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Motivations and Barriers to Treatment Uptake and Adherence Among People Living with HIV in Australia: A Mixed-Methods Systematic Review

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Abstract In Australia, approximately 30% of people diagnosed with HIV are not accessing treatment and 8% of those receiving treatment fail to achieve viral suppression. Barriers limiting effective care warrant further examination. This mixed-methods systematic review accessed health and social sector research databases between November and December 2015 to identify studies that explored the perspective of people living with HIV in Australia. Articles were included for analysis if they described the experiences, knowledge, attitudes and beliefs, in relation to treatment uptake and adherence, published between January 2000 and December 2015. Quality appraisal utilised the Mixed Methods Appraisal Tool Version 2011. Seventy-two studies that met the inclusion criteria were reviewed. The interplay of lack of knowledge, fear, stigma, physical, emotional and social issues were found to negatively impact treatment uptake and adherence. Strategies targeting both the individual and the wider community are needed to address these barriers.

Resumen En Australia, aproximadamente el 30% de las personas diagnosticadas con VIH no están accediendo al tratamiento; el 8% de los que han recibido el tratamiento no logran alcanzar niveles de supresión viral total. Las barreras que limitan la prestación de una atención médica integral y eficaz, necesitan ser examinadas detenidamente. Se realizó una revisión sistemática de los estudios que exploraron la perspectiva de las personas viviendo con VIH en Australia. Se utilizaron métodos mixtos para acceder a bases de datos de investigación en salud y del sector social entre noviembre y diciembre de 2015. Los artículos que se incluyeron para el análisis debían describir experiencias, conocimientos, actitudes y creencias, en relación a la adopción del tratamiento y adherencia al mismo, publicados entre enero de 2000 y diciembre del 2015. La evaluación de la calidad de los artículos utilizó la herramienta de evaluación de métodos mixta, versión 2011. Se revisaron setenta y dos estudios que cumplieron los criterios de inclusión. Las interacciones entre la falta de conocimiento, miedo, estigma, así como problemas físicos, emocionales y sociales produjeron un impacto negativo en la adopción y adherencia al tratamiento. Se necesitan estrategias dirigidas a los individuos, así como a la comunidad en general para hacer frente a estas barreras.

Keywords HIV · Australia · Knowledge · Attitudes · Beliefs · Barriers

Palabras clave VIH · Australia · conocimiento · actitudes · creencias · barreras

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Introduction

HIV has claimed over 34 million lives worldwide and continues to impact negatively on the lives of 37 million others who are infected, their families and the community as a whole [1, 2]. Halting the spread of HIV and caring for those infected are among the leading global health and humanitarian concerns [2, 3]. Global health strategies are directed

towards ending the epidemic by the year 2030 [4, 5]. While there are no cures for the disease, major advances in medical technology, particularly within the past decade, have resulted in the availability of tools for rapid diagnosis and new classes of antiretroviral therapy (ART) that have more favourable safety and tolerability profiles in addition to greater efficacy in suppressing viral replication [6]. In the fight against HIV, these advances have transformed the status of a person infected from having a terminal illness, to living with a chronic health condition, and provides hope for bringing the epidemic to an end [3, 4].

Research demonstrating effective management of HIV highlights four key areas: (i) early diagnosis, (ii) timely treatment with appropriate medication, (iii) near perfect life-long adherence to the treatment regimen, and (iv) commitment to risk reduction practices [2, 3, 5]. Early diagnosis not only allows for initiation of appropriate treatment to prevent deterioration in personal health, but may prevent an infected person from unknowingly transmitting the infection to others [2, 3]. Correlations between the consistent, appropriate use of antiretroviral medication and decreases in viral replication (leading to a decreased in morbidity and mortality), prevention of drug resistance and restoration and preservation of immune function have also been clearly demonstrated [7–10]. It has been estimated that, in order to achieve these benefits, life-long adherence levels of 95% or more need to be maintained [11]. Transmission reduction strategies on the part of people who are infected and people who are at risk are also central to stemming the transmission between individuals [12]. In addition, treatment as prevention (TasP) has been proposed as a means of securing further reductions in HIV incidence beyond those achieved by current prevention programs [3, 13]. To achieve the goal of ending the epidemic by 2030, world health authorities have set a global target of at least 90% diagnosis, treatment uptake and treatment adherence among all people living with HIV [5].

In Australia, it is estimated that approximately 27,150 people (0.14% of the population) currently live with HIV infection [14]. The Australian Government's framework for the management of the disease is aligned with the goals of the global health community, and reflects the need for timely and equitable access to testing and treatment, for measures to support medication adherence and for the promotion of risk reduction practices to limit the transmission of the virus [15]. While Australia can be considered to be performing relatively well when compared to other developed nations such as the United States and the United Kingdom [16], Australia still falls short of reaching either the global goal or domestic targets [5, 15].

In the Australian health and social context, there are laws to ensure that human rights and access to services for residents and visitors are protected [17]. A diverse range of awareness-raising campaigns and services that adopt interprofessional models of care have been developed and implemented with the aims of halting the HIV/AIDS epidemic and providing care for those affected [15]. Residents (and visitors from countries that have reciprocal agreements with Australia) are able to access diagnostic tests in accredited community-based settings at a subsidised price through the Medicare universal health insurance scheme[1] [18]. The cost of antiretroviral medication is also subsidised, through the Pharmaceutical Benefits Scheme [19]. It is important to note that relatively modest co-payments are required from the individual for both testing and antiretroviral medication [20]. However, surveillance statistics highlight key areas that are a cause for concern [14]. Specifically, while the prevalence of HIV has stabilised over the past few years, this rate represents the highest level seen over the past 20 years. Furthermore, at the end of 2014, it was estimated that approximately 12% of the people infected with HIV remained undiagnosed. Of the newly diagnosed cases, 28% were deemed to be at "late-stage". That is, this group of people has been carrying the virus for at least four years without being aware of their status [14]. Among people diagnosed as living with HIV, almost 30% were not receiving antiretroviral treatment [14, 15]. For those who elected to receive treatment, up to 10% failed to achieve adequate adherence and consequently, failed to achieve viral suppression [15].

HIV transmission rates in Australia are highest among men who have sex with men (MSM), as a result of unprotected sexual contact [14, 21]. Research indicates that the rate of testing among this group has been declining over the past 10 years [21]. Among Aboriginal and Torres Strait Islander people the rate of diagnosis has been increasing over the past five years with transmission through injecting drug use and heterosexual contact higher when compared to the Australian born non-Indigenous population [14]. Among people who were diagnosed late in their progression of the disease, the majority were migrants born in South East Asia or Sub-Saharan Africa [15]. Other groups identified to be at greater risk of HIV infection are people who have travelled overseas and mobile workers, sex workers, people who inject drugs and people in custodial care [15]. These statistics suggest that the core messages concerning the need for early detection, appropriate treatment and perhaps prevention measures, are not reaching some of people living with HIV (PLHIV), and people who are most at risk. It is important therefore, to identify the personal motivations and barriers, both perceived and experienced, that impact on the behaviour of PLHIV and people at risk, in relation to testing, treatment uptake, medication adherence and risk reduction practices. This

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[1] Medicare universal health insurance scheme refers to both the Pharmaceutical Benefits Scheme and Medicare Benefits Schedule.

information will be valuable for policy makers at the domestic level in formulating approaches that target the key areas of need if Australia is to optimise care for those who live with HIV and ultimately mitigate the transmission of infection among people living in Australia [15]. This mixed-methods systematic review is guided by the overarching research question: *What factors influence people living with HIV and at risk individuals in making decisions regarding testing, treatment uptake, treatment adherence and exposure prevention?* The study is presented in three parts. This first part focuses on understanding the factors that influence decisions regarding treatment uptake[2] and treatment adherence[3] among PLHIV in Australia. In studies to follow, the literature will be reviewed to facilitate understanding of factors that contribute to suboptimal testing, and to risk taking behaviours among PLHIV and among those who are deemed to be at risk of exposure.

Methods

Study Design

Qualitative, quantitative and mixed methods studies were reviewed. Specifically, quantitative studies were assessed to provide information regarding the demographic characteristics of PLHIV in Australia, their knowledge, attitudes and beliefs about HIV, ART and treatment outcomes and to determine whether there were patterns of associations between these intrapersonal variables and their treatment uptake and adherence behaviours. Qualitative literature that explored participants' lived experiences was also assessed utilising the principles of thematic analysis [22] to provide a more nuanced understanding of the determinants of these phenomena than could be discerned from the quantitative data alone [23]. The purpose of this research is to provide a greater understanding of the perspectives of PLHIV and to identify motivations and barriers to treatment uptake and adherence.

Search Strategy

Health and social sector research databases: Ovid Medline, CINAHL, Scopus, Health and Society Database, and Sociological Abstracts were accessed between November and December 2015 to identify published studies that described HIV/AIDS care in Australia from the perspective of individuals living with HIV/AIDS. The search involved the use of the keywords: Australia, HIV, knowledge, attitudes, beliefs and barriers. The use of these broader terms

allowed the identification of studies focused on treatment uptake and adherence in the Australian context. The electronic search strategy followed a similar pathway as exemplified by Table 1.

A Google search was undertaken to identify grey literature (such as Australian Government publications, periodicals, monographs, surveillance data) to facilitate understanding of Australian health and social contexts.

Inclusion/Exclusion Criteria

Articles were considered for analysis if they described the experiences, knowledge, attitudes and beliefs of people living with HIV in the Australian context, in relation to one or more of the following: i) living with HIV, ii) treatment uptake and iii) treatment adherence. To further contextualise the findings relative to the modern Australian setting, studies published prior to the year 2000 were excluded and the latest articles reviewed were published before December 15 2015. Review articles and grey literature were excluded from analysis but their reference lists were scrutinised and in some cases, yielded new articles to include in the analysis.

The Review Process

Articles uncovered from the five data base searches were combined and duplicate articles were removed. The title and abstracts of the articles were assessed by the primary author (AM) for their content and relevance to the objectives of the review. Only articles meeting the inclusion were retained. Abstracts were also reviewed by SD to identify any articles that were missed for inclusion into the study. The full-text of the remaining articles were read by AM and those that did not meet inclusion criteria were removed from the review. SD reviewed a random sample of the excluded articles as a measure of quality assurance to prevent relevant articles from being excluded.

Methodological Quality Appraisal

Quality appraisal utilised the Mixed Methods Appraisal Tool (MMAT) Version 2011 which, although relatively new, has demonstrated efficiency and reliability [24]. This tool was chosen because it allowed for the methodological quality of different types of studies to be evaluated using a one-page questionnaire. The tool was adapted for the purpose of the current review as presented in Table 2.

Quantitative studies were assessed according to four domains. Categorisation varied slightly depending on whether the study was a) a randomised controlled trial (RCT), b) a non-randomised study or c) a descriptive study. For example, the quality of RCTs was judged based on: i)

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[2] Treatment uptake refers to individuals decisions to access ART.

[3] Treatment adherence refers to the individuals' behaviour in taking ART at the dose, frequency, duration and in a manner as prescribed.

