# Transing dementia: Rethinking compulsory biographical continuity through the theorization of cisism and cisnormativity

Marjorie Silverman [a,*], Alexandre Baril [b]

[a] *School of Social Work, University of Ottawa, 120 University, Room 12044, Ottawa, Ontario K1N 6N5, Canada*
[b] *School of Social Work, University of Ottawa, 120 University, Room 12025, Ottawa, Ontario, K1N 6N5, Canada*

## ABSTRACT

Using theoretical tools from trans studies and disability/crip studies, we reconceptualize the self in the context of dementia. We illustrate that most dementia discourse, scholarship and intervention emphasize a maintenance of the pre-dementia self. We argue that the compulsory biographical continuity needed to maintain the pre-dementia self is based on interlocking forms of ageism, ableism, and cogniticism, and interacts with what we call cisism (the oppressive system that discriminates against people on the basis of change) and its normative components, cisnormativity* and ciscognonormativity. After providing a critical genealogy of the term cisnormativity*, we resignify and redeploy this concept in the context of dementia, demonstrating how it is useful for critiquing compulsory biographical continuity. Following the verbs queering and cripping, we propose a transing of dementia that leads to a new conceptualization of the self that is fluid and changing, rather than one anchored in multiple oppressions.

## Losing your mind, losing your self? Cisnormative assumptions behind compulsory biographical continuity

"The prospect of losing one's mind – as dementia's literal translation insinuates – is very frightening indeed. It suggests losing one's place in the adult world. It implies a painful amputation from one's former self. Once one descends into a state of increased cognitive deterioration, one imagines, layer upon layer of one's self disappear along with a lifetime of memories." (Haeusermann, 2019, 1).

In this quotation from an article questioning the "forced continuity" of the pre-dementia self[1] in dementia care, (Haeusermann, 2019, 1) identifies one of the most terrifying aspects of dementia for most lay people, researchers, and healthcare professionals: the potential "loss" of self. In representations of aging, care narratives, policy discourses, individual testimonials, and the social imaginary, dementia is perceived as problematic in a large part due to its often radical impact on the self. For many, the idea that we, or someone we love, may lose memories or change cognitively in potentially unrecognizable ways feels akin to

death. Dementia thus becomes something to be avoided at all cost, a thing both abject and unwanted. Such fears are an integral component of what fuels ableist and cogniticist attitudes towards dementia and ageist attitudes towards older adults more broadly. The term "cogniticism" that we coined refers to the "oppressive system that discriminates against people with cognitive/mental disabilities" (Baril & Silverman, 2019, 12). The normative components of this oppressive system are expressed through cognonormativity, a notion coined by King a few years earlier (King, 2016, 59).

This article argues that the fears fuelling widespread conceptions about loss of self in dementia, as well as the accompanying practices focused on preserving the pre-dementia self, or what (Haeusermann, 2019) calls "forced continuity", are grounded not only in ableism, cogniticism, and ageism, but also in cisnormativity and what we define below as "ciscognonormativity". While cisnormativity is a concept traditionally used in trans studies to refer to the normative component of a cisgenderist (or transphobic) system (Ansara & Hegarty, 2012; Pyne, 2011), we employ the notion of cisnormativity* in a wider sense, following Baril's invitation to broaden the concept by returning to its

---

[1] We use the term "dementia" to denote a variety of realities that lead to cognitive changes, including Alzheimer's disease and vascular dementia. Throughout the article, we refer to dementia as a cognitive disability; we approach dementia from a critical disability perspective rather than from a medical perspective (Aubrecht & Keefe, 2016; Shakespeare, Zeilig, & Mittler, 2019; Thomas & Milligan, 2018). Although we use the term "pre-dementia self", we do not endorse such a clear distinction between pre-diagnosis and post-diagnosis; it is simply a discursive mechanism to indicate changes to the self that occur with the onset of dementia.

historic origins as a prefix designating *sameness* (Baril, 2009; 2013). Throughout this article, our own arguments are expressed using cisnormativity* with an asterisk to indicate, like Baril, an expansive definition of the concept.[2] We use the concept of cisnormativity* to refer to normative expectations surrounding sex/gender continuity or sameness, as well as those surrounding multiple forms of continuity and sameness, such as biographical continuity for people living with dementia. Our conceptualization of cisnormativity* refers to the fact that, from a normative stance, we expect people to remain generally the same throughout their lives, an injunction here we call "compulsory biographical continuity", a term inspired by feminist, queer, and crip theories of "compulsory heterosexuality", "compulsory able-bodiedness", "compulsory able-mindedness" (Kafer, 2013; McRuer, 2003; Sandberg & Marshall, 2017), and "compulsory nostalgia" (Kafer, 2013). Certain age- and stage-based changes, including becoming an adult, becoming a parent, developing new professional identities, changing political affiliations, gaining new insights through personal development, changing religion, and gaining or losing weight, among others, are generally considered somewhat acceptable or, if not, are at least understood as not leading to a loss of self (although some may lead to discrimination or marginalization). Yet, in cases of significant cognitive changes like those that accompany dementia, the self is thought to be disturbed in a way that significantly breaks biographical continuity, thereby representing a threat to cisnormative* conceptions of the self. This is also true for other forms of impairments, as Kafer (2013, 42–43) reminds us:

> Indeed, fears about longevity "under any circumstances"—fears of disability, in other words—are often bound up in a kind of *compulsory nostalgia* for the lost able mind/ body, the nostalgic past mind/ body that perhaps never was. People with "acquired" impairments, for example, are described (and often describe themselves) as if they were multiple, as if there were two of them existing in different but parallel planes, the "before disability" self and the "after disability" self (as if the distinction were always so clear, always so binary). Compulsory nostalgia is at work here, with a cultural expectation that the relation between these two selves is always one of loss, and of loss that moves in only one direction. The "after" self longs for the time "before," but not the other way around; we cannot imagine someone regaining the ability to walk, for example, only to miss the sensation of pushing a wheelchair or moving with crutches.

To denote the particular form of compulsory biographical continuity imposed on people with cognitive disabilities, including those living with dementia, we have coined the terms "ciscognonormativity", a specific component of cisnormativity*, and "cisism", the larger oppressive system discussed in the third section of this article.

This article is divided into four sections. The first section explores the literature on personhood and concepts of the self in dementia studies to illustrate that although understandings of the self in dementia have expanded considerably – for example, towards non-pathological and critical perspectives and embodied notions of selfhood – most discourse, scholarship, and intervention related to dementia emphasizes the importance of biographical continuity and the preservation of the pre-dementia self. In the second section, we delve into the concept of cisnormativity, tracing its historical and genealogical roots and exploring its emerging scholarly resignification through the usage of the asterisk. In the third section, we propose to redeploy the concept of cisnormativity* in the context of cognitive disability. We apply the concepts of cisism, cisnormativity* and ciscognonormativity to dementia and illustrate how this oppressive system and its normative components are both interlocked with ableism, cognitism, and ageism and play a role in the epistemic injustices faced by people with dementia (i. e., injustices that impact them as knowledgeable subjects). In the fourth and final section, we mobilize epistemological and theoretical tools from trans studies to propose a transing[3] of dementia that aims to disrupt normative conceptualizations of the self in the context of dementia. Building on our trans-affirmative, crip-positive and anti-ageist paradigm of intervention with trans people living with dementia (Baril & Silverman, 2019), we rethink the notion of selfhood based on valuing fluidity and changeability, instead of on a cisnormative* injunction to sameness. We argue that people with dementia should not be required to comply with cisnormativity* and its compulsory biographical continuity in order to be considered worthy of recognition, agency, and epistemic credibility. With applications in multiple disciplines, including dementia studies, trans studies, queer and gender studies, crip/mad studies, and critical gerontology, we believe that reconceptualizing the self in dementia using conceptual tools from trans and disability/crip studies can help reduce the fear associated with dementia and its accompanying ableist, cogniticist, and ageist attitudes. Similarly, we believe that bringing the notion of cisnormativity* into dialogue with dementia can help broaden and de-centre trans studies from sex/gender issues. In other words, our proposed transing of dementia also entails a transing of both cisnormativity and trans studies.

