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**From self-stigma to self-worth: Understanding self-stigma
through developing, implementing and evaluating a self-
stigma intervention among people living with
HIV and AIDS**

“Change your thoughts and you change the world”

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Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. The work, upon which this thesis is based, was carried out in collaboration with a team of researchers and supervisors who are duly acknowledged in the text of the thesis. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property. The library may lend or copy this thesis upon request.

Signed: 

Date: 21 December 2023

List of prior published papers and author role

Chapter 3: Ferris France, et al., MacDonald, S., Conroy, R., Byrne, E., Mallouris, C., Hodgson, I., Larkan, F. **‘An unspoken world of unspoken things’: A study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland** Swiss Med Wkly. 2015;145:w14113 [accessed on 1 May 2015 at: <http://www.smw.ch/content/smw-2015-14113/>]

Author: Lead on conceptualisation, research design, data collection, analysis and writing

Chapter 4: Ferris France N, Macdonald SH-F, Conroy RR, Chiroro P, Ni Cheallaigh D, Nyamucheta M, et al. **‘We are the change’ 2019 - An innovative community-based response to address self-stigma: A pilot study focusing on people living with HIV in Zimbabwe (2019).** PLoS ONE 14(2): e0210152. <https://doi.org/10.1371/journal.pone.0210152>

Author: Lead on conceptualisation, research design, data collection, data analysis and writing

Chapter 5: Rich, C., Mavhu, W., Ferris France, N.E., et al, 2022 **Exploring the beliefs, experiences and impacts of HIV-related self-stigma amongst young adults living with HIV in Harare, Zimbabwe: A qualitative study.** PLoS One 2022 Vol. 17 Issue 5 Pages e0268498 <https://doi.org/10.1371/journal.pone.0268498>

Author: Research supervision, development of the research proposal, data analysis, and writing

Chapter 6: Ferris France, N., Byrne E., Nyamwanza O., Munatsi V., Willis N., Conroy R., Vumbuna S., Chinembiri M., Maedziso S., Katsanda M., Dongo T., Crehan E., Mavhu W., 2023 **Wakakosha “You are Worth it”: Reported impact of a community-based, peer-led HIV self-stigma intervention to improve self-**

worth and wellbeing among young people living with HIV in Zimbabwe Front.

Public Health 11:1235150. <https://doi.org/10.3389/fpubh.2023.1235150>

Author: Lead on conceptualisation, co-design of research design, data collection and writing. Contributor on data analysis.

Chapter 7: Ferris France, N., Lyons S., Cioringa A., Mavhu, W., Byrne, E., 2023

Interventions to reduce self-stigma among people living with HIV: A systematic review (*Currently under consideration for publication with Stigma and Health, Submitted, November 2023*)

Author: Lead on conceptualisation and analysis, team approach to screening, extraction of data and writing.

List of abbreviations

AYPLHIV	Adolescents and young people living with HIV
ACT	Acceptance Compassion Therapy
ARVs	Antiretroviral drugs
CATS	Community Adolescent Treatment Supporters
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
DBT	Dialectical Behaviour Therapy
FGD	Focus group discussion
FSW	Female sex workers
IBSR	Inquiry-Based Stress Reduction
JBII	Joanna Briggs Institute
KII	Key Informant Interview
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex
MBCT	Mindfulness-based Cognitive Therapy
MBSR	Mindfulness-based Stress Reduction
NGO	Non-governmental organisation
PICO	Population, Intervention, Comparison/control, Outcome
PLHIV	People Living with HIV
PPIE	Public Patient Involvement and Engagement
QoL	Quality of Life
RCSI	Royal College of Surgeons in Ireland
RCTs	Randomised Control Trials
SSI	Semi-structured interview
WEIRD	White, Educated, Industrialised/Individualised, Rich and Democratic
WHO	World Health Organization
UNAIDS	Joint United Nations Programme on HIV and AIDS

Personal statement

For the past 25 years my work has been centred around HIV-related stigma. I was always deeply moved by injustice and felt that the biggest injustice of all is a lack of compassion, understanding, solidarity and acceptance. This was particularly the case for people living with HIV (PLHIV), especially in the earlier days of the epidemic.

When I went through a divorce 15 years into my career, I experienced deep self-stigma – thoughts such as “they will think there is something wrong with me”, “I am unlovable”, “I am a failure”, “people will judge me” plagued my mind.

I discovered and starting practicing Inquiry-based stress reduction (IBSR): ‘The Work’ of Byron Katie. Through identifying what I was thinking and believing about what was happening in any given moment of that difficult time, I questioned my thinking and was able to, firstly, overcome self-stigma, and then, powerfully, I was able to embrace my self-worth, and my self agency and to turn my life around in so many positive ways. My daily practice became a training in IBSR and I subsequently became a Certified Facilitator. Since then I have worked with many groups and individuals on their stressful thoughts in life situations.

Turning back to my professional life, I realised that we, as a collective HIV movement, had overlooked an incredibly important part of stigma for people living with HIV. We had worked tirelessly to change what society think of PLHIV and to change the laws and practices that enabled discrimination in all settings. That is still an absolutely vital part of the HIV response. However, we overlooked self-stigma. We had been operating on the premise that if we changed how society viewed people living with HIV, self-stigma would reduce. We overlooked the important basis of self-stigma – that it is located within the individual in their thoughts and beliefs about themselves. We also overlooked the empowerment and agency that is possible when individuals believe that they are good enough, when they believe they am worthy,



that they belong.

In September 2019, I was invited to give a [TEDx Talk in Chiang Mai, Thailand](#) and titled it ‘The Journey from self-stigma to self-worth’ where I share this journey, starting with my own personal story of self-stigma and then translating it to my work with HIV in Ireland and Zimbabwe, and with sex workers in Vietnam.

In 2015, inspired by this work on self-stigma I co-founded a non-profit organisation called Beyond Stigma. As CEO of this organisation and using my experience and global network, I was well placed to advance the work described in this thesis as well as support work on self-stigma not just as it relates to HIV, but also to other issues such as obesity, tuberculosis, gender-based violence and within particularly stigmatised groups such as sex workers. This has included and continues to include not only implementation and research but also global advocacy for the importance of self-stigma.

This experience and this passion for making a positive change in people’s lives – to show that it was possible to go on a journey from self-stigma to self-worth lit a fire within me that lasts until today. A flame that burns deep inside to help us all better understand what self-stigma is, what causes it and what works to reduce it.

The world is what I believe it to be. Understanding the inner world of self-stigmatising beliefs and being able to question and shift those beliefs is where freedom lies. Then I am free to be the best version of myself that I can be filled with self-love, with self-worth and the agency to live my life to it’s full.

It is my hope that this body of work contributes to the recognition by people living with HIV, researchers, implementers, policy makers and donors of the importance of self-stigma, particularly among those most marginalised in our societies.

“I change, the world changes” Byron Katie

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For my dad – whose stories of being a scholar always inspired me

A project like this is always the work of a community of people. There have been a number of people who have held a protective, hugely encouraging and loving space around me - firstly when I came up the the notion of a PhD, and it was a notion at the beginning, and then later as I got my head around what I needed to do and then did it.

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Gratitude to the cold Irish sea for bring ing me to presence, whatever the day.

Dedicated to everyone who has ever believed they were not good enough.

Abstract

Background

Stigma is a global public health threat that can have consequences for the epidemiology of HIV and other health conditions. Though research has been conducted examining stigma in the context of HIV and AIDS, disability and illness, mental health and physical deformities, much less is understood about self-stigma. HIV-related self-stigma is the result of complex interactions between social, contextual, and self factors. Self-stigma can have serious negative effects, including feelings of isolation, lower quality of life and mental health status, impaired social interaction, and reduced health service utilisation, treatment compliance and adherence. This thesis aims to better understand self-stigma among people living with HIV, in terms of what it is and how it manifests through developing, implementing and evaluating a self-stigma intervention.

Methods

This doctoral work adopted a mixed methods research design using an implementation science approach, and is comprised of five studies. Study 1 was an exploratory qualitative study that explored the core beliefs of people living with HIV in Ireland (Chapter 3). Study 2 was an implementation mixed methods study to examine the potential role of an inquiry-based stress reduction (IBSR) intervention in helping adults living with HIV (PLHIV) to overcome self-stigma and associated states in Zimbabwe (Chapter 4). Study 3 was an exploratory qualitative study to explore the beliefs, experiences and impacts of HIV-related self-stigma amongst adolescents and young people living with HIV in Zimbabwe (AYPLHIV) (Chapter 5). Study 4 was a qualitative study to understand the perceived impact and process of an IBSR intervention aimed at increasing self-worth and wellbeing by reducing self-stigma among AYPLHIV in Zimbabwe (Chapter 6). Finally, Study 5 was a systematic review to identify, assess and summarise the extant literature to explore what interventions exist to reduce and measure self-stigma among PLHIV (Chapter 7).

Results

The first study (Chapter 3) identified core beliefs and functions of self-stigma, categorising them into four main areas: disclosure; sexuality and sexual pleasure; self-perception and body; and illness and death. Findings also indicate coping strategies such as community involvement, personal development, and positive attitude. The community-based intervention using IBSR developed and evaluated in the second study, (Chapter 4) demonstrated significant reductions in self-stigma, depression, and fears around disclosure. The third study (Chapter 5), found that self-stigma is frequently experienced by AYPLHIV in Zimbabwe, leading to negative self-perceptions, impact on relationships, and isolation. The fourth study (Chapter 6) built on the findings of the previous studies to develop and evaluate a peer-led intervention for AYPLHIV, combining IBSR with creative techniques and mindfulness, resulting in improvements in self-worth, self-agency, and communication. Findings of the fifth study (Chapter 7), a systematic review of interventions to reduce self-stigma among people living with HIV, identified 31 studies using various intervention approaches, the majority of which showed promise for self-stigma reduction.

Conclusion

Overall, this doctoral work makes a unique and valuable contribution to the existing gaps in that it increased understanding of the causes, impacts and core-beliefs of self-stigma as well as developed and evaluated an IBSR-based intervention that demonstrates improvement in wellbeing and self-worth among adults and adolescents living with HIV. A number of recommendations for research, policy and future practice are made.

Chapter 1: Background

1.1 Chapter overview

This thesis focuses on interventions that can support people living with HIV (PLHIV) move from positions of self-stigma to self-worth. In order to understand the rationale for this focus, this chapter begins by providing a short overview of HIV. It continues by outlining an assessment of the literature on self-stigma, giving an overview of the theoretical positioning of self-stigma, definition and meaning. Self-stigma and its implications for PLHIV as well as adolescents and young people living with HIV (AYPLHIV) are then discussed. Self-stigmatising core beliefs are explained along with a presentation of the current thinking about interventions to reduce self-stigma among PLHIV. Inquiry-based stress reduction (IBSR) is then explained, as a potential intervention approach for PLHIV used in two of the intervention studies included in this thesis. Finally, an outline of the overall aims and objectives of this thesis are presented.

1.2 HIV overview

HIV remains a major global public health issue, having claimed approximately 40.4 million lives to date with ongoing transmission in all countries globally (WHO, 2023). Although the number of new HIV infections and AIDS-related deaths have decreased markedly since the peak of the epidemic, it remains stark that little progress has been made in reducing new infections over the past 10 years (Bekker, 2018). Advances have been made around HIV treatment with UNAIDS data showing that today, 29.8 million of the 39 million people currently living with HIV (PLHIV) globally are receiving life-saving treatment (UNAIDS, 2023). An additional 1.6 million people received HIV treatment in each of 2020, 2021 and 2022. If this annual increase can be maintained, the UNAIDS global target of 35 million people on HIV treatment by 2025 will be within reach. Although not the same in every region, with appropriate treatment and support people living with HIV can expect to achieve a life-span of 70–77 years (Trickey, 2022) which means HIV is increasingly being seen as a chronic condition.

The highest HIV prevalence remains concentrated in sub-Saharan Africa, home to over two-thirds of people living with HIV globally (Delpech, 2022). In Zimbabwe where three of the studies in this thesis were conducted, and in Ireland where one study took place, HIV remains a challenge. In Zimbabwe in 2020, the prevalence of HIV among adults was 12.9%, which corresponds to approximately 1.23 million adults in Zimbabwe living with HIV and rates remain consistently higher among girls and women than men (Ministry of Health and Child Care, 2020). AYPLHIV (aged 10 – 24yrs) account for approximately 45% of new HIV infections globally, with 70% of these AYPLHIV living in in sub-Saharan Africa (Mark, 2019). AYPLHIV remain the only population where mortality rates continue to increase (Casale et al., 2019a, Ferrand et al., 2017a, Enane et al., 2018). Although rates are lower, HIV remains a significant public health challenge in Ireland. In 2022, 644 people were newly diagnosed with HIV (Q1-3) as compared to 523 for all of 2018. 77% of these diagnoses are in those who were previously diagnosed outside of Ireland (HPSC, 2022). In Ireland, where diagnoses are relatively few and the latest HIV treatment is widely available, there are still significant negative impacts on PLHIV and stigma remains evident (Foley, 2023).

As HIV can be considered a chronic condition, the focus of health services for PLHIV is moving from preventing illness and death to optimising quality of life and enabling the fulfilment of life goals. Challenges of living with HIV are likely to persist because fears of stigma around the outcomes of testing and disclosure remain despite effective HIV prevention programmes. Among the biggest barriers to effective HIV responses are societal and structural factors that put people in harm's way and prevent them from protecting their health and their wellbeing (UNAIDS, 2023). This includes criminalisation of laws and policies, gender and other inequalities, human rights violations and stigma and discrimination. HIV-related stigma continues to act as a significant barrier to prevention, testing and treatment (Parker et al., 2002, Castro and Farmer, 2005, Deacon, 2006).

1.3 Stigma and self-stigma: discourse and meaning

Exactly 50 years since Goffman's seminal work on stigma (Goffman, 1963) was first published, interest in research and the response to stigma has grown exponentially.

Stigma was defined by Goffman, a leading sociologist of this time, as an attribute that is significantly discrediting which in the view of others serves to reduce the person who possesses it. This attribute can be physical, health-related or behavioural. According to Goffman, to be stigmatised is to have your humanity challenged by the possession of a spoiled social identity. He claimed, '[b]y definition, of course, we believe [that] the person with a stigma is not quite human' (Goffman, 1963). Goffman also importantly identified stigma as a complex and multi-dimensional phenomenon (Goffman, 1963). Socially constructed notions of difference, inclusion, acceptability and fear drive evolving understandings of the different types of stigma, which also include notions of power and incorporate social psychological and socio-cultural approaches (Hatzenbuehler, 2013, Relf, 2021, Parker and Aggleton, 2003). More recently, the intersectionality of stigma, the points at which various types of stigma overlap and interact, is being recognised as key to understanding and addressing public health equities (Sievwright, 2022, Nelson, 2021, Stangl et al., 2013).

Stigma is often used in the literature interchangeably to mean both stigma and discrimination, even though they are conceptually and practically quite different. Stigma refers to an attitude or belief whereas discrimination is often seen as the behaviour or action that results from those attitudes or beliefs. Discrimination, sometimes called 'enacted stigma' occurs when stigma is acted upon. Discrimination may refer to any form of distinction, exclusion or restriction imposed on a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group (Ferguson et al., 2022). Although there is no universally agreed-upon list of types and definitions of HIV-related stigma, different types can include self-stigma/internal stigma/personal stigma/internalised stigma, anticipated stigma, perceived stigma, enacted stigma, externalised and structural stigma (Sievwright, 2022). The three major types of stigma at the individual level - enacted stigma (discrimination), anticipated stigma, and internalised stigma - are highly complex, interrelated phenomena (HDN, 2005, Nyblade, 2006, Earnshaw and Chaudoir, 2009). Figure 1 below shows the difference between stigma, discrimination and self-stigma.

Figure 1: Stigma, discrimination and self-stigma defined



Internalising stigma, leads to what Goffman called ‘*spoiled identities*’ or self-stigma (Pantelic et al., 2019). There is huge variation in definitions of self-stigma and also in how it is operationalised and applied by researchers (Link and Phelan, 2001). Link et al. in 1997 defined “self-stigma” as “*the extent to which people endorse negative beliefs and feelings associated with their stigmatized attribute and apply them to self*” (Link et al., 1997). Livingston and Boyd defined self-stigma as ‘*a subjective process, embedded within a socio-cultural context, which may be characterized by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual’s experiences, perceptions, or anticipation of negative social reactions on the basis of their [socially devalued identity or] illness*’ (Livingston and Boyd, 2010). Kalichman defines self-stigma as self-defacing internal representations of what it means to be a person living with HIV (Kalichman et al., 2009)

The definition of self-stigma developed in this research and used to guide the studies included in this thesis encompasses the main components of the definitions proposed by both Kalichman and Link (Kalichman et al., 2009, Link et al., 1997) but also broadens to reflect the importance of personal beliefs and better explains the manifestations. That definition is ‘Self-stigma is a mindset of negative beliefs, thoughts, and behaviours about HIV, which manifests as shame, guilt, feelings of

contamination, self-loathing, reduced self-efficacy, low self-esteem and self-rejection’.

In order to better understand the concept of self-stigma, breaking down the components that make up self-stigma is important. These include self-agency, self-worth, self-esteem, self-love, shame, guilt, depression (Kalichman et al., 2005, Kalichman et al., 2009, Link and Phelan, 2001). This is better understood when exploring how the impact of self-stigma interventions are measured, as researchers are looking to show impact on components of self-stigma that can then be understood as an impact on self-stigma as a whole. Self-agency, self-esteem and depression appear most commonly measured in self-stigma intervention studies (Lennon-Dearing and Hirschi, 2019, Mathew, 2022, Harding et al., 2019, Mundell et al., 2011, Barroso et al., 2014, Erlen et al., 2001).

Building on Goffman’s work, sociologists have continued to try to understand the phenomenon of stigma and self-stigma. Sociologist Karl Eriksson argues that the concept of self-stigmatisation is guided by a representational account of selfhood that fails to accommodate for resilience against, and recovery from, stigma (Eriksson, 2019). While some people with mental illness internalise stigma which affects their self-esteem and self-agency, others do not. There is also evidence that that some people respond to the idea of self-stigma with indignation and resistance, making them more resilient (Eriksson, 2019).

Work to understand self-stigma as it relates to mental illness has been helpful in informing work to understand the complexity of HIV-related self-stigma. One study among people with mental illness experiencing self-stigma, reported that self-stigma is not only related to receiving discrimination from others (Corrigan, 1998). Some people with mental illness for example, endorse stigmatising attitudes about themselves. Having awareness of a negative stereotype on its own however, is not enough for self-stigmatisation to develop. The stereotype also needs to be accepted and applied to the self (Corrigan et al., 2009). In the self-stigma concept, stigma experiences are inevitable and heavily influenced by cognitive priming (Link, 1989, Eriksson, 2019), the influences of society and the media on how we view something.

Self-stigma then, appears to exist internally and also be internalised. Researchers seem to agree that in awareness of self-stigma there is the possibility to overcome it (Corrigan et al., 2009) '*emancipation from a stigma relies on its discovery, that is, my discovery of change for me*' (Eriksson, 2019).

In undertaking research to better understand self-stigma and interventions to reduce it, it is important to be aware of prevailing discourses. For instance, if it is understood that self-stigma happens only as a result of external stigma, interventions may be targeted at reducing social stigma as a way of reducing self-stigma. However, understanding that self-stigma also lives in a person who has not experienced social stigma or discrimination, justifies interventions that start at the level of beliefs and judgement of the person.

1.4 Self-stigma, mental health and people living with HIV

Stigma is a global public health threat that can have consequences on the epidemiology of HIV and other health conditions (Pantelic et al., 2019). While considerable research has been conducted examining how stigma relates to HIV and AIDS, disability and illness, physical deformities (Ablon, 2002, Albrecht et al., 1982, Byrne, 1999, Jamison, 2006, Robertson M and C., 1997, Scambler and Hopkins, 1986, Watson et al., 2007), much less is understood about HIV-related self-stigma (Beck, 2011).

HIV-related self-stigma is the result of complex interactions between social, contextual and self factors (Figure 2 in Chapter 3). Self-stigma has serious negative effects. It can lead to a sense of isolation and lower quality of life and it negatively affects emotional reactions and causes emotional distress to many PLHIV (Simbayi et al., 2007, Crandall and Moriarty, 1995). Self-stigma has wide-reaching effects that include negative impacts on social interaction, health services utilisation, treatment compliance and adherence, and mental health status (Simbayi et al., 2007, Katz et al., 2013, Hua et al., 2014, Calabrese et al., 2015). Self-stigma also affects health seeking behaviour and can stop people seeking treatment and care services (Chesney and Smith, 1999). For example, PLHIV who anticipate high levels of HIV-related stigma are 2.4 times more likely to delay enrolment in care until they are very ill,

compared with people who do not expect to encounter stigma (UNAIDS, 2023). Lower self-esteem and self-efficacy as negative effects of stigma (Beck, 2011) can also be compounded by restrictive legal and/or socio-economic environments for PLHIV (Beyrer et al., 2015, UNAIDS., 2010).

In a 2023 report published by the Global Network of People living with HIV (GNP+), 84.5% of PLHIV reported experiencing internal stigma (GNP+, 2023a). There is evidence to show that PLHIV may experience self-stigma more frequently than they are actually stigmatised by other people (GNP+, 2011). For example, in a survey of 2306 adults in the general public in Cape Town, 38% of PLHIV interviewed reported feeling ashamed of their condition as compared to 16% of HIV-negative people who believed that PLHIV should be ashamed of their condition (Simbayi et al., 2007). Similar findings are reported in Ireland, where 84% of PLHIV feel they are viewed negatively by society whereas 54% of the general public shared that view (Stamp Out Stigma Campaign, 2007)

HIV and mental health are closely related, with co-occurrence of mental disorders such as depression and anxiety common (Bekker, 2018). Self-stigma has also been associated with poor mental health and development of depressive symptoms (Wight, 2000) and in predicting long-term coping and positive living (Kalichman et al., 2009). There are multiple reasons for this co-occurrence and many stem from the self-stigma and stress often associated with behaviours that can result in HIV transmission such as injecting drug use and sex between men (Bekker, 2018). Depression along with lack of social support are the most frequently reported factors that influence poor quality of life (Degroote et al., 2014). In particular, newly diagnosed PLHIV are at higher risk for depression (Bhatia et al., 2011).

1.5 Self-stigma and AYPLHIV living with HIV in Zimbabwe

As many AYPLHIV were born with HIV, they are significantly affected by stigma and self-stigma, and have experienced a great deal of stigma and shame throughout their young lives (Mavhu et al., 2013, Willis et al., 2018a, Mavhu et al., 2020). Their childhood experiences include frequent illness, poor school attendance and hospitalisation. AYPLHIV are often of small stature, have delayed puberty, skin

disfiguration and intellectual impairment (Mavhu et al., 2013). Many have lost one or both parents to HIV and research in Zimbabwe has found that multiple and intersecting drivers of stigma, including HIV, ill health, orphaning and poverty, make AYPLIV particularly vulnerable (Mavhu et al., 2013). In one study, 73% of AYPLIV reported stigma, and reported that this affected their medication adherence; 47% had virological failure (Mavhu et al., 2020). A 2023 study found that 57.5% of AYPLHIV experienced internal stigma (ZNNP+, 2023). In another study, AYPLHIV described feeling that because they were HIV positive, life was not worth living (Mavhu et al., 2013). As a result they deliberately did not take their medication so they could eventually die (Mavhu et al., 2013).

In order to enhance the positive adaptation and promotion of psychological wellbeing of this group, increasing self-esteem and self-agency, two components of self-stigma, is important (Mathew, 2022). Self-esteem is an important psychological factor and inner resource that contributes to the health and quality of life of AYPLHIV (Nyamaruze, 2021).

1.6 Stigmatising core beliefs and PLHIV

In shaping an individual's worldview, core beliefs that contribute to self-stigma can have a profound effect on the concept of self (Wenzel, 2012). Core beliefs can be defined as '*fundamental, inflexible, absolute and generalised beliefs that people hold about themselves, others, the world and/or the future*' (Beck, 2011). Core beliefs generally fall under themes of lovability (e.g., "I am undesirable"), adequacy ("I am incompetent"), and/or helplessness (e.g., "I am trapped") (Wenzel, 2012). When negative core beliefs are judgemental or inaccurate (e.g., 'I am worthless'), they can have a serious impact on a person's sense of self-efficacy, self-identity and wellbeing (Wenzel, 2012). It follows then, that common core beliefs among PLHIV such as those related to being 'unclean, undeserving, unlovable' can significantly moderate behaviour, for example decisions around disclosure or accessing treatment (Malta et al., 2005). Therefore, working with PLHIV to identify unhelpful core beliefs can support them to embrace a healthier belief system that can result in positive change (Wenzel, 2012). To date, not much is known about the core beliefs underpinning HIV-related self-stigma. Better understanding self-stigma core beliefs

can be significant in the design of interventions and programmes designed to reduce its harm.

1.7 Interventions to reduce HIV-related self-stigma

Approaches that target self-stigma are likely to benefit wellbeing and psychological outcomes among PLHIV (Kamen et al., 2015). Although there are many interventions targeting external stigma (Sengupta et al., 2011, Stangl et al., 2013), there is a dearth of interventions and measures that target individuals as well as provide tools to manage and overcome self-stigma (Kalichman et al., 2009). Of those that do exist, interventions to support PLHIV in dealing with self-stigma, particularly at the level of core beliefs, are lacking (France et al., 2015, Sengupta et al., 2011, Stangl et al., 2013). Stigma researchers have acknowledged that in order to successfully address self-stigma, approaches need to go beyond mass education and work within more ingrained belief systems (Kalichman and Simbayi, 2004). Given that stigma and self-stigma are components of the wider socially, culturally and structurally-created contexts, (Parker and Aggleton, 2003), multidimensional approaches tackling internal and external stigma are likely to yield the best results (Turan et al., 2017, Logie et al., 2018).

In terms of interventions that are potentially effective in this context, a 2011 systematic review found that stress-management interventions reduce psychological distress and improve psychosocial functioning among PLHIV (Brown and Venable, 2011). Such interventions can include cognitive behavioural approaches, as well as meditation, mindfulness, and relaxation-based stress management approaches. For example, a randomised control trial (RCT) study in the US found that an eight week mindfulness-based stress reduction (MBSR) approach showed a positive effect in reducing the impact of HIV treatment side effects and the psychological distress associated with antiretroviral drugs (ARVs) for PLHIV (Duncan et al., 2012, Jam et al., 2010). However, these studies did not specifically focus on self-stigma.

In the past 15 years, there has been a shift in the cognitive and behavioural therapy landscape, with the advent of “third wave” cognitive-behavioural approaches (Hook,

2021). This refers to a newer generation of therapeutic interventions that have their roots in cognitive behavioural therapy (CBT). Still with a strong emphasis on cognition, these approaches focus more on an individual's relationship to their thoughts and their emotions, rather than on the content of the actual thoughts themselves (Hayes, 2017). This approach encourages people to accept their thoughts without judgement rather than try to change them. The emphasis is on issues such as acceptance, values, mindfulness, goals and meta-cognition and includes approaches such as Acceptance and Commitment Therapy (ACT), Dialectical Behaviour Therapy (DBT), Mindfulness-based Cognitive Therapy (MBCT) and MBSR. ACT is a behaviour treatment approach designed from CBT that focuses on an individual's capacity to persist in or modify behaviour that emphasises openness to experience, connection to the present moment and engages in actions linked to valued goals (Feliu-Soler, 2018). DBT is a treatment approach aimed at supporting the change of behaviour and management of emotions using principles of CBT combined with mindfulness, acceptance and dialectics. MBSR is a systematic application of meditation as a self-regulation method to reduce stress and medical and psychological symptoms. MBCT integrates MBSR together with cognitive behavioural therapy techniques (Duncan et al., 2012)

1.8 Inquiry-based stress reduction (IBSR): 'The Work' of Byron Katie

As a novel third wave approach, inquiry-based stress reduction (IBSR): The Work (Katie and Mitchell, 2003, Lev-Ari et al., 2013) can be potentially effective as it works directly with individuals to systematically identify, question and overcome negative beliefs and the behaviours that result. IBSR was developed by Byron Katie (Katie and Mitchell, 2003, Katie and Mitchell, 2007) and supports participants in reducing their perceived level of stress by self-inquiry on thoughts and beliefs connected to stressful circumstances or symptoms. Widely used as a self-help intervention since the early 1980s, the effects of IBSR have only been empirically examined since 2013.

A recent systematic review of IBSR across a range of health areas identified 17 empirical studies (among which the study in Chapter 4 was one) and found that results across the studies were promising. Positive results have been shown in a

number of studies: on mental health and wellbeing with breast cancer survivors (Landau, 2016, Landau, 2021, Landau et al., 2015), on general population stress (Smernoff et al., 2015); on teacher burnout (Schnaider-Levi, 2017) and resilience; on chronic stress (Krispenz, 2019a); on stuttering (Feldman, 2021); on anxiety (Krispenz, 2018, Krispenz, 2019b), on interpersonal problems among nurses (Tajnia, 2022) and on building stress resilience and wellbeing (Smernoff, 2019).

For example, improved psychological symptoms and quality of life were reported in a non-clinical setting pilot study in the general population (Smernoff et al., 2015). A pilot clinical trial in breast cancer survivors in Tel Aviv, reported significantly lower levels of fatigue and improved sleep quality, physical, social, familial, emotional and functional wellbeing (Lev-Ari et al., 2013). However, only three studies used RCT designs, whereas seven used single-group design and four used quasi-experimental designs and the evidence suggested that more robust research should be carried out employing high-quality designs (Hook, 2021).

Inquiry-based stress reduction (IBSR): ‘The Work’ of Byron Katie is a way of identifying and questioning thoughts that cause shame, anger, fear and violence (Katie and Mitchell, 2003). As self-stigma is deeply rooted in a person’s belief system of how they view themselves, and how they perceive others view them (Beck, 2011), working with PLHIV on beliefs and thoughts is important. The beliefs that underlie shame, guilt, worthlessness and blame can be questioned with IBSR; allowing for new perspectives, insights and options that are kinder, more peaceful and empowering (Hook, 2021). IBSR uniquely combines in-depth inquiry of stressful thoughts with the process of cognitive diffusion, mindfulness and acceptance. Cognitive diffusion is where we choose a different relationship with the stream of thought and is particularly applicable to people dealing with negative self-referential thoughts such as ‘I am worthless’ (Masuda, 2010). Consistent with ACT principles and cognitive diffusion, IBSR does not encourage trying to change thoughts, instead, the process involves questioning the thought, exploring the effects of the painful thought, and considering alternative perspectives to the thought (Hook, 2021).

The IBSR process involves three steps. Step 1 involves identifying the stressful thought or belief that is linked to self-stigma that causes emotional distress. The participant then writes down the painful belief. Example of painful beliefs include “They think I’m a bad person” “HIV is a punishment from God”, “they will reject me [if they know I am HIV-positive]”.

Step 2 involves asking four questions. The first question asks if the belief is true. In this context, the word “true” is not used in a moral sense; rather, it asks whether the thought corresponds to the objective reality of the situation (Hook, 2021) . For example, the thought ‘they will reject me’, Q1. Is it true? The answer to Q1 can be yes or no (there is no right or wrong answer, just what the person believes). If the answer to Q1 is no, the person moves directly to Q3. If the answer is yes, the person moves to Q2. Q2 Can you absolutely know it is true? which asks whether they can be absolutely 100% sure that the thought is true. In most cases, there is some question or doubt, so the answer to Q2 is often a no (and whether the answer is a yes or a no, the person moves on to Q3). Q3 How do you react, what happens when you believe that thought? Asking the person to inquire and consider the effect of the belief on their life, to become aware of what happens when a person believes their thought. In this question, the connection (or fusion) between the thought and the effect of the thought is analysed. For example, when a PLHIV believes ‘they will reject me’, they can feel worthless, hopeless, fearful, angry, full of shame and often start to withdraw from social gatherings or not pursue relationships for fear of rejection. The mind plays images of situations from the past or future of rejection where the person sees themselves lonely and isolated. Q4 Who would you be without the thought? It asks the person to consider who they would be if they were unable to think the painful thought. This question is the opposite of Q3 and the person gets a chance to experiment with cognitive diffusion and separate themselves from the painful belief. For example, if the PLHIV were unable to think ‘they will reject me’ they could feel more peaceful and hopeful. They may join social gatherings, apply for a job or allow themselves to explore an intimate relationship. They may feel stronger in themselves and increase in self-worth. They may accept that rejection may happen, but not expect it from everyone.

Step 3, the final stage is called the ‘turnarounds’. The person is invited to consider whether the opposite of the painful belief might be true and is asked to share three examples of how the opposite could be true. It is important to note that the purpose of the turnaround is simply to support the person to consider alternative perspectives, not to change the thought. This often has the effect of loosening attachment from the original painful thought. There are most often three ways to turn a thought around. Turnaround to the opposite: for example ‘they won’t reject me’ or ‘they will accept me’, turnaround to the other: ‘I will reject them’ and turnaround to the self ‘I will reject me’. In each case the participant is invited to find genuine and specific examples where each turnaround could be as true or truer than the original thought and through this process participants gain understanding of the power of stressful thoughts, and the ability to question these thoughts.

IBSR is most often delivered by an IBSR-Certified Facilitator in groups or in individual sessions. A range of formats and dosages have been used in interventions to date (Hook, 2021). These include a time-intensive 9-day workshop, and/or 6 to 12 weekly interventions with both groups and individuals. Exercises during sessions support participants to work in dyads or small groups (Hook, 2021). This process is meditative and reflexive, and the participant is guided to search for the true and genuine answers to the four questions with no certain agenda or censoring of thoughts. In this way, the participants become more aware of their self-stigmatising thoughts as they occur. This can help in managing their own thoughts to better cope in what had previously been highly stressful situations (Katie and Mitchell, 2003, Rouleau et al., 2015).

IBSR was the approach used in two of the intervention studies included in this thesis. The author is a Certified Facilitator (Registered #1707001) of this method and has been using it as a personal practice for 14 years as well as working professionally hosting workshops and working with clients on-on-one. It seemed likely, primarily based on the evidence above together with the author’s personal and professional experience, that in the context of HIV self-stigma, working with underlying core beliefs using IBSR could be an effective strategy to increase self-worth and reduce self-stigma. The studies included in this thesis, were the first studies to use IBSR with PLHIV, and the first to be carried out in the Global South.

In order to design and assess the impact of an intervention, it is important to locate the intervention in a context such as Zimbabwe, where HIV prevalence is high.

In summary, this chapter illustrates that HIV is still a significant public health issue and that stigma and self-stigma can exacerbate the impact of HIV on PLHIV in Ireland, Zimbabwe and globally. The theory and meaning of stigma and self-stigma were presented followed by a description of why self-stigma is an issue for PLHIV as well as AYPLHIV. There are interventions, such as IBSR, that could be used to alleviate adverse impacts and support PLHIV in order to reduce self-stigma. Self-stigma core beliefs were broken down and finally a summary of interventions to reduce self-stigma as well as a description of IBSR was presented.

1.9 Research aims

The central aim of this thesis was to better understand self-stigma among PLHIV and how it manifests through developing, implementing and evaluating a self-stigma intervention.

The specific objectives of this PhD were to:

1. Improve the understanding of the beliefs associated with self-stigma among people living with HIV
2. Iteratively design and evaluate a psychosocial intervention based on inquiry-based stress reduction for people living with HIV;
3. Systematically review the existing literature that examines the effectiveness of self-stigma interventions for improving the well-being of people living with HIV;
4. Improve the operationalisation of the concept of self-stigma and propose a conceptual framework to better understand and guide interventions and research.

This overall aim and objectives were achieved through five studies (illustrated in Figure 2):

Figure 2: Five studies and PhD strategy

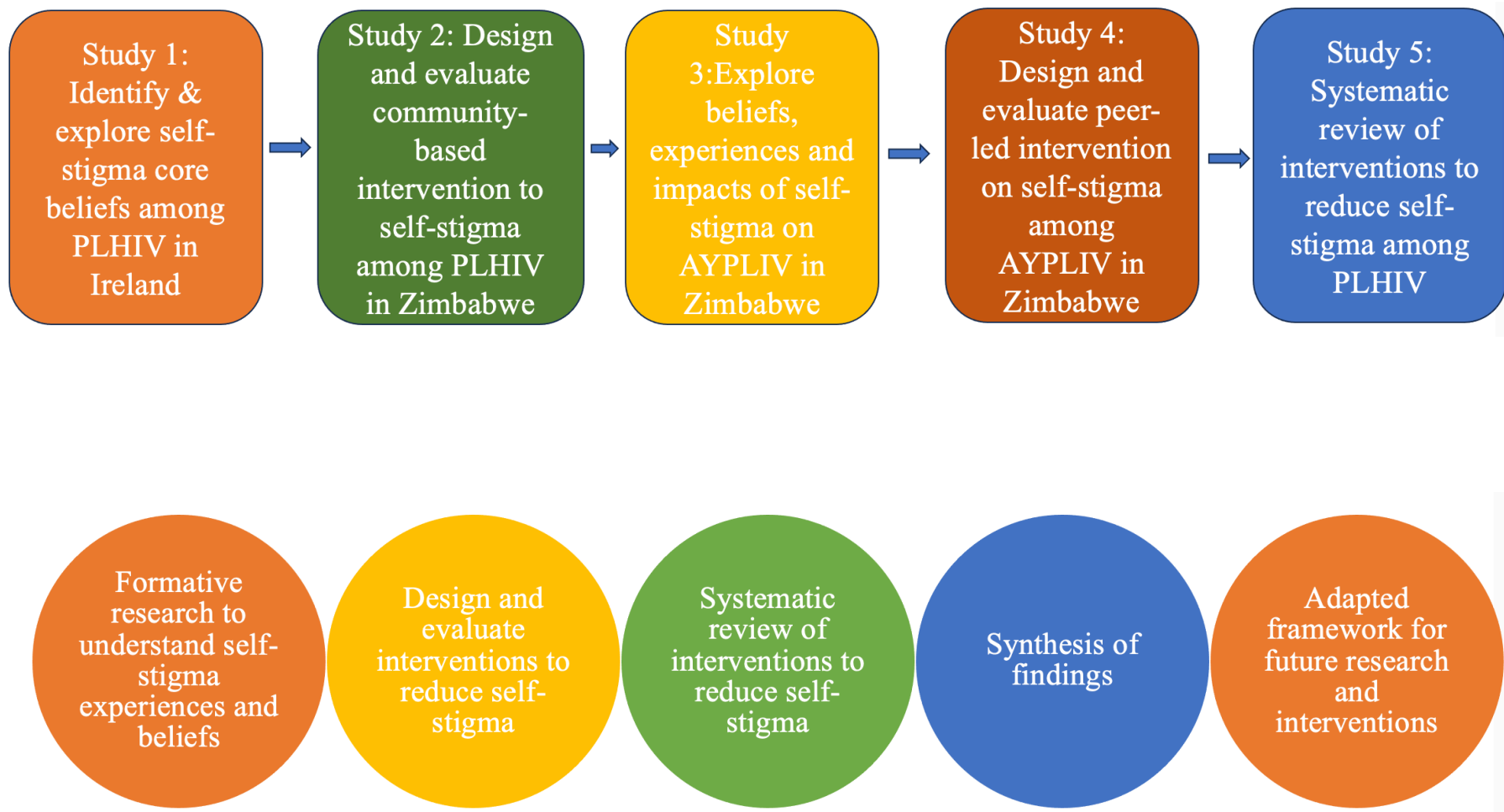


Table 1 demonstrates how each of the five studies, described in more detail in Chapters 3-7, relate to specific research objectives.

Table 1: Research objectives and published papers

Research objectives	Chapter 3	Chapter 4	Chapter 5	Chapter 6	Chapter 7
1. Improve the understanding of the beliefs associated with self-stigma among people living with HIV	X		X	X	
2. Iteratively design and evaluate a psychosocial intervention based on inquiry-based stress reduction for people living with HIV		X		X	
3. Systematically review the existing literature that examines the effectiveness of self-stigma interventions for improving the well-being of people living with HIV					X
4. Improve the operationalisation of the concept of self-stigma and propose a conceptual framework to better understand and guide interventions and research.	X	X	X	X	X

Chapter 2 outlines the overall methodology of the PhD thesis and Chapter 8 includes an overview of the contributions from this research, it's limitation and areas for future research.

1.10 Summary of papers and outputs

Study 1 (Chapter 3) was exploratory research to better understand the core and negative self-stigmatising beliefs and experiences of PLHIV in Ireland. Study 2 (Chapter 4) built on that exploratory research on beliefs and experiences and used it to design and evaluate an intervention using the approach of inquiry-based stress reduction in Zimbabwe. It also proposed a conceptual framework by which to understand self-stigma. Building on what was learned, Study 3 (Chapter 5) was exploratory research to better understand the core and negative self-stigmatising beliefs and experiences of AYPLHIV aged 18-24yrs. Study 4 (Chapter 6) then took that exploratory research as well as lessons learned from implementing the self-stigma intervention with adults, and designed and evaluated an intervention using inquiry-based stress reduction and creativity with AYPLHIV (aged 18-24yrs) in Zimbabwe. Study 5 (Chapter 7) provides the evidence base in a systematic review of HIV-related self-stigma interventions among PLHIV to better understand what programmes exist, highlight the gaps in current knowledge and make recommendations for future interventions.

Specific outputs from this research include

- A new definition of HIV-related self-stigma
- A conceptual framework for showing the complex interactions between social, self and contextual in helping to understand causes, consequences of self-stigma
- The Inside Out Framework for design of HIV self-stigma related interventions, research and policy based on the socio-ecological model
- Graphic showing flipped narrative beyond stigma, using strengths-based rather than deficit-based language
- Number of specific areas highlighted for future research

Chapter 2: Methodology

2.1 Chapter overview

This chapter outlines the overall research methodology that was employed across the PhD research, as well as describing with examples, the methods that were used in each study in this thesis. The role of the researcher, the research participants and the ethical considerations are discussed in terms of their influence on the overall research design, implementation and dissemination approach.

2.2 Overview of the study design

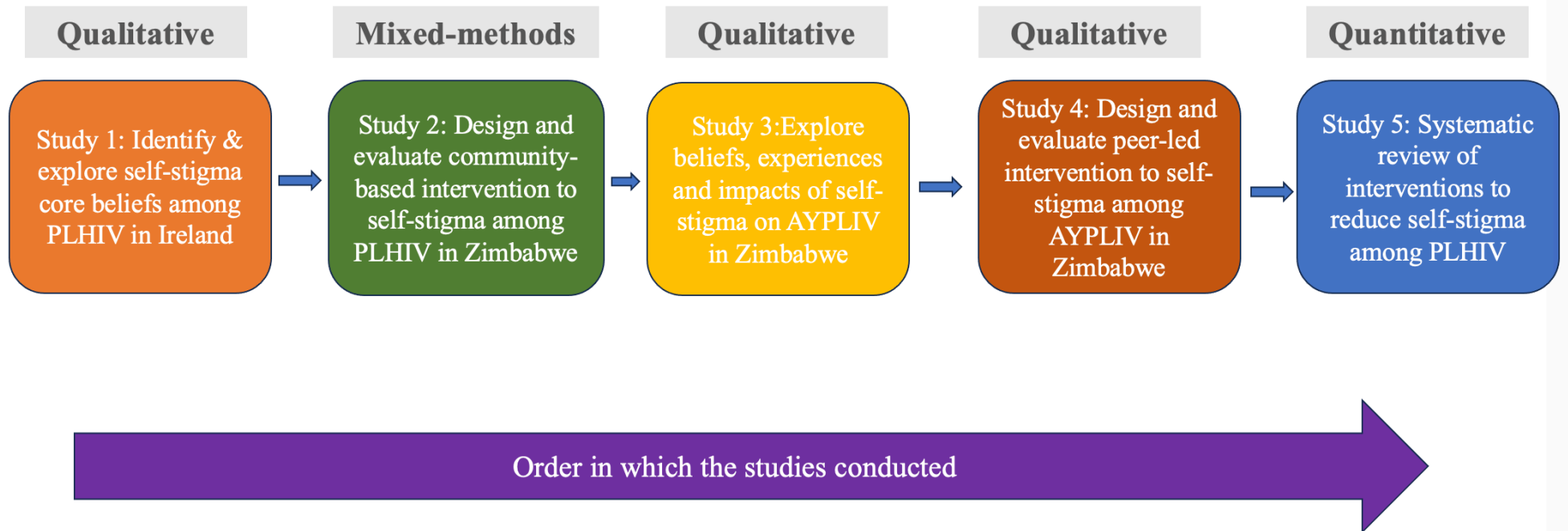
The main aim of this thesis was to better understand self-stigma among people living with HIV, in terms of what it is and how it manifests through developing, implementing and evaluating a self-stigma intervention. Three qualitative studies, one mixed-methods and one quantitative study were conducted under an implementation science approach. The studies are described briefly below:

- Study 1: An exploratory qualitative study using semi-structured interviews and thematic analysis to understand the core beliefs of PLHIV in Ireland to inform development of an IBSR intervention (Chapter 3).
- Study 2: An implementation study with mixed methods sequential explanatory data collection and analysis was conducted to examine the potential role of an IBSR intervention in helping PLHIV to overcome self-stigma and associated states. Quantitative data on participant's levels of self-stigma, depression and quality of life were collected. Qualitative semi-structured, key informant and focus group discussions (FGDs) were used to understand the impact, what changed as a result of the intervention and information about the process itself (Chapter 4).

- Study 3: An exploratory qualitative study was conducted using semi-structured interviews and explored the beliefs, experiences and impacts of HIV-related self-stigma amongst AYPLHIV in Zimbabwe (Chapter 5).
- Study 4: An implementation study using qualitative data collection and analysis was conducted using semi-structured and key informant interviews together with FGDs to understand the perceived impact and process of an intervention that sought to increase self-worth and wellbeing by reducing self-stigma among AYPLIV (Chapter 6).
- Study 5: A systematic review was conducted to identify, assess, and summarise the extant literature to explore what qualitative and quantitative interventions exist to reduce and measure self-stigma among PLHIV and identify possible further modifications to the intervention developed in this research (Chapter 7).

A summary of the study methods used in the thesis is presented in Figure 3:

Figure 3: Data collection and analysis methods



2.3 Research paradigm

Understanding relevant research paradigms helps us question our understanding of the world and how it is informed by how we view the world, what we think of as valuable and even what we consider to be the purposes of understanding (Cohen, 2018). Our assumptions about the nature of reality and the nature of things (ontological assumptions) are informed by our beliefs and values (epistemological assumptions), which in turn influence our ways of researching and inquiring (Cohen, 2018). As four of the studies in this thesis are exploring and questioning beliefs, ensuring awareness of research paradigms and that the best approaches are used in the studies is important.

At the epistemological level, multiple paradigms exist to help position and guide research. In general there are different research paradigms for qualitative and quantitative research, which are often presented as opposing (Pilcher, 2023). Quantitative research centres around the belief that reality is objective and measurable, where a fixed set of questions can be generated to answer a specific hypotheses (Guba, 1994). While some quantitative researchers would argue their work is exploratory, in general, quantitative research is considered confirmatory and deductive in approach (Guba, 1994). Qualitative research centres around the premise that the reality we perceive is constructed by our individual, social, cultural and historical contexts and seeks to provide an-depth understanding of real world problems (Korstjens, 2017).

There are different ways these philosophical differences can be presented. For example, Burrell and Morgan favour a more classical approach and present four paradigms Functionalist, Interpretive, Radical Humanist and Radical Structuralist as coming from quite distinct intellectual traditions and are presented as four mutually exclusive views (Burrell, 1979). Gilson, on the other hand presents these paradigms as operating along a continuum rather than as separate (Gilson, 2012). Creswell and Creswell (2018) present four different main paradigms or worldviews which are widely discussed in the literature: postpositivist, constructivist, transformative and pragmatic. These paradigms are distinct but not mutually exclusive. In the extant literature, a postpositivist paradigm is generally aligned with quantitative research

whereas a constructivist-interpretivist paradigm is aligned with qualitative research (Kaushik, 2019).

A pragmatist paradigm guided the overall positioning of this research. Pragmatism was found to encompass the most appropriate research methods, recognising the need for multipronged approaches, in particular when dealing with complex social problems, (Allemang, 2022) such as self-stigma. The aim of pragmatic research is to focus on human experience and use that as the primary means for building knowledge and understanding (Allemang, 2022). This paradigm allowed flexibility in ensuring that each study used the methods and approach most suited to their specific research question. For example, an interpretivist constructivist approach was used in the studies that were aimed at understanding beliefs and experiences, social constructions, related to self-stigma among PLHIV (Chapter 3, 4, 5 & 6). This is in keeping with the complexity of self-stigma and how it is shaped by social contexts and human experiences and was concerned with the core beliefs, how people interpret and make sense of their world. For the exploratory studies in Chapter 3 and 5, an interpretivist constructivist approach allowed for a deeper understanding of the lived experiences of individuals that could subsequently help inform the design of the therapeutic intervention outlined in Chapter 4 and 6.

The constructivist philosophy assumes there are multiple realities that knowledge is socially constructed from, and it highlights the importance of understanding multiple viewpoints of a particular phenomenon (Petty, 2012). Constructivists see reality as shaped by human experiences and social context and accept the varied and multiple meanings with which participants make sense of the world. Through social interactions with others and through historical and cultural norms that operate in a person's life, socially-constructed meanings are made (Creswell, 2018). Researchers who operate within this paradigm understand their own experiences, beliefs and background will influence their interpretations. Within constructivism, the interpretive perspective often uses interviews, thematic analysis and observations to understand the subjective meanings that individuals or groups assign to their experiences and lives (Creswell, 2018).

A postpositive approach was used for the quantitative aspects of the research and was useful in grounding the work on measurement of the intervention using scales (Chapter 4) and for the systematic review (Chapter 7). A postpositivist believes in a single objective, external, tangible, measurable reality (Young, 2020). Postpositivists argue that while we cannot have direct access to the objective reality, we can gather knowledge and understanding through systematic observation, measurement, and the application of rigorous scientific methods (Young, 2020).

In summary, a pragmatist paradigm allowed for different methods of inquiry to address the research questions in the most appropriate, and practical way (Allemang, 2022).

2.4 Design: Implementation science approach

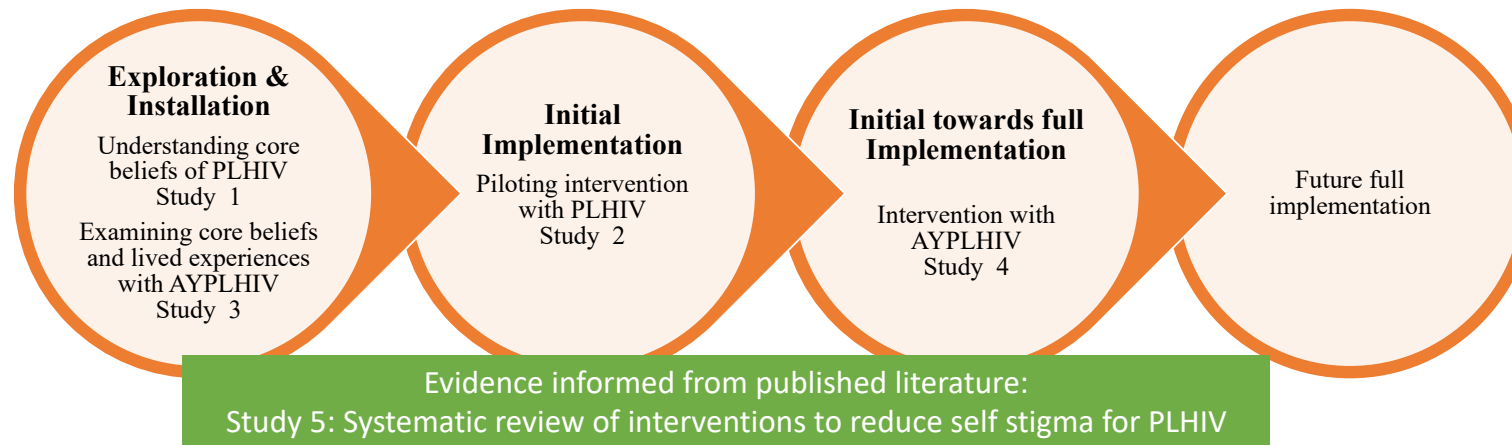
This research started as one exploratory study carried out with the aim of designing one intervention that could reduce self-stigma among people living with HIV. As a practitioner, my interest was in designing an intervention that would be robust, contextually appropriate, localisable and effective. As such, a practical and iterative approach was taken to conducting research based upon context and opportunities. For example, the first study was conducted in Ireland. Following a presentation of the research findings to a group from Trócaire, an Irish non-governmental organisation (NGO) based in Zimbabwe, I was invited to work with them to develop and deliver an intervention on self-stigma and HIV in Zimbabwe as part of their existing HIV programme.

Implementation science is defined as “*the scientific inquiry into questions concerning implementation—the act of carrying an intention into effect, which in health research can be policies, programmes, or individual practices (collectively called interventions).*” (Peters, 2013). Implementation research is concerned with the factors that affect implementation, the process and results of implementation. It is particularly aimed at understanding why and how interventions work in the real world and testing approaches to improve them (Peters, 2013) which fits well with the studies in this thesis. There are four stages of implementation that include 1) Exploration of the local context and identification of local innovations 2) Installation

of the capacity and the resources needed to implement an intervention, 2) Initial implementation , piloting and rapid adaptation to improve and understand fidelity and 4) Full implementation where an intervention is sustained, fidelity is reached and programme outcomes are realised (Westgard, 2020). Figure 4 below shows the implementation science stages for this research.

Figure 4: Implementation science stages

- Self-stigma is high for PLHIV
- Negative core-beliefs cause self-stigma
- Interventions can help
- Paucity of self-stigma interventions
- Addressing self-stigma leads to better health outcomes and increased wellbeing



- Better understand self-stigma beliefs
- Systematically review the existing literature
- Design and evaluate a self-stigma intervention
- Improve the operationalisation of the concept of self-stigma and propose a conceptual framework

Figure 5 below shows how each study builds on the next and where changes were made, underpinned by the evidence base situated in the systematic review. In implementation science a number of outcome variables are highlighted as important. These include adoption, appropriateness, feasibility, fidelity and sustainability (Peters, 2013). In the studies presented in Chapter 4, 5 and 6, particular emphasis was given to acceptability, appropriateness, feasibility and some learnings were noted in relation to fidelity.

Figure 5: Implementation science approach illustrating iterative process of implementation and change



2.5 Methods

In this section, an overview of the methodological considerations of the studies is presented, drawing on examples to support the description of the study design, data collection, analysis and dissemination. Full details of the methods for each study are contained in the respective Chapters 3 – 7 and Table 2 presents an overview of the methods used in the five studies:

Table 2: Overview of research approach and methods for the five publications

	Purpose	Study question	Approach	Sample population	Data collection methods	Data analysis methods
Study 1 (Chapter 3)	To understand the core self-stigmatising beliefs of people living with HIV in Ireland	<p>1. What are the core beliefs underlying HIV-related self-stigma among the studied group of people living with HIV?</p> <p>2. What are the functions of self-stigma among the studied group of people living with HIV?</p> <p>3. What coping strategies</p>	Exploratory qualitative	<p>17 people living with HIV. 6 were women, 10 were men, and 1 was transgender.</p> <p>Age range between 31–51 years (average age 43 years)</p>	Qualitative semi-structured interviews and written statements	Inductive and deductive thematic analysis

	Purpose	Study question	Approach	Sample population	Data collection methods	Data analysis methods
Study 2 (Chapter 4)	To examine the potential role of the IBSR intervention in helping people living with HIV to overcome self-stigma and associated States in Zimbabwe	<p>1. Does the intervention using IBSR: The Work of Byron Katie have the potential to influence self-stigma?</p> <p>2. Does the intervention have potential to influence stigma-associated states, such as shame, fear around disclosure, and depression?</p> <p>3. Does the intervention have potential to influence other areas of participants' lives beyond HIV self-stigma?</p>	Implementation mixed methods	23 people living with HIV (17 Female, 6 male, average age 41 years)	Quantitative applying validated scales; qualitative semi-structured interviews and FGD at three time points - immediately after, one month post and three months post intervention	Quantitative - using STATA and Wilcoxon matched-pairs signed rank test Qualitative semi-inductive iterative coding strategy using QDAMiner Lite)

	Purpose	Study question	Approach	Sample population	Data collection methods	Data analysis methods
Study 3 (Chapter 5)	To explore beliefs, experiences and impacts of HIV-related self-stigma amongst older adolescents and young adults (18–24 years) in Harare, Zimbabwe	What are the beliefs, experiences and impacts of HIV-related self-stigma among ALHIV?	Exploratory qualitative	16 adolescents and young people aged between 18-14 (average age 22). 8 male, 8 female	Qualitative semi-structured interviews	Inductive and deductive thematic analysis using NVivo

	Purpose	Study question	Approach	Sample population	Data collection methods	Data analysis methods
Study 4 (Chapter 6)	To report on the findings from a qualitative study that explored the perceived impact of an intervention to increase self-worth and wellbeing by reducing self-stigma among adolescents and young people in Zimbabwe.	Does the Wakakosha intervention using IBSR, increase self-worth and wellbeing by reducing self-stigma among AYPLHIV in Zimbabwe.	Implementation qualitative	60 AYPLHIV participated in the intervention. Focus group discussion (FGD) held with 12 (n=6 female) Another 12 (n=6 female) took part in individual in-depth interviews, 15 trainees took part in a FGD. 24 of 30 participants (n=12 female) took part in two separate FGDs (n=12 participants each) 2 local coaches key informant interviews	Focus group discussions Semi-structured interviews Key informant interviews Analysis of intervention activities (i.e., activity journals)	Inductive and deductive thematic analysis using NVivo 14 (QSR International, Melbourne, Australia)

	Purpose	Study question	Approach	Sample population	Data collection methods	Data analysis methods
Study 5 (Chapter 7)	To conduct a systematic review of interventions that exist to reduce and measure self-stigma among people living with HIV (PLHIV) derive appropriate recommendations	To understand what interventions exist to reduce self-stigma among PLHIV, highlight gaps and offer recommendations	Systematic review	31 qualitative and quantitative studies were included in the review from an initial 4,584 results.	PubMed, Embase and Web of Science were searched and Covidence review software was used to collect the data	Search results were dual screened using predetermined criteria. Data was extracted from each included study, analysed according to the criteria and categorised using the socio-ecological model. Findings were then grouped into common categories.

2.5.1 Study design

A variety of qualitative, mixed methods and quantitative methods were used in the five studies presented in this thesis. In each of the qualitative studies in Chapter 3–6, convenience and purposive sampling was used to recruit participants, in each case from community-based organisation for PLHIV. These community-based organisations were Open Heart House, the largest peer-support network for PLHIV at the time of the research in Ireland (17 study participants, Chapter 3); the Zimbabwe National Network of PLHIV (ZNNP+) (23 study participants, Chapter 4); and Zvandiri, an organisation that provides peer-support training and psychosocial support for AYPLHIV in Zimbabwe (16 and 60 study participants respectively, Chapter 5 and 6).

For the implementation study in Chapter 4 a sequential mixed methods design was used. Considerations for a mixed methods study included the weighting of the two components of qualitative and quantitative, the decision about timing of when each should occur and at what stage results would be combined (Tariq S, 2013). In this study there was a larger emphasis placed on the qualitative component as this was the first time this intervention had been implemented in Zimbabwe, and with the specific population of PLHIV. For this reason, it was important not just to examine the potential impact of the intervention on self-stigma, but also to understand the quantity and direction of changes in self-stigma and associated states and to investigate why these changes occurred and what other areas of participant's life might be affected. In addition, it was important to get feedback from participants on the intervention methodology and process itself. Using validated scales to measure changes on internalised stigma, quality of life and depression was important to understand if the intervention impacted any of these outcomes. Quantitative measures were administered first at each timepoint followed by qualitative focus group and semi-structured interviews. This study was also retrospectively registered as a clinical trial.

2.5.2 Data collection

Data collection took the form of semi-structured interviews and focus group discussions (Chapters 3, 4, 5, 6), written statements (Chapter 3 and Chapter 5), application of validated scales (Chapter 4) and a systematic review of the literature (Chapter 7). For example, qualitative data for the studies in Chapter 3, 4, 5 and 6 was collected using semi-structured

interviews, focus group discussions. Interviews were carried out in person and in private spaces within the community-organisations mentioned above and participants were made aware that counselling services were available if needed, as participants were sharing sometimes painful experiences and memories about living with HIV. In the case of the study in Chapter 5, the outbreak of COVID-19 meant there was an impact on both the sample size and a shift from in-person data collection to virtual. In this case, interviews were conducted via Zoom and WhatsApp in a private space on the Zvandiri (the local NGO) premises. Because the interviews were among AYPLHIV aged 18-22, a psychologist was present during the interviews to provide emotional support if needed. Interview guides to guide semi-structured interviews and focus group discussions are included in the Appendices of supplementary material for each study.

Written statements to identify core beliefs were collected in the study in Chapter 3, comprised of asking participants to write the response to the following open-ended statement “*I am HIV positive and that means that...*”. Participants with limited literacy dictated their responses. This same question was incorporated into the data collection in the study in Chapter 5. The approach is commonly used to draw out core beliefs as part of inquiry-based stress reduction: the work of Bryon Katie (Katie and Mitchell, 2003) and is also known as the Downward Arrow Technique, first introduced by Beck (Beck, 1979).

Questions used in the interview guides of the intervention studies in Chapter 4 and Chapter 6 included questions such as “*if you had to describe what you got out of this course, what would you say*”? This was to understand what participant’s themselves identified as outcomes of the intervention. Interview guides for the studies in Chapter 3, 4 and 6 were designed by the research team, led by the author, and included Zimbabwean researchers, and RCSI quantitative and qualitative researchers. A sample of questions used in the study in Chapter 5 are included below:

Box 1: Sample questions used in study in Chapter 5

Awareness: How do you think society perceives people living with HIV?

Is it different than those without HIV?

How do those perceptions make you feel?

Agreement: If you had to complete the sentence “I am HIV positive and that means that...” what would your response be?

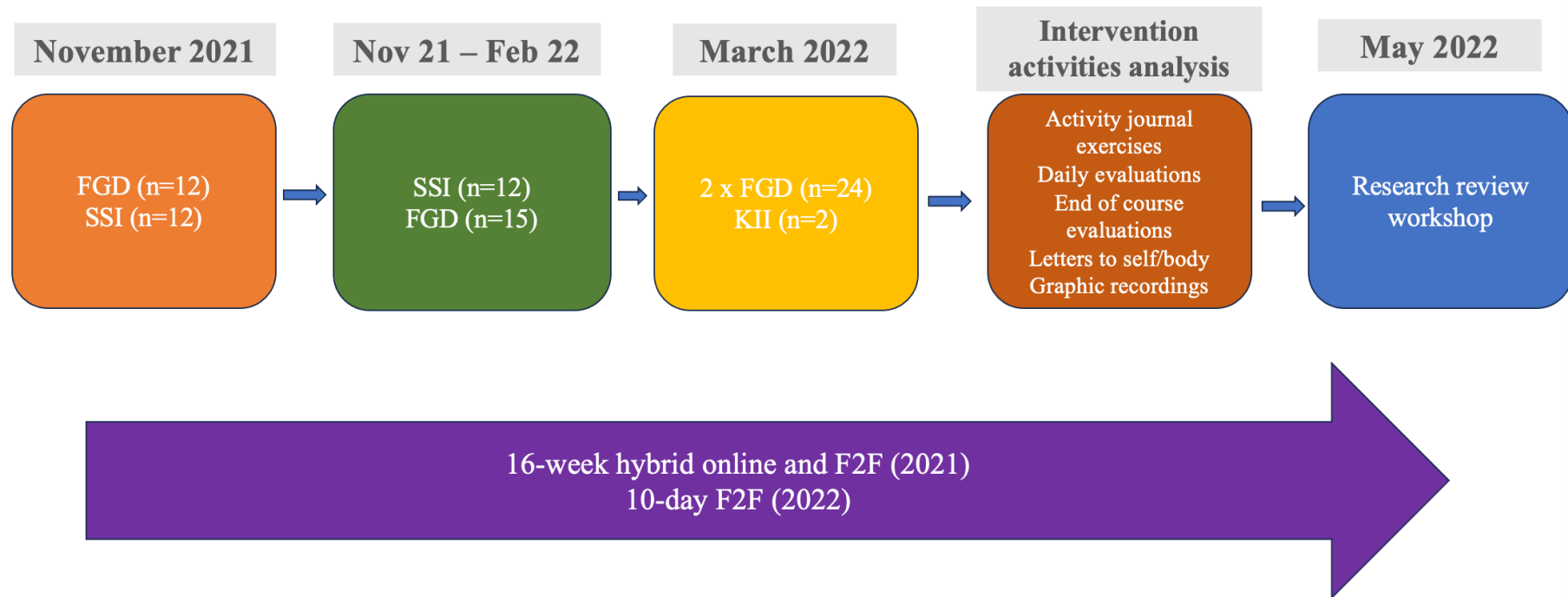
Application: How do these feeling and beliefs about yourself influence how you make life decisions?

Questions organised according to the three A’s of self-stigmatisation (Corrigan et al., 2009).

For the quantitative component of the intervention study in Chapter 4 data were collected using questionnaires that included scales and excerpts from the Internalised AIDS Stigma Scale (IASS) (Kalichman et al., 2009) (12 items), the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) (20 items), and the HIV/AIDS Targeted Quality of Life Scale (Holmes and Shea, 1998) (Holmes and Shea, 1998) (28 items), to measure mood, perceived stress, and quality of life. Quantitative data were collected just before the qualitative data collection described above, at each of the three timepoints in the study, before the intervention, just after the intervention and three months post-intervention.

For the study in Chapter 6 alongside semi-structured interviews, focus group discussions and written statements, data were also collected from intervention activities. This is illustrated in Figure 6 below:

Figure 6: Overview of data collection study in Chapter 6



Box 2: Example of intervention data collected during the exercises

Exercise: a letter to myself (self-forgiveness)

Dear me,

I wrote this letter to you so that you know that I have come to remembrance of all the things I did to you. I looked down upon you when I came to know that you are HIV positive. I did not believe in your potential. A lot came into my mind especially when I thought of your status, I thought you couldn't survive. I knew you had a purpose, but I had to let you down thinking you had no potential. I killed you and I even stopped taking my ARVs and on the contrary stopped maintaining your health.

Forgive me for who I was. Now I know I have changed I see hope, a better and greater future. You can do it no matter your status, nothing can stop you always look forward to fulfilling your goals.

Please accept this new me I have been lost but now I am convinced that I am found I believe in you, and you can do greater things, rise and shine I am always with you.

My status taught me that there are some situations that are beyond our control like being born positive. I am grateful that I am me and no one can be me. Now I do understand what it means to be positive. I love you and just be you.

Yours

Male participant, 19yrs old

Exercise: Fears/beliefs about disclosure

What are you afraid people will think, say or do if they knew about your HIV status?

-They will reject me

-They will judge me

-They will gossip about me

-They will separate from me

-They will see me like a moving grave

-They will start preparing my burial

-They laugh at me

-They will see me as unhealthy

Female participant, 20yrs old

Chapter 7, the systematic review identified and extracted both qualitative and quantitative studies from PubMed, Web of Science and Embase databases from inception until 31 August 2023. These databases were chosen based on expert recommendations made by Royal College of Surgeons in Ireland (RCSI) researchers as well as their relevance to the review question. Search strings were developed using the Population, Intervention, Comparison/control, Outcome (PICO) method for keywords. All references were imported into Covidence reviewing software (Veritas Health Innovation, Melbourne, Australia) and duplicates were removed. The author and two qualitative researchers took part in the initial title and abstract screening and full-text screening, with at least two reviewers screening each article independently. This reduced human error and increased the quality of the screening procedure. If there was a conflict, then the third researcher would review the article and the full team discussed the outcome. Following title and abstract screening, full-text articles were uploaded for the remaining studies. The full-text screening was completed by examining the articles for compliance with the inclusion/exclusion criteria. Again, two reviewers independently reviewed each article in Covidence. Conflict or clarification needed was discussed among three reviewers before a final decision was made.

2.5.2 Data analysis

In summary, inductive and deductive thematic analysis were used for the qualitative studies and a number of frameworks and models were used to guide and situate the analysis such as the HIV Stigma Scale (Berger et al., 2001), A conceptual model of HIV/AIDS stigma from five African countries (Holzemer et al., 2007a), the Internalised AIDS Stigma Scale IA-RSS (Kalichman et al., 2009) and the 3A's Framework (Corrigan et al., 2009). In terms of quantitative statistical analyses, Wilcoxon matched-pairs signed rank test was used for the data analysis of the intervention mixed method study in Chapter 4. For the systematic review in Chapter 7, data were analysed and categorised using the socio-ecological model (Krug et al., 2002).

