to be true than the stranger's. In fact, as Troy Jollimore notes, it is more likely to be true: poetry is hard to appreciate, and the friend's active, sympathetic attention seems precisely the ideal attitude best suited to really listen to and to appreciate the poem.⁴²

Cognitive disability, even more so than poetry, is difficult to appreciate. This is partly because society is prejudiced against cognitive disability and partly because the way in which things such as happiness or meaningful relationships manifest in one who is cognitively disabled may be unusual to most people who are used to the clarity of words. For instance, the way in which a severely cognitively disabled individual expresses pleasure may be subtle and easy to miss. Recall Kittay's example of how she can tell that her severely cognitively disabled daughter Sesha is enjoying a particular piece of music by the glint in her eye or how a slight upturn of the lip in a profoundly and multiply disabled individual is an expression of joy at the presence of a favourite caregiver.⁴³ Seeing these expressions of pleasure and recognising them for what they are requires patience, attentiveness, and an open mind. That they are missed by the disinterested observer may say more about the deficiency of the default state of observation than the value (or lack thereof) in cognitively disabled lives.

Of course, this is not to say there is no idealisation or even delusion in love. People are far from perfect, and love is not infallible. Nevertheless, I suspect that worries about delusion are somewhat overblown, particularly with respect to caregiver testimony about the cognitively disabled, which is additionally safeguarded from delusion by the responsible caregiver's need for accuracy. Love can also be the means by which truth and value are made more accessible, and that a loving gaze tends to result in more positive appraisals than a neutral one does not automatically mean that the loving gaze is deluded.

⁴¹Jollimore (2011), p37. Original example from Keller (2004), pp331–334.

⁴²Jollimore (2011), p37. Moreover, if the poem were terrible, the friend is also probably more likely to have a strong negative impression of it compared to the stranger since it is hard to have a strong impression of a poem you're not really listening to!

⁴³Kittay (2001), p568.

3. Conclusion

I have argued that in cases where cognitive disability impedes an individual's ability to speak for themselves, a caregiver may speak on their behalf, and their testimony is not only reliable but also may be especially insightful. Failure to take such testimony seriously because of prejudice against the value of caregiving as a profession or because of a narrow-minded view of medical (or philosophical!) experts being the only relevant authoritative voices not only risks epistemic injustice but also the loss of a highly valuable perspective into the well-being of the cognitively disabled and the value of their lives.

Acknowledgements. I am very grateful to Meghan Sullivan and Laura Callahan for their helpful comments on this paper.

References

- Amundson R.** (2005). 'Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics.' In D. Wasserman, J. Bickenbach and R. Wachbroit (eds), *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, pp. 101–124. Cambridge: Cambridge University Press.
- Barnes E.** (2015). 'Social Identities and Transformative Experience.' *Res Philosophica* **92**(2), 171–187.
- Campbell S.M. and Stramondo J.A.** (2017). 'The Complicated Relationship of Disability and Well-Being.' *Kennedy Institute of Ethics Journal* **27**(2), 151–184.
- Cherry M.** (2021). *The Case for Rage: Why Anger Is Essential to Anti-Racist Struggle*. Oxford, New York: Oxford University Press.
- Dodds S.** (2013). 'Dependence, Care, and Vulnerability.' In C. Mackenzie, W. Rogers, and S. Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford: Oxford University Press.
- Dormandy K.** (2022). 'Loving Truly: An Epistemic Approach to the Doxastic Norms of Love.' *Synthese* **200**(3), 218.
- Haybron D.** (2007). 'Well-Being and Virtue.' *Journal of Ethics and Social Philosophy* **2**(2), 1–28.
- Held V.** (2006). *The Ethics of Care: Personal, Political, and Global*. New York: Oxford University Press.
- Jollimore T.** (2011). *Love's Vision*. Princeton, NJ: Princeton University Press.
- Kawall J.** (2013). 'Friendship and Epistemic Norms.' *Philosophical Studies: An International Journal for Philosophy in the Analytic Tradition* **165**(2), 349–370.
- Keller S.** (2004). 'Friendship and Belief.' *Philosophical Papers* **33**(3), 329–351.
- Kenny K. and McGilloway S.** (2007). 'Caring for Children with Learning Disabilities: An Exploratory Study of Parental Strain and Coping.' *British Journal of Learning Disabilities* **35**, 221–228.
- Kittay E.F.** (1999). *Love's Labor: Essays on Women, Equality and Dependency*. London: Routledge.
- Kittay E.F.** (2001). 'When Caring Is Just and Justice Is Caring: Justice and Mental Retardation.' *Public Culture* **13**(3), 557–579.
- Kittay E.F.** (2009). 'The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield.' *Metaphilosophy* **40**(3/4), 606–627.
- Kohn R. and Verhoek-Oftedahl W.** (2011). 'Caregiving and Elder Abuse.' *Medicine and Health, Rhode Island* **94**(2), 47–49.
- Kontrimiene A., Sauseriene J., Blazeviene A., Raila G. and Jaruseviciene L.** (2021). 'Qualitative Research of Informal Caregivers' Personal Experiences Caring for Older Adults with Dementia in Lithuania.' *International Journal of Mental Health Systems* **15**(1), 12.
- McMahan J.** (2009). 'Radical Cognitive Limitation.' In K. Brownlee and A. Cureton (eds), *Disability and Disadvantage*. Oxford: Oxford University Press.
- Paul L.A.** (2014). *Transformative Experience*. Oxford: Oxford University Press.
- Raviv T., Warren C.M., Washburn J.J., et al.** (2021). 'Caregiver Perceptions of Children's Psychological Well-Being During the COVID-19 Pandemic.' *JAMA Network Open* **4**(4), e2111103.
- Reinhard S.C., Levine C. and Samis S.** (2012). *Home Alone: Family Caregivers Providing Complex Chronic Care*. Washington, DC: United Hospital Fund and AARP Public Policy Institute.
- Schulz R. and Eden J.** (2016). *Families Caring for An Aging America*. Washington, DC: The National Academies Press.

- Singer P.** (2009). 'Why We Must Ration Health Care.' *The New York Times*, July 15, 2009, sec. Magazine. <https://www.nytimes.com/2009/07/19/magazine/19healthcare-t.html>.
- Srinivasan A.** (2018). 'The Aptness of Anger.' *Journal of Political Philosophy* **26**(2), 123–144.
- Stockner M.** (1976). 'The Schizophrenia of Modern Ethical Theories.' *The Journal of Philosophy* **73**(14), 453–466.
- Stroud S.** (2006). 'Epistemic Partiality in Friendship.' *Ethics* **116**(3), 498–524.
- Zagzebski L.T.** (2012). *Epistemic Authority: A Theory of Trust, Authority, and Autonomy in Belief*. Oxford: Oxford University Press.

Sara Chan is a graduate student in the philosophy department at the University of Notre Dame.