

THE PERSON AS ENVIRONMENTALLY INTEGRATED DEMENTIA, LOSS, AND EXTENDED COGNITION

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How could I possibly be disintegrating as a human being, solely due to the slow deterioration of my brain?

Christine Bryden, *Will I Still Be Me?*

IN A 2022 REPORT, the World Health Organization described addressing dementia as “one of the greatest health challenges of our generation.”¹ This phrase neatly captures the terms in which public discussion about the condition tends to proceed: dementia is a health issue, and as with all health issues, we should primarily be concerned about prevention, early detection, and effective treatment. While these are certainly urgent demands, there are also socio-political dimensions to this issue that ought not to be neglected—namely the ways in which institutions and individuals treat people living with dementia.

For dementia self-advocate Christine Bryden, key among these concerns is the dominant narrative of dementia as a process that irreversibly sets those who live with it on a path to the destruction of their personal identities and of their personhood.² When presented with her diagnosis, she felt intense personal anguish that she attributes to this view, describing an “overwhelming fear of future non-being.”³ Reflecting also on the experiences of others, she rejects what can be termed the *loss narrative* as both stigmatizing and oppressive.⁴ The primary aim of this paper is to validate and philosophically bolster these claims.

In section 1, I highlight three widely disseminated distortions in the public understanding of dementia that reflect an implicit acceptance of the idea that it is a condition fundamentally characterized by loss such that those who live with it will inevitably lose their personal identities and their personhood. I then argue that this idea acts as a legitimating ideology for the stigma that people

1 World Health Organization, *A Blueprint for Dementia Research*, v.

2 Bryden, *Will I Still Be Me?* 16.

3 Bryden, *Will I Still Be Me?* 39.

4 Bryden, *Will I Still Be Me?* 62, 120.

living with dementia face, while contributing to their oppression by marginalization and cultural imperialism.

Personal identity and personhood, however, are distinct concepts, the losses of which have distinct implications. Even if it were true that people living with dementia lost their personal identities throughout the progression of the condition, such that they became metaphysically different people than they were at its onset, they would still have strong claims to be free from stigma and oppression. As I demonstrate in section 2, on the other hand, losing their personhood would remove them from the scope of justice altogether, such that any harmful effects engendered by social arrangements would only press on our relative moral concern. Challenging the loss narrative must begin, then, with a defense of the personhood of people living with dementia.

With this aim in mind, in section 3 I develop and defend an account of the person as environmentally integrated. Making novel links between feminist care ethics and the extended mind thesis, this account conceives of personhood as a relational attribute that is held by all those who share an environment of cognitive extension. As the progression of dementia does not threaten this status, all people living with dementia are persons and thus entitled to liberation from the social injustices entailed by the loss narrative.

1. STIGMA, OPPRESSION, AND THE LOSS NARRATIVE

Whether they are living with Alzheimer's disease, vascular dementia, frontotemporal dementia, or any of the other conditions that fall under the umbrella term "dementia," all who live with this condition experience a progressive deterioration in cognitive function.⁵ As most of us value our cognitive function, alongside the capacities that depend on it, it is reasonable to assume that most of us would experience the development of dementia as personally costly. It would therefore seem philosophically irresponsible to deny any connection between dementia and loss.

It is one thing, however, to note that dementia involves the deterioration of cognitive function and quite another to claim that these losses, in Dan Brock's terms, "ultimately destroy personal identity and personhood in the patient."⁶ This is the essence of the loss narrative, denounced by Bryden as stigmatizing and oppressive: it depicts dementia as a condition that withers away at fundamental features of who we are, such that those who develop it are irreversibly set on a path toward becoming indistinct human objects. It thus renders a life

5 World Health Organization, "Dementia."

6 Brock, "Justice and the Severely Demented Elderly," 73.

lived with dementia one that is *fundamentally* characterized by loss—not just of specific capacities but of personal identity and personhood.

In this section, I bolster the political case developed in Bryden's self-advocacy work against the loss narrative. I begin by outlining three key distortions in public understanding around dementia and the lives of those who live with it, each of which reflects the firm grip the loss narrative holds on public imagination. I then demonstrate the contribution of these distortions to a global stigma about dementia, arguing that the loss narrative acts as a legitimating ideology for the attitudes that underpin it. I then link these stigmatizing attitudes to structural injustices faced by people living with dementia worldwide, concluding that the loss narrative, both directly and indirectly, contributes to oppression.

1.1. Three Distortions

It is a well-established methodological norm within egalitarian political philosophy, particularly when dealing with questions concerning the position of social groups of which the speaker is not a member, to adopt some of the tenets of standpoint epistemology. Even if they do not sign up to the wider framework of understanding all knowledge claims as socially situated, it seems to me uncontroversial to think that egalitarians at the very least ought to accept that persons who experience structural injustice are likely to have insights that outsiders do not.⁷ In this light, the mere fact that it comes from Bryden, who identifies the public attitudes it engenders as an equal contributor to her “constant struggle” with dementia as the condition's symptoms themselves, gives us reason to take seriously the claim that the loss narrative is socially dominant.⁸

To leave the discussion here, however, would be to risk circularity. The aim of this section is after all to demonstrate that people living with dementia *are* a group who experience structural injustices (in part) *because* of the loss narrative. To begin such an argument from the claim that we should view the insights of dementia self-advocates as privileged due to their experience of structural injustice—a claim that is itself under contention—would be to veer dangerously close to begging the question. In order to bolster Bryden's argument, then, it is necessary to provide some evidence of the loss narrative in action. While to my knowledge no reputable studies on public adherence to this narrative exist, there is ample evidence of widespread distortions in understanding that reflect an underlying if often only implicit commitment to it. Here I explore three such distortions, providing sufficient evidence to begin analyzing its political effects.

7 This is a norm that can be traced back to Alcoff, “The Problem of Speaking for Others,” 5–32.

8 Bryden, *Will I Still Be Me?* 62.

The first of these distortions consists in a widespread negativity bias toward dementia. Both researchers and the public, as Bryden notes, overwhelmingly focus on what is lost during the progression of dementia, with little serious discussion of what might be gained.⁹ In research, this manifests through a historical focus on biomedical analyses of capacity loss at the expense of qualitative research on the experience of living with dementia.¹⁰ Despite some conscious movement toward the language of “living well” with dementia in public policy circles, alongside growing calls for the greater inclusion of those who live with the condition in research, the dominance of deficit-focused research remains for the most part intact.¹¹ Likewise, studies on attitudes toward lives lived with dementia consistently report pervasive negative characterizations, particularly among those who lack knowledge about the condition.¹²

To be clear, the mere observation of negative elements of living with dementia is not what is at issue. Rather, what makes this phenomenon a distortion in understanding is the excessive focus on these aspects of the condition, reflecting the idea that the condition is fundamentally characterized by inevitable and eventually total loss. Under such a paradigm, there is no need to pay any serious attention to the benefits or improved capacities that a person may accrue throughout the progression of dementia; indeed, these are rendered trivial if not definitionally impossible. There have been no extensive studies, for instance, into the extent to which people living with dementia, in tandem with a decline in memory, experience an increase in what Bryden calls a “sense of the present time, the sense of ‘now,’ of how to live each moment and treasure it as if it were the only experience to look and wonder at.”¹³ If the growing popularity of meditation and mindfulness practices is anything to go by, this is something that many people value and strive for, but it is rarely if ever thought of or publicly presented as a potential benefit of dementia in the present context, which is typified by widespread negativity bias.

