

**Developing a model of the individual and social processes involved in
living with HIV and TB co-infection in UK migrants**

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1. Executive Summary

HIV overview

Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system using the body's CD4 defence cells (white blood cells) to replicate. At the same time, HIV destroys these same cells that protect the body from illness. This results in a weakened immune system and can lead to people living with HIV (PLWH) becoming more susceptible to infections (World Health Organization – WHO, 2017). Higher CD4 counts are associated with improved outcomes. Acquired Immunodeficiency Syndrome (AIDS) is the most advanced stage of HIV infection. AIDS describes a set of symptoms and illnesses that happen at the final stage of HIV infection when the immune system has been significantly weakened.

HIV can either be transmitted through unprotected sexual contact, sharing intravenous drug equipment, mother to child transmission during pregnancy, birth or breast-milk, or through contaminated blood transfusions (AIDS.gov, 2015). Whilst there is currently no cure for HIV, treatment consists of Antiretroviral Therapy (ART) which fights HIV by interfering with the reproduction of the virus in the body (WHO, 2017). HIV remains a major public health concern. In 2018, 37.9 million people globally were living with HIV with 1.8 million people newly diagnosed with HIV in that year (United Nations AIDS – UNAIDS, 2018). In 2017, 102,000 people were living with HIV in the UK with 4,363 people were newly diagnosed with HIV (Public Health England - PHE, 2018a). In 2019, The UK government set out a commitment to eliminate transmission of HIV in England by 2030 (Department of Health and Social Care - DHSC, 2019).

Systematic review

Over half the clinical events and deaths occurring among those on ART are “non-AIDS defining” (Palella et al., 2006). AIDS-defining refers to illnesses attributable to the 26 serious and life-threatening diseases (Centers for Disease Control and Prevention – CDC; Ward, Buehler, Jaffe, & Berkelman, 1992) that occur in PLWH with the advanced stage of HIV infection (i.e., Acquired Immunodeficiency Syndrome – AIDS). The most common chronic physical health comorbidities in PLWH include non-communicable diseases such as diabetes mellitus, cardiovascular disease, chronic obstructive pulmonary diseases (e.g., Crothers et al., 2006, Sudano et al., 2006); and communicable diseases such as hepatitis (Turner et al., 2010) and tuberculosis (TB; Bruchfeld, Correia-Neves & Källenius, 2015).

Different comorbid physical health conditions in PLWH are often linked to HIV infection and its associated risk factors, including adverse effects of certain antiretroviral medication (Goulet et al., 2007). These risk factors can negatively affect health outcomes. In addition, economic and social conditions can influence individual and group differences in health status (Marmot & Wilkinson, 2005) and can mean that individuals with comorbid chronic physical health conditions are more vulnerable to poorer health outcomes. Managing the psychological challenges of living with HIV alongside comorbid physical health conditions can be difficult.

The aim of the systematic review was to consider the experiences of those living with HIV and comorbid physical health conditions. A systematic synthesis of the relevant qualitative literature aimed to help provide an improved understanding of the current

evidence base, and inform the design of new interventions/strategies to help support individuals with HIV and comorbid health conditions; and allow for identification of existing research gaps.

Inclusion criteria comprised HIV-positive individuals ≥ 18 years with common physical and chronic/difficult to treat/incurable comorbid health conditions. Only qualitative studies were eligible. Studies in peer-reviewed journals were retrieved from Scopus, PsycINFO, PubMed, and the Networked Digital Library of Theses and Dissertations and search terms were searched for as key words in titles and abstracts. The author carried out the searches and both the author and a second reviewer independently assessed the eligibility of retrieved articles. Details including authors, date of publication, location, HIV-status, design, nature of sample, age, gender, ethnicity, country of origin, findings of psychological outcomes and themes were extracted. The methodological quality of the studies was evaluated using criteria for a qualitative design and was carried out independently by the author and a second reviewer. A narrative synthesis approach was used to identify and understand key findings from the included studies (Popay et al., 2006). Disagreements were resolved by a third reviewer for eligibility and quality.

Twenty-two studies were included in the analysis. Studies were published between 2007 and 2018. Seven studies were conducted in South Africa; six in the USA; two in Ethiopia; two in India; one in Ghana; one in Zambia; one in Ireland; one in Canada; and one in the UK. For qualitative studies, 13 findings were extracted and grouped into five categories – Management of HIV and comorbid physical health conditions,

Psychological outcomes of HIV and comorbid physical health conditions, Preferences for care, Stigma, and Disclosure. Quotes from the texts were compiled to illustrate these findings. Two studies met all the quality appraisal criteria.

The findings are similar to previous research which has explored difficulties surrounding management of HIV and physical health conditions, HIV-disclosure, the presence of HIV-stigma and psychological outcomes in various HIV-positive populations. Limitations included the search strategy where key terms were only searched for in titles and abstracts. A strength of the review process was the independent reviewing of eligible studies and study quality by independent reviewers. The systematic review suggests that experiences of living with HIV and comorbid physical health conditions interact and can have a negative impact on mental health. Further research into the anticipated and experienced HIV-stigma that individuals living with HIV and comorbid physical health conditions face would aid understanding of how stigma related to HIV and other physical health conditions emerge in this population.

Empirical project

Tuberculosis (TB) is an infectious disease and the leading preventable cause of death worldwide for people living with Human Immunodeficiency Virus (HIV). TB usually impacts the lungs, but TB-causing bacteria can attack any part of the body. An individual's immune system can respond to TB in a variety of ways: the bacteria may be cleared, the individual may develop active TB and become unwell, or the bacteria may remain as latent TB infection (LTBI). TB treatment typically entails taking antibiotics over several months.

In the last two decades, TB has re-emerged in the UK, linked to HIV infection and migratory phenomenon (Lönnroth et al., 2015). In 2018, there were 10 million new cases of TB worldwide (WHO, 2018), with 5,102 UK cases in 2017 (WHO, 2018). In England, the prevalence of HIV co-infection among TB patients is between 5-9% (Kruijshaar et al., 2010), with 80.1% of HIV/TB co-infected individuals being non-UK born (PHE, 2018b). Experiences of being a migrant may complicate adjustment to HIV/TB co-infection including immigration status, acculturation (i.e., the adoption of the values and behaviours of the surrounding culture) and discrimination (Bhugra, 2004). Prior findings from low income settings cannot be generalised to UK migrants as there are differences in socio-medical contexts. No research has focused on adjustment for migrants with HIV/TB co-infection in high income countries.

HIV and TB pose a number of adjustment challenges. Similarities and differences exist between HIV and TB: TB is curable, whereas HIV is not; both conditions are infectious with potential public health risks, but with different transmission routes; treatment for active TB can be more complicated and prone to side effects than HIV; both can remain latent/undetected for many years and require monitoring one's health to limit negative health effects (WHO, 2012).

A qualitative Grounded Theory design was used. Semi-structured interviews were carried out with nine migrants living in the UK (six males, three females, aged 33 – 63 years, mean time in the UK = 11 years, five participants from Sub-Saharan Africa, two from Europe, one from South Asia and another from South-east Asia. Ethics was

obtained from an NHS ethics committee and Royal Holloway's ethics committee.

Participants were recruited via two HIV-services across London. Inclusion criteria included foreign born, with adequate spoken English, who received an HIV-positive test in the last three months onwards; and TB diagnosis in the last three months to five years. Participants were only excluded if there was any evidence of significant risk of harm to self or others. Participants were given the Hospital Anxiety and Depression Scale to provide some context to the sample. Participants were paid £10 for their participation in the research.

The interviews were transcribed, coded and seven theoretical codes were identified; Migrating to the UK, Ideas of HIV and TB prior to receiving diagnoses, Accessing healthcare up to the point of receiving HIV and TB diagnoses, Experiences whilst accessing specialist HIV and TB care, Managing Disclosure of HIV and TB, Managing mental health after receiving HIV and TB diagnoses, Appraisal and coping with HIV and TB. A theoretical model individual and social processes of living with HIV/TB co-infection in UK migrants was developed outlining how the codes interact.

The findings are similar to previous research in HIV populations which has found high-levels of HIV-stigma and HIV-disclosure anxiety. TB was disclosed more frequently by participants compared to HIV and this was linked to beliefs about it being curable. Services could run audits to identify reasons for high levels of stigma and provide interventions to attenuate this. There appeared to have been delays to testing for HIV and TB that were both patient and health system related. Risk perception for HIV and TB was low amongst participants, and there were missed opportunities for HIV and TB

testing by healthcare professionals. Reflective groups facilitated by Clinical Psychologists could be promoted to support healthcare professionals to raise issues around this including identifying any difficulties adhering to National Institute for Health and Care Excellence - NICE, and British HIV Association - BHIVA guidelines around routine testing for HIV and testing for TB where relevant symptoms exist. Participants' experiences of healthcare professionals in specialist services were positive. In particular, many appreciated being provided with information regarding medication alongside health-related progress updates and this appeared to help improve coping.

Integration, impact and dissemination

The systematic review and the empirical piece guided and informed each other throughout each research stage. Both the systematic review and the empirical piece focused on the lived experiences of HIV positive individuals with comorbid physical health conditions. The systematic review focused on illness experiences; and the empirical piece focused on the social and individual processes of living with HIV and TB co-infection. Relevant factors included HIV and comorbid physical health condition stigma processes, disclosure, and coping/adjustment, in addition to managing mental health difficulties. Participants in the systematic review were located in low- and high-income countries. Participants in the empirical piece were from the UK which is a high-income setting. The age of participants varied: participants in the empirical piece aged from 33 to 63 years; whilst participants in the systematic review had a larger age range from 18 to 69 years of age.

The systematic review and the empirical piece found themes relating to HIV and comorbid physical health condition stigma, HIV and TB-related distress and the

negative impact HIV and TB diagnoses can have on anxiety and mood. They both also found themes relating to disclosure decisions, and include examples of participants' decisions to share or not share with others their HIV and comorbid health condition statuses. Issues of coping and living with HIV and comorbid physical health conditions were also found in the systemic review and empirical piece alongside examples of positive adjustment and adjustment difficulties.

At all stages of conducting research, the researcher attempted to remain aware of differences between herself and participants (visible and invisible) and the degree to which she was located inside or outside the group being researched. She reflected on how her status within this space may shape and impact the research process and its outcomes.

The findings of the research have the potential to impact migrants living with HIV/TB co-infection, their friends and family, General practitioners (GPs) and other healthcare professionals working in the HIV and TB field. Other potential beneficiaries include faith leaders, organisations supporting migrants with HIV and TB, academics such as HIV and TB researchers, and HIV and TB policy makers (e.g. BHIVA, World Health Organization - WHO). The research could help increase the confidence and hope of people living with HIV and TB and increase knowledge and confidence of healthcare professionals and other agencies in how best to support migrants living with HIV/TB co-infection in a high-income setting.

Findings could be disseminated to key stakeholders, and teaching and training provided for GPs and other healthcare professionals. To help promote the potential impact of this

research, working groups with all involved agencies could be developed. In addition, the findings could help inform a social media campaign focused on encouraging early access to health services and challenging any stigmatising views about HIV and TB. Findings of the research (i.e., lay language summaries) will be provided to participants. In addition, to support others working in the field the findings will be presented to the HIV-service recruitment sites, and submitted to an academic journal alongside HIV-related conferences.

2. What are the experiences of people living with HIV and comorbid physical health conditions? A qualitative systematic review

Abstract

HIV is a virus that impairs the immune system via various transmission routes. Access to antiretroviral therapy (ART) has made it possible for people living with HIV (PLWH) to achieve longer, healthier lives. Along with increased life expectancy comes an increased burden of comorbid physical health conditions. Over half the clinical events and deaths occurring among those on ART are “non-AIDS defining” (Palella et al., 2006). Following an HIV diagnosis, a number of potential stressors exist relating to the diagnosis experience itself, the need to adhere to treatment, fear of death, HIV disclosure decisions, changes to intimate and non-intimate relationships and interactions within a complex medical system. For PLWH and comorbid physical health conditions, managing multiple conditions may compound these stressors. Consequently, a number of psychological factors are likely to be associated with navigating these potential challenges. Understanding these challenges is crucial to support this group of individuals. This systematic review considered the lived experiences of individuals with HIV and comorbid physical health conditions.

Articles were retrieved from Scopus, PsycINFO, PubMed and the Networked Digital Library of Theses and Dissertations. Their eligibility and quality were appraised by two independent raters and disagreements were resolved by a third rater. Twenty-two qualitative studies were eligible for inclusion in the review. A data synthesis was conducted.

The findings are similar to previous research which has explored difficulties surrounding management of HIV and comorbid physical health conditions, HIV-disclosure, the presence of HIV-stigma and consequent mental health problems in various HIV-positive populations.

Two studies met the full methodological appraisal criteria. Research and practice implications are discussed, with emphasis on the need for future research into the anticipated and experienced HIV- stigma that individuals living with HIV and comorbid physical health conditions face. This would aid understanding of how stigma related to HIV and other physical health conditions emerge in this population.

Introduction

HIV and comorbid physical health conditions

HIV is a virus that impairs the immune system via various transmission routes (see Executive Summary for further details on HIV; p.7). Access to antiretroviral therapy (ART) has made it possible for PLWH to achieve longer, healthier lives (National Institutes of Health - NIH.gov, 2019). Along with increased life expectancy comes an increased burden of comorbid physical health conditions (WHO, 2014). Over half the clinical events and deaths occurring among those on ART are “non-AIDS defining” (Palella et al., 2006). AIDS defining refers to illnesses attributable to the 26 serious and life-threatening diseases (CDC – Ward et al., 1992) that occur in PLWH with the advanced stage of HIV infection (i.e., Acquired immunodeficiency syndrome – AIDS). The most common chronic physical health comorbidities in PLWH include non-communicable diseases such as diabetes mellitus, cardiovascular disease, chronic obstructive pulmonary diseases (e.g., Crothers et al., 2006, Sudano et al., 2006); and

communicable diseases such as hepatitis (Turner et al., 2010) and tuberculosis (TB; Bruchfeld et al., 2015).

Comorbid physical health conditions in PLWH may be pre-existing or linked to ageing, but are often due to HIV infection and its associated risk factors including adverse effects of certain antiretroviral medication (Goulet et al., 2007). Health outcomes can be impacted by these risk factors and inequalities. The social determinants of health (SDH) such as psychosocial factors, socioeconomic circumstances, neighbourhood environment and political, economic and cultural drivers (Marmot & Wilkinson, 2005) can render people with comorbid chronic physical health conditions more vulnerable to poorer health outcomes. These individuals often need to engage more regularly with the broader health system beyond specialized HIV clinics to obtain the care they need (Narayan et al., 2014; Nigatu, Oldenburg, Elliott, Setswe & Woldegiorgis, 2013). Managing the psychological challenges of living with HIV alongside comorbid physical health conditions can be difficult.

Psychological factors

Following an HIV diagnosis a number of potential stressors exist relating to the diagnosis experience itself, the need to adhere to treatment, fear of death, HIV disclosure decisions, changes to intimate and non-intimate relationships and interactions within a complex medical system. For PLWH and comorbid physical health conditions, managing multiple conditions may compound these stressors. Consequently, a number of psychological factors are associated with navigating these potential challenges.

Stigma

Stigma has been conceptualised as a socially ‘devalued attribute’ which in turn affects the way people react to knowledge they do or do not possess the devalued attribute.

HIV has been offered as an example of such an attribute (Earnshaw & Chaudoir, 2009).

Previous research with individuals with HIV has identified three forms of stigma:

internalised (i.e. degree of shame/self-loathing felt); enacted (i.e., past experiences of discrimination); and anticipated (i.e. expectations of being the target of social

rejection/discrimination) (Earnshaw, Smith, Chaudoir, Amico & Copenhaver, 2013). It

can be useful to think about these separate processes of stigma and their potential

impact on adjustment. Stigma can lead people living with HIV to face social exclusion,

that is, being denied full access to various rights, opportunities and resources to which

other members of a different group (i.e., HIV uninfected) have access (Earnshaw &

Chaudoir, 2009). Research has shown that PLWH are routinely discriminated against

and excluded within their communities (Mbonu, van den Borne, & De Vries, 2009).

Research with PLWH has also found that a variety of additional stigmatized identities

(e.g., mental illness, sexual orientation) result in a greater social burden of illness,

impacting on maintaining psychological health (Chaudoir, Fisher, & Simoni, 2011).

Individuals with HIV and comorbid physical health conditions can face increased levels

of stigma. For example, PLWH and TB face stigma related to both conditions (Daftary,

2012), impacting on disclosure decisions for both conditions. This group also faces a

lack of support, poverty and feelings of hopelessness and helplessness, resulting in

complex challenges to ART adherence (Gebrekristos, Lurie, Mthethwa, & Karim, 2009;

Gebremariam, Bjune, & Frich, 2010; Naidoo, Dick, & Cooper, 2009). TB is a

communicable disease with public health risks, and is curable with treatment, whereas other comorbid physical health conditions may not be so. It is unclear to what extent findings can be attributed to other conditions such as diabetes mellitus and cardiovascular disease which are non-communicable and require on-going treatment.

Coping

Coping is defined as thoughts and behaviours that people use to manage the internal and external demands of situations that are appraised as stressful (Lazarus & Folkman, 1984). Studies have revealed that people living with HIV use a variety of coping strategies, such as distraction, social support, religion, acceptance, and direct action (i.e., taking active steps to address the stressor and its effects) (Burchardt, 2010; Deichert, Fekete, Boarts, Druley, & Delahanty, 2008; Hodge & Roby, 2010). In people without HIV who are living with long-term conditions such as diabetes, social support has been linked to improved coping and treatment adherence (Gallant, 2003; Ramkisson, Pillay & Sibanda, 2017), alongside higher levels of quality of life (Tang, Brown, Funnell & Anderson, 2008). Individuals with limited social support who are living with both HIV and a comorbid physical health condition may find it more challenging to cope and maintain a good quality of life without friends or relatives supporting them.

Mental health

Mental health refers to “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.” (WHO, 2014). Wellbeing refers to “diverse and interconnected dimensions of physical, mental, and social wellbeing that extend beyond the traditional definition of health. It includes

choices and activities aimed at achieving physical vitality, mental clarity, social satisfaction, a sense of accomplishment, and personal fulfilment” (Naci & Ioannidis, 2015, p121). For PLWH, poor mental health status can serve as a barrier to adequate ART adherence, and consequently decrease quality of life and increase mortality (Brandt, 2009; Clucas, Sibley, Harding, Liu, Catalan & Sherr, 2011; Sherr, Clucas, Harding, Sibley & Catalan, 2011). For individuals without HIV who have cardiovascular disease (Sin, 2016), lower levels of positive wellbeing have been found to be associated with increased stress reactivity and poorer coping skills.

Living with HIV is challenging, and anxiety and mood disorders, particularly depression, are the most common psychiatric diagnoses (Edmiston, Passmore, Smith, & Petoumenos, 2015; Kendall et al., 2014). In terms of HIV disease progression, having depression can significantly increase plasma viral load—even after effective ART is initiated (Ironson et al., 2005) – and accelerate the decline of CD4 cell counts (white blood cells that are an essential part of the human immune system). Given the evidence base on the effects that depression can have on HIV-related issues, it is important to gain a better understanding of the illness experiences of PLWH and comorbid physical health conditions.

Theories of adjustment and coping

Adjustment to HIV diagnosis can be both complex and difficult. The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) proposes that coping is part of a response to situations appraised as stressful. Many theories around adjustment relate to appraisal, that is, individuals' evaluations of the significance of the impact of an event on their wellbeing, and coping (Lazarus, 1993). The Transactional Theory of Stress and

Coping proposes two forms of appraisal: (1) Primary appraisal concerns the individual's appraisal of the stressors and the coping strategies they use for managing these stressors; (2) secondary appraisal concerns the assessment of whether they can cope with the possible benefits or threats. A meta-analysis (Moskowitz, Hult, Bussolari & Acree, 2009) of types of coping that related to psychological wellbeing in people with HIV found that "direct action" (e.g. finding a healthcare provider") and "positive re-appraisal" (e.g., I have learned something from this experience") were associated with better outcomes for people coping with HIV. Social support has also been cited as providing an important influence in moderating adjustment and coping to an HIV diagnosis (McDowell & Serovich, 2007; Peterson, Folkman & Bakeman, 1996; Schmitz & Crystal, 2000).

Moss-Morris' (2013) 'unified' model of adjustment cites multiple causal factors for poor adjustment that are relevant to individuals with HIV and comorbid physical health conditions. These factors include a change in identity and life roles, lower levels of social support and socio-economic status, difficult treatment regimens and an uncertain future. Good adjustment is proposed to be represented by less distress, less impact on identity, life roles, and relationships, good illness management and positive affect. This model highlights that individuals can be in adjustment equilibrium and disequilibrium at different times. As already outlined, it is likely that many aspects of living with HIV or chronic health conditions could be perceived as stressful and likely to be exacerbated in PLWH and comorbid physical health conditions.

The Common Sense Model (CSM; Leventhal, Meyer & Nerenz (1980) proposes that illness perceptions directly influence coping strategies, which then influence outcomes. Perceptions are conceptualised as lay interpretations of information and personal experiences that the individual has acquired. These are proposed to include five main cognitive domains: 1) identity (label and symptoms), 2) timeline, 3) consequences, 4) cause, and 5) perceived controllability/curability. In addition, a non-cognitive domain of emotional perceptions is included. The model proposes parallel processing of cognitions and emotions.

Barriers to managing HIV and comorbid physical health conditions

Managing beliefs and feelings linked to having HIV and comorbid physical health conditions can be compounded by the difficult social and economic circumstances faced by this group. Across and within countries worldwide, there is evidence that a social gradient in health exists where the lower an individual's socioeconomic position, the worse their health outcomes (WHO, 2014). Unemployment, poor education levels, lack of accessible quality healthcare and lack of basic sanitation and housing (Gilbert & Walker, 2002; Kasese-Hara, Mayekiso, Modipa, Mzobe, & Mango, 2008; Van Niekerk, 2001) can affect the wellbeing of PLWH. For those in high income countries, many living with HIV are migrants and can experience the pressure of finding an income and precarious housing, which can impede their ability to take care of their health and attend appointments regularly. Food insecurity can contribute to poor nutrition and impact mental and physical health, increasing the risk of developing comorbid conditions (Feldman, Alexy, Thomas, Gambone, & Irvine, 2015; Palar et al., 2015). Stigma relating to ethnicity, race, migrant status, class, age, gender and sexuality combined with HIV-stigma can further disadvantage those who occupy devalued statuses. In

addition, for migrants to high income countries, changes in medical context, with greater medication availability, differences in integrated care and limited social support may impact on adjustment positively and negatively.

From the research reviewed, it is likely that the consequences of living with HIV and comorbid physical health conditions will impact on wellbeing and mental health. These consequences could be an additional barrier in how this population manages living with multiple conditions. There is currently little information about the illness experiences of PLWH and a range of comorbid physical health conditions, therefore it is important to know more about the experiences of this population.

Aims of the systematic review

This is the first review that the author is aware of to consider the illness experiences of PLWH and comorbid chronic physical health conditions globally. A systematic synthesis of the relevant qualitative literature will help to provide an improved understanding of the current evidence base, and could inform the design of new interventions/strategies. This could in turn help support individuals with HIV and comorbid physical health conditions and allow for identification of existing research gaps. Any findings of this review may have implications for health services generally, in particular mental health services. Findings might also help guide healthcare professionals working with individuals with HIV and comorbid health conditions, and help update and/or reinforce existing guidelines for managing HIV with other conditions worldwide (e.g., British HIV Association – BHIVA – Standards of care for people living with HIV, 2018). Previous reviews of illness experiences and psychological factors have often focused singly on the illness experiences of those with

HIV or other physical health conditions. This review adopts a globally inclusive approach, as no prior reviews in low, middle- or high-income countries have been undertaken on the illness experiences of PLWH and a range of comorbid physical health conditions, to the author's knowledge.

Method

Study eligibility

Inclusion criteria were articles that report the experiences of adults (≥ 18 years) with HIV and any co-morbid health condition, including infectious and non-infectious diseases that were:

- Physical (causation and primary effects)
- Chronic/difficult to treat/incurable
- Non-AIDS defining (see Executive Summary for p.8 for a definition)
- Common (i.e., those that met the above criteria and are either on the WHO classification system for HIV infection, Stages 1 – 3, 2016. That is, not the AIDS defining illnesses attributable to the 26 serious and life-threatening diseases (CDC – Ward et al., 1992) that occur in PLWH with the advanced stage of HIV infection; the top 10 most common cancers worldwide, from GLOBOCAN (Global Burden of Cancer Study) estimates of incidence and mortality worldwide for cancers (Bray et al., 2018); the WHO top 10 global causes of death, (WHO, 2018); or the top 10 leading causes of disability – from the Global Burden of Disease Study (Wang et al., 2017).

