

This is an author accepted version of an article published in *Health and Social Care in the Community*.
The published version is available at:

Waling, A., Lyons, A., Alba, B., Minichiello, V., Barrett, C., Hughes, M., Fredriksen-Goldsen, K., & Edmonds, S. (2019). Experiences and perceptions of residential and home care services among older lesbian women and gay men in Australia. *Health and Social Care in the Community*, 27(5), 1251-1259.
<https://doi.org/10.1111/hsc.12760>

Experiences and perceptions of residential and in-home care services among older lesbian women and gay men in Australia

Author Order: Andrea Waling,¹ Anthony Lyons¹, Beatrice Alba¹, Victor Minichiello^{1,2}, Catherine Barrett⁴, Mark Hughes³, Karen Fredriksen-Goldsen⁵, Samantha Edmonds⁶

Correspondence

Dr Andrea Waling
Australian Research Centre in Sex, Health and Society
School of Psychology and Public Health
La Trobe University
Building NR6, Bundoora, Victoria, 3086, Australia
Phone: +61 3 9479 8765
Email: a.waling@latrobe.edu.au

Acknowledgements

We wish to acknowledge the following organisations for their input and feedback at various stages of this project: The National LGBTI Health Alliance, COTA Australia, Carers Australia, and SANE Australia.

Disclosure of interest

The authors report no conflicts of interest.

Funding

This research was funded by the Australian Research Council under grant number LP160100221.

1 Australian Research Centre in Sex, Health and Society; School of Psychology and Public Health, La Trobe University, Melbourne, Australia

2 School of Justice, Faculty of Law, Queensland University of Technology, Brisbane, Australia

3 School of Arts and Social Sciences, Southern Cross University, Gold Coast, Australia

4 Alice's Garage, Melbourne, Australia

5 School of Social Work, University of Washington, Seattle, United States of America

6 National LGBTI Health Alliance, Sydney, Australia

Title: Experiences and perceptions of residential and in-home care services among older lesbian women and gay men in Australia

Abstract: The needs of lesbian and gay older people regarding access and use of aged-care services remain under-researched. This paper reports the findings of 33 qualitative interviews with older lesbian women and gay men about their perceptions and experiences of residential aged-care and home-based aged-care services in Australia. The focus of this paper is their preparedness for using aged-care services. The results highlight that participants had a number of concerns related to accessing residential-care services in particular, including perceptions of a lack of inclusivity and concerns of potential for discrimination and hostility, loss of access to community and partners, decreased autonomy, and concerns relating to quality of care and the potential for elder abuse. Participants noted a number of strategies they employed in avoiding residential-care services, including the use of home-care services, renovating the home for increased mobility, moving to locations with greater access to outside home-care services, a preference for lesbian/gay specific housing and residential-care options if available, and the option of voluntary euthanasia to ensure dignity and autonomy. Participants, on the whole, were hopeful that they would never require the use of residential-care services, with some believing that having current good health or the support of friends could prevent this from happening. The findings suggest that lesbian and gay older people have a variety of concerns with aged-care and may need additional support and education to improve their perceptions and experiences of services, whether these are needed presently or in the future.

Keywords: sexuality; palliative care; end-of-life care; community services for the elderly; ageing; residential care

What is known about this topic:

- There is an ageing cohort of lesbian and gay people in Australia.
- Older lesbian and gay adults will require access to aged-care services.
- Lesbian and gay older people are at greater risk of experiencing or fearing the possibility of experiencing discrimination while engaging with aged-care services.

What this paper adds:

- An overview of the perceptions and concerns that some lesbian and gay older people have about aged-care services in Australia.
- A consideration of the strategies some lesbian and gay older people employ to avoid using aged-care services.
- An improved understanding of these issues, which may assist service providers and the development of interventions to more effectively support and meet the needs of this population.

Introduction

With an ageing population in most developed countries, there is likely to be increasingly large numbers of older lesbian and gay people who will need access to aged-care services. Older lesbian and gay people have a range of unique physical and mental health risk factors, whereby they are at increased risk social isolation and loneliness that has been found to lead to poorer physical and mental health increased mortality, and increased risk for developing cognitive impairment (Kim & Fredriksen-Goldsen 2014; Fredriksen-Goldsen *et al.* 2018). Research in a range of developed countries shows that these groups have significant concerns regarding residential aged-care (hereafter referred to as 'residential-care') services, including potential experiences of homophobia, ageism, lack of visibility, risk of exposure to biased treatment relating to sexuality, feeling unsafe, the potential to be abused, isolation, and poverty (Heaphy 2007, Hughes 2007, Bayliss 2000, Erdley *et al.* 2014, Smith *et al.* 2010, Harrison 2006, Phillips & Marks 2006, Tolley & Ranzijn 2006; Westwood 2016; Stein *et al.* 2010; Fredriksen-Goldsen *et al.* 2014; Fredriksen-Goldsen *et al.* 2011; Fredriksen-Goldsen *et al.* 2018).

