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LESBIAN, GAY, BISEXUAL, TRANSGENDER AGEING AND CARE: A LITERATURE STUDY

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There is an increasing body of research on ageing and end-of-life care (EOLC) of lesbian, gay, bisexual and transgender (LGBT) older people in the UK, USA and Australia. In contrast, in South Africa, despite progressive legislation to protect LGBT rights, there has been minimal research in this area. This article reports on a critical review of literature on ageing of the LGBT community. Key themes identified include discrimination by health care workers and health risks for LGBT older people alongside the need for training of health professionals. The article concludes with consideration of the needs of LGBT persons in South Africa.

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INTRODUCTION

There is a burgeoning body of research on ageing and end-of-life care in the LGBT community since the recognition that these communities are now ageing (Almack, 2007; Almack, Moss & Smith, 2015; Almack, Seymour & Bellamy, 2010; Concannon, 2009; Ward, Pugh & Price, 2010; Ward, Rivers & Sutherland, 2012; Westwood, King, Almack, Yui-Suen & Bailey, 2015). Furthermore, end of life care (EOLC) is increasingly associated with the experience of being old, with people in developed and developing countries living longer and dying more slowly (Holloway & Taplin, 2013), and with the majority of deaths occurring over the age of 65 and mortality rates being highest amongst the over 85s (Ruth & Verne, 2010). There are still gaps to address within this body of research; accessing the oldest generations is a challenge and often the focus of research has been on the "young old" (ages 50-69) and reflects white, middle-class, affluent, urban populations (Frederick-Goldsen & Muraco, 2010). There are also particular gaps in relation to the health issues of lesbian and bisexual women (Jones, 2012; Traies, 2012).

Living alone is a related key issue for older people across resource-rich countries; this is particularly salient to the LGBT population, given evidence which suggests that a higher proportion of LGBT elders live alone than their counterparts, with the incidence of living alone increasing with age (Almack *et al.*, 2010; Fredricksen-Goldsen, Emlet, Muraco, Erosheva, Hoy-Ellis, Goldsen & Petry, 2012; Stonewall Report, 2011). Even though older LGBT people may still be reluctant to disclose their sexual orientation, there have been significant legal and social shifts towards greater equality and protection for LGBT citizens.

The situation in South Africa is distinctly different. For example, because of the prevalence of HIV/AIDS in South Africa, the majority of deaths occur under the age of 65. The number of premature deaths to HIV/AIDS has risen significantly over the last decade from 39% to 75% in 2007 (Collins & Leibbrandt, 2007). The legislation dealing with older people in South Africa is the Older Persons Act 13 of 2006 (RSA, 2006b), which replaced the Aged Persons Amendment Act of 1998 . The Act's goal is to deal effectively with the plight of older persons by establishing a framework aimed at the empowerment and protection of older persons and at the promotion and maintenance of their status, rights, wellbeing, safety and security, and to provide for matters connected herewith. There is nothing in the Act dealing with diverse older persons, which highlights the particular challenges that older LGBT people in South Africa may face in terms of ageing and receiving care.

The first author was granted a three-month international fellowship with the Sue Ryder Care Centre for the Study of Supportive, Palliative and EOLC (School of Health

Sciences) at the University of Nottingham, England. The overall aim of this fellowship was to explore ageing and care research and practice relating to LGBT communities in the UK. In relation to this overall aim, there were three phases:

- Mapping out support networks around the UK focused on support for and with older LGBT communities;
- A critical review of recent literature in the field, published primarily in UK, USA and Australia;
- Transferring this learning to the South African context and to develop a project proposal on ageing and care of the LGBT communities for the University of the Western Cape (UWC) in South Africa.

This paper will be focusing on the results of the second phase, which was to examine the literature on ageing and care of the LGBT community in the UK, USA and Australia. Canada and Ireland are also included in the review as organisations have begun to explore health care services to the older LGBT population in those countries. The objectives were to compare and contrast the literature as well as to try and categorise the literature on ageing and care of the LGBT community in these countries.

