INTRODUCTION

HIV Futures 8 is a survey about the health and wellbeing of people living with HIV (PLHIV) in Australia. The study forms part of a series of cross-sectional surveys that have been run every two to three years since 1997. Funded by the Australian Government Department of Health, the aims of the study are to provide information about factors that support physical and emotional wellbeing among PLHIV. The study is designed to inform the Australian National HIV Strategy and guide community and clinical service provision for PLHIV.

In order to explore the complexity of factors that support health and wellbeing among PLHIV, HIV Futures 8 is a broad survey covering issues such as financial security, housing status, antiretroviral treatment use, general health issues, stigma and discrimination, clinical and support service use, aging, drug and alcohol use, sexual health, relationships, and social connectedness.

HIV Futures is run by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. Findings from HIV Futures 8 are presented as a series of short reports. These, along with more information about the study and copies of reports from previous HIV Futures surveys, can be found on the ARCSHS website: latrobe.edu.au/arcshs

METHODS

HIV Futures 8 is a cross-sectional survey of PLHIV. The survey was open to people aged 18 years or older who were currently living in Australia. Data were collected using a self-complete survey that could be filled in online or using a booklet that was supplied to prospective participants with a reply-paid envelope. Participants were recruited through electronic advertising in a range of forums including: advertisements sent through the email lists of HIV community organisations; advertising on relevant websites; social media advertising, particularly Facebook including targeted posts to Facebook groups for PLHIV; advertisements on ‘dating apps’ used by gay men and other men who have sex with men and; flyers and posters displayed in HIV clinics. Hard copies of the survey were distributed through the mailing lists of HIV community organisations and made available in the waiting rooms of HIV clinics and community services. Data were collected between July 2015 and June 2016.

Full details of the study protocol and method have been published elsewhere and are available on the ARCSHS website: latrobe.edu.au/arcshs/projects/hiv-futures

TABLE 1

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<tr>
<th>States and territories in which participants currently live</th>
<th>n</th>
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<tr>
<td>WA</td>
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*Nine participants did not identify their state/territory

Full details of the study sample have been published elsewhere (Power et al. 2017) and are available on the ARCSHS website: latrobe.edu.au/arcshs
BACKGROUND

An important component of the Australian response to HIV has been the establishment of services for people living with HIV. This includes a range of clinical services and community-based organisations that offer peer-support, professional counselling and wellbeing programs, as well as education and information-based services for PLHIV. More recently, these services have been augmented by online groups and forums designed to provide PLHIV with information and education as well as a forum to connect with others.

Services for PLHIV can be one way in which people living with HIV gain access to social and emotional support. It is well documented that feeling supported and connected to friends and family bolster health and wellbeing (Hawkey and Cacioppo, 2013). In this broadsheet we look at what Australian PLHIV told us about their engagement with HIV community services and clinical services, and their sense of feeling supported by family, friends and community, as well as other PLHIV.

This broadsheet is one of a series of short reports on findings from HIV Futures 8. All of these are available to download from the ARCSHS website: latrobe.edu.au/arcs hs

COMMUNITY AND SUPPORT SERVICES FOR PLHIV

In HIV Futures 8, we asked survey participants to tell us which community organisations they had used and the type of services they had found most valuable or useful over the years. These questions included both closed and open response questions.

Overall, 61.0% (n=536) indicated they had regular or occasional contact with HIV-related organisations, while 24.9% (n=219) had never had any contact (see Figure 1).

Figure 1. Responses to “Do you have contact with HIV-related organisations?”

People most likely to be in occasional or regular contact with HIV-related organisations were aged over 45 years (66%, compared with 51% of those aged 45 or younger, p<.05), and related to this, reported poorer overall physical health (SF-36 Physical Functioning Sub-scale, range 0-100, M=82.9 v M=87.1 for those not in contact with HIV organisations, p<.05). There were no differences with respect to area of living, with those in regional/rural areas just as likely to be in contact with organisations as those in city areas.

We asked participants to indicate which services provided by HIV organisations they had used in the past 12 months (see Figure 2). Responses revealed the important role that HIV organisations play in provision of peer-based social and support programs. Over half of the participants (56%, n=501) indicated they had used at least one service in the past 12 months. The most common type of services used were those that facilitated social contact between PLHIV (n=215, 43%), along with peer-based support programs (n=156, 31%), treatment forums/advice (n=156, 30%) and professional counselling (n=119, 24%) were the next most commonly used services.