**Holding on for dear life: The self in dementia**

Before surveying the conceptualization of the self in dementia scholarship, it is important to make a couple of important caveats. The first is that it is not the intention of this article to engage in a philosophical analysis of personhood or selfhood. This has already been done in key texts such as Parfit (1984), Dworkin (1986), Dresser (1995), Jaworska (1999), and Sabat and Harré (1992), among others. Higgs and Gilleard (2016) also provide an excellent discussion of the nuances and shortcomings of the term "personhood", explaining the differences between personhood as moral standing, metaphysical state, and its interpretation in many spheres of practice as person-centered care (see pages 11–26). Dewing (2007) also discusses various definitions of personhood as well as the pitfalls of the popularization and common usage of Kitwood's (1997) conceptualization of personhood. Although the terms "person/personhood" and "self/selfhood" are often used interchangeably in literature on dementia, the popularization of Kitwood's (1997) work led to increased use of the terms "person/personhood" within dementia studies. As a result, we also use "person/personhood" in this article's literature survey. However, following Sabat and Harré (1992), we have chosen to express our own arguments with the terms "self/

---

[2] Baril (2013; 2015) places an asterisk after certain terms beginning with the prefix cis, similar to the way some scholars in trans studies have placed an asterisk after the term trans*. As Hayward and Weinstein (2015) explain, using "trans*" with an asterisk opens up a world of possibilities, much like "trans-" with an hyphen. In a key article in trans studies, Stryker, Currah, and Moore (Stryker et al., 2008, 11) propose the use of "trans-" with an hyphen: "A little hyphen is perhaps too flimsy a thing to carry as much conceptual freight as we intend for it bear, but we think the hyphen matters a great deal, precisely because it marks the difference between the implied nominalism of "trans" and the explicit relationality of "trans-," which remains open-ended and resists premature foreclosure by attachment to any single suffix. Our call for papers reads: "Trans: -gender, −national, −racial, −generational, −genic, −species. The list could (and does) go on. This special issue of *WSQ* invites feminist work that explores categorical crossings, leakages, and slips of all sorts, around and through the concept 'trans-'." We are very aware of the current debates and controversies surrounding the use of the term trans* with an asterisk. Various trans people, activists or scholars used the asterisk in the early 2000–2010 to denote an inclusive definition of the term trans* as an umbrella encompassing transsexual, transgender and non-binary people. We are not using the asterisk in that sense, nor from an identity politics perspective. We are using the asterisk to open the term cisnormative to new significations.

[3] The polysemic verb "transing" is defined later in this paper. As discussed by Stryker et al. (2008, 13), "[t]hose of us schooled in the humanities and social sciences have become familiar, over the past twenty years or so, with queering things; how might we likewise begin to critically trans- our world?".

selfhood". Sabat and Harré's work makes reference to the constructed and positioned nature of the self and the fact that we have multiple "selves" that represent various facets of a seemingly cohesive whole. We find this focus on the positioned, constructed, performed, and discursive aspects of the self useful for reflecting on change and fluidity in the context of dementia. We therefore use the words "self/selfhood" to refer to a combination of elements that comprise someone's identity, including memories, narratives, personality, preferences, public personas, and more.

The concept of personhood has been foundational to countering the medical model's discourse about widespread loss in the face of dementia. Since the 1990s, following Tom Kitwood's (1997) pioneering work on personhood, there has been increasing awareness of the need to provide people with dementia with individualized care that meets their needs for attachment, relationality, respect, comfort, and recognition (Fazio, Pace, Flinner, & Kallmyer, 2018). In addition to advocating for personalized care, Kitwood was adamant that people with dementia can retain their identity and that care providers should help them maintain their pre-dementia identity. Kitwood's work became the basis of what we now call person-centered care practices, which, in the Global North, are often considered best practices in dementia intervention (Aubrecht & Keefe, 2016; Fazio et al., 2018). Anchored in the notion of personhood, individualized care practices have no doubt led to significant improvements in the lives of many people with dementia; nevertheless, it has not been a panacea. Many people with dementia remain stigmatized, narratively dispossessed (Baldwin, 2008), socially disenfranchised (Beard & Fox, 2008), and not always treated as people with valid opinions (Brannelly, 2011). Furthermore, the concept of personhood has been critiqued for not going far enough to rehabilitate the person with dementia. This critique has mainly come from scholars putting forth new conceptualizations of agency and social citizenship for people with dementia who state that personhood alone is insufficient to restore people with dementia's place in society. For example, Bartlett and O'Connor (2007; 2010), in their influential work on social citizenship for people with dementia, explain that "personhood is conceptualized as something that is conferred upon a person with dementia, conveying a unidirectional understanding which arguably continues to position a person with dementia as passively dependent upon others for affirmation" (Bartlett & O'Connor, 2007, 110). They, and others after them, have argued that people with dementia must be seen not only as people but also as active citizens, participants, and agents in the world (Baldwin & Greason, 2016; Bartlett & O'Connor, 2010; Boyle, 2014). O'Connor (2019) has recently argued that "citizenship-in-practice" means respecting the right of people with dementia to grow and change, as well as valuing their multiple, intersecting identities. Despite these important contributions emphasizing agency and the fluidity of the self, the citizenship literature does not, as we do here, engage with other fields of knowledge that also discuss the fluidity of the self, such as trans studies.

For the purposes of this article, our primary interest in the notion of personhood is its basis in the idea that people with dementia should be encouraged to retain their pre-dementia person or self, and that this idea has proliferated in dementia research and intervention. Emphasis on the pre-dementia self is evident even in the cutting edge "bodily turn" in dementia research and intervention, which has highlighted the way the body can be a tool to facilitate identity expression in people with dementia. For example, Kontos' (2004; 2005; 2006) pioneering ethnographic observation in care homes illustrated not only that the bodies of people with dementia can express selfhood, but that "the body is a substantive means by which persons with severe cognitive impairment engage with the world" (Kontos, 2005, 556). While Kontos' work argues that the body is a means of expression for the current self, it also emphasizes the sociocultural cues of the pre-dementia self thought to be retained in the body at a pre-reflexive level and expressed through music, movement, and gestural habits such as clapping one's hands, peeling an egg, or manoeuvring jewelry (Kontos, 2005). Along the same lines, Twigg and Buse (2013) and Buse and Twigg (2016; 2014) found

