

Understanding Concerns About Treatment-as-Prevention Among People with HIV who are not Using Antiretroviral Therapy

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Abstract The use of antiretroviral therapy to prevent HIV transmission is now advocated in many settings, yet little research has documented the views of people with HIV. Semi-structured interviews were conducted in Australia between 2012 and 2014 with 27 HIV-positive people not using treatment at the time of interview. Thematic analysis of views on treatment-as-prevention found that while many participants recognised potential prevention benefits, only a minority was in support of initiating treatment solely to achieve those benefits. A range of uncertain or critical views were expressed regarding who would benefit, risk reduction, and changing treatment

norms. Participants resisted responsibility narratives that implied treatment should be used for the public good, in favour of making considered decisions about their preferred approach to managing HIV. Engaging communities in dialogue and debate regarding the risks and benefits of treatment will be critical if this new prevention strategy is to engender public trust.

Keywords HIV treatment as prevention · People living with HIV · Australia · Qualitative

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Introduction

‘All biomedical technologies are also social interventions’ [1:5].

The potential for combination antiretroviral therapy (ART) to not only improve the health of affected individuals but also prevent onward transmission of HIV has been extensively discussed [2], and became the focus of increasing attention following the publication of successful trial results in 2011 (HPTN 052) [3] and 2014 (PARTNER) [4]. Although still evolving, the underlying principle of treatment-as-prevention (TasP) is to reduce HIV transmission risk by prescribing ART to people with diagnosed HIV in order to suppress their viral load to undetectable levels, thereby reducing the risk of transmission of infection to their uninfected partners, and also reducing community viral load, that is, the ‘aggregation of individual viral loads of people infected with HIV in a specific community’ [5]. The potential prevention benefits of TasP have been promoted widely by leaders in HIV prevention science [6, 7], and endorsed by UNAIDS [8] and the World Health Organisation [9–11]. Many government and non-government organisations around the world have also

revised their HIV strategies to accommodate the new possibilities offered by TasP [12–14]. In Australia, TasP is now explicitly promoted in the national HIV strategy [15] and barriers to accessing ART have been removed so citizens and permanent residents diagnosed with HIV, irrespective of CD4+ cell count, or the presence of symptomatic HIV disease, can access subsidised treatment [16]. A growing number of clinicians in Australia also now appear confident in recommending patients commence ART before CD4+ count drops below 500 cells/mm³, for both individual and public health benefits [17, 18].

However, concerns have been raised regarding the range of social and clinical complexities associated with TasP. For example, if the expectations now ascribed to TasP are to be achieved, the many persistent barriers that exist to linking and retaining people in HIV care and treatment will need to be overcome [19, 20]. Others have questioned the wisdom of increasing the number of people using ART without fully understanding potential long term adverse effects [21], the risk of a focus on TasP reducing financial support for other HIV prevention strategies [22–24], and the complex ethical issues associated with advocating individual treatment to attain a public benefit of reduced community viral load [25]. What is less well documented, as has been noted in two review articles [26, 27], are the views of people with diagnosed HIV. In the Australian setting, this research includes two key research studies to date. The first was a survey of HIV-positive and negative gay men which reported in 2011 that while both groups believed ART prevented serious illness, they were both sceptical about whether ART prevented the transmission of HIV (through either TasP or pre-exposure prophylaxis (PREP), which involves HIV-negative partners using ART to prevent acquisition of the virus) [28]. The second study comprised qualitative interviews with gay men who had recently seroconverted, and this research reported that some of the participants who were using ART attributed that use to the reduced risk of transmitting the virus to partners [29]. While other participants had delayed ART initiation because of fears about side effects, inconvenience and adherence issues, and in a few cases an underlying scepticism about HIV medicine, those who used ART to prevent transmission reportedly described their motivations as altruistic, feeling a sense of responsibility to ‘do the right thing’. Both studies collected their data before the release of the HPTN 052 and PARTNER study results, which may have influenced the views of PLHIV they reported. Nonetheless, the divergent views they reveal speak to a tension long recognised in the field of public health ethics ‘between the right of individuals to be left alone and the needs of the larger public’ [30: 174], along with the social complexities of associating particular health

practices with a ‘moral’ responsibility to do the right thing by others.