What HIV services or programs have you found most useful?

“Anything peer-based. Other positive people are the only ones that know and can relate to information and feelings and emotions. Retreats when available. Conferences and information sharing.” (Male, age 61)

“‘Planet Positive’ group functions Saturday afternoons to meet and talk with other HIV+ people (compare situation, health, knowledge, lifestyle choices, etc) informal social environment/not institution e.g., hospital or centre specific” (Male, age 59)

“Being able to talk to someone living with HIV who actually knows what’s going on. When I was diagnosed the people I had access to were very good but none of them were HIV positive and couldn’t relate to what I was experiencing. It was an isolating experience and made me feel incredibly alone” (Male, age 32)

“1. Peer support: at the early stage of diagnosis, peer support volunteer made me aware that I am not alone being HIV positive and how this journey will be about. 2. Phoenix workshop: it gave me the basic education I need to know about HIV” (Female, age 28)

“Newly Diagnosed Workshop was really good for me – it quite possibly saved me from spiralling down into a major depression and I learnt so much” (Male, age 45)

“I have found very useful the support groups of HIV positive participants. Especially when you had just been [diagnosed], I think it is very important to be able to talk and know more people that are in your situation” (Male, age 33)
CONNECTING WITH OTHER PEOPLE LIVING WITH HIV

Peer support and connecting with other PLHIV can help people to live well with HIV (Peterson et al. 2012). We asked participants how much time they spent with other PLHIV and the extent to which they received support from other PLHIV. Overall, 68.7% (n=605) reported spending time with other PLHIV, while 57.8% (n=500) reported receiving some support from other PLHIV (ranging from a little to a lot) (see Figure 3). Spending time with other PLHIV and support received from other PLHIV were positively associated with greater emotional wellbeing and higher resilience (see Figures 4 and 5).

PERCEIVED SOCIAL SUPPORT

Participants rated their assessment of social support and connection using ten survey items related to friendships, access to support, and social connection. Average scores were calculated ranging from -30 to 30, with higher scores indicating a greater perceived sense of social support (Baker, 2012). We compared these scores for different groups of participants (see Figure 6). Result showed that:

- with respect to age, PLHIV aged 65 years or older reported the highest levels of perceived social support (significantly higher than people aged 45-64).
- bisexual men were significantly less likely to report available social support than women, gay men, or heterosexual men (p<.05).
- there were no significant differences in perceived social support based on where participants lived.

Social support and wellbeing

Higher levels of perceived social support were linked to greater emotional wellbeing, resilience and greater physical health among PLHIV (see Figures 7 and 8).
WHAT HELPS PEOPLE COPE AND LIVE WELL?

We asked participants to describe in an open-ended response the main things in their lives that helped them cope or live well with HIV. Six hundred and twenty participants (69%) provided a response to this question. Relationships with partners, family, friends, children and other PLHIV featured most frequently in responses, along with staying healthy and having easy access to good medical care and affordable treatment. The main factors people listed that helped them cope and live well were:

- support from their partner, family or friends (n=259, 42% of responses)
- access to a supportive and/or non-judgemental doctor/medical care (n=81, 13%)
- staying physically healthy through diet and/or exercise (n=81, 13%)
- maintaining a positive attitude toward life (n=77, 12%)
- having a job or professional life to provide focus and motivation and/or a stable income (n=54, 9%)
- access to affordable antiretroviral treatment (n=51, 8%)
- hobbies, activities or creative pursuits and interests (n=45, 7%)
- HIV positive friends (n=38, 6%)
- services for PLHIV (n=33, 5%)
- pets (n=15, 2%)
- faith (n=7, 1%).

Figure 10: Distance travelled to visit doctor for HIV treatment by area of residence

There were 486 participants (54% of total sample) who indicated they saw their HIV GP/S100 prescriber or HIV specialist for general medical care (see Figure 11). Participants who saw their HIV provider for general medical care felt more supported by their healthcare providers than participants who saw non HIV providers for general medical care (see Figure 12).