Substantial progress has been made in Australia regarding awareness of lesbian and gay ageing and the imperative for aged-care services to respond to the needs of this group. The period has been characterised as one of partial institutionalisation of lesbian and gay ageing issues – where the issues raised in research, advocacy and activism in earlier decades have become partly incorporated within mainstream policy and practices (Hughes 2016). Spurred by a landmark Productivity Commission Report, the Australian Government implemented a range of measures, including development of a National Strategy on LGBTI Ageing and Aged Care, designation of older lesbian and gay people as a 'special needs' group under the Aged Care Act 1997, and allocation of funding for lesbian and gay-awareness training to aged-care providers. However, there is a lack of understanding of what these initiatives have meant for older lesbian and gay people in terms of their expectations for and experiences of aged-care, and whether all people have been able to benefit from these initiatives.

Studies conducted in Australia have examined experiences and perceptions of residential care, which broadly show a range of concerns and fears, including management of identity disclosure, lack of safe spaces for intimate relationships, and the need for culturally safe and inclusive services (Barrett 2008, Barrett *et al.* 2015, Crameri *et al.* 2015, Chamberlain & Robinson 2002, Harrison 1999, Hughes 2004, 2009, Waite 1995, Lovelock 2006, Cartwright *et al.* 2012). Research has also found lesbian and gay people tend to have low awareness regarding their legal options, with most avoiding or not being given the opportunity to discuss the issue with healthcare providers (Hughes & Cartwright 2014, 2015).

Alongside these developments, increased public concern has been focused on elder abuse, particularly in residential-care, which has drawn attention to the abusive nature of discrimination and mistreatment faced by older lesbian and gay people in residential care and other settings (Australian Law Reform Commission, 2017). In October 2018 the Australian Government announced a Royal Commission into Aged Care Quality and Safety, requiring Commissioners consider the diversity of older Australians and the barriers they face in accessing services. The safety and wellbeing of lesbian and gay people, including older people, were also negatively affected by the national debate and postal vote on marriage equality (Ecker & Bennett, 2017). During this time lesbian and gay people experienced increased rates of verbal and physical violence, harassment, and physical assault by those opposing the legalisation of same-sex marriage (Ecker & Bennett, 2017). Same-sex marriage was legalised in 2017, which may have implications for how older lesbian and gay people plan for their own ageing, including their relationships, finances, retirement, end-of-life decision-making, and housing. Other developed Western countries have also been implementing policies and strategies to address issues regarding aged care services and lesbian and gay older people (e.g. Frederickson 2018). Similar to Australia, these countries also experience challenges in their aged care service delivery regarding supporting lesbian and gay people.

It is in this context that new research is needed into how people plan (or do not plan) for the possibility of residential care in the future, and the strategies they may employ to avoid accessing these services. An understanding of contemporary broader perceptions and experiences of aged-care is needed to guide service providers and policymakers in addressing areas of concern and to develop appropriate support strategies. In particular, qualitative research is needed to provide more thorough understandings of different perceptions, motivations, and associated contexts in accessing services to ensure strategies can sufficiently target this population. To address these needs, this article presents a qualitative analysis of interviews conducted with older Australian lesbian women and gay men. We have not included bisexual/nonmonosexual, transgender, non-gender binary, and people with intersex variations as they have experiences that are quite different to that of lesbian women and gay men. This is not to suggest that people with intersex variations, or transgender people, do not identify as lesbian or gay, as many of them do. Rather, this is to acknowledge and respect their specific issues and needs that can be lost in broader considerations of lesbian and gay health and wellbeing.

The interviews covered a range of information on health and well-being, and aged care service use. One of the aims involved exploring participants' perceptions and experiences of residential care and home-care services, and the rationale behind current and future decision processes in accessing (or not accessing) aged-care services. In this article, we focus on findings related to this aim.

Methods

Participants

Participants were recruited as part of a two-phase study on health and well-being, with the first part involving lesbian and gay people aged 60 and over completing a national survey and the second involving in-depth interviews. Thirty-three interviews were conducted with 14 cisgender gay men and 19 cisgender lesbian women. As displayed in **Table 1**, most of the participants resided in urban areas

(76%), were aged between 60 and 70 years (73%), were retired (64%), and were not using home-care services (88%).

[INSERT TABLE 1 HERE]

Data Collection

Ethics approval for the study was received from the [BLINDED] Ethics Committee. The study was conducted from September 2017 to December 2017. Interviewees were drawn from participants who completed the survey, available online and in hardcopy, promoted through electronic advertisements placed on Facebook and community radio broadcasts, and sent by relevant community organisations to their contacts lists. In addition, flyers were circulated at community and social events involving lesbian and gay older people. Survey participants interested in being interviewed provided their name and contact details at the end of the survey. Also provided were age, sexual identity, gender identity, assigned sex, intersex variations, and whether they were receiving home-care services.

