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SOCIO-DEMOGRAPHIC FACTORS AND THEIR ROLE IN THE EXPERIENCE OF LIVING WITH HIV

Section A: A Thematic Synthesis of Black Women Living With HIV and Their Experience of HIV-related Stigma

Word count: 8,777 (1,187)

Section B: An Initial Examination of the Relationship of Demographic and Clinical Factors on the Outcome of HIV Cognitive Impairment in People Living with HIV

Word Count: 6,465 (407)

Overall Word Count: 15,273 (1,625)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2024

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

Thank you to Dr Jerry Burgess, Dr Clara O’Brien and Dr Fergal Jones who supervised and consulted on the project. Specially thanks to Chloe Seikus, who supported with the data.

To my family, thank you for your encouragement and support. I am eternally grateful and would not be where I am today without you. To my husband, you have been a true source of strength, love and support. You brought me humour when I needed it most during this process. Finally, to my dog, you have been the ultimate study companion.

Statement

HIV is an area that has received substantial research over the past 50 years. Initially, the planned topic for Section A was a systematic review of psychosocial risk factors that contribute to an increased likelihood of HIV associated cognitive impairment. However, it was not possible to disentangle psychosocial and medical risk factors from the large body of existing research. Considering this, and the remit of Section B, it was decided that Section A would focus on Black women living with HIV and their experience of HIV-related stigma.

Summary of Major Research Project

Section A is a systematic review of qualitative research which explores the experience of Black women living with HIV and HIV-related stigma. The review extracted and critically appraised sixteen studies. Seven themes were thematically synthesised. The themes included discrimination and intersectionality, distress, relationships, HIV knowledge and understanding, unwanted disclosures of HIV status, treatment and aging. The findings of the review are discussed in the context of Black women's experience of dimensions of HIV-related stigma, intersectionality and the existing literature. Clinical and research implications and recommendations for Black women and HIV-related stigma reduction are discussed.

Section B examined the relationship between clinical and demographic factors, of people living with HIV, and the outcome of cognitive impairment. The results showed that the RBANS total scale score was a significant predictor for the diagnosis of cognitive impairment. Due to the reduced sample size and missing data, further post-hoc analyses were completed. Patterns in the data were also observed between premorbid IQ and cognitive impairment diagnosis. Analyses were also completed on the missing data to identify any existing patterns. Future research with a larger sample is recommended to disentangle the complex relationship between HIV and cognitive impairment.

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Section C

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Abstract

The highest levels of HIV-related stigma are reported by Black women which consequently impacts their treatment regime, wellbeing and quality of life. Current research into the experiences of Black women living with HIV and HIV-related stigma provide some insights into the challenges they face. However, no prior research has attempted to collate their experiences. This systematic literature review of sixteen qualitative papers utilised thematic analysis to synthesise the experiences of black women living with HIV and HIV-related stigma. Seven themes were identified: discrimination and intersectionality; distress; relationships; HIV knowledge and understanding; unwanted disclosures of HIV status; Treatment and Aging. HIV-related stigma was found to impact every area of life for Black women living with HIV despite advances in treatment, reduced transmission and improvements in life expectancy. Discrimination from healthcare professionals profoundly impacted Black women's anticipation of HIV-related stigma and influenced their choices around disclosure. Further research is required to ascertain the current understanding of HIV and HIV-related stigma, on a community and national level and identify the gaps in service provisions for Black women living with HIV. Clinical recommendations include the renaming of clinics and the development of new and existing training programmes, on HIV and HIV-related stigma.

Introduction

Overview

This systematic review focuses on the experiences of Black women living with HIV (BWLWH) and their experiences of HIV-related stigma through the synthesis of qualitative research. This review is the first of its kind, to focus solely on BWLWH's experiences of HIV-related stigma. The analysis, synthesis and critical appraisal are presented, followed by the results and the implications.

HIV

Human immunodeficiency virus (HIV) is a viral infection contracted through unprotected intercourse, childbirth, breast feeding and the sharing of contaminated needles (World Health Organization, 2023). HIV attacks the immune system leaving the body susceptible to opportunistic infections (Levy, 2009). The discovery of antiretrovirals (ART) in 1987, which inhibits the replication of HIV, led to an increase in life expectancy for people living with HIV. ART significantly reduced opportunistic diseases and the likelihood of the disease's progression to AIDS if initiated early on (D'Arminio Monforte et al., 2004; Grinsztejn et al., 2014). However, there have also been several issues associated with ART including treatment toxicity, complex treatment schedules, drug resistance, the initiation of treatment, 'pill fatigue,' and access to treatment (Iacob et al., 2017). In 2022, the UNAIDs global statistics found that 77% of adults living with HIV were accessing ART. However, the percentage varied by region with only 51% accessing it in the Middle East and North Africa (UNAID, 2022).

Further advancement and the introduction of PrEP, an antiretroviral medication for those vulnerable to acquiring HIV due to serodiscordant relationships, has enabled people living with HIV to engage in intimate relationships with a significantly reduced likelihood of HIV transmission to their partner (Fonner et al., 2016). In addition to pharmacological advances, HIV education in schools, needles exchange programmes and self-testing initiatives have been essential in the management and reduction of HIV transmission (Johnson et al., 2017; Kirby et al., 2007; Wodak & Cooney, 2006). Despite these initiatives and efforts, HIV continues to be problematic with an approximate 1.3 million acquiring the virus in 2022 (WHO, 2023).

HIV and Ethnicity

In the United States, Black and Black African-American people make up 40% of the population living with HIV despite only representing 13% of the general population (HIV.gov, 2023). In the UK, Black African people made up 28.4% of all new HIV diagnoses. (National AIDS Trust, 2022). Black African, Black Caribbean and 'Black other' represented 35% of those receiving specialist HIV treatment in the UK (National AIDS Trust, 2022). When gender is taken into consideration, Black women are disproportionately affected by HIV when compared to other ethnicities in the US (HIV.gov, 2023). They are also found to have poorer health outcomes and face barriers such as reduced family support, poor quality healthcare and HIV-related stigma when compared to other groups (Geter et al., 2018).

The definitions of stigma, discrimination and prejudice

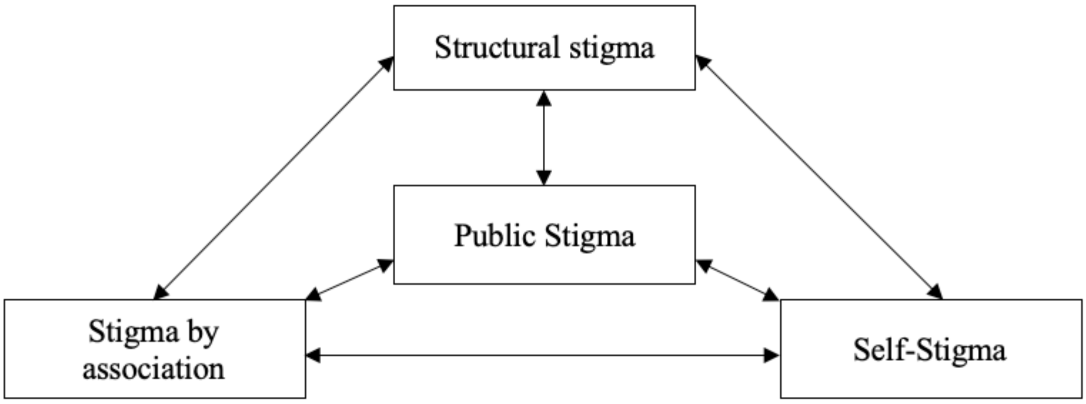
The first reference of stigma was made by the Greeks who physically marked individuals, with burns or scars, to enable the easy identification of immoral individuals such as slaves, criminals and traitors (Goffman, 1963). Goffman characterised stigma more broadly as an 'attribute that is deeply discrediting' (Goffman,1963, p.3). He proposed three different categories (including physical deformities, individual character blemishes, and tribal stigma) of stigmatised attributes that yielded a 'spoilt social identity' (Goffman, 1963). Notably, stigma is rooted in social context, and the acknowledgment of difference (Crocker et al., 1998). Stigma does not only involve the response of the other, to the individual possessing stigmatised attributes, but it also encompasses the stress experienced from the internalisation of negative societal attitudes regardless of their presence (Link, 1987). Link and Phelan proposed that the term stigma is applied when ‘labelling, stereotyping, separation, status loss, and discrimination co-occur in power situations’ (2001, p.367), which in essence suggests that prejudice and discrimination are components of stigma. The conceptualisation, and definition, of stigma is contentious due to the multidisciplinary involvement in research and its distinction from discrimination and prejudice. Taking this into consideration, this report will utilise the following definitions: prejudice is the preconceived beliefs about a certain group; discrimination is the enactment of these preconceived beliefs and stigma is the internalisation of unfair and discriminatory actions (Paradies et al.,2017).

HIV-related Stigma

HIV-related stigma is known to be a major barrier in the effective management of the HIV epidemic due to its negative impact on peoples’ engagement with preventative measures and treatment programmes (Mahajan et al., 2008). More recently, Pryor and Reeder (2011) proposed a theory of stigma to consolidate and incorporate the research in the field. The model comprised of four categories of stigma including public stigma, self-stigma, stigma by association, and structural stigma, all of which are interrelated (see Figure 1) (Bos et al., 2013). Public stigma is central to the model and is a reflection of perceiver’s prejudice and discriminatory responses to someone with a stigmatised characteristic or condition. Self-stigma represents the psychological and social impact of possessing a stigmatising characteristic. Stigma by association represents the response of others to those associated with the individual with a stigmatised characteristic, and structural stigma refers to the role of institutions and wider systems in the legitimisation of those with stigmatised characteristics (Bos et al., 2013). The experience of HIV-related stigma is dynamic and thought to change over time, particularly, in the context of disease progress to AIDs when there are fewer symptom free periods (Alonzo & Reynolds, 1995).

Figure 1

A diagram of Pryor and Reeder's model of stigma



HIV-Related stigma and Black women

Pryor and Reeder explained that intersectionality exacerbates an individual's experience of HIV-related stigma; 'the connections between HIV status and poverty, race, substance abuse, and non-normative sexuality have helped to mould HIV status into one of the most powerful stigmas in contemporary society (2011, p.3). This was echoed in research which identified BWLWH as one of the most stigmatised groups (Loutfy et al., 2012). HIV-related stigma is known to compromise an individual's ability to adhere to their treatment programme and has negative consequences for their wellbeing and quality of life (Chambers et al., 2015; Holzemer et al., 2009; Katz et al., 2013).

Objectives and rationale for this review

There have been several pieces of research into the impact of HIV-related stigma and discrimination on BWLWH. However, it is relatively scant compared to the vast amount of research in the field of HIV. A provisional search of PROSPERO did not identify any systematic reviews on BWLWH and their experiences of HIV-related stigma and discrimination. Prejudice was not referenced further in the search as the intention was to explore the experiences of BWLWH, through their internal and external experiences, rather than the views of others. Given the dynamic nature of stigma and the added complications of the disease's progression to AIDs, only those with HIV that had not progressed were searched and included (Alonzo & Reynolds, 1995). Although quantitative research can provide helpful insights, this review only included qualitative research. In doing so, providing richer insights into BWLWH's experiences of HIV-related stigma.

The review aims to answer the following questions:

1. What are BWLWH's experiences of HIV-related stigma?
2. What is the impact of HIV-related stigma on their lives?

Method

Search strategy

Initial scoping searches, completed on Google Scholar, identified various terms utilised in the literature to describe 'black' and 'experiences.' The search identified a small number of papers that focused on BWLWH and their experience of HIV-related stigma. An electronic database search was completed on four different databases (ASSIA, CINAHL, Medline and PsycINFO) on 6th November 2023 utilising the following search terms:

- Black* OR "Sub-Saharan African" OR African OR colour* OR color* OR Caribbean OR BAME OR BME
- women OR female*
- "Human immunodeficiency virus" OR HIV*
- stigma OR discrimination. The term prejudice was not utilised based on the definition adopted for this review (Paradies et al.,2017)
- experience* OR perception* OR view*

