

## Research

# Exploratory perceptions of successful ageing and preferences for information and support amongst sexually and gender diverse people living with HIV in Australia

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Received: 29 August 2024 / Accepted: 17 October 2024

Published online: 25 October 2024

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## Abstract

The current exploratory study investigates self-reported perceptions of successful ageing, and preferences for information access and support, amongst sexually and gender diverse people living with HIV in Australia. Cross-sectional data, derived from a larger survey, were extracted for 12 participants who self-reported as living with HIV and completed questions pertaining to successful ageing and information/support preferences. Qualitative responses regarding successful ageing were explored through thematic analysis while descriptive statistics were used to analyse information/support preferences. Themes of (1) social factors, agency, and autonomy; (2) physical and mental wellbeing; and (3) considerations of care needs and information were generated from qualitative data about successful ageing. General practitioners (83.3%) and HIV support services (75.0%) were the most preferred sources of information about ageing and care supports. Findings from this exploratory study identify opportunities for policy improvements, provision of funding, and coordinated community support to enable sexually and gender diverse people living with HIV to experience successful ageing in Australia.

**Keywords** Successful ageing · HIV · Information preferences · Sexuality · Gender identity · Australia

## 1 Introduction

Estimated global prevalence rates of HIV are increasing amongst people aged 50 and older, [1, 2] with recent modelling suggesting that by 2027, the largest proportion of people living with HIV (PLWH) in Australia will be aged between 55–59 years of age [3].

These models carry important public health implications. Premature ageing of the immune system amongst PLWH has been associated with increased rates of cardiovascular diseases, renal failure, hepatic comorbidity, risk of infection,

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and mortality, [4] with a national study in Australia finding greater odds of HIV-positive gay or bisexual men developing diabetes, thrombosis, or neuropathy when compared with HIV-negative gay or bisexual men [5].

While the health risks associated with HIV imply a need for specialised health and care service provision, a recent qualitative study revealed many unmet health and social needs amongst people aged 60+ living with HIV in Canada [6]. Past trauma, stigma, and uncertainty about the future shaped care preferences and engagement [6], emphasising the need for health policy to provide a life-cycle approach to comprehensive, affordable healthcare for PLWH [7]. An Australian report also highlighted the importance of place, agency, social support, and stigma in ageing with HIV, calling for social supports to address social isolation, improved education of health and care providers, and increased use of peer-led models of care for PLWH [8].

Recent research into ageing with HIV has emphasised the impact of psychosocial factors on the experience of ageing [9]. Social determinants of health and access to resources have been associated with quality of life amongst people aged 50+ living with HIV in Australia [10], supporting calls from Australian researchers for improved access to medical screening and care, including measures to reduce disadvantage, build resilience, and address psychosocial issues to facilitate successful ageing amongst PLWH [11].

There is a growing need for research that explores preferences for facilitating successful ageing. Recent research in Southern California identified that while similar definitions about successful ageing were shared between people living with and living without HIV, those living with HIV appeared to place less emphasis on longevity, and instead placing more importance on quality of life [12]. This aligns with previous research exploring concepts of successful ageing amongst PLWH. One qualitative study explored perceptions of ageing successfully amongst PLWH in Ontario, Canada, using constructivist grounded theory approaches to generate themes related to resilience, social support, environmental context, stigma, and maintaining health as important concepts for successful ageing, emphasising the importance of subjective perceptions of success [13]. Another study in Canada sought to understand the values and aspirations of PLWH over the age of 50 to create person-centred goals around successful ageing [14]. This study reported proactive themes towards successful ageing such as (1) accepting limitations and coming to terms with the realities of ageing; (2) the need for staying positive and happy; (3) maintaining social supports where connectedness with others was deemed essential of successful ageing; (4) taking responsibility of one's health and social service supports; (5) maintaining a healthy lifestyle; and (6) engaging in meaningful activities such as daily living, being able to take care of oneself, and volunteering [14].