that clothing and personal objects such as handbags help people with dementia to express their identity and to retain connections, memories, and continuity with their pre-dementia selves. Similarly, Ward and Campbell (2013) and Ward, Campbell, and Keady (2014) found that body work, including hair styling, was one way in which people with dementia were able to perform, and therefore maintain, aspects of their pre-dementia identity. This type of body-based research has paralleled the increasing popularity of arts-based interventions in dementia practice that rely on music, movement, theatre, or the visual arts to evoke expressions of the self, a self that relies on a certain continuity with the past (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016; Gray, Dupuis, Kontos, Jonas-Simpson, & Mitchell, 2020; Habron, 2013; Kontos & Naglie, 2007). Such body-based and arts-based research and interventions have been invaluable for improving the lives of people with dementia and highlighting the fact that people with dementia are able to retain agency. We are trying to build on this important work by inviting reflection on the fact that in dementia research and practice, as well as in critical dementia studies (with some exceptions), in addition to placing value on agency there is also value placed on the idea of maintaining biographical continuity. One example of such an exception is the work of Linn Sandberg (2018), who argues that maintaining continuity for people with dementia is accomplished through pressure to sustain normative gender and sexual orientation performativity.

Michael Bury (1982) was one of the first sociologists to argue that chronic illness disrupts the structures, routines, and relationships of one's life, which in turn threatens biographical continuity. Although not conceptualized in the context of dementia, Bury's notion of "biographical disruption" seems to have entered into the social imaginary, discourses, and scholarship regarding dementia. For many individuals, families, and practice milieus, there exists a desire to minimize the biographical disruption of dementia and to mitigate its impact on memories, narratives, and personal identity. Harnett and Jönson (2017) found that nursing care practices for individuals with dementia are often based on what these individuals were like prior to having dementia, hence reinforcing the idea of biographical continuity. They explain: "During interviews, biographical references to life outside the nursing home were frequently used to define personal needs. External life referencing was used to challenge traditional ideas where residents should adjust to institutional routines" (Harnett & Jönson, 2017, 3). In a similar vein, Haeusermann (2019), quoted at the beginning of this article, confirms that ethnographic observation in a dementia village in Germany shows that "living and caring in the dementia village frequently meant living with a past that was imagined through a former role as the public persona and as a biographical benchmark" (Haeusermann, 2019, 6). In other words, "forced continuity", which was assumed to be preferable, was often imposed on the person with dementia, leading to potentially insidious forms of violence (Haeusermann, 2019, 2). Continuity was not only imposed by the staff, but also desired and demanded by many family members who wished to see their loved one maintain their prior habits and appearance. This echoes Buse and Twigg's (2018) work on clothing and dementia, which found that many carers pushed for appearance maintenance in an effort to maintain normalcy and continuity and avoid further stigmatization.[4] Baril, Silverman, Gauthier, and Lévesque (2020) demonstrated that a similar phenomenon is true regarding end-of-life planning for trans

---

[4] Buse and Twigg (2018) explain that for people living with dementia and their carers, appearance maintenance was important for avoiding stigma and discrimination; in other words, the more the person with dementia could avoid problems (wearing the wrong type of clothing, wearing something in the wrong way, or something stained, etc.), the more they felt safe from stigma. It could be argued, therefore, that in most cases family members believe that maintaining continuity, including continuity in appearance, is helpful. We do not dispute this perspective; we are simply arguing that maintaining continuity can have potentially problematic side effects, such as those we raise in this paper.

people; activists, allies, and family members often encourage trans older adults to complete advance directives regarding gender in order to maintain gender continuity in the face of dementia.

We argue that interventions based on biographical continuity, even those intended to help people with dementia retain agency and empowerment, might have unintended consequences. While the desire to seek biographical continuity in the face of cognitive disability is understandable, especially when it can help avoid further forms of stigmatization and marginalization and maintain connectedness with the person with dementia, it also raises several questions. What are the assumptions behind the desire for continuity? What are its potential negative implications not only for people living with dementia, but also more generally for conceptualizations of the self linked to many other changes throughout the life course? While we honour and applaud important interventions and practices that value the individual needs of people with dementia and attempt to facilitate their expression of (continued) self, we critique the fact that the value collectively placed on pre-dementia selves, apparent in many spheres of dementia research and practice, including critical dementia studies, is too often based on a static notion of the self and what it means to be human. We are not critiquing the fact that many people with dementia and their support networks want to hang on to the self they used to be and might still feel they are. We are simply questioning the presumptions behind the emphasis on continuity and contend that the exaggerated value placed on the unchanged self keeps us locked in an oppressive narrative of fear and loss regarding dementia, a narrative that has very real discriminatory consequences on the lives of people with dementia, as we explicate in the third and fourth sections of this paper. Furthermore, as we argue in the following sections, the valuing of pre-dementia selves, and the compulsory biographical continuity required to maintain them, is based on interlocking forms of ageism, ableism, and cogniticism. These oppressions interact with cisism and its normative components, cisnormativity* and ciscognonormativity, in ways that lead to multiple forms of discrimination and injustice.

## A critical genealogy and resignification of the notion of cisnormativity

The concept of cisnormativity, at the heart of this article, is widely used today in a variety of scholarship. However, to our knowledge, a genealogy of the concept has never been undertaken. Because we mobilize this concept in a central way, yet depart from its traditional usage, we believe it is important to provide a detailed historical account of its usage and resignification, a detour that is itself a worthy contribution to the disciplines that mobilize this concept. Therefore, this second section proposes a genealogy of the historical and current usage of the prefix "cis-" and related terms, including "cisnormativity", in order to elucidate their pertinence for theorizing the self in the context of dementia in the third section. The origins of the prefix "cis-" can be summarized as follows:

In the field of natural science, the cis adjective is employed as the antonym of trans, the first referring to an element that is on the same side, the second, signifying "beyond" in its Latin origins, referring to an element belonging to both sides. More generally, the trans prefix designates, in contrast to the cis prefix, a transformation and a transition. The cis prefix is therefore associated with sex and gender terms to designate those people who decide not to undergo sex or gender transitions (Baril, 2009, 283–284, our translation).[5]

As explained by Enke (2012), biologist Leland Defosse is credited with coining the term "cisgender" in the mid-1990s, although her

attempts to disseminate the neologism were unsuccessful. According to Enke, two events contributed to the eventual widespread dissemination of the term: the first was the use of the terms "cisgender", "cissexual", and "cisterhood" by well-known transfeminist Koyama (2002), and the second was Serano's (2007) creation of derivative concepts, including cissexism, cissexual privilege, and cissexual assumption. While both Serano and trans communities more generally had provided multiple concepts to reflect on cisgender identities and privileges and prepared the field for new terms, it was not until 2009 that the notion of cisnormativity emerged in academic research. In the English and French literature, the concept of cisnormativity appeared simultaneously in the work of Bauer et al. (2009) and Baril (2009). Bauer et al. (2009, 356) define cisnormativity as follows:

Cisnormativity describes the expectation that all people are cissexual, that those assigned male at birth always grow up to be men and those assigned female at birth always grow up to be women. This assumption is so pervasive that it otherwise has not yet been named. Cisnormative assumptions are so prevalent that they are difficult at first to even recognize. Cisnormativity shapes social activity such as child rearing, the policies and practices of individuals and institutions, and the organization of the broader social world through the ways in which people are counted and health care is organized. Cisnormativity disallows the possibility of trans existence or trans visibility.