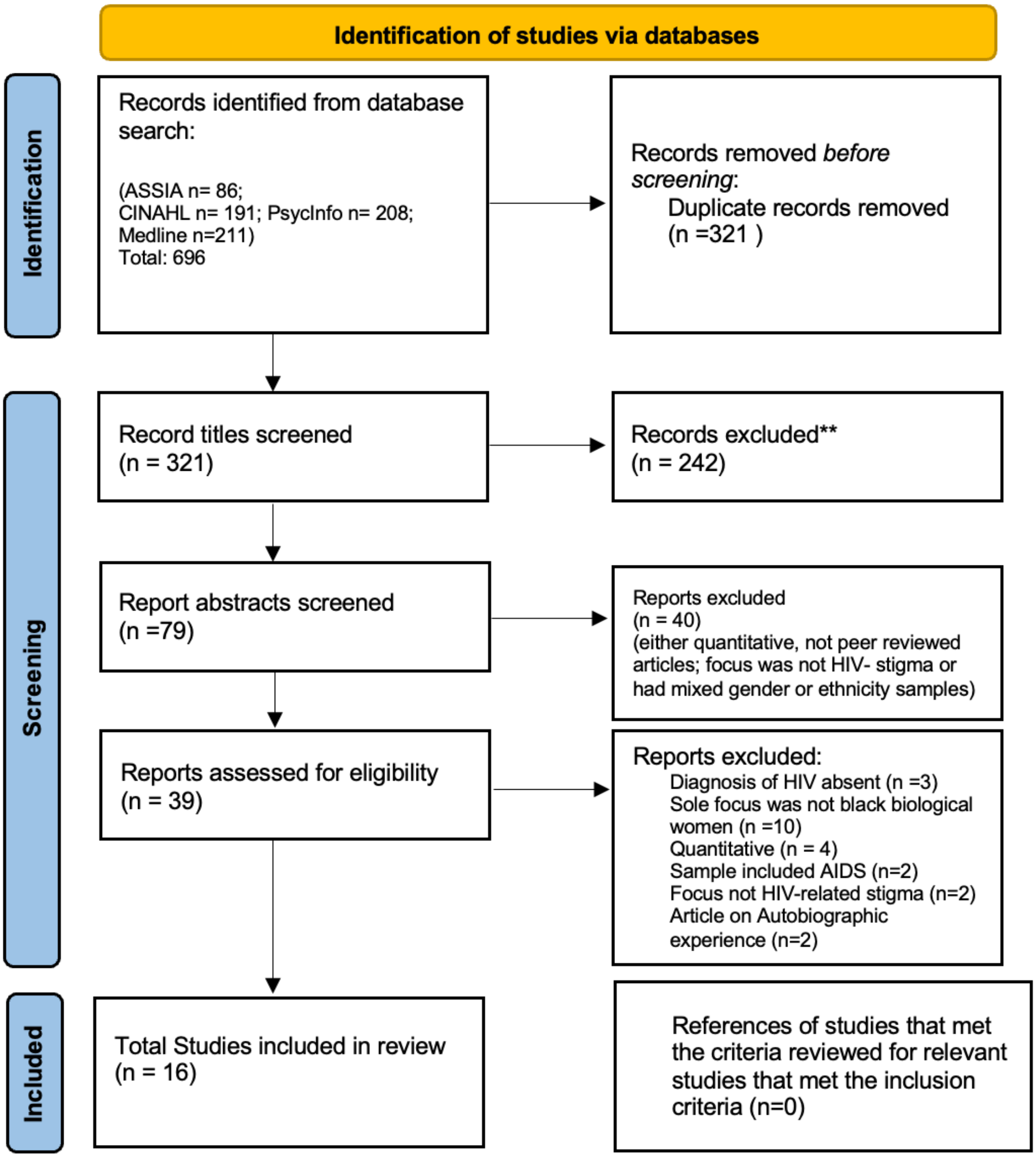
On CINAHL, Medline and PsycINFO the terms were searched for in the abstract section of the journals whereas they were searched by the 'everywhere but full text' function on ASSIA. The Truncation symbol (*) was used to minimise the risk of papers being overlooked as a consequence of different terminology. No date range was utilised for the search.

Study Selection

The database search produced a total of 696 papers. The search was then transferred to RefWorks to support with the removal of duplicates. However, on checking the remaining papers manually it was noted that a number of duplicates were overlooked by the automated function. The papers were then exported to Excel for ease of duplicate removal. Three-hundred-twenty-one papers remained. The inclusion and exclusion criteria were applied in a staged screening process at title, abstract and full text level. This resulted in 16 papers, all of which had their reference list checked manually for any relevant papers that met the inclusion and exclusion criteria. However, this did not result in any further papers. Further detail on the search process can be found in the PRIMSA diagram in Figure 2 (Page et al., 2021). Information on the final 16 papers can also be found in Table 1.

Figure 2

PRISMA diagram of study selection



Inclusion and Exclusion criteria

Inclusion

- Black women (biological women and living as women)
- Those Living with stage 1 to 3 HIV as defined by The World Health Organisation (WHO, 2005)
- Papers predominantly focused on BWLWHs experiences of HIV-related stigma
- Qualitative papers
- Peer reviewed papers only

Exclusion

- Studies including transgender women and men
- Those with stage 4 HIV with opportunistic infection, better known as the disease's progression to AIDS (WHO, 2005)
- Non-Black minority groups and Caucasian
- Quantitative studies
- Commentaries
- Book chapters

Reflexive Statement

As a white female trainee clinical psychologist, I do not claim to fully understand, or to have lived, the adversities experienced by Black women. However, I have lived experience as a dual national woman. I possess a strong interest in seeing equality, safety, security, and positive health outcomes for Black women. This interest contributed to my decision to review this topic. I read the literature with an understanding of this potential bias, with the aim to thoroughly search and accurately report the data as presented in the body of extant literature.

Data extraction

A data extraction proforma was utilised to summarise the 16 studies. The information extracted included the participants’ demographic information, the aim, the design and analysis, the main findings, themes relevant to the review, and the limitations. Table 1 outlines the information extracted from the 16 studies.

Table 1

Summary of studies for the review

Author, date	Title	Country and language of research	Participants	Aim of study	Design and Analysis
Anderson & Doyal (2004)	Women from Africa living with HIV in London: A descriptive study	London, United Kingdom Interviews conducted in English and some in French with the support of a translator	62 Black women from 11 different countries (Malawi, Burundi, Cameroon, Ghana, Tanzania, Zaire, Kenya, Nigeria, Zambia, Zimbabwe, Uganda) aged 20-58 years old	To explore the experiences and daily lives of Black African women receiving treatment in London.	Questionnaires on demographics and Interviews Thematic analysis
Arrey et al. (2017)	Perceptions of stigma and discrimination in health care settings towards sub-Saharan African migrant women living with HIV/AIDS in Belgium: A qualitative study	Belgium	44 sub-Saharan women	To investigate stigma and discrimination experienced by migrant sub-Saharan African women in healthcare settings and its consequences for health-seeking behaviour.	Semi-structured interviews and observations. Thematic analysis

Black et al., (2002)	Calculating the risks and benefits of disclosure in African American women who have HIV	South-eastern states of USA. English	48 African American women aged 22-65 of low income	To identify the processes involved and patterns of HIV diagnosis disclosure in African American women.	Notes from nursing interviews and notes. Notes of visits and nurse interactions analysed using content analysis
Buseh & Stevens (2006)	Constrained but not determined by stigma: Resistance by African American women living with HIV	Wisconsin, USA. English	29 African American women aged 25-54	To explore African women's narratives of living with HIV, their experiences of HIV stigma and their responses.	Up to 10 interviews over two years. Narrative analysis
Dale et al (2017)	Still I rise: The need for self-validation and self-care in the midst of adversities faced by Black women with HIV	Boston, Massachusetts, USA. English	Four black women born outside of USA and 26 African American women	To explore Black women's experiences of psychosocial factors associated with poor ART adherence, to support the development of an intervention.	Thematic content analysis and grounded theory
Hampton & Gillum (2022)	'It changes everything': The impact of HIV-related stigma on sexual health and intimacy among African American women	Upstate New York, USA. English.	16 African American women aged 28-63	To identify the way which HIV-related stigma impacts on sexual health and experiences of intimacy among African American women living with HIV.	Thematic analysis

James-Borga & Fredrickson (2018)	The voices of older African American women living with HIV disease	New York, USA. English.	10 African American women aged 50-76	To understand the experience of older African American women living with HIV.	Unstructured interviews Phenomenology
McDoom et al (2015)	How older Black women perceive the effects of stigma and social support on engagement in HIV care	Boston, Massachusetts, USA. English.	20 Black women aged 50-63	To gain an in-depth understanding of older Black women's experiences of stigma and social support and its impact on HIV care engagement.	Semi-structured interviews. Grounded theory
Ojikutu et al (2018)	African born women living in the United States: Unmet needs and opportunities for intervention	New York and Boston, United States. English	45 African born women that immigrated to and lived in Boston and New York.	To explore the psychosocial and mental health challenges of African born women living with HIV in Boston and New York City.	Semi structured interviews. Grounded theory
Peltzer, Domain & Teel (2016)	Infected lives: Lived experiences of young African American HIV-positive women	Midwestern Metropolitan Cities, USA. English	11 African American women living in or a near a Midwestern metropolitan city.	To examine HIV-infected African American women's experiences of psychological distress and their coping strategies.	Two interviews completed three to six months apart Hermeneutic phenomenological approach
Peltzer et al (2017)	A qualitative description of HIV-infected African American women's experiences of psychological distress and their coping strategies	Kansa and Missouri, USA. English	22 African American women aged 25-73	To understand the everyday experiences of young African American HIV-positive women.	Semi-structured interviews Inductive content analysis

Cannon Poindexter (2013)	HIV stigma and discrimination in medical settings: Stories from African women in New Zealand	New Zealand English	Four African women from eastern-sub–Saharan African nations living in New Zealand.	To understand the experiences of four HIV positive African women of discrimination in medical settings in New Zealand.	Secondary data from interview transcripts. Narrative analysis.
Rohleder & Gibson (2006)	‘We are not fresh’: HIV-positive women talk of their experience of living with their ‘spoiled identity’	South Africa English and isiXhosa	10 Black women aged 16-47 living in Khayelitsha	To explore how HIV positive women, who had received little to no support since diagnosis, experienced and managed stigma.	Narrative interview
Sangaramoorthy, Jamison & Dyer (2017a)	HIV stigma, retention in care, and adherence among older Black women living with HIV	Maryland, USA English	28 African American and seven Black African women aged 40-71	To explore older Black women’s experiences of HIV stigma, retention in care, and ART adherence over the lifespan.	Semi Structured interviews and surveys. Grounded theory

Sangaramoorthy, Jamison & Dyer (2017b)	Intersectional stigma among midlife and older Black women living with HIV	Maryland, USA. English	28 African American and 7 Black African women aged 40-71	To better understand the nature and intensity of HIV-related stigma, with a focus on how HIV- related stigma interacts and intersects with pre-existing social inequities based on gender, race, and age and how experiences of stigma change over time.	Semi-Structure interviews and surveys. Grounded theory
Vantyler & Sheild (2015)	Stories of African HIV+ Women Living in Poverty	Kibera, Kenya. English.	Nine Black African women (belonging to five different ethnic groups: Nubian, Kamba, Kikuyu, Kalenji, and Balulya) aged 32 to 43	To explore the experiences of HIV+ women living in poverty conditions in Kibera.	Two semi-structured interviews Narrative analysis

Data synthesis

Thomas and Harden's (2008) approach for thematic synthesis was adopted. The data were coded inductively, organised into themes that were closely related to codes and then into analytic themes utilising the researcher's interpretation. See table 2 for a summary of the analysis and synthesis process followed. The results and finding sections of each study were read thoroughly. Data that were relevant to BWLWH, their experience of HIV-related stigma and its impact was synthesised. Data that did not focus directly on HIV-related stigma were excluded. Researcher summaries were also included in the synthesis as some of the papers only referenced HIV-related stigma in this section.

A critical realist epistemological position was adopted for this review (Fletcher, 2017). Critical realism considers that reality is not constrained to empirical findings nor hermeneutical, but also abstract unobservable experiences and processes (Gorski, 2013). In adopting a critical realist approach, BWLWH's experiences of HIV-related stigma were explored whilst acknowledging their position and social context i.e the four planes of social being (Alderson, 2021; Maxwell, 2012). A critical realist approach assumes that BWLWH live in a society that sustains HIV-related stigma and that they have the potential to create change through the sharing of their experiences. Considering the epistemological position, papers which only referenced HIV- related stigma in the research summaries, and/or focused on the researchers' interpretation rather than direct quotations from BWLWH, were given less attention in the synthesis. Less emphasis was therefore given to Anderson & Doyal (2004), Black & Miles (2002), Peltzer, Domain & Teel (2016) and Peltzer et al (2017) in this review.

In the results section of this review direct quotes from BWLWH narratives are utilised and reflected in the surrounding text, followed by the parenthesis. Text utilised from the original researchers' summaries are presented as quotes and followed by a parenthesis. Outside of these quotes the interpretations are that of the researcher of this review.

Table 2

A summary of the analysis and synthesis process

Stages of thematic synthesis	Process
Extracting data from the studies and inductive coding	Each line of the ‘results’, ‘findings’ and research summaries were coded manually. All the codes were stored on excel and this enabled the easy identification of new and repeat codes that emerged from the data.
Organisation of codes	The codes were then grouped based on their similarities and differences. The groups were then coded descriptively to ensure that they did not move away from the data.
Generation of analytic themes	Analytical themes were generated through the reviewer’s perception of the descriptive themes and the research questions. The analytic themes go beyond the data presented in the original studies.

Results

Quality assessment

The quality of the 16 studies was appraised using the qualitative paper Critical Appraisal Skills Programme checklist (CASP, 2024). The CASP checklists consists of 10 questions to support readers to review qualitative papers in a systematic manner. The areas covered by the CASP checklist include: the aims; methodology; recruitment; the relationship between the researcher and participants; ethical considerations; data analysis; findings and value of the research. These areas helped shape the structure of the results section. In line with CASP guidelines, a scoring system was not adopted. The CASP checklist was selected as it is the most widely utilised tool in healthcare research, in the appraisal and inclusion process of qualitative research for systematic reviews (Dalton et al., 2017; Hannes & Macaitis, 2012). It is also easily incorporated into Thomas and Harden's approach to thematic synthesis (2008; Long et al., 2020). All the studies included in this review were deemed to be of medium to high quality. Considering this, it enabled the researcher of this review to have a more open perspective, remain in line with the critical realism epistemology and focus on the papers that contained more quotes and direct narratives from BWLWH. A summary of the CASP ratings can be found in Table 3.

Participants

Although the CASP (2024) checklist does not include a review of the participants demographics it felt necessary to comment. The studies included in this review were completed in several different countries (Belgium, Kenya, New Zealand, South Africa, UK and USA) spanning from 2002 to 2018. Several of the studies focused on the experiences of BWLWH who immigrated from Africa (Anderson & Doyal, 2004; Arrey et al, 2017; Ojikutu et al., 2018; Cannon Poindexter, 2013). A few of the studies were based in the USA and focused solely on the experience of African American women (Black et al., 2002; Buseh & Stevens, 2006; Hampton & Gillum, 2022; James, Borga & Fredrickson, 2018; Peltzer, Domain & Teel, 2016; Peltzer et al., 2017). Whilst others focused more broadly on the experience of BWLWH (Dale et al., 2017; McDoom et al., 2015; Rohleder & Gibson,.2006; Vantyler & Shield, 2015). Considering both the timeframe and context of the studies, the BWLWH and the researchers will have had varied life, cultural, family and religious experiences. Therefore, this review encompasses a rich diversity of realities. Although mostly positive, it will limit the conclusions that can be made from the review, due to the diversity of life experience amongst the BWLWH.