In the field of HIV prevention and management, many, overlapping and complex, social and medical expectations have been invested in the ‘responsibilised’ person with HIV over the course of the epidemic [31]. Governmentality research has demonstrated that neoliberal ideology, in settings such as Australia, explicitly privileges the enterprising, autonomous and self-regulating subject [32: 161] who accepts personal responsibility for ‘taking appropriate preventive action and exercising “informed choice” in the burgeoning biomedical marketplace’ [33: 393]. These responsibilising imperatives have been shown to underpin HIV prevention discourse, including the expectation that individuals make full use of effective treatment and monitoring technologies to manage the risk of transmission ‘as an individual, self-driven responsibility (and not as a community practice)’ [34: 176]. The increasing integration of TasP within national and international responses to HIV provides additional impetus to understand how the target consumers of HIV treatments are making ‘informed choices’ regarding the recommendation to treat for not only their own long-term health, but also for the benefit of others in their communities [31].

Our analysis explores critical or ‘resistant’ [35] views on TasP expressed by 27 Australian PLHIV who were not using ART at the time of interview. As background, the Australian epidemic is relatively small, with an estimated 26,800 people living with HIV at the end of 2013—approximately 0.15 % of adults older than 15—of whom 23,100 were aware of their HIV status [36]. Of these people living with *diagnosed* HIV infection, 17,700 were estimated to be using ART, and 16,600 to have achieved viral suppression. As these estimates are based on data from a number of different sources, there could be anywhere between 54 and 87 % of people living with diagnosed HIV infection in Australia who have achieved viral suppression through the use of ART. A considerable minority of PLHIV are therefore either not using ART, or are using ART and not achieving viral suppression. It is this minority that TasP aims to most directly engage in care and treatment. HIV care is provided in a number of settings in Australia, including private general practice clinics (operated as small businesses, employing one or more doctors accredited to prescribe HIV medications, freely chosen by patients, who receive a full or partial cost reimbursement from the government) and public, government-funded sexual health clinics or hospital departments (employing one or more doctors accredited to prescribe HIV medications, typically free or low cost to service users) [37, 38]. In this context, where treatment is relatively accessible and affordable for most people with diagnosed HIV, the views of health consumers and

providers on the risks and benefits of medications become the most influential factor in treatment uptake [17]. Understanding consumer views on the use of treatment to prevent transmission is therefore of critical importance to the HIV response.

Methods

Semi-structured interviews were conducted between September 2012 and February 2014 with people living with HIV in Australia who were not taking ART at the time of interview. Ethics approval was provided by the Human Research Ethics Committee of UNSW Australia. Participants were recruited nationally via advertisements posted on HIV community organisation 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, 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. A final question asked participants if they had 'any thoughts on using treatment to prevent (reduce the risk of) HIV transmission?', in case this issue had not already come up in response to other questions.

Interviews were audio recorded, transcribed verbatim, de-identified and pseudonyms allocated to protect participant confidentiality. Analysis commenced by importing transcripts into NVivo 10 and generating initial or 'open' codes to organise the main thematic categories across the data set [39]. Analysis commenced early in the course of data collection, and continued as further interviews were conducted, with the thematic categories subsequently refined and developed through a constant comparison approach to accommodate any new themes emerging in the data. For the purpose of this paper, codes capturing views on the use of treatment to prevent transmission were analysed again to identify the most dominant and divergent views.

Results

The participants interviewed for this study comprised 27 men and women; key characteristics are summarised in Table 1. A sample that reflects some of the typical diversity of the HIV positive population in Australia took part, with participants differing in terms of age, cultural background, relationship status, education and employment. There was also a variety in year of HIV diagnosis, and although 10 were ART naïve, the remaining participants had some (short- to long-term) histories of ART use. The positions on ART initiation that participants occupied at the time of interview are summarised in Table 2, and discussed where relevant throughout the presentation of results.

