CHAPTER TITLE:

Sexual Wellbeing and Rights in Later Life: developing an affirmative approach to older adult's sexual agency.

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INTRODUCTION

Social work is a human rights-based profession. Advocating and upholding human rights is a core activity embedded in the international definition of social work (IFSW, 2014). In the context of supporting older people, this intersects with the United Nations Principles for Older Persons (1991) which sets out independence, participation, self-fulfilment and dignity as integral principles to supporting older people to fully participate in society. Missing from both discourses on ageing and human rights is an understanding of *sexual rights*. The World Association for Sexual Health (WAS) (2014) identifies sexual rights as 'grounded in universal human rights' however social and cultural discourses compound the invisibility of older adults' sexual rights and inhibit discussion about the sexual wellbeing of older adults in social work practice contexts.

In this chapter we identify through a critical lens the sexual and gender discourses that limit recognition of sexual wellbeing in later life. We integrate messages from recent research on older people's sexual lives to broaden social work understanding of the diversity of sexual experiences across older age, gender and sexuality. We conclude with suggestions that affirm

and support the sexual rights and wellbeing of older adults. An intersectional approach underpins our discussion. Age, gender and sexuality are three interconnecting social structures for organising social life that generate inequalities in the ways in which older people from different social backgrounds and characteristics are represented, understood and supported (Calasanti, 2019). These intersections, if not recognised can generate further forms of inequality, exclusion and shame for people with care and support needs. While there is a considerable volume of research examining the interconnections between gender and sexuality the inclusion of ageing is important to intersectional perspectives (King *et al.*, 2019).

Sexual wellbeing and rights: key frameworks

The World Health Organisation's (2006) definition of sexual health makes explicit reference to '...a state of physical, emotional, mental and social well-being in relation to sexuality'. Across research studies sexual wellbeing is conceptualised and measured in different ways. Lorimer *et al.* (2019) identify three overarching domains: cognitive-affect (for example, selfreports on sexual self-esteem and anxiety), inter-personal (such as satisfaction with sexual relationships and communication) and, socio-cultural (for instance, understanding wellbeing in relation to gender norms and stereotypes). We are particularly interested in the *sociocultural dimensions of sexual wellbeing*, namely how socially endorsed notions of ageing, gender and older age filter contemporary understanding of older people's sexual expressions, agency, identity and relationships. In UK social work practice, the notion of wellbeing includes social and emotional wellbeing, protection from abuse and neglect, and support for self-definition within holistically designed support (Hafford-Letchfield, 2013).

The historical development of sexual rights is rooted in international lobbying for greater recognition of women's reproductive rights and protection from sexual violence. The 1994 UN International Conference on Population and Development (Cairo) acknowledged reproductive rights and sexual health as areas for global action (Altman and Symons, 2016) alongside the WAS Declaration of sixteen Sexual Rights encompassing WHO's definition of sexual health. WHO (2014) asserted that sexuality 'is a central aspect of being human throughout life, encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction' (p.1). Like human rights, sexual rights are universal and integral to the maintenance of health, inclusive of the right to enjoy sexual pleasure. While age is mentioned in the context of equality and non-discriminatory treatment, there is no discussion of how ageing processes and structures complicate sexual agency and how to support of older people's sexual desires, expressions and identities.

Richardson (2000) identified three strands of discourse on sexual rights: 1) rights to participate in sexual activities and practices; 2) rights to self-define, claim and express individual identities, inclusive of LGB and trans identities; and 3) rights recognised by public and social institutions, and the state recognition of stigmatised relationships. All three represent areas often denied to or disassociated from older people's lives, particularly older adults with care and support needs, or perceived as vulnerable. Key concepts and theories for developing a critical understanding of discourses that confound a more affirming understanding of older people's sexual rights are useful.

