‘Not Until I’m Absolutely Half-Dead and Have To:’ Accounting for Non-Use of Antiretroviral Therapy in Semi-Structured Interviews with People Living with HIV in Australia

Christy E. Newman, PhD,¹ Limin Mao, PhD,¹ Asha Persson, PhD,¹ Martin Holt, PhD,¹ Sean Slavin, PhD,²
Michael R. Kidd, MD,³ Jeffrey J. Post, MD, PhD,^{4,5} Edwina Wright, MD, PhD,^{6,7} and John de Wit, PhD¹

Abstract

Current debates regarding the use of antiretroviral therapy (ART) to promote both individual- and population-level health benefits underscore the importance of understanding why a subpopulation of people with diagnosed HIV and access to treatment choose not to use it. Semi-structured interviews were conducted between 2012 and 2014 with 27 people living with HIV in Australia who were not using ART at the time of interview. Analytic triangulation permitted an appreciation of not only the varied personal reasons for non-use of treatment, but also underlying views on HIV treatment, and the ideal conditions imagined necessary for treatment initiation. Policy goals to increase the number of people with HIV using ART must recognize the diverse explanations for non-use of ART, which include concerns about the various impacts of committing to lifelong pharmaceutical treatment use. Our research identified distinctive subgroups among people who are not using antiretroviral therapy, with a range of individual and social needs that may affect treatment decisions. These findings challenge assumptions about treatment non-use in resource-rich settings, revealing persistent consumer fears about the potent and unknown effects of HIV medications that deserve greater recognition in policy debate on treatment uptake.

Introduction

IN THE MORE THAN 30 YEARS that have passed since the human immunodeficiency virus (HIV) was first identified, major developments in the field of antiretroviral therapy (ART) have transformed both quality of life and life expectancy among people with HIV who have access to expert care and a continuous supply of medication.¹ While a range of adverse effects can still be experienced, the body shape changes and toxicities typical of 1990s drug regimens² no longer typify the use of HIV treatment, and the degree of adherence required to achieve viral suppression has also markedly decreased.³ Much of the literature on ART use today is therefore focused on understanding barriers to

treatment access among people living with HIV (PLHIV) in resource-limited or transitional settings,^{4,5} or in selected resource-rich settings such as the USA, where more than 50% of people with diagnosed HIV infection are not currently engaged with medical care,⁶ and persistent socio-economic barriers exist to treatment access.⁷

Less research attention has been paid to the personal and social factors that influence ART use in settings where treatment access is well supported and engagement with care is relatively common, such as Australia, Canada, and western Europe. Important barriers to linkage and retention to care and treatment continue to operate in these settings,^{8,9} but there are also minority of people with diagnosed HIV living in these countries who have access but choose to not use

¹Centre for Social Research in Health, UNSW Australia, Sydney, Australia.

²Australian Federation of AIDS Organisations, Sydney, Australia.

³Faculty of Medicine, Nursing and Health Sciences, Flinders University, Adelaide, Australia.

⁴Department of Infectious Diseases, The Prince of Wales Hospital, Sydney, Australia.

⁵Prince of Wales Clinical School, UNSW Australia, Sydney, Australia.

⁶Department of Infectious Diseases, The Alfred Hospital and Monash University, Melbourne, Australia.

⁷The Burnet Institute, Melbourne, Australia.

pharmaceutical therapies in the management of their HIV infection. This opens up a range of important and timely questions regarding how individuals account for their non-use of ART in an era in which the early and sustained use of HIV treatments is strongly recommended in order to prevent immunological damage and the secondary transmission of HIV to sexual partners.^{10,11}

In Australia (and elsewhere), approaches to prescribing ART have undergone considerable change in recent years.¹² Although treatment advocacy has been strong in this setting since the early years of the HIV epidemic,¹³ what is distinctive about recent developments are the explicit commitments to early initiation and high rates of ART use now being made by both government and non-government organizations.^{8,14} Successful results from the HPTN052 and PARTNER trials, which indicate ART use can dramatically reduce the rate of transmission of HIV in sexual partnerships, have been particularly influential in mobilizing this increased commitment to achieving sustained viral suppression in a greater proportion of PLHIV.¹⁵ The increased interest at both national and international levels in the potential individual and population benefits of treatment underlines the importance of understanding the views of people with HIV about ART, particularly people with diagnosed HIV who are choosing to delay or refuse ART.

With this in mind, our research explored how people with HIV accounted for their non-use of ART, in a setting with minimal structural barriers to access and growing policy and clinical support for treatment use. Three research questions were pursued in analyzing our qualitative data: *What reasons do people with HIV provide in explaining their non-use of ART at the time of interview? What underlying views on HIV treatment are revealed through this process? And what ideal conditions are imagined as necessary for the initiation of ART?* Bringing together the results of these analyses enabled a form of analytic triangulation¹⁶ that captured convergent perspectives on ART use, as well as a number of inconsistencies and contradictions. This contributes new and timely information on the non-use of ART, to inform and extend the rich history of social and clinical research on the lived experience of HIV medicine.

Understanding the non-use of antiretroviral therapy in Australia and comparable settings

Although a range of estimates have been made regarding the proportion of PLHIV in Australia who are not using ART, these are typically quite low, with recent research reporting ART coverage of 70–88%.^{17–19} One of these studies observed decreasing rates of ART non-use between the years 2010 and 2012, although non-use was associated with, among other things, younger age (85% of HIV positive men under 25 years were not using ART) and recent HIV diagnosis.¹⁷ Divergent and evolving views on ART initiation are reportedly held among PLHIV and those at highest risk of HIV in Australia, namely gay men. For example, a 2009 survey found that over one-third of Australian PLHIV disagreed that ART should be commenced immediately after an HIV diagnosis, regardless of CD4 counts.²⁰ A 2011 survey of HIV-positive and negative gay men then found that, while both groups believed ART prevented serious illness, negative men were more sceptical about the potential for ART use to reduce the risk of sexual

transmission.²¹ A more recent survey, conducted in 2013, found that both groups continued to believe in the health benefits of ART, but had diverging views about treatment as prevention (negative men continuing to be more sceptical about these potential benefits of ART), and early initiation (positive men being far less supportive of commencing treatment soon after diagnosis).²² Promoting the health, rather than preventive, benefits of ART continues to be most acceptable to both HIV positive and negative gay men in Australia.