Qualitative or mixed method study designs were included where qualitative results were reported separately. Studies that only report quantitative results were excluded. Studies were included from countries of all income levels.

Sources of information

Studies in peer-reviewed journals were retrieved from Scopus, PsycINFO, PubMed and the Networked Digital Library of Theses and Dissertations and citations on 10th October 2018. Following screening to help find articles that may have been missed by database searches, reference lists of relevant primary research articles were examined in addition to articles where these have been cited. Searches were restricted to studies conducted since 1 January 1996 due to effective antiretroviral medication becoming available from this time.

Search strategy

Searches were conducted using combinations of the following search terms:

Table 1: Systematic review concepts and search terms

Concept	Search Term
HIV	HIV OR “Human Immunodeficiency Virus” OR AIDS OR “Acquired Immunodeficiency Syndrome”
Comorbidity	Comorbid* OR Co-morbid* OR Multimorbid* OR Multi-morbid* OR Coinfection* OR Co-infection* OR “Dual diagnosis”
Illnesses	Tuberculosis OR TB OR Herpes OR Hepatitis OR “Cardiovascular disease” OR CVD OR “Heart disease” OR “Coronary artery disease” OR CAD OR “Ischaemic heart disease” OR IHD OR Hypertension OR Diabetes OR Stroke OR “Multiple Sclerosis” OR “Back pain” “Chronic obstructive pulmonary disease” OR COPD OR "Trachea cancer" OR "Bronchus cancer" OR "Lung cancer" OR “Oesophag* cancer” OR “Thyroid cancer” OR "Breast cancer" OR “Cervical cancer” OR “Bladder cancer” OR "Colon cancer" OR "Rect* cancer" OR “Colorectal cancer” OR “Prostate cancer” OR “Stomach cancer” OR “Liver cancer” OR

Concept	Search Term
	"Kidney disease" OR "Renal disease"
Views/experience:	View* OR Experience* OR Knowledge OR Opinion* OR Understand* OR Concern* OR Perception* OR Perspectiv* OR Cognition* OR Feeling* OR Preference* OR Decision* OR Attitude* OR Belief*
Qualitative:	Interview* OR Qualitative OR "Group discussion*" OR "Focus group*" OR "Grounded Theor*" OR Phenomenolog* OR "Action research" OR Ethnograph* OR Questionnaire* OR Anthropolog* OR Self-report* OR "Self report*" OR "Thematic analys*" OR Narrative* OR IPA OR "Interpretative Phenomenological Analysis" OR Survey*

Data collection

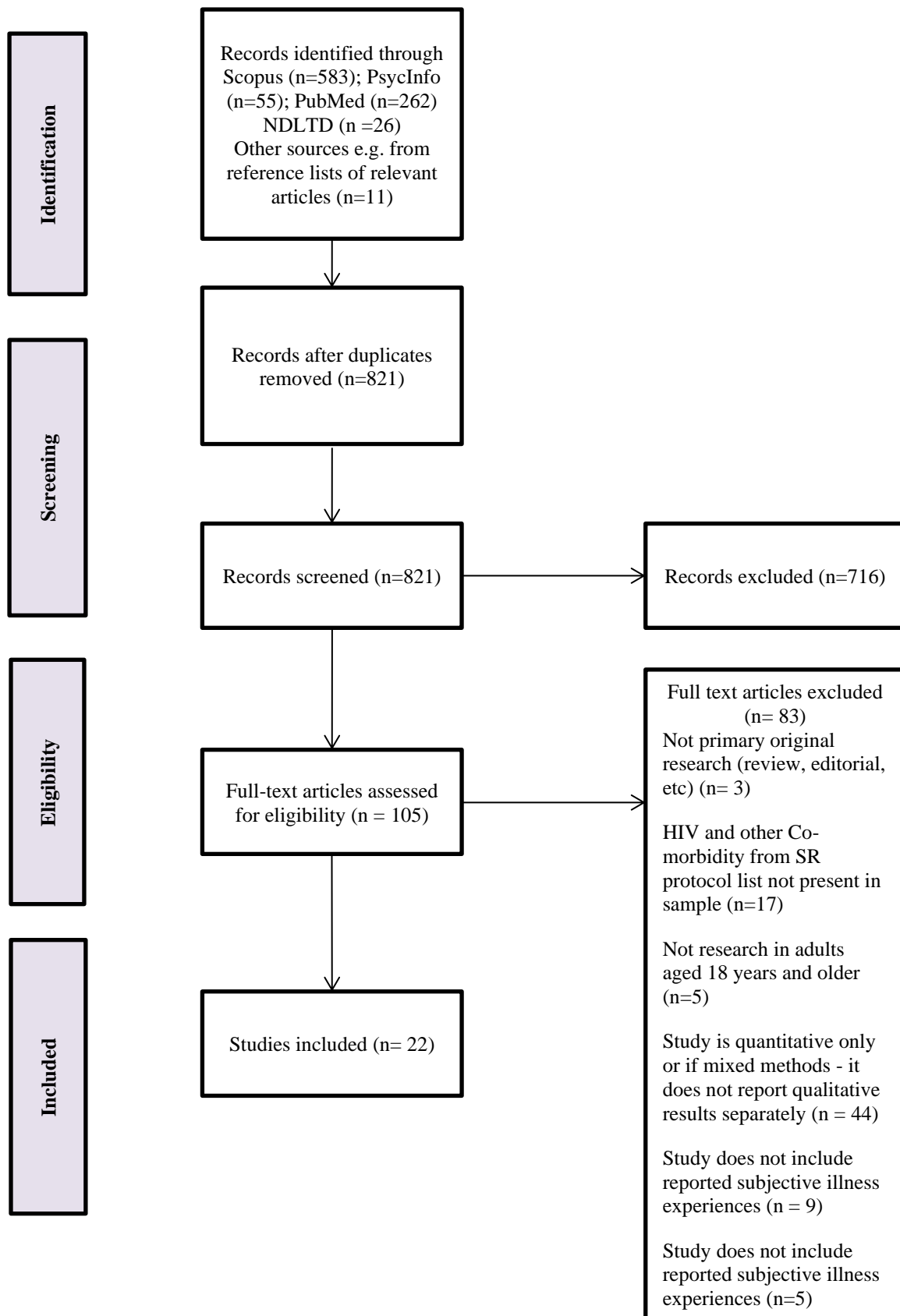
The Centre of Reviews and Dissemination (CRD) guidance for conducting systematic reviews was followed. The search strategy used to identify and screen for relevant articles was informed by PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines; Moher, Liberati, Tetzlaff, Altman, 2009; See Figure 1).

- *Identification:* The author carried out the search for the identification of studies, using the pre-specified search criteria outlined above. To help find articles that

may have been missed by database searches, reference lists of relevant primary research articles were examined in addition to articles where these have been cited. All duplications between databases were removed.

- *Screening:* Titles and abstracts were independently screened for eligibility by two reviewers (the author and an undergraduate psychology student). Articles considered relevant by either reviewer were retrieved in full text.
- *Eligibility:* Both reviewers independently assessed the eligibility of the retrieved articles. Exclusions were recorded in an Excel spreadsheet, with reasons given and kappa was calculated. Any disagreements were resolved by a third reviewer (the internal supervisor) to result in a final group of studies for analysis.

Figure 1. PRISMA flow diagram of the search eligibility process



Data abstraction

The following details were extracted from the articles: authors, date of publication, location, HIV status, comorbidity status, design, nature of sample, age, gender, ethnicity, country of origin, analytic method, and reported themes.

Quality assessment

The methodological quality of the studies was evaluated using criteria for qualitative designs. The quality criteria (see Table 2) were based on an adapted version of the Mixed Methods Appraisal Tool's (MMAT – Pluye et al., 2011) qualitative studies criteria. Two reviewers (the author and an undergraduate psychology student) assessed all included papers independently before comparing ratings. Any disagreements were resolved by the third reviewer (internal supervisor). The MMAT was adapted with criteria prioritised to help minimise the chance of articles being rejected despite appearing to substantively answer the MMAT questions. This was also completed to allow the MMAT to be operationalised in a way that supported the author and the undergraduate reviewer to use it.

Table 2. MMAT Qualitative study methodology assessment guide (adapted)

1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question?	Consider: (a) Are the sample inclusion/exclusion criteria and the sampling method clearly described and relevant to address the research question? (b) Are explanations given for why certain potential participants chose not to participate? If at least (a) is present, then choose YES.
2. Is the process for analyzing qualitative data relevant to address the research question?	Consider: (a) Is the data collection method clear (e.g. in depth interviews and/or group interviews, and/or observations and/or documentary sources)? (b) Is it clear what form of data was collected? (e.g. tape recording, video material, and/or field notes) (c) Have any changes made to methods been explained? (d) Does the qualitative data analysis address the research question? (e.g. Ethnography, Phenomenology, Narrative, Grounded theory, Case Study, Qualitative Description. If at least (a) and (d) are present, then choose YES.
3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	Consider: (a) Is the setting described clearly (e.g. region of country, urban/rural area, area of high unemployment)? (b) Are the similarities and differences between the study setting and other settings of the same type noted? If at least (a) is present, then choose YES.
4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?	Consider: (a) Is there a description of how findings relate to researchers' perspectives, roles and interactions with participants ("e.g. Identification of their disciplinary affiliation, what brought them to the question, and the assumptions they make about the topic of interest")? (b) Is the researcher's role influential at all stages (formulation of a research question, data collection, data analysis and interpretation of findings) (c) Do researchers explain their reaction to critical events that occurred during the study? If at least (a) is present, then choose YES.

Analysis

Inter-rater reliability was assessed using Cohen's Kappa = 0.47, indicating a moderate level of agreement between the reviewers.

Qualitative study findings were analysed. A narrative synthesis approach was used to identify and understand key findings from the included studies (Popay et al., 2006).

This process involved data extraction, evaluation and synthesis of findings across studies. To conduct the synthesis the author read and reread articles to identify emergent themes from each study. Themes that related to each other across studies were grouped together to develop categories by the author, verified by the internal supervisor, and a table was provided (see Table 4).

Results

Of the 937 studies identified through the initial search, 22 met inclusion criteria for review (see PRISMA flow diagram, Methodology section - Figure 1).

Overall study characteristics

Studies were published between 2007 and 2018. Seven studies were conducted in South Africa; six in the USA; two in Ethiopia; two in India; one in Ghana; one in Zambia; one in Ireland; one in Canada; and one in the UK. For further study characteristics and details on methodology and the sample please see Table 3 - Qualitative studies proforma.

Table 3. Qualitative studies proforma

Reference	Location and Population	Methodology and Sample	Themes
Amutah-Onukagha et al. (2018)	USA African American substance abusers with HIV and other chronic diseases (e.g., diabetes, hypertension, heart disease)	Grounded Theory Semi-structured interviews (SI) in three focus groups (FG) Purposive sampling Recruited from three community-based health centres <i>n</i> = 31; aged 21 to 67 years (mean age = 50 years) All females Response rate not stated	Six themes identified (1) Challenges pertaining to the management of comorbidities (2) Healthcare provider relationship (3) Mental health (4) Lack of social support (5) Nutrition (6) Access to health education An engaged and trusting relationship with their healthcare provider and having positive sources of support were reported as motivating treatment adherence. PLWH expressed more concerns with difficulty treating their comorbidities compared to managing only HIV.
Anku et al. (2017)	Ghana (four regions) TB-HIV co-infected patients	Normalisation Process Theory: inductive and deductive approaches. SI Purposive sampling 12 health facilities (separate, linkage, collaborative and fully integrated) <i>n</i> = 40; no data on age provided No data on gender provided Response rate not stated	Three themes identified (1) Coherence: sense-making of TB-HIV service integration (2) Experiences of co-infected patients - Opportunistic TB or HIV diagnosis - Inconsistencies in co-therapy administration - Separate clinic appointment dates for TB and HIV - Late TB diagnosis and prolonged TB treatment due to drug resistance (3) Views of co-infected patients on services received under the various models Participants with HIV and TB were diagnosed opportunistically, leading to treatment inconsistencies. Participants expressed negative experiences especially those accessing care in separate

Bova et al. (2010)	USA White – 48.7% Hispanic – 38.5% African American – 12.8%	Qualitative descriptive methods and qualitative content analysis	facilities. Six major themes identified as treatment barriers or treatment facilitating factors:
	HIV and HCV co-infected patients Age ≥ 18	SI Purposive sampling and later theoretical sampling Three HIV specialty clinics <i>n</i> = 39; age range = 34-56 years (mean = 45.1 years); 54% male Response rate not stated	Treatment barriers (1) Treatment fears (2) Vicarious experiences Treatment facilitators: (3) Experience with illness management (4) Patient-provider relationships (5) Gaining sober time (6) Facing Treatment head on
Chileshe et al (2010)	Zambia (rural) Most belonged to the Tonga ethnic group HIV/TB co-infected patients	Ethnographic case-studies SI Sampling strategy not stated; government health facility 7 patients; Age range 21 – 54 years. <i>n</i> = 7; 3 females and 4 males Response rate not stated	Two themes identified (1) Barriers to accessing ART: Economic, Social, Health facility (2) Outcomes – death, denial and transformation. After starting ART, an improvement in symptoms and a healthier physical appearance were perceived as positive.
Clouse et al. (2018)	South Africa Postpartum HIV-positive women with non-communicable diseases (NCD,	Inductive/deductive approach Open-ended interview (OI) Sampling strategy not stated,	Three themes identified: (1) Maternal factors (Knowledge of importance of care for mother and baby and follow-up care) and (Motivation to attend clinic/take ART linked to how mother feels currently, amount of medication at home, pre/post baby

	e.g., hypertension and diabetes) Age ≥ 18	recruitment site: Health Research Unit at hospital. $n = 25$; median age = 36 years Response rate not stated	complications; and perception of baby and mother's health) (2) Environmental factors (Clinic type and clinic operations) (3) Social Networks (male partners, shared condition, advice giving). Most women reported receiving care for HIV and the NCD in the same clinic. Barriers to follow-up included separate visit days and subsequent increased time commitment, long waits and misplaced paperwork, and experiencing enacted stigma from staff at the HIV clinic. Factors facilitating treatment adherence and care included social support and disclosure of HIV to partner. Women were more likely to turn to friends, partners and family for advice regarding HIV or the NCD, rather than a clinic.
Daftary (2012)* ¹	South Africa Adults with HIV/TB co-infection Age 18 – 50 years	Modified Grounded Theory SI Purposive sampling; Recruitment site: three ambulatory clinics providing TB and/or HIV care $n = 40$; age range = 21 – 47 years (average age = 34) 24 women; 16 men Response rate not stated	Five themes identified (1) Distinguishing TB from HIV (2) Linking TB to HIV (3) The visibility of TB/HIV (4) Silencing HIV (5) Foregrounding tuberculosis TB vs. HIV identity was associated with separate degrees of stigma linked to participants' experiences of labelling, negative stereotyping and discrimination. Patients deflected the dominant stigma of HIV through processes of HIV 'othering' – their symbolic distancing from persons affected by HIV, and 'covering' – their selective disclosure of illness (and identity associated) with TB over that of HIV.
Daftary et al. (2012)* ¹	South Africa Patients with HIV/TB co-	Modified Grounded Theory SI	Five themes identified: (1) Income and employer support

	infection Age 18 – 50 years	Purposive sampling; three urban/peri-urban ambulatory clinics. <i>n</i> = 40; 24 women and 16 men; age range = 21 – 47 years Response rate not stated	(2) Access to social assistance (3) Disclosure versus support (4) Delays with ART (5) Fears to adhere Many patients were unemployed and unable maintain a steady income source. Government-issued disability grants were a common source of temporary financial aid. Patients negotiated TB and HIV disclosure with caution. Disclosure was required to gain access to social and financial support, but the degree of information shared was balanced against the risk of losing support. TB only was often disclosed.
Daftary et al. (2013)* ¹	South Africa Patients with HIV/TB co-infection Age 18 – 50 years	Modified Grounded Theory OI and exploratory interviews Purposive sampling Three urban/peri-urban ambulatory clinics. <i>n</i> = 40; 24 women and 16 men; age range = 21 – 47 years Response rate not stated	Five themes identified (1) Missed opportunities for integration (2) Fragmented care (3) HIV nondisclosure (4) Contrasting clinic experiences (5) Patient preferences Participants encountered missed opportunities for TB and HIV service integration, and fragmented care for their dual infections. These issues appeared to impact participants' health-related decisions, particularly HIV nondisclosure to non-HIV healthcare workers.
Daftary et al. (2014)	South Africa Inpatients with HIV and multi-or XDR-TB	Thematic analysis FG Purposive sampling; Specialist TB hospital <i>n</i> = 23; age range = 18 – 56 years (median age = 36 years)	Three themes identified (1) Preferential adherence to ART (2) Greater social morbidity of drug-resistant TB (3) Lack of education and support for XDR-TB

		10 males and 13 females	
		Response rate not stated	
Daftary et al. (2007)	South Africa Inpatients with HIV and multi or XDR-TB	Thematic analysis SI	Two themes identified (1) Experiencing and perceptions of stigma and disclosure (2) The relationship between TB and HIV/AIDS
		Purposive non-representative sampling; Recruitment site: TB hospital <i>n</i> = 21; 10 males, 11 females average age = 31.9 years	Only themes relating to post-testing experiences are reported in this section: Patients were less likely to disclose their HIV status than their TB status. Patients received emotional support when they disclosed their TB illness to relatives, who appeared to make some connection between TB and HIV. Many co-infected patients preferred the singular disclosure of TB illness outside their network of close confidantes. TB was easier to speak about because it was less stigmatised and curable.
		Response rate not stated	
Farrell et al. (2014)	Location appears to be Ireland (not clearly stated) Ethnicity not stated Patients with HIV/HCV co- infection Age ≥ 18	Hermeneutic interpretive phenomenology. OI Purposive sampling Outpatient clinic at a large national hospital <i>n</i> = 5; 3 males, 2 females Response rate not stated	Six themes identified (1) A Defining moment (2) HIV versus HCV (anxieties) (3) Loneliness/Relationships (4) Coping with Stigma (5) Care (received) (6) Awareness of Mortality Participants described defining negative moments in their lives that resulted in developing positive health care strategies. Participants considered HIV manageable; however, HCV was more of a treatment burden. Participants feared rejection following a disclosure of HIV and chose to cope with stigma by disclosing only to close family members. Participants talked about significant relationships in their lives and the supporting roles these relationships played.
Furin et al.	India	Thematic analysis	Three themes identified

(2014)	Patients with HIV and MDR-TB	In-depth interviews	(1) Long pathways before MDR-TB treatment initiation (2) Diagnostic and treatment fatigue (3) Lack of faith in treatment efficacy
		Purposive Sampling; Outpatient MDR-TB treatment program supported by MSF	
		<i>n</i> = 12; 8 males; 3 females; 1 transgender person; age range = 25 – 55 years	
		Response rate not stated	
Gebremariam et al. (2010) ^{*2}	Ethiopia Patients with HIV/TB co-infection	Giorgi's phenomenological method	Eight themes identified
		In-depth interviews and FG	Facilitators:
		Maximum variation sampling strategy; 3 Health centres	(1) Beliefs about TB, TB treatment and co-infection (2) Pill burden and side effects (3) Lack of food (4) Interaction with health personnel (5) The challenges of DOT (6) Timing of ART (7) Stigma (8) Social Support
		<i>n</i> = 15 TB/HIV co-infected patients age range not stated.	
		7 males and 8 females	
		Response rate not stated	Participants identified factors that increased adherence to TB treatment, and those that acted as barriers.
Gebremariam et al. (2011) ^{*2}	Ethiopia Patients with HIV/TB co-infection	Giorgi's phenomenological method	Two themes identified
		In-depth interviews and FG	(1) Lay beliefs about the cause of TB (2) Associations between HIV and TB
		Maximum variation sampling strategy; 3 Health centres	The majority of patients were aware of an association between TB and HIV. Participants identified weight loss as a hallmark of HIV-related TB. The majority of patients believed that people in the

		<p>$n = 15$ TB/HIV co-infected patients (in addition; mean age 36.8 years, range 20 – 47 years.</p> <p>7 males and 8 females</p>	<p>community knew that there was an association between TB and HIV, and some feared that this would lead them to experience HIV-related stigma.</p>
Ion et al. (2013)	<p>Canada</p> <p>5 Canadian White; 1 Canadian-born Aboriginal; 1 – Black Caribbean descent</p> <p>Patients with HIV and symptomatic HSV-2 co-infection</p>	<p>Response rate not stated</p> <p>Hermeneutic phenomenological reflection and thematic analysis</p> <p>In-depth SI</p> <p>Type of sampling method not stated; HIV clinic</p> <p>$n = 7$; age range 38 – 57 (average 46 years old)</p> <p>All female</p> <p>Response rate not stated</p>	<p>Three themes identified:</p> <ol style="list-style-type: none"> (1) Overall health-related quality of life (HRQoL) and acceptance of HIV and HSV-2 infections (2) To “swim”: Experiencing positive HRQoL (Controlling disclosure, Social and spiritual support, Setting and maintaining boundaries in relationships) (3) To “sink”: experiencing negative HRQoL (Uncertainty, Anxiety, Negative body image)
Isaakidis (2013)	<p>India</p> <p>Patients with HIV/MDR-TB co-infection</p> <p>Patients with HIV and MDR-TB</p>	<p>Analytic method not clearly stated – appears broadly thematic</p> <p>In-depth interviews</p> <p>Purposive sampling; MSF clinic</p>	<p>Three themes identified</p> <ol style="list-style-type: none"> (1) Accessing treatment: “The last chance” (2) Being on treatment (3) Staying on treatment <p>Fragmented, non-integrated care and delays in initiation of effective treatment. Being on treatment resulted in medication side effects,</p>

		<p>$n = 12$ patients</p> <p>8 males; 3 females; 1 transgender person; age range = 25 – 52 years.</p> <p>Time since HIV comorbidity diagnoses</p> <p>Response rate not stated</p>	<p>and impacted participants financially as they could not work. Most patients had disclosed their HIV status only to their spouses and parents, but not to friends or the extended family. This limited patients' and their families' chances of seeking social and emotional support to cope. Family caregivers were crucial to maintaining the mental and physical health of patients.</p>
Lekas et al. (2011)	<p>USA</p> <p>African American or Puerto Rican</p> <p>HIV/HCV co-infected patients who were current or past injecting drug users.</p>	<p>Analytic method not stated – broadly thematic.</p> <p>In-depth interviews</p> <p>Type of sampling method not stated; 2 large public AIDS clinics. $n = 132$; Age range = 30 – 69 years (mean age = 49.9 years)</p> <p>69% men and 31% women</p> <p>Response rate not stated</p>	<p>Eight themes identified</p> <ol style="list-style-type: none"> (1) HIV is more stigmatising than HCV (2) Societal features of HIV, embodied features of HCV (3) HIV is perceived as more deadly than HCV and therefore more stigmatizing (4) The impact of HIV hygienic degradation rituals on HCV felt stigma (5) Perception of HCV as a contagious disease. (6) The public's ignorance about HCV (7) The participants' ignorance about HCV (8) HCV and HIV are equally stigmatizing because they imply drug use
Matima et al. (2018)	<p>South Africa</p> <p>Patients with HIV and type 2 diabetes (T2D)</p>	<p>Thematic content analysis</p> <p>In-depth interviews</p> <p>Convenience sampling; Community health centre treating both HIV and diabetes</p>	<p>Two themes identified:</p> <ol style="list-style-type: none"> (1) Perceived patient workload (Clinic-related, self-management) (2) Perceived patient capacity (Positive attitudes, Health literacy, Family support, Clinic-based support; Financial challenges to meet nutritional and clinic visits expenses)

		<p>$n = 10$ patients average age = 46.9 5 males and 5 females (results for healthcare workers not stated in this systematic review);</p> <p>Response rate not stated</p>	<p>Participants experienced “clinic-related workload” such as: the workload of attending two separate clinics for HIV and T2D and perceived and experienced power mismatch between patients and healthcare workers. Self-management related workloads were largely around nutritional requirements, pill burden, and stigma.</p> <p>The burden of these demands varied in difficulty among participants due to “capacity factors” outlined above.</p>
Monroe et al. (2013)	USA African American (94%)	<p>Editing style analysis</p> <p>FG</p> <p>Sampling method not stated; HIV clinic</p> <p>$n = 35$; age range = 43- 63 (mean age = 51 years)</p> <p>Male 54%; Females 46%</p> <p>Response rate not stated</p>	<p>Four themes identified:</p> <ol style="list-style-type: none"> (1) Comorbidities are a source of concern and frustration, sometimes eclipsing concern regarding HIV (2) Understanding of health conditions and medications promoted adherence (e.g., Effects of missed doses of medication, Linking disease manifestations and/or symptoms to not taking medication) (3) Simpler regimens with fewer side effects promote adherence (4) Untreated substance abuse and mental health issues hinder adherence (Substance abuse leads to difficulty engaging in care, Depression contributes to non-adherence to medications lifestyle recommendations)
Russ et al. (2012)	USA Asian Americans Patients HIV and HBV or HCV co-infection.	<p>Thematic analysis</p> <p>SI</p> <p>Respondent driven sampling; Recruitment site – Health Centre</p> <p>$n = 17$; age range = 20 – 61 (median = 46 years)</p>	<p>Two themes identified</p> <ol style="list-style-type: none"> (1) Individual and structural barriers to care (2) Stigma <p>Participants recognized the need for integrated, culturally and linguistically appropriate access to care while simultaneously acknowledging that stigma is a severe barrier to access to care.</p>

		<i>n</i> = 16; 14 Males; 2 Transgender male to female.	
		Response rate not stated	
Sinclair et al. (2011)	UK 11 White British; 2 White Other HIV-infected gay men who had undergone HCV treatment	Interpretative phenomenological analysis (IPA) SI Sampling Method not stated. HIV medical centre. <i>n</i> = 13; age range = 27 – 46 years Response rate not stated	Four themes identified: (1) HCV diagnosis and treatment (2) HCV treatment education (3) Change in sense of self (4) Sexual risk-taking Patients undergoing HCV treatment felt that HCV treatment experience was in some way more overwhelming than HIV treatment, carrying with it a greater sense of uncertainty and despair. Education and reliable information appeared to help foster a more general sense of empowerment over HIV-HCV co-infection and treatment. For some, non-adherence became the more adaptive strategy to fit their experience of life and living.
Warren-Jeanpiere et al. (2014)	USA African American HIV- positive. 22/23 women experienced co-morbid conditions such as cancer, diabetes, heart disease, hepatitis, TB.	Constant comparison approach (inductive approach) SI Purposive sampling; research study sites <i>n</i> = 23; age 52 – 65 years (mean age = 57 years) Response rate not stated	Four themes identified: (1) Taking one day at a time: Women's definitions of HIV self-management (meanings attached to HIV self-management and the social roles that influence women's self-management behaviours) (2) Age ain't nothing but a number (indicates that women do not place chronological boundaries on their age and that age is a state of mind) (3) Forget the single life (describes women's perceptions of the influence of romantic male companionship on their self-management behaviours and outlook for the future. (4) Daily life struggles (illustrates the barriers that many women face in their everyday lives, including lack of income and health insurance that influence their ability to self-manage their HIV and other comorbidities to their

satisfaction and suggests that HIV is not women's primary concern when it comes to self-managing their overall health)

Note. HBV – Hepatitis B; HCV – Hepatitis C Virus; HSV – Herpes Simplex Virus; T2D – Type 2 diabetes, NCD – Non-Communicable Disease, MDR-TB – Multi-Drug Resistant Tuberculosis; XDR-TB – Extensively Drug-Resistant Tuberculosis. SI – Semi-structured interview; OI= Open-ended interview; FG = Focus group.