While we recognize the invaluable contribution made by Bauer and her team (Trans Pulse Survey), we would like to underline that while they coined the term "cisnormativity" in their article and recognized the influence of Serano in their theorization, their definition of cisnormativity is very similar to what Serano described as "cissexual assumption". Serano (2007, 164–165) writes:

The second process that enables cissexual privilege is cissexual assumption. This occurs when a cissexual makes the common, albeit mistaken, assumption that the way they experience their physical and subconscious sexes […] applies to everyone else in the world. In other words, the cissexual indiscriminately projects their cissexuality onto all other people, thus transforming cissexuality into a human attribute that is taken for granted. […] Thus, while most cissexuals are unaware that cissexual assumption even exists, those of us who are transsexual recognize it as an active process that erases trans people and their experiences.

In her chapter "Dismantling cissexual privilege", Serano (2007) discusses not only the assumption that everybody is cissexual unless otherwise stated, but also, as reflected in the quotation by Bauer et al. (2009) above, the multiple areas in which cissexual assumption contributes to discrimination and erases trans people's identities and lives. Serano identifies five forms of violence anchored in cissexual privilege and assumption: trans-exclusion, trans-objectification, trans-mystification, trans-interrogation, and trans-erasure. While the coinage of "cisnormativity" by Bauer et al. (2009) represents an interesting development in the expansion of vocabulary formed with the prefix "cis-", their definition appears to use new vocabulary to analyze similar phenomena identified by Serano in her key work on cissexual assumptions and the various forms of violence and erasure faced by trans people.

In the same year, Baril (2009) also coined, in French, a variant of the term "cisnormativity:" "cisgendernormativity," sometimes written with parentheses "cis(gender)normativity." He writes: "Cisgendernormativity postulates that people who accept their gender assigned at birth are more normal than those who decide to live in another gender or undergo sex transition […]. In this way, a hierarchy is created between the two groups that allows the norm to reaffirm its power and justify its normality" (Baril, 2009: 284, our translation). This definition's lesser insistence on cissexual assumption and greater focus on the *normative*

---

[5] For a critical history of the terms "cis" and "cisgender", see also Enke (2012).

*aspects of cis identities* seem more aligned with the current meaning of cisnormativity, despite the fact that the definition by Bauer et al. (2009) is often quoted. This can be explained in part by Anglonormativity in academic research and in general, given that English has more "citational capital" than any other language. Ideas, concepts, and notions created in languages other than English rarely receive mention or attention. Baril specified in later work (Baril, 2013, 397) that "cis (gender)normativity" is the "normative dimension of the cisgenderist system."[6]

Two years later, Pyne made an important contribution to disseminating the concept in a similar way Baril did with the notion of cis (gender)normativity. Pyne (2011, 129) writes: "I argue for using cisnormativity as a lens to imagine social services that truly welcome trans people. Rather than focusing solely on acts of discrimination, the concept of cisnormativity highlights the privileging of a non-trans norm". It seems that Baril's and Pyne's sense of cisnormativity focussed on the "norm" have proliferated in the past decade, during which the term's popularity has increased exponentially. In 2015, a Google search of "cisnormative" produced 13,700 results (Baril, 2015, 163); in July 2021, the same search by us produces 166,000 results, a sure indication of the term's popularization.

While the prefix "cis-" could have been taken up by multiple disciplines and fields of study to create neologisms reflecting sameness and continuity in different contexts (e.g. dis/abilities, national identity), Baril (2013) demonstrates that, contrary to the prefix "trans-" used in other contexts (e.g. transabled, transnational, translingual), the prefix "cis-" has historically only been used by scholars in trans studies (Baril, 2013; 2015).[7] Stryker, Currah, and Moore (Stryker et al., 2008, 11) argue that the "trans-" prefix "remains open-ended and resists premature foreclosure by attachment to any single suffix". As such, they suggest "trans-" with a hyphen to indicate the prefix's expansion to multiple realities and contexts. Similarly, some scholars have called for "trans*" with an asterisk to denote the prefix's application in disciplines other than trans studies, and even in ontological reflections (Hayward & Weinstein, 2015; Tompkins, 2014). Baril (2013; 2015) argues that, in the spirit of what has been done with the terms "trans-" and "trans*" in the past decades, there is heuristic value in expanding the prefix "cis-" with the addition of an asterisk. Baril (2009; 2013) mobilizes the notion of cisnormativity* with an asterisk to refer to the normative system that broadly normalizes cis* identities (i.e., identities and body-minds that do not undergo transitions, transformations, or changes, and therefore remain the same) (Baril, 2013; 2015). That is indeed what we propose here, namely, a redeployment of the concept of cisnormativity* in the specific context of dementia.

## Cisism and ciscognonormativity: Intersections with ableism, cogniticism, and ageism

Applying the broader definition of cisnormativity* provided by Baril (2013; 2015), we argue that this concept is useful for theorizing and critiquing the compulsory biographical continuity experienced by people living with dementia. In other words, we use cisnormativity* to critique the idea that people should not change in radical ways, but rather follow prescriptive societal norms and expectations in relation to the continuity of self. In the case of dementia and other cognitive disability, we propose the term "ciscognonormativity"[8] to refer to the normative emphasis on retaining cognitive continuity, an integral component of compulsory biographical continuity. Ciscognonormativity, which is foundational to most interventions related to dementia, interacts with other normative systems, including heteronormativity and cis(gender)normativity. For example, Sandberg (2018) describes how maintaining intelligibility for people with dementia often rests on their performance of heteronormative sexuality and binary gender roles. As described in the first section, most scholarship and interventions related to dementia arrive at the same conclusion: that we should facilitate expressions of selfhood for people with dementia, especially the pre-dementia self. Favoring the maintenance of the pre-dementia self through body work, appearance, creative arts, or other methods relies on ciscognonormativity and compulsory biographical continuity.

Cisnormativity* and ciscognonormativity are normative components of a larger oppressive system. We propose the neologism "cisism" to refer to this larger oppressive system. While the goal of this article is not to theorize the relationship between cisism and its normative aspect, cisnormativity*, it is nonetheless important to note that cisnormativity* stems from cisism, a larger system of oppression that discriminates against people on the basis of change. Cisism and its normative aspects are deeply interlocked with other forms of oppression in the context of dementia, particularly ableism, cogniticism, and ageism. Not only do they function interdependently with these forms of oppression, but they are also important components of how these oppressions play out in the context of dementia. For example, cisnormativity* can be understood as one of the underlying mechanisms of ableism and cogniticism because it places value on the (cognitive) capacities of pre-disabled selves and therefore casts any change towards disability in a negative light. In other words, cisnormativity*, or compulsory biographical continuity, is part of what creates the abjection embedded in attitudes towards cognitive disabilities such as dementia. Similarly, cisnormativity* is also embedded in ageism. Echoing the prevalent discourse to prevent or halt any kind of disability, including cognitive ones, the pervasive discourse regarding aging involves the quest to retain/maintain youth, hence preserving the former self and combating the changes that come with aging (Sandberg, 2013). While ageism would still exist (as would ableism and cogniticism) without cisnormativity*, cisnormativity* is nonetheless one of the driving forces behind ageism's rejection of changes that come with age, a rejection that is even more pronounced when old age involves disability. In other words, old bodies and minds are denigrated and subjected to discrimination, and a cognitive disability that has the potential to fundamentally alter the self, like dementia, is seen as leading to further abjection.

