GLBTI Rights in Ageing Inc.

The support needs of Lesbian, Bisexual and Transgender Women Carers in Western Australia

Final Report

Kedy Kristal & Rowan Brooker (PhD)

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Acknowledgements

We are blessed to live on Whadjuk Noongar Country. We acknowledge that Noongar people remain the custodians of their Country, and that they continue to practice their values, languages, beliefs and knowledge. We pay our respects to the elders and knowledge holders of the Country on which we live, work, love and travel.

We would like to honour and recognise the past and ongoing work of the members of the lesbian, gay, bisexual, trans, intersex, queer and asexual (LGBTIQA+) community, and include anyone else who is diverse in sex, gender, or sexual orientation within this acronym. We would like to thank LGBTIQA+ people for their contributions to our society; particularly in areas of health and equality and acknowledge their experiences of prejudice and discrimination and celebrate their strength, resilience, and perseverance.

We especially acknowledge lesbian, bisexual, and transgender women, who are the focus of this report.

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Executive Summary

This report outlines exploratory research that GRAI (GLBTI Rights in Ageing, Inc) undertook on the experiences of lesbian, gay, bisexual and transgender (LGBT) women carers in Western Australia, with the support of a Department of Communities Women's Grant. Sixteen women completed an online survey, which enquired about the impacts of caring and any supports received, and three women also participated in in-depth and semi-structured interviews.

The research identified that all women who participated, regardless of identity group, reported that caring had impacted their mental health, with lesbian women being more likely to choose the 'strongly agree' response. Transgender women in our study all strongly agreed that caring had impacted their financial and housing security. LGBT women that had cared for a partner for 5 or more years were also particularly likely to experience financial strain. We found that lesbian women who were in a same sex relationship experienced an additional layer of strain due to experiencing discriminatory treatment in health and social services settings.

Support emerged as an area of intervention that would make a big difference to our research participants. Support includes the woman's social networks as well as the availability of formal supports. All of our participants indicated that caring had impacted their social networks to some degree. Similar to self-care, time and energy to go out and socialise was depleted for some of our participants, whilst others noted that their caring responsibilities made it hard to access social events.

The three in-depth interviews are presented as case studies within this report, and help to identify factors that contributed to the survey findings, as well as recommendations for other LGBT women carers.

Case Study 1: Casey is an Aboriginal and Torres Straight Islander lesbian in her 40's. Casey cared for her terminally ill mother for nearly a year, whilst living with her partner and children. Casey identified that although she was a community services worker with years of experience, she was surprised how hard it was to find support, even within her own organisation. Casey was also under time pressure because her mother's decline was so swift, and processes for accessing support were effortful and took a long time to be realised.

> *Start the process as early as you can. Start the process of contacting other organisations, and seeking help. Don't wait until you need it. I would probably also say, try not to do everything. Do try and delegate some of the care where you can (Casey, Aboriginal and Torres Strait Islander, lesbian).*

Case Study 2: Jamie is a lesbian in her 40's. Jamie is currently caring for her partner with mental health issues and her child, and has been doing so for over 5 years. Jamie only has the support of her mother and found that organisational supports such as her workplace EAP programme were inadequate.

> *You don't want to go to a group that's full of heterosexual people or cisgender people. No. Because you're less likely to share, which means you won't get as much out of it (Jamie, lesbian).*

Case Study 3: Kissia is a lesbian in her 30's who has cared for her mother with mental health issues since childhood. Kissia has also cared for a partner with mental health issues, and is currently single and lives alone. Kissia had difficulty accessing support as the carer of a parent with mental illness.

She was not recognised as an authority for her mother, and was too young to be recognised as a carer. When she was old enough to access support, it was often unavailable to her as a full-time worker trying to support both herself and her mother (i.e., the support was only available during business hours).

> *…so I was caring for my mum with zero supports or initially awareness of what this issue was. So, I developed a caring role from infancy. I remember the time I first consciously became aware I had to care for her. I was only seven years old.*

The report concludes with a summary of the ten key findings and recommendations for the Department of Communities and service providers.

Introduction

GLBTI Rights in Ageing (GRAI) was supported by the Department of Communities Women's Grants for a Stronger Future to undertake some initial research into the support needs of Lesbian, Gay, Bisexual and Transgender (LGBT) women living in Western Australia who are carers (unpaid or those on a carer's allowance). The purpose of the research was to explore the unique lived experiences of these LGBT women carers.

For the purposes of the research, carers were defined using the Carer's WA definition:

> A carer is someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged. (https://www.carerswa.asn.au/, retrieved 20th July, 2023).

For the purposes of this research, an unpaid carer may be receiving a carer's allowance. This is consistent with Australian research conducted by Alba and colleagues (2020), who also included women who received a carers allowance from the Australian government to provide daily care to someone with a disability or severe illness, or who is frail aged. People who were providing care in a professional paid role were not included in the research.

A note on terminology: The term 'gay' can be used as an umbrella term that includes same-sex attracted men and women. It can also be used more specifically to refer to gay men. When referring to the current study, the term LGBT refers to LGBT women. Where other research studies are reported that focused on gay men, this has been specifically identified within the report. Research studies that are documented within this report use varying acronyms (e.g., LGBT, LGBTQ), and we have followed their usage. When we refer to the LGBTIQA+ communities beyond this study, we have used the full LGBTIQA+ acronym.

Methods

We conducted an online survey using the Survey Monkey platform, and recruited participants via GRAI's Facebook page and via emails to community organisations in GRAI's training networks. LGBT women were invited to participate via the survey link provided on the research project flier (Appendix 1) and GRAI's social media platforms. The survey aimed to collect demographic data on this group of carers in Western Australia, as well assessing how much support the women had received and the impacts of caring on their wellbeing (health, mental health, financial and housing security, and social networks and connections).

To take part in the survey the women had to be living in Western Australia and to identify as a lesbian, bisexual/pansexual or transgender woman. The scope was limited to the experiences of women (i.e., a binary gender), so people who identified as non-binary were not included. We invited women who had been a carer in the past, as well as those who were currently caring, to participate.

The survey consisted of twenty main questions. The demographic questions asked about each woman's age, country of birth, whether they were Aboriginal or Torres Strait Islander, the sex they were assigned at birth, their gender identity, and their sexual orientation. We also collected information about the context in which each woman cared, including their living arrangements, relationship status, caring circumstances (caring currently or in the past), who they cared for and for how long. With regard to the impacts of caring, we asked each woman to assess the impacts of caring on their mental health, physical health, financial security, housing security, social networks and community connections, using a 7-point Likert scale (strongly agree, agree, somewhat agree, neither agree nor disagree, somewhat disagree, disagree, strongly disagree). We also assessed their supports, such as whether they received a carer's allowance, who they received support or respite from, the quality of that support, and what additional supports would have been helpful to them.

Women who had completed the survey were invited to participate in a one-on-one semi-structured interview. Four women accepted the invitation and attended a personal interview with Kedy.

Interview questions were informed by the research literature (below), and built on the questions asked in the survey. Questions varied with the woman's context, but usually included the following:

- Please outline your current context and your caring commitments?
- What has been the biggest impact of your caring role on you?
- What supports were around for you in your caring role?
- How did health/community organisations respond to you in your caring role? In relation to your LGBT status?
- What impacts did caring have on your physical wellbeing? Your family life?
- What would make the most positive difference for you?
- What advice would you give another LGBT woman before they took on a caring role?
- What is your number one recommendation for this research?

Data Analysis

We conducted quantitative analyses using Excel software. Qualitative and thematic analysis of the open-ended questions posed in the survey was completed using N-Vivo 10 software.

Literature Review

This literature review includes research articles that focus on lesbian, gay, bisexual or transgender (LGBT) carers and that were published within the past ten years (2013-2023). We couldn't achieve a review that focused entirely on women carers because very few research articles present findings that compare the experiences of men and women within lesbian, gay, bisexual, transgender (LGBT) communities. Whilst comparisons between lesbian women and gay men are possible, this becomes more difficult when bisexual men and women and transgender men and women are concerned, due to small sample sizes representing these groups. With one exception[1], we also excluded research studies that included a sample of predominantly gay men given our focus on the experiences of LGBT women carers. In total, seven main research articles and reports were identified for inclusion in this review.

What does it mean to be an informal carer?

Definitions of informal caring vary within the literature reviewed. After discussing the kinds of tasks that informal caregivers perform, Muraco & Fredriksen-Goldsen (2014) define informal caregiving as being delivered by "…a committed partner or spouse, friend, or community member who is neither paid nor a volunteer affiliated with a service organization" (p. 253). This definition focuses on those providing care to adults, as it doesn't include parents as caregivers. Similarly, the definition provided by Croghan and colleagues also focuses on care being provided to adults: "…the unpaid assistance of

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[1] Alba and colleagues (2020) was included because it was an Australian study and it presented findings based on gender.

any relative, partner, friend or neighbor who provides a broad range of assistance for *an older adult or an adult with* a chronic or disabling condition" (Croghan, Moone and Olson, 2014, p. 80, *emphasis added*). Boehmer and colleagues define informal caring succinctly yet broadly as "…providing unpaid help to an individual with a serious health condition" (Brohmer, Clark, Showalter & Fredman, 2018, p. 112). This definition allows for the inclusion of women who care for their children with special needs or grandchildren who are no longer in the care of their parents, as was the case in the present study.

In addition to being delivered by someone known to the care recipient, informal caregiving involves tasks such as managing medications, attending to the care recipient's emotional needs, providing hands-on personal care, and giving assistance with household routines and transportation (Boehmer et al., 2018; Muraco & Fredriksen-Goldsen, 2014). The Australian Government Workplace Gender Equality Agency reported that caregivers may also provide supervision and advocacy, and assist with service coordination (Commonwealth Government of Australia, n.d.). Informal caregivers may perform a variety of tasks in service of the person for whom they care.

Care-giving within the LGBTIQA+ communities

A significant proportion of all caregivers in the United States of America (USA) are lesbian, gay, bisexual or transgender (LGBT). The latest USA research report on caregiving (AARP and National Alliance for Caregiving, 2020) reported that of the 7,309 people who surveyed, the proportion of respondents who had served as unpaid caregivers was 21.3%. Of these people, 8% self-identified as lesbian, gay, bisexual or transgender. The Australian Bureau of Statistics (ABS, 2019) reported that 10.8% of the Australian population (1 in 9 people) were currently providing informal care, but they did not specify what proportion identified as LGBT.