With regard to reasons for non-use of ART, analysis of the Australian Gay Community Periodic Surveys found that, in addition to younger age and shorter duration since diagnosis, independent factors associated with ART non-use included lower rates of annual sexual health screening and not receiving social welfare payments, pointing to non-use of ART being associated with feeling well, and thus being less engaged with health and social care services.¹⁷ Qualitative studies have described the views of particular subpopulations, including recently diagnosed gay men²³ and women,²⁴ providing updated information to support the number of important research articles published on reasons for non-use in the years following the introduction of effective combination ART.^{25–27} All of these early studies identified key reasons for non-use as including fear of short- and long-term side effects, concerns about the safety and effectiveness of pharmaceutical treatments, doubts about the need to commence treatment, and reluctance to commit to a daily medication regimen. Similar reasons for non-use have been reported in research conducted in relatively comparable settings including the UK,²⁸ Germany,²⁹ Poland,³⁰ the USA,^{31–33} and Canada.^{34,35} Preference for alternative medicines were observed in a number of these studies, but particularly in the German and US research,^{29,36} and mistrust of medications and medical care providers was particularly stressed in research from the USA, as was the role of stigma and perceived cost of treatment.^{31,37–39} Other factors that influence the uptake of ART in Australia and comparable settings include an individual's capacity to make informed treatment decisions, such as health literacy and decision making ability.^{40,41} Tolerance of psychological and physical distress and discomfort,⁴² problems with illicit drug use,^{43,44} and the views of medical providers may also influence decisions to use ART.^{45,46} Although this is a broad body of literature, there have been no recent studies published that provide a more contemporary examination of the non-use of ART in a diverse sample of people with HIV.

Materials and Methods

This article reports findings from interviews conducted between September 2012 and February 2014 with people living with HIV who were not taking ART at the time of interview. Embedded within a larger multi-method study examining factors influencing ART initiation, this article is focused on the qualitative arm, which took an open-ended, interpretivist,^{28,47} approach to understanding the views and experiences of people with HIV regarding non-use of ART. Ethics approval was provided by the Human Research Ethics Committee of UNSW Australia (The University of New South Wales).

Participants were recruited nationally via advertisements posted on HIV community organization websites and in

community media aiming at an audience of people with HIV. Prospective participants contacted a representative at the National Association of People with HIV Australia (NAP-WHA), who assessed the potential participant's eligibility for the study (aged 18 or older, diagnosed with HIV, not taking ART, living in Australia) and then forwarded their contact details to the researchers. Interviews were conducted mostly by telephone, to facilitate ease of contact with participants living around Australia. Participants based in Sydney were interviewed in person if they preferred that option. Interviews were conducted using a semi-structured interview guide, which aimed to explore a diverse range of issues and experiences related to HIV treatment, including clinical history, awareness of, beliefs and information about treatment, discussions with care providers regarding treatment decisions, views on complementary and alternative medicine, and the costs and benefits of commencing ART.

Interviews were audio recorded, transcribed verbatim, and de-identified to protect participant confidentiality. Transcripts were analyzed in NVivo 10 software (QSR), firstly generating 'open' codes to organize the main thematic categories in the data set.⁴⁸ Analysis commenced during data collection, continuing as each interview was conducted, with thematic categories refined in order to achieve meaningful interpretive descriptions of individual themes and their relationships to each other.⁴⁹ For this article, a secondary analysis was conducted that focused on the three research questions noted in the introduction. These questions each reveal a distinct but complementary aspect of how participants accounted for their non-use of antiretroviral therapy: reasons for non-use, underlying views on HIV treatment, and conditions imagined necessary for ART initiation.

Results

Participant characteristics are reviewed in Table 1. In brief, 27 people took part, mostly men ($n=23$) who were gay-identified ($n=19$), reflecting patterns of HIV infection in Australia.¹⁹ However, the sample also included heterosexual or bisexual-identifying women ($n=4$) and men ($n=3$) with considerable demographic diversity in terms of age, cultural background, relationship status, education, and employment. Year of diagnosis ranged from 1986 to 2012, age at diagnosis from 20 to 61, and time since diagnosis from only a few months to 27 years. Ten participants had no history of ART use at the time of interview, while the remaining participants had used ART only during pregnancy or post-exposure ($n=3$), or for limited periods, less than ($n=9$) or greater than ($n=5$) 12 months in total. Participants reported that their recent CD4+ cell count was >500 cells/mm³ ($n=14$), 350–500 ($n=6$), and <350 ($n=4$). Synthesized demographic and clinical characteristics are listed for each participant in Table 2, and discussed where relevant throughout the results. However, it is important to note that only a few participants reported that they were determined never to use ART; the remainder were open to starting or restarting HIV medication in the near or distant future.