For the studies in Chapter 3–6, interviews were transcribed in full and data were then thematically analysed following the process of familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes (Braun, 2013). New themes were added as they emerged, including themes derived from the previous studies in this thesis, and this process continued until no more new themes arose and

data adequacy was reached (Braun, 2021). This inductive approach, rooted in the sociological theory of social constructivism, understands human experience as socially created and shaped by a person's engagement with their culture and society (Amineh and Asl, 2015). Table 3 provides an example of thematic analysis from the study in Chapter 4:

Table 3: Full list of themes from study in Chapter 4

CATEGORY	THEME	SUB-THEME
Guilt	Blame	Blame from others
		Blame from self
		Blaming others
		Anger
		Pessimism & negative attitudes
		Suspicion & mistrust
		Disappointment
	Forgiveness	Forgiving others
		Forgiving self
	Hate	Hate from others
Hatred of others		
Hatred of self		
Stigmatisation		
Disbelief	Surprise & shock	
Shame	Shaming by others	
	Being ashamed of self	
Worthlessness	Reduced worth by others	Rejection
	Feeling worth less than others	
Negative perceptions of others	Perceptions of PLHIV	
	Perceptions of HIV itself	
Restricted agency	Work/education/family/other	Cannot work/ attend education
		Fired from work
		Passed over for work
		Having children/a family
		Travel
	Building house/building on land	
	Financial	Need money to pay for drugs, food etc.
Hopelessness	No hope for the future	
	Cannot go on living	
Fearfulness	Disclosure	Afraid of what others will think
		Afraid of loss of income
		Afraid for family/ children/ dependents
	Health	Worried about dying
		Worried about medication effects
		Worried about other illnesses
		Fear of contagion
	Fear for future	Worried about children if dying
Worried about security of medication supply		
Feeling down & depression	Depressed because of HIV	
	Depressed because of what others have said	
	Grief & loss	
Health & physical wellbeing	Physical difficulties	
	Self-image	Physical appearance
	Self-harm	Alcohol & drugs
	Sexual issues	Destructive behaviour
		Lack of intimacy
Lack of spontaneity		
		Lack of pleasure
Coping strategies	Acceptance	
	Personal networks	Support from others
		Support from family
		Giving support to others
	Increased agency	Affirmative action
		Desire to improve
		Education & knowledge
	Self-support	Positive mentality
Self-worth		
Overcome negative internal thoughts		
Relationships	Improved communication with family	
	Improved communication with others	
General dimensions	Stress	
	Change	

For each study, a team led by the author, worked to analyse, code and review consistency of coding. For example, in the study in Chapter 3, the author analysed and coded the data which was then reviewed by an RCSI qualitative researcher and discussed. In Chapter 4, an RCSI researcher did the preliminary coding work which was then reviewed by the author, two RCSI researchers and a Zimbabwean researcher to discuss the nuances of the coding and ensure interpretation of the meeting and categorisation was appropriate. Qualitative data analysis software was used in the studies, specifically NVivo 12 (QSR International, Melbourne, Australia) in the studies in Chapter 4 and 6 and QDAMiner Lite version 1.4.1 (Provalis Research, Montreal, Canada) in the study in Chapter 5.

In addition to interview and focus group discussion mentioned above, in the study in Chapter 6, thematic analysis included the written data from a 156-page Activity Journal containing worksheets, exercises such as letter to the self or body and homework. Daily and post evaluations from both interventions as well as graphic recordings were also used to triangulate the data. A selection of this data is included below in Figure 7:

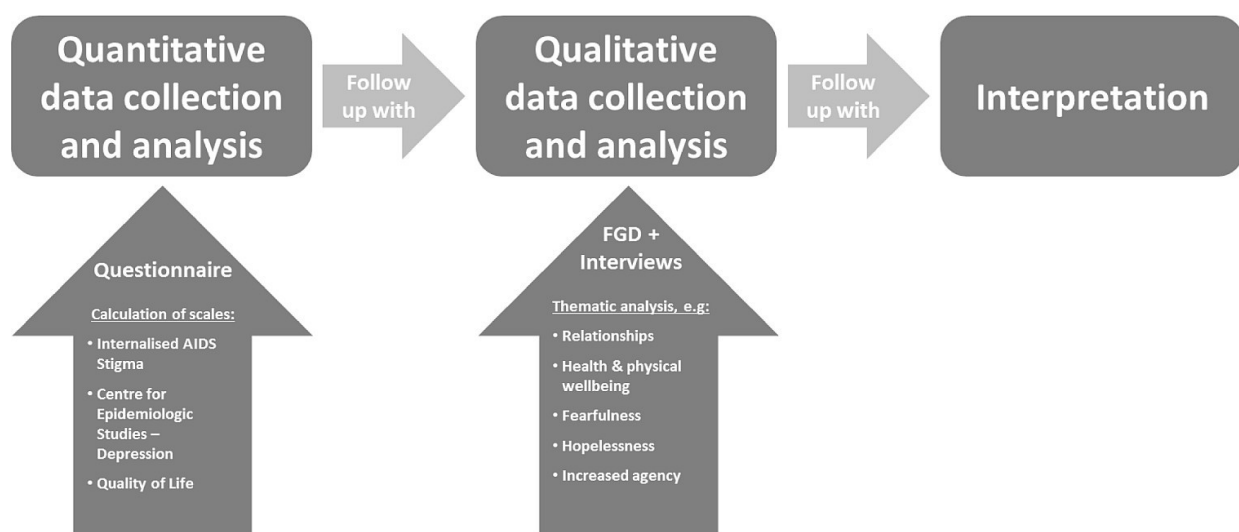
Figure 7: Example of graphical intervention data used to triangulate



In terms of quantitative data analysis, for the mixed methods study in Chapter 4, STATA version 15 (Stata Corp, Texas, USA) was used to calculate responses. Responses to each

questionnaire were coded numerically, and scale scores were calculated as the average of the items in the particular scale. The responses were matched by individual, and analysed taking into account all three data collection time points. Changes in score, together with their interquartile range (IQR) were presented. Changes in scores between baseline and 1- and 3-month follow-up were analysed using the Wilcoxon matched-pairs signed rank test. As a measure of effect size, r was calculated, based on the Z value of the Wilcoxon test, using the transformation $r = Z/\sqrt{N}$. Quantitative analysis was performed by an experienced quantitative researcher within the RSCI data science centre who was part of the team for that study. A research team, led by the author and including the quantitative researcher and two qualitative researchers then discussed and interpreted the data. An overview of this process is presented below in Figure 8:

Figure 8. Overview of sequential mixed methods study design for study in Chapter 4.



In the systematic review, Chapter 7, an initial search yielded 4584 studies of which 128 were included for full-review and 31 were fully extracted and included in the review. Data for the systematic review in Chapter 7 were assessed and analysed for quality across study types using the most commonly used checklists for particular research designs. The TIDieR Checklist (Hoffmann et al., 2014) guided the analysis of interventions to systematically understand their content based on a number of emerging themes around the intervention/programme, namely: theoretical basis; intervention characteristics; intervention approaches, content, and delivery; measurement and impact. The level at which implementation took place was also analysed using the socio-ecological model (Krug et al.,

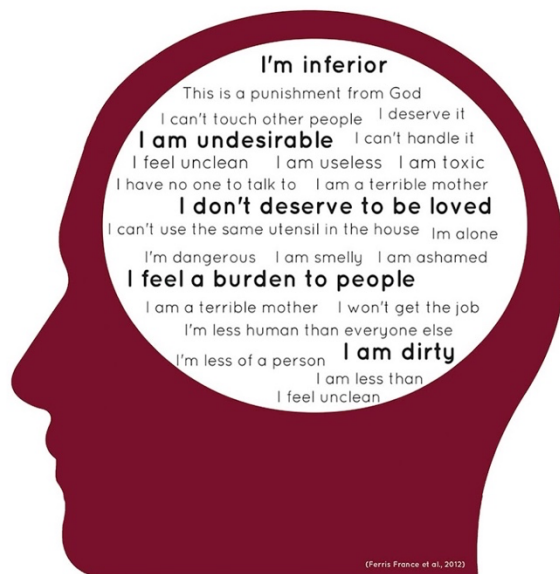
2002). Specific Annexes were produced for each of the analyses mentioned above. Finally, the Cochrane Handbook Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA) checklist (Page et al., 2021) was used to ensure all systematic review aspects were included. A comprehensive description of the systematic review methods is presented in Chapter 7.

2.5.2 Data dissemination

The 2013 version of the Declaration of Helsinki states '*Researchers, authors, sponsors, editors and publishers all have ethical obligations with regard to the publication and dissemination of the results of research*' (World Medical Association, 2013). Ensuring the results of the studies were disseminated and shared appropriately was a key priority of this research. This meant ensuring participants who took part in the study were able to see and comment on the results which in the case of the studies in Chapter 3 and 5, helped inform development of the interventions. It also meant that results were shared in several different and creative ways where the findings and the recommendations from the various studies were brought to the attention of global organisations that included policy makers and researchers with the potential to make change.

Research has shown that participants receiving feedback report feeling pleasure, feeling valued and feeling worthwhile (Bruhn, 2021). As the studies in this thesis were primarily about understanding self-stigma and testing an intervention to improve self-worth, the author felt it was particularly important to give feedback. Feeding back the findings in a simple and more visual way was another mode of analysis that assisted in validating our findings and was also useful when communicating our findings across different audiences. After each study, data was presented back to participants and interested stakeholders. For example, for the study in Chapter 3, a feedback session was conducted for Open Heart House which included participants of the study. An interactive PowerPoint presentation was shown together with a panel discussion featuring two of the participants and the researcher. More than 50 PLHIV attended the session. Figure 9, 10 and 11 are examples of how some of the findings from the studies were presented back to participants:

Figure 9: Self-stigmatising beliefs of PLHIV in Ireland (Chapter 3)



Data from the study in Chapter 4 was shared firstly with participants and then with the wider global community through a number of advocacy and research opportunities including webinars, meetings, national and international conferences and websites. Graphics were used to communicate the key findings:

Figure 10: Quantitative results (Chapter 4)

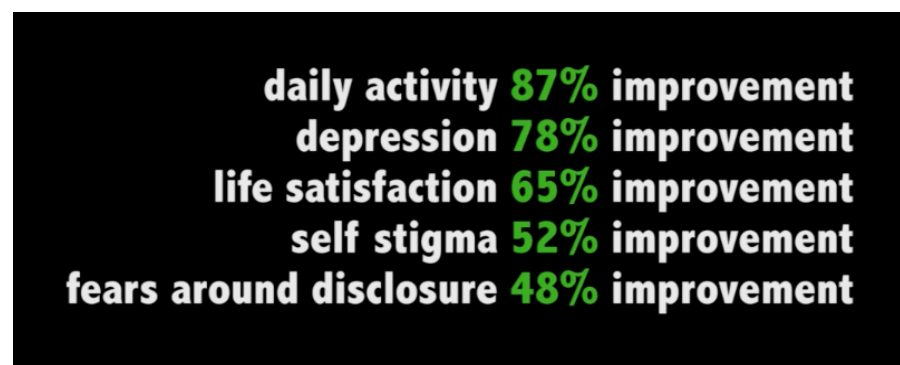


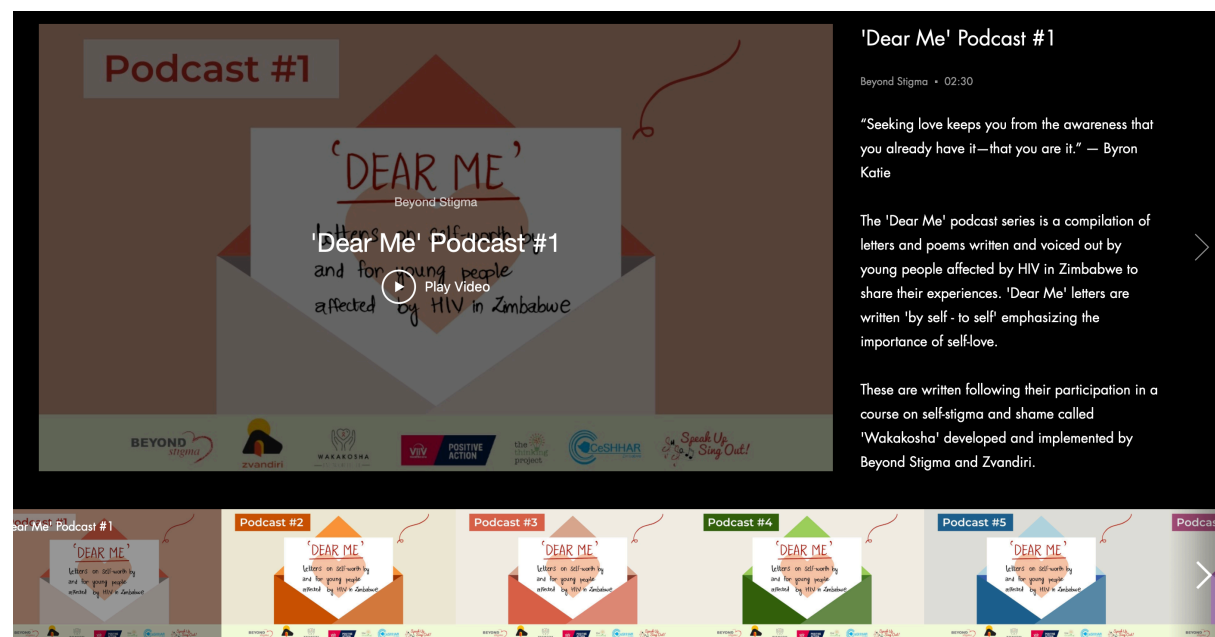
Figure 11: Qualitative results (Chapter 4)



The findings of this research have been presented in various ways, including the more traditional dissemination route of presentations at International and National Conferences detailed in Appendix A. In addition, with the support of the participants, a number of creative mediums have been used to communicate findings of the study in Chapter 6 and some are highlighted below.

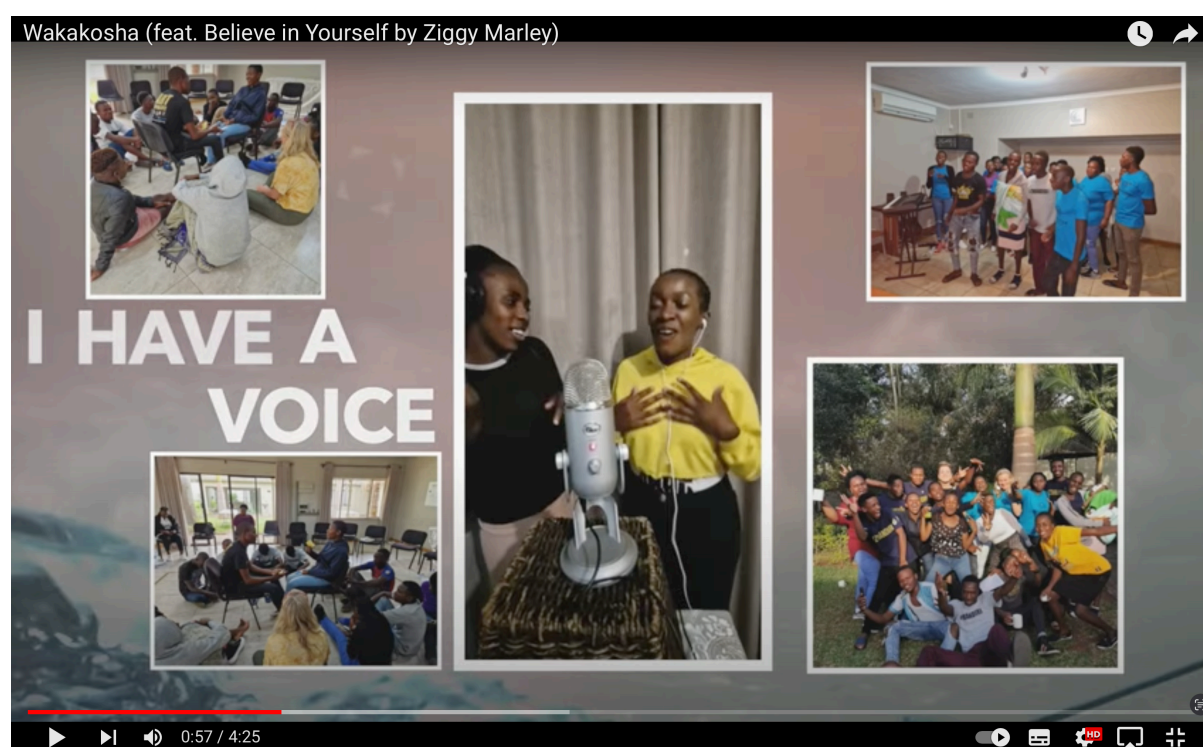
For example, with consent, a podcast series called 'Dear Me' (Beyond Stigma., 2022) was produced by recording the specific therapeutic exercise of writing a letter to myself. These letters were part of the curriculum under the theme of body. Each participant who wanted to be involved in this project, recorded their letter and a podcast series was produced and made available via typical podcast platforms including Spotify, Apple and also on YouTube (see Figure 12 below). Beyond Stigma and Zvandiri developed a social media strategy to disseminate the series to AYPLHIV in Zimbabwe as well as global advocacy and implementing agencies. 21 episodes were recorded and disseminated. The AYPLHIV who took part mentioned that they felt it was a positive way for their voices to be heard and their experience valued.

Figure 12: Creative data dissemination: Dear Me Podcast Series (Chapter 6)



A music video was recorded and disseminated by the AYPLHIV to share their experience and views about self-stigma and HIV, and how to overcome it (Crehan, 2022). Music and creativity were an integral part of the intervention in Chapter 6. As part of the curriculum, a professional musician and music coach worked with the AYPLHIV to write their own song about self-stigma. A workshop was held where the young people were supported to write lyrics based on their experiences of self-stigma and of the intervention. This was combined with analysis of feedback data from each session. Together the song was written and then performed, recorded and released as a music video. Dissemination included via a specific social media strategy of Beyond Stigma and Zvandiri and the music video was also played during the UNAIDS World AIDS Day event on 1 December 2022 that was livestreamed globally (see Figure 13).

Figure 13: Creative data dissemination: Wakakosha Music Video (Chapter 6)



Lastly, findings of the studies were shared via an international webinar with UNAIDS and the Global Network of People Living with HIV and AIDS (GNP+, 2023b). The author, an adult Coach living with HIV and one of the CATS Coaches (AYPLHIV) from the study in Chapter 6 spoke as part of an international panel to mark Global HIV Candlelight Memorial Day. This webinar was livestreamed globally and was aimed at national networks of people living with HIV and global, regional and national implementors and researchers.

The author believes that these examples illustrate meaningful dissemination of this research that has been able to reach the target population, people living with HIV as well as implementers and researchers.

2.6 Participant involvement in research

Within research, patient [participants] and public involvement and engagement (PPIE) is increasingly expected and recognised as adding value to research (Gilchrist, 2022). However, challenges persist to achieving meaningful involvement and engagement, particularly from participants who are hard-to-reach and seldom heard (Reynolds, 2021), such as PLHIV and within that AYPLHIV. Several efforts were purposively made in this research not just to ensure meaningful involvement, but also in recognition of the richness

participants add to the findings of the studies. For the two intervention studies in Chapter 4 and 6, participants were meaningfully involved in the research and design of the interventions at each stage of the research. For example, the first intervention was co-designed with two participants who then went on to become IBSR Coaches (Chapter 4). The interventions were co-delivered with Zimbabwean adult PLHIV and AYPLHIV who were trained and mentored to deliver the interventions (read more about this in Section 8.2.5 of Chapter 8). Participants were supported to deliver the research findings for the study in Chapter 4 during the 21st International AIDS Conference (AIDS 2016) held in Durban, South Africa (Beyond Stigma, 2016). For the study in Chapter 6, following the initial data analysis, a workshop was held with two adult Coaches living with HIV and three CATS Coaches (AYPLHIV) to present the findings and get their input on the interpretation on the analysis and into the discussion. Methods from the UNICEF approach of Visualisation in Participatory Planning Training were applied (UNICEF, 1993). As a result, the paper in Chapter 6 was co-authored by researchers, participants and Zimbabwean Adult Coaches living with HIV and CATS Coaches (AYPLHIV).

2.7 Reflexivity

It is acknowledged that within research the researcher is shaped by, and shapes the research processes and outcomes (Gilgun, 2008). Reflexivity is generally understood as awareness of the influence the researcher has on the people or topic being studied while simultaneously recognizing how the research experience is affecting the researcher (Gilgun, 2008). It is important to be cognisant of the role of the self in knowledge creation and the impact that personal experiences, opinions and biases have on the research (Berger, 2015). Below is a description of some of the influences my own experiences and views I was aware of during the research.

My disciplinary background is in social science, psychology and global public health and I have worked for over 25 years on HIV-related stigma within civil society, UN and the academic sectors. I have focused, for the most part on stigma as it relates to PLHIV, people affected by TB, sex workers, drug users and more recently people living with obesity. During this time, I have worked within and with marginalised communities and have always been interested in making sure their voices could be heard in whatever projects and programmes I was involved in. With a background in communication, my work with the World Health Organization (WHO) took me to Kosovo and Rwanda and involved qualitative interviewing

of women who had experienced violence with a view to meaningfully documenting their experiences. This combined work enabled me to work with people on emotional and intimate issues that were particularly challenging. From a young age, I was involved in mentoring young people and started to facilitate trainings on gender, adolescents and reproductive health and continued facilitating groups until now. I have always been interested in personal experiences and spent years working with PLHIV to support them tell their stories in their own words. Having worked in the NGO sector for over 15 years, I learned that a successful programme is not enough. That research is vital to demonstrate evidence and that the systematic process of research increases the learning of what works and what does not, and importantly why.

Due to divorce, I had my own deep and profound experience of self-stigma and shame, and discovered and used IBSR which had a hugely beneficial effect on my life and in which I was later trained. Coming into this research, I had a personal understanding of self-stigma and how it affects one's life and also how believing my thoughts was at the root of my suffering. That, together with my professional experience of HIV-related stigma, inspired me to do this PhD. This was a particular advantage in that I understood the disabling effects of self-stigma and I also understood the process of questioning negative core beliefs using IBSR and how powerful it is as an approach. I had also worked in Zimbabwe on and off for the past 15 years, so to that extent, understood the culture and the people in as much as is possible. Having worked in the NGO sector, I also knew that embedding interventions within the communities themselves is a sustainable and important part of meaningful engagement and change.

As a Certified Facilitator of IBSR and a trained Life Coach, I was involved in the design and the delivery of the interventions. The planning, design, implementation, and interpretation of qualitative research is influenced by a researcher's background, experiences, values and assumptions (Creswell, 2014, Guillemin, 2004). In four out of the five studies presented in this thesis (Chapter 4-7), there were a team of skilled researchers, local and international, involved in each study in the analysis and interpretation of findings, helping to ensure rigour and objective reporting and reduce the possibility of any bias by myself. Four of the studies were led by me, with one where I played a supervisory and technical role (Chapter 5). Some of the researchers were consistent and involved in all of the studies – this included one qualitative and one quantitative RCSI researcher. Their combined experience of research

spans 60 years in various topics of health, stigma, psychology, mental health and information systems in sub-Saharan Africa and in Ireland. Other researchers included young researchers starting their research careers together with experienced mixed methods Zimbabwean researchers with a great deal of experience on health and psychosocial issues related to AYPLHIV. Each of the researchers brought their own perspectives, experiences and helped make the research design and the interpretation of the findings richer.

Lastly, in 2015 I co-founded a non-profit organisation called Beyond Stigma. This enabled me to leverage the support of a group of very committed, experienced skilled researchers and implementers. It also meant we could develop institutional partnerships between Beyond Stigma and partner organisations in Zimbabwe and Ireland.

2.8 Ethical considerations

Four principles of ethical research guided this research (Braun, 2013): 1) the principle of respect which is concerned with confidentiality, privacy, consent and deception; 2) the principle of competence, being an ethical researcher, keeping standards of ethical decision-making and being aware of professional ethics issues; 3) the principle of responsibility, ensuring the rights of participants and that there is no potential risk or harm; and 4) the principle of integrity which refers to issues around accuracy, honesty and voice. Ethics were considered as a top priority in each of the studies, particularly as the focus was working with PLHIV and AYPLIV and on issues that are very personal and related closely to mental health. Special consideration was given to not just written informed consent but also oral informed consent to ensure participants thoroughly understood the research they were participating in. Psychologists and counsellors were present or made available for participants in case participants felt the need to seek more support following the exploratory research and the interventions. Ethics approval was obtained for four studies included in this thesis. Chapter 3 obtained from the Health Policy and Management Centre for Global Health Research Ethics Committee in the School of Medicine, Trinity College, Dublin. Ethical approval for the study in Chapter 4 was obtained from the Medical Research Council (MRC) of Zimbabwe (approval number MRCZ/A/1782). Ethics approval was obtained for the study in Chapter 5 from both the Health Policy and Management and Centre for Global Health Research Ethics Committee in the School of Medicine, Trinity College, Dublin and the Medical Research Council of Zimbabwe (#2604). The study in Chapter 6 was approved by

the National Ethics Committee, Medical Research Council of Zimbabwe (#2604), under the same project as the study in Chapter 5. Finally, no ethics approval required for the research included in Chapter 7 (Systematic Review) as there was no patient and public involvement and there was no involvement of animals.

2.9 Chapter summary

This chapter has described the overall approach taken in the studies that comprise this thesis – an implementation research design in the pragmatist paradigm. An overview of the data collection and analysis methods of the five studies was given. Additionally, the role of the researcher and research participants was described as this influenced the research design and dissemination strategy.

Chapter 3: “An unspoken world of unspoken things”: a study identifying and exploring core beliefs underlying self- stigma among people living with HIV and AIDS in Ireland

3.1 Commentary

A qualitative study carried out in Ireland to better understand the core self-stigmatising beliefs of people living with HIV and AIDS; the functions of self-stigma; and to learn more about strategies to overcome it. This study responded to the paucity of research internationally aimed at understanding causes and functions of self-stigma as well as the lack of interventions to mitigate its harmful effects. In this study, an existing conceptual framework on self-stigma was adapted and proposed. This paper was published in the Swiss Medical Weekly. 2015;145:w14113 with the following title: “An unspoken world of unspoken things”: a study identifying and exploring core beliefs underlying self- stigma among people living with HIV and AIDS in Ireland with the following authors:

Nadine Ferris France, Irish Forum for Global Health/Trinity College Dublin

Steve H. Macdonald, Irish Forum for Global Health

Ronan R. Conroy, Royal College of Surgeons in Ireland, Dublin, Ireland

Elaine Byrne, Royal College of Surgeons in Ireland, Dublin, Ireland

Chris Mallouris, UNAIDS, Geneva, Switzerland

Ian Hodgson, Independent Consultant

Fiona N. Larkan, Trinity College Dublin

The paper has been reformatted to fit the style of the thesis but was submitted and published according to the specifications of the journal.

3.2 Abstract

Principles:

Human immunodeficiency virus (HIV) related self-stigma – negative self-judgements resulting in shame, worthlessness and self-blame – negatively influences access to care and treatment, and overall quality of life for people living with HIV (PLHIV). Despite evidence that high levels of self-stigma exist among PLHIV, and is experienced to a far greater extent

than stigma received from the broader community, there is a paucity of research aimed at understanding causes and functions of self-stigma, and an absence of interventions to mitigate its harmful effects. Understanding the core beliefs underlying self-stigma is therefore essential.

Methods:

This pilot study used a qualitative approach to analyse interviews and written statements to uncover core beliefs underlying self-stigma, the functions thereof, and strategies used to overcome it, among a heterogeneous group of PLHIV in Ireland.

Results:

Core beliefs underlying HIV-related self-stigma were uncovered and grouped into four categories: disclosure; sexuality and sexual pleasure; self-perception; and body, illness and death. Reported functions of self-stigma included contributing to maintaining a “victim” status; providing protection against stigma received from others; and justifying non-disclosure of HIV status. To cope with self-stigma, participants highlighted: community involvement and professional development; personal development; and connection to others and sense of belonging. Findings were also used to create a conceptual framework.

Conclusions: This study helps fill identified gaps in knowledge about self-stigma as experienced by PLHIV. By understanding the core beliefs driving self-stigma, it will be possible to create targeted interventions to challenge and overcome such beliefs, supporting PLHIV to achieve improved wellbeing and lead productive lives free of self-limitation and self-judgement.

3.3 Introduction

Human immunodeficiency virus (HIV) infection is increasingly becoming perceived as a chronic disease. Those infected can expect to achieve a full life-span of 72–75 years (Nakagawa et al., 2012), if appropriate treatment and support are available. As a consequence, the focus of health services, and of those living with HIV, is turning from preventing illness and death to optimising quality of life and enabling the fulfilment of life goals. Even where HIV prevention programmes are effective, ongoing fears around the outcomes of testing and disclosure (and broader social implications of a positive HIV diagnosis) mean the challenges of living with HIV are likely to persist. HIV-related stigma acts as a significant barrier to

prevention, testing and treatment (Parker et al., 2002, Castro and Farmer, 2005, Deacon, 2006). Although Ireland has a relatively low incidence of HIV (Health Services Executive Health Protection Surveillance Centre, 2012), stigma and discrimination for those infected still pose a significant challenge: 49% of people living with HIV (PLHIV) in Ireland reported experiencing discrimination by friends and 43% by the local community (Stamp Out Stigma Campaign, 2007). Stigma occurs at varying, inter-related, levels: enacted stigma (discrimination), referring to actions or omissions as a result of stigma; societal/perceived stigma, where an individual anticipates or perceives themselves as stigmatised; and finally self-stigma – negative self-judgements resulting in shame, worthlessness and self-blame (Kalichman et al., 2009).

Socially derived stigma has been widely studied in people living with illness and disabilities (Scambler and Hopkins, 1986, Robertson M and C., 1997, Ablon, 2002, Jamison, 2006), but focussed rarely on self-stigma, also termed “internalised stigma”. In HIV, the Asia-Pacific Regional Analysis of the Stigma Index Study in nine countries, involving 4395 participants, found disturbingly high levels of internalised stigma manifesting as shame, guilt and self-loathing. For example, 75% of PLHIV in Pakistan reported they were ashamed of their HIV status, and in Sri Lanka, which reported the least self-stigma, 54% of participants reported being ashamed (GNP+, 2011). Self-stigma also has broader repercussions, leading to failure to seek treatment and use care services, reduced wellbeing (Simbayi et al., 2007), depression (Wight, 2000), low self-esteem and reduced self-efficacy (HDN, 2005), poor long-term coping (Kalichman et al., 2009), and lower quality of life (Earnshaw and Quinn, 2012). A recent study by Overstreet, cited in Cairns (2013) (Cairns, 2013), also found that people with internalised stigma were less likely to disclose their HIV status to partners or families. It would appear from the literature that self-stigma is experienced by HIV-infected people to a far greater extent than stigma received from the broader community (Kalichman et al., 2009, GNP+, 2011, Demchenko et al., 2011, Association des Veuves Vulnérables Affectées et Infectées par le HIV/ AIDS (AVVAIS). et al., 2009, Myanmar Positive Group (MPG) et al., 2010, Network of Networks of HIV Positives in Ethiopia (NEP+), 2011, Network of Zambian People Living with HIV/AIDS (ZNP+), 2012). Kalichman et al. (Kalichman et al., 2005) reported that, of 2,306 adults in the general public in Cape Town, 10% believed that PLHIV were dirty, contrasting with 27% of PLHIV who felt they were dirty; 13% of the general public believed that PLHIV had done something to deserve it, as opposed to the 41% of PLHIV who felt guilty about having been infected. The same pattern can be found in

Ireland, where 84% of PLHIV feel they are viewed negatively by society whereas 54% of the general public shared that view (Stamp Out Stigma Campaign, 2007). Lastly, the fact that self-stigma was observed as greater than levels of stigma in the general population strongly suggests that self-stigma is not just an internalisation of the prevalent social stigma, but a distortion and amplification of it.

“Stigma” was defined by Goffman in 1963 as “an attribute that is significantly discrediting” which in the view of others serves to reduce the person who possesses it. Goffman also importantly identified stigma as a complex and multi-dimensional phenomenon (Goffman, 1963). For Link and Phelan (2001), there is variability not just in definition, but also its application by researchers (Link and Phelan, 2001). Link et al. in 1997 defined “self-stigma” as “the extent to which people endorse negative beliefs and feelings associated with their stigmatized attribute and apply them to self” (Link et al., 1997). As they are central to the manifestation of self-stigma, core beliefs must be considered – i.e., the “fundamental, inflexible, absolute and generalised beliefs that people hold about themselves, others, the world and/or the future” (Beck, 2011). In shaping an individual’s worldview, core beliefs that contribute to self-stigma can have a profound effect on a sense of self-efficacy and concept of self (Wenzel, 2012). Understanding the core beliefs underpinning self-stigma can be a foundation for interventions and programmes designed to reduce its harm.

From the outset, the study reported on here was cognisant of gaps in interventions to support PLHIV in dealing with self-stigma. For example, Sengupta et al. (Sengupta et al., 2011) reported that, despite the negative impact of stigma on PLHIV, there have been surprisingly few intervention studies aimed at reducing HIV-stigma to date. This is particularly the case with self-stigma, which is under-represented in the research literature. Kalichman and Simbayi (Kalichman and Simbayi, 2004), who have widely published on HIV-related stigmas, acknowledge that approaches are needed that go beyond mass education and work within more ingrained belief systems.

The identification of unhelpful or negative core beliefs is the basis from which individuals can be supported in developing healthier belief systems through cognitive therapy strategies (Wenzel, 2012). The use of stress-management interventions also shows evidence of efficacy: Brown and Venable’s review (Brown and Venable, 2011) of literature reporting stress-management interventions for PLHIV, concluded that there is a growing body of evidence

demonstrating that these interventions – including cognitive behavioural interventions, meditation, mindfulness and relaxation – in the context of HIV can reduce psychological distress and improve psychosocial functioning. Among such interventions, the inquiry-based stress reduction (IBSR) technique, developed by Byron Katie (Katie and Mitchell, 2003, Katie and Mitchell, 2007) supports participants in reducing their perceived level of stress by self-inquiry on thoughts and beliefs connected to stressful circumstances or symptoms. IBSR has shown positive results in a trial among survivors of breast cancer (Lev-Ari et al., 2013), but has not yet been applied to the support of PLHIV. Another technique, cognitive behavioural therapy (CBT), is perhaps the most researched psychotherapeutic approach and has a growing reputation for being a highly effective treatment in dealing with stressful beliefs or thoughts (Hayes).

To successfully address self-stigma, core beliefs underlying this phenomenon must first be identified and contextualised. This study was designed to: (a) identify and gain understanding of core beliefs underlying self-stigma in PLHIV in Ireland; (b) enhance understanding of the phenomenon; and (c) inform interventions aimed at mitigating its harmful effects. Three research questions were formulated:

1. What are the core beliefs underlying HIV-related self-stigma among the studied group of people living with HIV?
2. What are the functions of self-stigma among the studied group of people living with HIV?
3. What coping strategies are used by participants to manage self-stigma?

3.4 Methodology and data collection

A qualitative approach within the interpretivist paradigm was adopted for this research. This allowed for a deeper understanding of the lived experiences of individuals that could subsequently help inform the design of a therapeutic intervention. Semi-structured interviews and written statements were used to gather information from participants. Each interview lasted approximately one hour and was recorded, with prior written consent. During interviews, participants were asked to write the following open-ended statement: “I am HIV positive and that means that...” (participants with limited literacy dictated their statements to the researcher). This approach is commonly used to draw out core beliefs as part of inquiry-based stress reduction: the work of Bryon Katie (Katie and Mitchell, 2003). A similar method is used in cognitive behavioural therapy (Williams and Garland, 2002).

Ethical approval for this study was granted by the Health Policy Management / Centre for Global Health Research and Ethics Committee at Trinity College Dublin. Participants were purposively selected from Open Heart House, the largest Irish peer-support network of PLHIV at the time of the research. Owing to the highly varied nature of the epidemiology of HIV in Ireland (Health Services Executive Health Protection Surveillance Centre, 2012), the studied group included a large degree of heterogeneity, incorporating male, female and transgender participants, as well as migrant individuals, drug users, men who have sex with men (MSM) and heterosexuals. Seventeen potential participants were approached, and all agreed to participate. Participants' ages ranged between 31–51 years (average age 43 years); 6 were women, 10 were men, and 1 was transgender. Participants had been living with HIV for between 3 and 29 years (average 11 years). Participants' nationality was predominantly Irish, but also included individuals from South, East and West Africa, and East and Central Europe. Further participant details are included in Table 1. Although there was diversity within the sample, it was too small to analyse across differences in gender, race, ethnicity and nationality. The core beliefs outlined in this study are therefore drawn from across the group as a whole.

A review of current frameworks and models for measuring stigma and self-stigma informed the analysis and thematic clustering of this study.

Early work by Berger et al. (Berger et al., 2001) highlighted four main categories to understand and measure stigma: personalised stigma, disclosure concerns, negative self-image and concern for public attitude. Poku et al. (Poku et al., 2005), in a qualitative study better to understand stigma, highlighted social rejection, financial insecurity, internalised shame, social interaction, self-worth, and body image as main dimensions. Providing more detail and broadening the categories on self-stigma, Holzemer et al. (Holzemer et al., 2007a) presented a framework that also included self-exclusion, negative self-perception and overcompensation.

Most recently, building on extensive formative qualitative and quantitative research on HIV-stigma, Kalichman et al. (Kalichman et al., 2009) developed the Internalised AIDS-related Stigma Scale (IASS). The framework drew upon previously validated scales and beliefs guided by the theoretical framework offered by Goffman (Goffman,

Table 1: Study demographics and participant information (n = 17), showing participants' medication status, country of origin, exposure group, employment and relationship status.

Currently taking ARVs:	
Yes	16
No	1
No. of years taking ARVs:	
Mean	9
Range	0.2–26
Country of origin:	
Ireland	11
Germany	1
Poland	1
Côte d'Ivoire	1
South Africa	1
Nigeria	1
Botswana	1
Exposure group:	
Heterosexual	9
IDU	4
MSM	3
Unknown	1
Currently employed:	
Yes	11
No	6
Ever been ill due to HIV:	
Yes	13
No	4
Has children:	
Yes	10
No	7
Currently with intimate partner:	
Yes	7
No	10
ARVs = antiretroviral drugs; IDU = intravenous drug use; MSM = men who have sex with men	

1963), and proposed six scale items covering self-defacing beliefs and negative perceptions. Interviews were transcribed in full, then thematically coded and analysed using an iterative coding strategy guided by the frameworks outlined above. The themes were continually and systematically updated as the data was analysed, reanalysed and grouped into various themes. New themes were added as they emerged, and this process continued until no more new themes arose and data saturation was reached (Silverman, 2000).

3.5 Results

Core-beliefs

Owing to the complex nature of stigma and self-stigma (Nyblade, 2006), some overlap occurred between the emerging themes. However, it was possible to group participants' core beliefs contributing to HIV-related self-stigma under four categories (Figure 1).

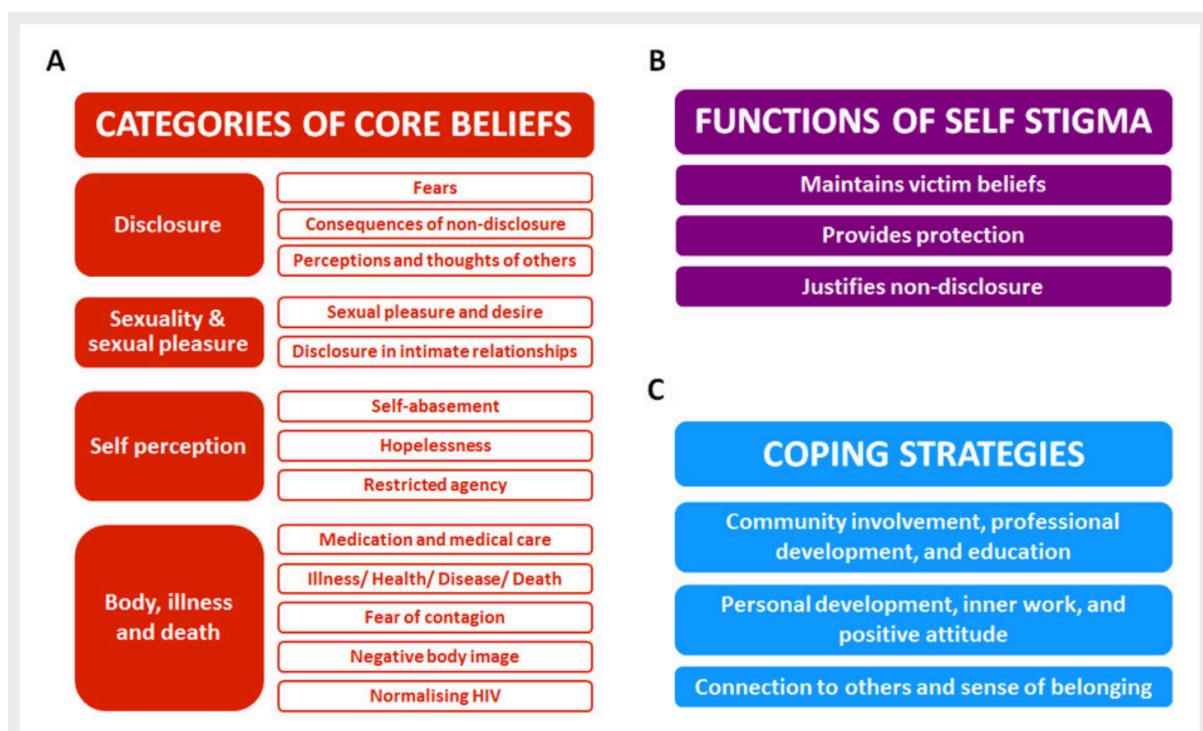


Figure 1

Framework for qualitative analysis of interview data.

Three main areas of analysis are shown: Categories of core beliefs (A, red), Functions of self-stigma (B, magenta) and Coping strategies (C, blue). Emergent themes were organised into categories (solid boxes), and subcategories where required (open boxes).

1. Disclosure: here, participants' core beliefs surrounding disclosure of their HIV status were reported – for example, some held the belief that others would reject them if they were discovered to be HIV positive.
2. Sexuality and sexual pleasure: this category included participants' core beliefs influencing sexual behaviour, such as the belief that they could no longer enjoy sex with an intimate partner.
3. Self-perception: the core beliefs held by participants about, for example, their sense of worth or agency fell into this category – such as believing that they were worthless or that they could not have a child or find employment because of their status.
4. Body, illness and death: in this category, beliefs surrounding the physical effects of HIV were recorded – for example, some of the participants believed that they were likely to suffer prolonged illness, and a slow death, as they had witnessed in other HIV patients.

Disclosure

Fears and consequences of disclosing one's HIV status are well documented elsewhere (Berger et al., 2001, Petrak et al., 2001, Parker and Aggleton, 2003, Medley et al., 2009). Notably, people with higher levels of self-stigma are more likely to avoid disclosing their status (Steward et al., 2008). We sought to understand more fully the beliefs contributing to fear and stress around disclosure, and within this category participants' beliefs were broadly grouped into three subcategories.

Fears

A fear of being talked about and ridiculed was expressed by many participants, as well as of being labelled and stigmatised. Here, beliefs about being rejected predominated: "I don't want people to throw me away, like if yesterday I was talking very good with this person, today you tell him you are HIV positive, tomorrow you can feel like he don't want to talk to you." (Participant K). Fears of betrayal had also engendered a lack of trust in many participants: "You can't trust nobody, so everyone is like an island...you stick to yourself, you sort your problems out yourself, you can't call on anyone because the person you think you can talk to and trust will end up betraying you." (Participant P) A variety of beliefs regarding disclosure within families were reported. These included the belief that non-disclosure could protect family members from emotional hurt, or that disclosure would

expose family members to secondary stigma. In certain cases where participants had already disclosed to their family a culture of silence emerged where HIV was never discussed.

Consequences of non-disclosure

Social exclusion and secrecy were commonly mentioned as outcomes of non-disclosure, in particular self-isolation and loneliness. Few participants reported actually losing friends, whereas most reported withdrawing themselves from social circles. Although social exclusion has been previously identified in the literature (Holzemer et al., 2007a, Brouard and Wills, 2006, Golden et al., 1982), it is possible that withdrawing from society is a bigger negative influence in the lives of PLHIV than actually being rejected – a finding supported by the Global Network of People living with HIV (GNP+) (GNP+, 2011). Some participants believed that they lived two lives – one open and honest amongst other people with HIV and another secretive, false and lonely in the outside world. “It’s almost like trying to bring these two worlds together, where it can be the same in both, so that’s exactly the point I’m at right now...bringing it out into my real life, and with the hope I can be like, the way I am here [in Open Heart House], where I can have the same energy.” (Participant I)

Perceptions and thoughts of others

A common belief among participants was that they were viewed as bad and different: “They think I’m a scumbag, the lowest of the low.” (Participant H) This was particularly linked with perceived judgements from others as to how they contracted HIV: “...if I had to tell somebody I had HIV, the first question they ask me is: ‘how did you get it?’... if I was to answer that question, ‘I got it through drugs’...you see the change in people – you see the look they give you, it’s like, ‘oh, she deserved that’...” (Participant B) Several participants also reported believing their HIV status was viewed by others as less “worthy” of sympathy than other diseases: “If you’ve done a survey and you asked people, ‘there’s two people there...that one has cancer, that one has HIV – who do you feel more sorry for?’, nine times out of ten, people say ‘cancer’.” (Participant A)

One participant suggested human interaction begins to be framed within the context of HIV, and becomes the over-riding perspective when dealing with others: “There is this thing when you are HIV positive, you become very sensitive to what people say and how they treat you.

You judge people...you become sensitive to what people do to you, because you feel they do it because you're HIV positive... So every single thing someone does to you, you read it as because you're HIV positive.” (Participant A)

Sexuality and sexual pleasure

Whereas some participants were currently involved in sexual relationships, many reported that sexual pleasure and intimacy were affected by their beliefs about self-image, fears of transmitting HIV, feelings of guilt, and lack of freedom. Here, core beliefs fell into two subcategories.

Sexual pleasure and desire

Here, participants described beliefs about never being able to have a partner, or that “normal” relationships could not be regained: “[In] my sex life, like he doesn’t say it, but I feel it, the intimacy is gone. The, you know, experimentation and stuff, all that’s gone, it’s just basic with the condom. I tried to say to him, you know I’m un-detectable, this is what the doctors say. But then I feel guilty for saying that, ‘cause I’m saying, sure he must be thinking this one just wants to have sex without a condom...does she want me to catch it and it’s not about that, it’s about trying to get back what we used to have.” (Participant A). Some reported sex was no longer spontaneous and they no longer had sexual feelings. Additional negative influences, such as fear of contagion, feelings of guilt for having sexual needs, and lack of energy and interest, were also mentioned. The inability to enjoy sex or any sexual aspect of a relationship was also discussed, and many participants believed their own sexuality had been lost or taken from them: “I feel like something has been stolen from me, because I can’t, as much as I’m sexually active, I cannot do that, I can’t just be free and do what I want to do.” (Participant Q)

Disclosure in intimate relationships

Outside of core beliefs affecting sexual behaviour itself, a common belief among participants was their inability to seek a new partner – the risk of rejection and discrimination was too great: “...I don’t know what to do, where to go, how to proceed. I’m afraid of telling the person, getting a bad reaction, and that person having that information that [they] can just tell anybody else...” (Participant F). Not all beliefs were negative, however, and some

participants shared their positive experiences of being honest and not experiencing rejection: “If anything I was more respected for being honest and being in the position to be able to give the information.” (Participant C).

Self-perception

Well documented in the literature on self-perception and self-stigma are issues of self-abasement and restricted agency (Kalichman et al., 2009). In this study, core beliefs affecting self-perception were reported across three subcategories.

Self-abasement

For one participant: “It’s great when I’m here in Open Heart House – I’m with [my own people]. But it’s different when I’m outside. It’s very hard...because I know I’m just the same as everybody else, and I don’t deserve, you know...but that dirty feeling still stands, no matter how much I wash, or how many clothes you buy, or how pretty you look. Inside [you still feel] that...worm picking away. Some days I feel toxic...as if there’s something eating away from the inside that no one else can see. But every day I feel a little bit less, like I’ve changed. You change when you’re diagnosed, and it’s not what people [say] to me. I really believe, it’s an unspoken world of unspoken things.” (Participant A) Another participant explained just how powerful the inner world of self-stigmatising beliefs was: “[My] inner dialogue was [that] God has punished and [put] the X on the red [door]. I felt like I couldn’t touch other people [and] couldn’t use utensils in the house that other people were using...I just felt really, really unclean all the time. I was one of the undesirables. I had really fallen...to an undesirable part of society and this was God’s choice and I was done.” (Participant F). Many participants shared feelings and beliefs about being different from others. For one: “I see everyone out there as the same but I’m different, and that I don’t have the same chances. You feel like this special case...a weakness.” (Participant I). A powerful theme in the data included beliefs about being less human, undeserving, and attributing self-blame. Illustrating how some participants devalue themselves one participant said: “If the world was ending me, and other people like me, would be left – we would not be saved.” (Participant A). Though many participants became emotional as they shared beliefs and experiences during interviews, it was sharing how they viewed *themselves* that caused the most distress. This suggests strongly the damaging influence of self-stigma in the lives of participants.

Hopelessness

Hopelessness and self-pity frequently emerged among participants' core beliefs. Several cited depression, suicidal thoughts, and feelings of hopelessness stemming from beliefs such as life being over, HIV being a killer disease, feeling a victim, being a burden to people, and not seeing any hope for the future. Though participants were answering questions specifically about HIV, responses encompassed their lived experience as a person, with HIV being just one of many difficult life challenges. "I've been abandoned by my parents, living on the streets of Dublin, [and] get HIV – so why I am on this planet? For punishment, punishment, punishment. That's all I seem to be getting. I can't find happiness anymore. Some days I try to be up but more times I'm down and there's only so much you can take as a human being. Sometimes I question myself: what am I living for? I don't see any life out there. I see nothing there for me. All I see is a brick wall and every time I try to get over it something knocks me back." (Participant J)

Restricted agency

In line with wider literature (GNP+, 2011, Demchenko et al., 2011), in relation to restricted agency, participants described a number of significant actions and opportunities they believed were not possible because they were HIV positive. For many, this included not being able to have a child, not being able to find work, or work in places of their choice, not being able to travel, having to choose friends carefully, and not being able to find a life partner: "It stops so many things." (Participant Q).

Body, illness and death

Among core beliefs shared by participants around medication and medical care, negative side-effects and an inability to take part in life activities were mentioned frequently. Here, core beliefs emerged across five subcategories.

Medication and medical care

In some cases, participants felt as though they were not treated properly as human in their dealings with medical services: "Sometimes you feel like a guinea pig, they are taking blood tests and they don't tell you what's it for." (Participant M)

Illness/health/disease/death

When discussing illness, most participants expressed fears about sickness and dying: “I [will] end up dying the way I have actually seen others people dying, which is piece by piece and become mentally deficient, physically deficient, and the fact that it is a slow process.” (Participant O). Beliefs that led to stress around health emerged frequently: “Health has become much more of a focus – any health. I get a cold, I get worried. I get a headache, I get worried.” (Participant O)

Fear of contagion

In addition to fears for their own wellbeing, core beliefs extended to the impact of their condition on the lives of others. Many believed they would be a risk to family and friends. For one: “I was paranoid because I didn’t know when I found out [my status]. I had my own cups, my own knives and forks, [and] I kept all of them. I wouldn’t kiss my grandchildren. Even now I won’t kiss them – my grandson asks why I turn my face away.” (Participant M)

Body image

Several participants shared beliefs about negative body image – including weight and body shape changes – that contributed to their self-abasing thoughts. Notably, self-perception had changed – even if physical changes had not yet occurred:

“It’s amazing what you see in the mirror that isn’t there; I really, really hated myself.” (Participant F). Demonstrating the complexities for some, one participant shared their experience: “For me, all this stuff is intermingled with trans identity. In order to go on hormones to get an ideal body shape to be a she, obviously I’ve had some breast development, not much. I’ve had to stop taking hormone replacement therapy because of contraindications [with HIV medication].” (Participant O).

Normalising HIV

Conversely, some participants stated that their self-image had improved, mentioning they now took more effort in self-care – for example giving up smoking and doing exercise.

Functions of self-stigma and coping strategies

In addition to core beliefs, the findings also provide insights into the functions of self-stigma (i.e. the “purpose” of self-stigma, as participants perceived it), and coping strategies to assist in its reduction (e.g. adaptations in behaviour and social interactions).

Functions of self-stigma

In the same way that social stigma may be seen to serve some function or benefit to society (Link and Phelan, 2006), it is also likely that self-stigma has a function or benefit to individuals. Participants’ responses highlighted three subcategories of functions of self-stigma (see fig. 1B).

Maintains victim beliefs

Self-stigma may subconsciously reinforce the individual as a victim, taking away the sense of personal agency and thereby contributing to a feeling of disempowerment: “Before someone can do anything to stigmatise me or discriminate me I’ve already felt the discrimination, because you need to blame someone for what is happening to you. If you go downstairs here [at Open Heart House] and ask 50 people that are HIV positive, they will say it’s not their fault. Everyone will explain to you that it’s not their fault – everyone will be a victim. Yes, it’s a strong word to call HIV positive people.” (Participant P).

By thinking negative thoughts about themselves, individuals may self-stigmatise in anticipation of being hurt by others: “I say all these things to myself first that when I do have to go out into the world to survive, the stuff that people thinking about, I’ve already thought about myself, so nothing can get through, so its like a protection mode, you self-stigmatise yourself so that other people can’t hurt you.” (Participant A).

Justifies non-disclosure

Self-stigma may serve as a reasoning tool to limit one’s life choices, and rationalise actions such as avoiding disclosure: “I come up with all the bad stuff that people can think about me. It’s to protect myself so that I don’t have to come out and say I’m HIV positive.” (Participant A)

Coping strategies

Many negative outcomes arising from being HIV positive and experiencing self-stigma had functional opposites in the coping strategies reported by participants. For example, several spoke of the importance of having a sense of belonging, acceptance, and a connection to others, thus directly addressing their feelings of social withdrawal and isolation. A sense of renewed agency was also reported, where participants found work or started volunteering after being diagnosed. Indeed, a sense of personal development strongly beneficial. Coping strategies were grouped into three broad subcategories (fig. 1C).

Community involvement, professional development and education

Some participants were motivated to return to education and, as a result, were now working – some for the first time. Participants sharing this view were engaged in community work and spoke of the sense of self-worth gained through providing support to others: “I would have never ended up in a job if I had never become HIV positive. It just gives me great joy to sit with somebody who is in great despair and desperation and to say to them, ‘I genuinely know what you are going through’.” (Participant A).

Personal development, inner work and positive attitude

Participants also shared positive beliefs about themselves, their lives and abilities, having come to a positive place through personal development, inner work, and finding peace. “I believe that I’m more accepting today – actually I fully accept who I am now. [Living with HIV is] a tiny part of who I am so it doesn’t stop me from doing absolutely anything.” (Participant C).

Connection to others and sense of belonging

The majority of participants shared the importance of the space created by Open Heart House in fostering a sense of belonging, providing support, and being community of people, they would not have otherwise met.

3.6 Discussion and conclusions

Core beliefs of participants: Rather than simply showing *levels* of self-stigma, the results of this formative study build our understanding of beliefs reported by PLHIV. Although these are likely to vary across geographies and cultures, a number of core beliefs reported by this

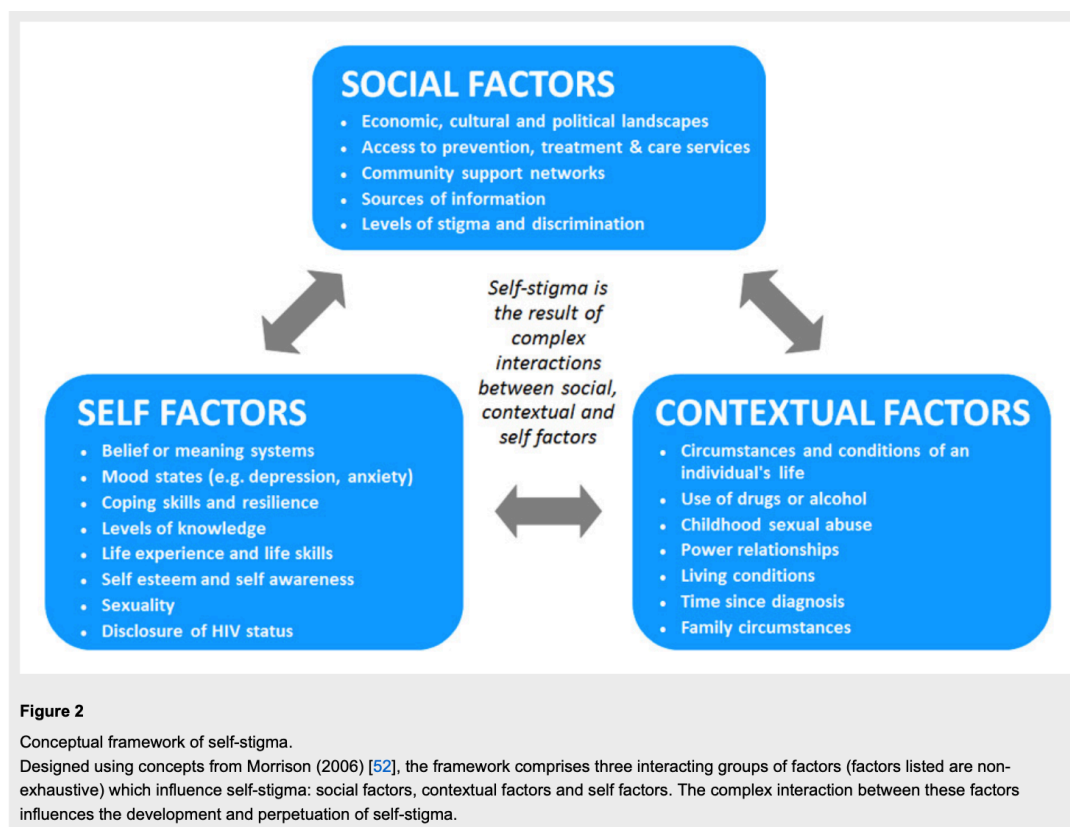
small and heterogeneous group could occur independently of gender, religion, or country – for example, the belief that one is “unclean”, undeserving of sympathy, or somehow unemployable because of being HIV-positive. Such generic core beliefs can significantly moderate behaviour, for example, decisions around disclosure or accessing treatment (Malta et al., 2005), and it is especially in the latter case that stigma represents a significant risk to the wellbeing of PLHIV. Recognising this clear danger, as well as the need to support PLHIV in achieving their life goals unhindered by self-imposed limitations, there is a now scope for targeted interventions to be created. The core beliefs reported from this study will also help inform future research and generation of meaningful measurement scales.

Functions of self-stigma: The results demonstrate key functions of self-stigma for participants. For example, it *maintains victim beliefs, provides protection, and can justify non-disclosure*. Unpicking the functions of stigma further could contribute substantially to our understanding of how to address it. For instance, although non-disclosure might protect against stigma received from others, to what lengths must someone go to hide their HIV status? Social withdrawal and even missing medication to maintain appearances have been reported among self-stigmatising PLHIV (Katz et al., 2013), again both representing a risk to overall wellbeing.

Coping strategies: Participants’ reported strategies for coping with HIV-related self-stigma included community involvement, personal development, and maintaining a connection with others. Like the previously reported *functions* of self-stigma, these had grounding in core beliefs, however in this case participants were able to challenge those beliefs. For example, in gaining employment, participants began to revise views of their lack of agency, and it was through interacting with others and undergoing personal development that they could overcome their feelings of isolation, or being worthless. Interventions to successfully address self-stigma could therefore incorporate techniques that include group, interpersonal or community interactions (Mburu et al., 2013).

Conceptual framework of self-stigma: Results from this study were incorporated into a conceptual framework of self-stigma (Figure 2), designed using concepts from Morrison (2006) (Morrison, 2006). This framework may be of use in visualising and understanding self-stigma as a complex, multi-dimensional phenomenon. In doing so, it may inform future research into HIV-related self-stigma, as distinct from social, perceived, or enacted stigma.

Despite the negative impacts of self-stigma identified in the wider literature and from participants in this study, interventions to support PLHIV in dealing with self-stigma, particularly at the level of core beliefs, are lacking. Stigma applied by, and to, the self is unlikely to be overcome by interventions aimed at the general public, since the negative beliefs held by PLHIV are often not representative of the population as a whole (Simbayi et al., 2007, Cairns, 2013, Kalichman et al., 2005). In this study, coping strategies such as personal development and inner work were highlighted as supportive, and a targeted approach incorporating these elements could prove beneficial. It is here that interventions such as IBSR (Katie and Mitchell, 2003, Lev-Ari et al., 2013) and CBT (Hayes) are more likely to meet with success: both utilise a strategy of working directly with individuals to systematically identify, challenge, and ultimately overcome self-imposed negative behaviours and beliefs. Such interventions, tailored to the context of HIV self-stigma and using knowledge of underlying core beliefs, may better equip participants with the mental tools and strategies to mitigate self-stigma.



These findings help fill previously identified gaps in knowledge regarding social and psychological factors around core beliefs about HIV and personal experiences (Kalichman and Simbayi, 2004), moving towards understanding the origins of self-abasing and negative

perceptions of PLHIV (Kalichman et al., 2009). In doing so, a small but concrete step has been taken to enable others to design interventions and programmes to address this complex and important issue. This study contributes a deeper view of the issue of self-stigma among PLHIV, and it is hoped that by directing more attention towards research and support for self-stigma, treatment adherence, access to services, and general wellbeing can be improved. The authors acknowledge that this study has limited representative potential for PLHIV in other settings, because of the relatively small number of participants. Additional research will therefore be useful in confirming that the experiences of self-stigma reported in this study also occur in other settings. Furthermore, there was considerable heterogeneity among participants in this study. However, it was also noted that the participants shared many common experiences and core beliefs underlying HIV self-stigma, and there were no instances where two participants reported contradictory experiences or beliefs.

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Chapter 4: We are the change’ - An innovative community-based response to address self-stigma: A pilot study focusing on people living with HIV in Zimbabwe

4.1 Commentary

Drawing upon the previous formative research (Chapter 3), a mixed-methods pilot study was undertaken in Zimbabwe with two groups of people living with HIV. An intervention was designed and delivered, and its effectiveness as a community-based intervention to reduce self-stigma, shame and associated states was evaluated and reported on.

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The paper has been reformatted to fit the style of the thesis but was submitted and published according to the specifications of the journal.

4.2 Abstract

Introduction

Self-stigma –negative self-judgements resulting in shame, worthlessness and self-blame – may play a crucial role in emotional reactions and cause emotional distress among many people living with HIV and other chronic illnesses. Furthermore, self-stigma negatively impacts on self-agency, quality of life, adherence to treatment, and access to services. High levels of self-stigma have been reported across many countries, however few programmes or interventions exist to specifically tackle this phenomenon. This paper reports the findings of a pilot study carried out in Zimbabwe using a programme incorporating “Inquiry-Based Stress Reduction: The Work of Byron Katie”, a guided form of self-inquiry which helps users to overcome negative thoughts and beliefs.

Objectives

The primary objective of this uncontrolled pilot study was to examine the potential role of the IBSR intervention in helping people living with HIV to overcome self-stigma and associated states.

Methods

23 people living with HIV (17 Female, 6 male, average age 41 years) were recruited from a local HIV support network, via open call for volunteers. All participants received the intervention, consisting of a 12-week facilitated programme using techniques derived from IBSR: The Work of Byron Katie. Qualitative and quantitative data were collected and analysed pre- and post-programme.

Results

After taking part in the intervention, participants reported significant improvements in factors including self-stigma (1-month follow-up vs baseline $Z = 2.1$, $p = 0.039$; 3-month follow-up vs baseline $Z = 3.0$, $p = 0.003$, $n = 23$, Wilcoxon Matched Pairs Signed Rank Test) and depression (1mo vs baseline $Z = 3.7$, $p = <0.001$; 3mo vs baseline $Z = 3.3$, $p = 0.001$). Qualitatively, participants reported improvements including lessened fears around disclosure of their HIV status, reduced feelings of life limitations due to HIV, and greater positive mentality. Improvements persisted at three-month follow-up.

Conclusion

With further development and larger comparative studies to confirm effects, the IBSR programme could become a novel tool to enable people living with HIV to support themselves in overcoming self-stigma

4.3 Introduction

Much has been published about stigma in relation to HIV and AIDS, mental illness, physical deformities, disability and illness (Ablon, 2002, Albrecht et al., 1982, Byrne, 1999, Jamison, 2006, Robertson M and C., 1997, Scambler and Hopkins, 1986, Watson et al., 2007).

However, much less is understood about *self-stigma*, or internalised stigma—influenced by “the fundamental, inflexible, absolute and generalised beliefs that people hold about themselves, others, the world and/ or the future” (Beck, 2011) —that is the stigma imposed upon the self by the self (HDN, 2005, Kalichman et al., 2009, Morrison, 2006). Self-stigma entails negative self-judgements, which at times may result in feelings of shame, worthlessness and self-blame (Kalichman et al., 2009, Ferris France et al., 2015, Link et al., 1997). The three major mechanisms of stigma at the individual level—enacted stigma, anticipated stigma, and internalised stigma—are highly complex, interrelated phenomena (HDN, 2005, Nyblade, 2006, Earnshaw and Chaudoir, 2009), the context of which is that of marginalisation where stigma operates as a multidimensional process, with that marginalisation as both a contributor and outcome (Parker and Aggleton, 2003).

It should not in any way be inferred that self-stigma is somehow the “fault” of the individual who experiences it. Stigma does not arise within an individual in isolation. Rather, stigma becomes internalised through exposure to the social, structural, and cultural contexts that feature enacted, anticipated, and perceived stigma (Ferris France et al., 2015, Parker and Aggleton, 2003). Individuals exposed to these contexts naturally absorb the harmful social and community attitudes towards a stigmatised condition (Parker and Aggleton, 2003) and may experience self-stigma without necessarily having been on the receiving end of enacted stigma (Scambler and Hopkins, 1986). It should also not be inferred that tackling self-stigma alone is enough to address the challenge of HIV stigma as a whole. Rather, as a multidimensional phenomenon, HIV stigma must necessarily be addressed via approaches that are targeted to its different levels and manifestations (Sengupta et al., 2011, Turan et al., 2017), with self-stigma being one component of the wider picture (Logie et al., 2018).

It is clear, however, that detrimental effects can arise as a result of the internalisation of stigmatising beliefs. For example, self-stigma can lead to a sense of isolation and may play a crucial role in the emotional reactions and cause emotional distress to many people living with HIV (PLHIV) (Simbayi et al., 2007, Crandall and Moriarty, 1995) and other chronic

illnesses (Livingston and Boyd, 2010). Furthermore, self-stigma may exert wide impacts on social interaction, health services utilisation, treatment compliance, and mental health status (Simbayi et al., 2007, Katz et al., 2013, Hua et al., 2014, Calabrese et al., 2015). It also has the potential for adverse behavioural effects including not seeking treatment and care services (Chesney and Smith, 1999). A study by Earnshaw (Earnshaw and Quinn, 2012) reported that people with chronic illness who had self-stigma accessed care less and had a lower quality of life. Furthermore, a study by Scambler and Hopkins on people living with epilepsy (Scambler and Hopkins, 1986) also highlighted the fact that nine out of every ten people interviewed admitted to suffering from self-stigma, although only one third could recall having experienced external stigma.

The damaging effects of stigma may also be compounded by restrictive legal and/ or socio-economic environments and practices that target those living with, or at increased risk of, HIV (Beyrer et al., 2015, UNAIDS., 2010). Such contributing factors are also reported to lead to low self-esteem and threaten self-efficacy of PLHIV (Beck, 2011). Internalised stigma has also been associated with the development of depressive symptoms (Wight, 2000), and it is likely that self-defacing internal representations are important in predicting long-term coping and positive living (Kalichman et al., 2009). This is especially relevant among PLHIV, where stigma in its many forms acts as a barrier to prevention strategies, access to care, and wellbeing across many dimensions (HDN, 2005, Katz et al., 2013, Chesney and Smith, 1999), as well as amplifying inequalities of gender, race and sexuality (Parker and Aggleton, 2003).

There is increasing evidence to show that PLHIV may experience self-stigma more frequently than they receive enacted stigma from other people (GNP+, 2011). For example, in a survey of 2306 adults in the general public in Cape Town, 38% of PLHIV interviewed reported feeling ashamed of their condition as compared to 16% of HIV-negative people who believed that PLHIV should be ashamed of their condition (Simbayi et al., 2007). Additionally, 13% of those interviewed believed that PLHIV did something to deserve it compared to 41% of PLHIV who felt guilty about having been infected with HIV. Importantly, although in this article we focus on self-stigma, the globally high rates of HIV stigma in its various forms should not be ignored. The 2014 Analytical Report of the Ukraine People Living With HIV Stigma Index showed that 40% of respondents had experienced external stigma, whereas 82% had experienced self-stigma (Demchenko et al., 2011). In a study across nine countries of the Asia Pacific region internalised stigma in the form of

shame, guilt and self-loathing occurred at high levels, ranging from 54% in Sri Lanka reporting feeling ashamed of their HIV status to 75% in Pakistan (GNP+, 2011). Additionally, the 2014 HIV Stigma Index for South Africa found that among 10,473 respondents, 43% reported experiencing internalised stigma, with 36% experiencing external stigma (South African National AIDS Council, 2015).

Poor health outcomes for people living with chronic illnesses, such as HIV, diabetes, cancer, may be linked with lack of psychosocial supports, and low quality of life (Passos and Souza, 2015, Antoni, 2013, Carlson and Bultz, 2003, Nicklett et al., 2013), and conversely the presence of adequate support is associated with improved health care access and coping with multidimensional aspects of living with HIV and related stigma (Paudel and Baral, 2015, Liu et al., 2013, Denison et al., 2015a, Kakietek et al., 2013). Furthermore, depression and social support are also among the most frequently and consistently reported factors influencing quality of life among PLHIV (Degroote et al., 2014), and Bhatia *et al.* have found that newly-diagnosed PLHIV are at high risk for depression and poor linkage to care (Bhatia et al., 2011)

Approaches that target self-stigma are therefore likely to benefit psychological function and wellbeing among PLHIV (Kamen et al., 2015). However, despite the range of interventions that exist targeting external stigma (Sengupta et al., 2011, Stangl et al., 2013), there is a paucity of measures that target and provide individuals with tools to manage and overcome *self*-stigma (Kalichman et al., 2009). Furthermore, even in studies where high levels of self-stigma have been reported, as with the Asia-Pacific Stigma Index nine-country study, no specific recommendations for interventions on self-stigma are made (GNP+, 2011). External and internal stigma equally have the opportunity and potential to create harm, and both are components of the wider socially- and structurally-created contexts that lead to marginalisation of PLHIV (Parker and Aggleton, 2003). Multidimensional approaches are therefore likely to yield the best outcomes, and the application of tailored interventions addressing both enacted stigma and internalised stigma, with the aim of improving treatment uptake and adherence, is supported by a growing body of work (Turan et al., 2017, Logie et al., 2018). There is also a broader need to increase provision of frameworks that enable practitioners to assess the social outcomes of interventions, given the breadth of influence that HIV exerts across all aspects of the lives of PLHIV (Mannell et al., 2014).