Table 1 Electronic search strategy for Medline Ovid®

Step	Medline Ovid®	
	Searches	Results
1	Exp Australia/	118,477
2	Barrier*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	182,087
3	Belief*.mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	54,170
4	Attitude/or attitude to health/or health knowledge, attitudes, practice/	197,477
5	Patient medication knowledge/	89
6	Knowledge/	8962
7	Exp HIV/	88,625
8	Hiv.mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	283,766
9	(Uptake and (treatment or medication or "antiretroviral therapy" or art)).mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	55,726
10	(Adherence and (treatment or medication or "antiretroviral therapy" or art)).mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	44,372
11	2 or 3 or 4 or 5 or 6	409,602
12	7 or 8	283,766
13	9 or 10	99,362
14	1 and 11 and 12 and 13	16
15	1 and 11 and 12	313

* inclusion of plural in search

clarity of the randomisation process, ii) clarity of the allocation concealment, iii) completeness of outcome data (≥ 80%), and, iv) level of dropout (< 20%). Mixed methods studies were assessed according to: i) appropriateness of the research design, ii) appropriateness of triangulation, and iii) appropriate acknowledgement of limitations. For qualitative studies, methodological quality was assessed according to the relevance/appropriateness of four domains relative to the research question: i) the data source ii) the analytical process, iii) the findings and iv) reflexivity. Given the diversity of the studies included in this review, only research articles published in peer-reviewed journals were included in the analysis. The search strategy, data table and study quality assessment were reviewed by SD and disagreement resolved by consensus.

Data Extraction and Analysis

The content of each study was reviewed by AM. Data were extracted and tabulated as follows: First author and year of publication, study aim, method, location, participant, and key findings. For qualitative studies and using the principles of thematic analysis [22], AM documented the themes that emerged from the data. A random selection of articles was independently reviewed by SD, who, using the same analytical procedure, thematically recorded the findings. The two authors each developed a code book, then discussed their views and agreed on a coding framework. AM thematically analysed the remaining articles and summarised the results according to the framework. The remaining authors each reviewed 5 articles relative to the framework and provided feedback. Feedback was discussed during team publication meetings and decisions were made based on the outcome of the discussion.

Results

A total of 1148 articles were identified through database and other searches. The process of review and elimination followed the PRISMA guidelines [25] as illustrated in Fig. 1, identified 72 articles for inclusion in the current study. Of the included studies, 34 used quantitative methods including cohort and cross-sectional designs, analysis of medical records and retrospective analysis; 30 used qualitative methods, including focus groups and semi-structured interviews and 6 used both quantitative and qualitative methods. One case report and one short communication article were included due to the insights they

Table 2 Methodological quality appraisal tool

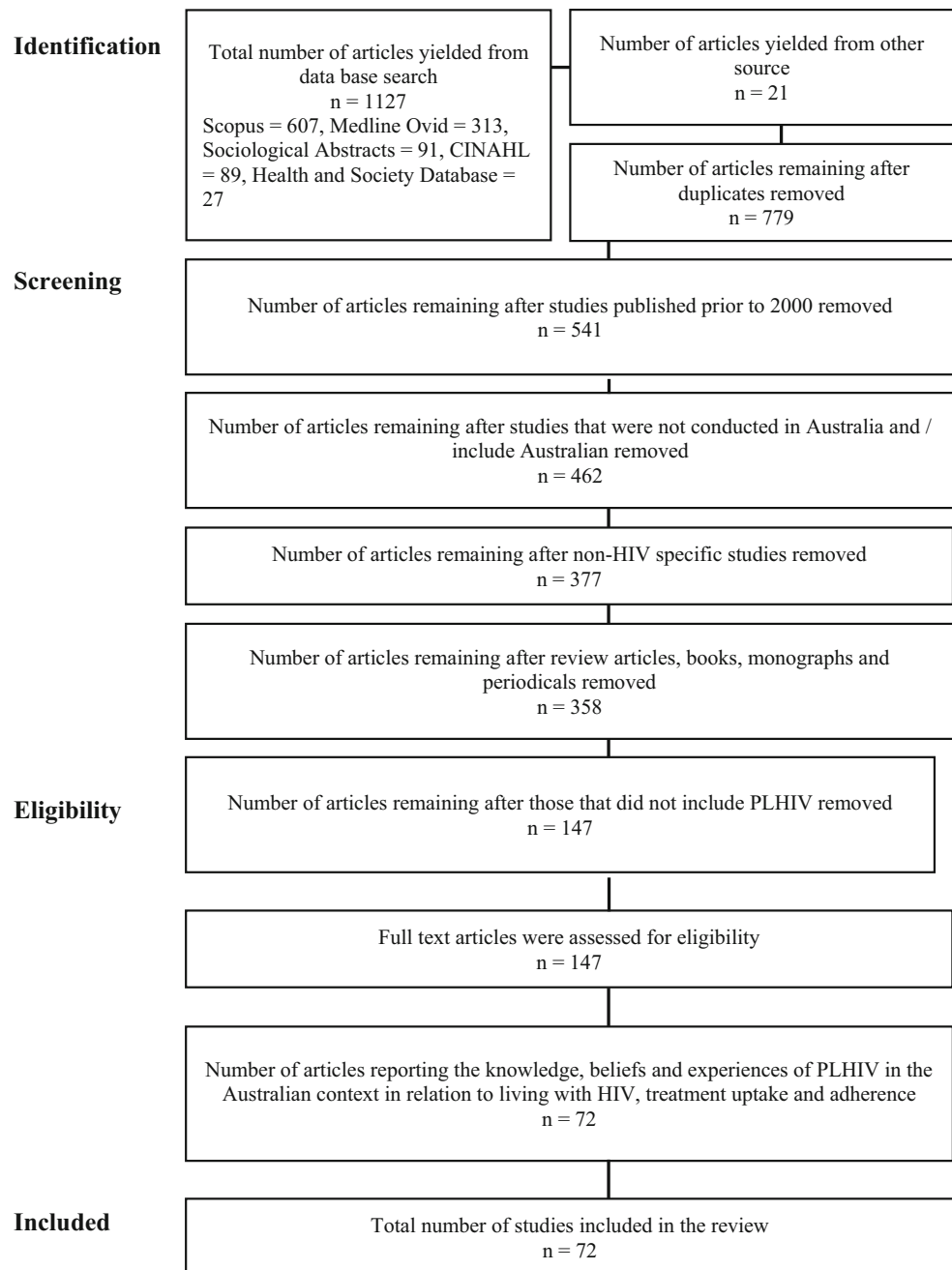| Types of mixed methods study component or primary studies	Methodological quality criteria	Authors' assessment		
		Yes 1	No 0	Not sure 0
Screening criteria				
1	Was the research question(s)/study objective(s) clearly defined?			
2	Did the data allow for the research question(s)/study objective (s) to be addressed?			
Quantitative descriptive				
1	Was the sampling strategy appropriate?			
2	Was the sample representative of the population?			
3	Was the tool(s)/measurement(s) used valid and reliable?			
4	Was the response rate acceptable?			
Quantitative non-randomised				
1	Was the recruitment strategy appropriate? (minimises selection bias)			
2	Was the tool(s)/measurement(s) used valid and reliable?			
3	Were the groups being compared similar?			
4	Were there complete outcome data			
Quantitative randomised controlled trials				
1	Was there a clear description of the randomisation process?			
2	Was there a clear description of the allocation of concealment?			
3	Were there complete outcome data?			
4	Was the drop-out rate $\leq$ 20%?			
Qualitative				
1	Was the data source appropriate?			
2	Was the method of data analysis appropriate?			
3	Was appropriate consideration given to how findings relate to the context of the research setting?			
4	Was appropriate consideration given to potential researcher influence?			
Mixed methods				
1	Was mixed methods design appropriate for answering the research question(s)/study objective(s)?			
2	Were methodological criteria for both qualitative and quantitative studies met?			
3	Was the integration of qualitative and quantitative data appropriate for answering the research question(s)/study objective(s)			
4	Was appropriate consideration given to the limitations resulting from integration of qualitative and quantitative data?			
Total score		0–2	3–4	5–6
Methodological quality rating		Poor	Satisfactory	Good

offered that were lacking from the findings of the peer-reviewed studies.

Scope

Table 3 summarises the pool of research that has explored the perspectives of key population groups, including PLHIV in general [26–69], MSM and bisexual men [70–82], Aboriginal and Torres Strait Islander People [83–85], immigrants from high prevalence countries [86–91] and other under researched populations [92–98], with regards to treatment uptake, adherence, and living with HIV in the Australian context.

Apart from those involving PLHIV as a group (n = 42), studies involving MSM (n = 16) were most common. Participants ranged in age from 16 to over 65 years and were able to provide full informed consent. Consistent with the population profile of PLHIV in Australia, the majority

Fig. 1 Flow diagram of study screening

Identification

Total number of articles yielded from data base search
n = 1127
Scopus = 607, Medline Ovid = 313, Sociological Abstracts = 91, CINAHL = 89, Health and Society Database = 27

Number of articles yielded from other source
n = 21

Number of articles remaining after duplicates removed
n = 779

Screening

Number of articles remaining after studies published prior to 2000 removed
n = 541

Number of articles remaining after studies that were not conducted in Australia and / include Australian removed
n = 462

Number of articles remaining after non-HIV specific studies removed
n = 377

Number of articles remaining after review articles, books, monographs and periodicals removed
n = 358

Eligibility

Number of articles remaining after those that did not include PLHIV removed
n = 147

Full text articles were assessed for eligibility
n = 147

Number of articles reporting the knowledge, beliefs and experiences of PLHIV in the Australian context in relation to living with HIV, treatment uptake and adherence
n = 72

Included

Total number of studies included in the review
n = 72

were male, homosexually identified and had lived with HIV for at least 12 months. Participants' socioeconomic status were wide-ranging, even within key populations, and including people living below the poverty line through to individuals with high incomes.

Quantitative studies (n = 34) reported participants' demographics and socioeconomic status, used a range of psychometric tools (some of which have been previously validated) and dichotomous or multiple choice questions to assess the knowledge, attitudes and beliefs of PLHIV, and used statistical methods to investigate relationships between these as well as observed or self-reported behaviours [26–46, 60–63, 65, 68, 70–73, 79, 81, 98]. Narrative data derived from interviews, group discussions and open-ended questions (n = 30) were used to explore treatment decisions that were poorly explained by quantitative means [47–49, 51–55, 64, 66, 69, 74–78, 80, 82–87, 90–96]. These studies directed enquiries towards lived experience, exploring perceptions of the past, present and future to draw on themes that interplay in the decision making process and provide insights about the motivations and barriers to treatment uptake and adherence. Six studies

Table 3 Summary of included articles according to methodology

First author/year/aim(s)	Method/location/participants	Outcome	Key findings		Motivations/facilitators
			Barriers		
Quantitative studies					
1. Begley, K. (2008) To determine variables associated with non-adherence to ART	Self-administered survey Sydney (n = 179)	Treatment adherence	Regular use of more than one type of recreational drug significantly increases likelihood of non-adherence		Strong belief in adherence self-efficacy and perceived seriousness of HIV alongside having experienced an HIV-related illness significantly lessened likelihood of non-adherence
2. Brener, L. (2013) To assess perceptions of visibility, disclosure, health status and centrality	Self-administered online survey Australia (n = 697)	Beliefs about HIV	People experiencing visible symptoms perceived greater experience of stigma		Community attachment was associated with reducing negative impact of visible symptoms
3. Broom, J. (2011) To determine the prevalence of comorbidities among PLHIV	Retrospective study (review of patient records) Queensland (n = 180)	Living with HIV	High rate of comorbidities was associated with failure to attend scheduled clinic assessments		
4. de Visser, R. (2000) To identify patterns of therapy choice	Self-administered survey questionnaire Australia (n = 894)	Treatment uptake and adherence	68% of people taking ART reported experiencing side effects		Majority participants expressed a belief that alternative therapies can reduce the side effects of ART.
			Over 11% respondents used only CAM (and not ART) in the management of HIV		People who used ART either alone or in combination with CAM were more likely to rate their doctor as an important source of information
			Over 8% respondents did not use CAM or ART		People who used CAM (either in combination or alone) were more involved in their health management than those who did not use CAM
			Women had significantly less favourable attitudes towards ART than men		
5. de Visser L. (2002) To report of the prevalence of CAM use among people PLHIV	Self-administered survey Australia (n = 924)		High prevalence of CAM use among PLHIV—potential for drug interaction with ART		
6. Edmiston, N. (2015) To assess the prevalence of comorbidity among PLHIV	Retrospective cohort study Regional New South Wales (n = 189)	Living with HIV	Heavy burden of multi-morbidity among PLHIV (approximately 85% participants had at least one, some with up to an additional 6 health conditions).		
			Mental health issues and cardiovascular disease were most prevalent coexisting health conditions among respondents		
7. Fairly, C. (2003) To test impact of educational program on adherence	Randomised controlled trial (Wedged design) Melbourne (n = 43)	Treatment adherence			Improvement in self-reported adherence.

