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# How do LGBTQI+ stroke survivors and their partners experience sex and sexuality after stroke?

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## ABSTRACT

**Introduction:** Stroke survivors and their partners experience changes in sexuality after experiencing a stroke. However, there is limited research into how stroke can change the experience of sexuality among LGBTQI+ stroke survivors and their partners. The aim of this study was to explore the experiences of sex and sexuality among LGBTQI+ stroke survivors and their partners post-stroke.

**Methods:** A qualitative phenomenological research design was used to explore the experiences of the participants. Interpretative Phenomenological Analysis (IPA) was used for the analysis of the data.

**Results:** Stroke survivors ( $n=18$ ) and partners of stroke survivors ( $n=5$ ) completed interviews where they were asked about their experiences of sex and sexuality post-stroke. Four main themes were identified which explored impact on sexual functioning, changes in sexual activity and behavior, relationships post-stroke and access to the LGBTQI+ community. Stroke survivors and their partners experienced negative changes in sexuality post-stroke.

**Discussion:** This study presents experiences previously not explored in existing stroke literature. The findings of the study can assist in the development of effective sexual rehabilitation interventions to help LGBTQI+ stroke survivors and their partners reclaim their sexuality post-stroke.

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## KEYWORDS

Sex; sexuality; stroke; stroke survivor; partner; Lgbtqi+

## > IMPLICATIONS FOR REHABILITATION



- LGBTQI+ persons are poorly served by existing approaches to sexual rehabilitation following stroke.
- Some stroke survivors and their partners have successfully navigated the impact of stroke on sexuality, but for many stroke results in ongoing feelings of perceived unattractiveness, withdrawal from sexual activity and relationship breakdown and loss.
- Rehabilitation professionals need to reflect on the degree to which interventions for sexuality post stroke are inclusive of and useful to LGBTQI+ stroke survivors.
- Adopting a strengths based approach which builds upon experiences of stroke survivors is critical to ensuring development of inclusive sexual rehabilitation services in the future


## Introduction

The World Health Organization (WHO) refers to sexuality as being a central part of being human throughout someone's lifespan. Sexuality includes aspects such as sex, eroticism, intimacy, pleasure, sexual reproduction, gender and sexual identities and can be experienced and expressed through different ways such as behaviors, fantasies, roles and relationships [1]. Previous research has reported that sex and sexuality are intricately connected to quality of life [2]. Persons who experience a stroke are often left with poor outcomes related to sexuality, due to difficulties caused by post-stroke impairments. These impairments may include issues with communication, sexual functioning (e.g., erectile dysfunction), physical impairment (e.g., hemiplegia) and change in roles and identities within relationships (e.g., partners required to take on a caring role) [3]. Despite recognition of these significant impacts, sexuality is rarely addressed during stroke rehabilitation [4] and up to 70% of stroke survivors report ongoing difficulties relating

to sexuality [5]. These difficulties are associated with increased rates of anxiety and depression and poorer overall quality of life [6].

Although there is an established body of research documenting the impact of stroke on sexuality, most research is focused on heterosexual people and little is known about the experiences of persons who identify as Lesbian, gay, bisexual, transgender, Queer & intersex (LGBTQI+). Some members of the LGBTQI+ community are at a higher risk of stroke, particularly transgender women using HRT (Hormone replacement therapy) [7,8]. These risks may also intersect with health disparities experienced by persons of color including African Americans and Hispanic people, who also have an increased risk of experiencing stroke when compared with white people [9]. A recent systematic review about the impact of chronic disease on LGBTQI+ persons' experiences of sexuality identified no existing stroke studies containing clear experiences regarding the impact of stroke on sexuality [10]. This

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omission is important because LGBTQI+ persons have health care needs and experiences relating to sexuality, which may be different to their heterosexual counterparts.

Homophobia, transphobia, or heterosexism in health settings can exacerbate existing health conditions due to experiences of heteronormativity, discrimination based on sexual orientation and mistreatment which may result in lower uptake and use of services by LGBTQI+ persons [11]. Partners of LGBTQI+ persons are often excluded from health interventions and/or conversations and subsequently, the impacts of chronic disease on partners are often not explored or understood [12]. When partners are included in research, findings identify an impact on partners such as changes in relationship dynamic and not having their own needs met [13]. These findings are consistent and comparable with existing stroke research in heterosexual populations [3].

While the small amount of LGBTQI+ chronic disease literature provides some knowledge around experiences of sexuality, there are still limitations within the research. Research is largely focused on the act of penis in anus (PIA) sex with the majority of studies addressing erectile dysfunction among men [14–16]. Although erectile function is important, failure to address broader aspects of sexuality is problematic because it fails to consider the complexity of disability and its impact on sexuality. Sexuality issues have traditionally been framed through a biomedical lens, reinforcing gender stereotypes, such as focusing on erectile dysfunction in men and emotional wellbeing in women. Recent studies have explored broader experiences of sexuality in both men and women [17,18]. However, in this population, less is known about the impact of stroke on sexual activity. Furthermore, even where LGBTQI+ persons have been included in research where the impact of sexuality is explored, these studies often do not perform subgroup analysis by sexual orientation or gender identity [19–21]. LGBTQI+ health research also often fails to sample the diverse sexualities that make up the community with many studies having more gay men and lesbian women than other gender and sexual identities such as bisexual, transgender or even intersex populations [22]. Historically, research has neglected to collect data on sexual orientation, leading to gaps in the representation of diverse sexual identities [23]. There is also no consistent measure that is available to help evaluate sexual dysfunction or impact on sexuality for this population when considering the impact that chronic health conditions have on sexuality. This can lead to disparities in the understanding of and the interventions provided by health professionals to address sexual dysfunction.