Given the projected increase in the number of older PLWH in Australia, it is timely and worthwhile exploring perceptions and preferences about ageing well while living with HIV in the Australian context. As such, the current paper is framed by the following research question: What views and preferences regarding successful ageing and support are held by sexually and gender diverse people living with HIV in Australia?

## 2 Theory of successful ageing

Despite ongoing debates surrounding the definition and utility of the 'successful ageing' theoretical framework, it remains a valuable lens through which to examine ageing in sexually and gender diverse PLWH [15, 16]. The original theory of successful ageing by Rowe and Kahn in 1997 emphasised continuation of health and lifestyle and avoidance of disease, [17] however this implied successful ageing was not possible when living with illness or disability, and ignored perceptions of wellbeing driven by subjective, cultural, and social factors [18, 19]. While acknowledging the impact of physical and mental wellbeing, a multidimensional approach [9] reflects a more holistic understanding of successful ageing, acknowledging that disease or disability does not preclude ageing successfully, and the role of psychosocial factors in successful ageing—as such, these domains are not mutually exclusive [9, 14, 20].

The importance of social connectedness for successful ageing has been emphasised in one qualitative study in the United States (US), in addition to physical, mental, and emotional health in perceptions of successful ageing among older LGBT people [21]. A subsequent quantitative study in the US examined perceptions of successful ageing in relation to quality of life [22]. While some trends differed across age groups, the results reinforced earlier findings, highlighting the beneficial effects of positive sense of identity and strong social support, and engagement (including employment and income), as well as participation in physical and leisure activities. Discrimination, chronic illness, and disclosure of sexual identity were associated with lower quality of life [22].

Similarly, research has demonstrated associations between psychosocial factors and perceptions of successful ageing amongst PLWH, [23, 24] adding weight to calls for clinicians to adopt a multidimensional approach to addressing

ageing and care needs of PLWH. [11, 25] Hence, in response to calls for further research into successful ageing amongst sexually and gender diverse older people [26], and to facilitate successful ageing amongst PLWH [11, 25], it is pertinent and appropriate to ask PLWH who are sexually and gender diverse what successful ageing looks like for them, and how they would prefer receiving information about ageing and care services.

### 3 Methods

#### 3.1 Survey development

In 2019 a working group (Queensland Ageing and Lesbian, Gay, Bisexual, Transgender, Intersex, Sistergirl, and Brotherboy Issues [QALSBI] working group) comprised of members of academic, government, and non-government organizations identified the need to revisit ageing and care services in Queensland, Australia. Importantly, the authors of this study are of diverse sexualities and genders, including holding intersecting identities such as ageing, living with HIV, culturally and linguistically diverse, disability, and living in a regional, remote or rural setting.

The group revised and deployed a survey developed by the LGBT Ageing Action Group in 2007–2008 to explore experiences and concerns about ageing among LGBTI, Sistergirl and Brotherboy people.<sup>1</sup> The survey was revised by the QALSBI working group in consultation with a Community Advisory Group (CAG) representing LGBTI, Sistergirl, and Brotherboy communities of intersecting backgrounds (such as First Nations Australians, culturally and linguistically diverse, abilities, age, spiritual affiliation), including those living with HIV to reflect social and political changes that have occurred since 2008 and to include current issues of importance. CAG members were given a \$100 gift card honorarium in appreciation for their time.

The full description of the survey can be found in the industry report *Building a Better Picture of LGBT Sistergirl and Brotherboy Ageing and Caring in Queensland* [27, 28]. The original survey and its questions were predominantly quantitative in nature, including demographic characteristics, exploring concerns about ageing, ageing/care service delivery, impacts of sexuality, gender or intersex variations on ageing/care service provision, and preferences about ageing/care service provision in Queensland, Australia. The survey also included several qualitative questions inviting participants to respond in their own words their opinions and hopes about ageing.

