

# Rendering visible the previously invisible in health care: the ageing LGBTI communities

Recent legislative and policy measures aim to raise awareness of the needs of older lesbian, gay, bisexual, transgender and intersex people

Ageing is often said to incur invisibility. Perhaps the most invisible and forgotten are lesbian, gay, bisexual, transgender and intersex (LGBTI) elders (Box).<sup>1</sup> This invisibility has consequences for access to health and aged care services, and the standard of mental and physical health among LGBTI elders has been notoriously lower than that of their heterosexual peers<sup>2</sup> (<https://lgbtihealth.org.au/wp-content/uploads/2016/07/SNAPSHOT-Mental-Health-and-Suicide-Prevention-Outcomes-for-LGBTI-people-and-communities.pdf>). Recently, there have been efforts to redress these gaps on a legislative and policy front, supported by a number of initiatives to raise awareness. This article briefly reviews this changing area of medicine and outlines some of the implications for clinical practice.



## Why invisible?

For many LGBTI elders, particularly the very old cohort, making themselves invisible by hiding sexual orientation, gender identity or intersex status was a necessary protection against discrimination and violence, and a way of avoiding imprisonment and loss of employment, social networks, family and friends. The need to stay safe extended to the medical profession, which previously defined homosexuality as “sexual deviation” or sociopathic personality and, as recently as the 1980s, offered or enforced medical or psychological “cures” for homosexuality.<sup>3-5</sup>

On a more benign level, or perhaps not so benign given its ageist underpinnings, LGBTI identities are usually associated with youthfulness rather than ageing, compounding the community perception that older people are asexual,<sup>6</sup> and entrenching the exclusion of the lived experiences of transgender and intersex elders. Such ageism, together with the perceived need of many LGBTI people to remain invisible, means that many aged care service providers may be unaware of their LGBTI clients.<sup>5</sup>

The invisibility of LGBTI elders extends to clinical research and academic discourse. It has been suggested that gerontology’s approach to sexuality and gender identity has been formulated from a heteronormative perspective and there has been an almost complete neglect of the transgender and intersex experience of ageing.<sup>7,8</sup>

## Legislative and policy reforms

In 2012, the Australian Government launched the National LGBTI Ageing and Aged Care Strategy as part of its Living Longer, Living Better aged care reform package (<https://lgbtihealth.org.au/resources/national-lgbti-ageing-strategy/>). The strategy set out the following goals and actions:

- LGBTI people will experience equitable access to appropriate ageing and aged care services.
- The aged care and LGBTI sectors will be supported and resourced to proactively address the needs of older LGBTI people.
- Ageing and aged care services will be supported to deliver LGBTI-inclusive services.
- LGBTI-inclusive ageing and aged care services will be delivered by a skilled and competent paid and volunteer workforce.
- LGBTI communities, including older LGBTI people, will be actively engaged in the planning, delivery and evaluation of ageing and aged care policies, programs and services.
- LGBTI people, their families and carers will be a priority for ageing and aged care research.<sup>9</sup>

Following this, the *Aged Care (Living Longer Living Better) Act 2013* expanded the meaning of “people with special needs” under section 11(3)(h) of the *Aged Care Act 1997* to include “lesbian, gay, bisexual, transgender and intersex people”. The effect was that allocation of subsidised places in residential care could be specified for LGBTI people to increase their diversity of choice. Further, the *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013* amended the *Sex Discrimination Act 1984* to preclude Commonwealth-funded faith-based aged care providers from discriminating in the delivery of services on the basis of sexual orientation, gender identity or intersex status.

## Implications for cultural competence of care professionals

Aged care providers need to be aware of these legal responsibilities with regard to LGBTI elders. The implementation of these policy and legislative reform

Carmelle Peisah<sup>1</sup>

Kim Burns<sup>2</sup>

Samantha Edmonds<sup>3</sup>

Henry Brodaty<sup>2,4</sup>

<sup>1</sup> School of Psychiatry, UNSW Sydney, Sydney, NSW.

<sup>2</sup> Dementia Centre for Research Collaboration, UNSW Sydney, Sydney, NSW.

<sup>3</sup> National LGBTI Health Alliance, Sydney, NSW.

<sup>4</sup> Centre for Healthy Brain Ageing, UNSW Sydney, Sydney, NSW.

[cpeisah62@bigpond.com](mailto:cpeisah62@bigpond.com)

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### Extracts from the My People study<sup>1</sup>

The My People study is a compilation of stories to assist aged care service providers understand the needs of lesbian, gay, bisexual, transgender and intersex elders.

