

APPROACHES AND BEST PRACTICE MODELS OF CARE FOR ADVANCING THE QUALITY OF LIFE FOR PEOPLE WITH HIV IN AUSTRALIA

BY DR KIRSTEN MACHON, HIERO BADGE AND BRENT ALLAN

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BACKGROUND

This paper was prepared on behalf of HIV Online Learning Australia (HOLA), a joint project of Health Equity Matters (formerly AFAO) and the National Association of People with HIV Australia (NAPWHA), to inform and promote a better understanding of best practice models of care to support quality of life (QoL) among people with HIV in Australia.

It focuses on the practical approaches and best practice models of care for advancing a quality of life for people with HIV, for staff that work at AIDS Councils and organisations across Australia. This paper considers the evidence around the determinants of health and wellbeing and protective factors in HIV care and support which can help promote a higher or improved quality of life, and factors which can diminish or reduce quality of life.

It includes considerations for workers providing peer support, health services, social and community services and health promotion for people with HIV through AIDS councils, HIV peer organisations and linked services, and encourages an integrated and holistic approach to service design and delivery to support QoL.

ABOUT THE AUTHORS:

Dr Kirsty Machon (she/her) has been involved in HIV-related journalism, advocacy and policy development since the mid-1990s. She is a former Chair of the Victorian AIDS Council (now Thorne Harbour Health), has worked for AFAO and NAPWHA, and is Executive Officer of Positive Women Victoria. She has a PhD focused on ethical aspects of evolutionary theory.

Hiero Badge (they/them) is a scholar and freelance researcher in the public health sector. Over the last three years, they have delivered projects for the Australian Federation of AIDS Organisations, the International Council of AIDS Service Organizations, the National Association of People with HIV Australia, Positive Women Victoria, Queensland Positive People, UNAIDS and more.

Brent Allan (they/them) has worked across a range of NGO organisations and agencies both in Australia and internationally, including high-level roles for both government, industry and NFP leadership positions. They have extensive experience in community services sector management, specialist business qualifications and is well regarded for exceptional high-level communication skills with numerous publications and presentations at local, state, and national and international levels. They are a passionate advocate for civil society participation in public policy, community-based research and equipping community service sector personnel with skills in knowledge translation.



WHAT IS 'QUALITY OF LIFE'?

'Quality of life' is much more than just the clinical markers of HIV control through effective treatment (undetectable viral load, a high CD4 count, or the absence of HIV-related disease or drug treatment side effects). As the literature review undertaken during research for this paper has stressed, access to anti-retroviral treatment (ART) alone is insufficient to address the complex health needs of people with HIV, especially those experiencing one or more risk factors or vulnerabilities.

QoL is a concept which considers multiple cultural, demographic, economic, physical, psychological and social variables that can affect overall health as well as psychological and social wellbeing. An important aspect in understanding quality of life is that while there are tools that can help measure it, it is self-determined—it is the individual person's own self-described experience of their health and wellbeing which those tools or instruments are seeking to understand, capture and respond to.

The World Health Organisation (WHO) emphasises the aspiration of a QoL-focused approach to health care and social services as being to deliver the "highest attainable standard" of health. Health, as defined in the WHO Constitution, is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.¹

A recent consensus statement on HIV and quality of life, incorporates those clinical, psychosocial, and socio-political domains which are necessary considerations in quality of life.²

In this paper, we take a similarly broad view and consider:

- psychological wellbeing and health
- mental health
- connectedness, belonging, and opportunities to participate
- access to quality healthcare, treatment, and support
- financial security and wellbeing
- housing and food security
- work and education
- being able to express oneself freely and safely within the terms of a person's culture or community
- freedom from the stigma and discrimination that can be associated with a HIV diagnosis, with racism, with sexism, living with a disability, and stigma/discrimination based on sexual choices, identity or gender identity
- impacts of trauma and distress
- legal and political freedoms.

Researchers have argued for quality of life to be included as "the fourth 90" alongside 90% population rates for diagnosis, linkage to treatment and care and virological suppression as the measurable targets of the HIV response. They have described the ambition to move beyond clinical markers alone as a measure of HIV health outcomes "the new frontier".³

The aspiration to generate a way of meaningfully measuring QoL inspired the [PozQoL scale](#), a validated quality of life tool developed by Australian researchers and explicitly designed to recognise and capture non-clinical dimensions to quality of life for service providers wanting to understand the impact of their services. PozQoL uses questions across four 'domains' (psychological, social, health concern, and functional) to provide an overall picture of a person's quality of life.

It is acknowledged that no one health intervention or peer service can be solely responsible for the achievement of a “quality of life” for any individual service user or recipient of care. However, peer support workers, peer educators, peer navigators and workers providing other support programs or services for people with HIV all have a unique and important role to play by being aware of, supporting and nurturing the factors and conditions which support higher self-reported quality of life, and removing or acting to alleviate the impact of factors that lead to quality of life.

The key is not just the provision of integrated care models through appropriate and timely referral and support to quality services. It is equally important to be thinking of and appreciating quality of life in a holistic way, and acting in awareness of its many dimensions, when designing or delivering services or health promotion.

Adjacent to service provision, is also an advocacy responsibility within and across agencies to improve services based on these aspirations through the sharing of information and practice.

Social and support services and other factors relevant to QoL in care

The aims of HIV treatment are well-established: to suppress viral load and maintain undetectable levels, preventing both disease progression and transmission. *Australia's Eighth National HIV Strategy* follows the lead of the fast-track cities initiative aiming to accelerate HIV control by ensuring:

- **95%** of people with HIV are diagnosed
- **95%** of those diagnosed are receiving antiretroviral therapy
- **95%** of those on antiretroviral therapy achieve an undetectable viral load.