*¹ = separate articles published using the same sample; *² separate articles published using the same sample

Synthesising findings

A narrative synthesis approach was used to identify and understand key findings from the included studies (Popay et al., 2006). In the first stage of this narrative synthesis, the author extracted the overarching themes presented by each study to identify themes most frequently discussed within the included studies. Using these overarching themes as a framework, subthemes and more detailed description were subsequently extracted from each study. Relationships between themes were explored. Initial analysis revealed five overarching themes that were frequently reported by the included studies: (1) Management of HIV and comorbid physical health conditions; (2) Psychological outcomes of HIV and comorbid physical health conditions; (3) Preferences for care (4) Stigma; (5) Disclosure. The key findings related to each of these five overarching themes are summarised here. Please refer to Table 4. Qualitative synthesis for example quotations.

Management of HIV and comorbid physical health conditions

Studies reported that many participants experienced difficulties managing HIV and comorbid physical health conditions. Themes linked to this were present in 13 of the studies. Many participants found HIV easier to manage than comorbid physical health conditions, especially when multiple medications did not control comorbid physical conditions. Participants experienced a lack of faith in treatment efficacy for comorbid physical conditions, particularly when early treatment had not worked. Participants spoke about how treatment barriers, including taking multiples medications for HIV and comorbidities were linked to forgetfulness and mixing up medication, fear of treatment and side effects. In addition, intentional non-adherence to treatment (i.e., missing/altering doses to suit one's needs) emerged as a maladaptive coping strategy to

help regain short term quality of life. Treatment facilitators included simpler regimens with fewer side effects. Some participants reported that experiencing physical manifestations of their illnesses motivated them adhere to treatment. Prior experience with illness management was helpful and participants discussed using strategies developed over time to manage these chronic conditions as a way to manage additional conditions. Participants reported that setting reminder alarms helped them to integrate taking medication into their daily routine. Participants believed positive attitudes helped them to accept and cope with living with HIV and comorbid conditions. Participants reported that having confidence in medical treatment, a supportive family, and strong beliefs in religious or cultural practices helped them to cope with their comorbidities.

Psychological outcomes of HIV and comorbid physical health conditions

Themes around psychological outcomes of HIV and comorbid physical health conditions were identified in 10 of the studies. Symptoms often made full-time work difficult to maintain and this moved participants towards economic hardship, alongside food insecurity, particularly where hospitalisation occurred (e.g., for extensively drug-resistant TB – XDR-TB, a form of TB which is resistant to at least four of the core anti-TB drugs). The nutritious food required by participants was expensive, and difficult to sustain. This impacted on treatment adherence as many believed it was more difficult to tolerate medication without it. Access to financial assistance was scarce and where this did exist, eligibility was conditional (e.g., a function of participants' CD4 count). As treatment could raise CD4 counts above the eligibility threshold, this resulted in participants feeling powerless and resentful of the governing system of social assistance. Many participants subsequently experienced depression and anxiety dealing with HIV and comorbidities and felt that mental health services from organizations they

were recruited from were inadequate. Participants with HIV and herpes simplex virus-2 (HSV-2) experienced anxiety and reduced health related quality of life linked to fear of potential transmission of HSV-2 and HIV to intimate partners, and fear of disclosure resulting in rejection and judgement from others. For some participants achieving good physical and mental quality of life was associated with how they perceived their HIV-positive status and how they made efforts to shift their self-perceptions to be “in a good place” (for HIV and HSV-2).

Preferences for care

Themes around preferences for care of HIV and comorbid physical health conditions were identified in 12 of the studies. Participants discussed the positive aspects of their relationships with health care providers and how these relationships helped them adhere to their medication regime. However, for some participants, disrespectful treatment by clinical staff occurred, often due to HIV stigma directed at participants. Participants described wanting more support and empathy from healthcare workers regarding their difficulties in managing comorbid conditions. Some found healthcare related information anxiety provoking, and others reported how not being given information about treatment side effects led them to feel that they coped more poorly with them. Participants with XDR-TB were very isolated and many felt demoralised and wanted to be encouraged and informed about their prognosis by healthcare workers. Several of these participants described how health providers informed their family about XDR-TB diagnoses, but did not provide additional information on how to live with it. This led to participants experiencing discrimination from family members. Participants wanted to be given the responsibility to take TB treatment in the same way that they had been counselled for ART, so that they would return home and self-administer medication.

Participants described wanting to learn skills to discuss their health more assertively with clinicians. Participants also reported that they would like to attend educational programmes on managing and understanding their comorbidities. Many participants expressed a wish for more integrated care as they had experienced delays in initiation of treatment which led to them feeling emotionally exhausted from a long help-seeking journey. Where fully integrated clinics did not exist, participants mentioned issues relating to inconsistencies in care and treatment for all illnesses (e.g., no access to previous medical test results between clinics). Separate clinic appointments dates and treatment failures appeared to lead to mixed messages about treatment which, in some cases, led to drug resistance. Many participants at non-integrated sites expressed interest in accessing integrated care. Some however preferred to attend separate clinics, fearing that accessing HIV services at integrated care sites would lead to their HIV status being disclosed to all other patients.

Stigma

Themes around stigma were identified in seven of the studies. Participants regarded HIV and comorbid conditions distinctly. TB was perceived as common and curable and those infected were not viewed as being at fault for having contracted it. HIV instead was considered to be more selective, affecting people based on their personal character, which left them vulnerable to contracting it. TB was seen as an interim setback to participants' routine lives that could be managed with treatment, and this prompted less concern. Many participants however believed that other people associated TB with HIV, as weight loss was viewed as an embodied sign of HIV illness. Many had seen HIV patients experiencing stigma and discrimination in their communities and feared this would happen to them. Participants experienced hepatitis C (HCV) as less likely to

evoke rejection and that it elicited compassion from others when attention was drawn to its physical features such as “malfunction of the liver”, thus deflecting social stigmatization. Where participants reframed HCV as a physical illness that could be transmitted in a variety of ways, this appeared associated with a reduction in stigma and feelings of shame, in particular compared to HIV. Participants internalized others’ attitudes about HIV which affected their self-perceptions. An HIV diagnosis invoked blame and shame, and worries about being gossiped about or viewed as infectious and disgusting. Participants also experienced sadness and fear linked to appraisals of HIV as permanent and related to death. Participants described examples of consequences of stigma including not being able to get a mortgage on a house because of an HIV diagnosis. After being diagnosed with TB, several working in temporary jobs reported not being permitted to have leave with many being dismissed from employment as employers worried about their infectiousness. Participants reported that this was also linked to TB’s stigmatizing association with HIV. HIV-related stigma interfered with participants’ journeys to acceptance of HIV. Participants who had come to terms with living with HIV and HSV-2 presented a positive perception of self and comfort with their identity. Others expressed regret for becoming infected and blamed those who they believed gave them HIV and HSV-2, and experienced poor health and quality of life.

Disclosure

Disclosure decisions linked to HIV and comorbid physical health conditions were difficult for many participants. Themes around disclosure were identified in 15 of the studies. Many participants considered HIV to be more stigmatising than their comorbid illnesses and only disclosed this to their spouses and parents, but not friends or extended family. Participants with TB spoke about it more readily and with more people than

HIV. Selective disclosures (i.e., disclosing to some people but not others) were tied to TB invoking less judgement and being considered curable and more acceptable than HIV. Although participants revealed how TB disclosure was easier than HIV, they realized that discussing TB could invoke suspicions about HIV. For participants with HSV-2, having control over disclosure reduced stress and enabled participants to maintain positive health related quality of life. Participants disclosed their HIV status to those they identified as trustworthy and who they predicted would be there in difficult times. When conversations were had with others about HIV, participants felt overtly discriminated, due to their perceived contagiousness. This perpetuated a sense of guilt, shame and helplessness, and led many to hide their illnesses. Several participants spoke about the embarrassment and loss of self-respect in taking Directly Observed Therapy (DOT – whereby treatment doses are observed in person by a health care professional) at the doctor’s clinic which they believed outed their TB and HIV status. In addition, for participants with HIV and HCV, being exposed to enacted stigmatization in the form “hygienic degradation rituals” (e.g. designating particular plates for participants’ sole use and disinfecting bathrooms) after disclosing their HIV status to friends and family, resulted in intense HIV felt stigma. These participants anticipated being subjected to similar HCV degradation rituals, which led to them concealing their HCV status and thus generated HCV felt stigma. Participants with HIV and hepatitis B or C (HBV/HCV) co-infection reported that they withheld information to avoid situations that would compromise their anonymity when accessing general health care as a means of protection against stigma. Most participants did not disclose HIV to employers, and accessed “vacation”/unpaid leave for HIV care. Non-disclosure limited participants’ and their families’ chances of seeking social and emotional support to cope, and resulted in

social withdrawal. Participants identified living with HIV and HVC as a lonely life linked to fear of rejection following disclosure of HIV. The difficulty of disclosure further undermined their ability to access ART, and social support was found to be crucial for participants' treatment. Families were a source of encouragement and comfort for those participants who had lost hope. Participants reported that family support was important and where it was lacking or totally unavailable, it led to distress and difficulties in managing HIV/T2D (Type 2 Diabetes; Matima et al., 2018).

Table 4. Qualitative synthesis

Category	Theme	Example
Management of HIV and comorbid physical health conditions	HIV is easier to manage than comorbid physical health conditions	“So hepatitis C, over the next, certainly currently and for the future will have more of an impact on me. And the HIV, through my self-care but mostly because of the medication and good fortune, has become a manageable lifetime illness, like diabetes is or asthma is, which is remarkable considering the point from which we started. Hepatitis C is another bag of chips and unfortunately I have – I underwent the treatment in ‘03 and ‘04 that was extremely difficult and to which I didn’t fully respond, so I probably face a slightly uncertain future there.” (Farrell et al., 2014)
	Treatment barriers e.g. pill burden, side effects	“To speak about myself, I really think it is difficult to express. Taking so many tablets, going through so much pain, I am fed up.” (Furin et al., 2014)
	Treatment facilitators e.g. simpler regimen, responsibility for treatment (via education)	“But this last [regimen], I can thank God that I’m not detectable and . . . this one is great-just one pill once a day,” and for diabetes, “my insulin . . . I was taking like 4 shots . . . Now I got the pen. The new pen that I stick myself twice, one in the morning, one in the evening. And that’s awesome.” (Monroe et al., 2013)
Psychological outcomes of HIV and comorbid physical health conditions	Psychological difficulties	“you get depressed, you don’t eat, so you don’t take your medication.” (Amutah-Onukagha et al., 2018)
	Psychological coping responses	“Just taking care of myself one day at a time to manage it. But just help me to manage it and live a productive life to a well-being as I possibly can. Just help me to manage like I do the rest of my ailments and carrying on to, you know, to be a balance in everything.” (Warren-Jeanpiere et al., 2014)
Preferences for care	Relationship with healthcare provider	“They [MSF staff] stood by me. They gave me emotional support, helped me find courage. R [nurse] said if ever I did not feel well, or felt that I needed to talk, I was to give her a missed call [on her mobile phone] and then she would call back. (...) It was like she was with me all the time, to help me whenever I needed help. (...) They have cared for me – more than my blood relatives.” (Isaakidis, 2013)
	Service Integration	“I prefer the one-stop-shop approach because, I don’t like to be moving ‘up-and-down’ the various units for treatment. Having treatment at the same facility and under the same roof for both infections and on the same date will be comfortable for me. That will also give me the opportunity to discuss with them [service providers] about my condition regarding both infections and it will also give them the chance to discuss and agree on what to do for me at a point in time... When we move in and out of the place [care centres] like that, people get to see us and gossip about us. “ (Anku et al., 2017)
Stigma	HIV versus other illnesses	“They take it [TB] a usual thing because they say it’s usual, it’s in everyone. It means it’s a thing which doesn’t select. [HIV,] there it’s difficult for them to take easy. They tell themselves that as you have HIV-positive, you are the thing which will leave the world.” (Daftary, 2012)

Category	Theme	Example
	Stigma and embodied features of illness	“More of the herpes and HPV than the HIV, yeah, because it’s right there in my face . . . I can feel that. It’s tangible. It hurts there. HIV is not tangible. You can’t feel it. You can’t see it.” (Ion et al., 2013)
	Consequences of stigma	“Now you know the people, maybe the people don’t like. They looking at you with the mind not with the eyes. With the mind they looking at you. How can I put it? You feel shit, so to say. You not yourself that time, because you’re like, you go home, you feel like demolish.” (Daftary et al., 2012)
Disclosure	Disclosure decisions	“There they laugh at each other. If you ever say you have TB, they become your doctors. It’s them who will say, ‘Yes, of course, TB is AIDS’ neighbor. It means she has got AIDS’, you see?” (Daftary, 2012)
	Silencing illness status	[I have not told my relatives] ‘cause, because, due to the fact that, hepatitis C is more, uh, I mean, a germ and a bacteria that’s picked up off of things. And then if I go to their house, and eat, you know, wondering when I leave, what are they doing, I mean, if they’re running to get Clorox, to wash this down, to do that, because see, I, experienced that with members of my family [for my HIV status]. (Lekas et al., 2011)
	Consequences of disclosure choices	‘I was dealing with it all by myself. I used to cry quietly. My mother in law was also very sad when she found out. (...) I only told her [my sister] and no one else. She also said she would not tell anyone as it was not something one can tell easily. She did not even tell her husband. I did not even tell my brother as his wife may just blurt it out in front of other people. (Isaakidis , 2013)

Quality assessment

For all studies: the sources of qualitative data were relevant to address the research question; and the process for analysing qualitative data was relevant to address the research question. For all studies except Farrell et al. (2014) appropriate consideration was given to how findings relate to the context. All studies except Amutah-Onukagha et al. (2018), Farrell et al. (2014) and Sinclair et al. (2011) did not give appropriate consideration to how findings relate to researchers' influences. Please refer to Table 5. for an overview of this using the MMAT critical appraisal tool (MMAT – Pluye et al., 2011).

Table 5. MMAT Critical appraisal tool results

Authors	1. Are the sources of qualitative data relevant to address the research question?	2. Is the process for analyzing qualitative data relevant to address the research question?	3. Is appropriate consideration given to how findings relate to the context?	4. Is appropriate consideration given to how findings relate to researchers' influences?	SCORE out of 4 (Score each Yes = 1; No = 0)
1. Amutah-Onukagha et al. (2018)	Yes	Yes	Yes	Yes	4
2. Anku et al. (2017)	Yes	Yes	Yes	No	3
3. Bova et al. (2010)	Yes	Yes	Yes	No	3
4. Chileshe et al. (2010)	Yes	Yes	Yes	No	3
5. Clouse et al. (2018)	Yes	Yes	Yes	No	3
6. Daftary (2012)	Yes	Yes	Yes	No	3
7. Daftary et al. (2012)	Yes	Yes	Yes	No	3
8. Daftary et al. (2013)	Yes	Yes	Yes	No	3
9. Daftary et al. (2014)	Yes	Yes	Yes	No	3
10. Daftary et al. (2007)	Yes	Yes	Yes	No	3
11. Farrell et al. (2014)	Yes	Yes	No	Yes	3
12. Furin et al. (2014)	Yes	Yes	Yes	No	3
13. Gebremariam et al. (2010)	Yes	Yes	Yes	No	3
14. Gebremariam et al. (2011)	Yes	Yes	Yes	No	3
15. Ion et al. (2013)	Yes	Yes	Yes	No	3
16. Isaakidis et al. (2013)	Yes	Yes	Yes	No	3
17. Lekas et al. (2011)	Yes	Yes	Yes	No	3
18. Matima et al. (2018)	Yes	Yes	Yes	No	3
19. Monroe et al. (2013)	Yes	Yes	Yes	No	3
20. Russ et al. (2012)	Yes	Yes	Yes	No	3
21. Sinclair et al. (2011)	Yes	Yes	Yes	Yes	4
22. Warren-Jeanpiere et al. (2014)	Yes	Yes	Yes	No	3

Discussion

Overview of study findings

This review aimed to synthesise findings on the illness experiences of individuals living with HIV and comorbid physical health conditions. Twenty-two qualitative studies were included, drawing from a variety of population groups. Five common themes emerged: (1) Management of HIV and comorbid physical health conditions; (2) Psychological outcomes of HIV and comorbid physical health conditions; (3) Preferences for care; (4) Stigma; (5) Disclosure. Previous systematic reviews have focused on the illness experiences and psychological outcomes of those with HIV alone (e.g., Breuer, Myer, Struthers & Joska, 2011; Lowther, Selman, Harding & Higginson, 2014), those with a different physical health conditions but without HIV (e.g., diabetes – Li, Drury & Taylor, 2014; cancer - Singer, Das-Munshi & Brähler, 2010), or HIV and a single comorbid health condition (e.g., for HIV and cancer – Hainsworth, Shahmanesh, & Stevenson, 2018). The current review examines the illness experiences of people living with HIV (PLWH) across a range of comorbid health conditions in low-, middle- and high- income settings. It is also only focused on qualitative studies compared to the above reviews.

Participants from studies in the current review described experiencing difficulty managing HIV and comorbid health conditions. HIV was found to be easier to manage than comorbid physical health conditions (e.g., Farrell et al., 2014). Treatment barriers for HIV and comorbid physical health conditions were highlighted – including pill burden and side effects. Treatment facilitators were outlined as being a simpler treatment regimen for HIV and being provided with education and enough autonomy to take responsibility for HIV treatment. Evidence from a quantitative study not included

in the current review found that multiple drugs co-administered with ART are an important predictor of non-adherence due to the associated pill-burden, side effects and drug interactions (Cantudo-Cuenca, Jiménez-Galán, Almeida-González & Morillo-Verdugo, 2014).

In the current review, participants commented on their preferences for care, including experiences of relationships with healthcare providers and service integration.

Participants appreciated feeling supported, however reports of stigma, not being given adequate information and not feeling involved in decision-making linked to services not being integrated were present in the literature. These findings were generally consistent across studies, and may help practitioners better recognize the specific need for patient-centred care, with a focus on supporting and educating this population. HIV and comorbid physical healthcare education sessions could be offered to newly diagnosed patients to help them to feel more supported within the healthcare system. Session content and delivery could be informed by patient involvement.

Findings of the review suggest that PLWH and comorbid physical health conditions experience stigma, in particular, stigma related to HIV versus other illnesses. The stigma associated with being diagnosed with HIV and comorbid physical health conditions impacted on people's relationships and experiences with the healthcare system, as did the physical and mental health symptoms associated with HIV and comorbid health conditions (e.g. fatigue, weakness, nausea, pain, depression and anxiety). Petrak, Doyle, Smith, Skinner and Hedge (2001) reported high levels of HIV-stigma and consequent mental health problems in a black African population in the UK, which fits with the findings of the current review. This study could not be included in the review as it included HIV-only participants. Misinformation and lack of education

may be the underlying cause of this stigma. Education, within the healthcare system, for family and friends of individuals diagnosed with HIV and comorbid health conditions may reduce stigma associated with them (e.g., Pretorius, Greef, Freeks & Kruger, 2016).

The current review highlighted that PLWH and comorbid health conditions experience psychological difficulties (e.g. Amutah-Onukagha et al., 2018). However, it is difficult to ascertain whether this is due to one illness over another, combined stigma or other factors. How individuals with HIV and comorbid physical health conditions specifically cope with stigma has not been explicitly explored. This is an area that would benefit from future research as it is unclear if, how and where HIV-positive individuals with comorbid physical health conditions access a range of support systems in addition to family (e.g., friends, religion, and support organisations).

Participants commented on disclosure, including disclosure decisions, silencing illness status, and the consequences of disclosure decisions. Participants regarded HIV and comorbid conditions distinctly; disclosure decisions linked to HIV and comorbid physical health conditions were difficult for many participants. Studies in the current review found that fear of transmission of communicable diseases was a factor cited in contributing to deteriorating relationships. Previous research has discussed the difficulties surrounding HIV-only disclosure (Doyal, 2009; Evangeli & Wroe, 2017) and the presence and impact of HIV-only stigma (Doyal, 2009; Earnshaw & Chaudoir, 2009). In addition, it has been proposed that a person's view of the world and their assessment of how they are able to respond to difficult situations is critical for successful coping (Lazarus and Folkman, 1984; Lazarus & Lazarus, 1991). Participants' ability to effectively cope and adjust to living with HIV and comorbid physical health

conditions appears to have been negatively impacted by stress linked to experiences of anticipated stigma. While it may be important for participants to disclose their HIV status to obtain needed resources and support, negative consequences may be associated with disclosure. Therefore, participants' decisions related to disclosure of their HIV status are likely to be influenced by their evaluation of the positive or negative consequences of disclosure.

