

'Things you can't talk about': engaging with HIV-positive gay men's survivor narratives

by Cheryl Ware

Abstract: This article uses oral history to explore the challenges HIV-positive gay men continue to face in the aftermath of the HIV/AIDS epidemic of the 1980s and 1990s, drawing on a selection of original life story interviews conducted with Australian gay men who were diagnosed when HIV was a terminal condition. While the histories focused on narrators' pasts, many used the interviews to discuss continuing issues with the debilitating physical effects of antiretroviral medication. Such topics are usually silenced by embarrassment, lack of an engaged audience and suggestions that, unlike many who were also diagnosed with HIV as a terminal condition, they are fortunate to be alive. The article considers how the author's subjectivity influenced which stories narrators felt comfortable telling and which they suppressed.

Keywords: Australia; gay men; HIV; survivor narratives; silence

This article explores how oral history interviews create rare platforms for engaging with HIV-positive gay men's survivor narratives in the aftermath of the HIV and AIDS epidemic of the 1980s and 1990s. It draws on a selection of original life story interviews conducted with gay men who were diagnosed with HIV as a terminal condition, before the introduction of highly active antiretroviral therapy (HAART) in 1996. The interviews primarily focused on narrators' memories of the 1980s and 1990s. Nevertheless, many men used the interviews to discuss the struggles they continue to face in their present lives, especially concerning the debilitating physical side effects of antiretroviral medications. In this regard, a willingness to take direction from narrators was a key factor in facilitating open-ended discussions about highly personal and intimate issues. Such topics are usually silenced by embarrassment, a lack of an engaged audience and suggestions that, unlike many people who

were also diagnosed with HIV as a terminal condition, these men are fortunate to be alive.

Additionally, this article considers how the author's subjectivity as a heterosexual, HIV-negative woman in her late twenties influenced the narrators' willingness – or, at times, reluctance – to discuss their concerns about the impact medication has had on their physical appearance. This article primarily focuses on interviews with Adrian Eisler, John Whyte and Victor Day.¹ Of the twenty-five narrators interviewed for this broader study, these men placed the most emphasis on the emotional impact of dealing with the lasting physical side effects of antiretroviral medication. While this is a small, non-representative selection, the chosen accounts illuminate these men's prevailing issues with treatment, and the value they placed on giving a voice to these experiences.

The HIV and AIDS epidemic decimated gay male populations around the world. After Australia's first AIDS-related death occurred in Melbourne in July

1983, the death toll continued to rise, peaking at 738 deaths in 1994 alone.² Trials for the first clinically-proven antiretroviral medication, zidovudine (AZT), began in Australia three years later in 1986. The availability of medication was largely due to the work of HIV and AIDS activists who lobbied the government to provide faster access to the potentially lifesaving treatment.³ Asha Persson provides an important overview of the 'unique history' of HIV medication from 1986. She argues that the 'accelerated approval of AZT in the USA was a precursor to what was to become a general process of enabling early access to new and often inadequately tested HIV drugs in Western countries'.⁴ In these instances, concerns about 'safety of unproven drugs were largely mitigated by a sense of urgency' when so many people were dying.⁵ Combination therapies started to be used in Australia six years later in 1992, although HIV remained a terminal condition until the introduction of protease inhibitors in 1996.⁶

The introduction of HAART can be traced to the Eleventh International AIDS Conference in 1996, whereby researchers first publicly reported the success of clinical trials that tested the effectiveness of combination therapy and protease inhibitors for treating the virus.⁷ By 1996, many of the men I interviewed had participated in trials for various antiretroviral medications and experienced a host of debilitating side effects. Any mention of the first clinically approved antiretroviral medication, AZT, aroused particularly unfavourable memories for many interviewees. While two of the men in this study 'tolerated' the treatment, others endured a combination of severe nausea, diarrhoea, headaches, insomnia and anaemia.⁸ Stephen Allkins was particularly critical of the treatment, and suggested that 'it felt like they put twenty guinea pigs on it and let them die'.⁹ Narrators also shared grim memories of the 'horse tablet' that was didanosine and the pain of having to inject other medications in the early 1990s. Further, while the introduction of combination therapy in 1996 came as a revolution for some men, others described dealing with peripheral neuropathy (nerve damage characterised by tingling or numbness), struggling to adhere to arduous treatment regimens and developing a resistance to certain medications.¹⁰ Yet, discontinuing medication when side effects became too severe was not a viable option. One of the other men I interviewed, Tim Alderman, attested to his body's dependence on medication. He explained: 'there was no knowing what would happen if you did go off, so if you did go off the drugs maybe you would die'.¹¹

