



## 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*

*different person* (emphasis in original). (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008, 641).

Here the abject embodiment of dementia is kept at bay through maintaining bodily order. Again it is the resident's hair that is noted as important, where 'stringy' hair is contrasted with blow-dried and set hair. Implicitly, the lack of normative standards of orderly femininity expressed through hair becomes an expression of something troubling, of abject embodiment of dementia and becoming other, 'a completely different person'. These examples of hair reference the perceived loss of respectable femininity, but there are cases where men with dementia are perceived as failing to desirably and intelligibly perform masculinity. Campbell (2012), for instance, points to shaving as an arena of masculine performance, and unshaven men with dementia may thus indicate a lack of control over appearance distinctly linked to a lack of control over one's gendered embodiment.

Another example where the embodiment and subjectivity of PWD are rendered abject concerns sexuality and sexual expressions. Following Butler (1993), the production of gender is intertwined with sexuality through the heterosexual matrix, whereby men and women emerge and become intelligible as men and women through the desire for and possibility to attract the opposite sex. In relation to ageing, the heterosexual matrix is evident in how decline discourses on old age also assume the asexuality of older people and how this has been accompanied by discourses on de-gendering in later life (Sandberg, 2011). However, recent shifts in discourses on old age have involved a re-sexualisation of third agers and a parallel re-gendering of later life (Sandberg, 2013). In contrast, the older PWD is assumed to increasingly lose their self and consequently also sexual subjectivity. This is evident from the apparent scholarly omission and lack of interest in sexual and intimate relationships and expressions of people with dementia and assumptions of decline in sexual interest due to dementia (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005).

One theme that stands out, however, regarding sexuality and dementia is 'inappropriate sexual behaviours' in dementia, sometimes also referred to as 'improper sexual behaviours', 'sexually ambiguous' or 'hyper-sexual behaviour' (Abdo, 2013; Benbow & Beeston, 2012). While there is no consensus on the definition of inappropriate sexual behaviours, the notion (and its synonyms) clearly point to sexuality in dementia as a problem that needs policing and regulating (Kontos & Martin, 2013). Studies of residential dementia care have shown that staff often experienced residents' sexual expressions as challenging to handle, and, in particular, male residents with dementia were found to be problematic (Archibald, 2002; Dupius, Wiersma, & Loiselle, 2012; Ward et al., 2005). This reaction to sexual expressions represents another way in which PWD are positioned as abject, out of control. But it could also be thought of in relation to gendered performativity, where the expression of an inappropriate (queer) sexuality challenges or transgresses a heterosexual matrix, and as a consequence an abject and unintelligibly gendered subject. It is noteworthy also that where PWD's problematic sexual behaviours are concerned, non-heteronormative sexual expressions are more often deemed problematic. In Archibald's study (2002), male residents' fondling of male staff was regarded as more challenging than that of female staff. Also, Abdo (2013, 594), in a literature review of sexuality and dementia, points to how 'changes in sexual preference' are discussed as one expression of inappropriate sexual behaviour. This suggests that heteronormativity and understandings of stable sexual/gendered selves are interwoven with 'sane', non-demented sexuality.

I have argued that the dehumanising discourse on dementia, in which people with dementia are understood as increasingly void of personhood and as abject, needs to be discussed too in relation to gender. The abjection of PWD, resulting from a cultural anxiety of the loss of bodily and cognitive control, could also be linked to perceived failures to normatively and intelligibly express gender through, for example, appearance and sexual expression.

## Sustaining selves as sustaining gender

Despite the pervasiveness of discourses on dementia as a degenerative brain disease that entails the advancing loss of self, they have not gone uncontested. The most influential challenge has come from the often-referred-to person-centred approaches to dementia, expounded by, for example, Kitwood (1997) and Sabat and Harré (1992). Their work has implied a significant shift in perspectives, away from the pathology and towards the person in dementia (Hydén, Lindemann, & Brockmeier, 2014). Contemporary Western conceptions of subjectivity, and the self, emphasise the brain and cognitive function as the locus for how we emerge as a person. This kind of 'personism' prioritises cognitive traits such as rationality, self-consciousness and individuality as human characteristics, which excludes cognitively impaired people (McLean, 2007). Person-centred and social interactionist approaches, in contrast, emphasise selves as accomplished in social interactions with others. However, as Campbell (2012, 88) succinctly points out:

Although this [person-centred approach] made a major contribution to thinking on dementia, academic discourses continue to centre on 'the person' and de-gender the experiences of those living with the condition.