Participants who expressed interest in being interviewed were selected via stratified random sampling. They were first grouped according to whether they identified as lesbian or gay, and further grouped according to whether they were using home-care services. This formed four main groups: lesbian women with (10) and without (97) home-care services, and gay men with (28) and without (233) home-care services, a total of 368 potential participants. Participants were assigned a number, and an online random number generator was used to select individuals to be contacted. Sampling according to the above four groups was done to ensure that lesbian women and gay men were well-represented, and to include at least some who were using home-care services, though not many in that group volunteered after initial contact. Selected participants were then contacted by email and given further details about the interviews. Interview participants were asked to email a signed consent form prior to their interview.

Interviews were conducted via telephone by the first-named author. Conducting telephone interviews allowed us to make the study available to participants across the country, including rural and regional areas. Interviews were conducted until data saturation was reached (Guest *et al.* 2006). Interviews were semi-structured, audio-recorded, took between 45 and 60 minutes, and transcribed by an external agency. Transcripts were verified, anonymised, and all participants assigned a pseudonym. Participants were offered the opportunity to review their transcript within four weeks of the interview, however, all participants declined.

Analysis

We employed a thematic analysis procedure (Ezzy 2002, Braun & Clarke 2006). The interviews were loaded into the software package NVivo for primary analysis by the first-named author, involving a close reading and preliminary coding of the transcripts. Emerging themes were noted using the interview schedule, and core study aims as initial code categories. Attention was paid to both recurring themes and patterns, as well as contradictions in the data to enable us to account for complexity and diversity in experiences of older lesbian and gay Australians. To ensure validity, the coding for a random sample of transcripts was reviewed by the third-named author. There was full agreement regarding the key thematic categories.

Findings

Three major themes emerged, and were similar for both gender groups: 1) perceptions and experiences of residential-care and home-care services; 2) alternative strategies to residential-care; and 3) hoping to never need residential-care, with a range of sub-themes within these. In Australia, a number of aged-care services exist to support health and well-being of older people. Home-care services range from a casually-employed worker assisting in the home, to providing transportation to address a client's decreased mobility, and to services responding to complex medical or nursing needs. Assisted living facilities and/or retirement villages enable individuals to reside in complexes where

they maintain independence, but may sign up for various services, such as cooked meals in common areas. Residential-care, like nursing homes, are designed for individuals with high-care needs, such as severe mobility barriers, or cognitive impairment such as dementia.

While there are a range of services available, most participants only spoke of residential-care when asked about aged-care services. Only four participants reported being aware of the availability of home-care services, all of whom were currently using these.

Perceptions and experiences of residential-care and home-care services

Concerns regarding residential-care services were negative, included a *lack of inclusivity* for lesbian and gay people, *a sense of loss* (community, autonomy, partners), and *poor quality of care* (elder abuse, workforce skills and capacity). The four participants who were aware of the availability of home-care services, of whom all were using these services, also raised concerns related to a *sense of loss* and *poor quality of care*. It is important to note that, while participants raised concerns that were specific to the lives of lesbian and gay people, they felt that some concerns were not exclusive to them and might be relevant to heterosexual communities. These are discussed in detail below.

Lack of inclusivity in residential-care

A number of participants expressed concerns that if they were admitted to residential-care facilities, they might be exposed to sexuality-based discrimination from staff and other residents and perceived a lack of protections for them:

Cody (66, gay): Well we do joke about having an aged-care place for gay men, but I think that might be an issue, because I've heard stories about people being, older people being discriminated against or not treated properly because they are gay.

For some, everyday experiences of heteronormativity (the assumption that all people are heterosexual) were noted as difficult to manage. This was linked to expectations around heterosexual family life that may or may not pair up with lesbian and gay people's experiences of life and relationships, such as monogamy, grandchildren, or gendered roles and expectations:

Peggy (72, lesbian): It's like going to a camping ground you know and it's one of those grey-haired old heterosexual mums and dads, and that's how they talk to each other you know, here's mum and here's dad, they don't have names anymore.

Participants also felt that residential-care providers needed better training for supporting and working with lesbian and gay people:

Mabel (60, lesbian): I audited nursing homes... And I would read things in notes like [KATIE] is always very comforted when her special friend [SASHA] comes to visit, and I would say to them do you think that maybe [SASHA] has been more than a special friend?...When I met [SASHA] it was fairly clear to me, and they'd go oh no, no, she wouldn't be any, no she wouldn't be one of them.