#### 3.2 Participants and recruitment

Multiple methods of recruitment were used to obtain a convenience sample, including distribution of flyers and social media tiles with a QR code/survey link through community and HIV-specific support organisations, and LGBTI, Sistergirl, and Brotherboy-specific organisations, including broader networks of the research team. The flyers described the study purpose as seeking to understand experiences and concerns of LGBTI, Sistergirl, and Brotherboy community members regarding ageing and care services, and invited people to complete the online survey. After reading the online participant information sheet, informed consent was obtained electronically by participants ticking a checkbox, allowing them to proceed and commence the online survey.

Data were included in this exploratory study if the participant (1) identified as a member of LGBT, Sistergirl, or Brotherboy communities; (2) self-identified as having been diagnosed with HIV; and (3) provided a response to at least one of four qualitative questions asking them to share their opinions and hopes about ageing (i.e., what it means to: (1) age actively; (2) age well; and what participants (3) look forward to about ageing; and (4) what they hope to see for older LGBT, Sistergirl, and Brotherboy people in the future). While twenty PLWH responded to the survey, twelve answered the qualitative survey questions and were included in the current study.

<sup>1</sup> Aboriginal and Torres Strait Islander peoples in Australia use the term 'Sistergirl' to describe gender-diverse people who have a female spirit and perform female roles in the community, and 'Brotherboy' to describe gender-diverse people who have a male spirit and perform male roles in the community. [39]

### 3.3 Data extraction

Quantitative data describing age, gender, sexuality, and geographical region were extracted from the larger data set, in addition to participant responses to the four qualitative questions regarding ageing, and their preferences regarding sources of ageing and care information and community-provided supports.

### 3.4 Data analysis

Frequency and proportions were calculated for nominal quantitative variables. Community-provided supports were synthesised into four categories: (1) Services; (2) Resources; (3) Social support; and (4) Support with services (see Table 1). As each category encompassed a different number of questions, the weighted average for each category was used.

Qualitative data were analysed using manifest content analysis, whereby all qualitative responses were read multiple times, coded, and then grouped into categories to develop common themes [29].

### 3.5 Ethical approval and informed consent

Ethical approval for the original survey was granted by the University of Southern Queensland's Human Research Ethics Committee (Approval No: H21REA098). All study activities complied with the ethical standards of the University of Southern Queensland's Human Research Ethics Committee, the 1964 Declaration of Helsinki and its later amendments, and the Australian National Statement on Ethical Conduct in Human Research (2007)—Updated 2018. After reading the online participant information sheet, informed consent was obtained electronically by participants ticking a box, which allowed them to commence the online survey.

## 4 Results

While the survey was also targeted towards persons born with innate variations of sex characteristics (also known as intersex variations/traits), no participants reported being born with innate variations of sex characteristics. In consultation with an intersex community representative (also a CAG member), and to avoid misleading readers or misrepresenting the experiences of people born with innate variations of sex characteristics, the results and discussion will only refer to sexually and gender diverse people.

**Table 1** Support categories

Type	Support
Services	LGBT, Sistergirl, and Brotherboy Communities-specific carers Provision of LGBT, Sistergirl, and Brotherboy communities' services
Resources	LGBT, Sistergirl, and Brotherboy Communities-specific resources on ageing/carers issues Information and referrals
Social support	Social groups/events Support groups Yarning circles <sup>a</sup> Intergenerational connections
Support with services	Advocacy Support in obtaining sensitive and appropriate assessment for service provision Support in accessing aged care and carers services

<sup>a</sup>Yarning is a storytelling practice within Aboriginal and Torres Strait Islander cultures in which a person is encouraged to tell their story from the position of their lived experience. Yarning and yarning circles promote Indigenous ontologies and improve cultural safety, and are key to decolonising research and health care practices with Aboriginal and Torres Strait Islander peoples [40].

