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Older LGBT+ Health Inequalities in the United Kingdom: Setting a Research Agenda

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Abstract

Lesbian, gay, bisexual and trans+[a] (LGBT+) people report poorer health than the general population and worse experiences of healthcare particularly cancer, palliative/end-of-life, dementia and mental health provision. This is attributable to: a) social inequalities, including 'minority stress'; b) associated health-risk behaviours (e.g. smoking, excessive drug/alcohol use, obesity); c) loneliness and isolation, affecting physical/mental health and mortality; d) anticipated/experienced discrimination and e) inadequate understandings of needs among healthcare providers. Older LGBT+ people are particularly affected, due to the effects of both cumulative disadvantage and ageing. There is a need for greater and more robust research data to support growing international and national government initiatives aimed at addressing these health inequalities. We identify seven key research strategies: 1) Production of large datasets; 2) Comparative data collection; 3) Addressing diversity and intersectionality among LGBT+ older people; 4) Investigation of healthcare services' capacity to deliver LGBT+ affirmative healthcare and associated education and training needs; 5) Identification of effective health promotion and/or treatment interventions for older LGBT+ people, and sub-groups within this umbrella category; 6) Development an (older) LGBT+ health equity model; 7) Utilisation of social justice concepts to ensure meaningful, change-orientated data production which will inform and support government policy, health promotion and healthcare interventions.

Key words: Health Inequalities; Social Determinants; sexual orientation; gender identity; ageing

Introduction

The United States (US) has led the way in establishing a lesbian, gay, bisexual and trans+ (LGBT+)[a] health inequalities research agenda [1] but there is still much to be done worldwide. LGBT+ people report poorer health than the general population and worse experiences of healthcare particularly cancer[2], palliative/end-of-life[3], dementia[4] and mental health provision.[5-6] Their poorer health may be attributable to: a) social inequalities, including 'minority stress',[7] i.e. the cumulative effects of lifelong exposure to prejudice and discrimination; b) health-risk behaviours (e.g. comparatively greater smoking, excessive drug/alcohol use and obesity than non-LGBT+ people) linked to stress adaptation; c)

loneliness and isolation, affecting physical/mental health and mortality.[8] Healthcare experiences are associated with anticipated/experienced discrimination and inadequate understandings of needs among healthcare providers.[9]

In Europe, there is growing governmental interest in promoting an LGBT+ health inequalities research agenda,[10-11] but no specific reference to *older* LGBT+ people (i.e. those aged 50+). This is even though they are more likely to be users of healthcare services and there being a range of health inequalities specific to their lives.[12] Indeed, older LGBT+ people are affected by *both* ageing issues common to all older people *and* issues specific to LGBT ageing.[13]

The generic ageing issues they share with all older people include[14]: biological ageing 'associated with the gradual accumulation of a wide variety of molecular and cellular damage' leading to 'a gradual decrease in physiological reserves, an increased risk of many diseases, and a general decline in the capacity of the individual' ultimately resulting in death. Although more people are living for longer and into 'older' old age, many are doing so with increasing physical and/or cognitive abilities and associated functional challenges. These in turn mean that many may need support with activities of everyday living (ADLs),[15] especially in older old age and may become reliant on others for informal and/or formal care and support. Many older people face living with unmet care and support needs.[16] These issues affect older people in different ways and at different stages of ageing. A great many economic, cultural and psychosocial factors affect the extent to which an older person is able to age 'well' or not.

Older age also involves changes in social roles and social status, and the need to deal with the loss of (ageing) friends and loved-ones.[14] Loneliness and isolation can be one of the perils of older age, impacting physical and mental wellbeing and ultimately morbidity.[17] On the other

hand, shifting motivations, priorities and psychological perspectives can also mean that older age can be a time of subjective well-being for many older people.[14]

In addition to these generic ageing issues, older LGBT+ people are also affected by how their minority sexualities and/or gender identities intersect with ageing. They are more likely than the majority ageing population to live alone, to be childfree (especially older gay men), and estranged from their biological families.[18] While many have 'families of friends'[19] these are often of the same generation, developing increased care needs at the same time and being less able to provide reciprocal care. Older gay and bisexual men are deeply affected by HIV/AIDS, through loss of friends in previous decades and increasing numbers with HIV living longer on treatments.[20] Older cisgender lesbian and bisexual women live longer than men, but with greater disabilities and age-related health conditions.[21] Older trans+ people are concerned about the possible need for personal care if their bodies are not congruent with a binary gender identity and also of being mis-gendered if they lose mental capacity.[22] Older LGBT+ people, especially older bisexual and trans+ people are more likely to have a history of poor mental health and to be concerned about mental health in older age.[12,18]

All of these concerns are nuanced by a wide range of intersecting factors, including socio-economic status; culture, race and ethnicity; disability; and religion.[23] Some older LGBT people are more successful than others in adapting and coping with ageing: those with strong psychological and social resources are likely to enjoy better health and practice more health-promotion behaviours.[24] However, the design of effective interventions to promote such positive adaptations is not yet well understood.