Sense of loss in residential-care and home-care services

One significant concern about residential-care was a perceived loss of privacy, autonomy, and independence. As with older heterosexual people (Gott *et al.* 2004), participants expressed similar concerns around a loss of independence and the inability to make choices:

Rachel (65, lesbian): I don't want to be a vegetable. I don't want to be incompetent, dependent... I think, I was going to say depersonalised. You are not independent. You have to have meals at a certain time and the situations I have seen I didn't like with other friends.

However, participants also noted that both residential-care and home-care services did not provide a sense of community, which is important for lesbian and gay people who have had to build communities in order to be resilient against experiences of discrimination and violence. Many gay and lesbian people may not have family support networks to advocate on their behalf, and thus a safe

environment was perceived as vital. Reduced access to external friends and families not residing in the facility was further raised as an issue, as well as an absence of other gay or lesbian people:

Devon (69, gay): I am just concerned about nursing homes and being isolated especially if you are alone as I probably will be...Being in a nursing home and maybe there is not another gay person there, that does bother me. Not being able to speak to other gay people or mix with them because of my age and also maybe there won't be any there.

Participants had concerns around access to internet technology services in residential settings, citing such access as vital to remaining connected to lesbian and gay online communities:

Jean (66, lesbian): If I need some sort of care I am going to want WI-FI as part of the system. I cannot imagine living in residential-care without internet.

For those in relationships, there was concern over separation from partners in residential-care. In some cases, this issue was acknowledged as one that could be experienced by heterosexual couples, but may be especially difficult to navigate for lesbian and gay older people due to stigma and history of persecution:

Percy (63, gay): What I do think about a lot is, well first of all I want a double bed when I go to aged-care, I don't want to live in a single bed, I want to be with [DAVID]

The few who were using home-care services, and who had mobility issues, also noted feeling isolated and frustrated that some services did not provide or support community events:

Ramona (78, lesbian): Now one of the gripes I've got about [HOME SERVICE] and I've voiced this many times is that most of the people that [HOME SERVICE] look after are elderly people and we aren't allowed to contact each other because of policy... I think people my age need to be able to get together.

Poor quality care in residential-care and home-care services

As found with older heterosexual people (Gott *et al.* 2004), all participants were concerned with the quality of care they would receive in residential-care settings. Participants had many concerns about the potential for abuse, including physical, sexual, emotional, and financial abuse. This was often

based on the experiences of family members and friends in residential-care, and the stories they had heard about in the media:

Mabel (60, lesbian): A lot of nursing homes where residents have been sexually abused, medicated beyond belief, financially abused by staff and family, and it's only those people that have got a really strong family support or advocate that survive that process.

Some participants gave accounts of witnessing cases they perceived as abuse:

Jackson (79, gay): I've experienced my mother being in one...I arrived at the home and I said where's mum and then my sister said oh she's in hospital... I went out to the hospital and here she is lying in a bed packed in ice covered in bruises...And I blew my lid at her [the nurse], I was told my mum had fallen out of bed, and she suffered very badly from hypertension and they had to pack her in ice to bring her temperature down, and I said how can she get to this situation.

In addition to elder abuse, participants had concerns about general standards of care in residential facilities:

Sadie (60, lesbian): I think it is shocking what is happening with aged-care. I don't think that they get fed well, I don't think that they are staffed well. They are often very low quality in the ones that are affordable.

Participants who were using home-care services also spoke about quality of care. While experiences of home-care services were largely positive, concerns were expressed about the quality of care, and particularly the casualisation of the aged-care sector, and associated turnover in staff who attended their home. Some participants noted that while it was good to have home-care services, such turnover meant having to repeat instructions to newcomers, as well as having to confront the possibility that workers might not be lesbian or gay friendly:

Percy (63, gay): One of the problems we've got is that every fortnight we have somebody new, so got to go through and explain the whole rigmarole of what our routines are and what the work is that needs to get done...So there's two levels of preparation you have to go through.

Who is this person we're going to get, are they going to be happy with us, and two, are they going to be able to do what we need them to do for us.

Hoping never to need residential-care

Fears and concerns about residential-care underpinned an expressed hope that residential-care would not become a reality for them:

Dusty (72, gay): It hasn't even been part of my thinking to do so, and touch wood or whatever you like to touch, I hope that that will not be the case for a long time off.

Some participants also attempted to avoid thinking about the possibility of needing residential-care services. Instead, they relied on beliefs about other ways they might be taken care of, such as by friends:

Peggy (72, lesbian): Look I don't like talking about death because I'm not going to die, that's my attitude, so I just block it you know...I just hope that I've got enough friends if I'm the first one to become unfit, that they'll look after me.

Participants often referred to being in good health as a reason they might avoid residential-care, though acknowledged that could change at any moment:

Dylan (66, gay): I haven't got to that stage yet and I sort of thought about it at some stage, but I thought oh well I'm not there yet, I'm not ready for an aged-care home or anything like that... I sort of sometimes wonder what might happen, but because I've got good health and everything, I own my own unit and I'm sort of independent, but I just don't bother about it.

