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Regulating, fostering and preserving: the production of sexual normates through cognitive ableism and cognitive othering

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ABSTRACT

People with cognitive disabilities are commonly positioned as risky sexual subjects. This article discusses the discursive production of *sexual normates* in the form of desirable and normative able-minded sexual subjects, in scientific research on the sexuality and cognitive disabilities of younger and older individuals (in particular those with dementia). We identify three interrelated discourses: regulating sexuality; fostering sexuality; and preserving sexuality. The first of these, regulation, pathologises sexuality of people with cognitive disabilities as faulty and in need of restriction. The second discourse, fostering, is more affirmative and argues for educating for a 'healthy' sexuality of people with cognitive disabilities, to mitigate risks of abuse. This discourse is more salient with younger people. The third discourse, preservation, in contrast, is more visible with older people with dementia and affirms sexuality so long as it is consistent with a 'genuine' or 'authentic' sexuality of the past. In conclusion, scientific research reinforces the cultural ideal of the rational and autonomous individual (and as such the mature/adult) capable of making independent decisions and engaging in healthy, good sex, based on stable sexual identities. Findings demonstrate how age intersects with cognitive ableism to intensify the cultural anxiety that exists around the sexualities of people with cognitive disabilities.

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Introduction

Coming from critical disability studies, dementia studies, and ageing studies respectively, we have long been discussing empirical, theoretical and methodological similarities and differences between our research fields, including the possibility of fruitful dialogues between them. Dialogues between these fields are rare, however. Although Alzheimer's disease and other forms of dementia involve cognitive and physical impairment, these are rarely discussed in relation to disability in either dementia studies or critical disability

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studies. For example, persons with dementia are rarely conceptualised as being part of a larger community of persons with disabilities in dementia studies. Similarly, critical disability studies scholarship rarely includes discussions of dementia (Shakespeare, Zeilig, and Mittler 2019). Yet, both people with dementia and people with other types of cognitive impairments are commonly positioned as problematic and 'risky' subjects, particularly when it comes to sexuality, albeit in varying ways. This article is a first step towards the development of a cross-disciplinary dialogue across these fields, with a primary focus on exploring the intersections between cognitive ableism, aging, and sexuality. More specifically, our interest in this paper is exploring the discursive production of sexual normates within scientific research on the sexualities of people who are produced as cognitive Others – that is people with cognitive disabilities.

Following a critical disability studies approach, we understand disability to be an unstable and contested category (Carlson 2003; Kafer 2013) and use the term cognitive Others intentionally to draw attention to the workings of cognitive ableism, that is prejudice or bias in favour of the interests of individuals who possess certain cognitive abilities (or the potential for them). Following Garland Thomson (1997, 7–8), our use of the terms 'normates/others' is likewise intentional to highlight how these are relational and how the normate can only be understood in relation to 'the array of deviant "others" whose marked bodies shore up the normate's boundaries'. Thus, in contrast to the medical model of disability which understands disability as an objective fact of bodies and minds, within a critical disability approach, disability is understood to reside within relationships of power through which one group – the normates – is legitimised by possessing culturally valued cognitive characteristics (e.g. adult able-mindedness). The normate subject only becomes visible when we critically interrogate the 'social processes and discourses that constitute physical and cultural otherness' (Garland Thomson 1997, 8–9). Dominant among these social processes and discourses are scientific discourses that both produce and regulate the sexualities of persons with disabilities (Galvin 2006). These discourses are particularly powerful narratives that have both epistemic and cultural authority in the production of boundaries between the normal/other and desirable/undesirable, and thus play a central role in the construction of sexual normates and sexual Others.

With the aim of bridging critical disability studies with dementia and ageing studies, we use cognitive disabilities as an umbrella term in this paper to refer to people with a range of disabilities, both developmental and those acquired later in life, including individuals with specific conditions such as autism and dementia. We agree with Carlson and Kittay (2009, 309) that this umbrella term is useful given the many similarities and 'overlapping philosophical and practical concerns' shared by individuals who are all discursively produced as cognitive Others. At the same time, we want to acknowledge that there may be important differences between the experiences of people with different types of disabilities, and thus we use specific terms (e.g. persons with dementia) when referring to specific concerns or a particular body of research.

Theoretical background

Sexuality is often understood as a fundamental facet of the human adult self. Developing a 'normally' functioning sexuality, i.e. one that is heterosexual and

reproductive, within a close relationship based on notions of romantic coupled love and stability, is assumed to reflect becoming an adult in normative and desirable ways (McRuer 2006; Kafer 2013). Furthermore, maintaining sexual activity within a couple throughout the life course is associated with being a healthy and functioning adult subject (Marshall 2012).

Disabilities and/or ageing are however ambiguously positioned vis-à-vis these assumptions of sexuality, with persons with disabilities constructed as being either asexual or paradoxically as having faulty sexualities that are problematic and undesirable, and thus in need of social or medical intervention. In drawing attention to the dominance of desexualisation we do not mean to suggest that asexuality is necessarily problematic or to deny that persons with disabilities can identify with an asexual identity. Instead, our aim is to demonstrate how the assumption of asexuality imposed on persons with disabilities functions to deny their sexual agency.