We contend that it is not only important to understand the relationship between cisism (and its normative components) and ableism, cogniticism, ageism, and other systems of oppression, but also that it is vital to comprehend its role in the many forms of epistemic injustice faced by people with dementia. Like other oppressions, cisist oppression can take on multiple forms, including political, social, legal, and epistemic. The relationship to epistemic forms of injustice is briefly mentioned here because it highlights some of the ways people with cognitive disabilities like dementia have been marginalized and silenced. Our arguments are based on Miranda Fricker's (2007) concepts of testimonial and hermeneutical injustice and Fricker and Jenkins (2017) concept of hermeneutical marginalization. The first two concepts are defined as follows: "Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective

---

[6] Ansara and Hegarty (2012) coined and defined the neologism "cisgenderism" in 2012.

[7] The following ironic comment by Enke (2012, 74) shows that the notion of cis has not been deployed in other disciplines: "Trans studies and disability studies together provide compelling insight about movement and change. Movement is integral to trans studies, but disability studies may do a better job of recognizing that bodies, abilities, and core identities change. For example, disability studies will not reify ability as a static *condition*: cis-abled?! Impossible". However, Baril (2013; 2015) coined many terms such as cisabled, cis-disabled, and so forth.

[8] In developing the term "ciscognonormativity", we have been inspired by King's (2016, 59) terms "cognonormative" and "cognonormativity", which refer to the normative systems governing cognitive abilities, as well as the term "cogniticism" that we coined in 2019, defined in the introduction.

interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (Fricker, 2007, 1). A precursor to these injustices, hermeneutical marginalization, occurs when someone "belong[s] to a group that under-contributes to the common pool of concepts and social meanings" (Fricker & Jenkins, 2017, 268). Despite the push to see people with dementia as persons and social citizens capable of retaining agency, they are often discredited as speakers and decision-makers by relatives, healthcare professionals and society at large, and furthermore, due to their marginal status, lack the conceptual tools necessary to make sense of and name their experiences. These conceptual tools are simply unavailable to many marginalized populations, and existing conceptual tools inadequately reflect marginalized individuals' experiences because they have been excluded from their creation. These injustices are evident in the fact that people with dementia are often categorized as "incapacitated" and their power to consent to medical treatments, end-of-life care, and other key decisions is frequently removed (Baril et al., 2020). Ciscognonormativity is foundational to these forms of epistemic injustice: the more one is able to retain one's former cognitive self, the more one is given decision-making power and taken seriously as an agent. For example, someone in the early stages of dementia, before its cognitive impacts become evident, retains more decision-making power than someone in the later stages who is perceived as having irreparably changed. In other words, from a ciscognonormative perspective, the only way to at least partially counter the abjection, injustice, oppression, and loss of control faced by people with dementia is to prove that they have to some extent retained their former self. We argue that all people with dementia, regardless of stage or severity, regardless of biographical continuity, should be able to uphold their epistemic agency.

The preceding discussion has exposed some of the oppressive systems and accompanying normative mechanisms at work in dominant conceptualizations of the self in the context of dementia. In the following section, inspired by the concept of transing, we propose new ways of conceptualizing the self with dementia.

## Transing and cripping dementia: Reflections on change and fluidity

As Kafer (2013) reminds us in the introduction of this article, disability is often perceived as having more detrimental impacts on the self, or as "undoing" the self in more life-altering ways, than other types of change. This is particularly true for cognitive disabilities like dementia. While many other life changes may lead to increased discrimination, oppression, and marginalization, such as becoming fat, changing religions, or undertaking a sex/gender transition, it seems as though cognitive disability is perceived as altering the self to the point of symbolic or social death (Beard, 2017), as evidenced in certain ways dementia is discussed, including comparing people with dementia to "zombies" (Behuniak, 2011). In other words, we seem to particularly question the selfhood of a person whose cognition is impacted. Even sex/gender transitions, which for many trans people often involve an important shift in biographical continuity, are not understood as resulting in as significant a loss of self as developing a cognitive disability. Although there may be questions about what actually changes in a person undergoing a sex/gender transition (Shrage, 2009), sex/gender transitions are often perceived as personal modifications or shifts *in* the self (Overall, 2009) rather than as a devastating loss *of* the self.[9]

---

[9] Based on cisgenderist and cis(gender)normative assumptions, it used to be the believed that the self was wasted and lost due to sex/gender transitions. Some still believe this, and try to prevent trans-affirmative care on this basis. Today it is more common to see sex/gender transitions as part of a personal journey. Even within transnormative and "trapped in the wrong body" discourses, the self is not understood to change, only the body (Bettcher, 2014; Radi, 2019; Riggs et al., 2019).

This growing acceptance is in part due to the work of trans activists and scholars who have succeeded in normalizing sex/gender transitions to some extent. This was not always the case, and trans and non-binary people are still subjected to significant forms of violence and discrimination (Ansara & Hegarty, 2012; Baril, 2019; Bettcher, 2014; Pyne, 2011; Radi, 2019; Serano, 2007). It is notable that one of the groups for whom sex/gender transitions are still considered unacceptable are older adults and people with cognitive disabilities. We have shown in our previous work that trans older adults deemed to have dementia are often subjected to forms of degendering and gatekeeping; the desire to transition is often interpreted, from a ciscognonormative perspective, as a by-product of their disability and therefore rejected (Baril & Silverman, 2019).

The reality is that, in many instances, disabled lives are still perceived as not worth living. As disability/crip scholar Kafer (2013, 42–43) articulates, "compulsory nostalgia" dictates that the disabled person must always long for the person they used to be, implying that their current life is not worth living. Kafer states: "This assumption that disability cannot be a desirable location, and that it must always be accompanied by a nostalgia for the lost able mind/body, is what animates 'the cure question' so familiar to disabled people: Wouldn't you rather be cured? Wouldn't you like to be as you were before? Wouldn't you prefer to be nondisabled?" (Kafer, 2013, 43). The same is true for cognitive disabilities. Kafer's words capture the harm in insisting on a former/historic self, as is the case in much dementia scholarship and intervention. While we find the pioneering work of scholars in critical dementia studies inspiring and foundational to our own thinking, we would like to invite scholars in gerontology and critical dementia studies to reflect more critically on the necessity of biographical continuity, that stems from implicit ciscognonormativity, in their theorization of dementia. We also invite them to question the ciscognonormative assumption that the pre-dementia self should be maintained by exploring reflections and conceptual tools developed in other disciplines, including trans studies and disability/crip studies. Some critical scholars have begun this work, for example Ward and Price (2016), who have argued for a reclaiming of the concept of senility "as a critical space that promotes the interrogation of a series of medicalised assumptions" (Ward & Price, 2016, 74). Yet, although they suggest beginning a "critical commentary in relation to dementia that both mirrors and connects with a radical critique in other fields" (Ward & Price, 2016, 65), their important work does not provide a clear vision of what that critical space might look like. Building on Ward and Price's idea of opening a critical space for new conceptualizations of dementia, we propose a new perception of the self with dementia in order to help combat the pervasive ableism, cognicism, ageism, and cisism embedded in current conceptualizations.

