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## Care in late life, end of life and in bereavement for the oldest LGBT generations around the globe

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 Sexualities

**Care in late life, end of life and in bereavement for the  
oldest LGBT generations around the globe**

Journal:	<i>SEXUALITIES</i>
Manuscript ID	Draft
Manuscript Type:	Special Issue: LGBT End of Life
Keywords:	LGBT old age, End of life, Intersectionality, Gerontology
Abstract:	<p>This special issue focuses on care in late life and at the end of life for people with diverse sexual orientations and gender identities, from an international perspective. There is a growing body of research demonstrating that LGBT people are a diverse and under-researched new ageing population, but less attention has been paid to the specific issues connected to care in late life and at the end of life. This Special Issue makes a contribution to that aim, with papers from South Africa, Lebanon, Hong Kong, Canada, US, UK, Netherlands and Spain thereby contributing to understandings of the heterogeneity of ageing, emphasising global differences, and the exploring the impact of these on the lives of our oldest LGBT generations around the world. Our focus of this special issue on care in late life and at the end of life for LGBT people not only makes a valuable contribution to expand our empirical and theoretical knowledge in this field but has even greater salience when situated within the COVID-19 global pandemic.</p>

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## Editorial

This special issue focuses on care in late life and at the end of life for people with diverse sexual orientations and gender identities, from an international perspective. We use the shorthand LGBT (lesbian, gay, bisexual, and/or trans) for convenience but it is important to recognise that this term (and related alternatives, such as LGBTQ, which are used by some authors in this special issue) are derived from Western theorisations of gender and sexuality and may not be recognisable or helpful in other contexts (Gosine, 2006). There is a growing body of research demonstrating that LGBT people are a diverse and under-researched new ageing population, but less attention has been paid to the specific issues connected to care in late life and at the end of life. While some of the issues will be similar to those facing all older people, existing research identifies separate issues that need to be addressed for older LGBT people entering their later and last years of life and into death and bereavement.

In some parts of the world, an increasing socio-cultural focus on 'equality' and 'diversity,' accompanied by legislative change around gender and sexuality, provides increased rights and recognition for LGBT people. However, it is important to note that such rights do not exist around the globe, and concerns about the rolling back of legislation and social progress remain real. Even where the current social and legislative climate is relatively inclusive, the legacy of living through times when legislation and social attitudes criminalised and stigmatised LGBT people may continue to have ongoing profound influences on LGBT people's social networks and their physical and mental health. These experiences can also heavily influence the way in which LGBT people think about and make preparations for their old age and last years of life as well as their access to services. In particular, current and past institutional barriers, and experiences of exclusionary or discriminatory interactions with medical and social care environments can have profound effects. This is further complicated by patterns of inequality that lead to multiple forms of marginalisation where the intersection of different aspects of someone's identity alongside sexual orientation and/or gender identity can render them more invisible or disparaged culturally.

Older LGBT people variously may have maintained privacy about their sexual orientation or gender identity over a lifetime or, during their life course, have not felt able to be open about their identity in some or all areas of their life. In both scenarios, there is evidence that LGBT people might feel unsafe in disclosing central aspects of their identity when accessing health, social care and housing provision in old age, and may prefer to rely on informal care within their own communities and from friends and family. This body of research comes largely from Western perspectives, therefore there is an urgent need to understand

