

**Developing a Model of Living with HIV in Individuals  
with Personality-related Difficulties**

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# Executive summary

## Background

Human Immunodeficiency Virus (HIV) is a blood borne virus that attacks the body's immune system by reducing the number of CD4 blood cells, making individuals more susceptible to infection and disease. HIV infection is associated with a wide range of symptoms, varying from symptoms of primary infection (e.g. rash and fever), to serious diseases associated with a suppressed immune system (e.g. hepatitis) (Adler, Edwards, Miller, Sethi, & Williams, 2012). Acquired Immunodeficiency Syndrome (AIDS) is the most advanced stage of HIV infection, when the CD4 count drops to a very low level, which makes individuals more likely to develop opportunistic illnesses. People with AIDS survive for about three years without treatment (CDC, 2016).

HIV can be transmitted through unprotected sexual contact, from mother to child transmission (either through pregnancy, birth or breastfeeding), or through sharing of equipment used for intravenous drug use (WHO, 2017). In the 1990's antiretroviral therapy (ART) was introduced and changed the clinical picture of HIV from being a fatal to a chronic illness. ART cannot cure HIV but it prevents it from replicating itself and it has been shown to reduce transmission of HIV by 96% (Hull, Wu, & Montaner, 2012). In 2016, 96% of people receiving a HIV diagnoses in the United Kingdom (UK) were on ART. For the first time, the death rates among people living with HIV was



comparable to the rest of the population in the UK (Public Health England, 2017a). However, HIV remains a major public health concern with 1.8 million new diagnoses in 2016 worldwide and around a million deaths a year (WHO, 2017).

Between 2000 and 2016, new HIV infections rates fell by 39% and HIV-related deaths fell by 33% due to the availability of ART (WHO, 2017).

Despite this success, levels of HIV acquisition vary notably across countries and sub-groups in the population (UNAIDS, 2013). In the UK, there were 4 363 new HIV infections in 2016. Fifty-four percent of these were reported among men who have sex with men, and 19% and 22% of diagnoses were among heterosexual men and women respectively (Public Health England, 2017a). HIV also continues to disproportionately affect individuals of black African ethnicity (Public Health England, 2017b).

HIV can be a demanding illness to live with and often represents a burden for people living with the illness (Remien et al., 2006). Stressors include ART adherence and potential side-effects, symptoms associated with illness progression, as well as adjustment and acceptance of living with a serious illness (Moskowitz & Wrubel, 2005). Other stressors include HIV disclosure, managing safe sex, as well as managing on-going relationships with HIV services. The ability to adjust and cope with the stressors associated with a HIV diagnosis is vital as poor adjustment can have detrimental effects on the individual's mental health and the progression of HIV (e.g. Bottonari, Roberts, Ciesla, & Hewitt, 2005; Remor et al., 2007). According to Moss-Morris' model

of adjustment, personality traits are key processes in how individuals adjust to a chronic illness (Moss-Morris, 2013). As personality-related difficulties may increase one's risk of contracting HIV (e.g. Hutton & Treisman, 2008), it can be hypothesised that there is a high prevalence of personality disorders (PDs) in individuals living with HIV.

PD is a way of understanding individuals whose personality seriously impacts on either their own lives or those of others in an unhelpful way. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM), PDs are defined as “an enduring pattern of inner experience and behavior that deviates markedly from the expectation of the individual's culture”. The pattern must be pervasive, inflexible, have an onset in adolescence or early adulthood and cause significant distress or impairment (DSM-5; American Psychiatric Association, 2013). The current classification in DSM-5 includes ten categories of PD, which can be divided into three clusters. Cluster A (described as ‘odd and eccentric’) includes paranoid, schizoid and schizotypal PD; Cluster B (‘dramatic and erratic’) includes antisocial, borderline, histrionic and narcissistic PD; and Cluster C (‘anxious and fearful’) includes avoidant, dependent and obsessive-compulsive PD (American Psychiatric Association, 2013).

Research has suggested that Cluster B disorders are most common PDs in individuals with HIV (Hutton & Treisman, 2008; Singh & Ochitill, 2006). Cluster B PDs are often characterised by behaviour associated with an increased risk of HIV acquisition, such as impulsive sexual behaviour, more sexual partners

and substance use (Durvasula & Regan, 2015). After infection, personality-related difficulties have been associated with reduced treatment adherence (Golding & Perkins, 1996) and poorer post-HIV diagnosis outcomes, such as poor physical health, mental health difficulties and poor support systems (Gerhardstein, Griffin, & Hormes, 2011). However, very few studies have explored the impact of personality-related difficulties in those living with HIV. Understanding the relationship between personality-related difficulties and HIV is crucial to the development of theoretical frameworks, tailored interventions and guidelines, to be able to better support this population.

### **Systematic review**

The literature above highlights that a better understanding of the relationship between PD and HIV is crucial to be able to develop targeted treatments. The prevalence of PD in HIV populations, however, remains unclear. In addition, there do not appear to be any reviews which have examined the associations of PD in individuals living with HIV. Understanding prevalence rates and associations of the two disorders is crucial to guiding the development of specific treatment guidelines as well as theoretical frameworks. Therefore, the current systematic review synthesised the literature exploring the prevalence and associations of PD and HIV. Studies were included if they reported prevalence rates and/or associations of PD in HIV. Thirty-four studies met the review's inclusion criteria. The review described and evaluated the reviewed studies, synthesised the data, and explored the relationship between the two disorders.

Across studies, there were significantly higher rates of PDs in HIV-positive individuals compared to HIV-negative populations, across inpatient settings, psychiatric emergency departments, substance use settings and community samples. In addition, there were a large variety of associations explored in the 34 studies. The associations were grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors. Variables where three or more studies indicated a relationship with HIV and PD included: gender, substance use, axis I disorders, quality of life and ART adherence. The review indicated that there was a higher prevalence of PD in HIV-positive males and substance users. Furthermore, PDs in people living with HIV were related to higher rates of Axis I disorders, decreased quality of life and reduced ART adherence. The review demonstrated that the relationship between HIV and PD may be influenced by several factors, which will be important to take into consideration when supporting this population. Future research could examine these factors to gain a clearer understanding of how the associated variables may impact on life with HIV and PD.

## **Empirical article**

The elevated risk of contracting HIV when living with PD has already been established, but the effect of PD when living with HIV is less researched. Despite the common comorbidity, and the potentially severe consequences and outcomes, there is very limited literature on personality-related difficulties

and wellbeing in HIV. To my knowledge, there have been no first-hand accounts of what it is like to live with HIV in individuals with personality-related difficulties. Understanding the impact of personality-related difficulties in people living with HIV is important to better support this population, as we will better understand the challenges they are faced with. The empirical article explored the impact of personality-related difficulties in people living with HIV. The participants were recruited from two HIV clinics. Nine adults presenting with personality-related difficulties met the criteria for Cluster B PD on a screening measure. They took part in semi-structured interviews about their life with HIV. The data was analysed using the qualitative method of Grounded Theory.

Eight theoretical codes were identified and a theoretical model indicating the diagrammatic representation of the relationship between the codes was generated. Findings suggest that the individuals present with difficulties experiences and deficits in the following areas prior to the HIV diagnosis: traumatic experiences prior to HIV; mentalizing deficit (self and others); difficulties identifying and regulating current emotions; and dysfunctional relationships. The model then suggests that these areas lead to; difficulties managing sex; dissatisfaction over the support they have received; negative feelings towards HIV and self before and after diagnosis; fear and shame impacting on life with HIV. Clinically, the current study suggests that there is a significant impact of personality-related difficulties when living with HIV. It is surprising that there is no specific guidance for people living with comorbid HIV and personality-related difficulties. The current study has identified many

barriers for treatment, which may indicate that individuals with personality-related difficulties and HIV may need different support and treatment compared to individuals living with either HIV or PD traits.

## **Integration, impact and dissemination**

### *Integration*

The literature within the review highlighted the problem, that is, there is a high prevalence of personality-related difficulties in people living with HIV and the traits have a significant impact on the individuals' lives. The literature provided a clear rationale for the systematic review and empirical article which both focused on the HIV and personality-related difficulties. Specifically, the systematic review explored the relationship between HIV and personality-related difficulties, in terms of prevalence and associated variables, whereas the empirical article focuses on the impact of personality-related difficulties when living with HIV.

The review highlighted that there was a high prevalence rate of PD in HIV, as well as multiple associations of the two disorders. The review findings were relevant to the empirical project as they informed areas to be further explored (e.g. symptoms of mental health, substance use and support). Therefore, it felt necessary to include questions on substance use, mood, socio-demographic variables and physical health in the empirical study.

## *Impact*

HIV can be a demanding illness and often represents a burden for people living with the illness (Remien et al., 2006). The ability to adjust and cope with the stressors associated with a HIV diagnosis is vital as poor adjustment can have detrimental effects on the individual's mental health and the progression of HIV (e.g. Bottonari, Roberts, Ciesla, & Hewitt, 2005; Remor et al., 2007). Dysfunctional personality traits are thought to have a negative effect on adjustment to chronic conditions (Moss-Morris, 2013). The current review and empirical relationship investigate the relationship between personality-related difficulties and HIV. This research contributes knowledge regarding the prevalence and associations of PD in HIV, but also indicates areas affected by the diagnosis where individuals may need extra support. The potential beneficiaries of this work are: a) individuals with personality-related difficulties and HIV b) friends and family of these individuals c) HIV clinicians d) clinical psychologists and other mental health staff e) GP and A&E staff f) support organisations and peer groups g) policy makers h) researchers.

## *Dissemination*

It is planned that the current research will be made more broadly available by publishing results in a journal article in an academic journal (e.g. AIDS & Behaviour and Clinical Psychology Review). Alongside this, the empirical abstract will also be submitted to the 2019 AIDS Impact conference. By disseminating the research findings in this way, researchers and clinicians

working in the field of HIV and mental health could become aware of the study's findings.

It is planned that I will disseminate the key findings written in lay language to the service users participating in the research. Disseminating findings with participants would allow feedback on what elements of the study could potentially be most useful to other service users. Once this has taken place, the feedback will be incorporated and findings will be disseminated at the participating services as well as relevant service user forums. To facilitate dissemination to clinicians it is planned that I will attend team meetings to present key findings. Feedback from team members will be important as the impact of the study will be maximised if the clinicians find the summarised information useful and feel able to incorporate it during consultations.



**A systematic review of the rates and associations of  
personality disorders in people living with HIV**

## Abstract

**Introduction:** Personality difficulties may increase one's risk of HIV and lead to poorer outcomes following an HIV-positive diagnosis. Despite this, the relationship between PDs and HIV is not understood. Understanding prevalence rates and associations related with the two disorders is crucial to guiding the development of specific treatment guidelines as well as theoretical frameworks. Therefore, the current systematic review synthesised the literature exploring prevalence and associations of PD and HIV. **Method:** Studies were included if they reported prevalence rates and/or associated variables of PD in HIV. Thirty-one studies met the review's inclusion criteria. The review described and evaluated the reviewed studies, synthesised the data, and explored the relationship between the two disorders. **Results:** Across studies, there were significantly higher rates of PDs in HIV-positive individuals compared to HIV-negative individuals, across inpatient settings, psychiatric emergency departments, substance use settings and community samples. In addition, there were a large variety of associated variables explored in the 34 studies. The associated variables were grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors. Variables where three or more studies indicated a relationship with HIV and PD included: gender, substance use, axis I disorders, quality of life and ART adherence. **Discussion:** The review demonstrated that there is a higher prevalence rate

of PD in people living with HIV compared to the HIV-negative population. The relationship between HIV and PD may be influenced by several factors, which will be important to take into consideration when supporting this population. Future research could examine these factors to gain a clearer understanding of how these associated variables may impact on life with HIV and PD.

# Introduction

## **HIV: General Overview**

As defined in greater detail in the Executive Summary (p. 8) HIV is a blood borne virus that attacks the body's immune system by reducing the number of CD4 blood cells, making individuals more susceptible to infection and disease. Acquired Immunodeficiency Syndrome (AIDS) is the most advanced stage of HIV infection, when the CD4 count drops to a very low level, making individuals more likely to develop opportunistic illnesses. People with AIDS survive for about three years without treatment (CDC, 2016). In the 1990's antiretroviral therapy (ART) was introduced and changed the clinical picture of HIV from being a fatal to a chronic illness. ART cannot cure HIV but it prevents it from replicating itself and it has been shown to reduce transmission of HIV by 96% (Hull, Wu, & Montaner, 2012).

HIV remains a major public health concern with 1.8 million new diagnoses in 2016 worldwide. HIV can be transmitted through unprotected sexual contact, from mother to child transmission (either through pregnancy, birth or breastfeeding), or through sharing of equipment used for intravenous drug use (WHO, 2017). There are 36.7 million people in the world living with HIV, suggesting a prevalence of 0.8% adults aged 15-49 years old worldwide (WHO, 2017). In 2017, the United Kingdom (UK) had an estimated 102 000 people living with HIV, suggesting a prevalence of 0.16% adults in the UK (Public Health England, 2017b).

HIV can be a demanding illness to live with and often represents a burden for people living with the illness (Remien et al., 2006). Stressors include adherence to medication, side-effects of treatment, symptoms associated with illness progression, a fear of death, financial difficulties, adjustment and acceptance of living with a serious illness, as well as being faced by HIV stigma (Moskowitz & Wrubel, 2005). Other stressors include HIV disclosure, negotiating safer sexual relationships, as well as managing on-going relationships with HIV services. The ability to adjust and cope with the stressors associated with a HIV diagnosis is vital as poor adjustment can have detrimental effects on the individual's mental health and the progression of HIV (e.g. Bottonari, Roberts, Ciesla, & Hewitt, 2005; Remor et al., 2007).

## **HIV and Mental Health**

In a recent population study in Sweden, Bauer-Staeb and colleagues (2017) found that prevalence of blood-borne viruses (e.g. HIV) was elevated in people with severe mental illness. The odds of HIV infection were nearly three times higher in people with severe mental illness than in the general population. The authors also found that having a history of substance misuse increased the odds of HIV infection in those with and without severe mental health difficulties (Bauer-Staeb et al., 2017). It has been proposed that the link between HIV and psychiatric disorders is bi-directional and influenced by many factors, for example HIV stigma and discrimination, family support and educational level. Other factors such as medication side effects, treatment

adherence, concurrent substance use and the course of HIV infection have also been found to influence the relationship (Chandra, Desai, & Ranjan, 2005).

Depression, anxiety disorders and substance use are more common in people with HIV than in the general population. Individuals with HIV are two to seven times more likely to meet diagnostic criteria for depression than individuals in the general population, and they present with lifetime rates as high as 40-50% for substance use (Owe-Larsson, Sall, Salamon, & Allgulander, 2009). In 2009 the New York State Department of Health AIDS Institute estimated that 13% to 23% of individuals living with HIV had comorbid mental health and substance use diagnoses (New York State Department of Health AIDS Institute, 2009).

## **Personality Disorders: General Overview**

As defined in greater detail in the Executive Summary (p. 10) personality disorders (PDs) are “an enduring pattern of inner experience and behavior that deviates markedly from the expectation of the individual’s culture”. The pattern must be pervasive, inflexible, have an onset in adolescence or early adulthood and cause significant distress or impairment (DSM-5; American Psychiatric Association, 2013). The current classification in DSM-5 includes ten categories of PDs, which can be divided into three clusters. Cluster A (described as ‘odd and eccentric’) includes paranoid, schizoid and schizotypal PDs; Cluster B (‘dramatic and erratic’) includes antisocial, borderline,

histrionic and narcissistic PDs; and Cluster C ('anxious and fearful') includes avoidant, dependent and obsessive-compulsive PDs (American Psychiatric Association, 2013).

It has been long known that there is a poor diagnostic reliability of PDs and poor temporal stability (Zimmerman, 1994) and, as such, the prevalence of PD in the general population ranges from 4-15% depending on studies. A recent meta-analysis presented a prevalence rate of 12.16% in the general population (Volkert, Gablonski, & Rabung, 2018). PDs are associated with high mortality (Skodol, 2016) and comorbidity (Moran et al., 2016). There is also a high level of comorbidity with other mental health disorders; 85% of patients with Borderline PD have at least one Axis I disorder of the DSM-5 and 74% have another PD (Grant et al., 2008). Furthermore, PDs are also associated with higher levels of alcohol and substance use, lower levels of education (Moran et al., 2016) and an increased risk for self-harm and suicide (Linehan et al., 2015) compared to people without PD. In addition to this, individuals with PD have been found to make less contact with psychiatric services, compared to individuals with other conditions such as schizophrenia and depression (Andrews, Issakidis, & Carter, 2001), as well as presenting with a low level of treatment adherence for psychological therapies (Martino, Menchetti, Pozzi, & Berardi, 2012).

## **Personality Disorders and Adjustment**

Personality traits and early life experiences are key processes contributing to how individuals adapt to a chronic illness (Moss-Morris, 2013). Brunault and colleagues found that psychological characteristics (e.g. PD) accounted for more of the variance of the individuals' quality of life (as reported on a questionnaire) compared to biological or physiological variables (e.g. treatment types and severity of illness) in individuals diagnosed with non-metastatic breast cancer (Brunault et al., 2016). This suggests that individuals with personality related-difficulties may find the emotional challenges of their physical illness even more daunting, and the physical symptoms or treatment adherence even more problematic, than someone without mental health difficulties. Furthermore, PDs are often accompanied by an Axis I diagnosis (e.g. depression or anxiety) further complicating the likelihood of positive coping with a physical illness and treatment adherence (Tyrer, Reed, & Crawford, 2015)

## **HIV and Personality Disorders: Impact**

PD difficulties, and particularly Cluster B PDs, are often characterised by behaviours associated with an increased risk of HIV acquisition, such as impulsive sexual behaviour, more sexual partners and substance use (Durvasula & Regan, 2015). In a sample of men involved in the criminal justice system, Borderline PD traits were strongly associated with HIV risk behaviours. The PD symptoms most associated with an increased risk of contracting HIV were abandonment worry and mood swings. Higher



Borderline PD scores (as measured on a questionnaire) were associated with sexual risk behaviours, including multiple partners and sex with non-monogamous partners (Scheidell et al., 2016).

Personality-related difficulties may also lead to poorer outcomes following diagnosis (e.g. Hutton & Treisman, 2008; Scheidell et al., 2016). In a review study, it was argued that individuals with HIV and PD difficulties often present with challenges in terms of engagement with care, medication adherence, difficulty with interpersonal skills and struggle with how to appropriately express their health care needs (Willinger, 2010). In another review, the authors argued that individuals with PD are often characterised by their dysfunctional interpersonal skills and poor impulse control, which frequently leads to disrupted HIV treatments. In addition to this, individuals often present with poor physical health, mental health difficulties, poor support systems and health-related quality of life (Gerhardstein, Griffin, & Hormes, 2011).

### **Personality Disorders in HIV: Rates and Associations**

PDs have been suggested to be risk factors for HIV (e.g. Scheidell et al., 2016) which indicates that the prevalence rate will be higher in individuals living with HIV compared to the population. The relationship between PDs and HIV, however, is not understood. It is therefore important to further explore study populations, sampling methods, diagnostic tools and other discrepancies to further understand the relationship between HIV and PD.

This will help us to understand the relationship between HIV and PD further to develop specific interventions and care.

In addition, there do not appear to be any reviews which have examined the associations of PD in individuals living with HIV. For example, it has been hypothesised that substance use may mediate the relationship between PD and HIV risk behaviours (Gerhardstein et al., 2011). The rates of substance use among individuals living with HIV are consistently higher than in the general population. Half of participants enrolled in a large national study in the US looking at HIV-positive individuals currently in care, reported illicit drug use during the previous year (Bing et al., 2001). In addition, a recent review highlighted that 45-86% of individuals with borderline PD also met criteria for lifetime substance use disorder (Trull et al., 2018). The relationship between PD and HIV appears to be influenced by many factors, and one of these may be substance use disorder. It will be important to further explore associated variables of PD in living with HIV to gain a better understanding of this common comorbidity. There are currently no specific guidelines for people living with comorbid HIV and PD so increasing the awareness and understanding of the relationships between the two disorders could assist in the development of specific guidance, interventions and care.

## **Aims and Objectives of the Current Review**

The current systematic review will synthesise the literature exploring the prevalence and associations of personality disorders in HIV, to answer the following research question:

- What are the rates and associated variables of personality disorders in samples of people living with HIV?

# Method

## Study Eligibility

The following inclusion criteria was used:

- Observational or experimental studies.
- Individuals with an HIV-positive diagnosis and a diagnosis of a personality disorders or scores on a personality disorder questionnaire/ self-report measure suggestive of a personality disorder diagnosis. All diagnostic systems and classifications of personality disorders (e.g. DSM-III, DSM-IV and DSM 5) were included.
- Quantitative or mixed methods studies where the rate of personality disorders in HIV are presented or can be calculated from available quantitative data.

## Sources of Information

Studies in peer-reviewed journals were retrieved from Pubmed, PsychINFO and Web of Science. Only studies published in English were included. All settings and locations were included and there was no date exclusion.

## Search Strategy

Searches were conducted using combinations of the following search terms:

- “HIV” or “AIDS” or “AIDS Viruses” or “Human immunodeficiency disease” and

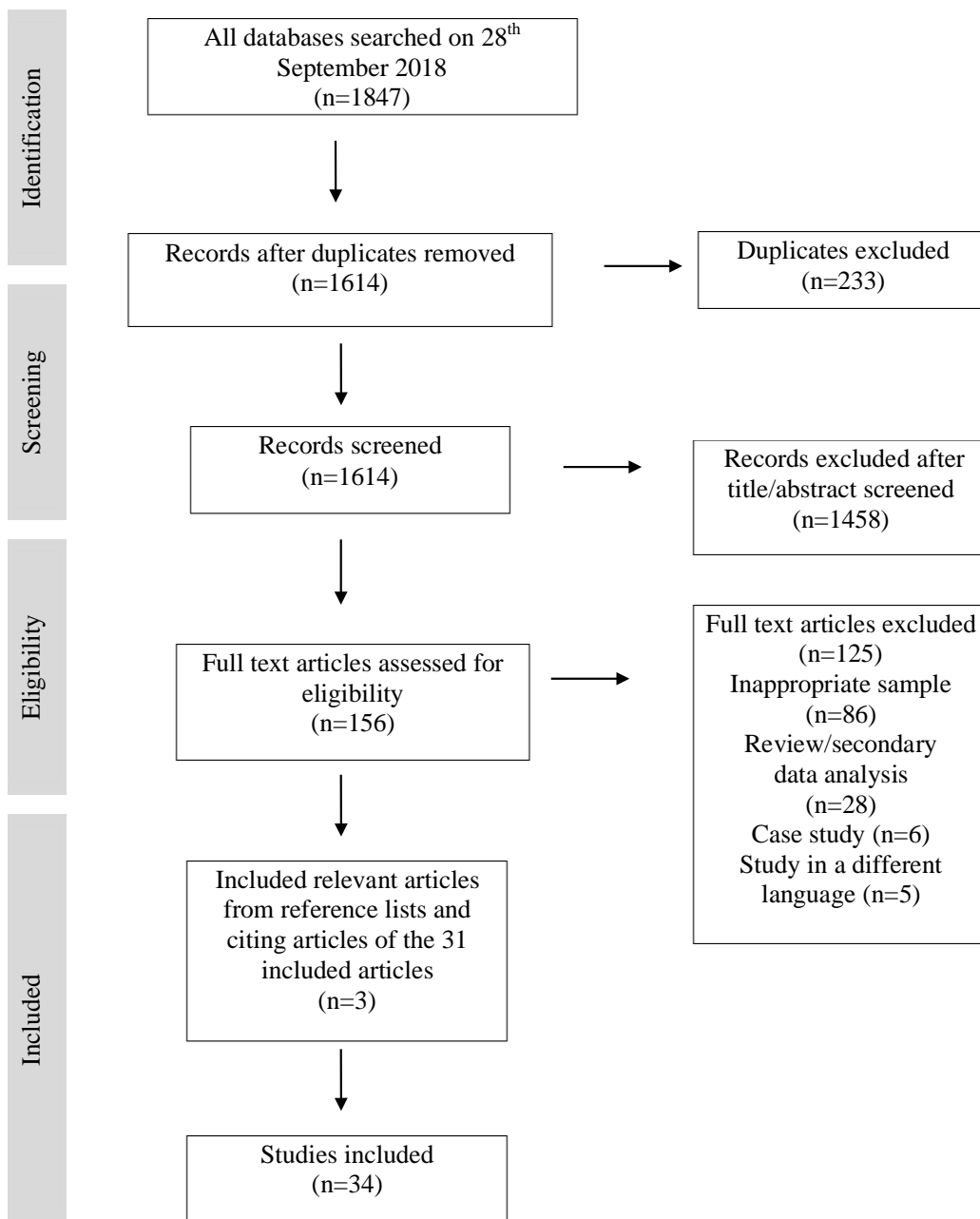
- “Personality disorder” or “personality difficulties” or “axis 2” or “interpersonal difficulties” or “personality dysfunction” or “personality-related difficulties”.

The terms were searched for as key words in titles and abstracts. In addition, the reference lists and citing articles of the included studies were searched.

## **Data Collection**

The data collection process followed the practice guidelines of PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) (see Figure 1 and Appendix L).

The researcher carried out searches for the identification of studies using the pre-specified search criteria in three databases (27th September 2018). The researcher removed any duplicate articles. Two reviewers (the researcher and an undergraduate psychology student) independently screened the remaining titles and abstracts for eligibility. Articles considered relevant by either reviewer were retrieved in full text. The two reviewers independently assessed eligibility of retrieved articles. Exclusions were recorded in an Excel spreadsheet, with reasons given. The inter-rater agreement between the two reviewers was Kappa = .57, indicating a moderate level of agreement between the reviewers (McHugh, 2012). A third reviewer (the academic supervisor) resolved any disagreements.



**Figure 1: Study Search Process**

## Data Abstraction

For each included study the following details were extracted:

- *Study information:* Authors, year of publication, location, study design, sampling strategy, response rate and sample characteristics (including sample size, gender, age and ethnicity).
- *Assessment tools:* Measures of PDs and associated variables.
- *Prevalence and associations:* Reported or calculated prevalence of PD in the HIV sample. Associations between PDs, HIV and associated variables.