KEY CONCEPTS AND CRITICAL PERSPECTIVES

Ageism and ageist erotophobia

Age as a social construction shapes the ways in which we understand and approach the sexual subjectivity of different age groups. Children are often represented as needing protection from sex and sexual desires while for older people sex is deemed to be no longer relevant – or people become 'post-sexual' (Moore and Reynolds, 2016). Perceiving older people as sexually inactive, in sexual decline or of beyond sexual attraction and desire, both as subjects of desire and as experiencing desires is common (Simpson *et al.*, 2017). Ageist expressions convey negative, dismissive or degrading beliefs and attitudes about older people and expressed in covert and subtle ways (Gendron *et al.*, 2016). In the context of sex and sexuality, older people in Global North societies are either denied sexual agency or the subjects of ridicule and disgust. Ageism includes the presumption that frailty and disability prevent the enjoyment of sexual activity based on its relegation to the boundaries of penetrative sex. Further, the lack of attention to sexual health problems or access to sexual health information and treatments reinforces an attitude of shame and disgust (Hafford-Letchfield, 2008; Nash *et al.*, 2015). These beliefs inhibit recognition of older people's rights to participate in consensual sexual activity and practices.

Ageist erotophobia, or expressions of 'disgust at the thought of ageing body-selves as sexual' (Simpson *et al.*, 2017, p. 244), can manifest through everyday cultural mediums such as the disparaging representation of older people's sexual libido on birthday cards, through to degrading practices such as the withdrawal of support to vulnerable older adults who express sexual desires and experience arousal. Gewirtz-Meydan *et al.* (2019) reviewed research that examined sexuality from the perspectives, attitudes and personal sexual experiences of older people themselves. They found that older people internalised these ageing stigmas and spoke about the tensions and challenges they experienced in their desires to express their sexuality within the constraints of social conventions that inhibited them from doing so. These

included the lack of professional support and the hegemony of penetrative sex. Such wider pressures gave rise to feelings of distress, disappointment, frustration, shock and fear of failure, which could lead to despair, devastation and a sense of hopelessness for older people (Loe, 2004). Older people's personal accounts of sex in later life also convey psychological and physical benefits, including self-reports on higher quality of life (Freak-Poli and Malta, 2020). Placing older people's voices at the centre of any analysis is therefore essential for recognising the meaning of sexuality in later life and how actively engaging with their perspectives can help to meet their needs and shape services and support.

Life course perspectives on LGBQ ageing

A commonly voiced expression by those administering care to diverse groups of older adults is that equal treatment is achieved by 'treating everybody the same'. However, this discourse of 'equal-same treatment' shuts down recognition of older people's sexual lives and histories that fall outside heterosexual markers and life-events (Willis *et al.*, 2016). Older lesbian, gay, bisexual and queer (LGBQ) people's lives diverge from the life-experiences of other older people because of the socio-legal history of marginalisation experienced by LGBQ citizens in the UK, and many other nations. Consequently, older LGBQ people may harbour concerns about 'risky visibility' in care environments, which may provoke homophobic or biphobic expressions from others (Westwood, 2016). The presumption of heterosexual ageing experienced by those identifying as LGBQ (amongst other marginalised or less recognised identities). This limits older people's rights to self-define, claim and express sexual identities outside the heterocentric norm. The concept of **heteronormativity** makes heterosexuality a normative marker of socio-sexual relationships and captures the 'myriad ways in which heterosexuality

is produced as a natural, unproblematic, taken-for-granted, ordinary phenomenon' (Kitzinger, 2005, p. 478). Heteronormative assumptions in social care practice render older LGBQ adults' sexual and romantic relationships, and circles of support, invisible to service providers (Almack, 2019).

Gerontological social workers should be attuned to the unique life course and lifehistories of older LGBQ individuals if they are to build a holistic understanding of the person they are supporting. The concept of *accumulative disadvantage* enhances our understanding of how historical experiences of homophobia, biphobia and sexuality-based discrimination impact on LGBQ people's concerns, expectations and wellbeing in later life. The work of Crystal and Shea (1990; 2017) identifies processes across the life course by which social advantages and disadvantages accumulate and shape the material, economic and cultural resources available to people in later life. Their model focuses 'on the ways in which earlylife advantages and disadvantages persist into late life' (1990, p. 911). For older LGBQ people unique social stressors experienced in earlier life, and associated negative coping practices (for example, smoking and alcohol consumption), can exacerbate health inequalities between LGBQ and heterosexual older people in later life (Kneale *et al.*, 2019). Experiences of historical marginalisation are also associated with lower identity affirmation and poorer mental health (Fredriksen-Goldsen *et al.*, 2017).

