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ORIGINAL PAPER

Yes to Recreational Drugs and Complementary Medicines But No to Life-Saving Medications: Beliefs Underpinning Treatment Decisions Among PLHIV

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Abstract
Despite the life-preserving benefits of antiretroviral therapy (ART), some people living with HIV (PLHIV) delay, decline or diverge from recommended treatment while paradoxically being willing to use potentially dangerous substances, such as recreational drugs (RD) and complementary medicines (CM). During 2016 and 2017, interviews were conducted with 40 PLHIV, in Australia to understand drivers underpinning treatment decisions. While many believed ART to be effective, they expressed concerns about long-term effects, frustration over perceived lack of autonomy in treatment decisions and financial, emotional and physical burdens of HIV care. In contrast, they ascribed a sense of self-control over the use of RD and CM, along with multiple professed benefits. The perceived burden of ART emerged as a motivator for deviating from recommended treatment, while positive views towards RD and CM appear to justify use. This study may serve as guidance for the development of future strategies to address barriers to treatment uptake and adherence and subsequently health outcomes for PLHIV in Australia and elsewhere.

Keywords HIV · Antiretroviral therapy · Recreational drugs · Complementary medicines · Beliefs

Introduction

Almost 40 years since its effects were first described, HIV continues to have severe impact on individuals, their families and the wider community [1–4]. Caring for people living with HIV (PLHIV) and ending the epidemic are key priorities reflected in global health and humanitarian strategies [5–7]. Effective management plans focus on: (i) early diagnosis, (ii) appropriate treatment, (iii) adherence to the prescribed therapy, (iv) risk reduction practices and (v) elimination of HIV-related stigma and discrimination [5, 8]. Early diagnosis not only enables timely initiation of treatment, thereby preventing disease progression and deterioration in the health of individuals, but also serves as a critical component of harm reduction [5, 6]. Contemporary antiretroviral medications have demonstrated superior effectiveness in suppressing viral replication when compared to previous treatment options [5, 9]. Timely initiation and adherence to antiretroviral therapy (ART) has been demonstrated to benefit people living with HIV (PLHIV) by preventing disease progression and death and is an important step forward in mitigating transmission [5, 8]. However, high levels of sustained life-long adherence, (about 95%) are required for optimum effectiveness [10, 11]. Strategies for effective HIV management, therefore, target both prompt and equitable access to appropriate treatment, as well as promoting adherence to the recommended regimen [5, 6]. Furthermore, considerable effort has been directed towards enhancing HIV knowledge, reducing HIV-related stigma and discrimination, as well as to promoting safe sex and harm minimisation practices [5, 6, 12]. Indeed, global health initiatives have

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resulted in a 43% reduction in HIV-related deaths since 2003 [6, 13]. However, the World Health Organization (WHO) warns that relaxing efforts in the fight against the disease at this critical time would have a rebound effect, leading to increased infection rates and the resumption of negative health impacts [6].

Initiatives for effective management of HIV in Australia are aligned with the revised global strategy for eradicating HIV by the year 2030 [6, 7, 14]. Australian data indicate that at the end of 2017, approximately 13% of PLHIV were not receiving treatment and approximately 5% of those who were prescribed ART had yet to achieve adequate viral suppression [15]. Surveillance data also indicate that over 75% of infections were attributed to male-to-male sex. A recent systematic review of Australian studies identified barriers to treatment uptake and adherence to include gaps between the services that are currently available and those that are needed by PLHIV, as well as a lack of recognition of the disease burden experienced by PLHIV, which extends beyond what can be attributed to the virus alone [16]. For the former, the review found that PLHIV needed contextualised information about treatment as, often, their medication knowledge was poor (particularly in the early stages after diagnosis), resulting in fears about side effects that impacted negatively on both treatment uptake and adherence. For the latter, the review revealed that stigma and discrimination are insidious and ingrained at the personal, health system and wider community levels, manifesting as major barriers at critical time points for effective management by diverting people from what might have been their intended course of action in the absence of fear. The review also reported on the high prevalence of recreational drug (RD) and complementary medicine (CM) use among PLHIV, with some authors raising concerns that use of either or both were often not disclosed to treating physicians.

RD include both licit substances (e.g. benzodiazepines, barbiturates, opioid analgesics) that have medical indications and illicit substances (e.g. amphetamines, cocaine, heroin) that are used to produce depressant, stimulant, or hallucinogenic effects for enjoyment or other non-medically prescribed purposes [17, 18]. Drug use for recreational purposes is reported to be common, particularly among Australians, who have been identified as the top consumers of these substances per capita [19]. For example, one study reported that almost 40% of the population aged 15 years and over had used one or more recreational drugs at some stage in their life and approximately 17% within the past 12 months [20]. According to a recent Australian survey of men who have sex with men [21], over two-thirds of respondents (63.9%) reported they had used RD in the prior six 6 months. This finding is of major concern given that, in the developed world, men who have sex with men make up the majority of PLHIV and are identified as having the greatest risk of contracting HIV [14, 22]. Indeed, national and international studies have confirmed that the use of RD places individuals across a range of population groups at greater risk of contracting HIV and well as negatively impacting on their economic, social, mental and physical health [23–28]. Despite high levels of RD use, it has been reported that some PLHIV are refusing ART [29–31]. These reports are supported by anecdotal evidence from clinicians working within the HIV community in Australia.

For people who take ART, either as prevention or as treatment, the potential for RD to interact with ART causing harm is of major concern [28, 32–37]. For example, Bracchi et al. [32] describe how RD such as benzodiazepines, ketamine, crystal methamphetamine, methylenedioxymethamphetamine and mephedrone can modulate the metabolism of commonly prescribed ART and decrease the concentration of some to subtherapeutic levels (with the consequent risk of treatment resistance), while causing the accumulation of others to toxic levels. As explained by Daskalopoulou et al. [28] the main mechanism of drug interaction occurs through the action of RD on the hepatic cytochrome p450 complex of enzymes, the nature and extent of which are yet to be fully understood. Even in the absence of potential RD-ART interactions, the negative consequences of RD use among PLHIV have been well documented [33–35, 37–42]. For example, in their meta-analysis of contemporary research, Langebeek et al. [11] found that the use of RD including alcohol was strongly associated with non-adherence to ART. A large body of evidence confirms the wide-ranging negative impacts of non-adherence [40, 43–48]. Other studies have demonstrated that RD use is associated with poor social, mental and financial health [33, 34, 38, 40, 42].

CM are also known as 'traditional' or 'alternative' medicines and include substances such as vitamins, minerals, herbal remedies, aromatic oils and homeopathic products [49]. The use of CM among PLHIV is common [50–65]. In a recent survey of Australians living with HIV (n = 1211), 53% of respondents reported they had used one or more CM in the 12 months prior to the study, 50% in the previous week [52]. CM also have the potential to interact with ART [66, 67]. A review by Brooks, George and Kumar demonstrated that CM-ART interactions also occur through shared metabolic pathways involving cytochrome p450 [66]. They summarised a range of plants, including, but not limited to, Cat's claw (*Uncaria tomentosa*), Echinacea species, Garlic (*Allium sativum*), Ginkgo biloba, Ginseng (*Panax ginseng* and *P. quinquefolius*), Goldenseal root (*Hydrastis canadensis*), Milk thistle (*Silymarin marianum*), St. John's-wort (*Hypericum perforatum*) that share metabolic pathways with ART. These plants or their extracts are found in many herbal remedies and supplements that are commonly used to manage ailments or promote health in western countries, including Australia [49]. Brooks group also identified foods

including fruits (e.g. grapefruit) and spices (e.g. black pepper), that impact on the metabolism of ART. These findings are significant as, in addition to the limited knowledge about the consequences of CM and interactions with existing ART, newer ART may share metabolic pathways with CM and the mechanisms and implications of which are yet to be understood. In addition, Stolbach et al. [67] highlighted through their review that CM may not only have potential to interact directly with ART, but may negatively impact on outcomes for PLHIV by interacting with other mediations prescribed for the treatment of coexisting conditions. Other authors have highlighted potential or demonstrated negative consequences, including death resulting from AIDS-related illnesses, when PLHIV elect to use CM as an alternative to ART [53, 55–59, 62, 65].