However, I will argue that although gender is not explicitly discussed as such, it figures implicitly in person-centred approaches, and the emphasis on sustaining the self in social interaction is closely intertwined with the reinforcement of gendered biographies, including gendered embodiment.

The following outlines person-centred perspectives on the self and the person: Kitwood (1997, 8) defines personhood as a 'standing or status that is bestowed upon one human being, by others, in the context of relationship and social being'. In a similar vein, Sabat and Harré (1992) understand the self as the enactment of a repertoire of different personae in social interaction. A person-centred approach thus argues that a loss of self in dementia is effectively a consequence of a 'malignant social psychology' where one's self is not sustained and recognised. Personhood and self in dementia could be undermined or challenged from social interactions that assume the PWD as confused and helpless. But the self can also be sustained if narratives of the self are upheld, such as in the co-authoring of life narratives between PWD and others (Burke, 2014; McLean, 2007).

To illustrate how selves are accomplished in interaction, Sabat and Harré (1992) draw on three ethnographic cases from a study of a day-care centre for brain-injured people. The interviewees, J.B., I.R. and M.K., were all diagnosed with Alzheimer's disease (AD), the most common form of dementia. J.B., a man and former academic, was a regular visitor but was unwilling to participate in the programme of daily activities; instead, he went for a walk. Sabat and Harré argue that if one follows a discourse on the AD sufferer as helpless and confused, his wandering could be understood through the lens of pathology as part of his illness. By taking his biography and his presentation of himself in the interview into account, however, his walking could be understood as coherent with his former self, where he prefers walking to engaging in what he perceives as meaningless pastimes at the day-care centre. In one interview, J.B. points to the potential status he may obtain from participating in Sabat and Harré's research. Thus, to partake in a joint construction of J.B. as an academic, and to affirm this storyline, the dean of the College of Arts and Sciences gives him a letter of commendation that praises his contribution to the project. This letter, the authors argue, becomes an important object for J.B. to (re) construct his academic self while living with AD.

Sabat and Harré then discuss I.R., described as 'a service oriented' woman very much involved in doing chores at the day-care centre, such as setting tables and helping other visitors. She also takes 'great pride in her appearance' (Sabat & Harré, 1992, 456). While I.R. is perfectly capable of accomplishing this nurturing self at the day-care centre, this self is undermined at home by her husband, who positions her as

incapable and helps her out with activities she performs at the day-care centre. Sabat and Harré argue, however, that rather than being deprived of her nurturing position, I.R. paradoxically preserves it by letting her husband care for her and thus making him feel needed.

With these examples, Sabat and Harré aim to show how the general storyline of AD sufferers as helpless, confused and incompetent becomes an obstacle to the constructions of selves and disrupts links to previous biographical selves. But the examples are also, albeit unintentionally, illustrative of how having one's self and storyline recognised is very much about the recognition of gendered life histories and gender relations. J.B., in collaboration with Sabat and Harré, constructs a masculine self by emphasising the significance of status and of wanting to maintain his professional self. In parallel, Sabat and Harré's description of I.R. clearly points to her accomplishing femininity through doing housework or looking after her appearance. These examples suggest that for a person with AD to become socially recognised is patently dependent on having the social recognition of one's gendered self, for example as an intellectual, academic male or as a nurturing woman who takes care of her looks.