Why not now: Understanding reasons for treatment non-use

To begin it is important to recognize that some people with diagnosed HIV who are not using ART have not yet received

a strong recommendation from medical providers that they should do so. A number of reasons were provided by participants along those lines, captured in the theme: **not yet needing medication**. As one man put it: “[The doctor] said I don’t need to take antiretrovirals yet...He says, ‘Your viral load is low and it’s, everything’s okay at the moment, within normal range’” [Andrew]. Some participants, however, had been encouraged to *consider* starting treatment, but preferred to wait until they observed clinical ‘evidence’ (through monitoring of viral load and CD4 counts) that supported a stronger recommendation to start treatment as soon as possible. An example comes from a participant diagnosed only a few months before the interview:

They do encourage getting on treatment sooner. However, they can understand...that I’d like to monitor the CD4 count myself and monitor the viral load and see where we go from there. Again, they don’t see it as being absolutely critical right now, because it’s such a new infection [Dominic].

Another subgroup of participants viewed themselves as an ‘elite’ group of long-term non-progressors, and believed they were likely to avoid ART use indefinitely: “I was born with some sort of genetic makeup that allows me, my body, to control this...[which] is pretty cool...And so I’m just happy that I am where I am” [Zach] This distinguishes a number of strands within the broader theme of *not yet needing medication*, each revealing a distinctive set of expectations regarding treatment initiation. However, none of these participants viewed non-use of ART as conflicting with medical advice: on the contrary, they conveyed a strong belief that the medical perspective aligned easily with their own preference to not use ART, and that health care providers would respect their desire to be an active participant in the monitoring and management of health.

This contrasted with a second theme, **questioning biomedicine**, which encompassed a range of doubts and concerns among some participants regarding the science, politics, and economics of HIV medicine. These participants were explicitly critical of biomedicine, and viewed HIV management practices as unduly influenced by the pharmaceutical industry. For example: “I’m left to just trust the word of a doctor and unfortunately I don’t trust the word of anyone...I don’t know whether the doctors are complicit with the drug companies [as] in, ‘Just push them on drugs and get them out,’ or whether the doctors just are too busy to care” [Alex]. What is interesting about this and similar accounts from participants who reported conflict with their care providers over the issue of HIV treatment (and related matters) was their continued engagement with medical care and the monitoring of viral load and CD4+ cell count. A number were explicitly invested in complementary or alternative medical (CAM) approaches to managing HIV, and many viewed ART as ‘chemicals’ that were ‘toxic’ to the body. However, the broader theme of ‘questioning biomedicine’ was not always contemporaneous with CAM use.

The three final themes in this section comprise reasons for non-use of ART that sought to *protect* attributes or experiences that participants believed could potentially be compromised by treatment. For example, the theme of **protecting wellbeing** encompassed the concerns all participants expressed regarding the potential side-effects of treatment, both short- and long-term. Side effects were believed to be not

TABLE 1. OVERVIEW OF KEY CHARACTERISTICS OF STUDY SAMPLE

<i>Category</i>	<i>Characteristic</i>	<i>Numbers</i>
Gender identity	Male	23
	Female	4
Sexual identity	Gay/homosexual man	19
	Heterosexual woman	4
	Heterosexual/bisexual man	4
Age	Mean (years)	43
	Range (years)	20–68
Country of birth	Australia	19
	English-speaking overseas country	4
	Non-English-speaking overseas country	4
Ethnic or cultural heritage	Anglo-Irish heritage	17
	Other European heritage	7
	African or Middle Eastern heritage	3
State of residence	New South Wales	12
	Victoria	5
	Queensland	5
	Western Australia, South Australia or Australian Capital Territory	5
Main source income	Full time	11
	Part-time	5
	Government payments	11
Annual income	Mean (AU\$)	\$53,500
	Range (AU\$)	\$11,000–\$120,000
Highest education	Postgraduate qualification	2
	Undergraduate qualification	13
	Diploma/trade certificate	6
	Primary/high school qualification	6
Relationship status	Single	21
	Partnered	6
Year of diagnosis	Median (year)	2003
	Range (years)	1986–2012
Age at diagnosis	Mean (years)	34
	Range (years)	20–61
Years since diagnosis	Mean (years)	10
	Range (years)	<1–27
Most recent CD4+ cell count	Unknown (cells/mm ³)	2
	<350 (cells/mm ³)	4
	350–500 (cells/mm ³)	6
	>500 (cells/mm ³)	14
History of antiretroviral therapy use	ART naïve	10
	During pregnancy or post-exposure only	3
	<12 months ART use	9
	>12 months ART use	5
Primary view on ART initiation at time of interview	Will [re]start when recommended	6
	Avoiding [re]starting as long as possible	13
	Does not want to ever [re]start treatment	5
	Dealing with other priorities for now	3
Number of HIV positive friends	None	3
	1–2	5
	3–5	7
	More than 5	12
Involvement with HIV positive organisations	Not at all involved	11
	Somewhat/not very involved	12
	Very involved	4
Use of complementary or alternative medicine (CAM)	No use of CAM	16
	Minimal use of CAM	4
	Regular use of CAM	7