In studies focusing on LGBT people, over a quarter reported that they were providing care to someone else, a significantly higher proportion than the statistics for the general population cited above. In a nationwide study of LGBT caregivers in the United States, Fredriksen-Goldsen and colleagues found that 27% of the 2650 LGBT adults aged 50-95 who participated their study were providing care for a family member, partner or friend (Fredriksen-Goldsen et al., 2011). In an Australian nationwide study of LGBT people aged 60 years and over, Alba and colleagues (2020) found that 29.7% of their final sample of 515 were caregivers. A Carers Australia (Victoria) fact-sheet estimated that between 15 and 30% of LGBT people were in caring roles (Carers Australia VIC, n.d.). In addition to being more likely to provide care, LGBTQ people are also more likely to be the primary caregiver (AARP and National Alliance for Caregiving, 2020).

Whilst the majority of caregivers are female in the general population, a gender imbalance is not always apparent amongst LGBT caregivers. The Australian Bureau of Statistics reported that females represented 68.1% of all primary carers (compared with 50.3% of men) (ABS, 2019). Similarly, Croghan and colleagues found that 22.2% of the lesbian, gay, bisexual, transgender, or queer (LGBTQ) people that were currently caring, two-thirds were women (66.3%) (Croghan et al., 2014). In an Australian nationwide survey of lesbian women and gay men aged 60 and over, Alba and colleagues found that more women reported being a carer (39.6%) than men (25.2%) (Alba et al., 2020).

However, in a large study of caregiving status and health amongst LGBT adults (18+) in 19 states across the United States, Boehmer and colleagues (2019) found that more gay and bisexual men were carers (29.6%) compared with LGBT women (19.7%). In a nationally representative study on caregiving adults aged 21-80 years, Boehmer and colleagues (2018) found that 9% of the sample were LGBT, and that caregivers were equally likely to be men as women. Fredriksen-Goldsen and colleagues (2011) found that the majority of LGBT carers were men (54% of the sample), compared with women (42.7%). These researchers summarised that… “the pattern of women assuming greater responsibility for caregiving roles does not hold among LGBTQ communities” (Fredriksen-Goldsen et al., 2011, p. 757). In conclusion, within the LGBT communities, it can’t be assumed that women are more likely to be carers.

Carers in the LGBT communities are more likely to provide care to friends than those providing care in the general population. The MetLife study on LGBT baby boomers, found that 21% were receiving care from a friend, compared with 6% of people in the general population (MetLife, 2010). Shiu and colleagues (2016), found that 52% of their sample of LGBT caregivers aged 50 and over were caring for a partner, whilst 44% were caring for a friend. They pointed out that LGBT people in general are less likely to have support from traditional sources such as biological children compared with the general population, and therefore may need to rely more on the support of friends in times of need. Fredriksen-Goldsen and colleagues (2011) found that 35% of LGBT caregivers were assisting a partner or spouse and that 32% were supporting a friend. These findings suggest that significant proportions of caregivers in the LGBT communities provide care to friends as well as partners.

Shiu and colleagues (2016) identified that caregiving demands varied depending on whether the LGBT person was caring for a partner/spouse or a friend. They found that those who were caring for a partner or spouse provided more types of care, over more hours, for longer periods of time, and spent more money on care than LGBT people caring for a friend. Increased caregiving demands were associated with perceived stress, and perceived stress was related to more depressive symptoms. By contrast, LGBT people who were providing care to a friend perceived less caregiving demands and less stress. However, they also experienced less social support for their role, and this was related to higher levels of perceived stress and more depressive symptoms. Croghan and colleagues (2014) also pointed out that non-kin caregivers (and care recipients) may experience additional stress because of the limited supports available to them. Overall, Shiu and colleagues found that the lower caregiving demands and less social support cancelled each other out, leading to similar levels of perceived stress and depressive symptoms regardless of whether the LGBT person cared for a friend or a spouse/partner.

Challenges, Impacts and Supports for LGBTIQA+ Caregivers

LGBT caregivers may experience some unique challenges compared with other caregivers. One of those challenges is financial hardship, since LGBTQ caregivers report high financial strain more often than non-LGBTQ caregivers (AARP and National Alliance for Caregiving, 2020). Fredriksen-Goldsen and colleagues (2023) examined the impacts of informal caregiving on the health-related quality of life of older LGBTQ caregivers over a three-year period. They found that a third of their sample of 754 LGBTQ caregivers aged 50-98 were living in financial hardship, which contributed to caregiving strain. Similarly, Boehmer and colleagues (2018) found that LGBT caregivers were more likely to be of low socioeconomic status and were significantly more likely to report financial strain and to tend towards poorer health and more emotional stress than their heterosexual or cisgender counterparts. Fredriksen-Goldsen and colleagues concluded that financial hardships…

> are also associated with lifetime victimization, poorer physical health, and barriers to health care access among LGBTQ older adults (Fredriksen-Goldsen et al, 2019) (Fredriksen-Goldsen et al, 2023, p. 757).

This amounts to a cluster of factors related to financial hardship that impact negatively on the wellbeing of LGBT caregivers.

When researchers looked into LGBT discrimination, they found that this is associated with poorer quality of life, and less help-seeking. A recent USA research report on caregiving found that LGBTQ caregivers experienced feeling discriminated against at work due to caregiving more often than non-LGBTQ caregivers (AARP and National Alliance for Caregiving, 2020). Fredricksen-Goldsen and colleagues (2023) identified that LGBTQ caregivers were also at risk of experiencing discrimination from service providers, either because of their LGBTQ status, or that of their care recipient. Barrett & Crameri (2015) found that 43% of their sample experienced discrimination in relation to their lesbian, gay, bisexual, transgender or intersex (LGBTI) identity or their care of an older LGBTI person. These day-to-day experiences of discrimination were found to lower LGBTQ participant's psychological and physical health-related quality of life, whilst identity stigma (negative feelings towards one's own sexual or gender identity) lowered caregiver's psychological health-related quality of life.

Relatedly, LGBTQ caregivers may be less likely to request respite, assistance or support because they anticipate experiences of discrimination (Fredricksen-Goldsen et al., 2023). Barrett and Crameri (2015) reported that 28% of their participants reported delaying access to services because they feared discrimination and only 38% reported accessing carer support services. Anticipation of discrimination by the caregiver or the care recipient, makes it less likely that support will be sought, which leaves the caregiver more vulnerable to emotional and physical strain. Also, caregiving research based in the USA found that doctors, nurses, and social workers were less likely to ask an LGBTQ carer what support was needed to help them care for their care recipient (AARP and National Alliance for Caregiving, 2020). In Australia, carers who are LGBTIQA+ are more likely to report that their care recipient had poor access to most services (Mylek & Schirmer, 2023).

Other researchers identified higher levels of poor physical and mental health amongst LGBT carers compared with non-LGBT carers. Boehmer and colleagues (2019) found that lesbian, gay or bisexual (LGB) caregivers reported poorer physical and mental health days in the past month, and had the highest likelihood of poor physical and mental health days, compared with other caregivers. Transgender caregivers had higher odds of reporting 14 or more days of poor physical or mental health, but this finding was not significant. Overall, LGBT caregivers are more likely to experience physical and mental health challenges whilst providing informal care to another person.

According to recently published research on carer wellbeing in Australia, LGBTIQA+ carers were one of five groups[2] that experienced a larger decline in wellbeing between 2022 and 2023, compared to other carer groups (Mylek & Schirmer, 2023). Psychological distress was also highest amongst LGBTIQA+ carers, along with four other carer groups[3]. A higher proportion of LGBTIQA+ carers had the highest probability of serious mental illness (37.4%) compared with other carers who reported high psychological distress (only carers aged 25-34 and carers working as a first responder had slightly higher probabilities of serious mental illness). LGBTIQA+ carers were also significantly more likely to report feeling lonely (49.7%), often or always, compared with all carers (Mylek & Schirmer, 2023). This finding is similar to that of the USA research report on caregiving, which found that LGBTQ caregivers more often feel alone (33%) compared with non-LGBTQ caregivers (20%) (AARP and National Alliance for Caregiving, 2020). LGBTQ carers were also least likely to find caring satisfying (43.5%) along with carers of people with autism spectrum disorder, mental illness and psychosocial disability, and those caring for children or grandchildren (Mylek & Schirmer, 2023).

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[2] Other groups were younger carers aged 15-24, carers engaged in study, carers of people with low assistance needs, and carers who identify as Aboriginal or Torres Strait Islander.

[3] Other carer groups experiencing high psychological distress were carers aged 25-44, carers of three or more people, those caring for 40 hours per week or more, and carers of people with autism spectrum disorder, other developmental disorders, and/or drug or alcohol dependency.

Whilst LGBT caregivers do experience some unique challenges, there are also some things that can improve their wellbeing whilst caring for another person. Researchers have found that those who engaged with their LGBTQ communities and were physically active fared better. Fredriksen-Goldsen and colleagues (2023) found that LGBTQ community engagement contributed to better psychological health-related quality of life amongst older LGBTQ caregivers. They also found that physical activity was protective, and led to better psychological and physical health-related quality of life. In addition, Barrett and Crameri (2015) found that some of the LGBTI caregivers in their study reported positive personal changes as a result of providing care. Some identified becoming a more compassionate person or feeling closer to the person they provided care for. Shiu and colleagues (2016) reported similar benefits and said that "Providing care to friends and loved ones can promote the personal growth of the caregiver as well as strengthen their relationship with loved ones" (p. 529). Additionally, they identified that LGBT caregivers had experienced personal gains such as higher self-esteem and more self-efficacy.

LGBT Women Carers

Alba and colleagues (2020)[4] conducted a nationwide survey of lesbian women and gay men aged 60 years and over. They found that lesbian women were significantly more likely to have a university degree and to care for a family of origin member, whereas gay men were more likely to care for a friend. Just under a quarter (22%) of the lesbian women cared for a relationship partner, and just under half (41.8%) indicated that they cared for an LGBTI person. When women who were caregivers were compared with those who were not, no significant differences were found in health, wellbeing or social support between the two groups. However, when women who cared for an LGBTI person were considered separately, they were found to be significantly less likely to feel supported. They were also significantly lower on positive mental health and physical health than lesbian woman caring for a non-LGBTI person (Alba et al., 2020). The researchers attributed these negative outcomes to "overall exposure to stigma, as well as issues related to marginalisation" (Alba et al, 2020, p. 212). Similarly, Boehmer and colleagues (2019) found that LGB women carers had the greatest likelihood of rating their overall health as 'fair' or 'poor' compared with gay and bisexual men who were carers. The research suggests that LGB women carers may experience greater negative impacts on their health and wellbeing whilst caring.

