

**LGBTQ+ OLDER CARERS: AN EXPLORATION OF THEIR HEALTH AND SOCIAL SUPPORT NEEDS**

**WREXHAM UNIVERSITY**

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|  |  |
| --- | --- |
| **Project Team** |  |
| Dr Joanne Pike Dr Joy Hall  | Acting Associate Dean Enterprise, Partnerships and EmployabilityFaculty of Social and Life Sciences |
| Dr Joy Hall | Visiting Professor (Nursing)Faculty of Social and Life Sciences |
|  Dr Nicki Lloyd-Jones | Senior Lecturer (Nursing)Faculty of Social and Life Sciences |
| Ms Justine Mason | Senior Lecturer (Mental Health and Wellbeing)Faculty of Social and Life Sciences |
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**Project Based at:**

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| **Faculty of Social and Life Sciences,** **Wrexham University, Mold Road,** **Wrexham, LL11 2AW** |

**EXECUTIVE SUMMARY**

**Project Title:**

**LGBTQ+ older carers: An exploration of their health and social support needs**

**Background and Rationale:**

It is estimated that 5.7 million adults are currently providing informal care to individuals aged 50 and older in the U.K. (ONS, 2021). Whilst in Wales there are an estimated 370,000 unpaid carers of all ages. It is estimated unpaid carers and families provide 96 per cent of the care in Wales, enabling vulnerable, sick and disabled people to maintain their independence and continue living at home (Carers Wales, 2023). Whilst 33% of the population look after, give help or support to family members, friends, neighbours and others, an increase from 29% in 2019- 2020 (Welsh Government, 2021, Carers Wales, 2023).

Current data (ONS,2021) demonstrates that 3.2 % and 0.4% of the UK population respectively identify as lesbian, gay or bisexual and transgender, equating to 1.5 million people. Whilst in Wales, this was 3% and 0.4% respectively, equating to approximately 77,000 people (ONS, 2023). Whilst there are no clear statistics on Lesbian, Gay, Bisexual or Transgender (LGBT) unpaid carers, the Office of National Statistics (ONS) calculates this figure at 1.5% of the population (Based on the estimates from Stonewall (2017) that 3.7 million people in the UK are LGBT, Carers UK estimates there are 390,000 LGBT unpaid carers in Britain.

The majority of the LGBTQ+ specific research and studies have been conducted in either the US or UK, with a dearth of work being undertaken within a Welsh context. However, over recent years the Welsh Government has been working to ensure that moving forward, Wales is a healthier and inclusive country. As such a plethora of acts and policy documents have been brought forward, including ‘Well Being of Future Generations Act’ (2015), ‘A Healthier Wales: Our Plan for Health and Social Care’(2021) and the recent ‘LGBTQ+ Action Plan for Wales ’ (2023). These have identified and recognised the unique issues faced by LGBTQ+ communities, including those encountered within the health and social care settings. Included in the LGBTQ+ Action Plan for Wales there is an action point stating, “Understand and improve the experiences of LGBTQ+ people in the health and social care sectors”. Furthermore, it appeared that no published work has been previously undertaken to explore the needs of LGBTQ+ older carers in North Wales. Therefore, a small study was undertaken by members of the nursing team, together with external partner organisations to begin to address this lack of information.

**External partners:**

Body Positive Cheshire & North Wales. (BPCNW), Unique Transgender Network North Wales, North & East Wales Carers Information Service (NEWCIS), Pride Cymru, Equality & Inclusion Department Betsi Cadwaladr University Health Board (BCUHB) - Advisory only.

**Overarching project aim:**

The project aimed to further explore and illuminate the social care and support needs of LGBTQ+ older carers in North Wales. It is anticipated that the project will contribute to the development of interventions with this marginalised population. Thus, helping shape future social care services, policies and research that will ensure care is welcoming for all people.

**Research Design and Methods:**

An online questionnaire, directed towards older LGBTQ+ carers (50+ years) was hosted by the JISC online survey site, this was widely advertised via the University’s social media outlets, relevant local LGBTQ+ groups (both Facebook sites and other social media mediums) together with our partner organisations own contacts and communication systems. The questionnaire was mixed methods with both quantitative and qualitative questions. And was scrutinised utilising both quantitative and qualitative methods.

**Findings:**

A small sample had been anticipated due to the relatively small LGBTQ+ community in north Wales, together with the narrow demographic focus of the research participants. Overall, 10 participants took part in the study, the majority of these identified as lesbian and between the ages of 55 – 64 yrs. With only one respondent identifying as transgender.

Not surprisingly, the lives of both the person being cared for and the carers had been drastically, negatively impacted by their illness/disability. With the majority identifying multiple sources of stress, including loss of employment, exhaustion from the physical aspects of caring, loss of their own life, social isolation and a worsening of their own mental health.

When exploring the potential impact of their LGBTQ+ identity on their caring role and interactions with the care systems, 50% of the participants had negative experiences with both agencies and care staff.

The main problem identified was the dominance of heteronormative practice by staff. This meant that the carers were repeatedly having to ‘come out’ to care staff – which they found added to their stress and exhaustion.

A number of themes were identified by the participants which they would find useful in being supported in the caring role namely:

* The provision of LGBTQ+ sensitive care and less assumed heterosexuality by care staff
* More frequent visits by care staff
* A listening ear and greater understanding from society
* Easier navigation through the health and social care systems
* More financial help and advice***.***

**Conclusions**

This study reinforces and informs literature on LGBTQ+ aging and considerations given to the lives and needs older LGBTQ+ carers. Furthermore, the main areas of concern that arose in this study have implications for practice and the policies that inform them.