We believe that a new conceptualization of the self in the context of dementia, one that allows for change and fluidity and that fights against cisism, cisnormativity*, and ciscognonormativity, can be accomplished in part by transing dementia. In direct contrast to the compulsory biographical continuity imposed by cisism and cisnormativity*, transing emphasizes fluidity and mobility (Noble, 2012) while also favoring liberation and disobedience (DiPietro, 2016). Stryker, Currah, and Moore (Stryker et al., 2008, 13) define transing as follows:

> "Transing," in short, is a practice that takes place within, as well as across or between, gendered spaces. It is a practice that assembles gender into contingent structures of association with other attributes of bodily being, and that allows for their reassembly. Transing can function as a disciplinary tool when the stigma associated with the lack or loss of gender status threatens social unintelligibility, coercive normalization, or even bodily extermination. It can also function as an escape vector, line of flight, or pathway towards liberation.

The history of "transing" is similar to that of "queering" and "cripping", which were coined from terms reclaimed by queer and disabled

communities to put forth anti-assimilationist perspectives (McRuer, 2003). According to Sandahl (2003, 37), "[b]oth queering and cripping expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity [...]." Like queer, crip, and trans scholars and activists who have opened a space for difference and change, and echoing Nordmarken's (2019, 45–46) "queer trans paradigm [that] assumes that identities, expressions, and bodies are not intransigent, but can be and are unstable, fluid, multiple, and/or anticategorical", we propose a queering, cripping, and transing of the notion of the self in relation to dementia to emphasize its fluidity and instability.

The concepts of queering and cripping have been taken up to a small extent in critical gerontology, although transing has yet to enter into dialogue with aging or dementia studies.[10] Sandberg and Marshall (2017) call for queering and cripping of what they call "aging futures" which, as they explain, "entails thinking differently about life courses – asking what lives are understood as desirable to live and thrive well into old age – but also interrogating how desirable old age is problematically framed by the exclusionary discourses of successful aging" (Sandberg & Marshall, 2017, 7). Similarly, Sandberg and King (2019) mobilize queer theory's focus on failure and the rejection of normalcy to argue that queering aging can lead us to question and reconsider how we think about old age and "successful aging". Bringing the notion of queering into dialogue with dementia more specifically, King (2016) proposes that queering dementia can mean rehabilitating the person with dementia because queering allows us to deconstruct what is normal and abnormal and validate different ways of being in the world.

Building on the work of these critical scholars, we propose that transing dementia gives us permission to value fluidity, transition, and transgression and has the potential to dismantle ciscognonormativity. Trans studies, which provides the conceptual tools necessary to understand oppression based on change, namely cisism and its normative aspects, cisnormativity*, can also bring us tools to reduce oppression.[11] We believe that the focus on the potential change and fluidity that comes from the prefix "trans-" (transformed into a verb) can lead us to rethink the dementia self in new ways. In other words, we believe that trans studies can lead us to value change instead of fearing it, an essential step towards reconceptualizing dementia. What would a reconceptualized notion of the self in the context of dementia look like? We begin by building on the approach we put forward regarding intervention with trans older adults with dementia in cases of potential gender "confusion" and reidentification with their sex/gender assigned at birth (Baril & Silverman, 2019). This approach, which values fluidity and change and is based on trans-affirmative, crip-positive, and anti-ageist principles, can serve as a basis for reconceptualizing the self with dementia. Even though this approach was initially designed for trans people with dementia, it can be applied to anyone with dementia or other forms of cognitive disability or impairment in order to lead us to a notion of selfhood that is both fluid and changeable.

In the same way that our approach described above favors gender fluidity, we support and validate cognitive fluidity in the context of cognitive disability. In other words, we assert that the self should not be bound by ciscognonormativity and biographical continuity and that people with dementia should be permitted to change while retaining the same respect, value, consideration, and rights as people without

disabilities. In practice, valuing this fluidity could translate into recognizing the person's wants and needs in the present moment, valuing their current identity, interests, and abilities rather than pursuing efforts to maintain their former self. This approach would involve de-emphasizing cisnormative* interventions that favor memory recall, body/appearance continuity, or activities the person used to enjoy but no longer does. In terms of rights, people with cognitive disabilities should be given the space to express their opinions and decisions and have these respected, even if they differ from those held in their past, and these opinions should not be interpreted as less legitimate or as symptoms of a "lost self" simply because they are expressed by someone with a cognitive disability. People with cognitive disabilities should be actively supported to retain their agency and decision-making capacity in all spheres of life. This process can be supported through concrete measures such as regular check-ins to express their needs and wishes using verbal or nonverbal means, repeating information using easily understood language or other means of communication, and having someone they trust to act as an interpreter (Baril et al., 2020). Baril et al. (2020) also explain that interpretations of capacity and consent must be fluid in order to respect and follow the ever-changing nature of the self.

This approach also needs to be resolutely crip-positive and anti-ageist. Advocating for a crip-positive notion of dementia means seeing cognitive disability not as leading to a decline or loss of self, but rather as an opportunity to accept and validate changes in selfhood. As Kafer (2013) explains, this means eschewing nostalgia for, and pedestalization of, the past self, as well as abandoning the classification of some lives as more valuable than others. In terms of anti-ageism, a re-conceptualized notion of the self in the context of dementia consists of letting people age in a variety of ways and valuing transformation and the aging process in all their facets. This directly counters dominant global movements and discourses of "successful aging", which insist on retaining a youthful mind and body and whose ableist perspectives cast any decline or disability as negative (Beard, 2017; Sandberg & Marshall, 2017). In such discourses, age is only acceptable when people remain productive, active, and disability-free, and retain biographical continuity (Sandberg, 2013).

Transing dementia is not only about valuing change and fluidity and respecting the current self with dementia, it is also about changing the way we approach the topic of dementia itself within research and practice. We believe transing dementia involves shifting the focus of scholarship and intervention towards "non-normative" subjects of dementia and using an intersectional approach to analyze multiple forms of marginalization, whether due to class, race, religion, sexual orientation, or otherwise (Crenshaw, 1989; Hill Collins, 2000). In the same spirit of intersectionality, we believe transing dementia involves placing dementia studies and critical gerontology into dialogue with multiple fields of study, including critical disability studies, mad studies, trans studies, and queer studies. Because transing involves deconstructing normative truths and crossing boundaries, scholarship that crosses such boundaries can also be understood as transing dementia. For example, the way we have mobilized cisnormativity* in this article (i.e. taking a concept from trans studies and using it to theorize dementia) is a form of transing dementia. In terms of intervention, transing dementia begins with recognizing the cisnormativity* and ciscognonormativity behind many common practices. As mentioned above, our intention is not to critique these practices, but to provoke critical reflection on the epistemological assumptions underlying numerous interventions, many of which value compulsory biographical continuity. We also recognize that simply removing the emphasis on biographical continuity within interventions is not necessarily realistic nor desirable. Although most people with dementia face stigma and discrimination, it is more pronounced for those who do not act in accordance with social norms (see, for example, the work of Buse & Twigg (2018), on the stigma faced by people with dementia who wear "inappropriate" clothing). In other words, our invitation to counter cisnormativity* and ciscognonormativity in the lives of people with dementia is not intended to put them in

---

[10] There is, however, a growing interest in trans gerontology. See, for example, Toze (2019), Kia (2019), Witten (2017), and Fabbre (2015), among many others.