Croghan and colleagues (2014) found that LGBT women were significantly more likely to indicate that their carer was a partner or spouse. Whilst LGBT older adults were less likely to have a partner or spouse (59.5%) compared to the general population (65.5%), lesbian women, bisexual women, and transgender women were found to be partnered at higher rates than the general population (Corghan et al., 2014). The researchers thought this was protective for those being cared for, since in the same article, it was concluded that relying on non-kin for care was a particular vulnerability for the LGBT community. However, it is doubtful that being partnered is protective for the person in the partnership providing the care.

Croghan and colleagues (2014) also found that bisexual adults were more likely to be caregivers than would be expected by chance, and that bisexual women were twice as likely to be carers compared with bisexual men. In this study, 50% of bisexual women were carers, followed by cisgender women (25.7%) and lesbians (24.4%).

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[4] Alba and colleagues (2020) were among the few researchers to report separate outcomes for lesbian women and gay men. Despite their research sample being dominated by gay men, this study was retained in the literature review because it was Australian and it made some useful gender-based comparisons.

To summarise, bisexual women may be carers at higher rates than other identity groups, lesbian women are more likely to care for a family of origin member, and LGBT women are more likely to care for a partner or spouse compared with the general population. Lesbian, gay and bisexual women carers are also be more likely to experience poorer health and wellbeing outcomes whilst caring. There is also some evidence that when lesbian women are caring for another LGBT person, they feel significantly less supported and experienced poorer mental and physical health outcomes than other carers.

Research on lesbian, gay, bisexual or transgender women carers is particularly lacking. More research is needed that identifies the particular needs of LGBT women carers, and the factors that contribute to poorer mental and physical health outcomes in particular. As noted above, research on bisexual and transgender women carers is particularly limited, due to smaller population sizes. The current research study aims to address some of the gaps in the literature on LGBT women carers by exploring their lived experiences of providing informal care.

Participant Demographics

Sixteen women who responded to the survey invitations were eligible to participate in this research[5] and supplied complete answers. In terms of identity, women were divided into three groups: lesbian (9 participants or 56% of the sample), bisexual/pansexual (4 participants or 25% of the sample), and transgender[6] (3 participants or 19% of the sample). Two women who participated were of Aboriginal or Torres Strait Islander heritage, and both were lesbian.

In terms of living arrangements, four of the women lived alone and had a partner, three lived alone and were single, and three lived with related adults. Two women lived with a partner, and two lived with a partner and children. One woman was single and living with children or young people, and one was living with unrelated adults. The only clear pattern based on identity grouping was that all of the single women living alone, single women living with children or partnered women living with children, were lesbians.

The women in our sample were equally divided into those who were currently caring (50%) and those who had cared in the past (50%).

Half of the women in our sample cared for a related adult (8). Five women reported caring for a partner (one had also cared for a related adult). Three women cared for a child, children or young people with special needs, and one woman cared for an unrelated adult. There was no obvious pattern based on identity grouping.

We didn't specifically ask if participants were caring for another LGBTIQA+ person (a study weakness). It was apparent that five people were caring for a partner and of those people, three identified as lesbian and two as bisexual/pansexual. One lesbian woman had cared for a relative who may have been transgender (they were identified as exhibiting autogynephilia behaviour by this carer). A trans woman identified that she was caring for an unrelated adult, but it wasn't possible to identify if this person was also LGBTIQA+ based on her survey responses.

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[5] That is, they were unpaid women carers who identified as lesbian, gay, bisexual or transgender who live in Western Australia.

[6] Although transgender women also identified as lesbian, or bisexual/pansexual, they were treated as a separate category (according their gender identity), as other research has done.

Only two women in our sample reported receiving carers allowance and both were currently caring; one for a child with special needs and one for their partner.

Most of the women in our sample (9) had been caring for 5+ years. Two women had been caring for 3-4 years, 2 for 1-2 years, and three for less than twelve months. There were no obvious patterns related to identity group, or care recipient.

Survey Data

Mental Health

Participants responded to the statement, ‘Caring has impacted my mental health’. All participants agreed with this statement to some degree: 10/16 strongly agreed (62.5%), 5/16 agreed (31.25%) and 1/16 (6.25%) somewhat agreed. Issues that contributed to the women’s experiences of mental health challenges included**:** caring for someone with a mental illness, the intensity of the caring role, household stress, dealing with government departments (e.g., Centrelink, Department of Child Protection), limited social contacts and support from others, the pressure and responsibility of caring, and witnessing death. As a result of these experiences, women reported feeling frustration, grief, worry, or loneliness as well as becoming drained, exhausted or burnt out.

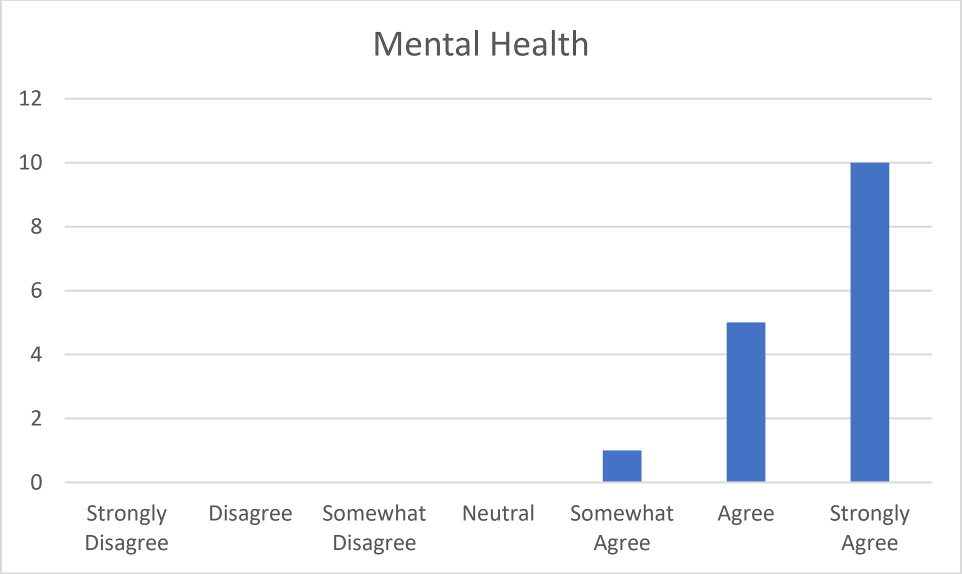

Figure 1. Number of participants and their responses to the statement, ‘Caring has impacted my mental health’.

For example, Jane (27, cisgender lesbian), strongly agreed and identified the impacts on her mental health of seeing her great aunt experience distress, pain, and dependence on others as she died:

> It was end-of life care for my great Aunt. I hadn’t experienced that before, and it was eye-opening how undignified dying was, particularly for the elderly - no one quite prepares you for seeing someone you care about being unable to perform seemingly simple acts like toileting, bathing and eating or drinking. Seeing their distress and pain was really hard, but I am glad I could help them get the care they deserved - even if it wasn’t good enough at times.

Julie (55, cisgender and bisexual/pansexual) also strongly agreed, and identified that caring for her mother was intense and challenging in the short term, but that longer term, worry about an ageing relative had been restrictive, constant and wearying:

> I have just finished caring for my Mum who was diagnosed with a terminal illness 5 weeks before her death. This caring was shared with my sisters and was rewarding but also very intense and challenging. I have previously provided ongoing care for my mum for many years, as well as my former parents in law, and at times former partners. I think that the worry about whether an aged relative is okay is constant and wearing. It also stops you going away or seeing friends or going places that would be hard to leave (like Optus Stadium), so it limits your life.

Ames (32, cisgender and bisexual/pansexual) agreed with the statement, and identified the challenges of performing painful medical procedures on her child, as well as not being able to solve his problems as impacting her mental health:

> I was caring for my son as his full-time carer due to an accident that we were all in back in 2014. He is a high care needs child who is tetraplegic and suffers from post obstructive hydrocephalus and autonomic dysreflexia among many other issues. It's incredibly draining and difficult to care for your own child, because you know the procedures you have to perform on them can be invasive and painful but they are needed to keep them alive. Not only this, but there is nothing you personally can do to fix the problem, you have no control of his medical outcomes and you have to have faith and trust in your Spinal Paediatric team.

In terms of mental health, 90% (9/10) of those who strongly agreed that caring had impacted their mental health were lesbian, whereas 80% of those who agreed with the statement were bisexual/pansexual (4/5). One lesbian responded that she somewhat agreed with the statement.

Physical Health

Participants responded to the statement, ‘Caring has impacted my physical health.’ Responses to this question ranged from neither agree nor disagree (4/16), somewhat agree (2/16), and agree (2/16) through to strongly agree (8/16 or 50%). No one disagreed with the statement. Those who provided explanations for their answer pointed to lack of sleep, exercise or good nutrition (2 participants), the fact that if they faltered physically there was no one else to do the caring role (1 participant), health issues that resulted from caring (1 participant) and stress-related health issues that resulted from caring (1 participant).

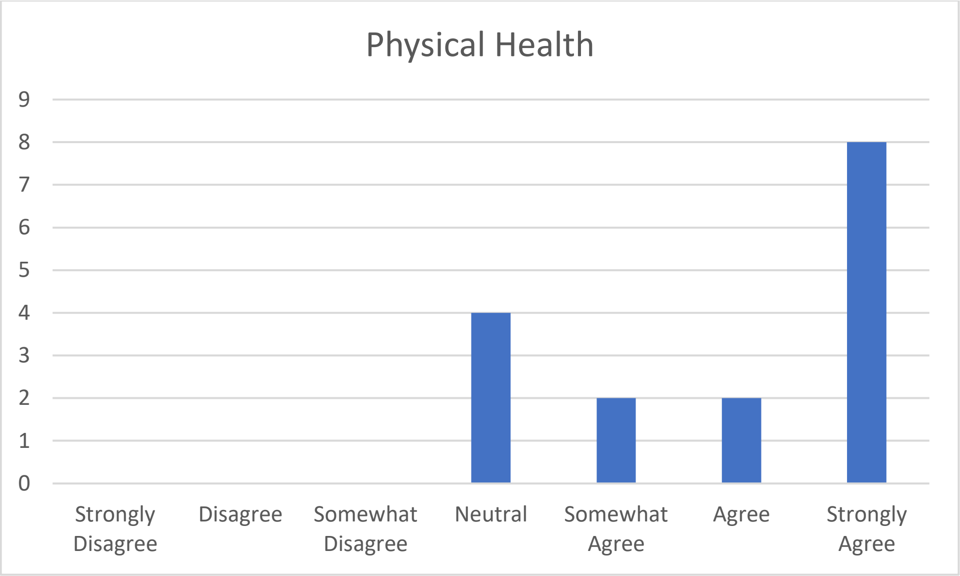

Figure 2. Number of participants and their responses to the statement, 'Caring has impacted my physical health'.