The experienced described by the older LGBTQ+ carers in this study very much reflected the experiences of older carers generally and those previously identified within the LGBTQ+ carers specific literature. Primarily around the devasting consequences on the lives of both the carer and the person for who they are caring of ill health and disability. This impacted on all aspects of these people’s lives and often leading to great stress, social isolation, financial loss and increased problems with their mental health. Added to this is feeling of the ‘loss of self’, becoming invisible as a person, simply becoming the carer and no longer a person in their own right. The picture given is one of people who are really struggling with the burden of care, often feeling unsupported by the health and social care services and by society in general. Feeling lost whilst trying to navigate their way through complex systems whilst trying to get the care and support needed by both their loved one and themselves.

Added to this ‘general burden’ the respondents in the study identified that they felt an extra layer of discomfort as they frequently experienced heteronormative practice from the staff within health and social care service/agencies. They felt this was necessary, in order to have the nature of their relationships validated, to have to ‘come out’ to the staff multiple times this being experienced at a time of exhaustion and great vulnerability. The respondents identified the need for health and social care staff to provide LGBTQ+ sensitive care. They also identified a need for greater understanding of their situation by society in general and also from members of the LGBTQ+ community.

**Recommendations**

* A larger scale exploration of the care and support needs of older LGBTQ+ carers across Wales. This could be achieved as part of the research component of the Welsh Governments LGBTQ+ Action Plan for Wales (2023).
* The outcomes of this study be made widely available to health and social care providers and carers support agencies, to help shape policy and practice.
* Develop further and implement staff awareness training particularly for staff working in social care and carer support agencies. Training to provide examples of lived experiences and concrete examples of best practice.
* Wider dissemination and adoption by care and support agencies of the existing LGBTQ+ Carer support toolkits (Carers Wales & Cymru Pride, 2017, Carers UK, 2023).
* Development of LGBTQ+ older carers specific support groups and resources, both face to face and online.

Both the UK and Welsh governments have taken important steps in the last few decades to improve the social conditions in which LGBTQ+ persons age. Indeed, recently the Welsh government has set out its vision to make Wales the ‘most LGBTQ+ friendly nation in Europe’ (Welsh Government, 2023). In order to make this vision a reality, a lot of work still needs to be carried out to create social environments, health and social care systems that are inclusive of diversity and able to appropriately support a diverse aging population.

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**Background & Rationale**

It is estimated that 5.7 million adults are currently providing informal care to individuals aged 50 and older in the U.K. (ONS, 2021). Whilst in Wales there are an estimated 370,000 unpaid carers of all ages. It is estimated unpaid carers and families provide 96 per cent of the care in Wales, enabling vulnerable, sick and disabled people to maintain their independence and continue living at home (Social Care Wales, 2017). Whilst 33% of the population look after, give help or support to family members, friends, neighbours and others, an increase from 29% in 2019- 2020 (Welsh Government, 2021, Carers Wales, 2021).

While caregiving is often a necessary and common social role, it negatively affects the physical and emotional health among caregivers through greater physical strain, higher prevalence of disease and disability, increased emotional stress, and higher rates of stress and depression (Carers UK 2022)

The interwoven nature of financial strain, social isolation, and barriers to accessing support creates a multidimensional cycle of burden such that caregivers’ physical and psychological health are shaped by a wide variety of complex and often interrelated factors (Fredriksen-Goldsen, Jen & Emlet et al, 2022). For example, caregivers report more negative physical and psychological outcomes, which have been found to be associated with the high demands of care provision (Achilike et al., 2020, Carers Wales, 2022).

These experiences are commonplace, a recent national survey (Carers Wales, 2022) found that many carers are struggling with poor mental and physical health. Nearly a quarter said their physical health was bad or very bad (24%) and 34% said their mental health was bad or very bad. Nearly a third of carers (32%) said they felt lonely often or always. Although carers are providing many hours of support to the person they care for, few are taking a break from caring, resulting in tiredness and, in some cases, exhaustion and burnout. 42% of carers haven’t taken a break from their caring role in the last year (Carers UK,2022)

 While we have gained considerable knowledge about caregiving in the UK and its impacts on caregivers, research in this area has focused primarily on heterosexual and cisgender populations. Unfortunately, to date, there has been a dearth of information that examines specific issues for LGBT unpaid carers in accessing and receiving health and social care.

Current data (ONS,2021) demonstrates that 3.2 % and 0.4% of the UK population respectively identify as lesbian, gay or bisexual and transgender, equating to 1.5 million people. Whilst in Wales, this was 3% and 0.4% respectively, equating to approximately 77,000 people (ONS, 2023). Whilst there are no clear statistics on Lesbian, Gay, Bisexual or Transgender (LGBT) unpaid carers, the Office of National Statistics (ONS) calculates this figure at 1.5% of the population (Based on the estimates from Stonewall that 3.7 million people in the UK are LGBT, Carers UK estimates there are 390,000 LGBT unpaid carers in Britain.