While narrators openly discussed the side effects they endured across the late 1980s and 1990s, they were less open about the lasting effects of HAART. Narrators only addressed these issues towards the end of an interview, or in John's case, via email after the interview had ended. This article explores some of the personal factors that may have stymied these discussions. In particular, some narrators' struggles to deal with the visible effects of medication were often

compounded by their concerns that the same treatment that is keeping them alive might also be damaging their overall health. Steven Berveling reconciled his understanding that 'the medication may cause a deep disharmony problem in my body that manifests itself in X years time and causes me to die' by conceding 'I'm gonna die anyway, so those things happen'.¹² Others were more overtly apprehensive. David Polson informed me that 'HIV isn't a problem anymore, but I've got this brain disease called Superficial siderosis, which is bleeding on the brain that was caused by trial medication'.¹³ Along similar lines, Adrian explained, 'I've now got type two diabetes which I firmly believe is also another side effect of medication'.¹⁴

Visible side effects also carry severe social implications. In recent years, social researchers have taken the lead in highlighting the paradox whereby HAART effectively treats HIV while making one's positive status more visible through identifiable physical changes.¹⁵ Lipodystrophy is a particularly common and well-recognised side effect of the medication. It is characterised by body fat shifting from the limbs to the abdomen and to the back of the neck.¹⁶ Medical sociologist Gill Green suggests that such physical changes can result in involuntary disclosure, especially 'within gay communities where the physical signs of AIDS are likely to be well known'.¹⁷ In the Australian context, Andrew Carr and Loren Brenner et al explore the stigmatising effects of visible symptoms, and the associated shame and rejection these individuals may experience.¹⁸ Persson has conducted particularly valuable studies into the visibility of lipodystrophy in Sydney's gay community. She argues that such visible symptoms have become 'taboo' and serve as an ominous reminder of both the devastation caused by the epidemic and the limitations of current medicine.¹⁹ In this regard, the challenges that narrators have had to overcome to live longer with HIV are marginalised by 'the current, supposedly triumphant fight against AIDS'.²⁰

By returning to the voices of gay men who have been living with the virus since the 1980s and 1990s, this article reveals how they deal with the physical effects of antiretroviral medication in the aftermath of the epidemic of that era. Such a study is currently missing from Australian historiography, although oral historians have conducted valuable investigations into other elements of long-term survival. Specifically, Robert Reynolds and Shirleene Robinson use oral history to explore how Australian gay male communities reflect on the emotional impact of the losses incurred across the 1980s and 1990s.²¹ Paul Sendziuk and Jennifer Power also use oral history interviews to explore the contributions of those who dedicated themselves to HIV and AIDS activism and other community-based organisations.²² Further, researchers involved in the 'HIV Futures' project at the Australian Research Centre in Sex, Health and Society explore HIV-positive individuals' physical and emotional health, relationships and financial security.²³ Researchers at the Centre for

Social Research in Health also conduct valuable and extensive studies into the sexual health of gay men living with HIV.²⁴ This article, therefore, provides original insight into how Australian HIV-positive gay men make sense of their experiences with the lasting physical side effects of HAART.