Kitwood's exemplification (1997) of how personhood is undermined in dementia also makes implicit reference to a loss of a gendered self. One such example is his discussion of the fictive AD-diagnosed Margaret B, whom Kitwood argues wanted "a "way of life", a continuity with her past, but her role as the homemaker was totally stripped away" as her husband took over all the household chores and day-care provided no work for her (Kitwood, 1997, 41). It is unclear from the context Kitwood presents how Margaret B. expresses a desire to retain her homemaker role. Rather it is inferred that since the woman's life had centred around the home, no longer being involved in household activities becomes a challenge to her personhood. Another example of how Kitwood conflates the erosion of self with the loss of a gendered self is his citation from Diana Friel McGowin's autobiographical work (1993) on dementia:

If I am no longer a woman, why do I still feel I'm one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? If no longer sensitive, why do moving song lyrics strike a responsive chord in me? .... (McGowin, 1993, cited in Kitwood, 1997, 73).

Kitwood does not note the use of the word 'woman' in this quote but instead uses it as a compelling illustration of McGowin's 'struggle to remain a person, despite her disabilities' (1997, 73). Being gendered thus implicitly equates to being a person and vice versa.

What is significant in the aforementioned examples (Kitwood, 1997; Sabat & Harré, 1992) is the connection to one's past and consequently continuity and coherence with an identity/personhood/self, which has been established throughout the lifecourse. Here it is possible to consider the work of Ahmed (2006) on queer phenomenology. Ahmed, drawing on Butler, understands gendered and sexual bodies as emerging through performativity, the reiterations of norms in temporal processes. Ahmed, however, develops the work of Butler by combining Butlerian approaches to gender with phenomenology's emphasis on spatiality and embodiment. To become gendered and heterosexual is to be oriented or 'directed' in specific ways towards the opposite sex, and by following these directions, one appears 'in line' (Ahmed, 2006, 66). Ahmed (Ahmed, 2006, 16) helpfully uses the path metaphor to visualise how the lines that direct our gendered and sexual bodies are performative. The path emerges as a line in the ground from repeated walking, and it exists only insofar as it is walked upon. We walk upon the path because it is there, but paradoxically the path exists only because we walk upon it. Following Ahmed, gender and heterosexuality are thus, like the path, lines that direct and shape us but are, in parallel, continuous accomplishments. Although not reflecting on ageing and the life course, Ahmed's discussions on 'being on line' as following gendered and heterosexual directions could be understood as taking up a particular normative life course (cf. Sandberg, 2016). The examples by

Sabat and Harré and Kitwood, which seek to reaffirm the significance of a (gendered) past, could thus be understood as attempts to put PWD back 'on line', to uphold the gendered 'path', which is necessary to sustain a coherent subject challenged by dominant discourses on dementia. The state of disorientation often associated with AD could, using this argument, be thought of as a loss of direction, not resulting from the brain disease itself but from not being recognised as gendered, of being 'out of line' and 'off line' with a gendered life course.

### Embodiment, appearance and the continuity of gendered bodies

Another aspect of how the continuity of self in dementia could be sustained is through maintaining embodiment and appearance, such as dress and hair, topics in which dementia studies has in recent years shown an increasing interest (Buse & Twigg, 2014; Campbell, 2012; Kontos & Martin, 2013; Twigg, 2010; Ward, Campbell, & Keady, 2014). Discussions of appearance in dementia often contain implicit (and in some rare cases explicit) references to gendered embodiment. For example, Lindemann (2009) discusses the family's responsibilities to sustain personhood in terms of 'holding' PWD in their identity. Lindemann exemplifies 'holding in identity' through a granddaughter's story about how her family go to see her grandmother with dementia in a nursing home and engage in past family activities. Appearance is part of this narrative as the granddaughter strongly associates her grandmother in the past with her red fingernails.

One day I gave her a manicure and pedicure, and I think we both felt better when her fingernails were shiny red again. Dad played his guitar for her, and that helped to steady her a little too. Mostly, though, we just sat with her, listening to her disjointed stream-of-consciousness observations, coaxing her to eat a few bites, and watching over her as she slept. (Lindemann, 2009, 421).