There is a need to explore and understand how sexuality is experienced in LGBTQI+ stroke survivors and their partners. This will assist health professionals to provide specific support and intervention that addresses the needs of LGBTQI+ stroke survivors and their partners. The current study attempts to address this need through exploring the complexities of sexuality and aims to provide much needed understanding for the LGBTQI+ stroke population while also potentially assisting in the development of essential interventions. This paper presents the findings that address the questions around the experiences and challenges of sexuality for LGBTQI+ stroke survivors and partners of LGBTQI+ stroke survivors.

## Methods

### Design

A qualitative phenomenological research design [24] was used to explore the experiences of LGBTQI+ stroke survivors and their partners in relation to sexuality after stroke. The study sought to

understand how sexuality had been addressed as part of the stroke rehabilitation journey but also to consider if being an LGBTQI+ stroke survivor impacted on the overall experience of rehabilitation. The current paper reports on stroke survivors' experiences of sexuality post-stroke while overall experiences of rehabilitation as an LGBTQI+ stroke survivor are reported elsewhere. Phenomenology was most aligned with our aim to understand the phenomenon of post-stroke sexuality rehabilitation in those who identify as LGBTQI+ through participant's personal lived experiences and perceptions.

The study design and reporting were informed by the COREQ Guidelines which assisted in ensuring rigor within this study [25]. Semi-structured interviews were conducted with 23 people and data was analyzed in line with Interpretative Phenomenological Analysis (IPA) processes [26]. Ethical approval was obtained from the Human Research Ethics Committee at the University of Sydney [2021/719].

The research team has a collective knowledge and experience in research, working with stroke survivors, persons with communication impairments and working with issues pertaining to disability and sexuality. The research team is made up of 3 university academics with PhDs and a PhD student. The research team have professional qualifications in social work (WK), occupational Therapy (MMG), speech pathology (EP) and rehabilitation counseling (RP). The team worked collaboratively to design, implement, and report the findings of this study. The research team had no prior existing relationships with any of the participants and the lead researcher informed the participants at the commencement of the interview of their qualifications (Bachelor of Social Work), occupation as a rehabilitation social worker, pronouns (he/him), credentials, and role within the research. However, there are members of the research team who identify as members of the LGBTQI+ community and used their experiences and knowledge to inform the design of the study.

### Inclusion and exclusion criteria

Participants were eligible to be included in the study if they: (a) self-identified as LGBTQI+, (b) had experienced a stroke or were a partner of someone who had experienced a stroke, (c) were 18 years+ and (d) resided in USA, United Kingdom, Canada, Australia, and New Zealand. The inclusion of these countries for recruitment was based on each country having stroke guidelines which recognize the importance and value of addressing sexuality post-stroke [27–30]. While there are significant differences in the design and delivery of stroke rehabilitation services across these countries, and in the level of protection offered to LGBTQI+ persons human rights, clinical guidelines for stroke rehabilitation in each country explicitly identify the importance of sexual rehabilitation. For this reason, a stroke survivor in UK, USA, Canada, New Zealand or Australia might reasonably expect rehabilitation services to address sexuality as part of the stroke recovery journey [31]. To enable participation of stroke survivors with communication impairments, project information was provided in an aphasia friendly format [32], this was accompanied by supported communication principles where required [33]. Participants who were deemed to not have cognitive capacity to participate within the study or had a preexisting neurological condition such as dementia were excluded from this study. Participants were asked to answer 4 questions about the study correctly to assess understanding and ability to participate within the study. Persons with cognitive impairments who were able to participate were provided with the opportunity to have their partner or a support person

assist with completing the interview. The interviewer conducting the interviews has experience with working and supporting persons with cognitive impairment. There were no exclusion criteria based on severity of communication impairment/aphasia or time since stroke was experienced.

### Recruitment

Social media (Facebook, Instagram, and X) and LGBTQI+ organizations were used to promote the study within the participating countries. The use of social media was seen as a valuable resource in recruiting an otherwise hard to reach population due to geographical location and lack of existing organizations connected with this population [34]. Organizations serving members of the LGBTQI+ community were sent an email with a description of the study and a request for them to advertise the study among their members. The research team aimed to recruit a diverse sample of participants using principles of maximum variation to include a wider range of sexual identities, ages, relationship status, location and stroke type. Study posters included details for potential participants to contact the researcher to express interest or to gain more information from a purpose made study website. Potential participants who contacted the first author were sent a participant information sheet about the study and a consent form to complete. Participants returned a signed consent form. Consenting and eligible participants and the lead researcher explored a suitable time for both parties to complete an interview.