The interviews that feature in this article were conducted as part of my doctoral study, which used oral history to explore HIV-positive gay men's intimate memories of the epidemic across the 1980s and 1990s.²⁵ Gay men were disproportionately affected by the virus.²⁶ They were not only the target of blame and proposed quarantine measures, but many also mobilised to assert an active role in Australia's national response to HIV and AIDS. I conducted oral history interviews with twenty-five gay men who were diagnosed with HIV when it was considered a terminal condition. I aimed to interview a diverse cohort and therefore placed few restrictions on the participant criteria. I simply limited participation to gay men who were diagnosed with HIV between 1982 and 1996, and who lived in Sydney between these dates. Participants were recruited through an advertisement in the online national gay newspaper, the *Star Observer*. The advertisement, which explained my interest in speaking to HIV-positive gay men 'about their life experiences', was also circulated by the AIDS Council of New South Wales, and on Facebook pages hosted by the Australian Lesbian and Gay Archives and Lost Gay Sydney. Both pages provide platforms for individuals to share photographs, newspaper clippings and anecdotes, and are popular among those who are interested in exploring Australia's LGBTIQ history. The interviewees were self-selected, and I accepted all the men who offered to participate in this study and met the research criteria.

The interviews that followed were guided by a set of open-ended questions that covered narrators' memories of growing up and 'coming out' as gay, learning about HIV and AIDS, receiving an HIV-positive diagnosis, their experiences with trial medication and the introduction of HAART. I rarely had to refer to the questions, however, as narrators spoke at length about each issue without being prompted. Most of the interviews lasted around three hours, well over the anticipated ninety minutes that was set out in the information sheet. While it is not unusual for oral history interviews to last several hours, I proposed an interview time of ninety minutes as I thought a longer interview might be draining for the interviewees, especially considering the intimate topics covered. Indeed, Donald A Ritchie advises oral historians to limit interviews to ninety minutes to two hours.²⁷ Narrators' openness is particularly noteworthy given each interview took place during a single meeting. As Linda Shopes argues, such conditions rarely provide sufficient time to establish trust between an interviewer and a narrator.²⁸ Their openness might suggest that they perceived me as a trusted audience, or that they found it easier to talk about difficult topics with a stranger.

Considering my positionality as someone who had not experienced the epidemic, it may be surprising these men were willing to speak with me. Wendy Rickard has highlighted the importance of a shared identity or shared experiences when interviewing individuals about difficult or traumatic experiences.²⁹ Others suggest that it is not possible to conduct oral history research with members of a group with whom one does not identify.³⁰ This is understandable, considering some communities' concerns about the interviewers' objectives.³¹ Certainly, my HIV-negative status, gender, sexuality and age meant that I had no first-hand experience with the events that featured most prominently across the interviews. I, therefore, could not offer the recognition that someone who had such experiences might have been able to provide. As I shall discuss, such differing subjectivities may have made some men reluctant to talk about visible symptoms.

For the most part, however, narrators seemed less concerned with my background than they were with having an opportunity to share their stories. Thomas Parker made this clear in our initial email correspondence. He anticipated the interview would likely raise 'emotional stuff but glad someone is doing some research'.³² Thomas's comment that 'someone' is conducting 'some' research is suggestive. In this context, a shared identity was less important than a shared understanding that his experience had yet to feature in the historical record. My explicit focus on narrators' personal experiences thus appears to have been a primary factor in establishing common ground. It underscores a point Alessandro Portelli has raised when speaking of 'a shared will to listen and accept each other critically' being instrumental in establishing trust between an interviewer and a narrator: some of the most important things he has had to offer narrators were 'ignorance and a desire to learn'.³³

Further, my subjectivity as someone who had not experienced the epidemic perhaps disturbed the power dynamic that usually exists in oral history interviews. Portelli has explored the interviewer's position of authority, arguing that 'in the interview, the initiative is taken by the interviewer, from whom the legitimacy to speak is ostensibly derived'.³⁴ It is also important to consider that interviewing people carries the implication that they have done something valuable, and that they have significant histories to share.³⁵ Several respondents seemed to notice this shift and emphasised that they wanted to participate in an interview 'to help' with the study. While acknowledging that I still had the authority to interpret the interviews, the emphasis I placed on the narrators' subjective experiences during the interviews perhaps reinforced the critical point that this was a history that I could not explore without their involvement.