## 4.1 Demographic characteristics

Of the 233 respondents who completed the original survey, twenty self-reported as living with HIV, and twelve participants living with HIV answered the four qualitative questions regarding ageing. Most participants were cisgender men (91.7%,  $n = 11$ ), with one non-binary person (8.3%). Most participants identified as gay (75.0%,  $n = 9$ ), with one identifying as gay and queer (8.3%), one as queer (8.3%), and one as same sex attracted (8.3%). The average age of participants was 58.8 (standard deviation = 10.4), ranging from 29 to 70. Most participants lived in metropolitan Queensland, Australia (83.3%,  $n = 10$ ), with two living in regional centres (16.7%). Out of the twelve participants, seven (58.3%) were born in Australia, while two were born in the UK (16.7%) and two in New Zealand (16.7%), respectively, with one person born in the US (8.3%). All participants primarily spoke English at home, and none of the participants identified as Aboriginal and/or Torres Strait Islander.

## 4.2 Qualitative results

Qualitative responses to questions regarding ageing well reflected the following themes: (1) social factors, agency, and autonomy; (2) physical and mental wellbeing; and (3) considerations of care needs and information.

*Social factors, agency and autonomy* Social connections were mentioned by several participants, with some describing the importance of having and maintaining "...good friends and supportive relationships" (gay, cisgender male, 61), others making reference to "having my social...needs met. Being valued and welcomed in the LGBTIQ+ community (gay and queer, non-binary, 61), with another participant suggesting "continuing to make a valued contribution to society" (gay, cisgender male, 58). Within this theme a few participants also made reference to "being visible, accepted and safe in the broader community" (same sex attracted, cisgender male, 60), with one specifying the importance of "real acceptance, not political correctness" for the future for older sexually and gender diverse people (queer, cisgender male, 67).

Agency was also mentioned by several participants, often in relation to desire to pursue their interests. While these activities varied among participants, they most often related to "...being able to engage in hobbies, pastimes, and travel independently for as long as I can" (gay, cisgender male, 54). Having a sense of purpose, or "having a reason to get up in the morning. Something to look forward to" (gay, cisgender male, 70), was also mentioned by some participants, including "maintaining meaningful connections and contributing to society in some way that is valued" by one participant (gay, cisgender male, 58).

*Physical and mental wellbeing* Sentiments pertaining to "Remaining active and healthy. Not feeling isolated" (gay, cisgender male, 63), "To stay...physically active—I swim and surf most days" (gay, cisgender male, 66), "Feel needed and wanted" (gay and queer, non-binary, 61), and "Keeping mentally active" (gay, cisgender male, 61) were mentioned by several participants as important to the ageing process. Similarly, one of the younger participants expressed "Having life outside of work, hobbies, exercise, [and] living life to the fullest" (gay, cisgender male, 29) as important to them to physically and mentally age well, while another participant expressed "Able to attend events and activities at [a] time and manner I choose. Not feeling depressed" (gay, cisgender male, 63). With one participant acknowledging limitations related to ageing: "Flourishing in as much as your mind and body will permit" (same sex attracted, cisgender male, 60).

*Considerations of care needs and information* Having their care and information needs met was described by many participants, with some commenting on the importance of responsive and person-centred care that provides "appropriate, flexible, tailored support" (gay, cisgender male, 54), and others referring to "access to LGBTIQ specific health and social care" (gay and queer, non-binary, 61), and specialist services. The need for "access to the resources and support so that I am able to age well. This includes financial and social support" (same sex attracted, cisgender male, 60) was also raised by one participant. Sexually diverse participants living with HIV also raised the importance of "Specific services for us. Proper care. A hub for the community" (gay, cisgender male, 29), "Specialist aged care providers" (gay, cisgender male, 58), and "Some sort of contact point of info hub that I can check my rights and activities open to me" (gay, cisgender male, 63). The twelve participants also provided insights to their preferences for accessing information and support linked to their sexuality and/or gender identity, ageing and PLWH. The below section delves into this aspect.