[11] It is interesting to note that trans communities, in addition to sometimes being transnormative (Riggs et al., 2019), can also be cisnormative* in their fear of what is sometimes called "detransition" (for example in the case of people with dementia who might reidentify with their sex/gender assigned at birth), and preference of gender continuity, such as in the preparation of end-of-life documents that emphasize gender continuity (Baril et al., 2020).

a position where they become even greater targets for violence and discrimination. We are simply inviting reflection on the possibility of abandoning current cisnormative* and ciscognonormative tropes. What would happen if we let change occur? Where would it lead? What can we imagine? Are we ready?

## Coda: Transing cisnormativity* to rethink critical gerontology and dementia studies

In this article, we have theorized the notion of the self in the context of dementia using tools and concepts from disability/crip studies and trans studies to propose a new conceptualization of the self that is fluid and changing rather than anchored in cisism and its normative components, cisnormativity* and ciscognonormativity. We believe that mobilizing concepts from trans studies (and to some extent queer and disability/crip theory), as well as the new neologisms we propose in this article, can provide critical gerontology and dementia studies with new tools to turn a critical eye on the conceptualization of self in scholarship and intervention and offer a new path forward. We also believe that such a reconceptualization of the self has the potential to lead to new approaches to theorizing aging and the life course more broadly, approaches that eschew normative conceptualizations in favor of celebrating change. These approaches have started to be explored in the invaluable work of critical dementia scholarship, but have yet to be developed from a trans studies perspective. Yet it is not only gerontology and dementia studies that would benefit from trans-disciplinary dialogue and transing of the self. The application of cisnormativity* beyond sex/gender, or "transing" cisnormativity, can lead to broadening trans studies and re-imagining how tools developed in trans studies can be used in a multitude of contexts. In other words, it proposes a transing not only of the self, but also of cisnormativity* itself and trans studies in general. Furthermore, focusing on dementia and old age may help de-center the focus on trans youth and adulthood that has historically been at the heart of trans studies. We hope that this work will serve to unmask some of the ageism, ableism and cognicism prevalent in trans studies (Baril, 2013; Kia, 2019; Toze, 2019; Witten, 2017). We also hope to encourage trans studies to examine its own insidious forms of cisnormativity* and restrictive notions of the self which sometimes favor post-transition gender identity continuity until the end of life. Ultimately, we hope that the ciscognonormative terror related to the loss of self in dementia, expressed in the quotation that opens this article, can be reduced by reconceptualizing what it means to live with cognitive disability.

## References

Ansara, G. Y., & Hegarty, P. (2012). Cisgenderism in psychology: Pathologising and Misgendering children from 1999 to 2008. *Psychology & Sexuality, 3*(2), 137–160.

Aubrecht, K., & Keefe, J. (2016). The becoming subject of dementia. *Review of Disability Studies: An International Journal, 12*(2 & 3), 1–19.

Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies, 22*(3), 222–228.

Baldwin, C., & Greason, M. (2016). Micro-citizenship, dementia and long-term care. *Dementia, 15*(3), 289–303.

Baril, A. (2009). Transsexualité et privilèges masculins. Fiction ou réalité? In L. Chamberland, B. W. Frank, & J. Ristock (Eds.), *Diversité sexuelle et constructions de genre* (pp. 263–295). Québec: Presses de l'Université du Québec.

Baril, A. (2013). *La normativité corporelle sous le bistouri: (re)penser l'intersectionnalité et les solidarités entre les études féministes, trans et sur le handicap à travers la transsexualité et la transcapacité*. PhD thesis. Ottawa: Institute of Feminist and Gender Studies, University of Ottawa.

Baril, A. (2015). 'How dare you pretend to be disabled?' The discounting of transabled people and their claims in disability movements and studies. *Disability & Society, 30*(5), 689–703.

Baril, A. (2019). Gender identity trouble: An analysis of the underrepresentation of trans* professors in Canadian universities. *Chiasma, 5,* 90–128.

Baril, A., & Silverman, M. (2019). Forgotten lives: Trans older adults living with dementia at the intersection of cisgenderism, ableism/cognicism and ageism. *Sexualities*, 1–15. OnlineFirst https://doi.org/10.1177/1363460719876835.

Baril, A., Silverman, M., Gauthier, M.-C., & Lévesque, M. (2020). Forgotten wishes: End-of-life documents for trans people with dementia at the margins of legal change. *Canadian Journal of Law and Society, 35*(2), 367–390.

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies, 21*(2), 107–118.

Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate*. Bristol: The Policy Press.

Bauer, G., Hammond, R., Travers, R., Kaay, M., Mohenadel, K., & Boyce, M. (2009). "I Don"t think this is theoretical; this is our lives:' How erasure impacts health Care for Transgender People. *The Journal of the Association of Nurses in AIDS Care, 20*(5), 348–361.

Beard, R. (2017). Dementia and the privilege of growing old. *Dementia, 16*(6), 685–688.

Beard, R., & Fox, P. (2008). Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss. *Social Science & Medicine, 66,* 1509–1520.

Behuniak, S. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society, 31,* 70–92.

Bettcher, T. M. (2014). Trapped in the wrong theory: Rethinking trans oppression and resistance. *Signs, 39*(2), 383–406.

Boyle, G. (2014). Recognising the agency of people with dementia. *Sociology, 29*(7), 1130–1144.

Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics, 18*(5), 662–671.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4* (2), 167–182.

Buse, C., & Twigg, J. (2014). Women with dementia and their handbags: Negotiating identity, privacy and 'home' through material culture. *Journal of Aging Studies, 30,* 14–22.

Buse, C., & Twigg, J. (2016). Materialising memories: Exploring the stories of people with dementia through dress. *Ageing and Society, 36*(6), 1115–1135.

Buse, C., & Twigg, J. (2018). Keeping up appearances: Family carers and people with dementia negotiating normalcy through dress practice. In G. Thomas, & D. Sakellariou (Eds.), *Disability, normalcy, and the everyday* (pp. 17–38). New York: Routledge.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of discrimination doctrine, feminist theory and antiracist practice. *University of Chicago Legal Forum, 89,* 139–167.

Dewing, J. (2007). Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing, 3*(1), 3–13.

DiPietro, P. J. (2016). Of Huachafaria, Asi, and M'e Mati: Decolonizing transing methodologies. *TSQ: Transgender Studies Quarterly, 3*(1–2), 65–73.

Dresser, R. (1995). Dworkin on dementia. *Hastings Center Report, 25,* 32–38.

Dupuis, S. L., Kontos, P., Mitchell, G., Jonas-Simpson, C., & Gray, J. (2016). Re-claiming citizenship through the arts. *Dementia, 15*(3), 358–380.

Dworkin, R. (1986). Autonomy and the demented self. *The Milbank Quarterly, 64*(Suppl. 2), 4–16.

Enke, A. F. (2012). The education of little cis. Cisgender and the discipline of opposing bodies. In A. Enke (Ed.), *Transfeminist perspectives in and beyond transgender and gender studies* (pp. 60–77). Philadelphia: Temple University Press.

Fabbre, V. D. (2015). Gender transitions in later life: A queer perspective on successful aging. *The Gerontologist, 55*(1), 144–153.