Figure 11: Type of provider seen for general medical care

Figure 12: Feeling supported by healthcare providers according to type of provider seen for general medical treatment

In a large country such as Australia, geography can present a barrier to people accessing specific or specialist medical services such as HIV treatment – particularly for those living in regional or rural areas. We asked participants how far they needed to travel to access HIV treatment (see Figure 10). The majority of people living in rural areas had to travel more than 50km to visit their doctor for HIV-related treatment (n=52, 62%). Even within cities, the majority of those living in outer suburban areas indicated they travelled more than 20 km to see a doctor for HIV treatment (n=62, 59%).

CLINICAL SERVICES

We asked participants a range of questions on their use of, and access to, clinical services for HIV management and general medical care. Almost two-thirds of participants (62%, n=522) saw their doctor for HIV-treatment at minimum every four months (see Figure 9). The majority of participants indicated they had access to bulk billing services, if needed, for general medical care (76.2%, n=682) and HIV treatment (85.3%, n=740).

Figure 9: Frequency of doctor visits for HIV-related treatment

What are the main things in your life that help you cope or live well as a person with HIV?

“Family, a job that affords me good food and a roof over my head, free healthcare so I can access my meds.” (Female, age 34)

“A steady relationship, acceptance of myself and my status/flaws/advantages, my two dogs, living in sunny and healthy [place], living in a house I love, doing a job I absolutely love ... Basically taking full control of my life and snipping out anything or anyone that threatens my happiness or that of my household. And Empire of the Sun. God, I love that band.” (Male, age 32)

“Good sleep routine. Enough money to pay my bills, rent and buy fresh food. Socialising with friends. Healthy sex life. Exercise. Work.” (Male, age 31)

“An extremely supportive and non-judgemental HIV specialist doctor. Strong resources and intellectual interests. Good friends, my cat, and my garden.” (Male, age 67)
Connecting Online

One in three participants (33.5%, n = 296) declared they are current members of online PLHIV social networks, including TIM (The Institute of Many Facebook group) or other formal online groups of networks such as the Ending HIV Network. TIM was the most popular network with 185 survey participants (20.7%) indicating they engaged with TIM regularly or occasionally.

Members of online PLHIV social networks tended to be younger than those not using online PHIV networks, but there were no significant differences in gender, sexuality, or location of residence. Controlling for differences in age, gender, sexuality, and location of residence, members of online PLHIV social networks reported higher perceived support from other PLHIV (M=2.10 v M=1.83, p<.05) than those who do not engage in social networks. Members of online networks also reported higher perceived social support in general (M=9.28 v M=7.50, p<.05).

PLHIV were most likely to join online networks to hear about other people’s experiences and to seek information and news relating to HIV (see Figure 13).

HETEROSEXUAL MEN

It is difficult to know how many heterosexual men are living with HIV in Australia. Currently national HIV surveillance data is collected on gender and mode of HIV transmission but not sexual identity. This means that within each category, the number of men who identify as heterosexual is unknown. For example, we don’t know the sexual identities of men who acquired HIV through injecting drug use. However, relative to the overall number of PLHIV in Australia, the number of heterosexual men living with HIV is very small.

There were 38 heterosexual men who completed the HIV Futures 8 survey. The small sample size makes it difficult to report on these data with sufficient statistical rigour, meaning data from heterosexual men tends to become lost in the overall findings.

We have chosen to include a small subsection on heterosexual men in this report as a way to highlight some of their stories and draw attention to service provision for heterosexual men living with HIV.

Of the 38 heterosexual men who participated in the study, 82% (n=31) were in contact with HIV-related organisations. This is likely to be an over-estimation of the proportion of heterosexual men connected to PLHIV services as participants were recruited for the survey through PLHIV organisations. Despite this, only 51% (n=19) indicated they knew other heterosexual men who were living with HIV, and 37% (n=14) indicated they did not know any other PLHIV. Only a minority (21%, n=8) of these men connected with other PLHIV using social media or online forums. However, most heterosexual male PLHIV still reported that they had good access to social support. On average, heterosexual men were no less likely than women or gay men to report lower levels of social support (see Figure 6).

We asked heterosexual men if there was anything else they would like to tell us about their experiences of living with HIV as a heterosexual man. Twenty-three men (61%) provided a response to this question. The major theme of the responses was that heterosexual men living with HIV in Australia felt like a ‘minority within a minority’, which led to feelings of isolation and loneliness. There was a sense that the needs of heterosexual men were not adequately met by the HIV sector, given the small number of HIV positive heterosexual men in Australia.