Research suggests that lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) caregivers experience greater loneliness, financial strain, and poorer health than non-LGBTQ+ caregivers (Anderson & Flatt, 2018, Anderson, Flatt, Jabson Tree et al, 2021, Carer UK, 2022). As a marginalized population, caregivers of LGBTQ+ older adults face distinct challenges that may impact their ability to provide and access adequate and inclusive care for their care recipient, as well as affecting their willingness to access support services available for informal caregivers. For instance, many LGBTQ+ caregivers experience social support challenges, such as being more likely to live alone, not have children, and being single. Often, caregivers of LGBTQ+ older adults cannot rely on the care recipient’s biological family to assist with care, as many were rejected by family who were not accepting of their sexual orientation and/or gender identity (Anderson,Flatt, & Jabson Tree et al, 2021) . LGBTQ+ older adults experience higher risks of disability, and LGBTQ+ caregivers and persons for whom they are caring, commonly experience discrimination when seeking health care and other aging-related social services (Anderson,Flatt, & Jabson Tree et al, 2021, Fredriksen-Goldsen, Jen & Emlet et al, 2022). LGBTQ individuals experience caregiving in unique ways when compared to their heterosexual and cisgender counterparts (Fredriksen-Goldsen, 2007). While the general population is most likely to provide care to an adult relative, LGBTQ older adults are more likely to provide care to a friend or partner, or someone with whom they do not share a legally recognized relationship (Croghan et al., 2014).

Qualitative studies and literature reviews have found that LGBTQ caregivers face unique risks—they have battled invisibility and insensitivity in mainstream caregiving support services and often lacked legal protections for their relationships (Muraco & Fredriksen-Goldsen, 2014). Historical forces such as prior experiences with discrimination inform fears of negative treatment, which in turn shape current willingness to access formal caregiving services and supports, added stress in transitions in care, and fear of disclosing one’s sexual orientation to providers (Butler, 2017; Cloyes et al., 2018; Di Lorito et al., 2021). Caregivers in these communities also have differing social networks and supports and are likely to depend heavily on LGBTQ communities and families of choice in the place of formal services (Knauer, 2016). Such challenges may be more pronounced among LGBTQ older adults of colour and individuals facing financial insecurities, making their care access situations particularly fragile or tenuous (Butler, 2017; Jones et al., 2018).

Furthermore, Policy Bristol (2017) and Hafford-Letchford et al (2018) showed that the needs of LGBTQ+ people in social care settings are not met. Whilst Westwood (2018) found that older LGBTQ+ people were more vulnerable to abuse and less likely to report it.

The majority of the LGBTQ+ specific research and studies have been conducted in either the US or UK, with a dearth of work being undertaken within a Welsh context. However, over recent years the Welsh Government has been working to ensure that moving forward, Wales is a healthier and inclusive country. As such a plethora of acts and policy documents have been brought forward, including ‘Well Being of Future Generations Act’ (2015), ‘A Healthier Wales: Our Plan for Health and Social Care’(2021) and the recent ‘LGBTQ+ Action Plan for Wales ’ (2023). These have identified and recognised the unique issues faced by LGBTQ+ communities, including those encountered within the health and social care settings. Included in the LGBTQ+ Action Plan for Wales there is an action point stating, “Understand and improve the experiences of LGBTQ+ people in the health and social care sectors”. Furthermore, it appeared that no published work has been previously undertaken to explore the needs of LGBTQ+ older carers in North Wales. Therefore, a small study was undertaken by members of the nursing team, together with external partner organisations to begin to address this lack of information.

**Project Aims:**

1. To explore the health and social support needs of LGBTQ+ older carers across North Wales.
2. To evaluate the robustness of the online questionnaire developed for the project.
3. Make recommendations for any amendments in questionnaire design and delivery, to inform future larger studies in the identified area.

(For the purposes of the project ‘health’ was taken to mean the healthcare needs of the individual).

Therefore, the project aimed to further explore and illuminate the social care and support needs of LGBTQ+ older carers in North Wales. It is anticipated that the project will contribute to the development of interventions with this marginalised population. Thus, helping shape future social care services, policies and research that will ensure care is welcoming for all people.

**Research Design and Methods**

***Data collection***

Due to the newness of the research area, it was not possible to use an existing, validated questionnaire. Therefore, drawing from the existing literature, a qualitative questionnaire was designed. In addition, due to the nature of the population of North Wales, the questionnaire was made available bilingually. The online questionnaire, together with participant information and helpful/help organisations and contact details was made accessible to participants on the JISC online survey platform. Furthermore, a paper-based questionnaire was made available, for those participants without easy computer access or skills.

The project team worked in partnership with the following LGBTQ+ and social care organisation across North Wales:

Body Positive Cheshire & North Wales. (BPCNW)

Unique Transgender Network North Wales

North & East Wales Carers Information Service (NEWCIS)

Pride Cymru.

Equality & Inclusion Department Betsi Cadwaladr University Health Board (BCUHB) - Advisory only.

Ethical approval was given by Wrexham Glyndwr University’s research ethics committee.

***Sample***

Initially, the project team anticipated a purposive sample of 20 participants. To be recruited through the promotion of the project and access to the questionnaire by both the partner organisations via their social media outlets and newsletters. And Wrexham University’s internal and external media and social media outlets e.g., Tweeter and Facebook. In addition, the information was widely cascaded via numerous LGBTQ+ Facebook sites across North Wales.

