

Ageing and Chronic Illness

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Biogs

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Abstract

In Western societies and globally there is an ageing demographic and public health issues, such as dementias, are subject to hyperbolic metaphor such as ‘tsunami’ and ‘time bomb’. This chapter reviews the state of knowledge regarding sexualities, ageing and chronic illness. In particular we focus on discursive research from across the social sciences that has enabled understandings of older LGBTQ people’s lives and experiences. In so doing we highlight research that has focused on ageism, and chronic conditions that impact older people (dementia and type 2 diabetes) including our own empirical research on these conditions, and on manifestations of heterosexism and heteronormativity in these contexts. Using illustrative examples that emphasise the intersection of language, sexuality, ageing and chronic illness we foreground this area as an important element of language and sexuality scholarship, and indicate future directions for the development of research focusing on these important topics.

Key words: ageing; chronic illness; dementia; discursive; LGBTQ

Dementia, Metaphor and Sexuality

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to see only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. [...] My subject is not physical illness itself but the uses of illness as a figure or metaphor. My point is that illness is *not* a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one’s residences in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped (Sontag, 1978, p. 3, emphasis in original).

As Susan Sontag highlighted in her classic book *Illness as Metaphor*, illness is inseparable from the language and metaphor through which we understand the experience. Sontag's focus was specifically on cancer and tuberculosis, and she draws a sharp distinction between the problematic 'lurid metaphors' and the actual lived experience of illness – one which, as she indicates here, should be unsullied by the language through which we understand it. Our focus in this chapter departs from Sontag in a number of key ways. First, we take a social constructionist – or at least a critical realist - stance (rather than the implied realist stance in the quote above) to exploring how language impacts on chronic illness and ageing. Second, we take sexualities as a critical lens in interrogating discursive and communicative approaches to health and illness. Third, we bring to the fore two different chronic illnesses, which constitute significant contemporary public health issues, namely dementia and type 2 diabetes.

In this chapter, we consider ageing and chronic illness in interconnected ways for three, similarly interconnected, reasons. The first, and most obvious, is that in Western societies, and globally, there is an ageing demographic (WHO, 2015), and chronic health problems disproportionately impact people as they age. Secondly, it would be reasonable to suggest that language and sexualities scholarship has not, historically, taken ageing and chronic illness as mainstays of analytic focus (cf. Peel & Harding, 2016). Finally, in offering this focus, we would not only wish to foreground issues connected to ageing and chronic illness as offering fertile ground for language and sexualities researchers, but also to tease out some of the salient themes in how such scholarship may wish to progress, especially with regard to LGBTQ sexualities.

Returning briefly to metaphor, in contrast to Susan Sontag's (1978) call to purify illness of metaphoric thinking, George Lakoff and Mark Johnson (2003) suggest that 'metaphors are not merely things to be seen beyond. [...] It is as though the ability to comprehend experience through metaphor were a sense, like seeing or touching or hearing, with metaphors providing the only ways to perceive and experience much of the world' (p. 239). So, the construction, prevalence, and context of use of metaphor are significant. To take a recent example, Zsófia Demjen, Elena Semino and Veronika Koller (2016) have suggested, based on interviews with UK palliative healthcare

professionals, that the difference between a ‘good’ and a ‘bad’ death is partly communicated through the frequency of contrasting metaphors (‘peacefulness’ and ‘openness’ for a ‘good death’ versus ‘struggle’ for a ‘bad death’). They demonstrate how metaphors are used to justify and evaluate deaths and those dying, and promote a particular ‘framing’ of a good death (Demjen, Semino & Koller, 2016).

More broadly, both public health and media discourse about ageing and certain chronic conditions, such as dementia, are replete with hyperbolic metaphor such as ‘tsunami’ and demographic ‘time bomb’ (Peel, 2014). When we analysed British newspaper media coverage – 350 articles focused on dementia and Alzheimer’s disease in 2010 to 2011– there was a ‘panic-blame’ framework evident. On the one hand, dementia was conveyed in catastrophic terms, communicating a public health ‘panic’ (a ‘tsunami’; ‘worse than death’; ‘Alzheimer’s epidemic’). On the other hand, and somewhat paradoxically, there was much evidence of a dementia ‘prevention’, individual responsibility and (potentially) blame discourse, which emphasised – sometimes contradictory - lifestyle recommendations to ‘stave off’ the condition (e.g., ‘Fatties 80% more likely to develop Alzheimer’s’, ‘Stick to a high-fat diet to avoid Alzheimer’s’) (Peel, 2014). Military metaphors, while having been dated back to at least the 17th Century as descriptors for illness generally (Lane, McLachlan & Philip, 2013) have, only relatively recently, been used in communication about dementia. Lane et al. (2013), in discussing the positive and negative aspects of military metaphors, draw our attention to their use in the dementia context. They note that public health and the use by charities of military metaphors – for instance the UK’s Alzheimer’s Society strapline ‘leading the fight against dementia’ – has likely contributed to the raised profile of dementia latterly. They caution, however, that:

‘[A]t an individual level a chronic illness such as dementia is arguably not usefully conceived as a battle. First, no curative treatments are available as “arsenal”. Secondly, many people with dementia are older and face other medical conditions or disability. These people may not be in a position to “fight”. [...] Military metaphors focus on the immediate “fight” and may impede conversations about the future. Additionally, fighting metaphors may leave some individuals feeling they have “lost” as the disease progresses [... and] from a broader

perspective, focus on “battling”, may distract from discussion about how our communities best care for and support an increasing number of people and their families as the population ages’ (Lane et al., 2013, pp. 282-3).

In our own interview and focus group research with informal carers of people living with dementia, we found ‘battling’ discourse in a different sense. Ironically, rather than military metaphor being levelled at the disease, in this research ‘many carers described the process of accessing health and social care services for the person they care for as a “battle” or “fight”’ (Peel & Harding, 2014, p. 655). For example, in the words, of James, one of the focus group participants:

‘You’re under immense strain caring for somebody who has, in effect, behavioural difficulties through no fault of their own and you’re under that mental, emotional, physical effort and at the same time you’re having to battle the system [...] you’re having to go to- it’s like being in World War III, you’ll go into one battle and another one starts’ (p. 656).

Therefore, we see here, while James stops short of describing going to ‘war’ explicitly, he makes vivid and detailed use of military metaphor directed at ‘the system’ of health and social care services which are ostensibly designed to enable and support people with dementia and their families.

So military metaphor can be levelled at many different ‘targets’. In other research, in this case online survey data with LGBTQ people living with various chronic illnesses, against ‘cultural stereotypes’: ‘[h]aving to battle the cultural stereotypes that queers (especially gay men) are supposed to be the fit, buff model of health, and that “these things don’t happen to us” has been a difficult mental barrier’ (Black gay man, USA, diabetes, sleep apnea, quoted in Jowett & Peel, 2009, p. 462).

Revisiting the commentary from Lane et al. (2013) above, a key component in considering ageing and chronic illness through the dual lens’ of language and sexuality has to be ‘our communities’. Critical, in our view, are LGBTQ communities as they age and experience chronic illness. And how discourses applied to these communities intersect with other crucial axis of oppression and marginalisation, such as gender, ethnicity, (dis)ability.

With regard to dementia again, there is increasing discursive space being made for understanding dementia as a gendered issue, with women being more affected than men (e.g., Erol, Brooker, Peel, 2015). And within this, there is now some recognition that lesbian and bisexual women, and LGBTQ people generally, are differently impacted by a discursive landscape, and resultant policy and care contexts, predicated on hetero- and cisgender normativity (Peel & McDaid, 2015; Semlyen, Brooker, Peel, in prep.; Westwood, 2014). An older lesbian, Rowena, for example, describes the importance of linguistic and sub-cultural recognition within the care home contexts, as: ‘[j]ust as it is important to have someone who speaks English or the same language as you, so you can communicate, I need someone who can “speak lesbian!” Our culture is different and we have different ways of doing things. It is a bit indefinable, but it is really important’ (Knocker, 2013, p. 11). So discursive space results in actual space, actual recognition, that acts as a counter to the invisibilising which often occurs in relation to LGBTQ ageing¹.

This invisibilising occurs on a number of planes, encapsulated in these two quotes: ‘The disappearance of older lesbians and gay men [and BTQ people] may seem somewhat analogous to a science fiction tale in which everyone over a given age suddenly vanishes as if to avoid tarnishing younger people’ (Stephen Pugh, 2002, p. 160, quoted in Clarke, Ellis, Peel & Riggs, 2010, p. 216); and ‘[i]nstitutions, they’re very straight. My god I hope I don’t have to go into a care home ... It frightens me that I am just going to be invisible, a nobody, that I am just going to be lost. (May, age 64, quoted in Westwood, 2014, p.10). The first quote, from Stephen Pugh, underscores the ageist discourse that has been identified in some parts of LGBTQ communities, most notably with regard to

¹ Of course, older LGBTQ people occupy a distinctive historical location – the discursive reinvention of homosexuality means that for some (especially those over the age of 65) formed their identities within a culture of stigmatisation of homosexuality. For others (i.e., those 50-65 years) within a culture of gay liberation which topicalised homosexuality as a positive identity despite social stigma. These cohort effects result in differing orientations to the self as LGBTQ, the extent of outness, and how they want to live out their lives as older LGBTQ people (Lyons et al., 2015; Rosenfeld, 1999).

a ‘youthist’ gay male culture (cf Tyler, Nodin, Peel & Rivers, 2016). The second, highlights the lack of recognition of older LGBTQ identities in care homes settings, and how the heteronormativity of ‘institutions’ would result in a lack of lesbian visibility. In the following section, we consider the discourses associated with physical change in ageing sexualities before returning to discursive invisibility in the context of sexuality and chronic illness.