People with HIV, clinicians, researchers and policy makers have all drawn attention to the need for measurable quality of life targets to be embedded across the HIV cascades of care.⁴

Viral suppression is not the only aspect of care relevant to QoL outcomes and within specific communities or subpopulations of people with HIV there will be specific needs and concerns, which are identified and explored in this paper.

WHAT DRIVES QUALITY OF LIFE?

Researchers have noted that health care should look beyond HIV-focused care alone to address the overall health and well-being of people with HIV 'in an integrated, people-centred manner.'

This paper draws on this research to emphasise that:

- biological and non-biological factors put people with HIV at higher risk of health concerns,
- mental health conditions are highly prevalent,
- the effectiveness of care should be assessed using more than medical outcomes alone,
- patient-reported health outcome measures can provide information about an individual's health care and QoL but also inform the more efficient use of health care resources and support system-wide advocacy to improve QoL for all people with HIV,
- HIV-related stigma and discrimination, including discriminatory laws, as well as the social environment fostered by these laws, constitute major barriers to care.⁵

In 2021, NAPWHA undertook a series of web-based community engagement events to build an understanding of how people with HIV define QoL. [The Australian Community Accord on Quality of Life for People with HIV](#) calls for partners in the Australian HIV response to make QoL the goal of HIV health promotion, service design and service delivery.

The Accord draws tools for measuring QoL, such as PozQoL and is broken into themes that represent **POSITIVE** QoL drivers (social, psychosocial, environmental and health factors that enhance quality of life) and **NEGATIVE** QoL drivers (factors which can diminish self-reported quality of life).

We have structured the discussion in this paper under each of these themes.

THEME 1 BELONGING⁶ (AND ITS NEGATIVE, ISOLATION)

Belonging: Feeling a sense of belonging and enough of the kinds of social connection that matter to the person living with HIV

Isolation: A prolonged lack of belonging, social contact and connectedness⁷

What this means

Feeling that you belong—that you have a place in the world—is a natural and essential component of human wellbeing. Belonging is in its simplest meaning a sense of fitting in, of feeling a valued member of a group or community.

An HIV diagnosis is a traumatic experience that can disrupt social and community connections and increase isolation. A lack of social connection has been associated with poorer mental health outcomes for people with HIV.⁸

A sense of belonging can flow from many social and cultural sources. People may consider themselves as belonging to family, a faith or church, a culture, or country of origin. Communities of belonging and care may also form around shared practices of cultural expression. For example, communities based on intellectual life, sexuality, or using drugs can all be considered communities of belonging or care. Feeling like you ‘belong’ can support a greater sense of meaning and purpose, and positively influences someone’s quality of life.

Belonging to a community of people with HIV

Evidence suggests connection with other people with HIV provides a sense of belonging and helps people adjust to a diagnosis. The following findings from around the world strongly suggest the power and value of feeling like you ‘belong’.

- Connection with others living with HIV can also be crucial for people who have been living with HIV for longer periods of time, and may struggle with the impacts of stigma, poorer mental health outcomes and social isolation.⁹
- HIV peer support programs in Australia and elsewhere have assisted people to navigate the clinical, emotional, and social aspects of living with HIV and been credited with a greater sense of belonging. In an important Australian study of people’s experiences of diagnosis, people “commonly reported that peer support programs offered a sense of belonging and connection to a broader HIV community. This established a network, sometimes separate to their existing social networks ... with whom to share experiences of HIV.”¹⁰
- Membership in a social group or network can positively affect quality of life and aid resilience for people with HIV.¹¹
- Being a member of a religious or faith community may provide social support and help people cope with stress.¹²
- Social support may assist people to cope, make better health choices, improve emotional well-being and reduce stress. In India, social support has been positively linked to treatment adherence and CD4 count.¹³

Belonging: Considerations for practice

- ✓ People with HIV can find 'belonging' in many different places, but what is key is finding the communities or activities that make sense within the context of a particular individual's life.
- ✓ It is important for services to ensure that peoples' needs are understood, and people are matched with the most suitable available HIV peer support.¹⁴
- ✓ Offering a range of activities and options for people with HIV to gather in different ways (considering age, sexuality, gender, spiritual belief, common interests) increases the likelihood people will find a supportive experience that supports QoL and is personally valued and sustainable.

Technology, online communities and belonging

The community-wide disruptions and lockdowns which occurred during the COVID pandemic disrupted both healthcare service delivery and the delivery of peer support and social support, forcing many services delivered face-to-face to be delivered online.

Many HIV , organisations' so reads 'Many HIV organisations and service providers and service providers accelerated online and digital health promotion, education, peer support, social support, clinical care and psychological care.

The cost of technologies, poor infrastructure, cognitive issues, anxiety, and concerns about online safety and privacy are among the factors that can exacerbate what has been called the digital divide or digital inequality.

It has been highlighted, for example, that while digital technologies can facilitate healing and cultural continuity for young people from marginalised communities, more targeted funding is needed to develop and promote these opportunities and evaluate their effectiveness.¹⁵ In Victoria, telehealth was largely found to be acceptable to patients at one major metropolitan HIV treatment centre, indicating that changes brought about by the COVID pandemic have not all been negative in relation to health service access.¹⁶

Technology: Considerations for practice

- ✓ Service providers widely recognise the unique benefits of online spaces and approaches to improve the accessibility of services. Though most agencies agree they do not replace face-to-face service delivery, one-on-one, group support, health promotion and education can all be effectively and cost-effectively delivered online and should be considered an essential part of the repertoire of service delivery.
- ✓ Consider prioritising programs to assist people to both access and utilise new technologies and improve digital literacy.
- ✓ Being transparent about privacy protection may assist some people to feel more comfortable in digital and online community spaces.
- ✓ Organisational websites an opportunity to share stories of lived experience and health promotion information and connect people to the value of peer support through readily accessible options, for example, podcasts and videos ([such as these from Positive Women Victoria](#))

THEME 2 MEANING

Where does HIV 'fit into' a person's life? What meaning and purpose can an individual find in living with HIV?