The above quote is an example of how the family members jointly support the grandmother's identity in her progressing dementia. And although not commented on by Lindemann, the manicure could also be understood as a way of holding the grandmother's gendered identity in place. Notably, the narrator remarks, 'We both felt better when her fingernails were shiny red again', suggesting that smartening up the grandmother's appearance was something enjoyable and pleasurable for both her and the granddaughter. This resonates with the findings of Ward et al. (2008, 641), namely work on appearance in dementia 'supported an expected form of (embodied) biographical continuity' important for relatives and which also created a sense of socially and bodily order that could also be discussed as a reiteration of gendered bodies that show continuity and coherence with a gendered past. The pleasure the narrator experiences by giving her grandmother her long, red, shiny fingernails back could in this respect be understood from the pleasure derived from re-invoking a gendered intelligibility to her grandmother's embodiment in dementia, to make her recognisable through her former gendered self. To put her grandmother 'back in line' is also to put herself in line, a reproduction of femininity over generations.

Other dementia studies work centres on appearance and more explicitly its relevance to the continuity of self as an aspect of 'embodied selfhood'. Pia Kontos (2004, 2006, 2012) has introduced the concept of 'embodied selfhood' into dementia studies to explicate how selfhood is continuously sustained through bodily habits, gestures and actions, even in severe AD, when language and memory may be significantly impaired. Drawing on ethnographic fieldwork on residential dementia care, Kontos points to how working on one's appearance becomes part of one's embodied selfhood in dementia. Anna, a resident, despite other difficulties, can carefully apply lipstick in a skilful manner. Another resident, Molly, always has to 'reach behind her neck to pull from under the bib a string of pearls so that they could be seen' (Kontos, 2004, 833). These examples suggest that embodiment in dementia is not inevitably abject and de-gendered but how work on one's gendered

appearance resides in the body's habitual performance. Twigg's work (2010) on dress and her research with Buse and Twigg (2014) on handbags in dementia also point to the potential of material objects to maintain gendered appearance and the concomitant support of the self in dementia. Moreover, haircare, e.g. haircuts, perms, could be understood as ways of maintaining selfhood in general and gendered selfhood in particular, as shown in Ward and colleagues' ethnographic work (2014) in hair salons for people with dementia. Since hair seems of great significance for how PWD emerged as abject, maintaining gendered appearance through hair is perhaps particularly important.

The above examples of appearance in dementia studies focus on the doing of femininity, which is not surprising given the greater emphasis on looks for women's gendered accomplishments. However, a notable exception is Campbell's work (2012) on shaving as an accomplishment of masculine appearance in dementia care settings. She also poses the significant question whether within dementia care shaving 'affirms masculinity or whether a gendered sense of self is being undermined through such everyday appearance-related activities and the way they are appropriated by the care regime?' (Campbell, 2012, 91).

If the dehumanising discourses on dementia, as a loss of self, involve abjection and a subsequent de-gendering of people with dementia, person-centred approaches that seek to sustain personhood in dementia have implicitly pointed to the significance of re-gendering. This could involve establishing a coherence and continuity with a gendered biography through social interaction and the co-authoring of life narratives between PWD and their families and carers or through work on gendered appearance, for example dress, hair, make-up and other body-work.

### The problems of reinforcing gender

Person-centred approaches to dementia have undoubtedly been immensely significant to the empowerment and recognition of people with dementia. Still, their re-gendering as part of acknowledging personhood entails some problems that need addressing, especially when considering gender in terms of normativity and power asymmetries. As Bartlett et al. (2016, 11) state, 'research into gender differences in relation to dementia care lacks a feminist perspective – that is, few researchers start from the premise that society tends to be unequal, hierarchical and based on masculinised values and that this needs to change'. The lack of feminist perspectives is not only visible in dementia care research but in studies of living with dementia in a wider sense. I will therefore now discuss how a further emphasis on the significance of gender for personhood in dementia may also help reinforce gendered binaries, overlook gendered power asymmetries and remove the possibility of disruption and change of gendered subjectivities and gender relations. Does sustaining persons and selves in dementia really involve all gendered embodiments and lives, or are some living with dementia more readily acknowledged as persons than others?