Even where changes appear to have made a person living with dementia happier, moreover, they are often interpreted through a second distortion in understanding: the denial of authenticity. Where this occurs, the person before onset is presented as the authentic self, with subsequent changes in values, preferences, and personality traits viewed as suspect, potentially inauthentic

9 Bryden, *Will I Still Be Me?* 47–48.

10 Dewing, “Participatory Research,” 11–12.

11 Webb, Williams, Gall, and Dowling, “Misfitting the Research Process.”

12 Chang and Hsu, “Relationship between Knowledge and Types of Attitudes towards People Living with Dementia,” 3777.

13 Bryden, *Dancing with Dementia*, 11.

manifestations of the underlying condition. In other words, such changes are understood as *losses* of aspects of the authentic self as opposed to the kind of changes in our identities that we all make throughout our lives.

This distortion conflicts with testimony from those who live with dementia about their sense of identity. A majority of respondents in a 2011 study of UK adults with early-stage dementia, for example, reported little change in their identities as a whole, despite changes to their personalities that had occurred since the development of the condition.¹⁴ This is corroborated by Bryden, who, despite the advanced state of her condition, reports experiencing a continuous sense of self.¹⁵ However, as is apparent in survey data, the denial of authenticity is a view that has been widely disseminated. In a 2011 study on adults in Northern Ireland, for instance, 75 percent of respondents agreed with the statement “once they have dementia the person you knew eventually disappears.”¹⁶ Likewise, many participants in a 2019 study of caregivers in the United States described dementia as a shameful condition, referring to those who live with it with phrases like “a shell of themselves,” “losing control,” “becoming like a child,” and “losing their mindset.”¹⁷

As with the first distortion, it is important to clarify the boundaries of the concern I am raising. Whether or not a person living with dementia is metaphysically the same person as they were at onset is not at issue here. While there is a lot at stake in the answer to that question, including the moral and legal force of advance decisions to refuse treatment and the norms that should govern the permissible continuance of intimate relationships they had before its onset, it does not bear directly on the question of *authenticity of changes* nor on the question of whether a person living with advanced dementia has a personal identity at all.¹⁸ A person, after all, could metaphysically be a different person than the one they were at onset yet nevertheless still possess a personal identity.

The core of this second distortion, rather, is the imposition of a hierarchical relationship between the person at onset and the person throughout the course of dementia, whereby the former is prized as the authentic self, such that the latter’s differences are understood in terms of loss rather than change. Embracing this distortion reflects an implicit commitment to the idea of destruction

14 Caddell and Clare, “I’m Still the Same Person,” 379–98.

15 Bryden, *Will I Still Be Me?* 121.

16 McManus and Devine, *Dementia*.

17 Lopez, Rose, Kenney, Sanborn, and Davis, “Managing Shame,” 183.

18 I have discussed the moral and legal force of advance decisions to refuse treatment elsewhere. See Carter, “Advance Directives,” 32–41. For an illuminating discussion regarding the norms that should govern the continuance of intimate relationships, see Kukla, “A Nonideal Theory of Sexual Consent,” 274–78.

of personal identity posited by the loss narrative, in the sense that it constructs dementia as a process that eats away at the authentic self, with every change in personal identity dragging the person who lives with the condition away from the person they really are and toward something hollowed out and inauthentic. Thus even small changes are subject to suspicion around their authenticity, representing under this distortion steps toward the inevitable destruction of personal identity involved in the progression of dementia.

This leads neatly to the third widespread distortion about dementia: fatalism. Those laboring under the assumptions of this distortion are unable to conceive of a life lived with dementia as worth living, reflecting an implicit commitment to the loss narrative's depiction of dementia as an irreversible descent into the loss of personal identity and personhood. Alongside denying or downplaying the benefits people may accrue through the development of dementia and questioning the authenticity of changes in their personalities and values, there is a tendency in both research and public discourse to deny or downplay the ability of people living with the condition to overcome the challenges posed by the physical deterioration of their neurological matter.

In research, this fatalism can be observed in the allocation of funding. Between 2011 and 2016, over 95 percent of research funding for dementia by G7 countries was allocated toward cures and disease-modifying treatment, with only the small fraction leftover allocated to research on improving the lives of those that live with the condition.¹⁹ Among the public, we can observe the far-reaching dissemination of this idea through survey data. In the 2023 Dementia Attitudes Monitor conducted by Alzheimer's Research UK, for example, only 12 percent of respondents considered improvements in quality of life a top priority for research, in comparison to the combined 63 percent who favored prioritizing research on cures, prevention, and medication to stop the development of the condition.²⁰

It is no doubt important to conduct biomedical research of this kind; to consider this a priority is not to have a distorted understanding of dementia. However, because this research is unlikely to benefit the majority of persons living with dementia today, placing such great emphasis on it is effectively to abandon attempts to improve their lives or to empower them to act. Fatalism of this kind represents a distortion in understanding because it proceeds from premises that are plainly false. The very existence of self-advocates like Bryden who are able to engage in written and spoken advocacy work while living with

19 Pickett and Brayne, "The Scale and Profile of Global Dementia Research Funding," 1888–89.

20 Alzheimer's Research UK, *Dementia Attitudes Monitor*, 55.

dementia stands as evidence against this idea.²¹ Moreover, as Bryden notes, it conflicts with our broader understanding of the effects of social context on capabilities and the well-established phenomenon of lifelong neuroplasticity.²² It also directly conflicts with the research data we *do* have on improving the quality of life of people living with dementia, which suggests that social relationships and social engagement correlate with better outcomes and that appropriate social organization can improve functional abilities.²³

The loss narrative, in sum, is evident in three distortions in public understanding of dementia: negativity bias, denial of authenticity, and fatalism. The first reflects the idea that a life lived with dementia is fundamentally characterized by loss, the second that dementia involves a destruction of personal identity, and the third that dementia sets a person irreversibly on a path to the loss of personal identity and personhood. As each of these distortions is widely disseminated, we have reason to think of the loss narrative as socially dominant and to take seriously Bryden's claims that it is stigmatizing and oppressive.