Lack of meaning may be experienced as lack of cohesion, purposelessness, or disorientation.

People may have many things in their life to which they attach meaning and which improve a self-reported quality of life including:

- family relationships, friendships, and social relationships,
- work: employment not only provides financial security but may additionally provide a source of identity and meaning that supports wellbeing,¹⁷
- hobbies, creative pursuits, art, music,
- sport and physical activity,
- religion,
- intellectual activity and the pursuit of education,
- sex and sexuality,
- volunteering, and
- pets.

'Meaning' of an HIV diagnosis

Meanings, both positive and negative, also attach to an HIV diagnosis. People may attach positive or negative 'life narratives' to their diagnosis. Examples of ideas associated with a positive narrative are notions such as surviving, thriving, overcoming adversity, gaining strength from challenges, or recognising the opportunities to develop cultural, community or friendship networks associated with HIV that a person may otherwise not have formed.

Negative 'narratives' may be strongly associated with the idea that HIV imposes its own meaning on a person and their life and that it is difficult to escape this. Examples of negative narratives and ideas: the belief that an HIV diagnosis means a person is bad or blameworthy; that HIV will inevitably lead to becoming physically unwell or remaining unwell; that HIV will reduce or preclude social connection; that HIV leaves little hope of a fulfilling sexual life, family or healthy relationships.

The meaning a person attaches to HIV is highly mediated by social and cultural narratives relating to HIV, which can differ in different social, political and cultural contexts.

Meaningful connections through peer support

Peer support can be a crucial factor in helping challenge negative narratives taken on because of the attitudes of others. People with HIV can often feel very alone in their experiences of stigma. Hearing that others have lived through this experience and the strategies they may have used to get through it can be immensely comforting and validating.

Peer support also plays a key role in helping individuals find value, purpose and connection following an HIV diagnosis.

Meaning and age

Attitudes to ageing across the community generally can often be negative. People may attach a negative meaning to ageing itself, or they may assume that ageing is always associated with a reduced quality of life. It may be assumed that ageing is associated with poorer QoL because people have lived longer with their HIV diagnosis, may have multiple health concerns, or may experience increased uncertainty in relation to income, housing, mobility or social support. However, the literature supporting this paper shows that an older age is not universally associated with a poorer quality of life.

In different settings, studies have shown that age relates to HIV health and wellbeing outcomes in a varied, complex picture highly influenced by clinical, social, and environmental factors. For example:

- Younger people with HIV have been found to have an increased likelihood of behavioural, cognitive and emotional difficulties (East Africa).¹⁸
- In the Australian *HIV Futures 10* report, 44% of respondents under the age of 35 reported a poor quality of life compared to just 15% of respondents aged over 65. *HIV Futures 9* highlighted that the age group of 50-64 might be vulnerable to reduced QoL linked to financial insecurity and that this age group may have needs not being met as support packages and policies are targeted to people over 65.¹⁹
- Ageing and stigma may interact in ways that can promote increased isolation and poor mental well-being, mediated by cultural factors (attitudes to older people and their bodies, sexual cultures which devalue older bodies) or other factors such as exercise, diet, reduced family or friendship networks, or poverty.
- One US study found people with HIV may view their diagnosis more positively, perhaps due to the effect of being a self-perceived 'survivor'.²⁰

Ageing: Considerations for practice

- ✓ Service providers and services should be aware that while older people with HIV may experience more complex health needs, it should not be presumed that older people experience poor quality of life or that HIV has an overwhelmingly negative meaning.
- ✓ Ways to support older people with HIV may include peer-led support and programs (e.g., elder advocacy, elder peer navigators), social support (age-appropriate events and activities), and linkage to care and support to help older people navigate the complex health system.
- ✓ Representing a range of bodies, ages and experiences in a positive way is important in service provision and in health promotion materials.

Meaning in religious and spiritual belief

The literature review highlights the central role religious and spiritual beliefs can play by offering meaning and community in the lives of many people with HIV. Having spiritual or religious beliefs has been associated in some studies with self-reported wellbeing, medication adherence, and decreased anxiety and depression among people with HIV. Young people in Africa, for example, may rely on spirituality and religion as sources of strength.²¹

Among people with HIV in Australia who are overseas-born, connection to family and community through cultural practice and spiritual or religious institutions can form an important aspect of overall connectedness and support.

As with the literature on ageing, however, religious or spiritual beliefs can have negative meanings for some people with HIV, particularly in relation to sexuality and gender. For instance, the belief that 'HIV is a punishment from God' has been shown to predict disease progression in adults.²²

Religious and Spiritual Belief: Considerations for practice

- ✓ Care and support models for HIV should not assume that religious beliefs or faith communities play an exclusively negative role in QoL.
- ✓ Service providers should consider how spaces where services are provided can be welcoming and friendly to people of different faiths.
- ✓ Referral pathways to pastoral care, working with faith-based communities to tackle HIV myths/stigma in culturally appropriate ways.
- ✓ Establishing partnerships with bodies representing multicultural and/or faith communities is important to reflect diverse client needs.
- ✓ Peer support workers/peer navigators should be supported with information and where relevant, training, to ensure they are able to work confidently and sensitively with people of different faiths and beliefs, including beliefs which may differ from their own experience or views.
- ✓ Peer support/peer navigator staff from within faith-based communities/cultures may add depth of lived experience to programs.