- “If lesbians wanted to go into an aged care facility as a couple you would be very lucky to find one that would accept you as such. You would even be lucky to find one that would give you adjoining rooms ... although it is illegal to discriminate there is always a way out.”
- “Bill’s funeral was a kind of coming out for me.”
- “I can’t talk to the staff about being gay because I am worried my care will be worse. I’m not able to live a gay man’s life here because there is no privacy.”
- “Nancy [born a boy (sic)] was married to Frank for 18 years. When Frank was dying they took him to hospital. Frank’s family told Nancy she couldn’t visit him because it was ‘family only’.”
- “That’s why I never leave my room except for some meals ... One of the other residents wants to flatten me because I’m a transsexual.” ♦

measures requires an informed and skilled health care workforce that demonstrates recognition and respect for those who identify as LGBTI and that ensures their safety and choice regarding aged care. An Australian Government fact sheet advises LGBTI elders that:

- they do not have to talk about any LGBTI-related needs but, if they do, the assessor will discuss how aged care providers will be able to support them;
- someone else can be present during the visit, including a partner or someone from their family of choice;
- the service finder on the My Aged Care website can help locate and compare local services — for some types of aged care, it is possible to search for providers that specialise in services for people who identify as LGBTI; and
- they do not have to tell providers that they identify as LGBTI but, if they do:
  - ▶ providers must respect their privacy and confidentiality;
  - ▶ they can ask how the provider makes people feel safe, included and respected;
  - ▶ they can discuss any LGBTI-related care needs with the provider; and
  - ▶ they can tell the provider about their partner or someone from their family of choice.<sup>10</sup>

Using this modelled approach, service providers can make changes to their organisation to support LGBTI-inclusive care.<sup>11</sup> These changes include the consistent use of LGBTI-inclusive language across organisational policies, intake procedures, forms and staff orientation and training, and the nomination of LGBTI champions as resource people to support other staff.<sup>11–13</sup> Aged and health care settings may prompt traumatic memories of previous experiences of discrimination by health professionals and others. Staff must be supported in their responsibility to protect the safety and rights of LGBTI elders from aggression (ie, both verbal and physical) from other residents, clients or patients, some of whom may have dementia.<sup>13</sup> Where service providers are unaware of LGBTI people in their care, they should presume that they are part of their service and may not be comfortable

with disclosure or choose not to disclose. This respects those who choose not to disclose, while still allowing their care needs to be met. Finally, contributions of the often silent LGBTI health care professionals to LGBTI services and programs<sup>14</sup> should not be underestimated, but rather, acknowledged and utilised.

### Clinical implications

The social and historical context of LGBTI people influences not only access to health care but also the presentations of many psychiatric disorders and the nature of family and caregiver support. The most highly studied example of this is dementia, the onset and progression of which bring several specific challenges to LGBTI people with dementia and their carers. In particular, the loss of self and LGBTI identities associated with cognitive decline is often compounded by institutionalised cultural incompetence, highlighting “the intersectionality of sexuality, stigma, and sickness”.<sup>8</sup> Among other specific complications of the illness, the breakdown of boundaries and impulse control can reveal secrets, including sexual orientation, gender identity or intersex status, causing unwitting disclosure, and complexities surround the meeting of needs for intimacy. Unsurprisingly, this may lead to behavioural and psychological symptoms of dementia such as aggression and anxiety, which individualised, person-centred assessment can best address.

With regard to family carer support, LGBTI elders are often not in close contact with their biological family, have no children or have children who do not accept their life decisions. It is important for clinical staff to understand the significance of LGBTI “family of choice”, which may not include generations of blood relatives but provides equally strong affective bonds and support.<sup>8</sup> LGBTI elders’ informal care networks must be recognised to ensure their continued involvement in the lives of residents, clients or patients in health care settings.<sup>6</sup>

LGBTI partners, family of choice and support networks frequently fulfil the same role as traditional families. LGBTI partners or, in their absence, an appointed enduring guardian or health attorney, unpaid carers, or friends and relatives with close continuing relationships with the person have the same rights regarding proxy decision making. Such rights have been embedded within guardianship and administration legislation across Australia since the late 1980s and early 1990s. Specifically, the same sex partner (assuming they are recognised as such) has the same rights as any spouse to act as the person responsible or statutory health attorney to give proxy treatment consent on behalf of a partner who is unable to provide consent themselves.<sup>15</sup>

It is essential that respect for choice in family carer and proxy decision makers is respected throughout life, particularly at the end of life. When this is not honoured and the biological family do not support the sexuality, intersex status or gender identity of a person who is lesbian, gay, bisexual, transgender or intersex, this may render the person vulnerable to the decisions of family members who do not value or respect who they are. To address these issues, information about LGBTI advance care planning is

available on the Australian Government's My Aged Care website.<sup>16</sup>

Finally, as well as recognising and respecting the informal care networks and decision making arrangements of LGBTBI people, there is an onus on clinicians to identify abusive situations, including harm and neglect by carers, reported by 22% of LGBTBI participants attending community-based social and recreation programs or groups in the United States.<sup>17</sup>

### Conclusion

We recognise that this brief overview barely touches on the complex and myriad issues affecting LGBTBI elders.

However, if we raise awareness in the medical community about these hard fought, only recently won, triumphs in reform, then we are making progress towards making the invisible visible.

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