Findings from these studies and anecdotal evidence drawn from personal experiences point to a puzzling phenomenon: despite the well-known life-preserving benefits of ART, some PLHIV are choosing to decline, delay or diverge from prescribed treatment, but are prepared to use potentially dangerous RD or CM. Recent research among adult residents of Australia's Gold Coast highlighted that drivers underpinning RD use were associated with perceived benefits in two key domains—improving social connectedness [18] and enhancing physical and social performance [17]. However, the studies did not specifically explore the perspectives of PLHIV or ask participants to disclose their sexual behaviour. Research among gay men reveals a commonly held perception that drug taking is both normal and acceptable behaviour [68]. However, this study did not specifically seek views of HIV positive individuals. Studies that have explored CM use among PLHIV have mainly focused on providing prevalence data [51–57, 61, 65], while those that have sought to understand the beliefs underpinning use have been conducted overseas in countries that may differ from Australia in areas such as access and cultural norms [62, 65]. Of the limited number of studies that sought to understand motivation for CM use among PLHIV in Australia, the majority involved small participant numbers [53, 58, 64].

While studies have highlighted a range of theoretical as well as demonstrated negative outcomes for PLHIV resulting from poor adherence to ART and from RD and CM use, to date no studies have investigated how beliefs about these three substance-types influence treatment decisions. Given the rapid pace with which HIV management has evolved and the importance of ART, both for individuals and for the global burden of HIV, understanding factors that might influence treatment decisions in the contemporary context can inform models of care that promote treatment uptake, adherence and therefore outcomes for PLHIV. The overall aim of this research was to unpack and understand the drivers underpinning treatment decisions among PLHIV in Australia today. Specifically, this study explores how PLHIV's beliefs about RD, CM and ART impact on treatment uptake and adherence.

Methods

This study utilised standard qualitative social science methods [69] as detailed below. Ethical clearance was granted by Griffith University and Queensland Health human research committees (HREC/15/QGC/256). Participant recruitment and data collection occurred between March 2016 and December 2017.

Participants

Participants were PLHIV, on Australia's east coast, primarily southern Queensland and northern New South Wales, who may have engaged in RD and/or CM use. Project information was disseminated through physicians, sexual health clinics, HIV support agencies and social media. Recruitment material included posters and postcard (the size of a credit card) that were displayed in common areas such as waiting rooms. Potential participants were invited to contact the project team member responsible for data collection directly, either via telephone or email.

In the early stages of the research, convenience sampling was employed to recruit participants who were easily accessible and motivated to participate in the study [70, 71]. As the study progressed, sampling became increasingly purposive [71, 72]. Potential participants were screened to enable selection of a diverse range of participants, leveraging both maximum variation and negative case sampling [73]. Participants were also asked about their preference of interview venue and mode. This step was taken to ensure that participants felt comfortable and safe, given the sensitivity of the topic and understanding that some participants may not be well enough (or willing) to travel to venues deemed suitable by the researchers. Sample size was determined by the principle of 'saturation' [69, 70], identified through continuous iterative data analyses. All participants were offered a $50 gift voucher as remuneration for their time and travel costs.

Data Collection and Analysis

An interview guide consisting of broad themes provided framework for exploration of participants' beliefs about ART, RD and CM as summarised in Table 1.

The interview questions were broad, to allow open dialogue between the interviewer and the participant. They encouraged the participant to share their ideas, thoughts and feelings in a safe space. A semi-structured interview framework was used to guide the conversation, allowing the

Table 1 Guiding questions for in depth interviews

Themes	Questions/prompts
Beliefs about ART	What are your thoughts about medicines used to treat HIV?
	Please tell me about some your experiences (if any) with ART
Beliefs about RD	What are your beliefs about recreational drugs
	Please tell me about some your experiences (if any) with recreational drugs
Beliefs about CM	What are your beliefs about complementary medicines?
	Please tell me about your experience(s) with CM

researcher to explore further aspects of the participants' narratives, thus enabling the uncovering of information unique to each participant, while, at the same time, focussing the conversation when necessary [74]. Individual interviews were conducted by a trained interviewer at a time and place that was convenient for the participants, with informed consent, audio recorded, transcribed verbatim and stored on password-protected servers, accessible only to the research team. Data collection and analysis followed a systematic framework as illustrated in Fig. 1.

A checklist was developed and reviewed at the end of each interview. As new material emerged, questions were updated to give the study a complete and detailed picture of the drivers underpinning participants' treatment decisions, providing conceptual relationships between components of interest [75]. Transcripts were analysed with the assistance of NVivo® software, guided by a modified grounded theory framework [73, 76, 77]. In summary, one researcher (AM) conducted of all the interviews, took field notes and prepared summary documents for the team. Summaries were circulated to all members of the research team as soon as possible after each interview. Interview recordings were sent to a professional transcribing service provider as soon as practical and returned transcripts were made available to the research team after checking for accuracy. That is, AM listened to the recording while reading the text and rectified any inaccuracies identified.

Data analysis occurred in three phases. In the first phase, the AM began a process of data reduction and formulation of explanatory models. The researcher met regularly with two other members of the team (DP and SD) to discuss the emerging data, make decisions about modifications to the interview guide and identify characteristics for future recruitment. In the second phase, AM, DP and SD read and reread the transcripts while reviewing comments from the remaining members of the research team (GR, MOS, AD) and began to build a framework for reporting the data. AM coded the data according to the framework (open coding), while DP and SD independently coded a random selection of five transcripts each. Variations in coding were discussed until consensus was reached. In the final phase, AM reviewed the coded items and thematically summarised the findings relative to the research question (axial coding). Dialogue between all members of the research team was maintained throughout the analytical process through monthly meetings and in preparation of this manuscript.

Results

Forty participants were interviewed. The majority (n = 30), elected to complete their interview face to face at a local sexual health clinic or at the interviewer's place of work. Nine participants completed their interviews by telephone,

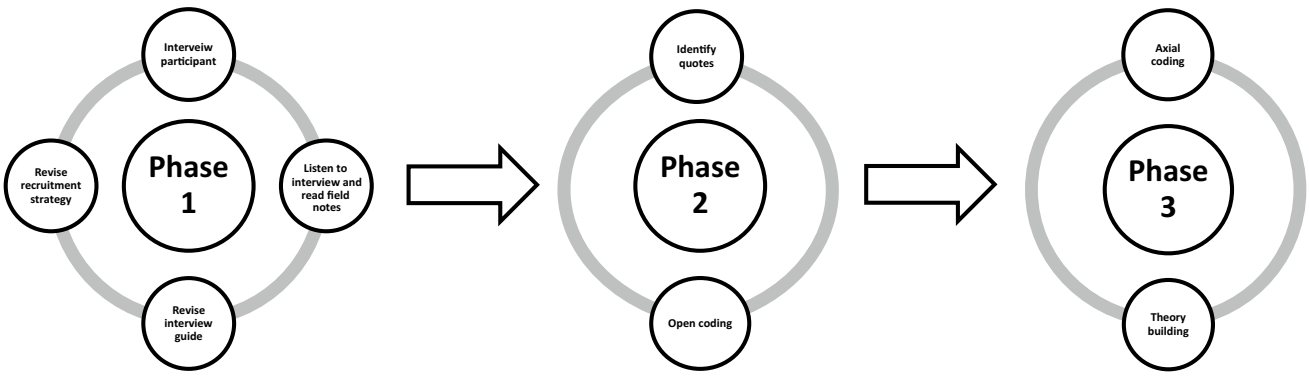

Fig. 1 Framework for data collection and analysis

one participant was interviewed via video link. The time taken to complete each interview ranged between 37 and 113 min. The average time taken was approximately 64 min.

Characteristics of the Research Participants

35 participants identified as male, four female and one transgender, aged between 24 and 76 years (mean = 49.7 years). Of the male participants, the majority (n = 25) identified as homosexual, one as bisexual and the remainder as heterosexual. All four female participants identified as heterosexual. Participants' characteristics, year of diagnosis and substance use profiles are summarized in Table 2.