The views expressed about TasP were initially striking in four ways. First, only four participants had never heard of TasP, suggesting high levels of awareness. Second, among the rest of the sample who had heard of TasP ($n = 23$), almost all were able to clearly articulate what TasP aims for, at least in its simplest form: that is, reducing infectiousness by encouraging PLHIV to take lifelong ART from as early as possible. Third, only four of the 23 participants who were aware of TasP expressed views which were fully supportive of this HIV prevention strategy. And fourth, the remaining participants ($n = 19$) articulated either uncertain or strongly critical views of TasP.

The 4 participants who expressed views in support of TasP all identified as gay men, were aged in their 20 or 30s, and had been diagnosed with HIV no longer than 2 years prior to the interview. Each of these men linked their positive views on TasP to the potential for ART to help them manage their fear of infecting their current or future male sexual partners. Another reason these men supported TasP was they all felt that taking ART was the 'right thing to do'. One participant saw the early initiation of ART as '*kind of the norm these days*', believing that most people were now started on treatments soon after diagnosis '*for their own health and also the transmission risk reduction*' [Zach]. Zach also believed this was having an effect on sexual practices among gay men, arguing that disclosure of HIV positive status is viewed as less concerning by prospective partners if accompanied by statements about being 'on treatment' and 'undetectable'. Conversely, a recently diagnosed participant explained that his main motivation to commence treatment would be to feel a *reduced* obligation to disclose, including to sexual partners but also to other relevant parties, such as dentists, which he had found particularly confronting in the past.

The remainder of this results section presents three thematic categories in the accounts of the 19 participants who expressed uncertain or critical views about TasP. It is important to note that with regard to concerns about TasP,

Table 1 Overview of key characteristics of study sample

Category	Characteristic	Numbers
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

Table 1 continued

Category	Characteristic	Numbers
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
Number of HIV positive friends	Dealing with other priorities for now	3
	None	3
	1–2	5
Involvement with HIV positive organisations	3–5	7
	More than 5	12
	Not at all involved	11
Use of complementary or alternative medicine (CAM)	Somewhat/not very involved	12
	Very involved	4
	No use of CAM	16
Minimal use of CAM	Regular use of CAM	4
		7

no new views were observed in the last few interviews, suggesting saturation was achieved. However, given the dynamic nature of the field of HIV prevention, the views of PLHIV are likely to have continued to develop since our interview data were collected.

Tensions Regarding Who Will Benefit

The main concern expressed by participants was that community debates about TasP appeared to shift the focus of treatment decisions onto the potential community-wide prevention benefits, rather than benefits for individuals living with HIV. Several participants felt strongly that the decision to commence ART required much consideration, and should be focused on whether it was the right time *for them* to start. As Benjamin put it:

What a lot of the research and the doctors say – well some doctors say – [is that] we should put everybody on treatment and, especially young people, straight away ... But, I am in two minds. I think, yes, it's a good idea to put everybody on treatment, then obviously they have a far greater chance of stopping the transmission and the spread. But at the same time ... I don't think it's good to be putting people on medication long term if they don't necessarily need to be on it. So like me, the doctor has said, "You're fine, you're healthy, you don't need to go on it just yet."

Table 2 Summary of demographic and treatment characteristics of individual participants

Pseudonym	Demographic characteristics	Treatment characteristics
Abby	50–60 year old heterosexual woman, 20–30 years since dx, recent CD4+ >500	<12 months ART use, avoiding restarting for as long as possible
Adam	20–30 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	30–40 year old gay man, 10–20 years since dx, recent CD4+ ~500	<12 months ART use, avoiding restarting for as long as possible
Andrew	60–70 year old heterosexual man, 2–5 years since dx, recent CD4+ >500	ART naïve, will start when recommended by doctor
Benjamin	20–30 year old gay man, 2–5 years since dx, recent CD4+ >500	ART naïve, avoiding starting for as long as possible
Bill	50–60 year old gay man, 10–20 years since dx, recent CD4+ >500	>12 months ART use, will restart when recommended by doctor
Caleb	30–40 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	40–50 year old gay man, 10–20 years since dx, recent CD4+ >500	>12 months ART use, avoiding restarting for as long as possible
Camilla	30–40 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	20–30 year old gay man, <2 years since dx, recent CD4+ >500	ART naïve, will start when recommended by doctor
Dominic	30–40 year old gay man, <2 years since dx, recent CD4+ >500	ART naïve, dealing with other priorities that preclude ART use for now
Eddy	30–40 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	60–70 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	40–50 year old gay man, 10–20 years since dx, recent CD4+ <350	<12 months ART use, does not want to ever restart treatment