The first author identified approximately 40 articles, reports, systematic reviews, guidelines and books from the countries identified above. Initially, I was guided by researchers within the Sue Ryder Centre who were working on the Last Outing Project, which was focusing on EOLC needs within the LGBT community in the UK. Furthermore, I had already sourced literature from Hughes (Australia) and Fredericksen-Goldsen (USA), who are regarded as other leading researchers in the field. Searches were carried out of peer-reviewed literature using database search engines such as EBSCO Host. The key words used were "lesbian, gay, bisexual, transgender", "ageing", "health and social care" and "end-of-life care". The peer-reviewed articles were sourced from a range of disciplines including gerontology, social work, sociology and the health sciences from 2004-2014. Reference lists were hand-searched from key articles to retrieve relevant references and to cross-check with searches undertaken. This search led the first author to gather a range of good practice guidelines as well as input on areas such as dementia, housing and palliative care from sources in the UK (including Opening Doors) and Australia. A number of visits were organised with academics and organisations in the UK (Birmingham, Worcester, Brighton, Swansea, Manchester and London) as part of the fellowship.

Several themes emerged as prevalent within the studies and other sources. It must be noted that some of the studies focused on LGB older persons, whereas other studies included the transgendered community. During the seminars and conferences that I also attended, there was a concern that this community (as well as the bisexual community) is not always given full recognition under the LGBT acronym. The themes include the following: discrimination against LGBT older people in the health and social care sector; legal ramifications for older LGBT people within EOLC; health risks in LGBT older people; and retirement housing for LGBT older persons. Gaps in the literature

were identified, with a specific focus on older lesbians, older bisexuals and older transgender people.

Good practice guidelines for older LGBT people were analysed to identify ways to address discrimination by health care workers which can be linked to intentional, but sometimes unintentional, linked to a lack of awareness of LGBT communities and their needs. Finally, there is a discussion on how the main findings could be utilised for research on LGBT older people in South Africa.

DISCRIMINATION AGAINST LGBT OLDER PEOPLE IN THE HEALTH AND SOCIAL CARE SECTOR

A number of studies identified that LGBT older people felt discriminated against and rejected by health care workers in hospitals and other settings.

GLEN (Gay and Lesbian Equality Network) (2011) in Ireland undertook a study on the experiences and needs of older LGBT persons. Using a mixed-methodology approach, they surveyed 144 older LGBT persons as well conducting 36 in-depth interviews. The findings that particularly relate to health care and ageing are the following:

- With regards to health services, 25% of the participants reported receiving poor quality of treatment;
- Roughly 60% of survey participants disclosed their sexual orientation to either some (34.2%) or all (28.5%) of their health care providers;
- One in five (22%) reported that they did not reveal their LGBT identity to health-care providers for fear of a negative reaction;
- Just one in three survey participants (32.5%) believed that health-care professionals had sufficient knowledge about LGBT issues. In addition less than half (42.9%) felt respected as an LGBT person by health-care providers.

In the UK a seminal study of LGBT ageing was undertaken by Heaphy and colleagues, probably the first of its kind in the UK. Heaphy (2003) examined the experiences of an ageing population (266 participants between the ages of 50 and 80). Only 34% believed that professionals were positive about LGB clients and 50% felt confident enough to be open about their sexual orientation in health-care settings; 33% concealed their sexual orientation in health-care settings. Fear of discrimination was also identified by Harding, Epiphaniou and Chidgey-Clark (2012) in a systematic review of research focused on LGBT EOLC. This fear may prevent clients from disclosing their sexual identity and this delays entry into care, particularly among older lesbian and gay men.

Cronin and King (2010) examined sexuality-blind conditions in current policy and practice with regards to care in the UK. Forty-five per cent (45%) argued that they had experienced discrimination when using social care services. Participants felt that they would have to go back into the closet when in a residential setting. In a study on older LGBT people with Alzheimer's, the Alzheimer Society (n.d) reports that even though these patients are more likely to need social services, they do not believe that the support will be able to meet their needs and so they avoid social services.