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
8. Fong, R. (2013) To identify factors associated with virological failure	Matched case–control retrospective analysis Victoria (n = 916)	Living with HIV	Treatment failure was associated with: history of alcohol consumption, smoking, AIDs diagnosis, history of and current hepatitis C infection, abnormal alanine aminotransferase, current protease inhibitor use, treatment experience, missed appointments and reported suboptimal adherence	
9. Gibbie, T. (2007) To explore relationships between depression, social support and adherence to ART	Survey questionnaire Melbourne (n = 80 PLHIV. n = 20 seronegative)	Living with HIV	Almost 30% PLHIV were non-adherent to their medication PLHIV significantly more likely to experience depression (correlated significantly with living situation and relationships). Being diagnosed with a current depressive episode was significantly correlated to recreational drug use	Social support may act as protection against depression
10. Giles, M. (2008) To report on the rate of uptake of recommended interventions to reduce mother-to-child transmission	Retrospective study: analysis of surveillance data Australia (n = 291)		Almost 1 in 4 women did not receive the recommended ART	
11. Gold, R. (2000) To identify reasoning behind decisions not to take up ART	Cross-sectional Australia (n = 270 PLHIV NOT taking ART)	Treatment uptake	Decision to take up ART negatively impacted by: Distrust of conventional medical approach, perceived difficulty in dealing with practical aspect of treatment demands, not wanting HIV to be central to life	Treatment need reassessed when necessity perceived.
12. Grierson, J. (2001) To evaluate changes in attitudes and behaviours over time	Longitudinal survey study Australia (T1 n = 925, T2 n = 924)	Treatment uptake and adherence	Decrease in proportion of PLHIV accessing ART attributed to unacceptable side effects and difficulties in managing treatment regimen	More positive attitudes towards treatment with increased numbers reporting they used longer timeframes when planning for the future.
13. Grierson, J. (2004) To demonstrate correlates of ART breaks	Cross-sectional Survey study Australia (n = 640)	Treatment adherence	Clinical breakers reported worse health than lifestyle and non-breakers Lifestyle breakers were younger than clinical breakers and non-breakers	

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
14. Grierson, J. (2005) To report on the health and wellbeing of PLHIV	Self-administered mail-back survey questionnaire Australia (n = 894)	Living with HIV	Clinical issues include: comorbidities, mental health problems, treatment failure	
			High rate of poverty reported among PLHIV	
			Approximately 40% respondents reported they had been discriminated against while accessing medical services as a result of their HIV positive status	
15. Grierson, J. (2007) To report on the health and wellbeing of PLHIV including community service utilisation and socioeconomic status	Self-administered mail-back survey Australia (n = 1059)		Over 30% of respondents reported a lack of information regarding the management of medication-related side effects to impact negatively on adherence	
			Only approximately 25% of respondents were in full-time employment	
16. Grierson, J. (2011) To demonstrate correlations between patient variables and adherence behaviour	Self-administered mail-back survey Australia (n = 867)		Alcohol and drug use, poor health, mental illness, high pill burden and experiencing discrimination were all found to negatively impact adherence	
17. Guy, R. (2013) To identify predictors of treatment interruption	Observational clinical cohort study Australia (n = 961)	Treatment adherence	Predictors of increased risk of treatment interruption include: initiating ART prior to 2006, male gender, HIV risk category MSM or o other/unknown exposure	Decreased risk of treatment interruption predicted by: co-infection with HPV and commencement of ART with TDF-FTC.
			Other factors identified to increase risk of treatment interruption include: poor/fair current health, mental health issues, alcohol/recreational drug use	
18. Herrmann, S. (2008) To evaluate adherence behaviour	Longitudinal intervention study— 6 months follow up Perth (n = 357)	Treatment adherence	55% respondents reported incomplete adherence over past month citing forgetfulness, unplanned circumstances, feeling ill/depressed/overwhelmed, difficulty in managing regimen and perceived toxicity/side effects	Older age was found to be the strongest predictor of adherence. Adherence rates improved over time post-intervention that incorporated multidisciplinary approach to care.

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
19. Herrmann, S. (2012) To determine level of alcohol, nicotine and other drugs among PLHIV and impact on treatment adherence	Self-administered survey Western Australia (n = 152 PLHIV completed alcohol and drug use survey n = 186 PLHIV completed nicotine use survey)	Treatment adherence	73% alcohol and drug use survey respondents reported consuming an average of 7 drinks per week 50% had engaged in sessional drinking Episodic drinkers were more common among people recently started on ART and associated with non-adherence Over 30% respondents used recreational drugs—most frequently amphetamine and benzodiazepines, with drug use reported more frequently among drinkers	82% of smokers expressed interest in smoking cessation.
20. Holt, M. (2013) To assess attitudes towards medicines, HIV treatments and ART-based prevention	Self-administered survey questionnaire Australia (n = 122 seropositive MSM)	Knowledge, attitudes, beliefs about treatment	Respondents understood the benefits of treatment but believed ART regimen to be too difficult to manage and were unconvinced about the preventative effects of treatment for onwards transmission	Both seropositive and seronegative men were supportive of ART being used for prophylaxis and access to PrEP being unrestricted
21. Hutton, V. (2013) To evaluate the impact of perceived stigma on wellbeing among PLHIV	Self-administered survey questionnaire (Multinational) Australia and USA (n = 128 PLHIV Australia, n = 146 PLHIV USA)	Living with HIV	Living with HIV in Australia was associated with a significantly lower level of reported subjective wellbeing Perceived stigma (from others) may negatively impact subjective wellbeing	
22. International collaboration on HIV optimism (2003) To assess attitudes towards treatment	Multi-country cross-sectional study Australia (n = 115 seropositive MSM in Australia, other countries not included in analysis)	Knowledge, attitudes and beliefs about treatment	Overall optimism low was (majority disagreed/strongly disagreed with statements: New HIV treatment will take the worry out of sex, If every HIV positive person took the new treatment, the AIDS epidemic would be over, People with an undetectable viral load don't need to worry so much about infecting others with HIV, HIV/AIDS is a less serious threat than it used to be because of new treatments)	
23. Knox, S. (2001) To assess changes in attitudes over time	Self-administered survey study Sydney (n = 3012 MSM approximately 30% PLHIV)	Knowledge, attitudes and beliefs about treatment	HIV positive men were more sceptical than other men about the ability of treatment to prevent transmission	PLHIV more likely to perceive treatment as protecting them from serious illness than seronegative men.

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings — Barriers	Motivations/facilitators
24. Koelmeyer, R. (2014) To explore associations of social determinants and health with self-rated health	Retrospective analysis of pooled data from Futures 5 and Futures 6 studies Australia (n = 1713)	Living with HIV	Experiencing discrimination was not found to be an independent predictor of the rating of health, which suggests that other social determinants make PLHIV more likely to experience discrimination	All social determinants of health other than ethnicity and region of residence were associated with reporting good–excellent health
25. Levy, R. (2004) To assess the effectiveness of multidisciplinary HIV adherence intervention	RTC 20 Week step-wedged technique Melbourne (n = 68)	Treatment adherence	Approximately 57% respondents reported ever forgetting to take their medication	Targeted educational intervention achieved significant positive outcomes in self-reported adherence behaviours but not in clinical measurements
26. McAllister, J. (2013) To evaluate the impact of financial stress on treatment adherence	Self-administered survey questionnaire Sydney (n = 335)	Treatment adherence	Almost 15% respondents reported they had delayed purchasing their medication and 9% reported they had stopped taking medications due to cost	
27. Murray, J. (2011) To investigate whether MSM not taking ART have contributed to increasing HIV diagnosis among this population group	Retrospective analysis of HIV diagnosis and death data from central registry	Treatment uptake	Findings suggest MSM living with HIV who decline treatment could be contributing to the increasing trend of diagnosis among the population group	
28. Pakenham, K. (2001) To explore the role of illness, resources and coping strategies	Survey questionnaire and structured interviews Australia (n = 114)	Living with HIV	Higher levels of perceived threat were found to be associated with poorer adjustment in all domains Reliance on passive, avoidant and emotion-focused coping were related to higher level of depression and distress	Higher levels of social support were related to better adjustment Reliance on problem-focused coping was associated with less depression
29. Skevington, S. (2010) The explore the role of social support in quality of life	Multinational cohort study Australia and other countries (n = 1281 PLHIV, n = 253 in Australia)	Living with HIV		Although social inclusion did not predict QOL, social inclusion was found to reduce barriers to accessing health and social services and also improved social support, both mechanisms subsequently improved QOL. Inclusion was found to enhance positive feelings, which improved perceived physical health
30. Sternhell, P. (2002) To evaluate the impact of psychiatric comorbidity on adherence	Self-administered survey Sydney (n = 79)	Treatment adherence	Non-treatment uptake associated with: psychiatric morbidity, scepticism about medication effectiveness and recent intravenous drug use	

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
31. Thorpe, R. (2008) To identify patterns of HIV service use according to gender	Cross-sectional national surveillance study Australia (n = 1000 each time)	Living with HIV	Stigma and discrimination from health professionals and health care providers were commonly reported e.g. in 2001, 58.1% women and 35.9% men reported they had experienced discrimination from health professionals/health care providers	
32. Van de Ven, P. (2000) To assess attitudes towards HIV treatment	Survey study Australia (n = 532 MSM, 81 of whom were seropositive)	Treatment uptake and adherence	High level of scepticism about treatment effectiveness expressed by participants	
33. Wilson, K.(2004) To identify predictors of non-adherence to ART	Self-administered survey questionnaire Melbourne (n = 200)	Treatment adherence	Factors significantly associated with poor/ non-adherence included: poorly organised lifestyle, using large amounts of marijuana and low self-efficacy	Participants who reported 100% adherence had significantly lower viral load than those who had poor adherence
34. Zablotska, I. (2009) To identify barriers to service utilisation	Survey study Sydney (n = 270)	Living with HIV	Access to hospital pharmacy was reported to be limited by inadequate opening hours and negative attitudes of staff Access to social services was reported to be limited by poor service quality, attitudes of staff Access to dental and psychological services limited by cost	
Qualitative studies				
1. Bartos, M. (2010) To explore impact of treatment optimism on sexual behaviour and to explore options for supporting people who are non-adherent	In-depth interviews, thematic analysis Australia (n = 76: n = 63 male, n = 13 female)	Living with HIV	Treatment adherence dependent on evaluation of HIV as experience. Those who identified HIV as central held less positive beliefs about treatment and reported more frequent incidence of nonadherence	People who viewed HIV as an experience held positive views towards treatment and were more inclined to report being adherent to treatment
2. Down, I. (2014) To explore determinants of HIV treatment decisions among MSM who were recently diagnosed as HIV positive.	In-depth interviews, data analysed using thematic analysis constant comparison method. All states in Australia except Northern Territory (n = 53 male who self-identified as gay or bisexual and were recently diagnosed HIV positive). Age range 24-57 years old Mean age at diagnosis = 36.9 years Interviews took place between 2 weeks and 2 years post diagnosis	Treatment uptake and adherence	Majority of participants reported very little knowledge related to treatment at the time of diagnosis Decisions regarding treatment based on attempts to balance competing ideas about health, treatment and coming to terms with living with HIV	All participants who had not initiated treatment indicated their intention to start in the near future