Brown and Vanable (Brown and Vanable, 2011), reviewing the stress-management intervention literature for PLHIV, concluded that there is evidence demonstrating that stress-management interventions reduce psychological distress and improve psychosocial functioning. These interventions include cognitive behavioural approaches, as well as meditation, mindfulness, and relaxation- based stress management approaches. Kalichman and Simbayi (Kalichman and Simbayi, 2004) acknowledge that approaches are needed that go beyond mass education and that work within more ingrained belief systems. In their 2011 systematic review of HIV stigma reduction interventions, Sengupta *et al.* also highlighted the need to incorporate research that builds understanding of stigma, and its drivers, to help create targeted interventions (Sengupta et al., 2011).

In this paper, we focus specifically on an intervention to address self-stigma among PLHIV in Zimbabwe, but similar interventions could likely be designed, and similar outcomes achieved, in relation to other chronic illness and diseases. The HIV prevalence in Zimbabwe for 2016 (most recent data at time of writing) is estimated to be 13.5%, with around 1.4 Million PLHIV, approximately 720,000 of whom are women aged 15 years and up (UNAIDS, 2016). HIV stigma continues to affect the lives of Zimbabwean PLHIV, with 65.5% of the 1,905 respondents to the 2014 Zimbabwe HIV Stigma Index reporting that they had experienced HIV stigma in one form or another. Among these, social exclusion and physical harassment or threats were the most common (21% and 19% of respondents, respectively). Within this context, internalised stigma also occurred, with 18.9% experiencing guilt or low self-esteem due to their HIV status, 17.9% experiencing self-blame, and 16.7% feeling ashamed. Fear of received stigma was also prevalent, with 37.2% afraid of being gossiped about, 17% afraid of sexual rejection, and 15.4% afraid of being verbally insulted (ZNNP+, 2014).

In light of the persistence of self-stigma, and the lack of proven interventions to address it, it is necessary to seek measures that support individuals to navigate it, particularly at a local level, adapted to the communities in which those most affected by self-stigma live. Participation of communities and local stakeholders has been identified as both a need and an enabler of comprehensive HIV prevention, treatment, and support in several settings, including Zimbabwe (Kakietek et al., 2013, Campbell et al., 2013, Lippman et al., 2014).

The multidimensional nature of stigma necessitates development of approaches that operate at different levels. As an addition to that toolkit of interventions, we sought to examine the

potential role of a stress reduction intervention, “Inquiry-Based Stress Reduction (IBSR): The Work of Byron Katie”, to help PLHIV to navigate self-stigma utilising a protocol derived from methods used in “The Work of Byron Katie” (Katie and Mitchell, 2003, Katie and Mitchell, 2007), and adapted for use in the Zimbabwean context. IBSR: The Work of Byron Katie is a facilitated meditative technique of self-inquiry used to manage stress and other negative thoughts, and this method has been previously demonstrated to positively affect psychological scales and mental health (Mitnik and Lev-Ari, 2015), as well as reducing psychopathologic symptoms such as depression, anxiety, and obsessive-compulsiveness (Leufke et al., 2013) in non-clinical groups. Elsewhere, the stress reduction approach using other interventions such as mindfulness has demonstrated positive effects in improving psychological status and reducing impact of HIV treatment side effects (Duncan et al., 2012, Jam et al., 2010).

The first IBSR: The Work of Byron Katie pilot clinical trial was been completed in breast cancer survivors in Tel Aviv, who reported significantly lower levels of fatigue and improved sleep quality, as well as physical, social, familial, emotional and functional wellbeing (Lev-Ari et al., 2013). Furthermore, IBSR: The Work of Byron Katie has recently been shown to be effective in improving psychological symptoms and quality of life in a pilot clinical study by Smernoff *et al.* in a non-clinical setting (Smernoff et al., 2015), and it has been used in a randomised controlled trial to examine the effect on psychological wellbeing among oncologically-healthy carriers of the BRCA1/2 mutation (Landau et al., 2015). Similar interventions can potentially be a cost-effective means to control stress and improve quality of life among the general population (Demarzo et al., 2014) (also reviewed in (Keng et al., 2011)), and have also been shown to create reductions in psychological distress, sleep disturbance and fatigue, as well as increases in positive psychological outcomes, in cancer patients, reviewed in Rouleau *et al.* (Rouleau et al., 2015). IBSR: The Work of Byron Katie has not previously been used to address HIV self-stigma, and has not been used in Zimbabwe. However, it was chosen opportunistically in this case since NFF and DNC are certified facilitators of the Work for Change, and both have past exposure and familiarity with IBSR as well as working in the area of stigma and PLHIV. Additionally, there was an opportunity afforded by the existing working relationship between Trócaire in Zimbabwe with the CONNECT Zimbabwe Institute of Systemic Therapy (ZIST) and the Zimbabwean National Network of PLHIV (ZNNP+). For these reasons, we decided to explore the potential of IBSR as a means of overcoming self-stigma among people living with HIV in the Zimbabwean

context, taking into account its potential as a psychosocial intervention as demonstrated by others, as well as the thematic alignment of its techniques with the professional counselling expertise of staff at CONNECT ZIST.

This pilot study was designed to test the possible influences and acceptability of IBSR: The Work of Byron Katie in the management of HIV self-stigma, and the following research questions were formulated:

1. Does the intervention using IBSR: The Work of Byron Katie have the potential to influence self-stigma?
2. Does the intervention have potential to influence stigma-associated states, such as shame, fear around disclosure, and depression?
3. Does the intervention have potential to influence other areas of participants' lives beyond HIV self-stigma?

Prior to commencing this pilot study, no local facilitators existed, therefore we conducted the intervention using internationally-certified facilitators sourced from outside Zimbabwe. This helped ensure that the intervention could be delivered with sufficient consistency and quality. We intended that this pilot study would help inform further studies that would a) explore any positive effects that might arise following to the intervention, and b) further refine the intervention itself. It would also lay the groundwork to create a programme to train local facilitators sourced from Zimbabwe and trained in the same manner, and to the same standard, as the internationally-certified facilitators, moving towards an entirely Zimbabwean-led programme of support for PLHIV to deal with self-stigma.

The intervention: Inquiry-Based Stress Reduction: The Work of Byron Katie

Our findings and recommendations from a formative qualitative study identifying core beliefs underlying self-stigma among PLHIV in Ireland (Morrison, 2006) informed the design of an operations research intervention pilot study that used a 12-week programme using techniques from IBSR: The Work of Byron Katie. Based on the research findings, a curriculum was designed to support participants to question and work through self-stigmatising beliefs (see [Figure 1](#), reproduced from (Ferris France et al., 2015)). Technical support and curriculum development was carried out by International Certified Facilitators of the Work of Byron

Katie, coordinated by The Work for Change organisation (<http://www.theworkforchange.org>). International Certified Facilitators have previously completed certification with The Worldwide Institute for the Work (<http://www.instituteforthework.com>) conducted over 2–5 years, consisting of 620 hours of study incorporating face-to-face workshops, facilitated remote classes, client contact hours, self-inquiry, and peer and mentor methods. The intervention curriculum was designed to start with a number of universal stressful thoughts about being HIV positive and from there to work systematically through more acute self-stigmatising core beliefs at a deeper level each week. During the process, participants were encouraged to identify, and inquire about, their stressful thoughts regarding shame, HIV status disclosure and other HIV-related issues, sexuality, sexual pleasure and intimate relationships, self-judgements and body, illness and death. The intervention aimed to improve management of specific emotional and psychological symptoms (relating to self-worth, stress, anxiety, depression, fears), and physical symptoms such as fatigue, and managing other medication-related side effects. Through the use of self-inquiry, subjects were taught to increase awareness of their thoughts and feelings, and to observe their emotional and physical responses during situations perceived by them as stressful.

The participant appraises their thoughts using the following questions: (1) *Is it true?*; (2) *Can I absolutely know that it is true?*; (3) *How do I react when I believe that thought?*; and (4) *Who would I be without the thought?* This process is meditative and reflexive, and the participant is guided to search for the true and genuine answers to the four questions with no certain agenda or censoring of thoughts. In this way, the participants become more aware of their self-stigmatising thoughts as they occur. The final stage involves ‘turnarounds’, where by turning the original thought or belief around in different ways—to the self, to the other and to the opposite, the participant experiences different interpretations of their own reality. By finding three genuine examples where each ‘turnaround’ is as true as the original thought, participants gain understanding of the power of stressful thoughts, and the ability to question these thoughts. This can help in managing their own thoughts to better cope in what had previously been highly stressful situations (Katie and Mitchell, 2003, Rouleau et al., 2015).

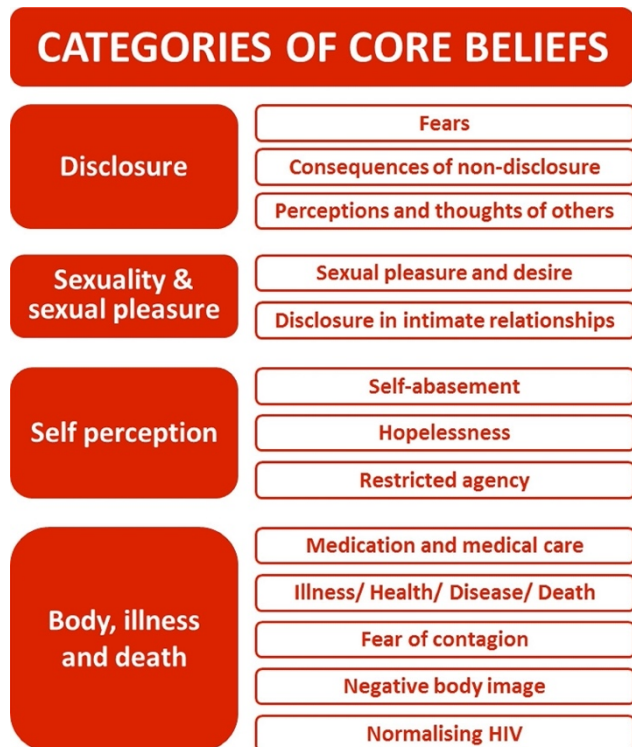
In doing so, subjects took an active role in investigating their stressful thoughts, regulating their stress and managing symptoms and emotions, thus enabling them to cope better with the distress related to self-stigma as a result of HIV. Two local facilitators worked with international certified facilitators to deliver and adapt the programme with two groups of participants (23 in total) drawn from support groups within ZNNP+. The participants took part in 12 four-hour group sessions run over 12 weeks at CONNECT ZIST, a weekly one-hour individual session with a facilitator also at CONNECT ZIST, as well as homework. Tools from IBSR: The Work of Byron Katie were used throughout the course to support participants to identify and list their beliefs and thoughts. A participant was considered active if they were present in at least 90% of the group and individual sessions. Participation was not incentivised.

Fig 1. Core beliefs which contribute to

HIV self-stigma. Showing core beliefs contributing to HIV self-stigma among persons living with HIV (unshaded boxes), which fall broadly across four categories (shaded boxes): Disclosure; Sexuality &

Sexual Pleasure; Self-perception; and Body, illness and death. (Reproduced from Ferris France *et al.*, 2015 (56) (Swiss Med Wkly. 2015;145:w14113) under a CC-BY License with permission from EMH Swiss Medical Publishers Ltd., original copyright 2015).

<https://doi.org/10.1371/journal.pone.0210152.g001>



4.4 Materials and methods

Ethical approval

Participants took part in this study freely and their involvement was not incentivised in any way. Prior to commencing the study, participants were asked to give written informed consent, and they were free to withdraw from the study at any time. Ethical approval for this study was granted by the Medical Research Council (MRC) of Zimbabwe (approval number MRCZ/A/

1782). The Royal College of Surgeons in Ireland (RCSI), Trócaire, and CONNECT ZIST, did not themselves require separate ethics submissions, and agreed to collaborate subject to the granting of the ethical approval by the MRC of Zimbabwe.

Participant recruitment

Participant recruitment commenced on 28 October 2013 and ended on 21 February 2014. Follow-up ended on 30 August 2014.

Clinical trial registration

This study was retrospectively registered as a clinical trial in the ISRCTN Registry (<https://www.isrctn.com/>), registration number ISRCTN17045085 (<https://doi.org/10.1186/ISRCTN17045085>) We had not registered this study as a clinical trial before commencement due to unfamiliarity with guidance around classification of trials. Nonetheless, ethical requirements by the Medical Research Council of Zimbabwe, our funders Trócaire, and partner organisations, were fulfilled throughout the study, with full protection (confidentiality, anonymity) and support given to the study participants, and all data has been reported faithfully without omission or bias towards positive or negative outcomes. There are currently no ongoing trials related to this study.

Adaptation of the intervention for the Zimbabwean context

This was the first trial of the IBSR: The Work of Byron Katie methodology to be conducted in Zimbabwe, as well as in the context of HIV self-stigma. The adaptation of the intervention and associated materials were greatly facilitated by involvement of the CONNECT Zimbabwe Institute of Systemic Therapy (<http://www.connect.co.zw/>). CONNECT is a welfare organisation established in 1983, registered with the Zimbabwean Department of Social Welfare in 1985, which conducts community outreach, counselling, training, and research incorporating psychosocial interventions around mental health care for people living with HIV and other conditions. These links were critical in facilitating participant recruitment, as well as logistical aspects of the project. The intervention was adapted for use in Zimbabwe through collaboration between CONNECT, Trócaire, The Work for Change, and the RCSI research team. To ensure truly local adaptation, two Zimbabwean PLHIV were supported to

attend a nine-day IBSR: The Work of Byron Katie training workshop in Germany, who then worked together with International Certified Facilitators in designing the curriculum. Systematic debriefings following delivery of each session with local and international facilitators ensured adaptation of the sessions to the local context where some modules were created to respond to cultural beliefs that emerged during discussions. Local Zimbabwean staff also role-played using the intervention tools to ensure suitability, and were present throughout the intervention work-shops to assist with translation of uncommon phrases, and to help with clarification of materials by adapting them into the local idiom.

Study design

Since this was the first time the intervention had been used against HIV self-stigma in Zimbabwe, we adopted a sequential explanatory mixed methods design for this study (Creswell and Clark, 2011) (Figure 2), in order to gain a deeper understanding of any possible influences than could be gained by quantitative measurement alone. Our dual aims were a) to measure the *quantity and direction* of changes in self-stigma and associated states as a result of the intervention, and b) to investigate possible reasons *why* these changes occurred, and what other areas of participants' lives might be affected. Addressing the first aim, we used quantitative questionnaires that incorporated previously-validated and well-established scales to measure HIV self-stigma, depression, and HIV-associated quality of life. In parallel to this, to achieve the second aim we employed semi-structured qualitative interviews and focus group discussions to gain understanding of the drivers of self-stigma among the participants and the ways in which they might have been influenced by the intervention, and uncover any unexpected areas which could be targeted in future interventions against HIV self-stigma.

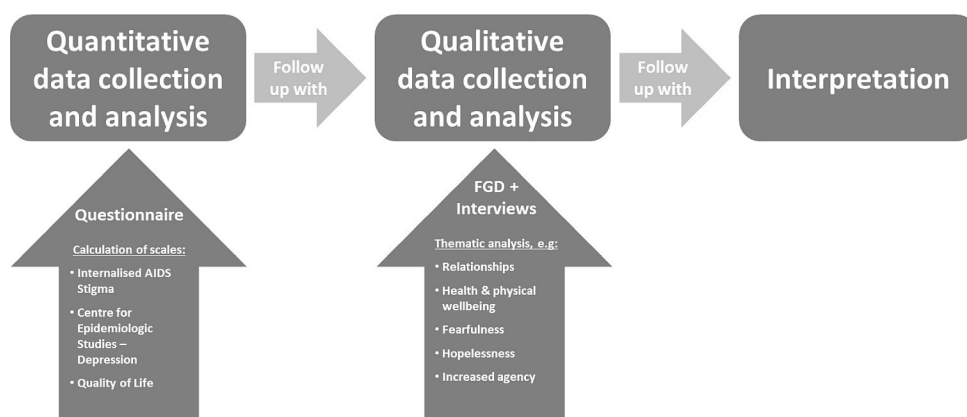


Fig 2. Sequential mixed methods study design. Initial data collection and analysis of quantitative scales was carried out using a questionnaire delivered to participants, incorporating items from the Internalised AIDS Stigma scale; Centre for Epidemiologic Studies–Depression scale; and HIV/AIDS Targeted Quality of Life Scale. This was followed by qualitative data collection and thematic analysis from Focus Group Discussions and one-on-one Interviews. <https://doi.org/10.1371/journal.pone.0210152.g002>

Data collection

Questionnaires, FGDs and interviews were administered by members of the research team (NFF, GS) in private locations at CONNECT ZIST (the same facility where the intervention took place). Intervention facilitators were an equal balance of female and male, and all had previously worked in qualitative and/ or quantitative research with PLHIV, in academic and NGO contexts. Researchers administered a structured questionnaire to all participants on three occasions: a day before the course, 1 month after the course and at 3-month follow-up. (For complete questionnaire see Supporting Material [S1 File](#)) Two separate focus group discussions (FGDs) (average duration 1h 32min.) were held on the day before, and a month after the intervention. Each FGD aimed to access an equal number of female and male participants. Six key informant interviews (average duration 26 min.) were also conducted with participants post-course. The FGDs and interviews were conducted in a semi-structured manner, guided by a set of open-ended questions such as “If you had to describe what you got out of this course, what would you say?”, with minimal interviewer interjections except to clarify or probe for greater detail. (The semi-structured FGD and interview guides are reproduced in full in Supporting Material [S2 File](#)) The interview / FGD members were drawn from the overall pool of 23 participants, and participants volunteered themselves for individual interviews following a general call, with no incentivisation or pressure to take part. The interview participants all also took part in the FGDs. None of the interviewees and focus group members requested transcripts after participating. All interviews and FGDs were conducted in English. Data were anonymised after collection, with individuals only known by their participant number. Team members performing analysis were blind to the identity of the participants.

Quantitative analysis

The structured questionnaire included scales and components of the Internalised AIDS Stigma Scale (IASS) (Kalichman et al., 2009) (12 items), the Centre for Epidemiologic Studies Depression Scale (CES-D)(Radloff, 1977) (20 items), and the HIV/AIDS Targeted Quality of Life Scale (Holmes and Shea, 1998) (28 items), to measure mood, perceived stress, and quality of life. Participants gave responses to questions on Likert type scales, for example ranging from “strongly disagree” to “strongly agree”. Responses were then coded numerically, and scale scores were calculated as the average of the items in the scale. The responses were matched by individual and analysed longitudinally. No scores were missing at any time point. Results of participants’ responses (raw data can be found in Supporting Material [S3 File](#), and calculations in the Supporting Material [S4 File](#)) on these scales were calculated using STATA version 15 (Stata Corp, Texas, USA). Changes in score, together with their interquartile range (IQR) are presented. Changes in scores between baseline and 1- and 3-month follow-up were analysed using the Wilcoxon matched-pairs signed rank test. As a measure of effect size, we calculated r , based on the Z value of the Wilcoxon test, using the transformation $r = Z/\sqrt{N}$

Qualitative analysis

The FGDs and interviews explored the concepts of stigma, self-stigma, depression, stress and quality of life, as well as the perceived triggers and consequences thereof on participants’ lived experiences. Discussions and interviews were recorded with prior informed consent, transcribed, then analysed using a semi-inductive iterative coding strategy in QDAMiner Lite version 1.4.1 (Provalis Research, Montreal, Canada), including themes derived from our previous work (Link et al., 1997), and new themes as they arose during coding. Three members of the research team (SM, NFF, EB) independently analysed transcripts until saturation was reached, then met to review for consistency and finalise the list of themes. For clarity in analysing the participants’ experiences of external and self-stigma, we chose to arrange categories and themes to distinguish internal challenges due to emotions, feelings, and anticipation of events, as well as tangible external experiences and outcomes. As a result, some categories appeared to overlap thematically but were kept distinct for the purposes of our analysis. For example, we coded *Negative Perceptions of Others* (Category) > *Perceptions of PLHIV* (Theme), where participants reported experiencing stigma or witnessing other

people relating negative preconceptions about PLHIV. This was in contrast to *Fearfulness* (Category) > *Disclosure* (Theme) > *Afraid of what others will think* (Sub-theme), in which participants reported that they themselves had felt afraid of the consequences if their HIV status were to become known. (For full list of themes, see Supporting Material [S5 File](#))

Participants

23 individuals volunteered for this study following an open call for participants between October 2013 and February 2014. All were members of Harare-based support groups which were part of the ZNNP+ network. At least 24h prior to taking part, participants were given an information leaflet outlining the purpose of the research, assurance of anonymity, confidentiality, and the right to withdraw at any time. 17 participants were female; 6 were male, and average age was 41 years, ranging from 25–54. Due to the stigmatised nature of minority sexual orientations in Zimbabwe, we did not ask participants to disclose their sexual orientations during recruitment, nor did we ask if they had acquired HIV through heterosexual or homosexual activity. Further participant details are included in [Table 1](#). All 23 participants received the intervention, and all took part until completion (all participants took part in all required sessions), commencing in late February 2014, with final follow-up in August 2014.

None were lost to follow-up. Participants were not previously known to the researchers before taking part in the study. Individuals were approached to take part in FGDs and interviews opportunistically, and none declined to participate. Eligibility criteria: Participants included were: 1) Individuals living with a positive HIV diagnosis for longer than three months; 2) Over 18 years of age; 3) Able to speak English with sufficient fluency to take part in group discussions; 4) Willing to provide informed consent and sign an informed consent form. Individuals excluded were: 1) Individuals with unknown HIV status; 2) Individuals diagnosed with HIV in the last three months; 3) Individuals currently undergoing psychotherapy treatment.

4.5 Results

Participant-reported improvement of self-stigma and associated measures post-intervention

Significant changes across a number of measures relating to self-stigma were reported by participants at follow-up, after taking part in the intervention. Follow-up scores for self-stigma were significantly improved (i.e. self-stigma was reduced) at both 1-month ($Z = 2.1, p = 0.039$) and 3-month ($Z = 3.0, p = 0.003$) timepoints compared to baseline. A similar trend was also recorded for depression at 1-month ($Z = 3.7, p = <0.001$) and 3-month ($Z = 3.3, p = 0.001$) timepoints. Daily activities were also improved at 1-month ($Z = 2.8, p = 0.005$) and 3-month ($Z = 2.8, p = 0.004$) timepoints. View of the future was not significantly different at the 1-month timepoint ($Z = 1.3, p = 0.198$), but was significantly improved at 3-months ($Z = 2.1, p = 0.033$). Feelings about being HIV-positive also were not significantly improved at the 1-month timepoint ($Z = 1.0, p = 0.323$), but were significantly improved at 3-months ($Z = 2.1, p = 0.038$). Fears around disclosure of HIV status were significantly reduced at both 1-month ($Z = 2.0, p = 0.046$) and 3-month ($Z = 2.0, p = 0.047$). Life satisfaction was significantly improved at the 1-month timepoint ($Z = 2.4, p = 0.017$), but not at 3-months ($Z = 1.7, p = 0.098$). No significant differences compared to baseline were reported for social support (total) (1-month $Z = 0.5, p = 0.615$; 3-month $Z = 1.5, p = 0.132$), social support (intimacy) (1-month $Z = 0.61, p = 0.543$; 3-month $Z = 1.2, p = 0.235$), or social support (help from others) (1-month $Z = 0.8, p = 0.402$; 3-month $Z = 1.5, p = 0.144$) ($n = 23$; results summarised alongside median difference, IQR, and effect size, in [Table 2](#)).

The quantitative data from the questionnaires showed that after taking part in the IBSR: The Work of Byron Katie programme, participants reported significant and sustained changes across several areas of their lives. However, whilst this clearly indicated the size and direction of the change, the scales used did not capture information regarding the circumstances, as well as the underlying drivers of such change. To address this, and to gain deeper understanding of the participants' experience of living with HIV, the FGDs and one-to-one interviews were analysed to capture a greater understanding of the complexities behind the data. In combination with post-course FGDs and interviews, this analysis allowed for the exploration of the wider context surrounding living with HIV, and the underlying sources of stress, stigma, self-stigma and associated negative outcomes, with which participants had been living, and often struggling to cope with, for many years.

Table 1. Characteristics of study participants.

Showing participants' age, sex, partnership, education, and employment status, and whether or not they had children.

<i>Age (years)</i>	
Mean	41
Range	25–54
<i>Sex</i>	
Female	17
Male	6
<i>Antiretroviral (ARV) use (years)</i>	
Average no. of years on ARVs	6.8
Range	3–13
<i>Living with stable partner</i>	
Yes	15
No	8
<i>Currently employed</i>	
Yes	7
No	16
<i>Completed form 4 education</i>	
Yes	15
No	8
<i>Has children</i>	
Yes	23
No	0

Table 2. Quantitative results from self-stigma and associated measures questionnaire post-intervention.

Showing baseline median, median difference and interquartile range, Z-score, effect size, and significance, between

baseline and 1- or 3-month follow-up timepoints, for participants' self-reported scores in scales for Self-stigma, Depression, Daily activities, View of the future, Feelings around being HIV+, Fears around disclosure, Life satisfaction, Social support (total), Social support (intimacy), and Social support (help from others) (n = 23).

Outcome measure	Baseline median	Baseline– 1 month				Baseline– 3 month			
		Median difference (IQR)	Z	Effect size (r)	sig	Median difference (IQR)	Z	Effect size (r)	sig
Self-stigma	0.83	0.17 (0–0.8)	2.1	0.43	0.039	0.5 (0–0.8)	3.0	0.62	0.003
Depression	1.25	0.3 (0.1–0.7)	3.7	0.77	<0.001	0.3 (0.1–0.7)	3.3	0.67	0.001
Daily activities	1.4	0.4 (0–1)	2.8	0.59	0.005	0.4 (0–1.2)	2.8	0.60	0.004

View of the future	1.67	0.3 (-0.3–0.7)	1.3	0.27	0.198	0.3 (-0.3–1.3)	2.1	0.44	0.033
Feelings around being HIV+	0	0 (0–1)	1.0	0.21	0.323	0 (0–1)	2.1	0.43	0.038
Fears around disclosure	0.4	0 (0–0.4)	2.0	0.42	0.046	0.2 (0–0.6)	2.0	0.41	0.047
Life satisfaction	2.75	0.75 (-0.1–1.3)	2.4	0.50	0.017	0.5 (-0.2–1.3)	1.7	0.35	0.098
Social support (total)	2.25	0.1 (-0.17–0.33)	0.5	0.11	0.615	0 (-0.17–0.6)	1.5	0.31	0.132
Social support (intimacy)	2.4	0 (-0.2–0.4)	0.61	0.13	0.543	0 (-0.2–0.6)	1.2	0.25	0.235
Social support (help from others)	2.14	0.1 (-0.3–0.3)	0.8	0.17	0.402	0.1 (-0.6–0.2)	1.5	0.30	0.144

<https://doi.org/10.1371/journal.pone.0210152.t002>

Self-stigma and negative influences on participants' lives: Fearfulness, shame, guilt, hopelessness, worthlessness, restricted agency, and negative perceptions of others

The narrative recounted by participants regarding HIV before the intervention, the circumstances surrounding their infection, and the possible influence this would have on their lives thereafter, was overwhelmingly negative. Participants' responses broadly fell into categories including *Fearfulness*, *Shame*, *Guilt*, *Hopelessness*, *Worthlessness*, *Restricted Agency*, and *Negative perceptions of others*.

The first category, *Fearfulness*, was experienced in a number of ways, such as fear surrounding disclosure of one's HIV status to others, fear for their dependents in the event of their death, and fear for their personal health:

"Before I attended the course, I thought that I may die soon. I was afraid of the side effects of ARVs. I disliked being positive." Post-course Interview Participant A10

A fear of suffering from other diseases which could accompany, or be worsened by, HIV was also reported by the participants. It became clear that they obviously had access to knowledge surrounding the broader health risks presented by living with HIV, but they also lacked mental tools or training to cope with the accompanying psychological burden:

“When I fall sick, I think the worst. For example, when I have rash on my body, I think its Kaposi Sarcoma . . . When you start coughing, you think its TB . . . Whenever I fall sick, I think the worst.”

Pre-course Focus Group A Some also spoke of experiencing several dimensions of *Shame* and *Guilt*—for example being ashamed of themselves as a person living with HIV, or over becoming HIV positive, as well as blaming those who had infected them, with some adding a negative dimension to ordinarily- positive life events:

“When I tested positive, I was ashamed of myself. I blamed myself for getting married.”

PrecourseFocus Group B

Within the category of *Hopelessness*, some participants reported feeling that their life was effectively over upon receiving their HIV positive diagnosis:

“After seeing that the results were positive, I felt it was the end of my life. I felt being vulnerable and being manipulated . . . The moment I was alone I became afraid, fearing the unknown . . . I was staying at home always, not doing anything. . . I told myself that I will not buy any new clothes. I didn’t want my relatives to take away my possessions upon my death.” Pre-course Focus Group A.

Some participants also reported holding negative beliefs about themselves, which fell into the broader category of *Worthlessness*, for example lack of self-worth, and which contributed to *Restricted agency*:

“I thought I was useless. Why should I go on and be educated when I’m [HIV] positive? I didn’t think I will live longer. It was like a death sentence to me. I just didn’t think there was life after being tested positive.” Pre-course Focus Group A.

Participants also often spoke of their sense of loss after their HIV diagnosis, describing negative situations that being HIV positive had caused. This in turn had perpetuated their sense of self-stigma:

“I tested positive in 2005. I lost everything that I had. I lost my beloved wife and son. I lost my job. Life was not easy. My in-laws took my children away from me. I just started staying alone. I suffered feelings of shame, guilt and loneliness.” Pre-course Focus Group B

Participants also spoke of the external stigma that they had received, which broadly fell into the category of *Negative perceptions of others*—this often manifested as negative perceptions of HIV, or those living with HIV. Some participants had believed that a diagnosis of HIV meant that life was effectively over, and this belief was also held by some families, resulting in an over-arching attitude of pessimism towards those living with HIV:

“One of my family members started isolating me from the family discussions. She was saying I was HIV positive and not capable of taking part in the discussions. It was as if the virus had affected my brain and I could no longer think or contribute anything.” Pre-course Focus Group B

Commonly-held perceptions of the source of an HIV infection also coloured interactions of others with the participants following a diagnosis of HIV:

“When I tested positive in 2008 and told my husband the results, he started throwing things everywhere in the house, calling me a prostitute.” Pre-course Focus Group B

Participants frequently reported that the impact of their HIV diagnosis extended beyond specific worries about physical health and dying: here, far more complex situations were reported, often exerting a significant detrimental effect on family and social lives. In particular, the reactions of family or social groups to an individual’s HIV status were frequently negative and disowning, rather than supportive:

“My sister’s husband couldn’t understand my situation and refused to keep me with my child. He said it was your fault to be HIV positive. I went on to stay with someone who was not my relative.” Pre-course Focus Group B

In addition to the seriousness of HIV/AIDS itself, often commonly-held (and frequently inaccurate) perceptions of HIV, and those who carry it, also coloured interactions of others with the participants following a diagnosis of HIV:

“When I tested positive in 2008 and told my husband the results, he started throwing things everywhere in the house, calling me a prostitute.” Pre-course Focus Group B

Participants reported that following HIV diagnosis, many aspects of their lives were subsequently impacted, contributing to self-stigma and stress, which had become significant moderators of self-perception, agency, and outlook. Whilst arising from many different sources, the outcome was consistently an adverse mental state which contributed to limitation on that individual's personal agency or ability to live in a manner that sustained wellbeing: *"I would always occupy myself with stressful thoughts."* Post-course Interview Participant A11

Possible influences of the intervention on self-stigma and personal wellbeing: Change and coping strategies

When speaking of the possible influences in their lives following the intervention, participant responses largely fell into the theme of *Change*, referring to multiple areas of their lives which had improved, and *Coping strategies*, encompassing the mechanisms and activities which were helpful in overcoming self-stigma, and building self-esteem and wellbeing. Examples of these included building acceptance of one's HIV positive status, and growing self-support such as taking on a positive mentality and overcoming negative thoughts.

Complementing the quantitative measures which indicated significant and lasting improvements in participants' wellbeing, a common qualitatively-reported outcome was that taking part in the intervention had fostered positive change throughout participants' lives as a whole:

"My life or the way I conduct myself should tell that I have been through this programme. People who live with me should see that my life has changed. They should see the change in me." Post-course Interview Participant A11

The post-intervention interviews and discussions yielded further detail regarding the circumstances surrounding these changes. Improvements had occurred across many areas, ranging from self-perception, personal appearance and self-care, through to interactions with family, colleagues and friends, as well as changes in outlook surrounding living with HIV. In particular, participants reported the realisation that overcoming self-stigma was an important step towards being able to mitigate stigma received from others:

"I learnt that the moment I worry about what people think about me, I am stigmatising myself. By stigmatising myself, I withdraw. When I withdraw, I am now allowing people to stigmatise me because I will be watching every movement that they will be doing. Yet it's not them doing

it to me but it would be me doing it to myself. Through doing 'The work', I feel that I am able to mix and mingle with anyone. I am no longer worried about what people think or say about me because the moment I do that I will be stigmatising myself. I now have a very free mind and I am now an outgoing person." Post-course Interview B6

Prior to taking part in the intervention, many perceived themselves to be 'different' or separate from others due to their HIV status, and as a result felt unable to view themselves, or be viewed, as 'normal'. Following the intervention however, a theme of acceptance was reported, which helped in coping with difficult internal thoughts:

"I have learned to accept my thoughts with understanding. The stressful thoughts that I have are not different from what other people are experiencing." Post-course Focus Group A

When speaking about difficulties encountered during interactions with others resulting from living with HIV, it was evident that many of the participants experienced shame, or worries about what others thought of them as PLHIV, however the intervention had enabled them to regain their sense of self-confidence:

"I used to be ashamed of myself. I didn't have confidence of what I was doing. Because of this training I am no longer ashamed of myself and the fact that I am [HIV] positive." Post-course Interview B4

Diminished feelings of shame and self-limitation were also accompanied by an enhanced feeling of self-worth as well as renewed self-agency, where participants reported that they now felt they could live in the same manner as those who are HIV negative:

"I have realised that with or without HIV, I am able to do what other people who are not HIV positive can do. I have discovered that I have got no limitations." Post-course Focus Group B

Several of the participants had described situations prior to the intervention where they felt uncomfortable disclosing their HIV status to others, however having taken part in the course, they had become significantly empowered to discuss such issues and were more comfortable in disclosure—in some cases experiencing unexpected positive outcomes:

"I used to find it difficult to disclose my status to some of my relatives. Due to the course, I have disclosed my status to those relatives. To my surprise, what I thought would be their reaction was totally different from what they did. I thought that some of them would be shocked and they would isolate me but nothing changed and their love for me has increased. I no longer have a

problem of disclosing my status even during social forums that I normally attend.” Post-course interview Participant B9

When speaking of education and knowledge following the intervention, participants’ responses were not limited to the benefit gained in dealing with internal thoughts: techniques and knowledge from the programme had been brought into a wide range of areas throughout their lives, for example improved communications with family members, and reduced social isolation. Furthermore, participants reported the intention to use the new knowledge gained to support other PLHIV. It was apparent that the intervention had presented them with a valued tool that potentially enabled them to manage the effects of their self-stigma, and in doing so created a sense of empowerment:

“I can deliver this programme in support groups for people living with HIV using the vernacular language. The course can also be delivered in schools using the English language . . . I can deliver the programme well to the women's group at my church. I conduct sessions on positive living at my workplace and I can use that as an opportunity to share what I have learned in the IBSR course.” Post-course Interview Participant A4

A further common theme among participants’ responses was a shift towards a more positive mentality. Whereas prior to the intervention, many reported pessimism and a lack of hope for the future, the post-course interviews and focus groups presented a more positively-framed outlook:

“I got infected in 1993 but I am in 2013, which is exactly 20 years living with the virus. Now, I think I will even live longer because I have learned to appreciate myself . . . I now look at myself better than what I used to do before. I look at myself as just a person with any other disease such as diabetes or cancer. Right now, I am very healthy and I don’t have any complaints.”

Post-course Interview Participant A11

All of the situations described by the participants were impacted upon by HIV, yet there was a paucity of reports of specific difficulties due to medication, actual HIV-related illness, or access to medical services. Instead, participants reported limitations caused by self- and perceived stigma, and the far-reaching consequences thereof, which were somewhat mitigated following the intervention:

“I now feel very comfortable with my positive status. I love myself. I understand that I can live peacefully whether I have a partner or not. I no longer stigmatise myself. I just feel I am as good as any other person.” Post-course Interview Participant A10

4.6 Discussion

This pilot study tested an intervention designed to help PLHIV to identify, control, and overcome the internal thoughts and beliefs that had previously created feelings of lowered self-worth, decreased agency, and negative mentality that contribute to self-stigma. Addressing our initial research question, *Does the intervention using IBSR: The Work of Byron Katie have potential to influence self-stigma*, the results clearly showed that after taking part in the intervention, the participants reported a significant reduction in levels of self-stigma. It is also note-worthy that many of the changes were maintained at 3-month follow-up, suggesting that the use of the intervention may facilitate longer-term control of self-stigma, with minimal refresher training. Several studies have indicated that reducing HIV self-stigma may improve access to care and wellbeing among PLHIV (Arrey et al., 2015a, Denison et al., 2015b), and our current results suggest that after more complete development and testing, techniques from IBSR: The Work of Byron Katie might be employed in the future as an intervention to help achieve this.

Addressing our second research question, *Does the intervention have potential to influence stigma-associated states, such as fear around disclosure and depression*, we found that measures of both fears around disclosure, and depression, were significantly reduced following the IBSR: The Work of Byron Katie intervention. The reduction of stigma-associated states such as anxiety and depression is likely to improve wellbeing among PLHIV (Kamen et al., 2015), and access to care is also likely to be improved if fears around disclosure can be overcome, particularly for those living in, or originating from, settings where HIV remains highly stigmatized (Arrey et al., 2015a, Valenzuela et al., 2015). In some cases, such as Life Satisfaction, the reported scores were significantly improved at 1-month, but not 3-month follow-up. Conversely, some measures were not significantly improved at 1-month follow-up, but were significantly improved at 3 months, such as Feelings around being HIV-positive, or View of the Future. This may have been due to certain aspects of the intervention taking longer to be internalised through repeated practice than others. If subsequent research shows these changes to be genuine effects of the intervention, supports such as refresher

training could be considered to help embed them more fully. It is not currently possible to judge the practical significance of the changes in scores for several reasons. First, the items are scored on arbitrary scales. It is not possible to assert that a specified change in, for example, Life Satisfaction score represents a ‘real’ change in life satisfaction. Furthermore, the score changes in this study are estimated from a small sample, and so are imprecise enough to caution against definitive claims.

It is, however, encouraging that even in a small sample we were able to show statistically significant changes across a range of measures of wellbeing. Further well-considered research will elicit whether such changes can be replicated across a wider range of participants and contexts, and full attention should be given to understanding the ways in which those findings might translate into practical outcomes for the participants. Beyond the patients’ self-reported reductions in measures such as self-stigma, fears around disclosure, and depression as empirical quantities, our qualitative observations contribute towards answering our third research question, *Does the intervention have potential to influence other areas of participants’ lives beyond HIV self-stigma?* The intervention’s participants reported a range of improvements across several aspects of their daily lives. Pre-intervention discussions illustrated the extent of participants’ negative outlook on life and lack of hope for the future, whereas post-intervention this had changed to a more positive dialogue, including making future plans, and improved self-image. Mannell *et al.*, in their 2014 assessment of indicator frameworks for the HIV response, highlighted the need for greater provision for monitoring the social drivers and outcomes of the epidemic (Mannell *et al.*, 2014), and often the scales used to measure the effects of stigma in HIV define the *how much*, rather than the *why*. Our current results suggest transformative change simultaneously across multiple aspects of an individual’s life. This is thematically consistent with our previous research where multiple contributing factors and circumstances shaped core beliefs driving self-stigma among PLHIV, presenting a broad range of areas where targeted support could improve wellbeing and quality of life (Ferris France *et al.*, 2015). Using interventions incorporating IBSR: The Work of Byron Katie to address the underlying causes and outcomes in this holistic manner could therefore represent a useful means to reduce HIV self-stigma.

It was most striking that the reported life changes reported after taking part in the intervention aligned in many cases with measures of psychological wellbeing, as proposed by Ryff and Keyes in 1995 (Ryff and Keyes, 1995) (Figure 3). The Ryff scales reflect dimensions such as

self-acceptance, autonomy, life purpose, and personal growth and development—all of which were areas of improvement reported by this study’s participants during interviews. We would therefore argue that the incorporation of the Ryff scales into monitoring frameworks to capture greater information about changes to overall wellbeing, as opposed to simply measuring the negative out- comes such as the level of depression or the amount of stigma experienced, or quality of life at a single point in time, will hold significant utility in shaping responses and tracking intervention outcomes among PLHIV. This presents a timely opportunity to add a structured measurement of improvements in *positive attributes*, rather than focusing exclusively on removing negative attributes or problems, and expecting that the patient will be ‘well’ thereafter. In the current context of HIV prevention and care, this is especially relevant: good medication compliance and access to health services now enable the focus to shift away from merely control- ling symptoms and remaining disease-free, towards promotion of wellbeing, maximizing productivity, and achieving life goals, within a normal 72–75 year life span (Nakagawa et al., 2012, Mugavero et al., 2010). However, this does not necessarily mean that PLHIV will be able to realise this potential; such a shift can only be fully achieved by providing access to health services in a manner that is free from external and internal stigma (Parsons et al., 2015), and the ongoing persistence of self-stigma (Sengupta et al., 2011, Demchenko et al., 2011) indicates that further modes of support must now be sought and implemented.

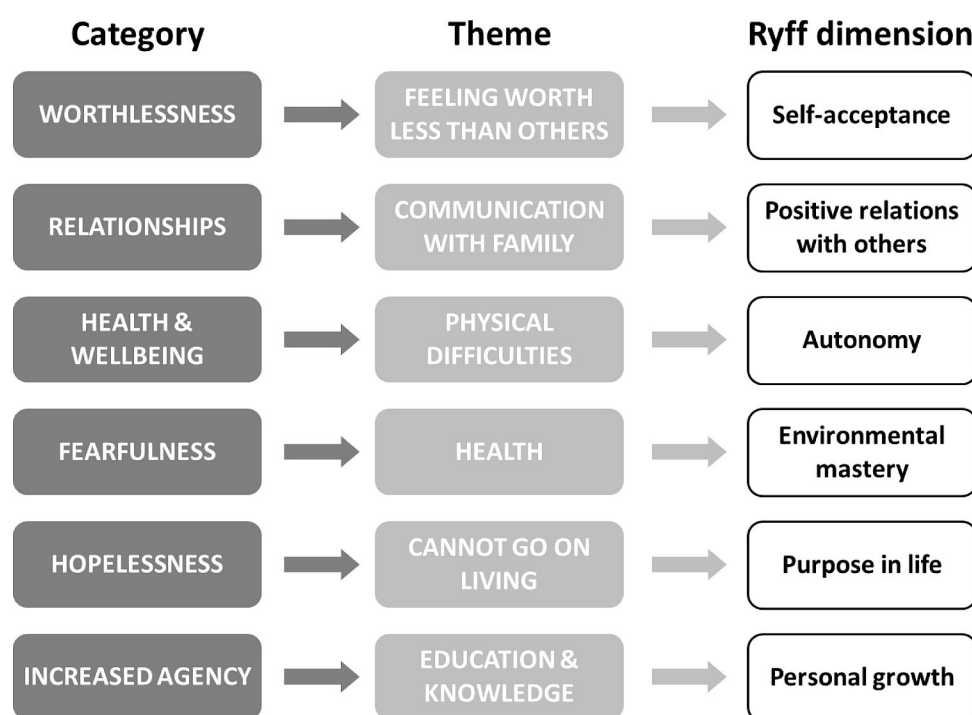


Figure 3. Alignment of themes from participant interviews with Ryff scales of wellbeing.

Showing categories (left column, dark grey), and themes (middle column; light grey) which emerged during thematic analysis of participant interviews and focus group discussions.

These broadly fell into the six dimensions of wellbeing (right column; unshaded), as proposed by Ryff and Keyes (100), suggesting that this scale may be of future utility in measuring outcomes following interventions that address HIV self-stigma.

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Additionally, rather than simply managing the negative symptoms of self-stigma, our current results suggest that changes also occurred in overall wellbeing among participants, driving positive behavioural changes such as improved relationships with family, accessing self-improvement opportunities, and passing on knowledge to others. This intervention could therefore be a promising candidate for further investigation incorporating a more rigorous study design and expanded scope to test its potential effectiveness among larger and more diverse populations.

For the purposes of this pilot study we used internationally certified facilitators, although we recognised that this would be a challenge in terms of resources and sustainability. However, we believed that this was a necessary step to show that the IBSR methodology could be delivered and have the potential to influence self-stigma and other associated states within the urban Zimbabwean setting. Given that the intervention was relatively intensive, both in terms of duration, and its use of trained international facilitators, potential avenues for exploration could now include steps to reduce the length of the intervention, for example to distil it to the ‘minimum unit’ required. To this end, we are currently implementing and testing strategies to transition the intervention from its current ‘high-resource’ model towards one which can be suitably scaled up to reach the wider community, supported by locally-sourced and trained facilitators. Eleven local facilitators have now been trained in this method using a ‘train the trainers’ model, whereby the international facilitators adapted the training to be applicable in a low-resource setting. These steps are aiding in terms of retention of participants, as well as in building local expertise, moving away from reliance on bringing in international staff, and the effect of these changes is currently being investigated by CONNECT ZIST, Trócaire, The Work for Change, and RCSI.

Based on our current findings, we suggest that IBSR: The Work of Byron Katie should be investigated further as a novel, community-based intervention to help overcome the self-stigma that prevents PLHIV from pursuing life opportunities to the fullest extent.

4.7 Study limitations

This was a small-scale pilot study which accessed participants from a single urban area in Zimbabwe, and did not contain a control group. As such, the results reported here cannot be generalised to the wider population. Future research in this area should incorporate larger pilot studies that feature a control group, before moving towards judicious use of best-practice methodologies including randomised controlled trials assigning participants either to the self-stigma intervention or an appropriately-considered comparator intervention.

Additionally, social stigma around minority sexual orientations in Zimbabwe precluded our asking participants to disclose their sexual orientations during recruitment, and we did not ask whether they had acquired HIV through heterosexual or same-gender sexual practices. Our findings, therefore, may not necessarily be generalizable across all sexual orientations. The characteristics and effects of stigma that affect different genders and sexualities are likely to vary, and future research should aim to investigate these differences in a sensitive manner, providing valuable insight into the complexities of stigma and self-stigma as they exert their effects on varied populations. This will be especially useful since it is likely that different groups will be responsive to different intervention modalities, therefore building the evidence-base in this area will yield important information for implementers. We also acknowledge that IBSR is an intensive intervention which requires a significant time investment both from participants and skilled facilitators. In this first instance, we utilised facilitators sourced from outside Zimbabwe due to a lack of local facilitators, and to assure quality. Subsequent work is now focused on building a sustainable intervention that is delivered by a team of trained facilitators sourced from Zimbabwe, with the aim of it becoming fully Zimbabwean-led.

Chapter 5: Exploring the beliefs, experiences and impacts of HIV-related self-stigma amongst adolescents and young adults living with HIV: in Harare; Zimbabwe: A qualitative study

5.1 Commentary

A qualitative study to understand the core beliefs, experiences and impacts of HIV self-stigma among young adults in Harare, Zimbabwe. This study highlights the beliefs particular to young people around self-stigma, shame and relationships, sex, disclosure, perception of others and the future. The findings of this study were used to inform the development of the intervention reported on in Chapter 6.

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The paper has been reformatted to fit the style of the thesis but was submitted and published according to the specifications of the journal.

5.2 Abstract

Background

HIV-related self-stigma is a significant barrier to HIV management. However, very little research has explored this phenomenon, particularly in sub-Saharan Africa. This study explored the beliefs, experiences, and impacts of HIV self-stigma amongst adolescents and young adults (AYALHIV) in Harare, Zimbabwe to inform future interventions. It aimed to capture the lived experience of self-stigmatisation among AYALHIV and its impact on their social context using Corrigan et al (2009) self-stigma framework of ‘awareness’, ‘agreement’, and ‘application’.

Methods

Virtual semi-structured key informant interviews were conducted between June and July 2020 with adolescents and young adults (Female = 8; Male = 8) living with HIV (18–24 years) in Harare, Zimbabwe. We conducted the interviews with a purposive sample of AYALHIV enrolled in Africaid’s ‘Zvandiri’ program which provides HIV support services. Interviews were mainly conducted in English and with three in Shona, the main indigenous language. Audio-recorded qualitative data were transcribed, translated into English (where necessary) and deductively coded using Corrigan et al.’s self-stigma framework. The outbreak of SARS-CoV-2 coincided with the commencement of data collection activities, which impacted on both the sample size and a shift from in-person to virtual interviewing methods.

Results

Sixteen respondents (50% male) took part in the interviews. The mean age of respondents was 22 years. All respondents reported HIV-related self-stigma either occasionally or frequently. Three main themes of self-stigmatizing experiences emerged: disclosure, relationships, and isolation. These themes were then analysed within the self-stigma development framework by Corrigan et al. (2009) known as ‘the three As’: awareness, agreement, and application of self-

stigmatizing thoughts. Respondents' experiences of self- stigma reportedly led to poor wellbeing and decreased mental and physical health. Gendered experiences and coping mechanisms of self-stigma were reported. Data suggested that context is key in the way that HIV is understood and how it then impacts the way people living with HIV (PLHIV) live with, and experience, HIV.

Conclusions

HIV-related negative self-perceptions were described by all respondents in this study, associated with self-stigmatizing beliefs that adversely affected respondents' quality of life. Study findings supported Corrigan et al.'s framework on how to identify self-stigma and was a useful lens through which to understand HIV-related self-stigma among young people in Harare. Study findings highlight the need for interventions targeting PLHIV and AYALHIV to be context relevant if they are to build individual resilience, while working concurrently with socio- political and systemic approaches that challenge attitudes to HIV at the wider societal levels. Finally, the gendered experiences of self-stigma point to the intersecting layers of self-stigma that are likely to be felt by particularly marginalised populations living with HIV and should be further explored.

5.3 Introduction

Stigma is a significant barrier to HIV treatment and management (Mahajan et al., 2008, UNAIDS, 2017). HIV remains a highly stigmatized condition because of what are considered high risk or taboo behaviours associated with its transmission, such as multiple and concurrent sexual partnerships, homosexual inter- course, drug use and sex work (Hutchinson and Dhairyawan, 2017, Kalichman et al., 2009, Reidpath and Chan, 2005, Saki et al., 2015). HIV-related stigma can be experienced as social or internalised self-stigma (Campbell et al., 2011). Social stigma is the outward discrimination towards people living with HIV (PLHIV) (Earnshaw et al., 2013). Self-stigma on the other hand, is experiencing negative judgements towards oneself resulting in feelings of worthlessness, shame and emotional distress (Ferris France et al., 2019c). For example, a self-stigmatizing thought is, 'I will never have a future because I am worthless and not good enough.' There is little research on self-stigma and how it impacts different population groups living with HIV (Watson et al., 2007). As a result, this study focuses on the beliefs and experiences of HIV self- stigma amongst young adults living

with HIV in Harare, Zimbabwe, an area deeply affected by the HIV/AIDS epidemic. Corrigan et al. (2009) identify three steps of self-stigmatisation (Corrigan et al., 2009). First, one has to have an awareness of a stereotype or negative perception. Then one has to agree with those beliefs, and finally, apply them onto one's self (Corrigan et al., 2009). This process is described as the three A's of self-stigmatisation, which are awareness, agreement, and application (Corrigan et al., 2009). While social stigma has been the primary focus of HIV stigma research, much less is known about HIV-related self-stigma (Watson et al., 2007). Studies have suggested that HIV-related self-stigma can have detrimental physical and mental effects on PLHIV (Ma et al., 2019). Research has shown that HIV-related self-stigma can result in non-adherence to HIV medication, lower quality of life and poor mental health (Ferris France et al., 2019c, Ferris France et al., 2015). A systematic review found that HIV-related stigma undermined antiretroviral therapy (ART) adherence by compromising general psychological processes (e.g. adaptive coping and social support), and 24/33 (73%) studies reported an association between HIV stigma and ART non-adherence (Katz et al., 2013). Researchers found that self-stigma can be experienced almost three times more than social stigma, demonstrating a need to both better understand and address this phenomenon (Simbayi et al., 2007). Data suggest that self-stigma among PLHIV intersects with age, gender and personal experiences (Hasan et al., 2012).

Self-stigma within Zimbabwean/sub-Saharan context

Over 1.4 million people are living with HIV in Zimbabwe and the adult prevalence rate of HIV is 12.7% (UNAIDS, 2019, UNAIDS, 2018). Young adults have been identified as a critical population affected by HIV and one third of all new infections in Zimbabwe are currently among people aged 15–24 years old (UNAIDS, 2019, UNAIDS, 2018). These young PLHIV can internalize negative stereotypes associated with HIV and experience feelings of isolation, negative self-image, worthlessness and suicidal thoughts (Ma et al., 2019). Previous research conducted in Zimbabwe showed that adolescents living with HIV (ALHIV) in Zimbabwe are particularly affected by stigma and self-stigma (Mavhu et al., 2013, Willis et al., 2018a, Mavhu et al., 2020). This report stated that 73% of ALHIV experienced stigma that affected their medication adherence and 47% had virological failure (Mavhu et al., 2020). The stigma experiences reported included abuse, negative self-perception, neglect, social isolation, and discrimination (Mavhu et al., 2020). Additionally, some of the indigenous terms used to identify PLHIV include derogatory terms that translate into “dead one” or “plagued”

(Mawadza, 2004). This linguistic phenomenon reinforces an unfavourable and hopeless view of HIV (Mawadza, 2004). Self-stigma contributes to high drop-out rates from HIV treatment and support programs among young people, leading to increased morbidity and mortality (Mavhu et al., 2020, Casale et al., 2019a, Boerma et al., 2016). Self-stigma can cause PLHIV to refrain from HIV testing, default on their medication, avoid going to health clinics and experience mental health problems, which increases negative health outcomes (Arrey et al., 2015b). It is particularly critical to address HIV-related self-stigma in sub-Saharan Africa, a region home to 85% of the world's adolescents living with HIV and the only population with increasing mortality rates (Casale et al., 2019a, Ferrand et al., 2017b, Enane et al., 2018).

Study focus and rationale

This research explored beliefs, experiences and impacts of HIV-related self-stigma amongst older adolescents and young adults (18–24 years) in Harare, a group with disproportionately poor HIV clinical and psychosocial outcomes (Boerma et al., 2016, Ferrand et al., 2017b, WHO, 2014). It aimed to understand the experience of self-stigmatisation within this population and context through Corrigan's framework of self-stigma: awareness, agreement, and application. This understanding will help inform self-stigma reduction interventions in Zimbabwe and sub-Saharan Africa more widely. Addressing HIV-related stigma in general and self-stigma in particular, is important for improving AYALHIV's clinical and psychosocial outcomes (Ma et al., 2019).

5.4 Methods

Design and setting

We conducted this qualitative study with adolescents and young adults living with HIV (AYALHIV) (18–24 years) enrolled in Africaid's Zvandiri program, in Harare, Zimbabwe. The Zvandiri (meaning 'As I am') program provides services, counselling, medication, and support to children, adolescents, and young people living with HIV in Zimbabwe and eight other countries (Mavhu et al., 2020, Willis et al., 2018b). Zvandiri aims to directly improve the wellbeing of this population thereby strengthening their engagement with services across the HIV prevention and care cascades (Mavhu et al., 2020, Willis et al., 2018b). This study used both convenience and purposive sampling to identify respondents as all were participants in

the Zvandiri programme and living, as young adults, with HIV. Sixteen respondents were interviewed; 12 (75%) were trained peer supporters known as Community Adolescent Treatment Supporters (CATS) and 4 were beneficiaries (a term used in Zvandiri for those clients who are not CATS). Purposive sampling guided an equal selection of females (n = 8) and males (n = 8). Interviews were conducted between June and July 2020. The out- break of SARS-CoV-2 coincided with the commencement of data collection activities, which impacted on both the sample size and a shift from in-person to virtual interviewing methods.

Theoretical paradigm and positionality

Deductive reasoning using Corrigan et al's (2009) self-stigma framework (Corrigan et al., 2009) informed the development of the interview guide (see [S1 File](#)). Questions were grouped by the three A's of self-stigma: awareness, agreement, and application in order to efficiently analyse the potential experiences of self-stigma (Corrigan et al., 2009). The interview guide was designed as a flexible semi-structured guide in order to facilitate the emergence of respondents' lived experiences. Therefore, this research was both deductive and inductive. Deductive analysis was used with the self-stigma framework to determine if respondents actually experienced HIV-related self-stigma. The discussions with the respondents were compared to Corrigan et al's (2009) self-stigma framework (Corrigan et al., 2009) in order to have consistency as to what is considered the experience of self-stigma. However, an inductive and phenomenological approach was also used to determine the themes within this framework of the beliefs and experiences of HIV-related self-stigma as experienced by the respondents. This inductive approach is rooted in the sociological theory of social constructivism; which understands human experiences as socially created and shaped by a person's engagement with their culture and society (Amineh and Asl, 2015). This paradigm describes reality as unique for different individuals based on how they make sense of the world through a combination of history, social norms, and community interactions (Teater, 2015). The social constructivist approach interprets the phenomenon of HIV-related self-stigma from the perspective of the respondents and their unique context which helped to develop the sub themes within Corrigan et al's (2009) three A's of self-stigma: awareness, agreement, and application (Corrigan et al., 2009, Teater, 2015). As adult researchers, we also employed self-critical epistemological awareness considering how our own perceptions and experiences could potentially influence interpretation of study findings. Our team included Zimbabwean researchers for local and in-depth context, as well as non-Zimbabwean self-

stigma experts. We privileged the voices of study respondents and ensured we set aside our own biases to maximise rigour during data analysis, interpretation, and reporting (e.g., through researcher triangulation).

Data collection, processing and analysis

All interviews were led by CR in English in the presence of Africaid's psychologist (VM) who was known to all research respondents. While the psychologist presence may have had some impact on what the respondents revealed, the familiar support provided by the psychologist ensured the safety and security of respondents and provided immediate emotional support if required. Additionally, the psychologist acted as a live translator in the event that any of the respondents needed to respond in Shona. Any translations were time stamped and recorded in the data.

Due to the COVID-19 pandemic, interviews were conducted virtually through the Zoom video conferencing platform because the lead researcher was unable to travel to Harare. With the support of a travel stipend, respondents came to the Africaid facility and participated in the interviews in a private space. Each interview lasted 30–45 minutes and was recorded with respondents' permission. The recorded interviews were transcribed (and the sections in Shona were translated) verbatim into English.

A summary of the discussion was written following each interview. These summaries and weekly analytical meetings amongst the research team informed development of a provisional coding framework. Half of the interviews ($n = 8$) were then independently coded by two researchers (CR, WM) using Corrigan et al's (2009) framework (Corrigan et al., 2009). Discrepancies were resolved through discussion (with EB) until consensus was reached. Any additional codes identified from this first set of transcripts were added to the coding framework. Transcripts were entered into NVivo 12 (QSR International, Melbourne, Australia) and fully coded using the modified coding framework; care was taken to identify any additional emerging codes. Codes were grouped and emerging themes were identified and supported with verbatim quotes. For example a theme was 'agreement' with negative judgements and sub themes included: worthlessness, hopelessness, and negative body image.

Ethical considerations

This study was approved by the Health Policy and Management and Centre for Global Health Research Ethics Committee in the School of Medicine, Trinity College, Dublin (as it was part of a MSc study for CR) and the Medical Research Council of Zimbabwe as the research was being conducted in Zimbabwe (#2604). Africaid provided information leaflets and consent forms to all the respondents at least seven days in advance of interviews. Written and oral informed consent were obtained from all respondents prior to participation. Confidentiality assurances were given during the consent process. Names and other personal identifiers were removed from transcripts before they were analysed. All information was stored in an approved cloud account that was double password protected and encrypted for protection. Only the lead researcher had access to the account and transcripts unless recorded permission was given to co-researchers. These procedures met the requirements of General Data Protection Regulation (GDPR) in full. Respondents received US\$5 bus fare reimbursements.

5.5 Results

Respondent characteristics

The mean age of respondents was 22 years. Most of the respondents 12/16 (75%), were CATS and equal number of male and female respondents (Table 1). The majority of respondents, 14/16 (88%), disclosed that they were born with HIV. Corrigan's self-stigmatisation framework (Corrigan et al., 2009) helped to analyse if the respondents actually experienced self-stigma and if so, what self-stigmatizing beliefs they applied onto themselves and the impacts of that. The data indicated that all the respondents experienced self-stigma (the judgements one has towards oneself including beliefs of worthlessness, hopelessness, and self-blame), but it was not felt all the time. Most of the respondents, 10/16 (63%), experienced self-stigma frequently (4 or more times a week) and 6/10 (37%) self-stigmatized only occasionally (once or twice a week). Study findings were grouped into Corrigan's self-stigmatisation framework (Corrigan et al., 2009) of the three As: awareness, agreement, and application.

Table 1. Characteristics of respondents in relation to the Zvandiri program (N = 16).

Respondent ID	Age	Female/Male	CATS or Beneficiary
01	24	Female	CATS
02	19	Male	CATS
03	22	Female	Beneficiary
04	22	Male	Beneficiary
05	24	Male	CATS
06	21	Female	CATS
07	18	Female	Beneficiary
08	20	Female	Beneficiary
09	22	Male	CATS
10	24	Male	CATS
11	23	Male	CATS
12	24	Male	CATS
13	24	Female	CATS
14	24	Female	CATS
15	22	Female	CATS
16	21	Male	CATS

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Awareness

The respondents were very aware of negative community beliefs through cultural norms and personal experiences. Fourteen of the sixteen (88%) respondents disclosed that they were born with HIV and were informed about their status at a young age. Therefore, they reported that they had endured years of discrimination, stigma and prejudiced community beliefs. Even those who were diagnosed much later, two of the sixteen (12%), were old enough to have an understanding of how others perceived PLHIV. They reported hearing gossip and negative comments about PLHIV that made the respondents aware of how their community viewed HIV.

Misconceptions about HIV perpetuated the fear and judgements their community had towards PLHIV. This awareness can come from ‘social stigma’, meaning open acts of discrimination towards people living with HIV. Respondents reported experiencing discrimination from friends, family, classmates and community members. *“My Aunt treats me bad when she comes*

here [Harare]. She doesn't even want to sit near me, talk to me or even shake hands with me. It makes me feel worthless.” (Participant 6, Female, CATS)

“Like from that time, they didn't want to share like a pen or ruler. And other stuff. And I was treated like someone who is always sick” (Participant 16, Male, CATS)

Awareness did not come exclusively from ‘social stigma’ and several respondents who had kept their status a secret described how they were aware of their community’s negative perception of HIV. They were cognizant of and internalised the mainstream stereotypes about HIV including that PLHIV are unclean, sleeping around, and contagious to touch.

“In the community it is very difficult because they think HIV is an airborne disease or something. That if you play with someone who is HIV positive that you will end up having AIDS or something.” (Participant 2, Male, CATS)

Agreement

The respondents agreed with several beliefs that underpin HIV stigma and stereotypes. Community beliefs typically include that PLHIV are dying, dirty, immoral, worthless or to blame for their condition (**Earnshaw et al., 2012**).

“Yes, I sometimes internalize it, especially when I am alone. I can agree that I am worthless, or I can't do certain things.” (Respondent 13, Female, CATS)

While most of the respondents did not outwardly say that they agreed with these negative beliefs and stereotypes about PLHIV, their responses demonstrated that they did agree with and experienced negative judgements towards themselves. This may be a result of internalizing negative cultural beliefs over time and agreeing with them. The respondents agreed with beliefs of worthlessness, hopelessness, and negative body image.

Worthlessness. When respondents were feeling down about their HIV status, they would describe feeling worthless. They reported that these feelings were more intense when they first found out about their status, causing several to become suicidal. Most respondents (88%) had known their HIV status for at least seven years and described that feelings of worthlessness

were more prevalent when they first found out their status. However, the belief of worthlessness was still present and impacting their life.

“When I am not positive [towards myself], I just feel I am not worth it. I don’t deserve to be on this planet at all. Because sometimes my family the way they treat me, it makes me feel like I am a burden to them.” (Respondent 15, Female, CATS)

These feelings of worthlessness have caused suicidal thoughts for many of the respondents. The respondents reported internalizing the belief that PLHIV did not deserve to live. This demonstrates how HIV-related self-stigma can make the respondents feel worthless and confined by their HIV status.

“Honestly, sometimes I wanted to kill myself. I thought why am I living in this world? I don’t have peace, I want peace. And I want freedom to do what I want.” (Respondent 5, Male, CATS)

“Initially, when I first found out, I wanted to commit suicide.” (Respondent 7, Female, Beneficiary)

Hopelessness. The respondents described days where they felt no hope for themselves or their future. This despair could be overwhelming and limiting, causing stress and sadness. This feeling of hopelessness was raised more frequently when discussing issues pertaining to interpersonal relationships with friends, romantic partners, and community members.

“Sometimes it makes me feel that there is nothing that I can do which makes me feel very hopeless and worthless and I become very stressed and I start thinking is there ever a time where I can live my life with people who care about me and love me and accept me.” (Respondent 13, Female, CATS)

A common community belief is that PLHIV are ‘about to die’. When the respondents agreed with this thought, they felt that their destiny was determined and hopeless. This despair could be overwhelming and limiting, causing them stress and sadness. They reported frequently asking themselves “why me?” They could not rationalize the suffering that their HIV had caused, making them feel hopeless.

“Why only me? Why only me? Why am I the only HIV positive person in the house? Why, why, why, why.” (Participant 1, Female, CATS)

Negative body image. Common stereotypes of PLHIV in Zimbabwe and elsewhere are that they are ‘unclean’ and able to spread HIV through touch (Campbell et al., 2011, Jugeo and Moalusi, 2014). Although the respondents knew that these misconceptions were not true, they admitted to internalizing the negative beliefs. *“Yeah, from the beginning I felt that I wasn’t worth sitting around people who are HIV negative because I would feel that I was unclean and that I would make them dirty. It has gotten better though.”* (Participant 14, Female, CATS)

These negative perceptions about their body made them feel like they smelled of HIV, should not sit next to people who are HIV negative, and that they could not be loved. This negative body image caused low self-esteem and inhibited the respondents from living their lives freely. *“When I heard that I was HIV positive, it lowered my esteem, I started being reserved. I started disassociating with people. I felt the self-stigma. I could walk and think it is written on the wall; on my forehead you know? I would walk and think it is readable that you are HIV positive. That it can be seen.”* (Respondent 4, Male, Beneficiary)

Application. After becoming aware of and experiencing HIV-related stigma, the respondents reported internalizing negative judgements expressed by members of their community. The application of these beliefs onto experiences in their lives reinforced their self-stigma. The key themes of self-stigmatizing experiences that became evident in the interviews included disclosure difficulties, self-isolation, and relationship complications.

Disclosure. The respondents reported that disclosure was extremely difficult because a lot of trust and time was needed to be able to tell someone about their HIV status. Disclosure is challenging for these respondents because of negative disclosure experiences and their fears of being socially rejected.

“It is difficult to tell people that you are HIV positive because you will struggle to walk in the community, in the neighborhood because people will humiliate you, they will shout at you, say terrible things about you because you are HIV positive.” (Respondent 9, Male, CATS)

The respondents reported worrying that they would lose their friends if they disclosed their status due to the shame of HIV. Therefore, many respondents kept their HIV a secret, even to the detriment of their health by quitting their medication. *“So, I was shy, I was embarrassed. Like I was still thinking, what will they say if they know I am like this? Will they even accept me? So, I just quit my medication which was quite stupid.”* (Respondent 4, Male, Beneficiary)

“So, my first year in high school, I was a boarder, and that was quite hard. You know you have to take your medication, but you live in a dorm with I think 8 girls and you need that privacy to take your medication. So, I had to quit.” (Respondent 3, Female, Beneficiary)

Isolation. Isolation and feeling alone was a common theme in the interview responses. Respondents reported being left out by friends and family, feeling like they had no one to talk to, and self-isolating due to their status. This caused self-stigmatisation and feelings of loneliness, shame and being silenced. Respondents endured being left out and separated from other people because of their HIV status and the belief that PLHIV are dirty or dangerous. Misconceptions by others about the virus caused others to exclude the respondents, causing them to feel alone and ‘unclean’.

“My grandma used to say you guys have to sit there, you have to have your own cups, you have to have your own things, you cannot share with others. So, it was so hard for me because always I couldn’t do what other kids could do because I was always being separated from other kids.” (Respondent 14, Female, CATS)

Experiences of stigma caused so much humiliation that the respondents felt deeply ashamed of their status and would isolate themselves. Respondents reported that their shame would hold them back from socializing with others, making them feel alone and without any- one to talk to.

“It is very painful, and I feel sad and sometimes I cry about it. And sometimes I feel that I shouldn’t even walk in the street or do things”. (Respondent 13, Female, CATS)

“It was really hard because I had no one to talk to. No one to express how I felt and even my own family, they didn’t even understand.” (Respondent 15, Female, CATS)

Respondents often felt alone because of their HIV status and unable to speak their minds. These feelings were perpetuated through self-stigmatisation by believing they were not worthy enough to have a voice.