Understanding the othering of the sexualities of people with cognitive disabilities and their exclusion from the sexual imaginary is significant to understanding cognitive ableism more generally, and how perceived mental and cognitive capacities matter for the shaping of gendered, sexual, and able-minded adult subjects (Ward and Price 2016; Kafer 2013). In what follows we will explore the workings of cognitive normativity and cognitive ableism in scientific research on the sexualities of younger and older individuals with cognitive disabilities. In particular, our focus is on scientific literature from Western contexts, and published in English or Swedish. We identify the presence of three interrelated discourses which stress the concern with managing the riskiness of the sexualities of cognitive Others: regulating sexuality; fostering sexuality; and preserving sexuality.

Regulating sexuality: risk/restriction discourse

Much of the scientific literature on sexuality and disability continues to be premised on the medical model, which assumes that disability negatively affects the sexuality of people with disabilities (Rembis 2010). People with cognitive disabilities are typically constructed as either asexual, or too sexual and/or engaged in problematic sexual practices and thus in need of professional intervention (c.f. Bertilsdotter Rosqvist 2014). As but one example, the sexualities of people with dementia have recently emerged as an object of surveillance within psychiatric and other professional medical literature (Kontos et al. 2016; Grigorovich and Kontos 2018). Through the establishment of categories such as ‘improper’ or ‘inappropriate sexual behaviour’ (ISB), the sexualities of people with dementia may be primarily constructed as problematic ‘behaviours’ or ‘symptoms’ of dementia. Definitions of inappropriateness are both expansive and circular, and classifications of ISB have included handholding, the use of pornography, masturbation, sexual interest in someone who is not a spouse, and homosexuality (Black, Muralee, and Tampi 2005). The sexual expressions of people with dementia are often described in scientific literature as being beyond the control of the individual and thus not the result of meaningful or purposeful erotic desire. For example, Mahieu, Van Elssen, and Gastmans (2011, 1141) describe ISB as:

[U]nhibited sexual behaviour or hypersexuality [that is] ... *beyond the person's control* ... and mostly arises *due to dementia*. It may include touching intimate body parts of care providers and bystanders, kissing and hugging that exceeds plain affection, disrobing oneself and others, using sexually suggestive language, attempting intercourse, and compulsive masturbation in both public and personal areas (emphasis added) .

Appropriate or 'normal' sexuality in the context of dementia is left largely unexplored in scientific research, suggesting that the sexual expressions of persons with dementia are never deemed acceptable regardless of the context in which they are expressed. The sexualities of people with dementia are sometimes constructed in the scientific literature as 'burdensome' and are largely perceived as interfering with the work or life of others (Black, Muralee, and Tampi 2005). For example, the pharmacological and non-pharmacological management of ISB is advocated to reduce caregiver burden and/or the risk for moving into a nursing home (Tucker 2010).

The medicalisation of and emphasis on psychiatric and other medical interventions to restrict and control the sexualities of people with cognitive disabilities in scientific research reflects what we refer to as a risk/restriction discourse. This discourse is part of a broader history of the management of the sexualities of persons with cognitive disabilities through compulsory sterilisation and reproductive regulation (see for example Wilson et al. 2011; Benbow and Beeston 2012; Tucker 2010). Within this discourse, people with cognitive disabilities are produced as being in need of close supervision and careful programming, either as potential perpetrators of sexually unwanted acts or as potential sexual victims (see for example Balogh et al. 2001). Historically, the risk/restriction discourse has been saturated by eugenic and scientific racism which focused on the control of the sexualities of young women with cognitive disabilities to prevent them from "producing 'degenerate' children" and establish racial purity (Carlson 2001, 132). However, the contemporary version of the risk/restriction discourse has since expanded to include younger and older persons as well as different gendered implications. Currently, both young and older women with cognitive disabilities are more likely to be constructed as being in need of protection, whereas young and older men with cognitive disabilities are more often perceived as being unable to control their sexual appetites (see, for example, Wilson et al. 2011). For example, in the literature on dementia, men with dementia are often constructed as potential sexual predators who target vulnerable women with dementia and female care providers (Archibald 1998; Ward et al. 2005). Such gendered assumptions are also reflected in quantitative research of prevalence of ISB (Alagiakrishnan et al. 2005) that suggest that this behaviour is far more common in men (93%) than in women (7%). Qualitative research with care providers similarly shows that the expressions of men with disabilities are more likely to be eroticised and pathologised, while the sexual expression of women with dementia is more likely to prompt a protective response (Archibald 1998; Ward et al. 2005). While we do not mean to imply that women living with dementia do not need protection from sexual abuse, the available research highlights how heteronormative assumptions regarding gender roles and sexual conduct likely influence service providers' perceptions of sexual risk and sexual vulnerability in the context of cognitive disability.