Table 2 continued

Pseudonym	Demographic characteristics	Treatment characteristics
Felix	50–60 year old gay man, 5–10 years since dx, recent CD4+ >350	>12 months ART use, does not want to ever restart treatment
Gerard	50–60 year old gay man, <2 years since dx, recent CD4+ >500	ART naïve, will start when recommended by doctor
Henry	20–30 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	40–50 year old gay man, 5–10 years since dx, recent CD4+ >500	<12 months ART use, avoiding restarting for as long as possible
Neil	60–70 year old heterosexual man, 20–30 years since dx, recent CD4+ <350	<12 months ART use, does not want to ever restart treatment
Paul	60–70 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	40–50 year old heterosexual woman, 2–5 years since dx, recent CD4+ <350	ART naïve, does not want to ever start treatment
Robert	60–70 year old gay man, 5–10 years since dx, recent CD4+ <350	>12 months ART use, avoiding restarting for as long as possible
Sam	50–60 year old gay man, 10–20 years since dx, recent CD4+ >500	<12 months ART use, avoiding restarting for as long as possible
Sarah	40–50 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	40–50 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	30–40 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	30–40 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

As can be seen in this quote, participants' concern about the concept of starting ART at CD4+ count above 500 cells/mm³ for the purpose of prevention did not necessarily mean they disagreed with the principles that underlie this approach, nor did it imply they were opposed to HIV therapies more generally. For Benjamin, his preference for deferring ART was based on concerns about side effects, accidental disclosure and lifetime commitment to a daily regimen. He found support for this decision from a doctor who advocated waiting until he felt ready, but he was also aware of the potential individual and public health benefits of treating early. This demonstrates that understanding the arguments behind getting more people onto treatment does not necessarily override all of the reasons why an individual and their treating doctor may feel that starting early may not be optimal.

Gerard also observed confusion in the treatment messages being conveyed to gay community members regarding individual and population health benefits:

I completely understand the public health imperative, that there is a chance here to reduce HIV transmissions. But I guess from a selfish perspective, I don't really understand what that statement means to me, as someone who's just contracted HIV ... What is the balance of research at the moment? [Is] there any benefit of really early commencement of treatment? ... Treatments, they're fantastic, they're great, but I know from my friends the long-term burden on the body and the unknown early onset of old age diseases ... That's not a reason not to do them, but ... Everyone says to me, "It's a serious decision to go on treatment." For good reasons, like adherence, you want to make sure you stay on them. [Gerard]

Benjamin and Gerard both distinguished between understanding the logic driving TasP and honouring their own concerns about starting treatment before it is clearly indicated for their individual health, both because of the potential risks and side effects that accompany any medication usage, and the increased burden of life-long treatment regimens that require strict adherence. They discuss this issue by seeking to 'balance' the potential benefits they are aware may apply in their own situation, with those of the potential benefits for the community, but in general frame their own concerns about treatment as the most important influence on treatment decisions.

Sarah, a heterosexual woman who had used ART mainly during pregnancy, expressed a belief that there was increasing pressure on individuals living with HIV to commence treatment:

Especially lately, [with] the treatment as prevention campaign, there's been a real focus on getting as

many people on meds as possible ... Doctors are like, "It's just best that you get on it, we want to reduce the community viral load." And I'm like, "Mmm, that's not a good enough reason for me to go on meds." ... My biggest issue would be around compliance and adherence. There's enough difficulty within the HIV positive population trying to get people to stay on their medications and adhere to them ... I know full well that there will be a time where I'll need to take meds ... and I'll be a hundred per cent compliant. [But] I don't believe I have needed to be on them [before now], except for the pregnancies.