## Quality assessment

The methodological quality of the studies was evaluated using a bespoke assessment tool (Table 1). A bespoke tool was developed as this is a mixed prevalence and association review and due to this some of questions of others tools not being suitable for the current study. The developed tool was based upon the Mixed Methods Assessment quality assessment tool (Pluye et al., 2011) and Joanna Briggs Checklist for prevalence studies (The Joanna Briggs Institute, 2017). The quality assessment tool was used to ascertain the risk of bias for included studies. The developed tool assessed dimensions of internal validity (e.g. detection bias and confounding) and external validity (e.g. sample representativeness and response rate). Two reviewers (the researcher and an undergraduate psychology student) assessed all included papers independently. A third reviewer (the academic supervisor) resolved

any disagreements. The biases highlighted by the assessment tool were considered in the subsequent interpretation of the data.

### **Data synthesis**

There was too much heterogeneity in the variables examined to combine the study results for statistical analysis, such as a meta-analysis. Therefore, the current study described and evaluated the included studies, synthesised the data and examined and compared the relationship of factors/variables included to answer the key objectives of the review.



**Table 1: Quality Assessment Tool for Quantitative Studies**

External validity	Sampling	Is the sampling clear and representative to address the research question?	<p>Consider:</p> <ul style="list-style-type: none"> <li>• Whether the sample is suitable to assess personality disorder traits in a HIV-positive sample e.g. used random sampling or sampled everyone from population and NOT used convenient sampling (e.g. only people who turn up at clinic)</li> <li>• Have the study used inclusion and exclusion criteria?</li> </ul> <p>➤ Both needed for yes</p>
	Response rate	Was the response rate adequate, and if not, was the low response rate managed appropriately?	<p>Consider:</p> <ul style="list-style-type: none"> <li>• Whether the study has a low response rate (&lt;70%). The authors should in this case clearly discuss the response rate and any reasons for non-response and compare persons in the study to those not in the study, particularly with regards to their socio-demographic characteristics.</li> </ul> <p>➤ Yes if the response rate is higher than 70% <u>OR</u> if the authors have assessed and not found any non-significant differences between responders and non-responders</p>
Internal validity	Detection validity: PDs	Were reliable and valid measurements used in the identification of personality disorder/personality disorder difficulties?	<p>Consider:</p> <ul style="list-style-type: none"> <li>• Whether either a diagnostic interview was used <u>or</u> a questionnaires which had either a) been used in previous studies or b) developed for the study and had reliability of <math>\geq 0.7</math> (e.g. internal consistency or inter-rater reliability).</li> </ul> <p>➤ Yes if authors used diagnostic interview <u>or</u> questionnaire (which had been used in previous studies <u>or</u> had a reliability of <math>\geq 0.7</math>).</p>
	Detection Validity: Associated variables	If associated variables are measured, were the majority of the measures used reliable and valid?	<p>Consider:</p> <ul style="list-style-type: none"> <li>• Whether either objective measures or self-report measures were used. Have the measures either been a) used in a previous study <u>or</u> b) they were developed for the study and had reliability of 0.7 (e.g. internal consistency or inter-rater reliability).</li> </ul> <p>➤ Yes if authors used diagnostic interview <u>or</u> questionnaire (which had been used in previous studies <u>or</u> had a reliability of 0.7) for a majority of the associated variables.</p>
	Control of confounding variables	Did the study control for potential confounders?	<p>Consider:</p> <ul style="list-style-type: none"> <li>• Whether the authors conducted multivariate analysis, i.e. an adjusted analysis where the authors have not just reported t-test and correlations but instead used for example partial correlations, multiple regression, adjusted odds ratio etc.</li> </ul> <p>➤ Yes if multivariate analysis is completed</p>

## Results

Of 1847 citations identified through the initial search, 31 articles met inclusion criteria for the review. An additional 3 studies were included from reference lists and citations leaving a total of 34 studies included in the review (see Figure 1).

### Overall Study Characteristics

Study characteristics are described in Table 2. All reports of multiple publications were included. Overall, the 34 studies relate to 33 datasets; two studies used data from one data set. All 34 articles were published between February 1990 and December 2017. Twenty-seven studies were conducted in the United States, two in Spain, one in the United Kingdom, one in the Netherlands, one in Romania and one in Italy. The location of one study was unclear.

Most studies were either cross-sectional (n=20), longitudinal (n=6) or retrospective (n=5) in design, however, there was also 1 prospective cohort study and 1 randomised controlled trial. Across all studies, sample sizes ranged from 1 to 22 606 (median: 93, inter-quartile range: 57-142) and overall 39 279 HIV positive participants were included. Across the thirty-three data sets, five studies looked at female only samples, five studies looked at male only and the remaining twenty-three studies had a mixed sample.

Across all studies, four studies recruited participants from inpatient admissions, two from psychiatric emergency departments, two from forensic institutions, and eight from substance use outpatient services. Participants from the remaining sixteen studies were recruited from community settings (such as HIV primary care and mental health outpatient services). Sixteen of the studies only included HIV-positive participants and seventeen studies included both HIV-positive and negative participants.

## **Assessment of Personality Disorders**

There was a great variability in how PDs were assessed. Seven studies listed that they based their diagnoses on the Diagnostic and Statistical Manual (DSM) but did not specify how the participants were assessed. One study stated that participants were diagnosed in hospital but did not state any further details. Six studies listed that they used the Structured Clinical Interview for DSM-IV Axis II Personality disorders (SCID-II; (First, Gibbon, Spitzer, Williams, & Smith Benjamin, 1997) and two studies used the SCID-II combined with International Personality Disorders Examination (IPDE; Loranger, 1997). Three studies used the Millon Clinical Multiaxial Inventory (MCMI-III; Millon, 1997), two used The Computer-Assisted SCID-II (CASII; First, Gibbon, Spitzer, Williams, & Smith Benjamin, 1997).

Four studies used the Diagnostic Interview Schedule (Robins et al., 2000) where one of these used a computerised version of the schedule. Two studies used different versions of the Personality Diagnostic Questionnaire-4 (PDQ-R and PDQ-4; Hyler et al., 1988). Two studies used the Psychiatric Research Interview for Substance and Mental Disorders (PRISM; Hasin et al., 1996) or the Spanish version of the PRISM (Torrens, Serrano, Astals, Pérez-Domínguez, & Martín-Santos, 2004). The remaining four studies used the Alcohol Research Center Intake Interview (Schuckit, Irwin, Howard, & Smith, 1988), Alcohol Use Disorder and Associated Disabilities Interview Schedule (AUDADIS-IV; Grant et al., 2003), Personality Factors Questionnaire based on the DSM-III-R (Brown, unpublished manuscript, 1987), or a structured

personality inventory from the Karolinska Psychodynamic Profile (KAPP; (Weinryb, Rössel, & Åsberg, 1991)). One study did not state any information in regards to how PD symptoms were assessed.

## **Data Synthesis: Prevalence**

To ensure brevity, when no specific disorder is mentioned in the result or discussion sections, it indicates any PD.

### *Inpatient settings*

Bansil and colleagues found a prevalence rate of 8.2% (1994) and 4.7% (2004) in a large sample of hospitalised HIV-positive women (Bansil, Jamieson, Posner, & Kourtis, 2009). Travin and colleagues explored prevalence and characteristics of 11 violent patients in an AIDS service. No participants met criteria for a PD (Travin, Lee, & Bluestone, 1990).

### *Psychiatric emergency departments*

Two studies explored prevalence rates of PD in HIV-positive patients treated in psychiatric emergency departments. One study found a prevalence rate of 8.6% for PD and 4.7% for Borderline PD, both significantly higher than for HIV-negative patients (Bennett, Joesch, Mazur, & Roy-Byrne, 2009). However, another study did not find a significant difference between groups. Ellis et al. found that 13% met criteria for PD in the HIV-positive group,

compared to 11% in the HIV-negative control group (Ellis, Collis, & King, 1994).

### *Forensic settings*

Two studies explored psychiatric disorders in incarcerated men and women in the US and Spain. Out of 81 HIV-positive female inmates in the US, 8.6% met criteria for Borderline PD and 18.5% met criteria for Antisocial PD on the SCID-II (Lewis, 2005). In inmates co-infected with Hepatitis C and HIV across 25 Spanish prisons, 75.9% received a PD diagnosis (Marco et al., 2015).

### *Substance use settings*

Across studies, HIV-positive substance users were more likely than HIV-negative substance users to have a PD (Brooner, Greenfield, Schmidt, & Bigelow, 1993; Gilchrist, Blazquez, & Torrens, 2011; McGurk, Miller, & Eggerth, 1994; Palmer, Salcedo, Miller, Winiarski, & Arno, 2003; Turrina et al., 2001), whilst controlling for confounding variables. However, one study found that there was no significant difference in the prevalence of PD in HIV-positive methamphetamines users compared to HIV-negative non-substance users (Moore et al., 2012).

In terms of prevalence rates, Turrina and colleagues found a PD prevalence rate of 36% in intravenous drug users (Turrina et al., 2001). The prevalence rates varied from 37% to 47% for Borderline PD in different studies (Gilchrist et al., 2011; Palmer et al., 2003), whereas the prevalence rates of Antisocial

PD across studies had a greater variation, ranging from 13% to 64% (Brooner et al., 1993; Gilchrist et al., 2011; Moore et al., 2012; Palmer et al., 2003).

A few of the studies also explored the rates of HIV in participants with PD. Two studies found that individuals with PD were more likely to be HIV-positive compared to those without PD (Brooner et al., 1993; Gilchrist et al., 2011), however, one study found a low prevalence rate of HIV in participants diagnosed with Borderline PD (Chen, Brown, Lo, & Linehan, 2007).

### *Community samples*

Nineteen studies recruited participants from community samples, including military personnel, primary care HIV clinics, and participants receiving psychological or psychiatric outpatient treatment.

### **Female only samples**

James et al. explored psychiatric disorders in HIV-positive pregnant women and found that 40% met criteria for a PD diagnosis (James, Rubin, & Willis, 1991).

### **Male only samples**

There was a great variation in prevalence rates of PDs in male only samples. The prevalence ranged from 17% to 61% across four studies (Johnson, Williams, Rabkin, Goetz, & Remien, 1995; Johnson, Rabkin, Williams,

Remien, & Gorman, 2000; Kooiman & Spinhoven, 1996; Lopes et al., 2012). One study found that there was a significantly higher prevalence of PD in HIV-positive (33%) compared to HIV-negative (15%) men (Perkins et al., 1993). They found there was a significantly higher prevalence of PDs in HIV-positive individuals compared to HIV-negative after controlling for age and ethnicity, although when controlling for education, the finding was reduced to a trend (Perkins et al., 1993). Another study found that HIV-positive men were significantly more likely than HIV-negative men to have a PD, however the difference was not significant when adjusting for socio-demographic variables (Lopes et al., 2012). Two studies did not find a significant difference between HIV-positive and HIV-negative men (Johnson et al., 1995b; Johnson et al., 2000).

### **Mixed gender samples**

Fourteen studies recruited mixed gender samples. The prevalence rates of PD varied from 12.6-33% across samples (Beatie, Mackenzie, & Chou, 2015; Bottonari & Stepleman, 2009; Jacobsberg, Frances, & Perry, 1995; Modrigan, Draganescu, Condratovici, Pavel, & Condratovici, 2017; Pace et al., 1990).

In terms of specific disorders, 2.5-65% of HIV-positive participants met criteria for Antisocial PD (Bauer & Shanley, 2006; Fellows, Spahr, Byrd, Mindt, & Morgello, 2015; Haller & Miles, 2003; Modrigan et al., 2017; Newville & Haller, 2012; Shacham, Önen, Donovan, Rosenburg, & Overton, 2016), whereas 5-30% of participants met criteria for a Borderline PD diagnosis across studies



(Fellows et al., 2015; Haller & Miles, 2003; Newville & Haller, 2012). In two different articles, Hansen et al (2007, 2009) found that a total of 28.4% of the study sample met criteria for Antisocial PD or Borderline PD (Hansen et al., 2009; Hansen, Vaughan, Cavanaugh, Connell, & Sikkema, 2007).

### **Data Synthesis: Associated variables**

There were a large variety of associations explored in the 34 studies. The associated variables explored can be grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors.

#### *Socio-demographic variables*

Five studies explored socio-demographic variables (Bennett et al., 2009; Brooner et al., 1993; Fellows et al., 2015; Lopes et al., 2012; Modrigan et al., 2017). In terms of gender, there were significantly more males than females meeting criteria for PD across studies (Fellows et al., 2015; Lopes et al., 2012; Modrigan et al., 2017). One study found that individuals with Antisocial PD were more likely to be an ethnic minority (Brooner et al., 1993)

#### *Substance use*

Across studies, substance users were more likely to have a PD compared to non-substance users (Bansil et al., 2009; Haller & Miles, 2003; James et al., 1991; Marquine et al., 2014), although one study did not find a significant

different between groups (Moore et al., 2012). In addition, three studies found that individuals with PD and substance use were more likely to be HIV-positive than those not using substances (Beyer, Taylor, Gersing, & Krishnan, 2007; Brooner et al., 1993; Chen et al., 2007)

### *Mental health*

Sixteen studies explored associations related to mental health, including suicidal ideation, axis I disorders, quality of life, defence and attachment styles.

#### **Suicidal ideation**

Two studies found an increase in suicidal ideation and suicide attempts in individuals with a PD diagnosis compared to individuals without PD (Bansil et al., 2009; Haller & Miles, 2003). In one study, Narcissistic PD was negatively associating with suicidal ideation, suggesting that this was a protective factor compared to other PDs (Haller & Miles, 2003).

#### **Axis I disorders**

Three studies found higher rates of Axis I disorders (two of these specified depression) in individuals with PD and HIV, compared to HIV-positive and HIV-negative individuals without PD (Bauer & Shanley, 2006; Johnson et al., 1995; Turrina et al., 2001). Two studies found that individuals meeting criteria for PTSD were more likely than those without PTSD to meet criteria for

Antisocial PD and/or Borderline PD (Fellows et al., 2015; Lewis, 2005). One study found that when participants with a current Axis I disorder were eliminated from the analysis, Borderline PD continued to be more frequent among HIV-positive than HIV-negative individuals (Jacobsberg et al., 1995).

### **Quality of life**

Three studies found that PDs was related to decreased health-related quality of life (Haller & Miles, 2003; Hansen et al., 2009, 2007). Interestingly, one study found that family/friends quality of life was negatively correlated with Narcissistic PD and positively correlated with Borderline PD (Haller & Miles, 2003).

### **Defence and attachment styles**

One study explored found that individuals with a PD scored higher for primitive and neurotic defence styles compared to individuals without PD. In addition, individuals with a PD had significantly lower scores on a measure of dependent attachment style than patients without a PD (Kooiman & Spinhoven, 1996).

### *High-risk sexual behaviour*

Two studies explored high-risk sexual behaviours as associated variables.

One study found that individuals with Borderline PD were more likely to report having multiple sex partners, and twice as likely to report irregular condom

use compared to individuals without Borderline PD traits, even after controlling for substance dependence (Newville & Haller, 2012). Marquine and colleagues found that Antisocial PD was found to be a univariable predictor of impulsivity/disinhibition, compared to individuals without PD, in a sample of HIV-positive participants with and without methamphetamine dependency (Marquine et al., 2014).

### *Health-related factors*

Eleven studies explored correlated relating to health, such as ART, HIV symptoms, awareness of HIV status, functioning and impairment.

### **Antiretroviral medication**

Across studies, PDs was associated with non-adherence (Modrigan et al., 2017; Moore et al., 2012; Palmer et al., 2003), although one study found that HIV-positive individuals with a PD were less likely to be non-adherent to medication compared to those without a PD (Bansil et al., 2009).

### **Symptoms**

PD was associated with increased HIV symptoms in one study (Hansen et al., 2007), however, another study did not find an association between PD symptoms and CD4 levels (Johnson et al., 1997).

### **Awareness of HIV status**

One study found an increased rate of PD in HIV-positive individuals not aware of their seropositive HIV status prior to the study (Jacobsberg et al., 1995), whereas another study found that individuals with and without a PD did not differ significantly with regard to the time they had known they were HIV-positive (Kooiman & Spinhoven, 1996).

### **Functioning and impairment**

One study found that the HIV-positive individuals with PD reported higher levels of psychiatric symptoms and poorer functioning compared to those without PD (Johnson et al., 1995).

### **Hepatitis C**

One study found that participants with HIV and Hepatitis C were significantly more likely to receive a Cluster B or Obsessive-compulsive PD diagnosis compared to participants with Hepatitis C only (Marco et al., 2015).

Table 2. Summary of studies

Reference	Location and context	Design, sampling and sample	Measurement of PDs	Measurement of associated variables	Prevalence, associated variables and associations between HIV and PDs
Bansil et al., 2009	United States  HIV women hospitalized with psychiatric diagnoses	Retrospective study. Systematic sampling.  Data from a nationwide inpatient care database  1994: N=13 037 Age (years); 15-34 (44%), 35-44 (42%), 45+ (14%)  2004: N=22 606 Age (years); 15-24 (3%), 25-34 (18%), 35-44 (40%), 45+ (40%)  100% female.  Response rate not reported.	Diagnosed in hospital. No further information.	<ul style="list-style-type: none"> <li>• Hospitalisation</li> <li>• Alcohol/substance use</li> <li>• Non-adherence with medical treatment</li> <li>• Suicide attempt/self-inflicted self-injury</li> <li>• Age</li> <li>• Year hospitalized</li> </ul> Information collected in hospital.	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• Prevalence of PD in inpatient women with HIV: 8.2% (1994) and 4.7% (2004). Significant difference <math>p &lt; 0.001</math> when controlling for associated variables.</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• HIV+ individuals with a PD &lt; without a PD non-adherent to ART AOR: 1.05 <math>p &gt; .05</math> (95% CI: 0.78-1.41) and more likely to disclose previous suicide attempt/self-inflicted injury AOR: 3.56 (95% CI: 2.27-5.59)</li> <li>• Alcohol/substance users were more likely to have a PD. AOR: 4.36 (95% CI: 3.68-5.16)</li> </ul>
Bauer & Shanley, 2006)	United States  Impact of Antisocial PD on the effects of HIV and ART on Event-Related brain potentials.	Cross-sectional study. Systematic sampling.  91 HIV+ 68 HIV- formed 3 groups: 1. HIV- 2. HIV+ and complying with ART 3. HIV+ and not complying with ART  Mean age=38-44; 42% female; 28% Caucasian  Response rate not	Measrue 5*	<ul style="list-style-type: none"> <li>• Age</li> <li>• Treatment status</li> <li>• Alcohol or drug use measured by the Addiction Severity Index, Michigan Alcoholism Screening Test and Drug Abuse Screening Test.</li> <li>• Depression measured by the Beck Depression Inventory (BDI-II)</li> <li>• Brain function measured through EEG</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• 43% ASPD in HIV+ (24% HIV-; <math>p &lt; .05</math>) when controlling for socio-demographic factors.</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• Neither HIV/treatment status nor the interaction of HIV/treatment status with ASPD were related to differences in alcohol or drug use. The only significant findings were related to ASPD.</li> <li>• No significant effects of ASPD on HIV disease severity</li> <li>• Higher rate of depression in the HIV+ group not receiving treatment &gt; HIV- control group</li> </ul>

		reported.			<p>(<math>p &lt; .05</math>)</p> <ul style="list-style-type: none"> <li>Participants with ASPD exhibited a significant decrement in frontal P300 amplitude in comparison to those ASPD-negative (<math>p &lt; .05</math>)</li> </ul>
Beatie, Mackenzie, & Chou, 2015	United States Prevalence of psychiatric and medical comorbidities in middle-aged and older adults	Cross-sectional study. Stratified sampling.  N=15 456 (46 were HIV+)  Age (years): 50-59 (45%); 60-69 (32%); 70+ (23%). 64% Males; 43% White.  87% response rate.	Measure 12*	<ul style="list-style-type: none"> <li>Sex</li> <li>Marital status</li> <li>Ethnicity</li> <li>Personal and household income</li> <li>Insurance</li> <li>Sexual orientation</li> <li>Hypertension</li> <li>Diabetes</li> <li>Arthritis</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>22% PD in HIV+ (<math>p &gt; .05</math>; compared to HIV-).</li> </ul>
Bennett et al., 2009	United States. HIV+ treated in psychiatric emergency departments.	Cross-sectional study. Stratified sampling.  N=553 HIV positive (1178 visits)  Mean age= 39 years; 84% Males; 61% Caucasian.  94% response rate.	Measure 1*	<ul style="list-style-type: none"> <li>Presenting to emergency services</li> <li>Gender</li> <li>Age</li> <li>Race</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>8.6% PD in HIV+ (<math>p &gt; .05</math>; compared to HIV-).</li> <li>4.7% BPD in HIV (<math>p &gt; .05</math>; compared to HIV-).</li> </ul> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>HIV+ were more likely to have a BPD diagnosis AOR: 2.1 (95% CI: 1.3-3.2) <math>p &lt; 0.01</math>, when controlling for gender, age and race</li> </ul>
Beyer, Taylor, Gersing, & Krishnan, 2007	United States. Prevalence of HIV in a psychiatric outpatient population.	Retrospective study. All patients included.  N=11 284 (130 were HIV+).  Mean age=41 years; 54% Males; 19% Caucasian.  Response rate not reported.	Measure 1*	<ul style="list-style-type: none"> <li>Substance use</li> </ul>	<p>Multivariate analysis: no.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>3.1% of HIV in PD (<math>p &lt; .001</math>; compared to national average)</li> <li>9.5% of HIV in PD + substance misuse (<math>p &lt; .001</math>; compared to psychiatric population)</li> </ul>
Bottonari & Stepleman, 2009	United States. Factors associated with Psychotherapy Longevity	Retrospective study.  N=82  Mean age=42 years; 33% female.  Reported good response rate	Measure 1*	N/A	<p>Multivariate analysis: no.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>12.6% PD</li> </ul> <p>Other relevant findings:</p> <ul style="list-style-type: none"> <li>PD &gt; non-PD to complete 6 sessions of therapy (<math>p &lt; 0.05</math>)</li> </ul>

Brooner et al., 1993	United States.  ASPD and HIV infection among intravenous drug users	Longitudinal study. Convenience sampling.  N=272 (33 HIV+)  Mean age= 36 years 72% Male; 60% Black  Response rate not reported.	Measure 9*	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Ethnicity</li> <li>• Current and Shorter lifetime duration methadone treatment</li> </ul>	Multivariate analysis: yes.  Prevalence of PD: <ul style="list-style-type: none"> <li>• 64% ASPD</li> </ul> Prevalence and associations of HIV: <ul style="list-style-type: none"> <li>• ASPD group &gt; non-ASPD had HIV (18 vs. 8% p&lt;.05), when controlling for ethnicity, gender and current methadone treatment.</li> <li>• Individuals in the ASPD group were more likely to be an ethnic minority, not currently and shorter lifetime duration of methadone treatment</li> </ul>
Chen et al., 2007	United States.  Rates of STDs in women with BPD and substance use.	Cross-sectional study. Random sampling.  N=184 (1 HIV+)  Mean age=31 years; 100% Female; 83% Caucasian  80% response rate	Measures 2, 3*	<ul style="list-style-type: none"> <li>• STDs was assessed using a medical history interview</li> <li>• Substance use was assessed using measure 2*</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• HIV in BPD: 1% (no statistical test)</li> <li>• HIV in BPD and substance use: 0%</li> </ul>
Ellis et al., 1994	United Kingdom.  Psychiatric illness and treatment in referrals to psychiatric liaison service	Retrospective study. All patients referred to service.  N=140 (70 HIV+ and age and sex-matched controls)  Mean age=33 years 60% Male  Response rate not presented.	Measure 1*	N/A	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>• PD in HIV+ group 13% (vs. 11% control group; p&gt;.05).</li> <li>• 73% of the PDs diagnosed met the criteria for BPD in the HIV+ group (vs. 42% control group; p&gt;.05).</li> </ul>
Fellows et al., 2015	United States.  Association between trauma exposure, PTSD and suicide attempts in people with	Prospective cohort study. Sampling strategy not reported.  N=316 (across 3 groups)  Mean age=44-46 years and 23-56% female  Response rate not	Measure 8*	<ul style="list-style-type: none"> <li>• Trauma exposure</li> <li>• PTSD (measure 8*)</li> <li>• Gender</li> </ul>	Multivariate analysis: yes  Prevalence: <ul style="list-style-type: none"> <li>• 8.5% ASPD in control group</li> <li>• 7.5% ASPD in trauma exposure but no PTSD (p&gt;.05)</li> <li>• 20% ASPD in trauma exposure and PTSD (OR 2.69, 95% CI 1.13-6.42, p&lt;.05).</li> <li>• 5% BPD control group</li> <li>• 9% BPD in trauma exposure but no PTSD</li> </ul>