Relationships. Relationships were a significant source of stress and self-doubt for respondents. As adolescents and young adults, all respondents had either experienced being in a relationship or expressed wanting to date. However, this was complicated by fears of disclosure, experiences of rejection, and the status of their partners. Respondents reported feeling hopeless about finding love and fearful about disclosing to a potential partner. By believing they were unlovable, respondents reported that they would self-sabotage relationships by ending or not engaging in them. These feelings generally got better over time as respondents saw other PLHIV engage in relationships.

“She said that in the past she didn’t use to date anyone because she was HIV positive and so she thought that would result in her being rejected.” (Respondent 13, Female, CATS. Translation from Shona by psychologist)

Many of the respondents had painful experiences of being rejected by a partner due to their HIV status. This led to most of the respondents to choose to date only HIV positive people in order to avoid disclosure. However, several respondents (44%) still expressed a desire to date someone not living with HIV.

“For me it was a big challenge because I was looking for another who was not HIV positive. I wanted someone who was HIV negative to date, but the issue was disclosure.” (Respondent 12, Male, CATS)

Secondary themes

Secondary themes are reported as important information that came up frequently, but were not as prevalent as the above-described themes. The secondary themes presented are gender differences and coping mechanisms.

Gender differences. The respondents were split evenly on whether they thought men and women experienced HIV-related self-stigma differently. While the interview responses demonstrated that men and women have the same self-stigmatizing beliefs, they suggested that

the experiences of self-stigma could be more intense for women due to their already marginalised position in society (Loutfy et al., 2012). Half of the respondents felt that experiences of HIV and self-stigma were worse for women.

“So, if a girl, if she’s positive they will think she is characterless, or she has been sleeping around with a lot of boys. For the boys, if you are HIV positive, it doesn’t really affect him as much.” (Respondent 1, Female, CATS)

“There is a difference between men and women. . . even if it’s a couple, it is the woman who goes to the facility. So, she is the one who usually is labelled as having HIV or her reputation is usually tarnished in the community because she is HIV positive. Whereas men are usually in hiding and not usually associated with infection even though they are HIV positive”
(Respondent 12, Male, CATS)

Coping strategies. The respondents shared how they were able to better manage their HIV and reduce their negative thoughts. These coping strategies included counselling, support groups, hearing shared experiences, and medication adherence. These interventions and support from Africaid helped ease self-stigmatizing beliefs for the respondents.

“I have had some group counselling with peers, with my primary counsellors at my facility, and some aunties at Zvandiri [Africaid]. They helped me a lot.” (Respondent 12, Male, CATS)

“And so, when I started seeing others, my peers that were surviving, that were going to school, that were graduating from university I realized that this [stigmatizing thoughts] wasn’t true, that there was hope.” (Respondent 13, Female, CATS)

5.6 Discussion

Corrigan et al. (2009) defined self-stigmatisation as a process in which a person becomes aware of negative stereotypes, finds that they agree with those judgements, and applies the stigmatized beliefs onto themselves (Corrigan et al., 2009). The data was analysed using this framework and the results of this study clearly report feelings, experiences, and beliefs that are consistent with Corrigan’s definition of self-stigma. Respondents reported the beliefs and feelings of worthlessness, hopelessness, and negative body image. These negative self-

perceptions were reinforced by the self-stigmatizing experiences of disclosure difficulties, isolation, and dating complications. Respondents all expressed having frequent (4 or more times a week) or occasional (once or twice a week) negative feelings towards themselves because of their HIV status.

All respondents were aware of the harmful stereotypes ascribed to PLHIV. They heard negative comments, witnessed intolerance, and endured personal humiliation as a direct result of their HIV status. There are several societal beliefs and cultural factors that made the respondents aware of HIV stigma. The negative association between HIV and the lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) community and the fact that acts of homosexuality are illegal in Zimbabwe adds additional stress and fear to PLHIV when disclosing their HIV status to friends, family, or partners-regardless of their sexuality (Mawadza, 2004). Despite most of the respondents being born with HIV, they still felt blamed for living with HIV and were associated with ‘immoral’ behaviours such as multiple sexual partners or drug use. Additionally, the respondents reported that being called in Shona the equivalent of “dead one” or “plagued one” led them to believe that their lives were hopeless. These stereotypes perpetuate negative conceptions of HIV and reinforced adverse cultural norms that the respondents internalised.

Not only were the respondents aware of the societal stereotypes of PLHIV, but they also agreed with many of the underlying beliefs associated with them. These negative self-perceptions included beliefs of worthlessness, hopelessness, and negative body image. These beliefs caused the respondents to feel limited in their agency to live their lives the way they wanted. However, the respondents explained that these beliefs were more intense when they first found out their diagnosis. Self-stigmatizing thoughts can decrease over time with proper interventions and are not a static experience. Most of the respondents had known their status for at least seven years. Therefore, it would be interesting to investigate further how self-stigmatizing beliefs vary with length of time knowing one’s HIV status and mode of transmission.

Believing that their lives were worthless and hopeless caused many of the respondents to experience depression or suicidal thoughts. This led to emotional distress which resulted in poor adherence to anti-retroviral regimens. When they believed their lives were no longer worthwhile or feared they would be severely judged, the respondents decided to stop taking

their medication. Without medication, the respondents experienced an increased viral count, causing extreme weight loss, and increased susceptibility to AIDS-related illnesses (Bae et al., 2011). Additionally, these beliefs deeply impacted their ability to easily connect with friends or family, inhibiting them from a support network.

Interestingly, while the respondents felt hopeless in their personal relationships and ability to be accepted by their community, they generally did not feel hopeless when talking about their career. Corrigan et al. (2009) explained that self-stigma can deter people from going after their dreams and careers due to feelings of worthlessness and hopelessness. However, in this study, most of the respondents explained that attending counselling sessions and seeing other PLHIV who had thriving careers were sources of inspiration and encouragement. Research has shown that support groups are a useful resource for facilitating self-acceptance and restoring the confidence that may be lost once one is diagnosed with a highly stigmatized infection such as HIV (Willis et al., 2018a, Mupambireyi et al., 2014b). This supports the transformative effects of support groups, however, these groups must also address self-stigmatizing beliefs that respondents' experience.

The respondents each spoke of several experiences in which they were aware of negative self-judgments including disclosure of their HIV status and dating with interpersonal relationships of paramount importance to this age group. As young adults, peer acceptance is extremely important for support and determining self-worth (Kim, 2016). It is an age where young people are trying to find their individuality, yet also desire community acceptance (Kim, 2016). Study respondents reported that living with HIV created a tension between the need to be themselves while also maintaining social and community acceptance.

Respondents felt that by disclosing their HIV status, they would not be accepted by their community. This realisation caused stress and fear in trying to decide whether to disclose to friends or family. Several of the respondents were still in school, a place that commonly facilitates gossip and social exclusion towards PLHIV (McElhaney et al., 2008). This caused most of the respondents to avoid disclosing their HIV status to anyone. However, the burden of this secret made many of the respondents feel shameful and stressed, leading them to avoid engagements with friends, skip doctor's appointments, and stop taking their medication. This caused both physical and emotional health problems for the respondents and likely explains

the high rates of virological failure seen in this group (Mavhu et al., 2020, Ferrand et al., 2017b).

By not disclosing or talking to anyone about their HIV, the respondents described an intense loneliness and isolation. It often was not that the respondents had literally no one to talk to. Instead, their self-stigmatizing beliefs made them feel so shameful and worthless that they were unable to initiate needed conversations for support. These feelings caused the respondents to self-isolate and pull away from friends, family, and social gatherings. Studies have shown that PLHIV silence themselves to avoid conflict, judgement, and to conform to societal standards (Dale et al., 2014, Enriquez et al., 2010). However, the respondents reported that the burden of living with the secret of their HIV status was extremely overwhelming to handle alone (Enriquez et al., 2010).

The respondents were 18–24 years old, an age range where dating and relationships are often important and a priority (Xia et al., 2018). This was clear because the topic was discussed at length in the interviews. However, as important as relationships were to them, dating also caused stress and complications for the respondents. Their self-stigmatizing beliefs made them feel hopeless to find a partner that would ever accept them. This was immensely saddening and discouraging for respondents who wished to start a family. Past rejection, abuse, and stigma caused low self-confidence and fear when trying to date or disclose to a partner. Studies have shown that anxiety and shame before or during disclosure in relationships are common for young adults with HIV (Hosek et al., 2000, Harper et al., 2014b). Therefore, when the respondents self-stigmatized, their shame normally caused them to end the relationship before they had to face disclosure. Beliefs of worthlessness and shame were most closely tied to dating and interpersonal relationships, indicating the importance of this topic.

Respondents who did decide to date, often found it easiest to date someone who also had HIV. This helped them to avoid the disclosure process and feel less ashamed. However, several of the respondents (44%) admitted to wishing they were dating someone who was HIV negative. This suggests deep rooted judgements towards themselves and HIV, because they could not even fully accept someone who shared in their same condition. There is little literature on this phenomenon with PLHIV and dating, however, this stigmatisation towards one's own group has been seen in other marginalised communities, such as those in the LGBTQ community and people with mental illnesses (Knaak et al., 2017, Puckett et al.,

2017). These studies linked that those who experienced self-stigma could also stigmatize others within their group due to the negative beliefs they hold about their group identity (Knaak et al., 2017, Puckett et al., 2017). Therefore, further research should investigate the complicated experiences of self-stigma and dating in this age group due to its importance and influence on the respondents.

This study had a gender balance of 50% men and 50% women. Both sexes reported very similar beliefs and experiences of HIV-related self-stigma. They shared the same feelings of worthlessness, hopelessness and negative body image when dating, disclosing their status and feeling isolated. Yet, both men and women in the study felt that society was harsher and more discriminatory towards HIV positive women than men. Half of the women ($n = 4$) discussed the possibility that the increased prejudice they experienced as women caused them to self-stigmatize more often and more intensely than men. A study undertaken by Duffy (2005) concluded that women with HIV were more discriminated and more frequently blamed for spreading HIV in Zimbabwe than men (Duffy, 2005). Reidpath et al. (2005) explain that by holding two stigmatized identities in society, such as being woman and a person living with HIV, one can experience layered or additive stigma, which can increase the frequency and intensity of self-stigma (Reidpath and Chan, 2005). This was only reported amongst half of women and we did not have quantitative scales to measure self-stigma intensity. Therefore, gender differences should be further explored as a potentially impactful aspect of self-stigma with a larger group of respondents.

Taking these findings into consideration for future interventions is critical in addressing HIV-related stigma. Study respondents were already receiving counselling and engaged in support groups. Additionally, most of the respondents were CATS which meant that they had training and on-going supervision in the provision of counselling which has been found to alleviate feelings of hopelessness, worthlessness, feeling unloved, isolation, depression and suicidality. That all of the respondents still reported self-stigmatizing beliefs despite the support highlights the need to specifically address self-stigma within the Zvandiri program (now in nine countries) and to remain mindful of CATS' own support needs. Previous research suggested a reduction in stigma among ALHIV supported by CATS (Willis et al., 2019) and further suggested that engagement with CATS improves self-acceptance, self-worth and confidence (Mavhu et al., 2013, Bernays et al., 2020, Grimsrud et al., 2020). Innovative

strategies to both enhance and sustain this transformative effect should continue to be explored.

Importantly, our study suggests that context is hugely key in the way that HIV is understood and then impacts the way that PLHIV live with, and experience, HIV. This is especially salient in the colloquial references to PLHIV which condemn these individuals some kind of “half-life”. As such, interventions that support PLHIV in general and AYALHIV in particular, need to be context-relevant if they are going to impact on self-stigma at all. Additionally, interventions should be systemically applied (i.e. policy and politics need to change attitudes at societal, community, household levels while HIV services build individual resilience in the meantime). It will be important to work across the entire socioecological framework since individuals are embedded within larger social systems and multiple levels of influence not only exist but are also interactive and reinforcing (Golden and Earp, 2012).

Of note, our team is currently piloting a peer-led intervention to support AYALHIV in Zimbabwe on the journey from self-stigma to self-worth using a combination of inquiry-based stress reduction, music, art and creative expression (all have been previously run separately and successfully by the team) (Ferris France et al., 2019c, Willis et al., 2018a, Wogrin et al., 2021, Råheim et al., 2016). Addressing and reducing self-stigma will likely enhance AYALHIV’s confidence to take medication, disclose their status safely, and take appropriate healthcare measures (Ferris France et al., 2019c). The spiral effect will be the much-desired improvement in AYALHIV’s clinical and psychosocial outcomes (Katz et al., 2013, Mavhu et al., 2020, Willis et al., 2018b).

5.7 Strengths and limitations

As a qualitative study, this research reports in-depth accounts and analysis of the lived experiences of HIV self-stigma. The interviews helped create a rich description of the thoughts and beliefs that PLHIV experience about themselves. Since there are very few studies on HIV self-stigma, this study makes a valuable contribution to the understanding of this important issue and provides an opportunity for Africaid’s Zvandiri programme and other HIV support interventions to specifically address the impacts of self-stigma.

There were some limitations to this study. CR, a non-Zimbabwean, led the interviews in English which may have made it difficult for respondents to connect with the researcher, in addition to creating a power imbalance (Råheim et al., 2016). A few of the respondents chose to respond to certain questions in Shona, which was translated live by the Zimbabwean psychologist (VM) present. Live translations have the potential to not capture all that was originally said or to be accidentally misinterpreted (Van Nes et al., 2010).

Due to the COVID-19 pandemic, availability of respondents was limited; therefore, twelve of the sixteen respondents were CATS. CATS have been trained to help young people living with HIV and teach them coping mechanisms, so this type of training and knowledge about HIV may have had an impact on their responses. The CATS training and increased access to HIV resources could alter their beliefs and therefore potentially report lower levels of self-stigma than other PLHIV. This limits the generalizability of the results of the study because most young PLHIV do not have as easy access to HIV resources as the CATS do. However, the fact that CATS still reported HIV-related self-stigma despite their training and experience as peer counsellors indicates that self-stigma is still a pervasive and unaddressed issue.

COVID-19 also caused the interviews to be online over video call rather than in person. In person interviews are generally regarded as the preferred method for talking about sensitive issues, such as HIV, so that the respondent feels more comfortable (Krouwel et al., 2019). Therefore, doing these interviews online could have inhibited the respondents from opening up as much as they may have wanted to about their HIV experiences. Despite these limitations, we still hope that we managed to elicit important self-stigma information that will inform stigma-reduction interventions.

5.8 Conclusions

This study explored the beliefs, experiences, and impacts of HIV-related self-stigma amongst young adults living with HIV in Harare. The results of this study are critical to our understanding of how adolescents and young adults in Harare, Zimbabwe experience HIV-related self-stigma and will inform Africaid's Zvandiri programme and other HIV support intervention's efforts to address the impacts of self-stigma. Coping strategies for self-stigma that were helpful for the respondents should be incorporated into existing and future HIV interventions by addressing self-stigmatizing thoughts in counselling, support groups,

inquiry-based stress reduction, art, meditation, and mindfulness techniques. This will help young adults struggling with HIV-related self-stigma to recognize their self-judgements and constructively change the way they view themselves. Additionally, engaging more young people in interventions that challenge self-stigma can help PLHIV build a community and support network that is clearly needed amongst this age group. By promoting awareness of self-stigma, PLHIV may be empowered to challenge the perspectives of others, attend social gatherings, talk to their partner about their HIV status, and proactively engage with HIV support services.

Chapter 6: Wakakosha “You are Worth it”: Reported impact of a community-based, peer-led HIV self-stigma intervention to improve self-worth and wellbeing among young people living with HIV in Zimbabwe

6.1 Commentary

A qualitative study carried out in Zimbabwe on the perceived impact of a self-stigma intervention (Wakakosha, ‘You are worth it’) among adolescents and young people aged 18-24 living with HIV in Zimbabwe. The intervention uses Inquiry-Based Stress Reduction (IBSR) at its core - a unique way of identifying and questioning deeply rooted self-stigma combined with mindfulness, meditation and creativity (music, poetry and art). The study responds to the lack of community-based and peer-led interventions among adolescents living with HIV. The intervention shows potential for reducing self-stigma and improving self-worth among AYPLHIV. Main themes that emerged were positive changes around self-judgement, self-confidence, self-worth, self-agency, body positivity, improved communication in the family, self-forgiveness and forgiveness of others.

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The paper has been reformatted to fit the style of the thesis but was submitted and published according to the specifications of the journal.

6.2 Abstract

Introduction

Self-stigma—negative self-judgements or core beliefs—can result in feelings of shame, worthlessness and self-blame, and impacts social interaction, mental health and health service utilization among people living with HIV (PLHIV). Few interventions target self-stigma among PLHIV and, to our knowledge, none until now for adolescents and young people LHIV (AYPLHIV) in sub-Saharan Africa. We present qualitative findings on the perceived impact of a self-stigma intervention (Wakakosha, “You are Worth it”).

Methods

Methods: The Wakakosha intervention adopted inquiry-based stress reduction (IBSR) at its core—a unique way of identifying and questioning deeply rooted self-stigma, combined with mindfulness, meditation and creativity. The intervention consisted of 16 × 3 hour group sessions. Supporting the intervention was a 156-page activity journal. We utilized a qualitative enquiry to explore the perceived impact of the intervention at various time points between November 2021 and November 2022, with 62 participants (n = 32 female). Discussions explored experiences of being involved in the intervention and any reports on

changes in relation to self-stigma and shame. Additionally, we reviewed intervention documentation and creative elements. A thematic analysis guided generation of themes across all data sources.

Results

Both intervention participants and coaches described the transformative effect of the intervention, detailing their experiences before and after. Main themes that emerged were positive changes around: self-confidence, self-agency, sense of purpose/meaning, body positivity, improved communication and personal/family relationships and, forgiveness. The intervention also transferred a set of practical skills on self-inquiry, mindfulness, meditation and creativity that continued to be used in participants' daily lives.

Conclusion

The Wakakosha intervention, using IBSR supported by music, creativity, writing and mindfulness techniques, showed potential for reducing self-stigma and improving self-worth among AYPLHIV. It also transferred practical skills to intervention participants and peer coaches, building their capacity to support others and deal with life challenges beyond HIV. The next phase is to continue supporting the young people to ensure fidelity as the peer coaches deliver the intervention to others. Study results indicate that culturally and practically, interventions to reduce self-stigma and/or improve self-worth operate at various levels and need to be designed and assessed at each level.

Key words: HIV, inquiry-based stress reduction (IBSR), self-stigma, intervention, self-worth, wellbeing, young people, internalised stigma

6.3 Introduction

More than four decades into the global HIV pandemic, stigma remains a major barrier to HIV treatment, management and care (Mahajan et al., 2008, UNAIDS, 2017, Stackpool-Moore et al., 2022a, Stackpool-Moore et al., 2022b, Ninnoni et al., 2023, Hutahaeen et al., 2023, van der Kooij et al., 2023). Goffman described stigma as, “an attribute that is significantly discrediting” which, in the view of others, serves to reduce the person who possesses it

(Goffman, 1963). Goffman also importantly identified stigma as a complex and multi-dimensional phenomenon (Goffman, 1963). The internalisation of stigma leads to what Goffman called ‘spoiled identity’ or self-stigma (Goffman, 1963, Pantelic et al., 2019). HIV-related self-stigma is experiencing negative judgements towards oneself resulting in feelings of shame, worthlessness, self-blame and, emotional distress (Ferris France et al., 2019b).

Self-stigma can result in non-adherence to HIV medication, lower quality of life and poor mental health (Ferris France et al., 2019b, France et al., 2015). A systematic review found that HIV-related stigma undermined antiretroviral therapy (ART) adherence by compromising general psychological processes (e.g. adaptive coping and social support), and 24/33 (73%) studies reported an association between HIV stigma and ART non-adherence (Katz et al., 2013). Multiple and intersecting drivers of stigma (HIV, orphaning, ill health, poverty) make adolescents and young people living with HIV (AYPLHIV) particularly vulnerable (Mavhu et al., 2013). Self-stigma contributes to AYPLHIV’s high rates of attrition from HIV treatment and care, treatment failure, morbidity and mortality (Casale et al., 2019, Boerma et al., 2016, Mavhu et al., 2020). In sub-Saharan Africa, home to 85% of adolescents living with HIV globally, adolescents are the only population with increasing mortality rates (Casale et al., 2019, Ferrand et al., 2017c, Enane et al., 2018).

While most stigma initiatives focus on averting discrimination (also known as enacted stigma) (Pantelic et al., 2019), the phenomenon of self-stigma is much less understood (Rich et al., 2022, France et al., 2015). However, approaches that target self-stigma likely benefit psychological function and wellbeing of people living with HIV (PLHIV) in general and AYPLHIV, specifically (Rich et al., 2022). As many AYPLHIV were perinatally infected, they experience a great deal of self-stigma and shame throughout their young lives, including as a result of taboos about being sexually active (Rich et al., 2022). Of note, research suggests that self-stigma is experienced by PLHIV to a far greater extent than stigma received from the broader community (France et al., 2015, Kalichman et al., 2009).

Self-stigma occurs at the individual level, but also influences interpersonal relationships, community participation and engagement and, ability to access rights and health services (France et al., 2015). We previously presented a framework comprising three interacting groups of factors (self, social, contextual) which influence the development and perpetuation of self-stigma (France et al., 2015). Further, the socio-ecological model provides a useful

framework for understanding how health and wellbeing are influenced by multiple factors at various levels (individual, interpersonal, community, societal) (Krug, 2002, Pantelic et al., 2019). However, few programs or interventions exist at the individual level and, to eliminate HIV stigma, it is necessary to work at multiple levels, including the individual, community and wider society (Stangl et al., 2013, Pantelic et al., 2019).

With reference to Zimbabwe, previous research has shown that AYPLHIV are particularly affected by stigma and self-stigma (Mavhu et al., 2013, Willis et al., 2018a, Mavhu et al., 2020). 73% reported stigma and this affected their medication adherence; 47% had virological failure (Mavhu et al., 2020). In another study, AYPLHIV felt that because they were HIV positive, life was not worth living and described deliberately missing their medication so that they could eventually die (Mavhu et al., 2013). Further, in a study exploring the experience and manifestation of depression in AYPLHIV, adolescents attributed their experiences of depression to a sense of ‘being different from others’, both due to their HIV status and the impact HIV has had on their life circumstances (Willis et al., 2018a). In the current study’s formative research with AYPLHIV (2021), all participants reported HIV-related self-stigma either occasionally or frequently and experiences of self-stigma reportedly led to poor wellbeing and decreased mental and physical health (Rich et al., 2022). At baseline, the Zvandiri-Friendship Bench trial of a Community Adolescent Treatment Supporters-delivered problem-solving therapy found 62% of adolescents LHIV at risk of common mental disorder. Intervention data confirmed recurring themes of low self-worth, shame and worthlessness (Chinoda et al., 2020).

Based on previous findings on the high prevalence and negative impact of self-stigma in AYPLHIV, coupled with the absence of individual-level interventions to address self-stigma (France et al., 2015, Sengupta et al., 2011, Stangl et al., 2013), we developed an intervention to be layered within an existing program, Zvandiri. The Zvandiri (meaning ‘As I am’) program (www.zvandiri.org), recommended in 2013 by the World Health Organization as a best practice program (WHO, 2013), is a theoretically grounded, multicomponent, peer-led, differentiated service delivery model for children, AYPLHIV in Zimbabwe and adopted/adapted in 11 other countries (Willis et al., 2018b, Mavhu et al., 2020, Bernays et al., 2020). The program’s effectiveness in supporting improved HIV outcomes was recently demonstrated in the Zvandiri trial (adjusted prevalence ratio of virological failure or death 0.58, 95% CI 0.36–0.94; $p=0.03$) (Mavhu et al., 2020). Zvandiri aims to directly improve

AYPLHIV's wellbeing and strengthen their engagement with services across the HIV treatment and care cascades, including through peer counselling, community outreach, digital health and support groups (Willis et al., 2018b).

Evaluations have illustrated peer-support groups' potential in significantly transforming AYPLHIV's perception of HIV as a debilitating infection which they are experiencing in isolation, to a manageable condition (Mavhu et al., 2013, Mupambireyi et al., 2014a, Bernays et al., 2020). A key function of peer-support groups is that they nurture self-acceptance and enhance self-esteem through connectedness with others who have shared lived experiences (Mavhu et al., 2013, Mupambireyi et al., 2014a, Bernays et al., 2020). However, support groups do not intentionally address self-stigma and as a result, may not necessarily ameliorate it (Rich et al., 2022). Further, while young people do well in support groups, they continue to struggle outside the group setting (Mavhu et al., 2013, Mupambireyi et al., 2014a). A specific intervention addressing self-stigma is likely to additionally support AYPLHIV to deal with life challenges outside of peer-support groups. Informed by our formative study (Rich et al., 2022) and our previous work on self-stigma in Zimbabwe (Ferris France et al., 2019), we co-developed and piloted a culturally appropriate, locally informed intervention for AYPLHIV (18-24 years) to address self-stigma. Specifically, the intervention sought to increase self-worth and wellbeing by reducing self-stigma among AYPLHIV in Zimbabwe. This paper reports on findings from a qualitative study that explored the perceived impact of this intervention on self-stigma. For this pilot intervention, involving a relatively small sample, a qualitative exploration of nuanced and detailed accounts was most appropriate to provide a deeper understanding of any changes, how the intervention worked and what could be improved (see discussion).

6.4 Materials and methods

Study design: Intervention overview

We sought to adapt and optimize an innovation we previously piloted among adults living with HIV in Zimbabwe—Inquiry-Based Stress Reduction (IBSR): The Work of Byron Katie (Ferris France et al., 2019). IBSR is a unique way of identifying and questioning thoughts that cause shame, anger, fear and violence. Working with beliefs is imperative as self-stigma is deeply rooted in a person's belief system. The beliefs that underlie shame, guilt,

worthlessness and blame can be questioned with IBSR; allowing for new perspectives, insights and options that are kinder, more peaceful and empowering¹. IBSR provides an opportunity to discover a new and kinder way of living within oneself and the world, no matter what is happening. It uniquely combines in-depth inquiry of stressful thoughts with the process of cognitive diffusion and mindfulness. The evidence base for IBSR is growing and effectiveness has been shown on stressful beliefs in relation to cancer, HIV and among high school teachers (Lev-Ari et al., 2013, Smernoff et al., 2015, Naomi et al., 2018).

The ‘Wakakosha: You Are Worth It’ project was a partnership between Zvandiri, Beyond Stigma and others. Local Coaches, previously trained in IBSR, themselves adults LHIV, co-delivered the intervention together with an internationally IBSR-trained Facilitator and an international Creativity Coach. In brief, the *Wakakosha* intervention aimed to equip AYPLHIV (aged 18-24 years) in the use of IBSR/self-inquiry to manage stressful beliefs, reduce self-stigma and grow their sense of self-worth and wellbeing. Following formative research in 2021 (Rich et al., 2022), a pilot one-day workshop was held with 12 AYPLHIV and feedback systematically collected. The intervention was then fully designed based on the formative research, the pilot workshop and, drawing on previous self-stigma interventions designed for adults LHIV and survivors of gender-based violence (Ferris France et al., 2019). Principles underpinning the intervention included youth-centred, do no harm, flexible and adaptable, safeguard confidentiality, respect, non-discrimination, inclusive of key populations, playful and promoting best practice.

The *Wakakosha* intervention curriculum was designed (by NFF & VM) to start with several universal stressful thoughts about being HIV positive and from there, to work systematically through more acute self-stigmatizing core beliefs at a deeper level each week. Introductory sessions on thinking, identifying and feeling emotions were also provided before progressing to the deeper issues in the curriculum. During the process, participants were encouraged to identify, and inquire about, their stressful thoughts regarding shame, HIV status, disclosure to others, sexuality, judgements of self/others, the body, illness and death. Overall, the intervention aimed to improve management of specific emotional and psychological symptoms (relating to self-worth, stress, anxiety, depression, fears). The intervention consisted of 16 three hour group sessions which included individual and pair work (Table 1).

¹ See www.beyondstigma.org for description of IBSR methodology

Table 1: Wakakosha session overview

Session#	Session Title
1	Self-stigma, emotions and me
2	The power of thinking
3	Introducing inquiry
4	Judgements about HIV
5	What others think of me
6	How HIV limits me
7	Deepening inquiry
8	ARVs and my story
9	My body
10	My body and sex
11	Forgiveness
12	Deepening inquiry
13	Shame and guilt
14	Relationships and fear of disclosure
15	Death and dying
16	My future

Each session contained a mix of theory, meditation, group and individual experiences of IBSR, music reflection and sharing of insights, with time for singing and songs carefully matched to a session's themes to enhance learning and healing (see Figure 1). Supporting the intervention was a 156-page activity journal that contained worksheets, exercises and homework. Techniques such as journaling, box-breathing, podcasts, letter writing, poetry and drawing were used throughout. The intervention was first designed to be delivered as a six-day residential face-to-face camp. Due to COVID-19, a hybrid of online and face-to-face was adapted and delivered over 16 weeks, with weekly homework and practice sessions supported by WhatsApp.

***Wakakosha* intervention implementation**

Thirty Zvandiri Community Adolescent Treatment Supporters (CATS) were initially recruited in 2021 to receive the intervention delivered by trained adult Coaches (local and international). CATS are 18-24 years-olds LHIV, trained, mentored and supported to deliver structured support groups, counselling and tailored community-based adherence support to their peers (Mavhu et al., 2020, Bernays et al., 2020). From this group, 15 were identified to be subsequently trained as peer Coaches, and attended a residential face-to-face, six-day immersive Training of Trainers in early 2022. Then a new group of 30 CATS was recruited and participated in the second delivery of *Wakakosha*, a 10-day face-to-face intervention (5 hours per day), this time delivered mainly by peer Coaches (supported by adult Coaches). Each day of the training and/or intervention was evaluated, and feedback used real-time to adapt and ensure the curriculum was meeting the young people where they were. Towards the end, participants produced a song and recorded a music video which showed their experiences of the program and what happens when self-stigma is addressed. They also produced a podcast series through which they shared their own letters and poems about the body and forgiveness (available: <https://www.beyondstigma.org/videos>).

Study design: qualitative evaluation

Study participants and research activities

A qualitative enquiry explored the perceived impact of the *Wakakosha* intervention at various time points. Firstly, in November 2021, a focus group discussion (FGD) was held with 12 of the 30 CATS who were the first to receive the intervention. Another 12 CATS took part in in-depth interviews (IDIs) between November 2021 and February 2022. Additionally, 12 of the 15 CATS recently trained as peer coaches took part in a FGD in March 2022. In addition, 24 of the 30 CATS recently trained by peer coaches took part in two separate FGDs in November 2022. We also conducted key informant interviews (KIIs) with 2 of the 4 adult Coaches who had facilitated the intervention sessions (Table 2). Further, we analyzed intervention activities (e.g., letters to self or body, activity journals and daily evaluations).

Table 2: Summary of qualitative data collection

Date	Participant Category	Method	Number
Nov 2021	First set of CATS	FGDx1	12 (n=6 female)
Nov 2021- Feb 2022	First set of CATS	IDIx12	12 (n=6 female)
March 2022	Peer Coaches	FGDx1	12 (n=6 female)
November 2022	Second set of CATS (trained by peer Coaches)	FGDx2	24 (n=12 female)
November 2022	Adult local Coaches	KIIx2	02 (n=2 female)

Qualitative data collection and processing

Individual interviews and FGDs explored experiences of being involved, any changes in relation to self-stigma and shame (including examples of increased self-worth, examples of doing things they would not have done before, for instance: dressing better, enrolling for a course, approaching someone with confidence, self-agency, self-esteem, self-love) (see sample interview questions in Table 3).

Table 3: Sample interview questions for intervention participants by domain of interest

Domain	Sample interview question
Overall experiences in program	Tell me about your experience in Wakakosha program. What did you like and dislike about the program?
Changes in thinking about self and HIV	What changed or stayed the same about how you think about yourself and HIV after taking part in this program?
Changes in self-stigma and shame	What changed or stayed the same about self-stigma and shame after taking part in this program?
Intervention components	Which components worked well or did not work well?
Intervention delivery	What do you think about the way the program was delivered? What worked well and what did not work?
Program recommendations	If the course were to be offered elsewhere, what should be maintained or changed? Why?

All discussions were led by two experienced Zimbabwean researchers (WM, ON) in private spaces and lasted approximately 30 minutes (individual interviews) and 1.5 hours (FGD). All discussions were conducted in Shona, the participants' language. With the participants' permission, the discussions were audio-recorded. The recorded interviews were transcribed and translated verbatim into English. Interviewers (WM, ON) reviewed all transcripts to confirm their accuracy. A summary was written for each individual interview or FGD.

Qualitative data analysis and validation

Half of the interviews (n=6) were thematically coded by two researchers (WM, ON), using deductive and inductive approaches by creating a coding framework based on the topic guides and adding codes iteratively (Braun and Clarke, 2006). WM, ON, EB met regularly to develop a common understanding of the codes and their application and, to discuss emerging patterns. These deliberations achieved *credibility* (ensuring researchers' representation of themes fit with participants' views) and *confirmability* (ensuring interpretations were clearly derived from the data) (Tobin and Begley, 2004). Researchers used memoing to consolidate emerging themes and as a reflexivity tool, whereby they kept a "self-critical" account of the research process and reflected on potential biases to enhance findings' *dependability* (Tobin and Begley, 2004).

Any additional codes identified from this first set of transcripts were added to the coding framework. Transcripts were entered into NVivo 14 (QSR International, Melbourne, Australia) and fully coded using the modified coding framework; care was taken to identify any additional emerging codes. Codes were grouped and emerging themes were identified and supported with verbatim quotes. A workshop was held with three peer Coaches (SM, MAK, TAD) and two adult Coaches (SV, MC) to review research findings and contribute to manuscript writing.

6.5 Results

Between November 2021 and November 2022, sixty young people LHIV, aged 18-24 years took part in the research. Of these, 30 (50%) were female. We also held discussions with two of the four female adult Coaches (see Table 2).

Overall, both intervention participants and Coaches described the transformative effect of the *Wakakosha* intervention, detailing their experiences before and after. The main themes that emerged were the existence of previous self-stigmatisation and the move to positive changes around: self-confidence and self-agency, sense of purpose and meaning in life, body positivity, improved communication and personal/family relationships, self-forgiveness and forgiveness of others. These themes are described in detail below.

Transitioning from previous self-stigmatisation

Participants described how they experienced self-stigma, including negative self-judgements, prior to enrolling onto *Wakakosha*. One participant noted that there were ‘...*certain things that might happen. Simply because you are HIV positive you will begin to personalize issues...* “*So this person did not see me when I was passing by...Has she heard something about me?*” *You might be assuming that someone has ignored you, yet this is all in your mind...*’ (Male 23yrs, FGD). Participants also described instances of negative self-judgement. ‘...*Telling yourself that you can’t do this because of your [HIV] status*’ (Female 23yrs, FGD).

Participants described effects of these self-stigmatisation experiences including self-isolation and depression. ‘*When I was home and we had visitors, I would shut myself in a room because I am HIV positive...I was worried that visitors would see me and guess my status. I was worried that family members would disclose my status to others. So, you are always alone in your room, and this causes so much stress because you are always assuming several issues*’ (Female 20yrs, FGD). One participant described how similar distressing experiences triggered perpetual suicidal thoughts. ‘*I was only thinking about death...It was better for me to die as there was no reason for me to continue living. My relationships were difficult and there were also challenges at home because of my [HIV] status*’ (Female 19yrs, IDI). Prior to the intervention, participants not only *agreed* with stereotypes or negative perceptions about themselves but *applied* them too, including the belief that they could not amount to anything.

Experiences after the intervention

Self-confidence and self-agency.

Intervention participants described gaining various skills including self-confidence. This often prompted them to pursue previously ‘impossible’ goals such as enrolling for academic and professional courses. *‘I encouraged her, and she enrolled for a teacher training course’* (Adult Coach, KII). Another participant reported pursuing a career as a nurse aide. Some participants reported renewed self-agency. A participant who had inherited a piece of land but was not using it productively due to self-stigma-induced loss of self-agency reclaimed it and started farming, remarking that, *‘I would tell myself that there was no way I could farm that whole piece of land...If I had not attended Wakakosha I would have surrendered the land to someone else’* (Female 24yrs, FGD).

Sense of purpose and meaning in life

After the intervention, participants affirmed a new sense of purpose in their lives as reflected by one who noted that, *‘After the training I learnt that there is nothing I can’t do, and I can do it’* (Male 21yrs, FGD). More so, the intervention inspired a sense of self-worth and purpose in the participants, with some rediscovering their entrepreneurial passions. Another participant labelled themselves ‘a jack of all trades’ attesting to a renewed entrepreneurial drive and passion for new vocations, stating that, *‘I am now involved in five things...welding, plumbing, art, building and fashion’* (Male 23yrs, FGD).

Body positivity

Because of self-stigma, participants, especially female ones, developed negative attitudes towards their bodies as evidenced by reports of having previously been ashamed of, and neglecting, their own bodies. A participant remarked that, *‘I used to hate my body, and I would say, “I don’t want my body because I am tiny. I don’t want my skin because it is too dark”’* (Female 20yrs, FGD). Yet another participant narrated, *‘I would ask myself why I was not gaining weight...my body was too thin. When I looked at other girls with bigger body structures, I would ask myself why I could not also get there’* (Female 23yrs, FGD). Participants further acknowledged different ways in which they mistreated their bodies, with one admitting to their body that they, *‘hurt you (body) terribly by not caring well and starving you because of my self-stigma...’* (Dear Me Podcast #4), while others engaged in

alcohol and drug abuse as well as deliberate self-poisoning in a bid to kill themselves (Dear Me Podcast #8, #13).

Such thoughts, however, changed upon completing *Wakakosha*. Noteworthy was the body positivity message that the intervention inculcated in participants, motivating them to reevaluate their beliefs and attitudes towards their bodies and embracing body positive routines. One participant remarked that, *'It was only after Wakakosha when I realized that I should be proud of my body because my face has not been reacting to the drugs that I am taking'* (Female 23yrs IDI). More so, a recurring message in the Dear Me Podcasts is that of participants committing to taking better care of their bodies through eating healthy, quitting alcohol and drug abuse as well as improved hygiene (See Dear Me Podcast #11, #12, #13).

Improved communication and personal/family relationships

Participants also reported improved communication and personal relationships. As participants were relatively young (18-24 years), forming relationships was one of their key considerations. Nearly all described previously struggling to come to terms with their emerging sexuality in the context of a life threatening, sexually transmissible infection. *'I would tell myself that "I am HIV positive; I cannot date someone who is HIV negative"'* (Female 22yrs, FGD). Even when they were now in relationships, participants would worry about family size and "curtailed" longevity. *'I was stressed. When I gave birth, my sister-in-law said "You should not have another child because you are going to die soon. Who will take care of your children?" So, I had told myself that it is fine to just have one child. I held on to those words...'* (Female 21yrs, FGD).

Post intervention, participants reported improved personal and family relationships. Most participants reported previously being bitter and angry towards their parents, relatives, and other members of the community. One participant reported that after the intervention relations thawed between him and his father, admitting that *'...now (after the intervention) I have realized that I am now more humane, I am no longer exchanging [harsh] words and I now respect him...'* Another participant was elated with how his love life had improved, stating that, *'My love life is now great. Yesterday was a wow for me. We were coming from church, and she invited me for dinner. It was excellent. My love life is now great'* (Male 22yrs, FGD).

Self-forgiveness and forgiveness of others

Many participants reported positive changes in self-forgiveness and in forgiveness of parents for passing on HIV. Most were bitter towards their parents but through the intervention, they were able to forgive and erase the negative thoughts, *‘Even to my dad, I used to believe he was stigmatizing me when I was young...he did not visit me. So, I just wrote a letter to both asking for forgiveness. I learnt about forgiveness because I was very bitter towards my parents about being the only child who was born with HIV in my family’* (Male 18yrs, IDI).

Through the intervention’s transformative effect, participants also learnt self-forgiveness as evidenced in the powerful messages of forgiveness in the Dear Me Podcast series.

Participants also asked for forgiveness for having put their bodies on the line by starving themselves and abusing alcohol (Dear Me Podcast #5, #13) while others forgave themselves for ignorantly indulging in risky sexual escapades (Dear Me Podcast #6, #11).

A male participant described how the *Wakakosha* intervention had helped him find closure.

‘So, I wrote a letter [as part of intervention activities] to both of them [deceased parents] asking for forgiveness...’ (Male 22yrs, IDI). He went on to describe what he did next. *‘One weekend I travelled to the rural areas, bought flowers, and went to their graves and “said” to them “I am very sorry for not forgiving you all along...” I then placed the flowers on their grave’* (Male 22yrs, IDI). Another male participant stated, *‘I wrote a letter to my mother asking for forgiveness. I was angry due to my status, saying “I am HIV positive because you were careless. You were careless with your life, and you gave birth to me fully aware of your status.” So, I wrote the letter asking for forgiveness because I was ignorant’* (Male 19yrs, IDI).

Some letters were addressed to surviving relatives. *‘...She was blaming her uncle (father’s young brother) for ill-treating her after her father’s death. But after doing the session, she realized that this uncle did all he could to provide for her and her siblings. For example, he paid their school fees. She wrote an “amendment letter.” She was now saying that she has actually realized that her uncle was not a bad person. He was actually a good person for taking care of her. As an uncle, he was not obliged to look after her when her parents passed on. So, she realized that she had to thank him’* (Peer Coach, IDI).

Experiences about the approach/process

Both intervention participants and Coaches described an overwhelming transformative effect of the intervention. CATS described for example, how they often spend time and effort offering peers support around adherence and overall wellbeing support, and rarely get the opportunity to introspect. Despite their mentorship, training, and support, they reported feeling unable to address personal challenges including self-stigma. One CATS summed up this shortcoming through a local proverb “*N’anga haizvirapi*” (*A traditional healer cannot treat themselves*) (Female 24yrs, IDI), an expression which underscores that CATS need support too. “*Also, it helps us the CATS. Yes, we might be trained but, in some instances, you will be focused on other people. But with Wakakosha you are also focusing on yourself*” (Male 24yrs, IDI).

Participants described in detail the new skills they had acquired. ‘*We were taught that if there are challenges, we should not see these as permanent. We should have positive and not negative thoughts only. For example, when faced with a situation, we could only view it from the negative side, without looking at the positive side. Through this program [Wakakosha] I was taught to look at both sides and then think about how I can overcome the problems that I am facing*’ (Male 23yrs, IDI). As with other participants, he found this problem-solving skill quite empowering.

CATS were also equipped with vital skills they now use to help their peers. ‘*I have skills that I am using on other people. There is one called box breathing. We would do this box breath whenever we were starting sessions. You would close your eyes and breath in and out... breath in and out. I normally use this when I am with a client who is disturbed and is facing some challenges. Maybe he is not calm...I can also ask them to give me their emotions from 1-10. By so doing, you will realize that I am feeling this emotion because of this and that. We will then start the counselling session*’ (Male 24yrs, IDI).

Commenting on the activity journal, a participant stated ‘*...In the “journal,” there were some “exercises,” and these were part of homework. You would ask yourself through the sheets the emotions that you were going through on that particular day. You would then circle. From there, you would then start doing an inquiry using that yellow card that contained the four questions and the turnaround prompts. And then stressful thoughts that caused you to be in*

that emotional state will begin to emerge. And then at the end of the day you will be in a different emotion' (Male 22yrs, IDI).

The acquired skill sets were not only helpful to intervention participants but also others. *'So, the skills that I am using on other people include inquiry and the yellow card. Out there, there are peers who might be having stressful thoughts. Sometimes when I contact a client, I will end up using that yellow card'* (Male 23yrs, IDI). Another participant highlighted how components of the intervention can be used beyond self-stigma situations, noting that, *'...When I go home and I start doing this with my aunt (55 years old), asking her to turn around her thoughts. Holding the yellow card and asking her about her thoughts on that issue. I will then ask her to do the turnaround thoughts... turn around to yourself. At the end of the day, she will start laughing asking if these were the activities we were doing, and I would say "Yes"'* (Male 22yrs, IDI). Overall, participants felt the skills they learned could be applied beyond self-stigma into their everyday lives, in particular the ability to solve problems.

Lastly, participants reported how creativity (music, drawing, poetry) helped them engage in challenging topics on self-stigma, thus promoting awareness and healing. *'The singing helped us easily share our feelings whether sad, happy or angry'* (Female 18yrs, FGD) (creativity component of this intervention to be reported separately).

Delivery challenges and recommendations

As already noted during the description of intervention delivery, due to COVID-19, some sessions had to be delivered online, which had its own challenges. Participants articulated some of the challenges. *'...Going forward, we will prefer face to face mentoring. There are instances when things are said, and you have to express your emotions...If it is online, no one can see what is going on. If you are discussing face to face, you can express your emotions and then you receive counselling'* (Male 21yrs, FGD). A local adult Coach weighed in, *'Especially when we were still doing this from home [online], it was worse. It was okay when we were coming to Zvandiri because they have a strong network connection. But from home, you could see the young people complaining that there is no power and this affects network connectivity. Therefore, I didn't like the online program at all, especially during the first days when everything was to be done online'* (Adult Coach, KII). Implementing an intervention

within a context characterized by erratic power supply, limited internet connectivity and exorbitant data charges involves ‘scaling a mountain.’

Some recommendations centred around ensuring intervention materials taken home do not result in inadvertent HIV status disclosure. *‘I would like to go back to [activity] journals. Those are for us participants who are attending the meetings. However, there is over emphasis on HIV. Yes, it’s good but I might be staying at a home where relatives and friends come. Maybe I have not yet disclosed to them. Through this CATS program, we have disclosed, and we are now used to this. But some people might be affected when they are going around with that “book” and someone opens the “book,” they will see text which reads, “Because of HIV....” If only they could find other words to talk about HIV in a way other people will not know HIV is being discussed’* (Male 24yrs, FGD). These concerns should be taken into consideration going forward.

6.6 Discussion

We qualitatively explored the perceived impact of ‘Wakakosha: You are Worth it,’ a culturally appropriate, locally informed intervention for AYPLHIV to address self-stigma. The evaluation revealed that the *Wakakosha* intervention effected positive changes on many aspects of self-stigma including self-judgements, self-worth, sense of purpose, self-agency in career and education, body image, self-forgiveness and forgiveness of others and improved communication with family and significant others. It also transferred a set of practical skills on self-inquiry, mindfulness, meditation and creativity that continued to be used in participants’ daily lives. We previously noted how interventions to support PLHIV in dealing with self-stigma, particularly at the level of core beliefs, are lacking (France et al., 2015, Sengupta et al., 2011, Stangl et al., 2013). Interventions such as *Wakakosha*, tailored to the context of HIV self-stigma and using knowledge of underlying core beliefs, may better equip participants with the psychosocial tools and strategies to mitigate self-stigma.

The emerging field of positive health perceives health as a state of wellbeing, not an illness and can be defined as an approach to health that recognizes factors that drive disease and illness and focuses on the processes that underpin good health and wellbeing (Bolier et al., 2013, Bristowe et al., 2020, Dulin et al., 2018, Dambi et al., 2022, Orth and Van Wyk, 2022). From our study findings, we can see many aspects of positive health emerging and being

strengthened (e.g., gaining self-confidence, a new sense of purpose in life, a sense of self-worth, self-agency and purpose). These and other findings (Okonji et al., 2020, Orth and Van Wyk, 2022) buttress calls for positive mental health interventions for AYPLHIV that are anchored upon the need to improve and evaluate human strengths and capabilities as enshrined in positive outcomes such as self-esteem, self-worth and flourishing (Bolier et al., 2013, Bristowe et al., 2020, Dulin et al., 2018).

In addition, what emerged from our study were also a number of cultural and contextual insights into positive health, namely the culture of discussing feelings and emotions, spirituality, and individual versus collective agency. In relation to feelings and emotions, in Zimbabwe, as in other sub-Saharan settings, culturally speaking or articulating feelings and emotions is uncommon (Bernays et al., 2020). Importantly, the intervention reportedly had a positive psychosocial effect on males who in this context are less able to discuss or express emotional concerns, largely due to hegemonic masculinity where males are socialised around toughness and concealing emotions (Bolton et al., 2007, McMullen et al., 2013). Cultural sensitivity in ways of doing this needed to be incorporated into the training.

What also emerges is the strong collectivist culture in Zimbabwe and thus the wellbeing of others is as, if not more, important for positive health. In positive psychology, as noted by Wong (Wong, 2011), there has been some inclusion of altruism (Batson et al., 2002) and compassion (Gilbert, 2009), but “there are cultural differences in the balancing act between *me* and *we*. ... we need to emphasise positive motivations, processes, activities, and outcomes for both individuals and groups” (Wong, 2011, p72). For an individual in Zimbabwe, as in most of sub-Saharan Africa, self-acceptance is bound up with acceptance within one’s community. Hence, for the AYPLHIV, it was difficult for them to separate themselves from the diminished status of their parents due to HIV infection, increasing the potency of the shame and self-stigmatizing beliefs they had about themselves and their parents. These difficulties of separating the self from others also strengthens the value of community and opinions of others regarding morality and HIV acquisition, which in turn fuels shame, self-stigma and the acceptance of social stigma and discrimination as well-deserved punishment for sexual deviance (Rich et al., 2022, Mavhu et al., 2013). Therefore, addressing self-stigma at individual and communal levels helps to defuse disempowering narratives in the individual first and this cascades to the community.

Participants reported changes at the household/family level as a result of the intervention. A potential limitation of this study was that we did not directly collect data at this level. In keeping with the socio-ecological model (Krug, 2002), as per the information reported by respondents, it is likely that a successful intervention at the individual level will have a positive impact at household/family level. Future explorations should explore changes beyond the individual more systematically.

Increasing attention continues to be paid to community-based peer-support programs as a mechanism to improve clinical outcomes and wellbeing (Bernays et al., 2020). While the predominate focus of research on peer support for AYPLHIV has focused on the potential benefits to those receiving peer support [26], there is also growing recognition of the essential need to focus on the health and wellbeing of the peer supporters themselves (Wogrin et al., 2021). This study demonstrates that peer supporters themselves also benefit from the various intervention activities. Ensuring support and ongoing mentoring for the peer Coaches is key to the ongoing success of this and other interventions (Bernays et al., 2020). As part of *Wakakosha*, an online Toolkit has been produced and will be tested to provide this support to the peer Coaches going forward.

Creativity clearly played a supportive role in the absorption, emotional processing and deepening of positive changes around self-stigma and shame, variables which are difficult to openly discuss without causing or triggering deep hurt or stressful thoughts around experiences within oneself and with others. Our team has previously used creativity on other difficult topics, including to explore experience and manifestation of depression in ALHIV (Willis et al., 2018a). Further exploration is needed to specifically measure and assess the impact of creativity on self-stigma and shame among AYPLHIV.

Our assessment was intentionally qualitative as though we could have used some quantifiable measures of program impact, these have a number of drawbacks. Firstly, they limit the number of domains that can be assessed; most of the outcomes as described above would not have been captured by standard measurement scales. Secondly, it is not possible with measurement scales to interpret differences in mean scores in terms of the lived experience of the participants. For example, a change in mean score over a group of participants does not tell us what proportion of participants materially benefitted. Comparing scales across different cultures has been likened to comparing chopsticks with forks if appropriate

adjustments in scales are not incorporated (Chen, 2008). Lastly, the qualitative approach respects the agency of the participants. Participants entered the program with their own individual hopes and aspirations. These were captured in an early activity called ‘This is Me’ embedded in the curriculum. We took the decision to assess the program relative to these individually valued outcomes rather than against universal ones.

Another limitation is that, as participants were already Zvandiri CATS with potentially lower self-stigma levels, the overall positive impact found here may not necessarily reflect what would occur in for example, CATS clients. Future initiatives should evaluate impact of the intervention when it is offered to CATS’ clients and AYPLHIV outside of the Zvandiri program. In addition, despite confidentiality assurances, participants may have felt obligated to largely report positive experiences whilst downplaying negative ones.

6.7 Conclusion

This intervention shows potential for reducing self-stigma and improving self-worth among AYPLHIV. The next phase of this intervention will be to continue training and supporting the young people to ensure fidelity and provide quality support as the peer Coaches deliver the intervention to others. Ongoing support and mentoring for the peer Coaches will take time and resources, particularly in the first few years of gaining traction for a new methodology such as IBSR. As this is a cognitive and mindfulness-based methodology, careful supervision and ongoing individual practice is important. Future research and evaluation should carefully consider spirituality and the communal view of positive health more broadly when looking at self-stigma and self-worth. It should also be cognizant of the cultural context and consider using the socio-ecological framework to reflect the various levels affected - the individual, family and wider society.

Figure 1: Wakakosha creativity example



Data availability statement

The original contributions presented in the study are included in the article, further inquiries can be directed to the corresponding author.

Ethics statement

This study was approved by the National Ethics Committee, Medical Research Council of Zimbabwe (#2604). The participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Chapter 7: Interventions to reduce self-stigma among people living with HIV: A systematic review

7.1 Commentary

There is a lack of knowledge about what interventions work to reduce self-stigma, and for those that do work, not much is understood about the approaches or components of the interventions and how they are measured. This paper details a systematic review of interventions that exist to reduce and measure self-stigma among people living with HIV (PLHIV) to derive appropriate recommendations.

This paper was first submitted to Stigma and Health in November 2023 “Interventions to reduce self-stigma among people living with HIV: A systematic review” with the following authors:

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Cioringa A, Uppsala University, Uppsala Sweden

Byrne E, Centre for Positive Health Sciences, Royal College of Surgeons in Ireland

Mavhu, W, et al., 2023, Centre for Sexual Health and HIV/AIDS Research

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Twitter: New #systematicreview by @nadineferrisfrance et al., highlight interventions to reduce self #stigma among people living with HIV

7.2 Abstract

Objectives

Over four decades into the global HIV pandemic, HIV-related self-stigma - a mindset of negative beliefs, thoughts, and behaviours a person holds about themselves - remains a major barrier to HIV treatment, management and care. HIV-related self-stigma is a persistent public health threat and leads to depression and other mental health problems, lowers adherence to antiretroviral medication, and acts as a barrier to health services. Not enough is known about what interventions work and how they work to reduce self-stigma. We conducted a systematic review of existing interventions that address self-stigma among people living with HIV (PLHIV) to address this gap.

Methods

We searched PubMed, Embase and Web of Science; used Covidence review software; dual-screened the results; extracted data from each included study; analysed the data using Cochrane guidelines and the TIDIER Framework, and categorised the content based on emerging themes around the intervention/programme.

Results

We included thirty-two studies in the review, with the majority (29/32, 91%) showing promise to reduce HIV self-stigma. Intervention approaches included working on thoughts, feelings and beliefs through a range of cognitive-based, inquiry-based, and mindful-based techniques, often with a forward-looking goal-setting focus. However, comparison of studies was difficult with different definitions and understandings of self-stigma, and different measurement scales. Many studies were small scale and lacked sufficient in-depth descriptions.

Conclusion

This study makes an important contribution to the field of HIV more broadly and HIV-related stigma, specifically, in proposing a common definition of self-stigma and providing in-depth descriptions of interventions in terms of content, type, level and effectiveness.

Clinical Impact Statement

Not much is understood about the approaches or components of self-stigma interventions for people living with HIV and how they are measured. We examined these types of interventions and found that there are a wide range across 12 countries, most leading to positive impacts on people's lives. These interventions included cognitive-based, mindfulness and inquiry-based techniques, reflective and creative bespoke training, and person-centred counselling approaches. Interventions mainly targeted the individual. This study provides an in-depth description of the curriculum content and the process of implementation for self-stigma interventions and suggests a common definition of self-stigma which would help us compare studies.

Keywords: Self-stigma, internalised stigma, HIV, interventions, systematic review

7.3 Introduction

HIV remains a major global public health issue, having claimed 40.4 million lives at the time of writing, with ongoing transmission in all countries globally (WHO, 2023). More than four decades into the global HIV pandemic, stigma remains a major barrier to HIV treatment, management, and care (Stackpool-Moore et al., 2022a, Stackpool-Moore et al., 2022b, van der Kooij et al., 2023). Stigma is a complex, multidimensional phenomenon and concept with many definitions, understandings and approaches. In Goffman's seminal work on stigma in 1963 (Goffman, 1963), he defined stigma as "an attribute that is deeply discrediting" which, in the view of others, serves to reduce the person who possesses it. Stigma emerges from a dynamic social process that is enacted and perpetuated through structures, organisations, communities, and individuals (Stangl, 2022). Much has been published about stigma in relation to HIV/AIDS, mental illness, physical deformities, disability, and illness (Ablon,

2002, Albrecht et al., 1982, Byrne, 1999, Jamison, 2006, Robertson and Katona, 1997, Scambler and Hopkins, 1986, Watson, 2007)

However, much less is understood about self-stigma, also called internalised, internal or personal stigma (Pantelic et al., 2019 Sprague, et al., 2019). Self-stigma can be defined as experiencing negative judgements towards oneself, resulting in feelings of shame, worthlessness, self-blame, and emotional distress (Ferris France et al., 2019). A systematic review found that HIV-related stigma, including self-stigma, undermined HIV medication adherence by compromising general psychological processes (e.g., adaptive coping and social support) (Katz et al., 2013). In the same review, 70% of the studies reported an association between HIV stigma and medication non-adherence (Katz et al., 2013). Self-stigma is experienced by people living with HIV (PLHIV) to a far greater extent than stigma received from the broader community (Kalichman et al., 2009).

Pantelic et al synthesised such evidence focused exclusively on low- and middle-income countries. They excluded qualitative studies but included other study designs and any study that had a self-stigma outcome, even if this was not the intervention's primary aim (Pantelic et al., 2019). Ma et al reviewed studies addressing stigma for PLHIV or family members that included psychosocially, cognitively, or behaviourally-oriented interventions that were experimental/quasi-experimental or pre-post design, with a self-stigma outcome. Studies without a quantitative component were excluded (Ma et al., 2019). Identified gaps from these reviews include the small sample sizes and scarcity of qualitative intervention evaluations, as well as general gaps in reporting (Ma et al., 2019). Heterogeneity across studies has also been identified as a challenge in relation to comparing these interventions. However, both of the studies mentioned above (Ma et al., 2019; Pantelic, et al., 2019), provided limited information about the intervention content and were published about five years ago and therefore, do not include the most recent literature. Other reviews in this area, such as Katz et al, assessed the relationship between HIV-related stigma and medication adherence; they mention self-stigma, although it was not the primary focus (Katz et al., 2013). Ferguson et al focused on identifying frameworks, measures and evaluations addressing internalised stigma and discrimination in healthcare settings, and stigma and discrimination at the legal or policy level, but not self-stigma interventions for PLHIV (Ferguson et al., 2022). Lastly, Stangl et al reviewed intervention studies whose aim was specifically to address intersectional stigma and discrimination, and qualitative studies were excluded (Stangl et al, 2023).

Therefore, while previous reviews have examined PLHIV, their friends and family as well as high-risk population groups, they are not exclusive to self-stigma interventions and exclude certain study designs and require updating. This systematic review includes all study types globally with a particular focus on the curriculum of specific HIV-related self-stigma interventions and how self-stigma is defined and measured. Our specific review question was: In existing interventions that address self-stigma among PLHIV what interventions work and how do they work?

7.4 Methods

Studies were identified and extracted from PubMed, Web of Science and Embase databases up to 31/10/2023. These databases were chosen based on expert recommendations and also, their relevance to the review question. Searches, using search strings, were conducted for title and abstracts in databases (see SM1). The search strings were developed using the Population, Intervention, Comparison/control, Outcome and Study (PICOS) method for keywords:

- Population: people living with HIV, i.e. any person who has been diagnosed with HIV and is living with it in everyday life
- Intervention: interventions or programmes that aimed to address self/internalised stigma
- Comparison/Control: some comparison before and after the intervention was included
- Outcome: some measure of impact on self-stigma or its components was included.
- Study designs: All study designs

All references were imported into Covidence reviewing software and duplicates were removed.

The inclusion and exclusion criteria were set and agreed by all authors, and studies were only included if they met all inclusion criteria. The inclusion criteria were that the study included an intervention/programme that:

- i. Focused on PLHIV;

- ii. Focused on the reduction of HIV/AIDS self-stigma;
- iii. Was described in sufficient detail to be replicable in some way, such as in terms of process, content, or method used;
- iv. Included a measure of self-stigma or ≥ 2 self-stigma components before and after the intervention;
- v. Was published in English.

Studies were excluded if the article:

- i. Did not include an intervention/programme;
- ii. Was a review article, conference abstract, or poster.

The Template for Intervention Description and Replication (TIDieR) Framework (Hoffmann et al., 2014) was used to ensure that all studies included met intervention description criteria, where possible (SM2).

7.4.1 Screening

Using Covidence, three authors (SL, NFF, EB) took part in the initial title and abstract screening and full-text screening, with at least two reviewers screening each article independently. If there was a conflict, the third reviewer would review the article and the full team discussed the outcome. Following title and abstract screening, full-text articles were uploaded for the remaining studies. The full-text screening was completed by examining the articles for compliance with the inclusion/exclusion criteria. Two reviewers independently reviewed each article in Covidence and conducted the quality review. Any and all conflict or clarification needed was discussed among three reviewers (SL, NFF, EB) before a final decision was made.

7.4.2 Data extraction

The study data extraction form was developed to obtain a detailed description of the intervention/programme and to obtain impact/evaluation details (SM3). We exported the extracted data into excel for further data analysis and synthesis. Due to variability in the self-stigma definition, the different quantitative studies impact measurement scales, and interventions' heterogeneity, it was not possible to conduct a data meta-analysis. Instead, a

meta-synthesis of intervention content was conducted. The Cochrane Handbook Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA) checklist (Page et al., 2021) was used to ensure all systematic review aspects were included (SM 4).

7.5 Results

7.5.1 Description of included studies

Our search yielded 5,061 results in total, 32 papers were included for full-text review, with 32 articles being fully extracted (Figure 1 & Table 1).

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)

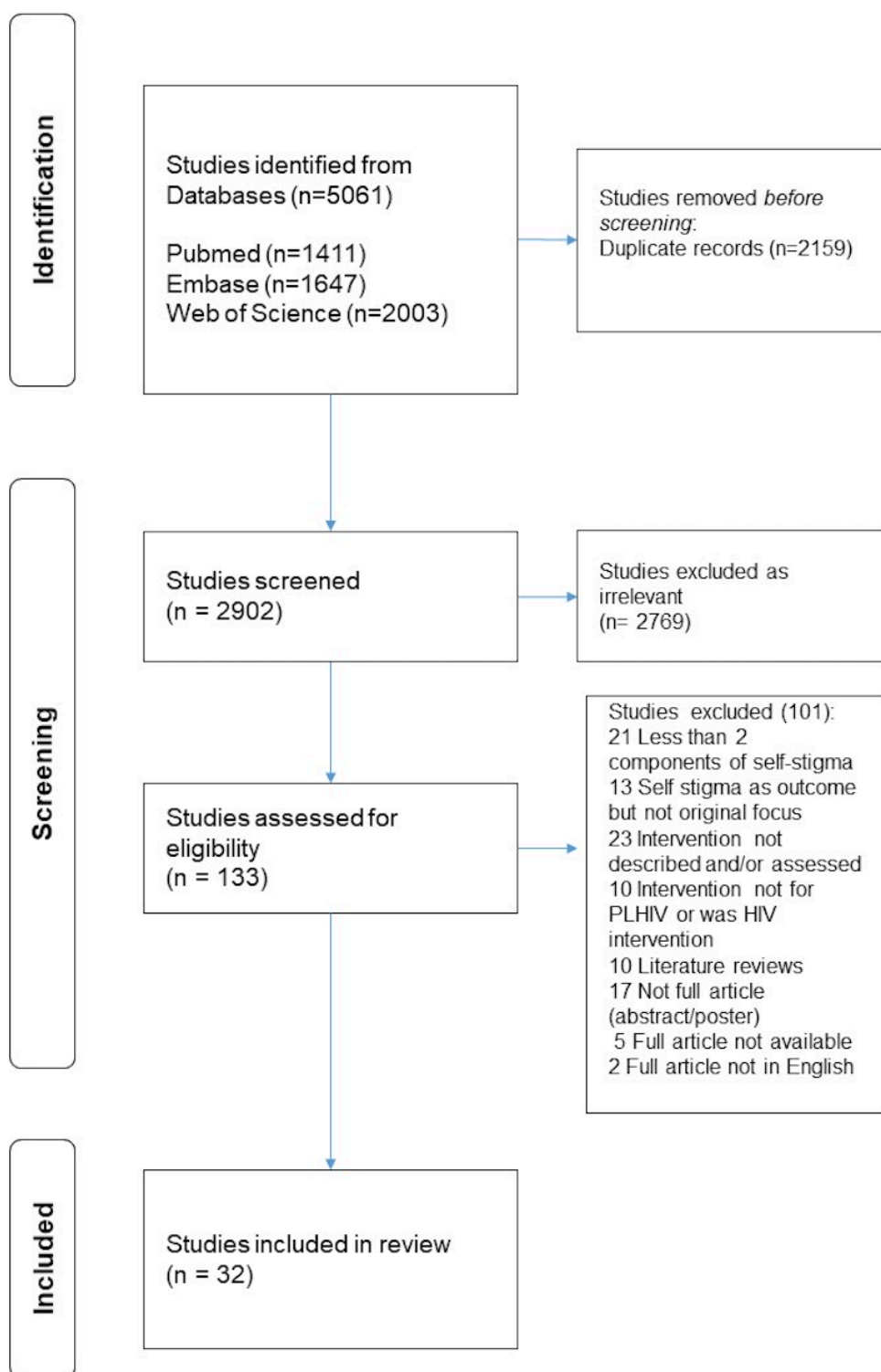


Figure 1. PRISMA flow chart illustrating the search, inclusion and exclusion process

Table 1: Articles included in full text extraction

Paper	Author	Year	Title	Source of publication
1	Barrington, C., Davis, D. A., Gomez, H., Donastorg, Y., Perez, M., & Kerrigan, D.	2021	I've Learned to Value Myself More": Piloting an Adapted Multilevel Intervention for Transgender Women Sex Workers Living with HIV in the Dominican Republic.	<i>Transgend Health</i>
2	Barroso, J., Relf, M. V., Williams, M. S., Arscott, J., Moore, E. D., Caiola, C., & Silva, S. G.	2014	A randomized controlled trial of the efficacy of a stigma reduction intervention for HIV-infected women in the Deep South	<i>AIDS Patient Care STDS</i>
3	Bartels, S. M., Guzmán Guevara, K., Pajarito Rompich, Y., & Barrington, C.	2022	Narratives of Change From Gay and Bisexual Men Living With HIV in an Emotional Well-Being Intervention	<i>AIDS education and prevention</i>
4	Batchelder, A. W., Moskowitz, J. T., Jain, J., Cohn, M., Earle, M. A., & Carrico, A. W.	2020	A Novel Technology-Enhanced Internalized Stigma and Shame Intervention for HIV-Positive Persons With Substance Use Disorders.	<i>Cognitive and Behavioral Practice</i>
5	Bryant, J. V., Carcioppolo, N., Lun, D., & Potter, J.	2023	Entertainment-education to reduce internalized stigma, increase intimate partner status disclosure intentions, and increase antiretroviral medical adherence intentions: A randomized controlled trial targeting black women living with HIV in the Southern U.S.	<i>Soc Sci Med</i>
6	Denison, J. A., Burke, V. M., Miti, S., Nonyane, B. A. S., Frimpong, C., Merrill, K. G., Abrams, E. A., & Mwansa, J. K.	2020	Project YES! Youth Engaging for Success: A randomized controlled trial assessing the impact of a clinic-based peer mentoring program on viral suppression, adherence and internalized stigma among HIV-positive youth (15-24 years) in Ndola, Zambia.	<i>PloS one</i>

Paper	Author	Year	Title	Source of publication
7	Denison, J. A., Packer, C., Nyambe, N., Hershow, R. B., Caldas, S., Miti, S., Sudarsan, S., Chen, M., Bernholc, A., Mwansa, J. K., & McCarraher, D. R.	2022	Family Connections randomized controlled trial: assessing the feasibility and acceptability of an intervention with adolescents living with HIV and their caregivers in Ndola, Zambia	<i>AIDS Care</i>
8	Edwards, S. D., & Edwards, D. J.	2009	Counselling for Psychological Well-Being in Persons Living with HIV/AIDS.	<i>Journal of Psychology in Africa</i>
9	Erlen, J. A., Mellors, M. P., Sereika, S. M., & Cook, C.	2001	The use of life review to enhance quality of life of people living with AIDS: a feasibility study. <i>Qual Life Res</i> ,	<i>Qual Life Res</i>
10	Ferris-France, N., Byrne, E., Nyamwanza, O., Munatsi, V., Willis, N., Conroy, R., Vumbunu, S., Chinembiri, M., Maedziso, S., Katsande, M. A., Dongo, T. A., Crehan, E., & Mavhu, W.	2023	Wakakosha "You are Worth it": reported impact of a community-based, peer-led HIV self-stigma intervention to improve self-worth and wellbeing among young people living with HIV in Zimbabwe.	<i>Front Public Health</i>
11	Ferris-France, N., Macdonald, S. H.-F., Conroy, R. R., Chiroro, P., Ni Cheallaigh, D., Nyamucheta, M., Mapanda, B., Shumba, G., Mudede, D., & Byrne, E.	2019	‘We are the change’ - An innovative community-based response to address self-stigma: A pilot study focusing on people living with HIV in Zimbabwe.	<i>PloS one</i>
12	Flickinger, T. E., DeBolt, C., Xie, A., Kosmacki, A., Grabowski, M., Waldman, A. L., Reynolds, G., Conaway, M., Cohn, W. F., Ingersoll, K., & Dillingham, R.	2018	Addressing Stigma Through a Virtual Community for People Living with HIV: A Mixed Methods Study of the PositiveLinks Mobile Health Intervention.	<i>AIDS Behav</i>

Paper	Author	Year	Title	Source of publication
13	Fuster-Ruiz de Apodaca, M. J., Molero, F., & Ubillos, S.	2016	Assessment of an intervention to reduce the impact of stigma on people with HIV, enabling them to cope with it.	<i>Anales de Psicología</i>
14	Harding, R., Wei, G., Gwyther, L., & Miti, E.	2019	Improving psychological outcomes for orphans living with HIV in Tanzania through a novel intervention to improve resilience: findings from a pilot RCT.	<i>AIDS Care</i>
15	Harper, G. W., Lemos, D., & Hosek, S. G.	2014	Stigma reduction in adolescents and young adults newly diagnosed with HIV: findings from the Project ACCEPT intervention.	<i>AIDS patient care and STDs</i>
16	Lennon-Dearing, R., & Hirschi, M.	2019	A photovoice empowerment intervention for women living with HIV.	<i>Journal of HIV/AIDS & Social Services</i>
17	Mathew, R. N., & Manjula, M. Y.	2022	Self-esteem and self-efficacy among HIV-positive adolescents: an intervention study	<i>HIV and AIDS Review</i>
18	Mundell, J. P., Visser, M. J., Makin, J. D., Kershaw, T. S., Forsyth, B. W., Jeffery, B., & Sikkema, K. J.	2011	The impact of structured support groups for pregnant South African women recently diagnosed HIV positive.	<i>Women Health</i>
19	Nestadt, D. F., Saisaengjan, C., McKay, M. M., Bunupuradah, T., Pardo, G., Lakhonpon, S., Gopalan, P., Leu, C. S., Petdachai, W., Kosalaraksa, P., Srirompotong, U., Ananworanich, J., & Mellins, C. A.	2019	CHAMP+ Thailand: Pilot Randomized Control Trial of a Family-Based Psychosocial Intervention for Perinatally HIV-Infected Early Adolescents.	<i>AIDS Patient Care STDs</i>

Paper	Author	Year	Title	Source of publication
20	Nyamathi, A., Ekstrand, M., Salem, B. E., Sinha, S., Ganguly, K. K., & Leake, B.	2013	Impact of Asha intervention on stigma among rural Indian women with AIDS	<i>West J Nurs Res</i>
21	Peltzer, K., Babayigit, S., Rodriguez, V. J., Jean, J., Sifunda, S., & Jones, D. L.	2018	Effect of a multicomponent behavioural PMTCT cluster randomised controlled trial on HIV stigma reduction among perinatal HIV positive women in Mpumalanga province, South Africa.	<i>SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance</i>
22	Peterkin, A., Espen, M. J., Hann, J., & Lawson, A.	2013	A pilot study of a narrative competence group to enhance coping and quality of life in patients with HIV.	<i>Arts & Health</i>
23	Pichon, L. C., Stubbs, A. W., & Teti, M.	2022	Snap out stigma photovoice project in the U.S. South.	<i>BMC Health Services Research</i>
24	Rao, D., Desmond, M., Andrasik, M., Rasberry, T., Lambert, N., Cohn, S. E., & Simoni, J.	2012	Feasibility, acceptability, and preliminary efficacy of the unity workshop: an internalized stigma reduction intervention for African American women living with HIV.	<i>AIDS Patient Care STDS</i>
25	Skinta, M. D., Lezama, M., Wells, G., & Dilley, J. W.	2015	Acceptance and Compassion-Based Group Therapy to Reduce HIV Stigma.	<i>Cognitive and Behavioral Practice</i>
26	Soro, D. B., Carrobbles, J. A., & García, M. A.	2021	Reducing stigma, depression and anxiety in people living with HIV through a Cognitive Behavioural Therapy group.	<i>Behavioral Psychology /</i>

Paper	Author	Year	Title	Source of publication
				<i>Psicología Conductual</i>
27	Suyanti, T.S., Keliat, B.A., & Daulima, N. H.C.	2018	Effect of logo-therapy, acceptance, commitment therapy, family psychoeducation on self-stigma, and depression on housewives living with HIV/AIDS	Enfermería Clínica
28	Tsai, A. C., Hatcher, A. M., Bukusi, E. A., Weke, E., Lemus Hufstedler, L., Dworkin, S. L., Kodish, S., Cohen, C. R., & Weiser, S. D.	2017	A Livelihood Intervention to Reduce the Stigma of HIV in Rural Kenya: Longitudinal Qualitative Study	<i>AIDS Behav</i>
29	Tshabalala, J., & Visser, M.	2011	Developing a Cognitive Behavioural Therapy Model to Assist Women to Deal with HIV and Stigma.	<i>South African Journal of Psychology</i>
30	Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoe, L., Dlamini, P., Durrheim, K., Cuca, Y., & Holzemer, W. L.	2009	Evaluation of a health setting-based stigma intervention in five African countries.	<i>AIDS Patient Care STDS</i>
31	Vaughan, S. M., & Kinnier, R. T.	1996	Psychological effects of a life review intervention for persons with HIV disease.	<i>Journal of Counseling & Development</i>
32	Yigit, I., Modi, R. A., Weiser, S. D., Johnson, M. O., Mugavero, M. J., Turan, J. M., & Turan, B.	2020	Effects of an intervention on internalized HIV-related stigma for individuals newly entering HIV care.	<i>AIDS</i>

7.5.2 Description of studies included

Thirty-two interventions were described in the 32 studies. Fourteen (44%) interventions took place in America (13 in the USA, 1 Guatemala), 11 (34%) in sub-Saharan Africa, 4 (13%) in Asia, 2 (6%) in Europe and 1 (3%) in the Caribbean (see Table 2). Of the 32 interventions, 11 (34%) were quasi-experimental, 10 (31%) were randomised control trials (RCTs), 7 (22%) were mixed methods, and 4 (13%) were qualitative. Six of the mixed methods studies and 1 RCT had a significant qualitative component included. There was a wide sample size range (5-699 participants) (See Table 2).