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
3. Giles, M. (2009) To explore influences in decisions regarding interventions to reduce mother-to child transmission	Semi-structured interviews, preliminary analysis utilised principals of thematic (inductive approach) followed by constant comparison method. Final analysis informed by framework arising from works by Sandelowski and Barroso (2003) Melbourne The study explored the perspective of 45 women living with HIV (aged between 18 and 44 years) and reports on the interviews with n = 15 women who gave birth after being diagnosed Demographic information specific to the 15 participants were not reported Among the 15 women, 3 had HIV-infected children and two women were pregnant at the time of the interview Some of the women did not speak English and required the services of interpreters	Treatment uptake and adherence	Major concerns: potential side effects, toxicity, teratogenicity Acceptance of interventions accompanied by high degree of fear and guilt	Preventing infection from mother to child
4. Gold, R. (2001) To explore reasons for decision not to access ART	In-depth interviews, data were analysed using grounded theory. Melbourne and Sydney n = 20 seropositive MSM. One participant self-identified as Aboriginal, one was of South-East Asian, one was Southern European and the remaining 17 were Australian (White/Caucasian). Age range 22–49 years old The range of time the men had been living with HIV ranged from 1 to 16 years. Of those who provided information about their viral load and T cell counts, the range reported were between 3000 and 447,600 and 103 and 980 respectively A broad range of HIV related illnesses were observed among the participants	Treatment uptake	Fear of medication side effects based on experience (friends and personal) Fear of toxicity related to long-term side effects Treatment regimen considered inconvenient	

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
5. Herrmann, S. (2012) The explore the impact of visa status on PLHIV	Semi-structured interviews, thematic analysis. Western Australia n = 22 PLHIV (n = 10 female, n = 12 male) who were temporary Australian visa holders, not eligible for Medicare subsidised ART Ethnic origin East African n = 12 Asian n = 7 Oceania n = 2 Europe n = 1 Age range = 23–43 years old	Living with HIV	Believed treatment would be interrupted upon return to country of origin and feared impending death.	Strong belief in effectiveness of ART was motivation for staying on treatment. Social and spiritual support moderated experience of living with HIV.
6. Holt, M. (2006) To explore the experience of living with HIV	Focus groups and in-depth interviews, discourse analysis New South Wales n = 15 gay male Age range in years = mid 1920 to mid 1950 Time living with HIV = 1–15 years	Living with HIV	Spending time with those who are pessimistic was perceived to have a negative impact on ability to have a positive outlook on life. Having a personality where HIV could thrive was perceived to be characterised by: anger, complaining, seeing self as victim, having negative outlook on life.	Perception that survival is equally dependent of state of mind and medication. Maintaining optimism, refusing to give up even when faced with seeing others around fall. Self-affirmation and self-regulation focused on self-value seem to empower the person to change their views of the world and to increase their ability to cope with HIV and other stresses.
7. Holt, M. (2011) To explore the perspective of gay men about the 'gay community'	Semi-structured interviews, data analysed using grounded theory. Sydney Interviews conducted over 2 timeframes: T1 = 2006–2007 and T2 = 2007–2008 T1 n = 31, T2 n = 29 HIV positive T1 = 9, T2 = 8 n = 24 participated in both T1 and T2 interviews	Living with HIV	Risk taking behaviour associated with greater perception of belonging within gay community.	Perceived less need to belong to community for support due to greater acceptance of homosexuality in society.

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings — Barriers	Motivations/facilitators
8. Jenkin, P. (2006) The explore the experience and impact of fatigue among adults living with HIV	In-depth interviews, thematic analysis. South Australia n = 15 PLHIV > 1 year (n = 2 female, n = 13 male), experiencing fatigue Average time living with HIV = 13.8 years Age range 33–62 years old	Living with HIV	Interplay between physical, emotional and financial issues placed pressure on relationships as consequence of not being able to fulfil perceived partnership requirement.	Strategies to manage fatigue included: listening to body, keeping busy, using CAMs, pushing beyond current level of activity, and deliberate choices made with regards to energy expenditure.
9. Kelly, A. (2008) To present the perspective of people living with AIDS dementia	In-depth interviews, ethnographic method Melbourne (n = 3)	Living with HIV		Insights into perceptions of personal loss and attitudes towards death.
10. Korner, H. (2007) To explore the perspective migrant PLHIV were not Australian citizens	Semi-structured interviews, thematic analysis Sydney n = 29 PLHIV (n = 7 female, n = 22 male), born outside of Australia, 28 of whom were born in a non-English speaking country 3 participants had been diagnosed with HIV in their country of origin, the remainder were diagnosed in Australia 9 of the participants were awaiting decisions on appeal of initial rejections of their application for residency	Living with HIV	High levels of stress were reported to be associated with uncertainty about being able to stay in Australia. Non-disclosure and protection of 'secret' resulted in withdrawal from ethnic community and diminished social networks leading to isolation.	Felt less stigmatised by Australian society.
11. Korner, H. (2007) To explore the circumstances of diagnosis among migrant population and their knowledge of HIV	Semi-structured interviews, thematic analysis Sydney n = 29 (n = 22 men, n = 7 women) Age range 29–58 years old median = 39 years old. n = 28 were born overseas (majority were born in Asia)	Living with HIV	Diagnosis often due to presenting symptoms (therefore late in disease progression). Participants reported very poor knowledge of HIV, treatment and support networks.	
12. Korner, H. (2007) To explore the perspective of PLHIV about disclosure and their experiences when disclosing their status	Semi-structured interviews, thematic analysis Sydney n = 29 (n = 22 men, n = 7 women) Age range: 29–58 years old median = 39 years old	Living with HIV	High degree of stigma and discrimination experienced from family and the wider community leading to a sense of shame and isolation at a time when people left most vulnerable	

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
13. McDonald, K. (2010) To explore practices and attitudes towards CAM	Semi-structured interviews, grounded theory Melbourne (n = 9 PLHIV who differ from, contest and employ the discourses of western medical science). Time living with HIV: 2–18 years n = 4 CAM practitioners	Treatment uptake and adherence	Resistance to ART uptake and adherence was associated with perceptions of ART initiation as acceptance of impending death CAM perceived to be able to delay disease progression High perception of health despite negative clinical indications among CAM users	CAM perceived to focus on holistic health not illness
14. McDonald, K. (2011) To explore decisions about ART in preventing mother-to-child transmission	Semi-structured interview, constant comparison method and underpinned by understanding of narrative mode of thought. Victoria (n = 16 women who gave birth after being diagnosed with HIV, n = 15 age under 40 years old) n = 13 living with HIV between 1 and 9 years, n = 3 living with HIV or 10 or more years	Treatment uptake and adherence	Decision regarding ART was underpinned by desire to protect baby from harm. Accepting treatment was associated with worry for themselves or for their child. Rejecting treatment dominated by perception of ART to cause harm to baby Women reported their fears were generally dismissed by medical professionals	Embraced by women who had had children prior to era of HAART. Accepting treatment required medication to be reframed as contributing to ensuring HIV negative baby.
15. Munro, I. (2010) Explore the perspectives of men who are for other men living with HIV	In-depth interviews, thematic analysis. Victoria (n = 12)	Living with HIV	Carers, some of whom are also HIV positive, often feel isolated, stigmatised and discriminated against	
16. Newman, C. (2007) To identify barriers and incentives to treatment uptake among Aboriginal people	Semi-structured interviews Western Australia n = 20 Aboriginal people living with HIV (n = 16 female, n = 4 male) n = 9 were not taking ART	Treatment uptake	Fear of disclosure, fear of discrimination (as result of disclosure) negatively impacted on treatment uptake and adherence Alcohol consumption was commonly identified as the key element of risk that led to acquiring HIV	Pregnancy was a key motivator for treatment uptake for some of the women Health services that recognised individual needs in providing psychosocial and welfare support alongside ongoing medical care were highly valued
17. Newman, C. (2007) To explore the experiences of Aboriginal people living with HIV	Semi-structured interviews, discourse analysis Western Australia n = 20 (n = 16 female. n = 4 male) n = 9 not taking ART	Living with HIV		Believed that everyday experience of health and illness can be directly influenced by frame of mind Taking steps to improve health rather than thinking about the illness

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
18. Newman, C. (2015) To explore reasons for non-use of ART	Semi-structured interviews, thematic analysis. New South Wales (n = 27 PLHIV not using ART) Age range = 20–68 years old Mean age 43 years old Mean age at diagnosis = 34 years Time living with HIV ≤ 1–27 years Mean time living with HIV = 10 years Relationship status: n = 21 single, n = 6 partnered	Treatment uptake	Decision to delay treatment initiation include: insufficiently strong recommendation to do so from Dr, waiting until clinical evidence of need for treatment, perceived self to be elite in halting disease progression	Treatment perceive to be required only when the body can longer handle the virus without treatment Reducing infectiousness to protect others
19. Newman, C. (2015) To explore the perspectives of PLIV who are not taking ART about TasP	Semi-structured interviews, thematic analysis. Australia (n = 27)	Treatment uptake	Concerns regarding the benefits of TasP clearly reflected with the majority of participants expressing their right to make considered decisions regarding treatment over taking treatment for the good of the public in preventing transmission	
20. Paxton, S. (2002) To explore the experience of disclosure among PLHIV	Semi-structured interviews Victoria n = 75 PLHIV (n = 43 female, n = 32 male) from 20 countries (n = 31 Africa, n = 30 Asia Pacific, n = 14 Australia) Sample biased towards people who are in the public media.	Living with HIV	Feelings of shame, loss and worthless were commonly reported after learning about diagnosis Discrimination from health care providers commonly reported	Choosing to publically disclose HIV status described as frightening and confronting and required high motivation coupled with great strength in character Reasons for disclosure were related to: wanting to prevent infection to others, wanting to challenge AIDs-related stigma
21. Persson, A. (2003) To explore perceptions of health in context of living with HIV	Semi-structured interviews, linguistic analysis New South Wales n = 16 Anglo-European gay male living with HIV. Time living with HIV: 3–15 years. Some of the participants were HIV symptomatic prior to commencing treatment, the majority were asymptomatic	Living with HIV	Experiences of symptoms were compared with clinical indicators and used as a means of assessing health and to make treatment decisions	

