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## Dementia and the gender trouble?: Theorising dementia, gendered subjectivity and embodiment

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### ABSTRACT

Despite person-centred approaches increasingly focusing on looking at the person in dementia instead of the pathology, the role of gender in dementia has been little explored. This article discusses how pervasive discourses on a loss of self and dementia as abject are interwoven with a de-gendering of persons with dementia. The cultural anxiety that dementia evokes in terms of loss of bodily and cognitive control could also be linked to a failure to normatively and intelligibly express gender when living with dementia. As a way to sustain personhood for people with dementia and challenge discourses on people with dementia as 'non-people', person-centred approaches have emphasised the collaborative work of carers, relatives and persons with dementia. Often implicitly, this also involves a 're-gendering' of persons with dementia where gendered biographies and pasts are upheld and gendered embodied selfhood is maintained through, for example, dress, hair and other aspects of appearance. This re-gendering could be of great significance for people with dementia to become intelligible as persons. Still, dementia studies must further consider non-normative expressions of gender and involve feminist theorising on gender as a power asymmetry since some embodiments and selves are more likely to be sustained in dementia than others.

### Introduction

Increasingly, the dominant biomedical model of dementia has been challenged by scholars advocating going beyond pathology and towards more person-centred approaches to dementia. A significant aim of these approaches has been to confront the longstanding medical and popular discourses which assume that the cognitive changes of dementia automatically lead to an 'unbecoming' or a loss of self (Fontana & Smith, 1989, 36; Herskovits, 1995). Instead of conflating the person living with dementia (here on abbreviated as PWD) with pathology/the brain disease, Kitwood (1997) and Sabat and Harré (1992), among others, have looked at sustaining personhood/selfhood in dementia through social interaction and communication. More recently these symbolic interactionist approaches have been developed and extended to also involve discussions on embodiment in dementia (Kontos & Martin, 2013).

Despite scholarly interest in focusing on persons, the self and, to some extent, embodiment in dementia, gender and how gendered subjectivities and embodiments are experienced and represented have received surprisingly little attention. As women are more often diagnosed with dementia, sex differences are noted in dementia studies,

while gender differences are overlooked. In a recent literature review of gender differences in dementia care, Bartlett, Gjernes, Lotherington, and Obstfelder (2016) show that the majority of studies deal with the gender differences in caregiving, while there are much fewer works on gender differences in lived experience among PWD. An exception is Hulko (2004, 2009; also O'Connor, Phinney, & Hulko, 2010), whose pioneering work explores intersecting identities of gender, class, race and ethnicity in people's experiences of dementia.<sup>1</sup> Hulko argues that although the influential work of Kitwood and that of Sabat and Harré are based on social constructionist theory, their writings leave 'little room for the articulation of the role and influence of intersecting identities based on class, gender, "race" and ethnicity' (2004, 41). In parallel, in a review of the growing field of embodiment in dementia, Kontos and Martin (2013) contend that there remains an opening for scholarly work that further explores how bodies in dementia intersect with gender, class, sexuality and ethnicity. Discussions on gender in intersections with other power asymmetries in dementia are consequently still conspicuously scarce.

The dearth of theoretical and empirical work on gender and dementia is also surprising since feminist gerontology is a significant strand within social and cultural gerontology, and gender and ageing

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<sup>1</sup> For other exceptions that explicitly discuss lived experiences of gender in dementia, see Phinney, Dahlke, and Purves (2013), Boyle (2013), Campbell (2012), Capstick and Clegg (2013) and Proctor (2001).

issues, in particular women's but increasingly men's, have been discussed by scholars for several decades (Arber, Davidson, & Ginn, 2003; Arber & Ginn, 1995; Calasanti & Slevin, 2001, 2006).

Given this scarcity, the article aims to initiate a theoretical discussion on gender and gendered embodiment in dementia. The article first explores the discourses on 'the demented' as abject and argues that the debasement of dementia is linked to both a de-gendering of dementia and a particular kind of unwanted femininity and masculinity that threatens the heterosexual matrix. Next, it discusses how person-centred approaches, in an attempt to challenge the abjection, engage in a re-gendering of PWD. The acknowledgement of the significance of gendered selves for people with dementia may be positive in how it recognises the continuity of the self in the face of the illness. Yet the unreflective re-gendering of PWD tends to overlook gender as a power asymmetry and risks reinforcing a matrix of normative gender, an imposition that obscures feminist discussions on gender as asymmetrical and removes the possibility of thinking of transgressions and disruptions of gender.

### Dementia, abjection and gender loss

The dominant dementia discourse is decline, loss and negativity (Herskovits, 1995; Kontos, 2004, 2006, 2012; Stirling, 1995). Critical scholars have repeatedly pointed to how biomedicine contributes to this discourse by focusing exclusively on dementia as pathology and on brain degeneration and cognitive loss caused by dementia illnesses (Kontos, 2004, 2006, 2012). The decline narrative of dementia is, however, also spurred by other scientific discourses, such as in nursing literature and in popular discourse on film, literature and mass media (Behuniak, 2011; Peel, 2014). Negative conceptions that stigmatise and dehumanise PWD and associate them with loss, death and devastation include metaphors and expressions, such as 'zombies', 'funeral without an end', 'private hell of devastation', 'catastrophe' or 'panic' (Behuniak, 2011; Herskovits, 1995; Peel, 2014). At the heart of these fearful discourses on dementia is its conceptualisation as a 'loss of self' or an 'unbecoming', where dementia ultimately deprives individuals of personhood (Herskovits, 1995).