Sexuality and Ageing: Discourses about Decline?

‘Healthy ageing’, ‘successful ageing’, ‘active ageing’; these are all terms that are peppered through gerontological and public discourse regarding ageing. In the UK, for example, following the National Service Framework: Older People (DoH, 2001), government rhetoric shifted towards ‘successful ageing’. Although this rhetoric has been enthusiastically adopted by some fit, health and socially engaged older people, the term (and implied neo-liberal mandate to remain ‘healthy’ in older age) has been subject to heavy critique, and belies the experiences of those with chronic or degenerative conditions.

- A youth-oriented culture that attributes sexuality to the young, healthy and beautiful results in stereotype of the ‘asexual older person’ – perpetuated in policy and Government agendas (Bouman, 2005 in Scherrer, 2009; Hinchliff & Gott, 2016) and more acute in the gay male community where emphasis on the gay scene and youthful bodies (Slevin & Linneman, 2010) resulted in men experiencing growing older as a process of marginalisation where they felt increasingly invisible (Lyons et al., 2015).
- The Asexual oldy narrative is one of decline – many (e.g. Vares et al 2007 in Scherrer 2009) highlight that sexuality is a natural necessary component for healthy ageing (Scherrer, 2009). The impotent/asexual old man image coexists alongside ‘the sexy senior’ where a continuing sex-life is understood as part of positive ageing (Sandberg, 2013).
- Ageing as physical inhibition of sexuality which can be medically enabled (Scherrer, 2009)
- Tendency to focus on sexuality through a largely heterosexist (and male) lens of sexuality as about function (or sexual performance). Discourse around ageing informed by medical discourse

on physical/biological ‘problems’ associated with ageing and sexual function rather than the diversity of sexuality and gender (Phillips & Marks, 2008) – e.g. re-sexing the ageing male body (Slevin & Linneman, 2010) which overlooks LGBTQ sexualities and downplays experiences of women (Sandberg, 2013).

- Importance of intimacy (i.e. emotion, touch, sensuality, etc) as a productive discourse to make sense of sexuality in later life (Sandberg, 2013) – changes to nature of ‘sexual fulfilment’ with age.

Phillips, J. & Marks, G. (2008). Ageing lesbians: Marginalising discourses and social exclusion in the aged care industry. *Journal of Gay and Lesbian Social Services*, 20 (1/2), 31-49.

- Intake documentation in aged care facilities is often framed within discourses of heteronormativity, and aspects of sexuality tend to be informed by medical discourse on physical/biological ‘problems’ associated with ageing and sexual function rather than diversity of sexuality and gender.
- Sexualities and genders alternative to the dominant heterosexuality were noticeably absent or silenced in brochures for aged care facilities – couples pictured were always heterosexual; and no brochure mentioned alternative sexualities.
- ‘Cultural diversity’ was always framed in relation to racial/ethnic minorities with no recognition of LGB sexualities as cultural difference.

Brown, M. T. (2009). LGBT aging and rhetorical silence. *Sexuality Research & Social Policy*, 6 (4), 65-78.

- For older LGBT adults, the term ‘queer’ is problematic as for historical reasons it has negative connotations that make them feel shut out.

- Exclusion of LGBT elders from queer theory and gerontological theory has resulted in the silencing of LGBT older adults and their lived experiences – this is a rhetorical move (possibly intentional or possibly a by-product of discourse) that renders elders invisible in queer theory and queerness invisible in ageing theory. This rhetorical use of silence renders LGBT older people invisible and powerless.
- This silencing in theory is echoed in human service practice – this has meant that LGBT elders have had to deny their sexual and gender identities to gain access to the social and material support available to older adults through traditional human service networks. Especially problematic for LGBT elders as they have often been rejected by their extended families so don't have social support through conventional family networks.
- LGBT society has not developed a concept of normative ageing – this is partly due to the AIDS crisis (which meant that many gay men died young) but partly also due to a construction of 'gay' as synonymous with 'young'.
- Today's generation of old LG may be voluntarily practicing their own rhetorical move of silence as a form of self-protection from perceived or actual ageism in the LGBT community and homophobia in the older-adult community.
- Ageing theory also ignores heterogeneity among older adults in terms of sexual identity, gender identity, and gender expression.
- Even feminist gerontological literature is problematic – although it interfaces with experiences of ageing women, it tacitly ignores transgender older women's bodies thus silencing the experiences of sexual minority and gender minority elders.