Alternative strategies to using residential-care

For participants who were thinking about the possibility of needing assisted living in the future, some spoke about alternative strategies that they would implement or were implementing. These included finding alternative *supportive housing or communities*, making use of home-care services and home renovations for *staying in the home longer*, and *euthanasia*.

Supportive housing or communities

Most of the participants were already residing in lesbian- or gay-friendly communities with access to health services. Some, however, recently moved:

Sadie (60, lesbian): Well I already have moved from my suburban house to a unit which is walking distance into the city, walking distance to my [RELIGIOUS] community, walking distance to [LOCAL] gym-I've taken that step so that I hope I can stay here as long as possible, and also be available for people who are likely to support me as I age.

Others spoke about potentially moving to accessible housing:

Finn (65, Gay): We certainly talk about longer term planning...[We want] to be sure that we can afford to move at some point, and it'll probably be an apartment that's all on one level.

Participants spoke of having a preference for housing, assisted-living facilities, villages, or residential-care services that were specific to lesbian and gay adults. This was based on beliefs that they would fit better in such environments, as they would have more in common, and be able to be open about their sexual identity without fear of discrimination:

Patrick (69, gay): I think it's necessary that there's home, there's places that are particularly for gay guys, you know for gay people. Because then you could be yourself, again like a lot of gay guys that go into nursing homes have to go back in the closet.

Rene (62, lesbian): I mean in a perfect world, it's not so much I'd love to have a lesbian only aged care facility, but it would be you know great to have, know of places where there was a predominant or a number, like it was known that there was a significant number of gays or lesbians who were there.

However, not all participants who spoke about lesbian-and gay-specific housing were fully supportive. Others were uncertain, stating that while they would prefer a mainstream service, they recognised the benefits of one that is lesbian and gay community specific:

Percy (63, gay): Well I mean there's always been this fight all our lives about lesbians and gays should be an equal and well-regarded part of the general community... But there's also a part of me that says sometimes you need to be with your own kind to just build up strength and build up solidarity... so there's a dynamic tension there between those two pulls, between the mainstream and the specialised service.

These perceptions were based on concerns around the potential for discrimination and stigma based on sexuality, and increased vulnerability as they age.

Staying in the home

Overall, participants indicated a preference to stay in the home as this would enable them to maintain their independence, feel safe, and continue to live their lives openly as gay men and lesbian women. The use of home-care services was preferred over entering a residential-care facility, but most participants were not at a point in which they felt they needed such services. As mentioned earlier, only four participants were already using home-based aged care services to assist with tasks such as cleaning and cooking, and three of them were single lesbian women:

Raomona (78, lesbian): I'm using [HOME SERVICE] they come once a week. One time to hang out the washing, make the bed, take me shopping, do the housework and the other time they just do whatever I want.

Participants did, however, note that they would prefer access to a home-care service to enable them to age in the home, though did not necessarily know what was available, and demonstrated a preference for a care worker to be lesbian and gay-friendly:

Drew (75, gay): If you had to have a nurse who came in or people came in to shower you or people came in to assist you in some other way with daily living, you'd really want to be able to have a choice of people who were gay friendly.

Some participants were currently relying on friends and family to support them, or used online services to assist with tasks such as gardening. Others were in the process of renovating, or had

already renovated their home, in particular to address current or future mobility issues, and provide a space for a live-in carer:

Chole (64, lesbian): We actually planned to age in place so we have bought a lift, had a lift installed. ...It is organised so that when we built the ensuite we built it with a wider door and level to the shower... Our total focus was on making sure that [HARRIET] and I can stay here until they carry us out of here in a box.

Euthanasia

For some participants, euthanasia was raised as an alternative to the perception of what might await them in residential-care services. They felt that euthanasia, with informed consent, should be an option for those suffering:

Phoebe (66, lesbian): If you are beyond help in that way, then I think you know euthanasia or you know assisted euthanasia is the way to go.

While not all participants felt they would choose euthanasia, they nevertheless wanted this to be an option:

Vaughn (66, gay): I have thought about when I can't handle things and euthanasia might be an alternative. I sort of want to be in control of my life.

This option was understood as a way to maintain autonomy, dignity, and freedom of choice, an important aspect after experiencing a potential lifetime of discrimination and restricted human rights as lesbian and gay people.