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist, 58*(S1), S10–S19.

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. New York: Oxford University Press.

Fricker, M., & Jenkins, K. (2017). Epistemic injustice, ignorance and trans experiences. In A. Garry, S. Khader, & A. Stone (Eds.), *Routledge companion to feminist philosophy* (pp. 268–278). New York: Routledge.

Gray, J., Dupuis, S., Kontos, P., Jonas-Simpson, C., & Mitchell, G. (2020). Knowledge as embodied, imaginative and foolish enactment: Exploring dementia experiences through theater. *Forum: Qualitative Social Research, 21*(3), 1–21.

Habron, J. (2013). 'A conversation without words' – Reflections on music therapy and dementia. *Dementia, 12*(1), 3–6.

Haeusermann, T. (2019). Forced continuity: Explorations of biographical narratives in dementia care. *Journal of Aging Studies, 49,* 1–8.

Harnett, T., & Jönson, H. (2017). "They are different now" – Biographical continuity and disruption in nursing home settings. *Journal of Aging Studies, 42,* 1–8.

Hayward, E., & Weinstein, J. (2015). Introduction: Tranimalities in the age of trans* life. *TSQ: Transgender Studies Quarterly, 2*(2), 195–208.

Higgs, P., & Gilleard, C. (2016). *Personhood, identity and care in advanced old age*. Bristol: Policy Press.

Hill Collins, P. (2000). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment* (2nd ed.). New York: Routledge.

Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy and Public Affairs, 28,* 105–138.

Kafer, A. (2013). *Feminist, queer, crip*. Bloomington: Indiana University Press.

Kia, H. (2019). (In)visibilities that vary: The production of aging lesbian, gay, bisexual, transgender, and queer subjects in chronic care. *Theory In Action, 12*(3), 1–20.

King, A. (2016). Queer(y)ing dementia – Bringing queer theory and studies of dementia into dialogue. In S. Westwood, & E. Price (Eds.), *Lesbian, gay, bisexual, and trans individuals living with dementia. Concepts, practice and rights* (pp. 51–64). Abingdon: Routledge.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham: Open University Press.

Kontos, P. (2006). Embodied selfhood. An ethnographic exploration of Alzheimer's disease. In Leibing, & L. Cohen (Eds.), *Thinking about dementia: Culture, loss, and the anthropology of senility* (pp. 195–217). Rutgers University Press.

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society, 24*, 829–849.

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia, 4*(4), 553–570.

Kontos, P. C., & Naglie, G. (2007). Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool. *Qualitative Health Research, 17*(6), 799–811.

Koyama, E. (2002). Cissexual/Cisgender. Decentralizing the Dominant Group. Retrieved from eminism.org/interchange/2002/20020607-wmstl.html.

McRuer, R. (2003). As good as it gets: Queer theory and critical disability. *GLQ: A Journal of Lesbian and Gay Studies, 9*(1–2), 79–105.

Noble, B. (2012). Trans. Panic. Some thoughts towards a theory of feminist fundamentalism. In A. Enke (Ed.), *Transfeminist perspectives in and beyond transgender and gender studies* (pp. 45–59). Philadelphia: Temple University Press.

Nordmarken, S. (2019). Queering gendering: Trans epistemologies and the disruption and production of gender accomplishment practices. *Feminist Studies, 45*(1), 36–66.

O'Connor, D. (2019). Practising social citizenship in a context of compromised decision-making capacity: Realizing and protecting human rights. *Elder Law Review, 12*(1), lvi–lxv.

Overall, C. (2009). Sex/gender transitions and life-changing aspirations. In L. J. Shrage (Ed.), *"You've changed": Sex reassignment and personal identity* (pp. 11–27). Oxford: Oxford University Press.

Parfit, D. (1984). *Reasons and persons.* Oxford: Oxford University Press.

Pyne, J. (2011). Unsuitable bodies: Trans people and cisnormativity in shelter services. *The Canadian Social Work Review, 28*(1), 129–137.

Radi, B. (2019). On trans* epistemology. Critiques, contributions, and challenges. *TSQ: Transgender Studies Quarterly, 6*(1), 43–63.

Riggs, D. W., Pearce, R., Pfeffer, C. A., Hines, S., White, F., & Ruspini, E. (2019). Transnormativity in the psy disciplines: Constructing pathology in the diagnostic and statistical manual of mental disorders and standards of care. *American Psychologist, 74*(8), 912–924.

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*, 443–461.

Sandahl, C. (2003). Queering the crip or cripping the queer? Intersections of queer and crip identities in solo autobiographical performance. *GLQ: A Journal of Lesbian and Gay Studies, 9*(1–2), 25–56.

Sandberg, L. (2013). Affirmative old age: The ageing body and feminist theories on difference. *International Journal of Ageing and Later Life, 8*(1), 11–30.

Sandberg, L. (2018). Dementia and the gender trouble?: Theorising dementia, gendered subjectivity and embodiment. *Journal of Aging Studies, 45*, 25–31.

Sandberg, L., & Marshall, B. (2017). Queering aging futures. *Societies, 7*(21), 1–11.

Sandberg, L. J., & King, A. (2019). Queering gerontology. In D. Gu, & M. E. Dupre (Eds.), *Encyclopedia of gerontology and population aging* (pp. 1–7).

Serano, J. (2007). *Whipping girl. A transsexual woman on sexism and the scapegoating of femininity.* Berkeley: Seal Press.

Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in mind: Thinking differently about dementia and disability. *Dementia, 18*(3), 1075–1088.

Shrage, L. J. (2009). Introduction. In L. J. Shrage (Ed.), *"You've changed": Sex reassignment and personal identity* (pp. 3–10). Oxford: Oxford University Press.

Stryker, S., Currah, P., & Moore, L. J. (2008). Introduction: Trans-, trans, or transgender? *WSQ: Women's Studies Quarterly, 36*(3–4), 11–22.

Thomas, C., & Milligan, C. (2018). Dementia, disability rights and disablism: Understanding the social position of people living with dementia. *Disability & Society, 33*(1), 115–131.

Tompkins, A. (2014). Asterisk. *TSQ: Transgender Studies Quarterly, 1*(1/2), 26–27.

Toze, M. (2019). Developing a critical trans gerontology. *British Journal of Sociology, 4*(70), 1490–1509.

Twigg, J., & Buse, C. E. (2013). Dress, dementia and the embodiment of identity. *Dementia, 12*(3), 326–336.

Ward, R., & Campbell, S. (2013). Mixing methods to explore appearance in dementia care. *Dementia., 12*(3), 337–347.

Ward, R., Campbell, S., & Keady, J. (2014). 'Once I had money in my pocket, I was every colour under the sun': Using 'appearance biographies' to explore the meanings of appearance for people with dementia. *Journal of Aging Studies, 30*, 64–72.

Ward, R., & Price, E. (2016). Reconceptualising dementia: Toward a politics of senility. In S. Westwood, & E. Price (Eds.), *Lesbian, gay, bisexual, and trans individuals living with dementia. Concepts, practice and rights* (pp. 65–77). Abingdon: Routledge.

Witten, T. M. (2017). Health and well-being of transgender elders. *Annual Review of Gerontology & Geriatrics, 37*(1), 27–42.