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
22. Persson, A. (2005) To explore perceptions of self when experiencing body shape change	Semi-structured interviews published and grey literature, linguistic analysis Sydney (n = 23 PLHIV experiencing lipodystrophy) Time living with HIV: 10–20 years Majority participants were Anglo-Australian male, aged between late 1930s to mid 1950s living in or near inner city Sydney	Living with HIV	Symptoms presentation caused distress and generated fears around identification, stigma and undesirability	Comparing one's self to others and assessing self to be fortunate not to be exhibiting the same degree of symptoms
23. Persson, A. (2008) To explore perceptions related to diagnosis, prior knowledge of HIV, impact of HIV on daily life, stigma and disclosure, relationships and sex, family and social connectedness	In-depth interviews, semi-structured interviews, field work, published and grey literature—thematic analysis New South Wales Interviews: n = 46 (20 couples who had differing HIV status) Age range: 23–70 years old	Living with HIV	Privacy was fiercely guarded. Disclosure was usually limited to partners, immediate family and close friends	Compartmentalising (keeping status separate from other parts of life) was seen as a strategy for keeping depression at bay
24. Persson, A. (2010) To assess attitudes towards treatment	Cohort study. Semi-structured interviews, thematic analysis. New South Wales (n = 47 PLHIV, n = 27 in HIV-discordant relationships)	Knowledge, attitudes and beliefs about treatment	Respondents were reluctant to believe claims of Swiss statement in the absence of further evidence Participants expressed concerns regarding the negative impact of people acting on the advice of the Swiss statement should the information prove to be incorrect	General understanding that undetectable viral load made a partner less as opposed to non-infectious Majority were positive about potential to de-stigmatise people living with HIV
25. Persson, A. (2014) To explore the perspective of heterosexual women living with HIV about the person who infected them	Semi-structured interviews, thematic analysis. Australia (n = 13) Age range 23–65 years old, Time living with HIV: 10 months to 19 years	Living with HIV	Reluctant to seek prosecution due to fear of exposing family	Positive outlook on navigating life with HIV
26. Thompson, S. (2009) To explore the impact of alcohol use among Aboriginal Australians living with HIV	Semi-structured interviews, thematic analysis. Western Australia (n = 20: n = 16 female, n = 4 male) Age range: 22–54 years old Age range at time of diagnosis: 16–49 years, time living with HIV ranged from a few months to several years.	Living with HIV	Heavy alcohol intake was identified as a key factor in acquiring HIV with loss of control reported as central to exposure. Most did not recognise the need to maintain adherence and some reported they only drank when they were not taking their medication. Some tried to 'catch up' on dose(s) missed.	While many increased alcohol use in the transition period, there was a general move towards reduction in substance use (including tobacco) and better nutrition. This was seen as part of looking after themselves and reducing the impact of HIV.

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
27. Thorpe, R. (2008) To explore the experiences of PLHIV with integration of CAM and ART	Semi-structured interviews, thematic analysis. Victoria (n = 18: n = 6 female, n = 12 male) Age range: 33–65 years old Self-reported length of time living with HIV: 4–25 years	Living with HIV	Minimising side effects of ART was most common reason cited for CAM use. ART seen as 'chemicals' that are likely to have a negative impact on the body. CAM perceived as 'safe' in comparison. Desire for holistic health was not matched with participant's understanding (generally poor) of the philosophy of CAMs.	
28. Thorpe, R. (2009) To explore beliefs of PLHIV about the role of CAM	Semi-structured interviews, thematic analysis. Victoria (n = 18: n = 6 female, n = 12 male) Age range: 33–65 years old Time living with HIV: 4–25 years	Living with HIV	Use of CAM was seen to have the potential to de-medicalise HIV management by focusing on aspects of health other than those directly affect by the virus.	
29. Tsarenko, Y. (2011) To explore perceptions of identity among PLHIV	Semi-structured interviews Australia, thematic analysis. n = 15 PLHIV (n = 7 female, n = 8 male) n = 12 living with HIV 11–25 years n = 3 recently diagnosed < 2 years Age range: 33–60 years old Mean age: 45.3 years old	Living with HIV	Diagnosis generally described as shocking, traumatic and utterly devastating. Lack of knowledge (about treatment options and support networks) at the time of diagnosis influenced decisions.	
30. Willis, J. (2011) To explore personal accounts of living with HIV	Narrative, analytic auto-ethnography n = 1	Personal account of living with HIV	Viewed self to be toxic and struggled to come to terms with new identity as an infected person	Living life with hope offered by new treatments that have greater safety and efficacy profiles

Mixed methods studies

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
1. Chow, M. (2012) To explore experiences and identify unmet health services needs of PLHIV and people at risk of contracting HIV	Survey questionnaire in-depth interviews Sydney Phase 1: n = 166 Persons accessing HIV ambulatory services (n = 124 PLHIV) n = 149 male, n = 10 female, n = 1 transgender) Age range: 21–71 years old Phase 2: n = 22 (none participated in Phase 1) n = 1 female, n = 21 male Age range: 34–67 years old	Living with HIV	Identified lack of information for heterosexual noted by heterosexual participants. Majority of respondents reported they would stop attending the clinic if their confidentiality was breached.	Satisfaction with health professionals associated descriptions of health professional as friendly, caring and helpful
2. Cummins, D. (2004) To identify barriers to health care access and to explore the experiences women living with HIV	Self-administered survey questionnaire (closed and open-ended questions) Sydney (n = 33) Age: n = 22 <45 years old Had dependent children: n = 11	Living with HIV	Approximately 30% respondents reported not taking ART. Many lived in isolation, reported negative experiences and a lack of knowledge about local HIV support services.	
3. Ezzy, D. (2000) To explore concepts of illness and hope among PLHIV	Survey questionnaire, in-depth interviews Multisite Quantitative: n = 914 Qualitative: n = 46 (n = 8 female, n = 38 male) Age range: 27–62 years old Mean age: 40 years old Time living with HIV: 1–14 years	Living with HIV	Contradictions among some with regards to treatment adherence e.g. stopped taking medication when using recreational drugs. Difficulty in complying with dosage regimen was also commonly reported	Self-perceived inner strength credited for survival given change in life circumstance as a consequence of being infected with HIV
4. Goode, M. (2003) To identify adherence issues in children and adolescents receiving ART	Survey questionnaire administered via telephone Australia (n = 18 parents of children living with HIV) Age range children: 4–14.5 years old Mean age: 7.6 years old Mean duration of current medication regimen: 32 months	Treatment adherence	Unpleasant taste, difficult reconstitution procedures, demanding regimen requirements conflicting with daily routine, lack of information specific to children were all cited by parents as barriers to treatment adherence	Parents' beliefs about the benefits of therapy for themselves was not always aligned with their beliefs regarding the benefit for their children i.e. greater effort made to adhere to prescribed therapy for children even though self-adherence behaviour may be poor

Table 3 continued

First author/year/aim(s)	Method/location/participants	Outcome	Key findings	
			Barriers	Motivations/facilitators
5. McDonald, K. (2001) To assess attitudes towards ART	Self-administered survey study and semi-structured interviews Australia Quantitative: n = 925 (n = 84 female, n = 841 male) Age range: 17 to 72 years old Mean length of time living with HIV: Male = 6.0 years, Female = 7.7 years Qualitative: n = 76 (n = 13 female, n = 63 male) Age range 25–62 years Mean length of time living with HIV: Male = 8.3 years, Female = 4.8 years	Treatment uptake and adherence	Men expressed more favourable attitudes towards ART than women. Uncertainty about the potential effect of ART may explain lower treatment uptake among women Medication side effects identified as a major contributor to non-adherence	
6. Thomas, S. (2015) To identify practices, attitudes and beliefs about therapy and about CAM	Survey questionnaire, focus groups Quantitative: n = 151 Qualitative: n = 12	Attitudes and beliefs about treatment	High prevalence of CAM use with a lack of disclosure to GP	CAM use perceived as complementary to ART
Other studies				
Ayton, D. (2007) To explore the experiences of Cambodian-born PLHIV	Survey questionnaire and in-depth interviews Victoria (n = 8: n = 5 male, n = 3 female)	Living with HIV	Primary language Khmer, many did not speak English Majority reported they had not been provided with information about HIV or about support groups. None of the participants had accessed HIV support services in year prior to interview	
Wooley, I. (2012) To provide examples of treatment interruption as consequence of travel	Case reports Victoria (n = 3: n = 1 female, n = 2 male) Age range: 40–60 years old	Treatment adherence	Treatment interruptions may result from treatment non-available and/or differences in treatment preferences in that country. Treatment interruptions may subsequently result in treatment failure	

used both quantitative and qualitative tools to collect and analyse data from participants to further facilitate understanding of the perspectives of PLHIV [56–59, 67, 97]. In addition, one case report [88] and one letter to the editor [89] were included in the review as they offered insights about living with HIV that were not adequately reflected in the published studies. Findings from analyses of the studies are presented below according to the methodology used. The methodological quality ratings of the articles are presented on Table 4. Finding from the review process are summarised in the following sections according to the methods used.

Determinants of Uptake and Adherence Behaviour Identified by Quantitative Means

Quantitative studies are summarised below according to the intrapersonal domains assessed and correlations between these and treatment uptake and adherence behaviours.

Knowledge

Studies seeking to assess the knowledge of PLHIV (n = 5), explored aspects of care such as biomedical treatment [26],

Table 4 Methodological appraisal

First author/year	Screening criteria		Quality criteria				Total score	Methodological quality rating	Comments/potential source of bias
	1	2	1	2	3	4	Out of 6		
Quantitative studies									
Begley, K. (2008)	1	1	1	1	1	1	6	Good	Cross-sectional study, opportunistic sampling of participants attending clinical services may be biased towards those seeking health care and under estimate incidence of non-adherence among those not seeking health services
Brener, L.(2013)	1	1	1	1	1	1	6	Good	Wide spread dissemination of project information and ease of use of the survey instrument enabled the capturing of a large number of respondents limiting bias and improving generalisability of the research findings
Broom, J. (2011)	1	1	1	1	1	1	6	Good	Retrospective study using patient records minimises potential bias resulting from recall errors
De Visser, R.(2000)	1	1	1	1	1	1	6	Good	Multiple strategies used to recruit participants reduces potential of selection bias
De Visser, R.(2002)	1	1	1	1	1	1	6	Good	Multiple strategies used to recruit participants reduces potential risk of selection bias
Edmiston, N. (2015)	1	1	1	0	1	1	5	Good	Older participants may result in over-representation of those with higher rates of age-related co-morbidities
Fairly, C. (2003)	1	1	1	1	1	1	6	Good	Retrospective study. Data obtained from patient records could be biased towards those seeking health care
Fong, R, (2013)	1	1	1	0	1	1	5	Good	Data collected via tertiary care facility, which may produce higher rates of treatment failure than among true population
Gibbie, T. (2007)	1	1	1	1	1	1	6	Good	Used previously validated and reliable tools and multiple recruitment strategies thus reducing potential bias
Giles, M. (2008)	1	1	1	1	1	1	6	Good	Multiple strategies used to recruit participants. Included women from linguistically diverse backgrounds. No mention of how participants' understanding of the research question was assured. Reporting of adherence to recommended interventions could also be influenced by social desirability
Gold, R. (2000)	1	1	1	1	1	1	6	Good	The authors acknowledged difficulty in recruiting participants to the study. Potentially, the resulting data could be influenced by those who have stronger opinions regarding ART
Grierson, J. (2001)	1	1	1	1	1	1	6	Good	Large national study, multiple recruitment strategies used. Minimal potential for bias
Grierson, J. (2004)	1	1	1	1	1	1	6	Good	Interrogation of data from large national study using rigorous mathematical analytical methods. Minimal potential for bias