1.2. *The Loss Narrative and Stigma*

A recent survey by Alzheimer's Disease International (ADI) suggests that the stigma of dementia is a pressing global problem, with 85 percent of respondents who live with the condition reporting the experience of it in at least one aspect of their daily lives.²⁴ This is corroborated by the accounts of dementia self-advocates like Bryden, who describes herself as being "surrounded by negative views of dementia," and Rukiya Mukadam, who reports a "very strong, very powerful" taboo about dementia within the British Kashmiri community to which she belongs and among Asian communities more broadly.²⁵

To conduct the survey, the ADI adopted a four-part model developed by Nicolas Rüsçh, Matthias C. Angermeyer, and Patrick W. Corrigan to explain the stigma of mental illness. On this account, stigma occurs when people with relative power internalize negative views about some group (stereotypes), which manifest as negative emotional responses (prejudice) and behavioral responses (discrimination).²⁶ Accordingly, to calculate the global prevalence of stigma, the ADI report uses self-reported experiences of discrimination attributable

21 Alongside Bryden, see Swaffer, *What the Hell Happened to My Brain?*; and Taylor, *Alzheimer's from the Inside Out*.

22 Bryden, *Will I Still Be Me?* 46–47.

23 Martyr et al., "Living Well with Dementia," 2136; and Poulos et al., "A Comprehensive Approach to Reablement in Dementia," 450–58.

24 Alzheimer's Disease International, *World Alzheimer Report 2019*, 14–15.

25 Bryden, *Will I Still Be Me?* 62; and Mukadam, "Time to Break the Taboo," 234–41.

26 Rüsçh, Angermeyer, and Corrigan, "Mental Illness Stigma," 529–39.

to prejudice grounded in stereotypes held by people with social power over others living with dementia.²⁷

For descriptive purposes such as these, the four-part model functions reasonably well. It is not obvious, however, that it offers a concept of stigma that is distinct enough for a philosophical analysis. What is being tracked after all is wrongful discrimination; the mere fact that it has a particular root cause does not by itself require the adoption of a separate concept of stigma. Indeed, it might be thought that the route from power to prejudice is the root cause in the overwhelming majority of wrongful discrimination cases, weakening further the case for describing it in any other terms. This model, in other words, lacks a distinguishing feature that tells us *what stigma is* and why it is of particular concern.

Elizabeth Anderson's approach to stigma fills this gap by introducing the idea of *legitimation*. In her terms, stigmatized people are presented as the "*proper* objects of dishonor, contempt, disgust, fear, or hatred on the basis of their group identities."²⁸ Stigma, then, consists not merely in powerful people holding stereotypes about a particular group that lead to prejudice and discrimination but in those ideas being held within a social context that causes them to be perceived as legitimate and the actions that follow from them justified. Wrongful discrimination resulting from stigma is, in this sense, either socially approved of or perceived by its perpetrators as such.

This insight can be incorporated into the model provided by Rüsich et al. via the addition of a fifth element: a *legitimizing ideology*. Stigma can then be said to occur when people with relative power propagate, adhere to, and reinforce a socially dominant set of ideas about a group (a legitimizing ideology), from which they derive negative views (stereotypes) that are socially approved of, which manifest as negative emotional responses (prejudice) and behavioral responses (discrimination) that are considered, under the prevailing set of social ideas, justifiable.

With the addition of this fifth element, wrongful discrimination resulting from stigma can be distinguished from cases that lack a clear legitimizing ideology. Here I have in mind those that result from unconscious bias rather than conscious commitment to particular stereotypes and prejudicial attitudes. This line is not always clear cut; wrongful discrimination against minority racial groups, for example, can involve both unconscious biases and commitment to tenets of white supremacy (whether the actors understand them as such or not). Not all such cases, however, are obviously the result of conscious adherence to a socially dominant legitimizing ideology. Consider, for instance,

27 Alzheimer's Disease International, *World Alzheimer Report 2019*, 17–33.

28 Anderson, "Equality," 43 (emphasis added).

employment discrimination against candidates with Northern English accents in the United Kingdom. Accent-based stereotypes and prejudices are well-observed phenomena in the United Kingdom, yet there is no widespread overt support for a set of ideas that would render legitimate the refusal to hire, for example, a person from Manchester for a middle-management role in an office merely because of their accent.²⁹ In such cases, we can say that there are stereotypes, prejudice, and discrimination, but they are not the result of stigma.³⁰

Armed with this distinct concept of stigma, we are better equipped to understand the relationship between the loss narrative and the wrongful discrimination against people living with dementia identified by the ADI. Many of the stereotypes mentioned in the report—including the belief that all people living with dementia are a burden to their families and the health care system, that they are incompetent, and that they are unable to contribute to society—clearly proceed from the widespread distortions in understanding that themselves involve implicit commitment to the idea of the loss narrative.³¹ Accordingly, the same can be said of the prejudicial and discriminatory behaviors included in the report. If one believes that people living with dementia are passive and will become decreasingly legitimate representatives of their own interests as the condition progresses, then one might feel justified in not taking their opinions seriously or in denying them choices.³² Even behaviors of aversion, like shunning or otherwise avoiding people living with dementia, make a certain kind of sense when coupled with the distortions of negativity bias, denial of authenticity, and fatalism;³³ persons might wonder why it is so important to maintain a social relationship with someone who, according to the legitimating ideology of the loss narrative, is irreversibly disintegrating in front of them.

Bryden is, in this sense, right to connect the stigma faced by people living with dementia to the loss narrative. The idea that people living with dementia are irreversibly set on a path to the destruction of their personal identity and

29 Sharma, Levon, and Ye, “50 Years of British Accent Bias.”

30 This may not be true for other British accents, especially where they more directly interact with the legitimating ideologies of white supremacy and Anglocentrism. Multicultural London English accents, for instance, seem quite clearly stigmatized due to their association with minority racial groups, discrimination against whom is afforded legitimacy by the socially dominant ideology of white supremacy. Likewise, working-class Glaswegian accents are plausibly understood as stigmatized because the discrimination that follows from widely held associations with violence and poor education is plausibly understood as socially sanctioned under the legitimating ideology of Anglocentrism—a set of ideas that places England and Englishness at the head of a hierarchy of nations and national identities within the UK.

31 Alzheimer’s Disease International, *World Alzheimer Report 2019*, 17.

32 Alzheimer’s Disease International, *World Alzheimer Report 2019*, 24.

33 Alzheimer’s Disease International, *World Alzheimer Report 2019*, 24.

personhood, alongside the distortions in understanding that assume it, seems to play the role of a legitimating ideology in the wrongful discrimination identified by the ADI report. Without its social dominance, absent another legitimating ideology, such behaviors would be the result of socially disapproved of, unconscious biases. The loss narrative is thus crucial to understanding why people living with dementia are stigmatized rather than merely subject to wrongful discrimination.

1.3. *The Loss Narrative and Oppression*

Let us turn now to Bryden's claim that the loss narrative contributes to the oppression of people living with dementia. On Iris Marion Young's influential account, oppression is an umbrella term referring to five distinct but related structural injustices: exploitation, marginalization, cultural imperialism, powerlessness, and violence.³⁴ While a case could be made that people living with dementia suffer from all five, here I want to focus on the two most clearly connected to the loss narrative: marginalization and cultural imperialism.