Firstly, many studies on personhood and self in dementia are based on the assumption of binary gender and a continuity and stability of gender over the life course as natural and desirable. For example, returning to the earlier discussed cases of the male academic, J.B., and the nurturing female, I.R. (Sabat & Harré, 1992), one may interpret these examples as ways of acknowledging the significance of a gendered biography for how one is understood as a subject. Still, thinking with feminist theorists like Butler (1993) and Ahmed (2006), gender performativity is not merely individual doings but a discursive process through which subjects are constituted as intelligible. From this perspective, it becomes just as relevant to reflect on how Sabat and Harré as researchers partake in gender performativity by reinforcing gendered narratives as a way to acknowledge the selves of PWD. Rather than assuming gendered binaries – in this case, men's public professionalism and women's private nurture – as natural and voluntary, this perspective suggests that these binaries are continuously constructed in discourse.

Although gender is significant for how we become recognised as persons at all, gendered binaries are also narrow and restrictive and fail to acknowledge how enactments of self are more complex, multifarious and open to change. By emphasising traditional sex roles, such as women as carers and men as professionals, other narratives of self may be lost. One may thus ask what cases and examples are used in research on personhood in dementia and how they reflect researchers' assumptions on gendered life courses. Many people may have negotiated or resisted normative gender throughout their life courses. In their study of how storytelling functions to establish and negotiate identity in dementia, Hydén and Örvulv (2008) use the example of Martha, who continuously returns to how she got her driver's licence and her own car. This story, rather than conveying traditional femininity, is one of challenging and overcoming restrictive gendered expectations on her generation. In contrast to the cases Sabat and Harré (1992) present, this suggests that acknowledging the person in dementia could just as much entail a biography that challenges and repudiates gendered scripts. One's gendered embodied selfhood throughout the life course could also have been non-normative and resistant to traditional femininity and masculinity. A bisexual woman in Jones's study (2011, 265) of ageing futures notes:

We have a list, [woman's name] and I have drawn a list of the things that we wouldn't allow to happen to either of us if we ended up in a care home. So mine was no polyester viscose dresses, no pink nail varnish, no perm and no cups of tea. That's very important.

The quote clearly points to a resistance to what Twigg (2010, 228) calls a form of 'assembly line production, with its imposition of a specific style, indeed a specific form of femininity' in dementia care settings. This resistance brings out questions that are highly relevant for dementia studies to consider, for example to what extent dominant or challenging gendered scripts are represented in research on personhood in dementia. It is also important to affirm experiences of dementia among trans\* people, who are still highly invisible in dementia research (Ward & Price, 2016).

Moreover, within feminist and queer theory, gender is commonly discussed as constantly unstable and incomplete reiterations and, as such, always open to failure/disruption/displacement. Yet the emphasis on inconsistencies in gendered selves may be more ambiguously taken up by scholars and professionals working on the recuperation of the self and personhood of people with dementia, where pointing to continuity rather than disruption is of great significance. This is evident in the work of Kontos, whose notion 'embodied selfhood' very much emphasises the continuity between one's self and the past and living with dementia in the present. However, for PWD, as they become ill, a break with gendered roles and embodiments of the past may, rather than being signs of pathology, be understood as a challenging normative and restrictive gender. As Ward and Price (2016, 61) suggest, some expectations on being a particular person may be lost when one is diagnosed with a dementia illness and, as such, 'the experience of dementia may actually generate an emancipatory space in which to explore, hidden, forgotten, or quite new aspects of self and identity in ways that may not previously have been possible'.

This potential for disrupting gendered performativity is seen in Capstick and Clegg's study (2013) of the wartime (both world wars) memories of three men with dementia. They show how these men were less prone to maintain the masculine performance of the 'stiff upper lip', which involves high cognitive self-control and little emotional expression, and instead produce alternative narratives of self, including stories of vulnerability and non-heterosexual experiences. Another example of how dementia may involve a freedom and challenge to normative gender is found in Boyle's study (2013) of the decision-making by PWD and how this is facilitated or not by spouses. Boyle describes how the husbands tried to retain their wives' executive capacity as housewives, roles that the wives with dementia did not necessarily seek. In one case, a husband referred to his wife as once a 'fairly normal