The aim of this paper is to stimulate debate about mapping the way forward for research and policy and to propose a European agenda.

Setting a Research Agenda

1. Large scale data

Public health agencies rely on mortality/morbidity data to measure health inequalities, shape policies, target interventions, and audit outcomes, including in relation to meeting statutory equality duties. There is a lack of large-scale quantitative data on older LGBT+ health, partly due to a lack of monitoring for sexual orientation/gender identity in routine healthcare services data collection, which urgently needs to be addressed. Other solutions include ensuring LGBT+ health research is older-age inclusive and older age health research is LGBT+ inclusive. Secondary analysis of large-scale health survey datasets pooled from multiple separate datasets is also an emergent way of creating larger samples for analysis.[25]

2. Comparative data

Understanding older LGBT+ health inequalities compared with the majority population requires robust comparative data. Very few studies have produced such data. Older LGBT+ people should be included in research in sufficient numbers to allow meaningful analysis. This means ensuring that a proportionate and statistically significant number of LGBT+ people should be included in all ageing research, and a proportionate and statistically significant number of older people should be included in research with LGBT+ adults. Making this an essential funding requirement would ensure that this is factored in to all research projects.

3. LGBT+ diversity and intersectionality

There has been very little comparison of the differential health experiences among older LGBT+ sub-groups across interacting and intersecting social differences (e.g. age, gender, class, ethnicity).[25] Studies which employ more purposive sampling would provide greater insights into both diversity and intersectionality.[26] This would enable policy-makers, commissioners and providers to better direct health interventions towards specific LGBT+ sub-groups.

4. Improving access to healthcare services

There is now a body of work identifying barriers and facilitators to older LGBT+ people accessing care and support services. However, less is understood about 'healthcare stereotype threat [which] is the threat of being personally reduced to group stereotypes that commonly operate within the healthcare domain'.[27] This is particularly in relation to older LGBT+ people[9] who are known to avoid healthcare services dues to concerns about prejudice and discrimination. Increased knowledge could improve healthcare professional's competency and confidence, resource allocation, inclusion in healthcare education, and developing a standard/quality framework for training.

5. Improving the quality of healthcare services

Research is needed to determine whether/how healthcare services' policies, procedures and practices are LGBT+ inclusive, and to evaluates training/interventions which develop healthcare staff competencies.[28-29] Specifically, healthcare staff should be able to:

> Understand older LGBT+ people's lives, histories and legal landmarks, and the health impacts of growing up under pathologizing and criminalising regimes;
>
> Understand how prior experiences of religious and/or medical 'cures' (often forcible) can inform older LGBT+ people's fears about engaging with medical services and/or faith-based healthcare staff;
>
> Understand and respect older LGBT+ people's relationship networks, including their 'families of friends', giving same-sex partners equal status and recognition as different-sex partners, and promoting LGBT+ community ties;
>
> Understand and respond sensitively to the personal care concerns of those older transwomen and transmen whose bodies may not align with their gender identity.
>
> Confidently challenge homophobia, biphobia and/or transphobia on the part of staff, other healthcare users, their families and friends.

6. Improving health promotion interventions

Few empirical studies have explored health promotion interventions for older LGBT+ people.[30] It is essential to understand what works best for whom, under what circumstances,

and also how allied service providers (e.g., housing/home care) can work inclusively to amplify what works well and promote older LGBT+ people's coping, health and wellbeing. This is relevant for all minority groups. Issues to be considered specifically in relation to older LGBT+ people include investigating the following: promoting individual, social and community supports and coping strategies; delivering health promotion campaigns which do not assume heterosexuality/ cisgender identities and which explicitly include older LGBT+ people; delivering health promotion campaigns specifically targeted at older LGBT+ people, e.g. addressing sexual health among older gay men, screening for cervical cancer among older lesbians, screening for breast cancer among transmen and so on.

7. Developing an (older) LGBT+ health equity model

The World Health Organisation has developed a social justice framework for the interactions between social inequalities and health. Yet despite compelling evidence of LGBT+ health inequalities, this framework fails to include them. We support calls for the WHO to include both sexual orientation and gender identity as social determinants of health and in all analyses of social inequalities and health[31-32] including in older age. Additionally, research should support the development of health equity models specific to older LGBT+ people.[33]

8. Aiming for substantive social justice

US, Canadian, Australian and European research, policymaking and healthcare delivery agendas have come a long way, as evidenced by the growing number of initiatives aimed at LGBT health inequalities. In order to achieve *substantive* social justice beyond a box-ticking exercise, we must produce meaningful research to support these agendas.