### Data collection

Data collection took place between February and July 2022, with semi-structured interviews conducted *via* videoconferencing (Zoom) for purposes of accessibility to participants in different geographical locations. Interviews were conducted by the lead researcher (WK) and were video and audio recorded and lasted between 45 and 60 min. Where both the stroke survivor and their partner were participating in the study, each participant was given the option of conducting the interview individually or as a couple. A total of 4 couples were interviewed together and 1 couple chose to complete interviews separately. The interview guide was developed by the research team based on their experience and expertise within the area of stroke and sexual rehabilitation. Interview questions asked participants about their experiences of sexuality before and after their stroke, experience of healthcare and rehabilitation during their stroke recovery. Data related to the questions around experiences of healthcare and rehabilitation are presented within another paper. Follow-up prompts were used to aide obtaining greater understanding of the experiences shared (Table 1).

No notes were made during or after the interviews and no repeat interviews were carried out with the participants. None of the participants who completed the consent form refused to participate or withdrew from the study.

### Data analysis

Data was transcribed verbatim, and interviews were formatted into tables for analysis in line with Interpretative Phenomenological Analysis (IPA) processes [26]. Transcripts were judged to be accurate when quality checked by the lead researcher and therefore were not returned to participants prior to analysis for member checking. The primary author used the following steps in the data analysis phrase:

(1) reading the transcripts and making exploratory notes (2) formulating subthemes from the exploratory notes (3) identifying connections between the subthemes and gathering them into themes (4) compiling the table of subthemes [26]. Each participant was considered as an individual even when interviewed with their partner. The steps of analysis were completed with each of the transcripts separately. After all transcripts were analyzed using the steps above, each table of subthemes were compared against each other. This process allowed subthemes to be identified across transcripts and led to the development of overall themes. The research team reviewed the tables of subthemes several times to ensure attention was given to the analysis. When differences of opinions arose, these differences were discussed and resolved through discussion and returning to the original text until consensus was achieved. No qualitative software was used in the analysis.

### Results

A total of 23 participants were recruited for the study: 18 stroke survivors, 5 partners (1 participant who was both a stroke survivor and partner of a stroke survivor). Demographic and stroke related characteristics of participants are presented in Table 2. Participants were aged between 28 and 74 years of age. The majority of participants had an ischemic stroke ( $n=12$ ), one participant had a hemorrhagic stroke and one had both ischemic and hemorrhagic stroke. Four participants could not recall the type of stroke they had. In addition to 12 gay men, we also recruited 5 lesbian women, 4 queer persons (3 women, 1 of whom was transgender, and 1 man), 1 bisexual non-binary person and 1 pansexual transgender man.

Four main themes were established from the data analysis to address how stroke impacts sexuality among LGBTQI+ stroke survivors and partners of LGBTQI+ stroke survivors. These major themes are: "It impacted my sex life," "Everything was affected because of stroke," "It's definitely had a bigger impact on relationships" and "I want to engage with the (LGBTQI+) community."

#### Theme 1: "it impacted my sex life"

Most participants identified that they experienced negative change(s) in relation to their sexual activity. These were experienced differently depending on the nature of the stroke and included changes on the physiological level, behavioral level and emotional level. Changes such as stroke-related physical impairment, erectile dysfunction, stroke-related fatigue and reduced sexual confidence were experienced.

#### "I Can't move myself, I'm paralyzed"

Many participants had hemiplegia of varying levels of severity. For these participants, hemiplegia meant they were unable to assume previously used positions for sexual activity resulting in decreased participation in sex:

because my left leg was paralyzed. I couldn't really sit up or kneel or yeah, assume any particular position and just became harder both for me and for any partner. So, I didn't feel I had any opportunity to experience sexual relations with anybody. – Participant 21, stroke survivor, 60-year-old, partnered gay man.

Mobility restrictions associated with hemiplegia also impacted participants' ability to engage in masturbation. As one stroke survivor reports:

**Table 1.** Interview script.

## Interview script

*Screening questions for informed consent*

1. Is this study about stroke and sexuality? (Y)
2. If you agree to be in this study, will I take a blood sample? (N)
3. If you agree to be in this study, will I ask you to tell me what your experiences of sexuality post stroke? (Y)
4. Do you have to be involved in this study even if you don't want to? (N)

(If the person answers each question accurately and is willing to participate in the research, they will be considered to have the capacity to consent to and participate in the research. If they do not answer these questions correctly, then it will not be clear that they have understood and can participate, and they will not be included.)

*Demographic questions*

1. The first question is to be able to obtain demographic details about yourself however, I will not ask you to identify yourself by name. The information I would like to know is:

Age:

The gender that you identify as:

Do you identify with pronouns: Y/N

Where do you reside currently?

*Stage two of this question:*

What was your age at the time of the stroke?

Are there any other existing health conditions?

If yes, are you taking any medication?