As mentioned, a willingness to take direction from interviewees appears to have been an important factor in facilitating open-ended discussions about the side effects of medication. Such an approach was paramount, considering the sensitive and potentially

painful topics that the interviews covered. These included being diagnosed with a terminal illness and losing lovers, partners and close friends. Following Dori Laub's recommendation that 'the listener [...] be *unobtrusively present* throughout the testimony', I was careful to avoid pressing narrators to discuss events that they were not ready to revisit.³⁶ While some scholars attest to the therapeutic potential of oral history interviews, Alistair Thomson, Wendy Rickard and Penny Summerfield, among others, stress the need to handle painful memories with much sensitivity.³⁷ Summerfield argues that a particular memory or an unsympathetic response from the interviewer may result in 'discomposure' or 'disequilibrium', manifesting in an interviewee's confusion, anger, discomfort and difficulty to sustain a narrative.³⁸ Taking direction from the narrators offered a respectful way of manoeuvring through personal and difficult memories.

Narrators' enthusiasm for the study can be understood as a reaction against the silence they felt suppressed discussions about living with HIV. Indeed, the interviews took place in 2014, eighteen years after the introduction of HAART transformed HIV from a terminal illness to a chronic condition that could be managed by taking antiretroviral medication. In the intervening years, deaths from HIV and AIDS-related conditions plummeted, and people started living longer and healthier lives. For many, the epidemic had been 'over' for nearly two decades. As the oral histories reveal, it is not over for those who survived. Many of these men have lived through an event so traumatic and incomprehensible that some could only compare it to surviving a war.³⁹ Yet, they felt that the broader community treats HIV and AIDS as issues from the past without considering the impact on those who are still dealing with the pain of what they experienced. For David Polson, the decreased attendance at the annual Candlelight Vigils was a clear indicator that 'I hate to say it, but the HIV community's been forgotten'.⁴⁰ Several other interviewees echoed David's frustration. They have found that, in some cases, beyond a few friends or family members, others were not interested in their personal stories of survival.

Dealing with disfigurement

Narrators' desires to engage in precisely the sorts of discussions that have been silenced in dominant societal discourse were particularly evident in Adrian's life story. Adrian was diagnosed with HIV after being hospitalised with pneumocystis pneumonia in 1995. He remained in the hospital for several weeks, and conceded, 'I was sick, but I didn't realise how sick I was'.⁴¹ He recalled that his health had deteriorated to the extent that he developed AIDS, and he was on the 'verge of dying' from pneumonia. Adrian's severely depleted immune system indicated that he might have been living with HIV for nearly a decade. Nevertheless, he struggled to articulate the challenges he continues to face while acknowledging that he is among the few who survived the epidemic. His prevailing struggles

with the physical side effects of antiretroviral medication are further suppressed by his acknowledgement that he was diagnosed with HIV in 1995, shortly before what he termed the 'revolution' of combination therapy that saved his life.

Adrian's reluctance to convey his enduring struggles was evident as it was over ninety minutes into the three-hour interview before he even alluded to the physical side effects of antiretroviral medication. He explained, 'next year will be... will be my twentieth anniversary of living with HIV/AIDS, and I'm still... hopefully still around. But, um, there's been quite a cost as you'll find out'.⁴² Two minutes later, Adrian cautioned that his life with HIV 'hasn't been all plain sailing as you'll find out'.⁴³ By that point in the interview, Adrian had described being diagnosed with an AIDS-defining illness, losing so much physical strength that he could not stand up to take a shower and being denied superannuation under his employers' 'AIDS exclusion clause'. I was therefore well aware that his experiences had not been 'plain sailing'. Such signposting, however, suggests Adrian was conscious that others might have had more challenging experiences than that which he endured. At the same time, he was ready to give voice to the severe challenges he faced while taking treatment.