For example, Jamie (46, female, lesbian) strongly agreed and identified that lack of money or time to exercise had impacted her physical and mental health:

> Not having the money or capacity to exercise. Not having the money to get psychological supports for myself; therefore, I comfort eat.

Kissia (36, cisgender lesbian) also strongly agreed and acknowledged that caring for her mother, who had severe mental health issues, had led to restrictions on her ability to care for herself, as well as ongoing health issues:

> Sleep, time/access to exercise and nutritious healthy meals. From my childhood caring role my mother's mental illness was severe and I experienced abuse and neglect resulting in serious ongoing health issues including rheumatic fever.

Julie (55, cisgender and bisexual/pansexual) somewhat agreed, but acknowledge that if she had been solely responsible for her mother's care, she would not have managed physically:

> I was fortunate to be able to share caring responsibilities. I could not have managed the physicality of care on my own.

Soairse (47, transgender and bisexual/pansexual) neither agreed nor disagreed with the statement, and identified how hard she works to maintain her physical fitness, as well as her worry about it failing:

> In this case it is both positive and negative. The positive part is that I am the only fully functioning person in the house. I take my duty of care seriously. I spend time working on being physically fit, because if my wife falls, I have to pick her up, and I can't do that if I'm not fit enough for the task…if I get sick, if I break, we're automatically in trouble. There is no one else. The negative aspect to this is that I don't necessarily get to enjoy life normally, I'm 47 … I worry about the potential for going too far… There is no one else.

In terms of physical health, there was a slight tendency towards lesbian participants agreeing that caring had impacted their physical health (8/12 participants), whilst most participants who neither agreed nor disagreed with the statement were transgender or bisexual/pansexual (3/4 participants).

Financial Security

Participants responded to the statement, ‘Caring has impacted my financial security’. Answers to this question were more spread out, with 2/16 participants disagreeing or somewhat disagreeing. 14/18 (77.7%) of respondents agreed to some degree, and half (8/16) strongly agreed. Most respondents who provided an explanation for their answer identified their loss of income or associated benefits because of their caring duties (5 participants). Others talked about the loss of education or job opportunities (2 participants) or having to cut down on costs because of having a lower income (2 participants). Others mentioned having to work less hours (1 participant), the difficulty of caring and holding down a job (1 participant), and the costs of caring for children (1 participant).

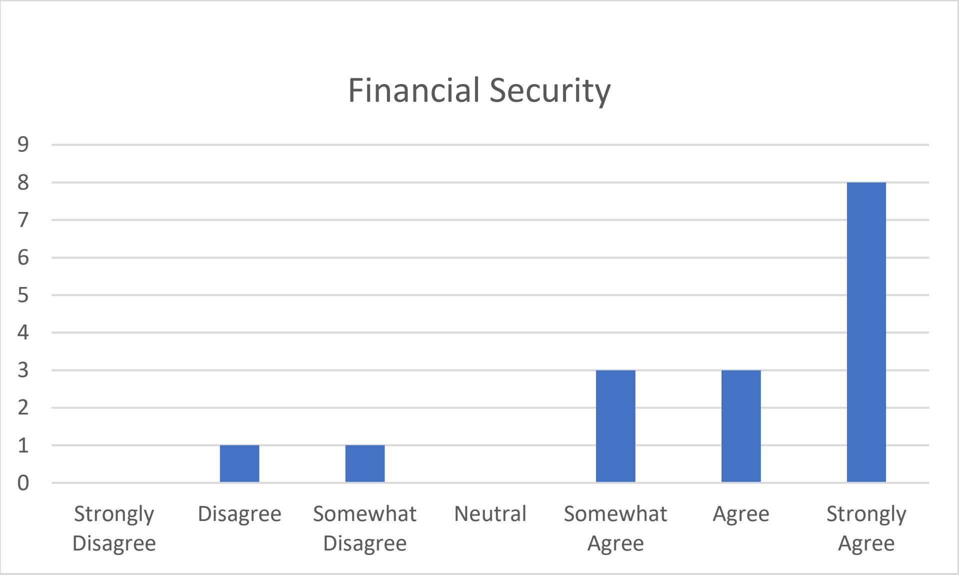

Figure 3. Number of participants and their responses to the statement, ‘Caring has impacted my financial security’.

Alana (57, cisgender, asexual lesbian) strongly agreed and identified the limits of being on a government parenting payment as well as the loss of superannuation payments due to her long-term caring role:

> I have only been able to work in the last three years. Parenting payment, which became jobseeker and even less, isn't great, and for all those years, I'm not accumulating superannuation, and so can look forward to even more poverty in my old age!

Soairse (47, transgender and bisexual/pansexual) strongly agreed and talked about leaving a well-paid job to care for her wife, which resulted in them cutting back on their standard of living:

> As my wife's condition deteriorated, we took everything we had and put it into our home, and thank God, because if it weren't for that we'd have failed a long time ago. We own our home; however, the support payments are quite poor and the DSP (Disability Support Pension) has not kept pace with the cost of living for a very long time. I had to effectively retire early from a well-paying IT career… I had to make a choice, and she is the most important thing to me. I left the career and began a new paired down life as her full-time carer.

Elisabeth (56, cisgender lesbian), also strongly agreed and identified that her caring role led to her working less hours:

> My choice to care to the extent I did meant that I had to work less hours as I simply didn't have the physical & emotional capacity to work more.

Jane (27, cisgender lesbian) only somewhat agreed with the statement, since her parents had financially supported her whilst she cared for her great aunt:

> I took time off work to care for my great Aunt, but I was lucky that my parents are in a financial situation where they could pay my bills during the time I spent helping. Their argument was that it was a lot cheaper than hiring a full-time night nurse, and more comforting for my Aunt.

In terms of identity groups, all transgender participants strongly agreed that caring had impacted their financial security. Other identities were mixed evenly across response options. However, with regard to those who were caring for a partner for 5+ years (two lesbian women and one transgender woman), all strongly agreed that caring had impacted their financial security.

Housing Security

Participants responded to the statement, 'Caring has impacted my housing security'. Just under half of our respondents disagreed (3/16) or neither agreed nor disagreed (4/16) with the statement, whereas 56.25% either agreed (4/16) or strongly agreed (5/16). Some who explained their answers pointed to the difficulty of affording housing payments when they had reduced work/income or were now solely responsible for them (4 participants). One participant lost their accommodation because of the mental health behaviours of the person they cared for. Others mentioned poverty, inability to save or reduced income and the impacts on their ability to afford accommodation or maintain it.

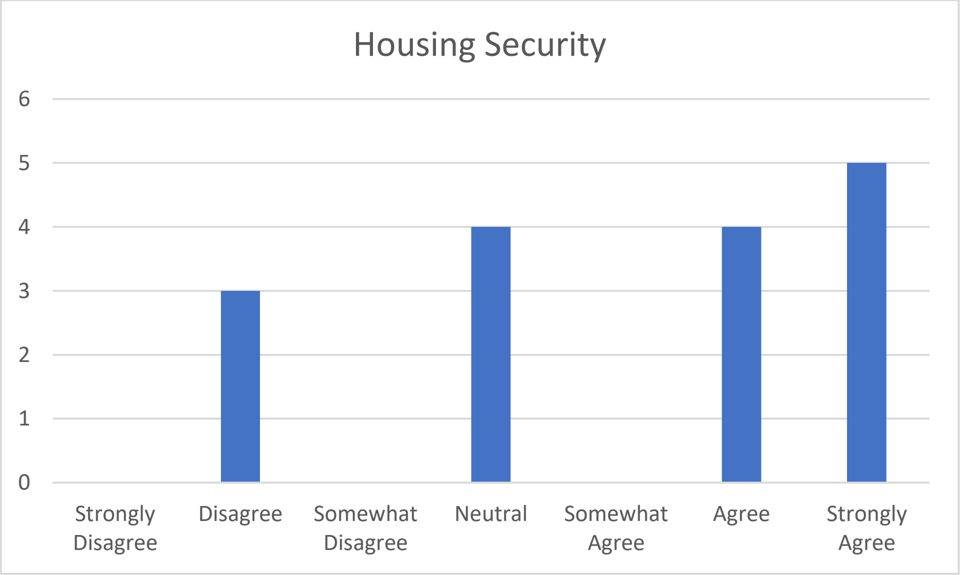

Figure 4. Number of participants and their responses to the statement, 'Caring has impacted my housing security'.

For example, Jamie (46, female, lesbian) expressed concern that she may not be able to afford the mortgage on her own much longer:

> With my partner not working as she was when we took on the mortgage, and interest rate rises, I don’t know how much longer I can afford the mortgage.

Kissia (36, cisgender lesbian) also strongly agreed and talked about losing accommodation at one stage of her caring career, and having to take full responsibility for the house payments at another:

> When I was younger, I lost accommodation (share house rentals) through my mother’s erratic behaviours. The worsening mental health of my ex-girlfriend meant she had minimal financial and daily-living contributions, placing full housing responsibility on me, which I struggled to cope with as my life stressors increased and (my) mental health worsened.

Soairse (47, transgender and bisexual/pansexual) agreed and identified that although they owned their own home, they still struggled with housing security:

> My partner and I own our house outright, so the roof over our head is not predicated on an income. However, the maintenance of the home is. As the cost-of-living crisis has really bitten harder and harder and taken increasing amounts of money for the same expenses, we are increasingly finding that our ability to maintain our property is compromised. I don't think we can stay here for much longer, and selling our home is a scary prospect in the market today, not least of all due to the trouble of trying to find a new place, while caring for someone who has a serious chronic illness. We're in trouble despite the enormous privilege of not having to manage a mortgage.