Participants' mean age at the time of diagnosis was 36 years old (mean age male = 36.9, mean age female = 30.3, $p = 0.342$). At the time of the interview, participants had been given their positive diagnosis between one month and 31 years (mean = 14 years) earlier. The majority (80%) reported contracting HIV through unprotected sex. Three participants, while not ruling out sexual contact, believed that they probably contracted HIV through injecting drug use. The remaining participants (n = 5) were uncertain about how they became infected and offered a range of potential sources including coming into contact with contaminated blood as a result of a road accident and stepping on a contaminated needle that had been discarded at a children's playground.

Twenty-two people (55%) reported that they had used RD in the past, while 16 participants (n = 14 male, n = 2 female) reported RD current use. The drugs that participants spoke about included, but were not limited to, "dope"/"pot"/"weed" (marijuana), "ecstasy"/"pingaz"/"MDMA" (methylenedioxymethamphetamine), "dexies" (Dexamphetamine), "coke" (cocaine), "H" (heroin), "ice" (crystal methamphetamine), "speed" (methamphetamine), "DMT" (*N*-dimethyltryptamine), "LSD"/"acid" (lysergic acid diethylamide), "special K" (ketamine), "GHB" (γ-hydroxybutyric acid) and "poppers" (alkyl nitrites). They also reported the illicit use of a range of prescription medications including benzodiazepines, barbiturates and opioid analgesics. Among current users, one participant reported never having used RD prior to diagnosis. Those who used RD prior to diagnosis were significantly younger than those who did not use RD when they were diagnosed (mean age RD use = 30.9, mean age did not use RD = 42.8, $p = 0.005$). At the time of interview, there were no significant differences between participants' mean age when compared according to their RD use status ($p = 0.117$).

Nineteen participants (48%) reported current or historical CM use. Current users (n = 11 male, n = 4 female, n = 1 transgender) described taking a range of products that contained vitamins, minerals, fish oils, and plant extracts (most often in combination), that they had purchased from pharmacies, supermarkets or health food stores in Australia. Some disclosed that they had used and/or were currently using, or were intending to use, a range of 'Asian' herbal remedies that contain plant and animal extracts. While black ginger (*Kaempferia parviflora*) was named to be a component of some of the remedies, the majority could not recall

Table 2 Participant demographic and substance use profile

Characteristic	Total		RD		CM	
	n	%	Current (%)	Historical (%)	Current (%)	Historical (%)
Gender						
Male	35	87.5	14 (40.0)	19 (54.3)	11 (31.4)	13 (37.1)
Female	4	10.0	2 (50.0)	3 (75.0)	4 (100.0)	3 (75.0)
Transgender	1	2.5	0	1 (100.0)	0	1 (100.0)
Age range (years)						
18–24	1	2.5	0	0	1 (100.0)	1 (100.0)
25–34	5	12.5	3 (60.0)	3 (60.0)	2 (40.0)	2 (40.0)
35–44	11	27.5	5 (45.5)	10 (90.9)	3 (27.3)	3 (27.3)
45–54	9	22.5	5 (55.6)	6 (66.7)	5 (55.6)	6 (66.7)
55 and over	14	35.0	3 (21.4)	4 (28.6)	4 (28.6)	5 (35.7)
Year of diagnosis						
1985–1989	5	12.5	3 (60.0)	3 (60.0)	2 (40.0)	3 (60.0)
1990–1994	5	12.5	2 (40.0)	4 (80.0)	2 (40.0)	3 (60.0)
1995–1999	6	15.0	3 (50.0)	4 (66.7)	2 (33.3)	2 (33.3)
2000–2004	5	12.5	1 (20.0)	2 (40.0)	2 (40.0)	3 (60.0)
2005–2009	7	17.5	3 (42.6)	4 (57.1)	2 (28.6)	1 (14.3)
2010–2014	5	12.5	2 (40.0)	3 (60.0)	1 (20.0)	1 (20.0)
2015–present	7	17.5	2 (28.6)	3 (42.9)	4 (57.1)	4 (57.1)

the names of other substances that comprised the product. There were no differences in the mean age of participants when compared according to their CM use status ($p=0.283$). The majority also described making particular effort to eat 'healthy' foods since being diagnosed.

All participants reported being prescribed ART. For some, their medications had not changed in over 5 years, and required them to take multiple doses. Others reported that they had been prescribed a number of different medications over time, each time reducing the number of tablets/capsules and the dosing frequency to their current single daily dose. However, participants' description of their medication taking behavior were highly variable and suggest deviations from the prescribed regimen (as discussed later).

Of the 38 participants who provided information about their viral load status, six (15.8%) reported they had yet to achieve an undetectable status. There were no significant differences between the age of those who reported having achieved an undetectable status and those who had not ($p=0.217$).

All except eight participants reported they were living with at least one other health condition, including and not limited to: arthritis, asthma, cancer, cardiovascular disease, diabetes, dementia, malnutrition, mental illness, and obesity. There were no significant differences between the mean age of those who reported living with co-existing health conditions and who were not ($p=0.688$). Among those living with co-existing conditions, the majority ($n=25$) reported that they were living with one or more mental health issue(s). Depression, anxiety and substance use disorder were most commonly reported. They also reported they had been, or were currently taking one or more prescribed medications for their co-existing health condition(s), that included the majority of drug classes, such as antidepressants, anxiolytics, antipsychotics, opioids and nonsteroidal analgesics, and sedatives. Among the six participants who reported they had yet to achieve adequate viral suppression, five reported that they were also living with at least one co-existing health condition, four identified as current CM user, 3 as current RD users and 2 as current users of both CM and RD.

Beliefs Underpinning Treatment Decisions

Participants shared their views regarding the role of ART, RD and CM in the management of their health, providing valuable insights for understanding how treatment decisions are made in the contemporary Australian context. Themes that emerged from analysis of the data are presented alongside quotes that have been coded to indicate whether the participant is male (M), female (F) or transgender (T), followed by their age in years, a capitalised R to indicate their past and/or current use of RD, and C to indicate past and/or current CM use. The final number preceded by "_" indicates the number of years since diagnosis. If two or more participants share the same status, a number enclosed by "()" is used to distinguish them as different participants.

Antiretroviral Therapy

Unanimously, participants believed that contemporary ART was highly effective in suppressing viral replication. Many provided evidence from their own lived experience that supported their views:

> … with treatment, I was absolutely shocked with how quickly I got better … I was so sick … if I didn't I probably would've gone downhill very quickly … F42RC_8

Those who chose to initiate treatment at the recommended time and reported near perfect adherence expressed the belief that ART prevented disease progression and preserved life. In addition, these participants also expressed a high level of trust in the knowledge and advice of their treating physicians and other health professionals in involved in their care:

> I never thought of rejecting them [ART] because … I have trust in doctors … if they didn't think it was going be any good for you or it was going to be detrimental to your health, they would or wouldn't do it depending on the circumstance … M61C_23

Reports of uncontested treatment uptake and adherence were particularly evident among older, heterosexual participants. Some were quick to initiate therapy because they feared that without treatment they would die. They also highlighted that contemporary ART had reduced pill burden when compared with previous treatments:

> I will continue to take my one pill a day because I can see that it works. I'm undetectable and have been for years … M43R_5

However, having to take a large number of pills was seen to be of little consequence to those who were already highly committed to adherence. Participants also spoke about the lack of side effects, although, as reflected in the comment below, many appear to perceive their experience as unique and somewhat unexpected:

> I'm very lucky. I only had very minor side effect or there'd be none. And they just changed one or two sorts of antiretrovirals and touch wood, they're very good … M70_20

Another group of participants who reported that they did not question the recommended therapy were immigrants to Australia. Comparing their experiences in Australia with what they had witnessed in other countries such

as India, Uganda, Kenya and Chile, they assessed themselves and other Australian PLHIV to be lucky:

> I think for me, it feels like—especially in Australia—there's no problem especially when it comes to treatment and medication. They're getting good treatment … M30_6

In contrast, some people believed that treatment initiation signified HIV as central to identity and reported delaying initiation until they felt psychologically strong enough to endure the burden and, at the same time, let go of their "uninfected" identity along with their hopes and dreams for the future:

> Medication made it real. Made HIV real. So, I sort of have this idea that if I started medication then I have a daily reminder of the fact that I was positive and I didn't want a daily reminder of the fact that I was positive … M28R_10

For some, initiating treatment was perceived as giving up on their own body. They appeared to believe that they owed it to themselves to continue fighting by delaying treatment:

> … I thought that if I started to take the medicine that means I'm giving in. And I didn't want to do that … F24C_2

Another aspect of identity perceived to be lost was the right for self-determination in the management of personal health. Participants reported being "told" to commence treatment and believed themselves to be seen by their doctors as "guinea pigs" and dehumanized, identified only as a disease needing to be treated:

> I don't know what half the stuff is that's gone in my body … I was on up to 16 pills three times a day. Every eight hours. No food an hour beforehand, no food an hour afterwards … So I became a slave to the drugs then became a slave to the HIV, not in control. Nothing … M52R_29

However, one participant likened the need to take medication to the need to brush his teeth—it was a routine that could be easily incorporated into daily life to maintain health:

> I know some people had issues with taking medicines because it might remind them or something. It didn't for me. So, you have to clean your teeth every day at least, so it's one of those things you do. I look at taking the pills as about the same as cleaning your teeth. Doesn't remind me that I had dirty teeth. Doesn't remind me that my teeth will fall out if I don't do it. It's just one of those daily routine things that you just do. The modern medication is once a day, I don't find it a burden at all … M59C_27

Delaying treatment was also viewed by some as a means of preserving therapy for later use, based on their beliefs that pharmaceuticals should not be used as first-line treatment. Many reported their experience with and preferences for CM, as discussed later:

> We were brought up to believe in natural therapy as first line of treatment with "food is medicine". Just try and avoid pharmaceuticals until they're absolutely necessary. Try other things first. So, if we got sick, dad would make us garlic-ginger-lemon-honey teas and we've had vitamin C … they'd take us to a naturopath first. F49RC_18

Some participants also believed that mutation would lead to the genesis of strains that are resistant to all drugs. Some reported they were already living with highly aggressive, treatment resistant strains. They believed that consideration should be made for conserving treatment options for future needs and also cautioned against the use of ART as pre-exposure prophylaxis (PrEP):

> I thought well, I'll keep them up my sleeve. If I can be okay without medication, I will not take medication until I need it … F49RC_18

Delaying or declining treatment also appeared to be related to the belief that ART was toxic. Long-term survivors often recalled experiencing intolerable diarrhoea, nausea and skin rashes as side-effects of past treatments, which eroded their dignity and underpinned their beliefs that current treatments were also toxic. Recently-diagnosed participants were also fearful about toxic effects of ART despite reporting a lack of experienced side effects. Many believed that the dangers of ART are yet to be recognized or are deliberately concealed by pharmaceutical companies who were seen as having a vested interest in hiding the truth. For some, this was reflected in the restrictions placed on access to ART, which requires them to obtain their prescriptions from specialized prescribers and to have their prescriptions dispensed at hospitals and specialized clinics:

> I know they're very toxic and poisonous. They're 'scheduled 8' drugs and there's only a handful of people that can prescribe them. They must be pretty toxic to the body and to the liver and to the rest of our—you know, our brain. I was once told from a specialist in Sydney that our brains don't grow as fast as people that don't have the virus because of the HIV medication … M46RC_25

This participant expressed fear that continuous use would result in damage to his organs, particularly his brain

and reported periodically stopping treatment to minimize potential harm. He also recalled ceasing treatment when he assessed the immediate side effects to be intolerable. The idea of deliberate nonadherence is discussed in detail later:

> They made me nauseous, they made me vomit, lots of diarrhoea. I think I was on them for about 6 weeks and I just said no, I've had enough, and I just went off them … M46RC_25

Fears about ART were further reinforced by participants' assessment that the rapid advancement of technology has resulted in the production of drugs that have hidden dangers, and the timeframe in which ART has featured in the medical landscape is too limited to evaluate the full potential for long-term harms. As exemplified by the comment above, some stopped taking ART when they experienced intolerable side-effects or self-assessed the need to do so. The decision to deliberately cease treatment was termed a treatment "holiday". Multiple benefits were attributed to holidays, including not having to worry about taking medication, experience side-effects or worry about long-term toxicities. For one participant who reported having taken multiple holidays, each was fondly recalled as having reinstated his attractive physique and increased energy levels. At the time of the interview, the participant reported experiencing treatment fatigue and was considering taking a holiday:

> Whenever I've had a drug holiday, I've actually just gone out and partied and lived a normal life and not bothered about it. I eat pretty much the same as I do, if anything I probably do more exercise because I find that when you're on the antiretrovirals they seem to put on weight … when I come off them, I lose weight and I lose weight really well and I get a nice body back. And then as soon as I go back on the antiretrovirals, I lose my six pack and I lose my nice muscly arms and yeah, it all, it all just reverse … M46RC_25

For another participant, her fear of potential harm to her baby and preference for not using pharmaceuticals prompted her to take a holiday while she was pregnant, a decision she did not disclose to her doctor. Another participant who reported having taken multiple holidays reflected on his HIV journey as being devoid of autonomy, resulting in both physical and psychological harm. He reported that his adherence behavior had recently improved as the result of newly-formed respectful relationships with this doctor and pharmacist. Recalling his conversation with his doctor, he explained that in his current relationship with his care team, he felt that his perspectives were valued and respected, enabling him to navigate his own journey in maintaining his health:

> … my depression wasn't about the drugs, it was about the fact that I was doing something I had no choice in again and this goes back to this choice again … and my doctor turned around and went "I'm going be the bus driver, but you're the tour guide. We'll only go where you want to go. If you want to pull the breaks, stop, whatever." From that day on to now, I'm the happiest man in the world with the treatment I get, how I feel about how I'm treated, and my choices—as in they're very informed all the time … M52R_29

Others reported taking holidays when travelling overseas to avoid inconvenience and possible immigration difficulties. For one participant, the deliberate decision to diverge from taking medication as prescribed was a strategy for overcoming financial constraints. He reasoned that by taking ART on alternate days, he could make his medications last longer:

> … if I know I can't get it, then I'm just going to have to take one, gap one, take one, gap one, so I'll stretch it out a little bit. At least I'm getting it in my system. Otherwise, if I could just walk up to the pharmacy and say I've got no money and can I please get my HIV medication. Don't you realise I would do that? … M40R_3

He echoed the wishes of many who reported financial hardship for consideration to be given to PLHIV due to the complexity of issues they face in managing both physical and mental health and impact on their ability to work and pay for food, housing and medication. These issues will be discussed in detail in future publications.

Complementary Medicines

Among current CM users, several reported that they held strong belief in "Eastern" medicines and herbal remedies, based on efficacy and safety profiles apparently established over thousands of years. Anecdotal evidence appeared to serve as sufficient reassurance:

> I mean, they've all been used for thousands of years in rainforest communities … even though there's probably less research gone into them, I think the fact that they've been consumed for such a long period of time. I guess, historically, they've had a lot more trial and error done with them than with the recent antiretrovirals … M36RC_0.25

Participants expressed the belief that herbal remedies can support the body both physically and psychologically to launch its own fight against HIV, are free from harmful effects and, as they are grown and harvested naturally, are free from "dangerous chemicals":

> … they've got a chemical shadow of the illness that you're trying to use it to or the symptoms that you're trying to treat. So, it's like micro doses rather than

> something antibiotics … It triggers their own immune system to fight the illness that's going on … F49RC_18

One participant reported that he had delayed initiating treatment in favour of using CM:

> Before I started treatment, I tried all the Chinese herbs. Boiling all the Chinese herbs and all the lotions and potions that the Chinese put out. I noticed my t-cells started to drop from 500 down to 300 and stuff like that, so I tried the Chinese herbs and I just thought and believed, yes, this will work. This will work. You put them into water. You boil them until they were reduced to basically nothing and then you pour more water in there, let them boil for another 4 h until they reduced to nothing, and you did it again and you'd boiled it down to about a quarter way and you ended up with 2 cups of stuff that looks like mud. And you would drink one cup and then the next morning you would drink the other cup … M46RC_25