Aims, Method and Design

Of the 16 studies, 15 had clear aims. Although Anderson and Doyal (2004) identified gaps in the research and provided direction for a rough aim, there was not a clear statement of aims. The research design of all the studies were deemed appropriate given the aims and intentions.

Sampling and data collection method

All the studies utilised interviews as their main method to elicit BWLWH experiences. Black and Miles (2002) completed interviews but made notes of the main themes rather than voice recordings. Purposive and snowball sampling methods were used by all the studies which was deemed appropriate given the research topic.

Ethical considerations

All 16 papers partially addressed ethical considerations. Two of the papers did not make explicit reference to ethical approval (Cannon Poindexter, 2013; Hampton & Gillum, 2022). Three of the papers utilised secondary data (Black & Miles, 2002; Cannon Poindexter, 2013; Hampton & Gillum, 2022). The studies that utilised primary data all referenced consent. Only a few of the studies considered the impact and offered further support or signposting (Anderson & Doyal, 2004; Arrey et al., 2017; Peltzer et al., 2016; Rohleder & Gibson, 2006).

Reflexivity

The majority of the papers made vague reference to the role of the researcher. Four studies referenced characteristics of the researcher, particularly in relation to ethnicity (Cannon Poindexter, 2013; Dale et al., 2018; James-Borga & Frederickson, 2018; Mcdoom et al., 2015). Only two of the four studies explicitly reflected further on the researcher's role and the influence it had on the expression of HIV-related stigma (Cannon Poindexter, 2013; James-Borga & Frederickson, 2018). One spoke of the efforts made to gain trust with community leaders and acknowledged the active role of the researcher in the shaping of the narrative, but it was not further critiqued . One of the studies used a translator for the interviews and addressed the potential impact on meaning and interpretation through translation (Rohleder & Gibson, 2006). Another study demonstrated insight into the role of the interviewer and made a marked effort to ensure that interviews were not completed by those under their medical care to avoid bias (Arrey et al., 2017).

Data analysis and findings

The analysis completed by 16 of the studies was deemed appropriate. The most utilised analysis was grounded theory (four), followed by narrative analysis (three), thematic analysis (three), phenomenological analysis (two), content analysis (two), and one which used a combination of thematic content analysis and grounded theory. One study did not explicitly state the analysis used (Rohleder & Gibson, 2006). Only three of the studies deemed their data to be saturated (Hampton & Gillum, 2022; Ojikutu et al., 2018; Peltzer et al., 2017).

Value of research

The value of the research is defined by the CASP framework as, contribution to the existing research, suggestions of future research and the application of findings to other populations (CASP, 2024). All of the studies built on the existing knowledge in the field. Most of the studies discussed recommendations and how they could benefit other populations with HIV. Whilst the remaining studies made little or no recommendations for future research (Arrey et al., 2017; Cannon Poindexter, 2013; Sangaramoorthy et al., 2017a).

Table 3

CASP quality assessment of the studies included in the review

	CASP Criteria									
Papers	Clear statement of aims?	Qualitative method appropriate?	Research design address the aims of the research?	Recruitment strategy appropriate?	Data collection addressed the research issues?	Relationship between researcher and participants considered?	Ethical issues considered?	Data analysis sufficient?	Clear statement findings?	Value of research?
Anderson & Doyal (2004)	Somewhat	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes	Yes
Arrey et al (2017)	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	Somewhat
Black & Miles (2002)	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes
Buseh & Stevens (2006)	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes
Dale et al (2018)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes	Yes
Hampton & Gillum (2022)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes	Yes
James-Borga & Fredrickson (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes
McDoom et al (2015)	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Somewhat

Ojikutu et al (2018)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes	Yes
Peltzer, Domain & Teel (2016)	Yes	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes
Peltzer et al (2017)	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Yes	Yes
Cannon Poindexter (2013)	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Somewhat	Somewhat	Somewhat
Rohleder & Gibson (2006)	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Somewhat	Somewhat
Sangaramoorthy, Jamison & Dyer (2017a)	Yes	Yes	Yes	Yes	Somewhat	No	Somewhat	Somewhat	Somewhat	Somewhat
Sangaramoorthy, Jamison & Dyer (2017b)	Yes	Yes	Yes	Yes	Somewhat	No	Somewhat	Somewhat	Somewhat	Somewhat
Vantyler & Sheild (2015)	Yes	Yes	Yes	Yes	Somewhat	Yes	Somewhat	Somewhat	Somewhat	Somewhat

Table 4

Themes and subthemes

Themes	Subthemes
Theme one: Discrimination and intersectionality	
Theme two: Distress	Emotional and Psychological distress HIV as punishment
Theme three: Relationships	Community interactions Professional relationships Inability to be authentic Close relationships
Theme four: HIV knowledge and understanding	Over cautious practice Ignorance
Theme five: Unwanted disclosures of HIV status	
Theme six: Treatment	Seeking treatment and adherence Advances in medication
Theme seven: Aging	

Themes

Discrimination and Intersectionality

The intersectionality of being Black, female and HIV positive was central to the experience of BWLWH. One BWLWH spoke about the different aspects of her identity and the challenges experienced as a Black female being further compounded by HIV:

> When it comes to Black women, it's just a part of what we go through. It [HIV] adds to the burdens we already have. It's just part of a Black woman's struggle. Being a woman there are cultural issues within your family. It adds more to the burdens (Sangaramoorthy et al., 2017a, p.524).

Another BWLWH spoke about the negative stereotypes of HIV and Black women in comparison to Caucasian women. 'Then it was of course, if you were a Caucasian female, "I'm so sorry!" but if you're a Black female, "drug user . . . prostitute" (Sangaramoorthy et al., 2017b, p.1333). This was echoed by another who spoke of the assumptions made about how the virus was contracted and not being seen as a person:

> I think a lot of people really don't look at the person singularly and how they came about and what happened, because we're not all drug users, we're not all screwing everybody, we're not all doing this and that. (Sangaramoorthy et al., 2017a, p.524).

Discriminatory practices were also observed in in the workplace and educational environment. An older unemployed BWLWH stated that 'stigma occurred in the workplace because they heard stories or knew of people getting fired' (Sangaramoorthy et al., 2017b, p.1337), which was also echoed by others' experiences. One student nurse spoke about discriminatory interactions with course staff. She was told by a teacher that it would be 'better if [she] change [her] course' as they were 'getting more African HIV' (Cannon Poindexter, 2013, p. 714). This interaction of overt racism, paired with hearing of other BWLWH's experiences of employment difficulties in the healthcare sector and her reduced capacity to fight the discrimination led her to drop out of nursing. A qualified nurse reflected on a conversation with her manager, where she was pressurised into disclosing her HIV status and made to sign a contract despite this not being mandatory:

> Is there something that you didn’t tell me when you started this course?’ I immediately knew what she was talking about….she made me sign a contract. I signed it at that time because I didn’t know what to do, but then I checked with Positive Women whether I actually had to do that. They said no (Cannon Poindexter, 2013, p.712).

Distress

Emotional and psychological distress. One woman spoke about how stress triggered, by HIV-related stigma in the workplace, manifested itself as physical health difficulties. ‘It was stressful. I didn’t realise how stressed out I was. I would wake up in the middle of the night with charley horses. I must have really internalised a lot of stress’ (Sangaramoorthy et al., 2017b, p.1337). Another spoke about suicidal ideation, ‘I didn’t want to be here anymore because the stigma that comes … you know everybody’s going to be looking and pointing and I’m feeling like everybody’s looking at me’ (Peltzer et al., 2017, p.232). The thought of being rejected, because of HIV-related stigma, was described by one woman to have ‘brought on a lot of depression’ (Peltzer et al., 2017, p.232).

HIV as punishment. One BWLWH spoke about being deserving of HIV due to her past experiences, ‘I feel like since my childhood, I have done nothing positive in life. First, I was molested by my stepfather. Then, I grew up wild, waking up in strange men’s rooms. Maybe this HIV stuff is what I deserve’ (Buseh & Stevens, 2006, p.8). Others used language associated with crime to describe their experiences. One BWLWH mentioned being ‘tagged’ in medical settings, another described the diagnosis as ‘a sentence’ and another likened the experience of the disease to being on ‘death row’ (Buseh & Stevens, 2006 p.8-9; Rohleder & Gibson, 2006, p.35).

Relationships

Community interactions. One woman spoke about the stigma she experienced in the community when she took her son to school, ‘I walked my little boy to school in the morning time and people used to grab their kids up and point at me and say, “See, that’s the lady right there. She got AIDS. She nasty.” That hurted my son.’(Buseh & Stevens, 2006, p.8)

Many of the BWLWH referred to HIV-related stigma in the community, particularly within the African community (Anderson & Doyal, 2004; Arrey et al., 2017; Ojikutu et al., 2018). One BWLWH stated that immigrants from certain African countries in the United States experienced higher levels of HIV-related stigma. She overheard comments such as, ‘Those Ugandans, they are all sick. They all have AIDS’ (Ojikutu et al., 2018, p.5). However, stigma was not exclusively from those belonging to African communities in the USA and it was perceived to be ‘a big problem’(Ojikutu et al., 2018, p.4). One BWLWH spoke about the difference she noticed, in community attitudes towards HIV, following a move from a northern to a southern state where she felt that they were, ‘backwards in terms of understanding and acceptance of people with HIV’ (Black & Miles, 2002, p.691).

Some BWLWH experienced church ‘sermons that focused negatively on people with AIDS’ and overheard fellow church goers comment, ‘that they would be afraid to sit next to someone with HIV,’(Black & Miles, 2002, p.691). One BWLWH spoke of her experience of rejection from a community member when she tried to do a good deed and offered to donate her clothes. She was met with the response, ‘well I don’t want their clothes, you know, cause you never know… they could have AIDS’ (Peltzer et al., 2016, p.232).

Professional relationships. Several BWLWH women spoke positively of their experiences with specialist HIV professionals. They referred to the specialist treatment centre as a place where they ‘felt comfortable and safe to talk about the HIV disease without fear’ and described staff as ‘family’ (Arrey et al., 2017, p.585). When given information by professionals that was unclear, one BWLWH spoke of seeking counsel from the AIDS foundation. ‘That’s when I contacted AIDS Foundation, asked them if it is a requirement that I have to tell my employer that I am HIV positive. They told me it wasn’t a requirement.’(Cannon Poindexter, 2013, p711).

Several women spoke of their interactions with different healthcare providers for issues unrelated to HIV. One woman shared that she felt her health concerns were not adequately checked and that she was dismissed due to her HIV status:

> When I got to the emergency unit, I informed them that I am HIV positive and told them what medications I take. I was sent to a mouth specialist, who refused to touch me and told me that he did not speak French (Arrey et al., 2017, p.587).

Another spoke about a trip to the dentist, when she was shouted at for not reminding them of her status. Despite it being on her electronic file, she felt that it resulted in her not receiving adequate care:

> I told her that since it was clearly stated in my medical file which she has access to, I found it unnecessary to tell her that. I left the dentist office with the opinion that I did not get the care I was supposed to have because I was still in pain days after (Arrey et al., 2017, p.587).

One spoke about general experiences of having her blood taken:

> They [healthcare professionals] act like they don’t want to touch you, especially when they are taking blood. Some of them go through the whole mask thing. I can read them. Don’t treat me like I just came out the garbage can’ (James-Borga & Frederickson, 2018, p.399).

Similarly, another woman spoke about a visit to the local clinic where she experienced the staff’s behaviour as rejecting and as if they did not ‘want to talk to [her] or touch [her] like she had ‘AIDS’ written across [her] forehead’ (Black & Miles, 2002, p.691).

One shared that her past experiences had left her feeling as though clinicians would not be able to see beyond HIV should she need critical care:

> I think I could be in a wreck and my arm would be hanging off and I'd be about to bleed to death, and all the doctors would see is someone with HIV. It's like everything is related to HIV, whether or not it really is' (Black & Miles, 2002, p.691).

Denial of care was also shared by one BWLWH:

> When I expressed my desire to have a child, my gynaecologist sent me to the psychologist. I did not understand the reason because I was not depressed and knew exactly what I was asking for. I know that in Belgium women with HIV get pregnant and have children. I would have been less worried if the doctor had given me some reasons why I could not have a child (Arrey et al., 2017, p.586).

Several women spoke about their experiences in hospital as inpatients. One BWLWH spoke about an experience she had when she was admitted with TB and how healthcare providers would not bring the food to her room, 'when the food came, they would never bring it in my room. They put it on top of the linen bin out in the hall. The tray would sit there for hours, and nobody would bring it in' (Buseh & Stevens, 2006, p.9). Similarly, another spoke about an admission for a knee operation where the nurse threw sanitary products at her. 'The nurse came in and she threw the pads at me, I felt like she felt like I was contagious' (Dale et al., 2018, p.5).

One BWLWH shared a negative interaction with a doctor, which consequently led her to question how others in the community would perceive her and caused her to withdraw:

> You feel if the doctor is going to treat you this way, and they know the medical ins and outs of HIV, what would a normal person do to you? That made me more withdrawn from people. It made me not want to disclose my status. Because if she treats me that way, how would a regular average person treat me? (Sangaramoorthy et al., 2017a, p.525).

Inability to be authentic. One BWLWH spoke about the inability to be open with family, 'I think I would feel better if I could just open up to... to my friends and they'd accept me' (Peltzer et al., 2017, p.232). Another shared a similar experience about having a 'big secret' that 'takes a toll… especially with friends' (Sangaramoorthy et al., 2017a, p.525).

Close relationships. Several women spoke about the impact that their HIV status had on their ability to form relationships. One woman spoke about how HIV had made 'it impossible … to open up to people freely and create relationships,' whilst another shared that she did not think anybody would want 'to be with someone that's positive'(Hampton & Gillum, 2022, p.1625). Another BWLWH spoke about ending an intimate relationship due to a fear of passing on HIV. 'If I can have sex with him, all the dirty things that come from me can make him very sick … I decided not to sleep with him again, but I still love him' (Rohleder & Gibson, 2006, p.34).