In Australia Hughes (2009) explored lesbian and gay people's concerns with ageing and accessing services. Nearly two-thirds of participants believe that their sexuality or gender identity may affect quality of services provided for them and 46% believed that service providers would be prejudiced and have a discriminatory attitude towards LGBT older people. Services may also be offered by conservative religious organisations, but it may be discriminatory.

LEGAL RAMIFICATIONS FOR OLDER LGBT PEOPLE WITHIN EOLC

Legal aspects were identified by a number of studies as a gap when dealing with EOLC for older LGBT people.

Hughes and Cartwright (2014) in Australia examined LGBT's knowledge and preparedness to discuss end of life (EOL) care planning options. Hughes and Cartwright refer to a study undertaken by the Metlife Mature Market Institute (MMMI) (2006) in the USA which examined the issue of legal options for LGBT people. MMMI (2006) found that 72% of LGBT persons interviewed reported that they had discussed EOL with someone, while 42% had completed an advanced directive; 58% had completed a living will and 34% had not; 60.4% were more likely to have completed a durable power of attorney regarding their health; 79% of lesbian and gay persons had not yet discussed with their health-care provider what should happen in the case of resuscitation; and 73% of them would like their health-care provider to know their views. Hughes and Cartwright (2014) report in their study that 72% of the sample knew that same-sex partners have the authority to make treatment decisions on behalf of their partner, but only 13% knew why this was the case.

Fredericksen-Goldsen and Muraco (2010) engaged in a systematic review of 58 articles published between 1984 and 2008 in the USA and Canada, which aimed to synthesise the recent state of social research on older lesbian, gay male and bisexual adults in order to summarise existing knowledge about these groups, to guide future research on ageing, and to identify the substantive issues affecting their lives. With regards to financial resources in the United States, same sex partners do not have automatic next-of-kin status for hospital visits and medical decision-making, nor do they have family leave benefits, bereavement leave or automatic inheritance of jointly-owned real estate and personal property (Hash & Netting, 2007). According to Pierre de Vos, Constitutional Law expert and lecturer at UCT (telephonic interview on the 26th of August, 2015), there is automatic next-of kin status for same-sex partners in South Africa, which includes all the benefits noted above. He argues that if families of LGBT people contested automatic inheritance of estates in a court of law, they would not be successful.

In the study by GLEN (Gay and Lesbian Equality Network) in 2011 on legal options for older LGBT persons in Ireland, only 1 out of 10 participants (10.9%) had written a living will and just 1 in 4 (24.6%) had given someone power of attorney. Higher percentages had discussed their final wishes with someone (47.5%) and written a last will and testament (61.5%). Further studies on LG wills have been published more recently which can enhance the options on legal rights for older lesbian and gay people (Monk, 2014; Westwood, 2015).

HEALTH RISKS IN LGBT OLDER PEOPLE

There is overwhelming evidence suggesting that the mental and physical health of LGBT people is poorer than that of their heterosexual counterparts, with associated consequences for the lifespan. For example, LGBT individuals are likely to have a higher incidence of life-limiting and life-threatening disease, attributed to risk behaviours such as smoking or alcohol abuse, which, in turn are linked to minority stress. Below is just one recent example of such studies, but others include Boehmer and Case (2004), McNeil, Bailey, Ellis, Morton and Regan (2012), and Fish and Karban (2015).

Fredriksen-Goldsen *et al*. (2012) undertook a quantitative study on ageing and health of the LGBT older community (over 55) in the United States in 2010. The total sample size for the national survey was 2 560. It was found that there are higher rates of disability among older LGB adults. Furthermore, LGB persons experience higher rates of mental distress and are more likely to smoke and to engage in excessive drinking. They also found that lesbian and older bisexual women have a higher risk of cardio-vascular disease and obesity, and that some gay and bisexual older men are more likely to have poor physical health. A further concern raised was that older LGB adults are at risk of social isolation, which links to poor mental and physical health, cognitive impairment and premature chronic disease and death. Contemplation of suicide was an ongoing feature among these adults. Nine per cent (9%) of the LGBT adults surveyed are living with HIV, while more than 1 in 5 bisexual men have contracted HIV. One quarter of older transgender persons needed to see a doctor, but could not afford it. Finally, services and programmes failed to take into account the unique circumstances that LGB persons are facing.