TABLE 2. SUMMARY OF DEMOGRAPHIC AND TREATMENT CHARACTERISTICS OF INDIVIDUAL PARTICIPANTS

<i>Pseudonym</i>	<i>Demographic characteristics</i>	<i>Treatment characteristics</i>
Abby	50- to 60-year-old heterosexual woman, 20–30 years since dx, recent CD4+ > 500	< 12 months ART use, avoiding restarting for as long as possible
Adam	20- to 30-year-old gay man, born in non-English speaking overseas country, 2–5 years since dx, recent CD4+ > 500	ART naïve, dealing with other priorities that preclude ART use for now
Alex	30- to 40-year-old gay man, 10–20 years since dx, recent CD4+ ~ 500	< 12 months ART use, avoiding restarting for as long as possible
Andrew	60- to 70-year-old heterosexual man, 2–5 years since dx, recent CD4+ > 500	ART naïve, will start when recommended by doctor
Benjamin	20- to 30-year-old gay man, 2–5 years since dx, recent CD4+ > 500	ART naïve, avoiding starting for as long as possible
Bill	50- to 60-year-old gay man, 10–20 years since dx, recent CD4+ > 500	> 12 months ART use, will restart when recommended by doctor
Caleb	30- to 40-year-old gay man, born in non-English speaking overseas country, 2–5 years since dx, recent CD4+ 350–500	ART naïve, avoiding starting for as long as possible
Calvin	40- to 50-year-old gay man, 10–20 years since dx, recent CD4+ > 500	> 12 months ART use, avoiding restarting for as long as possible
Camilla	30- to 40-year-old heterosexual woman, 5–10 years since dx, recent CD4+ > 500	ART use during pregnancy only, avoiding restarting for as long as possible
Chris	20- to 30-year-old gay man, < 2 years since dx, recent CD4+ > 500	ART naïve, will start when recommended by doctor
Dominic	30- to 40-year-old gay man, < 2 years since dx, recent CD4+ > 500	ART naïve, dealing with other priorities that preclude ART use for now
Eddy	30- to 40-year-old gay man, born in English speaking overseas country, < 2 years since dx, recent CD4+ > 500	ART use for post-exposure only, avoiding starting for as long as possible
Eric	60- to 70-year-old bisexual man, born in non-English speaking overseas country, 5–10 years since dx, recent CD4+ > 500	< 12 months ART use, avoiding restarting for as long as possible
Ethan	40- to 50-year-old gay man, 10–20 years since dx, recent CD4+ < 350	< 12 months ART use, does not want to ever restart treatment
Felix	50- to 60-year-old gay man, 5–10 years since dx, recent CD4+ < 350	> 12 months ART use, does not want to ever restart treatment
Gerard	50- to 60-year-old gay man, < 2 years since dx, recent CD4+ > 500	ART naïve, will start when recommended by doctor
Henry	20- to 30-year-old heterosexual man, born in non-English speaking overseas country, 5–10 years since dx, recent CD4+ > 500	< 12 months ART use, avoiding restarting for as long as possible
Matt	40- to 50-year-old gay man, 5–10 years since dx, recent CD4+ > 500	< 12 months ART use, avoiding restarting for as long as possible
Neil	60- to 70-year-old heterosexual man, 20–30 years since dx, recent CD4+ < 350	< 12 months ART use, does not want to ever restart treatment
Paul	60- to 70-year-old gay man, born in English speaking overseas country, 20–30 years since dx, recent CD4+ > 500	< 12 months ART use, does not want to ever restart treatment
Rachel	40- to 50-year-old heterosexual woman, 2–5 years since dx, recent CD4+ < 350	ART naïve, does not want to ever start treatment
Robert	60- to 70-year-old gay man, 5–10 years since dx, recent CD4+ < 350	> 12 months ART use, avoiding restarting for as long as possible
Sam	50- to 60-year-old gay man, 10–20 years since dx, recent CD4+ > 500	< 12 months ART use, avoiding restarting for as long as possible
Sarah	40- to 50-year-old heterosexual woman, 10–20 years since dx, recent CD4+ ~ 500	> 12 months ART use, dealing with other priorities that preclude ART use for now
Simon	40- to 50-year-old gay man, born in English speaking overseas country, 10–20 years since dx, recent CD4+ > 500	ART naïve, will start when recommended by doctor
Tom	30- to 40-year-old gay man, < 2 years since dx, recent CD4+ 350–500	ART use for post-exposure only, will start when recommended by doctor
Zach	30- to 40-year-old gay man, born in English speaking overseas country, 2–5 years since dx, recent CD4+ > 500	ART naïve, avoiding starting for as long as possible

only unpleasant but to also reduce capacity to fulfil parental or employment obligations. For example: *"It's really just the side effect problem, the impacts of medication on the body. And also then how that impacts on my capacity to work...on just my alertness and those sort of things"* [Tom]. Other concerns related to acquiring visible signs of a positive status, or serious impacts on cardiovascular, liver, and bone health.

Underlying these concerns was a fear that ART could diminish the sense of health and wellbeing they were enjoying at the time of interview. As one man put it: *"I feel great! I'm healthy, I'm getting enough sleep...a good balance of everything. Not taking the treatment at the moment...doesn't change how I feel today...So yeah. I'm going to roll with that...Because it's, it feels good"* [Dominic]. A few participants believed this contemporary experience of wellbeing was due to the immune system being left alone to do its own 'work', but this was not a dominant view. A more consistent position was one that sought to protect wellbeing in its current form for as long as the immune system was able to cope without 'help'. A secondary benefit of this approach, expressed by many of the participants, was keeping the broadest range of treatment options open in the future, by delaying the development of resistance to particular classes of treatment. What spans this diversity of reasons for non-use of ART is an investment in maintaining and protecting wellbeing as it is understood and experienced by the individual, even when that may set up a conflict or contradiction with medical views on how to protect short- and long-term health.

The next theme is **protecting way of life**, and this comprised three separate yet interrelated challenges associated with HIV medication use: access, adherence, and autonomy. Access issues were mainly reported by the minority of participants who did not have Australian residency and were therefore not eligible to access ART with government subsidies. However, a number of people with citizenship rights to subsidized medications and well-paid employment also identified the challenges of attending clinic appointments and filling medication prescriptions at hospital pharmacies during business hours as barriers to ART access. Adherence was a major concern for many people, but not all. Some believed that once they decided to start treatment, they would be fully committed to taking their medication exactly as prescribed. Others, as in the following quote, felt equally sure they wouldn't be able to do so:

That's impossible. I couldn't do that. I really couldn't. I mean, no matter where you are, you'd have to make sure, 'Oh, jeez, it's nine o'clock. I've got to go home and take that.' No, thank you. That would just wreck your whole social life [Rachel].