Those in relationships spoke about the challenges it had raised. One married BWLWH eluded that her relationship had declined and that her husband had told her that nobody would want her, which she then internalised. 'I'm married, but our relationship is like . . . now who is going to want me? I feel like I'm all used up… Ain't nobody going to want somebody like me. He even said that to me one time' (Sangaramoorthy et al., 2017b, p.1335). Other women spoke about the deception and betrayal they experienced as a consequence of their husbands' being HIV positive without their knowledge. One lady shared that her husband had given her HIV and that she 'found out when [she] was pregnant.' Similarly another shared how she only found out about her husband's HIV status when he died 'in prison and on his death certificate, it said complications due to HIV' (Sangaramoorthy et al., 2017b, pp.1335-1336). Another participant spoke about the fear of passing it onto her husband and how it contributed to the breakdown of their marriage despite his attempts to reassure her:

> When I got with my husband, I explained to him off the top what was going on and he still stayed with me … and I always had in the back of my mind … I feel like if I do this to you, I'm doing something that's not right … I think that's our biggest problem in our relationship because the way he wanted to be with me, I couldn't be with him like that. Because I felt like I was going to be killing him … I think that's a reason for my divorce. I think that's the reason –how I deal with people because I never want to feel like I'm the cause of somebody else's pain. (Hampton & Gillum, 2022, p.1625).

In contrast, another BWLWH spoke about her husband's awareness of her status and the way he would tell others when he was angry, 'I told him my status before marriage but whenever he gets mad at me, he decides to go around and tell everyone, 'Well she got a drawer with all those pills' or 'She's diseased'' (Sangaramoorthy et al., 2017b, p1336).

Many women 'witnessed discrimination or unsympathetic responses' from family members 'towards HIV-related topics or known HIV-positive people' (Anderson & Doyal, 2004, p.102). Alongside this, many experienced 'rejection' and 'eviction from their home' (Anderson & Doyal, 2004, p.102). One BWLWH recalled being told by her mother that she brought 'a lot of problems' to the family and asked her to 'move out of [her] house' and 'live with other people who are HIV' (Vantyler & Sheilds, 2015, p.909). Another lady spoke about the response of her children's father's family to her HIV status, who she lived with at the time. 'They told [her] to leave and locked [her] out of the house,' (Ojikutu et al., 2018, p.5). Similarly, another BWLWH shared that her 'family rejected' her and 'none of [her] family members would let [her] stay with them,' which resulted in her being homeless (Buseh & Stevens, 2006, p.9). This family also 'spread it all over town that [she] had AIDS' (Buseh & Stevens, 2006, p.9). One of the participants gave an implicit example of rejection where the level of stigmatisation from the family led her to enter an abusive marriage as refuge. 'This is how I ended up marrying the abuser. It was better than living in my family house'

(Sangaramoorthy et al., 2017b, p.1336). One woman added that she had a strong fear that her family 'without a doubt…would seek custody of her children' if they learned of her HIV status (Black & Miles, 2002, p.691). One BWLWH spoke about a shift in her perspective of friendship since having HIV, 'I figure if you're not my friend when I have this virus, then you wasn't my friend at all anyway' (Buseh & Stevens, 2006, p.13).

HIV knowledge and understanding

Overcautious practice. Many of the participants spoke of overcautious practices by friends, family and medical professionals. One BWLWH recalled a visit to her aunt's house and her 'washing the plates with bleach,' and giving her 'Styrofoam plates and Styrofoam cups,' when she visited (James-Borga & Frederickson, 2018, p.399). Another had a similar experience with her mother who made her use a 'plastic plate and fork' when she ate there and clean the bathroom if she used it when she visited (Sangaramoorthy et al., 2017a, p.525). One spoke about pulling away from a friendship due to feelings of discomfort from overcautious behaviours. 'I went in her bathroom. She went in there and sprayed off the toilet. That made me feel really uncomfortable. I haven't really seen her since and kept to myself' (Sangaramoorthy et al., 2017a, p.525).

Ignorance. One woman shared that, 'People (African immigrants) still lack a lot of information about HIV' (Ojikutu et al., 2018). Another spoke more broadly about 'uneducated people…that don't understand' and how 'they act like a person with HIV or AIDS ain't worth nothing' due to them being 'ignorant' (Buseh & Stevens, 2006). In contrast, another woman expressed that 'people are becoming more aware of it, but still not very comfortable with it,' (Sangaramoorthy et al., 2017a, p.523).

Unwanted disclosures of HIV status

Many of the participants spoke about their confidentiality being broken. One BWLWH spoke about the lack of confidentiality in prison which consequently impacted how she was treated. ‘They weren’t confidential in prison. Guards would talk about people who had the virus. They didn’t care who was around. I was harassed about having AIDS’ (Buseh & Stevens, 2006, p.9). Another spoke about the disregard of a friend, and the maternity unit she received care from, and feeling unable to pursue legal action due to the fear of others finding out:

> she had called the maternity unit where I had my baby to inquire about me and was told that I have HIV. My husband and I were very angry and had contemplated taking legal action against the clinic for unlawful disclosure. We did not pursue with legal action because we did not want more people to know my status,’ (Arrey et al., 2017, p.587)

One BWLWH spoke about her doctor contacting the Head of the Nursing Department, where she was studying, to inform them of her HIV-status without her consent. This led to her being pressured to disclose her HIV status despite it not being mandatory for training. ‘The doctor that I was seeing… rang the Head of Department and asked her if she was aware (of her HIV),’ (Cannon Poindexter, 2013, p.711). Another spoke about an experience in hospital where the nurse was talking loudly about her status and the fact that she needed to take her medication, ‘The guy [staff] came in and he’s like, “Well you got the virus and you need to take your meds” and he was at the door yellin’ this, everybody else can hear,’ (Dale et al., 2018, p.5).

One participant spoke about concealing her diagnosis from people that she did not trust to protect herself from judgement, ‘I won’t allow other people to downgrade me…When you disclose, you allow people to judge you,’ (Buseh & Stevens, 2006, p.12). Another stated that she ‘never told anyone’ and ‘never went back to teaching’ due to a fear of stigma following her diagnosis (Ojikutu et al., 2018, p.4). Another shared a similar perspective with selective disclosure. ‘Sometimes it’s best to keep it in the dark. It’s best for some people to know, but not everybody. Because there’s somebody out there that’s going to hate you and be cruel to you’ (Buseh & Stevens, 2006, p.12). Strategic disclosure for protection extended to family and was ‘a way to protect loved ones from bad news’ (Anderson & Doyal, 2004, p.10). This was echoed by other BWLWH who concealed their diagnosis to ensure their children did not carry their ‘shame,’ or become ‘the brunt of talk,’ and ‘harassment’ (Black & Miles, 2002, p.693). Many of the women spoke about not disclosing their HIV status to their children due to them either being ‘too young,’ ‘unable to cope’ and/or a fear that they may ‘inadvertently reveal their diagnosis to others’ (Anderson & Doyal, 2004, p.102; Black & Miles, 2002, p.693).

Treatment

Seeking treatment and adherence. Many of the BWLWH spoke about the impact that HIV and HIV-related stigma had on their willingness to seek treatment and their adherence. One spoke about the name of the clinic, and not being open to engaging in treatment if the name included, ‘“HIV,” “AIDS” or “infectious disease clinic”’(Mcdoom et al., 2015, p.97). In addition to this they expressed that a clinic located in an area separate to other hospital facilities was stigmatising:

> I don’t like how [name of hospital] isolates the infectious disease clinic away from every-f******-body else, like we’re not human. I find that very, very offensive. I don’t like how they separate. That really hurts my feelings. I already struggle on a daily basis, having to hide the fact that I’m HIV-positive (Mcdoom et al., 2015, p.97).

Another described travelling to a pharmacy far away from her home to avoid being identified as HIV positive. ‘There is a pharmacy close to where I live but I avoid going there to buy my medications because I don’t want to be identified as having HIV. I prefer to buy from another pharmacy far from where I live’ (Arrey et al., 2017, p.588).

Advances in medication. One researcher made the observation that ‘advances in treatment helped diminish feelings of internalised stigma and increased women’s sense of autonomy’ (Sangaramoorthy et al., 2017b, p. 1337). Whereas a BWLWH implied that stigma continued despite advances in treatment. ‘No matter how much we progress on the medical side, it’s still dinosaur age as far as just the human part’ (Sangaramoorthy et al., 2017a, p.523).

Aging

Some participants described aging as a protective factor against HIV-related stigma ‘being young, that’s a stigma in itself. Thank God I was older…Imagine that. The trauma, the mental, and the stigma. Your friends knowing. They don’t know how to deal with that’ (Sangaramoorthy et al., 2017b, p.133). Others described increased resilience and focus on health with age

> I think the thing with us older girls – or men – it’s more or less we’re on track about feeling better. We want to be better. We want to do the right thing. We’re not going to be dumb and stupid! Do you want to be in a casket? That’s the reality of it’ (Sangaramoorthy et al., 2017b, p.1337).

Discussion

Overview of findings

This review aimed to answer the following: What are BWLWH’s experiences of HIV-related stigma? And what is the impact of the HIV-related stigma on their lives? Overall, from the reviewer’s perspective, there was a consensus that HIV-related stigma negatively impacted almost every facet of life and that it could not be avoided. Many of the BWLWH spoke about the impact of this and needing to lie and hide their status due to anticipated stigma, which had negative consequences for both their mental and physical health. Depression, suicidal ideation and physical manifestations of stress were all touched upon (Peltzer et al., 2016; Sangaramoorthy et al., 2017b). The level of HIV- related stigma experienced by the BWLWH varied. However, the specific factors, and experiences for each individual, that contributed to this variation cannot be specifically commented on in this review as it was reliant on the information provided in the original studies. The researcher of this review has therefore commented on several factors which influenced BWLWH's experience of HIV-related stigma.

Intersectionality was identified as a key factor in the way that HIV-related stigma was experienced. Clear reference was made to the different assumptions and stereotypes held by others in the community towards BWLWH compared to Caucasian women (Sangaramoorthy et al., 2017b). For BWLWH the conversation quickly shifted to how HIV was contracted and the different immoral behaviours that they may have engaged in to acquire the virus, which led to BWLWH not feeling seen (Sangaramoorthy et al., 2017a). BWLWH referred to past choices and traumas as wrong doings and as a rationale for contracting HIV (Buseh & Stevens, 2006). BWLWH utilised language with criminal connotations to explain their experience of living with HIV, which implied a sense of wrong doing and judgement from wider society (Buseh & Stevens, 2006; Rohleder & Gibson, 2006). These societal attitudes were also reflected in the negative remarks made in church sermons and during social church chatter (Black & Miles, 2002). There were also examples of HIV-related stigma in the wider community where BWLWH overheard children being told by their parents to stay away from them and having goodwill gestures rejected due to a fear that their charity items may pass on HIV (Buseh & Stevens, 2006; Peltzer et al., 2016). It seemed that HIV-related stigma was interpreted by some BWLWH as ignorance. Whereas an opposing view was that people had an increased awareness but remained uncomfortable with HIV (Sangaramoorthy et al., 2017a).

Family rejection and eviction from the family home was a common experience for BWLWH (Anderson & Doyal, 2004; Vantyler & Sheilds, 2015). Many were viewed as a problem by family and told to live with others who shared a similar lifestyle and engaged in immoral behaviours (Vantyler & Sheilds, 2015). Although not directly stated, family may have experienced stigma by association, particularly if their local community held strong religious beliefs or beliefs around witchcraft. This further reflected the lack of understanding around HIV transmission and the stereotypical image of promiscuity and abuse of recreational drugs associated with HIV. Those that were not evicted experienced challenging environments with some leaving the family home on their own accord as a form of self-preservation (Sangaramoorthy et al., 2017b). Those who maintained contact with family witnessed members engaging in extreme cleaning practices and overcautious behaviours to reduce transmission (Sangaramoorthy et al., 2017a). In doing so, this demonstrated a lack of knowledge around HIV and/or ignorance which made the BWLWH extremely uncomfortable.

BWLWH in relationships referenced experiences with controlling partners who told others about their HIV status, or belittled them when angered, as a mechanism of control (Sangaramoorthy et al., 2017b). Those who described healthy HIV-serodiscordant relationships referenced the eventual breakdown of the relationship due to a fear of passing HIV onto their partner (Hampton & Gillum, 2022; Rohleder & Gibson, 2006). Many of the BWLWH felt that they had been deceived by their partners as they had concealed their HIV-status from them. Consequently, many had contracted HIV from their partner/spouse unknowingly and found out only from death certificates or through routine testing for health concerns unrelated to HIV (Sangaramoorthy et al., 2017b). Those who were not in relationships described a reduced desire to have a romantic relationship, due to the burden of their HIV status and the belief that no prospective partner would want to be with someone living with HIV (Rohleder & Gibson, 2006).

Healthcare professionals had a profound impact on BWLWH and their experience of HIV-related stigma. Stigmatising experiences included overcautious practices, inadequate care for concerns unrelated to HIV, and denial of care with particular reference to maternity and fertility (Arrey et al., 2017; Buseh & Stevens, 2006). There was a sense that healthcare staff, particularly those in non-specialist HIV services, could not see beyond the diagnosis of HIV (Black & Miles, 2002; James-Borga & Frederickson, 2018). BWLWH were seen to represent nothing but HIV in these situations and there was a felt sense that the human touch from clinicians was lost. This left some of the BWLWH with doubts about how those in the wider community may interpret their HIV- status. Particularly, as medical and healthcare staff have knowledge of HIV and are regarded as the carers of society yet they treated BWLWH as subhuman (Sangaramoorthy et al., 2017a). The knock-on effect of this was an increased anticipation of HIV-related stigma. Specialist HIV medical and support agency staff were praised by the majority, referred to as family and seen as a trusted resource (Arrey et al., 2017; Cannon Poindexter, 2013).