Marginalization, on Young's account, consists of a process by which a whole group of people are "expelled from useful participation in social life" such that they are blocked from exercising their capacities in "socially defined and recognised ways."³⁵ The ADI report, which is the largest global survey to date on attitudes toward dementia, does not address this face of oppression directly. Nevertheless, by observing the types of discriminatory behavior the respondents reported suffering from, a clear pattern of exactly this sort of expulsion can be discerned.

A significant number of respondents, for example, reported (i) having their rights and responsibilities taken away, (ii) being treated unfairly in their social life, and (iii) being avoided or shunned. One respondent, regarding the first category, told the researchers that he had lost "the right to work and at times to think for [himself]."³⁶ Another, regarding the second category, reported having been "shunned [in their] effort to help volunteer to prepare and serve [a] meal" at a clubhouse function.³⁷ Regarding the third, respondents reported no longer being called by close friends and being ostracized by faith communities.³⁸

This type of social exclusion is at the heart of Young's concept of marginalization: the relegation of a social group to the margins of a society such that they are denied opportunities to contribute in a way that grants them social

34 Young, *Justice and the Politics of Difference*, 40–41.

35 Young, *Justice and the Politics of Difference*, 53–54.

36 Alzheimer's Disease International, *World Alzheimer Report 2019*, 32.

37 Alzheimer's Disease International, *World Alzheimer Report 2019*, 27.

38 Alzheimer's Disease International, *World Alzheimer Report 2019*, 31.

recognition. Though it may not always be accompanied by material deprivation, especially when people living with dementia have substantial assets to fall back on, this form of social deprivation is a significant impediment to social equality. As Young argues when discussing the elderly as a marginalized group, “even if marginals were provided a comfortable material life within institutions that respected their freedom and dignity, injustices of marginality would remain in the form of uselessness, boredom, and lack of self-respect.”³⁹

No doubt the development of dementia is itself a significant impediment to exercising capacities in socially recognized ways. Yet as each of these examples illustrates, this natural barrier is often reinforced with social barriers. There is no reason why people living with dementia, especially in the early stages, ought to be excluded from the workplace entirely, why they cannot help to prepare a meal where assistance is available, nor why they cannot participate in social interactions with their friends and their wider communities. Such oppressive social marginalization clearly reflects widespread dissemination of the fatalist distortion about dementia, grounded in the loss narrative’s idea of irreversibility.

Turning to cultural imperialism, Young defines this face of oppression according to the conflict between the subjective experience of a subordinated group and a dominant group’s interpretation of that experience. Where this is operative, she argues that the subordinated group experiences a “paradoxical oppression” in which their own interpretations of their experiences are rendered partially or fully invisible, but they are “stamped with an essence” consisting of highly visible, widely known stereotypes about their experiences, which are derived from the dominant group’s perspective.⁴⁰

The effects of this face of oppression on people living with dementia are readily apparent in Bryden’s discussion of the loss narrative. The idea that dementia irreversibly sets those who live with it on a path to a loss of personal identity and personhood, she argues, is an “outsider’s view” that does not reflect the “insider’s experience.”⁴¹ While Bryden discusses gains in attentiveness to present time, the loss narrative instead presents dementia as a process that solely removes capabilities.⁴² While Bryden claims that she has experienced a continuity of self throughout the progression of her condition, the loss narrative instead presents dementia as a disintegration of self, such that people who live with the condition cease to represent their true and authentic characters.⁴³

39 Young, *Justice and the Politics of Difference*, 55.

40 Young, *Justice and the Politics of Difference*, 58–61.

41 Bryden, *Will I Still Be Me?* 11.

42 Bryden, *Dancing with Dementia*, 11.

43 Bryden, *Will I Still Be Me?* 23–25.

While Bryden clear-sightedly explains how she has used technology to adapt to and overcome the effects of dementia on her short-term and working memory, the loss narrative instead presents people living with dementia as passive and helpless in the face of a total annihilation of what it means to be a human.⁴⁴

This hiding of the insider's perspective under a thick cloud of outsider-derived stereotypes is the essence of cultural imperialism, and it has significant effects on those who experience it. As Young argues, because members of groups oppressed in this way are regularly forced to react to the behavior of others influenced by these stereotyped images, they must expend a significant amount of energy to resist internalizing them and to maintain the positive sense of themselves needed to challenge them.⁴⁵ Bryden describes exactly this phenomenon when discussing the heavy burden of reactions to her advocacy work, noting "I am thought to lack insight, so it does not matter if I am excluded. But if I do have insight, then I am said to lack credibility as a true representative for people with dementia."⁴⁶ Indeed, when she included brain scans in her presentation slides in order to prove her credibility, she was even accused of faking them, reporting in a 2005 interview that she was told "if your brain scans are really yours, you shouldn't be able to speak."⁴⁷

In sum, Bryden's claim that people living with dementia are stigmatized and oppressed by a socially dominant loss narrative is well supported. The widespread dissemination of three distortions in understanding about dementia—negativity bias, denial of authenticity, and fatalism—reflects implicit commitment to the loss narrative's depiction of dementia as a condition that inevitably and irreversibly leads to the loss of personal identity and personhood. These ideas, I have argued, act as a legitimating ideology in the stigma of dementia, as identified by the 2019 ADI report. Further, they are clear causal contributors to the oppression of people living with dementia through marginalization and cultural imperialism. The loss narrative stands therefore as an impediment to social equality for people living with dementia.

2. THE SIGNIFYING ROLES OF PERSONHOOD

The previous section bolstered the political case, originating in Bryden, against the loss narrative. These arguments, however, are not conclusive, because they are sufficient to motivate action to challenge the loss narrative only if all of

44 Bryden, *Will I Still Be Me?* 27–41.

45 Young, *Justice and the Politics of Difference*, 60.

46 Bryden, *Dancing with Dementia*, 40.

47 Rix, "I Live in a Little Cloud."

the claims underpinning it are wrong. In making these arguments, I offered evidence that contradicts the idea that losses incurred by dementia are irreversible and suggested that people living with dementia can possess personal identities no less authentic than those they possessed at onset (whether or not they are metaphysically the same person). I did not, however, address the claim that people living with dementia are at risk of losing their personhood. In part, I chose to omit discussion of this aspect of the loss narrative because it was possible to demonstrate the social dominance and stigmatizing, oppressive character of this set of ideas without doing so. Primarily, however, I chose to bracket this concern because it is of such consequence for the overall argument that it ought to be dealt with separately.

If it were true that dementia eventually causes a person that lives with it to lose their personhood, then the political case I raised in the previous section would be significantly undermined. It would remain the case that the loss narrative leads to distortions in understanding and carries a stigmatizing, oppressive character, but the appropriate response to the narrative would shift from disavowal to reform; it would be no kindness, after all, to deceive people living with the early stages of dementia into thinking that they would not experience this fundamental loss.