	HIV.	reported.			<p>(<math>p &gt; .05</math>)  18% BPD in trauma exposure and PTSD (OR 3.73, 95% CI 1.39-10.04, <math>p &lt; .01</math>).</p> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>• See above</li> <li>• Males with PTSD &gt; females with PTSD to meet criteria for BPD (OR=13.53, 95% CI [1.08–169.10], <math>p &lt; .05</math>)</li> </ul>
Gilchrist et al., 2011	Spain  Psychiatric, behavioural and social risk factors among drug users	Cross-sectional study. Convenience sample.  N=118 (32 HIV positive)  Mean age=39 years; 100% female  71% response rate	Measure 8* (Spanish)	<ul style="list-style-type: none"> <li>• Unprotected sex</li> <li>• Depression</li> <li>• Drug use</li> <li>• Ever injected with used syringe</li> <li>• Ever been in prison</li> <li>• Ever sex traded</li> <li>• Ever homeless</li> <li>• Ever had an HIV+ partner</li> <li>• Substance use disorders, major depressive disorder</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence of PD:</p> <ul style="list-style-type: none"> <li>• 46.9% BPD in HIV+</li> <li>• 46.9% ASPD in HIV+</li> </ul> <p>Prevalence and associations of HIV:</p> <ul style="list-style-type: none"> <li>• Participants with ASPD (OR 5.44; 95% CI 2.16-13.71) more likely to be HIV+ compared to non-PD when controlling for all the associated variables. The difference was not significant for BPD when controlling for the associated variables.</li> </ul>
Haller & Miles, 2003	United States  Suicidal ideation among HIV+ psychiatric patients	Longitudinal study. Convenience sampling.  N=190  68% Male; Mean age= 37 years; African American 68%; White 29%; Other 3%  54% response rate	Measure 4*	<ul style="list-style-type: none"> <li>• Suicidal ideation assessed by a structured interview</li> <li>• Drug dependence assessed with University of Michigan Composite International Diagnostic Interview (UM-CIDI)</li> <li>• Quality of life assessed with HIV Patient-Assessed Report of Status and Experience (HIV-PARSE).</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>• Depressive (40%), dependent (36%), passive-aggressive (35%), avoidant (31%), self-defeating (31%), borderline (BPD; 27%), antisocial (ASPD; 21%), and paranoid (21%) PD.</li> </ul> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>• Drug dependence (but not alcohol dependence) was significantly associated with ASPD (<math>p &lt; .001</math>) and BPD (<math>p &lt; .05</math>) in people living with HIV. 69% of ASPD and 55% of BPD were also drug dependent.</li> <li>• BPD (<math>p &lt; .01</math>) and Avoidant PD (<math>p &lt; .05</math>) were positively associated with suicidal ideation, whereas Narcissistic PD (<math>p &lt; .05</math>) was negatively associated.</li> <li>• Overall Quality of Life was significantly correlated with BPD (<math>p &lt; .05</math>). Family/friends quality of life was negatively correlated with Narcissistic PD (<math>p &gt; .05</math>) and positively</li> </ul>

					correlated with BPD ( $p>0.05$ ) in people living with HIV.
Hansen et al., 2007	United States.  BPD and ASPD indications on HIV and health-related quality of life (HRQoL) in AIDS-bereaved adults.	RCT study.  N=268  Age not reported. 65% Male; 54% African-American; 9% Hispanic, 10% other  83% Response rate	Measure 5*	<ul style="list-style-type: none"> <li>Grief severity measured using the Grief Reaction Index (GRI) (Lennon, Martin, &amp; Dean, 1990)</li> <li>Social support measured using Interpersonal Support Evaluation List (ISEL; Cohen, Mermelstein, Kamarck, &amp; Hoberman, 1985).</li> <li>Years since HIV diagnosis</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>28.4% ASPD or BPD</li> </ul> <p>Associated variables included in the structural equation modelling:</p> <ul style="list-style-type: none"> <li>PD indications were related to increased HIV symptoms and decreased HRQoL above and beyond the influences of social support and grief severity.</li> <li>PD indications were related to HIV-symptoms and decreased HRQoL indirectly through decreased social support and increased grief severity.</li> </ul>
Hansen et al., 2009	United States.  PD Indication, Social Support and Grief on Alcohol and Cocaine Use among HIV+ coping with AIDS-related Bereavement	RCT study (same sample as above).  N=268  Age not reported. 65% Male; 73% ethnic minorities.  83% response rate	Measure 5*	<ul style="list-style-type: none"> <li>Grief severity and social support see above</li> <li>Substance abuse scale (Sikkema et al., 2003).</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>28.4% ASPD or BPD</li> </ul> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>ASPD and BPD had a direct effect on cocaine use. No direct effect of PD on alcohol use.</li> <li>PD indirect effects on both alcohol use and cocaine use (<math>p&lt;.05</math>), with this relationship mediated by social support, but not grief. Participants with PD less likely to experience social support but more likely to use alcohol and cocaine.</li> <li>PD indication linked to increases in grief severity; and ASPD and BPD indications had indirect effects on grief through reduced perception of social support (<math>p&lt;.05</math>).</li> </ul>
Jacobsberg et al., 1995	United States.  Axis II diagnoses among volunteers for HIV testing and counselling	Longitudinal study. Recruitment procedures specified elsewhere.  N=260 volunteers (81 HIV+)  Mean age= 33 years	Measures 2,3*	<ul style="list-style-type: none"> <li>Knowledge of HIV status</li> <li>Current Axis I disorder (2*)</li> </ul>	<p>Multivariate analysis: no.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>33% PD (vs. 20% of HIV-). Only significantly different for Cluster B PD and BPD.</li> <li>11% Cluster A; 21% Cluster B; 16% Cluster C PD</li> </ul>

		82% Male  Response rate not reported.			Associated variables: <ul style="list-style-type: none"> <li>Rate of PD was higher in the group who were not aware of their HIV status (<math>p &lt; .05</math>)</li> <li>When Axis I disorder were eliminated BPD in HIV+ &gt; HIV- (<math>p &lt; .05</math>)</li> </ul>
James et al., 1991	United States.  Substance use and psychiatric findings in pregnant patients	Cross-sectional study. Convenience sampling.  N=55; 85% Black; 100% female; Mean age=24 years  Good response rate.	Measure 1*	<ul style="list-style-type: none"> <li>Substance use</li> </ul>	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>40% PD</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>84% PD in substance users (vs. 17% non-substance users; <math>p &lt; 0.001</math>). There was a higher rate of ASPD (<math>p &lt; 0.001</math>); BPD (<math>p &gt; .05</math>); mixed BPD and ASPD (<math>p &lt; 0.01</math>) in substance users compared to non-users.</li> </ul>
Johnson et al., 1995	United States.  Axis I Psychiatric Symptoms Associated with HIV and PD	Longitudinal study. Sampling strategy not reported.  N=162 homosexual men (110 HIV+)  100% male. Other demographics not reported.  Response rate not reported.	Measure 2*	<ul style="list-style-type: none"> <li>Depression as measured on the Hamilton Depression Rating Scale</li> <li>Anxiety measured on the Hamilton Anxiety Rating Scale</li> <li>Psychiatric symptoms measured on the Brief Symptom Inventory</li> <li>Functioning measured on the Global Assessment of Functioning Scale (DSM-III-R)</li> <li>Measure 2*</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>19% PD in both HIV+ and HIV- (<math>p &gt; .05</math>)</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>Axis I disorder in PD and HIV+ &gt; no PD or HIV (33% vs. 5%; OR: 10.0 <math>p &lt; .05</math>)</li> <li>Psychiatric symptoms and poorer functioning in PD and HIV+ with PD &gt; without PD.</li> <li>Current depression, anxiety and poorer functioning in PD and HIV+ &gt; all participants without PD.</li> </ul>
Johnson et al., 1997	United States.  Stability and Change in PD Symptomatology	Longitudinal study. Convenience sampling.  N=80 HIV+ homosexual men  100% Male; Mean age=38 years; 87% Caucasian  67% response rate (non-responders and responders, $p > .05$ )	Measure 2*	<ul style="list-style-type: none"> <li>CD4 levels</li> <li>HIV Symptom levels</li> <li>Psychological distress was measured by pooled scores on the Beck Hopelessness Scale (BHS; Beck, Weissman, Lester, &amp; Trexler, 1974), the Brief Symptom Inventory (BSI; Derogatis &amp; Melisaralos, 1983), the Global Assessment of Functioning Scale (GAP; American Psychiatric Association, 1987), the Structured Interview Guide (SIGH-AD) for the Hamilton Anxiety (HARS) and Depression (HDRS) Rating scales (Williams, 1988)</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>Stability of PD symptom levels ranged from low-moderately high.</li> <li>Change in PD symptom levels not associated with HIV status or change in CD4/HIV symptom levels.</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>Change in psychological distress predicted change in PD symptomatology accounting for 9% of residual change in SCID-II interview symptom totals (<math>p &lt; .02</math>) and 13% of residual change in total SCID-II questionnaire scores (<math>p &lt; .0001</math>).</li> </ul>

Johnson et al., 2000	United States.  Interpersonal difficulties associated with PD and Axis I disorders	Longitudinal study. Convenience sample.  N=140: 95 HIV+ and 45 HIV- men.  Mean age=39 years 88% Caucasian; 100% men  79% response rate (>.05)	Measure 2*	<ul style="list-style-type: none"> <li>Axis I disorders (Measure 2*)</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>17% PD in HIV+ (<math>p &gt; .05</math> HIV-)</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>HIV+ and PD (46%) &gt; HIV+ and no-PD (21%) met criteria for an Axis I disorder (<math>p &lt; .01</math>).</li> </ul>
Kooiman & Spinhoven, 1996	Netherlands.  Psychoanalytic aspects of PD in people with HIV	Cross-sectional study. Convenience sampling.  N=41 homosexual men  Mean age=40 years (PD) and 42 years (no PD); 100% men  98% response rate.	Measure 7*	<ul style="list-style-type: none"> <li>Time since diagnosis</li> <li>CD4 count</li> <li>Psychopathology was measured on the Hospital Anxiety and Depression Scale (HADS; Zigmond &amp; Snaith, 1983).</li> <li>Defense styles were measured on the Defense Style Questionnaire 36 (DSQ-36; Andrews, Pollock, &amp; Stewart, 1989).</li> <li>Attachment style was measured on the Adult Attachment Scale (AAS; Collins &amp; Read, 1990).</li> <li>Perceived Parental Care was measured on Parental Bonding Instrument (PBI; Parker, Tupling &amp; Brown, 1979).</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>61% PD</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>PD or no PD no difference on knowing the diagnosis, CD4 count or HIV classification (<math>p &gt; .05</math>)</li> <li>PD &gt; non-PD higher scores on the HADS (<math>p &lt; .01</math>), anxiety subscale (<math>p &lt; .01</math>)</li> <li>PD &gt; non-PD higher primitive (<math>p &lt; .01</math>) and neurotic (<math>p &lt; .05</math>) defense styles, and remained significant after partialling out the effect of anxiety and depression.</li> <li>PD &lt; non-PD dependent attachment style (<math>p &lt; .05</math>).</li> <li>Negative correlation between dependent attachment and the total score for the PDQ-R (<math>p &lt; .001</math>) and Clusters A (<math>p &lt; .001</math>) and C (<math>r = -0.46</math>, <math>p &lt; .001</math>), after correcting for anxiety and depression</li> <li>Perceived parenting style was not correlated with PDQ-R scores.</li> </ul>
Lewis, 2005	United States  PTSD in Incarcerated HIV+ Women	Cross-sectional study. All HIV+ inmates were approached.  N=81  Mean age=38 years; 100% women; 52% Black, 30% white, 16% Hispanics and 2.5% Native American	Measure 2*	<ul style="list-style-type: none"> <li>PTSD measured on the Post-traumatic Stress Scale for DSM-IV (CAPS).</li> <li>Axis I (2*)</li> <li>Past suicide attempts</li> <li>Outpatient psychiatric treatment</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>8.6% BPD</li> <li>18.5% ASPD.</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>ASPD in lifetime PTSD &gt; without lifetime PTSD (<math>p &lt; .01</math>). There was a trend for BPD group to have lifetime PTSD.</li> </ul>

		90% Response rate			<ul style="list-style-type: none"> <li>• PD + Axis I disorder in lifetime PTSD &gt; without PTSD (<math>p &lt; .02</math>).</li> <li>• Past suicide attempts were associated with Antisocial PD (<math>p &lt; .02</math>). Outpatient psychiatric treatment was not significantly associated with BPD or ASPD.</li> </ul>
Lopes et al., 2012	United States.  Prevalence of psychiatric disorders	Cross-sectional study. Stratified sampling.  N=34 653 (110 were HIV+).  HIV+ men: 55% white; 79% US-born, aged 18-44 (52%); 45-64 (43%), 65+ (5%)  HIV+ women: 70% non-white; 77% US-born, aged 18-44 (69%), 45-64 (20%), 65+ (11%)  70% response rate.	Not known.	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Socio-demographic variables: ethnicity, education, individual income, family income, employment status, marital status, urbanity, region, sexual orientation and STD</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence:</p> <ul style="list-style-type: none"> <li>• In 70 HIV+ men (compared to HIV- men), 43% received a PD diagnosis (OR 2.50, 95% CI: 1.34-4.67); 16% Schizotypal (OR 4.42, 95% CI: 1.99-9.82), 14% Schizoid (OR 5.06, 95% CI: 1.65-15.54), 15% Paranoid (OR 4.51, 95% CI: 1.53-13.26), 19% Borderline (OR 4.01, 95% CI 1.96-8.20), 15% Narcissistic (OR 2.15, 95% CI 1.00-4.61), 2% Histrionic (OR 0.88, 95% CI 0.17-4.59), 4% Antisocial (OR 0.64, 95% CI 0.14-2.99), 7% Obsessive-compulsive (OR 0.90, 95% CI 0.34-2.34), 12% Avoidant (OR 7.49, 95% CI 2.18-25.75) and 1% Dependant (OR 2.11, 95% CI 0.26-17.23).</li> </ul> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>• PD in HIV+ men &gt; HIV-. <math>p &gt; 0.5</math> when adjusting for socio-demographic associated variables.</li> <li>• There were no significant difference in the prevalence of psychiatric disorders between HIV+ and – women in adjusted or unadjusted models.</li> </ul>
Marco et al., 2015	Spain  Prevalence of PDs and their associated factors in prison inmates	Epidemiological, cross-sectional, multicenter study carried out in 25 Spanish prisons.  N=193 (58 HIV+)  Mean age= 40 years; 93% men  74% response rate	Measure 7*	<ul style="list-style-type: none"> <li>• Hepatitis C</li> </ul>	<p>Multivariate analysis: yes.</p> <p>Prevalence of PD:</p> <ul style="list-style-type: none"> <li>• 75.9% PD in individuals with Hepatitis C and HIV</li> </ul> <p>Prevalence of HIV in PD:</p> <ul style="list-style-type: none"> <li>• Patients with cluster B PD were more likely to be HIV-infected (OR 2.20, 95% CI 1.10-4.39).</li> </ul> <p>Associated variables:</p> <ul style="list-style-type: none"> <li>• No significant difference between HIV and Hepatitis C co-infection or Hepatitis C only.</li> <li>• In participants with Hepatitis C, HIV+ inmates were significantly more likely to receive a</li> </ul>

					Cluster B diagnosis (69 vs. 49.6%, $p < .01$ ) and obsessive-compulsive PD (29.3 vs. 14.8%, $p > .02$ ) compared to HIV-.
Marquine et al., 2014	United States.  'Frontal systems' behaviour in comorbid HIV and methamphetamine dependency (MA)	Cross-sectional study. Random sampling.  N=135 (64 HIV+)  Mean age=38-41 years (across the groups); 89% male.  Good response rate	Measure 6*	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Substance use and methamphetamine dependency assessed on the Composite International Diagnostic Interview (CIDI; Kessler &amp; Ustun, 2004).</li> <li>• Lifetime mood disorder was also obtained by the CIDI.</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• Not reported.</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• ASPD in MA &gt; not MA, regardless of HIV serostatus (<math>p &lt; .05</math>).</li> </ul>
McGurk et al., 1994	United States  HIV, substance dependency and psychiatric diagnosis	Cross-sectional study. Systematic sampling.  N= 46 (23 HIV+ and age- and gender matched controls)  Mean age=31 years for both groups; 93% Male.  Response rate not reported.	Measure 1*	N/A	Multivariate analysis: no  Prevalence: <ul style="list-style-type: none"> <li>• Prevalence not reported but HIV+ were significantly more likely to have a PD diagnosis (<math>p &lt; .002</math>).</li> </ul>
Modrigan et al., 2017	Romania  Personality Patterns in Young Adults with Nosocomial HIV	Cross-sectional study. Convenience sampling.  N=123  Mean age=27 years; 48% male  Good response rate.	Measure 4*	<ul style="list-style-type: none"> <li>• Gender</li> <li>• Treatment adherence was assessed using a questionnaire developed by the Department for monitoring HIV/AIDS from the Institute of Infectious Diseases. Good adherence when 95% ART, 80% non-adherent.</li> </ul>	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>• 28.5% had PD</li> <li>• Obsessive-compulsive (9.75%), avoidant (7.3%), Histrionic (7.3%), Narcissistic (4.9%), Depressive (2.4%), Antisocial (2.45%) and Schizoid (0.8%).</li> <li>• 48.5% met criteria for 1 PD, 51.5% met criteria for 1+</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• PD in males &gt; females (37% vs. 20%, <math>p &lt; .05</math>).</li> <li>• Multiple disorders men &gt; women (22% vs. 7.9%, <math>p &lt; .05</math>).</li> <li>• Reduced adherence to ART in PD vs. non-PD (<math>p &gt; 0.01</math>).</li> </ul>

Moore et al., 2012	Location unknown.  Impact of methamphetamine on ART adherence	Cross-sectional study.  125 HIV+ individuals in 3 conditions: either no, current or life time history of methamphetamine dependence/use  Mean age=40-45 years; 86-100% Male; 64-75% Caucasian  Response rate not reported.	Measure 6*	<ul style="list-style-type: none"> <li>• Methamphetamine dependence assessed by DSM-IV criteria using the Composite International Diagnostic Interview (CIDI; Wittchen, 1993). Good inter-rater reliability.</li> <li>• ART adherence assessed with the AIDS Clinical Trials Group (ACTG; Chesney et al., 2000)</li> <li>• Attention Deficit Hyperactivity Disorder (ADHD) assessed using the ADHD Module (L) of measure 6*</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• Prevalence of ASPD ranged from 9-16%; no methamphetamine dependence/use (9%), current dependence/use (13%), lifetime history of dependence/use (16%). (p&gt;.05)</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• See above.</li> <li>• Comorbid ASPD, ADHD and lifetime MDD diagnosis each predicted reported ART non-adherence.</li> <li>• ASPD did not uniquely predict ART non-adherence after accounting for the other predictors in the model (p&gt;.05).</li> </ul>
Newville & Haller, 2012	United States.  Axis II pathology and risk behaviours in people with HIV.	Cross-sectional study. Convenience sampling  N=179  Mean age=36 years; 75% Male; African American 63%  Response rate not reported.	Measure 4*	<ul style="list-style-type: none"> <li>• Drug- and sex- risk behaviours measured on the CMHS HIV Risk Questionnaire.</li> <li>• Substance dependence assessed by the University of Michigan Composite International Diagnostic Interview (UM-CIDI; Kessler et al., 1994).</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>• Depressive (47%), Passive-Aggressive (43%), Avoidant (38%), Dependent (37%), Self-defeating (33%), Borderline (30%), Schizoid (30%), Antisocial (26%), Paranoid (23%), Narcissistic (20%), Schizotypal (16%), Aggressive-Sadistic (11%), Histrionic (6%) and Compulsive (5%).</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>• Antisocial traits and PD was associated with both drug- and sex-risk behaviours, including lifetime (p&gt;.01) and recent IDU (p&gt;.001), recent sharing of injection equipment (p&gt;.001) and multiple sexual partners (p&gt;.01). Not significant after controlling for substance dependence.</li> <li>• BPD &gt; non-PD to report multiple sex partners (OR=2.65 95% CI 1.41-4.97, p&lt;.01) and irregular condom use (OR= 2.44, 95% CI 1.11-5.36, p&lt;0.05), even after controlling for substance dependence.</li> </ul>

Pace et al., 1990	United States  Prevalence of psychiatric disorders in HIV+ Air Force personnel	Cross-sectional study. Random sampling.  N=95  Age range=20-55; 90% Male  99% response rate.	Measure 10*	N/A	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>30.5% met criteria for at least one PD and 8.4% met the criteria for more than one PD.</li> <li>6.3% ASPD 6.3% avoidant, 4.2% obsessive-compulsive, 3.2% passive-aggressive, 3.2% BPD, 2.1% histrionic, 2.1% schizoid, 1.1% paranoid, 1.1% schizotypal.</li> </ul>
Palmer et al., 2003	United States  Psychiatric and social barriers to ART adherence in individuals with HIV, opioid dependence and a psychiatric disorder.	Cross-sectional study. Stratified sampling.  N=107  Mean age=43; 47% Males; 63% Hispanics, 27% African American, 7% Caucasian, 3% other of mixed ethnicity  71% response rate.	Measure 2*	<ul style="list-style-type: none"> <li>Medication adherence instrument adapted from the Adult AIDS Clinical Trials Group. Non-adherence was &lt; 95% adherence</li> </ul>	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>37% met criteria for BPD</li> <li>56% met criteria for ASPD</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>BPD was significantly associated with non-adherence to HIV medication (<math>p &lt; .05</math>). Adherence in BPD &lt; non-BPD (39% vs. 65%).</li> <li>BPD was associated with skipping HIV medication during the past weekend (<math>p &lt; .05</math>).</li> </ul>
Perkins et al., 1993	United States.  PD on coping, social support and mood	Cross-sectional design. Convenience sampling.  N=111 (58 HIV+ and 53 HIV-)  Mean age=29-31 years; 100% men.  53% response rate. Authors explored differences on age, gender and ethnicity.	Measure 2*	<ul style="list-style-type: none"> <li>Age</li> <li>Ethnicity</li> <li>Depression measured on the Hamilton Rating Scale for Depression</li> <li>Anxiety measured on the Hamilton Rating Scale for Anxiety</li> <li>Anger and tension measured on the Profile of Mood State (POMS)</li> <li>Hopelessness measured on the Beck Hopelessness Scale</li> <li>Denial and helplessness measured on COPE (Carver, Scheir and Weintraub, 1989).</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>PD in HIV+ &gt; HIV- (33% vs. 15%, <math>p &lt; .05</math>) after controlling for age and ethnicity. When controlling for education, the finding was reduced to a trend (<math>p = .11</math>).</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>No difference in the overall proportion of Axis I disorders in HIV+ and HIV- participants. No relationship between current major depression and PD (<math>&gt; .05</math>).</li> <li>In the HIV+ sample, PD &gt; non-PD greater mood disturbance (including depression, anxiety, anger, tension and hopelessness) and greater use of denial and helplessness when coping with the threat of AIDS as well as greater social conflict.</li> </ul>
Shacham, Önen, Donovan, Rosenberg	United States.  Psychiatric diagnoses in an	Cross-sectional design. All patients seen in service.	Measure 6*	<ul style="list-style-type: none"> <li>Socio-demographic variables</li> <li>Biomedical variables (e.g. viral load, overall health)</li> </ul>	Multivariate analysis: yes.  Prevalence: <ul style="list-style-type: none"> <li>65% met criteria for Antisocial PD.</li> </ul>



, & Overton, 2016	HIV+ outpatient population	N= 201. Mean age= 43 years; 69% Males; 72% African American.  Response rate not reported.			Associated variables: <ul style="list-style-type: none"> <li>None significant (further details not reported in the article)</li> </ul>
Travin et al., 1990	United States.  Prevalence and characteristics of violent patients	Retrospective study. Systematic sampling.  N=11 (seen by AIDS service)  Age ranges: 26-35 (73%), 35-45 (27%). 81% male.  Response rate not reported.	Measure 1*	N/A	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>0% met criteria for a PD diagnosis.</li> </ul>
Turrina et al., 2001	Italy  Depressive disorders and personality variables in intravenous drug-users.	Cross-sectional study. Random sampling.  3 groups: 1) HIV+ inpatient 2) HIV+ outpatient 3) HIV-outpatient  N=178 (127 HIV+ but only 50 for personality assessment)  Mean age=32.1 years; 67% Males; 56% pre-AIDS or AIDS  87% response rate	Measure 11*	<ul style="list-style-type: none"> <li>Drug use</li> <li>Depression measured on the Hospital Anxiety and Depression Scale (HADS; Zigmond &amp; Snaith, 1983). Good reliability.</li> </ul>	Multivariate analysis: no.  Prevalence: <ul style="list-style-type: none"> <li>36% PD</li> </ul> Associated variables: <ul style="list-style-type: none"> <li>HIV+ with a PD had a higher rate of depression (67% vs. 44%, p&gt;.05)</li> </ul>

ASPD= Antisocial PD; BPD = Borderline PD; ART=Antiretroviral treatment; 1= Diagnosis according to DSM; 2= SCID-II; 3= IPDE; 4= MCMI-III; 5= CASII; 6= Diagnostic Interview Schedule; 7= PDQ; 8= PRISM; 9= Alcohol Research Center Intake Interview; 10= Personality Factors Questionnaire; 11= KAPP; 12= AUDADIS-IV.

## **Methodological quality**

### *External validity*

Twenty-one of the 34 studies reported a clear and suitable sampling strategy to address the research question (see Table 3). Nineteen studies reported a good response rate, that is, at least 70% of those eligible to participate were recruited. Only 13 studies met both criteria for external validity.

### *Internal validity*

Thirty-two out of the 34 studies used reliable and valid measurements in the identification of PD/PD difficulties (see Table 3). Out of the 29 studies exploring associated variables, all but five used reliable and valid measures for the majority of associations. No discrepancy was indicated between self-reported measures and 'gold standard' structured clinical interviews when exploring the prevalence rates of PD in HIV in the current review. Out of all studies, 23 carried out multivariate analysis to control for potential confounding variables. In total, only 20 of the 34 studies provided evidence of meeting all criteria for internal validity.

Table 3: Methodological quality ratings for quantitative studies

	<i>External validity</i>		<i>Internal validity</i>		
	Sampling	Response rate	Detection validity: PDs	Detection validity: Correlates	Control of confounding variables
Bansil et al., 2009	✓	X	X	X	✓
Bauer & Shanley, 2006	✓	X	✓	✓	✓
Beattie et al.,	✓	✓	✓	✓	✓
Bennett et al., 2009	✓	✓	✓	X	✓
Beyer et al.,	✓	X	✓	X	X
Bottonari & Stepleman, 2009	✓	✓	✓	N/A	X
Bronner et al., 1993	X	X	✓	✓	✓
Chen et al., 2007	✓	✓	✓	✓	✓
Ellis et al., 1994	✓	X	✓	N/A	X
Fellows et al., 2015	X	X	✓	✓	✓
Gilchrist et al., 2011	X	✓	✓	✓	✓
Haller & Miles, 2003	X	X	✓	✓	✓
Hansen et al., 2007	✓	✓	✓	✓	✓
Hansen et al., 2009	✓	✓	✓	✓	✓
Jacobsberg et al., 1995	X	X	✓	✓	X
James et al., 1991 J	X	✓	✓	X	X
Johnson et al., 1995	X	X	✓	✓	✓
Johnson et al., 1997	X	✓	✓	✓	✓
Johnson et al., 2000	X	✓	✓	✓	✓
Kooiman & Spinhoven, 1996	X	✓	✓	✓	✓
Lewis, 2005	✓	✓	✓	✓	✓
Lopes et al., 2012	✓	✓	X	✓	✓
Marco et al., 2015	✓	✓	✓	✓	✓
Marquine et al., 2014	✓	✓	✓	✓	✓
McGurk, Miller, & Eggerth, 1994	✓	X	✓	N/A	X
Modrigan et al., 2017	X	✓	✓	X	X
Moore et al., 2012	✓	X	✓	✓	✓
Newville & Haller, 2012	X	X	✓	✓	✓
Pace et al., 1990	✓	✓	✓	N/A	X
Palmer et al., 2003	✓	✓	✓	✓	X
Perkins et al., 1993	X	X	✓	✓	✓
Shacham et al., 2016	✓	X	✓	✓	✓
Travin et al., 1990	✓	X	✓	N/A	N/A
Turrina et al., 2003	✓	✓	✓	✓	X

## Discussion

This review explored the rates and associations of PDs in people with HIV. Across studies, there were significantly higher rates of PDs in HIV-positive individuals compared to HIV-negative populations, across inpatient settings, psychiatric emergency departments, substance use settings and community samples. In addition, there were a large variety of associations explored in the 34 studies. The associated variables were grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors.