housewife' and was irritated that she no longer made an effort to be this person, whereas his wife with dementia, in contrast, said: 'um, I'm not particularly house-proud ... and, uh, I'm not going to sweep the floor every day, um ... (as) I'd rather be [pursuing a hobby]' (Boyle, 2013, 235). This example also suggests that the accomplishment of a gendered self, continuous with one's biography, may be of great(er) significance for relatives and spouses than for people with dementia (cf. Phinney et al., 2013). For couples, upholding the gendered subjectivity and embodiment of the PWD may, for instance, also function to sustain the non-ill partner's gendered subjectivity and embodiment. In this case, it may be relevant for the husband to sustain his wife as gendered, as a good housewife, as a way for him to accomplish masculinity because his intelligibility as a man is dependent on the heterosexual matrix.

Similarly, the work the care staff and relatives do on the appearance of people with dementia may be understood as a way of materialising gendered embodiment, of putting bodies in dementia back 'on line' as normatively gendered. As noted previously, relatives and care staff's pursuit of bodily and social order through maintaining an orderly appearance is difficult to disentangle from a desire for gendered intelligibility. Twigg (2010) observes, however, in relation to dress the difficulty of handling discrepancies between the former embodied self and new choices expressed by PWD. She (Twigg (2010), 228) raises the question of how to relate to people with dementia 'who may refuse to don certain clothes, "choose" bizarre or aberrant dress, or appear to find sloppy, informal clothes more comfortable than [sic] the smarter, more formal dress of their past'. This issue is closely linked to questions of gender: how should carers and staff relate to PWD' new gendered styles, including not only new choices of appearance but also other ways of gendered embodiment? A case that particularly underlines the desire for stability and non-ambiguity for carers and family is Jamie, a trans woman with dementia who starts displaying considerable gender ambivalence, which becomes troubling to staff, who do not know how to approach her (Marshall, Cooper, & Rudnick, 2015). From the lens of biomedicine, changes in gender identity are commonly understood as signs of pathology, and for Jamie, the pathologisation operates both in terms of dementia diagnosis and transgender experiences diagnosed as gender dysphoria. However, drawing on feminist and queer perspectives on gender as continuous accomplishments that are always unstable and open to change, being diagnosed with dementia may just as much be understood as a biographical disruption that also opens the way for changes, changes not necessarily consequences of cognitive impairments.

Moreover, from a feminist perspective, gender in dementia must also be considered in relation to gender as a power asymmetry. If women are constructed as Other vis-à-vis men throughout the life course, this is likely to impact on how selves/identities are sustained in later life. The cases where women were sustained as nurturers, housewives and as 'taking great pride in their appearance' and men as professionals clearly also reinforce gender relations connected to power and influence. Although little research has explored gendered experiences of dementia, there are indications that men's identities are more readily maintained than women's in dementia. Boyle's article (2013) on spousal support in decision-making in dementia shows that women carers were facilitating the autonomy of their male partners more so than the other way round. In line with this, Phinney et al. (2013) argue in their study of how families negotiated changing patterns of everyday experiences that for the men diagnosed with dementia, it was troublesome for both them and the family members when the once-assertive men became more resigned (cf. Hayes, Boylstein, & Zimmerman, 2009). The family members and partners were thus prone to underline the men's former strength and competence. The performativity of masculinity in dementia may be experienced as more imperative than that of femininity. Thinking also of gender in intersection with other power asymmetries, such as race and sexuality, these selves are even more liable to be undermined (cf. Hulko, 2004, 2009; Ward & Price, 2016).