Discussion

Participants' perceptions of residential-care services were entirely negative, and illustrated that they were not aware of the varying types of aged-care services available to them. There were particular concerns regarding possible lack of support for lesbian or gay people, poor quality of care and the

potential for elder abuse, and a loss of community, autonomy and access to partners. Some concerns were based on perceptions rather than direct experiences of residential-care, such as stories in the media. For others, concerns about residential-care were based on negative experiences involving people they knew, or on previous experiences working in the residential-care industry. On the whole, participants were hopeful they would not require residential-care and some avoided thinking about it. Some were also utilising or exploring alternative strategies to residential-care such as moving to areas where they believed they could be supported at home, using home-care services, renovating their homes to address mobility issues, or even considering voluntary euthanasia.

Overall, participants expressed some concerns that might also be shared by their heterosexual counterparts, such as a lack of autonomy, but that this can manifest differently, including feeling unable to express their sexuality, and maintain important connections to the lesbian and gay community. Many of the concerns about utilising aged-care services, whether home or residential-care, were related to the potential impact of discrimination as being lesbian or gay. Neville *et al.* (2015) and Crameri *et al.* (2015) suggest that this could be particularly acute for the current older generation given they lived during a time when homosexuality was criminalised and institutional discrimination was widespread, therefore potentially heightening fears around the increased likelihood of engaging with services and other institutions as they grow older. Other studies have identified concerns of lesbian and gay older people in relation to stigma and discrimination in accessing aged-care services both in Australia (e.g., Hughes 2007, 2008, Barret *et al.* 2015) and internationally (e.g., Heaphy 2007, Erdley *et al.* 2014, Smith *et al.* 2010). Regarding Hughes (2007, 2008) studies of similar issues, our findings expand his work by noting the strategies that lesbian and gay people use to avoid aged care services. Our findings also highlight that the concerns noted in Hughes (2007, 2008) work are still relevant today, and suggest the need to continue to do more to address these issues. While limited research has been done in Australia regarding experiences of aged-care workers in working with lesbian and gay residents and clients, studies in other developed countries have noted that residential-

care workers generally relied on heteronormative assumptions and practices, and were not always recognising the distinct health and care needs of lesbian and gay people (Simpson *et al.* 2016, Neville *et al.* 2014, Hafford-Letchfield *et al.* 2018).

These findings have a number of potential implications for policy and practice. In Australia, older lesbian and gay people are now regarded as a special needs group for the provision of aged-care and related services (Australian Government Department of Health, 2017). To help ensure services meet the needs of this population, our findings suggest a range of different concerns by lesbian and gay older people may need to be addressed. These are largely underpinned by a fear of stigma and discrimination. Ensuring services are experienced as culturally safe and lesbian and gay inclusive will be important, such as implementing lesbian and gay inclusive practice policies and training workers on utilising lesbian and gay inclusive language, enabling environments where lesbian and gay older people feel safe to be open about their sexuality, and addressing fears of abuse or loss of lesbian and gay community connections (Fredriksen-Goldsen 2018). Where services are already practicing lesbian and gay inclusiveness, it may be useful to develop strategies to reassure lesbian and gay older people about the safety of the service. For example, services should strongly consider engaging in the national LGBTI Australian accreditation programs, such as the Rainbow Tick Program, to ensure that services are inclusive, knowledgeable, and safe. Program evaluations should also be completed where services have undergone inclusive practice training to assess their long-term effectiveness.

Findings also suggest a need to develop and test evidenced-based interventions designed to support the use of aged-care services in this population. As we found in this study, some participants are avoiding services, which could result in some not using services they may need. As is also likely among many older heterosexual adults (Gott *et al.* 2004), we found a general preference among the participants in our study for staying in the home. Ensuring the availability of programs that assist them to do so as long as possible may be important, such as ensuring that home-care services and health

services near the home are inclusive. This is crucial, as many lesbian and gay people have created safe spaces for themselves, often in their own homes (Fredriksen-Goldsen *et al.* 2011), and the risk of being placed in a residential-care facility surrounded by people who may not understand or respect their sexual orientation could be distressing. These findings are relevant for international audiences in supporting their work towards creating inclusive-practice aged-care services for lesbian and gay older people.

There are some limitations to this work. The lack of participants in this study residing in residential-care, and the limited number of participants using home-care meant that we were not able to examine actual experiences of living in residential-care, or gain a more in-depth insight in home-care use, and future research is needed. While 38 of the potential participants were using home-care services, only four volunteered to be interviewed. Although we had participants aged over 70 years, future research is also needed to explore perceptions and experiences of the oldest group. An additional limitation is the focus on lesbian women and gay men. Bisexual men and women may have different experiences, as they can experience stigma from gay and lesbian communities, as well as mainstream communities. As most participants were of Anglo-Celtic background and middle-class, exploring experiences amongst lesbian and gay people of diverse cultural backgrounds and Aboriginal and Torres Strait Islander peoples, and of disadvantaged socioeconomic status are vital to help support those communities. Older transgender and intersex populations are also likely to have specific needs and experiences not shared by lesbian or gay older people, and future research is needed.