In employment and education, and within the healthcare system, the confidentiality of BWLWH was not upheld. Both healthcare provider and placement providers did not respect confidentiality and ignored procedural requirements around non-disclosure (Cannon Poindexter, 2013). Intimidation tactics were used on occasion to force HIV-disclosure which resulted in the dropout of BWLWH from university courses (Cannon Poindexter, 2013).

There were mixed views on the relationship between medical advances and HIV-related stigma. There was a sense that medical advances reduced stigma, however, another expressed that the understanding and caring side for those with HIV was still far behind

(Sangaramoorthy et al., 2017b, 2017a). This was further reflected by BWLWH who expressed the need to travel to pharmacies that were not located in their local area to avoid being identified as HIV positive in their own community (Arrey et al., 2017).

As a form of protection from HIV-related stigma, many did not discuss their diagnosis with others (Buseh & Stevens, 2006; Ojikutu et al., 2018). Strategic disclosure was a way of protecting the family from bad news and stigma-by-association (Anderson & Doyal, 2004; Black & Miles, 2002; Buseh & Stevens, 2006). However, a drawback of this was an inability to be open with friends and family, which took an emotional toll (Peltzer et al., 2016; Sangaramoorthy et al., 2017a).

Although not all of the above themes, and experiences, are unique to BWLWH they were included as these adversities remain an integral part of life, influencing their identity and shaping their experience of HIV-related stigma (Pryor and Reeder, 2011). BWLWH experience the cumulative effects of intersectionality which makes them one of the most stigmatised groups with HIV (Loutfy et al., 2012).

Strengths and limitations

This review aimed to, and provided, a synthesis of rich data on BWLWH and their experience of HIV-related stigma. In utilising qualitative papers, the narratives of BWLWH's and their experience of HIV-related stigma were captured. The majority of the studies in this review, 11-of-16, were undertaken in the United States and therefore voices of BWLWH living in the U.S may be more prominent. This may be reflective of greater attention and funding in the U.S for HIV related research compared to countries of lower economic status. Although this review aimed to capture of the experience of BWLWH it was noted that very few of the studies included Black Caribbean women. In the studies that Black Caribbean women were included, their experience was not distinguished from other Black ethnicities. As a consequence, potentially rich information was not captured on the role that differing cultures may have on the experience of HIV-related stigma. It was also noted that other areas of identity, such as socioeconomic status, sexual orientation and disability, received minimal attention or were overlooked. The above points are particularly relevant given the impact of intersectionality, and societal influence, on the experience of HIV-related stigma and therefore caution must be applied when interpreting the findings (Pryor & Reeder, 2011).

The definition and distinction of stigma, discrimination and prejudice is a contentious issue. It is acknowledged that the concept of stigma can locate the problem within the individual, with many past anti-stigma campaigns having little to no impact; whilst prejudice focuses on societal conceptions (Cooke, 2013). However, due to the intention of this review and the epistemological position it was necessary to focus on HIV- related stigma and discrimination. Given the challenges presented by the definitions, the implications of this review consider how BWLWH's experiences of HIV-stigma can guide societal level change. In doing so, challenging HIV prejudices in society, clinical practice and future research to support the elevation of the HIV-related stigma experienced by BWLWH.

Implications for clinical practice

Considering the impact of implicit and explicit HIV-related stigma from healthcare providers, it is paramount that HIV competency is improved and HIV prejudices challenged. This could include simple changes such as the renaming of HIV-specialist services to ensure that they do not include terms such as HIV or infectious diseases. The reviewing of existing staff training and/or the development of new programmes with BWLWH and the offer of reflective spaces to enable emotional processing. In doing so, upskilling staff and providing insight into the impact of HIV-stigmatising responses. It is also recommended that training programmes are rolled out to all clinical staff and patient-facing administrative roles, not just exclusively to those working in specialist HIV services. Additionally, it is also important for healthcare staff to acknowledge and support BWLWH with HIV-related stigma. This can be done through the acknowledgement of distress, distrust and maladaptive behavioural changes that it can cause to minimise the impact it has on their daily lives.

Implications for future research

Improving community knowledge of HIV and HIV-related stigma could assist in improving the quality of life of those BWLWH, not to mention reduction of transmission. Although there are existing programmes in place, misinformation persists. A review of the current gaps of HIV knowledge within different communities, the content of existing programmes and the incorporation of missing information may help to improve communities' knowledge and therefore their interactions and acceptance of BWLWH. Essentially, this is a process that would need to be completed on a national and community level to ensure the needs of individuals and the local communities are met. The above recommendations should be prioritised, particularly, in countries and communities with low budgets for education programmes and high rates of HIV prevalence. Additionally, further research may be helpful in the identification of support services from the perspective of BWLWH. In doing so, this could support the development of new services or holistic approaches, to aid and empower BWLWH to navigate their experience of HIV and HIV-related stigma.

Commentary on critical realism and reflexivity

Critical realism enabled the focus of the review to be BWLWH's experience of HIV-related stigma and the impact it had on their lives from their perspective. However, as an epistemological position it has received criticism due the researcher's perspective taking precedence, particularly, in relation to the recommended implications (Fletcher, 2017). It is worth reiterating that researcher's interpretations are fallible (Bhaskar, 2014) and in this case come from the perspective of a white dual national female. In reviewing the papers, I acknowledge that I am passionate about equality and positive health outcomes for Black women. A conscious effort was made to ensure that the themes arose directly from the narratives of BWLWH. However, due to this passion and previously academic knowledge, I acknowledge that I may have focused on challenging outcomes, and experiences, rather than stories of strength and resilience. This is due to my perspective that the current support, available for BWLWH and their experience of HIV-related stigma, remains inadequate.

Conclusions

The findings of this review of the literature clearly demonstrate that HIV-related stigma impacted every facet of life for BWLWH and provided support for Pryor and Reeder's theory of stigma (2011). The review provided helpful insight into the different manifestations of HIV-related stigma experienced by BWLWH. The implications focused on the identification of gaps in existing HIV knowledge for different populations. In doing so, enabling the development of educational programmes to tackle HIV prejudices. It is essential that BWLWH are involved in the co-production of education programmes to provide insight into their experience.

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SOCIO-DEMOGRAPHIC FACTORS AND THEIR ROLE IN THE EXPERIENCE OF LIVING WITH HIV

Section B: An Initial Examination of the Relationship of Demographic and Clinical Factors on the Outcome of HIV Cognitive Impairment in People Living with HIV

Word Count: 6,480 (422)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2024

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Since the introduction of antiretroviral treatment, the life expectancy and quality of life of people living with HIV (PLWH) has improved. Despite this, PLWH still continue to develop health complications and cognitive impairment. Research into cognitive impairment for PLWH is in its infancy in terms of diagnostic frameworks, socio-demographic and clinical factors. This secondary data analyses of data from 128 PLWH at a clinic in the Southeast of England, aimed to explore the relationship between race, a medical measure of HIV severity, premorbid IQ, neuropsychological test index and cognitive impairment diagnosis for a newer diagnostic framework which moves away from a previously problematic diagnostic framework. A binary logistic regression found the neuropsychological test index to predict cognitive impairment diagnosis in PLWH. Further analyses were also completed on the other predictors and for participants with missing data. Further research with a larger sample size is required to continue to explore the complex nature of cognitive impairment for PLWH and support the development of theory.

Introduction

HIV

HIV is a viral infection which depletes the immune system. Progression of the virus leads to increased damage of the immune system and increased susceptibility to disease (Levy, 2009). Since the development of HIV antiretroviral treatment (ART), people living with HIV (PLWH) experience fewer neurological complications, improved life expectancy, and a reduced likelihood of developing HIV-associated dementia (Lezak et al., 2004; Price & Brew, 1988). Considering this, the current cohort of PLWH are the first to have access to treatment and to age with HIV. Despite this, many continue to go onto develop a mild form of cognitive decline and associated motor symptoms (Heaton et al., 2010). CD4 T-cell count is a blood test which provides insight into the degree of immune depletion due to HIV and is a means of monitoring ART efficacy (Medicine, 2010). The CD4 'nadir' T-cell counts are the lowest T-cell counts recorded, which are usually recorded prior to the initiation of ART. Lower CD4 nadir counts are associated with greater progression of HIV, risk of opportunistic disease onset, and HIV neurocognitive impairment (Buisker et al., 2015; Ellis et al., 2011). The World Health Organisation (WHO, 2005) categorised HIV disease progression into clinical stages based on the CD4 nadir count: stage 1 is a CD4 lymphocyte count of ≥500 mm^3; stage 2 is between 350 − 499/mm^3 ; stage 3 is count of 200-349/mm^3; stage 4 is <200-mm^3. Stage 4 is considered as the disease's progression to AIDS.

HIV and cognition

Brain tissue is vulnerable to the effects of HIV; it is thought to temporarily damage the glia that are responsible for the maintenance of homeostasis in the neurons, which leaves both grey and white matter at risk of damage (Gendelman et al., 1994). The longer HIV is left untreated (i.e., with appropriate healthcare / antiretroviral treatment) the greater the damage to the brain (Grinsztejn et al., 2014; Merrill & Chen,1991). There has been an abundance of research into the different patterns of cognitive decline in HIV. Prior to the development and wider access of ART for PLWH, the pattern of cognitive decline was in line with a subcortical dementia, with changes observed in cognitive, behavioural and motor function (Navia et al., 1986). The picture since the introduction of ART has been less clear, with changes also being observed in cortical regions of the brain (Heaton et al., 2004, 2011).

Classification of Cognitive Impairment in PLWH

The classification and diagnosis of cognitive impairment in HIV is a disputed area. The most-known criteria and utilised system in research is the Frascati criteria of HIV-associated neurological disorder ("HAND"), which was developed in 2007 (Antinori et al., 2007). Over recent years it has come under scrutiny due to varying prevalence rates across different populations, limited reference to comorbidities, criticisms around inappropriate use of normative data in the scoring of neuropsychological batteries, and the over-attribution of low scores on neuropsychological testing to HIV at the exclusion of alternative explanations (Nightingale et al., 2014, 2021). The prevalence rate of HAND is not reflective of the presentation in clinical settings, given that the majority diagnosed with HAND are asymptomatic and cognitively healthy (Nightingale et al., 2021). Considering these issues, there has been a movement away from the sole use of the Frascati criteria and an emphasis on a full clinical assessment, i.e., taking a full medical history, ordering medical tests, having awareness of the differential diagnosis criteria of the different sub-types of the dementias, having collateral reports (e.g., from a partner), and including informed and critical use of neuropsychological testing which acknowledges individual test properties and the presence of low scores in the general population (Alford et al., 2019). The International HIV-Cognition Working Group proposed a new diagnosis, 'HIV-associated brain injury' (HABI) and have devised a framework to distinguish it from other types of brain injury (Nightingale et al., 2023). The recommended steps required to diagnose HABI include:

- the use of RNA suppression and HIV activity pathology
- awareness that low performance on cognitive assessments should not result in a diagnosis without supporting information from a full clinical assessment
- awareness that test's false-classification rates when interpreting the findings of cognitive assessments
- that cognitive impairment should be classified as low performance in combination with cognitive symptoms and evidence of pathology in neurological investigations
- that changes in cognition, noticed by the individual or another, should be considered 'cognitive symptoms' even if they do not hinder daily functioning

Several studies aimed to identify neuropsychological profile patterns for cognitive impairment in PLWH (Dawes et al., 2008; Gomez et al., 2019; Lojek & Bornstein, 2005; Molsberry et al., 2018). These studies utilised different forms of data analysis, different test batteries, and varied with their use of inclusion and exclusion criteria. Despite this, all the studies referenced the influence of ethnicity, socioeconomic factors, gender, education level, premorbid IQ, and treatment (e.g., medication) effects on neuropsychological profiles. However, given the criticisms of the Frascati criteria and its use in research, it is unclear whether diagnosis of cognitive impairment and the influencing factors would remain stable in the application of an alternative classification framework such as Alford et al (2019) or Nightingale et al. (2023).

Factors associated with cognitive impairment in PLWH

Alford and Vera (2018) completed a comprehensive review of the research into factors that leave PLWH more susceptible to the development of cognitive decline. As previously identified, it confirmed the multidimensional nature of cognitive decline in HIV and the influence of ART, viral load, cognitive reserve and individual differences. As with other research in cognitive decline, cognitive reserve (i.e., a combination of intelligence and education) is believed to be a protective factor in the development of cognitive decline in HIV (Foley et al., 2012). The review touched upon individual differences but did not comment on certain aspects of identity such as gender and ethnicity. Research into the prevalence of cognitive decline in PLWH found higher levels of diagnosis for females from less developed countries and with lower levels of education (Wei et al., 2020). The research recommended the use of a standardised neuropsychology battery in the assessment of cognitive decline for PLWH as they found it to impact the likelihood of a cognitive impairment diagnosis.

The research into the influence of ethnicity on cognitive impairment in HIV remains a complex picture. PLWH from the global majority were found to have an increased likelihood of being diagnosed with a cognitive impairment due to the years of education, and the associated norms on cognitive assessments, not factoring in 'quality of education' (Ryan et al., 2005). The recommendation was made to utilise reading ability rather than years of education, as an indicator of educational attainment. A study that looked at women living with HIV found that ethnicity continued to be an influencing factor after adjusting for education quality (Manly et al., 2011) However, it was unclear if this was due to other aspects of disadvantage. Although race and ethnicity may not directly influence cognitive impairment, it may be that individuals from the global majority share similar experiences of oppression, discrimination, and psychological distress, which in turn may increase their likelihood of receiving a diagnosis of cognitive impairment. Experiences of racism and discrimination are well known to negatively impact health outcomes (Hackett et al., 2020; Mays et al., 2007; Phelan & Link, 2015). Those from the global majority, born outside of the UK, experience further disadvantage with an increased likelihood of living in overcrowded dwellings and higher levels of unemployment, further adding to psychological stress (Crawley, 2010).