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3 experiences in other geo-political regions. This Special Issue makes a contribution to that  
4 aim, with papers from South Africa, Lebanon, Hong Kong, Canada, US, UK, Netherlands  
5 and Spain thereby contributing to understandings of the heterogeneity of ageing,  
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7 emphasising global differences, and the exploring the impact of these on the lives of our  
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9 oldest LGBT generations around the world.  
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12 The first three articles in this collection address issues of housing preferences, 'ageing in  
13 place' and forms of support and care and for older LGBT people. Lottman and King draw on  
14 findings from a UK study exploring how housing preferences and receiving a good quality of  
15 care involves social networks, connections and participation in wider communities and  
16 society. The paper identifies that older lesbian and gay people imagine and require distinct  
17 social networks of care and support, especially for envisaging housing and care needs in a  
18 fourth age (a time in later life when older people need care and support to go about daily  
19 living). In particular, they consider the role of 'families of choice' in older lesbian and gay  
20 people's lives, questioning whether such bonds are useful for different forms of care and  
21 support. Hoekstra-Pijpers picks up similar themes in her study from the Netherlands. She  
22 identifies a growing cohort of frail older LGBT people who will 'age in place'; needing care  
23 and support in their home space until a very advanced age. She discusses how personal  
24 care and LGBT histories/identities are intertwined. This highlights the importance of  
25 developing care and support services that can be more responsive to the needs of LGBT  
26 seniors who live independently. Long term care in the fourth age is a challenge – for LGBT  
27 people who continue to live independently and for those who imagine they may require  
28 residential care settings. Continuing the focus on care services, Villar et al., explore  
29 perceptions of staff members working in Spanish long-term care institutions for older people  
30 in supporting lesbian, gay and bisexual (LGB) residents. They identify significant barriers  
31 that older LGB people may face when attempting to express their sexuality due to the lack of  
32 awareness of sexual diversity in long term care settings. Staff also identified homophobic  
33 attitudes and behaviours from heterosexual residents.  
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47 These three articles identify important policy implications including a pressing need for care  
48 and support services to ensure they are LGBT-inclusive and comply with equality legislation,  
49 where it exists. We can learn from practice-oriented initiatives that promote and embed  
50 LGBT inclusivity, such as, in the UK, Opening Doors London's *Pride in Care* quality  
51 standard, Stonewall Housing's *Inclusion Standard* or similar schemes such as *The Pink*  
52 *Passkey* in the Netherlands (see Linschoten et al., 2016).  
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57 The studies reported in the first three articles come from Western Europe, where there have  
58 been significant advances in achieving equality for LGBT people over the past 20 years.  
59 Such progress requires ongoing vigilance to maintain and translate into practice but globally  
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3 many LGBT people experience much more hostile ageing environments. The fourth paper  
4 helps us to understand additional challenges faced in South Africa and different  
5 understandings of what 'old age' might look like, where average life expectancy is 62.5 years  
6 for males and 68.5 years for females. Henderson and Reygan highlight a lacuna in research  
7 addressing the care needs of older LGBTI people in South Africa. South African policy on  
8 care for all older people places a strong emphasis on ageing in place rather than a reliance  
9 on institutional settings, although resources are not sufficient to achieve this goal. In focus  
10 group discussions with older LGBT people in Western Cape and Gauteng provinces on their  
11 care needs, Henderson and Reygan found that the resource constraints negatively impact  
12 support services for older LGBTI people. Participants report on the ongoing invisibility of  
13 older LGBTI people in South Africa and a number of key themes emerged including rejection  
14 from families of origin, lack of healthcare provider knowledge, isolation in townships and  
15 trans exclusion. Overall the study found that resource constraints negatively impact support  
16 services for older LGBTI people.

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19 The next two articles turn our attention to advance care planning (ACP) for older LGBT  
20 people, which is designed to help people think about and plan their future care and support,  
21 while they have the capacity to do so. Globally, the take up of ACP amongst the general  
22 population is low (see Fagerlin and Schneider, 2004) but there are additional challenges for  
23 LGBT people. ACP can be particularly important to ensure LGBT people's important  
24 connections and social relationships can be legitimised in their end-of-life decision-making.  
25 However, undertaking and enacting ACP presents challenges which are underpinned by  
26 discrimination, marginalisation and heteronormativity. Heteronormative assumptions about  
27 end-of-life care can mean that biological family members rather than partners or friends are  
28 automatically first in line to become substitute decision-makers if there is no ACP in place.