### **Prevalence of Personality Disorders in People with HIV**

Nine studies found significantly higher rates of PDs in HIV-positive individuals compared to HIV-negative populations, across inpatient settings, psychiatric emergency departments, substance use settings and community samples. Five studies found that the prevalence of PD in HIV-positive individuals was significantly higher than individuals who were HIV-negative when controlling for socio-demographic variables. This suggests that there is strong evidence that prevalence rates of PDs are higher in HIV-positive individuals compared to their HIV-negative counterparts. Research has established that people with PD are at higher risk of contracting HIV, suggesting that the rates of PD in people living with HIV will also be higher. There are no clear evidence that interpersonal difficulties and identity problems improve significantly or reliably with treatment. Individuals may lose a standardised diagnosis of PD following

treatment but their identity difficulties often remain impaired (e.g. Bateman & Fonagy, 2008; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012). PDs are thought to be lifelong disorders (Bateman, Gunderson, & Mulder, 2015) and therefore impacting individuals before and after their HIV diagnosis. However, it is also important to note that research has shown that negative life events and life stressors (such as a HIV diagnosis) might increase the chance of a later PD diagnosis (e.g. Pagano et al., 2004; Skodol et al., 2005).

Interestingly three studies did not find a significant difference between HIV-positive and HIV-negative groups, when exploring differences in one psychiatric liaison team as well as in two male community samples. It is likely that the lack of difference in Ellis et al.'s study is due to not controlling for confounding variables. The sample was referred to a psychiatric liaison service from HIV services or general wards, suggesting that there was a high level of mental health disorders in the sample that should have been controlled for. In addition, it appears that there was a lack of statistical power in the sample, as the study was not able to detect a significant difference between a prevalence rate of 42% and 73% of Borderline PD in the two groups. There is very limited information reported about the two male samples, leaving the lack of significant findings unclear (Johnson, Rabkin, Williams, Remien, & Gorman, 2000; Johnson, Williams, Rabkin, Goetz, & Remien, 1995).

This review highlighted higher levels of PDs in HIV-positive forensic populations. The higher prevalence rates are in line with the findings of

previous research (e.g. Scheidell et al., 2016, 2017). Scheidell and colleagues found high levels of Antisocial and Borderline PD, which were strongly associated with HIV-risk behaviour, in incarcerated HIV-negative men. It is therefore difficult to ascertain whether the high levels of PDs is due to being HIV-positive or vice versa, as high levels of PDs are often also found in forensic settings regardless of HIV status (e.g. Culhane, Hildebrand, Mullings, & Klemm, 2016). This would need to be explored further in future research.

This review also found a high prevalence of PDs in substance use settings. Five studies found that HIV-positive substance users were more likely than HIV-negative substance users to have a PD, whilst controlling for confounders. However, one study found that there was no significant difference in the prevalence of PD in HIV-positive methamphetamines users compared to HIV-positive non-substance users. This is surprising as previous research have highlighted that the co-morbidity of substance use and mental health disorders such as PD, is high in the HIV-positive population (Willinger, 2010). In fact, another study in the review found that female inpatient substance users were four times more likely to have a PD compared to non-substance users (Bansil et al., 2009). It is worth noting that Moore and colleagues explored the impact of methamphetamine (i.e. a stimulant and often classified as a 'party drug') on Antisocial PD prevalence rates (Moore et al., 2012), whereas the other studies explored the effect of intravenous drugs. The findings may also be due to the PD diagnosis, as previous studies have found high levels of methamphetamine in Borderline PD samples (Dimeff, Rizvi, Brown, & Linehan, 2000). Therefore, it can be hypothesised that there

is an increased prevalence rate of PD in substance users, however it may dependent on substance type or PD diagnoses.

### **Associations of Personality Disorders in People with HIV**

There were a large variety of associations explored in the 34 studies. The associated variables were grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors. Variables examined by several studies where three or more indicated a relationship with HIV and PD included: gender, substance use, axis I disorders, quality of life and ART adherence.

Given the large amount of research into the psychological impact of receiving a HIV-positive diagnosis in individuals without PD, it was not surprising that the results of this review suggest that life with PD and HIV may also contribute to other mental health difficulties. Sixteen studies explored associations related to mental health, such as suicidal ideation, Axis I disorders and quality of life. Two studies found an increase in suicidal ideation and suicide attempts in individuals with a PD diagnosis compared to individuals without PD. Interestingly, Narcissistic PD was negatively associating with suicidal ideation suggesting that this might be a protective factor. This is in line with previous studies which has shown that individuals with Narcissistic PD were two times less likely to make a suicide attempt compared with non-Narcissistic individuals with and without PDs (Coleman et al., 2017).

Four studies found higher rates of Axis I disorders (three of these specified depression) in individuals with PD and HIV, compared to HIV-positive and HIV-negative individuals without PD. Two studies also found that individuals meeting criteria for PTSD were more likely than those without PTSD to meet criteria for Antisocial PD and/or Borderline PD (Fellows et al., 2015; Lewis, 2005). This is in line with the PD literature, suggesting that PDs are often accompanied by an Axis I diagnosis (Tyrer et al., 2015). For individuals living with HIV, an Axis I disorder (as well as PD) may further complicate the likelihood of adjusting to the HIV diagnosis as well as adhering to treatment.

Perhaps not surprisingly, the review also indicated that PDs were related to decreased health-related quality of life and poorer functioning in three studies. Two studies also explored the link between PD and HIV symptoms. One study did not find an association between PD symptoms and CD4 levels, whereas Hansen and colleagues found that PDs were associated with increased HIV symptoms (Hansen et al., 2007). It can be hypothesised that the higher level of HIV symptoms could be due to lower levels of ART adherence. Another potential reason could be that patients presenting with mental health concerns get diagnosed with HIV at a later stage compared to individuals without mental health difficulties (e.g. Bohnert & Latkin, 2009; Evangelini, Pady, & Wroe, 2016); however, this would need to be explored further.

Two other studies did not find an association between Antisocial PD and disease severity, however quality of life was positively correlated with Borderline PD (on a self-report measure). The higher levels of quality of life



results are surprising as previous studies have found that Borderline PD is linked with decreased levels of quality of life (e.g. Cramer, Torgersen, & Kringlen, 2006; IsHak et al., 2013). The same study found that family/friends quality of life was positively correlated with Borderline PD (Haller & Miles, 2003). It is worth noting the difference in how the authors assessed quality of life. In Haller and Miles study, quality of life was assessed by asking participants how their current quality of life was in six different areas on a 5-point Likert scale, whereas Hansen and colleagues assessed quality of life on a 55-item questionnaire (Hansen et al., 2007). It can therefore be hypothesised that there is a decrease in quality of life in individuals living with comorbid HIV and PD, but it is dependent on the quality of life measure used.

Across studies PDs were generally associated with lower rates of adherence to ART, however one study found that HIV-positive women with a PD were less likely to be non-adherent to medication compared to those without PD (Bansil et al., 2009). Similarly, one study found that individuals with a PD diagnosis were more likely to complete six sessions of therapy compared to non-PD patients (Bottonari & Stepleman, 2009). This is interesting as previous studies have listed that PD clients often find it difficult to engage in both psychological and pharmacological treatment and have a high level of drop out (e.g. Stoffers-Winterling et al., 2012). The surprising results could be due to lack of control of confounding variables (e.g. socio-demographic variables, types of therapy or other mental health disorders) (e.g. in Bottonari & Stepleman, 2009) and poor detection validity (e.g. in Bansil et al., 2009) as

PDs overall in the current review were associated with lower rates of treatment adherence. However it may be worth noting that other studies have argued that PD clients have more severe presentations, often with an increased levels of impairment, which may suggest that they are motivated to remain in care due to their desire to reduce their distress (Norén et al., 2007). It will be therefore be important for further studies to explore this relationship further.

As suspected, the findings of the review suggest that the socio-demographic variables in HIV-positive individuals (e.g. age, ethnicity, gender, employment status, marital status and sexual orientation) may impact on their mental health. The results in this review is similar to previous findings suggesting that socio-demographic variables (e.g. being male and an ethnic minority) are associated with higher levels of PDs (Eaton & Greene, 2018), increased HIV-risk (Lessard, Lebouché, Engler, & Thomas, 2016), poorer HIV test-seeking (Mirandola et al., 2016) and an increased level of HIV infection (Gelaw, Magalhães, Assefa, & Williams, 2019).

## **Strengths and Limitations of the Review**

A limitation of the review was the fact that the review was not unable to conduct a meta-analysis due to the large variability in populations (gender, settings etc.) and how PDs and associated variables were assessed. As previously noted, there is a poor diagnostic reliability of PDs and poor temporal stability (Zimmerman, 1994). In the current review 18 studies based

their diagnosis on DSM criteria. It is important to note the discrepancy even between the different DSM classification systems (e.g. deletion of passive-aggressive PD; American Psychiatric Association, 2013) and also within disorders (Oldham, 2015). For example, there are 256 ways that someone can meet criteria for Borderline PD; two patients could receive the diagnosis but share only one diagnostic criterion. This suggests that there may be a lot of heterogeneity in the included studies and samples.

Despite poor reliability and stability, it is important to note that the diagnostic system (e.g. DSM) is helpful in terms of standardising disorders as well as providing opportunities for treatment and research. In terms of the current review, DSM diagnostic criteria have been useful in highlighting areas individuals need to struggle with to receive a PD diagnosis. For example, to get a diagnosis of PD the individual will need to present with a problematic impact either for the individual themselves and/or their system. Continuum based assessments (e.g. self-report measures) on the other hand is helpful in highlighting individuals who may not meet full criteria for a diagnosis but still presents with PD traits. However, self-report measures are more sensitive to whether the individuals are able to assess themselves accurately, be honest about their difficulties and whether they understand and interpret the question correctly. It would be beneficial for future studies to assess whether there is a difference in PD prevalence depending on PD measures in HIV populations. However, in the current review no discrepancy was indicated between self-reported measures and 'gold standard' structured clinical interviews when exploring the prevalence rates of PD in HIV in the current review.

A limitation in the search strategy used is that key terms were only searched for in the titles and abstracts. The search strategy used was felt to be efficient given the lack of recourses available, whereas a more comprehensive search strategy may have found additional articles. No date cut off was used, which can be both a strength and limitation of the current review. It means that all suitable studies were included, however, a third of the included articles were published more than two decades ago. This is important to note as many studies were published before ART changed the clinical picture of HIV from fatal illness to a chronic condition, which most likely will have had an impact of the individuals' mental health. In addition, there has also been a change in how mental health disorders and other cultural variables (such as homosexuality) are thought about and perceived.

Another strength of the review process was that two independent reviewers assessed eligible for all studies and a third reviewer (the academic supervisor) resolved the disagreements. Similar strategies were used to appraise the quality of the studies included. This increased the reliability of decision making throughout the review process.

### **Strengths and Limitations of the Included Studies**

A limitation of the included studies was that all studies were conducted in high-income countries. Sixty-six per cent of people living with HIV are currently from Sub-Saharan Africa (Avert, 2017) but none of the studies

included in this review recruited from this population. This is very surprising and leads to a difficulty in generalising the findings from the current review. The impact of mental health on life with HIV and vice versa has previously been confirmed in Western societies (e.g. Treisman & Angelino, 2004), however research has identified the lack of understanding of prevalence and impact of mental health in Sub-Saharan populations (Parcesepe et al., 2018). The current review has highlighted that there is a high prevalence of PD in people with HIV in specific groups in Western societies (i.e. concentrated epidemics) and that it often is associated with impairment and other mental health difficulties. Studies in low income countries have indicated that there is no consistent variation in PD rates around the world (Tyrer et al., 2010). It is therefore important to further examine the prevalence and associations of PD also in African HIV-positive populations, where there is a more generalised epidemic, and where the majority of HIV-positive individuals live.

The quality appraisal highlighted that the studies in the review had high levels of internal and external validity. Twenty out of 34 studies met all the criteria for internal validity, suggesting that the majority of studies included in the review had good detection validity and controlled for confounding variables. In terms of internal validity, 13 out of 34 met all the criteria, suggesting that it limits conclusions that can be drawn from the study. Only nine studies met all criteria for both external and internal validity, suggesting that the quality of studies could be improved.

## **Clinical and Research Implications**

In terms of implications for future practice, the review has highlighted that there appears to be a large amount of consistency across the findings of the included studies. As hypothesised, multiple studies found that there is a higher prevalence rate of PD, and in particular Antisocial and Borderline PD, in people living with HIV compared to HIV-negative populations. The prevalence rate of PD has been estimated to be around 14% in the general population (Torgersen, Kringlen, & Cramer, 2001). In addition, the studies also highlighted the additional severity and impairment individuals with comorbid HIV and PD often face, such as additional mental health difficulties, poor health-related quality of life and medication adherence, which will need to be addressed, for example in therapy.

Theories of adjustment may be helpful when thinking about mental health and wellbeing in individuals with PD and HIV. Moss-Morris' model of adjusting to chronic condition (2013), proposes that background factors (e.g. personality traits and early life experiences) together with socio-demographic factors influence how people respond and adapt to stressors around their illnesses (Moss-Morris, 2013). It can therefore be hypothesized that individuals with PD have not adjusted well to the HIV diagnosis and may therefore be experiencing other mental health difficulties as a result. In fact, adjustment has been found to be difficult in individuals with comorbid PD and other chronic health conditions, such as diabetes and cancer (Hay & Passik, 2000). Brunault and colleagues also found that psychological characteristics (e.g. PD) were

strongly associated with quality of life in individuals diagnosed with non-metastatic breast cancer (Brunault et al., 2016). This suggests that individuals with PD find the emotional and other challenges of their physical illness even more daunting and the physical symptoms or treatment adherence even more problematic than someone without mental health difficulties. It will therefore be important to consider adjustment and wellbeing when thinking about treatment and support for people living with comorbid HIV and PD.

The findings suggest that prevention and treatments targeting PD and HIV will need to consider socio-demographic variables. For example, British HIV Association (BHIVA) indicated that HIV-positive individuals from Black and Minority Ethnicity (BME) backgrounds are less likely to be offered, engage in and remain in psychological talking therapies (BHIVA, 2011). Similar results were also found in the current review when looking at rates of HIV and methadone treatment in people from BME backgrounds. It is therefore vital that clinicians discuss any potential difficulties and discuss support options with people from this population, as well as offer culturally sensitive treatments (e.g. language, cultural sensitivity). It would also be important to further explore the relationship between PD and HIV in this population to be able to further develop effective treatments.

Research has also found a high rate of substance use in individuals at risk of HIV (Shuper et al., 2018), and in HIV-positive individuals (Bing et al., 2001). This is also an area important to keep in mind when thinking about treatment for individuals with comorbid PD and HIV, as research has highlighted

reduced treatment adherence for psychological therapies for both individuals with PD (Stoffers-Winterling et al., 2012) and substance use disorders (Andersson, Steinsbekk, Walderhaug, Otterholt, & Nordfjærn, 2018). It will therefore be important for future studies to consider the impact of comorbid substance use and PD diagnoses in individuals also living with HIV.

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). Research has indicated that the most effective treatment for individuals with co-occurring physical and mental health disorders is the so called ‘intra-agency model’ in which all disorders are treated together within a single treatment setting (Hendrickson, Schmal, & Ekleberry, 2004). Perhaps not surprisingly, this is not the norm for HIV and PD. HIV services do often not feel equipped to work with individuals presenting with PD difficulties (e.g. Willinger, 2010), as the individuals often require support from specialist PD services.

The National Institute for Health and Care Excellence (NICE) guidelines for treatment of Borderline PD, suggest that rather than outpatient therapy is being offered in isolation (which is the norm in HIV psychology services), it should be provided within a structured programme where the individuals with Borderline PD has other inputs and access to support between sessions (NICE, 2009). The British HIV Associations (BHIVA) standards of care (BHIVA, 2018), on the other hand, suggests that the mental health professional working with the individual should provide evidence-based care



for the mental health problem identified, have up-to-date HIV-specific knowledge and an established communication channel with HIV services. In practice, however, this is often not the case. Further research is necessary to explore ways in how to support individuals with this common comorbidity better.

## **Conclusions**

In conclusion, the systematic review found that there were significantly higher rates of PDs in HIV-positive individuals compared to HIV-negative populations, across inpatient settings, psychiatric emergency departments, substance use settings and community samples. In addition, there were a large variety of associated variables explored in the 34 studies. The review demonstrated that the relationship between HIV and PD may be influenced by several factors, which will be important to take into consideration when supporting this population. Future research could examine these factors to gain a clearer understanding of how the associated variables may impact on life with HIV and PD.

**Developing a Model of Living with HIV in Individuals  
with Personality-related Difficulties**

## Abstract

**Introduction:** HIV can be a demanding illness to live with and often represents a burden for people living with the condition. Personality traits and early life experiences are key processes contributing to how individuals adapt to a chronic illness. Despite the common comorbidity, and the potentially severe consequences and outcomes, there is very limited literature on personality-related difficulties and wellbeing in HIV. Understanding the impact of personality-related difficulties in people living with HIV is important to better support this population, as we will better understand the challenges they are faced with. The empirical article explored the impact of personality-related difficulties in people living with HIV. **Method:** Nine individuals (two female, 24-60 years) were recruited via HIV-services across London. The participants met criteria for Borderline or Narcissistic PD on a screening measure. They took part in semi-structured interviews about their life with HIV. The data was analysed using the qualitative method of Grounded Theory. **Results:** Eight theoretical codes were identified: 1) traumatic experiences prior to HIV; 2) difficulties mentalizing self and others; 3) difficulties identifying and regulating current emotions; 4) dysfunctional relationships; 5) difficulties managing sex; 6) dissatisfaction over the support they have received 7) negative feelings towards HIV and self before and after diagnosis; 8) fear and shame impacting on life with HIV. A theoretical model indicating the diagrammatic representation of the relationship between the codes was generated.

**Discussion:** The current study has identified many barriers for treatment,

which may indicate that individuals with personality-related difficulties and HIV may need different support and treatment compared to individuals living with either HIV or PD traits.

## Introduction

As defined in greater detail in the Executive Summary (p. 8) HIV is a blood borne virus that attacks the body's immune system by reducing the number of CD4 blood cells, making individuals more susceptible to infection and disease. In the 1990's antiretroviral therapy (ART) was introduced, changing the clinical picture of HIV from being a fatal to a chronic illness.

HIV is a demanding illness to live with and represents a burden for people living with the condition (Remien et al., 2006). Research has listed HIV stressors such as adherence to medication, side-effects of treatment, symptoms associated with illness progression, a fear of death, financial difficulties, adjustment and acceptance of living with a serious illness, as well as being faced by HIV stigma (i.e. an identifying mark or characteristic that can be associated with shame) (Moskowitz & Wrubel, 2005). Other stressors include HIV disclosure, negotiating safer sexual relationships, and managing on-going relationships with HIV services.

Personality disorders (PDs; see further details in executive summary p. 10) have been found to impair individuals' ability to cope and adjust to living with a chronic condition (Hay & Passik, 2000). The Diagnostic and Statistical Manual of Mental Disorders (DSM) defines PD as "an enduring pattern of inner experience and behavior that deviates markedly from the expectation of the individual's culture". The pattern must be pervasive, inflexible, have an onset

in adolescence or early adulthood and cause significant distress or impairment (DSM-5; American Psychiatric Association, 2013). Due to the high level of distress often displayed by people with PD, it can be hypothesized that the difficulties encountered by people living with HIV may be enhanced in people living with comorbid HIV and PD.

## **Theories of adjustment and coping**

The ability to cope and adjust to living with HIV is vital for a person's wellbeing and health progression. Coping styles refers to an individual's coping strategies, which have been related to distress and quality of life following diagnosis of a chronic illness (Johnson & Endler, 2002). Adjustment is more difficult to define. Stanton and colleagues suggested it is the ability to preserve functional status and present with low negative affect (Stanton, Revenson, & Tennen, 2007). The Transactional Stress and Coping model (Lazarus & Folkman, 1984) proposed that adjustment to a chronic illness is influenced by the individual's appraisal of the illness, coping strategies used and the individual's appraisal of the efficacy of the coping strategies used as well as their appraisal of their ability to manage the stressors.

Moss-Morris suggested it may be restrictive to only consider the absence of distress, and instead adjustment may be better defined as managing negative emotions and not being overwhelmed by them. She highlighted that adaptation is an on-going process (Moss-Morris, 2013). In her model of adjusting to chronic condition (2013), she proposes that background factors (e.g. personality traits and early life experiences) together with social and

environment factors (e.g. availability of social support and health care) influence how people respond and adapt to stressors around their illnesses. Illness-specific factors (e.g. symptoms, degree of disability, prognosis, side effect of treatment) determine the nature of the stressors or critical events that may disrupt emotional equilibrium and quality of life. The model suggests that good adjustment occurs when individuals are able to use cognitive and behavioural factors to maintain equilibrium. Moss-Morris defines good psychological, physical and social adjustment as less distress and interference with life roles and relationships, good illness management and high positive affect (Moss-Morris, 2013).

## **HIV and mental health**

As effective treatments for HIV became available and the view of the illness shifted from being a fatal to chronic illness, more people are coping with the chronic and complex course of the disease, as well as the many stressors associated with living with HIV (Miners et al., 2001). People living with HIV are often subjected to discrimination, stigma and social isolation (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). The ability to adjust and cope with the stressors associated with a HIV diagnosis is vital as poor adjustment can have detrimental effects on the individual's mental health and the progression of HIV (e.g. Bottonari, Roberts, Ciesla, & Hewitt, 2005; Remor et al., 2007). HIV has been found to both cause and exacerbate psychiatric disorders (Treisman & Angelino, 2004)

Depression, anxiety disorders and substance use are more common in HIV

patients than in the general population (Owe-Larsson, Sall, Salamon, & Allgulander, 2009). Research has found that 50% of those living with HIV have a mood or anxiety disorder, and 25% have a current substance use or dependence disorder (Bing et al., 2001), with lifetime rates as high as 40-50% for substance use (Owe-Larsson et al., 2009). It has been proposed that the link between HIV and psychiatric disorders is bi-directional and influenced by many factors, for example stigma and discrimination, family support, educational level, medication side effects, treatment adherence, concurrent substance use and course of HIV infection (Chandra, Desai, & Ranjan, 2005).

In a recent population study in Sweden, Bauer-Staeb and colleagues (2017) found that prevalence of blood-borne viruses (e.g. HIV) was elevated in people with severe mental illness. The odds of HIV infection were nearly three times higher in people with severe mental illness than in the general population. The authors also found that having a history of substance misuse increased the odds of HIV infection in those with and without severe mental health difficulties (Bauer-Staeb et al., 2017). For people living with severe mental health difficulties, an HIV diagnosis has been found to contribute to increased mental health-stigma (Walkup, Cramer, & Yeras, 2004) and have a negative effect on their quality of life (Cournos, McKinnon, & Sullivan, 2005).

Earnshaw and Chaudoir (2009) defines stigma as being a devalued attribute in society, which affects the way people react to the knowledge that they possess the valued attribute (i.e. HIV infected) or not (i.e. not infected). According to their HIV stigma framework, people without HIV might present



with stigma mechanisms such as prejudice, stereotyping and discrimination in response to people living with HIV. HIV stigma can lead people who live with the virus to face social exclusion and has been identified as a considerable barrier to HIV prevention and treatment efforts. For individuals living with HIV, Earnshaw and Chaudoir proposed that there are three different mechanisms of stigma; enacted (i.e. experienced discrimination), anticipated (i.e. expectation of this happening in the future) and internalized (i.e. negative beliefs and feelings associated with HIV about themselves). Stigma in HIV has been identified as a considerable barrier to HIV prevention and treatment efforts (Earnshaw & Chaudoir, 2009).

The presence of mental health disorders in HIV (and vice versa) has been established but the effect of mental health difficulties on individuals living with HIV is less researched. This is important as people with severe mental illness have an increased mortality rate of two to three times the general population and a reduced life expectancy of up to 20 years (Laursen, 2011).

Approximately 60% of the increase in mortality has been attributed to poor physical health (Laursen, 2011). In addition, individuals with severe mental illness receive less assessment and treatment for physical health difficulties than the general population (Crawford et al., 2014). In HIV, one study linked the presence of mental health disorders to lower rates of virologic suppression than those without mental health disorders, due to reduced antiretroviral therapy (ART) adherence (Yehia et al., 2015).

## **Personality disorder and Physical Health**

Personality traits and early life experiences are key processes contributing to how individuals adapt to a chronic illness (Moss-Morris, 2013). A recent meta-analysis suggested that there are numerous negative health outcomes associated with PD traits and diagnoses (Dixon-Gordon, Whalen, Layden, & Chapman, 2015). Brunault and colleagues found that psychological characteristics (e.g. PD) were more strongly associated with quality of life than biological or physiological variables related to the severity of the cancer or its treatment, in individuals diagnosed with non-metastatic breast cancer (Brunault et al., 2016). This suggests that individuals with personality related-difficulties may find the emotional challenges of their physical illness even more daunting and the physical symptoms or treatment adherence even more problematic than someone without mental health difficulties.

Gerhardstein and colleagues highlighted the many terms used in the Diagnostic and Statistical Manual (DSM) to describe the diagnostic criteria for PD indicating complications not only for the individuals themselves but also for HIV treatment. For example by hindering relationship with health care professionals by being suspicious, unforgiving, detached, reckless, solitary, deceitful, irresponsible, angry, self-important, rigid, unstable among others (Gerhardstein, Griffin, & Hormes, 2011). Furthermore, PDs are often accompanied by an Axis I diagnosis (e.g. depression or anxiety) further complicating the likelihood of positive coping and treatment adherence in people with physical illnesses (Tyrer, Reed, & Crawford, 2015). In addition to

this, research has found that Borderline PD is associated with poorer physical health than a healthy population (El-Gabalawy, Katz, & Sareen, 2010).

Previous studies have found adjustment difficult in individuals with comorbid PD and other chronic health conditions, such as diabetes and cancer (Hay & Passik, 2000). However, unlike other chronic conditions, many challenges in HIV are relational (due to the high level of stigma and it being a transmittable disease) which may be particularly difficult for individuals with significant personality-related difficulties (e.g. HIV disclosure, negotiating safer sexual relationships, managing on-going relationships with HIV services).