THEME 3

CARE (AND ITS OPPOSITE: NEGLECT OR DISREGARD)

Holistic HIV care goes beyond viral suppression and includes the full spectrum of issues and experiences that affects quality of life for people with HIV.

The Call to Action of the PozQoL Accord is that HIV care should in the first instance address the specific care needs for people with HIV. These are:

- comorbidities (conditions or illnesses a person may have alongside HIV)
- healthy living (supporting people with the tools and resources they need to maintain e.g., a healthy diet, exercise, and environment)
- mental health
- polypharmacy (the need to take multiple medications)
- treatment literacy (ability to understand how HIV treatment works and what its aims are)
- chronic pain.

A key principle of care which enhances quality of life is that it places the person with HIV at the centre of their care as an active partner and decision-making agent, rather than seeing the 'patient' as passive recipient of the knowledge of a clinical team. A review and discussion of client-centred models of care emphasised the following characteristics.

- Care providers work in partnership with the person living with HIV to identify and meet the person's needs.
- Clear, appropriate, and jargon-free language is used. People are equipped with knowledge rather than just provided with information.
- Care is coordinated, and inclusive of allied health and community services.
- The care environment is open, welcome, and enables discussion.
- Trust: privacy is maintained, and confidentiality is respected at all times.
- The care provider is respectful, withholds personal judgment and does not make assumptions or stereotype.
- The perspective of the person with HIV is listened to and valued; self-reported symptoms or side effects are taken seriously and never dismissed.²³

Meaningful engagement in service design and delivery: MIPA/GIPA

The principle of the Greater and More Meaningful Involvement of Positive People (MIPA/GIPA) aims to realise the rights of people with HIV, including the right to self-determination and participation in decision-making and to enshrine this through meaningful consultation, engagement and co-design at all levels of the HIV response.²⁴ The GIPA principles were first adopted by 189 United Nations member nations in 2001, and the principles have subsequently been amended to reflect importance that engagement is meaningful rather than tokenistic.

Organisations who want to examine how to deepen their understanding of how they are delivering on the MIPA principles, and address any gaps, can consider undertaking an audit process and several key HIV agencies in Australia have done this.

MIPA/GIPA: Considerations for practice

- ✓ Meaningful involvement and participation of people with HIV occurs at all levels of program conception, design, delivery and evaluation; consider tools such as reference or steering groups, focus groups, designated places on program design/planning teams.
- ✓ Peer-directed programs should be peer-led.
- ✓ Feedback from program participants input is sought and incorporated.
- ✓ Staff are aware of and understand the benefits and principles of MIPA.
- ✓ Consider an organisation wide MIPA audit to identify gaps and improve meaningful engagement of people with HIV in service delivery or design.
- ✓ Be an advocate for MIPA and encourage care and support partner services to involve and engage people with HIV in service design or delivery where relevant.

Safe and integrated referral pathways

It is crucial people with HIV are referred to safe and appropriate services that provide non-stigmatising care.

Consideration for practice

- ✓ Connect with and contact service providers in your referral networks to share up-to-date information and knowledge and the lived experience of people with HIV.
- ✓ Ensure services know and understand how to refer people to HIV peer support.

THEME 4 SUPPORT

Receiving support when times are tough from positive peers and organisations that provide social and support services

A lack of support can generate and exacerbate feelings of isolation, loneliness, and helplessness

Peer support and peer-led engagement

Peer support and peer navigation

The provision of care, social and emotional assistance, guidance, and information to people with HIV by people also living with HIV is a crucial and longstanding part of the Australian HIV response, used in both structured ways (paid staff and volunteers) and informal models.

There is a body of literature demonstrating the value peer support, which has been shown to have health benefits in areas that include medication adherence.²⁵ A [recent systematic review and meta-analysis](#) of over 20 studies involving over 7600 individuals showed that peer support increased retention in care and the likelihood of achieving viral suppression.²⁶ Recent Australian research based on interviews with program staff, peer workers and clinical care staff highlighted that peer support is a unique resource, supporting personal change and challenging stigma. Partnerships linking care teams to peer support programs may also beneficially influence quality of care.²⁷

Australian GPs interviewed about peer navigation programs in Queensland found peer navigators helped to normalise HIV, to alleviate fear and stigma, and to educate and translate clinical information for patients. GPs valued peer navigators as a bridge to social and support outside the clinic.²⁸ A particular strength was the capacity of peer navigators to develop practical and innovative solutions outside the scope of the clinic to enhance care. Lived experience of HIV—especially where this intersected with the clients' gender, cultural identity or sexual identity—was seen by GPs as an essential connection.

GPs also highlighted challenges for peer navigator roles and programs, including a lack of awareness of peer navigation opportunities, and uncertainty about how to refer or connect to the peer navigators. The need to be confident that confidentiality was protected for shared clients before referring was stressed, particularly for Aboriginal and/or Torres Strait Islander communities.

Australian research looking at the experience of people recently diagnosed with HIV found that a key benefit of peer support was that it offered firsthand and non-clinical perspectives on living with HIV.²⁹

Where services or health promotion cannot be peer-led, it should include participation and input of people with HIV right through from service conceptualisation and design to oversight, delivery evaluation and follow-up.

The [NAPWHA Australian Peer Standards](#) provide a framework for understanding best practice in the provision of peer support programs.