***Data Analysis***

The questionnaire was subject to a combination of qualitative descriptive analysis, to produce descriptive statistics, utilising the JISC survey platform statistics packages. Whilst the free text sections of the questionnaire were analysed using Braun and Clarkes (2006) model for thematic analysis. The researchers examined all transcripts independently to identify the emergent main themes and subthemes, and to establish consistency.

Demographic data included age, sexual orientation and gender identity of both the carer and the care recipient and the carers relationship to the care recipient. Together with the nature of the care recipient’s ill health and any health problems the carer themselves was experiencing.

***Reliability and Validity***

The controversies surrounding the issue of rigour in interpretivisit research have been highlighted in the literature (Caelli 2000; Le Vasseur 2003). The positivistic concepts of reliability and validity are not appropriate for judging qualitative work as these criteria presuppose that there is one single true account of social reality. Instead, the criteria of reliability, dependability and transferability (Silverman 2011) were considered to provide a useful assessment of the rigour of the ways in which data were collected and analysed.

***Ethical approval***

All research projects include some ethical issues and dilemmas and there is now a considerable literature on the ethics of research which includes specific reference to vulnerable populations (Zion *et al.* 2010; De Haene *et al.* 2010). Jacobsen and Landau (2003) suggest that the question of whether the research is needed is too infrequently asked, which can seriously undermine the ethical position of a study. The impetus for this study arose from the researcher’s growing awareness from a number of professional and social contacts, who had expressed their increasingly concern about the situation and plight of older LGBTQ+ carers they saw amongst their friends. This was particularly the case in terms of the health and social care help and support these individuals and couples were experiencing. Thus, the research was a response to an expressed need, from the group who were the focus of the study. The sensitive nature of this study meant that the ethical implications of the research were an important consideration. Although designed for clinical studies, the ethical principles as outlined by Beauchamp and Childress (2009) proved helpful, as did work by Seedhouse (2009) and Mauthner *et al.* (2002). These were applied by:

* Gaining approval from the research ethics committee Wrexham Glyndwr University (WGU).
* Utilising the data in a manner that complied with the Data Protection Act.
* Ensuring that all potential participants knew that they had the option to participate or not in the study.
* Ensuring that all potential participants knew that there was no connection between this study and the services individuals received from the health and social services or other agencies, and that non-participation would not adversely affect service provision.
* Ensuring that all potential participants knew that there was no promise of additional resources or help following completion of the study.
* Guaranteeing that all information would be treated in confidence and that no individuals would be identifiable in the final report.
* Ensuring that all information provided would not be utilised for purposes other than those identified as appropriate to the study.
* Guaranteeing that all questionnaires would be securely stored, and destroyed 5 years post completion of the study, as per WGU policy.
* Ensuring that all participants knew their participation was purely voluntary.
* Ensuring that all participants were made aware that as the online questionnaire would not allow the project team to access any participant details, any reporting of concerns about potential or actual abuse of the vulnerable older person could not be reported by the project team. Therefore, details of appropriate reporting and contact details would be provided to participants on the questionnaire site.

**Results**

***Respondent’s demographic profiles:***

A total of 10 respondents (carers) provided demographic information. The majority (50%) were between 55- 64 years whilst 40% were between 65 – 85 years. This differs from the known Wales carers demographic, which overall identified as younger (Carers Wales, 2022).

70% identified as women and 30% as trans women or non-binary. With 70% stating they were lesbian, 30% gay, asexual or pansexual. It is difficult to compare these with previous studies/surveys as the information requested was not comparable.

Overall, the people being cared for were older, with 75% being between 65 – 85+ years, again reflecting the national/UK picture (Carers & Centre for Care UK,2022). In terms of gender 70% identified as women, 20% non-binary and 10% the gender wasn’t listed. Whilst the sexual orientation demonstrated more diversity, with 50% identifying as lesbian, 10% each identified as gay, asexual or pansexual, together with 20% of care recipients being heterosexual (who were daughters of the person for who they were caring), shown in Table (1).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Characteristic** | **Years old** | **Number (Carer)** | **%****(Carer)** | **Number (Person being cared for)** | **%****(Person being cared for)** |
| Age  | 50- | 54 | 1 | 10 | 1 | 12.5 |
| 55- | 64 | 5 | 50 | 1 | 12.5 |
| 65 - | 74 | 2 | 20 | 2 | 25 |
| 75- | 85 | 2 | 20 | 2 | 25 |
|  |  85+ | 2 | 10 | 2 | 25 |
|  |  |  |  |  |  |
| Gender Identity | Female | 7 | 70 | 7 | 70 |
| Male | 0 | 0 | 0 | 0 |
| Trans Female | 2 | 20 | 0 | 0 |
| Trans male | 0 | 0 | 0 | 0 |
| Non -Binary | 1 | 10 | 2 | 20 |
| Gender variant/non-conforming | 0 | 0 | 0 | 0 |
| Not Listed | 0 | 0 | 1 | 10 |
| Prefer not to say | 0 | 0 | 0 | 0 |
|  |  |  |  |  |  |
| Sexual Orientation | Gay | 1 | 10 | 1 | 10 |
| Lesbian | 7 | 70 | 5 | 50 |
| Bisexual | 0 | 0 | 1 | 10 |
| Asexual | 1 | 10 | 1 | 10 |
| Queer | 0 | 0 | 0 | 0 |
| Pansexual | 1 | 10 | 0 | 0 |
| Sexual orientation not listed | 0 | 0 | 2 | 20 |
| Prefer not to say | 0 | 0 | 0 | 0 |

**Table (1): Age, sexual orientation & identified gender identity: Carers & person being cared for.**

Table 2 shows the relationships between the carer and person being cared for. The majority (70%) were couples, of whom 83.3% had been together for more than 10 years. Whilst 20% were family members (mother/daughter) and 10% was a friend.