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31 De Vries et al. examine the extent of ACP preparation (completed documents, discussions)  
32 among a national sample of 91 community-dwelling Canadian LGBT older adults (mean age  
33 68). The sample was disproportionately single and lived alone and about half of all  
34 participants reported more reliance on a chosen family than family of origin. Just over one-  
35 third of respondents reported having discussions about future care and end-of-life plans;  
36 those in a relationship were more likely to have engaged in discussions about and recording  
37 of ACP preferences while those with children were less likely to have completed  
38 documents). Makita et al. report on findings from the quantitative phase of a UK project, The  
39 Last Outing, which was designed to explore end-of-life care experiences and needs of LGBT  
40 people. They draw on a subset of 180 LGB older adults of the main study sample. Their  
41 findings differ from those reported by De Vries et al., in that respondents living alone more  
42 often reported that they had thought about making plans for their future care and treatment  
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3 preferences in contrast to respondents living with others. These disparities in findings  
4 suggest the need to further explore how LGBT people approach and make decisions on  
5 advance care planning, which take account of different jurisdictions with differing historical  
6 and legal contexts.  
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10 The next two articles focus on two particularly under-researched groups within the LGBT  
11 umbrella; transgender and bisexual older people. Baril and Silverman explore responses to  
12 the phenomenon of dementia-related 'gender confusion', when older trans people may seem  
13 to forget that they have transitioned. The authors develop a typology of academic framings  
14 and responses to this phenomenon namely: (1) a gender neutralization approach; (2) a  
15 trans-affirmative stable approach; and (3) a trans-affirmative fluid approach. They argue for  
16 the development of a fourth paradigm which takes an intersectional approach to explore the  
17 ways in which older trans people living with dementia are also affected by ageism and  
18 ableism/sanism.  
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24 There has also been little specific research globally focusing on bisexual older people.  
25 Fredriksen Goldsen et al's article begins to address this gap, drawing on the Aging with  
26 Pride: National Health, Aging, and Sexuality/Gender Study, which is the first national  
27 longitudinal study of LGBTQ older adults in the US. The sample size of this study facilitates  
28 an examination of the life events and life course experiences of bisexual older adults  
29 (N = 216) by generation. The authors identify three different bisexual generations – the Pride  
30 Generation, born 1950–1964; the Silenced Generation, born 1935–1949; and the Invisible  
31 Generation, born 1934 or earlier. Their discussion highlights important differences in the  
32 heterogeneity and intersectionality in bisexual lives, particularly for those in late life and  
33 those gender diverse.  
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40 Finally, addressing the need to develop more global understandings of LGBT old age, we  
41 have two commentaries on newly emerging research in this field in Lebanon and Hong  
42 Kong. Chirac reports a ground-breaking workshop on LGBT palliative care, held in Beirut.  
43 Health and social care professionals who attended reported increased understanding and  
44 confidence in working with older LGBT people at the end of their lives, and the workshop has  
45 led to promising further projects, despite the hostile legislative and social context. Suen adds  
46 to our understanding of sexual identities in non-Western contexts by discussing the salience  
47 of identities to older gay men living in Hong Kong. He identifies three distinct groups: those  
48 who prioritise family over sexual identity, those who do prioritise their sexual identity, and  
49 those who grew up elsewhere but are ageing in Hong Kong, which creates particular  
50 challenges as they negotiate later life.  
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3 These articles were largely written before the COVID-19 global pandemic but as we write  
4 this editorial, we are witnessing its devastating impact on communities around the world. As  
5 one example, while South Africa reports a steady increase in life expectancy, there are  
6 warnings that those gains may be lost over time due to COVID-19 deaths if not curbed by  
7 effective treatment protocols and a vaccine. It seems increasingly clear that inequalities are  
8 exacerbated by the pandemic and this is likely to increase disparities in what it means to be  
9 'old' as an LGBT person around the globe (United Nations Human Rights 2020).  
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15 A number of articles in this special issue have noted that LGBT older people are more likely  
16 to live alone and the COVID-19 pandemic has focused increased attention on social isolation  
17 and loneliness, particularly older adults. Many LGBT people have been cut off from some of  
18 their support structures (LGBT Foundation 2020); for example the face-to-face social support  
19 provided by LGBT organisations have been put on hold. However, older LGBT people may  
20 also have developed resilience and coping mechanisms over the course of their lives. In  
21 particular, online and virtual means of connection have played a part in some LGBT lives for  
22 many years, providing safe spaces and enabling friendships.  
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28 Our focus of this special issue on care in late life and at the end of life for LGBT people not  
29 only makes a valuable contribution to expand our empirical and theoretical knowledge in this  
30 field but has even greater salience when situated within the COVID-19 global pandemic.  
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