More significantly, if there is a significant subclass of people living with dementia who are no longer persons, and all those who live with dementia are irreversibly set on a path toward joining them, then the idea that the harms engendered by the loss narrative represent *injustices* would be significantly undermined. This is so because the concept of personhood carves out the normative landscape via three significant signifying roles such that our moral duties toward those who do not possess it differ significantly from those who do. Falling on the wrong side of it, as I demonstrate in this section, would weaken the ability of people living with dementia, particularly those with advanced dementia, to make moral and political claims on others.

These three signifying roles are well captured by Eva Feder Kittay, who describes personhood as a concept that “marks the moral threshold above which equal respect for the intrinsic value of an individual’s life is required and the requirements of justice are operative and below which only relative interest has moral weight.”⁴⁸ To claim that some being is a person is accordingly to signify one or more of the following three things about them: (1) that we owe stronger moral duties toward that being than those that are not persons (i.e., that they cross the relevant threshold), (2) that that being has the same moral status as other beings that are persons (namely, the status that entitles them to equal

48 Kittay, “At the Margins of Moral Personhood,” 101.

respect for the intrinsic value of their lives), and (3) that the duties we owe to that being are duties of social justice rather than those of basic moral concern.

Personhood often plays signifying role 1 in discussions about animal ethics.⁴⁹ A common argument, which can be traced back to the work of John Locke, goes something like this: while we may have some duties of moral consideration toward nonhuman animals, they are not *persons*, so they do not have the kind of strong claims against, for example, breeding for medical testing that persons do.⁵⁰ Scholars adopting such an argument will typically bolster this point by specifying a set of cognitive features necessary for personhood and then demonstrate that most if not all nonhuman animals do not possess them.⁵¹

Such conceptions of personhood, however, do not neatly divide human beings and nonhuman animals. Many arguments in favor of abortion rights, for instance, have been mounted in exactly these terms: that human fetuses do not possess the requisite cognitive capacities to meet the threshold of personhood.⁵² More troublingly for the subject of this paper, strong cognitive criteria have the effect of excluding a significant number of cognitively disabled persons, including those living with advanced dementia, thereby relegating them to a lower moral status than other humans. Indeed, Brock argues that it is instructive to compare the mental capacities of at least some nonhuman animals and people living with advanced dementia, concluding that neither meet the threshold necessary for personhood.⁵³

The serious consequences of such an exclusion are apparent in discussions that evoke personhood's second signifying role. Though sometimes taken to be a relatively thin concept, the moral equality of persons—understood as the idea that the interests of persons are of equal importance—is foundational to contemporary political philosophy, forming what Ronald Dworkin describes as a “kind of plateau.”⁵⁴ Beings who are not persons are not typically afforded this status, even when they are subject to the same political institutions as persons, meaning their interests can permissibly be disregarded or overruled without the strong justifications to which persons are entitled.

This distinction reflects relatively well our present-day consensus in Western societies on animal rights issues. While animal welfare concerns are taken

49 See Chan and Harris, “Human Animals and Nonhuman Persons,” 304–6.

50 See Locke, *An Essay Concerning Human Understanding*, 188.

51 Beauchamp, “The Failure of Theories of Personhood,” 310–18.

52 See Himma, “A Dualist Analysis of Abortion,” 48–55; Little, “Abortion and the Margins of Personhood,” 331–38; and Tooley, *Abortion and Infanticide*, 40–104.

53 Brock, “Justice and the Severely Demented Elderly,” 86.

54 Dworkin, “Comment on Narveson,” 25. On the “thin concept” of moral equality of persons, see Nathan, “What Is Basic Equality?” 7–8.

seriously, they are typically taken to be different in kind and importance from those of human welfare. So while there tends to be strong public disapproval of needless cruelty, there is general acceptance (subject to minority dissent, of course) on the permissibility of practices that would clearly violate the moral equality of persons if applied to them, such as those involved in livestock farming and animal testing. The implication of excluding some human beings from the status of personhood, however, is that they too do not possess strong claims of equal consideration, potentially legitimating practices that violate their interests for the sake of others. Kittay strongly rejects the questioning of the personhood of people with severe cognitive disabilities because of exactly these kinds of consequences—consequences that would too befall people living with advanced dementia if they were so excluded.⁵⁵

That nonpersons do not have the same moral claims on us that our fellow persons do of course does not mean that they have no claims at all: the case of animal welfare demonstrates this. Nevertheless, in discussions in which personhood plays signifying role 3, these are claims that are limited in *type* as well as strength. While we can be cruel or inhumane toward a nonperson, we cannot treat them *unjustly*: the requirements of social justice are operative only between persons.

Anderson adopts this type of argument when defending her second-person method of justifying principles of justice, stating that “a claim of justice is essentially expressible as a demand that a *person* makes on an agent whom the speaker holds accountable.”⁵⁶ Her primary interlocutor, G. A. Cohen, whom she charges with using a third-person form of justification—justification according to normative and factual premises to which the identity of the person making the argument and the audience are irrelevant—also seems to imply that persons, and persons alone, are the subjects of justice, framing the goal of egalitarian arguments about social justice as an inquiry into the currency it “requires *people* to have equal amounts of.”⁵⁷

If the personhood of people living with dementia were genuinely threatened by the condition, then the stigmatizing and oppressive effects of the loss narrative would not always equate to injustices. Even where they did, moreover, the urgency of addressing them would be blunted by the reinforcement of one of the key distortions the loss narrative engenders: fatalism. If all people living with dementia are irreversibly set on a path to losing the very status that entitles

55 Kittay, “At the Margins of Moral Personhood,” 106–7.

56 Anderson, “The Fundamental Disagreement between Luck Egalitarians and Relational Egalitarians,” 23 (emphasis added).

57 Cohen, “On the Currency of Egalitarian Justice,” 906 (emphasis added).

them to considerations of justice, then any injustices they face are guaranteed to end without the need to mobilize resources and energy against them. This would not absolve the society that failed to address or prevent them, but it would provide grounds to justify, on an all-things-considered basis, prioritizing other pressing issues of justice in circumstances of scarcity.

As with those victims of injustice that have long since died, there may remain a concern of historical injustice for those living with dementia that have lost their personhood. Consideration under this kind of framework, however, falls short of consideration as a standard subject of justice. The dead are not the direct beneficiaries of action to address historical injustice; in cases of individual injustice, it is their surviving loved ones who claim and receive restitution on their behalf, while in cases of group-based injustice, this role falls to surviving members of the social group. Losing their personhood likewise prevents those living with dementia from being direct beneficiaries of action to address those injustices they faced before their condition had progressed. And while loved ones and surviving members of the social group might be motivated to benefit those now nonpersons on whose behalf they have made claims of historical injustice, they would be under no moral obligation to do so. Worse still, historical injustice would cover only that which had occurred before the loss of personhood, so any continuing harms caused by these phenomena would not generate claims of injustice and would pull on only our relative moral concern.