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Number**  | **%** |
| Type of relationship | Partner/spouse | 7 | 70 |
| Ex-partner/Ex-spouse | 0 | 0 |
| Relative | 2 | 20 |
| Friend | 1 | 10 |
| Neighbour | 0 | 0 |
|  | Other | 0 | 0 |
|  |  |  |  |
| Length of partnered relationship with the person for whom they care? | Less than 1 years | 0 | 0 |
| 1 – 5 years | 1 | 16.7 |
| 5 – 10 years | 0 | 0 |
| More than 10 years | 5  | 83.3 |

**Table 2: Type and length of relationship with the person being cared for**

On the whole, this reflects the relationship demographic found in the general carer population, the with exception of a friend being identified as the carer (Carers UK, 2022). However, this is unsurprising within the LGBTQ+ community, where people s friends are often their ‘family of choice’ and within the lesbian community it is not uncommon for ex partners to maintain close friendships with and provide care for each other ( de Vries, Gutman & Humble, 2019).

***Type of disability/ ill health and its*** ***impact on the person being cared for:***

The people being cared for were experiencing a range of health and disability problems, both physical and mental health. Including neurological (MS), arthritis, cancer, bipolar disorder, and anxiety. There were clearly a wide variety of illnesses experienced, reflecting the broad spectrum of health problems experienced by people being cared for, together with their commensurate care needs. This variety calls for the support and potential intervention from a multitude of health and social care providers. Potentially causing the ‘care system’ to be a complex one for carers to negotiate, as will be seen later.

|  |
| --- |
| Person cared for impacted in multitude of ways. |
| Restricted & progressively worsening mobility leading to reduced independence, impacting both carer & cared for. |
| Social isolation |
| Drastically changed the carers life/altered for both cared for & carers. |
| Altered work/employment situation. |
| Alteration in relationship dynamics |

**Table 3 Impact of ill health & disability on the life of the person being cared for – themes**.

From the perspective of the carers, the ill health and disability being experienced had impacted on the person being cared for in a variety of ways. All of which had had a negative effect on the lives of both parties.

The majority stated that the person they cared for had experienced a progressive decline in their health and with it, their mobility, overall levels of functioning and independence. This severely impacted their day to day lives.

*“Very much . Brain wants to do things but breath and energy levels won’t let her.” [P4]*

Many of the carers said the person they cared for experienced altered mood states, excessive tiredness and exhaustion, which contributed to them having a reduced capacity to undertake everyday tasks.

 *“ Less mobile, some mood swings, no motivation, confusion, exhausted, unable to cook or clean” [P10]*

*“Mum just needs lots of day-to-day support with things she can no longer easily do, cooking, shopping, bed making, well pretty much everything… she can still wash and clothe herself” [P5]*

The difficulties being experienced had led the individuals gradually becoming more socially isolated, as their mobility became more impaired, and they became more dependent on the carer to ‘provide’ transport. Furthermore, the alterations to their mental health meant that they often withdraw from the usual social outlets.

Several of the people being for had been forced, by their ill health to give up work, this led to financial stresses and difficulties.

*“Initially she loved well, and we confined with normal life for a number of years. Then the cancer spread and she became unable to work ..” [P8]*

For some, but not all the couples in the study the ‘burden’ of ill health, disability and increased dependency had led to alterations in their relationship dynamics. Which had often become quite strained.

*“Physical condition - arthritis. Partner gets frustrated with not being as mobile or as independent. It is difficult as I am 14 years younger and now the age gap highlights the disability a lot more.” [P9]*

***Type of help and support needed and nature of care provider/provision:***

As Table 4 shows, the participants identified that the people being cared for had a broad spectrum of help, support and care needs.

|  |
| --- |
| Carers/visits |
| Physical |
| Practical |
| Emotional |
| Social |
| Transport (providing transport) |

**Table 4 Type of help/support/care needed.**

Most of the care and support was given by the carers.

*“Physical, practical, emotional, social. I provide that help. My partner does attend the Neuro Centre in Saltney some days. Also NHS physio at the moment.” [P2]*

*“Physical day – day support to dress and complete household tasks. She can no longer drive so I need to be her taxi to maintain any social contact, go to appointments etc. it is difficult as I work full time.” [P9]*

Whilst some identified that some was given by either other family members or outside agencies. For example, carers visits, community nurses, GP’s, carers agencies, cancer specialist nurses and specialist centres.

*“… (my sister) registered me as a carer, this meant that I someone would come and sit with my partner on a weekly basis. This allowed me to go shopping. …… As the illness progressed we were supported by the cancer nurse who arranged for a Hospital bed to be delivered and other essential equipment. We were also referred to the district nurse team and they assessed our needs and I had 2 carers visit 4 times a day.” [P8]*

This example also demonstrates that when people can negotiate the ‘care system’ they can feel well supported in their role as carers.

It is clear that the overall picture of the care needs of the people being cared for by participants in this study reflect the national picture in the U.K. Especially when exploring the position and needs of older people requiring care. It was therefore anticipated that the experiences of the carers would also be similar.