**Table 2** Preferred sources of ageing and care information

Source of information	N	%
General practitioners (physicians)	10	83.3
HIV support organisations	9	75.0
LGBT, Sistergirl, and Brotherboy communities-specific resources on options for support in my old age	7	58.3
Public health services	7	58.3
General information and referral service	6	50.0
LGBT, Sistergirl, and Brotherboy communities-specific health and support services	5	41.7
LGBT, Sistergirl, and Brotherboy communities-specific media	5	41.7
General community services	5	41.7
Government agencies	4	33.3
General media campaigns	4	33.3
LGBT, Sistergirl, and Brotherboy communities-specific support organisations	3	25.0

### 4.3 Preferences for accessing information and support

Table 2 reflects participant preferences for obtaining information from mainstream and LGBT, Sistergirl, and Brotherboy communities-specific sources. Participants ranked general practitioners as the most preferred source of information regarding ageing and care services (83.3%,  $n = 10$ ), followed by HIV support organisations (75.0%,  $n = 9$ ) with fewer participants preferring to receive information from general media campaigns or government agencies (33.3%,  $n = 4$ , respectively) or LGBT, Sistergirl, and Brotherboy communities-specific support organisations (25.0%,  $n = 3$ ).

Options for support from within the LGBT, Sistergirl, and Brotherboy communities regarding ageing and care were grouped into four domains: 1) services offered; 2) resources provided; 3) support regarding services; and 4) social support. Weighted proportions reflected that support with services (28.5%) was the most preferred type of support that participants would like to receive from community, followed by resources (26.6%), services offered (22.6%), and social support (22.3%).

## 5 Discussion

This exploratory study of perceptions of successful ageing and preferences for care services amongst sexual and gender diverse PLWH in the Australian context yielded results that align with previous research conducted globally, but novel within the Australian context. Similar to previous research exploring perceptions of ageing successfully amongst PLWH, participants in the current study emphasised the importance of maintaining social connections and supports, exercising agency in relation to lifestyle choices, activities, and personal responsibility [12–14, 24]. Findings also align with successful ageing themes found amongst PLWH in California that placed more emphasis on fulfilment and balance, adjusting to change, maintaining relationships, and choosing a proactive lifestyle compared with people living without HIV [12]. Establishing these preliminary insights into the Australian context provides directions for future research. They also provide information and insights to be seriously considered for policy makers, health service providers, HIV-specific support organisations, and LGBT communities-specific organisations to facilitate the provision of supports and services that maintain these activities and values that PLWH perceive as central for successful ageing.

Participants in the current study also discussed the importance of health and care services appropriate to their needs, echoing previous research calling for improvements to the organisation and provision of health and care services for PLWH [10, 11]. Through exploration of preferences regarding information provision, this study makes a novel contribution to the conversation about health policy and service provision through providing exploratory insight into how these improvements might be actioned. The majority of participants in the current study expressed a preference for receiving information from their general practitioner (GP; physician) (83.3%) or HIV support organisation (75.0%). The strong preference for receiving information from GPs reinforces the importance of trust in primary care



relationships for PLWH [30], and suggests that there is merit in providing support and resources for GPs to provide quality care for sexually and gender diverse PLWH as they age [31].

Preferences for the types of support that sexually and gender diverse PLWH would like to receive from LGBT, Sistergirl, and Brotherboy communities are consistent with a community-led and person-centred ethos and suggest that communities-specific organisations and HIV support organisations could expand the types of supports offered as PLWH age. HIV support groups are known to improve clinical outcomes [32], with strong evidence to support the value of peer-led support groups [33]. The current study also found that many participants hoped to receive support with ageing and care services and resources from LGBT, Sistergirl, and Brotherboy communities' organisations, revealing an opportunity for organisations to meet the needs of PLWH for information sharing and service support.