Fostering sexuality: risk/education discourse

Alongside the medical model of disability and sexuality, there is a competing discourse of risk/education. In this discourse, the problem of sexuality is perceived to be less the result of disability/pathology and more the result of a lack of a careful fostering, social barriers and negative societal attitudes. Unlike the risk/restriction discourse, where different biomedical interventions are commonly presented as solutions, the risk/education discourse emphasises the importance of fostering the sexuality of young people with intellectual disabilities or autism through cognitive normate-led educational interventions (Borawska-Charko, Rohleder, and Finlay 2017). This is based on a more affirmative, human rights perspective on sexual rights, that identifies negative social attitudes towards disability and sexuality as a barrier to appropriate sexuality. This discourse focuses on younger people with cognitive disabilities and how to support their development into future desirable sexual adults.

Within the risk/education discourse lack of access to sexual education is believed to place such young people at higher risk for sexual harm, or for committing sexual harm against others (see for example, Cambridge 1998; Galea et al. 2004; Murphy and Elias 2006; Swango-Wilson 2008; 2010; Isler et al. 2009). In addition, the discourse suggests that the lack of such education puts people with cognitive disabilities at risk of entering into sexually abusive relations from a lack of sexual self-responsibility or maturity (see for example, Balogh et al. 2001) or at risk of engaging in risky sexual practices from a lack of sexual knowledge or low self-esteem (Perry and Wright 2006). Harm in the context of such practices is typically characterised as the contraction of sexually transmitted diseases (Cambridge 1998; Galea et al. 2004; Murphy and Elias 2006; Isler et al. 2009) and unplanned pregnancy (Galea et al. 2004; Isler et al. 2009). The lack of education is further believed to lead to challenging, or socially devalued, sexual practices including sex in public places and sex work (Cambridge 1998). Overall, the risk/education discourse suggests that it is a lack of appropriate sexual education that prevents people with cognitive disabilities from 'fulfilling [their] participation in a primary aspect of human life, that of intimacy within a relationship' (Swango-Wilson 2010, 161).

This discourse promotes the management of negative attitudes and socially unacceptable sexual practices through education, rather than through biomedical intervention. Parents, health care providers, and other professionals, as well as people with disabilities themselves, are the primary targets for sexuality education. However, there is some disagreement as to the most appropriate content, form, and meaning of such education (Caruso et al. 1997; Swango-Wilson 2008). For example, sexuality education is said to be needed by people with cognitive disabilities to guide them in regard to appropriate sexual expression (Cambridge 1998; Swango-Wilson 2010). However, education is also represented as necessary for enabling them to take on certain adult roles, including developing stable and enduring sexual identities (Withers et al. 2001), heteronormative gender expression and the ability to form and maintain certain types of relationships. For example, Haight and Fachting (1986) argue that such education is needed because like all humans, persons with cognitive disabilities have the desires for love, closeness and intimacy. Similarly, Murphy and Elias (2006, 401) argue two decades later that such education is needed to enable young people

with cognitive disabilities to develop 'a sense of being attractive members of their genders with expectations of having satisfying adult relationships'. Sexuality education has been linked with increased general wellbeing and quality of life for people with cognitive disabilities (Galea et al. 2004) and credited with setting 'the stage for a healthier, safer, socially acceptable, and more fulfilling sexual life in adulthood' (Isler et al. 2009, 28).

Although the risk/education discourse represents a more sex-affirmative view of sexuality among cognitive Others, it is still taken for granted that their sexuality needs to be taught and defined according to the standards of cognitive normates. The underlying assumption of cognitive normality here holds people with cognitive disabilities to a higher standard of adult sexual development, one that steers them into a particular development path, which may conflict with their own individual developmental processes. Sexual, gendered and relational exploration and experimentation, as well as changes in sexual identities are commonly thought of as being an important stage of psychological development in the transition into (normate) adulthood (O'Dell, Brownlow and Bertilsdotter Rosqvist 2018) This kind of experimentation however becomes less likely for persons with cognitive disabilities who are to a greater extent urged to conform to stable sexual identities and expressions.

We argue that turning to critical research and pedagogies within queer and crip theory, may allow for affirmative discourses and practices regarding sexuality and cognitive disabilities, while at the same time actively challenging normative assumptions regarding 'good', 'desirable' and 'healthy' sexuality. This critical research agenda should preferably be based in the perspectives of people with cognitive disabilities themselves, rather than normate perspectives, and acknowledge the fluidity and diversity of sexuality between and within persons with cognitive disabilities. Finally, while sexuality may be of great significance for many persons, critical research and education should also recognise and affirm asexual identities and support of individuals who do not wish to be sexual or form romantic relationships.

Preserving sexuality: risk/preservation discourse

If scientific research on young people with cognitive disabilities seek to enable their emergence of a future desirable sexual adult self, the discourses that affirm the sexualities of older people with dementia are more focused on preserving an assumed authentic past sexual self. We describe this as the risk/preservation discourse.

Scientific literature on sexuality and dementia (including educational programmes for service providers) emphasises the dangers of sexuality for persons with dementia and the need for professional intervention to protect them from sexual abuse, particularly in institutional care settings (Wilkins 2015; Grigorovich and Kontos 2018; Lindsay 2010). Much of this literature focuses on raising the awareness of providers regarding the need to observe and manage the sexualities of persons with dementia by establishing their 'capacity' to consent to sex, and thus determine whether their sexual expressions are 'genuine' or 'authentic' (Wilkins 2015).