For Sarah, the advice to start ART to reduce community viral load was unconvincing. Her primary argument against this advice is that adherence is likely to be an ongoing challenge for people with HIV, which is not made easier by feeling pressured to start before they are ready. But a second concern for Sarah was feeling that the messages directed towards PLHIV implied that the use of treatment benefited everyone, when she did not feel they were of direct benefit to her at all. In Sarah's case, after using ART short-term, soon after seroconversion, she had experienced an extended period of 'non-progression' of HIV illness without the further use of ART, except during pregnancy. As we also saw in the previous quote from Gerard, when he described his personal concerns as 'selfish' in contrast to a 'public health imperative', Sarah's account reveals a concern that these kinds of specific and exceptional circumstances in the lives of people with HIV were being increasingly occluded by generic statements about the benefits to individuals of 'treating early'.

Tensions Regarding Risk Reduction

Concerns were also expressed regarding the potential for ART to reduce the risk of transmitting HIV. Some of these were based on a fear that TasP would lead some PLHIV to potentially misunderstand what reduced infectiousness meant in terms of risk of transmission. For example, one man said 'it would make me think, "Okay, my sperm's a bit safer than what it is, because they say so!"' [Neil]. Alex drew on similar concerns regarding semen viral load, and also noted the potential role of other sexually transmissible infections in increasing the risk of transmission:

It concerns me when people say things like, 'If you have an undetectable viral load you are at less risk of infecting somebody.' It concerns me because it doesn't cover [other] sexually transmitted diseases. So ... if you are undetectable in your blood and you have syphilis, and you're not completely undetectable

in your semen, you are definitely going to transmit both. It's irresponsible. Because the pills are meant to treat, not meant to cure or vaccinate ... I was told, "...You should tell yourself that 'I'm doing this so that other people don't catch HIV from me'." And I thought, "Well, no ... Even if I were on medications I would not have unsafe sex with a negative person." [Alex]

This account links changing beliefs about infectiousness with the reworking of narratives of responsibility in relation to HIV prevention. Alex believes that advocating TasP as a public health strategy will lead to an abrogation of responsibility among HIV positive people in relation to protecting their partners, due to misplaced beliefs regarding the effects of treatment on reducing their risk of transmission. He moves from statements of 'concern' about the 'irresponsible' conduct of others to establishing his own moral position, claiming that 'Even if I were on medications I would not have unsafe sex', ensuring his own conduct is beyond reproach.

In line with this, a number of participants also expressed a belief that 'treat early' messages implied the non-use of ART was irresponsible, which they found fitted poorly with their own sense of self. Indeed, several participants emphasised that they were well managed and posed little risk to others:

Getting early on treatment should be directed at ... people who have a reckless behaviour problem [in] living with HIV, like those who are likely to put others at risk ... If I was in a position of putting other people at risk, then I would take the medication but my partner, we are well aware, we're all mature. So I am happy to stay off it at the moment. [Henry]
Me, as a mum, now that I've had my children, who am I going to infect? ... If I was sexually active, or if I was sleeping around, you know, I could see the necessity for that. And I understand how that works with the gay community, that if they are going to sex on premises [venues] and have multiple partners, then the risk is there ... But I'm feeling pressure [to start treatment], just for the good of the community as a whole, when the likelihood or the risk of me infecting anybody is almost zero! [Sarah]

As Sarah notes, for people with HIV who are not currently sexually active or are in a seroconcordant relationship, commencing treatment for prevention reasons rather than for personal health benefits may be neither necessary nor relevant. While both quotes rely on an unhelpful distinction between the responsible self and 'reckless others', their overriding point is important: that the rhetoric of TasP's community benefits is unlikely to engage those

PLHIV who feel unrecognised for their enduring, considerable efforts in managing transmission risk in their everyday lives.

Tensions Regarding Treatment Norms

Finally, a number of concerns were expressed regarding a perceived change in community norms regarding the optimal time to commence treatment, as a result of TasP. This included a perception among some participants that they were being encouraged to initiate ART earlier than they felt ready, and that there was a rapidly diminishing possibility of receiving support from others—particularly casual sexual partners, peers and family—for choosing to not use ART. For example, Alex, a gay man with a complex treatment history, believed it was becoming increasingly difficult to discuss treatment options in a safe and open manner in the gay community:

If you go to places like [non government organisation], they're not sympathetic at all. In fact, they're incredibly pro-medication and they'll put you down ... I don't understand where it's come from and I don't understand why it's being pushed. [Alex]

While the field of HIV medicine cannot be characterised as having achieved a consensus regarding early initiation, despite a clear move in that direction [40], several participants provided similar accounts of what they felt was an emerging 'pro-treatment' imperative in HIV community settings, and a growing sense of social isolation regarding who they could talk to about their concerns; a theme we examine in more detail in forthcoming publications.