RETIREMENT HOUSING FOR LGBT OLDER PERSONS

A key theme that emerged from the literature survey was the absence of housing options for LGBT older people. In the systematic review undertaken by Fredricksen-Goldsen and Muraco (2010) in the United States and Canada, they identified one of the main sub-themes as independent living. Jackson, Johnson and Roberts (2008) argued for specific retirement housing for LGBT older persons.

Housing 21 (2013) in the UK conducted a qualitative study in Scarborough, Hereford, London and Brighton with 40 participants, using focus groups and in-depth interviews to broadly explore the needs and aspirations of older LGBT persons regarding access to housing. Housing 21 found it challenging to engage LGBT persons in the project. However, some participants had significant concerns about living in retirement communities or accepting care services. This feeling was mostly prevalent in the rural communities. Some felt very isolated and excluded in retirement communities, particularly as reminiscence sessions focused on weddings and children.

There were three recommendations that came out of the Housing 21 (2013) project. The first one was to make services accessible and earning the trust of LGBT people. Participants felt under-represented in corporate or promotional literature. The second recommendation was to expand training on diversity issues as this would better equip

staff to support LGBT older persons. Finally, it was recommended that informal support networks be endorsed. A further study by Carr and Ross (2013) supports this strategy.

GAPS IN THE LITERATURE

The literature identifies discrimination against LGBT people in terms of health-care workers, legal ramifications in terms of EOLC for the older LGBT community, health risks of older LGBT people, and retirement housing for older LGBT people. However, there are important aspects that relate in particular to lesbian, bisexual and transgendered older people's lives that may have been neglected. The book edited by Ward, Rivers and Sutherland (2012) has valuable chapters highlighting a nuanced description of the lives of lesbian, bisexual and transgender older persons, with valid recommendations on care strategies in old age and it also begins to address some of the gaps in the existing literature with chapters on older lesbians, bisexual people and transgender people. These include exploring the experiences of older lesbians (Traies, 2012), imagining bisexual futures as older people (Jones, 2012), and exploring the health and social care needs of transgender people in later life (Bailey, 2012) in the UK. These considerations add further complexity to aspects of the lives of older LGBT people.

Traies (2012) argued the necessity to challenge current assumptions about ageing and sexuality by acknowledging heteronormative and gendered imperatives and practices to develop a more contextualised understanding of older women who identify as lesbians. She agrees with Kehoe's (1986) assertion that older lesbians may face a triple invisibility – hidden from view by the combination of sexism, heterosexism and ageism. Older lesbians and older bisexual women are more likely to live longer than men and be less well-off in later life. Many may need to rely more on health and social care services for support, but have concerns about services being truly inclusive and safe.

Bisexual men and women may experience particular complexities in disclosing their own historical and ongoing relationships of care, which are important in old age and which may have involved both same-sex and opposite-sex relationships (Jones, 2012). Jones (2012) also suggests that we need to explore the positives of ageing. In her study of bisexual people imagining their future older selves, she argues that having led lives that often challenge normative expectations, bisexual people felt this would continue throughout their life course and into later life. Bisexual and trans people are a relatively new demographic and these are also communities that may face discrimination from within lesbian and gay communities as well as in the wider community.