PLWH have one of the most stigmatised health conditions (Pryor & Reeder, 2011). HIV-related stigma is associated with poorer health outcomes, higher levels of depression, lower levels of social support, reduced adherence to treatment regimes, and a reduced likelihood of engagement with health and social services (Rueda et al., 2016). For members of the global majority, HIV and HIV-related stigma add to the burden of an already discriminated and stigmatised identity. This is particularly evident in the experience of black women living with HIV and their experience of HIV-related stigma which was discussed in section A.

Models of dementia and their application in cognitive impairment in PLWH

Although the majority of PLWH will not develop HIV-associated dementia, cognitive impairment in PLWH can still be understood with existing theories in the field of dementia.

Biomedical model

The biomedical model assumes a simple relationship between biochemical and neurological changes in the brain and the onset and progression of dementia (Bond, 1992). Although the model has led to some advances in medication, to delay the progression of specific types of dementia such as Alzheimer’s, there remains no cure (Atri, 2019). The biomedical model has received criticism for being reductionist and overlooking the role of psychosocial factors (Collins & Fletcher, 2024). Given the current literature on cognitive impairment in PLWH, and the criticisms of the Frascati criteria, biomedical models remain insufficient in the explanation of cognitive impairment in PLWH.

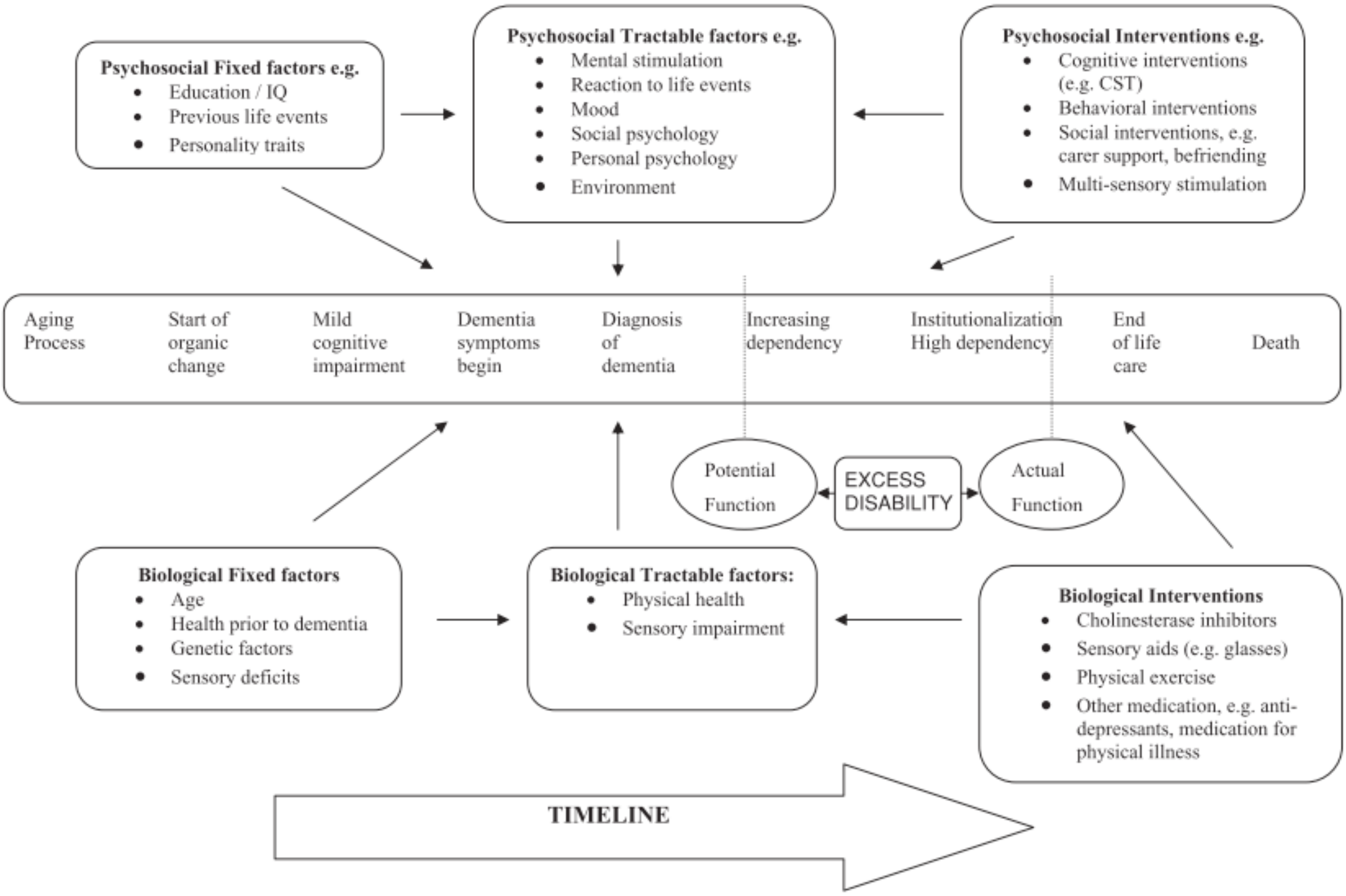
Biopsychosocial model

Considering the criticisms of the biomedical model, and the movement to integrate aspects of psychology and sociology into psychiatry, Kitwood proposed a biopsychosocial model of cognitive impairment (Engel, 1977; Kitwood, 1990). The model incorporated psychosocial factors and considered their interaction with neurology, in the onset and progression of cognitive impairment. Central to Kitwood's theory is the negative impact that 'malignant social psychology' and depersonalisation can have on the person with dementia through different social processes and interactions with their social world. Kitwood (1993) continued to advance the biopsychosocial model of dementia with the inclusion of the individual's past experiences, personality, and physical health as influencing factors. Kitwood's biopsychosocial model has been highly influential and contributed to a shift in the way individuals with dementia, and dementia care, are approached (Fazio et al., 2018). However, Kitwood's model did not incorporate the role of the 'physical environment' and 'mental stimulation' (Spector & Orrell, 2010).

In response to this, and other research in the area, an updated biopsychosocial model was developed to support clinicians in the formulation and development of personalised treatment plans (Spector & Orrell, 2010). The model's objective is to explain the trajectory of dementia and the influential psychosocial and biological processes, which consist both of fixed and changeable factors. The model can be found in Figure 1. The model is yet to be critiqued and evaluated for PWLH and cognitive impairment. However, considering the research around HIV, cognitive impairment and the complex interaction between biological and psychosocial factors, it is plausible that this model could provide a helpful structure when thinking about cognitive impairment for PLWH.

Figure 1

The biopsychosocial model of dementia (Spector & Orrell, 2010)



Measuring cognitive impairment in PLWH

Most of the research, on cognitive impairment in HIV, utilised long neuropsychology batteries to assess cognition. However, in clinical practice long neuropsychology batteries may not be feasible, given the high demand on resources and strain on healthcare systems. Considering this, shorter neuropsychology batteries tend to be favoured in clinical practice. At an HIV clinic in the Southeast of England, a time-efficient test battery was adopted (Alford et al., 2019). The battery incorporated the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS: Randolph et al., 1998) and Test of Premorbid Functioning UK version (TOPF-UK: Wechsler, 2009), amongst other measures. The RBANS takes 30 minutes to administer and assesses five domains of cognition including attention, language, visuospatial skills, immediate and delayed memory. A total score for overall cognition ability can also be calculated. The RBANS total scale index has been found to be reliable in the detection of Alzheimer's disease, mild cognitive impairment (MCI), and cognitive impairment in HIV (Costaggiu et al., 2021; Duff et al., 2008, 2010, 2023). Duff et al (2010) found the total scale score index to reliably detect cognitive impairment, whereas the findings for the separate domains were variable. These findings suggest that the RBANS is a suitable tool in the detection of cognitive impairment in PLWH given the complex nature between HIV and deferential diagnosis of cognitive impairment. The TOPF-UK can be administrated in under 10 minutes and is a valid measure of premorbid IQ and crystallised reading abilities in the presence of progressive neuropsychological conditions (Pearson, 2009). Despite this, neuropsychological assessments are well known to demonstrate acculturation (Boone et al., 2007). At present there is no research which looks at the relationship of the RBANS and TOPFUK outcomes, and cognitive impairment diagnosis in PLWH, and newer classification systems such as Alford et al (2019) and Nightingale et al (2023).

Aims and objectives

The aim of this study is to determine the relationship of socio-demographic variables, an HIV-related pathophysiology indicator, premorbid IQ estimate, neuropsychological test scores and diagnosis of cognitive impairment in PLWH. The analyses will be completed on secondary data collected by a specialist HIV memory clinic which utilised Alford et al (2019) framework to guide their diagnosis of cognitive impairment. All the factors utilised in this research are considered by the multidisciplinary team when assessing for a diagnosis of cognitive impairment in HIV. In doing so, the hope is to extrapolate potential explanations or theories for one of the first aging cohorts of PLWH, which may include race, education and access to healthcare. Additionally, it will also be the first study to assess the validity of the RBANS and TOPFUK as part of a holistic HIV memory assessment utilising Alford et al's (2019) criteria. The clinical and socio-demographic factors utilised in the study were selected based on the research in the field, which have been touched upon and the data available to the research team. The clinical factors incorporated in this study include the CD4 nadir count, the RBANS total score index and TOPF-UK score. The socio-demographic factors utilised include gender and race. In turn, this will support clinicians in the future classification of cognitive impairment for PLWH and inform personalised treatment. The project incorporates the NHS values of commitment to quality of care; everyone counts; improving lives and compassion (Department of Health, 2023).

Hypotheses

1. Those that receive a diagnosis of cognitive impairment will be more likely to be from the global majority, with a lower premorbid IQ, with lower scores on the RBANS total scale score and higher levels of damage to their immune systems (i.e., lower CD4 nadir count).

2. Those who do not receive a diagnosis of cognitive impairment will be more likely to from a white background, with a higher premorbid IQ, with higher scores on the RBANS total scale score and lower levels of damage to their immune system (i.e., higher CD4 nadir count).

Method

Design

This cross-sectional study was a secondary analyses, which analysed archival neuropsychological data and demographics from comprehensive HIV memory assessments completed by a clinical neurology and neuropsychology team at a specialist HIV clinic in the Southeast of England between June 2016 and January 2024.

Participants

Participants were aged between 29 and 76 (M=56) at the time of testing, had a diagnosis of HIV and reported concerns about their ‘memory’. They completed a neuropsychological assessment as part of a comprehensive HIV memory assessment. On receipt of the data for this secondary analysis, 40 of 128 participants had missing data and therefore were excluded from the dataset that the primary analysis was conducted. Sociodemographic information on the 88 participants utilised in the primary analysis can be found in Table 1.

Table 1

Sociodemographic of participants

	Participants			
	Male		Female	
	N	%	N	%
Total	75	85%	13	15%
Race				
Global majority	4	4.5%	8	9.1%
White	71	80.7%	5	5.7%

Ethical approval

On entering the clinic, a formal conversation was held between a member of the multidisciplinary team (MDT) and the service user to obtain consent for their anonymised data to be used for research purposes.

Ethical approval was obtained from a university board of research ethics (Ethics application code: ETH2223-0286) for the analysis of anonymised archival data.

Demographics, such as race, were kept as binomial categories in an attempt to further protect the anonymity of service users. Ethical considerations were completed in line and adhered to the guidance of the BPS code of human research ethics (Oates et al., 2021).

Power

Considering the missing data and power, the initial number of predictors was reduced to five. The data were kept at either binominal or interval (continuous) level. Fields (2024) recommended less than six predictors for samples smaller than 100 for a medium effect size.

Materials

Assessment at the clinic

The materials used as part of the wider comprehensive and neuropsychology assessment relevant to this project included:

Repeatable Battery for the Assessment of Neuropsychological Status (Randolph et al., 1998) total index score

The RBANS tests five domains of cognition including attention, visuospatial, immediate and delayed memory all of which contribute to a total index score of cognition. The RBANS total score index has demonstrated accuracy and sensitivity in the detection of cognitive impairment across different populations (Costaggiu et al., 2021; Duff et al., 2008, 2010b, 2023; Karantzoulis et al., 2013; Larson et al., 2005).

Test of Premorbid Functioning - UK version (TOPF - UK; Wechsler, 2009).