***The carers lives and experiences***

As shown in Table 5 and perhaps not surprisingly, given the ages of the carers (between 50 – 85+ years old), the majority were also experiencing a range of physical and mental health problems themselves. Interestingly, the percentage LGBTQ+ carers in this study experiencing ill health (70%) was greater than their national heterosexual counterparts (60%) Carers UK (2023). These conditions were often exacerbated by their caring responsibilities and, in common with carers across the UK, they often prioritised their caring responsibilities over their own health needs (Carers UK, 2022).

|  |
| --- |
|  Poly myalgia |
| intention Shake and mild Narcolepsy |
| Fibromyalgia. Osteoarthritis. Depression |
| Depression. Anxiety. Physical disability. Diabetes. |
| Anxiety, |
| Acute chest infections/pneumonia and have had sepsis etc. depression |
| Anxiety, intrusive thoughts, depression, lack of motivation, bouts of confusion and fatigue |

 **Table 5: Carers preexisting health conditions.**

As outlined in Table (6) and unsurprisingly becoming a carer had impacted the carers lives in numerous, frequently negative ways and drastic ways. As one respondent expressed.

*“ .. turned my life into hell “[P1]*

*With [P2] stating:*

*“Totally as the MS has got progressively worse, are lives are restricted, although we do have holidays, socialise and meet friends and family from time to time.”*

|  |
| --- |
| Drastically/totally changed the carers |
| Limited or no time/ life outside the home, restricted or no personal time, unable to leave the home for long periods |
| Social isolation |
| Altered work/employment situation |
| Negative impact on carers mental health |

Table (6) Impact of the carer’s responsibilities on the life of the carer – themes

The carers said how their life’s had become very limited and insular, with limited or no time for themselves, especially outside of the home. This had led to them feeling socially restricted and isolated. In places, the words used by the carers really expressed their levels of frustration and pain.

*“Can’t leave the house for long alone. Get showered at thinks I’ve been gone long. No life outside the home” [P4]*

*“I have no time for outside interests of my own leaving me very isolated” [P6]*

As with the people being cared for, the change in circumstances had led to increasing financial pressures, due to having to cease or alter work arrangements. Again, this reflects the national UK picture, one of transitioning into the role of unpaid carer with the commensurate increased financial hardship (Carers & Centre for Care UK,2022).

*“Gave up job, moved to the other end of the country, partner 300 miles away” [P9]*

It was also clear that the ‘burden’ of caring for many carers was extremely difficult and directly, negatively impacted their mental health. This was seen in terms of both ‘causing’ or exacerbating existing mental health problems.

*“I work full time so it feel as if I have no time to myself, as my free time is spent caring. I feel like the future is quite bleak and that her disability is affecting my own quality of life dramatically.” [P9]*

*“Difficult to have my own separate life, I also have mental health problems so life can be difficult suffering with anxiety, stress, depression, lack of freedom .....” [10]*

Several of the respondents said, when talking about their social isolation, that it would be good to have more understanding and support from within the LGBTQ+ community. To be able to meet other LGBTQ+ older carers to gain mutual support.

*“ … other than it would be so helpful to socialise with other LGB carers - as there would be greater understanding from within our own community.” [P2]*

*“There are very few social events for older lesbians where I could go to find support for my social needs” [P9]*

Unfortunately, the lack of understanding and lack of support groups are issues which perhaps arise from the carers being a small part of a minority group, one which has historically been ‘hidden’ and youth culture focussed (de Vries, Gutman, & Aine Humble et al, 2019, Kittle, Lee & Pollock, 2022).

***Support given to undertake the carer’s role***.

The carers said that they receive or had received help and support, of different types, from friends, family, carers agencies & health care professionals. However, most (70%) expressed that they would benefit from an increased level of support (although they were not always able to identify what).

***Additional help and support identified as needed by the carers***.

Other carers suggested multiple areas for improvement in services and practices. To lessen the burden of care, they felt, that more help was needed with day-to-day tasks of caring and the provision of more health and social care staff visits.

“*Someone to help with the day-to-day things.” [P6]*

*“Weekly visit of health care worker” [P4]*

*“Better support from social services and health services” [P7]*

***A listening ear and greater understanding from society.***

The carers also express their need for more guidance and emotional support and the desire of carers to have a ‘listening ear’, a person or persons who understand the carers situation. Together with greater recognition and understanding from professionals and society of the physical and mental health needs of carers (especially if they are the partner of the person being cared for).

*“..think there is an expectation that partners=just get on with it….recognition of the effect caring has is exhausting…” [P9]*

Within this was the plea for greater recognition of the exhausting impact of caring on the carer and the recognition of the carer as a person in their own right. Coupled with these was the need for the provision of more respite care.

*“Respite care. Someone to just LISTEN to me and recognise that I am still a person, not just a carer” [P6]*

***Easier navigation through the health and social care systems***

Easier and wider access to information on help and support available was also identified, with some carers clearly ‘searching in the dark’ for useful information about what is available to help them. With more signposting by staff to information, services and support groups being needed. The ‘world’ of health and social care services is a complex one for people to navigate, especially at times of great stress and vulnerability. It is one that people often need kind support and guidance through.

*“Finding out what help is available would be a start” [P10]*

*“Staff able to signpost patients/clients to good information and support services / Groups” [P3]*

This was perceived as a lack of proper assessment or holistic care, which was felt to be exacerbated by the carer’s sexual orientation and/or gender identity.