The findings from this study both align with and extend upon the multidimensional theory of successful ageing, by offering the perspectives of sexually and gender diverse people ageing with HIV in Australia, thereby contributing to the ongoing discourse in this area. Given that people ageing with HIV often do not experience an absence of disease and disability, [14, 34, 35] this research supports the notion that these factors are not the most critical components of successful ageing [14, 20]. Indeed, these findings reaffirm the centrality of psychosocial factors—such as access to appropriate health and care services, maintaining social connections and support, and exercising agency over lifestyle choices and activities—as key components of successful ageing [14, 15, 20, 21]. Contemporary understandings must reflect the changing narratives surrounding what it means for sexually and gender diverse persons to age well with HIV (as a chronic yet manageable health condition), including embracing and integrating resilience and strength-based theoretical paradigms [14, 20, 36–38].

Findings also identify potential policy and funding improvements to support sexually and gender diverse PLWH as they age. Given the projected incidence rates in Australia [3], it behoves policy-makers to take a proactive approach to developing policy provisions and access to funding and other resources to implement a life-cycle approach to HIV care [7]. Further research is needed to ensure that sexually and gender diverse PLWH receive the resources that they need, from within community and from health and care providers, to be able to experience successful ageing now and into the future [11, 23, 25].

## 6 Limitations

There are several limitations to the current exploratory study. Only twelve participants from the original survey both self-reported as living with HIV and completed the qualitative questions about ageing. While insights from this study regarding ageing reflect those found in the literature, they cannot be generalised to the wider population of sexually and gender diverse PLWH in Australia, and may also be subject to participation bias where only participants interested in the topic completed the questions. A larger, more in-depth study is needed to gain a more thorough understanding of the needs and preferences of sexually and gender diverse people ageing with HIV in Australia, including specific to carers. Additionally, the majority of participants identified as gay cisgender men, were from English speaking nations, with none identifying as Aboriginal and/or Torres Strait Islander meaning that broader diversity and intersectional factors amongst PLWH are not well represented in this sample, which highlights another important focus for future research.

Qualitative data were collected via the participant typing into a text box within the online survey, limiting the scale of the data that could be collected, and preventing researchers from being able to follow up and probe for more information. Further qualitative exploration of these questions in the form of in-depth, semi-structured interviews would yield greater detail to further inform health policy and service provision for sexually and gender diverse people ageing with HIV within and outside Australia.

**Acknowledgements** The authors express gratitude to the sexually and gender diverse people living with HIV who shared their perceptions about ageing well and preferences for information and support in Queensland, Australia. The authors would also like to acknowledge Lance Schema's contribution to the conceptualisation of this study.

**Author contributions** Annette Brömdal, Melinda Stanners, Amy Mullens, Lisa Beccaria, Joseph Debattista, Jennifer Sargent, Lisa Wojciehowski, Chris Howard, Ann Matson and Ged Farmer contributed to the design of the study. Data extraction, preparation, and analysis were performed by Melinda Stanners and Annette Brömdal. The first draft of the manuscript was prepared by Melinda Stanners and Annette Brömdal. All authors commented on all versions of the manuscript. All authors read and approved the final manuscript.

**Funding** This work was supported by the University of Southern Queensland with the first author as the lead investigator. The authors also acknowledge the financial support provided by Queensland Positive People, and Queensland Council for LGBTI Health.

**Data availability** The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available.

**Code availability** Not applicable.

## Declarations

**Ethics approval and consent to participate** The research was granted ethical approval by the University of Southern Queensland's Human Research Ethics Committee (Approval No: H21REA098). All study activities were performed in accordance with the ethical standards of the University of Southern Queensland's Human Research Ethics Committee, and with the 1964 Declaration of Helsinki and its later amendments, including the Australian National Statement on Ethical Conduct in Human Research (2007) – Updated 2018.

**Competing interest** The authors declare no competing interests.

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