Table 2: Study design, methods and effect

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
1	Barrington et al, 2021	Mixed Methods	Dominican Republic	Socio-behavioural surveys; Qualitative interviews	Clinic	Transgender female sex workers living with HIV	30 participants	Participants emphasized that trust and being treated with respect allowed them to relax and improve their self-esteem.
2	Barroso et al, 2014	Randomised control trial (RCT)	USA	Questionnaire including: Rosenberg Self-Esteem Scale (RSES); Coping Self-Efficacy Scale (CSES); Internalised HIV Stigma Scale (IHSS)	Clinic and home	Adult women living with HIV	99 participants	<p>Treatment-by-time effect:</p> <ul style="list-style-type: none"> - improved self-esteem (intent-to-treat: $p = 0.0308$; completers: $p = 0.0284$) - decreases in internalized stigma (intent-to-treat: $p = 0.0036$; completers: $p = 0.0060$), - improved coping self-efficacy (intent-to-treat: $p = 0.0414$; completers: $p = 0.0321$). <p>A medium effect of the intervention in terms of improving self-esteem was observed when compared with the control condition in those who completed the study.</p> <p>Magnitude of the intervention effect, however, was large with regard to reducing overall stigma, improving social relationships, and decreasing stereotypes in both groups.</p>
3	Bartels et al, 2022	Longitudinal qualitative study	Guatemala	Longitudinal qualitative interviews	Clinic	Gay and bisexual men living with HIV	10 participants	Participants experienced changes in their view of self and diagnosis perceptions, improved physical and mental health, increased interest in sex and relationships, and a clarification of their life goals. The intervention

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
								helped participants reach diagnosis acceptance, improve self-esteem, and gain self-efficacy for managing life with HIV.
4	Batchelder et al, 2020	Mixed Methods	USA	Questionnaire including: HIV and Abuse Related Shame Inventory (HARSI); Centre for Epidemiological Studies Depression Scale (CES-D) Qualitative interviews	Clinic	Adults living with HIV and with substance use disorders	10 participants (10 at baseline, 8 completed intervention but 5 for post face to face sessions and 5 post intervention follow-up results)	Largely commenting on feasibility of intervention Some variables showed improvement (e.g. decreased impact on behaviour over the entire period, and decreased HIV-related shame higher post face to face but remaining lower than baseline post intervention) and others showing fluctuation (e.g., depression and self compassion lower post face to face sessions but higher post intervention). Participants reported use of compassionate self-talk and changes in the way they thought about themselves (including experiencing less self-judgement). Some confusion of participants on self-compassion scale.
5	Bryant et al, 2023	Randomised control trial (RCT)	USA	Questionnaire including adapted: Internalised AIDS-Related Stigma Scale (IA-RSS) Berger HIV stigma scale (HSS)	Online	Women living with HIV	130	Statistically significant differences were not observed for internalized stigma

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
6	Denison et al, 2022	Randomised control trial (RCT)	Zambia	Questionnaire including: Internalised AIDS-Related Stigma Scale (IA-RSS)	Clinic	Adolescent men and women living with HIV and caregiver pairs	100 participants (50 pairs of adolescents and their caregivers)	Adolescents in the intervention group showed a greater reduction in HIV-related feelings of worthlessness and shame than the comparison group- not statistically significant
7	Denison et al, 2020	Randomised control trial (RCT)	Zambia	Questionnaire including: Internalised AIDS-Related Stigma Scale (IA-RSS)	Clinic	Adolescent and young men and women living with HIV	273 participants (137 Intervention, 136 Comparison)	Internalized stigma significantly reduced by a factor of 0.39 [interaction term OR:0.39, 95% CI:0.21,0.73] in the intervention (50.4% to 25.4%) relative to the comparison arm (45.2% to 39.7%)
8	Edwards et al, 2009	Quasi-experiment (Quantitative)	South Africa	Questionnaire including: Ryff Psychological Well-being Scale	Clinic	Adult men and women living with HIV	41 participants : 30 for the experimental group and 11 for control group	Patients' psychological well-being scores indicated significant improvements in perceptions of autonomy (F(1, 39)=8.78, p=.01), personal growth (F(1, 39)=65.69, p=.00), environmental mastery (F(1, 39)=17.9, p=.00), positive relations with others (F(1, 39)=4.93, p=.03) and self acceptance (F(1, 39)=5.36, p=.03) when compared with a conveniently selected, student control group Within groups analysis confirmed significant differences between the groups for purpose in life at post-test time only (t(39)=2.4, p=.02).
9	Erlen et al, 2001	Randomised control	USA	Questionnaire including:	Clinic	Adult men and women living with HIV	20 participants	Treatment group: improved overall quality of life and self-esteem compared with the control group over

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
		trial (RCT)		Centre for Epidemiological Studies Depression Scale (CES-D); Purpose in Life test; Rosenberg self-esteem scale (RSES); Ferrans and Powers Quality of Life Index (QLI)				12 months; less depressive symptoms over 12 months; and a greater purpose in life after 3 months. The effects were medium to small effects.
10	Ferris France et al, 2023	Qualitative	Zimbabwe	Qualitative interviews Focus group discussions Review of intervention documentation and creative elements	Hybrid - Online and face to face in NGO	Adolescent and young men and women living with HIV	62 participants	Main themes that emerged were positive changes around: self-confidence, self- agency, sense of purpose/meaning, body positivity, improved communication and personal/family relationships, and forgiveness.
11	Ferris France et al, 2019	Mixed Methods (Sequential explanatory design)	Zimbabwe	Questionnaire including: Internalised AIDS-Related Stigma Scale (IA-RSS); the Center for Epidemiologic Studies Depression Scale (CES-D); HIV/AIDS	NGO	Adult men and women living with HIV	23 participants	Statistically significant improvements in self-stigma and depression post-intervention, both at 1-month and 3-month timepoints. Participants reported greater positive mentality in the qualitative interviews and focus group discussions

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
				Targeted Quality of Life Scale; Focus group discussions; Interviews				
12	Flickinger et al, 2018	Mixed Methods	USA	Questionnaire including: Berger HIV Stigma Scale (HSS) Message analysis (qualitative)	Online	Adult men and women living with HIV	12 participants	12-month data showed a trend toward more improved stigma scores for posters on the community message boards versus non-posters (−4.5 vs −0.63) and for posters of stigma related content versus other content (−5.1 vs −3.3)
13	Fuster-Ruiz de Apodaca et al, 2016	Quasi-experiment (quantitative with a non-equivalent control group and pre-test and post-test measures)	Spain	Questionnaire including: Revised Berger's HIV Stigma Scale using a 4-point Likert-like scale; Battery of Psychological Predictors of Well-being and Quality of Life of People with HIV in Spain; Coping with Stigma Scale, Quality of Life Questionnaire	Not stated	Adult Men and Women living with HIV	221 participants : 164 intervention and 57 in the control group	Reduction of perceived stigma and avoidance strategies and an increase in perceived self-efficacy to cope with stigma, self-esteem, and quality of life
14	Harding et al, 2019	Randomised control	Tanzania	Questionnaire including:	Clinic	Children living with HIV	48 participants	2 weeks post baseline intervention effects were found on; Rosenberg Self Esteem Scale (SES) $d = 0.65$, $p = .001$;

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
		trial (RCT)		Brief Symptom Inventory (BSI); Rosenberg Self-Esteem Scale (RSES); Strengths and Difficulties Questionnaire (SDQ); Self-Efficacy Questionnaire for Children (SEQC); Focus group discussion				Self-efficacy questionnaire for children both “social” and “emotional” subscales, $d = 0.54$, $p = .008$ and $d = 0.63$, $p = .002$, respectively. At 9 weeks post baseline, significant effects remained for all measures and SES effect increased from medium to large ($T1 = 0.65$, $T2 = 1.33$).
15	Harper et al, 2014	Quasi-experiment (pre-post-test on accessibility and feasibility pre RCT)	USA	Questionnaire including: Berger’s HIV Stigma Scale (HSS); HIV/AIDS Targeted Quality of Life Scale	Clinic	Adolescents and young adults living with HIV	50 participants	Overall reductions in stigma (three dimensions: personalised stigma, disclosure concerns, and negative self-image). Only the combined-sample effects for negative self-image were maintained at 3-month follow-up.
16	Lennon-Dearing et al, 2019	Quasi-experiment (pre-post-test -	USA	Questionnaire including: Rosenberg self-esteem scale (RSES); Coping Self-Efficacy Scale	Not stated	Adult women living with HIV	23 participants	Mean scores on the Rosenberg Self-Esteem Scale increased from pretest ($M \text{ } \frac{1}{4} 23.18$; $SD \text{ } \frac{1}{4} 4.61$) to posttest ($M \text{ } \frac{1}{4} 24.71$, $SD \text{ } \frac{1}{4} 3.64$). Mean scores on the Coping Self-Efficacy Scale increased from pretest

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
		quantitative with one qualitative evaluation question at post-test)		(CSES); Patient Health Questionnaire (PHQ-9); one additional open-ended question during post-assessment				(M $\pm$ 182.06, SD $\pm$ 42.29) to posttest (M $\pm$ 209.24, SD $\pm$ 37.37). Results of paired sample t-tests only found a significant change on the Coping Self-Efficacy Scale (t $\pm$ -2.14, p $\pm$.048).
17	Mathew et al, 2022	Quasi-experiment (Quantitative)	India	Questionnaire including: Rosenberg's self-esteem scale; general self-efficacy scale (GSE)	Clinic	Adolescent men and women living with HIV	97 participants	There is a significant improvement in the level of self-esteem (t = 21.154; p < 0.001) and self-efficacy (z = 6.036; p < 0.001) post-intervention in the experimental group, and no such improvement was observed on both the variables in control group
18	Mundell et al, 2011	Quasi-experiment	South Africa	Questionnaire including: Rosenberg Self-Esteem Scale (RSES); Center for Epidemiologic Studies Depression scale (CES-D); Modified version of the Brief COPE; Multidimensional Social Support Inventory;	Clinic	Pregnant women living with HIV	361 participants (144 in intervention and 217 control)	Those who attended at least half of the intervention sessions exhibited improved self-esteem (t D 2.11, p < 0.05).

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
19	Nestadt et al, 2019	Randomised Control Trial (RCT)	Thailand	Questionnaire including: Strengths and Difficulties Questionnaire; Children's Depression Inventory; Perceived Stigma of HIV/AIDS Scale,	Clinic	Adolescent men and women living with HIV	88 families	The study was not statistically powered to detect differences in treatment effects, the CHAMP+ group significantly improved at 6 months in youth mental health
20	Nyamathi et al, 2013	Cluster randomised control trial (RCT)	India	Questionnaire including: Internalised HIV stigma scale (IHSS) Center for Epidemiologic Depression Scale (CES-D)	Clinic	Women living with HIV	68 participants	Reductions in internalized stigma from baseline to 6-month follow-up were associated with participation in the intervention.
21	Peltzer et al, 2018	Cluster randomised control trial (RCT)	South Africa	Questionnaire including: Berger's HIV Stigma Scale (HSS)	Clinic	Pregnant women living with HIV	699 participants	Baseline scores of overall HIV related stigma and the four scale factors (personalised stigma, disclosure concerns, negative self-image, and concern public attitudes) decreased at follow-up in the intervention group.
22	Peterkin et al, 2013	Quasi-experiment (pre-post test -	USA	Questionnaire including: Rosenberg self-esteem scale (RSES).	Clinic	Adult men living with HIV	31 participants	There was a trend towards an increase in participants' self-reported emotional self-efficacy (p ¼ .03), as measured by the Stanford Emotional Self-Efficacy Scale.

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
		quantitative)		Stanford Emotional Self-Efficacy Scale; Silencing the Self Scale; open-ended questionnaire				A significant increase in self-esteem (p , .01), as measured by the Rosenberg Self-Esteem scale
23	Pichon et al, 2022	Qualitative	USA	Qualitative interviews; Focus group discussions	Community	Adult men and women living with HIV	47 participants in session 1 and 34 in sessions 2 and 3	Photovoice facilitated discussion topics ranging from healing and recovery to overcoming factors of social determinants of HIV. A safe space for discussion was created.
24	Rao et al, 2012	Quasi-experiment((pre-post test without a control, quantitative)	USA	Questionnaire including: Stigma Scale for Chronic Illness (SSCI)	Clinic	Adult women living with HIV	24 participants	Led to decreased stigma from the start of the workshop to the end (p = 0.05) and 1 week after (p = 0.07) the last session of workshop
25	Skinta et al, 2015	Mixed methods	USA	Questionnaire including: Internalised HIV Stigma Scale Qualitative interview	Clinic	Gay or bisexual men living with HIV	5 participants	The three participants who had attended every follow-up session indicated some benefit from the group Participants reported some change in their experience of HIV related to the group
26	Soro et al, 2021	Quasi-experiment	Spain	Questionnaire including: Battery of Psychological	Government administration building in Spain.	Adult and adolescent men and	50 participants : 26 in the therapy	Declared stigma decreased significantly in the therapy group at the end of treatment (p= .050). With a medium-high effect size. It continued

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
				Predictors of Well-being and Quality of Life of People with HIV in Spain (10 items) Beck's Depression Inventory-II; State-Trait Anxiety Inventory		women living with HIV	group and 24 in the control group	to do so in a nonsignificant way in the follow-up until it resulted in a significant reduction between the first and the third measurement ($p = .005$) with a large effect size. Within the therapy group, internalized stigma decreased significantly at the end of treatment ($p = .005$), maintaining the same level of significance of reduction at follow-up. The effect sizes were large, both between the first and second measurements and between the first and third measurements. Depression clearly decreased in the therapy group at the end of treatment ($p = .001$) with a large effect size and remained reduced at follow-up ($p = .011$) with a medium effect size.
27	Suyanti et al, 2018	Quasi-experiment (Pre-post test)	Indonesia	Questionnaire including: Internalised Stigma of AIDS Tools (ISAT)	Not stated	Women living with HIV	60 participants	Significant decrease in self-stigma and depression ($p < 0.05$) in participants undergoing the proposed intervention .
28	Tsai et al, 2017	Longitudinal qualitative study (sub study of	Kenya	In-depth interviews	Home	Adult men and women living with HIV	54 participants	At follow-up, participants in the treatment arm described less stigma and voiced positive changes in confidence and self-esteem.

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
		main RCT)						
29	Tshabalala & Visser, 2011	Mixed methods	South Africa	Questionnaire including: The Brief Cope Scale The Serithi Internalised stigma scale Enacted stigma 3-point scale Rosenberg Self-esteem scale The Beck depression inventory-II Interviews Focus Group Discussions Therapy transcripts	Clinic	Adult women living with HIV	20 participants randomly assigned to experimental and control group	The women in the experimental group reported less negative ways of coping ($p < 0.05$), lower depression ($p < 0.001$) and lower internalised stigma ($p < 0.05$), as well as more positive ways of coping ($p < 0.05$) and higher levels of self-esteem ($p < 0.01$) than the control group. There was no change in the enacted stigma scores in both groups. Qualitatively, change in thought patterns and behaviour was observed in all of the women. They grasped that HIV will not cause their immediate death and that they can still live a healthy life. Their self-perception changed and the way they interpreted others' perception of them.
30	Uys et al, 2009	Mixed Methods	Lesotho, Malawi, South Africa, Swaziland (Eswatini), and Tanzania	Questionnaire including: HIV/AIDS Stigma Instrument–PLWA (HASI-P); General self-efficacy scale (GSE); Rosenberg self-esteem scale (RSES);	Clinic	Adult men and women living with HIV	41 participants	PLHA who participated in the project showed a significant reduction in overall perceived stigma ($t_{1/4} 3.16$, $df_{1/4} 40$, $p_{1/4} 0.003$). Their self esteem changed significantly ($t_{1/4} 2.57$, $df_{1/4} 40$, $p_{1/4} 0.014$), but not their self efficacy. Nurses who participated on the intervention teams demonstrated no change in stigma. There was no significant difference in self-esteem or

	Study Reference	Study Design*	Country of intervention	How self-stigma or components of self-stigma were assessed.	Intervention setting	Focus population	Sample size	Reported effect on self-stigma and components of self-stigma
				Written report (qualitative); Semi-structured interviews				self-efficacy scores of this group before and after the intervention
31	Vaughan et al, 1996	Quasi-experiment((Pre-post test with control - quantitative)	USA	Questionnaire including: Rosenberg self-esteem scale (RSES)	Clinic	Adult men and women living with HIV	27 participants	Although analyses revealed no significant differences between the interventions, statistical trends and participants' written evaluations favored the life review intervention. Attrition was a significant problem
32	Yigit et al, 2020	Randomised control trial (RCT)	USA	Questionnaire including: Revised Berger's HIV Stigma Scale, The Patient Health Questionnaire depression scale-PHQ-8)	Clinic	Adult men and women living with HIV	371 participants randomly assigned to control or intervention group (1:1)	The decrease in internalized stigma from baseline to 48 weeks was significantly larger in the intervention arm compared with the control arm.

7.5.3 Quality assessment

Quality was assessed differently across study types (SM 5) using the most commonly used checklists for particular research designs (Ma et al., 2020). Research designs were classified as described by the authors. For qualitative (n=4) and mixed-methods studies (n=6) and the RCT (n=1) reporting a significant qualitative component, the Critical Appraisal Skills Programme (CASP) (CASP, 2022) was used. The main limitation highlighted by this checklist was the few articles that described or considered the relationship between researcher and participants explicitly. For RCTs (n=10), the risk of bias (RoB-2) revised tool was used (Higgins et al., 2011). A common limitation highlighted by this tool was the lack of discussion on who had access to the outcome results as well as whether the allocation to intervention or control group was effectively concealed. Often, the intervention arm included additional sessions/workshops for participants; they therefore identified themselves as part of the intervention group by attending. Quasi-experimental studies (n=11) were assessed using the Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) (Tufanaru et al., 2019) - most of these studies did not have a control group. The mixed-methods studies (n=7) were assessed using the mixed-methods questions from the CASP Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2019), but in 3/6 (50%) studies, the qualitative component focused on intervention evaluation while the quantitative assessed intervention impact. In every case, at least two authors assessed different research designs using the checklist.

7.5.4 Description of interventions

There was considerable divergence across the reported studies. The TIDieR Checklist (Hoffmann et al., 2014) guided our analysis of interventions to systematically understand their content. While it was possible to extract some information from each described intervention and complete the checklist, there were significant gaps in the level of detail provided in most of the published studies. However, we were able to describe the content of the interventions in a number of areas, which are expanded on below: Theoretical basis; Level of implementation; Intervention participants; Intervention approaches, content and delivery; Intervention setting and implementation, and Reported effectiveness of intervention.

7.5.5 Theoretical basis

Interventions were not consistently embedded within a theoretical framework. Of those that used a theoretical framework, these included the five C's of Positive Youth Development (i.e. competence, confidence, connection, character, caring) (Denison et al., 2021), the theory of logotherapy (Vaughan & Kinnier, 1996), and the Comprehensive Health Seeking and Coping Paradigm (Nyamathi et al., 2013), Social Action (Nestadt et al., 2019), various narrative therapies (Harding et al., 2019; Peterkin et al., 2013), Social Cognitive Theory (Harper et al., 2014), Inquiry-Based Stress Reduction (IBSR) (Ferris France et al., 2023; Ferris France et al., 2019), Acceptance and Commitment Therapy (ACT) (Mathew, 2022), Beck's Cognitive Model (Tshabalala & Visser, 2011) and Empowerment Social Learning Theory (Rao et al., 2012). One intervention used a Systems Theory Perspective (Mundell et al., 2011).

Table 3: Intervention Details

	Author	Curricula at a glance	Trained Facilitators	Ecological model level	Intervention Category	Dosage of intervention	Homework
1.	Barrington et al, 2021	<p>Individual Sessions: Including HIV care and treatment, adherence, sexual health, relaxation and stress management, violence, substance use, and life plans. Self-esteem was a cross-cutting theme in all sessions.</p> <p>Peer navigation: Emotional, informational, and instrumental support for HIV care and treatment adherence.</p> <p>Community Mobilisation: social interaction develop trust, skill development and economic opportunities.</p>	A trained cisgender Dominican woman with a background in psychology.	Individual and society	Traditional person-centred counselling	8 individual counselling sessions, with continued peer and community navigation	No
2.	Barroso et al, 2014	45-min video presenting vignettes of five seropositive women and the ways in which stigma has affected their lives.	Untrained	Individual	Bespoke training	Watch a 45 min video weekly for 4 weeks + as much or as little as desired for weeks 5 to 12	No
3.	Bartels et al, 2022	<p>Session 1: social support and discrimination.</p> <p>Session 2: adherence, addictions, and HIV knowledge.</p> <p>Session 3: sexual health, diagnosis disclosure, partner relationships; and</p> <p>Session 4: developing a life plan.</p>	Therapists and co-therapist used for therapeutic group	Individual and family	Traditional cognitive-behavioural therapy (CBT)	4 individual health education and counselling sessions	No

4.	Batchelder et al, 2020	<p>Session 1: Review emotion glossary, differentiating self-conscious emotions. Introduce self-compassion and compassionate self-statements.</p> <p>Session 2: Introduce metacognitive awareness and cognitions and mindfulness.</p> <p>Sessions 3: Metacognitive awareness, cognitive reframing and self-compassion</p> <p>Session 4: Reflect on how emotions and thoughts impact behaviour. Practice awareness about oneself in relation to self-care. Revisit cognitive reframing</p> <p>Session 5: Review content covered over all sessions and practice exercises</p>	Not specified	Individual	Multi-pronged cognitive and mindfulness-based approach	5 individual sessions (one hour each)	No
5.	Bryant et al, 2023	Short film - Content of the film not included	Untrained	Individual	Bespoke training	Not specified	No
6.	Denison et al, 2022	<p>Session 1: Understanding HIV</p> <p>Session 2: Disclosure</p> <p>Session 3: Treatment and adherence</p> <p>Session 4: Nutrition and self-care</p> <p>Session 5: Growing and changing</p> <p>Session 6: Communication</p> <p>Session 7: Sex and relationships</p> <p>Session 8: Sexual health and positive prevention</p> <p>Session 9: Handling stigma and discrimination</p> <p>Session 10: Support network (adolescents)</p>	Healthcare providers at each clinic underwent a weeklong training and facilitated the 10 sessions held every other Saturday at their HIV clinic over a six-month period.	Individual, family and society	Bespoke training	Experimental group = 10 group sessions, control group = usual care	No

7.	Denison et al, 2020	Session 1: Orientation meeting with a health care provider, their assigned youth peer mentor, and an adult caregiver One-on-one meetings: X 6 Group meetings: Knowledge and skills to support their youth living with HIV.	Youth peer mentors were trained and hired	Individual	Bespoke training	Orientation meeting, monthly group meetings (12 sessions, 1 individual x 6 months; 1 group x 6 months)	Journals used to track adherence and reflect on journeys
8.	Edwards et al, 2009	Sessions 1-6: Definition and discussion of the everyday lived experience and improvement of each particular psychological well-being dimension.	Trained - psychologist and nursing personal	Individual	Traditional person-centred counselling	6 hourly sessions – one per day.	No
9.	Erlen et al, 2001	Session 1: Childhood years. Session 2: Focused on topics related to adolescence Session 3: focused on the adult years. Session 4: Summary, evaluation of the person's life as described during life review, and the termination component of life review.	Researchers took part in the study but no mention of formal training	Individual	Reflective and creative	Data collection session, 4 life review sessions lasting 1-2 hours.	No
10.	Ferris France et al, 2023	Session 1: Self-stigma, emotions and me Session 2: The power of thinking Session 3: Introducing inquiry Session 4: Judgements of HIV Session 5: What others think of me Session 6: How HIV limits me Session 7: Deepening Inquiry Session 8: ARVs and my story Session 9: My body Session 10: My body and sex Session 11: Forgiveness Session 12: Deepening Inquiry Session 13: Shame and guilt	Trained local coaches, previously trained in IBSR, themselves adults LHIV, co-delivered the intervention together with an internationally IBSR-trained facilitator and an international creativity coach	Individual and family	Multi-pronged cognitive and mindfulness-based approach	16 x 3 hr group sessions (hybrid) and 10 x 7 hour group sessions	Yes - Activity journal that consisted of worksheets and exercises. WhatsApp support

		Session 14: Relationships and fear of disclosure Session 15: Death and dying Session 16: My future					
11.	Ferris France et al, 2019	Session 1: Introduction Session 2: What others think about me because I have HIV Session 3: How HIV limits me Session 4: HIV treatment Session 5: My HIV Story Session 6: Me, my body and HIV Session 7: Shame and guilt Session 8: My sex life since HIV Session 9: Fears of disclosing my HIV status Session 10: Death Session 11: God and a friendly universe Session 12: Who I truly am	Two Zimbabwean PLHIV were supported to attend a nine-day IBSR: The Work of Byron Katie training workshop in Germany, who then worked together with International Certified Facilitators in designing the curriculum.	Individual, family and society	Multi-pronged cognitive and mindfulness-based approach	12 x 4 hour group sessions and one weekly individual session	Yes - Activity journal that consisted of worksheets and exercises WhatsApp support
12.	Flickinger et al, 2018	PositiveLink App: Daily queries of mood, stress, and medication adherence, tailored educational resources, access to the study team for individualized counselling and assistance. Community Message Board: Interact with other users on a secure anonymous community message board.	Study team - No training of staff or research staff mentioned.	Individual	Other	Access to PositiveLinks app and community message board	No
13.	Fuster-Ruiz de Apodaca et al, 2016	Session 1: Presentation and Stigma and discrimination, characteristics and consequences. Session 2: Self-esteem and coping with stigma. Session 3: Communication skills	Professionals working for the CESIDA - State Coordinator for HIV and AIDS in Spain	Individual	Multi-pronged cognitive and mindfulness-based approach	16 hours, distributed in 4 x 4-hour sessions.	No

		Session 4: Techniques of emotional self-control and planning goals and ending the workshop					
14.	Harding et al, 2019	Session 1: Memory Book Session 2: Memory Box Session 3: Tree of Life 1, Tree of Life 2 Session 4: Hero Book Session 5: Issuing of Certificates of Participation	Trained - qualified social workers, a clinical officer and a medical doctor.	Individual and family	Reflective and creative	5 day residential camp including one-on-one support throughout group activities	No
15.	Harper et al, 2014	Session 1: Decreasing negative feelings toward self and others living with HIV; Session 2: Increasing planned and strategic HIV disclosure to others. Session 3: Building supportive networks to combat fears and feelings of rejection. Session 4: Building skills to combat HIV-related discrimination and other forms of stigma	All intervention delivery staff members participated in a centralized 3-day training	Individual, family & society	Bespoke training	12 sessions: 2 individual sessions, 9 x 2hour gender-specific group sessions and another individual session	No
16.	Lennon-Dearing et al, 2019	Session 1: Introduction to photo sharing with photo examples and narratives. Session 2: Photo-taking instructions Session 3-5: (a) challenges that you have overcome in your life, (b) your proudest accomplishment, and (c) your hopes and dreams for the future. Sessions 6-7: Reviewing developed photos for poster collage to represent participants' stories.	Trained - first author, a social worker, and a peer facilitator who worked as an early intervention specialist	Individual	Reflective and creative	2 cycles of 7 weekly group sessions	A minimum of 3 photos between each session to share with the group
17.	Mundell et al, 2011	Sessions 1-10: HIV-related knowledge and the emotional impact	Trained - research assistants	Society	Bespoke training	10 weekly psycho-social	No

		of HIV infection, coping with stigma, discrimination and education on basic human rights, life planning and goal setting,				group intervention sessions	
18.	Nestadt et al, 2019	Session 1-11: Icebreaker activity and chapter of Tam's story. Topics include concerns about growing up with HIV, communication within families, HIV stigma, HIV treatment and adherence, coping with loss/bereavement, risk behaviour and responding to peer pressure, puberty and sexual relationships, future goals, and social support.	Existing lay staff in clinic and medical settings. No mention of formal training for this staff.	Individual, family and society	Bespoke training	One weekend per month over 6 month. 11 sessions in total.	No
19.	Mathew et al, 2022	Sessions: Awareness of health Time management and goal setting. Journaling, Non-judgmental awareness Dental hygiene, ABC Mindfulness practice, Nutrition Coping skills training, Challenging ineffective thoughts, Distancing negative thoughts, Puberty self-care Conflict resolution, Thought diffusion Self-soothing exercises Self-grooming, Decision-making Developing functional and effective thoughts, Cultivating self-compassion,	Study carried out by researcher but no mention of formal training given.	Individual	Multi-pronged cognitive and mindfulness-based approach	44 hours over 6 months	No
20.	Nyamathi et al, 2013	Sessions covered: (a) HIV/AIDS and dealing with the illness. (b) learning about ART and ways to overcome barriers.	Trained - Lay village women were trained over 3-days. The sessions, conducted by expert physicians,	Individual and family	Bespoke training	6 programme specific sessions in sequence lasting 45 minutes	No

		(c) parenting and maintaining a healthy home environment. (d) how to improve coping, reduce stigma, and care for family members. (e) basics of good nutrition and easy cooking tips; and (f) benefits of engagement in a life skills class	nurses, spiritual leaders				
21.	Peltzer et al, 2018	Sessions 1-6: HIV knowledge, prevention of vertical transmission, adherence to PMTCT and medication use, HIV testing, prevention of HIV transmission and stigma, HIV disclosure, communication with partners, intimate partner violence (IPV), infant feeding, safer conception, family planning and dual method sexual barrier use.	Trained lay health workers. Counselling by nursing staff	Individual and family	Traditional cognitive-behavioural therapy (CBT)	Four antenatal and two postnatal group sessions Control group consisted of standard care counselling by nursing staff during perinatal care plus time-equivalent attention-control videos	Homework addressed strategies practiced in the sessions
22.	Peterkin et al, 2013	Session 1: Feedback Coaching Subsequent sessions: Reading of participant work with reactions and discussion.	Co-led by a psychiatrist and an occupational therapist trained in group psychotherapy.	Individual	Reflective and creative	14–16 once weekly Sessions with pre and post questionnaires	Writing of a story to share in each session – Writing prompts were provided each week.
23.	Pichon et al, 2022	Session 1: PLWH completed the informed consent process, received an overview of the project integrating photovoice ethics, met other participants, received a camera and	Trained - 3 authors of the paper with extensive experience in HIV, intervention delivery and	Individual	Reflective and creative	3 sessions and 7 focus group sessions	Yes - Photo taking and reflection.

		<p>camera training, completed a standardized internalized stigma scale, discussed experiences of internalized stigma, and were instructed to take 3–10 pictures that capture images of stigma</p> <p>Session 2: PLWH shared their pictures and discussed their meaning. We conducted seven focus group discussions of images ranging from 3 to 5 participants each with a final total sample size of n = 31 PLWH – which was sufficient to reach saturation or repeated ideas and themes, which occurred after focus group 6</p> <p>Session 3: PLWH clarified or expanded on what they shared in previous sessions in a one-on-one interview and made final selections for the planned display.</p>	photovoice methodology. A licenced clinician				
24.	Rao et al, 2012	<p>All sessions: (1) practising relaxation and self-care, (2) sharing coping strategies from other group members, (3) viewing trigger videos and (4) discussing how to handle potentially stigmatizing situations with family, in the workplace, and in other settings, and (5) role-playing ways to navigate these difficult situations.</p>	<p>Trained - "An African American women living with HIV who worked as a peer advocate served as the primary workshop facilitator. A masters' level social worker assisted with facilitation and with leading break-out group sessions. The principal investigator</p>	Individual, family and society	Bespoke training	4-5 hour workshop sessions 2 consecutive weekday afternoons	No

			of the study, a licensed clinical psychologist				
25.	Skinta et al, 2015	Session 1: Core ACT perspectives. Session 2: Costs and unworkability of responding to HIV-related stigma Session 3: Values-driven behaviours to replace control efforts Session 4: Acceptance and mindfulness and how to apply these to concerns regarding HIV. Session 5: self-as-context versus self-as-content. Session 6: Willingness Session 7: Visualization of a compassionate friend. Session 8: Generalising acceptance, mindfulness, and defusion exercises learned during the course of the group.	Clinic workers (only a small number of providers were trained in cognitive-behavioural therapy)	Individual	Multi-pronged cognitive and mindfulness-based approach	8 therapy sessions across 8 weeks	No
26.	Soro et al, 2021	Session 1: Self-esteem Session 2: Communication skills Session 3: Emotional self-control skills Session 4: Continued previous content plus added anti-discrimination and conflict resolution.	People from the association for the support of people with HIV and AIDS in Aragon, Spain	Individual	Traditional cognitive-behavioural therapy (CBT)	Therapy group – 4 x 12-hour workshops	Between each session homework was requested in line with the contents discussed
27.	Suyanti et al, 2018	Used ACT, logotherapy and family psychoeducation but did not describe intervention topics or approach in any detail	Health professionals (implied)	Individual	Multi-pronged cognitive and mindfulness-based approach	Not specified	Not specified
28.	Tsai et al, 2017	Small loan and 8-session training program: agriculture and financial management.	Trained - research assistants each received 2 weeks	Society	Other	8-session training program	Purchase a locally available

			of intensive training on qualitative interviewing techniques				handheld water pump and associated agricultural implements & commodities
29.	Tshabalala & Visser, 2011	Session 1: Role of HIV in participant's lives Session 2: Powerlessness and loss of self-worth Session 3: Guilt, anger and negative self-evaluation Session 4: Self-pity, self-neglect, isolation, denial and suicide Session 5: Human rights and anti-discriminatory laws Session 6: Future goals Session 7: Challenges in lifestyle Session 8: Coping skills	Trained Therapist	Individual	Traditional cognitive-behavioural therapy	8 individual therapy sessions - the intervention A focus group and interviews - development of intervention	Yes.symptom relief, identify negative automatic thoughts, reflect on feelings of guilt could help with coping, listing of good qualities about themselves, practising of assertiveness. set future goals
30.	Uys et al, 2009	Intervention: (1) sharing information, (2) increasing contact with the affected group, and (3) improving coping through empowerment.	Trained - The project initiation workshop was facilitated by a nurse and PLHA based on a standard manual and both were trained over a period of 2 days prior to them running the workshops	Individual and society	Bespoke training	Five countries: Workshop of 21 hours (all), between 5-13 hour meeting x 1, between 8 – 20 intervention hours. Total range between 35 – 49 hours	Design a stigma reduction project within one month of receiving the intervention
31.	Vaughan et al, 1996	All sessions: The lifeline exercise, construction of personal genograms, and presentation of personal histories with the aid of photographs.	Trained - Group leaders for this study were three female advanced	Individual	Reflective and creative	6 life review sessions for 2 hours weekly plus orientation	Reflection on in session activities

			doctoral students in counselling psychology who were trained and supervised by the first author.			and follow-up sessions	
32.	Yigit et al, 2020	Session 1: Introduction to iENGAGE intervention. Sessions 2-4: maintaining a positive approach and participating in skills-building modules with the counsellors.	Trained counsellors- 2-Day in-person workshop - Training by behavioural scientists.	Individual	Multi-pronged cognitive and mindfulness-based approach	4 face to face sessions with personal contact calls, visit reminder calls and missed visit calls	No

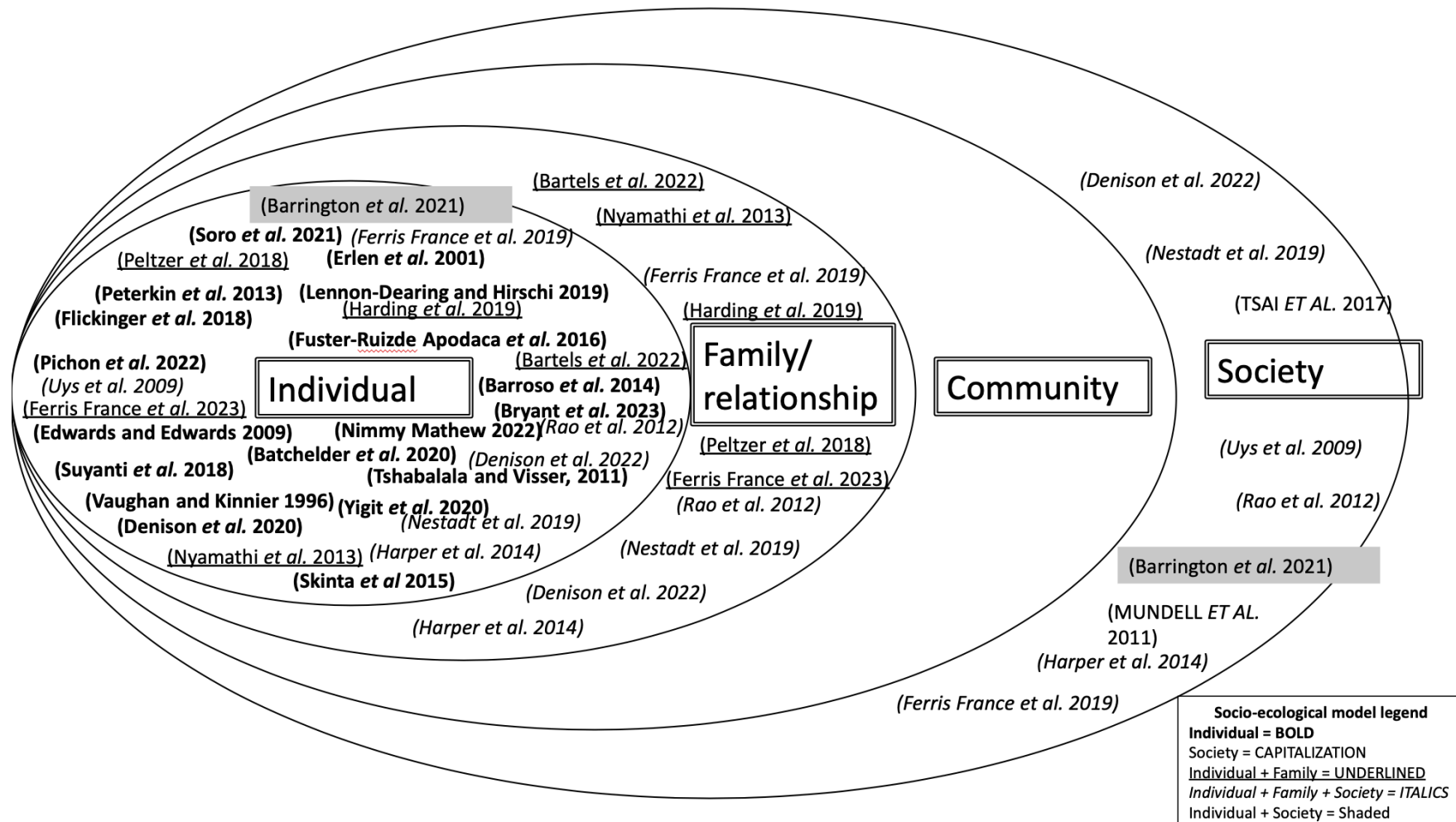
7.5.6 Level of implementation

Similar to Pantelic et al, we used the four levels of the socio-ecological model: individual, family/relationship, community, and society to assess the level of focus the intervention targeted (Pantelic et al., 2019). Allocation to levels was based on the intervention description, although this was hindered by the limited description of some studies. Interventions whose objectives or content focused on the personal level were classified as ‘individual’. Those interventions that included topics about relationships and/or family were classified as ‘family’. Interventions that addressed topics outside of the household but within the immediate environment of the individual were classified as ‘community’. Interventions that addressed societal factors such as human rights, legal empowerment or working with the healthcare system for example, were classified as ‘societal’. We found 18 individual level only interventions, 5 individual and family level, 5 individual, family and societal level, 2 individual and societal level and 2 societal level only. No intervention targeted the community level.

Figure 2 shows the socio-ecological levels at which the interventions included in this review operated. As 18/32 (56%) interventions targeted the individual, impact was measured largely at this level. Twelve (38%) operated at the individual and at least one other level, but impact was not measured beyond the individual level. For example, the impact on the individual who participated was assessed but not that on their family members or society.

Of the 31 studies, 25 interventions were developed with theoretical foundations or frameworks explicitly stated. Three used existing frameworks, namely: The five C’s of Positive Youth Development (Denison et al., 2021) the theory of logotherapy (Vaughan and Kinnier, 1996) and The Comprehensive Health Seeking and Coping Paradigm (Nyamathi et al., 2013). Over half (17/31, 54.84%) of the studies incorporated cognitive and behavioural elements (Bartels et al., 2022); (Biel Soro et al., 2021); (Peltzer et al., 2018), including Social Action (Nestadt et al., 2019), various narrative therapies (Harding et al., 2019); (Peterkin et al., 2013), Social Cognitive Theory (Harper et al., 2014a), Inquiry-Based Stress Reduction (IBSR), (Ferris France et al., 2019, Ferris France, 2023), Acceptance and Commitment Therapy (ACT) (Mathew, 2022), and Empowerment Social Learning Theory (Rao et al., 2012). One intervention used a Systems Theory Perspective (Mundell et al., 2011). Three interventions were tailor-made based on research and formative work in the local context (Ferris France et al., 2019); (Ferris France, 2023); (Nestadt et al., 2019).

Figure 2: Socio-ecological mapping of interventions



7.5.7 Intervention participants

PLHIV were the target group, with interventions targeting the following sub-groups within this population (see Table 2)

- Both adult men and women living with HIV (n=11)
- Adults living with HIV and with substance use disorders (n=1)
- Only adult men living with HIV (n=1)
- Gay and bisexual men living with HIV (n=2)
- Only adult women living with HIV (n=6) and pregnant (n=2)
- Transgender female sex workers living with HIV (n=1)
- Adult and adolescent men and women living with HIV (n=1)
- Adolescent and young men and women living with HIV (n=6)
- Children living with HIV (n=1)

7.5.8 Intervention approaches, content, and delivery

Interventions showed substantial divergence in terms of overall approaches and content (Table 3). An initial inductive analysis was carried out by in-depth reading and review of the interventions themselves, including approaches, elements used, dosage and frameworks referred to. Using previous systematic reviews (Ma et al., 2019; Pantelic et al., 2019) as a guidance, we developed six broad categories of approaches and then through deductive analysis, classified each intervention to the most appropriate category

- A. **Traditional cognitive behavioural therapy (CBT).** includes interventions that specifically use the methodology of CBT (Bartels et al., 2022; Peltzer et al., 2018; Soro et al., 2021; Tshabalala & Visser, 2011)
- B. **Multi-pronged cognitive and mindfulness-based approaches.** This includes programmes that bring in third wave psychological approaches – mindfulness, self-inquiry, awareness, such as Acceptance and Commitment Therapy (ACT) (Skinta et al., 2015), IBSR (Ferris France et al., 2023; Ferris France et al., 2019), combined CBT, awareness, motivational interviewing with creative elements such as music, art and drama (Mathew & Manjula, 2022), combined coaching and motivational interviewing

(Berger et al., 2001; Yigit et al., 2020), educational information (Fuster-Ruizde Apodaca et al., 2016). One intervention combined logotherapy commitment, acceptance therapy and family psychoeducation (Suyanti et al., 2018). One of the interventions in this category was mobile phone delivered (Batchelder et al., 2020).

- C. **Reflective and creative.** These included drawing on creative expression such as narrative therapy and narrative competence therapy (Harding et al., 2019; Peterkin et al., 2013), photovoice (Lennon-Dearing & Hirschi, 2019; Pichon et al., 2022) and life review (Erlen et al., 2001; Vaughan & Kinnier, 1996).
- D. **Bespoke training.** These included informational elements such as discussions, role-play and reflective activities (Denison et al., 2021; Harper et al., 2014), cartoons and structured discussion (Nestadt et al., 2019), discussion and journaling with sharing of experiences (Denison et al., 2021) and an educational video series (Barroso et al., 2014). One study included a short film (Bryant et al., 2023). Two interventions utilised structured peer support group meetings, drawing upon games, role-plays, storytelling, case studies, sharing of experiences (Mundell et al., 2011; Rao et al., 2012). One intervention combined accompaniment to health facilities and provision of food with the training (Nyamathi et al., 2013).
- E. **Traditional person-centred counselling.** This includes interventions that specifically use a person-centred counselling methodology (Barrington et al., 2021; Edwards & Edwards, 2009).
- F. **Other.** These included a livelihood intervention (Tsai et al., 2017), an information-giving intervention (Uys et al., 2009), and a mobile health empowerment intervention (Flickinger et al., 2018).

Most of the interventions targeted individual cognition, thoughts, emotions, and awareness, but were delivered in group settings. Overall, curricula focused on social support/relationship building, medication adherence/HIV knowledge, goal setting, coping skills, disclosure fears and communication skills. However, the approaches used to cover these topics varied, and included cognitive-based approaches, group discussions, role-plays and more bespoke methodologies. Many of the studies did not include detailed descriptions of the interventions, which not only made it difficult to understand the content, but also how it was delivered. Intervention details, including curricula summaries for interventions are included in Table 3.

7.5.9 Intervention setting and implementation

Twenty one interventions (66%) were delivered within healthcare/professional settings (clinics n=20 and clinic and home n=1). Three were in settings such as a Non-Governmental Organisation (NGO), government administration building and convenient locations in the community. One was home-based, two were online and one was hybrid online and face-to-face in an NGO. Four locations were not specifically stated.

Most interventions offered a structured course or a series of structured sessions ranging between 4 and 16 sessions for between 2 to 4.5 hours each. Some were delivered weekly, others over four weekends and yet others over a six-month period. Some interventions included homework and partner work and others included personalised follow-up by trained personnel. Most interventions were delivered face-to-face in groups or one-on-one with just two being delivered online (For more detail see Table 3).

Due to interventions' variability and little in-depth descriptions, it is hard to conclude whether there was a connection between dosage and results. However, most studies that reported a positive effect on self-stigma involved trained individuals delivering the intervention, with training ranging from one day to over two years. Trainees included healthcare workers, social workers, psychologists, PLHIV and community workers.

7.5.10 Reported effectiveness of intervention

As the definition of self-stigma varied by study type, measures of effectiveness also varied and ranged from descriptive outcomes/outputs to the use of a variety of scales. Scales were mainly used to measure self-stigma, self-esteem, self-efficacy, and quality of life (see Table 4). For this review, we specifically looked at scales and measures that potentially could be used to assess self-stigma components (positive and inverse positive). Though studies often included other measures, such as Center for Epidemiologic Studies Depression Scale (CES-D), we did not include these. Given the diversity of studies and the lack of a commonly agreed definition on self-stigma, there were also other scales or measurement types used.

Table 4: Scales used to measure self-stigma and components of self-stigma

Dimension reported	Scale used	Intervention assessed by scale
Self-stigma	HIV Stigma Scale (HSS) (Berger et al., 2001)	Bryant et al., 2023; Flickinger et al., 2018; Fuster-Ruiz de Apodaca et al., 2016; Harper et al., 2018; Peltzer et al., 2018; Yigit et al., 2020
	HIV/AIDS Stigma Instrument–PLWA (HASI-P) (Holzemer et al., 2007)	Uys et al 2009
	Stigma Scale for Chronic Illness (SSCI) (Molina & Ramirez-Valles, 2013)	Rao et al., 2012
	Internalised AIDS-Related Stigma Scale (IA-RSS), (Kalichman, 2008)	Byrant et al, 2023, Denison et al., 2020; Denison et al., 2022; Ferris France et al., 2019
	Internalised HIV Stigma Scales (IHSS) (Sayles et al, 2008)	Barroso et al., 2014; Nyamathi et al., 2013; Skinta et al, 2015
	Internalized Stigma of AIDS Tool (Phillips et al 2011)	Suyanti et al., 2018
	The Serithi Internalised Stigma Scale (Visser, et al., 2008).	Tshabalala, et al 2011
Self-esteem	Rosenberg self-esteem scale (RSES) (Rosenberg, 1965)	Barroso et al., 2014; Erlen et al., 2001; Harding et al., 2019; Lennon-Dearing & Hirschi, 2019; Mundell et al., 2011; Nimmy Mathew & M.Y., 2022; Peterkin et al., 2013; Tshabalala et al, 2011; Uys et al., 2009; Vaughan & Kinnier, 1996

Dimension reported	Scale used	Intervention assessed by scale
Self-efficacy	General self-efficacy scale (GSE) (Schwarzer, 1995)	Mathew, R.N. et al 2022; Uys et al., 2009
	Coping Self-Efficacy Scale (CSES) (Chesney et al., 2006)	Barroso et al., 2014; Lennon-Dearing & Hirschi, 2019
	Stanford Emotional Self-Efficacy Scale (Giese-Davis et al., 2004)	(Peterkin et al., 2013)
	Self-Efficacy Questionnaire for Children (SEQC) (Muris, 2001)	Harding et al 2019
Quality of Life	Battery of Psychological Predictors of Well-being and Quality of Life of PLHIV	Soro et al., 2021; Fuster-Ruiz deApodaca et al., 2016
	HIV/AIDS Targeted Quality of Life Scale (Holmes & Shea, 1998)	Ferris France et al., 2019; Harper et al., 2014
	The Ryff Psychological Well-being Scale (Ryff, 1989)	Edwards & Edwards, 2009
	Quality of Life Index (QLI) (Ferrans and Powers, 1985)	Erlen et al, 2001

Qualitatively, studies mainly used in-depth interviews (Barrington et al., 2021; Bartels et al., 2022; Batchelder et al., 2020; Ferris France et al., 2023; Ferris France et al., 2019; Skinta et al., 2015; Tsai et al., 2017) (Pichon et al., 2022; Uys et al., 2009) and four studies (Ferris France et al., 2023; Ferris France et al., 2019; Harding et al., 2019; Pichon et al., 2022) also used focus group discussions to explore intervention participants' perceptions of self. The main themes that emerged from these studies were: increasing health knowledge (for example Barrington et al., 2021; Bartels et al., 2022); focusing on the self and the present moment; and changing core beliefs and negative self-thoughts into positive ones (for example Ferris France et al., 2019). All qualitative studies reported, to some extent, reducing self-stigma or increasing self-agency, self-esteem, meaning in life, acceptance, coping skills, improved relationships, and/or psychological flexibility.

The majority (29/32, 91%) of the interventions reported positive effects on self-stigma among the participants - only three studies reported fluctuating or inconclusive results. However, only 16/29 (55%) studies had statistical significance and four studies reported positive long-term impacts (48-52 months - (Bartels et al., 2022; Erlen et al., 2001; Flickinger et al., 2018;

Yigit et al., 2020). Many of the studies were small scale; (11/32, 34%) had up to 30 participants, with only three participants completing the intervention in one study – see Table 2). Additionally, there was sometimes a lack of accuracy in using the precise scale title and so authors of this review had to make a judgement call based on reported details as to what scale was used. However, some of the described “scales” were not scales per se and were not validated.

7.6 Discussion

We conducted a systematic review to explore existing interventions to reduce self-stigma among PLHIV. We discuss our findings which offer some guidance for policy, programming and research in terms of defining self-stigma, highlighting issues with measurement and what appears to work and possibly not work in practice.

7.6.1 Defining self-stigma

A striking challenge in conducting this review has been the absence of a comprehensive definition of self-stigma. This review found that while comprehensive frameworks exist to contextualise the concept, there is no universally accepted definition or framework that can be applied to explore this phenomenon (Hempel et al., 2021). Studies can only be viewed and analysed based on the component’s researchers perceive as constituting self-stigma, and these vary greatly. Scales to assess self-stigma can include components of self-stigma outlined in the definition stated above as well as inverse positive components such as self-agency, self-esteem, self-worth, quality of life, making it challenging to identify, and to compare and contrast. From this review, we are proposing a definition of self-stigma that can be used by researchers and programme implementers going forward: "Self-stigma, is a mindset of negative beliefs, thoughts and behaviours about HIV, which manifests as shame, guilt, feelings of contamination, self-loathing, low self-esteem, and self-rejection”.

7.6.2 Measurement

The different scales used to measure self/internalised stigma (Table 4) reflect this phenomenon’s ambiguity. Ferguson et al (2022) found that there was considerable variation in how authors described or defined stigma (social) and thus comparisons between studies was difficult in terms of whether they were using the same framework or measures.

Similarly, we found that the scales used in studies focused on just one or two unidimensional components of self-stigma (or inverse components, such as self-esteem) and not adequately representing the complex phenomenon of self-stigma.

Our review noted that many of the components or inverse positive components measured in the quantitative studies indicated some positive changes as a result of the intervention, but the qualitative findings highlighted other issues that were not measured by these scales. This suggests that a more comprehensive approach to measuring the impact of an intervention would be to adopt a mixed-methods research design. Self-stigma as a holistic concept can be lost when we break it down to a scale. The results of positive self-stigma interventions show impacts in self-agency, autonomy, personal growth, personal goals in life, and other components. These nuanced elements of self-stigma and effects of interventions are more likely to be captured by using mixed methods and more in-depth qualitative research. Additionally, more in-depth description of interventions, that included more detail on the context, would enable greater learning of what works for whom and where. Such studies are more likely to generate more transferable findings and inform interventions that can address this complex phenomenon.

7.6.3 What worked and what did not?

Elements within interventions that reported a positive effect on self-stigma included working on thoughts, feelings and beliefs through a range of cognitive-based, inquiry-based, mindful-based techniques, often with a forward-looking goal-setting focus, with support of trained individuals - most often as groups with individual sessions and homework tasks. Most interventions employed more than one modality to address beliefs, behaviours and life goals, highlighting the utility of multi-pronged approaches. Unlike traditional CBT, the multi-pronged cognitive-based approaches introduced other additional techniques and questions as well as meditation and mindfulness to support realisations including for example, specific methodologies to support participants to identify and question self-stigmatising beliefs (Ferris France et al., 2019) or to identify costs and values and to start acceptance (Skinta et al., 2015). Mechanisms of impact were harder to delineate given the level of intervention description in the studies, but it does appear that no one off-the-shelf approach to self-stigma is applicable across all social contexts and circumstances. Interventions that were effective at reducing self-stigma were mainly group or group and individual based.

The socio-ecological model (Bronfenbrenner, 1979) provides a useful framework for understanding how health and well-being are influenced by multiple factors at various levels (individual, family/relationship, community, societal) (see Figure 2). In keeping with the socio-ecological model, it is possible that a successful intervention at the individual level will also have a positive impact at the family/relationship level. In addition, interventions that address multiple levels and address intersectional stigma are needed. Further, whilst it is widely understood that community-based HIV interventions are more successful when implementation is tailored to the country or community context (Dave et al., 2019; Mavhu et al., 2020), most of the interventions in this review were delivered in clinics or health settings. Pantelic et al also found that either self-stigma intervention design and research does not include community engagement or does not report on it (Pantelic et al., 2019). Limiting delivery to healthcare or clinic settings may miss the opportunity to work with, and train community groups to provide self-stigma interventions.

It is important to highlight what did not appear to be effective or where the same intervention was both significant and non-significant in different contexts. However, we are aware that there may be positivity bias in reporting results of interventions (Gluud, 2006), with interventions that did not work not being published and therefore, our findings would not include those. In the study by Batchelder et al, (2020), the impact of the intervention, a combination of in-person and mobile-phone delivered content for PLHIV with substance use disorders, was reported as not-significant. The intervention had eight participants, so a very small sample size from which to draw conclusions.

At times the same approach showed different results - for example, a Life Review study in the US was reported as not significant (Vaughan & Kinnier, 1996), while interestingly the same approach a number of years later, also in the US reported significant findings (Erlen et al., 2001). This would suggest different contexts, resources, training, delivery and fidelity determine an intervention's effectiveness. Of note, some studies show significant results for what seem relatively 'light' interventions (for example, Barroso et al., 2014; Suyanti et al., 2018, intervention is watching a video) suggesting that intervention intensity may not be the most critical aspect.

7.6.4 Limitations

Our study has some limitations. We focused on studies that set out to address self-stigma. We are aware that other studies designed for other purposes may also have an impact on self-stigma, but these were excluded, as this would have made the review too broad. We also only included studies with ≥ 2 components of self-stigma, as otherwise it would not be a self-stigma study. A study focusing on self-esteem, self-efficacy alone would have been excluded. We also categorised intervention approaches into six different categories. All of these categories were not specifically mentioned in every study and the authors of these studies could disagree with our categorisation.

Finally, due to resource limitations, we only analysed peer-reviewed articles published in English; this may have introduced language bias. Nevertheless, applying the PRISMA guidelines throughout increased the robustness of the review findings despite the inevitable methodological pitfalls.

7.8. Conclusions

In conclusion, this review adds to the previous reviews on interventions addressing stigma for PLHIV. We provide a critical overview of interventions to reduce and assess self-stigma among PLHIV. This study makes an additional important contribution to the field of HIV more broadly and HIV-related stigma, specifically, in relation to proposing a common definition of self-stigma and approaches to analysing interventions in terms of content, type, level and impact.

While HIV-related self-stigma interventions show promise, much still remains to be learned. Future studies should clearly state the definition of self-stigma they are using, explore longer-term and larger-scale studies, and could benefit from explicitly stating the theoretical framework they are rooted in. As most of the interventions were implemented in health or clinic settings, and delivered by professionals, more research is needed to understand the potential and effectiveness of self-stigma interventions delivered by trained PLHIV within community settings. It is critical that more detailed intervention descriptions are provided when publishing and sharing studies - the TIDieR checklist could be used for consistency and coherence.

In relation to approach, interventions that take a multi-pronged approach combining elements such as cognitive-based, inquiry, meditation, coaching, narrative therapy, music or art show promise. The socio-ecological model is useful in designing self-stigma interventions to understand the level at which the intervention is targeted, the nature of the intersectionality of self-stigma, and to support researchers and programmers to develop multi-level interventions.

Finally, it is more important than ever to stay cognisant that stigma and self-stigma are complex phenomena and that while there are similarities in the topics addressed and elements of interventions, no one size fits all contexts. In order to reach our global goal of ending AIDS as a public health threat by 2030, efforts to remove self-stigma as a barrier to effective HIV care, treatment and support should be intensified.

Declarative statements

Contributorship statement: NFF conceptualised the study with input from EB and SL. SL, EB and NFF screened and analysed the studies. AC and WM contributed to the interpretation of the findings. All authors contributed to the writing of the paper with NFF having the final responsibility.

Competing Interest statement: There are no competing interests for the authors of this systematic review.

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Ethics Approval Statement: There was no ethics approval required for this research as all literature, and therefore all the data used in this study, is in the public domain.

Data sharing statement: No data sharing was/will be carried out as no individual patient and public data was used in this research.

Patient and Public Involvement: Patients or the public were not involved in the design, conduct, reporting, or dissemination plans of our research.

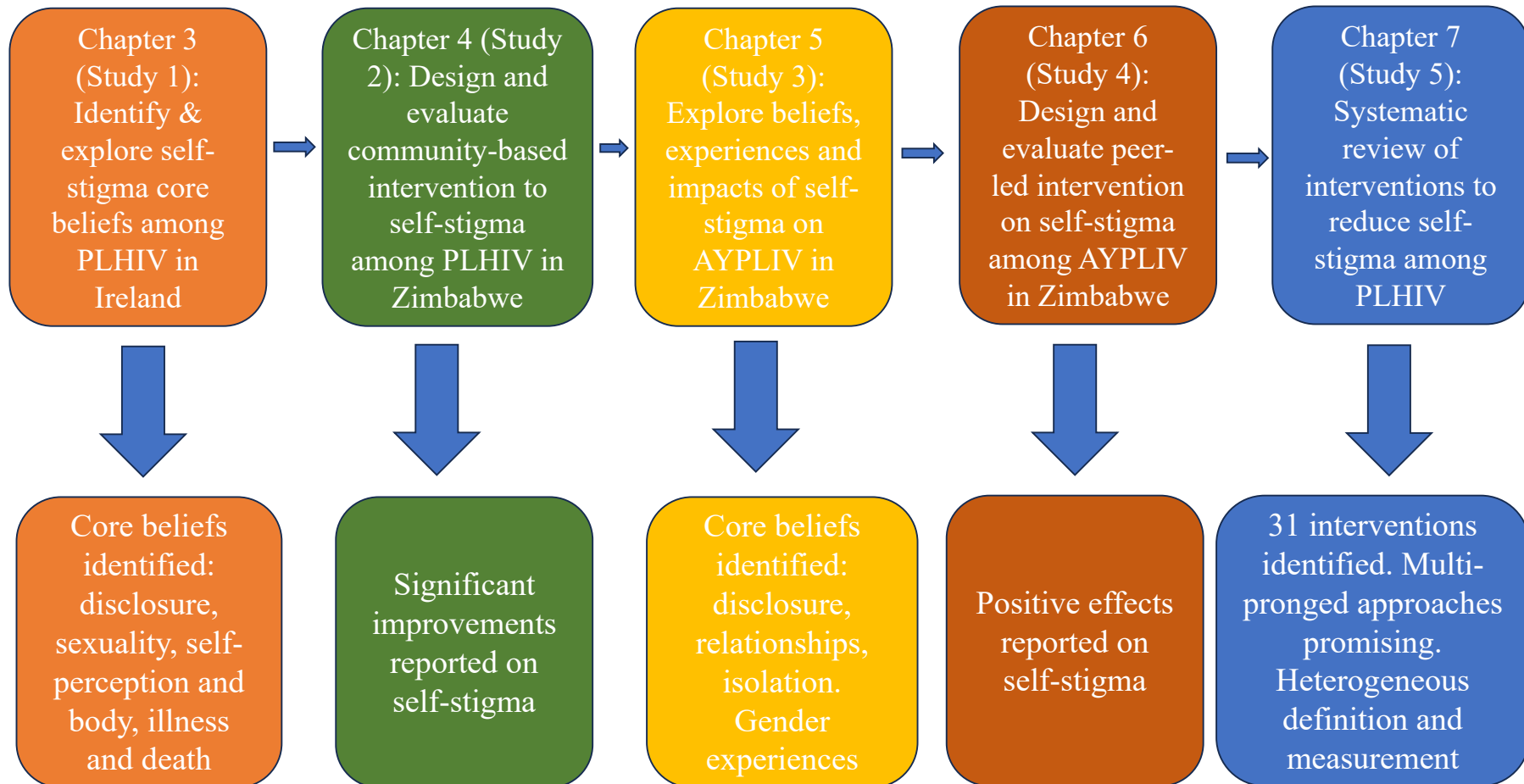
Chapter 8: Discussion

The aim of this chapter is to summarise the main findings and conclusions, and discuss the overall contribution of the five papers for research, practice and policies. The key information from each paper has been presented in the abstracts and a short summary of each is included in Appendix G. A summary of the main findings for each study is presented below in Figure 14.

This chapter presents in-depth interpretation of the findings according to each of the objectives of the thesis, highlighting the theoretical and policy, implementation and future research implications. Objective 3 to systematically review the literature is discussed throughout and is covered under Chapter 7. The chapter ends by discussing the overall strengths and limitations of the research and presents a conclusion.

This is the first study to explore and examine the self-stigmatising core beliefs of PLHIV and among only a small number of intervention studies worldwide to develop and evaluate a self-stigma intervention.

Figure 14: Overview of thesis findings



8.1 Objective 1: To improve the understanding of the beliefs associated with self-stigma among people living with HIV

The studies in Chapter 3 and 5 are the first studies to understand the beliefs that underpin self-stigma among PLHIV and as such have met a gap identified in the self-stigma literature (Kalichman et al., 2009). As well as raising interesting areas for future research, they can contribute to the development of effective self-stigma interventions.