Other participants were concerned about a perceived lack of consensus between community organisations and clinicians regarding treatment norms. Gerard, for example, who was diagnosed only a year prior to interview, said that he felt like 'a bit of a guinea pig' in what is 'a bit of a controversial area at the moment'. The decision to start treatments was made more complicated for Gerard by the diversity of opinions he was aware were being expressed by different trusted voices:

I'm aware of all the campaigns that are happening. But my doctor is ... advising me not to go on treatments yet. So there's a bit of, a sort of a discord or between the public campaigns and what I'm really hearing from my doctor. So that's kind of a bit confusing to me ... because it says, there are statements made, like ... 'starting treatment early has benefits,' or something. But ... I have to rely on the experts that I deal with in terms of getting what they think and their advice. So ... when I hear that, I think, "Well, maybe you could inform me a bit, in more detail,

about what the latest research is saying to back up that statement?” ... Or even, you know, or even maybe get the clinicians more on side before starting those campaigns and getting the message uniform at least? [Gerard]

This account reveals just some of the complexity for individuals who are in the position of making treatment decisions in an era of TasP. Gerard suggests that clinicians continue to play an influential role in supporting their patients in making sense of the current ‘evidence’ regarding ART benefits, but if their advice does not fit easily with that being made available through community sources, it may further complicate these experiences and decisions.

Additionally, several participants believed that new lines of difference were emerging in the ART recommendations of medical practitioners based in the ‘old school’ or ‘new school’ of HIV medicine, as well as between those employed in a public or private health care setting.

An HIV specialist ... said to me that he thought I should go on medication immediately, [because] everybody should be really on medication, from the date of diagnosis. Whereas my doctor is of the old school of thought, which is what I am, which is, you shouldn’t go until your markers drop below a certain level. [Simon]

My private doctor, stated that she doesn’t recommend me going on [ART], because they don’t know the long term effects ... she is more about protecting a person’s long term health and not actually just putting them on medication they don’t need to go on ... [But] the public sector has the public health in their best interest, when they make their calls, and what they actually *have* to recommend ... So they have different perspectives on how they look at my health, as the ‘public health’, and so forth. [Tom]

These commentaries on generational and health system distinctions in the prescribing practices of HIV doctors reveal the critical capacities of participants, and indeed their interest in thinking carefully about treatment decisions with reference to a broad range of influencing factors, including potential provider bias. Their perceptions of a lack of medical concordance regarding optimal ART initiation also challenge the possible presumption that people with diagnosed HIV who are yet to commence treatment hold ‘renegade’, or oppositional, views to the prevailing advice on treatment.

Discussion

Our interviews with people with HIV revealed a high awareness and understanding of TasP but also a substantial

number of concerns. This may be influenced by the fact that our participants were not using ART at the time of interview, and may therefore have been more likely to take a more critical position on the use of HIV treatment for any purpose. It is nonetheless important to pay attention to these ‘narratives of resistance’ [41] in order to appreciate the range of views held by affected communities regarding this important new public health intervention.

As there is little empirical research available at this point regarding PLHIV views on TasP, our discussion is focused on what our research contributes to the broader debate about the use of ART to prevent HIV transmission. For example, although not a major focus of this paper, we did note that the minority of participants with favourable views of TasP considered a major benefit of this approach to be a reduced anxiety about infectiousness. This has been recognised in the literature as a potential motivating factor for some PLHIV to commence ART [25]. Collins and Geffen have even gone so far as to claim that this is the major factor ‘likely to continue to drive individual decisions to start earlier treatment’ [42]. A few participants also reported a belief that reduced infectiousness would reduce their obligation to disclose HIV infection, in some contexts at least. While the numbers of participants expressing these views was small, they are important to recognise given that the law on disclosure in sexual situations in many jurisdictions still requires disclosure even if viral load is undetectable [43]. We have not seen elsewhere a description of the potential benefits of TasP in relation to a reduced sense of obligation to disclose to *other* interested parties, such as dentists.