Table 4 continued

First author/year	Screening criteria		Quality criteria				Total score	Methodological quality rating	Comments/potential source of bias
	1	2	1	2	3	4	Out of 6		
Grierson, J. (2005)	1	1	1	1	1	1	6	Good	Interrogation of data from large national study using rigorous mathematical analytical methods. Minimal potential for bias
Grierson, J. (2007)	1	1	1	1	1	1	6	Good	Interrogation of data from large national study using rigorous mathematical analytical methods. Minimal potential for bias
Grierson, J. (2011)	1	1	1	1	1	1	6	Good	Interrogation of data from large national study using rigorous mathematical analytical methods. Minimal potential for bias
Guy, R. (2013)	1	1	1	1	1	1	6	Good	Large multinational study. Used validated and reliable tools. Minimal risk of bias
Herrmann, S. (2008)	1	1	1	1	1	1	6	Good	Large longitudinal study. Statistical rigour demonstrated. Minimal risk of bias
Herrmann, S. (2012)	1	1	1	1	0	1	6	Good	No mention of the de-identification of the completed survey. Potential under-reporting, particularly with regards to illicit drug use may result from concerns about the implications of disclosure
Holt, M. (2013)	1	1	1	1	1	1	6	Good	Purposive sampling of MSM, large national study, used validated attitudinal scales in additional to dichotomous questions. Minimal risk of bias
Hutton, V. (2013)	1	1	1	1	1	1	6	Good	Cross-sectional study, large number of participants, validated and reliable tools used. Minimal risk of bias
International collaboration on HIV optimism (2003)	1	1	1	1	1	1	6	Good	Large multinational study, used validated and reliable tools. Statistical rigour demonstrated. Minimal risk of bias
Knox, S. (2001)	1	1	1	1	1	1	6	Good	Large number of participants, used validated tools and dichotomous questions. However, participants were recruited from a single large city and may therefore, not be representative of PLHIV living in other cities or regions
Koelmeyer, R. (2014)	1	1	1	1	1	1	6	Good	Reported on data collected as part of a large longitudinal national study. Multiple strategies used to recruit participants. High degree of generalisability and minimal risk of bias
Levy, R. (2004)	1	1	1	1	1	1	6	Good	Randomised controlled trail (step-wedged design) to test effective of intervention. Used validated tools in addition to objective clinical measures. Minimal risk of bias
McAllister, J. (2013)	1	1	1	1	1	1	6	Good	Hover, participants recruited from hospital outpatient clinic may result in those biased towards seeking health care
Murray, J. (2011)	1	1	1	1	0	1	5	Good	Data obtained from national repository
Pakenham, K. (2001)	1	1	1	1	1	1	6	Good	Large sample size, validated and reliable tools used. Finding mapped to framework. Minimal risk of bias
Skevington, S. (2010)	1	1	1	1	1	1	6	Good	Large multinational study using validated and reliable tools and analysed using rigorous mathematical methods
Sternhell, P. (2002)	1	1	1	1	1	1	6	Good	Only English-speaking patients were eligible to participate in the study, which may reduce the generalisability of the findings as non-English speakers are also part of the population group that may have psychiatric morbidities, but not represented in the sample

Table 4 continued

First author/year	Screening criteria		Quality criteria				Total score	Methodological quality rating	Comments/potential source of bias
	1	2	1	2	3	4	Out of 6		
Thorpe, R. (2008)	1	1	1	1	1	1	6	Good	Data collected as part of a large national study. Minimal risk of bias
Van de Ven, P. (2000)	1	1	1	1	0	1	6	Good	Data collect as part of process of scale development
Wilson, K. (2004)	1	1	1	1	1	1	6	Good	Large number of participants, used validated and reliable tools. Opportunistic recruitment of participants attending a sexual health clinic could be biased toward those seeking health care and thus under represent population not adhering to therapy
Zablotska, I. (2009)	1	1	1	1	0	1	6	Good	Data collected as part of large national study. Minimal risk of bias
Qualitative studies									
Barton. M. (2010)	1	1	1	1	1	1	6	Good	
Down, I. (2014)	1	1	1	1	1	1	6	Good	
Giles, M. (2009)	1	1	1	1	1	1	6	Good	
Gold, R. (2001)	1	1	1	1	1	1	6	Good	
Herrmann, S. (2012)	1	1	1	1	1	1	6	Good	
Holt, M. (2006)	1	1	1	1	1	1	6	Good	
Holt, M. (2011)	1	1	1	1	1	1	6	Good	
Jenkin, P. (2006)	1	1	1	1	1	1	6	Good	
Kelly, A (2008)	1	1	1	1	1	1	6	Good	
Korner, H.(2007)	1	1	1	1	1	1	6	Good	
Korner, H. (2007)	1	1	1	1	1	1	6	Good	
Korner, H (2007)	1	1	1	1	1	1	6	Good	
McDonald, K. (2010)	1	1	1	1	1	1	6	Good	
McDonald, K. (2011)	1	1	1	1	1	1	6	Good	
Munro, I (2010)	1	1	1	1	1	1	6	Good	
Newman, C. (2007)	1	1	1	1	1	1	6	Good	
Newman, C. (2007)	1	1	1	0	1	1	5	Good	
Newman, C. (2015)	1	1	1	1	1	1	6	Good	
Newman, C. (2015)	1	1	1	1	1	1	6	Good	
Paxton, S. (2002)	1	1	1	0	1	1	5	Good	
Persson, A. (2003)	1	1	1	1	1	1	6	Good	
Persson, A. (2005)	1	1	1	1	1	1	6	Good	
Persson, A. (2008)	1	1	1	1	1	1	6	Good	
Persson, A. (2010)	1	1	1	1	1	1	6	Good	
Persson, A. (2014)	1	1	1	1	1	1	6	Good	
Thompson, S. (2009)	1	1	1	1	1	1	6	Good	
Thorpe, R. (2008)	1	1	1	1	1	1	6	Good	
Thorpe, R. (2009)	1	1	1	1	1	1	6	Good	
Tsarenko, Y. (2011)	1	1	1	1	1	1	6	Good	
Willis, J. (2011)	1	1	1	1	1	1	6	Good	
Mixed methods studies									
Chow, M. (2012)	1	1	1	1	1	1	6	Good	
Cummins, D (2004)	1	1	1	1	1	1	6	Good	
Ezzy, D (2000)	1	1	1	1	1	1	6	Good	
Goode, M. (2003	1	1	1	1	0	0	4	Satisfactory	

Table 4 continued

First author/year	Screening criteria		Quality criteria				Total score	Methodological quality rating	Comments/potential source of bias
	1	2	1	2	3	4	Out of 6		
McDonald, K. (2001)	1	1	1	1	1	0	5	Good	
Thomas, S. (2007)	1	1	1	1	0	0	4	Satisfactory	
Zablotska, I. (2009)	1	1	1	1	1	1	6	Good	
Other									
Ayton, D. (2007)	1	1	1	0	0	0	3	Satisfactory	
Wooley, I.(2012)	1	0	1	0	0	0	2	Poor	

information recall [57], disease state [43], and social support services [35, 97]. Methods of assessment mainly required participants to answer Yes/No or to indicate True/False to statements describing aspects of the items being assessed. One study reported that among PLHIV, information regarding ART and the management of HIV were most commonly accessed through general practitioners and HIV specialists, while information about living with HIV was obtained from community support organisations and HIV-positive friends [35]. Overall, these studies highlight that knowledge of support services among PLHIV was poor. Information and support were important in both treatment uptake and adherence decisions, as reflected by participants' narratives in the section to follow.

Attitudes and Beliefs

The attitudes and beliefs of PLHIV (n = 10) were generally assessed using validated tools, many of which were Likert-type items that required participants to rate their level of agreement with statements depicting the nature of the disease prognosis and aspects of HIV management such as the role of ART, the effectiveness of ART, and the benefits and risks of using ART [26, 28, 33, 34, 58, 70, 79]. While the majority of studies reported that PLHIV believed ART to be effective in suppressing viral replication, that treatment should be initiated early and supported the use of treatment as prevention, they were highly sceptical about the effectiveness of ART in being able to reduce viral transmission and were highly concerned about long-term consequences of ART. Specifically, participants expressed strong beliefs that the long term side effects of ART were not fully understood and/or disclosed, or both, by the medical profession and the pharmaceutical industry. Conversely, there was strong belief among PLHIV regarding the effectiveness of a range of complementary and alternative medicines (CAMs) such as herbal remedies and acupuncture in buffering the negative side effects of ART and restoring health [28, 54, 59, 68]. Conflicting attitudes

and beliefs appeared to compound the traumatic impact of diagnosis, influence decisions regarding treatment and adherence, and complicate navigation of living with HIV.

Experience

Validated tools were also used to gather information about participants' lived experiences (n = 17), which include experience of stigma and discrimination, medication side effects, living with co-existing illness, and social and economic bearing of living with HIV that subsequently impacted on treatment uptake and adherence behaviour [26, 28, 32–34, 37–44, 46, 57, 72, 73]. These studies revealed that the vast majority of PLHIV had been subjected to stigma and discrimination from multiple sources including health care providers when accessing health and support services as a result of disclosure, live with a number of co-morbidities requiring multiple medication, had experienced a high degree of intolerable medication-related side effects, lived with a range of physical, emotional and financial challenges, were engaged in a range of negative social behaviours (such as alcohol and other substance use), and were not always adherent with treatment recommendations. These experiences had a range of negative consequences on treatment uptake and adherence as discussed below.

Correlates of Behaviour

Studies revealed that a lack of knowledge, scepticism about the effectiveness of ART, high levels of fear about medication side effects (both experienced and perceived) and substance use (alcohol and drugs), were negatively correlated with both treatment uptake and adherence [32, 33, 43, 58]. Indeed, two studies found fear of medication side effects to be the most commonly reported barrier among participants and demonstrated it to be an independent factor contributing to decisions not to access ART [31, 32]. Other studies found that uncertainties about

the long term effects of the medication [58], as well as a lack of belief in treatment efficacy and a distrust of biomedicines related to questions about the integrity of information sources, particularly those provided by pharmaceutical companies [28], were also correlated with delay/refusal of treatment.

Intolerable side effects, difficulties in managing the treatment regimen, concurrent use of alcohol and other drugs, a high burden of chronic co-morbidities, and difficulties in meeting medication related costs were found to be associated with poor adherence [33, 37, 57]. For example, one study found approximately 85% of PLHIV had at least one co-existing illness and some had up to six additional health conditions [29], while another study reported 52% of respondents were taking prescribed medications in addition to ART [35]. The burden of managing these co-morbidities is considerable with one study reporting that approximately 50% of PLHIV had a pill burden of greater than 10 per day [97]. The prevalence of economic disadvantage with subsequent dependency on government benefits as the main source of income is also high [31, 33, 35]. In a study to explore the impact of medication cost on ART uptake and adherence behaviour, almost 15% of participants reported they had delayed purchasing their medication and 9% reported that they had ceased taking their medication, because they were unable to meet the required costs [40]. During treatment interruption, viral load was demonstrated to rebound to levels comparable to those measured prior to treatment initiation [36]. Another study found that people who had a history of smoking and excessive alcohol consumption had a higher rate of treatment failure than non-smokers and those who consumed no alcohol [30].

In addition to medication-related barriers, the majority of PLHIV reported having received services delivered with stigmatising and prejudicial undertones from health professionals and health care workers when accessing health and social support services [35, 44, 72, 73]. Furthermore, self-stigmatising attitudes and beliefs appeared to heighten the vulnerability of PLHIV to anxiety, stress and depression and to impact negatively on health seeking behaviours, resulting in reduced physical and psychological health, social isolation and quality of life [27, 35].