It was over two hours into the interview before Adrian discussed the physical side effects of antiretroviral medication in further detail. He described the degradation he felt when he started taking treatment in the mid-1990s: '[diarrhoea] was not just embarrassing, but so socially isolating'. The pain of these memories is compounded by his persistent struggles with the visible changes medication has caused:

If I were to take off my clothes, what I'm intensely and acutely aware of is the change in my body shape that has been caused by lipodystrophy [...] I've also got something which is called a 'buffalo hump' which is very unflattering. But it means that the back of my neck, and around my neck, uh, I have a much fuller neck than I ever used to have [...] That... that, uh, disfigurement, which a lot of us feel we've now been disfigured, is now permanent even though the drugs that caused it are no longer around.⁴⁴

Adrian's account reflects the emotional distress caused by feeling disfigured. His shift from first- to second-person narrative, as indicated in his final sentence, was perhaps an important coping strategy. It enabled him to locate his own experiences amidst those of other long-term survivors and assert that he was not alone. In doing so, he moved from a discussion of his own grief to a broader commentary on a community that is dealing with the lasting impacts of HIV and AIDS.

Adrian's initial hesitance to discuss the physical side effects he faces can also be attributed to his faith in medical developments. The interview took place four days before he was scheduled to start a new treatment

regimen that involved taking a single pill each day. His testimony, therefore, reflects a tension between feeling fortunate to be alive and in a position in which HIV occupies a decreasing role in his life, and his awareness that he will continue to deal with the ongoing physical side effects of past medications. He explained:

The notion of going to a once a day pill next week with hopefully none of that side effect, you can imagine how [inhales deeply] how much I'm looking forward to that. But it... it's still not gonna um it's still not gonna take away the buffalo hump it's still not gonna reduce my... my lipid profile, um, but then again people say 'well shut up. You're still alive, so what are you whinging about?'⁴⁵

Adrian's deep inhalation underscores the paradox of eagerly anticipating his new treatment regimen while acknowledging that medication has irreversibly damaged his health. Nevertheless, his final statement reflects the extent to which the challenges he faces are marginalised amidst perceptions that, unlike many people who were diagnosed with HIV as a terminal illness across the 1980s and 1990s, he is fortunate to be alive. Other narrators echoed this silence. While Geoff Anderson experiences lipodystrophy and lipoatrophy, he concluded that 'side effects are better than not being alive, so you deal with them'.⁴⁶ Christopher Jackson appeared to be more comfortable in silencing discussions about the side effects of medication. He explained, 'people used to grumble and moan about the side-effects. And again, I would always be "yeah look, you know, you have a bit of diarrhoea, it's either that or die"'.⁴⁷

Adrian's awareness that he was the first person to be interviewed for this project also explains some of the conflicted feelings he expressed. At the time of the interview, he worked as the Community Support Network co-ordinator at a leading HIV and AIDS organisation in New South Wales. Individuals who volunteer as carers with the Community Support Network provide practical home-based support for people living with HIV, including cleaning, cooking and providing transportation. Adrian was therefore aware of the countless others who have been unable to return to work and who struggle to live on disability support pensions. In this respect, his description of his medication-induced physical 'disfigurement' raises important questions about whether he would be able to express these concerns outside of the distinct space created by the interview. Adrian's existing hesitance to convey his own struggles may have been amplified had he been speaking to someone who had been living with HIV since the 1980s and 1990s, and who may have had a more difficult experience. In this regard, my age was a particularly clear indicator that I was likely not directly affected by the epidemic. Conversing with an outsider, therefore, appears to have aided discussions about the ongoing physical side effects of HIV and antiretroviral medication.

Silencing survivors

As this article has demonstrated thus far, the project's emphasis on narrators' intimate lives created a platform whereby interviewees could give a much-needed voice to topics that are often silenced.