However, while he acknowledges that the remedy did not improve his health and indeed caused him to experience severe adverse effects that resembled the side effects that he had experienced with ART, he remained firm in his belief that CM shields his body from the harmful effects of exogenous poisons, including ART:

> I have a big belief in them. I do green smoothies every morning. I put chlorophyll in my green smoothies. I've been doing this for years, 7 years. I don't use any moisturisers—the only moisturiser I use is extra virgin cocoa oil, which is a natural product. Because whatever you put onto your skin seeps through your skin and into your bloodstream. I'm worried about pumping my body full of poisonous drugs to keep me alive, so putting more natural or alternative stuff into my body is better … M46RC_25

The beliefs of this participant were echoed by others who highlighted that, beyond supporting physical health, their self-determined treatment decisions supported the development of personal attributes such as mental toughness and resilience, qualities they believed to be valuable armor in their battle with HIV. Some also believed that foods were natural medicines that served as first-line defense when faced with challenges to health. Particularly among participants who had expressed concerns about the toxicity of ART, strategies for minimizing further exposure to "toxic chemicals" included using products such as almond oil to moisturize the skin and adding plant extracts such as chlorophyll to their food to counter balance the perceived toxicity of ART:

> I take a high dose of fish oil every morning. I take probiotics in the belief that it's going to help undo some of the damage that I know the antiretrovirals are doing when they're ingested, wiping out that good bacteria in your stomach. I would also take a multi [vitamin], vitamin C and then on top of that, I take, nutrition wise, super foods. I take Camu Camu, Gubinge powder, Ashwagandha and Lucuma powder which is Peruvian root vegetable as well. That's also good for the immune system … M36RC_0.25

Some also speculated that the true benefits of CM are yet to be discovered or are being hidden by pharmaceutical companies because of their vested interest in selling drugs. One participant held strong beliefs that the medical benefits of bananas are yet to be recognized and attested to feeling better and experiencing more positive results with ART since incorporating bananas into his diet:

> I strongly believe bananas was a very strong factor in me becoming undetectable so quick … bananas do a lot of things. They're very strong anti-virus … it does a variety of different things to you … M25RC_3

At the time of the interview, two participants reported that they were in the process of evaluating the potential benefits and risks of using CM instead of ART, but were currently using CM as an adjunct to ART. One participant was in the process of conducting internet searches to see if such products might exist overseas. The other spoke specifically about sourcing an 'Asian' herbal mixture from an overseas CM practitioner who has claimed to have demonstrated her products to be effective in treating HIV:

> … she [CM practitioner] is based in Kuala Lumpur. She has her own herb farm, so she grows all of her own herbs used in Chinese medicine. She does everything by hand, everything is grown, picked, dried, and ground, and even put in the tablet capsules by hand. And she has five HIV positive patients not on antiretroviral therapy in Kuala Lumpur that she's seeing, that she believes have had dramatic turnarounds with the CD4 count and viral load directly as a result of her Chinese meds. I'm not necessarily completely convinced but I would never shy away from taking the complementary medicine, especially herbal medicines … M36RC_0.25

Some also reported using CM to support conventional therapy for coexisting health issues e.g. glucosamine and fish oils for arthritis. However, others expressed the view that CM were only beneficial when dietary intake was inadequate. One participant, who despite believing vitamins to have a placebo effect, reported that taking vitamins at the same time as ART enabled her to focus on them, rather than on ART. Negative views regarding CM were expressed by participants who reported a lack of experienced benefits or

who assessed the absence of scientific evidence to be justification for their lack of effectiveness:

> There's a lot of misinformation out there, I think, about alternative therapies for all kinds of things, like cancer and HIV … obviously diet can help with general well-being, but I don't see it as directly impacting on viral load … M43R_5

In addition to reporting past expenditure of time and money on CM to be wasteful, some expressed the view that alternative therapy purveyors were opportunists who took advantage of people when they were at their most vulnerable.

Recreational Drugs

Drug use prior to diagnosis appeared to be influenced by lifestyles where use was common, associated with having fun and believed to be central to experiences:

> It was mainly cocaine, crystal meth and pot that I used, but I mean there was a lot of stuff around at the time … at the time it was just all just part of the scene. You just did, you just moved with it—probably to excess … MR54

Drugs were also reported to be inexpensive:

> I loved tripping. I used to trip because it was five dollars for a little acid trip … Heroin was a very interesting drug in the sense it was like, "Wow!". It just wipes everything … you're in a very mellow state … it just numbs you … M52R_29

Participants who reported high use prior to diagnosis speculated that they had contracted HIV through sexual encounters while under the influence of drugs. For some, being told that their lifespan was limited encouraged decisions to increase drug use. While some reported that this was to enjoy life to the full before their untimely demise, others reported increased use was to distract them from the turmoil that they experienced. Of the people who reported current use, most frequently, they reported using drugs as 'fun' owing to the positive feelings that they obtained, which appeared to be through enhancement of pleasurable activities such as sex. Drugs were also reported to alter thinking, perceived to enable users to experience extended periods of euphoria or allowing them to be distracted from having negative thoughts. For one participant who report he had not used drugs prior to diagnosis, drugs were a form of self-medication to numb the sadness he felt for the loss of his identity as an elite sportsman, the terror when confronted with health professionals covered head to toe in protective clothing and the isolation and subsequent depression he suffered when ostracized by teammates and family. He used drugs because they enabled him to escape from negative thoughts:

> I found that it was a release or an escape that they allowed periods of not dealing with my mortality. So, it was better to drink to excess and try substances because it was an escape and it allowed me to feel happiness and not deal with reality … M40R_20

While the participant has made effort to discontinue use, he admits to periods of relapse. Many others also reported that drugs enabled them to escape from painful memories and, simultaneously, to forget or simply not be aware of their reality. The "numbing" effect, in particular, appears to be an ascribed benefit that promotes use to relieve both physical and psychological pain. During times of excessive drug use, particularly the use of 'ice', participants reported they simply did not worry about taking their medications and were uncertain whether their lack of adherence lasted days, weeks, or months. Ice was also reported to impact on their finances and in some cases, caused them to become homeless, further challenging their ability maintain adherence and general health. However, many believed that some drugs used recreationally in the modern context, including amphetamines, had therapeutic origins and established safety profiles:

> Well ecstasy was actually invented overseas, I think in Germany or Switzerland as a marriage counselling drug. People that were having problems in their marriage were prescribed ecstasy to improve their love life. So that's where it all started and then it spread all around the world and it's known as "the love drug". Even at the love festival in Berlin it's readily available at $5 a tablet and it's the old formula, it's not the crap stuff that we have here in Australia … M46RC_25

They reasoned that the current legislation in Australia has resulted in unsafe manufacturing, which in turn has caused the negative consequences arising from use. Participants spoke about a range of strategies they used to mitigate potential harms. For one participant, rectal application of dissolved ice via a syringe (without a needle) negated the need for injecting (which he believed increased the potential for harm). Another participant reported travelling to Sydney specifically to purchase drugs from a dealer she trusted and advised against purchasing from those without an established reputation. These participants echoed calls by other current users for governmental regulation in the production of illicit drugs to improve safety. For those who continue to use ice, some made mention of intentions to seek help to stop using:

> … once you try ice, once it changes a chemical imbalance, so no matter what kind of problem you have you

are more likely to go back to that. I'm not going to lie, I love it, loved the feeling, love how to do it. I just hate the drug. Because it's a bad drug. It had destroyed my life twice. And I like the feeling it gives me. But I don't like what it does to my life eventually … M25RC_3

In contrast, some people reported they had stopped using drugs. Decisions to cease use immediately after diagnosis appeared to be underpinned by recognition of the need to focus on optimizing health in preparation for the journey ahead through proper housing and nutrition. Drugs were seen to detract from their ability to accomplish their goals. Commitment to cease using at a later stage appeared influenced by changed world-views or personal circumstances, including valuing of opportunities to achieve career goals, supporting others through their HIV journey, improving physical and mental health and recognizing that drug use had hindered progress across all domains. Some reported that they ceased using drugs only because they could no longer afford them. However, across the range of drugs, excluding marijuana, participants acknowledged they had faced difficulties in remaining drug free with many reporting periods of relapse. Those who had expressed negative views towards drugs, including past users, believed that drugs offered only temporary solutions and that the costs of addiction were more than financial. For example, one participant reported that despite all efforts to turn his life around, he was experiencing ongoing challenges to his ability to register as a health practitioner arising from an incident related to historical drug use. There was agreement among the majority of participants, whether they had engaged in RD use or not, that drugs were a temporary solution:

I think all of these escaping drugs, they can take the pain away for a short period of time, and I don't believe a lot of them give people any good at all … M59C_27

However, as reflected by the comment below, RD offered some participants benefits that they considered to outweigh the potential negative consequences, irrespective of one's HIV status:

First place, drugs are fun. This is the main reason people take drugs. They are fun. Don't let people tell you that they're not … M50RC_28

A framework for understanding the interplay of beliefs about ART, CM and RD in decisions regarding ART uptake and adherence is presented in Fig. 2.