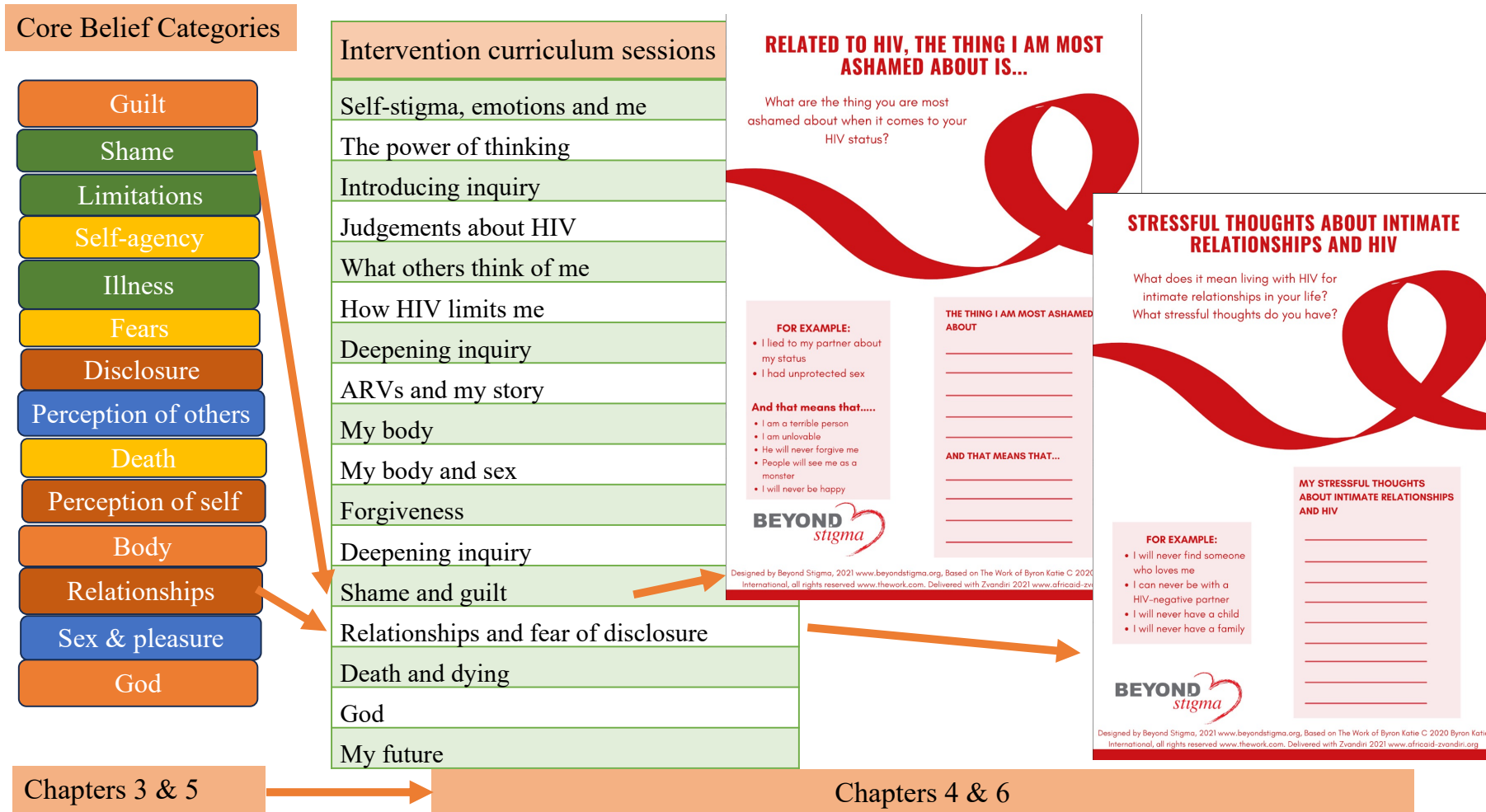
8.1.1 Self-stigma core beliefs

Self-stigma can be identified in negative emotions and cognitions (Li, 2020), and can appear as deeply-rooted negative beliefs, self-depreciation, feeling dirty and self-blame.

Understanding such beliefs is key to designing interventions and identifying coping strategies to address HIV-related self-stigma. Often, HIV-stigma research focuses on the *level* or extent of stigma in a person (Kalichman et al., 2009), community or society rather than explicitly focusing on the *understanding* of where it comes from and how it manifests in a person.

Focusing on negative core beliefs places the emphasis firmly on the person and their view of their world (Beck, 2011). Such a focus on core beliefs was central in four of the five studies presented in this thesis. Based upon existing frameworks and models for measuring stigma and guided by the overall theoretical framework offered by Goffman (Goffman, 1963), core beliefs were grouped and presented (Chapter 3 and 5) to better inform the interventions designed and evaluated (Chapter 4 and 6). Figure 15 shows how four of the studies were intrinsically connected by illustrating an example of how the research on core beliefs was turned into curriculum sessions in the interventions which were broken down into specific exercises designed to help participants identify their core beliefs and then inquire into them using IBSR.

Figure 15: HIV-self-stigma core beliefs linked to intervention exercises



8.1.2 Universality of self-stigma beliefs

The studies to better understand self-stigmatising beliefs were conducted in Ireland (Chapter 3) and Zimbabwe (Chapter 5), yet similarities were found across the study findings. For example in Chapter 3 with adult PLHIV in Ireland, themes emerged around disclosure; sexuality and sexual pleasure; self-perception; and body, illness and death. The same themes came out in the intervention development with adult PLHIV in Zimbabwe in Chapter 4. Though the core set of self-stigmatising beliefs appear to be similar, there were some culturally-specific themes. For example, with the adult PLHIV in Zimbabwe (Chapter 4), cultural core beliefs in relation to God emerged strongly such as ‘HIV is a punishment from God’ ‘I deserve HIV (meaning it was God’s will) and were subsequently integrated into the intervention.

Similarities in self-stigma beliefs and experiences can be found across people living with other stigmatised identities such as people living with chronic illnesses, mental health issues (Earnshaw and Quinn, 2012), sex workers (Huber, 2019), transgender people, men who have sex with men and people who inject drugs (Pantelic et al., 2019). For example, research carried out by the author in Vietnam with sex workers identified the same themes of disclosure, self-stigma and shame, sexuality and sexual pleasure and relationships as were found in the studies in Chapter 3 and 4. This could suggest the possibility of the universality of a core set of self-stigma beliefs as they are embedded in psychological processes, a key tenet of universalism (Kohfeldt, 2014). This universality of self-stigma beliefs could also suggest that interventions such as those in Chapter 4 and 6 are applicable to other stigmatised identities. To that end, based on the exploratory research mentioned above (Huber, 2019), using IBSR and a curriculum adapted from the interventions in Chapter 4 and 6, a workshop was delivered to sex workers and evaluated positively (Beyond Stigma., 2019). However, further research is needed to better understand cultural perspectives on HIV-related self-stigma.

In Chapter 5, in the study with AYPLHIV in Zimbabwe, while themes of worthlessness, hopelessness, negative body image, disclosure, isolation and relationships emerged, similar to the study of adult PLHIV living in Ireland (Chapter 3), there were nuanced differences between the adults and adolescents living with HIV in the Zimbabwe studies. With young

people, there was more emphasis around beliefs, not only related to disclosure within intimate relationships, but also beliefs about being able to date in the first place which is consistent with the wider literature (Nsibandze, 2021). Beliefs around loneliness were a key theme that emerged from the AYPLHIV, which is similar to findings in other studies in Zimbabwe reporting that AYPLHIV experience a common sense of isolation and rejection by peers (Willis et al., 2018a). These nuances identified in the two groups of PLHIV in Zimbabwe highlight the need for interventions to be tailored to the age group to ensure they adequately support individuals to address what is most important to them in relation to self-stigma.

This work on core beliefs contributes to our broader understanding of the origins and nature of self-abasing and negative perceptions of PLHIV, identified as a gap (Kalichman et al., 2009, Nyblade, 2022). However, much remains to be done.

8.2 Objective 2: To iteratively design and evaluate a psychosocial intervention based on inquiry-based stress reduction for people living with HIV: Implications for practice

Despite the range of interventions that exist to tackle HIV-related stigma, as can be seen from the systematic review in Chapter 7 and wider literature (Kalichman et al., 2009), there are not many that target HIV-related self-stigma. Of those that do exist, not enough is known about what effectively reduces self-stigma. In 2023, the new Global Stigma Index Report stated that from a sample of 30,751 PLHIV from 25 countries, 84.5% reported experiencing self-stigma (GNP+, 2023a). In light of this, the impetus to design and implement evidence-based HIV-related self-stigma interventions is even more pressing. The interventions developed and tested in this research demonstrated some good indications of feasibility and acceptability of the IBSR intervention. Responding to the gap in HIV-related self-stigma interventions, a number of key areas are highlighted below that can be used to support development of future self-stigma interventions, especially those being implemented in resource-poor settings as well as community-based interventions.

8.2.1 Awareness first

As can be seen from the intervention studies in Chapter 4 and 6, in order to be able to address self-stigma, individuals must be aware of their own beliefs, judgements and attitudes towards

themselves and towards others. This is evidenced by the 3A's approach used in the study in Chapter 5 (Corrigan et al., 2009). PLHIV can be unaware of what self-stigma is and find it difficult to identify and describe (MOSES, 2023). It is therefore important that interventions to tackle self-stigma start by defining and introducing what self-stigma is and moves through a process of awareness of how self-stigma occurs inside (Corrigan et al., 2009), before moving onto how to address it.

8.2.2 IBSR in practice

The two intervention studies included in Chapter 4 and 6 describe IBSR, a novel, third-wave psychological approach that was evaluated as having a positive impact for adults and AYPLHIV in Zimbabwe. This research is an important contribution to the wider literature on IBSR as it is the first time it has been applied in the Global South. All other IBSR-related studies included in the 2021 IBSR systematic review took place in the Global North (Hook, 2021).

An important part of ensuring IBSR was acceptable and feasible was localisation that included translation of the IBSR approach into the Shona language. This was a process carried out in a team that included Zimbabwean Coaches, the author and a local psychologist. It was important that the concepts and questions used in the IBSR method were well understood. Similar findings have been reported in another Zimbabwean-based study assessing the feasibility of administering cognitive behavioural therapy to improve ARV adherence (Bere, 2017). Additionally, a strong finding from both studies, Chapter 4 and 6, is that training, mentoring and support for the Zimbabwean Coaches is necessary so that the IBSR approach maintains fidelity and quality, with the ultimate aim of local sustainability and local capacity to implement. Furthermore, both interventions in this thesis, working with adults and AYPLHIV, took time to build basic awareness and literacy around feelings and emotions before progressing to the more cognitive, awareness topics of self-stigma. This is consistent with research and with the feedback from participants involved in the intervention design, that speaking or articulating feels and emotions is uncommon in Zimbabwe, as in other sub-Saharan settings (Bernays et al., 2020).

8.2.3 Self-stigma coping strategies

Self-stigma coping strategies identified by participants are an important starting point for building interventions and were identified in two of the five studies in this research. In Chapter 3, coping strategies identified included community involvement, professional development and education; personal development, inner work and positive attitude; connection to others and a sense of belonging (to community groups and support networks). For the AYPLHIV in Chapter 5, coping strategies included counselling, support groups, hearing shared experiences, medication adherence, acceptance of HIV status and activities related to self-support such as overcoming negative thoughts. These coping strategies provided an important framework upon which the interventions in Chapter 4 and 6 were designed. These findings are also consistent with the Coping Strategies Inventory (CSI) first developed by Lazarus and Folkman that divides coping strategies into eight coping factors grouped under emotion-focused coping and problem-solving coping (Silveira Silva, 2018).

8.2.4 Multipronged approaches and creativity

A scoping review by the World Health Organization (WHO) explored over 3000 arts-based health and wellbeing studies and found that the creative expression that occurs in arts participation can cultivate problem solving, creative thinking, and promote reconstruction of beliefs (Clift, 2020). The same review also found that emotional and aesthetic aspects of arts activities can provide a means of stress reduction and emotional regulation (Clift, 2020). Interestingly, currently in the literature, self-efficacy is being linked to arts-based programmes. For example, one study of an arts-based programme based in Israel found that individuals with mental health conditions who reported high self-stigma also reported lower creative self-efficacy and personal recovery (Nitzan, 2020). The notion of creative self-efficacy may have relevance in understanding how an intervention incorporating creative expression could shift self-stigmatising beliefs in that participants move from believing they are incapable to observing their own ability (Tierney, 2011).

Similar to the findings of the two interventions detailed in Chapter 4 and 6, the systematic review in Chapter 7 found multi-pronged approaches to tackle self-stigma appear promising where there is a combination of elements that included cognitive-based or inquiry-based

techniques, mindfulness, meditation, coaching, narrative therapy, music and art, tailored to the context.

Interventions working with young people can benefit from creative approaches (Ness, 2021). A study from Eswatini integrating creativity into a HIV treatment intervention among AYPLHIV, found beneficial psychosocial effects including a decrease in self-stigma (Ness, 2021). Similar to the study in Chapter 6, this programme used a creative-arts based programme that included singing, lyric writing, games and other forms of self-expression. An unpublished pilot workshop with AYPLHIV carried out in advance of the study in Chapter 6 helped develop a set of principles to guide development of the intervention in Chapter 6. Among these principles was '*playfulness*' and feedback to strike a balance between heavy (work on difficult topics such as shame) and light (fun, games, music, art). Building on the experience of Zvandiri about what works for AYPLHIV (Willis et al., 2018a), playfulness through creative and arts-based approaches were integrated as an important component of the intervention. In addition to IBSR, singing, poetry, drawing, dancing and games were incorporated into the curriculum and six Creativity CATS (Community Adolescent Treatment Supporters) were also trained to support delivery of the intervention. This is consistent with other interventions effective in reducing self-stigma highlighted in the systematic review in Chapter 7 that included music, art, drawing, cartoons, photovoice and games. Integration of creativity and the arts into health and wellbeing interventions has been a growing area of interest (Clift, 2020).

From the studies in this thesis, it was clear that is not just the content (self-stigma themes) and the methodology (IBSR), but also how it is delivered and integrated (creatively) that contributes to the effectiveness of the intervention in addressing self-stigma.

8.2.5 Meaningful involvement of PLHIV and community-based responses

An integral part of designing interventions must be the recognition that communities and PLHIV know best what they need and can meaningfully be involved in intervention design (Israel, 2010). It is widely known that community responses to HIV are the cornerstone of effective, equitable and sustainable programmes and that more research is required to understand the impact of responses that are peer-led or community-based (UNAIDS & Stop AIDS Alliance., 2015). However, the systematic review in Chapter 7 found that out of 31

self-stigma studies included, only five were embedded in existing community networks and structures. The rest were delivered mainly in healthcare facilities by health or social care professionals. The majority of self-stigma interventions are psychosocial/mental health interventions (Chapter 7). The availability of mental health professionals is important in this context. Only 19 countries in sub-Saharan Africa have state-endorsed mental health policies and few universities offer clinical and applied psychology graduate programmes (Spedding, 2017). With only 12 practising psychiatrists in Zimbabwe (Willis et al., 2019), finding innovative and quality ways to embed psychosocial programmes, such as those on self-stigma, within the community is even more important so they can be made more widely available.

The four studies included in Chapters 3-6 were all based within community networks of adults and AYPLHIV. In both community-based intervention studies (Chapter 4 and 6), the participant groups were meaningfully involved in the development, testing and adaptation of the interventions from the outset in keeping with principles of community-based participatory research (Israel, 2010) and in recognition that involvement is a key coping mechanism for self-stigma as mentioned above. Meaningful involvement can mean better results when interventions are designed to fit the context of people's lives (Eaton, 2019). The intervention in Chapter 4 worked with two local Coaches, adults living with HIV all part of the Zimbabwean National Network of PLHIV, to adapt and deliver the intervention. The intervention in Chapter 6 was co-led by four local Coaches living with HIV, who had originally been participants in the study in Chapter 4 and subsequently received training. They were joined by a team of 15 AYPLIV CATS Coaches, the author (a Certified Facilitator in IBSR), and an International Creativity Coach. The AYPLHIV who participated in the study in Chapter 6 are all 'Community AIDS Treatment Supporters – CATS' within Zvandiri, a local NGO that delivers health, hope and happiness to over 110,000 young people across eleven countries in sub-Saharan Africa. In all four studies, feedback sessions were held to present the findings to the participants. This not only ensures the interventions are appropriate, but also ensures wider support for participants (Bruhn, 2021).

By embedding the interventions in community organisations and including details of the process in the published papers, this research has contributed to filling gap identified by UNAIDS in understanding community-based responses and peer-led interventions (UNAIDS & Stop AIDS Alliance., 2015). It has also shown that delivering psychosocial interventions in

resource-poor settings are possible with the right supports in place. To this effect, the study in Chapter 4 was also included in a UNAIDS global publication as a case study to showcase best practice in community-based interventions (UNAIDS & Stop AIDS Alliance., 2015) p.55.

8.2.6 Gender

In the exploratory research with AYPLHIV in Chapter 5, gendered experiences and coping mechanisms of self-stigma were reported. In both Chapter 3 and 5 interview responses demonstrated that women and men have similar self-stigmatising beliefs, however, participants in Chapter 5 suggested that experiences of stigma could be more intense for women. The intervention in Chapter 6 had a positive psychosocial effect on males who in the cultural context are less able to discuss or express emotional concerns, likely largely due to hegemonic masculinity where males are socialised around toughness and concealing emotions (Bolton et al., 2007, McMullen et al., 2013).

There appears to be some nuances within the literature on gender, self-stigma and HIV. For example, an International Planned Parenthood Federation Report based on data available from the PLHIV Stigma Index (GNP+, 2023c) reported that while in Dominican Republic and Ethiopia women feel higher levels of shame and lower levels of self-esteem than men, men feel higher levels of guilt and self-blame than women. In Bangladesh, men reported higher levels of self-stigma across all components (shame, self-esteem, guilt and self-blame) (International Planned Parenthood Federation (IPPF), 2011). It appears though, that the authors of this report give more weight to shame than guilt, and self-esteem than self-blame, concluding in the report that women experience higher levels of self-stigma than men (GNP+, 2023c). The broader literature on guilt and shame also points to nuances of gendered experiences with women reporting higher proneness to shame and guilt (Benetti-Mcquoid, 2005, Hampton, 2014), and men reporting higher levels of guilt (Benetti-Mcquoid, 2005). From this data, it could make programmatic sense to provide more support for men on guilt and self-blame and for women on shame and self-esteem. It is important to better understand these potential differences within available data as it drives the development of interventions targeted at either men or women, or both. Currently, as informed by the systematic review in Chapter 7, nine of the self-stigma intervention studies were specifically designed to reach women living with HIV, whereas only four were specifically designed to reach men. Gender

differences in self-stigma require more in-depth analysis across larger data sets. In hindsight, given the potential gender differences and nuances described above, more focused qualitative questions specifically drawing out beliefs on shame and guilt from women and men would have been useful in this research and will be integrated into future research.

8.2.7 Fidelity

A key area within the interventions was fidelity - the degree to which an intervention is delivered as intended (Breitenstein, 2010, Borrelli, 2011) and how that affects delivery and replication potential. Fidelity is an important part of implementation science (Westgard, 2020). Key components identified by Fixsen include practitioner selection, pre-service and in-service training, ongoing coaching and supervision, practitioner performance evaluation (assessment of implementation fidelity), decision support data systems, facilitative administrative supports, and system interventions (Fixsen, 2005) and can be found within the studies in Chapter 4 and 6. With co-delivery of the intervention, care was taken to ensure training, ongoing support, supervision and feedback. This was also important given the psychosocial nature of the intervention itself and several lessons were learned. For instance, trainers must first be participants in the intervention to receive it for themselves. Working with an approach such as IBSR, a self-inquiry approach, it is important that the approach is first experienced before trying to learn and train it. In the context of Zimbabwe, having a community of practice and a mentoring programme proved an effective way to do this. Through the immersive Training of Trainers course conducted within the study in Chapter 6, a training manual was produced and was subsequently used to guide implementation by newly trained young people. For delivery, a team approach was used where AYPLHIV CATS Coaches were paired with adult PLHIV Coaches, and the curriculum was delivered in teams with morning and evening briefings. Daily participant evaluations also helped to see what was working and what needed to be adjusted, and these were supported administratively by Zvandiri staff. These measures helped ensure intervention fidelity and that the intervention was delivered as intended, particularly as it moved from trained adults (Chapter 4) to trained young people (Chapter 6). In the wider systematic review (Chapter 7), it was difficult to assess fidelity across the 31 interventions identified due to a lack of comprehensive intervention descriptions.

8.2.8 Challenge of scale up

One significant challenge for self-stigma interventions is the issue of scale up. As well as self-stigma being understudied in general, there is little evidence of well established, large-scale programmes to address it and more research is needed to inform decisions about how best to scale up such interventions (Pantelic et al., 2019). The systematic review presented in Chapter 7 found that while over three-quarters of the studies included reported a significant effect on reducing self-stigma, similar to the studies in Chapter 4 and 6, the majority are pilot or small scale studies.

One way to approach scale up to is support interventions with digital technology and online tools (Gibbs, 2020). In resource-poor settings such as Zimbabwe and other parts of sub-Saharan Africa however, this is not straightforward as issues of electricity, connectivity, the high cost of data, restrictive religious beliefs, lack of native languages on most platforms, low digital literacy and complicated user interface remain challenging (Mindu, 2023). However, lessons can be learned from broader health and wellbeing digital health initiatives in sub-Saharan Africa that are expanding rapidly (Kipruto, 2022). For example, integrating mental health support Aps into widely used existing social media platforms such as Facebook and WhatsApp appear promising (Mindu, 2023).

In scaling up self-stigma interventions, continuing to test the dosage and depth of an intervention is important in order to be able to understand how interventions can be adapted and still prove effective. The author led the development of a brief short form of the intervention presented in Chapter 4 to address self-stigma among people living with tuberculosis. It was designed so that NGO Facilitators could be trained to deliver the intervention in shorter workshops. A toolkit called: ‘From the Inside Out - a toolkit addressing tuberculosis-related self-stigma’ was tested in the Philippines, Indonesia and Kazakhstan (MacDonald, 2023). While findings were not as promising as the results from the full form intervention in Chapter 4, results showed improvements in self-reported knowledge and efficacy around self-stigma, self-compassion, and two dimensions of psychological wellbeing, positive relationships with others and self-acceptance.

8.2.9 Next steps in implementation

Building on the results of the study in Chapter 6, a follow-on intervention by and for AYPLHIV will be implemented in Zimbabwe. The intervention, will be multi-level, as well as multi-pronged, and will be designed upon the socio-ecological model. It will measure impact and experience at the individual, family and community level. The process and impact of creativity as a complement to IBSR will also be measured. The intervention will invest heavily to train, support and mentor the young people to ensure fidelity and provide quality support as the AYPLHIV CATS Coaches deliver the intervention to their peers. This will include development of an ongoing community of practice. A digital/online component of the programme will be further developed to provide weekly intervention nudges in the form of follow-up exercises and opportunities for practice. By year three of the intervention, the AYPLIV CATS Coaches will be delivering the intervention within HIV peer-support groups. Data will be collected at every stage to continue the learning and adaptation needed for a successful intervention.

8.3 Objective 4: To improve the operationalisation of the concept of self-stigma and propose a conceptual framework to better understand and guide interventions and research: Implications for theory and policy

This thesis contributes to the operationalisation of the concept of self-stigma through the learning and analysis around self-stigma definition and measurement. It proposes a new definition of self-stigma and a conceptual framework, based upon the socio-ecological model that can guide the development of interventions, policy and some of the broader theoretical discussions around self-stigma and its impact.

8.3.1 Definition

Similar to research by (Ferguson et al., 2022), the systematic review in Chapter 7 found considerable variation in how self-stigma is described and defined across interventions and research. This indicates a broad variability of understanding and lack of consensus about what self-stigma is. Called self-stigma, internal stigma, internalised stigma, personal stigma, perceived stigma, there are wide variety of explanations used by researchers (Kalichman et al., 2009) (Link and Phelan, 2006) (Ferguson et al., 2022) (Nyblade, 2022). Self-stigma is a

multifaceted phenomenon containing a number of components such as self-acceptance, self-esteem, self-worth, self-agency, shame, guilt, self-blame (Kalichman et al., 2005). However, in the literature self-stigma is regularly simplified and used interchangeably with terms such as self-esteem, self-acceptance or quality of life. Although self-acceptance for example, is a component of self-stigma, self-acceptance alone does not mean self-stigma. This is problematic for two reasons. Firstly, for the actual design and development of interventions in that interventions vary in what they try to address depending on which components of self-stigma are included in the design. In addition, depending on how the definition describes self-stigma, the intervention focus may change. If the definition speaks of a process of internalisation, the focus of the intervention may be on changing norms and beliefs of the wider community on the assumption that if social stigma changes, self-stigma improves. Whereas if the definition states negative self-judgements that result in shame for example, the intervention would focus on working with the individual on their own negative beliefs.

Secondly, the simplification and misuse of terms around self-stigma is also problematic for the measurement of intervention impact and levels of self-stigma. Measurement scales are designed based on a definition (Kyriazos, 2018) and broken down into categories upon which questions are created. The systematic review of interventions in Chapter 7 found six scales measuring self-stigma (Berger et al., 2001, Holzemer et al., 2007b, Molina and Ramirez-Valles, 2013, Kalichman et al., 2009, Mahajan et al., 2008), one used to measure self-esteem (Rosenberg, 1965), three for self-efficacy (Schwarzer, 1995, Chesney et al., 2006, Giese-Davis et al., 2004) and three for quality of life (Holmes and Shea, 1998, Ryff, 1989). To expand on an example, the HIV Stigma scale (Berger et al., 2001) contained four factors - personalised stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV, and was based on measurements of self-esteem, depression, social support and social conflict. The IA-RSS Internalised Stigma Scale, used in Chapter 4 (Kalichman et al., 2009), includes six items reflecting self-defacing beliefs and negative perceptions of people living with HIV/AIDS and is based on correlations to depression, social support, discriminatory experiences (Kalichman et al., 2009). With many scales being used to measure different aspects and the fact that definitions and measurements of self-stigma vary, understanding what is actually being captured, as well as comparing and assessing effectiveness and impact of interventions is difficult (Ferguson et al., 2022).

A good definition of self-stigma should state clearly what self-stigma is and what it affects so that the components are clear and can guide development of interventions and research. From the cumulative learning from the data analysis, findings and intervention results from the studies in this thesis, a new definition, expanding on existing definitions is proposed as follows: *Self-stigma is a mindset of negative beliefs, thoughts, and behaviours about HIV, which manifests as shame, guilt, feelings of contamination, reduced self-efficacy, self-loathing, low self-esteem and self-rejection*’.

8.3.2 Wellbeing, self-stigma and measurement: ‘The Good Life’

An unintended but important outcome of this body of work was around self-stigma and wellbeing, how people define their own wellbeing, how researchers measure it and how this fits with the current context and discourse on positive health and wellbeing. This was a common thread throughout all the studies included in this thesis.

As previously stated, scales to measure self-stigma remain problematic in terms of ability to compare across studies but also in terms of assumptions and position by which the starting point for measuring is defined. Although in a recent review, 50 measures for HIV-related stigma have been identified (Ferguson et al., 2022), there are no Core Outcome Sets for measuring HIV-related self-stigma, and issues of heterogeneity are a challenge for the field (Webbe, 2018, Williamson, 2012). A Core Outcome Set is an agreed, standardised group of outcomes to be reported by all studies within a research field (Webbe, 2018, Williamson, 2017). The availability of a Core Outcome Set for measuring HIV-related self-stigma would allow for increased understanding of the impact of interventions based on enhanced capacity to compare and contrast findings across studies. Such an understanding is, currently lacking in the evidence.

This thesis also highlighted issues around deficit-based and strengths based approaches to wellbeing research. For example, in the study in Chapter 4, a mismatch was discovered between the quantitative and qualitative results. Quantitatively, validated scales and components thereof, were used to measure the outcomes and reported significant results around items such as depression, quality of life and internalised stigma. The qualitative component of the research indicated that there were positive benefits, including personal growth, purpose in life and accessing education opportunities for participants, that were not

captured by the structured questionnaire. The mismatch between what had been measured and the participants' responses was stark. The questionnaires focused on the negative aspects of life whereas the participants focused on achievements and hopes in their qualitative feedback. Findings from the systematic review in Chapter 7, found psychosocial interventions are most often assessed quantitatively in terms of whether they affect levels of stigma, self-esteem, depression or quality of life. This approach is deficit-based, focusing on what is wrong with people, rather than what is right with them. In response to this, a subsequent HIV-related self-stigma intervention by the author in Zimbabwe, as yet unpublished, tested the Ryff scale and focused primarily on the positive attributes of the six domains of wellbeing - autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance (Ryff and Keyes, 1995). Although well-founded criticisms of the Ryff scale exist (Henrich, 2010) (Springer, 2006), preliminary indications suggest that the Ryff scale captured greater information about changes to overall wellbeing instead of simply measuring negative outcomes such as level of depression.

The findings of this thesis around measuring wellbeing and the impact of self-stigma interventions are aligned to current discourses around salutogenesis, positive psychology, wellbeing and health. In 1948, the World Health Organisation defined health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO, 1948). Traditionally, wellbeing was understood and measured as the absence of illness, e.g. reduction of mood disorders (Achor, 2010); thus, at the beginning of the century, the ratio of research published about depression/anxiety compared with happiness/wellbeing was 17:1 (Achor, 2010). This is why in line with the World Health Organisation, the Positive Psychology movement was created to redress the imbalance by focusing on what is right, rather than wrong with people (Seligman, 2000). Positive psychology was originally referred to as a science of a good life (Park, 2009). As part of this movement, wellbeing research expanded towards exploring the positive aspects of wellness, not only deficits (Arslan, 2019) and what makes life worth living (Park, 2009). Over the years, researchers' focus shifted from happiness, through to wellbeing and flourishing (Seligman, 2000), flourishing considered the highest level of emotional, social, and psychological functioning (Keyes, 2020). While much research is still needed into the most effective way to capture changes related to self-stigma interventions, adopting a Positive Psychology approach could be useful.

8.3.3 Language matters

It is well known that the language we use to describe HIV can either empower or stigmatize PLHIV (Dilmitis, 2012). For instance, we know not to use the terms ‘AIDS victim’ or ‘AIDS patient’ and instead to use the term ‘person living with HIV’. In-depth terminology guides have been produced to guide researchers, programmers and policy makers to ensure non-stigmatising language is used when talking about HIV (UNAIDS., 2015). Following on from this, it is clear from the research in this thesis, that language matters. For example, the study in Chapter 6 was named by the AYPLHIV ‘Wakakosha’ the Shona word for ‘I am worth it’. It was important for the young people in this study that the term was positive and strengths-based. In this respect, there may be a dichotomy in using the term ‘stigma’ itself. On the one hand, in the legacy afforded us by Goffman (Goffman, 1963), we need to use the word stigma to help us understand what it is and why it is a problem. On the other hand, I have come to see that the very use of ‘stigma’, ‘self-stigma’ and all terms associated with it, may contribute to the negative associations and stereotypes we are trying to negate.

Given that our experience of the world is shaped by the stories we tell ourselves as well as our interpretations of it (Pasupathi, 2010, Carrié, 2023), stories that are distorted and destructive, could negatively impact a person’s ability to live a fulfilled, purposeful life. Philosopher Michel Foucault in ‘The archaeology of knowledge’ (Foucault, 1972) shared that there are ideas that will have more dominance in a person’s life than others. He called these dominant discourses. Generally, discourses are viewed as the language that a person or institution uses to explain their understanding of the world or how it should be. Focusing on deficit-based language rather than strengths-based language can highlight the negative aspects of an individual’s identity or condition and overshadow the strengths, resilience and positive aspects (Grabow, 2021). It could also inadvertently reinforce notions of ‘us’ and ‘them’. While the term "stigma" and “self-stigma” are useful and necessary in understanding and addressing societal biases, it is important to balance it with narratives of resilience, empowerment, and the promotion of inclusivity (Grabow, 2021). Language can be immensely powerful tool that could reduce the burden of stigma and thereby have a meaningful impact on the lives of individuals with mental disorders (Cuttler, 2019).

From my own experience in practice, and from the results of the studies in Chapter 4 and 6, it has become clear that reframing language around self-stigma that emphasises the strengths,

achievements, and shared humanity of individuals or groups affected by stigma, may be supportive in counteracting the potential stigmatizing effects and foster understanding and support. Based on the learnings from the research presented in this thesis, the author developed Figure 16 to show how strengths-based language that goes beyond stigma could be used. Research is needed that looks at the impact of using terms such as ‘stigma’ and ‘self-stigma’ as well as exploring the benefits of strengths-based vs deficit-based language.

Figure 16: Flipping the narrative to a world beyond stigma

Flipped narrative	Socio-ecological level			
	Individual	Family/household	Community	Societal
External inclusion and acceptance	Care services provided and treatment prioritised	Included by family and peers	Increased empathy and change in beliefs = less gossip and negative attitudes	Included in life opportunities
Instead of				
<i>Stigma & discrimination</i>	Denied care services De-prioritised for treatment Negative thoughts & beliefs	Excluded by family and peers	Gossip, negative attitudes & abuse	Blocked from life opportunities
Self-worth/Self-agency	Accesses care and adheres to treatment	Actively participates in social scenarios	Doesn't let the feeling of anticipated gossip or negative attitudes affect them	Actively seeks out life opportunities
Instead of				
<i>Self-stigma</i>	Withdraws from care services Does not adhere to treatment	Withdraws socially	Anticipates or perceives gossip, negative attitudes, or abuse	Does not undertake life opportunities (education, professional etc)

8.3.4 New conceptual frameworks and theoretical implications

The field is not short of broad HIV-stigma frameworks for stigma and self-stigma, where a recent review identified 69 frameworks (Ferguson et al., 2022). Theories and frameworks powerfully influence how evidence is collected, understood, analysed and used, and have the power to clarify or confuse (Alderson, 1998).

A number of theoretical models, scales and frameworks were used and referred to inform the framework for the studies in this thesis, including the socio-ecological model (Krug et al., 2002); Corrigan's 3 A's (Corrigan et al., 2009); Berger's HIV Stigma Scale; (Berger et al., 2001) HIV/AIDS Stigma Instrument PLWA: HASI-P (Holzemer et al., 2007a); Internalised AIDS Stigma Scale (IA-RSS) (Kalichman et al., 2009); the Ryff scale (Ryff and Keyes, 1995); and the PLHIV Stigma Index 2.0 (Friedland, 2020). In terms of overall theory, this research was guided by Goffman (Goffman, 1963) and Link and Phelan (Link and Phelan, 2001). During this research, two gaps were identified and as a result two frameworks have been produced to contribute to understanding and to guide the development of practice, policy and research. The first one is a conceptual framework was adapted in the exploratory study in Chapter 3 (Figure 2) to help understand the complex interactions between social, contextual and self factors (Morrison, 2006). This adapted framework shows how individuals come with their own belief systems, life experience and resilience that have been influenced and influence their contexts such as childhood experiences, life circumstances and power relationships. These then in turn, are influenced and influence a variety of social factors such as levels of stigma, community support, economic and cultural situation. This framework is useful in understanding the causes of self-stigma and contributes to filling gaps previously identified regarding knowledge regarding social and psychological factors related to self-stigma and HIV (Kalichman and Simbayi, 2004).

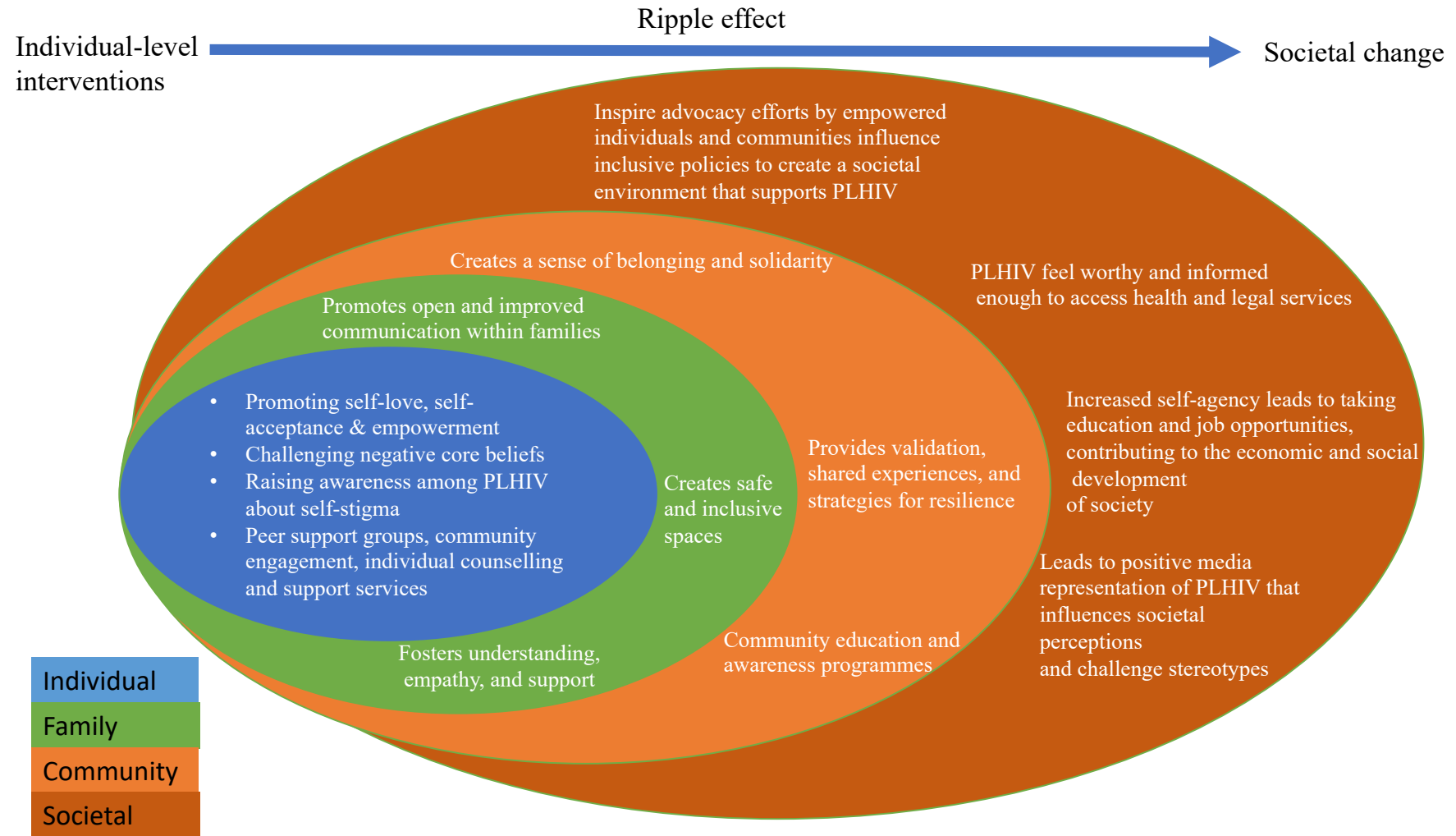
The second framework based on the socio-ecological model is called the Inside Out Framework and was developed by the author based on two conclusions identified from the research in this thesis. The first conclusion is that as stigma occurs at multiple socio-ecological levels, interventions should target multiple levels. Stigma-reduction interventions are most effective when they include components directed at a range of actors and socio-ecological levels (Heijnders M, 2006). It follows that as stigma occurs at multiple socio-ecological levels, stigma-reduction interventions must also target multi-level sources of

stigma (Nelson, 2021). While important, single-level interventions cannot address intersectional stigma (Nelson, 2021). A multi-level intervention, for example, may seek to support PLHIV to identify and question their self-stigmatising beliefs in a structured programme; as well as provide awareness and education for family and household members; conduct community education programmes to shift harmful norms about HIV through community dialogues and radio shows and provide stigma-reduction activities at the health facility level. However, the majority of health-related self-stigma frameworks, including those developed for HIV, explore psychological pathways at the individual level, focusing either on the individuals experiencing stigma, those perpetuating stigma, or both (Stangl, 2019). While contributing to understanding the factors that drive, and in some instances mitigate, the stigmatisation process for individuals, these frameworks limit implementers and researchers ability to inform the multi-level interventions required to meaningfully influence the stigmatisation process (Stangl, 2019).

The second conclusion is that there is a lack of recognition of the potential significant ripple effect of self-stigma interventions on wider socio-ecological levels. The systematic review in Chapter 7, using the socio-ecological model as an analytical framework, confirmed the lack of multi-level interventions. It found that the majority of studies, including the studies in Chapter 4 and 6, focused their intervention at the individual level and even though some had a focus at family or societal level, they were not explicitly designed to target multiple levels and did not measure impact at more than the individual level (Chapter 7). This highlights a gap in the understanding of the multi-level ripple effect a self-stigma intervention can have on family, community and society. For example, participants in the self-stigma intervention study in Chapter 6, reported positive changes in family relationships and in their job and education seeking behaviour. This is also important when considering the prevalent paradigm of ‘value-for-money’ (Jackson, 2012) that can influence governments and funders to look for large-scale interventions that impact large numbers of people at low cost. Societal and community-level stigma and discrimination interventions are regularly recognised as fitting this frame. When viewed as individual level, self-stigma interventions can be expensive relative to other broader stigma interventions. However, if designed and impact measured at multiple levels, self-stigma interventions may have the potential to be seen as ‘value-for-money’, but cost effectiveness studies would be needed.

To that end, the author proposes a new framework, based on the socio-ecological model, to support the design of interventions and research to understand and measure HIV-related self-stigma. Figure 17 shows the potentially far-reaching impact and ripple effect of a self-stigma intervention on the individual, the family, the community and the society. It is based partly upon the findings of the studies in Chapter 4, 6 and 7 and is supported by my own experience in practice. Appendix H contains a narrative description of Figure 17.

Figure 17: Inside Out: a framework for HIV self-stigma related interventions, research and policy



In summary, designing policies, interventions and research on HIV-related stigma that address multiple levels of the socio-ecological model is valuable as it acknowledges the interconnectedness and intersectionality of stigma across various levels of society. The adapted conceptual framework contributes to the broader understanding of the causes of self-stigma while the Inside Out Framework, can support greater understanding of the impact of self-stigma interventions across multiple levels.

8.4 Implications for future research

A number of areas and recommendations for future research have been identified from the findings of the studies included in this thesis, and are grouped under two headings:

8.4.1 Enhancing understanding of self-stigma

- Further research should:
 - Examine the nuances within the gender-dimensions of HIV-related self-stigma by exploring larger gendered data sets from existing studies such as the Global PLHIV Stigma Index Study, as well as conducting further qualitative studies
 - Use more creative approaches to explore the impact of arts-based approaches to reduce HIV-related self-stigma and the role of such approaches in shifting negative core beliefs
 - Explore the universality of self-stigma beliefs across marginalised groups such as sex workers, men who have sex with men, transgender people, drug users and people living with obesity
 - Examine the effect of language around stigma and self-stigma. For example, qualitative research is needed that looks at the impact of using terms such as ‘stigma’ and ‘self-stigma’ as well as exploring the benefits of strengths-based vs deficit-based language.

8.4.2 Intervention design and measurement

- Intervention research should:
 - Adopt a standardized and expanded definition of self-stigma

- Ensure detailed descriptions of interventions to enable replication, assessment of fidelity, evidence synthesis, and wider implementation (Craig, 2013, Hoffmann et al., 2014).
- Use the socio-ecological model to design, evaluate and measure self-stigma interventions to ensure a strong theoretical foundation and encourage more multi-level interventions.
- Continue to explore and test innovative ways to scale-up effective interventions including:
 - Larger scale studies involving bigger number of participants to better understand the effectiveness, impact and process of interventions using IBSR, ACT, coaching, mindfulness, creativity and other novel approaches.
 - Designing and testing context-appropriate digital health solutions for PLHIV
- Continue to explore the feasibility and effectiveness of community-based interventions to reduce self-stigma that ensure fidelity and quality of self-stigma approaches
- Ensure interventions are measuring what matters to the individual, rather than what is the matter with them
- Development of a 'Core Outcome Sets' for measuring self-stigma
- Ensure qualitative methods are used in self-stigma research as self-stigma and stigma are complex phenomena and existing quantitative scales alone struggle to capture the nuances.

8.5 Strengths and limitations

This section provides a summary of the overall strengths and limitations of this doctoral thesis. The strengths and limitations of each of the individual studies have been acknowledged and addressed in the relevant chapters. The central aim of this thesis was to better understand self-stigma among PLHIV and how it manifests through developing, implementing and evaluating a self-stigma intervention. Strengths will be presented first followed by limitations.

A strength of this thesis was that a variety of qualitative, mixed methods and quantitative methods were used. The studies had a strong theoretical basis drawing upon existing frameworks for self-stigma and was guided overall by the theoretical framing on the issue of stigma as outlined by (Goffman, 1963). Two of the studies in this thesis were carried out during COVID-19 and this was a strength in that the adaptation, forced by the circumstances due to COVID-19, meant more capacity was built locally to deliver the intervention and the content was better documented as many aspects were delivered online. The resulting creativity enabled the development of a hybrid intervention and an Online Toolkit to support the intervention and the training of CATS Coaches. It was a strength of this research that data was collected in both Ireland and Zimbabwe as it provided a cross-cultural view. The understanding of core-beliefs from Chapter 3 and 5, contrary to what might be the assumption, showed a great deal of similarities. The adult participants in the Zimbabwe intervention study felt solidarity and gained some comfort to know that adults living with HIV in Ireland had the same self-stigma and challenges.

In terms of limitations, the four primary data collection studies (Chapter 3–6) were studies with small numbers of participants, all carried out in urban areas (Dublin and Harare respectively). In particular, with reference to the intervention studies (Chapter 4 and 6), they were both run as small pilot studies and while the findings show positive results and acceptability, they may not be generalisable and further larger-scale studies are needed. However, as the studies were centrally about evaluating an intervention and learning about feasibility and acceptability, small pilot studies were appropriate (Pearson, 2020).

A limitation of this study was that gender and sexual identity was not applied as a specific lens by which to understand experiences of self-stigma. Gender-specific data could have contributed to a better understanding of how self-stigma is experienced in men and women and also related to particularly marginalised identities such as that of transgender people. However, a commentary on gender differences was included in the research in Chapter 5 and gender balance was considered in both of the intervention studies. A limitation in the research in Chapter 6 was that the impact and process of creativity itself was not measured qualitatively, in its own right. However, a retrospective study is now underway in this regard.

In the studies conducted in Zimbabwe Chapter 4, 5 and 6, the majority of participants were members of a local NGO network and already been trained and likely had a good knowledge of HIV and coping mechanisms. For this reason participants in these studies could potentially report lower levels of self-stigma in the exploratory research and report less change in the intervention studies than other PLHIV who are not trained or engaged in an active and supportive network, and therefore they may not have been fully representative of the whole population. However, as this was the first time IBSR was piloted in Zimbabwe, it was important that participants were firmly embedded within community structures. Also this was supportive in training AYPLHIV CATS Coaches to deliver the intervention as they had previous facilitation skills and were used to supporting their peers.

Finally, conducting the systematic review after the other research has both strengths and limitations. In terms of limitations, conducting the review before the other studies could have benefited in particular the design of the interventions and broadened the understanding of effective components of self-stigma interventions that could have been incorporated into the studies in this thesis. As a strength, however, conducting the systematic review after the other research meant a great deal of experience was already gained in intervention development which helped in analysing the interventions, their measurement and in the discussions and subsequent decisions around what constituted a self-stigma intervention.

8.6 Conclusions

This thesis fulfils the aim of better understanding self-stigma among PLHIV and how it manifests through developing, implementing and evaluating a self-stigma intervention. Overall, this doctoral work makes a valuable contribution to the existing gaps in knowledge around self-stigma and HIV on a number of levels. On a public health level, this research has increased understanding of the causes, impacts and core-beliefs of self-stigma. At the practical level, an intervention was developed and tested that has shown promise of feasibility and acceptability and demonstrated improvements in wellbeing and self-worth among adults and adolescents and young people living with HIV. This research provides a framework for designing future interventions, research and policy and makes recommendations for future work in this area. It also provides a comprehensive review and critique of existing HIV-related self-stigma interventions. Lastly, methodologically, it

illustrates how participants in the intervention can also be co-researchers and writers and how creative dissemination of research findings can be when working with people in practice

As a well known Southern African HIV activist, Justice Edwin Cameron said

“people can live with HIV, but cannot live with internal stigma”.

Box 3: What is known and what this thesis adds

What was already known about this topic

- HIV-related self-stigma is a global public health threat
- Adults, adolescents and young people living with HIV experience significant self-stigma and shame
- Self-stigma impacts health seeking behaviour, life-saving medication adherence, quality of life and increases depression
- Self-stigma is a neglected area in the response to HIV-related stigma
- There is a lack of interventions focused on HIV-related self-stigma

What this thesis adds

- A better understanding of self-stigmatising core beliefs that can be used to inform future interventions and research
- A clear definition of self-stigma to help inform self-stigma interventions, research and measurement
- A well-documented and positively evaluated community-based self-stigma intervention that shows impact on reducing self-stigma and improving wellbeing and self-worth for both adults and AYPLHIV
- A systematic review and analysis of HIV-related self-stigma interventions globally that includes both qualitative and quantitative studies
- A conceptual framework for showing the complex interactions that help understand the causes and consequences of self-stigma
- The Inside Out Framework to support the design of multi-level HIV self-stigma related interventions and research

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10. Appendix A: Publications and Conference presentations related to this research

Journal articles , publications and toolkits

- Heniff, L., Ferris France, N., et al Wakakosha: *How creativity enhanced an intervention to reduce self-stigma among young people living with HIV in Zimbabwe* (manuscript in preparation)
- MacDonald, S.H. & Ferris France, N., Hodgson, I., et al, “*From the Inside Out*” - a toolkit addressing tuberculosis-related self-stigma: A feasibility study", Submitted to BMC Global and Public Health, July 2023
- Ferris France, N. Hodson, I, MacDonald, S., Ramakant, B., Mitchell, E: *Inside Out: A toolkit to support people with TB deal with self-stigma and shame*, 2019 online: <https://www.kncvtbc.org/uploaded/2018/10/From-the-Inside-out-stigma-compressed.pdf>
- Jasmine Huber, Nadine Ferris France, Van Anh Nguyen, Hoai Huong Nguyen, Khuat Thi Hai Oanh & Elaine Byrne (2019) *Exploring beliefs and experiences underlying self-stigma among sex workers in Hanoi, Vietnam*, Culture, Health & Sexuality,
- Ferris France, N. Macdonald, S., Conroy, R., Ni Cheallaigh, D, Byrne, N., (2017); *Measuring self-stigma, wellbeing and self-agency among people with TB*; In TB Measurement Guidance, Mitchell E., van den Hoff, S., TB Challenge, USAID, KNCV,
- Macintyre, K, Bakker, M, Bergson, S. Bhavaraju, Bond, V, Chikovore, J. Colvin, C. Craig, G. M. Cremers, A. L. Daftary, A. Engel, N. France, N. Ferris, et al, *Defining the research agenda to measure and reduce tuberculosis stigmas*; The International Journal of Tuberculosis and Lung Disease, Volume 21, Supplement 1, 1 November 2017, pp. S87-S96(10); DOI:
- Fast Track Cities, London. *Empowerment Programme Framework: A Guide to Tackling Internalised Stigma* 2021 online <https://fasttrackcities.london/a-guide-to-tackling-internalised-stigma-for-people-with-hiv/>
- UNAIDS & STOP AIDS ALLIANCE. 2015. *Communities Deliver: The crucial role of communities in reaching global targets to end the AIDS epidemic.* . Geneva and Hove.

https://www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf

Conference presentations

- 24th International AIDS Conference, Heart of Stigma IAS Pre-Conference Symposium, 27 July 2022. *Self-stigma, shame and HIV*
- Humanity and Health: Global Imbalance and Social Inclusion: Irish Global Health Network Conference 2022. Preliminary presentation of Systematic Review of interventions to reduce self-stigma among people living with HIV
- International Union of Lung Disease (IULTD) Conference, The Hague, October 2018: Presentation TB: *Living with self-stigma and shame*
- Institute of the Work Convention, LA, 2017 ‘*I Change the World Changes*’: Presentation of ‘We are the Change’ programme, USA
- XXI International AIDS Conference, Durban, South Africa, 2016 ‘*Self-stigma and HIV – strategies for coping – let us do more than talk about it*’, Special Session
- Institute of the Work Convention, LA, 2016 Presentation of ‘We are the Change’ programme, USA
- International Conference on AIDS and STIs in Africa (ICAS), 2015 ‘*I Change the World Changes*’: Presentation of ‘We are the Change’ programme in Zimbabwe
- Invited Keynote Address at the 2014 Annual Father Michael Kelly Lecture on HIV/AIDS: ‘*An unspoken world of unspoken things*’
- Invited Mini Lecture at the 15th European AIDS Conference, Brussels, November 2013: Self-stigma: An unspoken word of unspoken things

Self-stigma and HIV/AIDS Baseline information

To be used together with the Interviewer Guide that contains clear instructions for administering this questionnaire.

Participant ID:

Group:
Personal details

1. What is your date of birth?: _____

2. How old are you? _____

3. Are you male or female? M____ F____

4. Circle the highest grade or year of school that you completed.

Grade: 1 2 3 4 5 Form: 1 2 3 4 5 6 University:

5. Do you currently work for money? _____ Y/N

6. Are you married or in a committed relationship with a person you live with? _____
Y?N

7. How many children, if any, do you have?

0 1 2 – 4 4+

8. How long have you been on treatment? _____ years

9. What ethnic group do you come from? _____

10. What is your religion

Section A:

	Completely true	Mostly true	Mostly false	Completely false
1. There are several people that you trust to help you solve problems				
2. There is no one that you feel comfortable talking to about intimate personal problems				
3. If you were sick and needed someone to take you to a doctor, I would have trouble finding someone				
4. If you needed a place to stay for a week because of an emergency, you could easily find someone who would put you up				
5. You fee that there is no one I can share your most private worries and fears with				
6. If you were sick, you could easily find someone to help you with your daily chores				
7. You feel a strong emotional bond with at least one other person				
8. When you need suggestions on how to deal with a personal problem, you know someone you can turn to				
9. If you needed an emergency loan there is someone you could get it from				
10. It would be difficult to find someone who would lend you their care for a few hours				
11. I have close relationships that provide me with a sense of emotional security and well-being				
12. You lack a feeling of intimacy with another person				

Section B:

	0 days	1-2 days	3-4 days	5-7 days
1. You were bothered by things that usually don't bother you				
2. You did not feel like eating; your appetite was poor				
3. You felt that you could not shake off feeling down even with help from your family or friends				
4. You felt that you were just as good as other people				
5. You had trouble keeping your mind on what you were doing				
6. You felt depressed				
7. You felt that everything that you did was an effort				
8. You felt hopeful about the future				
9. You thought your life had been a failure				
10. You felt fearful				
11. Your sleep was restless				
12. You were happy				
13. You talked less than usual				
14. You felt lonely				
15. People were unfriendly				
16. You enjoyed life				
17. You had crying spells				
18. You felt sad				
19. You felt that people disliked you				
20. You could not get going				

Section C:

	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree
1. I am actively involved in AIDS community issues				
2. It is difficult to tell other people about my HIV infection				
3. Being HIV positive makes me feel dirty				
4. There are many people in your life that you talk openly to about your HIV status				
5. You feel guilty that you are HIV positive				
6. You are ashamed that you are HIV positive				
7. In general, you feel proud of who you are				
8. You sometimes feel worthless because you are HIV positive				
9. It is your own fault that you are HIV positive				
10. Other than having HIV, you feel the same as everyone else				
11. You hide your HIV status from others				
12. More of your friends are HIV positive than HIV negative				

Section D:

Please answer the following Yes or No.

- | | | |
|--|-----|----|
| 1. Were you treated differently by your friends and family, once they found out you have HIV? | Yes | No |
| 2. Did your friends stop visiting or calling you when they found out you have HIV? | Yes | No |
| 3. Did family members stop visiting or calling you when they found out you have HIV? | Yes | No |
| 3. Has your HIV status ever caused you to lose a job? | Yes | No |
| 4. Has your HIV status ever caused you to lose a place to stay? | Yes | No |
| 5. Have you ever experienced discrimination because you are HIV positive? | Yes | No |
| 6. Are there people you have not told you are HIV positive because you are afraid of their reaction? | Yes | No |
| 7. Have you ever been hit or physically hurt because you are HIV positive? | Yes | No |
| 8. Has someone ever ended a relationship with you because you are HIV positive? | Yes | No |
-

••••

Section E:

	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree
1. You look forward to the future with hope and enthusiasm				
2. Sometimes you feel that everything is moving on ahead and leaving me behind				
3. You have great faith in future				
4. It is very hard for me to visualize what you will be like in five years				
5. The future seems vague and uncertain to me				

Section F

1. The following questions ask about your overall function in the past 4 weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None of the Time
a. In the past 4 weeks, I've been satisfied with my physical activity					
b. In the past 4 weeks, I've been physically limited in my ability to do routine household chores					
c. In the past 4 weeks, pain has limited my ability to be physically active					
d. In the past 4 weeks, I've been worried about not being able to do my job/routine daily activities as I have in the past					
e. In the past 4 weeks, I've felt that having HIV has limited the amount of work I can do at my job/routine daily activities					
f. In the past 4 weeks, I've been too tired to be socially active					

2. The following questions ask about your life satisfaction in the past 4 weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, I've enjoyed living					
b. In the past 4 weeks, I've felt in control of my life					
c. In c. In the past 4 weeks, I've been satisfied with how socially active I am					
d. In the past 4 weeks, I've been pleased with how healthy I've been					

3. The following questions ask about your health worries in the past 4 weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, I haven't been able to live the way I'd like to because I'm so worried about my health					
b. In the past 4 weeks, I've been worried about my CD4 count					
c. In the past 4 weeks, I've been worried about my viral load					
d. In the past 4 weeks, I've been worried about when I'm going to die					

4. The following questions ask how you've felt about your HIV medications in the past 4 weeks:

Have you taken HIV medication in the past 4 weeks?

No -> -> -> -> -> -> **Go to Section 5**
Yes -> -> -> -> -> -> **Continue with**
Question 4a

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, taking my medicine has been a burden					
b. In the past 4 weeks, taking my medicine has made it hard to live a normal life					
c. In the past 4 weeks, taking my medicine has caused unpleasant side effects					
d. In the past 4 weeks, I've been worried about the effects my medicine may have on my body					
d. In the past 4 weeks, I've been unsure about why I'm taking medicine					

5. The following questions ask how you've felt about being HIV positive in the past 4 weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, I've had regrets about the way I lived my life before knowing I had HIV					
b. In the past 4 weeks, I've been angry about my past HIV risk behavior					

6. The following questions ask about your disclosure worries in the past 4 weeks:

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, I've limited what I tell others about myself					
b. In the past 4 weeks, I've been afraid to tell other people that I have HIV					
c. In the past 4 weeks, I've been worried about my family members finding out that I have HIV					
d. In the past 4 weeks, I've been worried about people at my job/routine daily activities finding out that I have HIV					
e. In the past 4 weeks, I've been worried that I'll lose my source of income if other people find out that I have HIV					

7. The following question ask about your sexual
Experiences in the past 4 week:

	All of the time	A lot of the time	Some of the time	A little of the time	None Of the Time
a. In the past 4 weeks, it has been difficult to get sexually aroused					
b. If you have had sexual experiences in the past 4 weeks, have you enjoyed it					

Focus Group Discussion Guide (Pre-Programme)*Introductory notes:*

- Thank you for agreeing to take part in this programme on self-stigma called 'We are the change' inquiry-based stress reduction. We wanted to have a discussion with you today to understand some of your experiences about being HIV-positive and also ask you what you are hoping to get from the programme. If it's okay with you, we will record the session so that we can type up the session later. All information will be confidential and anonymised and will not be shared with anyone outside of the research team.
 - Introduce researchers
 - Introduce participants
-
1. When you were first diagnosed with HIV, describe the feelings you had at the time?
Probe, shame, guilt, self-loathing, isolation, negative self-image
 2. What do you think other people think about HIV-positive people?
 3. What are your biggest fears related to your being HIV-positive?
 4. What do you understand what we mean by self-stigma? What is your experience of self-stigma?
 5. What do you hope to get from this course 'We are the Change' – inquiry-based stress reduction

Focus Group Discussion Guide (Post-Programme)

Introductory notes: Thank you for agreeing to take part in this discussion to ask you to reflect on your experience of the programme. If it's okay with you, we will record the session so that we can type up the session later. All information will be confidential and anonymised and will not be shared with anyone outside of the research team.

1. If you had to describe what you got out of this course, what would you say?
2. What changes, if any did you experience in your daily life as a result of this programme?
Probe: among family, friends, work, social life
3. What changes did you experience, if any, about how you view and feel about yourself?
4. What did you learn about self-stigma?
5. What worked really well in this course?
Probe: length, topics covered, format, facilitators, homework, physical space, support, books/ipods
6. What did not work well in this course?
Probe: length, topics covered, format, facilitators, homework, physical space, support books/ipods
7. What other topics would you like to see covered in this course?
8. What would you do differently if we were doing the course again – what could be improved or changed?
9. How best could this course be delivered to others in Zimbabwe?
Probe: how can it be rolled out, local facilitators, within peer support groups etc.
10. What one word would you use to describe this course?

One-on-one Interview Guide (post-programme)

Introductory notes: Thank you for agreeing to take part in this conversation to ask you to reflect on your experience of the programme. If It's okay with you, we will record the session so that we can type up the session later. All information will be confidential and anonymised and will not be shared with anyone outside of the research team.

1. If you had to describe what you got out of this course, what would you say?
2. What changes, if any did you experience in your daily life as a result of this programme? Probe: among family, friends, work, social life

Please give specific examples

3. What changes did you experience, if any, about how you view and feel about yourself?

After initial response, ask specifically about disclosure, about what it means to live with HIV, about sex and sexuality, about body, about illness and about death

4. What did you learn about self-stigma?
5. What worked really well in this course?

Probe: length, topics covered, format, facilitators, homework, physical space, support, books/ipods

6. What did not work well in this course?

Probe: length, topics covered, format, facilitators, homework, physical space, support books/ipods

7. What would you do differently if we were doing the course again – what could be improved or changed?
8. What other topics would you like to see covered in the course?
9. How best could this course be delivered to others in Zimbabwe ?

Probe: how can it be rolled out, local facilitators, within peer support groups etc

10. What one word would you use to describe this course?

S3: S

available upon request

S : S

available upon request

S5: List of categories, themes, and sub-themes.

CATEGORY	THEME	SUB-THEME
Guilt	Blame	Blame from others
		Blame from self
		Blaming others
		Anger
		Pessimism & negative attitudes
		Suspicion & mistrust
		Disappointment
	Forgiveness	Forgiving others
		Forgiving self
	Hate	Hate from others
		Hatred of others
		Hatred of self
		Stigmatisation
Disbelief	Surprise & shock	
Shame	Shaming by others	
	Being ashamed of self	
Worthlessness	Reduced worth by others	Rejection
	Feeling worth less than others	
Negative perceptions of others	Perceptions of PLHIV	
	Perceptions of HIV itself	
Restricted agency	Work/education/family/other	Cannot work/ attend education
		Fired from work
		Passed over for work
		Having children/a family
		Travel
		Building house/building on land
	Financial	Need money to pay for drugs, food etc.
Hopelessness	No hope for the future	
	Cannot go on living	
Fearfulness	Disclosure	Afraid of what others will think
		Afraid of loss of income
		Afraid for family/ children/ dependents
	Health	Worried about dying
		Worried about medication effects
		Worried about other illnesses
		Fear of contagion
	Fear for future	Worried about children if dying
		Worried about security of medication supply
Feeling down & depression	Depressed because of HIV	
	Depressed because of what others have said	
	Grief & loss	
Health & physical wellbeing	Physical difficulties	
	Self-image	Physical appearance
	Self-harm	Alcohol & drugs
		Destructive behaviour
	Sexual issues	Lack of intimacy
		Lack of spontaneity
		Lack of pleasure
Coping strategies	Acceptance	
	Personal networks	Support from others
		Support from family
		Giving support to others
	Increased agency	Affirmative action
		Desire to improve
		Education & knowledge
	Self-support	Positive mentality
		Self-worth
		Overcome negative internal thoughts
Relationships	Improved communication with family	
	Improved communication with others	
General dimensions	Stress	
	Change	

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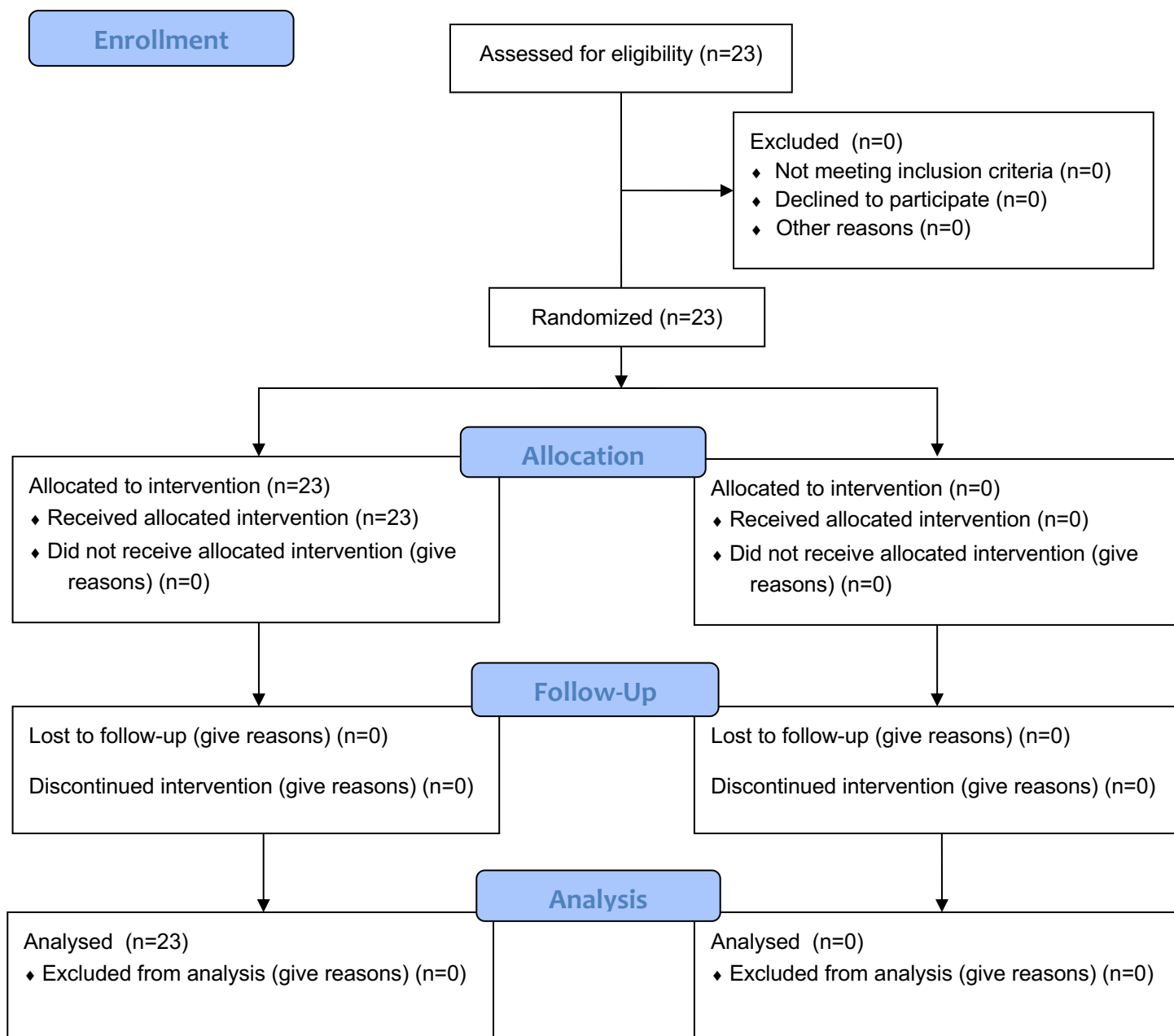
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CONSORT

TRANSPARENT REPORTING of TRIALS

CONSORT 2010 Flow Diagram



TREND Statement Checklist

Paper Section/ Topic	Item No	Descriptor	Reported?	
				Pg #
Title and Abstract				
Title and Abstract	1	• Information on how unit were allocated to interventions	Y	2
		• Structured abstract recommended	Y	2
		• Information on target population or study sample	Y	2
Introduction				
Background	2	• Scientific background and explanation of rationale	Y	3-10
		• Theories used in designing behavioral interventions	Y	3-10
Methods				
Participants	3	• Eligibility criteria for participants, including criteria at different levels in recruitment/sampling plan (e.g., cities, clinics, subjects)	Y	14
		• Method of recruitment (e.g., referral, self-selection), including the sampling method if a systematic sampling plan was implemented	Y	14
		• Recruitment setting	Y	14
		• Settings and locations where the data were collected	Y	12
Interventions	4	• Details of the interventions intended for each study condition and how and when they were actually administered, specifically including:		
		○ Content: what was given?	Y	8-10
		○ Delivery method: how was the content given?	Y	8-10
		○ Unit of delivery: how were the subjects grouped during delivery?	Y	10
		○ Deliverer: who delivered the intervention?	Y	10
		○ Setting: where was the intervention delivered?	Y	10
		○ Exposure quantity and duration: how many sessions or episodes or events were intended to be delivered? How long were they intended to last?	Y	10
		○ Time span: how long was it intended to take to deliver the intervention to each unit?	Y	10
○ Activities to increase compliance or adherence (e.g., incentives)	Y	10		
Objectives	5	• Specific objectives and hypotheses	Y	6-8
Outcomes	6	• Clearly defined primary and secondary outcome measures	Y	12
		• Methods used to collect data and any methods used to enhance the quality of measurements	Y	12-13
		• Information on validated instruments such as psychometric and biometric properties	Y	13
Sample Size	7	• How sample size was determined and, when applicable, explanation of any interim analyses and stopping rules	N/A	N/A
Assignment Method	8	• Unit of assignment (the unit being assigned to study condition, e.g., individual, group, community)	Y	14-15
		• Method used to assign units to study conditions, including details of any restriction (e.g., blocking, stratification, minimization)	N/A	N/A
		• Inclusion of aspects employed to help minimize potential bias induced due to non-randomization (e.g., matching)	N/A	N/A

TREND Statement Checklist

Blinding (masking)	9	<ul style="list-style-type: none">Whether or not participants, those administering the interventions, and those assessing the outcomes were blinded to study condition assignment; if so, statement regarding how the blinding was accomplished and how it was assessed.	Y	13
Unit of Analysis	10	<ul style="list-style-type: none">Description of the smallest unit that is being analyzed to assess intervention effects (e.g., individual, group, or community)	Y	12-14
		<ul style="list-style-type: none">If the unit of analysis differs from the unit of assignment, the analytical method used to account for this (e.g., adjusting the standard error estimates by the design effect or using multilevel analysis)	N/A	N/A
Statistical Methods	11	<ul style="list-style-type: none">Statistical methods used to compare study groups for primary methods outcome(s), including complex methods of correlated data	Y	13
		<ul style="list-style-type: none">Statistical methods used for additional analyses, such as a subgroup analyses and adjusted analysis	N/A	N/A
		<ul style="list-style-type: none">Methods for imputing missing data, if used	N/A	N/A
		<ul style="list-style-type: none">Statistical software or programs used	Y	13-14
Results				
Participant flow	12	<ul style="list-style-type: none">Flow of participants through each stage of the study: enrollment, assignment, allocation, and intervention exposure, follow-up, analysis (a diagram is strongly recommended)		
		<ul style="list-style-type: none"><ul style="list-style-type: none">Enrollment: the numbers of participants screened for eligibility, found to be eligible or not eligible, declined to be enrolled, and enrolled in the study	Y	14
		<ul style="list-style-type: none"><ul style="list-style-type: none">Assignment: the numbers of participants assigned to a study condition	Y	14
		<ul style="list-style-type: none"><ul style="list-style-type: none">Allocation and intervention exposure: the number of participants assigned to each study condition and the number of participants who received each intervention	Y	14
		<ul style="list-style-type: none"><ul style="list-style-type: none">Follow-up: the number of participants who completed the follow-up or did not complete the follow-up (i.e., lost to follow-up), by study condition	Y	12,14
		<ul style="list-style-type: none"><ul style="list-style-type: none">Analysis: the number of participants included in or excluded from the main analysis, by study condition	Y	14
		<ul style="list-style-type: none">Description of protocol deviations from study as planned, along with reasons	N/A	N/A
Recruitment	13	<ul style="list-style-type: none">Dates defining the periods of recruitment and follow-up	Y	14
Baseline Data	14	<ul style="list-style-type: none">Baseline demographic and clinical characteristics of participants in each study condition	Y	15
		<ul style="list-style-type: none">Baseline characteristics for each study condition relevant to specific disease prevention research	N/A	N/A
		<ul style="list-style-type: none">Baseline comparisons of those lost to follow-up and those retained, overall and by study condition	N/A	N/A
		<ul style="list-style-type: none">Comparison between study population at baseline and target population of interest	N/A	N/A
Baseline equivalence	15	<ul style="list-style-type: none">Data on study group equivalence at baseline and statistical methods used to control for baseline differences	N/A	N/A

TREND Statement Checklist

Numbers analyzed	16	<ul style="list-style-type: none"> Number of participants (denominator) included in each analysis for each study condition, particularly when the denominators change for different outcomes; statement of the results in absolute numbers when feasible 	Y	14,16
		<ul style="list-style-type: none"> Indication of whether the analysis strategy was “intention to treat” or, if not, description of how non-compliers were treated in the analyses 	N/A	N/A
Outcomes and estimation	17	<ul style="list-style-type: none"> For each primary and secondary outcome, a summary of results for each estimation study condition, and the estimated effect size and a confidence interval to indicate the precision 	Y	16-17
		<ul style="list-style-type: none"> Inclusion of null and negative findings 	Y	16-17
		<ul style="list-style-type: none"> Inclusion of results from testing pre-specified causal pathways through which the intervention was intended to operate, if any 	N/A	N/A
Ancillary analyses	18	<ul style="list-style-type: none"> Summary of other analyses performed, including subgroup or restricted analyses, indicating which are pre-specified or exploratory 	N/A	N/A
Adverse events	19	<ul style="list-style-type: none"> Summary of all important adverse events or unintended effects in each study condition (including summary measures, effect size estimates, and confidence intervals) 	N/A	N/A
DISCUSSION				
Interpretation	20	<ul style="list-style-type: none"> Interpretation of the results, taking into account study hypotheses, sources of potential bias, imprecision of measures, multiplicative analyses, and other limitations or weaknesses of the study 	Y	26-29
		<ul style="list-style-type: none"> Discussion of results taking into account the mechanism by which the intervention was intended to work (causal pathways) or alternative mechanisms or explanations 	Y	26-29
		<ul style="list-style-type: none"> Discussion of the success of and barriers to implementing the intervention, fidelity of implementation 	Y	28-29
		<ul style="list-style-type: none"> Discussion of research, programmatic, or policy implications 	Y	28-29
Generalizability	21	<ul style="list-style-type: none"> Generalizability (external validity) of the trial findings, taking into account the study population, the characteristics of the intervention, length of follow-up, incentives, compliance rates, specific sites/settings involved in the study, and other contextual issues 	Y	29
Overall Evidence	22	<ul style="list-style-type: none"> General interpretation of the results in the context of current evidence and current theory 	Y	28-29

From: Des Jarlais, D. C., Lyles, C., Crepaz, N., & the Trend Group (2004). Improving the reporting quality of nonrandomized evaluations of behavioral and public health interventions: The TREND statement. *American Journal of Public Health*, 94, 361-366. For more information, visit: <http://www.cdc.gov/trendstatement/>

12. Appendix C: Supplementary Material for Chapter 4

Interview Guide

(Note to interviewer: Questions in bullet form are meant to be probes. They do not have to be asked as they appear here. Rather, phrase and order questions according to the flow of interview).