Given the large amount of research into the psychological impact of being diagnosed with HIV across different populations, it was not surprising that the results of this review suggest that the experiences of PLWH and comorbid physical health conditions impact on psychological difficulties and coping responses. Also, in particular for individuals living in low income countries, poverty, housing difficulties and poor access to medical care negatively impacted on mental health. This is in line with Moss-Morris' (2013) 'unified' model of adjustment that cites multiple causal factors for poor adjustment that are relevant to individuals with HIV and comorbid health conditions. These factors include low socio-economic status, difficult treatment regimens and an uncertain future. Research in a high-income country – the UK – has also found that black African men and women living with HIV, reported difficulties in relation to employment, income, housing and residency status (Ibrahim, Anderson, Bukutu, and Elford, 2008). An additional area for research could include, quantitative research comparing how levels of mental health differ between individuals living with HIV and those living with HIV and comorbid health difficulties. This would allow insight into what the additional impact of living with a comorbid health condition is on PLWH's mental health in males and females of all age groups.

Strengths and limitations of the review

A strength of the current review is that it was conducted across high- middle- and low-income countries: seven studies were conducted in South Africa, six in the USA, two in Ethiopia, two in India, one in Ghana, one in Zambia, one in Ireland, one in Canada, and one in the UK. For the studies that did provide information about the age of their participants, this was consistent with an age range between 18 and late sixties. This suggests that the findings of this review can be transferable across much of the adult age span and to similar contexts. Another strength of the review process was that eligible studies and study quality were independently reviewed by a second reviewer with the resolution of any disagreements by a third reviewer. This practice helped to increase the reliability of decision making during the review process. An additional strength of the review process is that the quality of all included articles was assessed. This enabled informed decisions to be made about the reliability of studies' findings and whether they provided meaningful answers to the review question. The Networked Digital Library of Theses and Dissertations was used to search for unpublished and grey literature, which provided a more comprehensive view of the literature available. As a recommended approach was used to analyse the qualitative data (Popay, 2006), this is another strength of the review. This allows for the review to be replicated and increases the transferability of the results found.

A limitation of the search strategy was that the key terms were only searched for in the titles and abstracts and the authors were not contacted to determine additional demographic information. The search strategy was deemed efficient given the limited resources available for the review. Whilst this method enabled the majority of relevant articles to be found, a more comprehensive search strategy may have found additional

articles. There may have been studies missed by the electronic search. To further increase the likelihood of all relevant papers being identified citation chaining (i.e., searching backwards and forwards in time for materials that are cited by and also that cite an article or resource already found) could have been used. This would help improve robustness of the search and the likelihood that all of the relevant papers were identified.

Another limitation was the exclusion of non-English language studies. This limits transferability of findings to other settings/speakers of languages other than English. In addition, the findings from Anku et al. (2017), which focus on management of comorbid health conditions, need to be interpreted with care as the authors provide no demographic information about age or gender. Without this information, transferability is unclear. There were also issues resulting from the quality appraisal. These include the relatively low number of papers (four papers) where the researcher authors clearly acknowledged their contribution (and potential for bias) to the research findings. In addition, the Kappa agreement score reflecting inter-rater reliability (i.e., how different assessors respond to the same questions and how consistently they score the response) was moderate. Scales which are designed to give a summary 'quality' score can lead to an over-simplification of quality assessment and can have greater risk of problems with inter-rater reliability. This may be linked to researcher influences, for example where the undergraduate student-rater had less familiarity and expertise with the research process. This may have impacted on the importance they attached to rated features of the articles. To help improve inter-rater agreement among inexperienced raters, a pilot phase could occur where raters rate the quality of a subsample of articles to allow for the identification and clarification of areas of ambiguity.

Research implications

The review has many implications for future research. A future systematic review into this topic would benefit from a search strategy including searching for terms in the body of the article text as well as titles and abstracts. This may increase scope and allow for additional articles to be found, increasing knowledge of this area. HIV stigma is a theme that was elicited in many articles looking at individuals living with HIV and comorbid health conditions. Further research into the anticipated and experienced HIV-stigma that individuals living with HIV and comorbid physical health conditions face would aid understanding of how stigma related to HIV and other physical health conditions emerge in this population. Limited education and knowledge about HIV in low income countries has been found to lead to beliefs that support stigmatizing attitudes (Bos, Schaalma, & Pryor, 2008). In addition, Nyblade, Pande, Mathur, MacQuarrie, and Kidd (2003) found that many individuals linked behaviours that led to HIV with going against religious teachings and as a punishment from God due to sins being committed. Additionally, culture-informed beliefs exist about HIV, for example that it is caused by witchcraft in Tanzania and Zambia (Nyblade et al., 2003). Nyblade et al. (2003) also identified demographic factors that shape stigmatizing attitudes, for example individuals with low socioeconomic status were found to experience more stigma because of their inability to hide their status and seek the best care. It would be helpful to delineate specific cultural factors that contribute to stigma across different cultures and countries to help inform intervention efforts. It could also support researchers and healthcare practitioners in learning how best to minimise it. Also, other than non-disclosure, little is known about the strategies used by individuals with HIV and comorbid physical health conditions to cope with stigma. Research into these areas across a range of

settings may suggest changes that would greatly enhance the support that is offered to these groups.

Future research would also greatly benefit from providing more detailed demographic information about their participants. This includes: ages of participants, time since HIV and other physical health diagnoses, and sexual orientation, including whether participants are men who have sex with men (MSM). This would allow readers to gain an understanding of the participants included in the studies and allow for more effective comparison of studies looking at different risk groups. Future research into whether these themes are prevalent in other populations would be helpful. Studies included in the review did not refer to theories of adjustment. This may have been helpful when thinking about the wellbeing and mental health of HIV-positive individuals living with comorbid physical health conditions. For example, Leventhal, Meyer & Nerenz (1980) proposed the Common Sense Model (CSM) of illness representations – that individuals develop simultaneous cognitive and emotional representations about their illness, which can influence the way they appraise and manage their illness. Offering HIV and comorbid physical healthcare education sessions to newly diagnosed patients may help them to feel more supported within the healthcare system. Information provided on managing HIV and comorbid health conditions could support patients with the cognitive aspects of adjustment around illness beliefs, supporting them to learn coping strategies that can make managing their illnesses easier, reduce feelings of threat and increase beliefs about treatability and controllability. This can positively impact adherence. For example, intentional adherence is associated with the balance of perceived benefits and losses of taking medication, and the extent to which participants were prepared for the effects of medication (Wroe & Thomas, 2003).

Practice implications

This review has highlighted implications for future practice. The UK Standards of Care for People Living with HIV (PLWH) state that, “People living with HIV should receive care and support that assesses, manages and promotes their emotional, mental and cognitive well-being and health, and is sensitive to the unique aspects of living with HIV” (British HIV Association - BHIVA, 2018, p. 50). In addition, it states that “People with several long-term conditions, who face economic hardship and/or who have alcohol or substance use problems are more likely to have mental health difficulties that may be more complex. The standards for psychological care are likely to be of particular importance” (BHIVA, 2018, p. 41). The psychosocial needs of HIV-positive individuals with comorbid physical health conditions are not outlined in detail here and it remains a relatively under-researched area. BHIVA also advocates for the use of care coordinators as “People with multiple needs will often have a number of agencies or services involved in their care, but they may also be the least able to make best use of these services and face challenges in attending the multiple appointments that are often required (British HIV Association – BHIVA, 2018, p. 41). Given that this review has highlighted difficulties of living with HIV and comorbid physical health conditions, more could be done to help support this population to access and receive psychological support. Psychological support is defined as “any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing” (BHIVA, 2011, p.72). To help improve the support offered to PLWH and comorbid physical conditions, individuals who are not accessing psychological support, the situated-Information Motivation Behavioral Skills Model of Care Initiation and Maintenance is useful to draw on (Rivet Amico, 2011).

The model proposes that for someone to receive psychological support they or someone else: needs to be aware that they have difficulties that are appropriate for psychological support; needs to have the motivation to seek psychological support; and they or someone else needs to have the skills to obtain psychological support. These areas could be explored with patients, their families and healthcare professionals to find out what support PLWH and comorbid conditions would find most helpful to promote patient centred care.

In addition, psychoeducation could be provided on aspects of living with HIV and a physical health condition to patients alongside their friends and family. This may help to reduce the impact of stigma associated with living with these conditions.

Psychological interventions such as Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 1999) and Compassion Focused Therapy (Gilbert, 2009) have been found to help promote flexibility of responses to experiences of societal stigma and increase compassion whilst decreasing shame (i.e., an affective state linked with self-stigma) in a group of PLWH (Skinta, Lezama, Wells & Dilley, 2015). Such interventions could be provided in services with care taken to deliver these in culturally informed ways. BHIVA (2011) states that PLWH are entitled to screening to identify psychological support needs. It might be helpful to complete an audit on the number of people with HIV and comorbid physical health conditions receiving this, and the type of support offered and taken up. Demographic information could also be collected. Where screening doesn't happen, it would be helpful to identify reasons for this, and how to support clinicians with this. Where individuals are from black and minority ethnic (BME) communities living in high income countries, they are less likely to be offered or to take up, and more likely to drop out of, talking therapies (BHIVA, 2011). It is

suggested that clinicians discuss any potential difficulties and discuss support options (including services specifically for BME communities) with this group. This can support individuals to develop and maintain social relationships. BHIVA (2011) also recommends that PLWH should receive confidential and non-stigmatising care. The findings of the review, suggest that it may be helpful for clinicians to place emphasis on discussing confidentiality and building trust when working with PLWH and comorbid health conditions to help promote engagement.

3. Developing a model of the individual and social processes of living with HIV and TB co-infection in UK migrants

Abstract

In the last two decades, TB has re-emerged in the UK, linked to HIV infection and today's migratory phenomenon. HIV/TB co-infection is of psychological interest in UK migrants as stigma is associated with both conditions and may affect psychological, social, and physical adjustment. Experiences of being a migrant may complicate adjustment to HIV/TB co-infection including immigration status, acculturation and discrimination. No research has focused on adjustment for migrants with HIV/TB co-infection in high income countries. Interviews with nine participants (six males and three females; 33- 63 years) were analysed using Grounded Theory Methodology. A theory was developed that aims to explain the individual and social processes involved in living with HIV/TB co-infection in UK migrants who were recruited via two HIV-services across London. Semi-structured interviews were transcribed and coded. Seven theoretical codes were identified 1). Migrating to the UK 2) Ideas of HIV and TB prior to receiving diagnoses 3) Accessing healthcare up to the point of receiving HIV and TB diagnoses 4) Experiences whilst accessing specialist HIV and TB care 5) Managing disclosure of HIV and TB 6) Managing mental health after receiving HIV and TB diagnoses 7) Appraisal and coping with HIV and TB. The findings suggest that delayed access to care impacted the mental health of participants. Participants also anticipated stigmatising responses to disclosure of HIV and preferred to disclose about TB - linked to its perceived curability. Participants reported good relationships with healthcare professionals and many drew on religious beliefs to help them make sense and cope with their illness challenges. The research could help increase the confidence and hope

of people living with HIV and TB. In addition, it could help increase knowledge and confidence of healthcare professionals and other agencies in how best to support migrants living with HIV/TB co-infection in a high-income setting.

Introduction

HIV

HIV is a virus that damages the cells in the immune system and weakens its ability to fight everyday infections and disease (for more details on HIV, see the Executive Summary on p.7). Treatment consists of Antiretroviral Therapy (ART) which fights HIV by interfering with the reproduction of the virus in the body (WHO, 2017). HIV continues to be a major global public health issue. In 2018, 37.9 million people globally were living with HIV with 1.8 million people newly infected with HIV in that year (UNAIDS, 2018). In 2017, 102,000 people were living with HIV in the UK with 4,363 people were newly diagnosed with HIV (PHE, 2018a). The UK government has set out a commitment to end transmission of HIV in England by 2030 (DHSC, 2019).

Tuberculosis (TB)

TB is an infectious disease and the leading preventable cause of death worldwide for people living with Human Immunodeficiency Virus (HIV). TB usually affects the lungs, but TB-causing bacteria can attack any part of the body. When TB enters a person's immune system the bacteria may be cleared, the individual may become unwell with active TB, or the bacteria may enter a state of equilibrium with the immune system in which the host remains well but the bacteria remain 'dormant' – this is latent TB (LTBI). TB treatment typically entails taking antibiotics for several months.

Multidrug-resistant TB (MDR-TB) is TB that does not respond to at least isoniazid and rifampicin, the two most powerful anti-TB drugs (WHO, 2018).

TB accounts for around one in three AIDS-related deaths (UNAIDS, 2018). In 2017, 10.1 million people were diagnosed with TB, and of those, approximately 9% were living with HIV, largely in low- and middle-income countries (UNAIDS, 2018). It is estimated that 49% of people living with HIV and TB are unaware of their HIV/TB co-infection and are not receiving care (UNAIDS, 2018). HIV and TB infection and disease can increase the progression of one another (Mayer & Hamilton, 2010). In the last two decades, there has been a resurgence of TB in the UK, linked to HIV infection and increased migration of people from areas of the world where TB is more common than in the UK (Lönnroth et al., 2015). In 2017, there were 5,102 UK cases of TB (WHO, 2018). In England, the prevalence of HIV co-infection among TB patients is between 5-9% (Kruijshaar et al., 2010), with 80.1% of HIV/TB co-infected individuals being non-UK born (PHE, 2018b). Of note, non-pulmonary TB is not presented in PHE annual reports as it does not present a public health risk to others.

In 2014, PHE and the National Health Service (NHS) in England launched a “Collaborative Tuberculosis Strategy” to address the “marked contrast” between the higher incidence of TB in England compared to other high-income countries in Europe and North America (PHE, 2015). The ambition of the strategy was “to strengthen TB control, with the aim of achieving a year-on-year decrease in incidence” (PHE, 2015). In 2018, the first ever UN high level meeting on TB took place and set targets to treat 40 million people with TB by 2022.

HIV and TB pose multiple adjustment challenges. Similarities and differences exist between TB and HIV: TB is curable, whereas HIV is not; both conditions are infectious and have potential public health risks, but with different transmission routes; treatment for active TB can be complicated and prone to side effects than HIV. In addition, both conditions can remain latent/undetected for many years and require monitoring one's health to reduce the risk of negative health effects (WHO, 2012).

Migration

There is no consensus on a single definition of a 'migrant'. Definitions of 'migrant' vary across data sources, and between datasets and law. Migrants might be defined by foreign birth, by foreign citizenship, or by their movement into a new country to stay temporarily (sometimes for as little as a year) or to settle for the long-term. Worldwide, the incidence of TB rises with rising levels of deprivation. In high-income, low TB-incidence countries however, TB is also associated with immigration (Suk et al., 2009). The majority of HIV/TB co-infection cases – 80.1% in England (PHE, 2018b) occur in people who are foreign born. Migrants with HIV or TB can encounter challenges such as communication problems, loss of social support and adapting to new surroundings, which can impact on accessing healthcare and complicate adjustment to these illnesses. Many may have undergone traumatic experiences pre-migration such as loss, separation from loved ones and violence (Warfa et al., 2012). They may also experience enacted stigma - perceived actual experiences of stigma and discrimination (Ho, 2004; Kulane, Ahlberg, & Berggren, 2010). Migrants with TB have been found to anticipate discrimination and rejection from others (Coreil, Lauzardo, & Heurtelou, 2004; Tardin, Dominice Dao, Ninet, & Janssens, 2009). In addition, individuals try to safeguard family dignity (Shiu, Park, & Kearns, 2008) by not disclosing their TB diagnosis to

family or friends, which in turn reduces access to long-term support. Within the migrant populations, stigma has also been linked to culturally-held beliefs. For example, within the Sub-Saharan African population in Belgium, HIV stigma is linked to beliefs about HIV affecting “bad people”, and those who were sexually deviant (Manirankunda, Loos, Alou, Colebunders & Nöstlinger, 2009). Such attitudes towards HIV may influence the way migrants perceive and manage living with HIV in high-income countries (i.e., a country with a gross national income per capita of US \$12,056 or more, World Bank, 2019).

At present a research gap exists for understanding more about the role of stigma for migrants with HIV/TB co-infection in low prevalence/high income countries. It is important to note that although the term “migrant” is widely used in the academic literature, in public discourse it has, for some, developed xenophobic connotations. This is partly linked to news coverage from particular media outlets, alongside policies explicitly designed to restrict access to public services for people without the legal right to live in the UK. Research in the area must take care when using the term “migrant” to avoid reifying the experience of this heterogeneous group.

Stigma

Stigma has been conceptualised as a socially ‘devalued attribute’ which in turn affects the way people react to knowledge that they do or do not possess the devalued attribute. HIV has been offered as an example of such an attribute (Earnshaw & Chaudoir, 2009). Previous research with individuals with HIV has identified three forms of stigma that may be directed at HIV. Internalised stigma, enacted stigma and anticipated stigma (see p.19 for definitions; Earnshaw et al., 2013). Research with people with HIV has found that these different types of stigma result in greater social burden of illness and can

delay accessing medical care and decrease treatment adherence (Bogart et al., 2011; Gary, 2005).

Disclosure of HIV status is a psychosocial challenge for people with HIV and internalised stigma is a barrier to disclosure and linked to less perceived support (Overstreet, Earnshaw, Kalichman & Quinn, 2013). Disclosure is linked to positive health behaviours including adherence to treatment in people newly diagnosed with HIV (Hult, Wrubel, Bränström, Acree & Moskowitz, 2012). Support within relationships can provide comfort for people living with HIV (Harvey & Wenzel, 2002) and also facilitates adherence to treatment for people with TB (Ito, 1999). However, disclosure can leave people with HIV vulnerable to negative social evaluation from family, friends, sexual partners and employers and result in greater stigmatisation (Derlega, Winstead, Greene, Serovich & Elwood, 2004). Research with individuals with TB also shows that disclosure can impact negatively on holding employment (Kirwan, Nicholson, Baral, & Newell, 2009).

With regard to HIV/TB co-infection, research on stigma has occurred in high prevalence settings. For example, a South Africa based study (Daftary, 2012) found that HIV/TB co-infection resulted in a ‘double stigma’ where identities associated with TB became more undesirable and stigmatised. Participants perceived TB as making visible their HIV status. This reinforced the stigma of having HIV and perpetuated and renewed stigma against TB, impacting negatively on disclosure of both. Also, greater perceived/anticipated TB stigma has been found to be associated with non-disclosure of HIV/TB co-infection in a high incidence setting with the potential to negatively impact on relationships (Hayes-Larson et al., 2017). Ethnographic work has highlighted how

social barriers including stigma, nondisclosure and a lack of support challenge HIV/TB patients' help-seeking for dual care (Chileshe & Bond, 2010).

Psychological models of adjustment

Adjustment to HIV diagnosis is a complex and difficult task. Many aspects of HIV diagnosis are stressful, for example, the need to adhere to treatment, fear of death, disclosure decisions and interactions with a complex medical system. The Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) proposes that coping is part of a process in response to the demands of a situation that is appraised as stressful. A meta-analysis (Moskowitz et al., 2012) of types of coping that related to psychological wellbeing in people with HIV found that “direct action” (e.g. finding a healthcare provider) and “positive re-appraisal” (e.g., “I have learned something from this experience”) were associated with better outcomes for people coping with HIV. Social support can also moderate adjustment and coping to an HIV diagnosis (McDowell & Serovich, 2007; Peterson et al., 1996; Schmitz & Crystal, 2000).

Moss-Morris' (2013) model of adjustment aims to take a unified approach to the adjustment of chronic conditions and cites multiple causal factors for poor adjustment that are relevant to individuals with HIV and/or TB, including migrants. These factors include a change in identity and life roles, lower levels of social support and socio-economic status, difficult treatment regimens and an uncertain future. This model suggests good adjustment is represented by less distress, less impact on identity/life roles and relationships, good illness management and positive affect. This highlights that individuals can be in adjustment equilibrium and disequilibrium at different times.

The Common Sense Model (CSM; Leventhal, Meyer & Nerenz, 1980) of illness representations is also relevant to individuals with HIV and/or TB. It proposes that individuals develop simultaneous cognitive and emotional representations about their illness, which can influence the way they appraise and manage their illness. These are proposed to include five main cognitive domains: 1) identity (illness label and symptoms), 2) timeline (beliefs about how long the illness will last), 3) consequences (beliefs about the physical and social impact the illness will have), 4) cause (beliefs about the perceived cause of illness), and 5) perceived controllability/curability of the illness. In addition, a non-cognitive domain of emotional perceptions of illness (e.g., degree of worry or fear) is included.

Many studies into the effects of diagnosis have drawn parallels between it and the grief process (Kübler-Ross & Kessler, 2005). There can be a mourning for the loss of the self who was unaffected by health problems. In the same way as grieving, adjusting has been proposed to be a process rather than an event. The stages of grief (Kübler-Ross, 1969) can be a framework for understanding the adjustment to diagnosis. Stages to the process include (1) Denial 'This can't be happening'; (2) Anger 'Why me?', 'It's not fair', 'who is to blame?'; (3) Bargaining 'If only I could have done things differently'; (4) Depression 'I'm so sad', 'what's the point?', (5) Acceptance, 'It's going to be OK', 'I can take control and manage this'. Not everyone with a diagnosis will experience all of these emotional reactions, or in this particular order. Many people will shift between a number of these stages over many years.

Adjustment to HIV is challenging and many experience depression (Do et al., 2014; Sherr et al., 2011). Research on the link between HIV/TB co-infection and depression and anxiety has occurred in Ethiopia (a high prevalence HIV/TB co-infection region)

where higher rates of both mental health difficulties have been found for those with HIV/TB co-infection versus those solely with HIV (Deribew et al., 2010). These findings however cannot be generalised to UK migrants given the many differences in socio-medical contexts, and no research has focused on adjustment for migrants with HIV/TB co-infection in high income countries. HIV/TB co-infection in the context of migration may come with particular adjustment challenges. These include changes in medical context, with greater medication availability and differences in integrated care which may impact on adjustment.

Migrants may also be more isolated, with difficulties adjusting to a different country/language (Ho, 2004). Uncertainty of immigration status is a mental health risk (Kirmayer et al., 2011), and as TB is a statutorily notifiable disease, this may potentially impact on presenting for care and adjustment for some migrants. For TB, directly observed therapy (DOTS) treatment schedules that expect patients to attend to a TB clinic in their community daily, can reinforce existing stigma (Craig, Daftary, Engel, O'Driscoll, & Ioannaki, 2017). These adjustment difficulties may also be applicable to migrants with HIV/TB co-infection in low prevalence/high income countries, and further research on this is required.

Rationale for the current study

The literature supports the view that stigma is associated with HIV and TB and may affect presenting to care, treatment adherence, HIV/TB disclosure, psychological, social and physical adjustment and mental health outcomes. Research on HIV/TB co-infection has often occurred in high prevalence regions – for example, on experiences of stigma (Daftary, 2012) and disclosure (Hayes- Larson et al., 2017) and their potential to negatively impact relationships. These findings, however, cannot be generalised to UK

migrants given the many differences in socio-medical contexts, and no research has focused on adjustment for migrants with HIV/TB co-infection in low prevalence/high income countries.

The current study will address this gap by using a sample of UK migrants with HIV/TB co-infection. The term migrant is used in the current study to refer to any person who has come to reside outside the nation in which they were born. The change in setting is important as it is possible that the perceived impact of living with HIV/TB co-infection may be influenced by having lived in different settings. Also, there could be culturally-held beliefs linked to this, and this is an under-researched area. An increased understanding of the experience of UK migrants living with HIV/TB co-infection may aid the development of interventions focused on supporting adjustment in this population. Questions will be asked about participants' experiences of having each condition respectively and HIV/TB co-infection. In addition, further questions on perceptions of having these diagnoses in their country of birth and in the UK will be asked to understand more about culturally-held beliefs.

Research aims and question

The aim of the study is to develop a model of the individual and social processes involved in living with HIV and TB in UK migrants. The study aims to answer the following research question:

What is the perceived impact for UK migrants living with HIV/TB co-infection on disclosure of both conditions, relationships, help-seeking, identity and adjustment?

Method

Research design

A cross-sectional qualitative design was used, drawing on Grounded Theory (Charmaz, 2006) to design, analyse and report the findings of nine semi-structured interviews with UK migrants who had been diagnosed with HIV and TB co-infection.

Participants

Fourteen participants were approached by clinicians involved in their care at two HIV clinics, and nine people who fit the inclusion criteria agreed to participate in the study (see Table 6 for further demographic details). In addition, one person was recorded on the patient database as being foreign born and he was interviewed after consenting to take part. On discussion with him, it was found that he was born in the UK but migrated abroad and then returned to the UK. As this meant that he did not fit the selection criteria, his data were not eligible to be used. Out of the fourteen participants approached, four participants (three females and one male) declined to take part. The most common reason cited was worry that being interviewed about their experiences would be too emotionally distressing.