*Pre stroke questions*

1. Can you describe how you viewed your sexuality and sexual experiences prior to experiencing your stroke?

*Potential prompts:*

- *Gender and sexual identity prior to stroke*
- *Sexual and non-sexual activities that were explored or experienced.*
- *Relationships and relationship history*

*Stroke recovery questions*

2. Can you describe your experiences with your health, access and supports within the healthcare system and supports or lack of supports within the LGBTI and the broader community?

*Potential prompts:*

- *Experiences of healthcare prior to stroke*
- *Access to formal supports*
- *Experiences with healthcare professionals*
- *Inclusion of partner within healthcare provision*

3. Can you describe your experiences with your supports or lack of supports within the LGBTI and the broader community?

*Potential prompts:*

- *Access or lack of access to informal supports such as friends, family, etc*
- *Access or lack of access to the LGBTIQ+ community*

4. Can you describe the time when you had your stroke and the type of rehabilitation you received for this? (sexual rehabilitation – did they ask, was it offered, what did they receive as a response)

*Potential prompts:*

- *Experience of healthcare treatment and interventions received after stroke*
- *Experience of healthcare in relation to gender and sexual identity*
- *Sexual rehabilitation interventions received, including type*
- *Stroke related supports*

*Post stroke questions*

5. Can you describe how you view your sexuality and sexual experiences after experiencing your stroke and how you feel your stroke has impacted this?

*Potential prompts:*

- *Sexual experiences post stroke*
- *Sexual orientation post stroke*
- *How has stroke impacted sexual activity and non-sexual activity*
- *How has stroke impacted relationships*
- *Was your partner included in your healthcare interventions*

it was my right side that was affected. And that affected even my um solo sex life, everything that just everything. – Participant 23, stroke survivor, 45-year-old, partnered gay man

Because my bowel movements I can't, I don't like doing it and neither does my partner because I can't clean my bowels properly. So, it's frustrating. – Participant 1, stroke survivor, 74-year-old, partnered gay man.

Participants identified that the use of catheters created physical limitations and barriers for safe sexual activity. Impaired bowel movements led to avoidance of receptive intercourse due to concerns regarding transfer of fecal matter:

***"I'm definitely suffering a form of ED"***

Hemiplegia was not the only physical impairment impacting sexual activity, participants also identified concern with erectile



Table 2. Participant Demographics.

Participant	Survivor/partner	Gender identity	Transgender	Partnered at time of stroke	Partnered at time of interview	Sexual orientation	Age at interview	Age at time of stroke	Country	Type of stroke
1	Survivor	Man	–	Yes	Yes	Gay	74	71	AUS	Unknown
2*	Survivor	Woman	–	Yes	Yes	Lesbian	66	64	AUS	Unknown
3	Survivor	Woman	–	Yes	No	Queer	39	28	AUS	Ischemic
4	Survivor	Man	–	No	No	Gay	62	58	USA	Ischemic
5	Survivor	Non-binary	–	No	No	bi-sexual	31	29	USA	Ischemic
6	Survivor	Man	–	No	No	Queer	50	46	AUS	Ischemic
7	Survivor	Man	–	No	No	Gay	65	62	AUS	Ischemic
8	Survivor	Man	–	Yes	Yes	Gay	69	66	CAN	Unknown
9	Partner	Woman	–	Yes	Yes	Lesbian	32	N/A	CAN	N/A
10	Survivor	Woman	–	Yes	Yes	Lesbian	36	36	CAN	Ischemic
11	Survivor	Man	–	Yes	Yes	Gay	44	44	UK	Ischemic
12*	Survivor	Man	–	Yes	Yes	Gay	71	43/50	NZ	Ischemic
13*	Survivor	Woman	YES	Yes	Yes	Queer	40	40	CAN	Unknown
14*	Survivor	Man	YES	Yes	Yes	pansexual	29	23	AUS	Ischemic
15	Survivor	Woman	–	No	Yes	Lesbian	32	31	AUS	Ischemic
16	Partner	Woman	–	No	Yes	Queer	28	N/A	AUS	N/A
17*	Survivor & partner	Woman	–	No	No	Lesbian	58	57	AUS	Ischemic
18	Survivor	Man	–	Yes	Yes	Gay	59	55	UK	Ischemic
19	Partner	Man	–	Yes	Yes	Gay	56	N/A	UK	N/A
20	Partner	Man	–	No	Yes	Gay	28	N/A	NZ	N/A
21	Survivor	Man	–	No	Yes	Gay	60	52	NZ	Hemorrhage
22	Partner	Man	–	Yes	Yes	Gay	39	N/A	AUS	N/A
23*	Survivor	Man	–	Yes	Yes	Gay	45	44	AUS	Ischemic & Hemorrhage

Note.