Modulators of treatment uptake and adherence appear be underpinned by the beliefs that individuals hold about ART, CM and RD and their experiences with these substances. In summary, co-existing beliefs that ART is effective, that CM lacks evidence for effectiveness as treatment for HIV and that RD are counter-productive and have negative consequences, appear to promote treatment uptake and adherence. Conversely, perceptions of ART as toxic, having a negative impact on physical appearance and when treatment decisions are made without proper consideration for patient autonomy, alongside positive views about CM and RD, seem to be

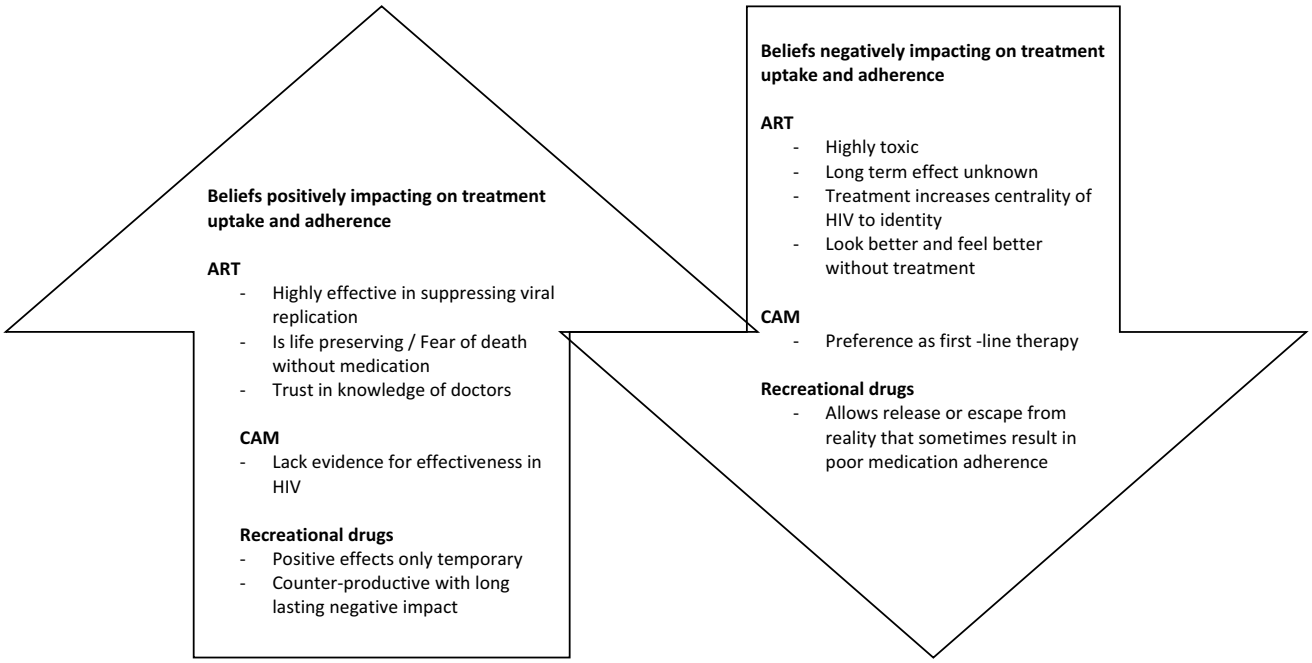

Fig. 2 Beliefs modulating treatment uptake and adherence

linked to delays in treatment initiation and divergence from the prescribed regimen are common.

Discussion

This research has highlighted that PLHIV in Australia hold wide ranging beliefs about ART, CM and RD that impact on their treatment uptake, adherence and, consequently, their health. While the vast majority believed ART to be highly effective, they were particularly fearful about the potential for harm, both immediate and long-term. This finding suggests that factors underpinning beliefs, such as medication knowledge, may be lacking or inaccurate. It is important, therefore, to direct effort towards understanding how beliefs about ART are formed. Furthermore, this finding suggests that health professionals are not fully addressing medication-related concerns of PLHIV and may not be discussing treatment options in a manner that supports autonomy in the decision-making process. These barriers may serve to disempower already vulnerable and distressed individuals and lead them to try to take control via other means for relief and as forms of self-medication.

Another key finding from this research in relation to beliefs about ART is that people construct their own meanings about medication adherence. Thus, while all reported that they had been prescribed ART, some had delayed initiating treatment while others had diverted from their recommended regimen. In the majority of cases, decisions to decline, delay or diverge from recommendations were deliberate and most often associated with regaining a sense of self-determination and restoring normality. This finding suggests that the burden of adherence extends beyond the commitment to taking the drug every day. Understanding how life with HIV is perceived and experienced by individuals may provide further insights about beliefs that impact on treatment decisions.

Consistent with findings from previous research [17, 18], some people engaged in RD use because they perceived their decision to be linked to a high degree of self-determination, including for self-medication purposes while, at the same time, assessing the risk to be minimal. While some expressed concerns regarding the negative impact of RD, none made mention of concerns regarding the potential for RD to interact with their prescribed ART. With mounting evidence demonstrating that concurrent RD and ART may result in a range of negative consequences [20, 28, 32, 35, 36, 38, 40], initiatives to improve outcomes for PLHIV must address the unmet needs that drive them to engage in recreational drug use. For many, these needs are related to mental health issues, for which they appear to use RD to self-medicate.

This research has also highlighted that CM use is common among PLHIV in Australia. Consistent with findings from previous research, the valuing of CM appears to be underpinned by the belief in its power to protect the body both from HIV and from the perceived harmful effects of ART [59, 60, 62, 64, 65, 78]. Of particular concern is that while participants in this study talked about disclosing their use or intended use of CM to their treating physicians, they were not always certain about the composition of those products. Furthermore, many were taking CM to facilitate management of coexisting health conditions and, although some questioned the effectiveness of the products, they did not appear to appreciate the potential for negative consequences arising from drug interactions.

The ascribed benefits of RD and the degree of self-determination, coupled with potential health benefits of CM without sided effects, are contrasted with concerns expressed regarding toxicity, and financial, emotional and physical burdens imposed by ART. The burden of treatment appears to be a strong motivator for declining, delaying or diverting from prescribed treatment, while positive views towards RD appear to justify use, particularly for mitigating negative states of mind. These findings suggest current strategies for optimising outcomes for PLHIV may not targeting the key issues that present as treatment uptake and adherence barriers.

Strengths and Limitations

There are limitations to our study that we acknowledge. Firstly, we were unable to recruit participants who elected only to use CM or who chose only to engage in RD use. However, we were able to recruit a broad cross-section of participants, who varied in age, gender, cultural background, time living with HIV and expressed beliefs. Within the above limitation, we continued to interview participants until we reached saturation, thereby giving voice to PLHIV in contemporary Australia. While our participant pool of 40 has provided a range of quantitative data, we refrained from making statistical comparisons and drawing inferences from our limited quantitative analyses. We have instead, focused on learning from our participants through adopting a systematic and rigorous approach to the analysis and reporting of the narratives that they shared. Throughout the process, we maintained open dialogue, thus providing further assurance that our interpretation were unanimous and accurately reflect the core messages expressed by the participants.