Conclusion

With an ageing population in Australia and many other developed countries, there is likely to be a growing number of lesbian and gay people entering older age and in need of support services. This study identified a range of concerns expressed by adults in this population about aged-care services, specifically related to issues of discrimination, inclusivity, and loss of autonomy, and many were

seeking ways to avoid this. While some concerns may be evident in heterosexual populations, others were specific to the impact of sexuality-based stigma. The identified concerns are likely to be useful for policymakers and service providers for ensuring that services needed to support older age are inclusive and sensitive to the various needs of this population.

References

- Australian Law Reform Commission. (2017) Elder Abuse – A National Legal Response. ALRC Report 131. Canberra: Australian Government.
- Barrett, C. (2008) My people: A project exploring the experiences of gay, lesbian, transgender and intersex seniors in aged-care services. Matrix Guild of Victoria & Vintage Men., Melbourne.
- Barrett, C., Cramer, P., Lambourne, S., Latham, J. R. & Whyte, C. (2015) Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners. *Australasian Journal on Ageing*, **34**, 34-38. doi: 10.1111/ajag.12271
- Bayliss, K. (2000) Social work values, anti-discriminatory practice and working with older lesbian service users. *Social Work Education*, **19**, 45-53. doi: 10.1080/026154700114649
- Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**, 77-101. doi: 10.1191/1478088706qp063oa
- Cartwright, C., Hughes, M. & Lienert, T. (2012) End-of-life care for gay, lesbian, bisexual and transgender people. *Culture, Health & Sexuality*, **14**, 537-548. doi: 10.1080/13691058.2012.673639
- Chamberlain, C. & Robinson, P. (2002) The needs of older gay, lesbian and transgender people: A report prepared for the ALSO Foundation. RMIT University, Melbourne.
- Cramer, P., Barrett, C., Latham, J. R. & Whyte, C. (2015) It is more than sex and clothes: Culturally safe services for older lesbian, gay, bisexual, transgender and intersex people. *Australasian Journal on Ageing*, **34**, 21-25. doi: 10.1111/ajag.12270
- Ecker, S., & Bennett, E. (2017) *Preliminary Results of the Coping with Marriage Equality Debate Survey*. Canberra and Newtown: The Australia Institute and the National LGBTI Health Alliance.
- Erdley, S. D., Anklam, D. D. & Reardon, C. C. (2014) Breaking Barriers and Building Bridges: Understanding the Pervasive Needs of Older LGBT Adults and the Value of Social Work in Health Care. *Journal of Gerontological Social Work*, **57**, 362-385. doi: 10.1080/01634372.2013.871381
- Ezzy, D. (2002) *Qualitative analysis: Practice and innovation*. Routledge, London, UK.
- Fredriksen-Goldsen, K. (2018). Shifting social context in the Lives of LGBTQ Older Adults. *Public Policy & Ageing Report*, **28**, 24-28. doi: 10.1093/ppar/pry003
- Fredriksen-Goldsen, K. I., Cook-Daniels, L., Kim, H.-J., Erosheva, E. A., Emlet, C. A., Hoy-Ellis, C. P., & Muraco, A. (2014). The physical and mental health of transgender older adults: An at-risk and underserved population. *The Gerontologist*, **54**, 488-500. doi:10.1093/geront/gnt021
- Fredriksen-Goldsen, K. I., Kim, H.-J., Emlet, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., . . . Petry, H. (2011). *The aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Seattle, WA: Institute for Multigenerational Health.
- Fredriksen-Goldsen, K., Jen, S., Bryan, A.E.B., & Goldsen, J. (2018). Cognitive impairment, Alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: needs and competencies. *Journal of Applied Gerontology*, **37**, 545-569. doi: 10.1177/0733464816672047.
- Fylan, F. (2005) Semi-structured interviewing IN J. Miles & P. Gilbert (Eds.) *Handbook of Research Methods for Clinical and Health Psychology*. Oxford University Press, New York, NY.
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, **18**, 460-467. doi: 10.1191/0269216304pm889oa
- Guest, G., Bunce, A. & Johnson, L. (2006) How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability. *Field Methods*, **18**, 59-82. doi: 10.1177/1525822X05279903
- Hafford-Letchfield, T., Simpson, P., Willis Paul, B. & Almack, K. (2017) 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**, e312-e320. doi: 10.1111/hsc.12521
- Harrison, J. (1999) A Lavender Pink Grey Power: Gay and Lesbian Gerontology in Australia. *Australasian Journal on Ageing*, **18**, 32-37. doi: 10.1111/j.1741-6612.1999.tb00086.x
- Harrison, J. (2006) Coming out ready or not! Gay, lesbian, bisexual, transgender and intersex ageing and aged-care in Australia: Reflections, contemporary developments and the road ahead. *Gay and Lesbian Issues and Psychology Review*, **2**, 44-53.
- Health, A. G. D. o. (2017) Review of the implementation of the National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged-care Strategy. Commonwealth of Australia, Canberra.
- Heaphy, B., Yip, A. K. T. & Thompson, D. (2004) Ageing in a non-heterosexual context. *Ageing and Society*, **24**, 881-902. doi: 10.1017/S0144686X03001600.
- Hughes, M. (2004) Privacy, sexual identity and aged-care. *Australian Journal of Social Issues*, **39**, 381-392. doi: 10.1002/j.1839-4655.2004.tb01189.x
- Hughes, M. (2007) Older Lesbians and Gays Accessing Health and Aged-Care Services. *Australian Social Work*, **60**, 197-209. doi: 10.1080/03124070701323824.
- Hughes, M. (2008) Imagined Futures and Communities: Older Lesbian and Gay People's Narratives on Health and Aged-care. *Journal of Gay & Lesbian Social Services*, **20**, 167-186. doi: 10.1080/10538720802179211.
- Hughes, M. (2009) Lesbian and Gay People's Concerns about Ageing and Accessing Services. *Australian Social Work*, **62**, 186-201. doi: 10.1080/03124070902748878
- Hughes, M. & Cartwright, C. (2014) LGBT people's knowledge of and preparedness to discuss end-of-life care planning