- Participants 2, 12 & 14 were partnered at the time of the stroke but were with new partners at time of interview.
- Participant 17 completed an interview as a stroke survivor and a partner of a stroke survivor.
- Participant 23 had 2 strokes in one day.
- Participant 12 experienced 2 strokes at different ages.
- All couples that participated within the study are grouped by a bolded line; all couples completed interviews together except for participants 20 & 21.

dysfunction. Some participants reported that their erectile dysfunction emerged following the stroke:

I'm now suffering a bit of erectile dysfunction. And I didn't know I was. And I was quite obviously embarrassed by it. – Participant 23, stroke survivor, 45-year-old, partnered gay man

For another participant erectile dysfunction had a direct impact on their new partner, requiring their partner to change their sexual role preference in relation to penetrative intercourse:

More so because he saw himself as a bottom, whereas clearly, I couldn't top. So... but he changed. – Participant 21, stroke survivor, 60-year-old, partnered gay man

However, other participants identified attributed erectile dysfunction to side effects of medications needed to manage stroke symptoms:

There was some which I had discussed with my stroke doctor, which was related to what medications I was on. – Participant 7, stroke survivor, 65-year-old, single gay man

### *"The 'not tonight honey' effect"*

For some participants, post-stroke fatigue was a significant factor which resulted in reduced sexual desire:

part of this is just fatigue. And I think that's just something a lot of people who have stroke have to deal with. And so, there's, you know, that not tonight honey effects. – Participant 13, stroke survivor, 40-year-old, partnered queer transgender woman

A number of participants described post-stroke fatigue as a significant factor which resulted in reduced sexual desire:

Not really, no. And I have thought about, you know, just trying some stuff for myself, you know, just to see how it feels and things like that, but I just didn't feel I had the energy for it. – Participant 11, stroke survivor, 44-year-old, partnered gay man

### *"The psychological aspect of just not feeling sexy"*

Some participants reported that physical impairments related to stroke had a significant impact on their body image and sense of self. Changes such as facial droop and hemiplegia impacted how participants could present themselves to others. Participants perceived their physical appearance and abilities as critical to their membership of, and acceptance by the LGBTQI+ community. Consequently, the impact of physical impairments caused by stroke on body image left stroke survivors feeling excluded from the LGBTQI+ community as outlined by Participant 21:

I guess the gay community attitude to disability and difference is really quite distressing. It's body image and body beautiful... simply doesn't include me. And that... it hurts your feelings, and it degrades what you think of yourself. – Participant 21, stroke survivor, 60-year-old, partnered gay man.

These participants also acknowledged that their negative changes with sexual confidence affected existing intimate relationships and new sexual relationships.

### *Theme 2: "Everything was affected because of stroke"*

Participants experienced changes with their sexual activity (other than intercourse) and their sexual behaviors. This theme explores the following subthemes: "It's strategies...to achieve what we need to achieve," "There is still cuddling and other things," "changes in sex, changes in behavior" and "Our sex life just basically died."

#### *"It's strategies...to achieve what we need to achieve"*

Many participants within the study explored ways to adapt sexual activity to accommodate the changes to their body brought about by stroke. Adaptations came in different forms including changes to timing, pace, positioning or even how they physically engaged in both penetrative and non-penetrative sexual activity:

I've no, no use of the right hand at all anyway. It doesn't affect us, rarely does it just instead of going like that, I have to go like that now, you know" (Participant giving hand gestures for masturbation). – Participant 18, stroke survivor, 59-year-old, partnered gay man

As identified in the following statement, some participants had partners engage in new ways and positions to adapt to the stroke survivors post-stroke impairments:

I'm virtually a top but it's hard for me to kneel because of my I don't can't support myself always on that stroke left side. So, you know, he has to actually position himself in a different way so I can achieve what we need to achieve, to penetrate and you know, have an orgasm. – Participant 12, stroke survivor, 71-year-old, partnered gay man

While for some, adapting to sexual activity post-stroke was successful, for others adaptation was not associated with positive outcomes and in some cases lead to a withdrawal from sexual activity:

So, is this working? Is this working sort of stuff, generally you used to be able to tell if it's working or not. So, in the end, it just became, it is what it is. You know, it's sort of took me back where I went 10 years without having sex with anybody. – Participant 17, stroke survivor and partner of stroke survivor, 58-year-old, single lesbian woman

### *"There is still cuddling and other things"*

Participants identified the use of non-penetrative sexual activities as a way to explore their need for sexual pleasure. Non-penetrative sexual activities considered by participants included oral sex, massage, and masturbation. Through participating in these activities' participants were able to continue to receive and provide sexual pleasure and sexual satisfaction to themselves and/or their partners:

we've done oral and that, and he lets me massage him. – Participant 1, stroke survivor, 74-year-old, partnered gay man

### *Changes in sex, changes in behavior*

Following their stroke, some participants explored a change in sexual behaviors with some including ethical non-monogamy, change in sexual roles and a reduction in dating patterns. Ethical non-monogamy was identified as a strategy that couples explored as a means of ensuring the stroke survivors' partners could have their sexual needs met. Stroke survivors who explored this with their partners did so due to concern for being unable to meet their partners sexual needs:

And you know, I've said to him, if he ever wants to do something with someone, I wouldn't be too upset. You know, because that that really doesn't bother me at all, you know, never has done, you know, it's not the end of the day, it's just a thing that happens between people, you know, it's just so what. – Participant 11, stroke survivor, 44-year-old, partnered gay man