Feeling locked into a strict routine of medicine-taking also drove concerns about a loss of autonomy for participants who felt that once they commenced ART they would no longer be able to enjoy spontaneity, flexibility, and self-determination. As one man explained: *"I just feel a certain level of independence, not having to take [ART]...I still am living and achieving and in control. And I feel as though I would become dependent on something to stay alive and to battle the virus"* [Simon]. Again, while there is diversity across these views, they all place particular value in existing ways of life, and view HIV medication as holding a specific threat to their capacity to maintain that, sometimes beyond what they ap-

peared to associate with other, non-HIV-related, medication-taking regimens.

Finally, participants described their non-use of ART as a means of **protecting sense of self**. HIV treatment was viewed as having the potential to trouble how participants experienced selfhood, both in terms of how they thought about themselves, and how others viewed them: *"I don't want it to define me. I don't want treatment to define who I am. And I don't let the virus define me either"* [Dominic]. Some participants worried that having to carry their medications in luggage when travelling or even storing it somewhere accessible at home would increase the risk of their status becoming known without their consent. Even filling scripts was viewed as a disclosure risk: *"You're opening yourself up to a dozen people that are now going to be seeing that script, and the chance and the likelihood of someone that I know in my community, [which] is still quite small...finding out that I'm positive"* [Sarah]. For some, ART use also represented a major psychological and emotional hurdle in coming to accept a conception of self as living with HIV. For these participants, a strong preference was expressed for avoiding any reminders of their HIV status at all. As one man put it: *"HIV in my life, presently, it's really not a big thing. I have this medical, or potential medical condition...It's something that's there but sometimes I actually forget that I'm HIV positive, which, I think, is a good thing"* [Sam]. This quote captures a way of framing HIV medication which featured across these diverse reasons for non-use: HIV remains only a 'potential' issue for the individual to have to acknowledge and address for as long as treatment can be deferred.

Where I'm at: Appreciating underlying views on HIV treatment

While the above analysis captured the varied reasons provided by participants for non-use of ART at the time of interview, participants also revealed broader views on HIV treatment, which then aligned individual accounts with particular and quite distinctive subgroups within our sample. The number of participants aligned with each of these subgroups has been summarized in Table 1.

The first underlying view on HIV treatment revealed in these interviews was that of **treatment acceptance**, that is, that ART initiation was inevitable, and would be started (or restarted) when recommended. Not surprisingly, this view was more commonly expressed by participants who were both ART naïve and recently diagnosed, but it was not limited to them. Indeed, the framing of ART use as 'inevitable' was common across most of our interviews, and speaks to a culture and context in which pharmaceutical treatment plays a central role in shaping the story of HIV diagnosis and care. Treatment acceptance, however, was distinguished by those accounts that described HIV treatment as 'just a waiting game'. For example, the following quote comes from a man who had been living with HIV for almost two decades: *"I don't want to leave it until my immune system is totally exhausted and it's not going to be able to recover despite taking drugs...[But] after eighteen years...it's just a waiting game, I guess? Just being aware and just watching and just waiting"* [Simon].

Treatment deferral was the second underlying view identified, and can be described as a more explicitly

recalcitrant version of treatment acceptance. These participants accepted there were probably good reasons to start ART, but expressed a strong desire to avoid that outcome as long as possible. For example, as one young man put it: “*I think if I don’t go on treatment my life will be a lot shorter...but I’m trying to hold off for as long as I can*” [Benjamin]. Again, treatment is constructed as ‘inevitable’, but the individual is also invested with the capacity and motivation to actively defer that eventuality: “*I know that I’m going to eventually need to go on meds, I know that. But I want to do everything I possibly can to delay that for as long as possible*” [Sarah]. The following quote provides some insight into the work involved in holding firm to the treatment deferral view:

[I] was given a script...[and] it took me a good six weeks and push from my family to even get it filled. And those tablets are currently sitting under my bed in their boxes. And, yeah, I’ve just been very hesitant to start taking them...I think that time will come, but for me it’s obviously taking a very long time!...I think everybody knows it’s inevitable, know what I mean? It’s going to happen, right?...[But] It’s like, “No! Not until I’m absolutely half-dead and have to” [Matt].

Treatment refusal was the third underlying view evident in the interview data. For these participants, the possibility of voluntarily commencing ART was viewed as remote at best, and in many cases, entirely unimaginable, as simply ‘not worth the risk’. Many who took up this position held deep fears regarding the potential side-effects of ART, as described in the theme: ‘protecting way of life’. Some had witnessed the highs and lows of HIV medicine since early in the epidemic, and therefore found it hard to place their trust in HIV medications. For example, one man explained that he: “*had friends who [have] got all the terrible lipodystrophy side effects...It’s now the medication that’s killing them*” [Paul]. Another felt the potential side effects were “*not worth my happiness*”, particularly since “*Ninety percent of my friends with HIV [were] on their meds for all these years but they’ve still passed away before me*” [Neil]. Treatment refusal was also interlaced with reasons for non-use based in ‘questioning biomedicine’. One participant explained that his distrust of “*pharmaceutical products*”, and a belief that “*you can find anything from nature to help you*”, had led to conflict with his doctor, who “*keeps begging me to go on the medication, but I just keep saying...“No, I don’t think I need [them]”*” [Ethan]. However, almost all of these participants remained engaged with HIV clinical care, including some who had deliberately sought out new providers willing to provide them with clinical services to monitor their HIV and manage symptomatic illness, without the use of ART.