Peer support should be safe for both the service recipient and the peer delivering/providing the service. This means:

- **Physically safe:** conducted in a safe environment where privacy can be respected
- **Psychologically safe:** staff and volunteers understand the personal and professional

limits of the service and of their own lived experience, are informed about and aware of the many ways trauma can affect people with HIV.

- **Professionally and clinically safe:** information or advice is not provided which the peer is not qualified or suitable to provide, and clients are referred to other services as needed. Workers and volunteers are given training and ongoing support.
- **Culturally safe:** in some circumstances it may be ideal for a service to be provided by a peer who also shares specific lived experience (such as being Aboriginal or Torres Strait Islander, gay, a woman, trans-identified, or a person with lived experience of injecting drugs).

Support considerations for some specific communities of people with HIV

In this section, we comment generally on the support needs of some specific communities of people with HIV, noting that issues for other communities (heterosexually identified men, people from diverse cultures, and men who have sex with men) are also discussed in other sections of this paper.

While we comment on some overall patterns and needs identified in research, it is emphasised that within all of these groups, individual experience and lived experience of HIV is diverse.

It's important to bear in mind what is sometimes referred to as 'intersectionality', that is, recognising people may identify as a part of several specific groups, for example, being an Aboriginal transgender woman. An intersectional approach recognises the cumulative effect that multiple forms or experiences of social marginalisation may have on quality of life.

Women

Women make up approximately 12 percent of people with HIV in Australia. Women have specific clinical needs across their life, including sexual health and reproductive needs, and different needs during menopause, and as women age.

Women report high levels of stigma and fear of stigma, due to the relatively small number and invisibility of women living with HIV in the Australian community.

Women have a higher likelihood of being diagnosed with HIV in a low caseload practice or in a hospital, rather than a higher caseload or HIV-experienced clinic.

Women may face significant additional life challenges, such as raising children, and/or family and gender-based violence.

Aboriginal and/or Torres Strait Islander people

Barriers to accessing care may explain an historically higher prevalence of HIV among Aboriginal and Torres Strait Islander people compared to prevalence in the Australian-born non-Indigenous population—though recent figures suggest this may be changing this may be changing, these should be considered in the context of interruptions to healthcare due to COVID-19.

Issues that affect QoL such as late diagnosis, not being offered or not seeking testing, not being aware of or using interventions such as treatment as prevention (TasP) and post-exposure prophylaxis (PEP), and discrimination and stigma regarding HIV have been identified.³⁰

Other factors that may affect QoL for Aboriginal and/or Torres Strait Islander people with HIV include financial stress, other health conditions, not being able to access culturally

appropriate services, geographical isolation of some communities, and lack of access to education or employment opportunities. Competing and complex life-demands on individuals can mean personal health is de-prioritised.³¹

Transgender, nonbinary and gender-diverse people

[A survey of 928 Australians](#) who identified as transgender, gender diverse or non-binary reported they had experienced:

- discrimination when accessing health care (26% of participants)
- verbal abuse (63%)
- physical assault (22%)
- depression (73%)
- anxiety (67%)
- self-harm (63%)
- attempted suicide (43%)

One third of participants (32%) identified better education for health care practitioners about trans and gender diverse people and their health as the top health priority for this group. Of this survey cohort, five people identified themselves as living with HIV.³²

Globally, the World Health Organisation emphasises that transgender people are at disproportionate risk of HIV, with the prevalence of HIV in transgender women reported as being as high as 28% in Eastern and Southern Africa.

Barriers to care include stigma and discrimination, the legal barriers, and violence. There may be high rates of participation in sex work within communities.

The US Centers for Disease Control and Prevention has [reported that HIV prevalence among transgender people is very high](#) in some US cities, as high as 58% in Atlanta, linked to issues including homelessness, high rates of participation in sex work, and lack of access to affordable medical care. Prevalence was very high among transgender people who identified as black (62%) and first nations trans people (65%).³³

People who inject drugs

In Australia, the prevalence of HIV among people who inject drugs is very low, due to important public health policies like needle and syringe programs and dispensing machines and peer-based harm reduction education—which have been mainstays of the response—and interventions such as safe injecting spaces. However, rates of hepatitis C, although now a curable condition, have been historically high.

People in the *HIV Futures* survey cohort who have reported past but not current use of injecting drugs reported greater levels of dissatisfaction with their experiences of receiving health care, and difficulties navigating the health care system, suggesting disparities of access. People currently using injecting drugs were more likely to have skipped or missed treatment doses for reasons including cost.

But this analysis also challenged some myths and stereotypes, finding self-reported QoL among those who reported current use of injecting drugs was higher than for the *Futures* cohort overall. This was attributed tentatively to the idea that some people who inject drugs may feel a part of a social community that provides a sense of attachment and belonging.³⁴

The *NAPWHA Stigma and Resilience Framework* (2019) highlighted that many people who inject drugs have a sense of being doubly stigmatised, and fear of discrimination and worry that accessing health services may place them at risk of being identified or even prosecuted.

Potential strategies investigated in the framework to reduce stigma and discrimination and its impacts on care included peer-led co-design of programs and services and their promotion.

THEME 5 INSECURITY (AND ITS OPPOSITE: STABILITY, SECURITY, ASSURANCE)

Not having secure living arrangements and life circumstances can affect health outcomes. Forms of insecurity can include poverty, insecure or insufficient income, precarious employment, food insecurity, and being homeless or living in unsatisfactory housing.