The studies also identified a range of practices that resulted in suboptimal adherence, which appear to be underpinned by attitudes and beliefs about detrimental long-term effects of ART [34, 38]. For example, one study reported non-adherence to be a deliberate decision to break from treatment in order to spend time away from medication, participants citing reasons to be based on lifestyle or clinical indications [34]. A break from treatment was perceived to enable the body to recover from the negative consequences of taking ART. This study also demonstrated

those who took breaks citing lifestyle reasons were more likely to report recreational drug use. Indeed, a number of studies have demonstrated concurrent use of alcohol and other drugs to increase non-adherence [30, 36, 38, 97]. In a study involving PLHIV who were non-adherent, 60% reported they sometimes simply "forgot" to take their medication, 25% reported that they sometimes did not take their medication when they were feeling unwell and 11% reported that sometimes they did not take their medication when they were feeling better [65]. These behaviours may also be underpinned by negative attitudes and beliefs and inaccurate knowledge about ART, as well as psychosocial and psychological issues. Willingness to access ART and to adhere to treatment were shown to be higher among those who feared transmitting the infection to their partners. Treatment adherence was shown to improve after a targeted intervention to improve medication specific knowledge and provided practical assistance in managing the treatment regimen, including the provision of unit dose packaging and reminder text messages [60].

Insights Gained from Qualitative and Mixed Methods Studies

Qualitative studies revealed a complex network of interrelated themes centred on emotional and physical challenges that intertwine with hopes and dreams to motivate a person, or to prevent them from optimising their treatment uptake and adherence behaviours [47–49, 51–55, 64, 66, 74–78, 80, 82–87, 90–96]. Being diagnosed as HIV positive was generally described as "shocking", "traumatic" and "utterly devastating" and the point at which participants' perceptions of the world were permanently changed. For some, diagnosis meant an end to a life that once held so much promise. For others, it was the undoing of roadmaps at a time when directions for a better life were starting to unfold. For a small minority, diagnosis was thought to be inevitable, given their involvement in high risk behaviours. Nonetheless, the impact of a positive diagnosis often manifested as sadness and distress caused by fears of impending death, fears of potentially having caused harm to others, fears of being judged and rejected, as well as fears of perceived harmful consequences of a life-long reliance on medication. While some spoke of religious faith and faith in the effectiveness of modern medicine, living with the knowledge that they were infected was, at the very least, extremely difficult [27, 48, 49, 52, 54, 55, 66, 75, 80, 82, 86, 97]. Many revealed that they had very little knowledge related to treatment at the time of diagnosis [55, 80, 86, 95], and spoke of treatment uptake and adherence in the context of attempting to balance competing ideas about illness and health, and trying to come to terms with living with HIV [64, 74, 83, 93]. Irrespective of their background or how they came to be infected, these

narratives spoke loudly of the interplay of feelings of fear in relation to stigma and discrimination, the known and unknown impact of treatment, the role of ART in the management of their health and of their enduring hope for a "normal" future [52, 54, 77, 83, 86, 92].

Fear of Stigma and Discrimination

Stigma and discrimination were commonly reported, to varying degrees, from a variety of sources including family, health care providers and participants themselves [51, 52, 76, 77, 80, 82, 83, 86, 89, 90, 92, 93]. These experiences impacted on the way people perceived themselves, their decisions about disclosure and, subsequently, their treatment uptake and adherence. In a study among MSM, participants spoke of the importance of image, where diagnosis served to change one's status from being healthy and desirable, to unhealthy and undesirable [76]. The fear of being viewed as undesirable and rejected were echoed loudly, particularly among the young and newly diagnosed. Another study among MSM reported that for men who were not in established relationships, decisions about disclosure weighed heavily given that both disclosure and non-disclosure could be seen as having equally devastating impacts [80]. For those in established relationships, serodiscordancy compounded fears of rejection if a partner chose to end the relationship and of self-loathing related to perceptions of one's own infectiousness and the potential for being a source of harm to the person they loved should the relationship endure.

Studies among migrant populations suggest the fear of being stigmatised following diagnosis appeared to be grounded in cultural beliefs that link the infected person with sexual and moral deviance [86, 89, 90]. These fears were compounded by their own experience of seeing the infected people as being subject to stigmatising, discriminatory and prejudicial behaviours such as people's reluctance to share eating and drinking utensils, as well as being insulted and called derogatory names. Among those whose citizenship status in Australia was uncertain, fear of deportation and impending death due to discontinuation of treatment and other mental health issues such as anxiety and post-traumatic stress, compounded the emotional turmoil of diagnosis [86]. High levels of anxiety associated with fears of having unknowingly transmitting the infections to others, particularly children, were also widely held, given that members of this group are often diagnosed late [92, 97, 99]. In a study involving Aboriginal and Torres Strait Islander peoples, participants revealed that they feared being found to have the medication, which would result in unwanted disclosure and subsequent negative labelling and rejection by their community [83, 90]. In a study involving heterosexual men, diagnosis and subsequent disclosure was associated with a fear of being incorrectly identified as gay [100].

Participant narratives provide valuable insights into how stigma, both perceived and experienced, was navigated by people living with the infection. For example, in the study involving Aboriginal and Torres Strait Islander people, fear of unwanted disclosure, which was a common occurrence, was associated with being in possession of medication and a lack of privacy for medication storage and administration [83]. Some participants felt forced to resort to hiding medication from others in the household. For others, this fear prevented them from accessing treatment altogether. Among migrant populations, there were widely held beliefs of needing to conceal a positive status in order to avoid stigma associated with the disease. In addition, language difficulties and unfamiliarity with the health and social service systems presented further barriers to accessing care [86, 89]. Ultimately, some did not access care, including treatment, despite a desire to do so. Among heterosexual men, the effort to avoid being labelled as gay prompted some to take measures to ensure non-disclosure, including delaying or rejecting treatment [100].

Living with HIV also had a range of physical impacts, which served to bear further on experiences of stigma and discrimination [48, 78]. For example in a study of PLHIV who were experiencing extreme fatigue, participants reported additional pressure was placed on their relationships as a consequence of not being able to fulfil household duties such as cooking, and cleaning. Fatigue also negatively impacted on their ability to fulfil their employment obligations and ignited fears that having to take frequent breaks would cause suspicion and/or disclosure of their HIV status to colleagues [48]. This was further exacerbated by frustration related to a perceived lack of understanding by health workers, who reportedly misdiagnosed the condition as depression. Not being able to contribute fully and de-validation of the depth of suffering served to undermine feelings of self-reliance and negatively impacted on assessment of self-worth. Consequently, there was a tendency to withdraw from social and employment relationships that further compounded the feelings of worthlessness, self-stigma and isolation.

Fear of Medication Side Effects

Alongside fears about stigma and discrimination, participants expressed a high level of concern about side effects of treatment that was further compounded by a lack of medication-specific knowledge [51, 69, 74, 80, 92, 93]. Different population groups expressed fears about different aspects of medication side effects. For example, one study involving MSM reported a fear of diarrhoea and vomiting,

a known side effect of some early ART regimens, to be associated with an image of being "dirty" and "soiled" [80]. This resulted in greater weighting being placed on quality of life without medication than increased longevity offered by treatment. In comparison, among women taking ART for prevention of vertical transmission, fears were directed towards the potential toxicity of the medication to the developing baby [92, 93, 97]. While the majority accepted treatment, the negative impact of their decision was evident in their narratives. For some, adherence to treatment recommendations diverged from their cultural and societal expectations. This divergence was perceived as discrediting them as mothers and some elements, such as avoiding breastfeeding, were in conflict with own beliefs and desires. Consequently, acceptance of these practices carried the risk of unwanted disclosure, with subsequent stigma and discrimination within their communities. A number of women reported they were forced to develop alternative stories to justify accepting treatment. The narratives of these women indicated they experienced fear, guilt and disappointment, and were frustrated at not feeling listened to by health professionals who were seen to be solely focused on treatment according to established guidelines. This is not to detract from the fear experienced by MSM, many of whom had seen friends and loved ones experience toxic effects of early treatments and held strong beliefs that not all long-term effects of current therapy are known or are not being disclosed [80]. Scepticism about reports of reduced infectivity after absolute life-long adherence was cited by some who argued that there was insufficient evidence to warrant beginning treatment [32, 80].

These studies provide valuable insights about the influences that impact on decisions regarding disclosure, treatment uptake and treatment adherence, highlighting the heavy toll of fears, as well as the tendency of some PLHIV to disconnect from social and personal relationships as a means of protection from these fears. These studies also convey the ongoing uncertainty that some individuals live with in relation to both known and unknown side effects as a result of accessing treatment.

The Role of ART

Decisions regarding treatment uptake and adherence are complex and multifaceted. They appear to be influenced by an individual's beliefs about the effectiveness of ART, as well how they view themselves in relation to the disease [32, 49, 51, 58, 74, 79, 80, 84, 93]. For the majority of participants, ART was perceived as integral to managing life with HIV. Beliefs that ART was effective in suppressing viral replication (and thereby restoring health), reducing infectiousness and preventing infection to others

underpinned decisions to start treatment. However, some viewed treatment uptake as conceding or surrendering control to HIV [41, 51, 74, 80, 92, 93]. Fears appeared centred on perceptions that ART could diminish one's sense of health and wellbeing due to concerns about intolerable side effects as well as anxiety about potential for harmful effects yet unknown [51]. That is, medication side effects might limit respondents' capacity to fulfil their parental duties and employment and social obligations as well as cause long term damage to their body. Some believed their current experience of wellbeing was due in part, to their decision to decline treatment thereby allowing their immune system to do battle with the virus as nature had intended. Personal qualities such as inner strength and self-awareness were perceived by some to enable them to be in-tune with their own body. For these people, HIV was seen only as a potential issue that did not have to be acknowledged or addressed until treatment became "necessary" [74]. Others appeared to have felt pride in resisting treatment. A sense of satisfaction was reported in being able to maintain clinical markers within "healthy" range independent of medication, and respondents were committed to maintaining health through lifestyle measures such as diet, exercise and the use of complementary and alternative therapies [80]. Among these participants, treatment was commonly reserved for a time when they perceived that their body could no longer handle the virus on its own.

Along similar lines, accepting treatment was seen to impact negatively on morale and, consequently, on respondents' ability to maintain good physical and mental health [74]. Being chained to a life-long commitment to the treatment regimen was assessed by some to be unmanageable given their personalities and personal circumstances [80]. Some assessed treatment as low priority when other concerns, such as managing family or attending to a sick partner, demanded their immediate attention [51]. Furthermore, negative emotions evoked by the physical act of taking medication served as constant reminders that participants had the infection and needed to rely on medication for the rest of their lives [32]. Therefore, treatment uptake was perceived as conceding to the virus and relinquishing power over current ways of life. These participants also expressed preference for allowing their own immune system to adjust to, and resist, HIV.

Others reported lacking the level of knowledge required for making treatment decisions and expressed a reluctance to become more knowledgeable due, in part, to feelings of being already overwhelmed by learning that they are HIV positive and by day to day issues of living with HIV [51, 80]. These individuals perceived doctors to possess expert knowledge and expressed a wish for their doctors to lead treatment decisions. Insufficiently strong

recommendation from doctor was provided as an explanation for their decision to delay or reject treatment. With heightened fears of medication side effects as previously discussed, some simply chose to delay treatment until improved options with better safety and tolerability profiles became available. Some who were asymptomatic, expressed a wish not to suffer side effects unnecessarily, given their current perception of good health [74]. Some also perceived themselves to be genetically superior in their ability to fight the virus and believed they would avoid the need for ART altogether, while others were waiting until they observed clinical evidence indicating a need to start treatment [51].