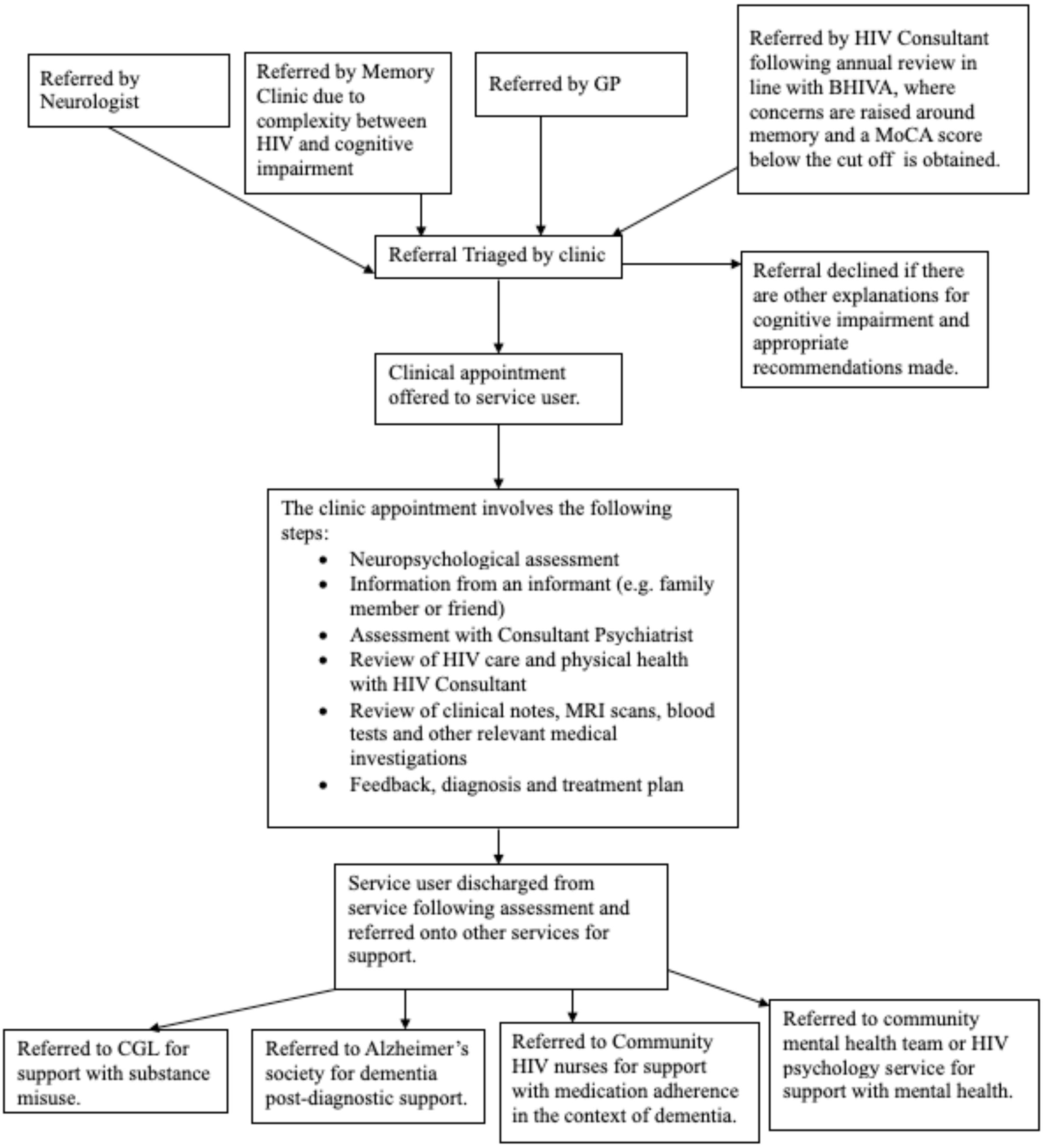
The TOPF - UK assesses crystalised reading skills and provides a valid premorbid score of IQ prior to the onset of cognitive decline (Pearsons, 2009). The TOPF-UK utilises both reading ability and years of education to provide a premorbid IQ score. In combining the two, it makes it a suitable measure of premorbid IQ in a diverse population where quality of education in English language may not be adequately accounted for by years of education.

CD4 nadir T -cell count

The CD4 nadir t-cell count blood tests provides information on the extent of damage caused to the immune system and therefore the stage of HIV disease progression prior to the initiation of antiretroviral treatment. The CD4 nadir t-cell captures the progression of HIV prior to the initiation of ART. Post- ART CD4 nadir correlates with cognitive impairment (Ellis et al., 2011).

Figure 2

A flowchart of the service users' journey



Research study

The assistant psychologist at the clinic anonymised, extracted and completed data cleaning on the relevant data from the assessments for this project. The anonymised data were then shared via encrypted NHS email with the research team at the primary researcher's university. The data were stored securely on NHS Microsoft OneDrive. The data were then analysed with SPSS.

Analysis

The independent variables/predictors utilising the following format:

- Gender at birth (binominal, female/male)
- Race (binominal, white/global majority)
- Measure of damage to immune system reflected by nadir CD4 count z-score (interval, mm^3)
- RBANS total score (interval, z-score)
- TOPF-UK percentile score (interval, z-score)

The dependent variable was diagnoses of cognitive impairment and was binary (yes/no) which was decided upon based on the critical appraisal of cognitive scores, multiple cognitive skill assessment, medico-physiological indicators, and subjective report of memory / cognitive difficulties in line with Alford et al. (2019).

Prior to running a binary logistic regression, the data were checked for multicollinearity. The VIF scores for each predictor were within acceptable range <4. Due to the amount of missing data, and the impact this had on power, a series of analyses were completed separately for each predictor and the dependent variable.

Analyses of missing data

Analyses were completed to ascertain if there was a relationship between data for the predictors and diagnoses for those with missing data. It also enabled comparisons between missing data and wider data set. An analysis was run for each predictor and the dependent variable for those with available data.

Results

A binary logistic regression was completed to investigate the relationship between race, premorbid IQ, RBANS score and nadir CD4 count and diagnosis of cognitive impairment. The dependent variable was diagnosis of cognitive impairment. The possible predictor variables were gender, race, premorbid IQ z-score, RBANS total index z-score score and CD4 nadir count z-score. All assumptions of the model were met and the Hosmer-Lemeshow goodness-of-fit was not significant (p= .954). The binary logistic regression RBANS total scale z-score was found to contribute to the model: B= -2.40, SE= .58, Wald= 0.03, p<.001, Exp (B)= .091, 95% CI [0.03, 0.29]. For every unit increase in RBANS total scale score the odds of receiving a diagnosis decrease by 90.9% (95% CI .03, .28). This result remained significant when adjusting with Bonferroni correction(p=0.01). The other three predictors, gender, premorbid IQ, and race were non-significant (p > .05). The output from the regression can be found in Table 2.

Table 2

Output for the binary logistic regression and all predictors

Predictors	B	Wald	Exp (B)	Sig.	95% CI
CD4 Nadir	.68	2.45	1.96	.12	.84, 4.58
Gender	.42	.12	1.52	.73	.15,15.7
Premorbid IQ score	.07	.03	1.08	.86	.47, 2.46
Race	-1.15	.88	.34	.35	0.03, 3.53
RBANS total score index	-2.40	17.05	.09	<.001	.03, .28

Given the reduced sample size, due to missing data, and therefore reduced power further analyses were completed for each predictor and the dependent variable of cognitive impairment diagnosis.

Gender and Diagnosis

A chi-square test of independence was performed to examine the relation between gender and diagnosis of cognitive impairment. The relation between these variables was non-significant χ^2 (1, N = 88) = 0.913, p = *0.339*). Gender was not found to increase the likelihood of diagnosis.

Race and Diagnosis

A chi-square test of independence was performed to examine the relation between race and diagnosis of cognitive impairment. The relation between these variables was non-significant χ^2 (1, N= 88) = 0.645, p = *0.422*. Race was not found to increase the likelihood of diagnosis.

Premorbid IQ and Diagnosis

A binary logistic regression was completed to investigate whether there was a relationship present between premorbid IQ and diagnosis of cognitive impairment in PLWH. The outcome of interest was diagnosis. The assumptions of the model were met and premorbid IQ in the logistic regression was found to contribute to the model: B= -.727, SE= .29, Wald= 7.72, p= 0.005, Exp (B)= .455, 95% CI [0.261, 0.793]. The probability of no diagnosis decreases by 45% with one unit change in TOPF-UK z-score. 14.4% of the diagnosis outcome can be accounted for by the predictor of premorbid IQ.

RBANS total index z-score and Diagnosis

A binary logistic regression was completed to investigate whether there was a relationship present between RBANS total index score and diagnosis of cognitive impairment in PLWH. The outcome of interest was diagnosis. The assumptions of the model were met and RBANS total score index was found to contribute to the model: B= -2.112, SE= .48, Wald= 19.377, p= 0.001, Exp (B)= .121, 95% CI [0.047, 0.310]. The probability of no diagnosis decreases by 12% with one unit change in RBANS total index Z-score. 50% of the diagnosis outcome can be accounted for by the predictor RBANS Total index. The RBANS predicted presence of diagnosis accurately in 89% and the absence of diagnosis in 61% with an overall accuracy of 81%.

CD4 nadir count and diagnosis

A Mann-Whitney U was performed to evaluate whether the outcome of diagnosis differed based on the CD4 Nadir count. There was no significant difference between the outcome of diagnosis of cognitive impairment and CD4 nadir count, U=649.5, p=0.352.

Missing data

40 participants were excluded from the dataset and the initially planned binary logistic regression due to missing data. Table 2 provides information on those excluded.

Table 3

Information on participants excluded from the main dataset due to missing data

	Male		Female	
	N	%	N	%
Total	27	68	13	32
Race				
Global majority	0	0	8	20
White	17	42.5	2	5
Data missing	10	25	3	7.5
Nadir CD4 Count				
Data missing	15	37.5	10	25
TOPF-UK				
Data missing	9	22.5	6	15
RBANS				
Data missing	6	15	0	-
Diagnosis				
No diagnosis	6	15	2	5
Diagnosis	20	50	11	27.5
Data missing	1	2.5	0	-

Gender and diagnosis

Eleven-of-13 excluded females received a diagnosis of cognitive impairment. The females from the missing data group represented 50% of the females assessed at the service and from the overall sample. The males that were excluded represented 36% of males assessed at the service and the overall sample.

A chi-square test of independence was performed to examine the relation between gender and diagnosis of cognitive impairment. The relation between these variables was non-significant χ^2 (1, $N = 40$) = 0.315, $p = 0.575$). Gender was not found to increase the likelihood of diagnosis those with incomplete data.

Race and diagnosis

Twenty-seven individuals had information for race. One of the 27 had information missing for diagnosis. Of the 26, eight were from the global majority and 100% received a diagnosis of cognitive impairment. In comparison only 67% of the 22 white individuals received a diagnosis of cognitive impairment.

Premorbid IQ and diagnosis

Twenty-five individuals had information for premorbid IQ. A Mann-Whitney U test was performed to evaluate whether premorbid IQ differed for cognitive impairment diagnosis. The results indicated that there was no significant difference in premorbid IQ score between those who did and did not receive a diagnosis, U=40.0, p=0.28. Nineteen had a diagnosis with a mean z-score of -0.11 and a range of -1.86 to 2.04. Six did not receive a diagnosis with a mean z-score of 0.35 with a range of -0.64 to 1.63.

RBANS total index z-score and diagnosis

Thirty-four individuals had information on RBANS total index score but one had information missing for diagnosis. A Mann-Whitney U test was performed to evaluate whether RBANS total index score differed cognitive impairment diagnosis. The results indicated that those who received no diagnosis had significantly higher RBANS total scale scores compared to those who received a diagnosis, U= 11.5, p<.001.

Twenty-five received a diagnosis of cognitive impairment and had a mean z-score of -0.32 with a range of -0.67 to 2.82. Eight did not receive a diagnosis and had a mean z-score of 1.08 with a range of -0.02 to 2.86.

CD4 nadir count and diagnosis

Fourteen individuals had information on nadir CD4 count and diagnosis. Thirteen-of-14 received a diagnosis and had a mean CD4 nadir count z-score of 0.80 with a range of -1.31 to 1.72. Only one person did not receive a diagnosis of cognitive impairment therefore it was not possible to calculate the mean, range or run further statistical analysis.

Discussion

The study is one of the first to explore the relationship between demographic and clinical factors and the diagnosis of cognitive impairment for the first cohort of aging PLWH, that utilises Alford et al's (2019) diagnostic framework, which moves away from the Frascati criteria. From the overall analysis, the RBANS total index score was the only predictor found to significantly influence diagnosis. Post-hoc tests of the separate independent variables and the dependent variable of cognitive impairment were run for the whole dataset and for those with incomplete data.

The RBANS overall index score was found to influence the outcome of diagnosis of cognitive impairment for PLWH. This supports the research that suggests that the RBANS is sensitive in the early detection of cognitive impairment in HIV (Costaggiu et al., 2021). However, as with most of the research in the field, Costagiu et al. (2021) utilised the Frascati criteria to guide diagnosis of cognitive impairment. The Frascati criteria is not representative of the cohort of PLWH that presents to memory services, as a large number of those meeting the diagnostic criteria do not experience cognitive impairment or exhibit difficulties with activities of daily living (Nightingale et al., 2021). Additionally, the study completed by Nightingale et al. (2021) excluded those with psychiatric co-morbidities. Although the intention of this exclusion was clear, in terms of its confounding impact on cognitive impairment, the results may not be representative of the PLWH that present to memory services as many experience several co-morbidities. Therefore, this study acts as an extension of these findings, demonstrating the RBANS sensitivity for cognitive impairment in HIV for a clinical population experiencing cognitive difficulties. Considering this, this study supports the use of the RBANS total score, as part of a comprehensive HIV memory assessment, in the detection of cognitive impairment PLWH.

Although the TOPF-UK was not significant in the overall analysis, the separate analysis of the scores and diagnosis outcome suggested that the TOPF-UK may relate to diagnosis. This supports existing research in the field of cognitive decline and HIV, which concludes that high premorbid IQ is protective against cognitive impairment (Foley et al., 2012). For both, the whole data set and those with incomplete data, no patterns were observed between race and diagnosis. This finding supports previous research that stated that the use of appropriate norms and a measure that incorporated education quality, such as the TOPF-UK used in this study, would reduce the likelihood of race influencing a cognitive impairment diagnosis (Ryan et al., 2005). However, these findings contradict other research in the field which suggest that race and ethnicity continue to be influential after controlling for education quality (Manly et al., 2011). However, the sample size of this current study may not have been not adequate to detect this effect.

The CD4 nadir count was not found to influence the outcome of diagnosis for the post-hoc comparisons of the full dataset and the missing data, which contradicts existing research (Buisker et al., 2015; Ellis et al., 2011). This finding supports the notion that the biomedical model is insufficient in the explanation of cognitive impairment for PLWH (Collins & Fletcher, 2024). However, this must be interpreted tentatively given the small sample size and the large range of CD4 nadir values amongst the sample.