Inclusion and exclusion criteria

Inclusion criteria:

- Participants were migrants (i.e. a person born outside the UK). This includes both long- and short-term migrants.
- Received a positive HIV test at any time from three months onwards, and a TB diagnosis between three months to five years at the time of interview. This

timeframe allowed for some adjustment to diagnosis, and for some post-test events to occur that are in line with the research questions. Participants with active, latent or cured TB were included.

- Participants were of any gender and 18 to 64 years old.
- All participants had a degree of English Language proficiency (i.e. understanding and responding to questions in English) to help ensure they could fully engage in the interview. This was assessed by clinicians at the relevant service.

Exclusion criteria:

- Evidence of significant risk of harm to self or others (e.g., self-harm, suicidal ideation). This was assessed by clinicians at the relevant service.

Recruitment source

Participants were recruited at specialist HIV-services with HIV/TB joint clinics at two London hospitals. Patients accessed these services following a referral by sexual health clinics, other hospital departments or GPs once they were diagnosed with HIV infection. Staff at the HIV services included HIV consultants, clinical nurse specialists and health advisers.

Data collection

Interviews

Data were collected via face-to-face semi-structured interviews (audio recorded). The interview schedule (Appendix A) was developed by the researcher and reviewed by academic and field supervisors. Questions asked were linked to participants'

experiences of HIV and TB before being tested for each condition, how they came to be tested for HIV and TB, experiences of finding out a positive result for HIV and TB, attendance at specialist clinics, taking medication, relationships with healthcare professionals prior to and after diagnosis, HIV and TB disclosure, relationships with family, friends, sexual partners and employers, and how they felt about having HIV/TB co-infection.

Feedback on the interview schedule was sought from a service user who did not fully meet the study's inclusion criteria (i.e., he was diagnosed with HIV; and with TB more than five years ago) on content and areas of the questions, and the language used. The service user commented on four aspects: First, he queried the use of the word 'migrant' on the participant information sheet as he wondered if this would be perceived as a stigmatising label. He reported that after reading through the interview protocol he felt more assured that the word 'migrant' was acceptable and that he did not think there was a better alternative word or phrase to be used. Second, he wondered how applicable it was to ask participants about what it was like learning English as a new language, as there may have learnt it a long time ago. He agreed that it would be useful to retain the questions as there may be participants who had learnt English more recently. Third, the service user commented on his own experience of increasing his alcohol intake to help himself cope with his HIV and TB diagnoses and advised that a question on coping and substance use could be included. Fourth, he commented on his experience of how continuity of care can be compromised if different clinics are accessed and to include a question on this. The interview schedule was adapted in response to the feedback comments. A mock interview with the academic supervisor provided further

opportunity to practice using the interview schedule, refine questions, and receive feedback.

Measures

Participants completed a demographics questionnaire to provide additional contextual information (Appendix B). Participants' most recent Viral Load, CD4 count and treatment information were obtained from their medical records (Appendix C). The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983; See Table 7) was also completed by participants, as it has been identified as a useful screening tool for depression in HIV populations (Savard, Laberge, Gauthier, Ivers & Bergeron, 1998) and can help contextualise the qualitative experiences of participants.

Grounded theory

Grounded Theory methods are suitable for studying individual processes, interpersonal relations and reciprocal effects between individuals and larger social processes. The approach is also useful for studying personal experiences and emotions (Charmaz, 1995, cited in Smith, Harré & Van Langenhove, 1995). Grounded Theory's distinctive feature is that it facilitates the development of theories to explain behaviour (Charmaz, 1998) that can provide further understanding of many processes present for the HIV/TB co-infection population. In the context of adjustment in UK Migrants with HIV/TB co-infection, this is particularly applicable because many of the key processes after receiving a diagnosis are social (e.g. disclosure to friends, family, partners and employers, help-seeking and discussing the diagnosis and management of both conditions with health professionals). The resulting model was grounded in the data to allow for suggestions of causal connections that could support the development of HIV/TB co-infection interventions facilitating adjustment.

Table 6. Participant Demographic Information

Pt #	Age at interview (years)	Gender	Employment status	Relationship Status	Children	Region of birth	Immigration Status	Time in UK (years)	Time since diagnosis (years) at interview	Most recent CD4 count (cells/uL; time since)	Most recent Viral load (copies m/L; time since)	On ART	TB Treatment (duration)
1	33	Male	Employed	In a relationship and living together	No	Europe	EEA National	5	HIV (1yr 2m) TB – P & LN (1yr 1m)	350 (1m)	435 (1m)	Yes	Treated – Ended (6m)
2	53	Female	Employed	Married	No	Southern Africa	EEA National	10	HIV (1yr 9m) TB – MDR, P (1yr 8m)	452 (1yr)	<20 (8m)	Yes	Treated – Ended (1yr 7m)
3	42	Male	Unemployed	In a relationship but not living together	Yes	East Africa	UK National	24	HIV (1yr 7m) TB – LN; P; brain abscesses (1yr 7m)	238 (5m)	51 (1m)	Yes	Treated – Ended (11 m)
4	34	Male	Employed	Single	No	Europe	EEA National	9	HIV (6yrs) TB - P (1yr 11m)	785 (11m)	31 (6m)	Yes	Treated – Ended (6m)
5	54	Male	Unemployed	Married – separated and not living together	Yes	South Asia	EEA National	3	HIV (2yrs 11m) TB - P (2yrs 11m)	750 (1yr 6m)	<20 (1m)	Yes	Treated – Ended (1yr)

Pt #	Age at interview (years)	Gender	Employment status	Relationship Status	Children	Region of birth	Immigration Status	Time in UK (years)	Time since diagnosis (years) at interview	Most recent CD4 count (cells/uL; time since)	Most recent Viral load (copies m/L; time since)	On ART	TB Treatment (duration)
6	43	Male	Unemployed	In a relationship but not living together	No	West Africa	Asylum seeker awaiting decision	5	HIV (1yr) TB – D (1yr)	143 (1m)	81 (1m)	Yes	Treated – Ended (1yr)
7	49	Female	Unemployed	Single	Yes	Southern Africa	Indefinite Leave to Remain	16	HIV (9yrs 2m) TB - Sp (1yr 10m)	358 (5m)	<40 (5m)	Yes	Treated – Ended (1yr)
8	50	Male	Unemployed	Married	Yes	East Africa	Indefinite Leave to Remain	13	HIV (11yrs) TB - P (4yrs 6m)	412 (7m)	<20 (1m)	Yes	Treated – Ended (9m)
9	63	Female	Employed	Single	Yes	South-east Asia	Expired tourist visa	18	HIV (2yrs 4m) TB - LN (2yrs 4m)	275 (1m)	94 (1m)	Yes	Treated – Ended (6m)

Note. Participants' regions of birth are specified rather than countries of birth to retain anonymity. An undetectable viral load is <50 copies/mL; TB – MDR = Multi-Drug Resistant; P = Pulmonary; LN = Lymph node; D = Disseminated; Sp = Spinal.

Theoretical sampling and theoretical saturation

Grounded Theory methodology often makes use of theoretical sampling – the process of data collection directed by evolving theory rather than predetermined population dimensions (Strauss, 1987). Data collection should continue until theoretical saturation (also known as data saturation) is met (when no new information or themes can be observed in the data). However, there is little guidance on the sample size needed for saturation to occur (Guest, Bunce & Johnson, 2006; Vasileiou, Barnett, Thorpe & Young et al., 2018). The study aimed to use theoretical sampling but given the limited time-frame to recruit participants and four participants declining to take part, this was not possible. All available participants were recruited. For the current study, the specificity of the research aims and the constrained inclusion criteria – foreign born individuals who have been diagnosed with HIV and who have had a diagnosis of TB within the past five years – meant that the study was more likely to reach saturation of themes with a relatively small sample. However, the relatively small sample size meant that theoretical sufficiency was unlikely to have been reached - where all categories were developed to a sufficient extent to explore their relationships and draw conclusions (Charmaz, 2006; Dey, 1999).

Table 7. Self-reported Hospital Anxiety and Depression Scale

Participant #	HADS Anxiety score ¹	HADS Depression score ²
P1	4	1
P2	4	1
P3	3	6
P4	6	3
P5	16*	16*
P6	7	9
P7	4	10
P8	2	0
P9	13*	7

Note. ¹ 0-7 normal anxiety, 8-10 mild anxiety, 11-14 moderate anxiety, 15-21 severe anxiety

² 0-7 normal depression, 8-10 mild depression, 11-14 moderate depression, 15-21 severe depression. * Indicates a clinically significant score.

Reflexivity

A constructivist approach views research as constructed, rather than discovered, which in turn fosters the researcher's reflexivity about their actions and decisions (Charmaz, 2006). Charmaz (2006) advises that researchers reflect on their own preconceptions of the data and the research process to ensure that the researcher's position, privileges, perspective, and interactions are accounted for as part of the research reality. As the researcher for this study, I am a 36-year old, Iranian-White heterosexual, female Trainee Clinical Psychologist. For part of the study I was working in a sexual health and HIV-service and this experience has helped me understand some of the issues facing those living with HIV such as concerns around stigma, disclosure and adjusting to living with a health condition. In addition, hearing about a family relative of mine experiencing TB in Iran at a time when treatment was not readily available increased my interest in the area. I believe it is valuable to think about individual and systemic ways of conceptualising presenting concerns and I try to maintain a curious stance (Cecchin, 1987) to help develop and revise a multiplicity of views relating to individual and social

processes. This stance contributed to the way that I understood difficulties associated with HIV and TB, such as stigma and adjustment. I had some understanding about HIV and TB prior to the study.

Procedure

Participants were sampled systematically from HIV-specialist services. All eligible participants were provided with information about the study by their clinicians via a telephone call or on the day of their appointment. If participants were interested in taking part and consented to be contacted by the researcher, they were either telephoned or met after their appointment and taken to a separate clinic room to discuss the study further. For those who were interested in taking part, a suitable time to complete the interview was arranged. Prior to starting the interview, the researcher gained informed consent which included going through the Participant Information Sheet (Appendix D), informing participants that they could withdraw from the process at any time, that the interview would be stopped immediately if they become upset or wished to terminate their involvement, the boundaries of confidentiality and how their data would be stored. Consent forms were signed by participants and the researcher (Appendix E).

Nine participants first completed the demographics questionnaire and then HADS between October 2018 and March 2019. Interviews were face-to-face and conducted in private rooms within the HIV clinics. Interviews lasted between 66 and 97 minutes (mean of 82 minutes). At the end of the interview, participants were provided with the opportunity to debrief and reflect on the experience. No participant left the interview demonstrating any clear distress.

Payment

Participants were paid with a £10 voucher for participating in the study. Travel expenses (up to £12) were reimbursed if they travelled to the clinic on a non-appointment day to participate in the study. All participants gave receipt of payment (Appendix F).

Analysis

Transcription

The audio-recorded interviews were transcribed verbatim by the primary researcher onto a computer for coding. The primary supervisor commented on an uncoded transcript.

Coding

Charmaz (2006) describes coding as the process of actively processing and naming the verbal data, and defining what is happening within the data. Coding within Grounded Theory occurs in three stages: First, open coding is used to generate a range of ideas and occurs inductively in the initial stages. Fragments of data (e.g., words, lines and text) are assigned names or codes to explore what is happening in the data. During this stage, the researcher conducted careful sentence-by-sentence coding for each transcribed interview. The internal supervisor verified the codes of two transcripts.

Second, with continuous data collection and simultaneous analysis, the coding becomes focused to explore reoccurring codes prevalent in the data. This process allowed the researcher to link together initial codes and make phenomena explicit that the participants might not have actively conceptualised (Appendix G). The internal supervisor verified the focused codes. Discussions between the researcher and internal

supervisor were held to examine the language used to describe the focused codes and to ensure that the codes were mutually exclusive. The internal supervisor looked at the relationship between lower and higher order codes to check for coherence and the extent that the analysis was logical. Feedback was also provided where codes covered similar content and could be merged. Codes were modified and developed as a result of this feedback and discussion.

Third, theoretical coding refined the final concepts. Focused codes were reviewed to see how they relate to each other, and then by reviewing memos, focused codes were shaped into theoretical codes and emergent Grounded Theory. Memos help minimise preconceptions of what the researcher thought was in the data, and help the researcher organise thinking about how the data fit together to form patterns and any emerging possible links between codes (Charmaz, 2006; Glaser & Strauss, 1967) (Appendix H). The internal supervisor also verified the theoretical codes and provided feedback on the language used to name the codes and the placement of the focused codes under each theoretical code. Following this, the internal supervisor provided peer review on the theoretical model and discussed with the researcher how the theoretical codes interacted with each in a diagram.

Ethical approval

Full ethical approval was gained from an NHS Research Ethics Committee (REC), as well as Research and Development (R&D) and Health Research Authority (HRA) approval, and approval from Royal Holloway University of London College REC. Ethical approval was received in July 2018 (Appendix I and J).

Ethical considerations

During the interviews, participants were asked to talk about sensitive experiences and it was important to ensure that they gave informed consent to what their involvement in the research would entail. Clinicians at each testing site, who were already aware of potential participants' HIV and TB-statuses, made the first point of contact. Participants were not contacted until three months post diagnosis to allow for some adjustment to diagnosis, and for some post-diagnosis events to occur for their experiences to align with the research questions. There was a named clinician at each testing site to offer support to participants if needed.

Quality assurance

Published guidelines on quality in qualitative research (Elliott, Fischer, & Rennie, 1999) were adhered to – *Owning one's perspective*: The researcher kept memos throughout to maintain self-reflexivity on the research process. These memos covered information on theoretical orientations and personal anticipations – those known in advance and those that become apparent during the research; *Situating the sample*: Participants' demographic information can be found in Table 6 to aid the reader's understanding of the sample and assess the transferability of findings; *Grounding in examples*: An extract of a transcript is included in Appendix G to show the process of interviewing and coding. The results section contains example quotes for each theme identified; *Providing credibility checks*: The internal supervisor provided credibility checks by reviewing and providing feedback on the interview schedule, interview style, coding and the developing theoretical model; *Coherence*: Coherence was aimed for by naming the theoretical codes and appropriately summarising the analysis whilst attempting to preserve nuances in the data. The emergent theory was mapped out diagrammatically

and a narrative of the model provided, to show clear and logical relationships among categories; *Accomplishing general vs specific research tasks*: Clarification of research conclusions that only apply to the participant group studied was made; *Resonating with readers*: The researcher aimed to present material in such a way that readers judge it as an accurate representation of the subject matter. This was done by examining and prioritising the language used by participants in the formation of codes and categories to support the validity of the resulting theoretical model. Data were presented in a way that expanded and sought to clarify readers' understanding of individual and social processes involved in living with HIV/TB co-infection in UK migrants.

Results

Data analysis identified seven theoretical codes that form the proposed theoretical model. These are shown in Table 8. The theoretical codes consist of 19 focused codes, each containing specific properties that were produced at the initial coding stage. A diagrammatic representation of the relationships between the theoretical codes is outlined and discussed. Quotes from the participants have been used to illustrate codes, and demonstrate how they are grounded in the data. Any identifiable participant information has been removed to ensure confidentiality, and the participants are referred by their designated participant number (P1 to P9).

Table 8. Theoretical Codes, Focused Codes, Initial Codes

Theoretical codes	Focused Codes	Properties of the code (initial codes)
Migrating to the UK	Reasons for migrating	Reflecting on pre-migratory life events Seeking new opportunities in the UK
	Life in the UK	Enjoying living in the UK Thinking about immigration status Describing employment conditions Supporting families abroad financially Identifying cultural differences related to social interactions
Ideas of HIV and TB prior to receiving diagnoses	Perceptions of HIV and TB in countries of origin	HIV being linked to death TB being considered common and linked to poverty
	Perceptions of HIV and TB in the UK	Not hearing people talk about HIV or TB in the UK
Accessing healthcare up to the point of receiving HIV and TB diagnoses	Prior testing for HIV	Receiving negative prior HIV test results
	Experiencing delays in HIV and TB testing	Feeling unwell and visiting the GP and hospital multiple times Presenting for emergency care Having multiple medical tests in hospital Feeling frustrated at the diagnostic uncertainty
	HIV and TB Testing experiences	Consenting to having an HIV test Not thinking about HIV or TB
Experiences whilst accessing specialist HIV and TB care	Receiving treatment for HIV and TB	Feeling distressed by the pill burden Feeling distressed by medication side effects Identifying reasons for non-adherence of HIV medication Getting into a routine of taking HIV and TB medication Describing challenges of having additional physical health conditions
	Financial burden	Not working and the financial impact of being unwell Describing precarious housing situations
	Relationship with healthcare workers after being diagnosed with HIV and TB	Caring and trusting relationships with HIV and TB healthcare workers Feeling hope when provided with information from healthcare workers Frustration and disappointment regarding non-responsive care Experiencing gratitude towards healthcare workers who provided support with gaining financial/housing entitlements
Managing Disclosure of HIV and TB	Disclosing HIV and TB status to others	Telling others about being HIV+ and their responses Partners and family members being tested for HIV and TB Preferential disclosure of TB over HIV+ status linked to TB's perceived curability Contemplating future disclosure of HIV
	Deciding not to disclose HIV and TB status to others	Silencing HIV following HIV diagnosis Not wanting others to worry about their health Distress linked to breaches of confidentiality

Theoretical codes	Focused Codes	Properties of the code (initial codes)
Managing mental health after receiving HIV and TB diagnoses	Feelings following HIV and TB test results	Feeling shock and disbelief following HIV and TB test results Experiencing worries and low mood Suicidal ideation and attempts
	Post-HIV and TB diagnosis and stigma	Describing HIV and TB-stigma Expressing or experiencing race related stigma
	Accessing psychological and HIV specific support	Attending HIV support organisations Identifying reasons for not attending HIV support organisations Being referred to and seeing mental health professionals
Appraisal and coping with HIV and TB	Thinking about how HIV was acquired	Confusion over how HIV was acquired Anger towards/regarding perceived sources of HIV
	Religious beliefs/practices in the context of HIV and TB	Feeling despair and praying to God for recovery Feeling protected by God Attending church
	Adjusting to living with HIV and TB	Believing that TB can be cured Reminding oneself of undetectable HIV status Positives of knowing HIV status
	Hopes for the future	Wanting to help others who are in need Wanting to return to work Hoping to socialise more and to be in a relationship

Migrating to the UK

Reasons for migrating

Four people reflected on pre-migratory life events and included events ranging from traumatic events such as war and threats to life, to a stressful marital split.

“I came from – from the wars, famine... the hardships and all that”. (P3)

Eight participants spoke about coming to the UK to seek new opportunities including escaping from difficult pre-migratory life events, to gain an education and to work.

Life in the UK

Five participants commented on how much they enjoy living in the UK and five participants spoke about changes to their immigration status – three of whom have

experienced fear linked this. One participant, arrived on a student visa and was, at the time of interview, seeking asylum. This participant worried that being returned to West Africa would mean that he could not access medical care for an additional diagnosis of kidney disease:

“What is really the problem with me is the dialysis, this alone. Going to [detail of West African country removed] with this is just like a death sentence, because I know of a lot of people that died because they could not, erm, meet up with the financial implications”. (P6)

Another participant described the waiting period to receive indefinite leave to remain as “scary” (P7).

One participant was in the UK on an expired tourist visa and she lived with the daily worry that she would be sent to prison.

“They will catch me, they will catch me, then they will put me to the jail!”. (P9)

All nine participants commented on working, and three described their concerns over receiving low pay. Three participants described supporting families abroad financially. One participant commented on how he felt an obligation to work rather than continue his education when he came to the UK from East Africa aged 18.

Three participants identified cultural differences between their countries of origin and the UK, where they perceived it as strange that that people living in the UK take less initiative to socialise.

“In this country, nobody have life. Everybody open the door, you go out, work, close the door, you go sit in your house.” (P8)

Ideas of HIV and TB prior to receiving diagnoses

Perceptions of HIV and TB in countries of origin

Four participants commented about their experiences of HIV being linked to death in their countries of origin:

“Well, the media portrayed it as a very scary thing. [...] ¹ Thin people, people lying on mattresses that are on the floor unable to move... erm, withering away... dying”. (P2)

Three participants from Sub-Saharan Africa linked TB to poverty:

“In [detail of East African country removed], quite a lot [have TB] because most poor people they get that because they live in tight place”. (P3)

Perceptions of HIV and TB in the UK

Five participants commented on not hearing anyone talk about HIV or TB in the UK prior to being tested.

¹ An ellipsis [...] denotes that a section of the extract has been removed to promote the clarity of the quote. Words placed between square brackets have been added by the researcher so that the extract can be easily understood. ¹

Accessing healthcare to the point of receiving HIV and TB diagnoses

Prior testing for HIV

Two participants spoke about previously being tested for HIV. This happened at sexual health services (SHS) and they received a negative result. One female participant described applying for a mortgage in Southern Africa and receiving a result indicative of HIV.

Experiencing delays in HIV and TB testing

Three participants noted that they had felt unwell and visited the GP and/or hospital multiple times before being going on to be tested for HIV and TB:

“I went to this hospital and the first thing they told me was, “This is not a problem, you have to go to your GP”. I said, I already went to my GP six times”. (P1; who was subsequently diagnosed with HIV and TB when he returned to his to seek care in his region of origin in Europe).

In total, seven participants described presenting for emergency care. All patients recalled attending hospital as out-or inpatients and having multiple tests performed, which many perceived as an unpleasant experience. Two participants spoke about feeling frustration towards there being diagnostic uncertainty.

“I kept asking “what’s going on?” and they said they still need to do more tests, more exams and more blood [...] The worst period of my life”. (P1)

HIV and TB testing experiences

Six participants spoke about consenting to have HIV tests, with two participants recalling presenting to emergency care so unwell that they are unsure if they were conscious enough for consent to be sought. One participant was not asked for consent when she was tested for HIV during an antenatal blood test. Seven participants described not thinking about HIV when they waited for the test results. All participants did not anticipate that they had TB.

Experiences whilst accessing specialist HIV and TB care

Receiving treatment for HIV and TB

Five participants spoke about there being a pill burden when taking HIV and TB medication together:

“Errrm, oh Jesus... I start with a big cocktail in the morning – at 7 o’clock in the morning. It would come with a cup. I remember one time I counted and there were like – just in the morning – there were like 17 pills in that cup”. (P1)

Six participants commented on there being medication side effects when taking HIV and TB medication together:

“It’s like you just feel a sort of whizzing sensations on the ears [...] I just felt unwell. Sometimes, I thought, ‘I just feel sick’. So unwell. If I’ve eaten, then I’d bring up food. So I just didn’t like it”. (P7)

Five participants commented on reasons for HIV medicine non-adherence including feeling “lazy” (P9) and not being a “medicine person” (P2). In addition, for one participant:

“When I was diagnosed I was well and there was nothing wrong with me. [...] So I left my medication for almost three years. I decided not to take it”. (P7)

Three participants spoke about getting into a routine of taking HIV and TB medication. Four participants described the challenges of experiencing additional physical health conditions such as cytomegalovirus (a virus in the herpes family that can spread from person to person through body fluids), hepatitis, kidney disease, diabetes mellitus and chronic pain.

Financial burden

Four participants described their worries about how having HIV and TB had a negative impact on their finances due to them not working, as this put them at risk of eviction/homelessness. Three participants reported living in temporary/precarious housing after being diagnosed with HIV and TB:

“I try to sleep in [detail of London station removed] for two nights! On the third night, I’m sitting down in [detail of location of London takeaway restaurant removed] and that time I saw my friend, and then my friend tell me that, “Oh, I have a friend! Oh, so I will ring my friend and you can go in her house”. (P9)

Relationship with healthcare workers after being diagnosed with HIV and TB

Nine participants described experiencing caring and trusting relationships with HIV and TB healthcare workers:

“Same with [detail of nurse’s name removed], She was very lovely every time she comes, big smile, and then she’d say, “how are you?”. Oh so lovely, yeah, because none of my family and none of my friends come to visit me, so I was happy, I was happy”. (P5)

Two participants spoke about feeling hope when provided with information from healthcare workers.

“Yeah, they let me know, and how and why, and the treatment, how’s it going. Yeah, they gave me quite good information. It gave me hope”. (P3)

Four participants experienced non-responsive care at times which elicited frustration and disappointment.