- options. *Health & Social Care in the Community*, **22**, 545-552. doi: 10.1111/hsc.12113.
- Hughes, M. & Cartwright, C. (2015) Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning. *Australasian Journal on Ageing*, **34**, 39-43. doi: 10.1111/ajag.12268
- Hughes, M. (2016) Towards the inquiry into aged-care and beyond: the promise and challenge of a new era in LGBTI ageing. Chapter 9 in E. Peel & R. Harding (Eds.). *Ageing and Sexualities: Interdisciplinary Perspectives*. London: Ashgate, pp.183-204.
- Kim, H.-J., & Fredriksen-Goldsen, K. I. (2014). Living arrangement and loneliness among lesbian, gay, and bisexual older adults. *The Gerontologist*, **56**, 548-558.
- Lovelock, G. (2006) Addressing gay, lesbian, bisexual and intersex ageing in Western Australia. *Gay and Lesbian Issues in Psychology Review*, **2**, 91-92.
- Malta, S. (2012) Using Online Methods to Interview Older Adults about Their Romantic and Sexual Relationships. In M. Leontowitsch (Ed.) *Researching Later Life and Ageing: Expanding Qualitative Research Horizons*. Palgrave MacMillan, London, UK.
- Neville, S., Kushner, B. & Adams, J. (2015) Coming out narratives of older gay men living in New Zealand. *Australasian Journal on Ageing*, **34**, 29-33. doi: 10.1111/ajag.12277.
- Neville Stephen, J., Adams, J., Bellamy, G., Boyd, M. & George, N. (2014) Perceptions towards lesbian, gay and bisexual people in residential care facilities: a qualitative study. *International Journal of Older People Nursing*, **10**, 73-81. doi: 10.1111/opn.12058.
- Phillips, J. & Marks, G. (2006) Coming out, coming in: How do dominant discourse around aged-care facilities take into account the identities and needs of ageing lesbians? *Gay and Lesbian Issues and Psychology Review*, **2**, 67-77.
- Simpson, P., Almack, K. & Walthery, P. (2016) 'We treat them all the same': the attitudes, knowledge and practices of staff concerning old(er) lesbian, gay, bisexual and trans residents in care homes. *Ageing and Society*, 1-31. Doi: 10.1017/S0144686X1600132X.
- Smith, L. A., McCaslin, R., Chang, J., Martinez, P. & McGrew, P. (2010) Assessing the Needs of Older Gay, Lesbian, Bisexual, and Transgender People: A Service-Learning and Agency Partnership Approach. *Journal of Gerontological Social Work*, **53**, 387-401. doi: 10.1080/01634372.2010.486433.
- Stein, G. L., Beckerman, N. L. & Sherman, P. A. (2010) Lesbian and Gay Elders and Long-Term Care: Identifying the Unique Psychosocial Perspectives and Challenges. *Journal of Gerontological Social Work*, **53**, 421-435. doi: 10.1080/01634372.2010.496478.
- Sturges, J. E. & Hanrahan, K. J. (2004) Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research*, **4**, 107-118. doi: 10.1177/1468794104041110.
- Waite, H. (1995) Lesbians Leaping Out of the Intergenerational Contract. *Journal of Gay & Lesbian Social Services*, **3**, 109-128. doi:10.1300/J041v03n03_07
- Westwood, S. (2016) 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK. *Health & Social Care in the Community*, **24**, e155-e163. doi: 10.1111/hsc.12265