It should be noted that some theorists do think of justice as applying to nonpersons, such that they use the concept of personhood in a way that does not invoke signifying role 3. Even when this is the case, however, a distinction between persons and nonpersons is made, such that justice for nonpersons is of a different priority or of a different kind to justice for persons. Richard Arneson, for instance, has recently stated that principles of justice apply to persons “and other beings as well” but considers the latter a “complication” that needs to be “set aside.”⁵⁸ Likewise, Martha Nussbaum dedicates a chapter of her influential monograph *Frontiers of Justice* to the issue of “Justice for Non-Human Animals,” providing a set of arguments that use the same theoretical framework as those that apply to persons but are distinct in their conclusions.⁵⁹

Justice arguments of this kind, if coupled with a conception of personhood that validated this component of the loss narrative, would still present a problem for the political case I raised in section 1. If justice for nonpersons were of a different kind than that of persons, then it is possible that the propagation of stigmatizing and oppressive language would not represent as serious as an

58 Arneson, “Responsibility and Distributive Justice,” 412.

59 Nussbaum, *Frontiers of Justice*, 325–405.

injustice for the former as for the latter (or may not represent an injustice at all). We do not after all tend to describe negative language used toward animals as stigmatizing or otherwise unjust unless we have a prior commitment to them holding the same moral status and, as such, being worthy of the same level of respect as persons.⁶⁰

In sum, because personhood plays three crucial signifying roles in carving out the moral landscape, the political case against the loss narrative would be severely blunted if it were true that people living with dementia were at risk of losing it. Because persons are typically taken to have a higher moral status than nonpersons, the interests of those people living with dementia who had lost their personhood would be of lower weight. Because only persons are typically taken to be moral equals, they would not be entitled to equal consideration in the formation of political and social structures. Finally, because only persons are typically taken to be subjects of justice (and even when nonpersons are included, they are not typically included in the same way as persons), the urgency of tackling the stigma and oppression engendered by the loss narrative would decrease significantly. Successfully rejecting the loss narrative, then, requires defending the personhood of all people living with dementia.

3. THE PERSON AS ENVIRONMENTALLY INTEGRATED

Defending people living with dementia against the idea that the condition inevitably and irreversibly threatens their personhood will not on its own suffice to overcome the social dominance of the loss narrative entirely. It is nevertheless a necessary first step toward that goal. Of the available accounts of personhood in the literature, however, there are few that are promising for making it. Evidently, most accounts that rely on some cognitive “performance criterion,” to use Michael Bérubé’s term, will support the loss narrative because of the cognitive deterioration involved in dementia; persons living with advanced dementia are unlikely to meet Jeff McMahan’s criterion of having a “rich and complex mental life,” for instance.⁶¹ Perhaps more surprisingly, as Bryden notes, social accounts such as dementia studies pioneer Tom Kitwood’s view of personhood by social bestowal can have a similar effect.⁶² Where such accounts render one’s personhood reliant on recognition by others—recognition that people living with dementia are at great risk of not receiving due to the social

60 For a representative argument of the latter kind, see Milburn and Cochrane, “Should We Protect Animals from Hate Speech?” 1149–72.

61 Bérubé, “Equality, Freedom, and/or Justice for All,” 100; and McMahan, *The Ethics of Killing*, 45.

62 Bryden, *Will I Still Be Me?* 22–23.

injustices they face—they render it, in the words of Hojjat Soofi, “unreasonably socially contingent.”⁶³

In light of this, I aim in this section to develop and defend an account of personhood that is inclusive of all people living with dementia and that presents them as no more at threat of losing it than any other person. On this account of the person as environmentally integrated, personhood is a relational attribute, possessed by all those who share an environment of cognitive extension. In building this view, I make novel links between the extended mind thesis and feminist care ethics. The section begins therefore with a summary of the former, after which I flesh out my account by reference to the latter. I then close by considering some objections.

3.1. *The Extended Mind Thesis: A Primer*

In an influential 1998 article, Andy Clark and David Chalmers defend two distinct but related claims about the nature of human cognition. First, drawing on phenomena such as the use of calculators and writing tools, they argue that aspects of the external environment are often intimately involved in our cognitive processes in such a way that they both support and enhance them. Second, they argue that under specific conditions, these aspects of the external environment are rightly considered constituent parts of our minds.⁶⁴

The first of these claims, at least for those of us who find ourselves increasingly reliant on technology to complete cognitive tasks, ought to be intuitive. Our social world abounds with cognition-supporting artefacts (among other extra extracranial elements), without which certain processes would be difficult or even impossible to engage in. Few but the most gifted mathematicians, for instance, could intracranially complete the kind of complex calculations supported by calculators, and even then, it is unlikely they would be able to do so at speed. Likewise, few but the most gifted musicians would be able to compose and arrange a complex piece of music for multiple instruments without the aid of music manuscript paper. It is the second claim, however, that distinguishes the *extended* mind thesis from cognate theories about cognitive scaffolding, stirring significant controversy along the way.⁶⁵

In developing their argument, Clark and Chalmers ask us to consider the following two cases:

63 Soofi, “Normative Force of Appeals to Personhood in Dementia Care,” 888.

64 Clark and Chalmers, “The Extended Mind,” 9–12.

65 For a representative argument in favor of cognitive scaffolding but against cognitive extension, see Sterelny, “Minds,” 465–81.

Inga hears from a friend that there is an exhibition at the Museum of Modern Art and decides to go see it. She thinks for a moment and recalls that the museum is on 53rd Street, so she walks to 53rd Street and goes into the museum. . . . Otto suffers from Alzheimer's disease, and like many Alzheimer's patients, he relies on information in the environment to help structure his life. Otto carries a notebook around with him everywhere he goes. When he learns new information, he writes it down. When he needs some old information, he looks it up... Today, Otto hears about the exhibition at the Museum of Modern Art and decides to go see it. He consults the notebook, which says the museum is on 53rd Street, so he walks to 53rd Street and goes into the museum.⁶⁶

Otto's notebook, Clark and Chalmers argue, plays the same role as Inga's biological memory in retrieving the address of the museum.⁶⁷ It is thus subject to what has since been termed the *parity principle*, expressed by Clark in solo-authored work as: "if, as we confront some task, a part of the world functions as a process which, were it done in the head, we would have no hesitation in recognizing as part of the cognitive process, then that part of the world is (for that time) part of the cognitive process."⁶⁸

The extended mind thesis evidently represents a radical reconceptualization of the metaphysics of cognition. It should be noted, however, that the second claim is not intended to entirely subsume the first; some—likely most—extracranial elements are genuinely merely supportive. This is so because, as Clark has since emphasized, the "no hesitation in recognizing" condition of the parity principle is fairly stringent, requiring that the extracranial element (a) is reliably and typically invoked, (b) contains information that is more or less automatically endorsed, and (c) contains information that is easily accessible as and when required.⁶⁹ While Otto's notebook meets these criteria, other artefacts that might be used to retrieve the address of the museum, such as a rarely-consulted book or a device with access to the internet, would not.