Although there is currently no consensus on the definition of sexual capacity, nor how this should be evaluated and by whom, the scientific literature generally

identifies physicians as those best positioned to determine this using standard neuropsychological instruments for assessing cognitive ability (Wilkins 2015; Grigorovich and Kontos 2018). For example, the Mini Mental Status Exam is often identified as clinical tool that along with an interview could be used to assess whether the person with dementia can reflect on their sexuality and verbally articulate that they know who is initiating sexual contact, what sexual activities they desire to engage in, and their ability to avoid exploitation (Wilkins 2015). The sexual expression of people with dementia who are unable to demonstrate such capacity is consequently deemed unintentional and/or not consensual, and thus harmful, with care providers instructed to curtail and redirect such expressions to non-sexual pursuits (DTSC (Dementia Study Training Centres) 2014; Alzheimer's Society of Ontario 2014). For example, the sexual expression of married persons with dementia towards individuals who are not their spouse, as well as same sex sexual expression, are often interpreted as inauthentic and/or symptoms of disinhibition rather than authentic sexual desires (Ward et al. 2005; Bauer et al. 2013; Sarikaya and Sarikaya 2018).

The emphasis on preserving the genuine or authentic adult self of the past is also reflected in the literature on dementia and sexuality in the context of marital/coupled relationships in community-based settings. However, unlike the professional literature focused on the sexualities of people living with dementia in institutional settings, the sexualities of persons with dementia living at home are not understood as only arising from pathology. Instead sexual problems are also constructed as stemming from the changes that dementia prompts to intimate relationships; for example, the increasing dependency of the person with dementia, loss of reciprocity and companionship within couples, and behavioural changes, are identified in the research as leading to decreased desire/unease on the part of the cognitive normate partner/spouse (Nelson 2006; Simonelli et al. 2008; Davies et al. 2010; Sanders and Osterhaus 2013). Yet, even in this more affirming literature, the sexuality of people with dementia is positioned primarily as a problem and/or burden to cognitive normates, in particular for the partner/spouse. For example, in the opening vignette of Kuppuswamy et al. (2007) research article a husband with dementia is described as being 'gentle, sweet and tender' before the onset of dementia with the couples' sex life being like 'dessert after dinner' in the past. The husband's subsequent physical and social changes is however described as causing 'a good marriage [to become] less than perfect' (76) and great distress to his wife. This is but one example in the literature of how sexuality in the (couple's) past is positioned as unproblematic and positive, whereas sexuality in the present when living with dementia becomes troublesome.

While scientific research on couples primarily highlights problems, there is a greater acknowledgement of the possibility of overcoming these problems than in the risk/restriction discourses prevalent on sexuality and dementia in institutional spaces. In particular, the preservation of the couples' sexual or intimate relationship is seen being key to 'maintain[ing] the feeling of being a couple' (Eloniemi-Sulkava et al. 2002, 57) and as serving as a 'bridge to the past' (Wright 1998, 178). Continued sexual intimacy is further emphasised as a way to reaffirm the identities and feelings of self-worth of both the person with dementia and their partner/spouse (Davies et al. 1998; Hayes, Boylstein, and Zimmerman 2009; Nelson 2006). The preservation of the coupled

relationship thus becomes a way of securing a positive sexual adult self in the present, by connecting it with a presumed genuine and authentic stable sexual adult self in the past.

In risk/preservation discourse, similarly to the risk/restriction and risk/education discourses, cognitive normate sexualities are falsely positioned as being conscious and voluntary, rather than “based to some degree on irrationality with little attention paid to pros and cons or future implications” (Wilkins 2015, 720). By representing the changing sexualities of people with dementia as problematic, this literature implicitly suggests that normate sexuality is stable throughout the life course; that is that partners, sexual preferences and identities will essentially remain the same throughout our lifetimes. Finally, similarly to the risk/education discourse present in research on young people with cognitive disabilities, research on older people with dementia almost exclusively foregrounds the experiences and attitudes of cognitive normates (e.g. the ‘non-afflicted’ partners/spouses of people with dementia, and health care providers), which in effect produces older persons with cognitive disabilities as cognitive Others.

Concluding discussion

Throughout this paper we have explored the intersections between cognitive ableism, ageing and sexuality by analysing how sexuality is discussed within scientific research on younger and older people with cognitive disabilities. In doing so, we have sought to gain deeper understanding of the discursive production of people with cognitive disabilities as cognitive Others, and the parallel (implicit) production of cognitive normates and normate sexuality. We have argued that the sexuality of people with cognitive disabilities continues to be defined through a discourse of risk/restriction rooted in the medical model, which effectively pathologises their sexualities as faulty, and thus in need of close surveillance, control and rehabilitation. This medicalisation of the sexualities of people with cognitive disabilities is harmful not only because it contributes to their cultural exclusion, but also because it continues to sustain eugenic and racist classifications of normal/abnormal and healthy/pathological individuals. This has particular significance for persons living with cognitive disabilities in long-term care homes and other ‘total institutions’ (Miles and Parker 1999; Grigorovich and Kontos 2018), as such discourses justify the denial of their sexual rights and the suppression of voluntary intimate and sexual relationships through physical and chemical restraints and oppressive organisational practices (e.g. prohibition of co-habitation, prohibition against use of sexual materials, and staff not knocking before entering residents’ private rooms).