Introduction/Demographics

- Tell me a little bit about yourself and where you grew up?
 - Age
 - Married, unmarried, partner?
 - Work or school?
- How long have you been involved with Africaid?
- How would you describe yourself to other people?

I am now going to ask you some questions about your experiences living with HIV

General questions about living with HIV

- How long have you known your HIV status?
- Describe what it is like living with HIV
 - How has your HIV status effected your daily life?
- Have you disclosed to your friends and family about your status?
 - Why or why not?
 - If no: Do you normally try to keep your HIV status a secret from others?
 - Why or why not?
 - What has been your experience when you either tell people or they find out you are living with HIV?

Awareness

- How do you think society perceives people living with HIV?
 - How do those perceptions make you feel?
 - Are these perceptions different for men and women?
- What are some of the challenges you or other young adults face living with HIV?
 - Do you think that young adults face challenges around HIV that are different than people living with HIV who are older or younger?

Agreement

- How does your HIV status make you feel?
 - Do you think your age or gender influence those feelings?
- Did finding out that you are living with HIV change your perception of yourself at all?
 - If yes: How so?
 - Probe: Has that perception changed over time? Child versus now adult?

Application

- We are going to try an exercise that you can either write down or think about. I will give you a few minutes to complete the sentence: I am HIV positive and that means that...
- How do these feeling and beliefs about yourself influence how you make life decisions?
- What are your current hopes and goals for the future?
 - Has your feeling towards yourself or your HIV status impacted these goals?
- How has living with HIV impacted your friendships or relationships?

Recommendations

- What do you think could be done to help people cope with their HIV status better or reduce self-stigma?

Conclusion

- Is there anything else you wish to tell me that we have not covered?

13. Appendix D: Supplementary Material for Chapter 6

Developing and piloting an intervention to support adolescent and young people living with HIV in Zimbabwe on the journey from self-stigma to self-worth

Principal Investigator: Vongai Munatsi

FGD & in-depth interview guide: Young people

(Note to interviewer: Questions in italics are meant to be probes. They do not have to be asked as they appear here. Rather, phrase and order questions according to the flow of the discussion).

Understanding of the program

- What do you think the course is trying to achieve?

Previous self-stigmatization

- What was it like before taking this course? *Probe on how they thought about HIV, self, body etc.*

Overall experiences in program

- Tell me about your experience in the Wakakosha program.
- What did you like and dislike about the program? *Why?*
- What did you learn/get from it?

Changes in thinking about self and HIV

- What changed or stayed the same about how you think about yourself after taking part in this program?
- What changed or stayed the same about how you think about HIV after taking part in this program?

Changes in self-stigma and shame

- What, if anything has changed about self-stigma and shame - *[probe here for examples of increased self-worth - examples of doing things before they would not have done before, for instance, dressing better, enrolling for a course, approaching someone with confidence self-agency, self-esteem, self-love etc)*

Intervention components

- Which components worked well or did not work well? *Please explain.*
- Can you tell me about the music curriculum and training component of the program. *How you feel about it, would you recommend it for others, then why / why not? etc, then probe for (express your emotions, helped you heal etc)*

Intervention delivery

- What do you think about the way the program was delivered?
- *What worked well and what did not work?*
- Can you comment on the online sessions? *How similar or different were they to the face to face session? Which delivery mode do you prefer? Why? If the course were to be offered again, which mode should be used? Why?*

Program recommendations

- If the course were to be offered elsewhere, what should be maintained or changed? *Why?*
- Who should deliver the program? *Why?*
- Anything else they want to say about the course?

: S

M

SM : Search strategy

V5 -Final

“Intervention*” OR “Programme” OR “Programmes” OR “Program” OR “Programs” OR “Therapy” OR “therapies” OR “Group” OR “Support” OR “Session” OR “sessions”

"self-stigma" OR "internal stigma" OR “internalised stigma” OR “internalized stigma” OR "felt stigma" OR "core beliefs" OR "self-agency" OR “self-acceptance” OR “self-love” OR “guilt” OR “personal stigma” OR “self-esteem” OR “self-respect” OR “self-image” OR “self-perception” OR “self-shame” OR “self-worth” OR “worthlessness” OR “self-blame” OR “disgrace” OR “self-judge”

“HIV” OR “human immunodeficiency virus” OR “acquired immunodeficiency syndrome” OR “AIDS” OR “human immune-deficiency virus” OR “acquired immune-deficiency syndrome” OR “people living with HIV AIDS” OR “PLWHA” OR “PLHIV” OR “HIV patients” OR “HIV-infections” OR “HIV-positive” OR “people with HIV”

SM2: The TIDieR (Template for Intervention Description and Replication) Checklist*:

Information to include when describing an intervention and the location of the information

Item number	Item	Where located **	
		Primary paper (page or appendix number)	Other [†] (details)
1.	BRIEF NAME Provide the name or a phrase that describes the intervention.	Table 1 & 2	
2.	WHY Describe any rationale, theory, or goal of the elements essential to the intervention.	Table 2	
3.	WHAT Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	SM5 Quality review	
4.	WHO PROVIDED Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	Table 2&3	
5.	HOW For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	Table 3	
6.	WHERE Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	Table 3	

7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	Table 2	
WHEN and HOW MUCH			
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	Table 3	
TAILORING			
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	Table 3	
MODIFICATIONS			
10.*	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	Table 3	
HOW WELL			
11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	Table 2 & Table 4	
12.*	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	Table 2	

**** Authors** - use N/A if an item is not applicable for the intervention being described. **Reviewers** – use ‘?’ if information about the element is not reported/not sufficiently reported.

† If the information is not provided in the primary paper, give details of where this information is available. This may include locations such as a published protocol or other published papers (provide citation details) or a website (provide the URL).

‡ If completing the TIDieR checklist for a protocol, these items are not relevant to the protocol and cannot be described until the study is complete.

* We strongly recommend using this checklist in conjunction with the TIDieR guide (see *BMJ* 2014;348:g1687) which contains an explanation and elaboration for each item.

* The focus of TIDieR is on reporting details of the intervention elements (and where relevant, comparison elements) of a study. Other elements and methodological features of studies are covered by other reporting statements and checklists and have not been duplicated as part of the TIDieR checklist. When a **randomised trial** is being reported, the TIDieR checklist should be used in conjunction with the CONSORT statement (see www.consort-statement.org) as an extension of **Item 5 of the CONSORT 2010 Statement**. When a **clinical trial protocol** is being reported, the TIDieR checklist should be used in conjunction with the SPIRIT statement as an extension of **Item 11 of the SPIRIT 2013 Statement** (see www.spirit-statement.org). For alternate study designs, TIDieR can be used in conjunction with the appropriate checklist for that study design (see www.equator-network.org).

SM3: Data Extraction Template

Background

Study ID

Title

First Author

Year

Journal

Describing intervention

Specific focus on reducing self-stigma - Self-stigma, self-worth, self-esteem, self/personal agency, QoL, and others (Autonomy, mastery, etc.)

Type of intervention – Cognitive, peer support, etc

Level of Intervention – Individual, family, community, society

The number of people included

Delivery of intervention – Trained or untrained

Length and frequency of intervention/Dose

Components of Intervention – Framework 2012, Ecological Model

Country – Continent – WHO regions

Setting – Online, home-based, clinic, urban, rural?

Population – adult, adolescence, women, men, mixed

Evaluation

Type of Evaluation – Qualitative (Case studies, QI, Action research, descriptive, ethnographic) or quantitative (RCT, Longitudinal, cross-sectional, etc.) or Mixed-methods

The methodology described in detail – described recruitment, data collection, and data analysis – Yes or No

The scale/measure used – group by different scales

Reported impact on Self-stigma (Self-stigma, self-worth, self-esteem, self/personal agency, QoL, and others (Autonomy, Mastery, etc.) – don't put a lot of detail – no need for statistics but include effect size

Other reported impacts – disclosure, employment, depression, education, etc

Timing of evaluation – is it baseline, follow-up?



SM4: PRISMA 2020 Checklist

Section and Topic	Item	Checklist item	Location where item is reported
TIT			
Title	1	Identify the report as a systematic review.	Title Page
ATAAT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Appendix
RTT			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 5
ST			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 7
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 7/8
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 7/8
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 7-26
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 7-26
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 7 - 8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item 5)).	Page 7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 7 -10
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 7-10
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 7-10
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Page 7-10
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A



PRISMA 2020 Checklist

Section and Topic	Item	Checklist item	Location where item is reported
Abstract			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Page 9
Study characteristics	17	Cite each included study and present its characteristics.	Page 10-26
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 29
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 10-26
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Page 29
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Page 10-26
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Page 29
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Page 10-26
Discussion			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 26-30
	23b	Discuss any limitations of the evidence included in the review.	Page 29
	23c	Discuss any limitations of the review processes used.	Page 29
	23d	Discuss implications of the results for practice, policy, and future research.	Page 4-30
Tables, Figures, and Additional Materials			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 29
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendices linked in paper after references,



PRISMA 2020 Checklist

Specific Checklist for Abstract reporting

Section and Topic	Item #	Checklist item	Reported (Yes/No)
TITLE			
Title	1	Identify the report as a systematic review.	Yes
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Yes
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	No
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Yes
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	No
Synthesis of results	6	Specify the methods used to present and synthesise results.	Yes
RESULTS			
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Yes
Synthesis of results	8	Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).	Yes
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	No
Interpretation	10	Provide a general interpretation of the results and important implications.	Yes
OTHER			
Funding	11	Specify the primary source of funding for the review.	N/A
Registration	12	Provide the register name and registration number.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <http://www.prisma-statement.org/>

SM5: Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP 2022)										
	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?
Publication	Q1: Was there a clear statement of the aims?	Q2: Is a qualitative methodology appropriate?	Q3: Was the research design appropriate to address the aims of the research?	Q4: Was the recruitment strategy appropriate to the aims of the research?	Q5: Was the data collected in a way that addressed the research issue?	Q6: Has the relationship between researcher and participants been adequately considered?	Q7: Have ethical issues been taken into consideration?	Q8: Was the data analysis sufficiently rigorous?	Q9: Is there a clear statement of findings?	Q10: How valuable is the research?
Barrington et al, 2020 (mixed methods)	Yes 'The purpose of this article is to describe acceptability and initial outcomes of the adapted intervention and to explore intervention experiences to identify recommendations for improvement.	Yes - assessed intervention experiences in qualitative in-depth interviews with a subgroup of 20 pilot participants at the end of the 12-month implementation period	Yes - mixed methods	Don't know - interviews with 20 participants but 30 were in the study - don't indicate how these were selected and doesn't indicate how the original 30 were recruited - seem to have connections with local organisations but not made explicit.	Unclear - a cisgender researcher interviewing transgender women - may have been better to use a peer interviewer though results show peer navigators are not accepted well.	No had trained cisgender Dominican woman with a background in psychology but didn't include relationship with authors of article	No - No mention of ethics	No - Not very detailed - All interviews were audio-recorded, transcribed verbatim, and analyzed in Spanish; illustrative quotes were translated to English for inclusion in this article; first wrote an analytic summary to summarize each participant's overall intervention experience, then analyzed data for each intervention component, coding for perceived impact, strengths, challenges, and recommendations; used a matrix to summarize and compare coding outputs across participants	Yes - Has a number of themes presented	Yes - Useful to complement the survey. ' Participants emphasized that trust and being treated with respect allowed them to relax and improve their self-esteem. Limited trust and cohesion among trans women, however, limited more extensive engagement with peer navigation and community mobilization components' but main qual analysis was about evaluating the intervention
Bartels et al, 2022	Yes - 'The aims of our study were to: (1) describe the changes experienced by recently diagnosed or re-engaged individuals during their first year of HIV care and (2) determine if and how an emotional well-being intervention contributed to these changes'	Yes - exploring experiences	Yes - indepth interviews	Don't know - unclear where particiaptns were recruited from, though outline inclusion criteria well - also not sure why 10 were chosen for interviewing from sample of 113	Yes	Yes	Yes	Yes - very clear on analysis process	Yes - Has a number of themes presented	Can be used to assess whether intervention works and changes that can be made - changes in views of self and diagnosis perceptions, improved physical and mental health, increased interest in sex and relationships, and a clarification of their life goals, as well as acceptance, improved self-esteem, and gaining self-efficacy for managing life with HIV

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP 2022)										
	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?
Publication	Q1: Was there a clear statement of the aims?	Q2: Is a qualitative methodology appropriate?	Q3: Was the research design appropriate to address the aims of the research?	Q4: Was the recruitment strategy appropriate to the aims of the research?	Q5. Was the data collected in a way that addressed the research issue?	Q6. Has the relationship between researcher and participants been adequately considered?	Q7. Have ethical issues been taken into consideration?	Q8. Was the data analysis sufficiently rigorous?	Q9. Is there a clear statement of findings?	Q10. How valuable is the research?
Batchelder et al, 2020 (Mixed methods)	No - quite far into the article it does state 'While the aim of this proof-of-concept study was to assess preliminary feasibility and acceptability of this intervention in this hard-to-reach population, we obtained several pre and post self-report measures of HIV self-care (e.g., viral load and ART adherence' but has a lot more detail included than this.	Yes - in terms of acceptability	Yes - could have included other data collection	Yes - indicates gatekeeper and also practitioners recruitment process. Unclear on sample size	Yes - exit interviews (n=8)	No - not details given	Yes - in terms of conduct and ethics committee approval	Don't know - no detail	Yes - presents a number of themes	Yes - useful in terms of conducting trial - Qualitative component was a proof of concept stage so organised in terms of perceived need, content. Exit interviews with participants- participants reported improved self-care behaviours, learning about and utilising compassionate self-talk, and changing the way they thought about themselves which included experiencing less self-judgement
Ferris-France et al, 2019 (Mixed methods)	Yes - The primary objective of this uncontrolled pilot study was to examine the potential role of the IBSR intervention in helping people living with HIV to overcome self-stigma and associated states	Yes - mixed methods	Yes - part of mixed methods	Yes - recruitment clearly explained	Yes - interviews and FGD as well as scales	Yes - relationship between the researchers explained and one group acted as gatekeeper for recruitment	Yes - ethics committee approval	Yes - clearly outlined	Yes - themes included	Yes - will inform changed in intervention - participants reported improvements including lessened fears around disclosure of their HIV status, reduced feelings of life limitations due to HIV, and greater positive mentality

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP 2022)										
	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?
Publication	Q1: Was there a clear statement of the aims?	Q2: Is a qualitative methodology appropriate?	Q3: Was the research design appropriate to address the aims of the research?	Q4: Was the recruitment strategy appropriate to the aims of the research?	Q5. Was the data collected in a way that addressed the research issue?	Q6. Has the relationship between researcher and participants been adequately considered?	Q7. Have ethical issues been taken into consideration?	Q8. Was the data analysis sufficiently rigorous?	Q9. Is there a clear statement of findings?	Q10. How valuable is the research?
Ferris-France et al, 2023	Yes - to provide a deeper understanding of any changes, how the intervention worked and what could be improved	Yes - exploring understandings, what worked and what did not work	Yes - interviews and FGD	Yes recruited facilitators, coaches and particiaptns of the intervention	Yes - local researchers & conducted in local language	Yes - part of ongoing interventions and working with a local NGO. However, not explicit on researcchers who conducted the data collection - one though also mentioned as designer of currirulum.	Yes - ethical clearance obtained from Medical Research Council of Zimbabwe	Yes, data analysis process and validation with participants conducted. no code book provided,	Yes clear themes identified and described	Yes - these results will help adapt next iteration of the intervention
Flickinger et al, 2018 (mixed methods)	Yes - The objectives of this study were to understand the discussion of stigma within the virtual community of the Community Message Board (CMB) and to evaluate change in participants' stigma levels after 12 months of follow-up.	Yes - analysing content of message board	Yes - part of mixed methods study	Yes - recruitment process explained	Yes - content analysis	No - not explained	No - No mention of ethics	Yes - cearly outlined how messages were analysed	Yes - themes included	Yes - informed next stage of research - message analysis involved categorising according to content and assigning frequency to posts. Gives example of enacted stigma/discrimination; self-stigma; positive threads (expressing companionship, positive thinking/purpose , blessings/ affirming God's love, and the will to overcome) but does not relate this to a time period such as pre and post intervention
Harding et al, 2019 (RCT)	Yes - This study aimed to evaluate a theory-based intervention compared to usual care for orphaned children on HIV treatment in Tanzania, in terms of feasibility, acceptability and preliminary outcomes	Yes	Yes - FGD nested in an RCT	Yes	Yes - but only 1 FGD	No - not explained	Yes - ethics committee approval	No - very brief performed by one author and reviewed by another	Yes - some discussion included but limited	Yes - nested part of RCT

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP 2022)										
	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?
Publication	Q1: Was there a clear statement of the aims?	Q2: Is a qualitative methodology appropriate?	Q3: Was the research design appropriate to address the aims of the research?	Q4: Was the recruitment strategy appropriate to the aims of the research?	Q5: Was the data collected in a way that addressed the research issue?	Q6: Has the relationship between researcher and participants been adequately considered?	Q7: Have ethical issues been taken into consideration?	Q8: Was the data analysis sufficiently rigorous?	Q9: Is there a clear statement of findings?	Q10: How valuable is the research?
Pichon et al, 2022	Yes - The purpose of this paper is to explain how PLWH in the U.S. South used Photovoice to communicate stigmatizing lived experiences and contextualize their intersection with multi-level sources of support.	Yes - used interviews and FGDs	Yes as looking at lived experiences	Yes	Yes	Yes - long term relationship with gatekeeper organisation	Yes - was exempt as non-human research?? Though ethics of using photovoice for this vulnerable group was discussed	Yes - very well explained	Yes	Yes
Skinta et al, 2015 (Mixed methods)	Yes The aim of the current study is to describe one example of the integration of ACT and CFT techniques, as well as to describe the response of participants to this pilot group. The session-by-session outline provided below specifically notes how concepts and common interventions within these approaches were described or implemented to be specific to the experience of persons living with HIV.	Yes - The final assessment appointment included a qualitative interview regarding the acceptability of the intervention as well as an opportunity for the participant to provide feedback on whether he experienced this intervention as useful.	Yes - interviews with different scale measurement	No - limited by time in terms of recruitment	No as details of how the interview was conducted are not given	No	No - No mention of ethics	No - no details given on how interview was analysed	No - limited	Not organised into themes - quotes from one or two participants

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP 2022)										
	Section A: Are the results valid?						Section B: What are the results?			Section C: Will the results help locally?
Publication	Q1: Was there a clear statement of the aims?	Q2: Is a qualitative methodology appropriate?	Q3: Was the research design appropriate to address the aims of the research?	Q4: Was the recruitment strategy appropriate to the aims of the research?	Q5. Was the data collected in a way that addressed the research issue?	Q6. Has the relationship between researcher and participants been adequately considered?	Q7. Have ethical issues been taken into consideration?	Q8. Was the data analysis sufficiently rigorous?	Q9. Is there a clear statement of findings?	Q10. How valuable is the research?
Tsai et al, 2016	Yes - the goal was to explore the intervention's perceived impacts on HIV stigma and to understand the mechanisms through which any stigma-related changes may have occurred.	Yes - looking at mechanisms	Yes - interviews	Yes but note it is described elsewhere	Yes - locally trained research assistants used	Yes - part of ongoing collaboration	Yes - ethical clearance, registration of trial and local context taken into account	Yes - detailed account of analysis given	Yes - themes included and discussed	Yes - longitudinal study showing positive benefits - participants in the treatment arm described less stigma, voiced positive changes in confidence and self-esteem and observed that other community members perceived them as active, economically productive, and contributing citizens
Tshabalala et al, 2011 (Mixed methods)	Yes the aim was to develop an intervention and evaluate it	Yes looking at experiences of women living with HIV with respect to stigma and coping mechanisms.	Yes - interviews and analysis of therapy sessions	Yes - purposive sampling technique. Nurses of a Wellness Clinic referred to the researcher five HIV-positive African women who were receiving treatment from the clinic and who experienced difficulties in dealing with stigma.	Yes - in local language	No, but assume link was with the clinic and the clinic had the link with the participants	Yes, ethically approved by the Ethics Committee of the Faculty of Humanities, University of Pretoria and the Provincial Government of Mpumalanga.	Yes, though limited description and no coding book provided	Yes - themes outlined	Yes - helped design and evaluate an intervention

Risk of bias (RoB-2) revised tool (Higgins et al., 2011)								
		Selection		Performance	Detection	Attrition	Reporting	Other
		Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Anything else
Barroso et al., 2014	100 participants (control 49; 51 intervention)	yes	Concealment before allocation	Yes	Yes	87 analysed (8 intervention; 3 control lost to follow up)	All results reported	All participants got an iPod
Bryant, et al 2023	130 black women living with HIV (64 in control; 66 in intervention)	Yes - just state they were randomly assigned but no description of the process	Yes - were working on computer so would have been hard to know if each person was doing the same as the other	Yes - as working on their own would have been hard to know who was in each group	Yes - survey done on computer as post-test	Not mentioned, but as it was a once off event all would have been expected to complete	All results reported	Initially recruited via Facebook, but then used a survey software platform that provides research panels. Those in control were able to watch the short video if they wanted to after the intervention group had completed their post test
Denison et al., 2020	273 participants (137 intervention; 136 control)	Yes but purposive sampling of study sites	Concealment before allocation	Randomised but once allocated received the intervention so would know which group they were in	unclear - some tests part of routine visits which would be known to HCP and client, but did not state if other results were shared, such as self stigma scores	32 lost to follow up (11 intervention; 21 control)	All results reported	HCP felt their care changed due to being involved in intervention and therefore the usual care given to the control group may have changed
Denison et al., 2022	100 participants	yes	Concealment before allocation	Not after allocation. .	Not mentioned	1 lost to follow up	All results reported	Reported cross contamination between control and intervention in paper
Erlen et al, 2001	20 participants (10 each arm)	Yes - but allocated by investigator - no criteria given	Concealment before allocation	Intervention activities different to standard care so once allocated not blinded	Intervention activities different to standard care so once allocated not blinded	3 lost to follow up (presume from intervention group)	All results reported	Convenience sample from 3 clinics and randomised by investigator with no process explained.
Harding et al., 2019	48 participants (24 intervention and 24 waitlist control)	yes but sequence generation not mentioned - just allocated by researcher	yes to children	yes	yes	1 dropped out but was replaced	All results reported	
Nestadt et al., 2019	88 families (45 intervention; 43 standard care)	yes - process explained	Concealment before allocation	Intervention activities different to standard care so once allocated not blinded	Intervention activities different to standard care so once allocated not blinded	No attrition	All results reported	Relied on self report measures
Nyamathi et al., 2013	68 participants (34 each arm)	Notes cluster randomised	Unclear as process of randomisation not included	Yes	Yes except for some blood results	No attrition	All results reported	Rural villages only - randomisation process not detailed
Peltzer et al., 2018	699 participants (357 standard care; 342 enhanced care)	Just notes that clinics were randomised	Unclear as process of randomisation not included	Yes	Yes	Lost 16 due to technical difficulties at the start (n=683), 228 attrition, so 455 completed follow-up assessment	All results reported	Little detail on randomisation process and how lost to follow-up were divided across control or intervention
Yigit et al., 2020	372 participants (186 control and intervention)	yes	Concealment before allocation	Until after baseline	Don't know	Final survey 314 (155 intervention; 159 control)	All results reported	Recruited all from well-off centre and didn't adjust for attention control conditions

Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) (Tufanaru et al., 2019)									
Authors	1. Is it clear in the study what is the ‘cause’ and what is the ‘effect’ (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?
Edwards et al, 2009	Yes Ryff’s Psychological Well-being Scale (PWB) = the dependent variable	No - inpatients in hospital compared to a convenience sample of university studenys	No	Yes 30 inpatients formed an experimental group which received the intervention as treatment condition or independent variable, while the control group, which consisted of 11 students, was simply pre- and post-tested without any intervention.	Ryff Psychological Well-being Scale	No mention of drop outs	Both groups were pre-tested and post tested	Yes, appropriate scales used	Yes, analyzed using repeated measure analysis of variance
Fuster-Ruizde et al 2016	Yes The dependent variables were perception of stigma—enacted and internalized—, self-esteem, perception of selfefficacy, strategies used to cope with stigma—primary control, secondary control, and avoidance—and quality of life.	Yes, The contingency analyses (Pearson’s chisquare) and analysis of variance found no significant differences in any of the sociodemographic variables (p >.10) in the experimental and control groups	Yes, control recieved tratement as usual	non-equivalent control group and pre- and posttest was used- 221 people with HIV (164 intervention & 56 control)	Perceived stigma (1st edition: revised and reduced version (Bunn et al., 2007) of the Stigma Scale of Berger et al: 2nd ed: Battery of Psychological Predictors of Well-being and Quality of Life of People with HIV in Spain (Remor et al., 2012). These facets assess two dimensions of stigma: Enacted Stigma and Internalized Stigma) Self esteem; Perceived self-efficacy to cope with stigma; Quality of Life	yes difference explained	Yes all outcomes measured for both groups	Yes, appropriate scales used	Analysis of variance (MANOVAS and ANOVAS) was conducted to determine pretest differences and differential scores in both groups, and analysis of covariance (MANCOVAS and ANCOVAS) was performed to assess the efficacy of the program.
Harper et al, 2014	Yes	Fifty youth (28 male, 22 female; mean age = 19.24 years) newly diagnosed with HIV from four geographically diverse clinics participated in a onegroup pretest-posttest design study	N/A	No	Berger’s HIV Stigma Scale	completed assessments at baseline, post-intervention, and 3-month follow-up	Yes	Yes	Yes

Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) (Tufanaru et al., 2019)									
Authors	1. Is it clear in the study what is the ‘cause’ and what is the ‘effect’ (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?
Lennon-Dearing et al, 2019	yes	No - one-group pretest–posttest design	No	No	Rosenberg self-esteem scale (RSES); Other: Coping Self-Efficacy Scale (CSES) Patient Health Questionnaire	Don't know - 23 participated but 15 active throughout the whole process	N/A	Yes	Yes, Descriptive statistics were used to analyze the data from the three quantitative measures. Paired sample t-tests were run to analyze the data and look for trends.
Mathew et al, 2022	Yes	Yes, selected from same population group but no comparison of demographics given	Yes shorter intervention for control	a quasi-experimental non-equivalent control group design	Rosenberg’s self-esteem scale (RSES); general self-efficacy scale (GSE) (1995) by Ralf Schwarzer & Matthias Jerusalem	No loss to follow up	Yes all outcomes measrued for both groups	Yes, appropriate scales used	correlated t-test for self-esteem and Wilcoxon signed-rank test for self-efficacy scores
Mundell et al, 2011	Yes	recruited from four antenatal clinics in two townships	Women self selected for intervention	No	Center for Epidemiologic Studies Depression scale (CES-D, Radloff, 1977); Rosenberg Self-Esteem Scale (RSES) Modified version of the Brief COPE Multidimensional Social Support Inventory	Lost 23% to follow up (82) - 15 in intervention and 67 in non-intervention - followed up post test x 2	Yes	Yes	Adjusted regression analysis
Peterkin et al, 2013	Yes	No - one-arm, non-randomized intervention study, utilising pre- and post-measures	N/A	No	Rosenberg self-esteem scale (RSES) Impact of Event Scale Brief Symptom Inventory Short version of the Symptom Check List-90 Social Environment Scale Silencing the Self Scale Stanford Emotional Self-Efficacy Scale	For those who were lost to follow up dropped them from the study so in the end analysed results for those who completed pre and post questionnaires	N/A	Yes	paired t-tests

Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) (Tufanaru et al., 2019)									
Authors	1. Is it clear in the study what is the ‘cause’ and what is the ‘effect’ (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?
Rao et al, 2012	Yes	2 groups receiving the intervention were similar and recruited in the same way.	Both groups received same intervention	No	Stigma Scale for Chronic Illness	24 completed base line (13;11) - 12;9 completed post test 2; 12;7 completed post test 3	Yes stigma scale measured	Yes	Yes
Soro et al, 2021	Yes - effect on declared stigma, internalized stigma, depression and state anxiety and at follow-up trait anxiety	Yes, based on fact that people with more recent diagnosis are more likley to participate	Yes, control received treatment as usual, but weere wait listed for thereapy if they chose it.	Yes. quasi-experimental study with a non-equivalent control group and non-random assignment of participants to groups	A scale of stigma associated with HIV and AIDS. Beck Depression Inventory-II State-Trait Anxiety Inventory (STAI)	26 started and 18 completed and responded at 4 months	Outcomes on stigma, depression and anxiety are assessed and compared to a group of people with HIV who do not participate in the therapeutic intervention before treatment, at the end of treatment and four months after completion	Yes appropriate scales were used and described	Yes normality tests to evaluate the suitability of using parametric tests for the comparison of the dependent variables. Kolmogorov-Smirnov test with Lillefors correction of significance. Intra-group comparisons were made for the dependent variables between each of the three measurement moments through the Student t-test for related samples. The effect size was also calculated with Cohen's d Comparisons were made between the two groups using the Student t-test for independent samples and the effect size was calculated for the differences between the group
Suyanti et al, 2018	Yes	purposive sampling technique - 0 housewives living with HIV/AIDS. Two groups: group intervention 1 (logotherapy and ACT) and intervention 2 (logotherapy and FPE)	2 groups received some similar parts of intervention	No control - comparison group	Internalized Stigma of AIDS Tools		Yes all outcomes measrued for both groups	Yes	Univariate and bivariate analyses. Equality analysis was conducted using the chi-square test and independent t test, and the effects were analyzed using paired t test.

Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies (non-randomised experimental studies) (Tufanaru et al., 2019)									
Authors	1. Is it clear in the study what is the ‘cause’ and what is the ‘effect’ (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?
Vaughan et al, 1996	Yes - explains dependent and independed factors	Yes - all selected from the one site	Yes - a group life review intervention (n = 8), a traditional support group (n = 9), or a waiting list (n = 10).	Yes - 3 groups	compared on psychological measures of optimism, self-esteem, purpose in life, coping ability, psychological distress, and death anxiety. (Brief Symptom Inventory, Dealing With Illness-Coping Inventory, Purpose in Life test, Rosenberg Self-Esteem Scale, Life Orientation Test, and Death Anxiety Scale.)	Attrition was a serious problem - from 41 pretested to 27 completed (14 dropped out) - reported on 27.	Yes	Yes, appropriate scales used (	multivariate analyses of covariance (MANCOVAs) and analyses of covariance (ANCOVAs)

CASP Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2019)					
Authors	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Barrington et al, 2022	No. Conducted baseline and endline (12-months) surveys to compare HIV care and treatment outcomes and qualitative interviews to assess intervention experiences with a subsample	Two different questions: (i) describe acceptability and initial outcomes of the adapted intervention (ii) explore intervention experiences so methods appropriate for separate questions	Not really - quant explored the outcomes and the qual evaluated the experiences of the intervention	Addressing different questions	Quant: socio-behavioral surveys in Spanish to assess acceptability, intervention retention, and trends in HIV care and ART adherence. Qual: qualitative in-depth interviews (more detailed review included in this SM under qualitative studies review)
Batchelder et al, 2021	Yes - described as proof of concept study	Yes	Yes	Not really divergent but qual offering understanding on intervention and also likelihood to practice some of skills learned - complementary results	HIV and Abuse Related Shame Inventory (HARSI); Self-Compassion Scale CES-D Five Facet mindfulness Qual: interviews (more detailed review included in this SM under qualitative studies review)
Ferris France et al, 2019	Yes describes study as uncontrolled pilot study but does indicate it as a mixed methods study in the methods section	Yes	Yes	Yes - have discussion on gaps in understanding if focus only on quant/scales and need for indepth interviews to understand better	Internalised AIDS Stigma Scale (IASS) (Kalichman et al., 2008); the Center for Epidemiologic Studies Depression Scale (CES-D); HIV/AIDS Targeted Quality of Life Scale Qual good (FGD & interviews) (more detailed review included in this SM under qualitative studies review)
Flickinger et al, 2018	Yes - described as prospective mixed methods study	Yes, but qual and quant addressing different questions	Yes, quant built on qual	No as results were complementary - qual provided categories and quant related categories with stigma	Berger's HIV Stigma Scale (HSS) Qual: message analysis -(more detailed review included in this SM under qualitative studies review)
Skinta et al, 2015	No - mixes measuring self-stigma with evaluating the intervention. Stands out more as a quantitative uncontrolled intervention study.	No	No as the qual was on acceptability rather than the impact of the intervention	Qual and Quant Not reporting on the same themes/areas	Qual: quotes from one or two participants but mainly was to evaluate acceptability of programme rather than exploring self-stigma (more detailed review included in this SM under qualitative studies review) Quant: (Acceptance and Action Questionnaire–II; Internalised HIV Stigma Scale (Sayles et al., 2008);)
Tshabalala et al, 2011	Yes, described as a mixed methods design	Yes - qual was used to develop intervention and quant to assess its impact	Yes sequentially	Qual describes the experiences of stigma and help design the intervention, but quant looks at the impact	Qual - Interviews and FGD and analysis of therapy sessions (more detailed review included in this SM under qualitative studies review) Five psychometric instruments: The Brief Coping Scale (Carver, 1997). The Serithi Internalised Stigma Scale (Visser et al., 2008). Enacted Stigma (Visser & Makin, 2004). The Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1979) The Beck Depression Inventory-II (BDI-II) (Beck, Steer, & Brown, 1996)
Uys et al, 2009	described as multiple-case study design	Not really as qual focused on addressing different question on intervention description and quant on scales	Not really - more parallel studies on description and then impact separate	Not focusing on same topics so not divergent	HIV/AIDS Stigma Instrument–PLWA (HASI-P) Generalised self-efficacy scale (GSE) Rosenberg self-esteem scale (RSES) Qual: not discussed much

15. Appendix F: Paper Summaries

A study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland (Chapter 3)

Chapter 3 presented the first qualitative formative study aimed to identify core beliefs of people living with HIV as well as better understand the functions of self-stigma and coping strategies used to overcome it. In order to be able to design interventions that would reduce self-stigma, it is first important to understand what self-stigma is, how it manifests and why. Rather than focus on the levels of self-stigma which is what many studies to date have done (Kalichman et al., 2009, Simbayi et al., 2007, GNP+, 2023b), this study enhanced understanding of the core beliefs by first eliciting and identifying beliefs and then grouping them into four main categories identified during the analysis of disclosure, sexuality and sexual pleasure, self-perception and body, illness and death. These categories are consistent the wider literature on HIV-related self-stigma beliefs as can be seen in some of existing scales used to measure self-stigma (Berger et al., 2001) (Kalichman et al., 2009) and in two studies by the author, Chapter 5 and (Huber, 2019).

Erving Goffman believed stigma serves a purpose in society- social control - to maintain social norms and hierarchies (Goffman, 1963). The function of stigma is therefore to assign a socially discrediting label to individuals or groups, in this case PLHIV, which leads to their devaluation and exclusion from society (Goffman, 1963). This study found that self-stigma serves three functions which starts to answer the complex question of why people self-stigmatise: 1) to maintain victim beliefs that may subconsciously reinforce the individual as a victim removing a sense of personal agency, 2) to provide perceived protection from external judgement and 3) to limit life choices and justify actions such as non-disclosure.

Lastly, strategies to cope with self-stigma were identified and are consistent with coping strategies identified in the study in Chapter 5 as well as other studies in the wider literature (Huber, 2019, Silveira Silva, 2018)). These strategies included community involvement, professional development and education, personal development, inner work and positive attitude and connection to others and a sense of belonging.

The findings were intended to, and have (see Chapter 4 and 6), supported the development of concrete and specific interventions to reduce self-stigma among people living with HIV.

An innovative community-based response to address self-stigma among people living with HIV in Zimbabwe (Chapter 4)

Chapter 4 based on the formative study presented in Chapter 3, was a community-based intervention designed based upon Inquiry-based Stress Reduction (Katie and Mitchell, 2003). Designed as mixed methods study, it addressed the paucity of interventions that target and provide individuals with tools to manage and overcome self-stigma (Sengupta et al., 2011a, Stangl et al., 2013b). The intervention effects reported significant changes across a number of measures. Reduction in self-stigma, depression, daily activities, and fears around disclosure all improved significantly at 1 and 3-month timepoints compared to baseline. The qualitative component of the study found positive changes across a number of themes including fearfulness, shame, guilt, hopefulness, worthlessness, restricted agency, and negative perceptions of others. This is in keeping with the themes also identified in the formative studies in both Chapter 3 and Chapter 5 showing how the intervention positively affected self-stigma core beliefs in this sample. The study also reported positive change throughout participants' lives as a whole as well as enhancing coping strategies. Overall, the study using IBSR, showed significant reduction in levels of self-stigma and associated states and appears feasible and acceptable in the context of Zimbabwe. The findings suggest transformative change simultaneously across multiple aspects of participants' lives including daily activities, hopes for the future and improved self-image.

Exploring the beliefs, experiences and impacts of HIV-related self-stigma amongst young adults living with HIV in Harare, Zimbabwe (Chapter 5)

Chapter 5, the third formative qualitative study, found 63% of participants in Harare, Zimbabwe reported experiencing HIV-related self-stigma frequently (4 times per week) and 37% experienced it occasionally (once or twice a week). Participants, adolescents and young people aged 18-24 years are a group with disproportionately poor HIV clinical and psychosocial outcomes (Boerma et al., 2016a, Ferrand et al., 2017a, Who, 2014) and for whom stigma and self-stigma can result in non-adherence to HIV medication, lower quality of life and poor mental health (Chapters 3 and 4). Participants described the negative impact

on their lives of living with HIV, in terms of negative self-perceptions including beliefs of worthlessness, hopelessness and negative body image. These impacts are similar to findings other studies by the author included in this thesis (Chapter 3) and not included (Huber, 2019). As the participants were 18-24 years old, dating and relationships are particularly important (Xia et al., 2018) and fear of disclosure often led to the end of relationships and to decisions to date HIV-positive people, while wishing to date HIV-negative people. Secondary themes included gender differences and coping strategies. Participants reported poor wellbeing and decreased mental and physical health as a result of self-stigma. This study also found that self-stigmatising beliefs appeared to be more intense when they first found out their HIV status, although this would need to be investigated further.

A community-based, peer-led HIV self-stigma intervention to improve self-worth and wellbeing among young people living with HIV in Zimbabwe (Chapter 6)

Drawing upon the findings of the study in Chapter 5 and lessons learned from the study in Chapter 3, Chapter 6 is a culturally and age-appropriate, community-based, peer-led intervention was designed based upon IBSR, supported by music, creativity, writing and mindfulness techniques and showed potential for reducing self-stigma and improving self-worth among AYPLHIV. Few interventions target self-stigma among PLHIV and, to our knowledge, none until now for AYPLHIV in sub-Saharan Africa. The first iteration of the intervention was co-delivered with four Zimbabwean Coaches and an internationally Certified Facilitator (the author). The four Zimbabwean Coaches had been participants in the second study, Chapter 4, and were then subsequently trained as Coaches. The second iteration of the intervention was delivered by 15 AYPLHIV CATS Coaches and the four Zimbabwean Coaches with support by the author (an internationally Certified Facilitator).

Positive changes were seen across a range of self-stigma and related areas. Improvements in self-judgement, self-confidence, self-worth, self-agency, body positivity, improved communication in personal and family relationships and forgiveness and self-forgiveness were noted. Participants reported a transformative effect of the intervention, not just related to HIV self-stigma, but also in relation to everyday life within situations involving friends and family. The combination of this inquiry-based, cognitive-based, mindfulness-based approach together with the creative use of music, writing and poetry appears feasible and acceptable as an intervention to support AYPLHIV deal with self-stigma. A number of areas

for further research were also identified including looking carefully at the role of spirituality and the communal view of positive health more broadly as well as using the socio-ecological framework to better understand, design and carry out research on interventions to reduce self-stigma among PLHIV.

Systematic review of interventions to reduce self-stigma among PLHIV (Chapter 7)

Chapter 7, the fifth study, was a systematic review which identified interventions to reduce and measure self-stigma among PLHIV and make recommendations and also addresses Objective 2 of this thesis: Systematically review the existing literature that examines the effectiveness of self-stigma interventions for improving the well-being of people living with HIV. This was the first review of its kind to include qualitative studies as well as quantitative studies and also responded to the lack of knowledge about what interventions exist to reduce self-stigma. The review included 31 studies – interventions to reduce self-stigma - and presented findings about the types of intervention, the theoretical basis, level at which the intervention operates, implementation and measurement. Over three-quarters of the studies included, reported a significant effect on reducing self-stigma, however, the majority are pilot or small scale studies and may not be generalisable. Interventions in this review were classified in two ways. 1) using the socio-ecological framework, the level at which the intervention targeted and 2) the intervention approach used (for example cognitive behavioural therapy, acceptance commitment therapy etc). Seventeen studies targeted the individual level, four at individual and family, six at individual, family and society, three at individual and society and one society level only (see Figure XX in Section 8.11).

Interventions were grouped into six main categories of approaches. Traditional cognitive-behavioural therapy, multi-pronged cognitive and mindfulness approaches, reflective and creative, bespoke trainings, traditional person-centred counselling and other. Multi-pronged approaches, where interventions use multiple components, appear promising. Divergence on clear and consistent definition of self-stigma poses a real challenge to understanding of what in interventions is actually being addressed and also in measuring self-stigma (Ferguson et al., 2022). The lack of detail in the descriptions of interventions makes it difficult not just to assess for quality but also to replicate the studies conducted.

The review identified a gap and the need for more research into community-based interventions and noted that measurement of impact has been limited to the individual and does not for the most part, measure impact on family and community impact, although qualitatively reported (see Figure XX). Lastly, the review recommended using the socio-ecological model as a way of designing, evaluating and writing up interventions to reduce self-stigma in order to better reflect the importance of impact and ripple effect of individual-based interventions at family, community and societal levels.

16. Appendix G: From the Inside Out: a new framework for HIV self-stigma related interventions, research and policy

Individual Level

By promoting self-love, self-acceptance and empowerment at the individual level, PLHIV can develop a positive self-perception and feel worthy of belonging and love, which can influence their interactions within their household, community, and society. Challenging negative core beliefs, educating PLHIV about self-stigma and myths can help them challenge self-stigmatizing beliefs and reduce self-stigma. This can lead to increased confidence, self-agency and willingness to engage with others without fear of judgment. Peer support groups and community engagement, individual counselling and support services can support PLHIV to address self-stigma, enhancing their overall well-being, and providing them with coping strategies to navigate stigma-related challenges. Programmes that challenge negative core beliefs and increased self-worth can improve health seeking behaviour and adherence to medication.

Household Level

Empowering PLHIV at the individual level can positively impact their households. Increased self-acceptance, self-love, self-worth and education can promote open and improved communication within families, fostering understanding, empathy, and support.

By challenging stigmatizing beliefs and providing support mechanisms, households can become safe and inclusive spaces that reject self-stigma, including secondary self-stigma, and encourage the overall well-being of PLHIV and their families.

Community Level

Peer support groups at the individual level can create a sense of belonging and solidarity among PLHIV. This sense of community can help negate self-stigma by providing validation, shared experiences, and strategies for resilience. Community education and awareness programmes play a vital role in dispelling HIV-related myths, challenging stigmatizing attitudes, and promoting empathy and acceptance. This can lead to a reduction in self-stigma as the community becomes more informed and supportive.

Societal Level

Advocacy efforts and policies influenced by work at the individual level can help create a societal environment that supports PLHIV. This includes protecting their rights, challenging discrimination, and promoting inclusivity and meaningful participation in national policy processes.

Work at the individual level can also mean a PLHIV feels worthy and informed enough to access health care services and legal support, promoting equity and not just access.

Individuals with less self-stigma also increase self-agency and start to take education and job opportunities, thereby contributing to the economic and social development of society more fully. Positive media representation of PLHIV can influence societal perceptions, challenge stereotypes, and reduce self-stigma by fostering understanding and empathy.

Working at the individual level can have a ripple effect on households, communities, and society. By addressing self-stigma at the individual level, we can promote self-acceptance, self-love education, and support, leading to positive changes in how individuals value and support themselves as well as how they are perceived, treated, and supported in their community. It can also lead to a more cohesive society lessening the ‘us’ and ‘them’ narrative, broader inclusivity and empathy, and a conducive and supportive policy environment that results in greater access and uptake of health services and legal rights.

“An unspoken world of unspoken things”: a study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland

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Summary

PRINCIPLES: Human immunodeficiency virus (HIV) related self-stigma – negative self-judgements resulting in shame, worthlessness and self-blame – negatively influences access to care and treatment, and overall quality of life for people living with HIV (PLHIV). Despite evidence that high levels of self-stigma exist among PLHIV, and is experienced to a far greater extent than stigma received from the broader community, there is a paucity of research aimed at understanding causes and functions of self-stigma, and an absence of interventions to mitigate its harmful effects. Understanding the core beliefs underlying self-stigma is therefore essential.

METHODS: This pilot study used a qualitative approach to analyse interviews and written statements to uncover core beliefs underlying self-stigma, the functions thereof, and strategies used to overcome it, among a heterogeneous group of PLHIV in Ireland.

RESULTS: Core beliefs underlying HIV-related self-stigma were uncovered and grouped into four categories: disclosure; sexuality and sexual pleasure; self-perception; and body, illness and death. Reported functions of self-stigma included contributing to maintaining a “victim” status; providing protection against stigma received from others; and justifying non-disclosure of HIV status. To cope with self-stigma, participants highlighted: community involvement and professional development; personal development; and connection to others and sense of belonging. Findings were also used to create a conceptual framework.

CONCLUSIONS: This study helps fill identified gaps in knowledge about self-stigma as experienced by PLHIV. By understanding the core beliefs driving self-stigma, it will be possible to create targeted interventions to challenge and overcome such beliefs, supporting PLHIV to achieve improved wellbeing and lead productive lives free of self-limitation and self-judgement.

Key words: HIV; stigma; self-stigma; core beliefs; PLHIV; inquiry-based stress reduction; cognitive behavioural therapy; IBSR; CBT; self-worth

Introduction

Human immunodeficiency virus (HIV) infection is increasingly becoming perceived as a chronic disease. Those infected can expect to achieve a full life-span of 72–75 years [1], if appropriate treatment and support are available. As a consequence, the focus of health services, and of those living with HIV, is turning from preventing illness and death to optimising quality of life and enabling the fulfilment of life goals. Even where HIV prevention programmes are effective, ongoing fears around the outcomes of testing and disclosure (and broader social implications of a positive HIV diagnosis) mean the challenges of living with HIV are likely to persist.

HIV-related stigma acts as a significant barrier to prevention, testing and treatment [2–4]. Although Ireland has a relatively low incidence of HIV [5], stigma and discrimination for those infected still pose a significant challenge: 49% of people living with HIV (PLHIV) in Ireland reported experiencing discrimination by friends and 43% by the local community [6]. Stigma occurs at varying, inter-related, levels: enacted stigma (discrimination), referring to actions or omissions as a result of stigma; societal/perceived stigma, where an individual anticipates or perceives themselves as stigmatised; and finally self-stigma – negative self-judgements resulting in shame, worthlessness and self-blame [7].

Socially derived stigma has been widely studied in people living with illness and disabilities [8–11], but focussed rarely on self-stigma, also termed “internalised stigma”. In HIV, the Asia-Pacific Regional Analysis of the Stigma Index Study in nine countries, involving 4395 participants, found disturbingly high levels of internalised stigma manifesting as shame, guilt and self-loathing. For example, 75%

of PLHIV in Pakistan reported they were ashamed of their HIV status, and even in Sri Lanka, which reported the least self-stigma, 54% of participants reported being ashamed [12]. Self-stigma also has broader repercussions, leading to failure to seek treatment and use care services, reduced wellbeing [13], depression [14], low self-esteem and reduced self-efficacy [15], poor long-term coping [7], and lower quality of life [16]. A recent study by Overstreet, cited in Cairns (2013) [17], also found that people with internalised stigma were less likely to disclose their HIV status to partners or families.

It would appear from the literature that self-stigma is experienced by HIV-infected people to a far greater extent than stigma received from the broader community [7, 12, 18–22]. Kalichman et al. [23] reported that, of 2,306 adults in the general public in Cape Town, 10% believed that PLHIV were dirty, contrasting with 27% of PLHIV who felt they were dirty; 13% of the general public believed that PLHIV had done something to deserve it, as opposed to the 41% of PLHIV who felt guilty about having been infected. The same pattern can be found in Ireland, where 84% of PLHIV feel they are viewed negatively by society whereas 54% of the general public shared that view [6]. Lastly, the fact that self-stigma was observed as greater than levels of stigma in the general population strongly suggests that self-stigma is not just an internalisation of the prevalent social stigma, but a distortion and amplification of it.

“Stigma” was defined by Goffman in 1963 as “an attribute that is significantly discrediting” which in the view of others serves to reduce the person who possesses it. Goffman also importantly identified stigma as a complex and multi-dimensional phenomenon [24]. For Link and Phelan (2001), there is variability not just in definition, but also its application by researchers [25]. Link et al. in 1997 defined “self-stigma” as “the extent to which people endorse negative beliefs and feelings associated with their stigmatized attribute and apply them to self” [26]. As they are central to the manifestation of self-stigma, core beliefs must be considered – i.e., the “fundamental, inflexible, absolute and generalised beliefs that people hold about themselves, others, the world and/or the future” [27]. In shaping an individual’s worldview, core beliefs that contribute to self-stigma can have a profound effect on a sense of self-efficacy and concept of self [28]. Understanding the core beliefs underpinning self-stigma can be a foundation for interventions and programmes designed to reduce its harm.

From the outset, the study reported on here was cognisant of gaps in interventions to support PLHIV in dealing with self-stigma. For example, Sengupta et al. [29] reported that, despite the negative impact of stigma on PLHIV, there have been surprisingly few intervention studies aimed at reducing HIV-stigma to date. This is particularly the case with self-stigma, which is under-represented in the research literature. Kalichman and Simbayi [30], who have widely published on HIV-related stigmas, acknowledge that approaches are needed that go beyond mass education and work within more ingrained belief systems.

The identification of unhelpful or negative core beliefs is the basis from which individuals can be supported in developing healthier belief systems through cognitive therapy strategies [28]. The use of stress-management interventions

also shows evidence of efficacy: Brown and Venable’s review [31] of literature reporting stress-management interventions for PLHIV, concluded that there is a growing body of evidence demonstrating that these interventions – including cognitive behavioural interventions, meditation, mindfulness and relaxation – in the context of HIV can reduce psychological distress and improve psychosocial functioning. Among such interventions, the inquiry-based stress reduction (IBSR) technique, developed by Byron Katie [32, 33] supports participants in reducing their perceived level of stress by self-inquiry on thoughts and beliefs connected to stressful circumstances or symptoms. IBSR has shown positive results in a trial among survivors of breast cancer [34], but has not yet been applied to the support of PLHIV. Another technique, cognitive behavioural therapy (CBT), is perhaps the most researched psychotherapeutic approach and has a growing reputation for being a highly effective treatment in dealing with stressful beliefs or thoughts [35].

To successfully address self-stigma, core beliefs underlying this phenomenon must first be identified and contextualised. This study was designed to: (a) identify and gain understanding of core beliefs underlying self-stigma in PLHIV in Ireland; (b) enhance understanding of the phenomenon; and (c) inform interventions aimed at mitigating its harmful effects. Three research questions were formulated:

1. What are the core beliefs underlying HIV-related self-stigma among the studied group of people living with HIV?
2. What are the functions of self-stigma among the studied group of people living with HIV?
3. What coping strategies are used by participants to manage self-stigma?

Methodology and data collection

A qualitative approach within the interpretivist paradigm was adopted for this research. This allowed for a deeper understanding of the lived experiences of individuals that could subsequently help inform the design of a therapeutic intervention. Semi-structured interviews and written statements were used to gather information from participants. Each interview lasted approximately one hour and was recorded, with prior written consent. During interviews, participants were asked to write the following open-ended statement: “I am HIV positive and that means that...” (participants with limited literacy dictated their statements to the researcher). This approach is commonly used to draw out core beliefs as part of inquiry-based stress reduction: the work of Byron Katie [32]. A similar method is used in cognitive behavioural therapy [36].

Ethical approval for this study was granted by the Health Policy Management / Centre for Global Health Research and Ethics Committee at Trinity College Dublin.

Participants were purposively selected from Open Heart House, the largest Irish peer-support network of PLHIV at the time of the research. Owing to the highly varied nature of the epidemiology of HIV in Ireland [5], the studied group included a large degree of heterogeneity, incorporating male, female and transgender participants, as well

as migrant individuals, drug users, men who have sex with men (MSM) and heterosexuals. Seventeen potential participants were approached, and all agreed to participate. Participants' ages ranged between 31–51 years (average age 43 years); 6 were women, 10 were men, and 1 was transgender. Participants had been living with HIV for between 3 and 29 years (average 11 years). Participants' nationality was predominantly Irish, but also included individuals from South, East and West Africa, and East and Central Europe. Further participant details are included in table 1. Although there was diversity within the sample, it was too small to analyse across differences in gender, race, ethnicity and nationality. The core beliefs outlined in this study are therefore drawn from across the group as a whole.

A review of current frameworks and models for measuring stigma and self-stigma informed the analysis and thematic clustering of this study. Early work by Berger et al. [37] highlighted four main categories to understand and measure stigma: personalised stigma, disclosure concerns, negative self-image and concern for public attitude. Poku et al. [38], in a qualitative study better to understand stigma, highlighted social rejection, financial insecurity, internalised shame, social interaction, self-worth, and body image as main dimensions. Providing more detail and broadening the categories on self-stigma, Holzemer et al. [39] presented a framework that also included self-exclusion, negative self-perception and overcompensation.

Most recently, building on extensive formative qualitative and quantitative research on HIV-stigma, Kalichman et al. [7] developed the Internalised AIDS-related Stigma Scale (IASS). The framework drew upon previously validated scales and beliefs guided by the theoretical framework offered by Goffman [24], and proposed six scale items covering self-defacing beliefs and negative perceptions.

Interviews were transcribed in full, then thematically coded and analysed using an iterative coding strategy guided by the frameworks outlined above. The themes were continually and systematically updated as the data was analysed, reanalysed and grouped into various themes. New themes were added as they emerged, and this process continued until no more new themes arose and data saturation was reached [40].

Core beliefs

Owing to the complex nature of stigma and self-stigma [41], some overlap occurred between the emerging themes. However, it was possible to group participants' core beliefs contributing to HIV-related self-stigma under four categories (fig. 1A).

1. Disclosure: here, participants' core beliefs surrounding disclosure of their HIV status were reported – for example, some held the belief that others would reject them if they were discovered to be HIV positive.
2. Sexuality and sexual pleasure: this category included participants' core beliefs influencing sexual behaviour, such as the belief that they could no longer enjoy sex with an intimate partner.
3. Self-perception: the core beliefs held by participants about, for example, their sense of worth or agency fell into this category – such as believing that they were

worthless or that they could not have a child or find employment because of their status.

4. Body, illness and death: in this category, beliefs surrounding the physical effects of HIV were recorded – for example, some of the participants believed that they were likely to suffer prolonged illness, and a slow death, as they had witnessed in other HIV patients.

Table 1: Study demographics and participant information (n = 17), showing participants' medication status, country of origin, exposure group, employment and relationship status.

Currently taking ARVs:	
Yes	16
No	1
No. of years taking ARVs:	
Mean	9
Range	0.2–26
Country of origin:	
Ireland	11
Germany	1
Poland	1
Côte d'Ivoire	1
South Africa	1
Nigeria	1
Botswana	1
Exposure group:	
Heterosexual	9
IDU	4
MSM	3
Unknown	1
Currently employed:	
Yes	11
No	6
Ever been ill due to HIV:	
Yes	13
No	4
Has children:	
Yes	10
No	7
Currently with intimate partner:	
Yes	7
No	10

ARVs = antiretroviral drugs; IDU = intravenous drug use; MSM = men who have sex with men

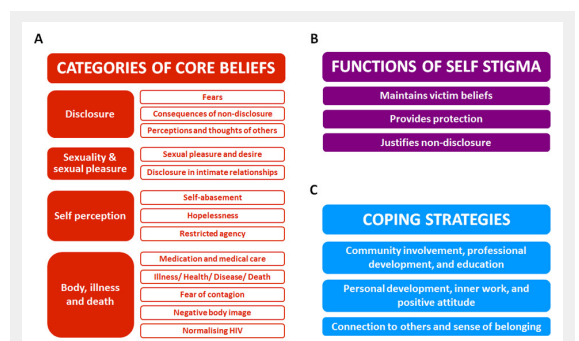


Figure 1

Framework for qualitative analysis of interview data.

Three main areas of analysis are shown: Categories of core beliefs (A, red), Functions of self-stigma (B, magenta) and Coping strategies (C, blue). Emergent themes were organised into categories (solid boxes), and subcategories where required (open boxes).

Disclosure

Fears and consequences of disclosing one's HIV status are well documented elsewhere [37, 42–44]. Notably, people with higher levels of self-stigma are more likely to avoid disclosing their status [45]. We sought to understand more fully the beliefs contributing to fear and stress around disclosure, and within this category participants' beliefs were broadly grouped into three subcategories.

Fears

A fear of being talked about and ridiculed was expressed by many participants, as well as of being labelled and stigmatised. Here, beliefs about being rejected predominated:

"I don't want people to throw me away, like if yesterday I was talking very good with this person, today you tell him you are HIV positive, tomorrow you can feel like he don't want to talk to you." (Participant K)

Fears of betrayal had also engendered a lack of trust in many participants:

"You can't trust nobody, so everyone is like an island...you stick to yourself, you sort your problems out yourself, you can't call on anyone because the person you think you can talk to and trust will end up betraying you." (Participant P)

A variety of beliefs regarding disclosure within families were reported. These included the belief that non-disclosure could protect family members from emotional hurt, or that disclosure would expose family members to secondary stigma. In certain cases where participants had already disclosed to their family a culture of silence emerged where HIV was never discussed.

Consequences of non-disclosure

Social exclusion and secrecy were commonly mentioned as outcomes of non-disclosure, in particular self-isolation and loneliness. Few participants reported actually losing friends, whereas most reported withdrawing themselves from social circles. Although social exclusion has been previously identified in the literature [39, 46, 47], it is possible that withdrawing from society is a bigger negative influence in the lives of PLHIV than actually being rejected – a finding supported by the Global Network of People living with HIV (GNP+) [12]. Some participants believed that they lived two lives – one open and honest amongst other people with HIV and another secretive, false and lonely in the outside world.

"It's almost like trying to bring these two worlds together, where it can be the same in both, so that's exactly the point I'm at right now...bringing it out into my real life, and with the hope I can be like, the way I am here [in Open Heart House], where I can have the same energy." (Participant I)

Perceptions and thoughts of others

A common belief among participants was that they were viewed as bad and different:

"They think I'm a scumbag, the lowest of the low." (Participant H)

This was particularly linked with perceived judgements from others as to how they contracted HIV:

"...if I had to tell somebody I had HIV, the first question they ask me is: 'how did you get it?'... if I was to

answer that question, 'I got it through drugs'...you see the change in people – you see the look they give you, it's like, 'oh, she deserved that'..." (Participant B)

Several participants also reported believing their HIV status was viewed by others as less "worthy" of sympathy than other diseases:

"If you've done a survey and you asked people, 'there's two people there...that one has cancer, that one has HIV – who do you feel more sorry for?', nine times out of ten, people say 'cancer'." (Participant A)

One participant suggested human interaction begins to be framed within the context of HIV, and becomes the overriding perspective when dealing with others:

"There is this thing when you are HIV positive, you become very sensitive to what people say and how they treat you. You judge people...you become sensitive to what people do to you, because you feel they do it because you're HIV positive... So every single thing someone does to you, you read it as because you're HIV positive." (Participant A)

Sexuality and sexual pleasure

Whereas some participants were currently involved in sexual relationships, many reported that sexual pleasure and intimacy were affected by their beliefs about self-image, fears of transmitting HIV, feelings of guilt, and lack of freedom. Here, core beliefs fell into two subcategories.

Sexual pleasure and desire

Here, participants described beliefs about never being able to have a partner, or that "normal" relationships could not be regained:

"[In] my sex life, like he doesn't say it, but I feel it, the intimacy is gone. The, you know, experimentation and stuff, all that's gone, it's just basic with the condom. I tried to say to him, you know I'm undetectable, this is what the doctors say. But then I feel guilty for saying that, 'cause I'm saying, sure he must be thinking this one just wants to have sex without a condom...does she want me to catch it and it's not about that, it's about trying to get back what we used to have." (Participant A)

Some reported sex was no longer spontaneous and they no longer had sexual feelings. Additional negative influences, such as fear of contagion, feelings of guilt for having sexual needs, and lack of energy and interest, were also mentioned. The inability to enjoy sex or any sexual aspect of a relationship was also discussed, and many participants believed their own sexuality had been lost or taken from them:

"I feel like something has been stolen from me, because I can't, as much as I'm sexually active, I cannot do that, I can't just be free and do what I want to do." (Participant Q)

Disclosure in intimate relationships

Outside of core beliefs affecting sexual behaviour itself, a common belief among participants was their inability to

seek a new partner – the risk of rejection and discrimination was too great:

“...I don’t know what to do, where to go, how to proceed. I’m afraid of telling the person, getting a bad reaction, and that person having that information that [they] can just tell anybody else...” (Participant F)

Not all beliefs were negative, however, and some participants shared their positive experiences of being honest and not experiencing rejection:

“If anything I was more respected for being honest and being in the position to be able to give the information.” (Participant C)

Self-perception

Well documented in the literature on self-perception and self-stigma are issues of self-abasement and restricted agency [7]. In this study, core beliefs affecting self-perception were reported across three subcategories.

Self-abasement

For one participant:

“It’s great when I’m here in Open Heart House – I’m with [my own people]. But it’s different when I’m outside. It’s very hard...because I know I’m just the same as everybody else, and I don’t deserve, you know...but that dirty feeling still stands, no matter how much I wash, or how many clothes you buy, or how pretty you look. Inside [you still feel] that...worm picking away. Some days I feel toxic...as if there’s something eating away from the inside that no one else can see. But every day I feel a little bit less, like I’ve changed. You change when you’re diagnosed, and it’s not what people [say] to me. I really believe, it’s an unspoken world of unspoken things.” (Participant A)

Another participant explained just how powerful the inner world of self-stigmatising beliefs was:

“[My] inner dialogue was [that] God has punished and [put] the X on the red [door]. I felt like I couldn’t touch other people [and] couldn’t use utensils in the house that other people were using...I just felt really, really unclean all the time. I was one of the undesirables. I had really fallen...to an undesirable part of society and this was God’s choice and I was done.” (Participant F)

Many participants shared feelings and beliefs about being different from others. For one:

“I see everyone out there as the same but I’m different, and that I don’t have the same chances. You feel like this special case...a weakness.” (Participant I)

A powerful theme in the data included beliefs about being less human, undeserving, and attributing self-blame. Illustrating how some participants devalue themselves one participant said:

“If the world was ending me, and other people like me, would be left – we would not be saved.” (Participant A)

Though many participants became emotional as they shared beliefs and experiences during interviews, it was sharing how they viewed *themselves* that caused the most

distress. This suggests strongly the damaging influence of self-stigma in the lives of participants.

Hopelessness

Hopelessness and self-pity frequently emerged among participants’ core beliefs. Several cited depression, suicidal thoughts, and feelings of hopelessness stemming from beliefs such as life being over, HIV being a killer disease, feeling a victim, being a burden to people, and not seeing any hope for the future. Though participants were answering questions specifically about HIV, responses encompassed their lived experience as a person, with HIV being just one of many difficult life challenges.

“I’ve been abandoned by my parents, living on the streets of Dublin, [and] get HIV – so why I am on this planet? For punishment, punishment, punishment. That’s all I seem to be getting. I can’t find happiness anymore. Some days I try to be up but more times I’m down and there’s only so much you can take as a human being. Sometimes I question myself: what am I living for? I don’t see any life out there. I see nothing there for me. All I see is a brick wall and every time I try to get over it something knocks me back.” (Participant J)

Restricted agency

In line with wider literature [12, 18], in relation to restricted agency, participants described a number of significant actions and opportunities they believed were not possible because they were HIV positive. For many, this included not being able to have a child, not being able to find work, or work in places of their choice, not being able to travel, having to choose friends carefully, and not being able to find a life partner:

“It stops so many things.” (Participant Q)

Body, illness and death

Among core beliefs shared by participants around medication and medical care, negative side-effects and an inability to take part in life activities were mentioned frequently. Here, core beliefs emerged across five subcategories.