Elisabeth (56, cisgender lesbian) agreed because her reduced work hours and income impacted her housing security, as did Dee (59, cisgender lesbian) who said she had no extra money to save for housing.

In terms of identity groups, all transgender respondents strongly agreed that caring had impacted their housing security. Other identities were mixed evenly across response options.

Social Networks

Participants responded to the statement, ‘Caring has impacted my social networks’. All of our participants strongly agreed (2/16), agreed (10/16 or 62.5%) or somewhat agreed (4/16) with the statement. Three participants identified that caring left them with little energy for going out, and another three said that their caring responsibilities limited their access to social events or outings. Two participants said that their friends didn’t understand the limits on their ability to socialise and had dropped away.

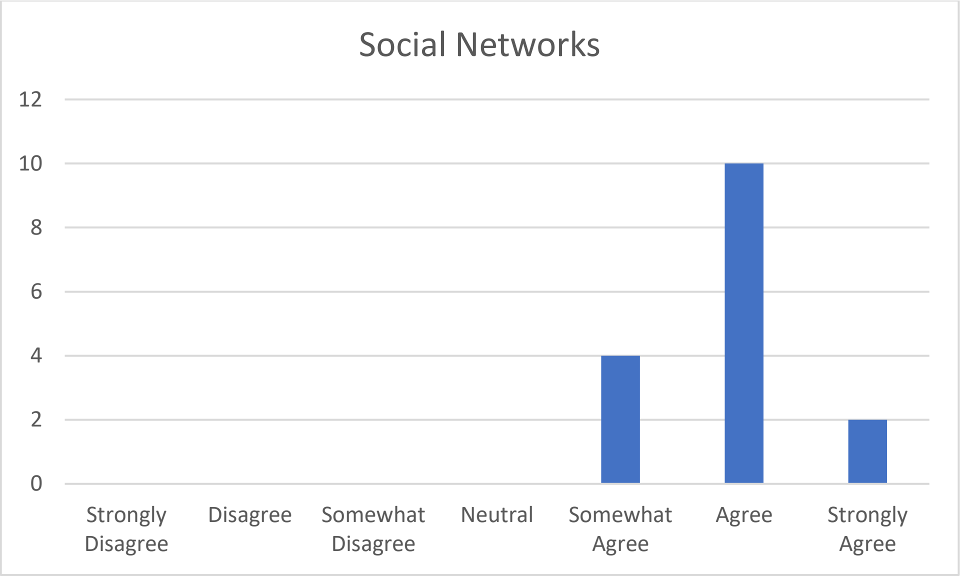

Figure 5. Number of participants and their responses to the statement, 'Caring has impacted my social networks'.

Pauli (59, transgender and lesbian) strongly agreed and identified her "Inability to get out and find friends and social relationships" as well as her "Inability to have other visitors at home" because of caring for someone with psychological disabilities. Ames (32, cisgender and bisexual/pansexual) said that there was "Not a lot of time to have a social life around a child who needs 24-hour care." Jamie (46, female, lesbian) also agreed and acknowledged that "We have lost a lot of friends who just don't get it." Julie (55, cisgender and bisexual/pansexual) somewhat agreed and explained, "There is only so much energy that we have. I live with disability and so choose between caring or going out."

In terms of social networks, there was a slight tendency towards lesbian participants strongly agreeing or agreeing with the statement that caring had impacted their social networks (9/12)[7], whereas bisexual or transgender participants were more likely to somewhat agree with the statement (4/5).

Support, respite, and additional supports that would have been useful

Table 1 (below), outlines the women's responses about where they received support or respite (if at all), the quality of the support that they received, and any additional supports that they would have found useful.

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[7] One trans participant strongly agreed and two bisexual/pansexual participants agreed with the statement.

Table 1: Where participants received support/respite from, the quality of the support received, and additional support(s) that would have been useful.

Participant	Family	Friends	Orgs	None	Quality	Additional Support Needed
Alana	X	X	X		When they were younger, DCP would arrange a camp for school holidays and a weekend respite once a month. All were pretty good, but it wasn't respite that I needed. After years of no contact from the mother, DCP sent my granddaughter (who is still with me) to visit her mother with no support counselling before or after. After she overdosed, DCP still did nothing to get her support. DCP have been a complicating factor in what already is/was a challenging situation.	Psychological counselling, long-term and regular. Any kid who goes into care carries trauma. DCP claim trauma-informed practice, but to get a psychology appointment is impossible.
Alva Ames	X	X	X		We have carers 2 hours in the mornings and 2 hours at night for all except Saturday mornings, we also have around 5 hours community respite which my son refuses to do. We also get a few hours here and there for school holidays and for his weekly physiotherapy but my son insists on one of the parents being there with him. The main respite I would get was on the fortnightly weekend visits he would have at his father's place.	Not to have to deal with the insurance company daily would be a wonderful respite! As my son gets older and does not want to be around family 24/7, he will require his own space as well as independence (i.e., he will need a live-in carer to be with him).
Anne Casey	X	X	X	X	My mother has a terminal lung disease affecting her ability to complete simple daily task. NDIS declined application. Aged Care agreed to assist with house maintenance, but with an out-of-pocket cost. Living on a pension mum could not afford the amount of support required. Which meant that instead of spending meaningful time with Mum, I had to assist daily with showering, cooking cleaning etc. the impact on my family life, physical health & mental health was significant. My experience with supports offered where negative.	Considering how time poor I was working, running a family, and assisting Mum twice a day every day, I would have liked connection to services to be a simpler process. I'd like the NDIS to review their standards for incurable diseases (we were refused funding). I work in the community services industry and even I didn't know where to get support for a person with a terminal and incurable disease. Decline is fast and services need to be available quickly. Assistance to get Mum to and from appointments would have taken some strain off. Support with filling in forms and connecting to available supporters would have been incredibly useful.
Dee Jane	X		X	X	Insufficient, costly and time consuming. Not gentle/caring, quite awkward about the situation, waste of money but better than nothing.	A night nurse being available. If the Silver Chain nurses had been available more frequently as opposed to 1-2 hours in the evening, it would have been very helpful (if they were able to do more and were trained better).
Julie	X		X		Helpful but take a lot of work to organise. Through palliative care we had an amazing nurse who provided support in the middle of the night, plus some counselling.	Having people to talk to who get it would be helpful.

Participant	Family	Friends	Orgs	None	Quality	Additional Support Needed
Kissia				X	I did not receive support or respite in my caring roles. My mental health care plans helped me to manage the impact of my caring role on me.	Long-term psychology services. Respite services and programs need to be provided after hours, as do therapy services. Access to funding to pursue education and pay bills. Psychoeducational programs are very limited/basic and are rarely offered after hours.
En	X	X			Minimal. Time to talk and debrief, some support with buying groceries occasionally.	The offer to take some of the burden or share it around. Suggestions of low-cost services that could provide support. Also connecting with people in similar scenarios.
Pauli				X		Financial support, social support.
Missy	X		X		The quality of the cleaners we used to have access to were good, however, that stopped when our father passed.	
Elisabeth	X	X	X		Although my Mum had a Level 4 ACAT package, it wasn't enough for use to keep her at home, which she and Dad would really have wanted.	Lots more support would have helped us keep Mum at home (e.g., carer support 4-6 hours per day to provide care, meals, respite). Overnight carers at home would have enabled Dad to get away for the occasional family weekend.
Wisteria			X		It was all very good, the staff at the respite centre were caring and supportive.	Family support would have been helpful.
Saoirse				X		Any.
Jamie	X				Mum gave me verbal support.	Financial counselling. Respite for me.

Overall, the most common source of support for our participants was family support (9/16 or 56.25%), followed by support from community organisations (8/16 or 50%). Friends provided support to 5/16 of our participants (31.25%) and 5/16 (31.25%) reported that they had no support whatsoever.

Six participants mentioned the word ‘respite’ in their comments in response to the two support/respite questions. Each woman had a different position in relation to respite.

- Kissia said that she did not receive any respite, but that if it were provided, after hours would have been most helpful to her.
- Alana said that she did receive respite from the care of her grandchildren, but that this was not what she really needed.
- Ames said that when her special needs child went to school, that was her respite, and it allowed her time to “deal with doctors or specialist calls, making sure all of his consumer materials were stocked up and managed along with dealing with lawyers and the Insurance Commission of WA…”.

Ames also said that they were offered community respite but that her son refused to participate. Other opportunities for respite were limited by his insistence that a parent be present. Ames' only respite was when her sone went to his father for fortnightly weekend visits.

- Elisabeth mentioned respite amongst a list of other supports that would have allowed her to keep her mother at home whilst she was ill and dying.
- Wisteria was very happy with the respite services that she received, and she felt that the staff were caring and supportive.
- Jane reported that the respite services that she received were "insufficient, costly and time consuming."

Regarding the quality of community organisation support received by participants, Wisteria was completely happy and said "it was all very good". Missy was also happy with the quality of the cleaning support that her family received whilst caring for her dad. Julie reported that the support she received was "helpful", but that it had been a lot of work to set it up. We know from her other responses that she was trying to juggle the care of her mother and full-time work.

Other participants reported that the support they received from community organisations was insufficient. Ames received regular daily support but said that she only really got respite when her son went to his dad's house fortnightly for the weekend; Casey reported that the support she received was limited and had associated out-of-pocket expenses; Elisabeth said that although her mother had been assessed for a Level 4 Aged Care Assessment (ACAT) package, it was insufficient to keep her Mum at home; and Jane said the support she received to care for her Great Aunt was insufficient and neither gentle nor caring. Alana reported that support she received from the Department of Child Protection was insufficient and that a lack of support at critical times made things worse for her and the grandchildren in her care. Part of her issue was being recognised as a relative because she was caring for her partner's biological grandchildren after her death. (5 insufficient and 3 happy-ish)

Most survey participants (12/16 or 75%) made suggestions about additional supports that would have been helpful to them. The most common suggestions were 'talking to people who understand' (3 participants) and better home help such as live-in support, overnight care, or assistance with caring, meals and respite (3 participants). Psychological counselling was suggested by two participants, and financial counselling was suggested by another two participants. Family support was suggested by one participant and psychoeducational support by another. Two participants felt that respite would have been of most help to them, and another two said that a simpler way to connect to services was needed. Two participants brought up the need for better funding or low-cost services, and one participant suggested that better service provision (such as support with physical care and getting her mother to appointments) would have taken the pressure off and led to more quality time for her and her mother.