Poverty and insecure or insufficient income

Multiple studies have highlighted financial stress and poverty as risk factors for reduced quality of life among people with HIV. Poor self-rating on measures for poverty is associated with higher rates of anxiety and other mental health concerns and unemployment is a significant predictor of depression.³⁵

The *HIV Futures* study, tracking the self-reported lived experience of Australians with HIV over more than twenty years, has found, as recently as 2022, an overall picture suggesting a greater vulnerability to financial security than the Australian population as whole, with:

- 30.3% reporting their main source of income to be social security (e.g., pension, disability pension or other government benefit)
- 26.5% reporting an annual household income of less than \$30,000
- 17.2% experiencing financial stress in the past 12 months (inability to pay, or difficulties in paying, a mortgage, rent or bills).

Women were more likely than men to have experienced financial distress compared to the cohort overall. *HIV Futures 9* also found that women were less likely than men in the cohort to own their own home, and more likely to be living in a single-income household. Women reported overall lower average incomes compared to both the Australian population and men in the study.³⁶

Employment

Poverty and/or unemployment are two critical factors affecting quality of life. In the *HIV Futures 10* cohort, 57.6% of respondents were in the paid workforce, compared with an overall Australian workforce participation rate of 66.8%.³⁷

Among the reasons people with HIV may not participate in the paid workforce are:

- Older age
- Having been out of the workforce for a substantive period due to an HIV diagnosis
- Poor health or comorbidities, including mental health issues
- Experience or fear of discrimination at work or in the job market
- Visa status affecting ability to work
- Limited ability to access technologies such as computers or smartphones
- Language barriers

Employment: Considerations for practice

- ✓ Technology support programs for clients (HIV sector and other programs) e.g., such as those offered by the Australian government.
- ✓ Small grant programs or specific programs to support return to work are available through some state-based HIV services organisations, for example, the Positive Women Victoria Rose Fund, and Positive Life NSW Employment and Vocational Support program of activities. Queensland Positive People's Hope Fund can support work-readiness costs such as obtaining a driver's license.

Education

Along with income and employment, education can be an important socioeconomic determinant of quality of life and affect access to care and support.

Education: Considerations for practice

- ✓ There are opportunities to support the education needs and goals of people with HIV through skills-based programs such as work-ready or work-entry programs. Small grant programs may assist with the cost of preparing for or entering education. For example, Positive Women Victoria's Rose Fund offers grants towards course fees or equipment.

Food Insecurity

Food insecurity refers to being unable to access sufficient edible and nutritious food to maintain good health and in the case of children, healthy development. Although often associated with middle-income or low-income country and community settings, food insecurity is a significant issue in higher-income countries as well, influenced by factors including:

- homelessness, housing insecurity or the high cost of housing
- unemployment
- inability to legally work e.g., due to visa or immigration status
- isolation
- geographical issues, e.g., the expense of fresh foods in remote communities, or the inability to access fresh food markets due to transport or distance
- mobility, e.g., living with a disability
- lack of social or family support
- difficulties in accessing food support services (for example, the stigma associated with this, eligibility, lack of knowledge of services, or high levels of service demand)
- mental health stresses within households
- prioritising the cost of healthcare (blood tests, medication co-payments, doctor visits).

HIV stigma may make some households more vulnerable to food insecurity by increasing social or community isolation. One US study suggested that food insecurity was a stronger predictor of depression or poor mental health than income alone. Food insecurity has also been linked to depression, stress, or feelings of disempowerment and may affect social connectedness.³⁸

People with HIV who may be more vulnerable to food insecurity are:

- older women and women living alone on low incomes
- people who are homeless or have insecure housing
- refugees, asylum seekers, or people whose residency status limits their ability to work
- people, including Aboriginal or Torres Strait Islander people, living in geographically remote communities where fresh food is expensive and choices are limited
- those for whom mobility or lack of social support affects knowledge about or access to services.

Food insecurity: Considerations for practice

- ✓ Ensure staff at services are aware of referral pathways to local services supporting access to safe food.
- ✓ Consider access to quality food as a potential need to explicitly ask about and address in client induction processes.
- ✓ As food insecurity can affect many people and may be a source of shame, it is important not to make assumptions about who may or may not be experiencing or at risk of food insecurity.
- ✓ Catering for client events should ensure food available to reflect a variety of cultural needs.
- ✓ If your service cannot offer a food voucher service or pantry service, it may be possible to partner with or set up a referral arrangement for your client group.

THEME 6 STIGMA

There are many and various ways in which people are devalued as people for having HIV.

Stigma is an impediment to flourishing, inclusion and self-fulfilment.

'HIV stigma' refers to the ways people may be judged, socially or personally devalued, or treated as different or lesser simply for having HIV. Stigma can manifest through labelling, stereotyping, social separation, devaluation of social status, and discrimination.³⁹

A 2022 series in *Journal of the International AIDS Society* emphasises that stigma is not just individual or interpersonal but structural and embedded in discriminatory political and social policies identified right around the globe that can affect individuals' QoL. One crucial response is peer support, but system-wide peer-led interventions are also called for to address stigma and discrimination in social and health services.^{40,41}

This is not just a problem in overseas settings. In 2022 the Australian Stigma Indicators Monitoring Project found 37% of *HIV Futures 10* respondents had experienced some form of HIV-related stigma in the prior 12 months. One-third said health care workers treated them negatively or differently.⁴² In Vietnam, it was found that multiple actions can be needed to tackle HIV-related stigma in the health care system, beginning by educating senior managers and medical opinion leaders using messages co-created with affected communities to challenge fear and misconceptions.⁴³

The Stigma Indicators project also suggests that people with HIV commonly experience negative attitudes from potential sexual partners.