“It’s like it was kind of “Oh, medication. I haven’t got much time”, then they would go. I wanted somebody to sort of clarify to me what was that”. (P7)

Four participants spoke about how they were provided with support with entitlements to financial and housing assistance:

“They gave me HC2 certificate [that provides full help with health costs], which enabled me to claim. Before that time, there was no claiming, so I had to borrow

money, borrow money to go to the hospital. The nurses were very, very helpful”.

(P5)

Managing disclosure of HIV and TB

Disclosing HIV and TB status to others

Seven participants described disclosing their HIV status to at least one person close to them and, on the whole, received reassuring responses:

“I told him, it was like forever, and then afterwards, when I told him, at the time he was so – it was so instant that he just hugged me. He was shocked, and he just said, ‘don’t worry’”. (P2)

Three participants spoke about partners and family members being tested for HIV and one participant’s family members were tested for TB. One participant who was an inpatient found it very difficult when his partner was diagnosed with HIV and he was not available to be at home with him to offer him support.

“Being in hospital and [detail of participant’s partners name removed] tried to discover the HIV – if he has it as well... and then he had it, and then he didn’t know how to get support. But, because I was not very good in my mind I couldn’t...because I was taking 30 pills a day”. (P1)

Four participants spoke about preferentially disclosing that they have TB over HIV to friends and family, linked to TB’s perceived curability:

“I mean, TB, everyone knows – like my family. [...] I mean TB again is not something that I – that I thought, “Oh my God, I’ve got TB!”. There’s a cure.

When I got HIV, then yes, I thought like, “Oh my God, I’ve got HIV, now what am I going to do? I don’t want to tell”. (P4)

Six participants contemplated future disclosure of HIV and many displayed concerns about the anticipated responses of others (e.g. blame, rejection):

“And if I say this, “I have HIV, or I have this”, would they help me like that? They will think that you did, you deserve it, because they don’t know if I did or not”. (P5)

Deciding not to disclose HIV and TB status to others

Seven participants spoke about not wanting to disclose their HIV diagnosis for fear of being judged and rejected following HIV disclosure:

“They say “Ohhh he is positive, don’t go close to him, don’t eat together, don’t do it”, maybe it give you stress. And then you feel down, and then you go split with your friend and everything and then you go your own way”. (P8)

Three participants described deciding not to disclose their HIV or TB status as they did not want others to worry about them and their health.

“I don’t even want to think of it because the response [from the participant’s mother] will not be good – on her own health, not mine”. (P6)

Two participants experienced breaches of confidentiality regarding their HIV status. Participants were shocked and upset by this. One participant had requested a letter to show her children's school regarding her recovering from illness and advising that a relative would instead be attending her children's school that was located abroad.

"I asked for the letter for a supporting document to my children's school because it's like, I just want to get better and get back to work. The doctor said, 'This patient has HIV, the viral load is such and such'. The next appointment I saw the doctor I said, 'I didn't expect you to be saying...'" (P7)

For another participant, working as an in-house carer, her employer took her to a GP and asked her to show the GP her medication. This doctor then disclosed her HIV status to her employer, who responded by ordering her to leave her job and the accommodation she was living in for fear that she would "infect" their children:

"I give the medicine because, three times they ask me, 'you are taking medicine, and you give me the prescription, the one you are taking, so that I will know what to prescribe for the cough'. The doctor told the [detail of employer removed] that I have HIV. [...] The doctor shared... they shared. But the doctor do not know that I didn't tell them that I have HIV!" (P9)

Managing mental health after receiving HIV and TB diagnoses

Feelings following HIV and TB test results

Six participants reported feeling shock and disbelief following their HIV and TB diagnoses:

“I don’t believe!” I said, “no! how come that I have HIV?! [...] No... errr.... I don’t believe, I don’t believe that I have TB!”. (P9)

Four participants reported cognitions and worries relating to death:

“I was worried about my daughter. I didn’t want to die”. (P3)

All participants experienced worries and low mood after being receiving their HIV and TB test results. On the HADS, one participant scored in the clinical range for anxiety and depression, and one for anxiety only.

One participant described how he did not disclose to his mother about his diagnoses as he did not want to worry her. He felt low when his mother asked him to return to West Africa to see her:

“[The participant’s mother] has been telling me, “when are you coming back, when are you coming back? Do you want me to die before you come?”. That is it. So, if you go through this questionnaire [the HADS] you will see some of the answers there. There are things that are weighing me down”. (P6)

This participant (P6) also spoke about experiencing suicidal ideation although his HADS scores did not meet the threshold for anxiety or depression.

Another participant who scored the highest on the HADS for anxiety and depression attempted to take his own life when he was discharged from hospital having been an inpatient for three months:

“I climbed the bridge there – to give up. I didn’t see nobody coming when I climbed, and suddenly, two lady there [...] They both caught me, like, and start talking softly, “where you live? We come and leave you home”. They come home and leave me like that. I thinking what to do, then this come in my mind, “you are not giving up your life”. (P5)

Post-HIV and TB diagnosis and stigma

Two participants spoke about experiencing HIV related stigma from others, including a healthcare professional when accessing HIV and TB services.

“Even here at this clinic. I don’t know how many [detail of healthcare profession removed] are infected with HIV but it’s like I just felt so much stigma, “how can a [detail of healthcare profession removed] be infected with HIV?”. It’s like, there’s so much stigma attached to it”. (P7)

Two participants had experiences that demonstrated an intersection between TB and race-related stigma. A white participant from Southern Africa spoke about disclosing her TB status to her mother:

“And then I told her [participant’s mother] about TB, and it was like, “Oh! The garden boy has TB. All these blacks in this town have the TB. So you’ve got it as well now?” So... it hurt, it really hurt”. (P2)

Accessing psychological and HIV specific support

Two participants commented on attending HIV support organisations and found them beneficial:

“Yes, yes – to learn and sort of be open to other people who have got the same. To sort of be in the company of people with the same problem.” (P7)

Four participants identified reasons for not attending HIV support organisations, linked to not believing it would be emotionally beneficial to discuss their experiences with others. One participant indicated that he believed support groups give the impression of being helpful whilst only the organisers benefit.

“Just normally, any supporter, they think about themselves. Not think about anyone. And then they ask money from somewhere and they do some small thing and then after that they take money, they put in their pocket and take camera and photos and everything about how they spent money.” (P8)

No participants reported attending any TB related support groups.

Three participants had experiences of being referred to and seeing mental health professionals after being diagnosed with HIV and TB. Two participants saw psychologists who they experienced as inattentive and unhelpful:

“The hospital had a psychologist come to see me. I didn’t like her [...] She annoyed me! She was like, you know, ‘I have to spend 30 minutes with this guy, ‘so how do you feel today?’. And I have no patience to people who don’t want to speak with me – just doing their job.” (P1)

Appraisal and coping with HIV and TB

Thinking about how HIV was acquired

Four participants spoke about their confusion over how HIV was acquired and three participants expressed their anger towards perceived sources of their HIV infection. One participant made a parallel between his beliefs about the origin of HIV and how he acquired HIV. In both cases he appears to place the responsibility on women and spoke about his anger towards his wife linked to his beliefs:

“When I was studying, it says like the HIV came from monkey. I didn’t understand... lady were having sex with monkey, and that lady have got that HIV from that monkey and she was sex with other men and that spread, like – same thing as that bitch my wife who gave what I have. She spread on me I think – I am guaranteed that”. (P5)

Religious beliefs/practices in the context of HIV and TB

Many participants spoke about their religious beliefs and practices in the context of HIV and TB. Two participants felt despair and prayed to God for recovery:

“I ask for healing. “Oh God, why you give it to me this one!” (P8)

Three participants spoke about feeling protected by God and this reducing their levels of worry.

“Ahh! I should have been dead by now – if I’m back home. I still know it’s the plan on God. Even coming here in the first place”. (P6)

“Well, I was brought up in a religious way. We know that [...] not all the problems they come to sort of punish you. Problems, they come.... your.... faith will be tested. You will still come out of it. It’s just a matter of time... [...], you know. You have got faith... you’re hoping for.... Then it’s like, [...] you know that God will help you to come out of that, whatever that... and... that’s put me in a position that I no longer worry about anything. I don’t worry about anything”. (P7)

Four participants attended church and found this helpful:

“Religion is good, and then you go church and you attend to church, like social life, community, everything is good”. (P8)

Adjusting to living with HIV and TB

Participants commented on a number of things that linked to adjustment to HIV and TB.

Six participants spoke about the belief that TB can be cured:

“You know, to get back to normal, you treat TB. TB, when you look after yourself, then you take the medication, you are free”. (P8)

Three participants found it helpful to remind themselves of having an undetectable HIV viral load. All participants spoke about the positives of knowing their HIV status and these included limiting unknowingly passing on HIV and fast access to medical help.

“Oh, knowing about it? Yeah, yeah of course! If I was not in a relationship – not me and [detail of name of participant’s partner removed], if I didn’t know, I would have passed it on to this person”. (P1)

“That whenever I need healthcare, I can just make a phone call and be seen by a doctor – convenience”. (P4)

Hopes for the future

Two participants reported wanting to help others in the future who are in need.

Participant 2 spoke in particular about feeling so strongly about helping another woman that she is prepared to overcome her inclination not to share with others her difficult experiences.

“I became very passionate in myself. I’d love to help one woman in my life before I die, who has experienced what I have and allow them just to enjoy their life, and not to have to go through it quietly. And I know I’m an introvert and I would rather keep it in than let other people realise how much it hurts”. (P2)

Three participants spoke about wanting to return to work and to socialise more and to be in a relationship.

Theoretical model of the individual and social processes involved in living with HIV and TB co-infection for UK migrants

The main aim of this study was to develop a theoretical model of the individual and social processes involved in living with HIV and TB co-infection for UK migrants.

Figure 2 outlines how the seven theoretical codes relate to each other in an explanatory model of living with HIV and TB co-infection for UK migrants. The black arrows present the processes described by participants, as captured in the theoretical codes. For example, the model indicates that participants' experiences of migration (e.g., experiences of multiple stressors) and ideas of HIV and TB (e.g., low risk awareness) impacted on them accessing healthcare prior to receiving HIV and TB diagnoses.

Experiences whilst accessing specialist HIV and TB care and how patients managed disclosure decisions led to post-diagnosis phenomena such as appraisal and coping with HIV and TB. A bidirectional relationship is hypothesised between appraisal and coping with HIV and TB and managing disclosure of these. The model indicates that there are several processes that seem to affect how mental health is managed including:

disclosure decisions - for example where planned (intentional) disclosure occurred, participants experienced reassuring responses which appeared to offer them support and improve their ability to cope. In addition, experiences whilst accessing specialist care - for example receiving support and being provided with information and updates about HIV and TB and their health - led participants to feel more hopeful and to cope better with having both diagnoses.

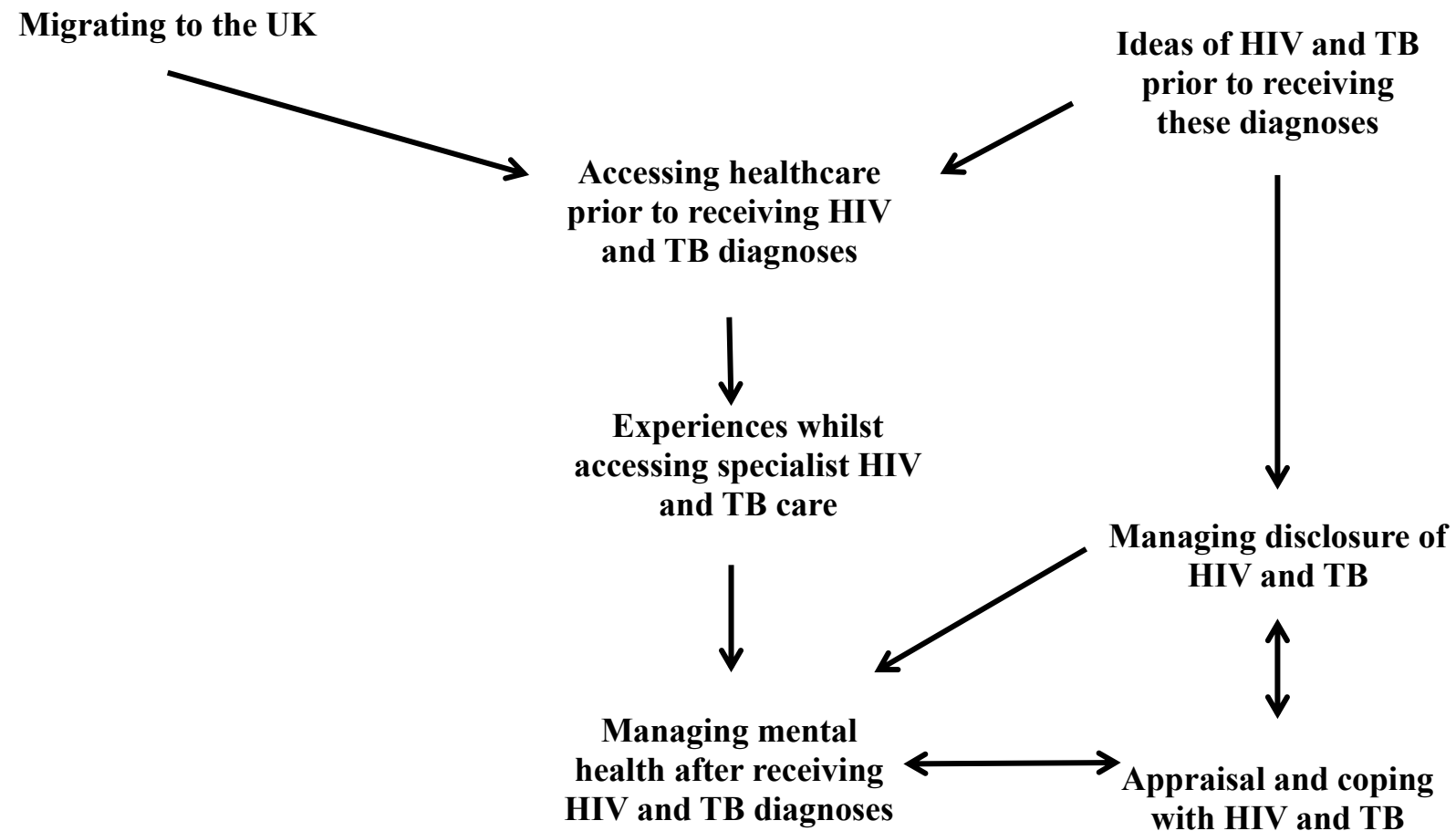


Figure 2. Theoretical model of the individual and social processes involved in living with HIV and TB co-infection for UK migrants

Discussion

Overview of study findings

This study explored the individual and social processes involved in living with HIV and TB co-infection in UK migrants. The study aimed to answer the following research question: What is the perceived impact for UK migrants living with HIV/TB co-infection on disclosure of both conditions, relationships, help-seeking, identity and adjustment?

Four participants had experienced stressful pre-migratory events (i.e., traumatic events such as war and threats to life, and a stressful marital split) prior to coming to the UK. This is in line prior research which outlines how migrants often have life experiences involving loss, separation from loved ones and violence (Warfa et al., 2012). In addition, seven participants did not have family members living in the UK and prior research has outlined how this can result in a lack of social support (Wilkinson & Marmot, 2003).

There appeared to have been delays to testing for HIV and TB that were both patient and health system related. Once in the UK, many participants had not considered the possibility that they had HIV and TB and seven presented to emergency care with severe symptoms. They did not label their physical health symptoms as related to HIV or TB when they were tested. Low risk perception in the current sample may in part link to the degree of variation in sample rates of HIV and TB co-infection in participants' countries of origin. For example, four of the nine participants were from countries that the WHO does not define as "high TB/HIV-burden countries" (i.e., high TB/HIV burden countries are defined as those that account for 97% of the estimated global

number of HIV-positive TB cases; WHO, 2015). This combined with the low incidence of HIV/TB co-infection in the UK (i.e., in 2017, 2.8% (139/4,924 of people with TB were estimated to be co-infected with HIV; PHE, 2018) may have further decreased awareness of the risk of having these conditions.

The HIV and TB diagnoses often occurred after multiple tests were carried out by UK sexual health clinics or health professionals located in hospitals. Many tests were provider initiated based on symptoms (i.e., when participants presented to Accident and Emergency). Although no official figures exist for the broader group of UK migrants, previous research has found that Sub-Saharan Africans are the community most affected by late HIV diagnosis in the UK (Nash et al., 2018). It appears that there were barriers to testing and missed opportunities for HIV and TB diagnoses. GPs and other health professionals may be reluctant to test their patients for HIV and TB even when faced with someone from an at-risk group presenting with HIV and TB symptoms. Different recommendations exist for testing for HIV: Since 2008, The National Institute of Health and Care Excellence (NICE) in the UK, and BHIVA's testing guidelines for HIV (BHIVA, 2008) recommend a routine offer of HIV testing to young people and adults in primary care settings where HIV prevalence exceeds 2 in 1000. BHIVA's (2008) testing guidelines for HIV also recommends routinely offering tests for all men and women known to be from a country of high HIV prevalence.

Only three participants spoke about previously being tested for HIV. Seven participants reported not thinking that they had HIV and all did not think that they had TB. This finding might be explained in part by the Precaution Adoption Model (Weinstein & Sandman, 1992). The model outlines seven stages of how a person comes to a new

decision, and how that person can take the decision and make it become an action. The stages covered are: (1) being unaware of the issue, (2) unengaged by the issues, (3) Deciding about acting, (4) Deciding not to act, (5) Deciding to act (6) Acting, and (7) Maintenance. Although most participants were aware of HIV and TB in their countries of origin, it appears they did not think that they would be at risk of HIV or TB. They reported not hearing HIV or TB spoken about in the UK and were unengaged by the issues prior to their test results. A decision to be tested did not therefore need to be made. Increased awareness and knowledge of HIV and TB in the UK may have helped participants to move from being stage 2 to stage 3.

There may be additional behavioural and psychological factors that explain HIV and/or TB risk perception. A systematic review by Evangelaki, Baker, Pady, Jones and Wroe (2016) examined the relationship between such factors and current HIV-risk perception. They found that the presence of symptoms perceived to be consistent with HIV was related to HIV-risk perception. In addition, many studies included in this review showed a lack of a relationship between one's own sexual risk behaviour and risk perception and this may be because in some situations one's behaviour is not appraised as an HIV-risk behaviour, perhaps because in the past similar behaviour did not result in HIV infection. Risk appraisal processes may therefore mediate the relationship between risk behaviour and risk perception in line with the Common Sense Model (CSM; Leventhal, Meyer & Nerenz, 1980) of illness representations. This appraisal process may act to minimise anxiety about current risk. Positive associations have been found between perceived HIV risk and HIV testing, and between HIV knowledge and testing. Participants may not be aware that their behaviour may have put them at risk and not

gone for HIV testing which is consistent with the findings of Evangeli, Pady and Wroe (2016).

All participants engaged well with HIV-specialist care after being diagnosed with HIV and TB and described good relationships with healthcare professionals at the HIV specialist services. The current model indicates that experiences whilst accessing specialist HIV and TB care helps participants manage their mental health following HIV and TB diagnoses. Receiving support and being provided with information and updates about HIV and TB and their health, led participants to feel more hopeful and to cope with having both diagnoses. It may be that receiving information altered participants' illness perceptions around controllability/curability. This is in line with the Common Sense Model (Leventhal, Meyer & Nerenz, 1980) that proposes that illness perceptions can influence coping strategies.

Participants reported feelings of anxiety and low mood following HIV and TB positive test results. Four participants experienced cognitions and emotional distress during TB treatment, that related to having a near-death experience (i.e., a traumatic stressor) when very unwell. A systematic review of evidence has found that in intensive care unit (ICU) survivors, post-traumatic stress disorder (PTSD) symptoms are common and negatively impact on quality of life (Davydow, Gifford, Desai, Needham, & Bienvenu, 2008). Of note however, no current PTSD features were spoken about, and no participants were accessing psychological support at the time of the interview. One participant scored above the clinical threshold for anxiety and depression and one other participant for anxiety on the HADS. One of these participants expressed anger towards his wife as he believed that he acquired HIV from her, the other expressed helplessness

around her diagnosis and multiple stressors including financial difficulties. Both these participants had not been offered psychological support following their HIV-diagnosis. Three other participants had been offered psychological support. Two males from Europe who disengaged quickly, explaining that they felt unheard, and one female from Southern Africa who was unaware whether there would be follow-up beyond an initial session. The other participants appeared to be adjusting well in relation to mental health. Two participants had attended HIV support groups and reported finding it helpful listening to the experiences of others. The majority of participants were not found to have anxiety or depression at the time of the interview and this may indicate that they experienced time-limited adjustment difficulties that were resolved. It appears that many participants moved between stages proposed by the Stages of Grief model (Kübler-Ross, 1969) which can be a framework for understanding adjustment to diagnosis. Stages included strong denial, anger (with turmoil), bargaining (wish for illness to go away), depression (withdrawal from the world), and later acceptance of the diagnosis and a new life with HIV.

Participants spoke about concerns related to being rejected and isolated should they disclose their HIV and TB statuses. For those participants admitted to hospital, they engaged in masking and concealing strategies for their HIV and TB diagnoses. Over time participants made the decision on whether to share or not their HIV and TB statuses. This is not surprising and much evidence exists around HIV-stigma (Earnshaw & Chaudoir, 2009). Eight participants told at least one person of their HIV status. All told at least one person about their TB status. All participants expressed concerns around disclosing their HIV-status to some groups, with some participants preferring to disclose that they have TB only. The model of disclosure anxiety proposed by Evangeli

and Wroe (2017) fits with many of the disclosure concerns that participants reported. This model has four components: (1) HIV core beliefs, (2) a trigger event, (3) a threat interpretation resulting in HIV-disclosure anxiety processes and (4) cognitive, affective, behavioural and physiological processes maintaining this. It is suggested that internalised HIV-stigma linked to negative HIV core-beliefs can predispose a person to disclosure anxiety. In the current study, diagnosis appears to act as a trigger event which led to decisions around who to disclose to, linked to perceptions of threat. Most often close family members were told about HIV. With regard to TB some participants shared only this diagnosis with a wider group of family and friends, whilst others chose not to share their TB diagnosis with many others. All participants who were in relationships that pre-dated their HIV and TB diagnoses disclosed their HIV and TB statuses to that person. Previous research in a low-income setting has found that a “double stigma” exists for HIV and TB, whereby disclosure of TB is often interpreted as the person also having HIV (Daftary, 2012). In the current study, this was not explicitly spoken about by participants, however the three participants from Sub-Saharan Africa spoke about not wanting to share their HIV or TB diagnoses with wider family and friends as they anticipated that they would experience discrimination. The current model suggests that where planned disclosure (HIV and TB disclosure that is intentionally made to chosen others) has occurred participants have had reassuring responses. This can help participants cope with living with HIV and TB as support can be gained from others around them via disclosure. This can in turn help participants manage their mental health following their HIV and TB positive results.

All participants spoke about moving towards adjusting and coping with their HIV and TB diagnoses and experiences. Moss-Morris’ model (2013) proposes that good

adjustment to chronic illness involves less distress, less interference/impact on life roles and relationships and good illness management. According to this, most participants appeared to be moving towards good adjustment. All demonstrated effective illness management by adhering to ART. In addition, from their descriptions, most participants experienced lower levels of HIV and TB related distress compared to when they were initially diagnosed. Five participants spoke about the importance of their religious beliefs in appraising and coping with their HIV and TB diagnoses. They linked this to feeling protected by God and that there was a plan for them. Spirituality/religion in PLWH has been found to improve health/quality of life directly and through mediating factors (active coping - healthy behaviours, optimism, social support) to help people cope with stressors, especially stigma/discrimination (Szaflarski, 2013). It appears that although participants experienced threatening primary appraisals of HIV and TB, in time secondary appraisals emerged indicating that the stressors were manageable. This is in line with Lazarus & Folkman's transactional model of stress (1984).

Strengths and limitations of the study

There had been limited research into the individual and social processes of living with HIV and TB co-infection in a high-income country. A strength of this study, is that it addressed this research gap. In addition, service-user feedback was sought on the interview schedule prior to data collection to ensure relevancy and understandability of content. Peer review was provided by the internal supervisor on the initial coding table for sense and clarity alongside frequent supervision. The sample was diverse (e.g., from different countries of origin, time since diagnosis and time living in the UK) and this suggests that the current proposed model could apply to a wide population. The narrow age range of participants however, increases the internal validity of the study, but

decreases the transferability. This study met a number of quality criteria, for example situating the sample – including participants’ demographic information to aid the reader’s understanding of the sample and assess transferability of findings; grounding in examples (e.g. use of example quotes throughout the results section for each identified theme), Credibility checks were provided by the internal supervisor (e.g. on interview schedule, coding and the developing the theoretical model); Coherence - by naming the theoretical codes and appropriately summarising the analysis whilst attempting to preserve nuances in the data (for more details on this please see pp. 89 – 90).