Conclusions

This study has highlighted that an optimal model of care for PLHIV must take into account treatment reservations and people's desire to go beyond what modern ART currently

offers. This information should serve as guidance for the development of strategies to address barriers to treatment uptake and adherence and consequently health outcomes for PLHIV in Australia and elsewhere.

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Compliance with Ethical standards

Conflicts of interest All authors declare that they have no conflicts of interest

References

1. UNSAIDS. How AIDS changed everything. 2015. http://www.unaids.org/sites/default/files/media_asset/MDG6Report_en.pdf. Accessed March 21 2019.
2. AVERT. Global HIV and AIDS statistics. [Internet]. 2017. http://www.avert.org/professionals/hiv-around-world/global-statistics. Accessed March 21 2019.
3. World Health Organization. HIV/AIDS. [Internet]. http://www.who.int/mediacentre/factsheets/fs360/en/. Accessed March 21 2019.
4. Williams CKO. Global HIV/AIDS burden and associated diseases. Cancer and AIDS: Part II: cancer pathogenesis and epidemiology. Cham: Springer; 2019. p. 59–96.
5. World Health Organization. Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. 2014. http://apps.who.int/iris/bitstream/10665/128048/1/9789241507431_eng.pdf?ua=1&ua=1. Accessed March 21 2019.
6. World Health Organization. Global update on the health sector response to HIV, 2016–2021. https://apps.who.int/iris/bitstream/handle/10665/246178/WHO-HIV-2016.05-eng.pdf?sequence=1. Accessed March 21 2019.
7. UNAIDS. 90-90-90—An ambitious treatment target to help end the AIDS epidemic. [Internet]. http://www.unaids.org/en/resources/documents/2017/90-90-90. Accessed March 21 2019.
8. AIDSinfo. Current guidelines. [Internet]. http://aidsinfo.nih.gov/guidelines. Accessed March 22 2019.
9. Cambiano V, Lampe FC, Rodger AJ, et al. Long-term trends in adherence to antiretroviral therapy from start of HAART. AIDS. 2010;24(8):1153–62.
10. Paterson DL, Swindells S, Mohr J, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. Ann Intern Med. 2000;133(1):21–30.
11. Langebeek N, Gisolf EH, Reiss P, et al. Predictors and correlates of adherence to combination antiretroviral therapy (ART) for chronic HIV infection: a meta-analysis. BMC Med. 2014;12:142–142.
12. UNAIDS. The gap report. 2014. http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf. Accessed March 21 2019.
13. UNAIDS. On the fast-track to end AIDS. 2016. http://www.unaids.org/sites/default/files/media_asset/20151027_UNAIDS_PCB37_15_18_EN_rev1.pdf. Accessed March 21 2019.
14. Australian Government Department of Health. Eighth National HIV Strategy 2018–2022. http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/$File/HIV-Eight-Nat-Strategy-2018-22.pdf. Accessed March 21 2019.
15. Kirby Institue. HIV, viral Hepatitis and sexually transmissible infections in Australia. Annual surveillance report 2018. [Internet]. 2018. https://kirby.unsw.edu.au/sites/default/files/kirby/report/KI_Annual-Surveillance-Report-2018.pdf. Accessed March 21 2019.
16. Mey A, Plummer D, Dukie S, Rogers GD, O'Sullivan M, Domberelli A. Motivations and barriers to treatment uptake and adherence among people living with HIV in Australia: a mixed-methods systematic review. AIDS Behav. 2017;21(2):352–85.
17. Mey A, Plummer D, Anoopkumar-Dukie S, Domberelli A. What's the attraction? The role of performance enhancement as a driver of recreational drug use. J Subst Use. 2018;23(3):294–9.
18. Mey A, Plummer D, Anoopkumar-Dukie S, Domberelli A. What's the attraction? social connectedness as a driver of recreational drug use. J Subst Use. 2018;23(3):327–34.
19. United Nations Office on Drugs and Crime. World drug report. 2015. https://www.unodc.org/documents/wdr2015/World_Drug_Report_2015.pdf. Accessed March 21 2019.
20. Butler S. The prevention of substance use, risk and harm in Australia: a review of the evidence. Drugs. 2005;12(3):247–8.
21. Lee E, Mao L, Lea T, et al. Gay community periodic survey: Melbourne. 2017. http://unsworks.unsw.edu.au/fapi/datastream/unsworks:45702/bin55ae0d15-45d4-4e85-b4d6-bd4d14eabb27?view=true. Accessed March 21 2019.
22. Broady T, Mao L, Lee E, et al. Gay community periodic survey: Tasmania 2018. http://unsworks.unsw.edu.au/fapi/datastream/unsworks:55228/bin2d640fa7-71b3-4372-bb3b-1fd49f94494f?view=true. Accessed 10 Feb 2019.
23. Freeman P, Walker BC, Harris DR, et al. Methamphetamine use and risk for HIV among young men who have sex with men in 8 US cities. Arch Pediatr Adolesc Med. 2011;165(8):736–40.
24. Hembling J, Bertrand J, Melendez G, Ponchick L. Drug users and HIV risk in Guatemala City, Guatemala. J Drug Issues. 2019;49(2):296–307.
25. HIV.gov. Substance use and HIV risk. [Internet]. 2018. https://www.hiv.gov/hiv-basics/hiv-prevention/reducing-risk-from-alcohol-and-drug-use/substance-use-and-hiv-risk. Accessed Feb 10 2019.
26. Kong TSK, Laidler KJ. The paradox for chem-fun and gay men: a neoliberal analysis of drugs and HIV/AIDS policies in Hong Kong. J Psychoact Drugs. 2019;31:1–9.
27. Lee MP, Chan ML, Chan YT, et al. Survey on drug use among people living with HIV in Hong Kong. Int J Ment Health Addict. 2018;16(6):1312–21.
28. Daskalopoulou M, Rodger AJ, Phillips AN, Speakman A, Lampe FC. Prevalence of recreational drug use is indiscriminate across antiretroviral regimens of differing drug–drug interactions among MSM. AIDS. 2016;30(5):810–2.
29. Newman CE, Mao L, Persson A, et al. '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. AIDS Patient Care STDS. 2015;29(5):267–78.
30. Gold RS, Hinchy J, Batrouney CG. The reasoning behind decisions not to take up antiretroviral therapy in Australians infected with HIV. Int J STD AIDS. 2000;11(6):361–70.
31. Gold RS, Ridge DT. "I will start treatment when I think the time is right": HIV-positive gay men talk about their decision not to access antiretroviral therapy. AIDS Care. 2001;13(6):693–708.
32. Bracchi M, Stuart D, Castles R, Khoo S, Back D, Boffito M. Increasing use of 'party drugs' in people living with HIV on antiretrovirals: a concern for patient safety. AIDS (London, England). 2015;29(13):1585–92.