People can internalise stigma as negative self-image. Stigma contributes to poor health outcomes.⁴⁴ It can have severe personal but also public health consequences. In Iran, stigma has been linked to people avoiding HIV testing, poor treatment adherence, and limited access to healthcare.⁴⁵ Stigma can affect sexual, romantic and social relationships and is associated with anxiety, depression, poor general health and suicidal feelings.⁴⁶ HIV stigma and discrimination can also negatively affect self-assessed mental well-being.⁴⁷

Types of stigma

HIV stigma can take different forms.

Anticipated stigma: awareness of negative stereotypes and ideas about HIV and the expectation or fear that these will lead to discrimination.

Enacted stigma: discrimination, marginalisation and violence that people with HIV may face from others. Enacted stigma is strongly associated with poor quality of life.

Internalised stigma: when a person with HIV 'accepts and endorses' harmful beliefs and feelings like shame, guilt, negative self-judgement, this may lead to self-isolation or withdrawal from social interaction or support.

An often-overlooked form of stigma is **stigma-by-association** affecting the partners or children of people with HIV through negative judgment or stereotype. People living with HIV may fear the impact of disclosure on family members and partners and in particular, children.

Other stigma resources

The [National Strategic Framework to Address HIV Stigma and Build Resilience Capacity for People Living with HIV](#) (2019) is a comprehensive exploration of HIV stigma, its effect on specific communities, and a framework for service providers to address and respond to its impacts.

HOLA has recently provided an [important paper](#) outlining considerations for organisations who may want to design, implement or evaluate programs or measures to address and tackle HIV stigma.

THEME 7 DISTRESS

Distress is characterised by an acute or chronic lack of psychological ease intruding on everyday life

Trauma and distress

People may experience distress as acutely linked to a specific occurrence or event, such as a HIV diagnosis, the death of a close friend or family member, a relationship or marriage breakup, or an event such as job loss or a sudden change in personal circumstances.

Distress may also be chronic and ongoing, and linked to trauma.

Trauma refers to the complex set of emotional, psychosocial, and physiological effects and impacts that can follow from a major life-threatening or life-changing event such as an accident, a violent crime, a sexual assault, war, or natural disaster. Impacts of trauma may continue for many months and years after the initial shock of the event. HIV can be traumatic and lead to ongoing distress for a number of reasons, including:

- the shock of diagnosis
- the stress of stigma or discrimination
- the effect of isolation or loss of connection to community or family, and
- illness associated with HIV.

Trauma may also be compounded by other traumatic or distressing events or circumstances such as:

- intergenerational trauma
- experiencing or fleeing from war or torture
- racism
- homophobia
- family violence, gender-based violence, sexual assault.

Sexual trauma and women

Research in the United States has linked HIV transmission in women to an increased likelihood of having experienced sexual trauma.⁴⁸ Sexual trauma can have ongoing personal impacts, including increasing the likelihood of self-harm or of risk-taking behaviours as a response to traumatic experience.

Intergenerational trauma

Intergenerational trauma is a discrete form of trauma which occurs when traumatic effects of events are passed across generations without exposure to the original event.

This form of trauma has been shown to affect families and individuals where there have been community-wide specific impacts of social events, such as the intergenerational effects flowing from the forced removal of children from parents and the impacts of racial discrimination in Indigenous communities with impacts including poorer health outcomes, higher rates of incarceration, and high rates of mental health concerns, alcohol and drug use, and the disconnection of communities.

Asylum seekers and refugees

Intergenerational trauma may be an issue for people from communities fleeing war, and people who are refugees or asylum seekers can experience mental illness, anxiety and post-traumatic stress. However, rates of access to care or support may be low, and affected individuals may seek support more readily among their own communities than by accessing professional health services, including specific services for people who are survivors of torture.⁴⁹

Late testing and diagnosis

A late diagnosis of HIV is often an unexpected diagnosis, and may be associated with stigma and trauma, potentially exacerbated by symptomatic illness. In Australia, individuals from some population groups may be at risk of being diagnosed with HIV late.

For the population group of heterosexually identified people, for example, the proportion of those living with HIV to have been diagnosed has tracked from 84% in 2017 to just 85% in 2021, whereas 93% of gay and bisexual men living with HIV are estimated to have been diagnosed in 2021.⁵⁰

Among transmissions attributed to heterosexual sex, a concerning 58.4% were diagnosed late. Australian surveillance data estimates that at the end of 2021 the proportion of people with HIV but unaware of their status was highest among people born South-East Asia and Latin America (25% each), then Sub-Saharan Africa (10%), compared to those whose exposure risk was male-to-male sex (7%).⁵¹

The Australian peer-led community organisations who provide peer support for people with HIV all confirm a sharply increasing number of referrals from new clients from countries of origin in South-East Asia and Sub-Saharan Africa, including women and heterosexually identifying men.

Improving timely diagnosis through testing: Considerations for practice

- ✓ Increase access to rapid and point-of-care testing (models and examples include the SAMESH program vending machine program in South Australia, the RAPID clinic and program in Queensland, the Pronto clinic in Victoria) to encourage testing quickly and in privacy.⁵²
- ✓ Advocacy: raise awareness and increasing knowledge among low-caseload GPs to promote HIV testing as part of routine sexual health testing to de-stigmatise the testing experience.
- ✓ Increase awareness and promote availability of home testing with appropriate information and linkage to care and support.
- ✓ Promote opt-out testing for HIV as part of routine sexual health monitoring to destigmatise and normalise HIV testing.

Lack of information or incorrect information provided at diagnosis

Women and heterosexually identified men may have a higher likelihood of being diagnosed in a clinical setting such as a general practice where the clinicians may not be experienced in HIV management, increasing the risk of a traumatic diagnosis experience.