We have argued for the existence of a more affirmative discourse of risk/education in relation to young and people in midlife with cognitive disabilities. In this discourse, sexuality education for both care providers and young people with cognitive disabilities is understood as a way to mitigate their future ‘risky’ sexual self, by preventing their sexual abuse and fostering ‘healthy’ heteronormative gender expressions and relationships. An affirmative discourse is much less visible in relation to older people with cognitive disabilities (particularly dementia), whose sexualities are more often represented using the discourse of risk/preservation. However, this discourse is only

affirmative if sexuality is understood as conscious/deliberate and consistent with sexuality in the past; changes in sexual preferences and identities are continuously positioned as problematic or undesirable. A desirable sexuality in the context of older persons with cognitive disabilities is thus constructed as the imagined authentic (stable) sexuality (of the past) that should be safeguarded. This is reflected in the emphasis given to sexual capacity in both scientific literature and educational guides for practice where people with cognitive disabilities are encouraged to provide verbal consent to sexual activities and display particular awareness of choices regarding sexuality. It is also reflected in literature on coupled/marital relationships where continued sexual intimacy is understood as supporting marital relationships and maintaining self-worth and well-being for both people with dementia and their partners/spouses.

Comparing these three discourses on cognitive disabilities and sexuality reveals how assumptions about ageing and the life course are implicated in the construction of normative sexuality. The focus on access to sexuality education for younger and mid-life people with cognitive disabilities in particular can be understood in relation to the longstanding history of linking intellectual disabilities with childhood (Kafer 2013). People with cognitive disabilities are often positioned as immature, innocent and vulnerable. Furthermore, children in developmental theory are often conceptualised as 'unfinished' adults, in the mode of becoming, which suggests the potential for emerging maturity (Kafer 2013, 54). The emphasis on education in the context of research on sexuality and young persons with cognitive disabilities thus reflects a belief in their potential becoming – that is, in their imagined move from a state of childish immaturity towards adult maturity. In turn, the lesser emphasis on education in research on older persons with dementia reaffirms the broader cultural representation of older people, as decomposing or 'un-becoming subjects' – characterised by their loss of adult selfhood (Krekula, Närvänen, and Näsman 2005; Herskovits 1995). The de-gendering – or the loss of the gendered self—that is presumed to accompany loss of selfhood further forecloses their possibilities for sexual subjectivity (Sandberg 2018).

There are thus different temporalities at stake in discourses of sexuality and cognitive disability. If younger people with cognitive disabilities are produced as eternally emerging adults, their (not yet adult) sexuality is seen as posing a social threat of non-normative reproduction (unwanted pregnancies and motherhood socially deemed as insufficient, (Bertilsson Rosqvist and Lövgren 2013) and sexual abuse. Guarding the sexuality of people with cognitive disabilities (including both its regulation and empowerment) thus becomes a way of securing (future) society and making sexual and intimate citizenship conditional upon their conformity to norms of 'good' adult sexuality (i.e. sex for the sake of heterosexual love and monogamous coupledom) (Gill 2010).

In contrast, the discursive production of older people with cognitive disabilities as vanishing adult selves, and thus vanishing sexual capacity, is not positioned in relation to securing a normative sexual future. Instead, the affirmation of coupled sexuality in dementia is positioned as a way of re-establishing a link to their adult past, to what is presumed to be a more authentic or genuine sexual adult self (prior to cognitive changes). Changes in the sexual preferences or expression of persons with dementia are thus seen as particularly threatening as they are thought to undermine the stability and continuity of an adult sexual subjectivity, and perhaps more widely, the Western modernist subject.

Although there are differences in how sexuality is conceptualised in relation to younger and older persons with cognitive disabilities, there is a shared cultural anxiety associated with their sexualities. As Margrit Shildrick (2009, 84) argues:

[I]f any coming together of bodies, and more specifically the intercorporeality of much sexuality, is encompassed within an implicit anxiety about the loss of self-definition, then that anxiety – which operates within all of us – is at its most acute when the body of the other breaches normative standards of embodiment.

While Shildrick is discussing corporeal difference, we would argue that her argument is just as salient, if not more so, for cognitive differences. The breaching of normative standards of cognitive function seems to engender a particular cultural anxiety, which appears largely related to an unwanted asymmetry in relation to sexuality. This is most evident in the focus on consent to sex across scientific research, which appears to be one of the most pressing issues in relation to cognitive Others. The emphasis on consent in both the scientific literature and in educational guides for practice suggests that sexual-decision-making is conceptualised as being primarily dependent upon cognitive capacities, overlooking other relational and emotional/affective capacities (Grigorovich and Kontos 2018).