While most of the participants who experienced a change in sexual behavior were stroke survivors, partners of stroke survivors also experienced a change in their sexual behavior. This included avoiding sex for fear of hurting their partner, changes to how they explored sexual activity and changes to exploring consent before engaging in sexual activity with their stroke affected partner:

I think it was a case of I was initially right at the beginning concerned about consent, because [participant 18] had a brain injury. And I didn't want him to feel that he was being pushed into anything or doing anything he didn't want to do. But I think he made that quite clear

that you did want to do what you wanted to do. – Participant 19, partner of stroke survivor 18, 56-year-old, gay man

### *"Our sex life just basically died"*

Some participants identified a cessation in sexual activity post-stroke. While cessation in sexual activity was contributed to by a number of issues post-stroke, some participants identified that they faced rejection or a lack of interest from others post-stroke:

I had the problem with being unable to get erect and I basically gave up on the idea of sex, because most people weren't even interested. – Participant 21, stroke survivor, 60-year-old, partnered gay man

While stroke survivors identified a complete cessation in sexual activity post-stroke, some partners also shared this experience:

So yeah, it was just...I think our sex life just basically died to death. – Participant 17, stroke survivor and partner of stroke survivor, 58-year-old, single lesbian woman

### *Theme 3: "it's definitely had a bigger impact on relationships"*

This theme was made up of subthemes that explore both positive and negative experiences of relationships after stroke. The subthemes within this theme included: "She couldn't see her best friend anymore," "I'm his partner, I'm his carer" and "Stroke brought us closer together."

#### *"She couldn't see her best friend anymore"*

Sexual activity and behaviors were not the only focus of experiences shared by participants. Participants identified that their stroke fundamentally altered their non-intimate relationships. While these participants did not provide clear reasons, stroke was suggested as a contributing factor for the breakdown of these relationships:

There are a couple of people from my previous life who, who have pulled away because of the stroke. – Participant 5, stroke survivor, 31-year-old, single bi-sexual non-binary person

#### *"I'm his partner, I'm his carer"*

Participants who were partnered during their participation in the study also shared experiences where their stroke had an effect on their partner. Partners found this impact caused them to take on the role of a caregiver instead of that of a partner:

Well, I was {participant 23's} carer, and {participant 23} needed care and {participant 23} needed help with a lot of things that it just wasn't on my mind, as well as his mind. And then um yeah, like the days just got longer, and I was working, caring, cleaning, doing so much that, like, I was just exhausted. – Participant 22, partner of participant 23, 39-year-old, gay man.

Two participants identified that partners not only provided care with physical tasks but also became communication partners to assist with communication due to aphasia. These participants identified that due to their need for assistance with communication, they became dependent on their partner, further causing these partners to shift more into the 'carer' role:

He helps me. I say, I don't know. What am I trying to say? He goes, yeah, and he goes, tells me about the in-phone conversation. Oh, I don't know what I'm saying. He answers the phone and goes on. – Participant 8, stroke survivor, 69-year-old, partnered gay man.

This was not a unique experience; other partners acknowledged the impact that their partner's stroke had on them in similar ways. Partners also observed a shift in their focus of making time for themselves to putting their focus on their partner. For example, one partner notes that providing care and support for the stroke survivor meant neglecting their own care needs and wellbeing:

I didn't look after myself though, yeah, I didn't. I rarely went out by myself. My entire focus was on {partner}. – Participant 17, stroke survivor & partner, 58-year-old, single lesbian woman

#### ***“Stroke brought us closer together”***

The impacts of stroke shared by participants were not all viewed negatively, some participants shared positive outcomes including the view that stroke made the relationship closer. One couple, whose intimate relationship developed after the stroke, identified that the experience of stroke was a catalyst to the formation of a friendship which subsequently developed into an intimate relationship:

I guess the experience of {participant 15} having a stroke brought us closer together as friends. And that's, I'm sure, probably contributed to us ending up dating. – Participant 16, partner of participant 15, 28-year-old, queer woman

#### ***Theme 4: “I want to engage with the (LGBTQI+) community”***

This theme explores the experiences of stroke survivors in engaging and accessing the LGBTQI+ community. The subthemes within this theme include: “There is no accessibility to the LGBTQI+ community,” “Stroke makes it hard to form new relationships” and “I'm putting myself out there again.”