There is evidence that as a population, women may be less likely to be provided with important information at diagnosis, including information that if taking antiretroviral treatment and achieving an undetectable viral load, HIV cannot be transmitted to sexual partners (“undetectable = untransmittable”, or U=U) or the knowledge that women living with HIV may safely become pregnant and breast-feed.⁵³

Improving the diagnosis experience: Considerations for practice

- ✓ [NAPWHA's HIV101](#) project is an online resource which is aimed at improving the experiences and outcomes of a HIV diagnosis, particularly for clinics with no existing HIV caseload or a low caseload. The [Victorian HIV Service](#) HIV Connect can link GPs to experienced HIV clinicians by phone and may be a model for other states.
- ✓ Introduce or include programs to support heterosexually identifying men, examples include specific peer navigator programs such as those offered through Queensland Positive People and Living Positive Victoria.
- ✓ Utilise pathways to referral connection such as the [Heterosexual Men's Advocacy Network \(HetMan\)](#), a national network supported through NAPWHA.
- ✓ Health promotion focused on general practitioners may also help ensure the diagnosis experience is not stigmatising for heterosexually identifying men accessing services.
- ✓ Offer health promotion programs or versions of resources which do not assume the knowledge held by many gay and bisexual men.

Criminalisation of HIV

In Australia, several jurisdictions have legislation that enables the criminal prosecution of people with HIV related to HIV transmission. This can lead to significant anxieties and increase the burden of stigma and shame. Laws criminalising HIV transmission have a broadly negative impact on wellbeing, a situation that is exacerbated for gay and bisexual men, and other people with HIV who may face intersecting forms of marginalisation based on race, gender or class.⁵⁴

Numerous studies of HIV criminal prosecutions around the world show that women, sex workers, racial minorities, gay and bisexual men, transgender people, immigrants, and Indigenous people are disproportionately charged and convicted, often resulting in long custodial sentences. Data from surveillance used to track HIV outbreaks may be open to misuse in HIV criminal cases.⁵⁵ Australian research suggests the fear of accidental or even deliberate misuse of health data is especially high for some women born overseas in countries with a low trust of government integrity and may be a factor in women choosing not to participate in HIV clinical trials.⁵⁶

Criminalisation: Considerations for practice

- ✓ Care and support providers and HIV service organisations all have a crucial role in supporting and promoting legal reforms and advocating for the repeal of discriminatory laws which inaccurately represent the risks and harms associated with HIV, or which criminalise HIV.
- ✓ Care and support providers can partner with legal services to provide workshops to support legal literacy for people with HIV and staff.
- ✓ Care providers can also provide reassurance to people with HIV by ensuring services are operating at best practice when it comes to the protection of client confidentiality and service data, and ensuring clients are aware of how their privacy is protected.

IN SUMMARY

- Quality of life is a concept extending far beyond clinical care alone and includes multiple cultural, demographic, economic, physical, psychological and social factors that can affect overall health, as well as psychological and social wellbeing. It is about how an individual sees their own quality of life.
- There are validated tools, such as PozQoL, which can be used to assess self-reported quality of life, and which may be applicable for some health and clinical care settings to help understand the impact of interventions, programs and services on QoL for people with HIV.
- Stigma and discrimination can affect people with HIV in multiple ways. Stigma is not just something that occurs between individuals, but is structural, and can be embedded in health and social policy. People designing or delivering health or social services or health promotion interventions can help tackle stigma, particularly by ensuring services are peer-led where possible, that people with HIV are involved at all levels of service design and delivery, and that the design and implementation of services reflects current HIV science and social experience.
- The Greater and More Meaningful Involvement/Engagement of People Living with HIV (MIPA/GIPA) is a well-established internationally recognised principle to ensure health care, health policy and interventions understand and are responsive to the changing needs of people with HIV. Organisations can consider undertaking MIPA/GIPA audits to identify service gaps and opportunities for improving the QoL of people with HIV in service design and delivery.
- A sense of belonging is crucial for the wellbeing of people with HIV. One aspect of this is peer support and peer-led programs to reduce isolation and share experience, but service design and delivery can also benefit by acknowledging the sense of belonging that can come from family, relationships, shared cultural experience, spiritual or religious belief, and the unique communities of practice that can form around sexual practice or identity, or social practices like the use of drugs.
- HIV does not affect all communities or individuals in the same way, and there are specific communities or groups of people who may have unique needs, including gay and bisexual men, heterosexually identified people, women, people who are born overseas, Aboriginal and Torres Strait Islander people, and people who are transgender or gender diverse. An understanding of the principle of intersectionality—the idea that people may have multiple identities and engage in a variety of life practices within and across communities but may also experience cumulative effects of social marginalisation—is an important principle for improving QoL outcomes.
- Supporting QoL is not the responsibility of any single individual, program, health promotion intervention or health service, but may require engagement with multiple service providers, to consider not just clinical needs, but health and social needs ranging from spiritual needs to food to education.
- Technologies can be valuable tools to enhance connection and engagement, but are rarely sufficient in isolation, and the differential ability to access technologies for a range of reasons must be recognised. Service providers may identify ways to support greater access to or use of beneficial technologies.
- Each person living with HIV is a unique individual. From ageing, to the use of injecting drugs, there are strong bodies of evidence to remind us that quality of life is supported by interventions, practices and services which begin with an open mind and a willingness to challenge assumptions and stereotypes, and which are responsive to the individual at the centre of care.
- All providers of peer and social support, clinical care and health promotion can play a role as advocates for quality of life in all its dimensions.

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