For older LGBQ people experiences of discrimination from health and social care professionals during young adulthood can deplete their trust and confidence and inhibit individuals from accessing care and support services, including social work, and from disclosing their identity and intimate relationships to service providers. The criminalisation of sex between men has permeated the life stories of older gay and bisexual men who were experiencing young adulthood in the 1950s and 1960s. Partial decriminalisation was achieved

in 1967 in England and Wales (an unequal age of consent remained in place for those engaged in same-sex activity until 2001). While the sexual lives of lesbians and bisexual women were not outlawed in the same way the social environments in which they lived were extremely hostile to their intimate relationships and social affiliations (Wilkins, 2015). The personal histories of older LGBQ adults in the UK were also overshadowed by the medical classification of homosexuality as a mental disorder. Homosexuality was listed as a disorder under the International Classification of Diseases until 1990. Some older adults will have experience of conversion therapies to 'cure' homosexual desires (King, 2019). These traumatic experiences severely cripple trust in health and public authorities including social workers perceived as representing the interests of the state rather than the best interests of the individual.

Sexual identity categories do not reflect the diversity of older LGBQ people's lived experiences (King and Cronin, 2013). Experiences of health, wellbeing, social support and caring vary according to intersections across gender, ethnicity, disability and, of course, age. There is a danger that helping professionals, including social workers, attribute common features to older LGBQ people's relationships that may, at best, disregard areas of commonality shared with other older adults or, at worst, lose focus on the individuality of older people's life-experiences and significant relationships (King and Cronin, 2013). Equally, these identities do not tell us much about the sexual practices and sexual health of older LGBQ adults, a topic we know little about, and how sexual experiences differ across gender, social environments and power dynamics. One illustrative finding from the UK Government Equalities Office (2018) survey of LGB (and trans) people (a survey of over 108,000 participants) is the differences across those reporting experiences of conversion therapy. Older respondents were more likely to report this (10 per cent of those 65+ years)

than younger age groups and respondents identifying as Black, Asian and minority ethnic were more likely to report this compared to White respondents. This finding highlights how experiences of conversion therapy are compounded by ethnic minority status *and* by older age, casting light on the additional heteronormative stressors and institutional racism experienced by LGBQ people within these groups. It reiterates the value of recognising how oppressive professional interventions experienced in earlier decades impact on older people's understanding of their sexual identity, agency and resilience.

Queer perspectives on ageing

Queer theory is a nebulous cluster of social and linguistic perspectives from across the humanities, education and social sciences that are rooted in postmodernist and post structural approaches to social identities, including gender and sexuality, as discursive. Identity categories are understood through language and available discourse and are therefore open to deconstruction and questioning (Yep *et al.*, 2003). Emerging in the 1990s, queer perspectives debunk 'the stability of identity categories by focusing on the historical, social and cultural constructions of desire and sexuality intersecting with other identity markers, such as race, class, and gender, among others' (Yep *et al.*, 2003, p. 2). Through a queer lens, essentialist notions of sex, gender and sexual orientation as being innate and pre-determined are rejected in favour of performative approaches where instead these subject positions are sustained through iterative social and cultural practices (Butler, 1990). Michel Foucault's (1998) historical analysis of the ways in which medical and legal institutions construct and perpetuate sexual types illustrates the binary between heterosexual and homosexual

identities; a pervasive knowledge framework that serves to separate homosexual identities and desires as inferior and often invisible (Sedgwick, 1990).