#### ***“There is no accessibility to the LGBTQI+ community”***

Participants reported that having access to LGBTQI+ events or venues allows them to connect with their peers, which can be a form of support and understanding of issues pertaining to being LGBTQI+ such as discrimination. For some participants, their stroke had caused difficulty with accessing these spaces due to physical impairments (i.e., hemiplegia), post stroke fatigue and accessibility issues. These participants have also highlighted that due to the impact of these barriers, they felt excluded from the LGBTQI+ community due to their disability. This feeling of exclusion for participants meant losing their connection to the community and not having the support that they once felt from the community:

there were so many disability access problems with Mardi Gras. But when I discussed it when they said they had no disability plan, which kind of shocked me because I used to work in events. I mean, they had nothing in place. There's nothing in place for Saturday night's parade. I just found that a bit strange and ludicrous. – Participant 7, stroke survivor, 65-year-old, single gay man

#### ***“Stroke makes it hard to form new relationships”***

With stroke survivors being unable to access LGBTQI+ venues and events due to their stroke impairments, opportunities to form new relationships were restricted. This restriction meant a missed opportunity for stroke survivors to engage and form new relationships:

I can't hang out with people for very, very long. Anyways, just because I get tired, right? And everyone has been respectful boundaries and stuff like that around it. So, I haven't done any like, you know, queer dances” [Referring to impact from post-stroke fatigue]. – Participant 13, stroke survivor, 40-year-old, partnered queer transgender woman.

When having the chance to access LGBTQI+ venues and events post-stroke changes (i.e., physical impairments, appearance, and fatigue) caused difficulty leading to feelings of self-conscious about how others view them within these spaces:

I feel like people don't want to get too close to me, because they're afraid that they'll have to volunteer for something... like they might have.... They're afraid I will ask them for a ride home or something. I don't get invited to parties, but I just felt like they overlooked me for stuff like that. You know? – Participant 4, stroke survivor, 62-year-old, single gay man

Other participants identified experiencing internalized stigma, which affected their ability to form new relationships. These participants identified that over disclosure of their stroke resulted in failure in forming new relationships with others. Some viewed this over disclosure as a way of avoiding rejection due to their stroke impairments. This is identified in the quote from participant 3:

like things that I felt that when I was dating someone, especially dating somebody new, I felt like I had to tell them about it. Like, I'll just let you know of the fucking terrible shit about me. So, you can just leave now kind of thing. So, I'd be like, oh, I had like a stroke. And, you know, now I can't do this, or now I can't do that. Or, you know, my memory is horrible. – Participant 3, stroke survivor, 39-year-old, single queer woman

#### ***“I'm putting myself out there again”***

While many found that stroke impacted negatively on forming new relationships, a smaller number of participants had success in exploring new friendships/relationships post-stroke. These participants identified that by focusing on positive aspects of post-stroke life that they were able to identify new opportunities:

Anyway, in January, because I'm not wanting to let the grass grow under my feet. And being the sort of person I am, I found a new lady friend whom I'm still seeing. And we have, yeah, and we have a very healthy sex life. – Participant 2, stroke survivor, 66-year-old, partnered lesbian woman

## **Discussion**

This is the first known study to explore post stroke sexuality in LGBTQI+ stroke survivors and LGBTQI+ stroke survivors' partners. The main purpose of the study was to determine whether stroke changes the sexual experiences of LGBTQI+ stroke survivors and their partners, and if so, to understand the nature of those changes. In the present study, stroke caused negative experiences of sexuality in a variety of ways for LGBTQI+ stroke survivors and partners. Areas affected included sexual functioning, relationships, and identity which is consistent with previous stroke and health studies that explore the challenges impact of stroke and chronic disease on sexuality [10,35]. This study also explored how LGBTQI+ persons navigate changes in sexuality post-stroke, including the use of adaptation strategies and alternative sexual activities in an attempt to ensure that opportunities to express their sexuality were still maintained. Additionally, partners of LGBTQI+ stroke survivors were found to experience a change in their role of partner to carer and how this negatively affected their own personal needs. This change has also been found in existing stroke research which demonstrates changes in relationship roles and routines within heterosexual relationships [3].



The majority of participants identified their stroke was the primary cause of their sexual dysfunction. Many participants identified physical impairments such as hemiplegia or post-stroke fatigue. These issues contributed to sexual dysfunction due to decreased mobility or ability to initiate sexual activity due to fatigue. Erectile dysfunction was another physical aspect of sexual dysfunction experienced by some of the male participants within this study. Erectile dysfunction has been identified within LGBTQI+ health research [36–38] and existing stroke literature [39,40] as a significant sexual dysfunction experienced by men. This can affect heterosexual and non-heterosexual men in similar ways with varying levels of impact and distress. The variations in quality of an erection is important when exploring sexual intercourse such as penis-in-vagina (PIV) and anal sex [41]. Due to the level of erection non-heterosexual men require, those with even mild forms of erectile dysfunction may find difficulty in engaging in anal sex [42]. Even with the use of erectile aides such as Viagra and penile prostheses there is still no certainty that the quality of erection required will be achievable [43].

It is important to acknowledge that erectile dysfunction is not the only form of sexual dysfunction which can be experienced by LGBTQI+ stroke survivors. Issues with bowel management were also highlighted as an issue of concern in relation to sexual activity. Bowel management issues such as inability to pass feces impact one's desire for receptive intercourse. While it was acknowledged that medication was prescribed for bowel management, there was no clear discussion or acknowledgement on how the effect of bowel difficulties could impact on sexual activity from health professionals as reported by the participant. There has been limited attention paid to the impact of stroke related bowel impairment on sexuality, however the significance of bowel impairment on sexual functioning has been recognized among people with spinal cord injuries [44]. For health professionals this might point to the need for greater understanding of the impact of bowel impairments on sexual activity and the need to consider sexual activity when managing bowel concerns.