And finally, how should one think of enabling particular gendered

practices that clearly reinforce asymmetrical gender relations? Touch, sexual expression and sexual practices, for instance, may be ways of sustaining gendered embodied selfhood in dementia but may also be part of upholding gendered power, where men's sexuality is prioritised and women's bodies are understood as sexually available to men. An interesting example of this is given in Archibald's case study (2002) of a dementia residential care home that regularly held a 'bar night' for the residents and where staff attempted to create a pub atmosphere. On these nights, however, the staff reported that the residents could become 'sexually disinhibited' and 'would place their arms around the waists of the female care workers and touch their breasts or bottoms or make sexually suggestive remarks' (Archibald, 2002, 306). Archibald argues that the bar nights became contexts where the boundaries and roles between carers and residents were blurred, and the 'interaction became as that between man to barmaid' (Archibald, 2002). Rather than understanding the residents' sexual overtures as resulting from dementia, we can understand them as part of embodied selfhood, where masculine and heterosexual styles that have materialised over time persist and shape interactions and continue as a means of expression. This issue is also reflected in my ongoing study of intimate coupledom and experiences of sexuality among people with AD and their partners. In one case, a female partner of a man with AD tells of her husband's unwanted sexual advances and how she 'put up with' still having intercourse with him although she had no desire for this. The reason for this, she argues, was that she recognised that as the disease progressed, still having sexual intercourse was important for his maintained sense of self, and he was notably 'proud of still being able to get an erection'. These examples point to the ethical dilemmas and problems of maintaining masculinity and men's gendered and sexual embodiment in dementia that may sometimes infringe on women's bodily integrity and sexuality.

## Conclusion

This article has sought to put gender on the dementia studies agenda. Dehumanising discourses on dementia, where people with dementia emerge as abject, should be understood in relation to de-gendering and how PWD are positioned outside a heterosexual matrix of gendered intelligibility. The article argues, however, that although person-centred approaches to dementia have hardly discussed the role of gender for emerging as a person at all, gender figures implicitly as significant for sustaining selves in dementia. Researchers as well as relatives and carers of people with dementia could thus be understood to be re-gendering PWD. This re-gendering could involve collaborative work to uphold gendered biographies and life histories as well as maintaining gendered embodied selfhood by enabling an appearance continuous with one's past. Sometimes this is done in collaboration with people with dementia, but there are also cases where gendered embodiment and selves of the past are enforced by carers and relatives who desire biographical continuity.

Challenging the pervasive discourses that dehumanise PWD is an ethically and politically important project that may significantly contribute to the 'liveability' of dementia, and a re-gendering may be an important part of this project. However, thinking of gender in dementia must involve understandings of how people may not have lived normatively gendered life courses and that those life courses may not be as readily recognised. The re-gendering of some PWD, which will help their intelligibility as persons/subjects, may still depend on the abjection of some lives that do not conform to regulatory practices of gender formation and overlook how gender is also power asymmetry. This becomes particularly significant for LGBT\* people living with dementia. Moreover, changes in gendered subjectivity and embodiment when living with dementia are not necessarily consequences of pathology but are a more general reflection of the gender as fluid and open to disruption and change throughout the life course. In some cases, the representation of dementia as disorientation and being 'sans everything'

may in fact emerge as a position free from norms and expectations.

There is an evident need for further feminist interventions in dementia studies and developing some of the questions raised here. How do asymmetrical gender relations impact on living with dementia? If person-centred approaches advocate sustaining selves in dementia, whose selves are enabled and how is this linked to prioritising men and masculinities over women and femininities? How does sustaining or undermining gendered selves intersect with other asymmetries? And do we want all gendered embodiments and selves to be sustained, in particular in cases of malignant masculinities?

This article is the first attempt to shape discussions on gendered subjectivity and embodiment in dementia by highlighting some of the problems and issues related to both the de-gendering and re-gendering of PWD in research, care practice and everyday social interactions. While the article's main focus has been on theoretical dialogues between dementia studies and gender studies/feminist theory, we also need more empirical work that explores the gendered nature of care, health and social professions, how gender is accomplished by care staff, relatives and significant others, and how they relate to changes in gendered embodiment and subjectivity in people with dementia. There is, moreover, a need for more research that further examines the experiences of gendered subjectivity in dementia and how PWD relate to dementia's impact on gender and gender relations (cf., for example, Campbell, 2012; Hulko, 2004, 2009; Phinney et al., 2013). This research would play a very significant role in deepening our understandings of what dementia care and living with dementia as gendered experiences entails.

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