We cannot do these complex perspectives justice here but social gerontology has been slow to engage with these. Hughes (2006) argued that queer perspectives invite us to consider how other binaries that separate 'young/ old' operate in parallel with the heterosexual/ homosexual binary to marginalise older people's expressions of sexual desire and intimacy. An additional binary is the cultural distinction between sexual/post-sexual that accompanies assumptions about appropriate age, sex and youthfulness. Queer perspectives invite us to think beyond identity categories for understanding older adult's sexual lives and to develop an awareness of 'the erotic in old age' (Hughes, 2006, p. 57). This opens up recognition of and support for non-coital expressions of sexuality between people of same and different genders and to embrace different sexualities, abilities and disabilities in later life (Hughes, 2006). Queer perspectives help to trouble and subvert ageist and normative assumptions about older age and sex. Moore and Reynolds (2016) however, argue that a subversive politic does not take into account corporeal dimensions to sexual agency and the ways in which issues of frailty, disability and physical decline may prevent a 'reinvention of the sexual self' (p. 7). Social workers supporting older people will be familiar with the ways in which these changes in physical function alter older people's everyday agency, identity and experiences of relationships. The impact on older adult's sexual agency is another critical consideration.

Like the expression 'queer', the term 'senile' has historically conveyed a social stigma and a sense of 'the other' and represents a dominant discourse rooted in medical perspectives on dementia as a deficit condition of mental decline (Ward and Price, 2016). Ward and Price propose that the notion of '*senility*' be reclaimed as a critical platform for interrogating dominant discourses that limit alternative understandings of dementia as a lived

experience beyond medical approaches. This reclaiming provides a springboard for 'antinormalisation' politics and to move away from an agenda of integration (living by social norms) towards a more subversive understanding of dementia (Ward and Price, 2016). Social workers supporting those with dementia will focus on the individual service users' lived experience and life-story and form therapeutic alliances with service users that allow them opportunities to understand their identity and experience of the social world within and beyond medical perspectives.

Heterosexuality and gender in older women and men

Trends observed on later life relationships have similarly challenged aspects of those institutions that shore up heterosexuality. Demographic trends show that older people in England and Wales are getting married and divorced in greater numbers (taking into account the ageing population) (ONS, 2017). These so-called 'silver splicers' and 'silver separators' have led to 'brides' and 'grooms' aged 65 and over, going up by 46 per cent in the last decade (the population grew by 20 per cent in the same period and as a proportion of the single, divorced or widowed population). Research into the sexual health and wellbeing of men and women in later life (Lee *et al.*, 2016) shows increasing expectations concerning sexual fulfilment. At the same time there are dominant if not restricted ways of thinking about the sexual pleasure of heterosexual older people, framed by gender stereotypes. The sexuality of older women may become constrained by biological changes, understood through cultural pathology as decline and loss of attractiveness, and the moral constraints of being a good wife/partner and/or mother/grandmother. This is beginning to change for those of the baby boomer generation. They will have encountered the countervailing influences of feminism (Bassnett, 2012), in politics, education and work experience and loosening social

attitudes towards sex, particularly outside of marriage and sexual monogamy (Gilleard and Higgs, 2007). While encouraging to see these social scripts being reinvented for women in later life, double-standards persist whereby older women face moral censure for transgressing an approved ageing femininity (Gewirtz-Meydan *et al.*, 2019).

Those heterosexual men and women wishing to continue with penetrative sex but experiencing challenges, may need sensitive information about erectile dysfunction and vaginal dryness (as well as physical health, for example, cardiology and respiratory complications, arthritis) and require support for the impacts on their psychological and social wellbeing (for example, loneliness, depression and isolation) (Hughes *et al.*, 2015). There is a higher incidence of problems among black and minority ethnic older women (Asiedu *et al.*, 2017). In the UK those of black African ethnicity carry a disproportionate percentage of HIV, with 38 per cent of new diagnoses among heterosexual black African men and women, including those born in the UK, as well as those born in Africa (Public Health England, 2019). Further, older women who lack power in sexual relationships, experience less sexual self-efficacy and partner negotiation impacting on their practice of safe sex (Meyer *et al.*, 2020). Poor engagement of care professionals with their issues and concerns makes the situation more complex and discriminatory (Hafford-Letchfield, 2008).