It is important to note that across the literature on sexuality and cognitive disabilities, little consideration continues to be given to the voices and experiences of persons living with these disabilities. For example, persons living with dementia are rarely consulted about their sexual needs or involved as research participants in scientific studies on sexuality (for exceptions see, Frankowski and Clark 2009; Bauer et al. 2013; Harris 2009). Similarly, it has only been quite recently, that first-hand narratives by young(er) people with cognitive disabilities talking about sexuality have emerged (Löfgren-Mårtenson, 2008; Kulick and Rydström 2015). In consequence, the sexuality of persons with cognitive disabilities continues to be defined by cognitive normates as a risky problem to be suppressed or managed through redirection or education. Although more affirmative discourses emerge, which contributes to the recognition of the sexual rights of persons with cognitive disabilities to some extent, they allow for only a 'conditional' (Wilson et al. 2011) or 'good enough' sexuality that reflects ableist and heteronormative ideals (e.g. monogamy, heterosexuality, and 'vanilla' non-kink sexual practices). The queer sexual and relational experiences of people with cognitive disabilities, including for example BDSM and polyamory, thus still remain to be explored and researched. There is therefore an urgent need for further queering and crippling of sexuality that takes cognitive ableism into concern, within both research and social policy. This, may in turn, contribute to education and training on sexuality that recognises and affirms the fluidity of sexual identities, and acknowledges a diversity of sexual expressions and practices, including the desire of some individuals not to engage in sexual activity or form romantic relationships. And most importantly, research and practice that challenges normative assumptions regarding sexuality and cognitive disability, including the pathologisation of sexuality among people with cognitive disabilities.

The critical analysis of scientific research on sexuality and cognitive disability presented in this paper demonstrates how the production of cognitive normate sexuality reinforces the cultural ideal of the rational and autonomous individual (and as such

the mature/adult) capable of making independent decisions and engaging in 'healthy' 'good' sex, based on stable sexual identities. By considering how ageing and the life course are implicated in scientific research on sexuality and cognitive disability, this article further extends understanding of how the discourse of risk further intensifies the cultural anxiety that already exists around the sexualities of people who are produced as cognitive Others. Our hope is that our cross-disciplinary analysis will encourage others to disrupt and resist the production of cognitive ableism through intersectional cross-disciplinary research and scholarship on cognitive disability and sexuality.

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References

- Alagiakrishnan, K., D. Lim, A. Brahim, A. Wong, A. Wood, A. Senthilselvan, W. Chimich, and L. Kagan. 2005. "Sexually Inappropriate Behaviour in Demented Elderly People." *Postgraduate Medical Journal* 81 (957): 463–466.
- Alzheimer Society of Ontario. 2014. *Shifting Focus: A Guide to Understanding Dementia Behaviour*. Toronto: Alzheimer Knowledge Exchange, and Behavioral Supports Ontario. http://www.alzheimer.ca/sites/default/files/files/on/shifting-focus/shifting_focus_full_guide.pdf
- Archibald, C. 1998. "Sexuality, Dementia and Residential Care: Managers Report and Response." *Health & Social Care in the Community* 6 (2): 95–101.
- Balogh, R., K. Bretherton, S. Whibley, T. Berney, S. Graham, P. Richold, C. Worsley, and H. Firth. 2001. "Sexual Abuse in Children and Adolescents with Intellectual Disability." *Journal of Intellectual Disability Research : JIDR* 45 (Pt 3): 120–194.
- Bauer, M., L. McAuliffe, R. Nay, and C. Chenco. 2013. "Sexuality in Older Adults: Effect of an Education Intervention on Attitudes and Beliefs of Residential Aged Care Staff." *Educational Gerontology* 39 (2): 82–91.
- Benbow, S., and D. Beeston. 2012. "Sexuality, aging, and dementia." *International Psychogeriatrics* 24 (7): 1026–1033.
- Bertilsdotter Rosqvist, H. 2014. "Becoming an 'Autistic Couple': Narratives of Sexuality and Couplehood within the Swedish Autistic Self-Advocacy Movement." *Sexuality and Disability* 32 (3): 351–363.