The final underlying view on HIV treatment evident in participant accounts was **treatment as low priority**. These participants deflected taking up a primary position on ART with reference to the many other pressing issues that they were managing at the time of interview. For example, the two women who took part in the study who had young children both explained that their parenting responsibilities took priority over treatment initiation, as they did not feel they had the support that may be required while they were adjusting to medication. As Sarah put it, “*You cannot be projectile vomiting and diarrhoea and not sleeping, with children, you*

can’t do it”, revealing considerable anxieties about the potential effects by ART, and significant prioritization of the care needs of children. Another subgroup were finding it difficult to make ends meet:

I am in a new country, I need money. I do cleaning...I stay awake all through the night and I have to do a lot of scrubbing and a lot of sweeping...if I have to combine all that with taking drugs, it’s going to be really, really huge. But I need to survive in Australia [Adam].

For a few participants, treatment decisions were being deferred due to mental illness or other experiences of significant emotional distress. One participant was involved in criminal proceedings relating to his HIV infection, and was struggling to achieving the kind of stability he believed was required before commencing ART: “*You have to be in the right place, in the right mindset, in the right time. You know, the stars have to align, and the moon and Jupiter!*” [Dominic]. This envisioning of a perfect moment in which all of the various factors align to make it possible to start treatment is explored in more detail in the following section.

Maybe then: Imagining ideal conditions for treatment initiation

Participant accounts of treatment non-use also provided insights into the conditions imagined necessary before ART initiation could be considered. Three consistent ‘visions’ were constructed by participants when imagining an ideal future involving the use of ART. The first, **treating sickness**, imagined a time when the body would be no longer able to manage HIV infection without treatment. The point at which an individual imagined they would be convinced of the clinical need for treatment differed, but was often conceptualized as experiencing physical deterioration—“*I’ll have to feel a whole lot worse*” [Robert]—or recognizing a turning point on a continuum between wellness and illness: “*taking treatment will be kind of a red line in regard to the health levels of the body*” [Caleb]. For some, a particularly dramatic experience of sickness would be the only evidence sufficient to convince them that commencing ART was necessary: “*I’d have to be really sick*” [Ethan], or “*actually being hospitalized*” [Matt]. This form of future envisioning twins with the present-day theme of ‘protecting wellbeing’, imagining a time when the health that is so highly valued today can no longer be maintained, thus removing the possibility of sustaining a life without HIV treatment.

The second ideal condition for treatment initiation, **treating for others**, focused on external drivers such as treating to reduce infectiousness, or to satisfy the demands of loved ones. Most participants were aware of the potential for ART to reduce the risk of sexual transmission of HIV infection, and a minority were very much in favor of commencing ART to care for sexual partners: “*If I go on treatment, it is a way of...protecting whoever my partner may be in the future*” [Adam]. While some of these accounts relied on idealized impressions of what those future relationship scenarios might look like, two participants valued the potential for ART to reduce the risk of transmission to their current HIV-negative partners. There was also some recognition that treating for others could have secondary benefits for the individual in reducing their own fears of passing on HIV to sexual partners: “*One of the things that*

probably would make me...[start] is the fear of actually passing it on to anyone else...[ART is] kind of like [an] advantage in a way [to] stop me from spreading this" [Eddy]. Other participants anticipated that a growing pressure from loved ones, particularly partners and family, would eventually convince them to use ART. However, this wasn't always seen to satisfy all of the conditions they wanted fulfilled before initiating ART: "My sister was...pretty strong on me filling the script. So...now it's kind of a matter of every couple of days it's like, 'Well, have you started yet? Have you started?...It's like, 'No, I haven't. I'll start when I'm ready!'" [Matt]. This imagining of a potential future scenario that is foreseeable but nonetheless out of reach aligns with the narrative frame of 'treatment deferral', but integrates a more explicit recognition of the role of family or intimate partners in conceptualizing treatment decisions.

The final ideal condition described in these interviews, **improved treatment options**, was markedly utopian, revealing an investment in the potential for science to continue to achieve remarkable successes in HIV medicine, including treatments which are even more tolerable and safe than they are today. As Sam put it: "hopefully, as time goes on...those adverse side effects can be avoided more than now. I'm not saying totally but more." Fears about the potential harms of medication drove these beliefs about better options being developed in the future. As Rachel argued: "Find [a treatment] that's going to work [and] that's not going to hurt me as well". For some, these visions were presented as impossible goals, imagined only in order to reveal how unlikely it is that these ambitious criteria for commencing ART will ever be fulfilled: "If they came up with a tablet that, one tablet that done the job of all the others, and it made me feel good? [But] that's not likely to happen, so no" [Neil]. Others were open to being better convinced by the safety and effectiveness of ART, but felt that the risks remained too significant at this point to outweigh any potential benefits. As Felix, for example, put it: "I would need to be ill and it would need to be definitely linked to the HIV and you [would have to] show me why the specific medications recommended would benefit me". This is a particularly compelling statement from a man reporting very low recent CD4+ cell counts, considerable ill health, and significant conflict with care providers regarding his decision to refuse HIV treatment. Nonetheless, Felix did not take up a position of 'treatment refusal' overall, as he was more focused in the interview on advocating for a future for HIV medicine that featured safer, more effective treatments for the management of HIV infection. What is revealed by these visions of a 'perfect' future for HIV medicine is, in sum, a deep, underlying reluctance to countenance the use of ART in its current forms, countering contemporary representations of ART as safe and effective.

Discussion

Qualitative interviews with people living with diagnosed HIV in Australia generated a number of useful insights regarding the non-use of HIV treatment today. Despite considerable diversity across the accounts of non-use provided by these participants, many of the individual reasons remain largely unchanged from those described in the literature over the past few decades. This reveals an enduring set of fears among at least a minority of PLHIV regarding the use of

antiretroviral therapy which are essential for policymakers and clinicians to recognize and respond to appropriately. The categories developed in our analysis that organized reasons for non-use into recurrent themes may offer helpful ways forward in this regard, distinguishing clinical ambivalence regarding the need for treatment from consumer 'questions' about biomedical approaches to HIV management, and foregrounding the value many people invest in living their life medication 'free'. Analytic triangulation also made it possible to appreciate not only personal reasons for not using treatment, but also the underlying views on HIV treatment they reveal, and the conditions imagined as necessary for treatment initiation. Distinctive subgroups of people with diagnosed HIV were also identified, each of which is likely to prefer and benefit from different strategies of engagement.