Its limited range of application nevertheless has not spared the second claim of the extended mind thesis from criticism. Fred Adams and Ken Aizawa, for example, have argued that it rests on a "coupling-constitution fallacy" that inappropriately labels all elements coupled with the mind as part of it and that its proponents have failed to demonstrate that external elements like Otto's notebook are genuinely part of the mind because they have not demonstrated that they

66 Clark and Chalmers, "The Extended Mind," 12–13.

67 Clark and Chalmers, "The Extended Mind," 13.

68 Clark, "Memento's Revenge," 44.

69 Clark, "Memento's Revenge," 46.

bear the “mark of the cognitive.”⁷⁰ Likewise, Keith Butler has dismissed it on the grounds that the “final locus of computational and cognitive control resides in the head of the subject.”⁷¹ While there is insufficient space to do justice to these debates here, it is worth briefly summarizing the responses Clark has made to these critics, as they help to clarify the shape and boundaries of the thesis.

Regarding Adams and Aizawa, Clark has responded that the thesis does not involve the claim that external elements can be by themselves cognitive. The point rather is that they can sometimes be properly considered parts of a cognitive system, consisting of both internal and external resources. So in the case of Otto, it is not that the notebook itself believes that the address of the Museum of Modern Art is at 53rd Street but that the cognitive system of which both Otto’s brain and the notebook are a part holds that belief. Consequently, the “mark of the cognitive,” whatever it consists in, is borne by the whole system, not its constituent parts.⁷²

Regarding Butler, Clark has disputed the very idea that the “final locus of computation and cognitive control” determines the boundaries of the agent. Long-term memory stores after all play no more of a part in Inga’s final choosing than Otto’s notebook does, but both contain information that significantly influences their bearers’ identities as agents. While it might be appropriate to identify the locus of final choosing with consciousness or subjectivity, then, Clark argues that to do so with the cognitive agent is to “shrink the mind and self beyond recognition, reducing [its bearer] to a mere bundle of control processes targeted on occurrent mental states.”⁷³

While it is not without its critics, then, the extended mind thesis should not be caricatured. It does not imply that all cognition-supporting extracranial elements are parts of their users’ minds—only those that meet conditions of deep integration. It does not imply that external elements are capable of bearing mental states (by themselves)—only that they can be parts of a cognitive system that bears those states. Finally, it posits only that cognition can be (and often is) extended: related but distinct concepts like consciousness and subjectivity may very well be entirely intracranial.

3.2. *Sharing an Environment of Cognitive Extension*

If the extended mind thesis is right, it requires a significant shift in the way we think about cognition. More broadly, it also requires a significant shift in what

70 Adams and Aizawa, “Defending the Bounds of Cognition,” 67–68.

71 Butler, *Internal Affairs*, 205.

72 Clark, “Coupling, Constitution, and the Cognitive Kind,” 96–97.

73 Clark, “*Memento’s* Revenge,” 55–56.

we think of as core human capabilities. Clark anticipates this in solo-authored work, arguing that human beings are primed to both seek cognitive support from external sources and integrate those elements into our cognitive systems, making us “natural-born cyborgs.”⁷⁴

It would be tempting, given both the centrality of dementia to Clark and Chalmers’s case for the extended mind thesis and Bryden’s extensive use of technology to enable her to write, to ground the conception of personhood necessary to challenge the loss narrative in this status.⁷⁵ “Persons as natural-born cyborgs” would be an account that included people living with dementia and that presumably encouraged reverence of the extracranial elements they rely on to fulfil cognitive functions. It might thus be a politically useful account to rally around when advocating on the behalf of those living with dementia.

It is not obvious, however, that such an account could successfully play the three signifying roles typically played by conceptions of personhood to carve out the moral landscape. The ability to extend one’s mind (or indeed, having a mind that is capable of being extended) is certainly impressive, but it seems morally arbitrary—akin to flight or other species-specific abilities. Without additional information, it is difficult to see how the ability could possibly be used to justify a moral hierarchy between those beings that have it and those that do not. Furthermore, it seems like a capacity that some are able to exercise better than others, calling into question its ability to ground the moral equality of persons and, by implication, its suitability for determining the scope of justice—the issues with using scalar properties in this way are the subject of extensive debate in the literature on moral equality.⁷⁶

This is a significant problem, because any account of personhood I develop here needs to be conceptually robust enough to replace those in common usage. If not, then it is unlikely to gain traction as an alternative, dampening its ability to contribute to overcoming the loss narrative. Instead of developing a conception of personhood grounded in the mere capacity for cognitive extension, then, I want to further complicate—and hopefully strengthen—this picture by introducing an additional element: the moral significance of human relationships.

Theorists working in feminist care ethics have long criticized the idea of the independent rational agent, highlighting the unique extent and length of human juvenile care needs and the complex ways in which human beings depend on

74 Clark, *Natural-Born Cyborgs*, 31.

75 Bryden, *Will I Still Be Me?* 27–34.

76 For a helpful summary of the relevant literature, see Sher, “Why Are We Moral Equals?” 17–29.

one another to meet their needs as adults.⁷⁷ It is in this spirit that Kittay rejects theories of personhood that would exclude her cognitively disabled daughter, arguing that our moral duties toward one another originate in and depend on for their character “a matrix of relationships embedded in social practices through which the relations acquire meanings.”⁷⁸ Similar arguments have been made by Hilde Lindemann, who draws attention to the social practices we engage in to initiate other humans into personhood and hold them there through recognition and social identity shaping.⁷⁹ Personhood can be understood in this light as a *relational attribute*: conferred through relationships and given meaning through the social practices within which they are embedded.

While there are great strengths to this view, the process by which the relationships gain such significant moral meanings—significant enough to ground the kind of moral hierarchy engendered by the three signifying roles of personhood—is a little hazy. In Kittay’s description of the process, no causal link is offered to explain the conferring of moral meanings onto social relations by social practices, leaving a key component of the care ethics view of the moral significance of human relationships unspecified. Similarly, while Lindemann’s account of the relational composition and reinforcement of personal identity is sociologically persuasive, it is not immediately clear we should think that these practices are a source of moral *value*. This lacuna can be filled, I propose, by introducing the view of human cognition implied by the extended mind thesis.

As cognition is strongly environmentally determined, so too is our collective ability to generate, develop, and adhere to moral concepts. Social practices accordingly can be said to confer social relationships with moral meaning because of the way they build and develop the environment into which our minds must extend to be able to engage in moral reasoning. Productive practices, for instance, generate material goods, some of which become objects of moral reasoning—about what they are for and who should receive them—and some of which, such as writing implements, support it by enabling persons to work through and communicate their solutions to complex problems. Likewise, cultural practices, such as those from which languages develop, support us in thinking abstractly and communicating moral ideas to others. In short, such relationships can be said to confer personhood because they are embedded in the social processes from which this moral concept, along with the rest of morality itself, emerges—a quality that is not morally arbitrary and is thus suitable for grounding the moral distinction between persons and nonpersons.