- Bertilsdotter Rosqvist, H., and V. Lövgren. 2013. "Doing Adulthood through Parenthood: Notions of Parenthood among People with Learning Disabilities and Autism." *Alter* 7 (1): 56–68.
- Black, B., S. Muralee, and R. R. Tampi. 2005. "Inappropriate Sexual Behaviors in Dementia." *Journal of Geriatric Psychiatry and Neurology* 18 (3): 155–162.
- Borawska-Charko, M., P. Rohleder, and W. M. L. Finlay. 2017. "The Sexual Health Knowledge of People with Intellectual Disabilities: A Review." *Sexuality Research and Social Policy* 14 (4): 393–409.
- Cambridge, P. 1998. "Challenges for Safer Sex Education and HIV Prevention in Services for People with Intellectual Disabilities in Britain." *Health Promotion International* 13 (1): 67–74.
- Carlson, L. 2001. "Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation." *Hypatia* 16 (4): 124–146.
- Carlson, L. 2003. "Rethinking Normalcy." In: *Science and Other Cultures*, edited by R. Figueroa and S. Harding, 154–171. New York: Routledge.
- Carlson, L., and E. F. Kittay. 2009. "Introduction: Rethinking Philosophical Presumptions in Light of Cognitive Disability." *Metaphilosophy* 40 (3–4): 307–330.
- Caruso, S.M., R.B. Bruce, D. Hopkins, M. Lauer, S. Russell, E. Meranto, and K. Stisser. 1997. "The Development of a Regional Association to Address the Sexuality Needs of Individuals with Disabilities." *Sexuality and Disability* 15 (4): 285–291.
- Davies, H. D., L. A. Newkirk, C.B. Pitts, C. A. Coughlin, S. B. Sridhar, L. M. Zeiss, and A. M. Zeiss. 2010. "The Impact of Dementia and Mild Memory Impairment (MMI) on Intimacy and Sexuality in Spousal Relationships." *International Psychogeriatrics* 22 (4): 618–628.
- Davies, H. D., A. M. Zeiss, E. A. Shea, and J.R. Tinklenberg. 1998. "Sexuality and Intimacy in Alzheimer's Patients and Their Partners." *Sexuality and Disability* 16 (3): 193–203.
- DTSC (Dementia Study Training Centres). 2014. *Sexualities and Dementia: Education Resource for Health Professionals*. Queensland. <https://dta.com.au/resources/sexualities-and-dementia-education-resource/>
- Eloniemi-Sulkava, U., I. L. Notkola, K. Hämäläinen, T. Rahkonen, P. Viramo, M. Hentinen, S. L. Kivelä, and R. Sulkava. 2002. "Spouse Caregivers' Perceptions of Influence of Dementia on Marriage." *International Psychogeriatrics* 14 (1): 47–58.
- Frankowski, A. C., and L. J. Clark. 2009. "Sexuality and Intimacy in Assisted Living: Residents' Perspectives and Experiences." *Sexuality Research & Social Policy* 6 (4): 25–37.
- Galea, J., J. Butler, T. Iacono, and D. Leighton. 2004. "The Assessment of Sexual Knowledge in People with Intellectual Disability." *Journal of Intellectual & Developmental Disability* 29 (4): 350–365.
- Galvin, R. 2006. "A Genealogy of the Disabled Identity in Relation to Work and Sexuality." *Disability & Society* 21 (5): 499–512.
- Garland Thomson, R. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.
- Gill, M. 2010. "Rethinking Sexual Abuse, Questions of Consent, and Intellectual Disability." *Sexuality Research and Social Policy* 7 (3): 201–213.
- Grigorovich, A., and P. Kontos. 2018. "Advancing an Ethic of Embodied Relational Sexuality to Guide Decision-Making in Dementia Care." *The Gerontologist* 58 (2): 219–225.
- Haight, S. L., and D. D. Fachting. 1986. "Materials for Teaching Sexuality, Love and Maturity to High School Students with Learning Disabilities." *Journal of Learning Disabilities* 19 (6): 344–350.
- Harris, P. B. 2009. "Intimacy, Sexuality, and Early-Stage Dementia: The Changing Marital Relationship." *Alzheimer's Care Today* 10 (2): 63–77.
- Hayes, J., C. Boylstein, and M.K. Zimmerman. 2009. "Living and Loving with Dementia: Negotiating Spousal and Caregiver Identity through Narrative." *Journal of Aging Studies* 23 (1): 48–59.
- Herskovits, E. 1995. "Struggling over Subjectivity: Debates about the "self" and Alzheimer's disease." *Medical Anthropology Quarterly* 9 (2): 146–164.
- Isler, A., D. Beytut, F. Tas, and Z. Konk. 2009. "A Study on Sexuality with the Parents of Adolescents with Intellectual Disability." *Sexuality and Disability* 27 (4): 229–237.