Transgender people may also have led lives at odds with cultural norms and social expectations and may continue to similarly challenge normative expectations in old age. For some who have transitioned later in life, Bailey (2012) states that there may be feelings of inhabiting a new life and living to catch up on time lost. There will be differences for those who transition at an earlier stage in life to those who have decided to transition later in life. Transgender people are still among the most stigmatised groups in the UK (Bailey, 2012; Whittle, Turner & Al-Alami, 2007). A survey undertaken by the Scottish Transgender Alliance in 2008 highlights the socio-economic consequences of being transgender and considers the corresponding knock-on effects for pensions and

planning in later life. The same survey reports that two thirds of the respondents felt that they would receive negative care in later life because of their transgender status. They cited lack of education about transgender health care. One respondent felt that "things are slowly changing", implying socio-political gains for the transgender community, whereas three respondents related that they might commit suicide as they did not want to "grow old", which is a disturbing finding.

Returning to Jones's (2012) argument about successful/positive ageing – overall there are few articles depicting successful ageing in the LGBT community. One exception is a report from Fredricksen-Goldsen *et al*. (2013) in the USA, who argue that family and community support together with health-promoting behaviours such as physical activity and substance non-use contribute to better physical and mental health. They suggest that income and employment, together with focusing on successes rather than economic status, can further contribute to a better life. The young old may be more likely to have better prospects as a consequence of a raft of social and legislative changes that promote greater acceptance and protection of LGBT people. Nevertheless, little is known about points of transition in older age or ill-health and their consequences. For example, levels of confidence and assertiveness may be affected in transitions from active and independent lives through to frailty or to conditions that require care and support (Almack, in press). Furthermore, the socio-legal position of LGBT people varies internationally and the above discussion needs to be put into context in relation to the challenges facing LGBT older people in poorer countries and in areas of the world where LGBT people are still criminalised rather than protected by laws such as those that now exist in the USA, Canada, Australia, UK and other parts of Europe. In such contexts, where same-sex relationships are not legally recognised, this may mean that one's partner is not involved in one's care or that dying wishes may not be recognised by families of origin, who may override decisions. Other issues include a potential lack of support networks, and loss and grief not being fully acknowledged.

GOOD PRACTICE GUIDELINES FOR OLDER LGBT PEOPLE

There is an increasing number of checklists for good practice guidelines and training options for care providers when dealing with the older LGBT community in the UK, Ireland, USA and Australia, and they could provide important recommendations for studies in South Africa. GRAI (2010) in Australia argues for best practice guidelines for accommodating older gay, lesbian, bisexual, transgender and intersex (GLBTI) people. A research project report provides management and staff with a practical tool to assist in adopting practices to create an inclusive, rather than an exclusive, environment that is accepting and welcoming of all GLBTI people. It highlights issues specific to older GLBTI people. Practical strategies are provided to assist in promoting a greater understanding of, and better accommodation and services for, GLBTI elders. Opening Doors (2010) in the UK is more specific in detailing a response to discrimination by health care workers and outlines a possible check-list for social care providers. Items include the following:

- Organisation-wide ways to be friendly (this includes images in rooms that are gay friendly and human interest stories on the LGBT community);
- Ensuring older LGBT people are supported by LGBT-friendly staff (training on equality must include training on working with LGBT older people; unpacking homophobia and discrimination; recruiting of staff who are accepting of diversity);
- Case management and social care assessment (ensure LGBT-friendly environment where space is made available for privacy), be clear about confidentiality and include open-ended questions about their lives).

Furthermore, Westwood *et al.* (2015) in the UK have summarised some good practice guidelines with regards to health and social care provision for older LGBT people that could be considered within the SA context. They include the following:

- Inclusive consultation in service design and delivery (which aligns with the GRAI report in Australia);
- Appropriate equality and diversity-specific policies for LGBT people;
- Creating a safe working environment for staff and service users;
- Appropriate language and cultural representation;
- Person-centred assessment and care planning, and a robust staff training strategy;
- Tendering for contracts where service providers show evidence on how they will meet LGBT needs;
- Mobilisation, equality and human rights legislation to challenge inadequate provision of health and social care services;
- There is a need to recognise transgender issues (for example, transgender women who have transitioned later must shave regularly).