“I have only meet one [other] heterosexual male since my diagnosis in 1997 and that took 13 years. Even though I understand the challenges of being in a minority within a minority, I have developed a skill to associate with all PLHIV”

“It’s somewhat lonely, the gay guys have more fun it seems”

“It is very difficult (not fun at all). Makes it almost impossible to have a new relationship as HIV+ gets in the way. Who needs to be rejected by potential life partners it sucks!”

“Not enough peer support”.

“Loneliness”.

“It’s really hard disclosing my relationship to a woman in a relationship beginning – it is easier to break off the relationship before it becomes sexual. At my age… it would be easier just to have a friendship or companionship, but the HIV does come into play – as far as my mindset goes”.

“Very isolated as the focus is far from on heterosexual men”.

“While it is understandable that the Australian focus of the HIV sector is on the gay community it bothers me. The global situation is that it affects everyone. Like most things in Australia, we have a self-centred view of HIV that doesn’t fit the global situation”.

SUMMARY AND CONCLUSIONS

Community-based organisations play a unique role in the provision of social and support services for PLHIV in Australia. The importance of these services is shown in these findings. Survey participants told us that the programs and services they most value are those which facilitate opportunities to meet other PLHIV, either in formal group settings or through informal social events. Developing connections with other PLHIV can reduce a sense of isolation, normalise the experience of living with HIV and allow people to meet others who share similar experiences. This can be important even for people who have strong family connections and broad social and support networks. For participants in this study, spending time with other PLHIV was associated with a greater sense of resilience and emotional wellbeing.

Social support more broadly – from family, friends and communities – was also associated with greater wellbeing and resilience. When we asked participants what helped them cope and live well as a person with HIV,
support from a partner or family was the most common response. This is not unexpected. Social connectedness is important for wellbeing in all people (Hawkyard and Cacioppo, 2013). From a service provision perspective, it is worth noting that some PLHIV may have less access to social support than others. Specifically, the findings showed that men who identified as bisexual were significantly less likely to report access to social support than other men or women. Previous studies have shown bisexual Australians report poorer mental health than lesbian or gay people (Leonard et al, 2015). It is possible that this is related to a lower sense of social connectedness or support.

Access to supportive, non-judgemental doctors, affordable clinical services and HIV treatment were also noted by many survey participants as things that helped them cope and live well with HIV. Interestingly, participants who felt most supported by their healthcare providers were those who saw the same doctor for HIV care and general medical care. It is possible that those who felt most supported by their healthcare provider were those who had a longer-term, trusting relationship with one main physician, rather than seeing multiple providers for different health concerns.

These findings show the extent to which PLHIV value access to good information and education about HIV. After social and support services, participants were most likely to utilise community-based HIV services to source information about HIV treatment. Several participants also told us that they highly valued the information about HIV they received at workshops for people newly diagnosed with HIV. This information helped them make sense of their diagnosis and develop confidence to manage HIV into the future.

Finally, these results show the increasing importance of online forums for PLHIV. Approximately one in three participants indicated they are currently part of an online network of PLHIV. The reasons why people went online to connect with other PLHIV were similar to the reasons people sought out face-to-face services. People valued hearing about others’ experiences with HIV and connecting with other PLHIV, as well as sourcing news and information about HIV. Further research is needed to explore the ways in which PLHIV benefit from online PLHIV networks and how these complement face-to-face services, but these findings indicate real potential for providing extra support for PLHIV.

Thoughts and commentary

The way in which HIV positive people connect with each other, find support, build resilience, and flourish has changed somewhat in recent years. This has run parallel with extraordinary changes in the way People Living with HIV (PLHIV) access treatment, live more openly, and have greater confidence in the science of treatment as prevention.

This is due to an extraordinary joint effort from funded organisations, grassroots movements, and researchers. However, what we define as service provision, support, and peer-based organisations (all vital in the fight to end HIV and HIV stigma) is rapidly shifting.