In relation to biopsychosocial models of cognitive impairment this study partially supports the role of education and premorbid IQ in the development of cognitive impairment for PLWH (Spector & Orrell, 2010). The RBANS total index score indicates that changes in cognition, due to HIV's deleterious neuropathological effects, are reflective of the global integration of segregated brain structures and functions (Park & Firston, 2013), all of which are known to be impacted and shaped by factors such as disease including HIV, access to education and earlier life experiences of deprivation, trauma, abuse and neglect (Halpin et al., 2002; Kitwood, 1993). Although this study cannot comment further on other aspects, as it was limited by the number of variables, the findings are promising as they suggest that there are parallels present between the biopsychosocial factors that contribute to the development of dementia and cognitive impairment in PLWH. Therefore, this study can contribute to the ever-growing pool of research to support the understanding of the brain, its functions and the impact of HIV on cognition.

Strengths

This study is one of the first to complete data analysis on data from PLWH for a clinic utilising a diagnostic system centred around the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013), which moves away from the Frascati criteria and towards HABI (Nightingale et al., 2023).

It is also one of the first studies that look at the use of the RBANS total index score and its sensitivity in the detection of cognitive impairment for PLWH. This study found the RBANS total index to accurately detect the presence of cognitive impairment in 89%. Neuropsychology measures that assess general knowledge, vocabulary and comprehension have been known to be susceptible to acculturation (Tan, Burgess & Green, 2021). Despite this, this research did not find a relationship between race and diagnosis. Potentially demonstrating that the use of a formal framework, that takes into consideration a range of clinical and demographic factors, reduces the impact of acculturation on the outcome of diagnosis.

The sample of this study included a mixture of men and women living with HIV. Some of the past research in HIV and cognitive decline has utilised solely male samples therefore drawing conclusions, which may not be appropriate to generalise to females (Molsberry et al., 2018). The sample was also reflective of the population of PLWH who access services, including those with co-morbidities such as substance misuse and mental health difficulties. Although these factors were not commented on directly, these individuals have been frequently excluded from research in the field of HIV and cognitive impairment. Post-hoc tests were also completed on missing data, that were excluded from the main analysis. The missing data made up a large portion of women and members from the global majority. In doing so, providing insights on women and those from the global majority which would have otherwise been excluded.

Limitations

The original sample size of 128 was adequate in terms of power and effect size for the selected number of predictors. However, due to missing data the number of predictors were reduced through the collapsing of categories and the entire removal of certain predictors. The project initially set out to include education level and birthplace, but the remaining predictors were prioritised based on the existing research in the field. The initial dataset for females was small and further reduced upon removal of those with missing data. Similarly, this was the case for those from a global majority background. An effort was made to not exclude these individuals from the analyses. In doing so, some of post-hoc findings, on the missing data, were presented as percentages to enable the reader to make comparisons as the data did not meet the assumptions of parametric and non-parametric testing. Therefore, caution must be taken when drawing conclusions from this data as the percentages may be due to chance rather than a significant effect.

Commentary from the service provided insight into the high levels of missed appointments amongst women from the global majority, therefore suggesting that the sample and population supported by the HIV memory clinic may not be reflective of those from global majority groups with HIV. As suggested by past research referenced in section A, HIV related stigma is prominent within global majority communities and can significantly influence engagement with services for a variety of reasons. To maintain confidentiality and the anonymity of the participants, the study was unable to utilise specific ethnic group classifications. In doing so, any potentials differences between different ethnicities were not captured.

The RBANS demonstrated that it has a reduced accuracy in the detection of no diagnosis compared to the detection of cognitive impairment diagnosis. This suggests that the RBANS has issues with false positive results in the detection of cognitive impairment in PLWH. Although this point was considered in the development of the diagnostic framework used by the clinic and the HABI criteria, it is unclear how much weighting neuropsychological assessments such as the RBANS have on the overall diagnosis and how open the frameworks are to the interpretation of different clinicians (Alford et al., 2019; Nightingale et al., 2023). This may be particularly poignant when assessing members of the global majority due to the added issue of acculturation in neuropsychological testing.

The dependent variable of diagnosis was collapsed down from an ordinal variable (i.e., mild, major, and none), which was in line with the DSM-V criteria for cognitive impairment to a binary outcome (i.e., diagnosis/no diagnosis). Due to this, information on the distinction between mild and major impairment was lost and further conclusions on the cause of cognitive impairment could not be drawn. It was therefore not possible to comment on the differences in the data between the development of organic changes, such as dementia, and functional problems such as low mood.

The initial plan was to run a focus group with service users and experts by experience, on completion of the project, to discuss the findings and the writing style of the report. The aim of this was to ensure that the findings, and final report, were accessible to those without specialist knowledge. However, due to the time constraints of the doctorate it was not possible to facilitate a focus group and therefore the voices of experts by experience were not captured in relation to this report.

Clinical Implications

This study provides supports for continued use of the RBANS as part of Alford et al's (2019) diagnostic framework in the diagnosis of cognitive impairment in HIV as a move away from the Frascati criteria. Considering the small number of females from global majority backgrounds in the sample and the commentary from the service that certain ethnic groups are less likely to attend appointments, it is essential to identify the different levels of healthcare provision that service users are lost at prior to an HIV memory assessment. Alongside the identification of reasons for missed appointments, it would be beneficial to compare the numbers of HIV diagnosis in the local community compared to the number of referrals to the HIV memory service. This would enable the identification of any discrepancies and enable service development. It is essential to ensure that PLWH access services for cognitive impairment due to the negative consequences that cognitive impairment can have on quality of life and the maintenance of HIV treatment plans. Engagement and continued outreach with different community groups, primary care services and tertiary services who offer support to PLWH may also be beneficial in the identification of nonattendance and any potential issues with referral pathways.

Recommendations for Future Research

More research is needed in HIV and cognitive impairment, particularly, in relation to the new diagnostic framework proposed by Nightingale et al. (2023) and certain demographic and clinical features. An extension of this study with a larger sample and additional predictors would support further conclusions around the influence of demographic and clinical factors on cognitive impairment in HIV. For example, factors such as birthplace and specific ethnicity categories, may give insight to aspects of adversity and stress which may contribute to an increased likelihood of cognitive impairment for PLWH. This research provides partial support for the application of the biopsychosocial model of dementia (Spector & Orrell, 2010). To establish whether the theory can explain cognitive impairment for PLWH, it is recommended that the relationship between the other factors in the model and diagnosis of cognitive impairment are researched (Spector & Orrell, 2010). Additionally, it is advised that research into the service user experience of contact with general, HIV, and HIV memory health services is undertaken. This may include factors that may contribute to disengagement and non-attendance of appointments. In the case of HIV-stigma the identification of specific issues relevant to the local community may be helpful to support the further development of local initiatives.

Conclusions

The intention of this research was to contribute to the knowledge on cognitive impairment for PLWH and help to ascertain the different factors that contribute to a diagnosis of cognitive impairment. The overall analysis did not find premorbid IQ, race, or CD4 nadir counts to influence the outcome of diagnosis. However, it found the RBANS total index score was sensitive in the detection of cognitive impairment within a diagnostic framework that moved away from the Frascati criteria. This study contributes to an area of research that is still in its infancy, which requires further research efforts to contribute to theory and the development of treatments for PLWH and cognitive impairment. In the future it would be helpful to repeat this study with a larger sample and greater number of predictors to help disentangle the different influencing factors on cognitive impairment in HIV.

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Section C

Appendix 1

Examples of theme and subtheme quotes

Theme	Subtheme	Quote
Aging		‘Being young, that’s a stigma in itself. Thank God I was older. Fifteen, 16, 17, they’ll have HIV. Imagine that. The trauma, the mental, and the stigma. Your friends knowing. They don’t know how to deal with that’. (Sangaramoorthy, et al.,, 2017b, p.1333) ‘Age was also described as contributing to stigmatisation, particularly due to heightened feelings of defenceless and helplessness’ (Sangaramoorthy, et al., 2017b, p.1334) ‘I think the thing with us older girls – or men – it’s more or less we’re on track about feeling better. We want to be better. We want to do the right thing. We’re not going to be dumb and stupid! Do you want to be in a casket? That’s the reality of it’ (Sangaramoorthy et al., 2017b, p.1337)
Discrimination and intersectionality		When it comes to Black women, it’s just a part of what we go through. It [HIV] adds to the burdens we already have. It’s just part of a Black woman’s struggle. Being a woman there are cultural issues within your family. It adds more to the burdens (Sangaramoorthy et al., 2017a, p.524).
Distress	Emotional and psychological distress	I didn’t want to be here anymore because the stigma that comes … you know everybody’s going to be looking and pointing and I’m feeling like everybody’s looking at me’ (Peltzer et al., 2017, p.232) ‘It was stressful. I didn’t realise how stressed out I was. I would wake up in the middle of the night with charlie horses. I must have really internalised a lot of

		stress'(Sangaramoorthy et al., 2017b, p.1337) 'The first thing you ask is, "How'd you get it? What did you do?" . and I think a lot of the depression comes from knowing what to expect . just the thought of the rejection is what a lot . brings on a lot of the depression.' (Peltzer et al., 2017, p.232)
	HIV as punishment	'I feel like since my childhood, I have done nothing positive in life. First, I was molested by my stepfather. Then, I grew up wild, waking up in strange men's rooms. Maybe this HIV stuff is what I deserve,' (Buseh & Stevens, 2006, p.8) 'You ain't no better than a person that's on death row when you got this disease' (Buseh & Stevens, 2006, p.8)
HIV Knowledge and understanding	Overcautious practice	'she was washing the plates with bleach and ….every time we come here she'll give me Styrofoam plates and Styrofoam cups. Everybody else got glass and I got Styrofoam.' (James-Borga & Frederickson, 2018, p.399). 'When my mother knew I was positive, when I go to her house, if I used the bathroom I had to clean it. If I ate, I had to use a plastic plate and a fork.' (Sangaramoorthy et al., 2017a, p.525). 'One time I went to my girlfriend's house when I first told her. I went in her bathroom. She went in there and sprayed off the toilet. That made me feel really uncomfortable. I haven't really seen her since and kept to myself.' (Sangaramoorthy et al., 2017a, p.525)
	Ignorance	People (African immigrants) still lack a lot of information about HIV' (Ojikutu et al., 2018, p.5) 'There's certain people that are uneducated. If they are afraid of me, fine, I

		won't come around. They're uneducated about HIV, okay. I'm educated because I have it. So, either they want to be educated, or they want to stay in that dumbfounded way.' (Buseh & Stevens, 2006, p.12) 'People are becoming more aware of it, but still not very comfortable with it,' (Sangaramoorthy et al., 2017a, p.523)
Relationships	Close relationships	'it impossible … to open up to people freely and create relationships,' (Hampton & Gillum, 2022). 'I would never be in a relationship where someone will be accepting of it. I don't think anyone wants to be with someone that's positive unless they've been around somebody else that was positive, and they know that certain things can and cannot happen. But otherwise… they don't want it. Nobody wants to be stuck taking a pill,'(Hampton & Gillum, 2022, p.1625). 'I'm married, but our relationship is like . . . now who is going to want me? I feel like I'm all used up… Ain't nobody going to want somebody like me. He even said that to me one time,' (Sangaramoorthy et al., 2017b, p.1335).
	Inability to be authentic	'it impossible … to open up to people freely and create relationships,' (Hampton & Gillum, 2022, p.1625). 'I think I would feel better if I could just open up to... to my friends and they'd accept me,' (Peltzer et al., 2017, p.23). 'takes a toll… especially with friends,' (Sangaramoorthy et al., 2017a, p.525).
	Community interactions	'I walked my little boy to school in the morning time and people used to grab their kids up and point at me and say, "See, that's the lady right there. She got AIDS. She nasty." That hurted my son.'(Buseh & Stevens, 2006, p.8)

		‘Those Ugandans, they are all sick. They all have AIDS’ (Ojikutu et al., 2018, p.5)
	Professional relationships	‘Most of the participants from the AIDS Reference Centre (ARC) described it as the only place where they ‘felt comfortable and safe to talk about the HIV disease without fear’. (Arrey et al., 2017, p.585) ‘A majority of the participants said the doctors and nurses at the ARC were ‘like family’ and strongly attributed their resilience to HIV to the support and empathy they obtained from health care professionals’ (Arrey et al., 2017, p.585) You feel if the doctor is going to treat you this way, and they know the medical ins and outs of HIV, what would a normal person do to you? That made me more withdrawn from people. It made me not want to disclose my status. Because if she treats me that way, how would a regular average person treat me? (Sangaramoorthy et al., 2017a, p.525).
Treatment	Advances in medication	‘Advances in treatment also helped diminish feelings of internalised stigma and increased women’s sense of autonomy’ (Sangaramoorthy et al., 2017b, p.1337) ‘No matter how much we progress on the medical side, it’s still dinosaur age as far as just the human part’(Sangaramoorthy et al., 2017a, p.523)
	Seeking treatment and adherence	‘There is a pharmacy close to where I live but I avoid going there to buy my medications because I don’t want to be identified as having HIV. I prefer to buy from another pharmacy far from where I live.’(Arrey et al., 2017, p.588) I don’t like how [name of hospital] isolates the infectious disease clinic away from every-f******-body else, like we’re not human. I find that very, very offensive. I don’t like how they separate. That really hurts my feelings. I already struggle on a daily basis, having to hide the fact that I’m HIV-positive(Mcdoom et al., 2015, p.97).

		‘They specifically described being reluctant to receive medical care at clinics with the terms “HIV,” “AIDS,” or “infectious disease clinic” in their names. In addition to clinic names, other women noted that the location of a clinic could also make them easily identifiable as HIV-positive.’ (Mcdoom et al., 2015, p.97)
Unwanted disclosure of HIV status		she had called the maternity unit where I had my baby to inquire about me and was told that I have HIV. My husband and I were very angry and had contemplated taking legal action against the clinic for unlawful disclosure. We did not pursue with legal action because we did not want more people to know my status,’ (Arrey et al., 2017, p.587) ‘They weren’t confidential in prison. Guards would talk about people who had the virus. They didn’t care who was around. I was harassed about having AIDS,’ (Buseh & Stevens, 2006, p.9). ‘the doctor that I was seeing… rang the Head of Department and asked her if she was aware (of her HIV),’ (Cannon Poindexter, 2013, p.711)

Appendix 2

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