## **HIV and Personality Disorders**

High levels of psychological distress are common among people living with HIV (Owe-Larsson et al., 2009). The prevalence of PD in the general population has been estimated to be around 14% (Torgersen, Kringlen, & Cramer, 2001). The prevalence of PD has previously been suggested to be somewhere between 19-36% in people living with HIV, with Antisocial and Borderline PD being the most common (as seen in the systematic review chapter) (Hutton & Treisman, 2008; Singh & Ochitill, 2006). Gerhardstein et al. (2011) highlighted four areas that are commonly affected in people living with comorbid HIV and PD; mental health, compromised physical health, poor health-related quality of life and poor support systems.

PD difficulties are often characterised by behaviours associated with an increased risk of HIV acquisition, such as impulsive sexual behaviour, more sexual partners and substance use (Durvasula & Regan, 2015). In a sample of men involved in the criminal justice system, Borderline PD traits were strongly associated with an increased HIV risk. The PD symptoms most associated with an increased risk of contracting HIV were abandonment worry, mood swings and shifts in opinion. Higher Borderline PD scores on a questionnaire were found to be associated with sexual risk behaviours, including multiple partners and sex with non-monogamous partners (Scheidell et al., 2016).

Personality-related difficulties may also lead to poorer outcomes following diagnosis (e.g. Hutton & Treisman, 2008; Scheidell et al., 2016). It has been argued that individuals with HIV and PD traits present with challenges with treatment adherence, engagement with care, difficulty with interpersonal skills and expression of needs (Willinger, 2010), but this has not been examined empirically. In Romania, researchers found that a third of the patients with nosocomial HIV (i.e. patients infected in hospital) presented with PD traits, most commonly dependence, avoidance and compulsiveness. The individuals with comorbid HIV and PD traits had significantly lower medication adherence which had implications for disease progression (Modrigan, Draganescu, Condratovici, Pavel, & Condratovici, 2017).

Despite severe consequences and poor outcomes, there is very limited literature on personality difficulties and wellbeing in HIV. In the United States,

Hansen and colleagues (2009) found that Borderline and Antisocial PD (assessed using a computer assisted structured clinical interview) was negatively associated with HIV symptoms and health-related quality of life (measured using questionnaires) in HIV positive adults who recently had been bereaved. In addition to this, the authors found that individuals with PD presented with higher grief severity and difficult relationships, which in turn also was associated with HIV symptoms and quality of life (Hansen et al., 2009). Similarly, Perkins and colleagues, also in United States, found that individuals with comorbid HIV and PD showed significantly higher rates of depression and anxiety, hopelessness, as well as greater use of denial and helplessness when coping with the threat of AIDS compared to individuals not meeting criteria for a PD (Perkins et al., 1993).

Individuals with personality-related difficulties often present with challenges in terms of engagement with care, medication adherence, difficulty with interpersonal skills and struggle with how to appropriately express their needs (Willinger, 2010). These individuals are often described by their dysfunctional interpersonal skills, poor impulse control and lack of flexibility, which often leads to disrupted and self-defeating experiences (Gerhardstein et al., 2011). In Hansen and colleagues' (2009) study, social support was related to decreased HIV symptoms and increased quality of life, suggesting that social support is an important factor for individuals' wellbeing. This is interesting as researchers and clinicians often describe clients with comorbid HIV, PD and substance use as the most challenging clients to support and treat (e.g. Willinger, 2010).

## **Rationale for the Current Study**

Mental health difficulties in HIV are a recognised problem and research can help in its understanding, treatment and prevention. The elevated risk of contracting HIV when living with PD has already been established, but the effect of mental health difficulties when living with HIV is less researched. Despite the common comorbidity, severe consequences and poor outcomes, there is very limited literature on personality-related difficulties and wellbeing in HIV. To my knowledge, there have been no first-hand accounts of what it is like to live with HIV in individuals with personality-related difficulties. Exploring the self-reported experiences qualitatively will enable us to better support individuals living with this common comorbidity, as we will better understand the challenges they are faced with.

The current study aims, therefore, to build on some of the findings in previous research, suggesting that PDs have a negative impact on living with HIV. Due to the severe nature of PD, and their tendency to be under-diagnosed (Morgan & Zimmerman, 2015), the present study aims to investigate the impact of personality-related difficulties (i.e. individuals showing traits of PD) on individuals living with HIV.

## **Research Aims and Question**

The aim of the current study is to develop a model describing the social and psychological processes associated with living with HIV in a sample of adults

with personality-related difficulties. The study aims to explore the impact of personality-related difficulties in people living with HIV.

## **Method**

### **Design**

A cross-sectional qualitative design was used. Participants took part in semi-structured interviews. The data was analysed using Grounded Theory (Charmaz, 2006).

### **Participants**

Participants were recruited from specialist HIV-services at two inner London NHS trusts, consisting of multidisciplinary teams (consultant physicians, nurse practitioners and sexual health advisors) running 8-10 HIV consultant clinics a week. Their caseloads were estimated to be around 1000 patients.

Demographic and clinical information is presented in Table 4. All participants reported taking ART.



Table 4: Participant Demographic Information

Pt No	Age	Gender	Employment status	Sexuality	Relationship Status	Ethnicity	Time since diagnosis	CD4 count (cells/uL) at diagnosis	CD4 count (cells/uL) at interview	Viral load (copies m/L) at interview
P1	26	Male	Employed	Homosexual	Single	White	2 years	311	428	<20
P2	55	Male	Unemployed	Homosexual	Single	White	34 years	255	558	<20
P3	24	Male	Unemployed	Bisexual	Single	Mixed	9 months	Missing	Missing	Missing
P4	43	Male	Unemployed	Heterosexual	Married	Black	18 years	703	825	<20
P5	34	Male	Employed	Homosexual	Single	White	8 years	488	1165	<20
P6	60	Female	Unemployed	Heterosexual	Single	Black	22 years	359	673	<20
P7	47	Male	Unemployed	Homosexual	Single	White	19 years	412	407	<20
P8	52	Male	Unemployed	Homosexual	Single	White	25 years	290	628	<20
P9	45	Female	Employed	Heterosexual	Single	White	3 years	567	894	<20

## *Inclusion and exclusion criteria*

### **Inclusion criteria**

- 18 years and over
- Received a HIV-positive diagnosis more than 6 months ago, to allow for adjustment to diagnosis.
- Scoring above clinical cut-off on a screening measure (International Personality Disorder Examination, IPDE; Loranger, 1997)
- Good spoken English, to ensure they could fully engage in an interview.
- Comorbid conditions were not assessed and therefore not ruled out.

### **Exclusion criteria**

- Evidence of significant risk of harm to self or others. This was defined as no episode of life threatening or deliberate self-harm which required medical attention within the last one month, no recent suicide attempt within the last 3-months, and no current expression of suicidal intent or plans. Risk was assessed by clinicians at the relevant service.

## **Data collection**

### *Interviews*

Data was collected through semi-structured interviews. The interviews were conducted face-to-face in HIV clinics and were audio recorded. The interview schedule was developed by the researcher and then reviewed by academic and

field supervisors, as well as experts working in the field of personality disorders. Questions were formed around the experience of longstanding relational and emotional issues in the context of living with HIV (Appendix A). A mock interview with the academic supervisor was conducted. It provided opportunity to receive feedback and practice using the interview schedule.

### *Service User Development*

Service user feedback was collected on the interview schedule. Feedback was sought from two service users (one male with an HIV diagnosis and one female diagnosed with Borderline PD) on the language used, areas of questions and content of the interview. The service users made suggestions around the order of questions and language used. They also felt more attention could be paid to positive experiences with services and relationships. The interview schedule was adapted based on this.

### *Measures*

Potential participants were asked to complete a screening measure to assess their eligibility to take part in the study. Participants were administered the International Personality Disorder Examination (IPDE; Loranger, 1997). The IPDE has been reported to have good reliability and validity in a variety of PD samples (Carcone, Tokarz, & Ruocco, 2015). Participants who met the clinical threshold for Cluster B PDs were invited to take part in the study (Table 5).

After being accepted in to the study, participants completed a demographics questionnaire to provide additional contextual information (Appendix B). They also completed the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) (Appendix C). The HADS has been identified as a useful screening tool for depression in people living with HIV (Savard, Laberge, Gauthier, Ivers, & Bergeron, 1998). Information about the participants' viral load and CD4 count at the time of diagnosis and recruitment, as well as medication at the time of recruitment, were obtained by a database from their medical team (Table 4). Participants self-reported questionnaire scores and current alcohol and drug use are presented in Table 5.

### *Grounded theory*

Grounded theory methods are particularly suitable for studying personal experiences and emotions, as well as interpersonal relations (Charmaz, 2006). Grounded theory is often used to develop explanatory theories of basic social processes and behaviours (Starks & Brown Trinidad, 2007). This is particularly applicable for the study as it aims to explore the personal experiences of the individuals interviewed, by exploring the impact of personality-related difficulties on living with HIV.

Charmaz (2006) grounded theory approach was preferred over others (e.g. Glaser or Straus & Corbin) due to its epistemology and approach. Charmaz (2006) states that we construct our world and the approach places an emphasis on the researcher to bring interpretations to the data. This suggests that the

researchers perspective will have an impact on the actions and decisions taken throughout the study. Glaser on the other hand suggests that the coding and theory emerge from the data. I felt that the study would benefit from the constructivist epistemology and approach and that it was in line with my own values as a researcher.

**Table 5:** Self-reported Questionnaire scores and Demographic information

Pt no.	IPDE Cluster B <sup>1</sup>				HADS		Self-reported substance use	
	Antisocial	Borderline	Histrionic	Narcissistic	Anxiety Score <sup>2</sup>	Depression Score <sup>3</sup>	Weekly alcohol use	Monthly drug use
P1	2	6	5	7	5	2	18 units	Crystal meth, GHB
P2	4	5	1	6	8	7	0 units	N/A
P3	3	6	2	2	14	7	0 units	Cannabis
P4	1	6	3	4	18	6	0-3 units	Cannabis
P5	0	5	3	6	6	6	0-3 units	Cannabis
P6	0	5	2	0	11	9	0-3 units	N/A
P7	2	6	1	3	16	10	27 units	Ketamine
P8	0	6	5	4	13	9	62 units	N/A
P9	0	5	2	6	13	7	6 units	N/A

1= Clinical threshold > 3; 2= 0-7 normal anxiety, 8-10 mild anxiety, 11-21 moderate anxiety; 3= 0-7 normal depression, 8-10 mild depression, 11-21 moderate depression,

### *Theoretical sampling and Theoretical saturation*

Grounded theory relies on theoretical sampling, which is defined as a process of on-going data collection where previous analysis influences the decisions about subsequent data to be collected. Data collection should continue until theoretical saturation is met, when the complete range of constructs that make up the theory is fully represented by the data (Starks & Brown Trinidad, 2007). There is little guidance on the sample size needed for saturation to occur (Charmaz, 2014). Due to limitations with recruitment, theoretical sampling was not possible and all available participants were recruited. However, due to specific inclusion criteria and research aims the study was more likely to reach data saturation with a relatively small sample.

### *Reflexivity*

Charmaz acknowledged that the researcher is a “a part of the world we study, the data we collect, and the analyses we produce” (Charmaz, 2014, p.17). Reflexivity allows the researcher to acknowledge their perspective, privileges and interactions will influence their actions and decisions throughout the study (Charmaz, 2014). As the researcher for this study, I reflected on the experiences I brought to the study. I am female, Swedish, bisexual and born with a hand deformity. I think this have helped me understand some of the issues facing those living with HIV such as stigma/discrimination, concerns around disclosure and adjustment of living with a condition. To encourage reflection on these issues and my position as the researcher, I kept a

reflective diary and regularly discussed relevant observations with my supervisors.

## **Procedure**

The researcher together with the academic supervisor attended several meetings at the research sites for the set-up of the study and preparation for the research to commence. Multiple discussions were held with clinicians about how to approach and talk to potential participants about the study. All individuals were identified through HIV clinics via targeted sampling by clinicians. Clinicians at the services identified individuals who they thought met the inclusion criteria and would be suitable for the study. All potential participants were provided with detailed information about the study by their clinicians. If participants were interested in taking part in the study and the researcher was available on site, they were taken to a separate room in the clinic to discuss the research further. If the researcher was not available on site, the potential participant was provided with contact details of the researcher or gave consent for their contact details to be shared with the researcher.

During the first meeting the researcher gained informed consent by going through the Participant Information Sheet (Appendix E) and Consent Form (Appendix F). The documents listed information about withdrawal from the study, boundaries of confidentiality, how the data would be stored and that the interview would be stopped immediately should they become upset or wish to



terminate the interview. The participant and researcher both signed the consent form. Once consent had been obtained the screening measure was completed to assess eligibility. All participants met the clinical threshold for the study. Participants were invited to complete the interview immediately or at a later day should they wish to.

Prior to starting the interview, participants completed the HADS and a demographic questionnaire (Appendix B). The interviews were semi-structured to provide structure and themes to the interview, but to be able to respond to participants' individual stories during the conversations. Summary statements and reflections were used throughout the interview to clarify the information given and to provide room for elaboration.

Interviews took place between 26th November 2018 and 13th March 2019. Nine interviews took place face-to-face in private rooms within the HIV clinics. Interviews lasted between 58 and 88 minutes (mean of 80 minutes). At the end of the interview, participants were given the opportunity to debrief and reflect on the experience. None of the participants left the conversations demonstrating any clear distress.

### *Payment*

Participants were reimbursed for out of pocket expenses they incurred to participate in the study. Travel expenses (up to £12) were reimbursed if they were travelling to the clinic especially to participate in the research and not to attend a clinic appointment. Participants were also paid a £10 voucher for participation in the study.

## Analysis

### *Transcription*

The audio-recorded semi-structured interviews were transcribed verbatim after being anonymised onto a computer for coding.

### *Coding*

Grounded Theory coding consists of three stages: initial coding, focused coding and theoretical coding (Charmaz, 2014):

- *Stage 1: Initial coding.* Initial coding is when data from the transcript is studied closely and named. The aim of initial coding is to remain open to the possible theoretical directions of the data whilst making sense of the content and staying close to what was said in the interview. The academic supervisor gave detailed feedback on the transcript of one interview and verified the codes of two transcripts.
- *Stage 2: Focused coding.* Focused coding is the synthesizing of initial codes and provides a direction for analysis. It involves attending to how initial codes account for the data and the constant comparison and refinement of codes, concepts and categories (Charmaz, 2014). The focused codes were discussed and verified with the academic supervisor. Codes were modified and developed as a result of the feedback and discussion.
- *Stage 3: Theoretical coding and diagramming.* Theoretical coding and diagramming involves exploring and specifying possible relationships

between focused codes. The researcher reviewed memos to link and synthesise the focused codes into theoretical codes. The final stage allowed application of an emerging theoretical model to the data (Charmaz, 2014). The interactions between the theoretical codes were discussed with the academic supervisor. The academic supervisor provided feedback on the theoretical model.

### *Writing memos*

Memos were written throughout the coding process to record thoughts and hypotheses emerging from the data (Birks & Mills, 2011). Memos encouraged a critical reflexive stance by facilitating acknowledgment of own assumptions and how they may have influenced actions and decisions throughout the study

### **Ethical approval**

Full ethical approval was gained from an NHS Research Ethics Committee (REC) and Royal Holloway University of London REC. Ethical approval was received in August 2018 (Appendix I). R&D approvals from the two NHS saFoundation trusts were obtained in September.

### *Ethical considerations*

During the interview, participants were asked personal questions about sensitive topics. If an individual became upset or disclosed risk to themselves or others during the interview, usual clinic safeguarding procedures were

followed. Interviews were conducted at the relevant service and the clinical team was available to offer support to participants if needed. In an attempt to minimise distress and allow time to adjust to living with HIV, participants were not contacted if they had received their HIV diagnosis in the last 6 months. In addition, the participant information sheet identified and listed some of the areas that the interview was likely to cover. At the end of every interview, there was time for the participant to debrief and reflect on the experience. Participants were informed of the limits of confidentiality.

## **Quality assurance**

The research followed Elliot and colleagues' proposed guidelines on good practice and quality in qualitative research (Elliott, Fischer, & Rennie, 1999).

- *Owning one's perspective.* The researcher reflected on their own contribution to the research process by for example writing memos and reflections following interviews and coding.
- *Situating the sample.* Demographic and descriptive data of the participants have been reported in Table 4 and 5.
- *Grounding in examples.* The themes in the analysis have been based on examples from the interviews. Quotes have been used throughout the results section.
- *Providing credibility checks.* The interview guide, transcript, themes and model developed have been discussed with internal and external supervisors to improve the quality of the research.

- *Coherence.* Coherence was aimed for by naming the theoretical codes appropriately, giving a clear summary of the analysis and by providing both a diagram and narrative description of the model developed.
- *Accomplishing general vs. specific research tasks.* The data and conclusions drawn from the study have been described as a description of the participants' experiences, which cannot be generalised to everyone.
- *Resonating with readers.* Resonance was determined by preserving the language of participants in the coding and themes to support the validity of the theoretical model. The summary of the analysis has been written to provide a clear sense to the reader to hopefully expand their understanding of personality-related difficulties and HIV.

## Results

The analysis of the data identified eight theoretical codes that form the proposed theoretical model. The theoretical codes consist of 19 focused codes. Each focused code contains specific properties (initial codes) that were produced when coding the transcripts. Participant quotes have been used to illustrate codes, and demonstrate how the codes are grounded in the data. Any identifiable participant information has been removed to ensure confidentiality, and the participants in the study are referred to by their designated participant number (P1 to P9). A theoretical model indicating the diagrammatic representation of the relationships between the theoretical codes is outlined and discussed.

**Table 8:** Theoretical codes, focused codes, initial codes

<b>Theoretical codes</b>	<b>Focused Codes</b>	<b>Properties of the codes (initial codes)</b>
Traumatic experiences prior to HIV	Difficult experiences prior to HIV	Reflecting on maltreatment and difficulties during childhood Reflecting on being a victim of physical assault Reflecting on difficulties coming out as gay prior to HIV Reflecting on mental health prior to HIV
Feelings towards HIV and self before and after diagnosis	Thoughts about HIV prior to diagnosis	Reflecting on having negative thoughts about HIV prior to diagnosis Reflecting on not knowing much about HIV prior to diagnosis
	Thoughts about HIV at time of diagnosis	Reflecting on lack of worries around HIV when diagnosed Reflecting on taking the HIV diagnosis as an indicator of being bad Reflecting on uncertainty around how contracted HIV Reflecting on trying to find out how they contracted HIV Reflecting on level of responsibility for the diagnosis Feeling angry with others following diagnosis
	Adjustment to HIV	Reflecting on difficulties with adjustment Reflecting on the process of adjustment Feeling negative emotions or shame
Fear and shame impacting on life with HIV'	Impact of HIV on aspects of life	Reflecting on the negative impact of HIV on relationships Reflecting on the impact of HIV on mental health Reflecting on impact on work Reflecting on feeling concerned about the future
	Worrying about disclosure	Reflecting on deciding not to tell people about HIV Reflecting on HIV not being the business of others Worrying about stigma from others Reflecting over having to support others following disclosure
Difficulties managing sex following HIV diagnosis	Managing safe sex	Managing disclosure about HIV to sexual partners Reflecting on managing safe sex Reflecting on worrying about infecting others Reflecting on worries about getting other sexually transmitted diseases
	Sexual activity	Reflecting on change in sexual activity
Difficulties identifying and regulating current emotions	Difficulties with emotions	Reflection on finding emotions difficult Reflection on management of difficult emotions Displaying negative emotions in the session Reflecting on difficulties with anger
	Mental health difficulties	Describing symptoms of low mood and high levels of anxiety

		<ul style="list-style-type: none"> <li>Reflecting on isolating self</li> <li>Externalising blame for mental health difficulties</li> <li>Reflecting on management of mental health</li> <li>Reflecting on the impact of HIV on mental health</li> </ul>
	Risk to self	<ul style="list-style-type: none"> <li>Reflecting on having attempted suicide</li> <li>Reflecting on suicidal ideation</li> </ul>
Difficulties mentalizing self and others	Self-reflection	<ul style="list-style-type: none"> <li>Describing a negative view of self</li> <li>Describing a positive view of self</li> <li>Displaying traits of narcissism</li> <li>Displaying difficulties understanding self</li> </ul>
	Difficulties mentalizing others	<ul style="list-style-type: none"> <li>Finding it difficult to know how others would describe them</li> <li>Displaying an inconsistent sense of how others see them</li> <li>Reflecting on not feeling understood by others</li> <li>Displaying difficulties in understanding others</li> </ul>
Dysfunctional relationships	Difficulties with romantic relationships	<ul style="list-style-type: none"> <li>Reflecting on having a fear of relationships</li> <li>Reflecting on choosing the wrong partners</li> <li>Reflecting on not having been treated well in romantic relationships</li> <li>Reflecting on not having ended negative relationships</li> <li>Reflecting on dating others with HIV</li> </ul>
	Interpersonal difficulties	<ul style="list-style-type: none"> <li>Reflecting on having high expectations of others</li> <li>Reflecting on difficult interactions with others</li> <li>Reflecting on not trusting others</li> <li>Reflecting on change in relationships</li> <li>Reflecting on having isolated self</li> <li>Reflecting on worrying about interactions with others</li> </ul>
Dissatisfaction over the support received	Perceived support from significant others	<ul style="list-style-type: none"> <li>Reflecting on support they haven't received</li> <li>Reflecting on not having asked for support</li> </ul>
	Support for HIV	<ul style="list-style-type: none"> <li>Reflecting on not finding services supportive</li> <li>Reflecting on what support they would have wanted for HIV</li> </ul>
	Support for mental health	<ul style="list-style-type: none"> <li>Reflecting on times they have not felt supported around their mental health</li> <li>Reflecting on what support they would have wanted for mental health</li> </ul>
	Reflecting on medication	<ul style="list-style-type: none"> <li>Reflecting on ART adherence</li> </ul>



## Traumatic experiences prior to HIV

### *Difficult experiences prior to HIV*

There appeared to be strong evidence for difficult interpersonal experiences prior to the HIV diagnosis. Five participants reflected on being maltreated or having difficulties during their childhood; where four of the five participants (all male) reflected on having been physically assaulted by family members or partners.

I grew up like an animal. Even though my father cared for us yeah, but the way he raised us, there was no... we wasn't seeing our family [...] it was just kids raising each other... and... things happened there as well [abuse] (P4)

It was observed that the majority of the participants identifying as homosexual discussed difficulties disclosing their sexuality prior to HIV. Three of the participants reflected on HIV disclosure being affected by the negative experiences around coming out as gay.

When they knew I was gay [...] that didn't go down very well for neither of them [parents]. Umm... so I think... this disclosure was tainted by that (P7)

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<sup>1</sup> 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.

There appeared to be strong evidence that the participants presented with mental health difficulties prior to the HIV diagnosis. The majority of patients disclosed having suffered from high levels of anxiety or low mood. One participant spoke about having attempted to commit suicide prior to the HIV diagnosis.

[...] when I was younger, I'd tried twice to take an overdose. At two separate occasions. Once I was taken, stomach pumped and whatever  
(P8)

## **Feelings towards HIV and self before and after diagnosis**

### *Thoughts about HIV prior to diagnosis*

The majority of the participants spoke about having had negative thoughts about HIV prior to diagnosis. Three participants reflected on having 'stigma' about HIV or that HIV would be their worst nightmare prior to diagnosis.

Before I was HIV positive I just used to think every HIV person is a freak. They like going around having sex... and they don't care about anybody else and they will transmit it to anybody else. (P3)

Three participants reported not knowing much about HIV prior to diagnosis. They reflected on having thoughts of HIV being a death-sentence.

The funny thing is that I was obsessed about HIV but I never actually got myself that informed to the point of knowing it was not a death-sentence anymore (P9)

### *Thoughts about HIV at time of diagnosis*

Almost all participants discussed the thoughts they were having about HIV at time of diagnosis. Although the majority of the participants were aware of how they contracted HIV (either through consensual unprotected sex or having been victim of sexual assault), three participants (diagnosed in the 1980/90s) displayed uncertainty around how they contracted HIV. Two participants who were diagnosed in hospital when they were very unwell described trying to find out how they contracted HIV.

I still don't know, like... I used to wake up in the hospital... or being awake until 4 o'clock in the morning thinking, thinking, thinking, and then wake up and 'oh I don't know how I got it' (P7)

The majority of the participants reported a negative reaction and difficulties coming to terms with the diagnosis. Interestingly, two male participants reported lack of worries around HIV at the time of diagnosis and also reported a low level of responsibility for having contracted HIV. On the contrary, three participants (two female and one male), who described having a high level of HIV-stigma prior to the diagnosis, reflected on taking the HIV diagnosis as an indicator of being bad.

That's why I'm saying I just feel like a failure, completely. It's made me feel in so many ways... so many ways in my life (P6)

### *Adjustment to HIV*

The majority of the participants discussed the process of adjustment or reported difficulties with adjustment to the HIV diagnosis. Two participants reported finding it difficult to come to terms with HIV and described having moments when it is still difficult to live with HIV. Five participants discussed the process of adjustment. They reflected feeling like they had to 'get on with it' (P8) or to 'deal with it' (P2)

I kind of processed it more mechanical [...] I said just give me the medicine immediately so we can work this out, and just solve the problem, in a way... and that's just how I dealt with it (P1)

There appeared to be strong evidence for negative emotions and shame towards HIV and self. All participants but two described a high level of shame or reflected on feeling negative emotions towards HIV or self. Two middle-aged gay men described feeling like HIV has ruined them.

I feel like damaged goods because of it [HIV] (P7)

I've got this invasion on my personal being, by this disgusting virus [...] what else is responsible for destroying you, or by its very presence

being inside your body, having absolutely negative impact for me [...]  
this sinister virus, you know. (P2)

## **Fear and shame impacting on life with HIV**

### *Impact of HIV on aspects of life*

There appeared to be strong evidence for a perceived negative impact of HIV on different aspects of the participants' lives. The majority of the participants reflected on the negative impact on relationships.

I couldn't go and ask a woman out. I couldn't... it was just difficult...  
(P4)

Interestingly, two of the participants discussed a positive impact of HIV on mental health as it had made them work on their low mood and anxiety. However, many of the participants spoke about feeling concerned about the future. Nearly half of the participants had noticed an impact on work, where four of the participants have not been able to work due to having been very unwell at the time of diagnosis and reported difficult emotions coming to terms with this.