Lee *et al.*'s (2016) research showed that a significant proportion of older men remain sexually active into their 70s and 80s. However, when men do experience difficulties, for example with erectile dysfunction, medical and pharmaceutical interventions are typical, focussing on restoring penetrative and heteronormative sexual activities (Gledhill and Schweitzer, 2014). Sexual decline is considered more challenging for men given fears of loss of status and greater reluctance than women to seek help. Social norms around men's

experiences of sex and intimacy can put their sexual health at risk and impact on their mental health (Gewirtz-Meydan *et al.*, 2019).

Experiencing a sexual difficulty can be a source of distress and relationship disruption and depression has been reported by people with experience of sexual difficulties in middle and late adulthood (Hinchliff *et al.*, 2018). Self-reports of poorer mental health are associated with declines in desire and the frequency of sexual activity amongst older people, highlighting how physical health and sexual wellbeing are intertwined and are therefore important to address in social work practice (Jackson *et al.*, 2019). For social workers it is important to assess how changes or fluctuations in mental and sexual wellbeing may be impacting on the intimate relationships of older service users and to explore what these difficulties and stressors may be.

Older heterosexual people will benefit from support concerning alternatives to penetrative sexual practices and with accompanying feelings of disappointment and selfrecrimination (O'Brien *et al.*, 2012). Many older persons have learned to approach sex in a more sensual way, and intimacy can become more important for example, through increased activities such as kissing, touch, physical closeness (previously regarded as 'foreplay' but now central to the sexual/intimate repertoire). Where there is sexual violence, embarrassment of not being able to maintain an erection or fear of losing a partner, some research has demonstrated the benefits of older people being able to talk to their friends and peers about sex (Ussher *et al.*, 2014). This includes 'letting off steam' about an unsatisfying sex life. Older adults increasingly have expectations that care and nursing homes will accommodate couples and sexual intimacy, including private living spaces, shared beds and access to safer sex materials (Rahn *et al.*, 2020; Nash *et al.*, 2015). While care homes are shared, communal environments the need for separate, safe and comfortable spaces that uphold the privacy and

dignity of residents and their intimate partners of all sexual and gender identities is a core requirement.

Intimate partnerships can be supportive and deeply valuable to people at the end of their lives where many changes occurring, both physically and emotionally, and may influence individuals and couples' attitudes about sexuality (Bridget, 2014). The sense of emotional connection and intimacy derived from sexual activity can take on new significance in the context of terminal illness. The sense of specialness from being close to someone physically and emotionally, desiring another and being desired in return can be a lifeaffirming act to those who are dying (Taylor, 2014).

CASE STUDY

Doreen, an 80-year-old White heterosexual woman has been widowed for 12 years. She lives alone in supported housing, has mild emphysema and diabetes and more recently, her memory has deteriorated quite rapidly. Doreen has two children, Tony aged 58 and Marina aged 48 who live a couple of hours away. They see her every two weeks or so. Three months ago, Doreen met Ted, a Black Caribbean man aged 68 years, at a community group for falls prevention. Ted recently moved in with Doreen. Doreen tells Tony and Marian of her intention to marry Ted and to use her savings to take Ted on a luxury cruise. Tony contacts the adult safeguarding team saying that Doreen is at risk. He states that Doreen 'always been a conservative and deeply religious woman'. Tony is very concerned whether Doreen is capable of consenting to 'all what's happening' and refers to Ted as an 'lecherous old man'.

Key questions to consider:

1. What do you think might be Tony's main concerns?

2. What might be some of the assumptions informing Tony's response?3. What are the issues that you would want to explore in relation to Doreen's sexual rights and wellbeing?