Limitations of the study include the sample size. The number of interviews required for Grounded Theory remains contested and by some it has been suggested that 12 interviews are sufficient. Others however, believe the number needs to be higher than this (Charmaz, 2006). The current sample size may therefore be too small and limit transferability and credibility of the findings. It is also unlikely that all categories reached theoretical saturation however common themes did consistently emerge.

Although theoretical sampling was aimed for, this was impacted by limitations with recruitment, for example recruiting mainly men to the study. Three women declined to participate citing worries of emotional distress, and one man declined as he was undergoing TB treatment and felt that being interviewed would be tiring. It is unknown if the four eligible others who declined to participate were different from the nine participants that chose to take part. It may be that the participants who agreed to be interviewed were experiencing better adjustment. In addition, more variation in the sample relating to migration status (the majority had settled status) and those who are still undergoing TB treatment could help improve transferability of findings. Due to time limitations, the Grounded Theory model was not shown to participants and it

would have been helpful for this to be validated by them. All the recruitment sites were based in London and these clinics had integrated HIV and TB care. It may be that this impacts on transferability of findings as the setting of other clinics may be different. Although all participants were proficient at speaking English, at times, it appeared that participants did not quite understand questions asked and some needed to be simplified. Use of an interpreter may have helped capture greater nuances of participants' experiences, in particular, participants may have felt more confident and expanded on emotional responses to living with HIV and TB. At present it is difficult to ascertain whether this is a cultural phenomenon, a consequence of having to focus on more practical matters of surviving, or linked to language difficulties. In addition, only one service user was recruited for consultation, in part linked to limited time available for this. It would have been helpful to consult more service users on the interview schedule regarding relevance and understandability of content.

Implications for future research and practice

Implications for practice include demonstrating the negative impact delays to care have on UK migrants with HIV and TB co-infection (e.g., on managing mental health). Six participants who were told that an HIV test would be carried out actively consented to it. Sharing this finding with healthcare workers might help reduce any reservations they may have about patients' reactions to being offered an HIV test and support early diagnosis. A UK report also found that primary care professionals tended to underestimate rates of TB within their area. A report by the Health Protection Authority (2010) found that in addition to requiring more information on TB diagnostic tests and clearer referral pathways, GPs also wanted to know more about screening for latent TB. Clarifications around existing guideline for testing high risk groups for HIV and TB

could help avoid delays and promote early diagnosis. At present, BHIVA (2019) advises that healthcare professionals make referrals for suspected TB to specialist services with experience of managing HIV/TB co-infection. To promote good patient centred care, current study findings could also help advise healthcare professionals on the information and support migrants find most helpful following HIV and TB diagnoses (e.g., information on medication and progress updates). The findings show the positive experiences of participants with HIV and TB co-infection including continued engagement with HIV-specialist clinics and positive and supportive relationships with healthcare professionals. This information could be helpful for individuals who are considering having an HIV test and encourage them to seek care earlier across settings. In addition, there were low levels of risk perception and high levels of stigma. It could be helpful to run an audit in services to find out the reasons why there is such a high level of stigma and how to respond to reduce it. Also, psychologists could work with professionals to create ways to raise and discuss issues (e.g. in reflective groups) that are linked to late testing and diagnosis of HIV and TB in this population.

It may be that testing being routine rather than relying on professionals is helpful (e.g., in GP practices in areas of high prevalence). This would mean that testing is targeted rather than provider initiated for HIV. It is important to note that since 2008, The National Institute of Health and Care Excellence (NICE) in the UK, recommends a 'routine offer of HIV testing' to all 15 – 59-year olds in primary care settings where HIV prevalence exceeds 2 in 1000. With regard to future research, participants in the current study were 33 years old to 63 years old. It would be useful to learn more about

the experiences of younger migrants in the UK living with HIV and TB co-infection and about what facilitates adjustment.

Five participants spoke about how their religious beliefs have been helpful for them to cope and adjust to their HIV and TB co-infection diagnoses. It would be useful to conduct an audit on how many healthcare professionals in HIV services do enquire about religious beliefs as links could be made with religious organisations and leaders in the community to support patients. This is not currently promoted in BHIVA Standards of Care (2018). Future research could include migrants in the UK who are still on TB treatment and interviews with family members to learn more about disclosure decisions and mental health support in this population. Any work being done with family members of patients would require consent to share diagnoses from patients.

In addition, ways to reduce stigma and risk perception in this population could include providing information on HIV and TB in an accessible, culturally appropriate way via social media and community/faith groups. Evidence indicates that education and direct contact with someone who has HIV can help to reduce stigma (Brown, Macintyre & Trujillo, 2003). Also, for healthcare workers, reflective groups around the challenges of asking for consent to test for HIV during an antenatal blood tests could be held.

Reflective discussions could also occur here on taking care not to breach confidentiality of HIV status. This is important to note, as participants experienced breaches in confidentiality in the current study and for one participant this had very serious consequences, resulting in her losing her job and being told to leave her home.

To help test the model empirically, interventions could be provided and their outcomes monitored. For example, to support the reduction of stigma and help manage disclosure and mental health after receiving HIV and TB diagnoses, individual and group psychoeducation could be provided to patients, their family and friends. Psychological interventions such as motivational interviewing could help support continued HIV and TB treatment adherence. In addition, interventions such as Acceptance and Commitment Therapy and Compassion Focused Therapy can help support flexibility of responses to experiences of stigma and increase compassion whilst reducing shame and self-stigma. These interventions could be provided in culturally informed ways in services by psychologists working with other health professionals to support positive appraisals of living with HIV and TB and coping. Impact on outcomes such as depression and anxiety and broader quality of life measures could be monitored. Future work could be embedded in the Medical Research Council (MRC) Framework on complex interventions to develop and evaluate interventions. The MRC Framework (Craig et al., 2008) specifies four key stages to complex intervention development: (1) Development, (2) Feasibility/Piloting, (3) Evaluation, and (4) Implementation. It emphasises the importance of reporting findings at each stage of development.

4. Integration, Impact and Dissemination

Integration

I began working in an HIV field as a Trainee Clinical Psychologist in 2018. My interest in HIV originated from my interest in stigma, disclosure and physical and mental health conditions that are often “invisible”. My interest in TB developed when having conversations with my mother and people she knew, including a family relative, who had been diagnosed with TB in India and Iran. I learnt that this happened at a time and location when medication was not so accessible and this raised my awareness of international health inequalities. These experiences led me to want to learn more about the re-emergence of TB in the UK, in part linked to HIV and migratory phenomenon. Over time, I gained basic knowledge of HIV and TB and issues linked to stigma and the psychological impact of receiving HIV and TB diagnoses. This combined with guidance and support from my academic supervisor helped me to progress towards conducting the systematic review and empirical project.

The systematic review and the empirical piece guided and informed each other throughout each research stage – including development of research questions, analysis and write up phases. A qualitative systematic review appeared suitable as it allowed for a more in-depth examination of illness experiences in those with HIV and comorbid physical health conditions. Quantitative research appeared unlikely to be able to capture this depth. It also helped me familiarise myself with qualitative research approaches prior to embarking on the empirical project. Both the systematic review and the empirical piece focused on the lived experiences of HIV positive individuals with HIV and comorbid physical health conditions. The systematic review focused on illness

experiences; and the empirical piece focused on the social and individual processes of living with HIV and TB co-infection. Relevant factors included HIV and TB stigma processes, disclosure, and adjustment, in addition to managing mental health difficulties. The location of participants was different across the two pieces of work. Participants in the systematic review were located in low- middle- and high- income countries. Participants in the empirical piece were from the UK – a high income setting. The age of participants varied, with the participants in the empirical piece aged from 33 to 63 years. The participants in the systematic review had a larger age range from 18 to 69 years of age.

Both pieces of work examined the experiences of men and women. The systematic review and the empirical piece found themes across low-and high-income settings relating to HIV and comorbid physical health condition stigma, and HIV and comorbid physical health condition related distress – in part linked to treatment and stigma processes. In addition, a theme was found on the negative impact HIV and comorbid physical health condition diagnoses can have on mood. They both also found themes on disclosure decisions, and included examples of participants deciding to tell and not tell others about having HIV and a comorbid health condition. Examples of positive adjustment and challenges to adjustment were also found in both pieces of work.

Prior to commencing research, I had a general understanding about HIV including how it was often transmitted through sex, and the stigma associated with being HIV-positive. I had less familiarity with stigma processes present around having other comorbid health conditions and I found it surprising to learn about research indicating a “double stigma” around HIV and TB in South Africa. I had thought about TB as a disease from the 1800s, I and remembered learning about how the poet John Keats died from

“consumption” (i.e., a term previously used for TB where individuals with the disease lost a large amount of weight) when I was at school. Until starting the current research, I did not realise that HIV/TB co-infection was so prevalent in Sub-Saharan Africa.

Reading about the stigma that individuals with HIV and comorbid physical health conditions face, helped inform questions on the interview schedule for my empirical piece (e.g. asking about – HIV and TB disclosure and participants’ pre-testing knowledge of HIV and TB in their countries origin and/or the UK). It was interesting to see that this notion of “double” stigma – where TB was thought to indicate HIV diagnosis – was not spoken about by the participants in the empirical piece. On reflection, this may be in part linked to around half of participants originating from countries and then living in the UK where the prevalence of HIV and TB co-infection are not amongst the highest. HIV and TB may not therefore have been at the forefront of their experiences to draw on.

Reading about some of the experiences of individuals in the systematic review literature helped me to realise the impact of disjointed services and a lack of financial resources on patient care and adjustment. In addition, listening to the financial difficulties that participants in the empirical piece faced was particularly shocking. For one participant, a doctor breached her confidentiality and disclosed to her employer that she had HIV. This led to her being told to leave her job as a domestic worker/carer – a place where she also lived. My contextual knowledge gained through the systematic review helped me to understand the data more and added to my thinking around the perceived impact of living with HIV and TB.

When conducting the systematic review and the empirical piece I tried to consider Burnham's social graces (Burnham, 2013) and I reflected on my gender, age, ethnicity, education, class and religious beliefs. These factors may have influenced the degree to which participants did or did not feel comfortable to speak about issues during the interviews. It may be that being an Iranian-White female who passes as White and sounds as though I am from an English middle-class background influenced the discussions I had with participants. This influence may relate to me being in a position of power and participants feeling less able or comfortable to describe difficult emotional circumstances to me. Male participants spoke about being "fine" and at times it was difficult to gain information about emotional experiences from them. This also helped me to reflect further on being a researcher who did not speak the first language of many participants. I wondered about the nuances of their experiences that I may have missed because of this. Females who agreed to participate appeared to speak in more depth about their experiences and may have felt comfortable speaking to a female interviewer. Of note, three of the four people who approached to take part were women who cited the worry that being interviewed about their experiences would be too emotionally distressing. It would be interesting to hear more about the experiences of females to learn whether they have experienced particular forms of gender-linked discrimination. Listening to a participant speak out his ideas of how women spread HIV by having sexual relations with monkeys elicited feelings of confusion and frustration in me that my role was not an educative one. Hearing these ideas led me to again wonder further about gender-linked discrimination that women with HIV face. In addition, listening to participants speak about the intersection between TB and race-related stigma led me to wonder about wider experiences of structural racism that may be present for UK

migrants and how these issues can be responded and challenged by healthcare professionals and community groups.

Both the systematic review and the empirical piece involved synthesising findings to create overarching themes. Although I tried to remain aware of potential biases, it is possible that my own perspectives influenced the findings. It may be the case that my coding was influenced by confirmation bias where I was looking to confirm my prior beliefs. I tried my best to adhere to quality guidelines for completing qualitative research and my findings were discussed with my academic supervisor. In addition, I reflected on ideas of “insider” and “outsider” researchers. Gair (2012) suggests that the notion of insider/outsider status can be “understood to mean the degree to which a researcher is located either within or outside a group being researched” (p. 137). I reflected on how in many ways I was an outsider researcher as I did not share the direct experiences of many of the participants. It may have been helpful to hold intimate knowledge of such experiences, in particular in interpreting the results of the study. Of interest, researchers have attempted to move past a strict “insider/outsider” dichotomy to emphasize that researchers fall in the “the space between” the two extremes (Dwyer & Buckle, 2009). It has been helpful and at times difficult to reflect on where I am positioned within this space to explore how my status may have affected the research process and its outcomes.

Impact and dissemination

Findings of this research have the potential to positively impact a number of different stakeholders including migrant populations living with HIV and TB co-infection in the UK, their family members, healthcare professionals working with this group, service

providers (e.g., general practices), and commissioners. In addition, findings may be helpful for support organisations and community/faith leaders supporting this group.

To help disseminate results to migrant populations living with HIV and TB-co-infection, a key summary of the findings could be provided on HIV support websites (e.g., the National AIDS Trust, Positively UK and Terrance Higgins Trust). Information could be provided on entitlement to NHS care, opportunities to test for HIV and TB in primary care and sexual health clinics, follow-up after HIV testing, the benefits of medication adherence, positive experiences with disclosure and examples of adjustment. This may help promote hope to individuals accessing information pre- or post-diagnosis of HIV/TB co-infection. Any information shared would need to be provided in an accessible format (e.g., simple, clear prose in a variety of languages) for individuals whose first language may not be English. Although all participants in the sample were selected to meet the selection criterion of English language proficiency, there may be others who are not proficient and would benefit from this. Participants of the study will be provided with a short summary in lay language to inform them of the study results. This summary can also be provided to healthcare professionals to give to individuals following HIV and TB testing in a range of settings including primary care, sexual health clinics and hospitals. This has the potential to support them to feel increased hope and confidence and to promote engagement with services. Friends and family members of individuals with HIV/TB co-infection could also be provided with study findings around positive disclosure experiences to increase their awareness of the challenges these individuals may be facing and how best to support them.

To support early diagnosis and support for individuals with HIV/TB co-infection, a factsheet with key findings can be provided to the Royal College of General

Practitioners (RCGP), alongside individual GP practices in high HIV and TB prevalence areas. Information could be provided on UK BHIVA guidelines for testing for HIV and TB; guidelines around differential diagnoses; the impact of delayed HIV and TB diagnoses on migrants to the UK; information migrants may find helpful following positive HIV and TB test results (e.g., benefits of taking medication consistently, and impact on life expectancy); and maintaining good relationships/support between patients and specialist services. A summary of the findings could be disseminated to PULSE (i.e., a website for GP news, including information on clinical, political, commissioning and practice). GPs may find that learning about patients' experiences helps them to feel better equipped to offer HIV and TB testing/refer onwards for TB testing at specialist services. In addition, training could be organised between GPs and other healthcare professionals working in sexual health services (SHS). This could help strengthen links between local HIV-services and GP surgeries to support earlier diagnoses of HIV and TB.

Healthcare professionals working in HIV services could benefit from the research findings. I aim to present the study's findings to healthcare professionals at team meetings. These professionals include HIV doctors, health advisors, nurses, clinical and counselling psychologists. They may find it helpful to learn about the experiences of migrants in the UK, testing across services (e.g., SHS, Accident and Emergency). Raising awareness on this may help professionals support and work clinically with this population. The study highlighted that some participants experience distress from the pill burden and side effects of taking HIV and TB medication. Having conversations and reflective practice in this setting may support clinicians to remain aware of these challenges for patients. Clinicians can gain ideas of how to speak with patients about

challenges and barriers linked to medication intake. It could also help clinicians learn that the support they are providing around informing patients about medication is perceived as helpful by a migrant population with HIV and TB. The findings of the empirical piece will be submitted to an academic journal such as *AIDS Care*. The research will also be presented at conferences (e.g., the AIDS Impact conference). The aim of this is to make the research findings accessible to clinicians and academics working in the HIV and TB field and raise awareness about suggestions for future research.

Research has found that religion serves important roles in coping, survival and maintaining overall wellbeing within HIV-positive migrant communities and can influence physical and mental health (Arrey, Bilson, Lacor & Deschepper, 2016). According to the BASSLine survey (Dodds et al., 2008) of HIV-positive Africans in England, over 70% of black Africans are Christian and just under 20% are Muslim, while only 6% report having no religion. Five participants in the current research reported that they were religious and that their beliefs had been very helpful in adjusting to living with HIV and TB. Faith leaders can help to promote HIV and TB awareness, along with providing clergy with information about HIV and TB prevention and treatment. It may be helpful for faith leaders and institutions to have their support for migrants living with HIV and TB acknowledged. This could help increase their confidence in supporting this population. To help disseminate findings, a working group could be organised where key stakeholders are invited. These could include faith leaders from high HIV/TB prevalence communities, representatives from HIV support organisations, migrants with experiences of living with HIV/TB co-infection and healthcare professionals. Relationships between these organisations and individuals can

be fostered and further strengthened. This can also help with the promotion of health services amongst these communities with the aim of supporting the reduction of stigma of having HIV and TB.

Participants reported feeling more hope when updated by healthcare professionals about the positive effects of medication and when they were updated on their progress. To promote this on a largescale with ease of accessibility for patients, social media pages could be generated. This could be done by people who have experiences of living with HIV and TB. Evidence from HIV campaigns has shown that testimonials from PLWH are helpful in removing and correcting misinformation. Evidence indicates that this can support empathic understanding which reduces stigma (Brown et al., 2003).

Testimonials could be provided in the form of mobile phone apps, access to videos that contain interviews with migrants with HIV and TB experiences. Given the concerns around confidentiality found in this population, it may be that an online forum can be set up with anonymous participation in a variety of languages. In addition, in a qualitative systematic review of the experiences of peer support workers (PSW) in health (including those with HIV), PSW experienced feelings of belonging and reframing of the past to provide meaning to experiences of suffering. It also found that it enhanced an awareness of their ability to participate and 'give back' to others (MacLellan, Surey, Abubakar & Stagg, 2015).

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Appendices

Appendix A: Interview Schedule – Adjustment in UK Migrants with HIV and TB

1	<p>I'd like to learn what life like is for you... Prompts: Tell me about your background: Origins: Where do you come from? Current: Where do you live? Family: Who is in your family? Employment: What do you do for a living? Arrival in UK: When did you come to the UK? What was it like coming to the UK? Living in UK: What is it like living in the UK? Learning English: Did you have to learn English when you came to the UK? How has it been learning a new language? Immigration status: What was your immigration status when you were first diagnosed with HIV and TB and what is it now? If relevant – what has it been like having an uncertain immigration status?</p>
2	<p>I'd like to learn about your experiences of HIV and TB before being tested for either condition... Where were you tested for HIV and TB? Before being tested: What were your experiences of HIV and TB in your country of birth? What were your experiences of HIV and TB in the UK Did you know anyone with either HIV or TB?</p>
3	<p>I'd like to learn how you came to be tested for... HIV TB Prompts:</p> <p>a. First diagnosis: I'd like to ask you - which condition you were diagnosed with first: When: When was that? Where: Where did this happen? how was that? Tests: What kind of test/s did you have – blood test or scan? How was that? Knowledge of being tested: Did you know you were being tested for HIV and TB? If you did know, how was this explained to you? Whose idea was it to get tested for HIV and TB? Did you think you might be HIV positive/have TB? How did you feel about testing for these? Waiting for results: What was it like waiting for the results of HIV and TB tests?</p> <p>b. Second diagnosis: I'd like to ask you - which condition you were diagnosed with second: When: When was that?</p>

	<p>Where: Where did this happen? how was that?</p> <p>Tests: What kind of test/s did you have – blood test or scan? How was that?</p> <p>Knowledge of being tested: Did you know you were being tested for HIV and TB? If you did know, how was this explained to you?</p> <p>Whose idea was it to get tested for HIV and TB?</p> <p>Did you think you might be HIV positive/have TB? How did you feel about testing for these?</p> <p>Waiting for results: What was it like waiting for the results of HIV and TB tests?</p>
4	<p>I'd like to know what your experiences were after finding out the positive result ...</p> <p>HIV</p> <p>TB</p> <p>HIV/TB together</p> <p><i>Prompts:</i></p> <p>Current treatment: Are you still receiving treatment for HIV and TB? How is that going?</p> <p>Previous treatment: If you have previously had TB, what does it feel like to have gone through treatment? For both at the same time?</p> <p>Did you know anyone who had HIV and TB in your country of birth and/or the UK? How did that influence you?</p> <p>Do you know anyone who has been treated in your country of birth and/or the UK? What are your thoughts on that?</p>
5	<p>I'd like to learn more about your attendance at the HIV clinic and a TB clinic...</p> <p><i>Prompts:</i></p> <p>Attending HIV and TB clinics: What have been your experiences of attending HIV and TB clinics?</p> <p>HIV and TB clinics distance: Were the clinics near one another? How was this for you? Helpful?</p> <p>If you have had experience of attending HIV and TB clinics abroad, how did it compare to your experience in the UK?</p> <p>Current attendance: Are you still attending? How long have you been attending/did you attend for?</p> <p>Have you always attended the same clinics or have you changed for any reason?</p> <p>What was it like starting medication for HIV and TB? How has it been consistently taking medication?</p> <p>Have you had any contact with support organisations for either HIV or TB?</p> <p>How has that been? What was difficult about this? What made it easier for you to attend?</p>
6	<p>What was your relationship like with healthcare professionals before you were diagnosed with....?</p> <p>a. HIV</p> <p>b. TB</p> <p><i>Prompts:</i></p> <p>How did healthcare professionals share your diagnoses with you? How was that experience abroad and/or in the UK?</p> <p>Tell me how your relationship with healthcare professionals developed after</p>

	<p>being tested abroad and/or in the UK?</p> <p>What was your relationship like with healthcare professionals whilst attending HIV and TB clinics (abroad and/or UK)? Have you felt able to trust them, and that they were knowledgeable? How helpful were they?</p> <p>Have you been seen by any other healthcare professionals since being given your diagnoses abroad and/or in the UK? (e.g. psychologist) How has that been?</p>
7	<p>Tell me who you have told about being HIV positive and/or being diagnosed with TB?</p> <p><i>Prompts:</i></p> <p>(If disclosed) can you tell me a bit about what that was like; what has been the response of others (abroad and/or in the UK)? What were your reasons for disclosure?</p> <p>(if not disclosed) what has prevented you from telling people?, e.g., not feeling the need, not wanting to, not having the confidence to).</p> <p>Future disclosure: Do you intend to disclose to anyone in the future? e.g. partner, children, parents, siblings, friends, colleagues? Why might that be?</p> <p>Anticipated responses to disclosure: How do you think people will respond if they knew – good or bad responses? What fears might others have if they knew?</p>
8	<p>Can you tell me about your relationships with other people in your life (abroad/and or in the UK) at the moment and how they may have changed since the diagnoses? How have people responded?</p> <p><i>Prompts:</i></p> <p>Family</p> <p>Friends</p> <p>Sexual partners</p> <p>Employers</p> <p>What has happened? How do you feel about yourself?</p>
9	<p>How have you felt about having diagnoses of:</p> <p>HIV</p> <p>TB</p> <p>HIV/TB together</p> <p>What has it been like knowing that you have HIV and (had) TB (and both)? – what was the impact? What is it like now?</p> <p>How has it been maintaining doing things you like doing? How has it been to maintain your activity levels?</p> <p>How has it been handling any problems arising linked to the illnesses?</p> <p>Has there been anything that has helped you cope? E.g. talking to others, others may find themselves drinking or taking substances, other people like not to think about it. Has this impacted on your life? If what ways?</p> <p>How have you felt about socialising and relationships (friendships and sexual relationships)?</p> <p>What have been your experiences linked to employment; migration status; housing?</p> <p>Have you experienced feelings of acceptance/hopelessness? Can you tell me more?</p> <p>What are the benefits and negatives of knowing HIV and TB status?</p> <p>What are your feelings about the future? E.g. For work, friendships,</p>

Appendix B: Demographic questionnaire

Date:

1. What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other (specify) _____

2. What is your date of birth?

Day/Month/Year _____

3. What is your country of birth? _____

4. When did you come to the UK? _____

5. What is your immigration status?

- ☐ UK National
- ☐ EEA National
- ☐ Discretionary leave to remain
- ☐ Indefinite leave to remain
- ☐ Study or work visa(s)
- ☐ Husband/Wife sponsorship
- ☐ Asylum seeker awaiting decision or a Refugee or under Humanitarian Protection

6. What is your ethnic group?

- ☐ White
- ☐ Mixed / multiple ethnic groups
- ☐ Asian / Asian British
- ☐ Black / African / Caribbean / Black British
- ☐ Other ethnic group

7. What is your main language?

- ☐ English
- ☐ Other, write in (including British Sign Language)

8. What is your religion?

- ☐ No religion
- ☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh

- ☐ Any other religion, write in _____

9. Which of these qualifications do you have?

- ☐ No qualifications
- ☐ O' Levels/GCSEs or Equivalent
- ☐ AS- Levels or A' Levels or Equivalent
- ☐ Vocational Qualifications
- ☐ Undergraduate Degree (for example BA, BSc)
- ☐ Postgraduate Diploma or Degree (for example MA, PhD, PGCE)

10. Last week, were you:

- ☐ Employed or Self-employed?
- ☐ Away from work ill, on maternity leave, on holiday or temporarily laid off?
- ☐ Retired (whether receiving a pension or not)?
- ☐ Student?
- ☐ Other

11. Are you currently in a romantic relationship?

- ☐ No, I'm single
- ☐ Yes, I'm in a romantic relationship

Appendix C: HIV and TB Medical Information

Date:

Date of HIV diagnosis:

Current HIV viral Load:

Current CD4 cell count:

HIV Treatment regimen:

Is HIV treatment ongoing?: ☐ Yes

☐ No

Date of TB diagnosis:

TB status: ☐ Active

☐ Latent

☐ Cured

Start date of TB treatment:

TB Treatment regimen:

Duration of TB treatment:

Is TB treatment ongoing?: ☐ Yes

☐ No

Any previous or current co-morbid diagnoses (i.e. physical health conditions)

Any additional medications currently being taken? _____

Appendix D: Participant information sheet



Adjustment in UK Migrants with HIV and TB Co-infection

Participant Information Sheet

You have been asked to participate in a study about adjustment in individuals with HIV and TB co-infection, which is being carried out by Yvonne Whelan, a Trainee Clinical Psychologist, in collaboration with ----- Hospital

Thank you for your interest in the research study. Please read this information sheet carefully. If you want to discuss the study with a member of clinic staff or someone close to you before making a decision about taking part, please feel free to do so. You can also ask Yvonne any questions you might have about the study.