Case Studies

Casey

Casey is a 45-year-old woman of Aboriginal or Torres Strait Islander descent, who identifies as lesbian. She cared for her mother, who was suffering from a terminal lung disease, 2-3 times daily for about eight months (her mother lived around the corner from her). Casey was living with her partner and children. Casey strongly agreed that caring impacted her mental and physical health. She also agreed that caring impacted her financial security and her social networks.

Casey's first challenge was finding appropriate supports. Casey is a community services worker with years of experience in disability and aged care, and was surprised that she didn't know where to get support for a person with a terminal and incurable disease. Even within her own organisation, she struggled to find help. She was also under a lot of time pressure because her mother's physical decline was swift, but applying for services was slow. She was turned down by the NDIS but aged care agreed to help with house maintenance, with an out-of-pocket expense. Casey said it took "forever" (six months) for the aged care supports to come through. Casey was left to assist her mother with daily showering, cooking, and cleaning, transporting her to her many appointments, etc.

> *I guess, when you're faced with a short life expectancy, it feels like a waste of time doing all of this processing of paperwork and phone calls and then you just go, oh stuff it, I'll just do it.*

Casey's main support was her wife, who took over parenting and allowed Casey to focus on her mum and keeping her job. However, the family and financial pressures were very real for Casey. She described that period as being "a roller coaster". Around the time that her mother became ill, Casey met her wife and her she moved in with her. They were starting a relationship and decided to get married before Casey's mum passed away, so that she could be there. Casey and her wife were began fostering a teenager with a lot of traumas in her background.

> *So, you know, trying to develop that relationship while still caring and grieving. The loss of mum was incredibly difficult.*

In addition to the family challenges, funds were tight. Casey reported that even with the aged care funding, they were required to pay $10 or $15 per hour to get supports. All they could afford was a support worker to come in and help with some cleaning. Towards the end of her mum's life, Silver Chain were coming in, but the personal care still fell to Casey.

> *Towards the end, Silver Chain would come in to do a standby and help her out. But like even emptying her commode and things like that, that was all me… It's a lot. It also changes your relationship a lot.*

Casey identified that her mum had been reticent about asking for help, and tended to prefer Casey doing much of her personal care. Casey pointed out that no one questioned that or said "she doesn't have to". Casey felt that it was expected of her as the only daughter. For Casey, there was grief about doing so much of the physical care, and not having the time or energy to spend quality time with her mother before she passed away.

> *I did explain to her that the time I spend with her could be used for something different, other than me doing her washing. I mean we could be having…an experience.*

The impacts of caring on Casey were enormous. She wasn't able to eat well or exercise, or simply have time for herself. She was under so much stress it affected her physically and impacted her asthma to the degree that she was hospitalised. At that time, she was hit with a double whammy - she was diagnosed with the same terminal lung disease that her mother suffered from. After her mother had passed away, Casey obtained mental health supports through her work EAP program and through the fostering agency (Casey was a foster parent as well). She reflected,

> *…now it's my life and now I know. It's hard because you know what's going to happen...It's an odd place to be, but I'll do what I can while I'm here.*

Casey reflected that providing care to someone is based on natural relationships, and that not everyone has them. Casey's advice to any other LGBT woman starting to care for someone is,

> *Start the process as early as you can. Start the process of contacting other organisations, and seeking help. Don't wait until you need it. I would probably also say, try not to do everything. Do try and delegate some of the care where you can.*

Casey also identified that having a support coordinator would have been incredibly useful in her caring situation. Someone who knew the system, where she could say what was needed and they could identify where to go for help. Someone with links into free services or volunteer services would have been ideal, Casey identified.

Jamie

Jamie is a 46-year-old female who identifies as lesbian. Jamie currently cares for her partner, who has multiple mental health disorders, that include extreme anxiety and acute episodes of psychosis. Jamie also cares for her elderly mother as required. For example, when her mother went in for an operation, Jamie moved in and cared for her as she recovered. Jamie has been caring for over five years, whilst living with her partner and her partner's child. Her only personal source of support is her mother, who provides verbal encouragement. She also gets indirect support from her partner's parents, who take their grandchild as much as possible. Jamie strongly agreed that caring has impacted her mental health, physical health, financial security, housing, and social networks.

Jamie mainly provides emotional and psychological support to her wife, and especially when her wife needs to attend appointments or interact with the world outside of their home. Providing this level of support in addition to running a charity and working full-time, leaves Jamie feeling overwhelmed and burnt out at times. However, Jamie said that the charity work "fills her cup" and helps her to keep going, plus Jamie feels she doesn't have a choice.

Jamie has had to let go of things like keeping the house and yard tidy to prioritise her relationship with her wife:

> *We make time every night, unless she's not travelling too well. But we have a routine at night where we might just sit and read together or I'll read and she'll watch telly, but we're doing it together…We're still holding hands or we could just be sitting there and having a cup of tea and chewing the fat. But we make sure we get that quality time every day.*

As a couple, Jamie and her wife have lost a lot of friends, who Jamie says, "Just don't get it". When Jamie's wife has a panic attack and they need to cancel arrangements at the last minute,

> *I'll ring them and say look we can't come I'm so sorry and then, after a third or fourth time, people get pretty jacked off. So, you know, we only have a few friends now.*

Jamie also reported that financially, things are tough. As the sole earner in the house, she has to make one wage stretch to cover everything such as the mortgage and bills. Jamie said that her partner was working when they took on the mortgage, but now she is trying to manage it on her own, and with interest rises, she doesn't know how much longer she can afford it.

Jamie and her partner are in the process of applying for a Disability Support Pension (DSP) and off the back of that, will apply for National Disability Insurance Scheme (NDIS) support. Jamie is looking forward to the support that this will hopefully provide, such as having help with cleaning the house, gardening, home maintenance, or grocery shopping.

Jamie did try and get some support for her mental health from a community organisation. However, she didn't find it helpful, and as a mental health professional of 30+ years, was unimpressed with the questions she was asked at times. Her work employee assistance program (EAP) was also a short-term source of support, but with limited sessions. She also found it hard to find a practitioner who was a good fit for her there. She decided that going private and getting her own psychologist was her best option.

Because Jamie and her wife are obviously a same-sex couple, they are more vulnerable to experiences of bias or prejudice when interacting with health or social services. Jamie said that their general practitioner (GP) is "absolutely amazing" and goes above and beyond to make them both feel supported and cared for. However, Jamie described her experiences with Centrelink as "the most troubling". Jamie has to take the day off to attend Centrelink appointments and to get her wife "mentally prepared", but her experience of attending was,

> *Oh, you just get these looks. And you know exactly what they're thinking… it's kind of a look of disdain and distaste… I think they don't even know that they're doing it. Um, sometimes I think it's their immediate visceral or gut reaction, and it just happens without them even realizing. It just washes across their face and you think wow you're a bit of an arsehole. But they're in positions of power over you. You know, it's the difference of $600 or not in the budget. So, you very*

> *well can't go, 'hey listen I just saw that look in your face. What's the problem?' Because they're just as likely to turn around and have you kicked out or something, you know?*

Jamie also reported experiencing some discrimination in health-based settings, particularly from culturally and linguistically diverse (CALD) staff and in religion-based organisations. She mentioned a time when her wife was an in-patient and the doctor didn't record her as a partner/wife, but as the next of kin instead. Jamie experienced that as, "a complete refusal to acknowledge me as the partner", without saying it overtly.

Jamie's advice to another LGBT woman carer is to "Look after your own health. Your own bit of mental health… In particular, because if you don't do that, you won't cope with anything." Her key recommendation for the research is to make sure that support workers and services are completely inclusive and that they don't just "talk the talk". Forms in particular need to be inclusive, which Jamie says is "the first indication of where this service is at". She also suggested that carer support groups needed to be inclusive, with LGBTIQA+ staff/participants because people who are allies "can't truly grasp the difficulties, because they haven't lived it."

> *You don't want to go to a group that's full of heterosexual people or cisgender people. No. Because you're less likely to share, which means you won't get as much out of it.*

For Jamie, that involves understanding that a lot of lesbian women have basic level trauma, and that they need a woman carer or service provider who is going to start with what their needs are.

Kissia

Kissia is a 36-year-old woman who identifies as lesbian. Kissia also identifies as the child of a parent with mental health issues (COPMI). She lives alone, but still cares for her mother, whose schizophrenia was undiagnosed when she was a child. Kissia also cared for an ex-partner for a year when her partner's mental health deteriorated. However, managing her partner's mental health and their daily living tasks ultimately ended the relationship. Kissia strongly agreed that caring had impacted her mental health, physical health, financial security, housing security, and social networks.

Kissia's main life challenge has been caring for her mother, whose undiagnosed schizophrenia impacted her safety and wellbeing from infancy (her father left before she was born). Kissia said that child protection, the education department, and the police were involved, but due to system issues and restrictions, little was done to support her. Her childhood was characterised by neglect, moving home regularly, missing school, and living on the streets, where she was exposed to abuse from other people. She cared for her mother from as early as she could remember:

> *…so I was caring for my mum with zero supports or initially awareness of what this issue was. So, I developed a caring role from infancy. I remember the time I first consciously became aware I had to care for her. I was only seven years old.*

Kissia pointed out that carer support groups tend to focus on adult carers. She wanted her story to be told to highlight the situation of children who care for adults, and their lack of legal standing as carers, combined with the immense responsibility of caring for an adult. As a child, Kissia looked after household things like making sure bills were paid, as well as emotionally supporting her mother (e.g., calming her when she was feeling paranoid or distressed). She felt that support groups didn't acknowledge the amount of caring she did, and said that it was hard to listen to parents talking about the challenges of caring for their child (care that she had never received). Her felt that she would have benefited from a more specific support group that focused on the needs of COPMI's.

Part of the caring challenge for Kissia was that her mother was undiagnosed for a long period. Because she didn't get involved with drugs or alcohol, was Caucasian, and highly educated (a professor with a PhD), she wasn't picked up as being an at-risk parent for some time. Kissia was well behaved, and managed to get herself to school, so she wasn't identified as being at-risk either. Kissia explained that even when issues were identified, support was not put in place for her:

> *Even when the police were involved, even when education services, child protection, all of them were involved… I was outright told by police I had to leave home for my safety because of it. I asked if I was going to be put into care and their response was … we don't have a place for you. But the conversations were …because I wasn't a problem child, it was just presumed that I would sort it out. Or [because] I was still trying to at some point go to school … they were … we know she's not at home, you're not eating, but you can get yourself to school. It's fine.*

Kissia's mother also refused to engage with services, which limited the amount of support available to Kissia. Because Kissia couldn't consent to services on her mother's behalf, she was left without help as a result.