33. Feldman MB, Kepler KL, Irvine MK, Thomas JA. Associations between drug use patterns and viral load suppression among HIV-positive individuals who use support services in New York City. Drug Alcohol Depend. 2019;197:15–21.
34. Troiano G, Mercurio I, Bacci M, Nante N. Hidden dangers among circuit parties—a systematic review of HIV prevalence, sexual behaviors and drug abuse during the biggest gay events. J Hum Behav Soc Environ. 2018;28(8):983–91.
35. Phanuphak P, Phanuphak N. Time for action on methamphetamine use and HIV. Lancet HIV. 2018;5(7):339–40.
36. Sangiovanni RJ, Jakeman B, Nasiri M, Ruth L, Mahatme S, Patel N. Relationship between contraindicated drug-drug interactions and subsequent hospitalizations among patients living with HIV initiating combination antiretroviral therapy. AIDS Res Hum Retrovir. 2019. https://doi.org/10.1089/AID.2018.0205.
37. Sewell J, Cambiano V, Miltz A, et al. Changes in recreational drug use, drug use associated with chemsex, and HIV-related behaviours, among HIV-negative men who have sex with men in London and Brighton, 2013–2016. Sex Transm Infect. 2018;94(7):494.
38. Montgomery L, Bagot K, Brown JL, Haeny AM. The association between marijuana use and HIV continuum of care outcomes: a systematic review. Curr HIV/AIDS Rep. 2019;16(1):17–28.
39. Pepper N, Zúñiga ML, Reed MB. Prevalence and correlates of "popper" (amyl nitrite inhalant) use among HIV-positive Latinos living in the U.S.-Mexico border region. J Ethn Subst Abuse. 2019;07:1533–2659.
40. Pool ERM, Winston A, Bagkeris E, et al. High-risk behaviours, and their associations with mental health, adherence to antiretroviral therapy and HIV parameters, in HIV-positive men who have sex with men. HIV Med. 2019;20(2):131–6.
41. Prasad A, Kulkarni R, Shrivastava A, Jiang S, Lawson K, Groopman JE. Methamphetamine functions as a novel CD4+T-cell activator via the sigma-1 receptor to enhance HIV-1 infection. Sci Rep. 2019;9(1):958. http://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC6353873&blobtype=pdf.
42. Ogbuagu O, Marshall BDL, Tiberio P, et al. Prevalence and correlates of unhealthy alcohol and drug use among men who have sex with men prescribed HIV pre-exposure prophylaxis in real-world clinical settings. AIDS Behav. 2019;23(1):190–200.
43. Gupta RK, Wainberg MA, Brun-Vezinet F, et al. Oral antiretroviral drugs as public health tools for HIV prevention: global implications for adherence, drug resistance, and the success of HIV treatment programs. J Infect Dis. 2013;207(Suppl 2):S101–6.
44. Cadosch D, Bonhoeffer S, Kouyos R. Assessing the impact of adherence to anti-retroviral therapy on treatment failure and resistance evolution in HIV. J R Soc Interface. 2012;9(74):2309–20.
45. Fogarty L, Roter D, Larson S, Burke J, Gillespie J, Levy R. Patient adherence to HIV medication regimens: a review of published and abstract reports. Patient Educ Couns. 2002;46(2):93–108.
46. Nachega JB, Hislop M, Dowdy DW, Chaisson RE, Regensberg L, Maartens G. Adherence to nonnucleoside reverse transcriptase inhibitor-based HIV therapy and virologic outcomes. Ann Intern Med. 2007;146(8):564–73.
47. von Wyl V, Klimkait T, Yerly S, et al. Adherence as a predictor of the development of class-specific resistance mutations: the Swiss HIV cohort study. PLoS ONE. 2013;8(10):e77691.
48. Wilson KJ, Doxanakis A, Fairley CK. Predictors for non-adherence to antiretroviral therapy. Sex Health. 2004;1(4):251–7.
49. Australian Government Department of Health Therapeutic Goods Administration. Complementary medicines. [Internet]. 2019. https://www.tga.gov.au/complementary-medicines. Accessed Feb 14 2019.
50. Abou-Rizk J, Alameddine M, Naja F. Prevalence and characteristics of CAM use among people living with HIV and AIDS in Lebanon: implications for patient care. J Evid Based Complement Altern Med. 2016;2016:11.
51. Bahall M. Prevalence, patterns, and perceived value of complementary and alternative medicine among HIV patients: a descriptive study. BMC Complement Altern Med. 2017;17(1):422.
52. Braun LA, Forrester CA, Rawlins MD, et al. Complementary medicine use by people living with HIV in Australia—a national survey. Int J STD AIDS. 2016;27(1):33–8.
53. de Visser R, Ezzy D, Bartos M. Alternative or complementary? Nonallopathic therapies for HIV/AIDS. Altern Ther Health Med. 2000;6(5):44–52.
54. Kelso-Chichetto NE, Okafor CN, Harman JS, Canidate SS, Cook CL, Cook RL. Complementary and alternative medicine use for HIV management in the State of Florida: medical monitoring project. J Altern Complement Med. 2016;22(11):880–6.
55. Littlewood RA, Vanable PA. Complementary and alternative medicine use among HIV-positive people: research synthesis and implications for HIV care. AIDS Care. 2008;20(8):1002–18.
56. Littlewood RA, Vanable PA. A global perspective on complementary and alternative medicine use among people living with HIV/AIDS in the era of antiretroviral treatment. Curr HIV/AIDS Rep. 2011;8(4):257–68.
57. Lorenc A, Robinson N. A review of the use of complementary and alternative medicine and HIV: issues for patient care. AIDS Patient Care STDS. 2013;27(9):503–10.
58. McDonald K, Slavin S. My body, my life, my choice: practices and meanings of complementary and alternative medicine among a sample of Australian people living with HIV/AIDS and their practitioners. AIDS Care. 2010;22(10):1229–35.
59. Mills E, Wu P, Ernst E. Complementary therapies for the treatment of HIV: in search of the evidence. Int J STD AIDS. 2005;16(6):395–403.
60. Owen-Smith A, DePadilla L, DiClemente R. The assessment of complementary and alternative medicine use among individuals with HIV: a systematic review and recommendations for future research. J Altern Complement Med. 2011;17(9):789–96.
61. Suwassa L, Jutatip S, Ladaval ON. Factors related to the use of complementary and alternative medicine among people living with HIV/AIDS in Bangkok, Thailand. Health Sci J. 2013;7(4):436–46.
62. Syed IA, Sulaiman SAS, Hassali MA, Thiruchelvam K, Syed SH, Lee CKC. Beliefs and practices of complementary and alternative medicine (CAM) among HIV/AIDS patients: a qualitative exploration. Eur J Integr Med. 2016;8(1):41–7.
63. Thomas S, Lam K, Piterman L, Mijch A, Komesaroff P. Complementary medicine use among people living with HIV/AIDS in Victoria, Australia: practices, attitudes and perceptions. Int J STD AIDS. 2007;18(7):453–7.
64. Thorpe RD. 'Doing' chronic illness? Complementary medicine use among people living with HIV/AIDS in Australia. Soc Health Illn. 2009;31(3):375–89.
65. Pan X, Zhang A, Henderson GE, et al. Traditional, complementary, and alternative medical cures for HIV: rationale and implications for HIV cure research. Glob Public Health. 2019;14(1):152–60.
66. Brooks KM, George JM, Kumar P. Drug interactions in HIV treatment: complementary and alternative medicines and over-the-counter products. Expert Rev Clin Pharmacol. 2017;10(1):59–79.
67. Stolbach A, Paziana K, Heverling H, Pham P. A review of the toxicity of HIV medications II: interactions with drugs and complementary and alternative medicine products. J Med Toxicol. 2015;11(3):326–41.
68. Lea T, Hammoud M, Bourne A, et al. Attitudes and perceived social norms toward drug use among gay and bisexual men in Australia. Subst Use Misuse. 2019;16:1–11.

69. Lune H. Qualitative research methods for the social sciences. 9th ed. Long Beach: Pearsons; 2017.
70. Marshall MN. Sampling for qualitative research. Fam Pract. 1996;13(6):522–6.
71. Teddlie C, Yu F. Mixed methods sampling: a typology with examples. J Mix Methods Res. 2007;1(1):77–100.
72. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health. 2015;42(5):533–44.
73. Glaser B, Strauss A. The discovery of Grounded Theory: strategies for qualitative research. Chicago: Aldine Publishing Company; 1967.
74. Kallio H, Pietilä A-M, Johnson M, Kangasniemi M. Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. J Adv Nurs. 2016;72(12):2954–65.
75. Brinkmann S, Kvale S. Interviews: learning the craft of qualitative research interviewing. 3rd ed. Denmark: Sage; 2015.
76. Pope C, Ziebland S, Mays N. Analysing qualitative data. In: Pope C, Mays N, editors. Qualitative research in health care. Hoboken: Blackwell Publishing Ltd; 2007. p. 63–81.
77. Layder D. Understanding social theory. London: Sage; 2006.
78. Thorpe RD. Integrating biomedical and CAM approaches: the experiences of people living with HIV/AIDS. Health Sociol Rev. 2008;17(4):410–8.