In relation to the three major ‘tensions’ identified in this analysis, questions about ‘who will benefit’ from TasP have been discussed in the literature, including an analysis of the ethical issues which noted that ‘TasP approaches have been criticised for prioritising a public health benefit ... over the health of the patient’ [25]. We believe our analysis provides timely evidence of how individual PLHIV understand and seek to manage these tensions in developing their own views on and responses to treatment recommendations. A consistent message communicated by participants with concerns about TasP was that treatment decisions should be made with reference to the context and priorities of *individual* life circumstances, rather than as a public health imperative. This view seemed to be based predominantly on concerns about the nature of HIV medication itself—life-long, daily pill-taking, with unknown implications for long-term health—which requires a major commitment by the person taking up ART. As Collins and Geffen remind us: “The choice to use treatment should be made by the person taking medication, even when prescribed under population-based health guidelines” [42]. Yet our participants suggested that some people with HIV may not feel that the

choice to use treatment is fully theirs to make in the context of community-wide messages promoting early uptake of HIV medication. We also observed concerns regarding a perceived conflict between these messages and those received from medical practitioners, which created additional stress and confusion for individuals regarding best practice. As Hirsch has argued: ‘The social desirability of ART, rarely questioned within biomedical and public health research, hinges in complex ways on the variability both of ART’s local meanings and of values about what comprises a good life’ [44: S22]. Thus, we need to not only appreciate the variable ‘local meanings’ ascribed to HIV medicine by people with HIV, care providers and other trusted voices, but to also contextualise these meanings in relation to what people with HIV value about their own way of life, which may not fit easily with messages about taking daily medication for the public good.

With regard to risk reduction, the concerns expressed by participants were typically influenced by representations of the self as moral and responsible, and ‘others’ as reckless and risky. This played out through the use of two related but distinctive narratives, both of which sought to question the viability of TasP in real world settings. The first examined whether people with HIV as a broad, diverse population, would all fully understand the logic of TasP, and achieve the level of adherence and monitoring (through regular viral load testing, for example) required to ensure a reduction in new infections was achieved. The second questioned the presumption that TasP was relevant or applicable to all PLHIV, given previous personal experiences of managing the risk of transmission without the use of treatment. Both of these concerns point to important issues that are already the subject of discussion in the field of HIV prevention, particularly the complex relationship between biomedical and behavioural approaches to prevention [45]. What we feel is particularly important to conclude from our analysis, however, is that not all people with HIV will feel ‘addressed’ by messages about the risk reduction potential of TasP without a concurrent recognition that prevention is far more complex than simply taking daily pills. Indeed, there are many ways in which the existing efforts of individuals and communities already work to reduce the risk of transmission, and have done for many years [22]. These accounts remind us that if public health messages seek to further ‘responsibilise’ the person with HIV through encouraging the use biomedical treatments [46], but do not also include explicit recognition of the effort expended in ‘navigating risk in everyday life’ [1: 4], this can have the unintended effect of being read as applicable only to imagined, ‘irresponsible’ others.

In discussing our findings on perceptions of changing ‘treatment norms’, it is important to recognise first that there have been considerable changes in the recommended

thresholds for initiating ART over the years [42]. This provides essential background to understanding why the current trend towards promoting early uptake—both for individual and population-level health benefits—may be interpreted cautiously by affected communities [47]. Genuine community engagement has been a clear and guiding principle of the national and global response to HIV, including consulting with communities regarding interventions that will affect people with HIV [48]. Our analysis suggests, however, that some people with HIV may feel the promotion of early uptake and use of treatment to prevent transmission has been occurring without sufficient recognition of the concerns of those who may be reluctant to start. Some of our participants believed pro-treatment messages promoted by government and community organisations ignored the fears that could be held by people with HIV about initiating a lifelong regimen of medication, which were often in line with their clinicians’ concerns. A key message throughout the literature on public health ethics is that dialogue is essential to engendering public trust in evolving health priorities, and that communities therefore need to be supported in operating as ‘places of mutual support, respect, and self-esteem’ [30: 172]. This suggests that further efforts need to be taken to strengthen community engagement regarding TasP, to ensure that the types of concerns we heard expressed in these interviews are able to be shared through safe, supported mechanisms for participatory dialogue and debate.