- Kafer, A. 2013. *Feminist, Queer, Crip*. Bloomington: Indiana University Press.
- Kontos, P., A. Grigorovich, A. P. Kontos, and K. L. Miller. 2016. "Citizenship, Human Rights, and Dementia: Towards a New Embodied Relational Ethic of Sexuality." *Dementia* 15 (3): 315–329.
- Krekula, C., A. L. Närvänen, and E. Näsman. 2005. "Ålder i Intersektionell Analys." *Kvinnovetenskaplig Tidskrift* 26 (2–3): 81–94.
- Kulick, D., and J. Rydström. 2015. *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Durham, NC: Duke University Press.
- Kuppuswamy, M., H. Davies, A. Spira, A. Zeiss, and J. Tinklenberg. 2007. "Sexuality and Intimacy between Individuals with Alzheimer's Disease and Their Partners." *Clinical Gerontologist* 30 (3): 75–81.
- Lindsay, J. R. 2010. "The Need for More Specific Legislation in Sexual Consent Capacity Assessments for Nursing Home Residents." *The Journal of Legal Medicine* 31 (3): 303–323.
- Löfgren-Mårtenson, L. 2008. "Love in Cyberspace: Swedish Young People with Intellectual Disabilities and the Internet1." *Scandinavian Journal of Disability Research* 10 (2): 125–138. doi: [10.1080/15017410701758005](https://doi.org/10.1080/15017410701758005)
- Mahieu, L., K. Van Elssen, and C. Gastmans. 2011. "Nurses' Perceptions of Sexuality in Institutionalized Elderly: A Literature Review." *International Journal of Nursing Studies* 48 (9): 1140–1154.
- Marshall, B. L. 2012. "Medicalization and the Refashioning of Age-Related Limits on Sexuality." *Journal of Sex Research* 49 (4): 337–343.
- McRuer, R. 2006. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.
- Miles, S. H., and K. Parker. 1999. "Sexuality in the Nursing Home: Iatrogenic Loneliness." *Generations* 23: 36–43.
- Murphy, N. A., and E. R. Elias. 2006. "Sexuality of Children and Adolescents with Developmental Disabilities." *Pediatrics* 118 (1): 398–403.
- Nelson, N. 2006. "Caregiving and the Sexual Relationship in Dementia." In *Supporting the Caregiver in Dementia: A Guide for Health Care Professionals*, edited by S. M. LoboPrabhu, V. Molinari, and J. W. Lomax, 117–131. Baltimore, MD: Johns Hopkins University Press.
- O'Dell, L., C. Brownlow, and H. Bertilsdotter Rosqvist. 2018. *Different Childhoods: Non/Normative Development and Transgressive Trajectories*. Abingdon: Routledge.
- Perry, B. L., and E. R. Wright. 2006. "The Sexual Partnerships of People with Serious Mental Illness." *Journal of Sex Research* 43 (2): 174–181.
- Rembis, M.A. 2010. "Beyond the Binary: Rethinking the Social Model of Disabled Sexuality." *Sexuality and Disability* 28 (1): 51–60.
- Sandberg, L. J. 2018. "Dementia and the Gender Trouble?: Theorising Dementia, Gendered Subjectivity and Embodiment." *Journal of Aging Studies* 45: 25–31.
- Sanders, S., and J. Osterhaus. 2013. "Birth of a Stranger: Intimacy, Sexuality and Dementia." In *Living, Loving, and Loss: The Interplay of Intimacy, Sexuality, and Grief*, edited by B. DeFord and R. Gilbert, 121–149. Amityville, NY: Baywood Publishing Company.
- Sarikaya, S., and B. Sarikaya. 2018. "Aripiprazole for the Treatment of Inappropriate Sexual Behavior: Case Report of an Alzheimer's Disease Patient Known as Heterosexual with Recently Shifted Sexual Orientation to Same Gender." *Journal of Alzheimer's Disease Reports* 2 (1): 117–121.
- Shakespeare, T., H. Zeilig, and P. Mittler. 2019. "Rights in Mind: Thinking Differently about Dementia and Disability." *Dementia* 18 (3): 1075–1088.
- Shildrick, M. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality*. Basingstoke: Palgrave Macmillan.
- Simonelli, C., F. Tripodi, R. Rossi, A. Fabrizi, D. Lembo, V. Cosmi, and L. Pierleoni. 2008. "The Influence of Caregiver Burden on Sexual Intimacy and Marital Satisfaction in Couples with an Alzheimer Spouse." *International Journal of Clinical Practice* 62 (1): 47–52.
- Swango-Wilson, A. 2008. "Caregiver Perceptions and Implications for Sex Education for Individuals with Intellectual and Developmental Disabilities." *Sexuality and Disability* 26 (3): 167–174.

- Swango-Wilson, A. 2010. "Systems Theory and the Development of Sexual Identity for Individuals with Intellectual/Developmental Disability." *Sexuality and Disability* 28 (3): 157–164.
- Tucker, I. 2010. "Management of Inappropriate Sexual Behaviors in Dementia: A Literature Review." *International Psychogeriatrics* 22 (5): 683–692.
- Ward, R., and E. Price. 2016. "Reconceptualising Dementia: Towards a Politics of Senility." In *Lesbian, Gay, Bisexual and Trans* Individuals Living with Dementia: Concepts, Practice and Rights*, edited by S. Westwood and E. Price, 65–78. Abingdon: Routledge.
- Ward, R., A. A. Vass, N. Aggarwal, C. Garfield, and B. Cybyk. 2005. "A Kiss is Still a Kiss? The Construction of Sexuality in Dementia Care." *Dementia* 4 (1): 49–72.
- Wilkins, J. M. 2015. "More than Capacity: Alternatives for Sexual Decision Making for Individuals with Dementia." *The Gerontologist* 55 (5): 716–723.
- Wilson, N. J., Parmenter, T. R. Stancliffe, R. J., and R. P. Shuttleworth. 2011. "Conditionally Sexual: Men and Teenage Boys with Moderate to Profound Intellectual Disability." *Sexuality and Disability* 29 (3): 275–289.
- Withers, P., I. Ensum, D. Howarth, P. Krall, D. Thomas, D. Weekes, C. Winter, A. Mulholland, T. Dindjer, and J. Hall. 2001. "A Psychoeducational Group for Men with Intellectual Disabilities Who Have Sex with Men." *Journal of Applied Research in Intellectual Disabilities* 14 (4): 327–339.
- Wright, L. K. 1998. "Affection and Sexuality in the Presence of Alzheimer's Disease: A Longitudinal Study." *Sexuality and Disability* 16 (3): 167–179.