What is the study about?

The aim is to explore the experiences of foreign born individuals who have been diagnosed with both HIV and TB.

Worldwide, many people with TB have an HIV diagnosis. In the last two decades, TB has re-emerged in the UK, in part linked to HIV infection. At present, little is known about the experiences of individuals who are foreign born living with HIV/TB co-infection in the UK. We hope our findings will help clinicians to provide better care for people who have HIV/TB co-infection.

Why am I being asked to take part in the study?

You have been approached to participate because you have been diagnosed with HIV and TB and you attend the clinic where the study is taking place. To participate in this study, you must have:

- 1) Been diagnosed with HIV at least 3 months ago
- 2) Been diagnosed with latent or active TB at least 3 months ago and within the last 5 years.
- 3) Been born abroad

What will the study involve?

You will be asked interview questions about your experiences of living with HIV and TB. You will also be asked some background questions about yourself (e.g. your age, gender, birthplace, length of time in the UK, immigration status, employment status and relationship status), and an additional brief questionnaire on mood. The interview will take place in a private room at the clinic you attend. If there is no space at the clinic, a room at Bedford Square, London (Royal Holloway Campus site) may be available. You can be interviewed on a clinic day or different day. The interview and questionnaire should take no longer than 1 hour 15 mins to complete in total. With your consent, the interview will be audio recorded to make sure no important information is missed.

The researcher, Yvonne, will also require access to your medical details and this will be limited to information on: the date of your HIV and TB diagnoses, your TB status (including whether active, latent TB or cured), your CD4 cell count, viral load, when you started treatment, your treatment regimen and whether it is ongoing.

What are the risks of taking part?

We do not think there are any particular risks associated with taking part in the research. However, if you feel worried or distressed during the study please feel free to let the researcher know. You will be able to access support from the clinic you attend (i.e., ----- Hospital) if required.

What are the benefits of taking part?

One potential benefit of taking part in this research is that you may find it helpful to reflect on your experiences of having HIV and TB co-infection. You may also find it a positive experience to know that you are informing research which would go on to help

other people with HIV and TB. This knowledge could help to develop better health services for people in your situation.

Will I get paid for taking part?

We will reimburse your time for taking part in the study (£10 in a high street voucher). If you decide to attend an interview on a different day to your routine clinic appointment, you will also be reimbursed for travel expenses.

Is my personal information kept confidential?

Your information and responses will be kept completely confidential unless you tell us something that indicates you are at risk of harm. There are a few other situations where there may be a legal obligation to disclose information outside of your healthcare team - for example, if there is a risk of harm to someone else. These situations are extremely uncommon and we would discuss this with you before telling anyone else. Otherwise, your healthcare team and the researcher will make sure that your personal information remains private.

You will be assigned a unique number to identify you throughout the study. All data will be stored in a password-protected database that only the research team will have access to. The research team includes: **Yvonne Whelan, (Trainee Clinical Psychologist, Royal Holloway University of London - RHUL), Dr Michael Evangeli (Reader at Royal Holloway, University of London and Dr Stuart Gibson (Clinical Psychologist at ----- Hospital).**

Dr Michael Evangeli will store the signed consent forms. These will be kept separately from anonymised participant data and will be stored for two years for audit and research *governance* monitoring before being destroyed. A separate USB associating the ID number with the participants' names will be stored apart from the data and destroyed once it is no longer necessary to contact participants or obtain further information about them (e.g., once a journal article is published, up to two years after the study has ended). This file will have its own password.

The audio recording will be stored securely as a password-protected file on an encrypted USB. Once the interview has been transcribed it will be stored using an anonymous identification number and the recording will be deleted. Anonymous quotations from the interviews may be used in the reports for this study with all identifying information removed.

We will ask you to provide an email address to be sent a summary of the study findings. This is optional. If you choose to provide this information, your email addresses will be stored in a separate password-protected database from your responses; there will be no direct association between your email addresses and your responses.

What will happen to the results of the study?

The research will be submitted in partial fulfilment of a doctorate degree in Clinical Psychology. We aim to publish its results in a peer-reviewed journal and at conferences. The published data will be anonymised and no participants will be identified. If you would like, we will send you a summary of the findings via the email address you provide.

Who is organising and funding the research?

The research is being led by Yvonne Whelan and is being funded by Royal Holloway, University of London (RHUL), as part of the doctorate programme in Clinical Psychology. This study has been reviewed and approved in accordance with an NHS ethics committee as well as the College Ethics Committee at RHUL.

Who should you contact with questions?

This project is supervised by **Dr Michael Evangeli (Clinical Psychologist and Reader at Royal Holloway University London) and Dr Stuart Gibson (Clinical Psychologist at the ----- Hospital).**

The main person to contact for this project is Yvonne Whelan, Trainee Clinical Psychologist as the Department of Clinical Psychology, Royal Holloway University of

London (RHUL). You can get in touch in the following ways if you have any questions about the research at any time.

- Email: -----
- Phone: ----- (this is an answering message service - please say your message is for Yvonne Whelan, leave a message clearly stating your name and phone number.)

Who should you contact with a complaint?

If you have any complaints about this research or how it is conducted please contact the Patient Advice and Liaison Service (PALS) who can offer confidential advice, support and information:

----- participants please contact the ----- Healthcare PALS on: -----
or email -----

What happens next?

If you are interested in taking part, you will be given the opportunity to meet with Yvonne on the same day as your clinic appointment (if she is available on the site) to discuss whether you wish to take part in the study. If you do, you will be given the option to be interviewed that day, or to attend at a date and time more convenient to you.

If Yvonne is not available on the site on the day of your clinic appointment, you can contact her on the details provided above.

Thank you very much for taking the time to read the information sheet. If you are happy to participate, please complete the consent form on the next page (This will be shown to you in person).

Appendix E: Consent form for participants



Consent form - For Participants

Project Title: Psychological Adjustment in UK Migrants with HIV and TB Co-infection

Name of researcher: Yvonne Whelan (Y.Whelan@nhs.net)

You have been asked to participate in a study about psychological adjustment to HIV and TB co-infection in UK migrants, which is being carried out by Yvonne Whelan, trainee clinical psychologist at Royal Holloway University of London, in collaboration with ----- Hospital clinic.

Have you (please initial):

	Yes	No	Not Applicable
Read and understood the information sheet about the above study?			
Had the opportunity to ask questions?			
Got satisfactory answers to your questions?			
Understood that participation is voluntary and you are free to withdraw from the study at any time? (without giving reason and without it affecting your care)			

Understood that the researcher (who is outside the direct healthcare team) will require access to your medical details such as the date of your HIV and TB diagnoses, your CD4 cell count, when you started treatment, your treatment regime and whether it is ongoing.			
Understood that your information will be kept confidential throughout the research process, unless you tell us something that indicates you or someone else is at risk of harm. (We would discuss this with you before telling anyone else.)			
Understood that as part of the study your interview will be audiotaped and transcribed. The tape will be destroyed once transcribed.			

Do you agree to take part in the study? (please initial)

Yes	
No	

Participant Signature: _____

Date:

Participant please print name here: _____

Date:

Researcher Signature: _____

Date: _____

When complete, two photocopies to be made: 1 copy for participant; 1 copy for researcher and 1 (original) to be kept in medical notes.

Appendix F: Payment Receipt



Title of project

Receipt of Payment

I confirm I have received a payment of £_____ for participating in the above research study, conducted by Yvonne Whelan, Trainee Clinical Psychologist, Doctorate in Clinical Psychology, Royal Holloway University of London

No.	Date	Name	Amount	Signature

Trainee Signature

Supervisor Signature

Appendix G: Example of transcript with initial and focused codes

Transcription	Initial Codes	Focused Codes
I: Just to clarify, when were you diagnosed with HIV?		
P1: last year.		
I: And then was it around the same time that you had TB?		
P1: Yes, everything at the same time – so, I was just feeling like I didn't want to eat, I was losing weight. I mean, I went six times to the hospital in here. They just kept telling me that I had gastric issues, and then I was not feeling okay, and then one day I went to work and I barely could work, and then I spoke with my mum, and she said, you're flying to today home, and then I fly home on the same day, and then I went next day to the hospital. They kept saying the same thing, and then my mum said, "no you're going to come with me", so I went to my mum's place, they give me multiple exams, they said, "there's nothing wrong with you, but we do need to see what it is". They needed to do more exams and then when I was waiting for it, I felt bad again and then I went to the hospital.	<p>Feeling unwell and visiting the GP and hospital multiple times</p> <p>Presenting for emergency care</p> <p>Having multiple medical tests in hospital</p>	Experiencing delays in HIV and TB testing
I: How were you feeling bad, in what way?		
P1: Vomiting, I didn't have any appetite, losing a lot – weight loss, no strength, no power for anything... and then the day that I went and they discover, my doctor asked me to open my mouth, and then he saw my tongue and he said – I don't know if it's the same thing here as in [detail of	Consenting to having an HIV test	HIV and TB Testing experiences

European country removed], they have to ask you if they can give you an HIV test?		
I: So they asked you beforehand?		
P1: He asked me, yeah if he could do it and I said “oh sure no problem”, and then he did it.	Consenting to having an HIV test	HIV and TB Testing experiences
I: So how was it explained to you that you were going to be tested for HIV, did they sort of talk you through... or...?		
P1: I think it was like just a normal conversation. I think I was inside with him, and he asked me what was going on with me, and then he started to check me – my eyes, ears, tongue, and then, we were talking and he told “I want to do some exams – urine, blood tests, and I would like to add the HIV one as well”. It was like a very casual conversation.	Being told that he would receive multiple tests including HIV	HIV and TB Testing experiences
I: Okay, it sounds like it was the doctor’s idea for you to be tested... for having HIV... And I’m just wondering if you thought at the time – if you had any thoughts about whether you were HIV positive?		
P1: No, because I went... so, this was November 2016, I did the test. I went to an STD clinic, and they would call me if everything – if anything was wrong. No-one called me, so... I wasn’t restless? I think everything was fine.	Not thinking about HIV or TB	HIV and TB Testing experiences
I: So were you still wondering if you were, or did it put your mind at ease?		
P1: In November? No, I just did like a random test, just to see.		
I: Okay, and when you didn’t hear anything back you		

thought –		
P1: Everything is fine. So I kept living my life, and not think about the subject.	Believing he had received negative prior HIV test results	Prior testing for HIV
	Not thinking about HIV or TB	HIV and TB Testing experiences
I: Okay, and then in terms of the later test – it sounds like you had it in [detail of European country removed] in hospital – was it linked to [detail removed]		
P1: No, it was a public hospital, and I just felt really bad on that day, and my mum said let's go to the hospital, you have high fever, let's go.	Presenting for emergency care	Experiencing delays in HIV and TB testing
I: Okay, so when the doctor said, I'm going to suggest testing for HIV how did you feel about being tested?		
P1: Yeah, I was fine. Something was wrong with me, they had to know what was going on.	Consenting to having an HIV test	HIV and TB Testing experiences
I: And then in terms of waiting for the results, what was it like waiting?		
P1: I was not expecting – that it was just one more day in the hospital without them knowing what was going on. It was just – they were going to tell me that I had a gastric issue again – that's what I thought.	Not thinking about HIV or TB	HIV and TB Testing experiences
I: And then, thinking a bit more about after being tested, finding out the positive result for HIV, did you also find out about the TB at that time?		
P1: No.		
I: No? Okay... So when did you find out about the TB?		
P1: So after the doctor told me I was positive, he told me to go in two or three days to an appointment. To another		

doctor – infectious and contagious diseases – so we had an appointment for a doctor who takes care of this, and then he checked me, and he told me, “you’re not leaving the hospital”.		
I: Did you know at that time that you were being tested for TB?		
P1: No! So it was basically it was like a – you just – he just note my symptoms – again – tongue, eyes, and then checked my legs, checked my neck behind, to see if he find anything, and then, yeah, he told me, you’re not leaving the hospital. You’re going from here upstairs to a room.	Feeling frustrated at the diagnostic uncertainty	Experiencing delays in HIV and TB testing
I: And then, how long was that gap between being tested for HIV and TB?		
P1: I don’t want to lie, but I would say between 3 weeks and a month, because the doctor that I had – they didn’t know what was going on. So they only discovered about CMV two weeks after I’d been in the hospital. I kept asking “what’s going on?” and they said they still need to do more tests, more exams and more blood.	Having multiple medical tests in hospital	Experiencing delays in HIV and TB testing
I: What was that like?		
P1: The worst period of my life.	Experiencing extreme worry and low mood	Feelings following HIV and TB test results
I: In what way?		
P1: All the exams, they were like, painful – colonoscopies, endoscopies, put tubes inside of my nose to get some liquid from my lungs. The fact that I had – they were taking blood constantly, so my arms start to get sore. Then after that came the medication and I couldn’t	Having multiple painful medical tests in hospital Experiencing worries and low mood	Experiencing delays in HIV and TB testing

sleep, so I had a lot of anxiety crisis.		
I: You experienced anxiety....?	Experiencing worries and low mood	Feelings following HIV and TB test results
P1: Yes, because of the stress that I had was so hard that... I stopped seeing from my right eye. I don't know how to say it in English, but a blocked nerve, and there was a point they sedate me so much – I don't remember.	Experiencing worries and low mood	Feelings following HIV and TB test results
I: Okay, so there's a period you don't remember so well...		
P1: It stopped because my mum came to see me, and she was like, "this is too much sedatives. I'm not having this". So she spoke to the doctor, to reduce it because I was having too much.	Reflecting on his mother telling the doctors to give him a lower dose of sedatives because the dosage was too high.	Receiving treatment for HIV and TB
I: And what was that like then, when it was reduced?		
P1: It was still really bad. I think it was the most of – mixed of emotions. I had to deal with the fact that I had it, I had to hide it, being in hospital and [detail of participant's partners name removed] tried to discover the HIV – if he has it as well... and then he had it, and then he didn't know how to get support. But, because I was not very good in my mind I couldn't...because I was taking 30 pills a day...	Experiencing worries and low mood Feeling distressed by the pill burden	Feelings following HIV and TB test results Receiving treatment for HIV and TB
I: Okay, so lots and lots of medication		
P1: We discovered after – [detail of participant's partner's name removed] told me there was four days you, "called me more or less the same time and said exactly the same thing every time you called me!"	Feeling distressed by medication side effects - frequently phoned up partner an repeating	Receiving treatment for HIV and TB

	himself.	
I: What was it that you were telling him about?		
P1: He was telling me something that I was speaking with him about my brother. It happens sometimes.		
I: Okay, so it was a period that you were on quite a lot of medication and were anxious as well? You had some worries going through your mind?		
P1: Yeah, so I had my things in here, I had the room in here, I had to pay bills, and I wasn't working. I had money together, but not enough for living five months in London and not working.	Not working and the financial impact of being unwell	Financial burden

Appendix H: Example memo

09/11/2018

Participants so far have spoken about not wanting to disclose HIV. I was surprised at such delays to be diagnosed with HIV and TB. They each had multiple tests. Different levels of comfort around sharing TB status. A participant from Europe spoke of not wanting to share TB beyond close friends, whilst participant from Southern Africa was happy to share TB with friends and colleagues. Belief that TB is just an illness. Participants anticipate stigma and don't want others to respond differently to them.

22/12/2018

Themes of delayed access to HIV and TB diagnosis and treatment. Participant spoke about anger towards his wife and depression and suicide attempts – this is different from others experiences so far – I wonder why?. It is interesting to note that he had not been offered access to psychological support. Themes of religion are emerging. Participants have the sense that that God has a plan for participants lives providing hope and meaning. Both participants speaking about God have been men, although from different regions – [detail of South Asian country removed] and SSA. It would be interesting to see if religion has provided comfort to others. Financial difficulties and housing issues have surfaced and appear particularly stressful.

05/03/2019

Participants have again spoken about the importance of religion and that there is a plan for their lives. Precarious housing and worrying about going into arrears a stressful

experience. Once again appreciating the support from hospital staff to gains stable accommodation.

Appendix I: NHS ethics approval



Dr Yvonne M. Whelan
Department of Psychology, Clinical Psychology Doctoral
Programme
Royal Holloway University of London
Egham, Surrey
TW20 0EX

12 July 2018

Dear Dr Whelan



Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Developing a model of the individual and social processes involved in living with HIV and TB in UK migrants.
IRAS project ID:	242524
Protocol number:	N/A
REC reference:	18/LO/0895
Sponsor	Royal Holloway, University of London

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should formally confirm their capacity and capability to undertake the study. How this will be confirmed is detailed in the "summary of assessment" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	242524
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It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Annette Lock

Tel: 01784 414388

Email: annette.lock@rhul.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 242524. Please quote this on all correspondence.

IRAS project ID	242524
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Yours sincerely

Maeve Ip Groot Bluemink
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Annette Lock, Royal Holloway, University of London – Sponsor Contact*
[REDACTED]

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [RHUL professional indemnity policy schedule]	1	26 July 2017
HRA Schedule of Events	1 (HRA final)	30 May 2018
HRA Statement of Activities	1 (HRA final)	30 May 2018
Interview schedules or topic guides for participants [Interview Schedule]		14 June 2018
IRAS Application Form [IRAS_Form_02052018]		02 May 2018
Other [242524 Responses to REC Questions - v1.0 14.06.18]	1	14 June 2018
Other [RHUL public liability Insurance 17.07.2017]	1	17 July 2017
Other [Participant Information sheet]	5	18 June 2018
Other [Interview Schedule]	5	18 June 2018
Participant consent form [Participant consent form]	2.0	05 January 2018
Referee's report or other scientific critique report [RHUL Research Sub-committee review]	1.0	12 January 2018
Research protocol or project proposal [242524 Research Proposal]	2.0	05 January 2018
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator]	3	03 May 2018
Summary CV for student [Summary CV for student]	3	03 May 2018
Summary CV for supervisor (student research) [Summary CV for Chief Supervisor]	5	03 May 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research stages flowchart]	1.0	05 January 2018
Validated questionnaire [Hospital Anxiety and Depression Scale]	4	03 May 2018

IRAS project ID	242524
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Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A Statement of Activities has been submitted and it is intended for this to be used as the contract between the Sponsor and NHS sites.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. There will be no financial provisions to the sites.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments

IRAS project ID	242524
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Section	Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one type of participating NHS organisation; therefore, there is only one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor's position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

Local Collaborator (LCs) are expected for this type of study. The LCs have been identified at the NHS sites and are listed in IRAS Form [Part C].

GCP training is not a generic training expectation, in line with the [HRA/HCRW/MHRA statement on training expectations](#).

IRAS project ID	242524
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HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken.

Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio

Appendix J: Royal Holloway University Ethics approval (July)



Ethics Review Details

You have chosen to self certify your project.	
Name:	Whelan, Yvonne (2016)
Email:	
Title of research project or grant:	Developing a model of the individual and social processes involved in living with HIV and TB in UK migrants
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Michael Evangel
Email address of Academic Supervisor:	
Funding Body Category:	No external funder
Funding Body:	
Start date:	15/07/2018
End date:	15/07/2019

Research question summary:

Aims:

This study aims to develop a model of the individual and social processes involved in living with HIV/TB co-infection in UK migrants

Research Question: What is the perceived impact for UK migrants living with HIV/TB co-infection on disclosure of both conditions, relationships, help-seeking, identity and adjustment?

Research method summary:

10 adult participants will be asked interview questions in person at the NHS HIV clinic they attend alongside some background questions about themselves and an additional validated questionnaire – the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) which will be completed on paper. This will be conducted by Yvonne Whelan (Trainee Clinical Psychologist and Chief Investigator) who will gain informed consent from participants face to face before any interview is conducted.

During the interview, participants will be asked about their experiences of living with HIV and TB abroad and in the UK. Interviewing individuals with HIV/TB co-infection can help provide insight into the perceived impact of living with HIV/TB co-infection in UK migrants.

The chief investigator will audio record, transcribe and code the data and then analyse the data using Grounded Theory. During data analysis, codes, concepts and categories will be compared within and between each other to highlight similarities and differences in the data (Glaser & Strauss, 1967).

Risks to participants

Does your research involve any of the below?

Children (under the age of 16),

No

Participants with cognitive or physical impairment that may render them unable to give informed consent,

No

Participants who may be vulnerable for personal, emotional, psychological or other reasons,

Yes

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),

Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),

No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),

Yes

Details,

NHS Ethics has been obtained (see attached folder for The favourable opinion of the REC letter and letter of HRA approval).

Please note:

Participants will be provided with a consent form which outlines the boundaries of confidentiality and provides information on data storage. During the interview as participants will be asked personal questions that may cause distress, informed consent will need to be gained from each participant. It will be checked with participants that they are fully aware of the extent of their involvement in the research process. It will also be highlighted to participants that they can withdraw from the process at any time.

In addition, no particular risks are associated with taking part in the study, however if participants become distressed when interviewed, it will be stopped and they will be informed/signposted to relevant staff involved in their care at their HIV clinic). A named clinician at each testing site will be identified to support the lead researcher if risk issues arise.

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?,

No

Is there a risk that participants may be or become identifiable?,

No

Is pain or discomfort likely to result from the study?,

No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,

No

Does this research require approval from the NHS?,

Yes

If so what is the NHS Approval number,

REC reference: 18/L0/0895 and IRAS project ID: 242

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?,

No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?

No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?

No

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?

No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?

No

Details,

Please note:

Participants will be provided with a consent form alongside a written information sheet to consent to the Chief Investigator, Yvonne Whelan, having access to their medical records for information relevant to the research study e.g. CD4 count (a type of white blood cell that fights infection) and TB status at time of diagnosis; and being audiotaped alongside the retention of their data, which will be stored securely with transcripts anonymised. The risks and benefits of participation will be outlined in the information sheet.

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?

No

Will the research be undertaken on private or government property without permission?

No

Will geological or sedimentological samples be removed without permission?

No

Will cultural or archaeological artifacts be removed without permission?

No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?

No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?

Yes

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?

No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?

No

Is there any reputational risk concerning the source of your funding?

No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?

No

Details,

The following information is in the Participant Information Sheet: "Your information and responses will be kept completely confidential unless you tell us something that indicates you are at risk of harm. There are a few other situations where there may be a legal obligation to disclose information outside of your healthcare team - for example, if there is a risk of harm to someone else. These situations are extremely uncommon and we would discuss this with you before telling anyone else."

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, NDJT004

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