Conclusion

Inclusion of older LGBT+ people and their advocates is essential in developing this agenda. The provision of care and support to older LGBT+ people is a 'litmus test'[34] for how well

healthcare agencies deliver services to minority groups. This research agenda takes us one step closer towards passing that test.

Notes

a. Trans+ (t+) is an umbrella term to encompass individuals who identify as transgender, agender, gender fluid and/or non-binary

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Competing Interests

There are no competing interests for any author

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drafts were re-circulated on multiple occasions, further feedback was provided by all of the co-authors, and the final draft (submitted) was approved by all authors.

The co-authors contributed as follows:

Dr Paul Willis: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution about health and social care provision about which he has published extensively, e.g. Willis, P., Maegusuku-Hewett, T., Raithby, M., & Miles, P. (2016). Swimming upstream: The provision of inclusive care to older lesbian, gay and bisexual (LGB) adults in residential and nursing environments in Wales. *Ageing & Society*, *36*(2), 282-306.

Professor Julie Fish: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution about heteronormative healthcare about which she has published previously (e.g. Fish, J., & Karban, K. (Eds.). (2015). LGBT health inequalities: International perspectives in social work. Policy Press.)

Professor Trish Hafford-Letchfield: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution about staff training about which she has published extensively, e.g. Hafford- Letchfield, T., Simpson, P., Willis, P. B., & Almack, K. (2018). Developing inclusive residential care for older lesbian, gay, bisexual and trans (LGBT) people: An evaluation of the Care Home Challenge action research project. *Health & social care in the community*, *26*(2), e312-e320.

Dr Joanna Semlyen: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution in relation to mental

well-being (she is a psychologist) and about secondary data analysis in LGBT+ health research about which she has published previously, e.g. Semlyen, J. (2017). Recording sexual orientation in the UK: Pooling data for statistical power. *American Journal of Public Health* 107, 1215-1217, https://doi.org/10.2105/AJPH.2017.303910

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Dr Brian Beach: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution about policy implications having recently authored a report on older LGBT+ health inequalities for the International Longevity Centre: Beach, B. (2019) *Raising the equality flag: Health inequalities among older LGBT people in the UK*. London: ILC-UK.

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Dr Dylan Kneale: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution about methodology having recently led a UK systematic literature review: Kneale, D., Henley, J., Thomas, J., & French, R. (2019). Inequalities in older LGBT people's health and care needs in the United Kingdom: a systematic scoping review. *Ageing & Society*, 1-23, doi:10.1017/S0144686X19001326

Dr Michael Toze: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Made a particular contribution in relation to older transgender health issues, on which his PhD was based, and in which field he is an emerging scholar, e.g. Toze, M. (2019). Developing a critical trans gerontology. The *British Journal of Sociology*, 70(4), 1490-1509.

Dr Laia Becares: substantial contributions to the conception of the article and thematic analysis; feedback on drafting and re-drafting; final approval of the submitted article; agreed to be accountable for article content. Make a particular contribution in relation to gender and health inequalities research, about which she has previously published, e.g. Bécares, L. and Zhang, N. (2017) Perceived interpersonal discrimination and older women's mental health: accumulation across domains, attributions, and time. *American Journal of Epidemiology*, 187 (5), 924-932.

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SUMMARY BOX

What is already known on this subject?

LGBT+ people report poorer health than the general population and worse experiences of healthcare particularly cancer, palliative/end-of-life, dementia and mental health provision. This is attributable to: a) social inequalities, including 'minority stress'; b) associated health-risk behaviours (e.g. smoking, excessive drug/alcohol use, obesity); c) loneliness and isolation, affecting physical/mental health and mortality; d) anticipated/experienced discrimination and inadequate understandings of needs among healthcare providers. Older LGBT+ people are particularly affected, due to the effects of both cumulative disadvantage and ageing. There is a need for greater and more robust research data to support growing international and national government initiatives aimed at addressing these health inequalities.

What this study adds

We identify seven key research strategies: 1) Production of large datasets; 2) Routine inclusion of LGBT+ people in ageing research and older people in LGBT+ research; 3) Exploration of diversity and intersectionality among cohorts of LGBT+ older people; 4) Investigation of healthcare services' capacity to deliver LGBT+ affirmative healthcare and associated education and training needs; 5) Identification of effective health promotion and/or treatment interventions for older LGBT+ people, and sub-groups within this umbrella category; 6) Development an (older) LGBT+ health equity model; 7) Utilisation of social justice concepts to ensure meaningful, change-orientated data production which will inform and support government policy, health promotion and healthcare interventions.