*“I am told to apply to another agency, who tells me to apply to another agency etc etc “ [P6*]

*“Some health professionals just discharge my partner back to gp without proper assessment or send her to other departments and won't take responsibility.” [P7]*

***More financial help and advice.***

As identified earlier the financial impact of caring can be immense, adding greatly to the pressures and stress felt by both the carer and the person for who they are caring. More financial recompense for the loss of income for the unpaid carers was alluded to by the women in this study. With one describing her inability to reduce her paid working hours to be able to care for her loved one but being unable to afford to do so. Thus, adding greatly to the physical and emotional toll she was experiencing.

*“Being able to afford to work fewer hours. The threshold for carer's allowance is high. Attendance allowance is £100pw which helps but really only covers the basics.” [P9]*

As was anticipated, the experiences of the older LGBTQ+ carers who took part in this study were very similar to those generally experienced by older carers across the UK and within the global literature (Carers UK, 2022, 2023). Furthermore they also reflected the experiences identified within the previous LGBTQ+ specific literature (Carers Wales & Cymru Pride 2017, LGBT Health & Wellbeing, 2020, Anderson, Flatt; & Jabson Tree, et al, 2021, Di  Lorito, Bosco & Peel et al, 2021).

Given the perceived ‘hidden’ nature of the community, particularly geographically dispersed population of North Wales the study was interested in the concerns and experiences of the older LGBTQ+ carers when accessing health and social care services locally.

***Impact of carers sexual orientation and/or gender identity on communicating and accessing services/agencies***

Although 70% of respondents stated that they felt extremely comfortable or comfortable disclosing their sexual orientation/ gender identity when communicating with services/agencies, with 10% (n1) stated they felt extremely uncomfortable. With further analysis of other questions pertaining to experiences with services/agencies it appears that this carer identified as transgender, so their experiences were reflective of the those of other transgender persons (Wales & Cymru Pride 2017, Government Equalities Office, 2018, LGBT Foundation, 2020, LGBT Health & Wellbeing, 2020). Unfortunately showing a diversity of experiences dependent upon a person’s gender identity rather than sexual orientation, perhaps reflecting the differences seen in societal attitudes pertaining to the LGBTQ+ community. This is demonstrated in the differences in the numbers of reported hate crimes experienced by members of the LGBTQ+ community (Stonewall, 2017).

***Heteronormative practices and the need for LGBTQ+ sensitive care****.*

Whilst the majority (90%) identified that their sexual orientation and/or gender identity had not affected their ability to obtain good health and social care from services. They went on to describe numerous experiences of heteronormative practice encountered across the years and currently*.* The most common experience was one of assumed sexual orientation and staff failing to recognise or consider alternative relationships, everyone assumed to be heterosexual i.e., heteronormative practice.

*“The normal response to us now is as mother/daughter which is hard and reinforces the ageing process. Also, when asked about lifts etc many professional still say husband which means more "coming out" and then seeing their embarrassment and apologising.” [P9]*

The heteronormative practice experience meant that the carers had to repeatedly ‘come out’ to their care providers, which is both embarrassing and exhausting for the carers and uncomfortable for the practitioners.

*“Gendered language, relationship assumptions, recognition of the effect caring has is exhausting and having to explain our relationship on top adds to the exhaustion and can be deflating.” [P9]*

*“Having to come out all the time, there is usually an assumption that we are sisters!” [P2]*

In addition, the heteronormative practice meant that practitioners were missing vital information about the person being cared for. Which can directly impact on their health situation, care needs and in some instances can lead to unsafe practice.

*“It meant we had to explain time and time again that we are both Transgender and Gay. As these can have an effect on your individual care needs.” [P3]*

Several of the respondents had previously had bad experiences with health care staff, which had made them wary of the care systems and staff. This is due to the negative history of the LGBT community in the U.K. where lesbians, gay and transgender persons may choose to hide their sexual orientation and gender identity thus remain ‘hidden’ from health and social care practitioners due to fear of negative attitudes and consequences. This may be especially true of older members of the LGBTQ+ community whose ‘formative years’ were lived in a homosexual and transgender hostile legislated world – where ‘the love that dare not speak its name’ (Douglas, 1894)was the lived reality of day-to-day life (Oram & Turnbull, 2001, Jennings, 2007). Understandably, colouring their views health care in our current society.

*“One doctor refused to see us when we had to go to them when accessing the fertility clinic to "prove we were acceptable people to have donor insemination". Today, the carer is both expected to care but is not given the same recognition as a husband straight away. Once professionals know us. it is better. “[P9]*

*“.. Also I wasn’t allowed to be next of kin when my partner was diagnosed with MS almost 30 years ago. This has changed now.” [P2]*

Unfortunately, the respondent’s experiences were not unique, as they clearly reflect the experiences of people from the LGBTQ+ community for far too many years. Studies have shown since the 1970 and 1980’s that practitioners across specialities lack the knowledge, skills and attitudes to feel comfortable with working with patients and carers from the LGBTQ+ community (Woods & Madetta,1976, Webb, 1988, Zeng, Liu & Loke, 2011, Stonewall, 2015, Hall, 2019).