John was particularly enthusiastic about having an opportunity to talk about his experiences of living with HIV. John was diagnosed with HIV in 1984 at the age of thirty-seven. He lived with the virus for another sixteen years before his health declined and he started to take antiretroviral medication in 2000. John's enthusiasm for this study was – at least in part – a reaction against doctors whom he felt expressed little interest in his physical health or his emotional wellbeing. His motivation was evident from our initial correspondence. He informed me that he was 'most happy to become part of your research, in part because no medical person that has crossed my path in the last ten years has been the slightest bit interested in why I continue to survive'.⁴⁸ John's emphasis on *why* rather than *how* he continues to survive is suggestive. It reflected the disappointment, frustration, and anger that had accumulated over the thirty years he had been living with HIV. Above all, it encapsulated his anger at medical professionals, with whom he had 'los[t] a hell of a lot of faith'.⁴⁹ He appears, then, to have drawn on the oral history interview for validation that his story of survival was significant and meaningful.

John's enthusiasm for an opportunity to talk about his personal life led to frank and detailed descriptions of the psychological impact of having HIV. During the interview, he explained that he had suffered from bouts of severe depression, experienced 'complete treatment failure' with anti-depressants and had been placed in psychiatric care after a suicide attempt. As was the case with Adrian, however, John was considerably more hesitant to discuss the visible effects of antiretroviral medication. Apart from a brief comment about hair loss, John did not mention any of the other visible side effects he endures. The significance of this silence became apparent two days after the interview when I received an email from John with the subject heading 'Additional info – depression, body image, and grief'. Focusing on his visible symptoms, John confessed:

Body image mentally and physically, becomes blighted, a regular feature for many positive guys, by the rotten and dreaded 'Lypo' sisters... Lipodystrophy, and Lipoatrophy. The first rearranges the fat distribution on your body, in my case a pot belly, and most unattractive 'man boobs', and in many cases you grow a hump on the back of your neck. The second is clearly responsible for giving me the 'Belsen look' – a wasting and gaunt look, and sunken cheeks [...] These bodily changes can certainly cause some embarrassment, and a big disincentive to removing your top, whether at the beach, or to simply catch a few rays, and that most essential Vit. D.⁵⁰

The openness with which John divulged his body image issues via email suggests it was a deliberate omission during the interview. This silence exposes the psychological distress caused by displaying visible symptoms. His reference to the 'Belsen look', an allusion to the Bergen-Belsen Nazi concentration camp, is particularly macabre. Further, John's assertion that lipodystrophy is 'clearly responsible' for his appearance reflects his certainty that such symptoms were noticeable during the interview. John may have therefore felt more comfortable discussing visible symptoms of HIV when they were not, as he understood, in plain sight.

John's willingness to discuss these symptoms via email also raises questions about why he felt he could discuss the unseen physical effects of antiretroviral medication, including diarrhoea, but not the visible changes. His assertion that these body changes 'cause some embarrassment' is telling. In this regard, my age may have caused the strongest barrier. While my positionality as someone who had not experienced the epidemic appears to have helped Adrian to articulate his struggles with side effects of antiretroviral medication, it had an adverse effect on John. He may have felt particularly embarrassed speaking to someone who had not undergone the physical changes that often accompany ageing or illness, and therefore felt I could not understand, nor empathise with, the extent to which such physical changes had damaged his self-esteem.

In addition to being silenced by possible embarrassment, narrators' discussions about the impact HIV has had on their lives are also suppressed by dominant depictions of HIV survivors that have prevailed since the 'people with AIDS self-empowerment movement' of the 1980s.⁵¹ This was especially apparent in my interview with Victor Day. Victor's determination to portray himself as a survivor was apparent from the first email he sent me in response to my advertisement. He simply stated that he was '[d]iagnosed in 1986 – doing well. Open to participating. Let's talk'.⁵² From the outset, he was determined to portray himself not as someone who has been affected by illness for thirty years, but as someone who continues to persevere.