Finally, a training programme could be drawn up in developing programmes to address discrimination by health care workers in SA. Reygan and D'Alton (2013) piloted a training programme for health and social care professionals providing oncological and palliative care to lesbian, gay and bisexual clients in Ireland. Over 200 oncology and palliative care staff participated in training in pilot sites. One of the findings was that staff became more familiar with LGB-related language and terminology, became knowledgeable about LGB health issues, and reported becoming more confident in providing care to LGB clients. Reygan and D'Alton (2013) suggest that training be made available across the health services in Ireland and included in postgraduate courses for trainee health and social care professionals.

IMPLICATIONS FOR LGBT AGEING AND CARE RESEARCH IN SOUTH AFRICA

It is clear from these studies that discrimination of LGBT people continues within health-care settings in the different countries mentioned. The guidelines as outlined by the British organisations and others set out advice on good practice, but are not wholly

embedded in policy and regulatory frameworks – thus often reliant on staff goodwill or the commitment of individuals for these guidelines to be followed and implemented across services. This would impact on the kind of services that LGBT persons might receive.

Legal implications, health risks and retirement options are also key themes that must be addressed when looking at the landscape of LGBT ageing and care. There need to be educational workshops facilitated by legal experts as well as social workers on legal options for older LGBT people. Health risks must be identified and addressed on a number of levels. Individual assessments as highlighted by Westwood *et al*. (2015) could form the basis of intervention, but there is also a need for support groups and macro strategies to be implemented. Retirement options must be exposed to the wider LGBT population. As indicated in a conference on housing in London in 2014, there are various options being adopted in Holland and in the UK. These appear to be directed at the more affluent LGBT community and there is concern that financial constraints on working-class LGBT people would impact on the kinds of retirement options open to them. This would be particularly pertinent to older LGBT retirement in countries such as South Africa. There is little literature on successful ageing that highlights the belief that growing old is "not for sissies". However, the studies that have been completed indicate the importance of social participation as well as encouraging health-promoting behaviours and routine health check-ups.

What are the implications for LGBT ageing and care research in South Africa? LGBT persons in South Africa have had "rights" for a limited time; these derive mainly from the Constitution of 1996, which states that LGBT people cannot be discriminated against, as well as from the Civil Unions Act of 2006 (RSA, 2006a), which allows for same-sex marriage. There is scant evidence that LGBT older people are following up on their legal rights regarding EOLC and this needs investigating. Health care, including health risks, is still very much focused on services to those suffering from opportunistic infections, so there is limited focus on LGBT persons with ageing and health-care concerns. Furthermore, public health care in South Africa is seriously compromised by a lack of resources, competent staff and decisive leadership. There is limited social work intervention in dealing with older LGBT clients or older clients in general. However, there is a need for health and social care workers (doctors, nurses, psychologists, social workers etc.) to receive training similar to that available in, for example, the UK, Australia and Ireland. Retirement options for LGBT persons are another aspect that is superseded by lack of retirement options for the broader population.

As outlined at the beginning of this paper, one of the objectives was to put together a proposal for an "exploratory" research project on the needs and concerns of LGBT ageing persons in South Africa. This could be similar to the GLEN (2011) study, which identified the experiences and needs of the older LGBT population in Ireland. However, before that can be undertaken, there is a need for a discussion with relevant role players, key informants and potential stakeholders on how to take this process forward. This could include the Department of Health and the Department of Social Development as well as the NGO sector. There is a need to get clarity on what services exist for the aged

population (as well as defining what is considered as "old" in South Africa), including EOLC in South Africa, and whether these services provide for the LGBT population. There must be an acknowledgment that, despite the Civil Unions Act (of 2006) (RSA, 2006a), there is still homophobia and discrimination in South Africa (Henderson, 2015) that could have a negative effect on the kinds of services available to older LGBT persons. However, there are older LGBT persons in South Africa who would benefit from such an investigative study and it could pave the way for better services as well as good practice guidelines being developed in South Africa that would address the care needs of the older LGBT population.

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