Although the loss of self through the loss of cognitive function is central to how dementia is conceptualised in decline discourses, dementia as loss is also very much linked to negative embodiment and a wider loss of control of bodily functions. In the later stages of dementia, difficulty maintaining personal hygiene, problems with eating and increasing urine and faecal incontinence come to further signify a more fundamental loss of control. As such, the morphology of the body in dementia very much figures as 'the abject or the grotesque' (Stirling, 1995, 150) in biomedical and cultural discourses. This echoes a more general pervasive discourse on old age where ageing and later life are characterised primarily as a time and stage of decomposition and a loss of bodily and cognitive functions but which has in recent years been substituted by new social and cultural imaginaries of 'third agers', who are urged to resist and reject pathological/abject ageing, such as dementia, performance, consumption and self-realisation (Gilleard & Higgs, 2011).

Abject and abjection are concepts most commonly associated with the psychoanalytic work of Julia Kristeva (1982), who maintains that the formation of the subject is always dependent on abjection, the expulsion of which threatens to 'disturb identity, system, order' (Kristeva, 1982, Campbell, 2012, 91). She connects the abject particularly to the lack of control of bodily fluids and corporeal waste, most notably represented by the feminine (maternal) body through menstruation. The process of abjection is, however, never stable and fulfilled, and the abject is never fully externalised but exists on the margins of the liveable and 'threatens to bring about the collapse of meaning or challenges the coherence of the clean and proper body' (Hughes, 2009, 405). The abject could be used more generally to understand the repudiation of the disabled/ageing body in ableist/ageist societies (Hughes, 2009;

Sandberg, 2008). However, theorising the positioning of PWD as abject is particularly salient since dementia is commonly understood as a liminal state between subject and Other, life and death, and reason and being 'out of one's mind'. In dementia both the body and the mind are seen as in a state of progressing decomposition and, as such, a threat to the 'proper' body.

The abject also features prominently in queer theory, for example in Judith Butler's early work (1990, 1993), where the homosexual abject comes to figure as that which threatens to destabilise the heterosexual matrix. Butler argues that the discursive production of intelligible bodies and subjects is intrinsically linked to becoming recognised as gendered. But she notes that 'this exclusionary matrix by which subjects are formed thus requires the simultaneous production of a domain of abject beings, who are not yet "subjects" but who form the constitutive outside to the domain of the subject' (Butler, 1993, 3). The 'unliveable' abject is consequently constantly repudiated, yet necessary for the production of the subject.

The abject, the 'unliveable' and 'uninhabitable' zones of social life, which Butler terms those who cannot be intelligibly gendered, also have resonance with lives and embodiments in dementia, with those presumed lost or 'sans everything'. The dehumanising discourse on dementia as a loss of personhood is intertwined with a loss of gender and gendered intelligibility. The body in dementia also becomes abject largely because of a loss of gender (or normative expressions of gender). The abjection of dementia embodiment and subjectivity is thus not only linked to its lack of bladder and bowel control, eating habits or personal hygiene or loss of rationality but also to gender performativity.

One of the ways PWD are represented as abject is by referring to their diminishing control over appearance. This is seen in Chatterji's ethnographic study (2006) of a Dutch nursing home. She describes Mrs. Klasen, a resident, as follows:

The image of her in the somatic ward had been that of a woman tottering on the edge of chaos, restrained with great difficulty. She had limp, dank hair falling from a point in the centre of her head (the rest had fallen out as a result of radiation treatment). This set her apart in a room full of perms and well-groomed buns. She sat in a wheelchair with a restraining belt around her, a catheter tube visible on the side. (Chatterji, 2006, 234).

This description very much evokes an imagery of dementia as abject through terms depicting decomposition ('hair falling', 'sat in a wheelchair'), leakiness ('catheter tube visible') and madness ('restraining belt', 'tottering on the edge of chaos'). Her abject presence is described as troubling to the other residents (who were not suffering from psychogeriatric illnesses) because of her non-normative bodily behaviour expressed through screaming, fidgeting and dribbling. But her appearance is also presented as disruptive. Her evident lack of interest in her appearance is juxtaposed with the other (female) residents with 'perms and well-groomed buns' (Chatterji, 2006, 234). Implicit in this description is the disorderly subject who cannot conform to normative standards of femininity through maintaining appearance, most notably through haircare. In Chatterji's description, the abject status of Mrs. Klasen is not due to dehumanising care practices but because of her state of illness. There are, however, also examples of how the abject embodiment of dementia is understood as caused by bad care. In their study of care practices in residential dementia care, Ward and colleagues argue that 'appearance and presentation served as a barometer of the provision and quality of care' (2008, 640). During an interview with a carer, they expressed concern about what could be understood as a resident's transformation into an abject dementia embodiment because she was moved to another unit:

When I go down there, her hair is looking so stringy and everything. Every morning, every day, most of the morning I come in, I try to shower my residents and wash their hair, blow-dry it, set it and everything. I go down there and look at her: *she's a completely*

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