During the interview, Victor openly discussed his relationships with his family, his painful sexual experiences during his adolescence and into early adulthood, and his sense of isolation from the broader gay community. It was therefore not immediately clear that he was holding back. Victor's tone changed fifty-three minutes into the ninety-minute interview, and he disclosed that his sense of 'doing well' was a position he felt compelled to project. He described the difficulty of:

Wanting to present to the world that I'm you know... normal or something. But having to work with all the social services and having to present, you know, the best case for the best, you know. Having to be sick for people who needed me to be sick and having to be well for people who wanted me to be well, and neither was really true, you know. I wasn't necessarily as sick as I wanted the social services to understand...

Which is complicated in a way that, because in a way, I don't wanna be, I mean, this is just research, so it's off the cuff, but... It's also very difficult to balance because I might feel okay today but then tomorrow when I just can't do anything, and I sit on the couch. I need to be able to speak to that when it's not happening.⁵³

Victor's assessment of his current situation reflects the persistent struggle between needing to be 'sick' enough to receive the necessary support from social services while trying to live what he understood to be a 'normal' life. Victor's housing situation – whereby he could live in a government-subsidised private rental rather than in public housing – and his physical appearance enabled him to uphold this image. He explained his fortune at having injections to treat lipodystrophy and concluded that in comparison to other people who may display visible symptoms, 'I look alright'.

The extent to which an oral history interview that explicitly focused on the narrator's intimate memories encouraged Victor to abandon the persona he felt compelled to project in his everyday life became apparent during the final five minutes of the interview. He explained:

You allow me to be HIV-positive. And that's, you know, that brings up a whole emotional thing about, uh, I mainly have to be doing so well. I mainly have to be doing so well, like, I mean you have to be more than HIV-positive. You know? It's like, knowing that there's this strong feeling that I have to keep pursuing good health, knowing that like my gut's not good, and my, you know, bowels and all that is all a bit messy, and that's particularly messy for someone who has anal sex. And, these are all just, you know, things you can't talk about, you can't share. And... it's only when someone sits with me and says, 'I'm interested in the fact that you are HIV', that I realise that I spend most of my time being better than HIV, fighting.⁵⁴

Victor's willingness to discuss his prevailing struggles with HIV suggests that his desire for an opportunity to talk about these issues was one of the reasons he agreed to participate in an interview. Indeed, his assertion that he cannot discuss the physical challenges of having HIV because they are 'things you can't talk about' reveals how the interview provided him with a space to discuss topics that would otherwise remain silenced. As was the case with John and Adrian, Victor's narrative is therefore not only marginalised in dominant histories, but also in a society that he feels is reluctant to talk about HIV, especially among those who have been living with the virus for some time. Victor was further silenced by his lack of a support network. He described himself as a 'loner' who struggles to establish relationships as people find him 'too intense'. Such intimate topics, therefore, remained unspoken outside of the distinct space that the interview provided.

Although Victor acknowledged the severe impact HIV has had on his life, he was not willing to relinquish his position as a survivor outside of the interview. Victor was more concerned with anonymity than any of the other interviewees, and he reminded me not to mention certain places he had lived as he was concerned that he would be identified. He explained that his former willingness to be 'open' about his HIV-positive status had led to unwanted sympathy from people who opened doors for him and treated him as someone who was unwell. My positionality as a stranger conducting a one-off interview perhaps gave Victor the freedom to openly acknowledge how severely he was, and continues to be, affected by the epidemic, without the risk of being treated differently in his everyday life. It illustrates the significance of his earlier qualification that 'this is *just* research'.

The oral history interviews not only created a distinct space for narrators to discuss highly intimate issues, but they also encouraged a new focus, namely, on how they dealt with the lasting impacts of the epidemic in their private lives. Victor's account is a particularly explicit indicator that discussions about the physical side effects of antiretroviral medication are not permitted outside of the interview. This is not only because he, like John, considered these topics highly embarrassing, but also because these men felt particularly isolated, without access to a regular support

network. In this regard, the oral history interview provided him with a distinct – albeit short-lived – space to acknowledge the extent to which he continues to be affected by the virus.