Negotiating intimate relationships for trans older people

The experiences of trans people in negotiating intimate relationships has been overlooked in research on sexuality and ageing. Riggs et al.'s (2018) work identified four themes in research, first the effects of cisgenderism, second, the effects of gender dysphoria upon some people's capacity to negotiate intimate relationships, third the impact of medical aspects of transitioning, and fourth, the importance of recognising and valuing the unique and positive ways that many trans people negotiate intimate relationships (p. 86-7). The concept cisgenderism denotes a dominant social hierarchy around gender and self-definition and associated attitudes and beliefs. Individuals self-defining their gender are perceived as inferior or lacking validity in comparison to those whose sex assigned at birth matches their gender identity (Ansara, 2012). Riggs et al. (2018) stress the importance of paying attention to the rich and holistic accounts of trans people's lives, which includes acknowledgement of their intimacy needs and expressions. Social workers and other professionals and providers must work much better with trans people to develop alternative ways of understanding and working with their own bodies. This might include being more aware of physical or psychological safety when meeting potential new partners, and in their relationships with existing ones. It includes ensuring preparation and support to go through any physical changes as an important area in trans healthcare.

Riggs *et al.* (2018) remind us that some trans people may adopt a celibate or asexual identity upon transitioning and as with any major life change may reprioritise or take

pragmatic decisions around their sexuality or sexual expression. Some trans individuals may commence social and medical transitioning in mid to later life (Willis *et al.*, 2020) and hence these decisions are of high concern to older adults. Being cognisant of the support needed, educating ourselves and not imposing cisnormative understandings on what constitutes sexual expression are important. Within the context of social care, trans older adults have voiced concerns about potential comprises to their individual dignity and privacy in care settings, such as transphobic views expressed by care staff or other service users in the same setting (Willis *et al.*, 2020). Social workers need to recognise the care needs of trans service users and be prepared to challenge the cisgendered assumptions of care workers and other professionals and to help dismantle such assumptions.

SUMMARY: CRITICAL MESSAGES FOR PRACTICE

Throughout this chapter we have identified a range of critical perspectives and concepts for enhancing gerontological social work in this subject area. In practice these perspectives provide the theoretical foundations for enabling older service users to express and exercise sexual agency and to promote sexual rights as integral to rights-based practice with older people. We initially introduced the notions of sexual wellbeing and sexual rights and the lack of recognition of these in current rights discourse for older people. Social workers as change agents and human rights advocates are well-placed in older people's care and support services, including health care settings, to promote the sexual rights and agency of older individuals. This may require facilitating challenging and highly sensitive conversations with service users, their significant others and other professionals. This however is familiar territory to gerontological social workers. Social workers should be mindful of the discourses of shame, guilt and recrimination some older people will hold about this subject and held on

to throughout their lives. Silence can inhibit these conversations and sustain these internalised discourses. Equally, deeply held religious beliefs and values held by others, including staff providing care, about sex and sexuality across the life course may require exploring and questioning.

There are many ways in which social workers can exercise affirmative practice to older people's sexual rights and wellbeing:

- Place older people's voices at the centre of any analysis and recognising the meaning of sexuality in later life actively engaging with their own perspectives can help to meet their needs and shape services and support. Be attuned to the unique life course experiences, life-histories and sexual stories of older individuals, including those experiencing non-heterosexual ageing.
- Gaining the trust and confidence of the older service user is first priority before initiating conversations about sex and intimacy – this will take time and does not lend itself to single assessment or review meetings.
- Assess how changes or fluctuations in mental and sexual wellbeing may impact on the intimate relationships of older service users and explore what these difficulties and stressors may be.
- View sexuality from a broad perspective, addressing its biological, psychological and social aspects, and the diverse range of sexual desire, attractions and intimacy needs of people in later life.
- Explicitly consider how sex and intimacy may be a part of planning care and support particularly for those with a dementia and/or at the end of life.
- Family members or close friends may play a critical role in supporting their loved one and providing them with the opportunity to enjoy intimate moments at the end-of-life.

- Ensure privacy for sexual expression and invest in staff development and time to open up sensitive conversations about how to support choices in this respect. Reluctance to address issues or being over-cautious can deny autonomy in the form of ageist erotophobia.
- Working with gender diversity must include the person's experiences of intimacy as part of a broader psychosocial assessment to support people to live fulfilling and meaningful intimate lives as they determine them to be.

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