77 Held, *The Ethics of Care*, 10.

78 Kittay, “At the Margins of Moral Personhood,” 111.

79 Lindemann, *Holding and Letting Go*, 1–30.

Note that there is no need here to invoke the kind of performance criteria that can scupper the ability of an account of personhood to justify the moral equality of persons and in turn the ability for such an account to ground justice considerations. While the environment of cognitive extension from which moral concepts are derived is developed through the performance of social practices, it is not active participation that confers personhood but *presence*. To be a person on this view is merely to be integrated into an environment in which these practices are operative, such that one is both shaped by it and contributes to shaping it merely through one's presence as a particular kind of being in a particular kind of relationship that is itself part of the overarching matrix.⁸⁰

All people living with dementia, at any stage of progression, can be a part of this matrix of overlapping relationships merely by being situated in the right sort of relationships. While it is certainly possible that someone might be cruelly cut off from relating in this way, the kind of extreme actions necessary to do so could just as easily be targeted at persons without dementia. To fully remove such a person from the matrix, all those with whom they have significant relationships would need to be removed from it, all records that indicate that they are a specific person who has related to the overarching environment in specific ways over time would need to be destroyed, and they would need to be so completely cut off from human contact that they would have no opportunities to form relationships that would reconnect them to an environment of cognitive extension. As well as being a plausible conception of personhood, then, the idea of the person as environmentally integrated also provides grounds to challenge the loss narrative.

3.3. *Three Objections*

I have sketched out a conception of personhood that combines insights from care ethics and the extended mind thesis in order to include people living with dementia and to challenge the loss narrative. Fully exploring its wider consequences is far beyond the scope of this paper and the limited space available. Nevertheless, before closing I want to respond to three pertinent objections that could be made, as each will help to further clarify the account. The three objections pertain to over-inclusion, over-exclusion, and misguidedness.

The first two of these objections are standard fare for any account of personhood: such accounts need to draw the line somewhere and so will inevitably

80 Note that this presence is active and continuing, not static. The continued existence of persons living with dementia in an environment related in specific ways to other persons and artefacts leads to continual reshaping of the meaning-making practices that arise within it, just as does the presence of other persons. For an exploration of these sorts of dynamics, see Chapman, Philip, and Komesaroff, "Towards an Ecology of Dementia," 209–16.

face backlash for including certain beings and excluding others. At this stage, I can anticipate two such arguments that this account may face: first, that by making the key criterion for personhood relational, it risks including beings or even objects that some eccentric persons report relationships with; and second, that by doing so it excludes human beings we are not related with yet we ought to recognize as persons—namely, so-called uncontacted peoples who live without sustained contact with the international community.

Regarding the first, it ought to be noted that care-ethics-style reasoning requires a two-way relationship; a person is not in the relevant sort of relationship with their car merely because they profess to love it, for instance.⁸¹ Accordingly, though it is presence and not performance that determines whether a being is a person, that presence depends on the existence of very minimal capacities to relate to other humans—that is, those elements of social cognition that involve detecting and responding to other humans, which appear to be preserved to at least a minimal degree in the progression of all dementias.⁸² While this might rule inanimate objects out, some may yet be concerned that it captures at least some nonhuman animals kept as pets, such as dogs and cats, all of whom may turn out to have such capacities. If such a conclusion is entailed, however, it is not necessarily so bizarre as to undermine the account; our practices suggest that we do in fact regard certain nonhuman animals as possessing a significant moral status when we are related to them in particularly meaningful ways, so it would not be too much of a stretch from common-sense moral reasoning to describe them as persons.

Regarding the second argument, it ought to be noted that such peoples, if they are in the right kinds of relationships with each other, do share an environment of cognitive extension. It is not *our* environment, but that does not preclude them from possessing personhood—that is, being persons *to each other*. While what being a person means may differ across matrices of overlapping relationships, we can recognize from within our own the practices of meaning-making and moral reasoning that take place in others, especially among other humans whom we can reasonably assume would be persons to us were we related to them in the right sort of ways. The account therefore does not entail that we have no moral duties toward outsiders or reasons to treat them as persons merely because they do not share *our* environment of cognitive extension.

81 Noddings, “Care Ethics and ‘Caring’ Organizations,” 77–79.

82 See Heitz et al., “Cognitive and Affective Theory of Mind in Dementia with Lewy Bodies and Alzheimer’s Disease,” 373–81; Harciarek and Cosentino, “Language, Executive Function and Social Cognition in the Diagnosis of Frontotemporal Dementia Syndromes,” 178–96; and Batra, Sullivan, Williams, and Geldmacher, “Qualitative Assessment of Self-Identity in People with Advanced Dementia,” 1260–78.

The last potential criticism concerns the wisdom of the entire enterprise. Kittay has raised significant concerns about the practice of making moral distinctions between human beings—a practice with a dark and bloody history.⁸³ Along these lines, a critic might object that we would be better off rejecting the concept of personhood altogether due to the political risks it may pose to human beings (or nonhuman animals) who might fall—or be falsely thought to fall—on the wrong side of the threshold. Indeed, it has been argued that a focus on personhood is not even particularly helpful in the specific case of people living with dementia.⁸⁴

To this I make two (tentative) responses. First, it might seem that we need a way of distinguishing morally between human beings in order to resolve conflicts around abortion rights, the status of anencephalic children, the moral permissibility of embryonic research, and cognate issues. And even if objectors do not accept that it is philosophically necessary, they ought to consider why the use of a conception of personhood might be *politically* necessary. The political context is one in which the term “personhood” is used and widely invoked. Postponing the defense of the personhood of people living with dementia to engage in the much more arduous enterprise of extinguishing it from our moral vocabulary entirely comes with a significant opportunity cost that is likely to serve members of this group badly in the short to medium term.

The account of the person as environmentally integrated, then, can be used to defend the personhood of people living with dementia and can resist some of the concerns raised here. Because it is not based on a morally arbitrary attribute, it is suitable for playing the signifying role of establishing a moral hierarchy between persons and nonpersons. Because it is not based on a performance criterion, it is suitable for grounding the idea that persons are morally equal, which in turn can ground the idea of social justice. By combining insights from care ethics and the extended mind thesis, the idea of loss of personhood present in the loss narrative can be rejected.

4. CONCLUSION

In this paper I have bolstered the political case made by self-advocate Christine Bryden against a key contributor to social injustices faced by people living with dementia: the loss narrative. By examining the distortions it engenders and its contribution to stigma and oppression, I have argued that there are strong and urgent reasons to challenge it. In order to do so, however, it is necessary

83 Kittay, “At the Margins of Moral Personhood,” 114–26.

84 Higgs and Gilleard, “Interrogating Personhood,” 773–80.

to develop an account of personhood that is inclusive of people living with dementia, such that the idea of the loss of personhood contained within the narrative can be rejected. I have therefore set out an account of the person as environmentally integrated.

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