What I call the “circle of chairs” model of peer support is becoming less relevant, while alternative and less formal models of networking are providing much needed space and support. As HIV Futures 8 clearly shows: “Controlling for differences in age, gender, sexuality and location of residence, members of online PLHIV social networks reported higher perceived support from other PLHIV (M = 2.30 vs. M = 1.83) than people who do not engage in social networks. Members of online networks also reported higher perceived social support in general (M = 9.28 vs. M = 7.50).”

This is, of course, an imperfect scenario. It is imperfect for the funded PLHIV organisations who are dealing with ever-shrinking funding and ever-shrinking membership engagement as, in a new millennium, younger and/or recently diagnosed PLHIV are more resistant to this “bricks and mortality” model of peer support.

But it is also imperfect for the increasingly marginalised, high-needs PLHIV for whom peer-lead, largely online interventions do not and cannot meet their complex needs.

Nonetheless, it is telling that an independent online movement such as TIM are in some ways performing just as well as (and sometimes better than) funded organisations with arguably greater institutional memory and understanding of state and federal policy, PLHIV behaviours, and HIV treatments.

We are charged with far less responsibility, of course, and we are not interested in replacing pre-existing organisations. However, the independent, grassroots space created by TIM clearly appeals to the PLHIV community as a different forum for engagement outside the heavier infrastructure of existing organisations, and all the historical weight they carry with them.

The relative instability of independent online movements like TIM and others is a valid concern. All rely completely on contributions of volunteers at every level; most are driven by individuals or small groups of PLHIV. We ask you to just trust us as we operate a 24/7 digital drop-in centre for PLHIV and write the rules on our own terms.

But why wouldn’t we? HIV Futures 8 is showing us that many in the PLHIV community have moved online, and are better for it. It’s now up to the sector to keep up, make space, and acknowledge that independent movements driven by the PLHIV community aren’t “new kids on the block.” Rather, we are direct descendants of the same grassroots movement that gave birth to Australia’s incredibly effective HIV sector.

At Living Positive Victoria, we are fortunate to be able to offer peer support and social connection activities tailored to heterosexual men living with HIV (HMLHIV). Peer support is delivered by paid staff who are themselves HMLHIV. However, heterosexual men are often reluctant to engage with peer support services. Straight men are vulnerable to feelings of stigmatisation when contemplating accessing HIV services. There is also the influence of deeply held notions of masculinity, and what it means to be a man in contemporary Australian society. For example, “real” men are stoic and tough, and should be able to rely solely upon their own coping ability. We face similar challenges engaging heterosexual men from CALD backgrounds.

While we have a small number of straight men who comfortably access social events alongside gay men, it is more common for straight men to be deterred by the belief that community based HIV sector services are run by gay men for gay men. The challenge is breaking down that perception, and relaxing the mindset that it is problematic for straight men. What we hear from some of these men is entirely consistent with the findings of Futures 8: HMLHIV feel left out by the HIV sector’s response. For this reason, it is important to deliver services that cater to the needs of heterosexual men.

Part of Living Positive Victoria’s response has been to facilitate a peer led heterosexual male-only ‘cook and chat’ support group in addition to individual peer support. The group has developed slowly and we are constantly reviewing and assessing our methods to increase participation. We suspect that straight men are partly held back by concerns about confidentiality and being judged by the other men.

When HMLHIV do attend the group their apprehension often dissolves. When basic ground rules are established, including agreeing to a code of confidentiality and respect for each other’s opinions, it takes very little to get these men talking, sharing their experiences and sharing humour. Generally, men who attend say that it was a positive experience and that they enjoyed connecting with others. They also report feeling relieved, like a process of normalisation has taken place. This can verge on pride and a sense of having overcome adversity. The men generally value the opportunity to tell their story to the group and hear other straight men’s stories.

Disclosure features heavily in discussions; disclosing to romantic partners, sexual partners, family and friends. Navigating sexual relationships is another common theme, particularly the frustration of avoiding sexual encounters and reclaiming sexuality. Internal stigma, feelings of loss, the impact of diagnosis on employment, and living with a secret are also recurring topics. Group attendees say that the group is important to them because they have no other outlet for discussing HIV and receiving support.

As noted in Futures 8, many HMLHIV feel like a minority within a minority. The peer support programs we offer specifically for heterosexual men, along with other programs such as our annual retreat, help these men connect socially and create a pathway to thriving with HIV.

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SUGGESTED CITATION


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REFERENCES