Hosseini, K. (2015). Hypervisibility: Toward a conceptualization of LGBTQ aging. *Sexuality Research and Social Policy*.

- Medical surveillance plays an increasingly influential role in limiting expressions of non-normative sexuality and gender identity in old age – absence of same-sex sexuality and gender non-conformity within the context of the life course may not only be pertinent, but also necessary.
- Silencing of accounts of LGBTQ aging may be reflective of a broader regime of governance that functions to deploy hypervisibilized queerness and gender variance to monitor and limit expressions of non-normative sexuality and gender identity in old age.

Hinchliff, S. & Gott, M. (2016). Ageing and sexuality in western societies: Changing perspectives on sexual activity, sexual expression and the ‘sexy’ older body. In E. Peel & R. Harding (Eds.), *Ageing and sexualities: Interdisciplinary perspectives* (pp. 11-31). Aldershot: Ashgate.

- Sexuality of women and men at middle and late adulthood sits in a contradictory position – representations of active sexuality of older heterosexual adults are visible in the media yet there is a clear aversion to naked old bodies – older bodies are presented differently from younger bodies (often partially covered). Older bodies also tended to be mocked or presented in derogatory ways.
- Older (women’s) bodies portrayed as undesirable or unloveable – reinforce the message that older female sexuality is not something to be taken seriously. Women are also disproportionately disadvantaged when compared to men.

Potts, A., Grace, V. M., Vares, T. & Gavey, N. (2006). ‘sex for life’? Men’s counter-stories on ‘erectile dysfunction’, male sexuality and ageing. *Sociology of Health & illness*, 28 (3), 306-329.

- Traditionally, male sexuality in older age represented in negative terms associated with decreasing erectile capacity and flagging sexual performance - still evident in Western constructions of mid-to-late life male sexuality – but evidence of the emergence of a newer

anti-decline narrative thanks to the biomedicalisation of sexuality and the use of pharmaceuticals.

- biomedical model of sexuality seeks to reduce all men's bodies and sexual experiences to a universal model of male (hetero)sexuality – we argue for placing greater research emphasis on the diversity of men's experiences of sexuality, individually and in the context of their relationships, and of exploring the changes that occur in sexual practices and pleasures with time and experience.
- Emphasis on effect of erectile changes in older age perpetuates a sense of inadequacy and abnormality, rather than positive opportunities for increased sensuality, intimacy and experimentation.

King, A. (2016). Troubling identities? Examining older lesbian, gay and/or bisexual people's membership categorisation work and its significance. In E. Peel & R. Harding (Eds), *Ageing and Sexualities: Interdisciplinary perspectives* (pp. 163-181). Aldershot: Ashgate.

- When sexuality/sexual identity is made relevant to interaction, certain categories are brought into play because sexuality is an accountable identity – typically people use a socially recognisable category (e.g. bisexual) then clarify how they fit or distance themselves from that category. For example 'lesbian' then 'we really don't label ourselves do we?'. Similarly with gender – e.g. positioning as 'male' but distancing from 'ordinary male' as 'has sex with other men'.
- Participants did not unquestioningly accept sexuality as a/ a single category wholly indicative of who they are as a person, or b/ as being applicable to them without some form of clarification and shaping. Particularly without some recourse to gender.
- When categories of age were made relevant: did not want to be considered 'past it'; 'lesbian' is hearably age positioned category, as well as being associated with sexuality and gender; rejection of the category 'old' or 'older'.

- Identifying someone as an older lesbian, gay or bisexual person is not straightforward; it involves complex identity categorisation work, played out through the performative use of identity categories and their associated attributes within interactions.

Sexuality and Chronic Illness

Diabetes (esp. Peel et al 2005; Jowett et al 2012 – JHP) and dementia

Concluding Remarks

This chapter has reviewed the state of knowledge regarding sexualities, ageing and chronic illness. In particular we focus on discursive research from across the social sciences that has enabled understandings of older LGBTQ people's lives and experiences. In so doing we highlighted research that has focused on ageism, and chronic conditions that impact older people (including type 2 diabetes and dementia) including our own empirical research on these conditions, and on manifestations of heterosexism and heteronormativity in these contexts. Using illustrative examples that emphasise the intersection of language, sexuality, ageing and chronic illness we foregrounded this area as an important element of language and sexuality scholarship.

Future directions of language and sexualities research focused on ageing and chronic illness

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