Further insights into individual views about the role of ART were demonstrated in their narratives regarding the role of CAM in the management of HIV [28, 49, 53, 54, 59]. Some participants expressed a belief that ART were chemicals with toxic effects and their use in the management of HIV was unduly influenced by pharmaceutical companies who had questionable motives [49, 51]. In contrast, they believed CAM to encourage holistic healing through embracing the mind and body connection, thereby encouraging physical, emotional and psychological health [49]. Thus, while ART initiation was seen as admission of impending death, CAM was viewed as being able to strengthen the body's ability to overcome the virus, thereby delaying disease progression. Perceptions of ART as a daunting imposition on day to day life and with the threat of viral resistance still looming in the background despite these efforts, provided some with further disincentive for use. These perceptions appear to have been formed by experiences seeing health professionals evaluate ART success as being the absence of symptoms, low viral load and favourable CD4 counts, with perceived disregard for how an individual might see their situation, health, or quality of life. Reinforced by their experiences of "quick transaction" type relationships with health professionals compared with their often enduring relationship with CAM practitioners, such as massage therapists, acupuncturists and naturopaths, these factors gave rise to perceptions of conventional approaches to HIV management as *dehumanising*, focusing on the virus and not the person. In addition, there was strong belief in the effectiveness of CAM as a means of negating a range of perceived negative side effects of ART [28]. Furthermore, the effectiveness of CAM appeared to be assessed not according to its ability to treat the virus, but rather in its ability to nurture the body and mind to enable it to fight the virus [49]. This is particularly evident in narratives that highlight perception of health among PLHIV whose objective clinical markers indicated otherwise. These perceptions facilitate understanding of the high prevalence of CAM use among PLHIV, and may provide an explanation for why some people choose to reject ART and use only CAM.

Narratives describing treatment adherence tell of the interplay between perceptions of an unmanageable treatment burden, such as the relentless demands of the treatment regimen, intolerable medication side effects (both experienced and perceived), and the impact of emotional, psychological and social issues such as isolation, depression and alcohol and other substance use [49, 58, 74, 80, 92, 93, 101]. While life before HIV diagnosis was remembered by some as the 'good times', there was also underlying belief that risk-taking behaviours may have paved the way to becoming infected [85, 96]. For example, in a study involving Aboriginal and Torres Strait Islander People, the use of alcohol and other substances was identified as a key factor in acquiring HIV, with a sense of loss of control being central to exposure [85]. However, while alcohol and other drugs continued to be used, most acknowledged that the substances provided only temporary comfort, did not solve their problems, and in some cases, made the situation worse. Denial was also commonly expressed as a means for stopping the experience of living with HIV from being overwhelming and to becoming the central focus of identity.

In the difficult times following diagnosis, many relate their risk-taking behaviours to subsequent non-adherence [75, 85]. For example, some reported stopping medication when using recreational drugs and when drinking heavily. Behaviour that resulted in non-adherence also appeared to be linked to their perceptions about adherence. For example, one participant argued that they maintained adherence by reconciling doses missed during periods of heavy drinking with 'catch up' doses afterwards [85]. Another participant omitted doses in order to 'save' them for continuation of therapy should the person subsequently face deportation [86]. Parents administering ART to their children identified difficulty in managing the treatment regimen, inability to prepare the medication according to mixing instructions, the unfavourable taste of the medicine and fear of long-term side effects as resulting in omission of doses, thereby impacting on therapy [57].

Treatment delays or rejection, denial, alcohol and other substance use were commonly reported among PLHIV as means of coping with the stresses of life with HIV that further compounded health, financial and social problems. However, despite these beliefs and behaviours, the majority expressed stronger fears about the consequences of remaining untreated. Furthermore, and in contrast with the perceptions of ART previously discussed, some viewed treatment uptake as being proactive in taking control of their bodies and not allowing the virus to replicate unchecked, in addition to being a means of protecting others from the disease, and viewed ART as an intervention through which one can hope to live a *normal* life.

Hope for a Normal Future

Narratives following diagnosis that describe embracing a life with HIV suggest acceptance that although far from ideal, life was manageable and highlight the central role of ART in achieving this [48, 51, 55, 80, 83, 85–87, 92, 93, 101]. The desire to be treated 'like normal' was universal, along with an emphasis on taking personal control of life through self-care, both physical and emotional. Furthermore, a desire to live in combination with social and spiritual support appeared to buffer the experience of living with the illness, and to prompt behavioural change [51, 85, 86]. Narratives commonly told of attempts to live a normal life despite diagnosis by directing thinking towards the future. Desires were expressed in terms of commitment to fulfilling personal goals such as maintaining health, having a successful career and children. Self-care included steps individuals had taken towards improving their health through appropriate housing, improved nutrition, reducing alcohol intake and strengthening social and family connections, as well as to taking ART. The initiation of therapy was perceived not only to reduce their own viral load, with consequent improvement in health, but also to contribute to reducing the burden on the community.

Taking control for maintaining health through positive treatment uptake and treatment adherence behaviours were seen to encourage personal growth, possibly by drawing on inner strength [55, 85]. Indeed, self-perceived inner strength was credited for being able to overcome many barriers, given the negative changes in life circumstances as a consequence of being infected. For some, taking responsibility also meant self-regulation, including disengagement from social interactions that had encouraged risk-taking behaviours [85]. This perception of being able to take back control served to empower people to make further changes to improve their physical, emotional and psychological health.

The belief that everyday experiences of health and illness can be directly influenced by frame of mind was also prominent [83, 84]. Deliberate actions taken to overcome challenges imposed by HIV (such as fatigue and addressing fears such as disclosing status) were seen to contribute to an optimistic outlook, including being more focused on goals and having greater purpose in life [48, 80]. Maintaining optimism, self-affirmation and self-value empowered individuals to change their perspective and was seen as a means of defeating the negative impact of the disease. Hope for the future was seen as the pivotal point through which one chose to either be dying, or to be living with HIV.

Discussion

The Australian health system has recently implemented changes to the rules and regulations concerning the prescribing and dispensing of antiretroviral medication with the aim of improving treatment uptake and adherence through better access [102]. In addition, the licenced use and funding for PrEP is currently under consideration [103]. At this pivotal time, it is prudent to reflect on the voices of Australians living with HIV in order to identify their specific needs and the barriers that limit optimal care.

This review reveals that there are gaps between the services that are currently available and those necessary for optimal treatment for PLHIV, and that the burden of the disease is far reaching, with detrimental consequences to the individual beyond what can be attributed to the virus alone. The need for information about treatment and the availability of support organisations, particularly during the early stages after diagnosis was highlighted alongside the need for information to be disseminated across the broader community. Specifically, more resources for vulnerable groups such as pregnant women and migrants are needed. The wish for information (and services) to be delivered in a manner that is non-threatening and takes into consideration the individual's personal, cultural and religious beliefs has also been clearly expressed. Contextualised information regarding the side effects of medications and how to manage them is particularly lacking. Insufficient knowledge and subsequent fears related to side effects impacted negatively on both treatment uptake and adherence. In light of the new ARTs that have more favourable safety and tolerability profiles, contextualised information may be a means of encouraging both. When individuals received information and care in the absence of negative judgement, they were better able to make informed decisions and to maintain a sense of self-worth amid the emotional challenges, particularly soon after their diagnosis when their knowledge of disease management is low and they are particularly vulnerable. The need for health professionals to deliver individualised care without prejudice has been clearly highlighted.

Information and service delivery must also consider the needs of populations such as those who lack English proficiency and may lack the skills required for navigating the health system and social support networks. Consideration must also be given to the cost structure around medication, given the vast majority of PLHIV also live with co-morbidities, which impact on them emotionally, physically and financially and were identified to impose considerable hardship that resulted in suboptimal treatment uptake and adherence. Research should be directed towards identifying

the specific information and service needs among key population groups in order to develop information resources that address the areas of deficiency.

Stigma and discrimination were commonly perceived and experienced and impacted negatively on disclosure, treatment uptake and adherence. While arguably treatment uptake and adherence can be ultimately deemed to be the responsibility of the individual, it is clear from the narratives that stigma and discrimination are insidious and ingrained at the personal, health system and wider community levels, and manifest as major barriers to accessing care. Attempts to guard one's self from the impact of stigma and discrimination only served to isolate further people who are already vulnerable, thereby depriving them from what might have been their intended course of action in the absence of fear. Strategies that address the stigmatising attitudes and beliefs held about people who are infected are also needed. These strategies should target members of the health professions, support organisations and the community at large, as well as the individuals themselves since self-stigma also appears to be prevalent among PLHIV. The importance of connectedness within personal relationships and with the community, were clearly demonstrated to buffer the negative effects of living with HIV. Thus, strategies to reduce stigma and discrimination should also aim to engage PLHIV with the community at large and vice versa. These strategies must be informed by research that seeks to understand the underlying reasons, at both the individual and community level, for stigmatising attitudes and beliefs.

Strategies to address social issues such as harmful use of alcohol and other substances are required as a means of supporting medication uptake and adherence, as well as reducing risk taking behaviours that have been shown to have further negative impact the health of those who are infected and may put others at risk. As an example, research should focus on understanding the paradoxical relationship between participants' simultaneous willingness to use recreational drugs and reluctance to accept ART, especially when the former can be dangerous and the latter life-saving. Similarly, research should explore the perspectives of those who choose not to access ART, but choose instead CAM as a means of managing their health. These studies may provide insights valuable to understanding the determinants of decisions that extend beyond what is currently deemed rational in the realm of contemporary medicine. Furthermore, observational studies suggest a high prevalence of psychological, psychosocial and socioeconomic issues among PLHIV. It is also commonly reported that these issues have a negative impact on treatment uptake and adherence. What is lacking is research to determine how these variables interplay in the management of HIV.

Limitations

There are some limitations of this research and these are acknowledged. Firstly, only articles published in peer-reviewed journals were included in the review. It is possible that grey literature and unpublished works would offer further insights that may have enhanced understanding in this topic area. However, accessing these resources and attempting to validate the quality of such research would have been difficult and time consuming. Given that this review included quantitative, qualitative and mixed methods research, the regrettable exclusion of grey literature is justified. Secondly, quality assessment of the included studies utilised a relatively new tool that is largely untried. Furthermore, the tool assessed only the methodological quality and not the validity of study findings. However, the tool allowed a holistic approach to the quality appraisal process that promoted the utilisation of the researchers' skills and judgement in assessing the value of the contribution of each article to the knowledge pool. It provided flexibility for the inclusion of research that may have been imperfectly executed, but still offered valuable insights important to understanding the perspectives of people who live with HIV. Finally, the review included studies published between 2000 and 2015, some of which reported on data collected prior to the year 2000 and may therefore, relate to aspects of care and medication that are no longer in common use or have changed significantly. However, these studies provided understanding of the perspectives of PLHIV that may have been neglected in more modern studies. Thus, the inclusion of the earlier research is justified, though its current applicability must be considered in this light.

Conclusion

This study highlights how people attach different meanings to being HIV positive and to their personal identity, the role of ART, CAM and other substances in their lives, as well as the role of social and cultural communities in which they are embedded. The study sheds light on the impact of living with HIV on decisions regarding disclosure, treatment uptake and adherence. While the study provides clues, more research is needed to understand how these meanings are generated and how they give rise to rationales regarding HIV management. In addition, a review of studies focused on testing and risk taking behaviour is required to provide a holistic overview of the barriers and facilitators to the effective management of HIV in the Australian context.

Compliance with Ethical Standards

Conflict of interest The authors declare there are no existing or potential conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

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