An underlying concern that became apparent through our analysis relates to the perception that TasP threatens the agency of the individual to choose if and when to start ART. While it is essential that the autonomy of the individual in making treatment decisions continues to be respected, it is also important to recognise that in an era in which responsibilised citizens are urged to ‘live life like an enterprise’ [33: 393], it can be of little surprise that a public health narrative promoting the use of lifelong medication to achieve benefits for the broader community may be read with some concern. Our participants demonstrated many of the characteristics associated with the ‘emergence of new forms of citizenship and conceptions of self’ in advanced liberal settings [33: 392]—making rational, considered decisions, balancing the advice of multiple expert sources, thinking carefully about their own long-term health outcomes—even though this did not necessarily conclude with an alignment in their views with those currently promoted by public health. This is important to recognise, particularly at a time when there is a risk that those people who choose not to use ART, or who feel troubled by the assumptions underlying TasP, may find their views increasingly marginalised.

As this paper reports on qualitative research, we do not have sufficient numbers of participants to draw strong

conclusions about subgroups. However, we do wish to note that there appeared to be very little association between particular views on TasP and clinical or sociodemographic characteristics. We observed some minor differences. For example, all four participants who supported treatment as prevention were ART naïve and recently diagnosed, compared with many of those with concerned views having at least some treatment experience. However, in general, both the treatment naïve and experienced participants expressed sophisticated understandings of the tensions between individual and public health priorities regarding TasP. This suggests that treatment history alone cannot account for whether an individual is supportive or critical of the idea of commencing treatment to prevent transmission, nor how much they understand about the history and complexity of HIV medicine. Recent CD4 + T cell count also did not play an obvious role in shaping participant views, nor did their understandings appear to be differentiated by age, gender, sexuality, cultural background or relationship status.

The limitations of our analysis include that all data were collected in Australia, a setting which enjoys high levels of public and community investment in HIV diagnosis and management, and in (relatively) accessible health care more generally. The views of the PLHIV we interviewed about TasP are likely to be influenced by this context, and to potentially differ from other contexts, particularly those settings in which HIV incidence is much higher. Data was collected since the release of the HPTN 052 study results, but before the PARTNER study results in March 2014. As a qualitative analysis, we cannot extrapolate from our findings to make broader population inferences, nor claim these to be likely to be transferable to other settings or groups. In addition, interview participants included mainly gay-identified men, and although this fits with the epidemiological profile of HIV infection in Australia, it does mean heterosexual men and women may hold a range of additional perspectives on TasP that were not able to be captured through these interviews. The main limitation of our research is that we were deliberately seeking the views of PLHIV who were *not* using treatment at the time of interview, and so may have held more critical views on ART that would other people living with HIV. However, most of our participants expressed largely positive views on the potential health benefits of HIV treatment, suggesting that their concerns about TasP cannot necessarily be explained by their broader views on the value of biomedical therapies.

Conclusions

The views of people with HIV are central to understanding the challenges and complexities of engaging with HIV care, commencing and continuing treatment and achieving

adherence over time. The various concerns identified in this paper expand the range of issues and complexities that need to be taken into account by those involved in prioritising and implementing TasP through policy and practice. The people we interviewed were largely questioning of the notion that individual decisions to start ART should take account of the potential prevention benefits, particularly if there are no clear and convincing reasons to start for their own health benefits. Many participants felt that TasP messages overlooked the potential diversity of needs and situations of individuals, who each have a unique story to tell, live in a particular social context, and have a specific health and social history which they feel must be taken into account when making decisions about treatment. There was a clear investment in the agency of the individual in making treatment decisions, albeit with the input of trusted health care providers. Global frameworks for HIV prevention may have undergone rapid change, but given the long history of contention regarding where responsibility lies in the prevention of HIV, it is far from clear that affected communities and those providing their health care have been sufficiently engaged in this process.

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