Conclusion

Together, the oral histories reveal narrators' determinations to convey their prevailing struggles with antiretroviral medication, and to give voice to an experience that many felt has been overlooked. This was most apparent when narrators spoke of the distress caused by dealing with visible and intrusive physical side effects of antiretroviral medication. Such topics are often marginalised amidst dominant accounts that focus on the effectiveness of the antiretroviral medication. Narrators' struggles are further silenced by embarrassment, isolation, and their understandings that they are considered the fortunate few who have survived the epidemic.

While narrators were initially hesitant to discuss the visible effects of medication, their eventual openness is noteworthy, especially considering my subjectivity as an outsider to the HIV-positive gay male community. The critical factor in fostering such open-ended discussions was our shared understanding that the epidemic is not over, that their experiences should not be forgotten, and that I could play a role in bringing their histories to a wider public.

NOTES

1. Victor Day is a pseudonym. The other narrators in this study are referred to by their real names. All were asked if they would like their interviews to be anonymised.

2. An HIV/AIDS Timeline Emphasising the Australian/New South Wales Perspective [web page]. Accessed online at www.acon.org.au/wp-content/uploads/2015/04/History_of_HIV_5th-Edition.pdf, p 11, 10 April 2018.

3. Dennis Altman, *The End of the Homosexual?*, Queensland: University of Queensland Press, 2013, p 118; Dennis Altman, *Power and Community*, London: Taylor and Francis, 1994, pp 71-75; Paul Sendziuk, *Learning to Trust: Australian Responses to AIDS*, Sydney: University of New South Wales Press, 2003, pp 211-218; Graham Willett, 'How we saved our lives: the gay community and the Australian response to AIDS', *HIV Australia*, vol 12, no 3, 2014, pp 4-7; Graham Willett, *Living Out Loud: A History of Gay and Lesbian Activism in Australia*, St Leonards, NSW: Allen and Unwin, 2000, pp 184-195.

4. Asha Persson, 'Incorporating pharmakon: HIV, medicine, and body shape change', *Body and Society*, vol 10, 2004, p 47.

5. Persson, 2004, p 47.

6. An HIV/AIDS Timeline Emphasising the Australian/New South Wales Perspective [web page]. 10 April 2018.

7. Demetrius James Porche, 'One world. One hope: XI International Conference on AIDS', *JANAC*, vol 7, no 5, 1996, pp 94-96.

8. The physical effects of AZT were recognised from the late 1980s. See Douglas D Richman and others, 'The toxicity of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex', *New England Journal of Medicine*, vol 317, no 4, 1987, pp 192-197.

9. Interview with Stephen Allkins, born in Sydney, 1960, DJ; recorded by Cheryl Ware, 6 August 2014.

10. Lars Kallings and Craig McClure, *20 Years of the International AIDS Society: HIV Professionals Working Together to Fight AIDS*, Switzerland: International AIDS Society, 2008, p 29.

11. Interview with Tim Alderman, born in Sydney, 1954, writer; recorded by Cheryl Ware, 29 October 2014.

12. Interview with Steven Berveling, born in the Netherlands, 1957, lawyer; recorded by Cheryl Ware, 17 July 2014.

13. Interview with David Polson, born in Christchurch, 1954, motivational

speaker; recorded by Cheryl Ware, 18 June 2014.

14. Interview with Adrian Eisler, born in London, 1954, community support network co-ordinator; recorded by Cheryl Ware, 23 May 2014.

15. Persson, 2004, p 52.

16. Asha Persson, 'Facing HIV: body shape change and the (in)visibility of illness', *Medical Anthropology*, vol 24, no 3, 2005, p 243.

17. Gill Green, *The End of Stigma? Changes in the Social Experience of Long-Term Illness*, Oxford: Routledge, 2009, p 61.

18. Loren Brener, Denton Callander, Sean Slavin and John de Wit, 'Experiences of HIV stigma: the role of visible symptoms, HIV centrality and community attachment for people living with HIV', *AIDS Care*, vol 25, no 9, 2012, p 1171; Andrew Carr, 'HIV lipodystrophy: risk factors, pathogenesis, diagnosis and management', *AIDS*, vol 17, 2003, p S145.

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