The impacts on Kissia's mental health were profound. She said that the police forced her to leave home at 15 for her own safety. However, her mother's erratic behaviour continued to impact her. Kissia explained that she lost "everything" including jobs and relationships, because she continued to take responsibility for her mother. Kissia also identified that because she was raised by a schizophrenic, she had taken on her mother's paranoid world view. She also felt suicidal, but didn't act on it, "largely because I had a duty to my mother". At 19, Kissia's mental health was very poor, but she found a GP who was supportive, and who helped her to access a good psychologist through a mental health plan. Before that, people hadn't taken Kissia seriously because she was so intelligent and self-aware. With support and monitoring, Kissia continued to work full-time to support herself and her mother, and she started to reclaim her own wellbeing and establish boundaries with her mother.

As a young woman, Kissia also worked hard to provide a home for her mother, so that she didn't become homeless:

> *she cannot maintain housing in public housing, [and] does not engage in mental health housing, [and] cannot maintain private. So, I was cycling through putting out problems, paying lots of money,*

> *having to build relationships and convince the department not to follow their processes, which would evict her. So, in the end, my only solution was to buy her a house and know that it's going to be trashed and destroyed, which is exactly what's happening. But she is in the house I bought her, and she's stable.*

Prior to buying her mother a home, she had been paying for her mother's rent and clothing as well as putting herself through TAFE. Getting her mother diagnosed was something that Kissia also worked hard to achieve. This meant that her mother could receive a Disability Support Pension (DSP) and meet some of her own living costs. Kissia worked to establish some healthier boundaries with her mother, and to get her to take responsibility for some of her own bills and expenses, as well as the way that she interacted with Kissia.

Being raised by a schizophrenic also had negative impacts on Kissia's relationships. She said that she had relationships "that weren't so great". In her longer-term relationship, Kissia thought things were okay, as her partner's mental health issues (an eating disorder and borderline personality disorder) were well managed. However, her partner had a bad relapse and her mental health deteriorated. Kissia's partner stopped working and Kissia found herself working to support her partner as well as her mother, whilst studying for a Master's degree. When her girlfriend started to go out partying, getting drunk and sleeping around, Kissia ended the relationship.

An ongoing relationship stressor for Kissia was her mother's lack of understanding about her being in same-sex relationships. Whilst her mother appeared to understand at times, she would then ask Kissia when she was getting married again and what guy she was with. Kissia also found it difficult to get services to understand that the woman she was with wasn't just a friend, but was a partner. She had to argue for that woman's right to be with her when her mother was unwell or "going off". Kissia said that she had to come out again each time the worker caring for her mother changed.

Prior to being an adult, it was very difficult for Kissia to make friends and keep them, because of her mother's erratic behaviour, and because she had to move so often. Kissia identified that developing a good friendship circle in adulthood had been integral to her survival. She could call on her friends when she was upset, and they would help her identify when she needed more support:

> *…because of that friends group I can call them if I'm upset … we can catch up and spend time together or if I'm low they might just come over, or just [make] caring gestures … As in my friend, was the one that eventually said, I wasn't okay and asserted that I needed help. And because I have a good friend's group, I ask that they tell me if they notice things and I will listen to them. So, I've developed a very good friendship group where they can sometimes go, hey, are you okay?*

Kissia has learnt to reach out for help and support before her friends suggest it is needed now. Now Kissia prioritises her own well-being and tries to meditate at least 15 minutes per day, and do calming exercises at night. She also has a plan around how she manages her mother.

Kissia's advice to other LGBT women who are carers to be aware of their boundaries and their own mental health warning signs. She said,

> *They need to be okay themselves and need to prioritise that sometimes, which is super hard, I understand that. But you can't prioritize that if you don't even pick up on it. So, you need to pick up on it, and you need to connect and do things every day. You can't just wait for it to crash.*

Kissia's felt that this might be harder to achieve in the context of gay relationships, which she felt required a higher level of support and input because, "there's so many problems in the world that you want to stand by people a lot more". She said that this means you may have to work harder to hold "healthy dynamics" in the context of a same-sex relationship. Kissia also felt that it was important for health services to be understanding and supportive of gay relationships. She said it added stress to an already challenging situation to have to justify the presence of a same-sex partner when her mother was being treated.

Discussion and Summary

This section of the report will revisit the literature review and our research findings, and highlight areas of commonality, as well as any potential extension of the research literature on LGBT women carers.

Alba and colleagues (2020) found that lesbian women were significantly more likely to care for a family of origin member, and that just under a quarter cared for a relationship partner. Gay men were found to be more likely to care for a friend. In our study, half of our LGBT women participants cared for a related adult, and just over a third cared for a relationship partner. Only one participant cared for an unrelated adult. These patterns of care are consistent with those identified by Alba and colleagues.

Alba and colleagues also identified that just under half (42%) of their research participants had indicated they were caring for an LGBTI person. It is possible that our sample of carers had similar rates of care for LGBTIQA+ people, but this can't be confirmed definitively. We know that three lesbian women cared for their same-sex partners. It is not clear whether our bisexual/pansexual participants who cared for a partner were in same-sex relationships (which would make them more visible), or if their partners identified as members of the LGBTIQA+ community. It was similarly unclear whether our participant who cared for an unrelated adult was caring for another member of the LGBTIQA+ community. Based on our review of the literature, this is an important factor in identifying an additional layer of carer stress or strain.

Shiu and colleagues (2016) identified that LGBT people who care for a partner/spouse tend to provide more types of care and for longer They also experienced more financial strain than those caring for a friend. In our research sample, this finding was confirmed with regard to those carers who had been caring for a partner or spouse for 5 or more years, since all strongly agreed that caring had impacted their financial security. One participant who had cared for their partner for between 1 and 2 years and was currently caring, agreed that caring had impacted her financial security. One participant who had cared for a partner for less than twelve months, and no longer cared for them, somewhat disagreed that caring had impacted her financial security. Overall, our findings suggest that the amount of time that an LGBT woman has cared for her partner is related to how much financial strain they are likely to experience or report. Further research would be required to confirm this finding.

Shiu and colleagues (2016) also suggested that overall, those caring for a friend (unrelated adult) perceived less caregiving demands and experienced less stress. We had one participant (Pauli) that cared for an unrelated adult and they strongly agreed that their caring had impacted their mental health, along with the other domains that we surveyed. This carer was helping someone with psychological disabilities and they reported that "There is a constant minefield of behaviours and triggers to watch for. It is extremely wearying, and leads to a general lack of self-care". This experience did not support the conclusion reached by Shiu and colleagues. It is also possible that caring for someone with mental illness is more stressful than caring for someone with physical health problems. In that case, the type of caring entailed in the role is also relevant to caregiver demands and stress, in addition to the relationship with the person being cared for. This may be a fruitful avenue for future research.

Both Fredriksen-Goldsen and colleagues (2023) and Boehmer and colleagues (2018) identified that financial hardship was related to caregiver strain or emotional stress. This finding was confirmed in our sample, where all of the women who strongly agreed that caring had impacted their financial security also strongly agreed (7/9) or agreed (2/9) that caring had impacted their mental health. Of note, all three of our trans women research participants reported that caring had impacted their financial and housing security. However, the relationship between financial security and mental health was not the same when mental health was considered first. Although all of the women in our sample agreed with the statement that caring had impacted their mental health, not all agreed that caring had impacted their financial security. Assessment of financial strain is an important factor to consider when assessing caregiver strain, and is likely to be associated with emotional distress.

Alba and colleagues (2020) found that when lesbian women cared for another LGBTI person, they felt less supported, and reported lower positive mental health and physical health than lesbian women caring for a non-LGBTI person. These negative outcomes were attributed to exposure to stigma and marginalisation. Our study is limited in its ability to reach conclusions about the wellbeing of women caring for a member of the LGBTIQA+ community compared with those caring for someone in the non-LGBTIQA+ community. However, relevant themes emerged in the interviews that were conducted, that impacted both interviewees who had same sex partners.

Both Jamie and Kissia discussed discriminatory experiences within their carer roles. Jamie, who cares for her same sex partner, reported that there was a "a complete refusal to acknowledge me as the partner" when she accompanied her wife to hospital. She also noted that they both felt uncomfortable when attending Centrelink appointments, as they felt that Centrelink staff looked at them with disdain or distaste. Jamie worried that if she made a comment about the stares or looks, their Centrelink payments might be stopped. Kissia also experienced issues getting hospital staff to acknowledge that her partner had a right to be present with her when she was supporting her mother. She also mentioned the burden of needing to come out and identify her female companion as a partner repeatedly as staff members changed shift.

Both Jamie and Kissia strongly agreed that their caring roles had impacted every domain that we surveyed. Our findings lend support to Alba and colleagues' finding that caring for another LGBTI person can lead to experiences of stigma. In addition, having a same sex partner and caring for someone else can attract the same kind of negative attention. It is likely that LGBT carers who feel stigmatised by their LGBT identity in their caring role will experience more mental and emotional strain. However, other influences on mental health were identified by our survey respondents also.

These were multi-factorial and included things like being distressed by a person's declining health and impending death, dealing with government departments, having limited social contact or not having someone understanding to speak to, the intensity and pressure of the caring role, and other household or family stressors. Women reported feeling a range of emotions about their caring roles, ranging from grief, to frustration, and loneliness. Feeling drained, burnt out or exhausted were also mentioned by women in relation to their mental health.

Alba and colleagues (2020) suggested that lesbian women caring for an LGBTI person were significantly lower on positive mental health and physical health than lesbian women caring for a non-LGBTI person. Boehmer and colleagues (2019) found that LGB women carers were more likely to rate their overall health as 'fair' or 'poor' than gay and bisexual men who were carers. Our research was not able to make between group comparisons as these researchers did, but we were able to explore whether women who agreed that caring had impacted their mental health also indicated that caring had impacted their physical health. We found that of the ten women who strongly agreed that caring had impacted their mental health, all either agreed (2/10) or strongly agreed (8/10) that caring had also impacted their physical health. It is interesting to note that the majority of women who strongly agreed that caring had impacted their mental health were also lesbian (8/10 women).