***Interventions proposed by the respondents to improve service provision.***

Table (7) shows the responses given by the respondents when asked how current service provision could be improved, including the methods.

|  |  |  |
| --- | --- | --- |
| **Type of support identified** |  | **Suggested ways to provide additional care & support** |
| Emotional support |  | Phone helpline |
| Good signposting by staff to good information, support services & groups |  | Support group |
| More frequent visits by health carers |  | Face to face |
| Support available for the carers |  | Large print information sheets |
| Support for the carer after the person being cared for dies |  | Online  |

 **Table (7): Identified ways to improve services provided to carers.**

*“Face-to-face and group. Some online is great but human contact when you are caring is important. The LGBTQ+ scene has always been a more youth orientated community. We need more for the 50+ among us now” [P9]*

As can be seen there was a variety of delivery methods were identified, really demonstrating that ‘one size doesn’t fit all’. Obviously, this has implications for any future service developments.

**Limitations**

In addition to the limitations with the questionnaire outlined above, the main limitation of the project was the disappointing small number of responses. This was despite the wide promotion via social media, support groups and organisations across North Wales. The difficulty with recruitment was seen to be in part due to the relatively small numbers of older LGBTQ+ carers in North Wales and the issue that the LGBTQ+ community is traditionally seen as ‘hard to reach’. Additionally, the research team are relatively unknown both the carers and LGBTQ+ communities. Thus, they may not have been seen as credible as other teams from other organisations or agencies. It would possibly be useful when undertaking further studies and work, for the research team to work with more established organisations such as Carers Wales and Stonewall Cymru to gain more credibility.

**Conclusions**

This study reinforces and informs literature on LGBTQ+ aging and considerations given to the lives and needs older LGBTQ+ carers. Furthermore, the main areas of concern that arose in this study have implications for practice and the policies that inform them.

**Aim one:**

* To explore the health and social support needs of LGBTQ+ older carers across North Wales.

The experienced described by the old LGBTQ+ carers in this study very much reflected the experiences of older carers generally and those previously identified within the LGBTQ+ carers specific literature. Primarily around the devasting consequences on the lives of both the carer and the person for who they are caring of ill health and disability. This impacted on all aspects of these people’s lives and often leading to great stress, social isolation, financial loss and increased problems with their mental health. Added to this is feeling of the ‘loss of self’, becoming invisible as a person, simply becoming the carer and no longer a person in their own right. The picture given is one of people who are really struggling with the burden of care, often feeling unsupported by the health and social care services and by society in general. Feeling lost whilst trying to navigate their way through complex systems whilst trying to get the care and support needed by both their loved one and themselves.

Added to this ‘general burden’ the respondents in the study identified that they felt an extra layer of discomfort as they frequently experienced heteronormative practice from the staff within health and social care service/agencies. They felt this was necessary, in order to have the nature of their relationships validated, to have to ‘come out’ to the staff multiple times this being experienced at a time of exhaustion and great vulnerability. The respondents identified the need for health and social care staff to provide LGBTQ+ sensitive care. They also identified a need for greater understanding of their situation by society in general and also from members of the LGBTQ+ community.

**Aims two and three:**

* To evaluate the robustness of the online questionnaire developed for the project.
* Make recommendations for any amendments in questionnaire design and delivery, to inform future larger studies in the identified area.

The questionnaire consisted of 35 questions (including sub sections), which appeared to flow easily. Whilst undertaking the analysis, it was clear that there were glitches in the questionnaire which meant that incomplete information was provided for some questions. Furthermore, several of the questions appeared to overlap with respondents providing similar answers to a few questions.

In addition, the questionnaire was hosted by JISC online surveys, which allowed for relatively easy access. Unfortunately, however, it was not directly accessible, with respondents having to be directed to the Wrexham University’s Social Inclusion Research Institutes website. This represented a potential obstacle to potential responds and is something which would need to be addressed with future online surveys. Additionally, although the research team had anticipated that some respondents may not have been happy to complete an online survey and had provided a mechanism for providing respondents with a hard copy, no respondents requested this option.

Despite the small numbers of respondents, overall, the questionnaire, with the necessary amendments was seen as a robust tool for use in future projects. In addition, the themes identified in the free text sections will be very useful when constructing both further research projects and especially for semi- structured interview schedules. These would allow for a much deeper exploration and understanding to emerge, to help shape further service provision.

**Recommendations**

* A larger scale exploration of the care and support needs of older LGBTQ+ carers across Wales. This could be achieved as part of the research component of the Welsh Governments LGBTQ+ Action Plan for Wales (2023).
* The outcomes of this study be made widely available to health and social care providers and carers support agencies, to help shape policy and practice.
* Develop further and implement staff awareness training particularly for staff working in social care and carer support agencies. Training to provide examples of lived experiences and concrete examples of best practice.
* Wider dissemination and adoption by care and support agencies of the existing LGBTQ+ Carer support toolkits (Carers Wales & Cymru Pride, 2017, Carers UK, 2023).
* Development of LGBTQ+ older carers specific support groups and resources, both face to face and online.

Both the UK and Welsh governments have taken important steps in the last few decades to improve the social conditions in which LGBTQ+ persons age. Indeed, recently the Welsh government has set out its vision to make Wales the ‘most LGBTQ+ friendly nation in Europe’ (Welsh Government, 2023). In order to make this vision a reality, a lot of work still needs to be carried out to create social environments, health and social care systems that are inclusive of diversity and able to appropriately support a diverse aging population.

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