I had a work capability assessment and I've been signed off work since 2000 [...] I'm not saying I was ever perfect but this, if people strive for 100% this knocked a good 30% off. You know... and... so you only ever going to be 70% off what your ideal could be (P7)

### *Worrying about disclosure*

There appeared to be strong evidence for disclosure being a difficult area for the participants. Three participants described having decided to not tell people about HIV due to high levels of worry. For the majority of participants there appeared to be a lot of worries about how others would perceive them following disclosure. Five participants spoke about worrying about stigma from others.

[...] because you see every time you say 'oh I'm HIV', people think 'ah, prostitutes' (P4)

A few participants spoke about the difference disclosing HIV to other health conditions and the two female participants spoke about having to support others following HIV disclosure.

You need to be here for the person you are telling. Which is crazy because you are the one who needs to be supported, but you need to support the other people. [...] I guess if you have other diseases like cancer [...] you can tell people, you get sympathy or support [...] In our case, most of the time you don't, you have to rely on yourself. (P9)

## **Managing sex following HIV diagnosis**

### *Managing safe sex*

There was a difference in the ways the participants managed disclosure to sexual partners following diagnosis. Only one participant reported not disclosing HIV whereas the majority reported always telling their sexual partners. There appeared to be strong evidence for worries around managing safe sex with four participants reflecting on it during the interview.

[...] we only did blow jobs and kisses sort of thing, we never had... any kind of risky sex. (P8)

There appeared to be a high level of worry about infecting others, where almost half of the sample reflected on having such worries despite being undetectable (i.e. when the virus exists in such small quantities that it can't be detected by standard blood tests and HIV is therefore untransmittable) .

There is always going to be that worry [...] you took the tablets in the morning, but you didn't have enough food with it, or it didn't stay in your system long enough, you know... there is a million different things that you can start worry yourself about... when it comes to the bio-availability of the drugs in your system. (P5)

The two female participants also worried about getting other sexual transmitted diseases.

It's like an obsessions... that somebody will give me something worse  
[...] there are so many sexually transmitted diseases... (P6)

### *Sexual activity*

There was evidence for a change in sexual activity following diagnosis. The majority of the sample reflected on having noticed a decrease in sexual activity, both in terms of intercourse and masturbation.

You feel dirty. You just feel put off sex (P4)

I had a physical shock, I couldn't feel anything, it's still a bit hard now, but for nearly 2 years I couldn't even touch myself [...] I got to a point when I couldn't even put my fingers down there without crying. (P9)

## **Difficulties identifying and regulating current emotions**

### *Difficulties with emotions*

There appeared to be strong evidence for a difficulty identifying and regulating emotions, with all participants reflecting on this during the interview. In addition, four participants displayed high levels of negative emotions in the session. A majority of the sample reflected on finding emotions difficult in general and nearly half described using negative coping strategies to manage their emotions.



I ummm am a bit dead on the inside [...] they [emotions] basically keep being stuck in my head, most of the time. (P1)

[...] the way I survive is just to block it [...] 'don't think about it!' (P6)

There was evidence of anger, with more than half of the sample reflected on having difficulties with anger.

I do have anger problems. And I do shout sometimes. (P2)

### *Mental health difficulties*

There was very strong evidence for mental health difficulties in the sample.

Seven participants described symptoms of low mood or high levels of anxiety.

When I saw the picture of the statue, it kind of explained how you feel.

You are there but you are empty... and you can see straight through, to the background (P8)

The majority of the sample reflected on how they cope with their mental health difficulties in the interviews. There was a strong evidence for negative management strategies that may have exacerbated some of their symptoms. For example, a third of the sample reflected on having isolated themselves, whereas another third (all male) reported taking illicit drugs as a management strategy for their mental health difficulties.

I became a prostitute because I needed in a weird, perverse kind of way [...] I got self-esteem from people paying me for sex [...] you are on the hamster wheel of sex, drugs, partying and going out (P7)

### *Risk to self*

There appeared to be a moderate level of risk to self at the time of the interviews, with two middle aged male participants reporting having attempted suicide, which they spoke about in a matter of fact manner. In addition, more than half the sample disclosed current or past suicidal ideation, where the following quotes relate to suicidal ideation after the HIV diagnosis.

I went to the fuel station and I actually bought paraffin and then I came in the house and I poured it on myself. Then I light up the light and then my wife came. (P4)

I got suicidal. I... got to the point where I was making notes and writing letters 'you had to put the code...' [to provide information to others after their death] and 'I had a good run'... (P7)

## **Difficulties mentalizing self and others**

### *Self-reflection*

The interviews showed that more than half of the participants described a negative view of self.

This useless woman who [...] is 60... and it is going to be worse from now because I've not achieved anything on this planet. (P6)

On the contrary, four male participants described themselves in a positive way. Out of these, three participants displayed traits of narcissism in the way they described themselves.

I consider myself to be a wise soul. And there is... wise souls are often... I suppose they, at some sense they are perceived as a bit on an enigma and at other time... umm... a loner. And I can tell you now... loners are people that have transcended to some degree. (P2)

It was evident from the interviews that near half of the sample displayed difficulties understanding self and would often tell conflicting information during the interview.

I was a very emotional despondent individual when I was younger.

Umm... very reactionary, very defensive... I took a very carefree attitude towards life. (P2)

### *Difficulties mentalizing others*

The majority of the participants displayed difficulties mentalizing others during the interview. There appeared to be evidence that five of the participants found it difficult to know how others would describe them.

I don't know that's kind of like what does other people think of me is not something I ask people, like 'what do you think of me?' (P5)

Three participants displayed an inconsistent sense of how others would describe them and often giving opposite descriptors. A third of the sample reflected on not feeling understood by others and this was often linked to negative emotions such as feeling alone with their difficulties.

[...] no really truly, they have no clue. (P4)

## **Dysfunctional relationships**

### *Difficulties with romantic relationships*

There appeared to be strong evidence for difficulties with romantic relationships with all but three participants reflected on having a fear of

relationships. The majority of the participants reported avoiding relationship with others.

I need to accept the fact that I have HIV and live well with it... instead of rushing into a relationship because I desperately need someone validating me again (P9)

Nearly half the sample reflected on relationship patterns in the past, with three middle aged participants reported not having been treated well in romantic relationships, and two reflected on not having ended negative relationships and choosing wrong partners.

I always end up with this misogynist guy because the guy was very abusive [...] there was no respect towards me (P9)

There appeared to be mixed views of dating others with HIV, with two people saying they would not date others with HIV and one indicating that he only dates others with HIV due to a high level of concern about onward transmission.

My romantic relationships have always been with people who were positive [...] because I would never want to live with myself giving it to somebody else. (P7)

### *Interpersonal difficulties*

There appeared to be strong evidence for interpersonal difficulties throughout the sample. Six participants reflected on difficult interactions with others.

I know when he [friend] is lying [...] but he doesn't like it when I catch him out on it [...] It's all because he is not ready, you know, he has got his own boundaries, but I don't care. I'm your friend and I care about you, I want to tell you how it is. (P3)

There was some evidence of having high expectations of others; three male participants described when friends and partners have not met their expectations. A few of the participants reflected on finding it difficult to trust others. More than half of the sample had noticed a difference in relationships since the HIV diagnosis, with two participants giving the example of having isolated themselves. A third of the sample also reflected on worrying about interactions with others due to the HIV.

If you meet somebody new it is like you are carrying a 100-weight baggage. (P8)

## **Dissatisfaction over the support received**

### *Perceived support from significant others*

There appeared to be evidence of dissatisfaction with the support they had received (or not received) from significant others. Five participants described situations where they had not felt supported.

My sister is the one I told immediately [...] she was in denial throughout. In fact, she is the one who could have given me support but for some reasons [...] I didn't get what I wanted from her when I told her. I regretted it afterwards. (P6)

It was interesting to note that despite the dissatisfaction over the lack of support, the majority of participants reflected on not having asked significant others for support. This suggests that significant others may not have been aware of the support the individuals would have wanted to receive.

I didn't really ask much of my friends. (P9)

### *Support for HIV*

The majority of participants reported finding HIV services very helpful. Three participants described depending on the support they receive from their HIV consultant, as they did not have anyone else to talk to about their HIV-related

or mental health difficulties. However, two participants reflected on not finding services supportive.

People think I'm crazy, obviously when you have depression people think you are making these things up. (P6)

What I struggled with was finding a role model. I didn't find one single woman, heterosexual European woman with a job, I could relate to. Most of the groups are either African ladies with huge problems, but really nothing to do with HIV. (P9)

All participants but one reflected on areas they would like to change in terms of support for their HIV.

I don't know what [support] I am entitled to or what I'm not entitled to. (P3)

We used to have longer appointments and now they are shorter appointments. But I... I even write down things to say. (P8)

### *Support for mental health*

Nearly half the sample reflected on times they have not felt supported around their mental health. Three male participants described feeling like services did not try to help them as they were deemed too complicated or too demanding,



whereas a female participant reported that the National Health Service was not able to meet her needs so she attended private therapy instead.

My opinion is that, if it's demanding and it requires too much headspace then you are considered as a patient as complicated, you are profiled as a result. (P2)

I've been speaking to them [mental health services]. But every time they say 'you've got a lot of baggage and I don't think we can accommodate because we can only see you for a few times' (P4)

A third of the sample reflected on what support they would have wanted in terms of their mental health. Two male participants discussed issues of integration of care; they argued that more focus should be spent on relationship issues and other mental health difficulties within the HIV clinic. Two other participants discussed how current models of care don't fit their and other peoples' needs.

It's kind of contradictory you have an HIV diagnosis which... may or may not influence your relationship problems... and then the point of getting help would be building up another relationship with a health care professional outside of HIV to fix... or to guide you from having problems with relationships... (P1)

I think for me it was strict to only have been given 8 sessions of therapy [...] and at the start it was suppose to be Cognitive Behavioural Therapy but the therapist looked at me and said let's put it aside, we need to do another thing with you [...] It was one huge queue for people who wanted to do evenings. It wasn't really fitting my need, and I think it would be the same for a lot of professionals. (P9)

### *Reflecting on medication*

Nearly half of the sample reflected on difficulties with ART adherence. Three participants diagnosed in the 1980/90s reported strong levels of negative emotions around having to take medication and not feeling 'normal' while taking them. One female participant reported having refused to take the medication for eight years due to side effects. Another participant stated it was a big difference between taking ART and self-medicating with drugs. Both of these participants spoke about HIV clinicians not knowing about the side effects.

2001 up to 2009 or 2010, I refused to take medication [...] I refused to take medication completely because at that time they did not know about the side effect (P4)

But what they don't know is the changes that taken those drugs has in your life [...] You never feel normal on them, those drugs, never [...] I hate the thought I have to take drugs. I hate it. I absolutely detest it [...] there is

a big difference between taking drugs for fun and then having to take them  
to live (P2)

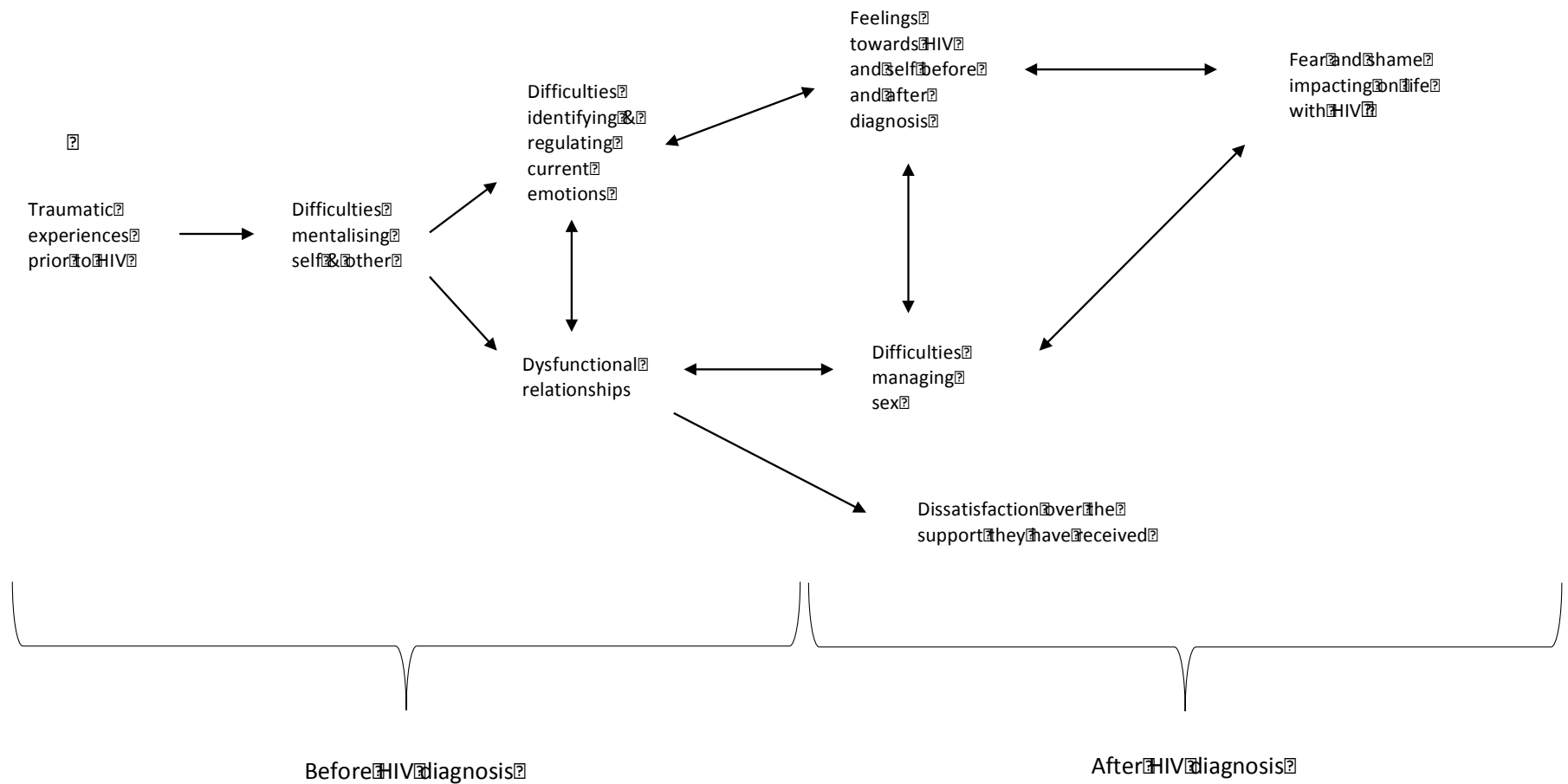
## **Theoretical model of living with HIV in individuals with personality-related difficulties**

The main aim of this study was to develop a theoretical model describing the social and psychological processes associated with living with HIV in a sample of adults with personality-related difficulties. Figure 2 outlines how the eight theoretical codes relate to each other in an explanatory model highlighting the impact of personality-related difficulties in people living with HIV. The diagram presents the chronological phases of life before and after HIV diagnosis and the black arrows present suggested relationships between the theoretical codes.

The model and previous research (e.g. Bateman & Fonagy, 2003) indicate that due to traumatic experiences prior to the HIV diagnosis (often in their childhood), participants present with challenges mentalizing self and others. The difficulty mentalizing self has led to challenges identifying and regulating emotions, which in turn lead to complicated feelings towards HIV and self following diagnosis, and as a result there is a significant impact of fear and shame on life with HIV. The difficulties mentalizing others has led to dysfunctional relationships and furthermore, dissatisfaction over the support they have received (or not) from significant others and services. Finally, it was evident in the current sample that negative feelings towards HIV and self following diagnosis, together with dysfunctional relationships, lead to anxieties over managing sex.

There was a particular strong link between difficulties identifying and regulating current emotions and feelings towards HIV and self before and after diagnosis, as well as to the impact of fear and shame on life with HIV. There was also a strong relationship between dysfunctional relationships and dissatisfaction over the support they had received.

In summary, it can be assumed that personality-related difficulties may have an impact on life with HIV in regards to the feelings individuals have towards their HIV diagnosis as well as self. The model also suggests that individuals may have difficulties managing sex. Individuals may present with dissatisfaction over the support they have received from services (e.g. mental health care) and significant others. Finally, personality-related difficulties may also lead to fear and shame impacting on life with HIV.



**Figure 2.** Theoretical model of living with HIV in individuals with personality-related difficulties

## Discussion

This study explored the impact of personality-related difficulties in individuals living with HIV. Nine adults presenting with personality-related difficulties meeting criteria for Borderline or Narcissistic PD on the IPDE were interviewed about their life with HIV. The study aimed to answer the research question; how do personality-related difficulties impact individuals living with HIV? Eight theoretical codes were identified and a theoretical model indicating the diagrammatic representation of the relationship between the codes was generated.

### **Overall Findings: Before HIV diagnosis**

#### *Traumatic experiences prior to HIV*

In line with the risk factors for Borderline PD (e.g. Herman, Perry, & van der Kolk, 1989) the majority of the participants presented with traumatic experiences in their childhood. Two of the participants hypothesised that the early life experiences and trauma had lead them to have anger issues as well as difficulties trusting others. The diagnostic criteria for PD states that the difficulties must have an early onset (American Psychiatric Association, 2013), which indicates that the personality-related difficulties were present prior to the HIV diagnosis. This is also in line with research suggesting PD traits to be risk factors for HIV (Durvasula & Regan, 2015).

### *Mentalizing deficits*

It was evident that near half of the sample displayed difficulties understanding self and others. The interviews indicated that the participants found it difficult to imagine how others would describe them and they displayed inconsistencies in their suggested descriptions. The findings can be explained by a mentalization deficit often found in individuals with PD, and particularly in Borderline PD (Bateman & Fonagy, 2010). Mentalization is the ability to reflect upon, and to understand the state of mind of oneself and others. Mentalization allows us to have insight into what we are feeling and why, and it also gives us the ability to see behaviour as organised by mental states. Mentalization deficits can lead to difficulties understanding self and others (Bateman & Fonagy, 2010).

### *Difficulties identifying and regulating emotions*

All participants presented with difficulties identifying and regulating emotions. This finding is supported by previous studies where Borderline PD patients have been found to exhibit high levels of alexithymia (i.e. inability to identify and describe emotions in the self) and have difficulty in describing their emotions in social situations (New et al., 2012). In the current sample, the participants described using negative coping strategies to manage their emotions, for example, substance use, self-harm and sex work. The substance use finding is unsurprising as research has highlighted a strong comorbidity between PD and substance use disorder (Trull et al., 2018). In fact, Hansen and colleagues (2009) found that PD indications had a



significant effect on both alcohol and cocaine use, but that the relationship was mediated by social support (Hansen et al., 2009). The use of self-harm to regulate emotions in PD is also well known (e.g. Turner, Jin, Anestis, Dixon-Gordon, & Gratz, 2018). Previous studies have shown that the relationship between sex work and self-esteem is complex, where sex work can be perceived as having a positive short-term effect but in the end has a long-term negative effect on the individual's self-esteem as well as their sense of self (Benoit et al., 2018).

### *Dysfunctional relationships*

There appeared to be strong evidence for interpersonal difficulties throughout the interviews, with individuals describing finding it difficult to trust, which may have been associated with high expectations of others. There also appeared to be strong evidence for difficulties with romantic relationships, which was also evident by the fact that all participants but one were single. Difficulties with relationships are in line with the diagnostic criteria for Borderline PD. Research has also shown poor relationship quality and stability in couples when one partner suffers from Borderline PD (Bouchard, Sabourin, Lussier, & Villeneuve, 2009). It was interesting to note that some participants reported a change since the HIV diagnosis, as it can be hypothesised that participants due to their personality-related difficulties presented with dysfunctional relationships prior to the HIV as well. However, additional relationship stressors could be explained by mentalizing difficulties, as the capacity to

mentalize tend to be particularly absent at moments of high stress (i.e. around the HIV diagnosis) (Bateman & Fonagy, 2016).

## **Overall Findings: After HIV diagnosis**

### *Feelings towards HIV and self before and after diagnosis*

There was evidence of difficulties with adjustment, including negative feelings towards self and HIV following diagnosis. It is hypothesised that neglect and abuse during childhood can disrupt mentalization and lead to maladaptive strategies to cope with trauma, leaving the capacity to mentalize vulnerable to being disrupted in moments of high stress (Fonagy & Luyten, 2009). Moss-Morris (2013) proposes that early life experiences and personality will have an impact on adjustment, which could be seen in the current sample. According to Moss-Morris' model, good psychological, physical and social adjustment involves less distress and interference with life roles and relationships, good illness management and high positive affect (Moss-Morris, 2013). Based on this together with the participants' high HADS anxiety scores, suggest that there was poor adjustment in the sample. In fact, all participants but two described a high level of shame and reflected on negative emotions towards HIV or self. Two participants who reported a negative view of HIV prior to the diagnosis, described feeling like HIV had ruined them. This confirms Lazarus and Folkman's model that the individual's appraisal of the illness will have an impact on adjustment (Lazarus & Folkman, 1984). However, it is important to note that although Moss-Morris mentions personality traits in her model, there is no specific theory of adjustment for people with personality-related

difficulties. The process of adjustment to HIV might be different to the adjustment to other health conditions.

### *Fear and shame impacting on life with HIV*

There appeared to be strong evidence for a perceived negative impact of fear and shame on different aspects of the participants' lives with HIV. The participants reflected on the negative impact on relationships. There appeared to be strong evidence for HIV disclosure being a difficult area for the participants, and three participants described having decided to not tell people about HIV due to high levels of fear and shame. Previous research has found that there is higher HIV disclosure anxiety in women (Holmes & Shea, 1997). In the current sample, both women reported very high disclosure anxiety.

There appeared to be worries about how others would perceive them following disclosure. This is not surprising as anticipated HIV stigma is well documented (Earnshaw & Chaudoir, 2009). Three participants spoke about the negative cultural views held about HIV in the countries they were born in, including HIV being linked to 'prostitution' and immoral sexual behaviour. This is in line with research which has shown that HIV stigma was linked to culturally-held beliefs about HIV affecting people that were 'bad' or 'sexually deviant' (Manirankunda, Loos, Alou, Colebunders, & Nöstlinger, 2009).

Evangeli and Wroe's (2017) model of HIV disclosure anxiety highlighted disclosure concerns some of the participants shared. The model outlines four

components: HIV core beliefs; a trigger event; a threat interpretation resulting in HIV-disclosure anxiety and processes (e.g. cognitive, affective, behavioural) maintaining this. It suggests that the participants' internalised HIV-stigma and thoughts about the HIV diagnosis indicated in the current study, may predispose individuals to disclosure anxiety. The disclosure anxiety is heightened during specific 'trigger events', in the current study it appears that those were around sexual relationships and wanting close relationships with friends. As the model suggests, the high and persistent level of anxiety about disclosure displayed in the majority of participants in the current study, has an impact on the individuals' quality of life and their social and occupational functioning.

### *Difficulties managing sex following HIV diagnosis*

There appeared to be strong evidence for worries around managing safe sex in the sample. There appeared to be a high level of worrying about infecting others, where almost half of the sample reflected on having such worries despite being undetectable. This was particularly evident amongst females in the current sample which is interesting as a fear of infecting sexual partners despite being undetectable has been reported in a female sample (Keegan, Lambert, & Petrak, 2005). In the current sample, some participants indicated that the fear of disclosure and/or onward transmission had led to significantly reduced sexual activity and relationship avoidance (Hibbert et al., 2018; Peyre et al., 2019). On the contrary, one participant presenting with a high level of Narcissistic traits stated that he was not worried about managing safe sex as

'you either have it [HIV] or you don't' (P1). This is not surprising as previous studies have shown that HIV-positive individuals scoring high in Narcissistic features had more HIV risk factors in terms of risky sexual behaviours (Martin, Benotsch, Perschbacher Lance, & Green, 2013).

### *Dissatisfaction over the support received*

There appeared to be evidence for a high level of dissatisfaction over the support participants had received (or not received) from significant others. Five participants described situations where they had not felt supported. It was interesting to note that despite the dissatisfaction over the lack of support, the majority of participants had not asked significant others for support. This suggests that significant others may not have been aware of the support the participants would have wanted or needed.

In terms of managing their HIV, the majority of participants reported finding HIV services very helpful. Three participants described depending on the support they receive from their HIV consultant, as they did not have anyone else to talk to about their difficulties. All participants but one, however, reflected on areas they would like to change in terms of support for their HIV, such as longer appointments, further information about what support they are entitled to, as well as more diversity in support groups.

It is also worth noting the high level of ART adherence in the current sample, as all patients had an undetectable viral load. This may be surprising, as

research has indicated low levels of ART adherence in people with PD (e.g. Modrigan et al., 2017; Moore et al., 2012; Palmer et al., 2003). However, research has indicated that good patient provider relationship, which can be seen in the current sample, is associated with increased ART adherence (e.g. Beach, Keruly, & Moore, 2006). In addition, previous studies have indicated a strong relationship between depression and poor ART adherence (e.g. Sin & DiMatteo, 2014) and the current sample did not report symptoms of depression on the HADS.

The participants did not describe themselves as having PD, despite their scores on self-report measures; instead the majority stated that they have difficulties with low mood or anxiety. This is in line with previous research which has suggested that individuals with PD have a poor insight into their difficulties (e.g. Fonagy & Bateman, 2006; Gabbard & Horowitz, 2009). It appeared that the participants felt less supported around their mental health compared to their HIV. Three participants described feeling like they had been deemed 'too complex' by services and not been offered enough therapy sessions or the correct treatment. Research has suggested that Borderline PD is often viewed negatively by mental health professionals and the general population, but also by individuals themselves. The negative view may lead to minimisation of symptoms and not receiving the best service (Aviram, Brodsky, & Stanley, 2006), for example by being diagnosed (or self-diagnosed) with the wrong disorder (Richardson & Tracy, 2015).

The reasons behind the large discrepancy in satisfaction between HIV and mental health services are unknown. However, it can be hypothesised that the long-term, and often very boundaried, relationship with HIV services where clinicians take charge over treatments (e.g. ART) may be preferable to patients with PD. In particular perhaps when it is compared to short-term mental health treatments where individuals may be more encouraged to take responsibility for their treatment.

The participants also highlighted that they would have found it beneficial to address their relationship and mental health issues within the HIV services they were seen in. This is line with previous research which has indicated that the intra-agency model in which all disorders are treated concurrently within a single treatment setting is the most effective for individuals diagnosed with co-occurring disorders (Hendrickson, Schmal, & Ekleberry, 2004; Remien et al., 2019).