This is one of the first studies to actively recruit non-heterosexual women and provides new insight into the impact of stroke on women's sexuality. This study offers new insights into how women experience sexuality, highlighting that some seek intimate relationships and sexual activity. This is important as previous research has largely focused on relational aspects of sexuality for women, shaped by gender stereotypes and biomedical models of sexuality [17]. The current study indicates there is a need to consider sexual function and the impacts of acquired disability when exploring the broader understanding of sexuality and sexual wellbeing within non-heterosexual women.

This study highlights experiences of discrimination that participants experienced post-stroke within the LGBTQI+ community. For participants in this study, the LGBTQI+ community was considered to be a form of safety and inclusiveness prior to experiencing their stroke, however this was no longer the case post-stroke. This experience speaks to the challenge of intersecting forms of discrimination/oppression or the challenge of holding multiple minoritized identities [45]. A number of participants had identified that they felt excluded for the fact they no longer were perceived to be 'body beautiful' due to physical changes in appearance caused by stroke [46]. Previous research has identified an emphasis on the focus on physical attractiveness in gay men being of significant importance when exploring relationships with other gay men [47]. This can have substantial impacts on quality of life due to body image concerns, self-esteem, ability to engage in intimate relationships and emotional and psychology wellbeing [48].

Our study is one of the first to include LGBTQI+ partners of stroke survivors. Data from this study acknowledges that LGBTQI+ stroke survivor partners identified having experienced a change in their relationship dynamics and saw their role change from that of a partner to more of a carer. This is evident in existing stroke literature [3] and also LGBTQI chronic health literature which has often described how the partner ends up taking on completing tasks or care needs that the affected partner would otherwise normally do [10]. A previous study has found that same sex couples have been found to provide more emotional care than their heterosexual counterparts regardless of gender [49]. The partners within this study have all identified providing their stroke affected partner's with the support. The consequences of this on partners can lead to their own needs not being addressed, causing relationship strain or breakdown and even further isolating them from their engagement within the LGBTQI+ community further impacting their sexuality [50].

There are a number of limitations to this study, there was a high prevalence of gay men (12 in total or 52.2%) and therefore this paper provides limited insight into experiences of people from other diverse sexualities and genders. This limitation is a common finding with previous LGBTQI+ health literature, often resulting in a lack of representation of men and women who are bisexual, lesbian and transgender or gender expansive [10]. While this study has gone beyond the experiences of gay men, it is possible that had we been able to recruit a more diverse sample, we may have been able to identify a more complete understanding of the impact of stroke on LGBTQI+ sexuality. As research has identified, the experiences and health needs of gay men can differ from other sexualities and genders such as Lesbian, bisexual, transgender and gender expansive people [51]. Future research could enhance the recruitment of sexually and gender diverse stroke populations by incorporating a co-design approach within the research design, an approach that was not used in this study. Another limitation of this study is the lack of representation from the intersex population. While the aim was to recruit the diverse range of populations outside of the heterosexual norm, the complexities of sex, sexuality and gender have proven to be challenging. Understanding and accurately representing the intersex population is more challenging than what we had previously considered.

The findings from this study have illustrated the challenges and limitations that LGBTQI+ stroke survivors and their partners face due to experiences of changes in sexuality post-stroke. This paper has identified a number of areas that can assist in the development of clinical and rehabilitation interventions to aide this population:

1. Further research is needed to understand how multidisciplinary team members can build up these effective strategies to ensure that all LGBTQI+ stroke survivors and partners can continue to meaningfully express their sexualities. The form and approach to such support should be determined in collaboration with stroke survivors and their partners.
2. There were challenges identified related to physical changes, perceived unattractiveness, changes to identity, and lack of access in community spaces, which could result in feelings of exclusion from the LGBTQI+ community. Interventions that focus on broader aspects of sexuality, such as body image, sexual confidence, and relationships can provide much-needed support, enhance education, and potentially alleviate some of these challenges.

3. Sexual rehabilitation frequently relies on heteronormative assumptions which are often neither inclusive of nor useful to members of the LGBTQI+ community. Health professionals need to design sexual rehabilitation programs to take into account challenges experienced by LGBTQI+ persons such as difficulties with PIA (Penis-in-anus) or access to formal supports as well as addressing topics such as PIV (Penis-in-vagina).
4. Health professionals require sufficient training to help build confidence in their ability to address sexuality regardless of the persons sexual or gender identity. This is also in line with existing stroke research in heterosexual populations.

This study has achieved the beginning of an understanding of how LGBTQI+ stroke survivors and their partners experience sexuality post-stroke. The experiences reported by participants within this study can start to assist with the development of knowledge into the impacts of stroke on sexuality in LGBTQI+ stroke survivors and LGBTQI+ stroke survivors partners. The findings can also assist in the development of important resources and interventions for post-stroke sexuality for the LGBTQI+ population.

### Ethics statement

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