The relationship between the mental and physical health was less strong for those who agreed (5 participants) or somewhat agreed (1 participant) that caring had impacted their mental health. The majority response what to 'neither agree or disagree' that caring had impacted their physical health (4/6) and the remaining participants either somewhat agreed (1 participant) or strongly agreed (1 participant). Those in the agree or somewhat agree group were evenly split between bisexual/pansexual women and lesbian women (3/6). In summary, it seems likely that women whose mental health is strongly impacted by their caring role will also experience physical challenges.

Based on the written comments that women made about how caring had impacted their physical wellbeing, there seem to be four key ways that caring impacted their physical wellbeing. One was having enough time for exercise and self-care. Second was the challenge of physical tasks involved in caring, such as lifting and turning a care recipient. The third was the impacts of caring (and stress) on the quality of sleep that a carer got, as well as whether they could effectively unwind and relax. Lastly, some women experienced stress-related health issues or physical health issues as a result of the ongoing strain of their caring role. These four areas indicate that the relationship between physical wellbeing and mental health is not always direct. Assessments around physical health need to include the support context of the carer, because women with more support are likely to have more time for self-care and exercise, will have help with physical care demands, and will likely feel less stressed by their caring (short term and longer term).

Having acknowledged the relationship between physical wellbeing and support, it is worth noting that many of our participants were not only providing care to someone; they were also trying to manage jobs and other family responsibilities. This is evident when we consider our three interview participants. Casey was living with a partner and children (including a foster child) and was caring for her Mum who lived close by. She was working full-time as well. Casey was attending to many of her mother's physical needs and strongly agreed that caring impacted her mental and physical health. Jamie was also living with a partner and her partner's child. She was working full time and doing a lot of voluntary community work. Jamie was her partner's primary carer and also cared for her mother whenever needed. Jamie strongly agreed that caring impacted her mental and physical health. Kissia was taking responsibility for her mother's wellbeing whilst working full-time in order to support both herself and her mother. She was trying to run her own household and have relationships as well as be there when her mother needed. Kissia also strongly agreed that caring impacted her mental and physical health. Assessment of carer strain needs to take into account all of the other things that women are doing around their caring roles, as well as the amount of support or assistance available for caring itself.

Fredricksen-Goldsen and colleagues (2023) suggested that LGBTQ caregivers may be less likely to request respite or support services because they anticipate experiences of discrimination. Similarly, Barrett and Camini (2015) reported that 28% of their survey participants delayed access to services because they feared discrimination. This research study did not directly ask LGBT women carers whether they feared discrimination when trying to access services and for some participants this may not have been relevant because they were not readily identifiable as LGBT. This was likely the case for those caring for a relative, or those who were single; which was the majority experience for those who took part in this research. Discrimination was experienced by those in same sex relationships within our research sample, as discussed above.

However, our survey and interview data were helpful in identifying some reasons why women had not accessed adequate support or respite care. Casey identified that although she was a community services worker with years of experience, she was surprised how hard it was to find support, even within her own organisation. Casey was also under time pressure because her mother's decline was so swift, and processes for accessing support were effortful and took a long time to be realised. Kissia had difficulty accessing support as the carer of a parent with mental illness. She was not recognised as an authority for her mother, and was too young to be recognised as a carer. When she was old enough to access support, it was often unavailable to her as a full-time worker trying to support both herself and her mother (i.e., the support was only available during business hours). Jamie only had the support of her mother and found that organisational supports such as her workplace EAP programme were inadequate.

Our survey respondents also experienced barriers around being able to afford support, navigate access to services, and deal with service providers. We know that just under a third of our survey participants reported that they received no support at all and many received support from family (9/16) or friends (5/16). Only half of our participants reported receiving support from community organisations and there were mixed experiences regarding the quality of that support, with only one person reporting that the support was excellent. Likewise, only one person reported that the respite service that they had received had been a helpful experience.

Support has emerged as an area of intervention that would make a big difference to our research participants. Support includes the woman's social networks as well as the availability of formal supports. All of our participants indicated that caring had impacted their social networks to some degree. Similar to self-care, time and energy to go out and socialise was depleted for some of our participants, whilst others noted that their caring responsibilities made it hard to access social events. Two participants pointed out that people around them didn't really understand the social challenges of being a carer, and as a result their social connections slipped away. In addition, professional supports may also be lacking. Our literature review identified that LGBTIQA+ carers may be offered less support in their caring role by front-line social and health workers, and that their care recipient often had poor access to most services. Many of our research participants indicated that support was not forthcoming, or was inadequate to their needs, or was an additional stress.

Our three interview participants made recommendations for the kinds of supports that would have been useful for them, and other LGBT women. Casey acknowledged that not all women have the natural relationships that would provide support whilst caring. She thought that a good support coordinator would be very helpful in finding appropriate supports in a particular caring scenario, and especially links to free or voluntary services. Since many of our participants reported financial strain, links to low-cost or free services would be helpful in reducing both financial and emotional strain.

Jamie's recommendation was that support workers and service providers that are engaged are 'completely' inclusive (not just tokenistic), including inclusive forms and practices. Jamie recommended an LGBT support group for women carers, where they would be more likely to have experiences in common, and to share how they were coping. In addition, Jamie wanted these groups to be trauma-informed, in acknowledgement that "a lot of lesbian women have basic level trauma, and that they need a woman carer or service provider who is going to start with what their needs are". Kissia also recommended that health services have a good understanding of gay relationships and implied that supports, particularly out-of-work-hours supports, would help LGBT women carers to look after their mental health. For Kissia, mental health and wellbeing were a priority.

Key Findings & Recommendations

1. Any assessment of the impact of caring on LGBT women carers should take into account other demands that the woman is managing (e.g., work, other family commitments), as well as their social context (e.g., supportive family/friends, and access to organisational supports).

   Service providers need to take into account the extraneous demands and the social context when assessing the support needs of LGBT women carers.

2. LGBT women who care for a partner for 5+ years are likely to experience considerable financial strain, and to need financial assistance.

   Assess the financial circumstances of any LGBT woman who is caring for a partner, and where appropriate provide financial support.

3. LGBT women carers who are under financial strain will also likely need emotional supports, due to the likelihood of emotional strain co-occurring. Transgender women carers are potentially at higher risk in this area.

   Where financial strain is experienced by LGBT women carers, provide both physical and emotional supports.

4. All LGBT women carers are likely to experience mental health challenges as carers, and need appropriate mental health supports.

   Don't wait for LGBT women carers to ask, they all need culturally appropriate mental health supports.

5. Since all of our participants reported that caring impacted their mental health, caring for a care recipient with mental health issues may be particularly taxing. This is an area for further exploration.

   Conduct more research that explores whether caring for a care recipient with mental health issues adds additional strain to LGBT carers.

6. Medical and social organisations that provide support to LGBT carers, or care recipients who are LGBT, need to have engaged comprehensively with cultural safety and trauma informed practices that serve LGBT people.

   The Department of Communities could ensure that LGBT cultural safety is embedded in social services organisations that provide services to carers or care recipients. Ideally the Department of Health (WA) would do likewise.

7. Our research participants reported experiencing difficulties accessing appropriate services and navigating service provider processes.

   Consideration should be given to care coordinator positions, which link LGBT women carers with appropriate service providers (especially culturally safe providers), and particularly low cost and voluntary services. Ideally the Commonwealth Department of Health would ensure that its Carefinder program staff are appropriately trained in cultural safety.

8. A key way to ameliorate the strain experienced by LGBT women carers is via social supports. *Provide multi-faceted social supports that include health promotion campaigns that raise awareness about carer needs, as well as support groups that are specifically for LGBT carers and held out-of-hours, and perhaps online (for ease of access).*

9. Another key way to ameliorate the strain experienced by LGBT women carers is to provide practical supports that allow them to take care of their own needs; especially physical needs such as self-care, relaxation, and exercise.

   Reach out to LGBT women carers and offer them ways to participate in self-care and physical exercise that are culturally safe.

10. LGBT women carers who care for an LGBTIQA+ care recipient need additional levels of support and advocacy, due to discriminatory experiences or the fear of experiencing bias, prejudice or discrimination from service providers.

    Provide advocacy services specifically tailored to LGBT women carers who care for an LGBT care recipient.

Study Limitations and Future Directions

This research study included a very small sample of LGBT women carers. More intensive and targeted recruitment strategies would be needed to attract a larger, more representative sample. Of the 16 women who completed the survey, three returned for interview and all were lesbian. Ideally, other identity groups would have been represented in the in-depth interviews also. Payment of interview participants could be considered as a way to attract more women to participate in an interview, considering that the target group is time-poor and often financially stretched.

There are two main areas that the survey could have asked about that would have provided better insights into the experiences of LGBT women carers. Firstly, the survey could have asked women to identify if their care recipient was a member of the LGBTIQA+ community. If that was the case, a good follow-up question would have been to identify the gender of the person being cared for, to identify same-sex relationships in addition to those who identified as transgender (these groups are more visible and are likely to attract more discriminatory responses from service providers). Secondly, the survey could have explicitly asked women to report any discrimination that they experienced as LGBT carers.

Six main areas that warrant further research emerged from this study:

1. It is important to identify LGBT women who are caring for another LGBTIQA+ person to explore any additional carer stress or strain that occurs.
2. Further research would ideally take into account the amount of time that an LGBT woman has cared for her partner to fully explore any associations with financial strain. Our prediction is that financial strain increases with the length of time a woman has cared for her partner.

3. Further research could explore whether caring for someone with a mental illness is associated with more stress and strain than caring for someone who is physically ill.
4. A larger sample of transgender women carers would help to confirm whether financial strain is a common experience for this group of carers.
5. The relationship between mental health and physical health could be explored in more depth, to identify pathways between poor mental health and poor physical health as well as identifying women carers at higher risk of poor physical health.
6. Further research on factors that contribute to carer strain (e.g., working commitments, responsibility for other family members) could assist with the development of a checklist that helps identify LGBT women carers who have higher support needs.

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Appendix One: GRAI's LGBT Carers Research Poster

Are you a Lesbian, Bisexual, or Transgender Woman Carer? (past or present)

GLBTI Rights in Ageing (GRAI) has been supported by the Department of Communities Women's Grants for a Stronger Future to undertake some initial research into the support needs of Lesbians, Bisexual and Transwomen who are carers (paid or unpaid).

Take our survey here

GRAI

GLBTI Rights in Ageing Inc.

https://bit.ly/LBTCarer