### **Strengths and Limitations of the Study**

Hannes' (2011) quality assessment guide of qualitative studies helped to highlight the strengths and limitations of the current study. In terms of credibility, the internal supervisor provided feedback and regular supervision on the coding process and development on the model. Verbatim quotes have been used throughout the results section to support the coding, and negative cases have been highlighted. In regards of transferability, the characteristics of the reference population of people with HIV and personality-related

difficulties are unknown due to limited research. One limitation of the study was that it was not able to recruit participants with Antisocial PD, despite research indicating that it is one of the most common PDs in people living with HIV. However, the diverse nature of participants in the current study (e.g. variation in age, gender, sexuality, employment, ethnicity and time since diagnosis) suggests that the model could be applicable to a wide population, in particular in patients with Borderline PD and Narcissistic PD in high-income settings. All potential participants who agreed to be approached by the researcher after the initial conversations with HIV clinicians agreed to take part in the study. In terms of dependability and confirmability, regular debriefings with supervisor and peers as well as memo writing after the interviews helped the researcher to keep a self-critical reflexive stance throughout the research process. In addition, the research followed Elliot and colleagues' proposed guidelines on good practice and quality in qualitative research (Elliott et al., 1999). The current study therefore appeared to meet the majority of the criteria according to the quality assessment guide (Hannes, 2011).

There is an ongoing debate regarding the numbers of interviews sufficient for Grounded Theory, some suggest that 12 interviews are enough and others believe more participants are needed for data saturation (Charmaz, 2014). It can therefore be assumed that the current study's sample size is small and may limit the credibility of the findings. It is likely that not all categories reached theoretical saturation, however the majority of themes were consistently elicited across participants to form the Grounded Theory.



However, due to specific inclusion criteria and research aims the study is more likely to have reached data saturation with a small sample.

Due to the small size of the available population, theoretical sampling was restricted and all available participants were recruited. This is a limitation of the study as theoretical sampling is closely associated with Grounded Theory methodology. Theoretical sampling is thought to explore and expand the theory rather than validating without the risk of bias. It may therefore limit the credibility of the current findings.

It is important to note that some theoretical sampling was possible. For example, in memo 1 (appendix H) it was reflected on the high level of anger displayed in the first three interviews. I queried whether this was due to the narcissistic traits found in the participants. Due to the limited sample, it was not possible to only approach specific participants, however, discussions were held with clinicians about traits that can be found in other personality disorders, e.g. Borderline PD, so they would be able to identify other PD traits and not only Narcissistic PD. I was subsequently able to interview participants who did not display Narcissistic traits but who presented with high levels of anger to further understand and satisfy the theme of anger. It would have been useful to do this with other themes as well, such as the link between physical health difficulties and isolation (see memo, appendix H), however, due to the time restraint of a Doctoral thesis as well as the very limited sample this was not possible.

A limitation of the study is that comorbidities were not assessed and excluded, however this is also a strength as it increased the external validity of the study. Another limitation was the use of self-reported questionnaire as a screening measure for the study. It would have been beneficial to use a diagnostic tool such as the SCID-5 (First, Williams, Benjamin, & Spitzer, 2015), but due to time restrictions this was not possible. It is worth noting that the participants' regular clinicians identified personality-related difficulties and therefore approached them about the study, suggesting that the IPDE screening measure was backed up by the assessment of clinicians.

Another strength of the study was that service-user feedback was sought on the interview schedule prior to the interviews to ensure clarity and sensitivity of the questions.

## **Research Implications**

The study has confirmed that personality-related difficulties impact on life with HIV. The study indicated several areas that appear to be affected (e.g. managing sex, relationship with care and substance use). Future research with larger samples would allow the examination of different areas of impact, both quantitatively and qualitatively. It would, for example, be interesting to explore the self-reported change in relationships in the current sample as it can be hypothesized that individuals presented with dysfunctional relationships already, prior to the HIV diagnosis. It would also be interesting to explore ART adherence and explore what factors contributed to this. There was a high level of alcohol and substance use in the current sample and two

participants described their substance use as a way to 'self medicate' their difficulties. However, research has indicated that there are many motivational processes underlying substance use and it would be useful to explore the function of substance use further in this population (Meyer, King, & Ferrario, 2016). Furthermore, it would be interesting to explore the experience of prescription vs. non-prescription drugs quantitatively people living with PD and HIV.

Larger samples would also allow comparison of different personality-related difficulties, such as Antisocial PD as previous research has suggested that it together with Borderline PD is the most common PD diagnosis in people living with HIV. It would allow comparisons of Cluster A and C PDs and the impact of these on life with HIV. In addition, very few qualitative studies with individuals with personality-related and health difficulties have been conducted and future research could examine the individuals' relationship with care in other health conditions, such as cancer or diabetes.

## **Clinical Implications**

The findings of the current research highlight that there are several areas Borderline and Narcissistic personality-related difficulties may impact on when living with HIV. It has been argued that the UNAIDS 90-90-90 target (90% people living with HIV diagnosed, 90% of these on treatment, and 90% of these virally suppressed) should be expanded by a fourth '90' to include good health-related quality-of-life (BHIVA, 2018). For individuals with personality-related difficulties, emphasis needs to be placed on the areas highlighted in the model to be able to ensure good health-related quality-of-life. Clinically,

this suggests that individuals with personality-related difficulties and HIV may need different support and treatment compared to individuals living with either HIV or PD traits.

The participants stated that they felt supported in terms of the HIV but felt less supported around their mental health difficulties, which were often very specific to their HIV (e.g. adjustment, disclosure anxiety, worries around managing sex). In the British HIV Associations (BHIVA) standards of care (BHIVA, 2018), there is no specific guidance for people living with comorbid HIV and personality-related difficulties. Instead the guidance instead suggests that the mental health professional working with the individual should provide evidence-based care for the mental health problem identified, have up-to-date HIV-specific knowledge and an established communication channel with HIV services. However, this is often not the case. The participants in the current sample reported limits to the service offered at specialist HIV psychology services (e.g. short-term therapy, limited evening appointments). Instead they attended private clinics or secondary-care mental health difficulties. However, many of the difficulties experienced in the current sample were related to the HIV, which may not be addressed in a non-specialist service and goes against the suggestion of an intra-agency model (Hendrickson et al., 2004).

Although the National Institute for Health and Care Excellence (NICE) guidelines for Borderline PD emphasis the need to also focus on the physical health of the individuals, there is no specific guidelines for treatment of comorbid PD and physical health difficulties (NICE, 2015). This is surprising as Dixon-Gordon et al. highlighted that personality-related difficulties were

associated with poorer short-term cognitive behavioural therapy outcomes in a randomized trial for patients with unexplained physical symptoms (Dixon-Gordon et al., 2015), suggesting that PD may complicate the treatment of medical problems. The authors explored various mechanisms for why PD may result in poorer health outcomes and suggested that biological vulnerabilities (e.g. health difficulties), behavioural risk factors (e.g. overeating, smoking and substance use) and environmental factors (e.g. insufficient medical care, poor social and occupational functioning) that may influence the individual's health outcomes (Dixon-Gordon et al., 2015). Further exploration of mechanisms underlying the negative impact of personality-related difficulties in HIV is needed.

The NICE guideline for Borderline PD states that evidence base for psychological therapies in the treatment of Borderline PD is relatively poor (NICE, 2009). However, the guideline specifically suggests that Dialectical Behaviour Therapy (DBT) and Mentalization Based Therapy (MBT) are effective in reducing suicide attempts and self-harm, anger, aggression and depression. MBT also reduces anxiety and overall Borderline PD symptomatology and improves employment and general functioning, whereas DBT is effective in reducing self-harm in women. The guideline recommends that rather than outpatient therapy offered in isolation (which is the norm in HIV psychology services), individuals should be seen within a structured programme where the individuals with Borderline PD has other inputs and access to support between sessions (NICE, 2009).

On the contrary, the BHIVA guidelines highlights that there has been a shift towards more self-management and/or primary care low intensity treatment for people living with HIV. The current study suggests that there are many barriers for effective treatment that might not be able to be addressed in primary care services. Individuals with more severe and enduring difficulties, such as personality-related difficulties, may need a more specific pathway in place to ensure early detection and long-term support, as well as possible referral to appropriate services if HIV psychology services are unable to address their needs. It will also be important to keep in mind the interpersonal difficulties found in this client group, so an emphasis needs to be placed on the communications between services to ensure adequate support for the patients, but also to prevent splitting (i.e. the division or polarization of teams into good and bad by focusing selectively on their positive or negative attributes) between services. A preferable option, due to the high prevalence of PD in HIV, would be to introduce specific PD pathways in HIV services offering tailored support to individuals with this common comorbidity.

# Integration, impact and dissemination

## Integration

The systematic review provided a clear rationale for the empirical project and assisted this research. The literature within the review highlighted that there is a high prevalence of personality-related difficulties in HIV and this often leads to a high level of impairment and many additional issues. The existent literature provided a clear rationale for the systematic review, which focused on the prevalence and associations of personality disorders (PD) in HIV, but also the empirical piece, which focused on the impact of personality-related difficulties when living with HIV. The review informed the development of the empirical article.

The systematic review provided an up to date summary of prevalence rates and associations of PD in people living with HIV. The high prevalence rate of PD in HIV across different samples and settings indicated that this common comorbidity needed to be explored further. To my awareness there had not been a review investigating the associations of PD in HIV. The findings highlighted that the associated variables assessed can be grouped into five categories: socio-demographic variables, substance use, mental health, high-risk sexual behaviours, and health-related factors. The review findings were relevant to the empirical project as they informed areas to be further explored (e.g. symptoms of mental health, substance use and support)

The majority of the areas highlighted by the review were incorporated within the mood and demographics questionnaires used in the empirical study (e.g. substance use, mood, socio-demographic variables and physical health). The associated variables highlighted by the review also informed the interview guide as the findings indicated areas that may be impacted when living with PD and HIV. For example, the review highlighted that substance use and mental health difficulties are associations of PD in HIV. The empirical project therefore incorporated questions on substance use and mood in the demographic questionnaire as well as highlighted these areas to be explored in the qualitative interview.

### *Reflections upon recruitment*

The review highlighted the need to explore personality-related difficulties in people living with HIV in a diverse sample to increase the transferability of findings. The empirical study planned to use theoretical sampling, however, challenges with recruitment for the empirical project presented themselves early on. The first challenge was securing recruitment sites. Originally, the study had intended to recruit from both HIV clinics and PD services. Due to small number of HIV-positive patients, as well as reconstructions being under way and a described lack of capacity at many PD services, no PD service was able to act as a recruitment site. It was therefore decided to focus recruitment from HIV health clinics and HIV psychology services. Five HIV services were approached and four of these expressed interest in the study. In the end, one recruitment site failed due to lack of availability of rooms. The two HIV



psychology sites were very involved during the start-up phase of the project. However, when recruitment was due to commence they voiced concern about speaking to patients about the project, and especially around discussing potential PD traits. I responded to this by attending further meetings at the recruitment sites together with my academic supervisor. During the meetings we provided guidance on risk and background information on PD for the sites, as well as made it clear that participants were not going to be given a PD diagnosis. It was also agreed that I would change the title of the study from “personality-related difficulties in people living with HIV” to “longstanding emotional and relational issues in people with HIV” as clinicians stated that they would find it easier to talk to potential participants about emotional and relational issues instead of personality difficulties. During the meetings it was also agreed that the recruitment would focus on patients already diagnosed with PD at one of the sites. The other site would only approach potential participants where interpersonal difficulties had been spoken about in therapy (i.e. in more relational therapy modalities such as Cognitive Analytic Therapy) and only when it was deemed the right time during the therapy.

In the end the recruitment failed at the latter site and only one participant was recruited from the first site. I responded to the challenges in recruitment by focusing and recruiting from one HIV clinic. This meant that most participants were sourced from one recruitment site. Recruitment was more successful here as clinicians were able to identify patients presenting with personality-related difficulties and they felt able to approach the suitable candidates about the study. Recruitment from this one specific site limited the transferability of

the results but meant that I could recruit the number of participants needed for the study.

The difficulties in securing recruitment sites and the extra meetings caused delays in starting recruitment, which had a knock-on effect throughout the project. Once recruitment could commence it became clear that it was difficult to recruit a sample. It was found helpful to be available on site during HIV clinics to answer questions from HIV consultants and nurse practitioners as well as to remind staff about the project. It was also helpful to be available for potential participants so they could ask any questions they may have prior to deciding whether they wanted to participate in the study.

In the end, I found it useful to recruit the majority of participants from one site. I found the interviews very challenging, often involving high level of emotions (e.g. anger and sadness) and many of the participants presented with risk to self. It was therefore helpful to have a good working relationship with the service and an understanding of how the service worked with risk. There was always a clinician available for a quick debrief/check in after the appointment so they could be notified about any concerns. However, it may be worth noting that I was often not informed of risk issues prior to the interviews, which made the conversations challenging and I sometimes had to resort to risk management instead of focusing on the interview questions.

In terms of my own experiences around recruitment, I found the interviews very interesting but challenging. I often reflected on the experiences I brought

to the study. I am female, Swedish, 30 years old, bisexual and born with a hand deformity. I think this helped me understand some of the issues facing those living with HIV such as stigma/discrimination, concerns around disclosure and adjustment of living with a condition. However, I also recognised how some of the participants may consider some of our differences (e.g. being female, young and of white ethnicity) and find it difficult to open up about some of their difficulties they faced (e.g. managing sex, racism).

During the recruitment phase I was on placement in a PD service, which helped me manage the high level of distress, sadness and anger often displayed by the participants. However, it also made me more aware of the difference in seeing patients presenting with similar difficulties on placement and during my interviews. In a specialist PD service, we manage the high level of risk and challenging dynamics as a team. We often assess and interview patients in pairs and have regular debriefs and meetings to discuss the presenting difficulties but also the countertransference (i.e. the emotions raised in us). I found it difficult to not work as part of the treatment team while conducting the interviews, although it is important to note I felt supported in terms of risk issues. I also found it difficult to manage being both a researcher and a clinician, to not resort to only being a clinician and try to manage the patients' difficulties and safeguarding concerns, but also to focus on the interview guide and conduct the research. In terms of the countertransference and the negative feelings I often was left with, I found it helpful writing memos following the interviews and engaging in regular debriefs with the academic

supervisor and peers. It often left me wondering how staff felt following their appointments with this patient group (discussed further below).

### *Reflection upon service user involvement*

According to Arnstein's (1969) ladder of participation, there are different levels of service-user involvement. These range from 'no control' (i.e. service users being passive consumers) to 'full control' (i.e. service users control decision making at the highest level). In the current research study, service users were not involved in the development of the systematic review and therefore were in the 'no control' area of the ladder of participation. For the empirical piece, service user feedback was used to assist development of the participant information sheet as well as the interview guide. According to Arnstein's ladder of participation, this suggests that the current study sits at the 'participation' levels, i.e. service users made suggestions and influenced outcomes (Arnstein, 1969).

Service user feedback was sought from patients at HIV clinics and from university links at a recovery college. Two individuals, one with a HIV diagnosis and one with a PD diagnosis, were happy to give feedback on the participant information sheet and interview guide. They were asked to give feedback in terms of the clarity, relevance, comprehensiveness, as well as being asked for any other comments. Their feedback led to adaptations to the order of questions and language used. More attention was also paid to positive experiences with services and relationships. Service users were sent

the final questionnaire so they were informed of the influence their feedback had made. Due to time constraints and a small sample size, further feedback and opportunity for more service user involvement was limited. In addition, it would have been preferable to consult service users prior to the development of the draft versions so that the service user involvement would have driven the development of the information sheet and interview guide.

According to the Department of Health's (2005) research strategy, the empirical article met some of the aspects by involving service users in the design and reporting of research. Due to time constraints, service users were not involved in the analysis stage of the research. It would have been useful to consult service users about the theoretical themes and in the development of the model to add to my own understanding and interpretation of the data.

## **Impact**

HIV remains a major public health concern with 1.8 million new diagnoses in 2016 worldwide (WHO, 2017). It has been estimated that there are 36.7 million people in the world (WHO, 2017) and 102 000 people in the United Kingdom living with HIV (Public Health England, 2017b). Although there has been an increasing amount of research exploring the mental health of people living with HIV, very limited research has explored the link between personality-related difficulties and HIV. The current review and empirical research have investigated the relationship between personality-related difficulties and HIV. This research contributes knowledge regarding the

prevalence and associations of PD in HIV, but also indicates areas affected by the diagnosis where individuals may need extra support.

### *Potential Beneficiaries*

The potential beneficiaries of this work are a) individuals with personality-related difficulties and HIV b) friends and family of these individuals c) HIV clinicians d) clinical psychologists and other mental health staff e) GP and A&E staff f) support organisations and peer groups g) policy makers h) researchers.

### **Individuals with HIV and personality-related difficulties**

The findings of this research could potentially have an impact for individuals with personality-related difficulties and HIV. Only one participant reported they had a diagnosis of PD, whereas the majority described mixed anxiety and depression symptoms. This is in line with previous research suggesting that individuals with PD have poor insight into their difficulties (Gabbard & Horowitz, 2009). By increasing the individuals' awareness, that is, either that the symptoms are line with a PD diagnosis or an explanation associated with that diagnosis (e.g. in schema/CBT/CAT model of Borderline PD) the service users may be able to have a greater understanding and acceptance of why they are feeling as they do (e.g. Fonagy & Bateman, 2006). In addition, it could lead to extra support being put in place.

The situated Information-Motivation-Behavioural skills (IMB) model suggests that information (i.e. clinician and client have knowledge about difficulties), motivation (i.e. clinician and client are motivated to seek/refer for treatment) and behavioural skills (i.e. treatment is available and clinician/client know how to access it) are needed to engage in a healthy behaviour such as engaging in treatments (Rivet Amico, 2011). By helping to ensure that relationships are discussed during their consultations in HIV services, there will be 'information' (and perhaps 'motivation') according to the IMB and the service users will be more likely to be referred to targeted treatments (e.g. mentalization based therapy; Bateman & Fonagy, 2010) if available.

The study hopes to increase the participants' and supporting staffs' awareness of areas that may be impacted when living with personality-related difficulties and HIV. This would hopefully mean that service users would be able to access the right support. Borderline PD patients often have very poor insight into their difficulties (Fonagy & Bateman, 2006; Gabbard & Horowitz, 2009). By increasing service users' awareness that the use of alcohol and substances is a way to 'self-medicate' and manage negative emotions, or that mentalization deficits may lead to interpersonal difficulties, it may lead service users to being more willing to access support. Another area is the impact of personality-related difficulties on the adjustment to the HIV diagnosis. By increasing service users' and health care staffs' awareness of the impact of personality-related difficulties on adjustment and how the individual's view themselves following the diagnosis, it may normalise the experience for service users as well as facilitating access to support from services.

A short summary of the key findings written in lay language will be provided for the participants in the study as well as for other attendees of the participating HIV-services. A poster of the key findings will also be placed in HIV clinic waiting rooms. In addition, the summary will be distributed to HIV websites such as the Terrence Higgins Trust and Body & Soul. The summary aims to inform participants and other non-professionals of the result of the study.

### **Friends and family of individuals**

The significant others of people with HIV and personality-related difficulties may also benefit from the research, as it may increase their awareness of some of the challenges this population face. Findings will be distributed to family and friends of individuals through posters in HIV clinic waiting rooms and HIV websites.

### **HIV clinicians**

The findings of this research could potentially have an impact for HIV clinicians working with this patient group. The result from the systematic review indicates that there is a higher prevalence of PD in people living with HIV compared to the healthy population. This suggests that clinicians at HIV services are very likely to see patients with PD. Although the empirical study showed that the participants often felt supported by HIV services, it is still important to think about HIV clinicians as beneficiaries of this study. By



increasing services awareness of the high proportion of patients with PD that present to their services, it may motivate training initiatives. Training has been found to increase clinicians empathy, improve their attitudes toward patients with Borderline PD and their desire to work with them (Shanks, Pfohl, Blum, & Black, 2011).

During the set up stage of the current project, clinicians voiced their anxieties over treating patients with a PD diagnosis. This is in line with previous studies that have highlighted that individuals with PD often are challenging to treat (e.g. Kaplan, 1986; Willinger, 2010). In line with this, I found the interviews challenging and was often left with negative feelings afterwards and it left me thinking about the impact on the treatment team and the HIV clinicians that see the individuals on a regular basis.

In terms of countertransference, clinicians often feel strong negative feelings when treating individuals presenting with personality-related difficulties (Colli & Ferri, 2015). Clinicians might feel overwhelmed with patients' behaviour or the responsibility they feel caring for the patient. In addition, they might feel expected to provide ideal care and be left feeling 'not good enough'. It is also common to feel fearful and anxious about patients' wellbeing. By summarising and disseminating the key findings across both review and empirical findings for HIV clinical staff, it could facilitate a discussion around the countertransference clinicians may feel treating this population. This would help normalise some of the negative feelings for clinicians and increase their awareness of the common difficulties often found in the relationship with this

client group. The project may also be able to highlight areas that staff may need extra support when treating this patient group. For example, it is important for staff involved with patients presenting difficulties to take care of themselves, which can be through recognising strong emotional reactions and ensuring that there is support available to discuss these reactions and share the load. It is also helpful to stick to agreed boundaries and treatment plans as much as possible, for example by setting limits, be clear of intentions and limits of service and keeping a consistent and non-judgmental approach (e.g. Saper & Lake, 2002).

Increasing the HIV clinicians' understanding of the difficulties individuals may face when living with personality-related difficulties and HIV will also help them discuss certain areas with patients during consultations. Disseminating findings through presentations at team meetings with the involved HIV services and to the wider HIV community (e.g. at BHIVA) would also allow feedback on what elements of study could potentially be most useful to other clinicians and services.

### **Clinical psychologist and other mental health staff**

The findings from the empirical study could have an impact on clinical psychologists and other mental health staff. Prior to the current study, very limited research had explored the impact of personality-related difficulties when living with HIV. The results from the systematic review highlighted settings where personality-related difficulties are more common, indicating

settings where PD should be explored and assessed further. In addition, the review highlighted common associations of PD and HIV (for example substance use and other mental health difficulties), which will be important for mental health staff to further assess when working with individuals from this patient group. As mental health care for HIV patients move towards primary care and/or self-management (British HIV Association, 2011), summarising and disseminating the key findings across both review and empirical findings will increase non-HIV specialist psychologists' and other mental health care staffs' understanding of areas that might be affected when living with HIV and personality-related difficulties. In addition, the model developed in the empirical study could be used to further explore the areas identified in individuals living with personality-related difficulties and HIV. The model can also be used as basis for a formulation of the individual's presenting difficulties to be able to further understand the relationship between personality-related difficulties and life with HIV.

### **GP and A&E Staff**

GP and A&E staff are other potential beneficiaries of this research. It may be helpful for these healthcare professionals to be more aware of the experiences of individuals presenting with personality-related difficulties and HIV, as having more knowledge about the difficulties they may experience could help them support and work clinically with this population. Findings could be disseminated through factsheets highlighting the key findings. It may be that GP and A&E staff are not aware of some of the difficulties highlighted in the empirical study and by increasing their awareness it enables clinicians

to understand the individual's difficulties further. In addition, it may help GP and A&E staff to manage interpersonal difficulties with this client group as well as crisis management. Helping to give clinicians a focus when having these conversations could help to ensure effectiveness and is crucial given current resource and time-limited service settings.

### **Support organisations and peer groups**

Support organisations (e.g. the Terrance Higgins Trust) and peer groups organised by voluntary organisations offer information, support and guidance to individuals with HIV. The current findings could be used for these organisations to help support individuals living with the diagnosis. For example, factsheets containing the key findings could be sent to group facilitators and counsellors working for these organisations to increase their awareness of areas affected. Overall, this would help these organisations to support service users during different phases of life with HIV.

### **Policy makers**

The research may have a positive impact on policy makers, such as BHIVA, WHO and NICE. The British Psychological Society (BPS) and the British HIV Association (BHIVA) jointly suggested a stepped care model of psychological support for adults living with HIV. However, there are currently no guidelines for support and treatment for individuals living with HIV and personality-related difficulties. According to BPS and BHIVA model (2011), individuals with HIV and personality-related difficulties should be seen by 'mental health

specialists'. The guidance also specifies that if the mental health professional is not based within the HIV service, they should have up-to-date HIV knowledge and established communication with a HIV service (BHIVA, 2011).

The National Institute for Health and Care Excellence (NICE) guidelines states that evidence base for psychological therapies in the treatment of Borderline PD is relatively poor (NICE, 2009). The guideline recommends that rather than outpatient therapy offered in isolation (which is the norm in HIV psychology services), individuals should be seen within a structured programme where the individuals with Borderline PD has other inputs and access to support between sessions (NICE, 2009). The guidelines conclude that the state of knowledge about the treatments available for Borderline PD is in a development phase and further research needs to be undertaken before stronger recommendations can be made about specific treatments.

The empirical piece highlighted that personality-related difficulties have a large impact on life with HIV and that individuals may need further support from services. Therefore, the current study's findings could be outlined and summarised to provide helpful suggestions as to how guidelines can be written to support individuals living with HIV and personality-related difficulties. One example of this is to incorporate some of the principles of care for people with PD being seen as PD services, such as working closely as a team supporting the individual, setting limits, be clear of intentions and limits of service and keeping a consistent and non-judgmental approach (e.g. Kendall et al., 2009).

## **Researchers**

Findings highlighted prevalence and associations that may be related to life with PD and HIV. It also highlighted the impact of personality-related difficulties in people living with HIV. This could inform researchers' future investigation of the relationship between the two disorders. Future research with larger samples would allow the examination of different areas of impact, both quantitatively and qualitatively. It would also be interesting to explore ART adherence further as the findings of the current study contradicted previous studies suggesting poor adherence in individuals with PD.

Furthermore, there was a high level of alcohol and substance use in the current sample and two participants described their substance use as a way to 'self-medicate' their difficulties. It would be interesting to explore the experience of prescription vs. non-prescription drugs quantitatively in this population. Larger samples would also allow comparison of different personality-related difficulties, such as Antisocial PD as well as Cluster A and C PDs, and the impact of these on life with HIV.

## *Maximising Impact*

To maximise the impact of findings for clinicians, the results highlighted by the review and empirical article could be used to help prompt questions during assessments and consultations. For example, the review highlighted common associations that will be important for clinicians to assess further during consultations with this population. The empirical piece highlighted areas commonly affected by personality-related difficulties when living with HIV.

Clinicians could then focus conversations on these specific areas. Alongside the discussions, the areas could be highlighted when thinking about care plans and treatment for the individuals, supporting individuals to identify and cope with the difficult situations better (e.g. adjusting to diagnosis, managing safe sex, disclosure, relationships and support with significant others and health care staff).