In taking a broad perspective on these insights, it is important to recognize that the views of pharmaceutical consumers have been the subject of considerable attention across the health and social sciences, in researching lay understandings of and engagement with medications.⁵⁰ While recognizing the many benefits pharmaceutical products have afforded populations around the world, relieving suffering and reducing mortality in innumerable ways, understanding why some 'consumers feel ambivalent about medicines'⁵¹ requires continuous, critical reflection, if policy and clinical responses to evolving health priorities are to succeed. The research on lay perspectives also asserts that consumer 'resistance' to recommended drug therapies is neither rare nor unjustified, given that reluctance to use a medication as prescribed is often based on reasonable concerns about the safety, effectiveness, or social meanings of treatment use.⁵² With this in mind, the implications of our analysis will now be discussed as opportunities to counter potentially unhelpful assumptions about the non-use of antiretroviral treatment in responses to the complex issue of HIV treatment uptake in developed world settings.

First, we believe that our analysis demonstrates that *treatment non-use cannot be explained as a lack of engagement with HIV medicine*. On the contrary, many of our participants were choosing to not use ART with either the support or knowledge of their treating physicians, whose views on the optimal time to initiate ART continue to evolve.¹² Additionally, even those who were determined to resist a medical recommendation to start ART remained highly engaged with HIV care, visiting specialist clinics regularly, and mostly describing strong, trusted relationships with providers. They also reported views on HIV medicine that were heavily invested in the potential of science to develop safer, more effective treatments, even those who preferred employing CAM approaches to managing their HIV.⁵³ But this was very much conceived as a future goal, rather than something they were willing to countenance as a possibility today. What distinguished this group was therefore not lack of engagement, but a lack of sufficiently convincing 'proof' that they should start using ART. While it is possible that the proof some of our participants were seeking was impossibly idealized (i.e., promising guaranteed successful outcomes and zero adverse effects), it nonetheless focuses attention towards conversations already in play regarding medication use, rather than simply assuming that people will use treatments once they are 'engaged' in care.

This leads us to a second conclusion, which is that *treatment non-use is not (necessarily) driven by irrational or unreasonable beliefs about HIV medicine*, or at least, it is unhelpful to 'explain away' people who do not use ART on this basis. The accounts provided by our participants align with the views of Pound et al, who have argued that it is often reasonable and justified to think very carefully before committing to a lifetime regimen of medicine-taking.⁵² Pharmaceutical products have both intended and unintended effects, and few consumers are likely to be unaware of the potential harms they risk in the pursuit of potential benefits, or the clinical uncertainties that continue to be associated with the use of ART for the management of health and/or the prevention of transmission.⁵⁴ As several participants noted, the effects of using ART over the very long-term remain unknown.⁵⁵ Nor can people with HIV be completely assured that sufficient new classes of treatments will be developed to provide continued viral suppression if they develop resistance to the currently available options.⁵⁶

Nonetheless, we do not intend also to suggest that all of the beliefs expressed by our participants should be viewed as 'rational' and 'reasonable'. Clearly, health-related decisions inspire a range of responses, including fears and anxieties that discourage trust in medicine, and in medical providers. The capacity of individuals to make informed decisions about health care and treatment also varies, and can be influenced by age, cognitive capacity, substance dependence, and many other factors.^{35,40-44} Views on medications are also diverse, and can diverge dramatically from those recognized as valid or evidence based in biomedicine. However, as is well recognized in the literature, consumers have always made sense of medications in their own ways, often becoming 'naïve scientists' who generate their own conclusions about what medicines do, and even choosing to change dosages or stop using medications for a period to observe the effects.⁵⁷ Interpreting these and other ways of engaging with medications as 'irrational' fails to appreciate that consumers inhabit the bodies and lives that are affected by treatment use, and that their decisions are made from this perspective. This suggests that the best way forward, in supporting people being asked to make treatment decisions, is to continue to appreciate the breadth and diversity of beliefs that shape their thinking, and to provide specific forms of support and understanding regarding the subjective dimensions of that process.

A third conclusion can be drawn regarding these complexities: *treatment non-use does not suggest a lack of care for the self*. In fact, thinking carefully and cautiously about medical advice in this context reveals a deliberative practice which is entirely aligned with caring for the self, with a particular focus on wellbeing, way of life and sense of self. As Pound has argued, research on consumer 'resistance' to taking medicine has typically focused on identifying false or faulty perceptions of meanings, which means that 'the more mundane issues about the physical reality of medicines and the effects they have on peoples' bodies and minds are obscured.'⁵² Thus, it has to be recognized that fears consumers may hold about an issue such as 'side effects,' widely reported in the research from Australia and elsewhere,^{23,25,28,30} are not simply misguided concerns that need to be corrected, but are legitimate fears based on the very real possibility (and sometimes personal experience) of a treatment having unintended effects. It also reveals the social context of such fears,

when a problem such as 'not feeling well' has significant implications for a person's functional capacity to fulfil social and economic roles, such as working, caring for loved ones, or simply feeling alert and active in everyday life.⁵⁸ Having said that, we note that many participants feared the use of HIV medicine but did not report similar concerns about other forms of medical care and treatment, including antibiotic 'pills' or antifungal treatments. HIV medicines were invested with a particular potency, representing a greater risk to the self, than other medical interventions, which needs to be better appreciated in policy and clinical activities relating to treatment uptake.

The broader social context of medicine-taking also leads us to a fourth conclusion, which is that *treatment non-use does not mean people just need more time before they are ready*. There is a large body of literature on psychological barriers to ART initiation, which places particular weight on the notion that readiness for HIV treatment requires full 'acceptance' of one's HIV-positive status.^{24,25} There are a number of 'stages of readiness' models,⁵⁹ but the one proposed by Kremer et al. argues that treatment use and adherence moves through five stages: precontemplation, contemplation, preparation, action and maintenance, and relapse.³⁶ While this model is cyclical and recognizes the likelihood of 'failures' in treatment adherence, it nonetheless is based upon an assumption of temporal linearity and forward movement across these stages, which does not necessarily fit with the ways our participants explained their views or experiences, of treatment.

If you approach the issue of treatment non-use as one of delayed psychological acceptance, this assumes the person is stuck in a stage of 'faulty' thinking which time and support can advance them beyond. Different opportunities for and directions in conversations on treatment may be opened up if it is better recognized that sometimes it is the medication itself which is viewed as too risky, invasive, or inflexible for prospective consumers to countenance. Similarly, viewing the prospective consumer as engaged in an iterative, shifting process of deliberation which draws on their own, particular, past (treatment histories), present (contemporary concerns), and future (ideal conditions) perspectives on ART may be helpful in opening up a productive and ongoing dialogue on treatment use.

As a fifth conclusion, we also believe this suggests that *treatment non-use in resource-rich settings demands ongoing, critical appraisal of structural and social barriers to access*. Although not a large proportion, a minority of participants provided clear examples of structural barriers, including financial costs and time limitations (getting to appointments or filling scripts), and social barriers, such as fear of disclosure, or obligation to maintain social roles as employees, carers, and so on. This reminds us that a recommended treatment regimen will not be an easy 'fit' with the lives of every person with diagnosed HIV, and that some people will require additional forms of support. Research has demonstrated that if full and proper account is not taken of the broader social and structural context and conditions of everyday life, and if support services are not made available to address areas of instability and challenge, there is a very high likelihood that adherence will not be achieved, and that continued engagement with health care systems will be threatened.^{9,43,60} Efforts continue to be made to reduce systemic and structural barriers to access in Australia, such as the restriction of ART

dispensing to selected hospital pharmacies, which may reduce people's concerns about disclosure.⁸

This leads us to our final conclusion, which is that *treatment non-use cannot be adequately understood or addressed by a one-size-fits-all model*. As we have reported in this analysis, and has been well documented in the social research literature on HIV and medicine,⁶¹ a body with HIV is not inhabited or experienced the same way by everyone, nor are choices about health, illness, and treatment understood or revealed in uniform, predictable ways. For some, a trained clinician strongly advising that it is time to start, based upon bloodwork indicating a deterioration in clinical markers, was viewed as a sufficient condition in which to start ART. For others, only hospitalisation would serve as proof that ART was required (and even in these cases could continue to be doubted, revealing tensions in what Thomas et al. have called 'the perceived legitimacy of different forms of medical knowledge and treatments').⁶² Participant accounts also revealed a view that has been previously documented in the literature, which proposes that the safest strategy for long-term health is to defer treatment.^{30,63}

However, amongst the diversity of perspectives of people with HIV published in the pharmaceutical treatment literature, those who occupy a position of 'treatment refusal' have received the least attention. Refusing treatment is, in contrast, a phenomenon that has been examined in the fields of immunization,⁶⁴ breast cancer,⁶⁵ and eating disorders,⁶⁶ among many others. Of some relevance to the field of HIV medicine, the broad category of 'non-vaccinating parents' has been stratified by Leask et al. into five distinctive subgroups: the 'unquestioning acceptor', the 'cautious acceptor', the 'hesitant', the 'late or selective vaccinator', and the 'refuser' of all vaccines.⁶⁴ These researchers advise that understanding nonvaccination requires an acceptance of the quite different motivations and concerns of these subgroups. They 'advocate respectful interactions' with the more explicitly critical groups so as to avoid 'excessive persuasion and adversarial debates'.⁶⁴ A similar approach is well advised in the HIV treatment arena, which has the potential to increasingly marginalize those people who choose not to use treatment, as greater emphasis is placed on encouraging the early, and lifelong, use of ART.⁶⁷

The limitations of our analysis are chiefly related to setting, which may restrict relevance to countries with comparable health care and social systems. We also acknowledge that qualitative research involves looking deeply at a small amount of data, which increases the risk of the findings not applying more broadly, or being overly particular to the individuals involved. Our participants were selected on the basis of their non-use of ART at the time of interview, and so may hold more negative views of HIV treatment than PLHIV who are using ART. A large proportion of our participants were well at the time of interview, with high CD4 counts, which is likely to have influenced their views on the early use of treatment. Nonetheless, we believe that current policy efforts to increase treatment uptake underscore the importance of understanding why even a small minority of diagnosed HIV-positive people with access to treatment choose not to use it. Our findings challenge assumptions about treatment non-use in resource rich settings, revealing persistent consumer fears about the potent and unknown effects of HIV medications that deserve greater recognition in

policy debate on treatment uptake. Future research could usefully examine the little understood influence of family, partner and friendship networks on treatment decisions, particularly in an era of treatment-as-prevention, in which 'protecting others' is likely to become more established as an imperative to treat.

Continuing examination of the evolving relations between treatment consumers and prescribers is also warranted, to consider how these influence treatment uptake in the field of HIV medicine. Qualitative social research may offer the most useful ways forward in understanding and integrating these diverse perspectives across different health system settings.

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Address correspondence to:

Dr. Christy Newman
 Centre for Social Research in Health
 Room 309, John Goodsell Building
 UNSW Australia
 Sydney NSW 2052
 Australia

E-mail: c.newman@unsw.edu.au