## **Dissemination**

It is planned that the current research will be made more broadly available by publishing results in a journal article. It is hoped that both the review and empirical study will be published in an academic journal (e.g. *Clinical Psychology Review* and *AIDS & Behaviour*). The aim of this is to disseminate the findings of the research to clinicians and academics specifically working within the HIV-field to increase awareness of the impact of personality-related difficulties when living with HIV. Alongside this, the empirical abstract will also be submitted to the 2019 AIDS Impact conference. By disseminating the research findings in this way, researchers working in the field of HIV research could become aware of the study's findings.

To facilitate dissemination to clinicians it is planned that I will attend team meetings to present key findings. It may be that clinicians are not aware of some of the challenges presented in the empirical article and by increasing their awareness it enables clinicians to have the necessary conversations with patients around how to manage the difficulties raised in the research before

they become a problem (e.g. how to manage safe sex). To help clinicians incorporate the information into their clinical practice, a summary will be made which outlines key findings. This could include a summary of areas for health care staff to assess further during consultations. A brief summary or checklist may make it easier to translate key findings into consultations and assessments with service users. To make sure the clinicians find the summary useful, feedback will be sought prior to delivering feedback about what they think would be helpful to their practice. Feedback from team members will be important as the impact of the study will be maximised if the clinicians find the summarised information useful and feel able to incorporate it during consultations.

It is planned that I will disseminate the key findings written in lay language to the service users participating in the research. Disseminating findings with participants would allow feedback on what elements of the study could potentially be most useful to other service users. Once this has taken place, the feedback will be incorporated and findings will be disseminated at the participating services as well as relevant service user forums. Lastly, it is hoped that by developing and establishing relationships with multiple potential beneficiaries this will help to maximise the impact of the current study. For example, it is planned that I will present the findings to the PD service I am currently based in.



### *Evidencing Impact*

As previously discussed, effective disseminations will lead to increased awareness as well as changes in the clinician's clinical practice. To be able to demonstrate that these activities have been achieved the impact will need to be evaluated. To explore the usefulness of my attendance at staff meetings and the information sheets given, it will be important for staff to be able to give anonymous feedback. The feedback could be given online through distribution of an online questionnaire, which could be circulated via email. The questions could include asking whether they felt the information had increased their awareness at the time of the meeting, but also whether the information had influenced their practice at a later date. It would also be useful to explore the staff's experience of incorporating the key findings into practice qualitatively at a later time point.

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# Appendices

## Appendix A: Interview Schedule

IRAS Project ID: 243185

Version: 3

Date: 16/07/2018

- 1. How would other people describe you?**
  - How would you describe your relationships with others?
  - How would you describe how you cope with difficult situations/interactions with others?
  
- 2. What was your life like prior to your HIV diagnosis?**
  - Has your life changed since diagnosis?
  - E.g. relationships, education, employment, interests
  - Can you tell me what it was like when you received your HIV diagnosis?
  - How long do you think you were positive until diagnosis?
  - Optional: What factors do you think led you to receive a HIV diagnosis?
  
- 3. How have you felt about being HIV positive since your diagnosis?**
  - How does living with HIV affect your life now (e.g. anger/guilt/future thinking/hope/goals)?
  - How do you think the diagnosis has impacted on your relationships?
  - Has the HIV diagnosis changed the way you see yourself (e.g. stigma/shame)?
  - Do you have any concerns about your future? Relationships?
  
- 4. How do you manage your emotions (e.g. sadness, anger)?**
  - What strategies do you use to cope with your emotions? Helpful?
  - Have you noticed you experience different emotions since diagnosis?
  - How do you manage stress/difficulties around your HIV diagnosis?
  
- 5. How were your relationships with partners, friends, family and sexual contacts before diagnosis?**
  - How are they now after diagnosis?
  - Have your relationships changed since your HIV diagnosis?
  - How do you feel about how other people have reacted to your HIV diagnosis?
  - Have you had any positive or negative experiences of sharing your HIV status? How did you manage this?
  - How do you feel about your decisions to disclose or not disclose?

- Have you noticed a difference in how people react towards you since the diagnosis?

**6. How would you describe your part in relationships in your life now?**

- With partners, friends, family, sexual contacts?
- Have you noticed any patterns in your relationships?
- Would you like anything to be different in your relationships?
- Optional: Manage sexual contacts/Grindr/other apps

**7. Tell me about your experiences with therapists/counsellors/psychologist/MH professionals?**

- How have you experienced care from HIV services?
- How have your relationships been with health care staff?
- How have you felt supported?
- Are there times you have not felt supported?
- Would you have liked anything to be different?
- Have you noticed a difference in the healthcare you receive?

**8. How do you think your HIV affects your ability to have close relationships?**

- What difficulties have you had with keeping close relationships in your life?
- What do you think makes it difficult to keep close relationships?

*In a minute we'll be coming to an end but I'd just like to ask...*

**9. Do you have any suggestions for services working with clients with longstanding emotional and relational difficulties who are diagnosed with HIV?**

- Do you have any suggestions in how services could have better supported you with these difficulties?
- Are there times when services have been able to support you well?

**10. I've come to the end of everything I want to ask, is there something else you feel is important?**

**Debrief:**

We are now coming to an end of the interview. How have you found talking to me?

## Appendix B: Demographic questionnaire

What is your age?

---

Which gender do you identify as?

- Female
- Male
- Other
- Prefer not to say

Which ethnic group best describes you?

- Asian
- Black
- Mixed
- White
- Other: \_\_\_\_\_

What is your country of birth?

---

What is the highest degree or level of school you have completed?

- CSE/O-levels or equivalence
- GCSE or equivalent
- A-levels or equivalent
- Undergraduate degree
- Masters degree
- Doctorate or other postgraduate degree
- Other: \_\_\_\_\_

How would you describe your current employment status?

- Employed full time
- Employed part time
- Unemployed
- Student
- Other: \_\_\_\_\_

What is your relationship status?

- Single
- In a relationship and living together
- In a relationship and not living together

How would you describe your sexual orientation?



- Bisexual
- Gay
- Heterosexual
- Lesbian
- Other: \_\_\_\_\_
- Prefer not to say

**What is your living situation?**

- Living alone
- Living with partner
- Living with parents
- Living with friends
- Other: \_\_\_\_\_

**Do you currently take any medication?**

- Yes, please specify: \_\_\_\_\_
- No
- Prefer not to say

**Do you have any other health conditions?**

- Yes, please specify: \_\_\_\_\_
- No
- Prefer not to say

**When did you receive your HIV diagnosis?**

\_\_\_\_\_

**In which country did you receive your HIV diagnosis?**

\_\_\_\_\_

**What was your CD4 count at diagnosis?**

\_\_\_\_\_

**What is your current CD4 count?**

\_\_\_\_\_

**What is your current viral load?**

\_\_\_\_\_

**Do you have any (current or past) mental health difficulties?**

---

**Have you engaged in talking therapies?**

---

**How many units of alcohol do you consume per week?**

---

**In the past 12 months have you used any non-prescribed recreational drugs?**

---

## Appendix C: HADS

### Directions

Please read every sentence. Circle the answer that best describes how you have been feeling during the LAST WEEK.

You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important.

- |                                                                               |                                   |   |
|-------------------------------------------------------------------------------|-----------------------------------|---|
| 1. I feel tense or 'wound up':                                                |                                   | A |
|                                                                               | Most of the time                  | 3 |
|                                                                               | A lot of the time                 | 2 |
|                                                                               | From time to time, occasionally   | 1 |
|                                                                               | Not at all                        | 0 |
| 2. I still enjoy the things I used to enjoy:                                  |                                   | D |
|                                                                               | Definitely as much                | 0 |
|                                                                               | Not quite as much                 | 1 |
|                                                                               | Only a little                     | 2 |
|                                                                               | Hardly at all                     | 3 |
| 3. I get sort of frightened feeling as if something awful is about to happen: |                                   | A |
|                                                                               | Very definitely and quite badly   | 3 |
|                                                                               | Yes, but not too badly            | 2 |
|                                                                               | A little, but it doesn't worry me | 1 |
|                                                                               | Not at all                        | 0 |
| 4. I can laugh and see the funny side of things:                              |                                   | D |
|                                                                               | As much as I always could         | 0 |
|                                                                               | Not quite as much now             | 1 |
|                                                                               | Definitely not so much now        | 2 |
|                                                                               | Not at all                        | 3 |
| 5. Worrying thoughts go through my mind:                                      |                                   | A |
|                                                                               | A great deal of the time          | 3 |
|                                                                               | A lot of the time                 | 2 |
|                                                                               | From time to time, but not often  | 1 |
|                                                                               | Only occasionally                 | 0 |
| 6. I feel cheerful:                                                           |                                   | D |
|                                                                               | Not at all                        | 3 |
|                                                                               | Not often                         | 2 |
|                                                                               | Sometimes                         | 1 |

	Most of the time		0
7. I can sit at ease and feel relaxed:		A	
	Definitely		0
	Usually		1
	Not often		2
	Not at all		3
8. I feel as if I am slowed down:		D	
	Nearly all the time		3
	Very often		2
	Sometimes		1
	Not at all		0
9. I get a sort of frightened feeling like “butterflies” in the stomach:		A	
	Not at all		0
	Occasionally		1
	Quite often		2
	Very often		3
10. I have lost interest in my appearance:		D	
	Definitely		3
	I don't take as much care as I should	2	
	I may not take quite as much care		1
	I take just as much care		0
11. I feel restless as I have to be on the move:		A	
	Very much indeed		3
	Quite a lot		2
	Not very much	1	
	Not at all		0
12. I look forward with enjoyment to things:		D	
	As much as I ever did	0	
	Rather less than I used to		1
	Definitely less than I used to	2	
	Hardly at all		3
13. I get sudden feelings of panic:		A	
	Very often indeed		3
	Quite often		2
	Not very often	1	

	Not at all	0
14. I can enjoy a good book or radio/TV program:		D
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

## **Appendix D: International Personality Disorder Examination**

Not included due to copyright restrictions

## **Appendix E: Participant Information Sheet**

### **Patient information sheet**

**Project title:** Longstanding emotional and relational issues in people with HIV

**IRAS Project ID:** 243185

**Version:** 6

**Date:** 26/11/2018

You have been asked to participate in a study carried out by Emma Larsson, Trainee Clinical Psychologist at Royal Holloway, University of London, in collaboration with X (removed due to confidentiality) and X (removed due to confidentiality).

#### **Invitation:**

This research study is trying to understand how the challenge of managing emotions and difficulties with forming and maintaining relationships affect individuals living with HIV. Before you decide if you want to take part it's important that you understand why this study is being carried out and what will happen if you take part. Please read this 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 Emma any questions you might have about the study.

**Email:** emma.larsson1@nhs.net

**Telephone:** 01784 414 012 (this is the university answer machine, you will be asked to say whom the message is for and to leave your name and contact details so that Emma can call you back).

#### **What is the study about?**

People's early life experiences and personality traits influence how they cope with the demands of everyday life, which can include how they adapt to living with a life-long illness. Some individuals may struggle with making and keeping close relationships by, for example, getting into very intense relationships that don't last, or being very private, finding it hard to open up and trust people they don't know very well. This could happen with family, friends or people at work. Some individuals may describe feeling 'empty' inside, or describe their feelings as always changing. Others take chances, can be impulsive and find it hard to keep out of trouble. Sometimes people find it hard to describe who they are or what is important to them, almost lacking a sense of identity.

We would like to find out more about how these difficulties can have an impact on living with HIV. We believe our findings may help develop better support and

services for people living with HIV. The study forms part of a Royal Holloway University Doctoral thesis research project.

### Who can take part in the study?

You have been invited to participate due to having been seen at X (removed due to confidentiality). Healthcare professionals in these services have been asked to invite people that they have met who they think would be suitable for this study.

You have been approached to participate because you, together with your clinician, have discussed some of the difficulties mentioned in the above section. To participate in this study you must complete a questionnaire to see whether you are eligible. If you would like to meet with Emma to speak about the details of the study and see whether you are eligible please contact her on the contact details above or speak to your clinician at the clinic.

### Do I have to take part?

This study is separate to any healthcare that you may be receiving from the clinic and taking part is entirely voluntary. You may withdraw from the study at any time, without giving a reason. If you withdraw from the study, however, the data collected will be kept in the study. If you decide to take part (or not) this will not affect the standard of your care in anyway.

### What will happen in the interview?

Emma (who is a Trainee Clinical Psychologist) will meet you in a private room to answer any questions you may have about the study.

If you decide to participate, you will firstly be asked to complete a brief questionnaire to see whether you are eligible to take part in the study. If you are eligible to take part, you will be given the option to be interviewed that day, or to attend at a more convenient date for you. The interview will take approximately 60 minutes and will be in a private room either at the clinic you attend or at Royal Holloway University.

At the start of the interview, Emma will ask you to complete a short questionnaire about your mood. The interview will then take place, beginning with some questions about your life with HIV as well as asking questions about relationships and other parts of your life. Emma will also ask some general questions about yourself (e.g. age, ethnicity and occupation). With your consent the interview will be audio recorded. This is to make sure that no important information is missed. To allow you to be able to speak freely, we ask that you attend the interview alone.

The consent form also asks your permission for Emma to access your medical records to collect some basic information about your HIV (CD4 count, viral load and medication). The information is needed to further understand your health and well-being.



### Will the interview be confidential?

Yes the interview is confidential. In very rare cases, if you say something during the interview that suggests that you or someone else might be at risk of serious harm, Emma may need to speak to your clinical team so that they are able to provide you with support. This would be discussed with you first.

The interview will be audio recorded so that it can be transcribed (written out) and analysed at a later date. The recording will be deleted once it has been transcribed. The transcribed data will be stored as a word document in a password protected folder on a computer that is also password protected. The consent form, which we will ask you to sign if you decide to take part in the study, will be kept in locked filing cabinets at the clinic and will be kept for two years after completion of the study and then destroyed.

### What are the risks of taking part?

Some people might find talking about their relationships and diagnosis of HIV difficult, or in some cases upsetting. You will be given the opportunity to reflect on your experience of the interview immediately afterwards with Emma. If you feel that you need to speak to someone else after this meeting, suggestions will be made to help you with this.

### What are the benefits of taking part?

You may find talking about your experiences helpful. The information you provide will help to increase knowledge about the impact of difficulties with relationships when living with HIV. This knowledge could help to develop better services and support for people like you in the future.

### Will I get anything personally for taking part?

If you are eligible to take part in the study, we will reimburse your time for taking part in the interview with a £10 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.

### What will happen to the results of the study?

The research will be submitted in partial fulfilment of a doctorate degree in Clinical Psychology. For participants who opt-in to be informed of the results of the study, overall findings will be fed back via an email. We aim to publish the study's result in a peer-reviewed journal. The published data will be anonymised and no participants will be identifiable.

### Who has reviewed the study?

The research is being led by Emma Larsson under the supervision of Dr Michael Evangeli (Clinical Psychologist and Reader), Dr Caroline Coffey (Clinical

Psychologist) and Dr Naomi Adams (Clinical Psychologist). The study 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 by an NHS ethics committee as well as the College Ethics Committee at RHUL. This means that these Committees are satisfied that your rights will be respected, that any risks have been reduced to a minimum, and that you have been given enough information to decide whether to take part or not.

### Who should you contact with questions?

Emma Larsson (Trainee Clinical Psychologist) is the main researcher for the study. For more information, please contact her via the details above.

Dr Michael Evangeli (Clinical Psychologist and Reader) at Royal Holloway University of London is supervising the study together with Dr Caroline Coffey (Clinical Psychologist) at X (removed due to confidentiality) and Dr Naomi Adams (Clinical Psychologist) at X (removed due to confidentiality).

### 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:

Please contact the X (removed due to confidentiality) PALS on: 0300 XXX XXX (removed due to confidentiality)

### What happens next?

If you are interested in taking part, you will be given the opportunity to meet with Emma on the same day as your clinic appointment (if she is available on site) to discuss whether you wish to take part and whether you are eligible to take part. If you do decide to participate, you will be given the option to be interviewed that day, or attend at a more convenient date for you. If Emma is not available on site on the day of your clinic appointment, you can contact her on the contact details above to arrange a time to meet. Alternatively, you can let your clinician know you are interested in taking part in the study and they will pass on your contact details so Emma can contact you to arrange a meeting.

**Thank you for taking the time to read this information sheet.**

## Appendix F: Consent Form

**Project Title:** Longstanding emotional and relational issues in people with HIV

**Name of researcher:** Emma Larsson ([emma.larsson1@nhs.net](mailto:emma.larsson1@nhs.net))

**IRAS Project ID:** 243185

**Version:** 4

**Date:** 23/08/2018

You have been asked **to participate in a study exploring** how difficulties with managing emotions and forming and maintaining relationships affect individuals living with HIV.

The study is being carried out by Emma Larsson (trainee clinical psychologist) at Royal Holloway University of London, in collaboration with X (removed due to confidentiality)

*Please initial*

	Yes	No
1. I confirm that I have read and understood the information sheet for the above study and that I have had the opportunity to ask questions which have been answered satisfactorily		
2. I understand that participation is voluntary and I can withdraw from the study at any time, without giving reason and without it affecting my care. I understand that the data collected will be kept in the study if I withdraw from the study.		
3. I agree to have my interviews with Emma Larsson (Trainee Clinical Psychologist) audio recorded		
4. I understand that information will be stored confidential in password protected folders on a computer and in locked cabinets at the clinic		
5. I agree to have anonymised information and quotes from my research interview published in a peer-reviewed journal		
6. I agree to my clinical records (CD4 count, viral load and medication) being accessed by the researcher		
7. I agree to take part in the above study		

\_\_\_\_\_  
Name of participant

*Emma Larsson*

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix G: Example of transcript with initial codes

<p>Pt7: Umm... I'm not saying I was ever perfect but this, if people strive for 100% this knocked a good 30% off. You know... and... so you only ever going to be 70% off what your ideal could be. Sometimes it knocks even more off because... I got into, when I moved down to London, I got into... umm... doing a lot of ketamine... and selling it as well to finance my habit. I did it for a long time. I don't think my feet touched the ground for about 3 years. Umm... I became a prostitute because I needed in a weird, perverse kind of way, people paying me... because I had a lot of... I had a gym body and I was also... I got self-esteem from people paying me for sex... in a weird kind of way. Umm... gosh I wasn't planning on telling you about that. Umm... it's not like I needed the money particularly, it was some warped way of validation. Umm... and yes I used to go and party and have a long list of sexual partners... because of all... I was careful but I just thought... the world changes when you... because you are either positive or your not positive... and once you are, you can't get positive again. So, that... even that fulcrum of left or right. Umm... yes you can get all sort of other nasty things... but, that big... either the lights are on or off for HIV, the big scary one. And if the lights are on, then...</p>	<p>Feeling like the HIV knocked at least 30% of his potentials</p> <p>Reflecting on getting into drugs when moving down to London</p> <p>Reflecting on financing his drug habits by selling drugs</p> <p>Reflecting on not touching the grounds due to drugs</p> <p>Reflecting on becoming a prostitute</p> <p>Reflecting on getting self-esteem from people paying him for sex</p> <p>Reflecting on not needing the money from selling sex but needed validation</p> <p>Reflecting on having a long list of sexual partners</p> <p>Feeling like the world changed when became positive</p> <p>Reflecting on not being able to get positive again</p> <p>Reflecting on not needing to worry about HIV anymore</p>
<p>Do you think you kind of stopped caring for other things then? To catch another STD?</p>	
<p>Pt7: Yeah... Umm... and there was a time when, you know, if people... if you meet somebody and they go 'are you positive', I would say 'yes I am,' and somebody would go 'oh good' and then walk away and so... you think ok, well suck it up... but you...</p>	<p>Reflecting on not caring about other STDs</p> <p>Reflecting on being rejected due to HIV</p>
<p>How was that for you? To hear that or to see someone else's reaction?</p>	
<p>Pt7: You learned to brush it off. It hurts in</p>	<p>Having to learn to brush of</p>

<p>the beginning because that's what reinforces the damaged goods kind of feeling... but then, then I learnt... sort of... cover those... if people were pushing those buttons that would hurt you, I learnt to cover those buttons... I, saying 'I'm not going to answer your question, but I'm guessing your negative but you should treat everyone as they are positive... because gay men with a hard on, on drugs, they are going to lie through their teeth if they want to sleep with you. So, you need instead of asking the question, you need to protect yourself against all the liars that are out there, you are just lucky that I'm being honest. So it's up to you if you want to protect your status...'</p>	<p>others negative reactions to HIV  Feeling like others negative reactions to HIV reinforced his view of damaged goods   Learning to protect himself in the way he disclosed HIV to sexual partners</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

## **Appendix H: Example memo**

11/01/2019:

All three participants so far have displayed high levels of anger throughout the interviews. They have also all currently single and report a longstanding difficulties with relationships. I noticed that they often wanted to be in charge of the interview and talk about areas they wanted instead of following the questions. All participants reported narcissism traits on the IPDE screening measure. I wonder if this can be linked?

07/02/2019:

There was a high level of risk in the interview yesterday. I found it difficult to manage being a researcher as well as clinician as I ended up having to manage the risk. I have been finding this balance difficult throughout the interviews. I wonder if this specific patients group stirs up more worries in me than others? This is in line with previous research indicating a large amount of countertransference issues in PD populations.

11/03/2019:

The three last participants reported poor physical health due to the HIV. They were all diagnosed late and were therefore very poorly. They have also all isolated themselves. I wonder if this is due to the physical health difficulties or the personality-related difficulties as other patients without physical health difficulties have also isolated themselves.

## Appendix I: NHS ethics approval



Miss Emma Larsson  
Doctorate in Clinical Psychology  
Royal Holloway, University of London  
TW20 0EX

07 August 2018

Dear Miss Larsson



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

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

**Study title:** Developing a model of living with HIV in individuals with personality-related difficulties  
**IRAS project ID:** 243185  
**REC reference:** 18/LO/0962  
**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.).

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: 01784414388

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 **243185**. Please quote this on all correspondence.

Yours sincerely



IRAS project ID	243185
-----------------	--------

Juliana Araujo  
Assessor  
Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Sponsor Representative: Ms Annette Lock, Royal Holloway, University of London  
Lead NHS R&D Office Representative: Mr Rameez Subhan, Noclor research support for CNWL*

## Appendix J: Royal Holloway University Ethics approval

### Memorandum

**To:** Emma Larsson

**From:** Lyn Ellett (on behalf of the Research Sub-Committee and Course Executive)

**Date:** 12<sup>th</sup> January 2018

**Copy To:** Michael Evangeli

**Re:** Main Research Project Proposal

---

The Research Sub-Committee has considered your Main Research Project Proposal response and has decided to give you **Approval**. Your research costs have also been approved. Please note that if these costs change and you do not re-submit an amended form for approval prior to incurring any additional costs, these additional costs will not be reimbursed.

#### Feedback for Systematic Review:

- The proposed question for your systematic review fits nicely with the focus of your empirical study. You may want to consider including 'peer reviewed studies' only as an eligibility criteria, to avoid unpublished studies, dissertations etc, unless you want to include these.

"In addition, as your proposed study is qualitative, please keep the following points in mind throughout your major project:

1. Justification for choosing a qualitative approach instead of a quantitative approach for the research questions you wish to address.
2. Providing a rationale for the particular method you chose as opposed to other methods, including the stated philosophy behind the method.
3. Reflecting on your own contribution to the research process.
4. Stating and adhering to published quality standards.
5. Stating what potential contribution to knowledge your study can make. Whereas many qualitative approaches discourage predicting specific outcomes, this does not preclude anticipating in general terms how outcomes

you foresee will be useful to future steps in research and practice. These should be stated in specific enough terms that the reader of your eventual thesis can judge whether or not you achieved the goals you set out to achieve."

**Now that you have received approval it is time to apply for ethics. Please keep Annette informed and where possible provide copies of all applications, letters and approvals. Also, please ensure that if RHUL is your sponsor, Annette is sent all participant signed consent forms.**

## Appendix K: NHS ethics amendment

### Amendment Categorisation and Implementation Information

Dear Miss Larsson,

<b>IRAS Project ID:</b>	243185
<b>Short Study Title:</b>	Longstanding emotional and relational issues in people with HIV
<b>Date complete amendment submission received:</b>	23 August 2018
<b>Amendment No./ Sponsor Ref:</b>	NSA1 (23/08/2018)
<b>Amendment Date:</b>	23 August 2018
<b>Amendment Type:</b>	Non-substantial
<b>Outcome of HRA and HCRW Assessment</b>	<b>This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything further.</b>
<b>For NHS/HSC R&amp;D Office information</b>	
<b>Amendment Category</b>	<b>C</b>

Thank you for submitting an amendment to your project. We have now categorised your amendment and please find this, as well as other relevant information, in the table above.

#### What should I do next?

If you have participating NHS/HSC organisations in any other UK nations that are affected by this amendment **we will** forward the information to the relevant national coordinating function(s).

**You** should now inform participating NHS/HSC organisations of the amendment.

- For NHS organisations in England and/or Wales, this notification should include the [NHS R&D Office](#), [LCRN](#) (where applicable) as well as the local research team.

#### When can I implement this amendment?

You may implement this amendment **immediately**. Please note that you may only implement changes described in the amendment notice.

**Who should I contact if I have further questions about this amendment?**

If you have any questions about this amendment please contact the relevant national coordinating centre for advice:

- England – [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net)
- Northern Ireland – [research.gateway@hscni.net](mailto:research.gateway@hscni.net)
- Scotland – [nhsg.NRSPCC@nhs.net](mailto:nhsg.NRSPCC@nhs.net)
- Wales – [research-permissions@wales.nhs.uk](mailto:research-permissions@wales.nhs.uk)

Additional information on the management of amendments can be found in the [IRAS guidance](#).

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

Please do not hesitate to contact me if you require further information.

Kind regards

**Hayley Kevill**

**Health Research Authority**

Ground Floor | Skipton House | 80 London Road | London | SE1 6LH

[E. \[hra.amendments@nhs.net\]\(mailto:E.hra.amendments@nhs.net\)](mailto:E.hra.amendments@nhs.net)

[W. \[www.hra.nhs.uk\]\(http://www.hra.nhs.uk\)](http://www.hra.nhs.uk)

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## Appendix L: PRISMA checklist



### PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	18
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	19-20
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	26-27
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	28
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	29
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	29
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	29
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	30
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	30
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	N/A
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	32
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	32-33



## PRISMA 2009 Checklist

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<b>METHODS</b>			
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Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	29
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Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	32-33