Medication and medical care

In some cases, participants felt as though they were not treated properly as human in their dealings with medical services:

“Sometimes you feel like a guinea pig, they are taking blood tests and they don’t tell you what’s it for.” (Participant M)

Illness/health/disease/death

When discussing illness, most participants expressed fears about sickness and dying:

“I [will] end up dying the way I have actually seen others people dying, which is piece by piece and become mentally deficient, physically deficient, and the fact that it is a slow process.” (Participant O)

Beliefs that led to stress around health emerged frequently:

“Health has become much more of a focus – any health. I get a cold, I get worried. I get a headache, I get worried.” (Participant O)

Fear of contagion

In addition to fears for their own wellbeing, core beliefs extended to the impact of their condition on the lives of others. Many believed they would be a risk to family and friends. For one:

“I was paranoid because I didn’t know when I found out [my status]. I had my own cups, my own knives and forks, [and] I kept all of them. I wouldn’t kiss my grandchildren. Even now I won’t kiss them – my grandson asks why I turn my face away.” (Participant M)

Body image

Several participants shared beliefs about negative body image – including weight and body-shape changes – that contributed to their self-abasing thoughts. Notably, self-perception had changed – even if physical changes had not yet occurred:

“It’s amazing what you see in the mirror that isn’t there; I really, really hated myself.” (Participant F)

Demonstrating the complexities for some, one participant shared their experience:

“For me, all this stuff is intermingled with trans-identity. In order to go on hormones to get an ideal body shape to be a she, obviously I’ve had some breast development, not much. I’ve had to stop taking hormone replacement therapy because of contraindications [with HIV medication].” (Participant O)

Normalising HIV

Conversely, some participants stated that their self-image had improved, mentioning they now took more effort in self-care – for example giving up smoking and doing exercise.

Functions of self-stigma and coping strategies

In addition to core beliefs, the findings also provide insights into the functions of self-stigma (i.e. the “purpose” of self-stigma, as participants perceived it), and coping strategies to assist in its reduction (e.g. adaptations in behaviour and social interactions).

Functions of self-stigma

In the same way that social stigma may be seen to serve some function or benefit to society [48], it is also likely that self-stigma has a function or benefit to individuals. Participants’ responses highlighted three subcategories of functions of self-stigma (see fig. 1B).

Maintains victim beliefs

Self-stigma may subconsciously reinforce the individual as a victim, taking away the sense of personal agency and thereby contributing to a feeling of disempowerment:

“Before someone can do anything to stigmatise me or discriminate me I’ve already felt the discrimination, because you need to blame someone for what is happening to you. If you go downstairs here [at Open Heart House] and ask 50 people that are HIV positive, they will say it’s not their fault. Everyone will

explain to you that it’s not their fault – everyone will be a victim. Yes it’s a strong word to call HIV positive people.” (Participant P)

Provides protection

By thinking negative thoughts about themselves, individuals may self-stigmatise in anticipation of being hurt by others:

“I say all these things to myself first that when I do have to go out into the world to survive, the stuff that people thinking about, I’ve already thought about myself, so nothing can get through, so its like a protection mode, you self-stigmatise yourself so that other people can’t hurt you.” (Participant A)

Justifies non-disclosure

Self-stigma may serve as a reasoning tool to limit one’s life choices, and rationalise actions such as avoiding disclosure:

“I come up with all the bad stuff that people can think about me. It’s to protect myself so that I don’t have to come out and say I’m HIV positive.” (Participant A)

Coping strategies

Many negative outcomes arising from being HIV positive and experiencing self-stigma had functional opposites in the coping strategies reported by participants. For example, several spoke of the importance of having a sense of belonging, acceptance, and a connection to others, thus directly addressing their feelings of social withdrawal and isolation. A sense of renewed agency was also reported, where participants found work or started volunteering after being diagnosed. Indeed, a sense of personal development strongly beneficial. Coping strategies were grouped into three broad subcategories (fig. 1C).

Community involvement, professional development and education

Some participants were motivated to return to education and, as a result, were now working – some for the first time. Participants sharing this view were engaged in community work and spoke of the sense of self-worth gained through providing support to others:

“I would have never ended up in a job if I had never become HIV positive. It just gives me great joy to sit with somebody who is in great despair and desperation and to say to them, ‘I genuinely know what you are going through’.” (Participant A)

Personal development, inner work and positive attitude

Participants also shared positive beliefs about themselves, their lives and abilities, having come to a positive place through personal development, inner work, and finding peace.

“I believe that I’m more accepting today – actually I fully accept who I am now. [Living with HIV is] a tiny part of who I am so it doesn’t stop me from doing absolutely anything.” (Participant C)

Connection to others and sense of belonging

The majority of participants shared the importance of the space created by Open Heart House in fostering a sense of belonging, providing support, and being community of people they would not have otherwise met.

Discussion and conclusions

Core beliefs of participants: Rather than simply showing levels of self-stigma, the results of this formative study build our understanding of beliefs reported by PLHIV. Although these are likely to vary across geographies and cultures, a number of core beliefs reported by this small and heterogeneous group could occur independently of gender, religion, or country – for example, the belief that one is “unclean”, undeserving of sympathy, or somehow unemployable because of being HIV-positive. Such generic core beliefs can significantly moderate behaviour, for example, decisions around disclosure or accessing treatment [49], and it is especially in the latter case that stigma represents a significant risk to the wellbeing of PLHIV. Recognising this clear danger, as well as the need to support PLHIV in achieving their life goals unhindered by self-imposed limitations, there is a now scope for targeted interventions to be created. The core beliefs reported from this study will also help inform future research and generation of meaningful measurement scales.

Functions of self-stigma: The results demonstrate key functions of self-stigma for participants. For example, it *maintains victim beliefs, provides protection, and can justify non-disclosure*. Unpicking the functions of stigma further could contribute substantially to our understanding of how to address it. For instance, although non-disclosure might protect against stigma received from others, to what lengths must someone go to hide their HIV status? Social withdrawal and even missing medication to maintain appearances have been reported among self-stigmatising PLHIV [50], again both representing a risk to overall wellbeing.

Coping strategies: Participants’ reported strategies for coping with HIV-related self-stigma included community involvement, personal development, and maintaining a connection with others. Like the previously reported *functions*

of self-stigma, these had grounding in core beliefs, however in this case participants were able to challenge those beliefs. For example, in gaining employment, participants began to revise views of their lack of agency, and it was through interacting with others and undergoing personal development that they could overcome their feelings of isolation, or being worthless. Interventions to successfully address self-stigma could therefore incorporate techniques that include group, interpersonal or community interactions [51].

Conceptual framework of self-stigma: Results from this study were incorporated into a conceptual framework of self-stigma (fig. 2), designed using concepts from Morrison (2006) [52]. This framework may be of use in visualising and understanding self-stigma as a complex, multi-dimensional phenomenon. In doing so, it may inform future research into HIV-related self-stigma, as distinct from social, perceived, or enacted stigma.

Despite the negative impacts of self-stigma identified in the wider literature and from participants in this study, interventions to support PLHIV in dealing with self-stigma, particularly at the level of core beliefs, are lacking. Stigma applied by, and to, the self is unlikely to be overcome by interventions aimed at the general public, since the negative beliefs held by PLHIV are often not representative of the population as a whole [13, 17, 23]. In this study, coping strategies such as personal development and inner work were highlighted as supportive, and a targeted approach incorporating these elements could prove beneficial. It is here that interventions such as IBSR [32, 34] and CBT [35] are more likely to meet with success: both utilise a strategy of working directly with individuals to systematically identify, challenge, and ultimately overcome self-imposed negative behaviours and beliefs. Such interventions, tailored to the context of HIV self-stigma and using knowledge of underlying core beliefs, may better equip participants with the mental tools and strategies to mitigate self-stigma.

These findings help fill previously identified gaps in knowledge regarding social and psychological factors around core beliefs about HIV and personal experiences [30], moving towards understanding the origins of self-abasing and negative perceptions of PLHIV [7]. In doing so, a small but concrete step has been taken to enable others to design interventions and programmes to address this complex and important issue. This study contributes a deeper view of the issue of self-stigma among PLHIV, and it is hoped that by directing more attention towards research and support for self-stigma, treatment adherence, access to services, and general wellbeing can be improved.

The authors acknowledge that this study has limited representative potential for PLHIV in other settings, because of the relatively small number of participants. Additional research will therefore be useful in confirming that the experiences of self-stigma reported in this study also occur in other settings. Furthermore, there was considerable heterogeneity among participants in this study. However, it was also noted that the participants shared many common experiences and core beliefs underlying HIV self-stigma, and there were no instances where two participants reported contradictory experiences or beliefs.

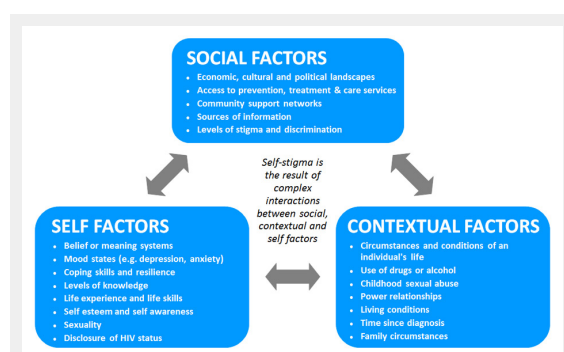


Figure 2

Conceptual framework of self-stigma.

Designed using concepts from Morrison (2006) [52], the framework comprises three interacting groups of factors (factors listed are non-exhaustive) which influence self-stigma: social factors, contextual factors and self factors. The complex interaction between these factors influences the development and perpetuation of self-stigma.

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Figures (large format)

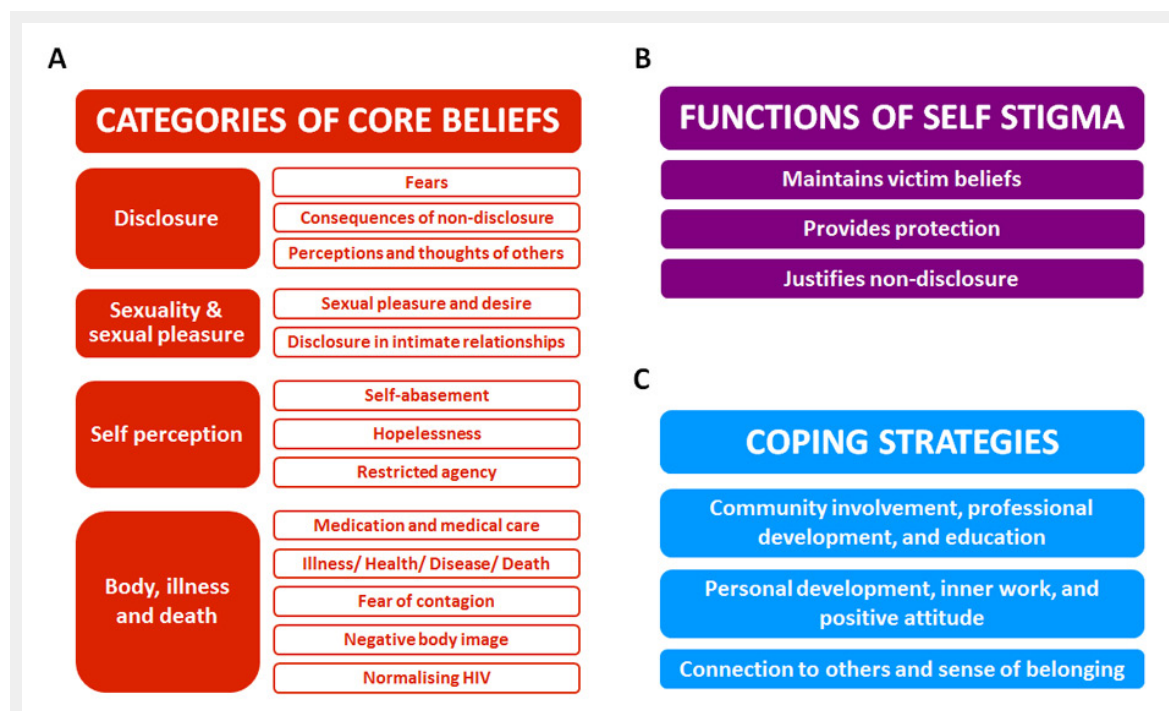


Figure 1

Framework for qualitative analysis of interview data.

Three main areas of analysis are shown: Categories of core beliefs (A, red), Functions of self-stigma (B, magenta) and Coping strategies (C, blue). Emergent themes were organised into categories (solid boxes), and subcategories where required (open boxes).

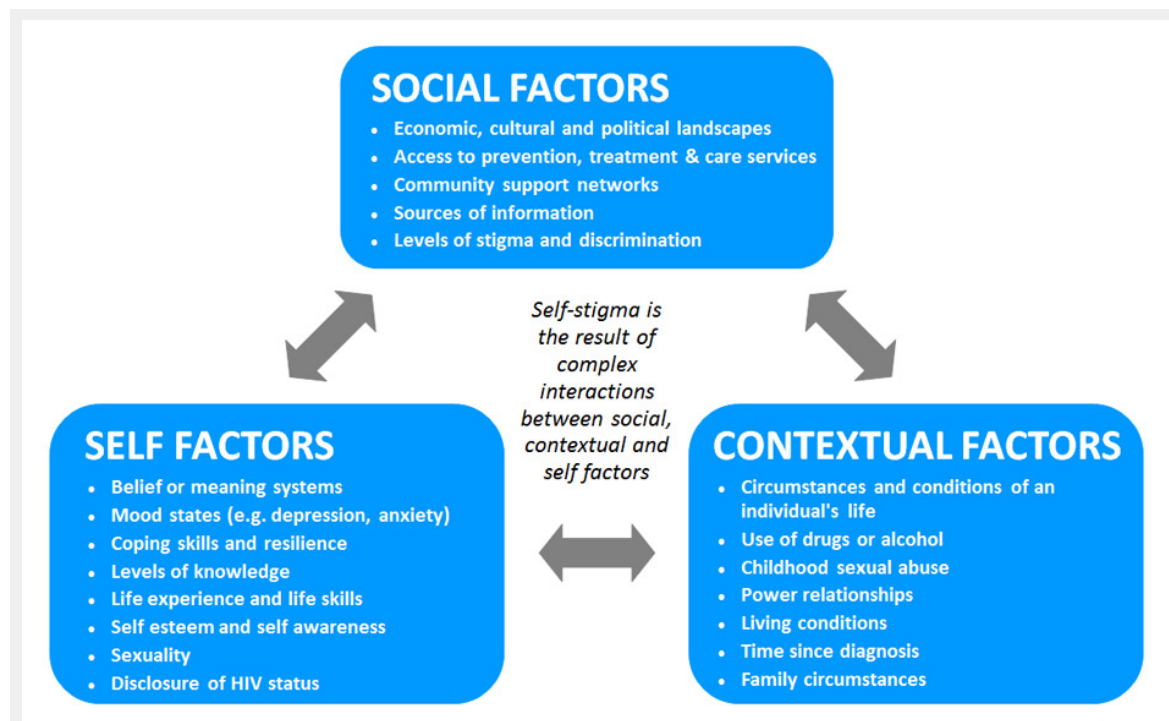


Figure 2

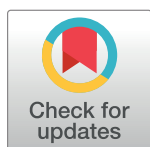
Conceptual framework of self-stigma.

Designed using concepts from Morrison (2006) [52], the framework comprises three interacting groups of factors (factors listed are non-exhaustive) which influence self-stigma: social factors, contextual factors and self factors. The complex interaction between these factors influences the development and perpetuation of self-stigma.

RESEARCH ARTICLE

'We are the change' - An innovative community-based response to address self-stigma: A pilot study focusing on people living with HIV in Zimbabwe

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Data Availability Statement: Raw data from the quantitative analysis in this manuscript is available in Supporting Material S3. However, qualitative data is derived from confidential interviews and focus groups. In line with the personal nature of these discussions, and the terms of informed consent to which participants agreed, the full transcripts have not been made available. Illustrative anonymised verbatim quotes have been included in this manuscript where necessary to support the findings of the analysis. Anonymised

Abstract

Introduction

Self-stigma—negative self-judgements resulting in shame, worthlessness and self-blame—may play a crucial role in emotional reactions and cause emotional distress among many people living with HIV and other chronic illnesses. Furthermore, self-stigma negatively impacts on self-agency, quality of life, adherence to treatment, and access to services. High levels of self-stigma have been reported across many countries, however few programmes or interventions exist to specifically tackle this phenomenon. This paper reports the findings of a pilot study carried out in Zimbabwe using a programme incorporating “Inquiry-Based Stress Reduction (IBSR): The Work of Byron Katie”—a guided form of self-inquiry which helps users to overcome negative thoughts and beliefs.

Objectives

The primary objective of this uncontrolled pilot study was to examine the potential role of the IBSR intervention in helping people living with HIV to overcome self-stigma and associated states.

Methods

23 people living with HIV (17 Female, 6 male, average age 41 years) were recruited from a local HIV support network, via open call for volunteers. All participants received the intervention, consisting of a 12-week facilitated programme using techniques derived from IBSR: The Work of Byron Katie. Qualitative and quantitative data were collected and analysed pre- and post-programme.

excerpts from transcripts relevant to this study may be requested from the RCSI Data Science Centre at: data@rcsi.ie

Funding: The intervention was funded by Trócaire (www.trocaire.org) as part of their activities supporting PLHIV in Zimbabwe. Our main contact person within Trócaire was Ms. Deirdre Ni Cheallaigh (DNC). No specific grant was assigned to this study. DNC and BM are employees of Trócaire, and GS is an independent consultant employed by Trócaire. Although Trócaire funded the study, beyond the stated involvement of DNC, BM and GS, the organisation did not take part in study design; collection, analysis, and interpretation of data; writing of the paper; or decision to submit for publication.

Competing interests: I have read the journal's policy and the authors of this manuscript have the following competing interests: DNC and BM are employees of Trócaire, and GS is an independent consultant employed by Trócaire. Although Trócaire funded the study, beyond the stated involvement of DNC, BM and GS, the organisation did not take part in study design; collection, analysis, and interpretation of data; writing of the paper; or decision to submit for publication. This does not alter our adherence to PLOS ONE policies on sharing data and materials, with the sole restriction that qualitative data used in this study was derived from confidential interviews and focus groups, therefore in line with the personal nature of these discussions, and the terms of informed consent to which participants agreed, the full transcripts have not been made available. Illustrative anonymised verbatim quotes have been included in this manuscript where necessary to support the findings of the analysis.

Results

After taking part in the intervention, participants reported significant improvements in factors including self-stigma (1-month follow-up vs baseline $Z = 2.1$, $p = 0.039$; 3-month follow-up vs baseline $Z = 3.0$, $p = 0.003$, $n = 23$, Wilcoxon Matched Pairs Signed Rank Test) and depression (1mo vs baseline $Z = 3.7$, $p = <0.001$; 3mo vs baseline $Z = 3.3$, $p = 0.001$). Qualitatively, participants reported improvements including lessened fears around disclosure of their HIV status, reduced feelings of life limitations due to HIV, and greater positive mental-ity. Improvements persisted at three-month follow-up.

Conclusion

With further development and larger comparative studies to confirm effects, the IBSR programme could become a novel tool to enable people living with HIV to support themselves in overcoming self-stigma.

Introduction

Much has been published about stigma in relation to HIV and AIDS, mental illness, physical deformities, disability and illness [1–7]. However, much less is understood about *self-stigma*, or internalised stigma—influenced by “the fundamental, inflexible, absolute and generalised beliefs that people hold about themselves, others, the world and/ or the future” [8]—that is the stigma imposed upon the self by the self [9–11]. Self-stigma entails negative self-judgements, which at times may result in feelings of shame, worthlessness and self-blame [10,12,13]. The three major mechanisms of stigma at the individual level—enacted stigma, anticipated stigma, and internalised stigma—are highly complex, interrelated phenomena [14–16], the context of which is that of marginalisation where stigma operates as a multidimensional process, with that marginalisation as both a contributor and outcome [17].

It should not in any way be inferred that self-stigma is somehow the “fault” of the individual who experiences it. Stigma does not arise within an individual in isolation. Rather, stigma becomes internalised through exposure to the social, structural, and cultural contexts that feature enacted, anticipated, and perceived stigma [12,17]. Individuals exposed to these contexts naturally absorb the harmful social and community attitudes towards a stigmatised condition [17] and may experience self-stigma without necessarily having been on the receiving end of enacted stigma [6]. It should also not be inferred that tackling self-stigma alone is enough to address the challenge of HIV stigma as a whole. Rather, as a multidimensional phenomenon, HIV stigma must necessarily be addressed via approaches that are targeted to its different levels and manifestations [18,19], with self-stigma being one component of the wider picture [20].

It is clear, however, that detrimental effects can arise as a result of the internalisation of stigmatising beliefs. For example, self-stigma can lead to a sense of isolation and may play a crucial role in the emotional reactions and cause emotional distress to many people living with HIV (PLHIV) [21,22] and other chronic illnesses [23]. Furthermore, self-stigma may exert wide impacts on social interaction, health services utilisation, treatment compliance, and mental health status [21,24–26]. It also has the potential for adverse behavioural effects including not seeking treatment and care services [27]. A study by Earnshaw [28] also reported that people with chronic illness who had self-stigma accessed care less and had a lower quality of life. Furthermore, a study by Scambler and Hopkins on people living with epilepsy [6] also highlighted

the fact that nine out of every ten people interviewed admitted to suffering from self-stigma, although only one third could recall having experienced external stigma.

The damaging effects of stigma may also be compounded by restrictive legal and/ or socio-economic environments and practices that target those living with, or at increased risk of, HIV [29,30]. Such contributing factors are also reported to lead to low self-esteem and threaten self-efficacy of PLHIV [9]. Internalised stigma has also been associated with the development of depressive symptoms [31], and it is likely that self-defacing internal representations are important in predicting long-term coping and positive living [10]. This is especially relevant among PLHIV, where stigma in its many forms acts as a barrier to prevention strategies, access to care, and wellbeing across many dimensions [14,24,27], as well as amplifying inequalities of gender, race and sexuality [17].

There is increasing evidence to show that PLHIV may experience self-stigma more frequently than they receive enacted stigma from other people [32]. For example, in a survey of 2306 adults in the general public in Cape Town, 38% of PLHIV interviewed reported feeling ashamed of their condition as compared to 16% of HIV-negative people who believed that PLHIV should be ashamed of their condition [21]. Additionally, 13% of those interviewed believed that PLHIV did something to deserve it compared to 41% of PLHIV who felt guilty about having been infected with HIV. Importantly, although in this article we focus on self-stigma, the globally high rates of HIV stigma in its various forms should not be ignored. The 2014 Analytical Report of the Ukraine People Living With HIV Stigma Index showed that 40% of respondents had experienced external stigma, whereas 82% had experienced self-stigma [33]. In a study across nine countries of the Asia Pacific region internalised stigma in the form of shame, guilt and self-loathing occurred at high levels, ranging from 54% in Sri Lanka reporting feeling ashamed of their HIV status to 75% in Pakistan [32]. Additionally, the 2014 HIV Stigma Index for South Africa found that among 10,473 respondents, 43% reported experiencing internalised stigma, with 36% experiencing external stigma [34].

Poor health outcomes for people living with chronic illnesses, such as HIV, diabetes, cancer, may be linked with lack of psychosocial supports, and low quality of life [35–38], and conversely the presence of adequate support is associated with improved health care access and coping with multidimensional aspects of living with HIV and related stigma [39–42]. Furthermore, depression and social support are also among the most frequently and consistently reported factors influencing quality of life among PLHIV [43], and Bhatia *et al.* have found that newly-diagnosed PLHIV are at high risk for depression and poor linkage to care [44]. Approaches that target self-stigma are therefore likely to benefit psychological function and wellbeing among PLHIV [45]. However, despite the range of interventions that exist targeting external stigma [18,46], there is a paucity of measures that target and provide individuals with tools to manage and overcome *self-stigma* [10]. Furthermore, even in studies where high levels of self-stigma have been reported, as with the Asia-Pacific Stigma Index nine-country study, no specific recommendations for interventions on self-stigma are made [32]. External and internal stigma equally have the opportunity and potential to create harm, and both are components of the wider socially- and structurally-created contexts that lead to marginalisation of PLHIV [17]. Multidimensional approaches are therefore likely to yield the best outcomes, and the application of tailored interventions addressing both enacted stigma and internalised stigma, with the aim of improving treatment uptake and adherence, is supported by a growing body of work [19,20]. There is also a broader need to increase provision of frameworks that enable practitioners to assess the social outcomes of interventions, given the breadth of influence that HIV exerts across all aspects of the lives of PLHIV [47].

Brown and Vanable [48], reviewing the stress-management intervention literature for PLHIV, concluded that there is evidence demonstrating that stress-management interventions

reduce psychological distress and improve psychosocial functioning. These interventions include cognitive behavioural approaches, as well as meditation, mindfulness, and relaxation-based stress management approaches. Kalichman and Simbayi [49] acknowledge that approaches are needed that go beyond mass education and that work within more ingrained belief systems. In their 2011 systematic review of HIV stigma reduction interventions, Sengupta *et al.* also highlighted the need to incorporate research that builds understanding of stigma, and its drivers, to help create targeted interventions [18].

In this paper, we focus specifically on an intervention to address self-stigma among PLHIV in Zimbabwe, but similar interventions could likely be designed, and similar outcomes achieved, in relation to other chronic illness and diseases. The HIV prevalence in Zimbabwe for 2016 (most recent data at time of writing) is estimated to be 13.5%, with around 1.4 Million PLHIV, approximately 720,000 of whom are women aged 15 years and up [50]. HIV Stigma continues to affect the lives of Zimbabwean PLHIV, with 65.5% of the 1,905 respondents to the 2014 Zimbabwe HIV Stigma Index reporting that they had experienced HIV stigma in one form or another. Among these, social exclusion and physical harassment or threats were the most common (21% and 19% of respondents, respectively). Within this context, internalised stigma also occurred, with 18.9% experiencing guilt or low self-esteem due to their HIV status, 17.9% experiencing self-blame, and 16.7% feeling ashamed. Fear of received stigma was also prevalent, with 37.2% afraid of being gossiped about, 17% afraid of sexual rejection, and 15.4% afraid of being verbally insulted [51].

In light of the persistence of self-stigma, and the lack of proven interventions to address it, it is necessary to seek measures that support individuals to navigate it, particularly at a local level, adapted to the communities in which those most affected by self-stigma live. Participation of communities and local stakeholders has been identified as both a need and an enabler of comprehensive HIV prevention, treatment, and support in several settings, including Zimbabwe [42,52,53].

The multidimensional nature of stigma necessitates development of approaches that operate at different levels. As an addition to that toolkit of interventions, we sought to examine the potential role of a stress reduction intervention, “Inquiry-Based Stress Reduction (IBSR): The Work of Byron Katie”, to help PLHIV to navigate self-stigma utilising a protocol derived from methods used in “The Work of Byron Katie” [54,55], and adapted for use in the Zimbabwean context. IBSR: The Work of Byron Katie is a facilitated meditative technique of self-inquiry used to manage stress and other negative thoughts, and this method has been previously demonstrated to positively affect psychological scales and mental health [56], as well as reducing psychopathologic symptoms such as depression, anxiety, and obsessive-compulsiveness [57] in non-clinical groups. Elsewhere, the stress reduction approach using other interventions such as mindfulness has demonstrated positive effects in improving psychological status and reducing impact of HIV treatment side effects [58,59]. The first IBSR: The Work of Byron Katie pilot clinical trial has been completed in breast cancer survivors in Tel Aviv, reporting significantly lower levels of fatigue and improved sleep quality, as well as physical, social, familial, emotional and functional wellbeing [60]. Furthermore, IBSR: The Work of Byron Katie has also recently been shown to be effective in improving psychological symptoms and quality of life in a pilot clinical study by Smernoff *et al.* in a non-clinical setting [61], and it has also been used in a randomised controlled trial to examine the effect on psychological wellbeing among oncologically-healthy carriers of the BRCA1/2 mutation [62]. Similar interventions can potentially be a cost-effective means to control stress and improve quality of life among the general population [63] (also reviewed in [64]), and have also been shown to create reductions in psychological distress, sleep disturbance and fatigue, as well as increases in positive psychological outcomes, in cancer patients—reviewed in Rouleau *et al.* [65].

IBSR: The Work of Byron Katie has not previously been used to address HIV self-stigma, and has not been used in Zimbabwe. However, it was chosen opportunistically in this case since NFF and DNC are certified facilitators of the Work for Change, and both have past exposure and familiarity with IBSR as well as working in the area of stigma and PLHIV. Additionally, there was an opportunity afforded by the existing working relationship between Trócaire in Zimbabwe with the CONNECT Zimbabwe Institute of Systemic Therapy (ZIST) and the Zimbabwean National Network of PLHIV (ZNNP+). For these reasons, we decided to explore the potential of IBSR as a means of overcoming self-stigma among people living with HIV in the Zimbabwean context, taking into account its potential as a psychosocial intervention as demonstrated by others, as well as the thematic alignment of its techniques with the professional counseling expertise of staff at CONNECT ZIST.

This pilot study was designed to test the possible influences and acceptability of IBSR: The Work of Byron Katie in the management of HIV self-stigma, and the following research questions were formulated:

1. Does the intervention using IBSR: The Work of Byron Katie have the potential to influence self-stigma?
2. Does the intervention have potential to influence stigma-associated states, such as shame, fear around disclosure, and depression?
3. Does the intervention have potential to influence other areas of participants' lives beyond HIV self-stigma?

Prior to commencing this pilot study, no local facilitators existed, therefore we conducted the intervention using internationally-certified facilitators sourced from outside Zimbabwe. This helped ensure that the intervention could be delivered with sufficient consistency and quality. We intended that this pilot study would help inform further studies that would a) explore any positive effects that might arise following to the intervention, and b) further refine the intervention itself. It would also lay the groundwork to create a programme to train local facilitators sourced from Zimbabwe and trained in the same manner, and to the same standard, as the internationally-certified facilitators, moving towards an entirely Zimbabwean-led programme of support for PLHIV to deal with self-stigma.

The intervention: Inquiry-Based Stress Reduction: The Work of Byron Katie

Our findings and recommendations from a formative qualitative study identifying core beliefs underlying self-stigma among PLHIV in Ireland [12] informed the design of an operations research intervention pilot study that used a 12-week programme using techniques from IBSR: The Work of Byron Katie. Based on the research findings, a curriculum was designed to support participants to question and work through self-stigmatising beliefs (see Fig 1, reproduced from [12]). Technical support and curriculum development was carried out by International Certified Facilitators of the Work of Byron Katie, coordinated by The Work for Change organisation (<http://www.theworkforchange.org>). International Certified Facilitators have previously completed certification with The Worldwide Institute for the Work (<http://www.instituteforthework.com>) conducted over 2–5 years, consisting of 620 hours of study incorporating face-to-face workshops, facilitated remote classes, client contact hours, self-inquiry, and peer and mentor methods.

The intervention curriculum was designed to start with a number of universal stressful thoughts about being HIV positive and from there to work systematically through more acute

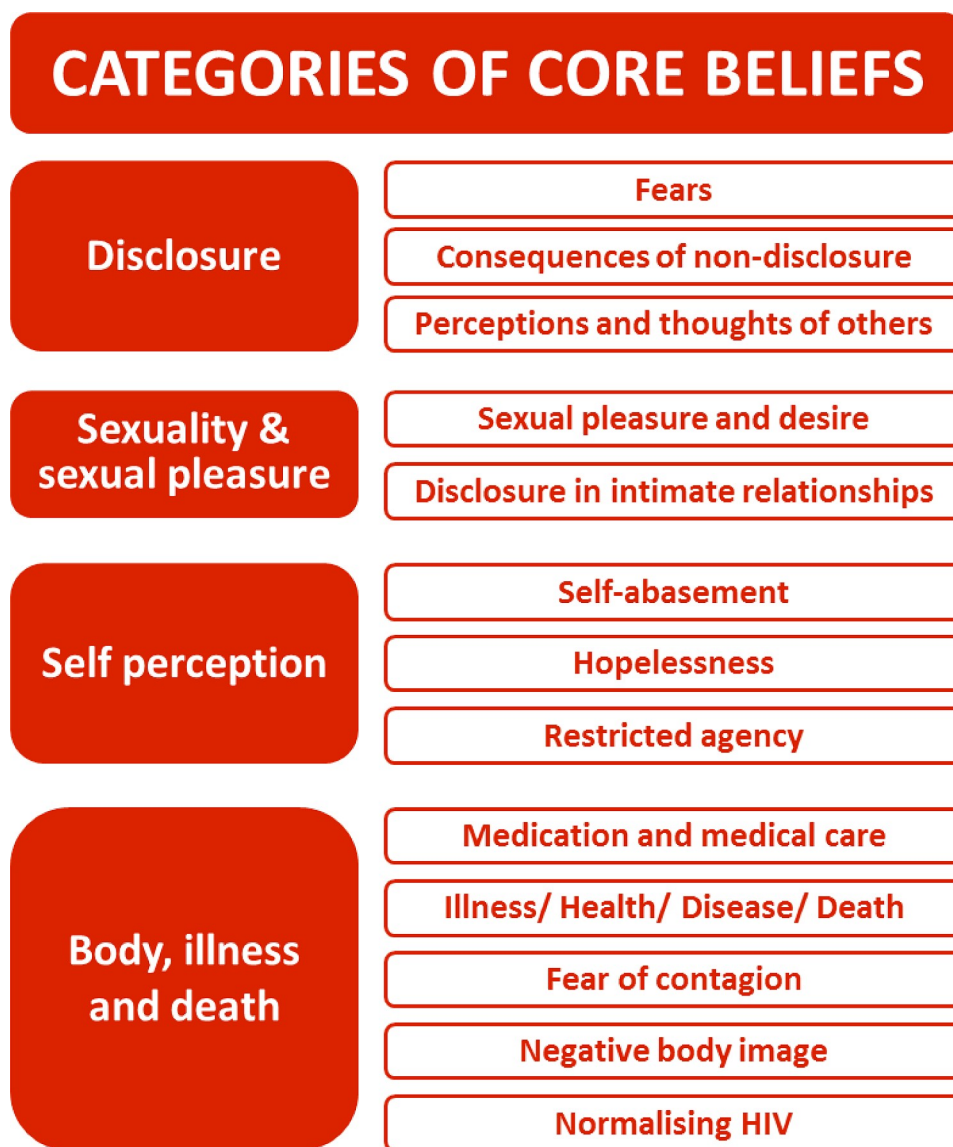


Fig 1. Core beliefs which contribute to HIV self-stigma. Showing core beliefs contributing to HIV self-stigma among persons living with HIV (unshaded boxes), which fall broadly across four categories (shaded boxes): Disclosure; Sexuality & Sexual Pleasure; Self-perception; and Body, illness and death. (Reproduced from Ferris France *et al.*, 2015 [12] (Swiss Med Wkly. 2015;145:w14113) under a CC-BY License with permission from EMH Swiss Medical Publishers Ltd., original copyright 2015).

<https://doi.org/10.1371/journal.pone.0210152.g001>

self-stigmatising core beliefs at a deeper level each week. During the process, participants were encouraged to identify, and inquire about, their stressful thoughts regarding shame, HIV status disclosure and other HIV-related issues, sexuality, sexual pleasure and intimate relationships, self-judgements and body, illness and death. The intervention aimed to improve management of specific emotional and psychological symptoms (relating to self-worth, stress, anxiety, depression, fears), and physical symptoms such as fatigue, and managing other medication-related side effects.

Through the use of self-inquiry, subjects were taught to increase awareness of their thoughts and feelings, and to observe their emotional and physical responses during situations

perceived by them as stressful. The participant appraises their thoughts using the following questions: (1) *Is it true?*; (2) *Can I absolutely know that it is true?*; (3) *How do I react when I believe that thought?*; and (4) *Who would I be without the thought?* This process is meditative and reflexive, and the participant is guided to search for the true and genuine answers to the four questions with no certain agenda or censoring of thoughts. In this way, the participants become more aware of their self-stigmatising thoughts as they occur. The final stage involves ‘turnarounds’, where by turning the original thought or belief around in different ways—to the self, to the other and to the opposite, the participant experiences different interpretations of their own reality. By finding three genuine examples where each ‘turnaround’ is as true as the original thought, participants gain understanding of the power of stressful thoughts, and the ability to question these thoughts. This can help in managing their own thoughts to better cope in what had previously been highly stressful situations [54,66].

In doing so, subjects took an active role in investigating their stressful thoughts, regulating their stress and managing symptoms and emotions, thus enabling them to cope better with the distress related to self-stigma as a result of HIV. Two local facilitators worked with international certified facilitators to deliver and adapt the programme with two groups of participants (23 in total) drawn from support groups within ZNNP+. The participants took part in 12 four-hour group sessions run over 12 weeks at CONNECT ZIST, a weekly one-hour individual session with a facilitator also at CONNECT ZIST, as well as homework. Tools from IBSR: The Work of Byron Katie were used throughout the course to support participants to identify and list their beliefs and thoughts. A participant was considered active if they were present in at least 90% of the group and individual sessions. Participation was not incentivised.

Materials and methods

Ethical approval

Participants took part in this study freely and their involvement was not incentivised in any way. Prior to commencing the study, participants were asked to give written informed consent, and they were free to withdraw from the study at any time. Ethical approval for this study was granted by the Medical Research Council (MRC) of Zimbabwe (approval number MRCZ/A/1782). The Royal College of Surgeons in Ireland (RCSI), Trócaire, and CONNECT ZIST, did not themselves require separate ethics submissions, and agreed to collaborate subject to the granting of the ethical approval by the MRC of Zimbabwe.

Participant recruitment

Participant recruitment commenced on 28 October 2013 and ended on 21 February 2014. Follow-up ended on 30 August 2014.

Clinical trial registration

This study was retrospectively registered as a clinical trial in the ISRCTN Registry (<https://www.isrctn.com/>), registration number ISRCTN17045085 (<https://doi.org/10.1186/ISRCTN17045085>) We had not registered this study as a clinical trial before commencement due to unfamiliarity with guidance around classification of trials. Nonetheless, ethical requirements by the Medical Research Council of Zimbabwe, our funders Trócaire, and partner organisations, were fulfilled throughout the study, with full protection (confidentiality, anonymity) and support given to the study participants, and all data has been reported faithfully without omission or bias towards positive or negative outcomes. There are currently no ongoing trials related to this study.

Adaptation of the intervention for the Zimbabwean context

This was the first trial of the IBSR: The Work of Byron Katie methodology to be conducted in Zimbabwe, as well as in the context of HIV self-stigma. The adaptation of the intervention and associated materials were greatly facilitated by involvement of the CONNECT Zimbabwe Institute of Systemic Therapy (<http://www.connect.co.zw/>). CONNECT is a welfare organisation established in 1983, registered with the Zimbabwean Department of Social Welfare in 1985, which conducts community outreach, counselling, training, and research incorporating psychosocial interventions around mental health care for people living with HIV and other conditions. These links were critical in facilitating participant recruitment, as well as logistical aspects of the project. The intervention was adapted for use in Zimbabwe through collaboration between CONNECT, Trócaire, The Work for Change, and the RCSI research team. To ensure truly local adaptation, two Zimbabwean PLHIV were supported to attend a nine-day IBSR: The Work of Byron Katie training workshop in Germany, who then worked together with International Certified Facilitators in designing the curriculum. Systematic debriefings following delivery of each session with local and international facilitators ensured adaptation of the sessions to the local context where some modules were created to respond to cultural beliefs that emerged during discussions. Local Zimbabwean staff also role-played using the intervention tools to ensure suitability, and were present throughout the intervention workshops to assist with translation of uncommon phrases, and to help with clarification of materials by adapting them into the local idiom.

Study design

Since this was the first time the intervention had been used against HIV self-stigma in Zimbabwe, we adopted a sequential explanatory mixed methods design for this study [67] (Fig 2), in order to gain a deeper understanding of any possible influences than could be gained by quantitative measurement alone. Our dual aims were a) to measure the *quantity and direction* of changes in self-stigma and associated states as a result of the intervention, and b) to investigate possible reasons *why* these changes occurred, and what other areas of participants' lives might be affected. Addressing the first aim, we used quantitative questionnaires that incorporated previously-validated and well-established scales to measure HIV self-stigma, depression, and

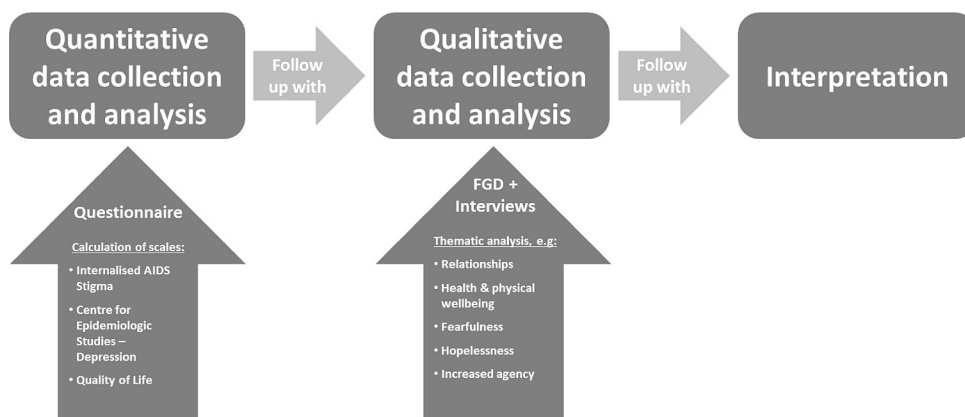


Fig 2. Sequential mixed methods study design. Initial data collection and analysis of quantitative scales was carried out using a questionnaire delivered to participants, incorporating items from the Internalised AIDS Stigma scale; Centre for Epidemiologic Studies–Depression scale; and HIV/AIDS Targeted Quality of Life Scale. This was followed by qualitative data collection and thematic analysis from Focus Group Discussions and one-on-one Interviews.

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HIV-associated quality of life. In parallel to this, to achieve the second aim we employed semi-structured qualitative interviews and focus group discussions to gain understanding of the drivers of self-stigma among the participants and the ways in which they might have been influenced by the intervention, and uncover any unexpected areas which could be targeted in future interventions against HIV self-stigma.

Data collection

Questionnaires, FGDs and interviews were administered by members of the research team (NFF, GS) in private locations at CONNECT ZIST (the same facility where the intervention took place). Intervention facilitators were an equal balance of female and male, and all had previously worked in qualitative and/or quantitative research with PLHIV, in academic and NGO contexts. Researchers administered a structured questionnaire to all participants on three occasions: a day before the course, 1 month after the course and at 3-month follow-up. (For complete questionnaire see Supporting Material [S1 File](#)) Two separate focus group discussions (FGDs) (average duration 1h 32min.) were held on the day before, and a month after the intervention. Each FGD aimed to access an equal number of female and male participants. Six key informant interviews (average duration 26 min.) were also conducted with participants post-course. The FGDs and interviews were conducted in a semi-structured manner, guided by a set of open-ended questions such as “If you had to describe what you got out of this course, what would you say?”, with minimal interviewer interjections except to clarify or probe for greater detail. (The semi-structured FGD and interview guides are reproduced in full in Supporting Material [S2 File](#)) The interview / FGD members were drawn from the overall pool of 23 participants, and participants volunteered themselves for individual interviews following a general call, with no incentivization or pressure to take part. The interview participants all also took part in the FGDs. None of the interviewees and focus group members requested transcripts after participating. All interviews and FGDs were conducted in English. Data were anonymised after collection, with individuals only known by their participant number. Team members performing analysis were blind to the identity of the participants.

Quantitative analysis

The structured questionnaire included scales and components of the Internalised AIDS Stigma Scale (IASS) [10] (12 items), the Center for Epidemiologic Studies Depression Scale (CES-D) [68] (20 items), and the HIV/AIDS Targeted Quality of Life Scale [69] (28 items), to measure mood, perceived stress, and quality of life. Participants gave responses to questions on Likert-type scales, for example ranging from “strongly disagree” to “strongly agree”. Responses were then coded numerically, and scale scores were calculated as the average of the items in the scale. The responses were matched by individual and analysed longitudinally. No scores were missing at any time point. Results of participants’ responses (raw data can be found in Supporting Material [S3 File](#), and calculations in the Supporting Material [S4 File](#)) on these scales were calculated using STATA version 15 (Stata Corp, Texas, USA). Changes in score, together with their interquartile range (IQR) are presented. Changes in scores between baseline and 1- and 3-month follow-up were analysed using the Wilcoxon matched-pairs signed rank test. As a measure of effect size, we calculated r , based on the Z value of the Wilcoxon test, using the transformation $r = Z \div \sqrt{N}$.

Qualitative analysis

The FGDs and interviews explored the concepts of stigma, self-stigma, depression, stress and quality of life, as well as the perceived triggers and consequences thereof on participants’ lived

experiences. Discussions and interviews were recorded with prior informed consent, transcribed, then analysed using a semi-inductive iterative coding strategy in QDAMiner Lite version 1.4.1 (Provalis Research, Montreal, Canada), including themes derived from our previous work [12], and new themes as they arose during coding. Three members of the research team (SM, NFF, EB) independently analysed transcripts until saturation was reached, then met to review for consistency and finalise the list of themes. For clarity in analysing the participants' experiences of external and self-stigma, we chose to arrange categories and themes to distinguish internal challenges due to emotions, feelings, and anticipation of events, as well as tangible external experiences and outcomes. As a result, some categories appeared to overlap thematically but were kept distinct for the purposes of our analysis. For example, we coded *Negative Perceptions of Others* (Category) > *Perceptions of PLHIV* (Theme), where participants reported experiencing stigma or witnessing other people relating negative preconceptions about PLHIV. This was in contrast to *Fearfulness* (Category) > *Disclosure* (Theme) > *Afraid of what others will think* (Sub-theme), in which participants reported that they themselves had felt afraid of the consequences if their HIV status were to become known. (For full list of themes, see Supporting Material [S5 File](#))

Participants

23 individuals volunteered for this study following an open call for participants between October 2013 and February 2014. All were members of Harare-based support groups which were part of the ZNNP+ network. At least 24h prior to taking part, participants were given an information leaflet outlining the purpose of the research, assurance of anonymity, confidentiality, and the right to withdraw at any time. 17 participants were female; 6 were male, and average age was 41 years, ranging from 25–54. Due to the stigmatised nature of minority sexual orientations in Zimbabwe, we did not ask participants to disclose their sexual orientations during recruitment, nor did we ask if they had acquired HIV through heterosexual or homosexual activity. Further participant details are included in [Table 1](#). All 23 participants received the intervention, and all took part until completion (all participants took part in all required sessions), commencing in late February 2014, with final follow-up in August 2014. None were lost to follow-up. Participants were not previously known to the researchers before taking part in the study. Individuals were approached to take part in FGDs and interviews opportunistically, and none declined to participate. Eligibility criteria: Participants included were: 1) Individuals living with a positive HIV diagnosis for longer than three months; 2) Over 18 years of age; 3) Able to speak English with sufficient fluency to take part in group discussions; 4) Willing to provide informed consent and sign an informed consent form. Individuals excluded were: 1) Individuals with unknown HIV status; 2) Individuals diagnosed with HIV in the last three months; 3) Individuals currently undergoing psychotherapy treatment.

Results

Participant-reported improvement of self-stigma and associated measures post-intervention

Significant changes across a number of measures relating to self-stigma were reported by participants at follow-up, after taking part in the intervention. Follow-up scores for self-stigma were significantly improved (i.e. self-stigma was reduced) at both 1-month ($Z = 2.1, p = 0.039$) and 3-month ($Z = 3.0, p = 0.003$) timepoints compared to baseline. A similar trend was also recorded for depression at 1-month ($Z = 3.7, p = <0.001$) and 3-month ($Z = 3.3, p = 0.001$)

Table 1. Characteristics of study participants. Showing participants' age, sex, partnership, education, and employment status, and whether or not they had children.

Age (years)		
	Mean	41
	Range	25–54
Sex		
	Female	17
	Male	6
Antiretroviral (ARV) use (years)		
	Average no. of years on ARVs	6.8
	Range	3–13
Living with stable partner		
	Yes	15
	No	8
Currently employed		
	Yes	7
	No	16
Completed form 4 education		
	Yes	15
	No	8
Has children		
	Yes	23
	No	0

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timepoints. Daily activities were also improved at 1-month ($Z = 2.8, p = 0.005$) and 3-month ($Z = 2.8, p = 0.004$) timepoints. View of the future was not significantly different at the 1-month timepoint ($Z = 1.3, p = 0.198$), but was significantly improved at 3-months ($Z = 2.1, p = 0.033$). Feelings about being HIV-positive also were not significantly improved at the 1-month timepoint ($Z = 1.0, p = 0.323$), but were significantly improved at 3-months ($Z = 2.1, p = 0.038$). Fears around disclosure of HIV status were significantly reduced at both 1-month ($Z = 2.0, p = 0.046$) and 3-month ($Z = 2.0, p = 0.047$). Life satisfaction was significantly improved at the 1-month timepoint ($Z = 2.4, p = 0.017$), but not at 3-months ($Z = 1.7, p = 0.098$). No significant differences compared to baseline were reported for social support (total) (1-month $Z = 0.5, p = 0.615$; 3-month $Z = 1.5, p = 0.132$), social support (intimacy) (1-month $Z = 0.61, p = 0.543$; 3-month $Z = 1.2, p = 0.235$), or social support (help from others) (1-month $Z = 0.8, p = 0.402$; 3-month $Z = 1.5, p = 0.144$) ($n = 23$; results summarised alongside median difference, IQR, and effect size, in Table 2).

The quantitative data from the questionnaires showed that after taking part in the IBSR: The Work of Byron Katie programme, participants reported significant and sustained changes across several areas of their lives. However, whilst this clearly indicated the size and direction of the change, the scales used did not capture information regarding the circumstances, as well as the underlying drivers of such change. To address this, and to gain deeper understanding of the participants' experience of living with HIV, the FGDs and one-to-one interviews were analysed to capture a greater understanding of the complexities behind the data. In combination with post-course FGDs and interviews, this analysis allowed for the exploration of the wider context surrounding living with HIV, and the underlying sources of stress, stigma, self-stigma and associated negative outcomes, with which participants had been living, and often struggling to cope with, for many years.

Table 2. Quantitative results from self-stigma and associated measures questionnaire post-intervention. Showing baseline median, median difference and interquartile range, Z-score, effect size, and significance, between baseline and 1- or 3-month follow-up timepoints, for participants' self-reported scores in scales for Self-stigma, Depression, Daily activities, View of the future, Feelings around being HIV+, Fears around disclosure, Life satisfaction, Social support (total), Social support (intimacy), and Social support (help from others) (n = 23).

Outcome measure	Baseline median	Baseline– 1 month				Baseline– 3 month			
		Median difference (IQR)	Z	Effect size (r)	sig	Median difference (IQR)	Z	Effect size (r)	sig
Self-stigma	0.83	0.17 (0–0.8)	2.1	0.43	0.039	0.5 (0–0.8)	3.0	0.62	0.003
Depression	1.25	0.3 (0.1–0.7)	3.7	0.77	<0.001	0.3 (0.1–0.7)	3.3	0.67	0.001
Daily activities	1.4	0.4 (0–1)	2.8	0.59	0.005	0.4 (0–1.2)	2.8	0.60	0.004
View of the future	1.67	0.3 (–0.3–0.7)	1.3	0.27	0.198	0.3 (–0.3–1.3)	2.1	0.44	0.033
Feelings around being HIV+	0	0 (0–1)	1.0	0.21	0.323	0 (0–1)	2.1	0.43	0.038
Fears around disclosure	0.4	0 (0–0.4)	2.0	0.42	0.046	0.2 (0–0.6)	2.0	0.41	0.047
Life satisfaction	2.75	0.75 (–0.1–1.3)	2.4	0.50	0.017	0.5 (–0.2–1.3)	1.7	0.35	0.098
Social support (total)	2.25	0.1 (–0.17–0.33)	0.5	0.11	0.615	0 (–0.17–0.6)	1.5	0.31	0.132
Social support (intimacy)	2.4	0 (–0.2–0.4)	0.61	0.13	0.543	0 (–0.2–0.6)	1.2	0.25	0.235
Social support (help from others)	2.14	0.1 (–0.3–0.3)	0.8	0.17	0.402	0.1 (–0.6–0.2)	1.5	0.30	0.144

<https://doi.org/10.1371/journal.pone.0210152.t002>

Self-stigma and negative influences on participants' lives: Fearfulness, shame, guilt, hopelessness, worthlessness, restricted agency, and negative perceptions of others

The narrative recounted by participants regarding HIV before the intervention, the circumstances surrounding their infection, and the possible influence this would have on their lives thereafter, was overwhelmingly negative. Participants' responses broadly fell into categories including *Fearfulness*, *Shame*, *Guilt*, *Hopelessness*, *Worthlessness*, *Restricted Agency*, and *Negative perceptions of others*.

The first category, *Fearfulness*, was experienced in a number of ways—for example, fear surrounding disclosure of one's HIV status to others, fear for their dependents in the event of their death, and fear for their personal health:

“Before I attended the course, I thought that I may die soon. I was afraid of the side effects of ARVs. I disliked being positive.” Post-course Interview Participant A10

A fear of suffering from other diseases which could accompany, or be worsened by, HIV was also reported by the participants. It became clear that they obviously had access to knowledge surrounding the broader health risks presented by living with HIV, but they also lacked mental tools or training to cope with the accompanying psychological burden:

“When I fall sick, I think the worst. For example, when I have rash on my body, I think its Kaposi Sarcoma . . . When you start coughing, you think its TB . . . Whenever I fall sick, I think the worst.” Pre-course Focus Group A

Some also spoke of experiencing several dimensions of *Shame* and *Guilt*—for example being ashamed of themselves as a person living with HIV, or over becoming HIV positive, as well as blaming those who had infected them, with some adding a negative dimension to ordinarily-positive life events:

“When I tested positive, I was ashamed of myself. I blamed myself for getting married.” Pre-course Focus Group B

Within the category of *Hopelessness*, some participants reported feeling that their life was effectively over upon receiving their HIV positive diagnosis:

“After seeing that the results were positive, I felt it was the end of my life. I felt being vulnerable and being manipulated . . . The moment I was alone I became afraid, fearing the unknown . . . I was staying at home always, not doing anything. . . I told myself that I will not buy any new clothes. I didn’t want my relatives to take away my possessions upon my death.” Pre-course Focus Group A

Some participants also reported holding negative beliefs about themselves, which fell into the broader category of *Worthlessness*, for example lack of self-worth, and which contributed to *Restricted agency*:

“I thought I was useless. Why should I go on and be educated when I’m [HIV] positive? I didn’t think I will live longer. It was like a death sentence to me. I just didn’t think there was life after being tested positive.” Pre-course Focus Group A

Participants also often spoke of their sense of loss after their HIV diagnosis, describing negative situations that being HIV positive had caused. This in turn had perpetuated their sense of self-stigma:

“I tested positive in 2005. I lost everything that I had. I lost my beloved wife and son. I lost my job. Life was not easy. My in-laws took my children away from me. I just started staying alone. I suffered feelings of shame, guilt and loneliness.” Pre-course Focus Group B

Participants also spoke of the external stigma that they had received, which broadly fell into the category of *Negative perceptions of others*—this often manifested as negative perceptions of HIV, or those living with HIV. Some participants had believed that a diagnosis of HIV meant that life was effectively over, and this belief was also held by some families, resulting in an overarching attitude of pessimism towards those living with HIV:

“One of my family members started isolating me from the family discussions. She was saying I was HIV positive and not capable of taking part in the discussions. It was as if the virus had affected my brain and I could no longer think or contribute anything.” Pre-course Focus Group B

Commonly-held perceptions of the source of an HIV infection also coloured interactions of others with the participants following a diagnosis of HIV:

“When I tested positive in 2008 and told my husband the results, he started throwing things everywhere in the house, calling me a prostitute.” Pre-course Focus Group B

Participants frequently reported that the impact of their HIV diagnosis extended beyond specific worries about physical health and dying: here, far more complex situations were reported, often exerting a significant detrimental effect on family and social lives. In particular, the reactions of family or social groups to an individual’s HIV status were frequently negative and disowning, rather than supportive:

“My sister’s husband couldn’t understand my situation and refused to keep me with my child. He said it was your fault to be HIV positive. I went on to stay with someone who was not my relative.” Pre-course Focus Group B

In addition to the seriousness of HIV/AIDS itself, often commonly-held (and frequently inaccurate) perceptions of HIV, and those who carry it, also coloured interactions of others with the participants following a diagnosis of HIV:

“When I tested positive in 2008 and told my husband the results, he started throwing things everywhere in the house, calling me a prostitute.” Pre-course Focus Group B

Participants reported that following HIV diagnosis, many aspects of their lives were subsequently impacted, contributing to self-stigma and stress, which had become significant moderators of self-perception, agency, and outlook. Whilst arising from many different sources, the outcome was consistently an adverse mental state which contributed to limitation on that individual's personal agency or ability to live in a manner that sustained wellbeing:

“I would always occupy myself with stressful thoughts.” Post-course Interview Participant A11

Possible influences of the intervention on self-stigma and personal wellbeing: Change and coping strategies

When speaking of the possible influences in their lives following the intervention, participant responses largely fell into the theme of *Change*, referring to multiple areas of their lives which had improved, and *Coping strategies*, encompassing the mechanisms and activities which were helpful in overcoming self-stigma, and building self-esteem and wellbeing. Examples of these included building acceptance of one's HIV positive status, and growing self-support such as taking on a positive mentality and overcoming negative thoughts.

Complementing the quantitative measures which indicated significant and lasting improvements in participants' wellbeing, a common qualitatively-reported outcome was that taking part in the intervention had fostered positive change throughout participants' lives as a whole:

“My life or the way I conduct myself should tell that I have been through this programme. People who live with me should see that my life has changed. They should see the change in me.”
Post-course Interview Participant A11

The post-intervention interviews and discussions yielded further detail regarding the circumstances surrounding these changes. Improvements had occurred across many areas, ranging from self-perception, personal appearance and self-care, through to interactions with family, colleagues and friends, as well as changes in outlook surrounding living with HIV. In particular, participants reported the realisation that overcoming self-stigma was an important step towards being able to mitigate stigma received from others:

“I learnt that the moment I worry about what people think about me, I am stigmatising myself. By stigmatising myself, I withdraw. When I withdraw, I am now allowing people to stigmatise me because I will be watching every movement that they will be doing. Yet it's not them doing it to me but it would be me doing it to myself. Through doing ‘The work’, I feel that I am able to mix and mingle with anyone. I am no longer worried about what people think or say about me because the moment I do that I will be stigmatising myself. I now have a very free mind and I am now an outgoing person.” Post-course Interview B6

Prior to taking part in the intervention, many perceived themselves to be 'different' or separate from others due to their HIV status, and as a result felt unable to view themselves, or be

viewed, as 'normal'. Following the intervention however, a theme of acceptance was reported, which helped in coping with difficult internal thoughts:

"I have learned to accept my thoughts with understanding. The stressful thoughts that I have are not different from what other people are experiencing." Post-course Focus Group A

When speaking about difficulties encountered during interactions with others resulting from living with HIV, it was evident that many of the participants experienced shame, or worries about what others thought of them as PLHIV, however the intervention had enabled them to regain their sense of self-confidence:

"I used to be ashamed of myself. I didn't have confidence of what I was doing. Because of this training I am no longer ashamed of myself and the fact that I am [HIV] positive." Post-course Interview B4

Diminished feelings of shame and self-limitation were also accompanied by an enhanced feeling of self-worth as well as renewed self-agency, where participants reported that they now felt they could live in the same manner as those who are HIV negative:

"I have realised that with or without HIV, I am able to do what other people who are not HIV positive can do. I have discovered that I have got no limitations." Post-course Focus Group B

Several of the participants had described situations prior to the intervention where they felt uncomfortable disclosing their HIV status to others, however having taken part in the course, they had become significantly empowered to discuss such issues and were more comfortable in disclosure—in some cases experiencing unexpected positive outcomes:

"I used to find it difficult to disclose my status to some of my relatives. Due to the course, I have disclosed my status to those relatives. To my surprise, what I thought would be their reaction was totally different from what they did. I thought that some of them would be shocked and they would isolate me but nothing changed and their love for me has increased. I no longer have a problem of disclosing my status even during social forums that I normally attend." Post-course interview Participant B9

When speaking of education and knowledge following the intervention, participants' responses were not limited to the benefit gained in dealing with internal thoughts: techniques and knowledge from the programme had been brought into a wide range of areas throughout their lives, for example improved communications with family members, and reduced social isolation. Furthermore, participants reported the intention to use the new knowledge gained to support other PLHIV. It was apparent that the intervention had presented them with a valued tool that potentially enabled them to manage the effects of their self-stigma, and in doing so created a sense of empowerment:

"I can deliver this programme in support groups for people living with HIV using the vernacular language. The course can also be delivered in schools using the English language . . . I can deliver the programme well to the women's group at my church. I conduct sessions on positive living at my workplace and I can use that as an opportunity to share what I have learned in the IBSR course." Post-course Interview Participant A4

A further common theme among participants' responses was a shift towards a more positive mentality. Whereas prior to the intervention, many reported pessimism and a lack of hope for the future, the post-course interviews and focus groups presented a more positively-framed outlook:

"I got infected in 1993 but I am in 2013, which is exactly 20 years living with the virus. Now, I think I will even live longer because I have learned to appreciate myself . . . I now look at myself better than what I used to do before. I look at myself as just a person with any other disease such as diabetes or cancer. Right now, I am very healthy and I don't have any complaints." Post-course Interview Participant A11

All of the situations described by the participants were impacted upon by HIV, yet there was a paucity of reports of specific difficulties due to medication, actual HIV-related illness, or access to medical services. Instead, participants reported limitations caused by self- and perceived stigma, and the far-reaching consequences thereof, which were somewhat mitigated following the intervention:

"I now feel very comfortable with my positive status. I love myself. I understand that I can live peacefully whether I have a partner or not. I no longer stigmatise myself. I just feel I am as good as any other person." Post-course Interview Participant A10

Discussion

This pilot study tested an intervention designed to help PLHIV to identify, control, and overcome the internal thoughts and beliefs that had previously created feelings of lowered self-worth, decreased agency, and negative mentality that contribute to self-stigma. Addressing our initial research question, *Does the intervention using IBSR: The Work of Byron Katie have potential to influence self-stigma*, the results clearly showed that after taking part in the intervention, the participants reported a significant reduction in levels of self-stigma. It is also noteworthy that many of the changes were maintained at 3-month follow-up, suggesting that the use of the intervention may facilitate longer-term control of self-stigma, with minimal refresher training. Several studies have indicated that reducing HIV self-stigma may improve access to care and wellbeing among PLHIV [70,71], and our current results suggest that after more complete development and testing, techniques from IBSR: The Work of Byron Katie might be employed in the future as an intervention to help achieve this.

Addressing our second research question, *Does the intervention have potential to influence stigma-associated states, such as fear around disclosure and depression*, we found that measures of both fears around disclosure, and depression, were significantly reduced following the IBSR: The Work of Byron Katie intervention. The reduction of stigma-associated states such as anxiety and depression is likely to improve wellbeing among PLHIV [45], and access to care is also likely to be improved if fears around disclosure can be overcome, particularly for those living in, or originating from, settings where HIV remains highly stigmatised [70,72]. In some cases, such as Life satisfaction, the reported scores were significantly improved at 1-month, but not 3-month follow-up. Conversely, some measures were not significantly improved at 1-month follow-up, but were significantly improved at 3 months, such as Feelings around being HIV-positive, or View of the future. This may have been due to certain aspects of the intervention taking longer to be internalised through repeated practice than others. If subsequent research shows these changes to be genuine effects of the intervention, supports such as

refresher training could be considered to help embed them more fully. It is not currently possible to judge the practical significance of the changes in scores for several reasons. First, the items are scored on arbitrary scales. It is not possible to assert that a specified change in, for example, life satisfaction score represents a 'real' change in life satisfaction. Furthermore, the score changes in this study are estimated from a small sample, and so are imprecise enough to caution against definitive claims. It is, however, encouraging that even in a small sample we were able to show statistically significant changes across a range of measures of wellbeing. Further well-considered research will elicit whether such changes can be replicated across a wider range of participants and contexts, and full attention should be given to understanding the ways in which those findings might translate into practical outcomes for the participants.

Beyond the patients' self-reported reductions in measures such as self-stigma, fears around disclosure, and depression as empirical quantities, our qualitative observations contribute towards answering our third research question, *Does the intervention have potential to influence other areas of participants' lives beyond HIV self-stigma?* The intervention's participants reported a range of improvements across several aspects of their daily lives. Pre-intervention discussions illustrated the extent of participants' negative outlook on life and lack of hope for the future, whereas post-intervention this had changed to a more positive dialogue, including making future plans, and improved self-image. Mannell *et al.*, in their 2014 assessment of indicator frameworks for the HIV response, highlighted the need for greater provision for monitoring the social drivers and outcomes of the epidemic [47], and often the scales used to measure the effects of stigma in HIV define the *how much*, rather than the *why*. Our current results suggest transformative change simultaneously across multiple aspects of an individual's life. This is thematically consistent with our previous research where multiple contributing factors and circumstances shaped core beliefs driving self-stigma among PLHIV, presenting a broad range of areas where targeted support could improve wellbeing and quality of life [12]. Using interventions incorporating IBSR: The Work of Byron Katie to address the underlying causes and outcomes in this holistic manner could therefore represent a useful means to reduce HIV self-stigma.

It was most striking that the reported life changes reported after taking part in the intervention aligned in many cases with measures of psychological wellbeing, as proposed by Ryff and Keyes in 1995 [73] (Fig 3). The Ryff scales reflect dimensions such as self-acceptance, autonomy, life purpose, and personal growth and development—all of which were areas of improvement reported by this study's participants during interviews. We would therefore argue that the incorporation of the Ryff scales into monitoring frameworks to capture greater information about changes to overall wellbeing, as opposed to simply measuring the negative outcomes such as the level of depression or the amount of stigma experienced, or quality of life at a single point in time, will hold significant utility in shaping responses and tracking intervention outcomes among PLHIV. This presents a timely opportunity to add a structured measurement of improvements in *positive attributes*, rather than focusing exclusively on removing negative attributes or problems, and expecting that the patient will be 'well' thereafter. In the current context of HIV prevention and care, this is especially relevant: good medication compliance and access to health services now enable the focus to shift away from merely controlling symptoms and remaining disease-free, towards promotion of wellbeing, maximizing productivity, and achieving life goals, within a normal 72–75 year life span [74,75]. However, this does not necessarily mean that PLHIV will be able to realise this potential; such a shift can only be fully achieved by providing access to health services in a manner that is free from external and internal stigma [76], and the ongoing persistence of self-stigma [18,33] indicates that further modes of support must now be sought and implemented.

Additionally, rather than simply managing the negative symptoms of self-stigma, our current results suggest that changes also occurred in overall wellbeing among participants, driving

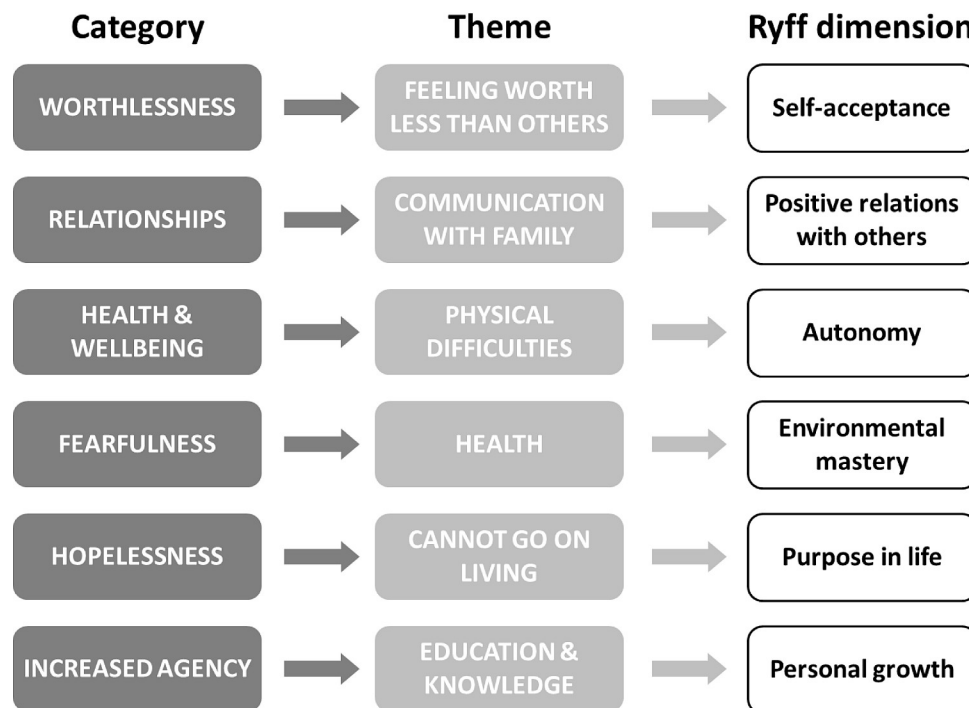


Fig 3. Alignment of themes from participant interviews with Ryff scales of wellbeing. Showing categories (left column, dark grey), and themes (middle column; light grey) which emerged during thematic analysis of participant interviews and focus group discussions. These broadly fell into the six dimensions of wellbeing (right column; unshaded), as proposed by Ryff and Keyes [73], suggesting that this scale may be of future utility in measuring outcomes following interventions that address HIV self-stigma.

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positive behavioural changes such as improved relationships with family, accessing self-improvement opportunities, and passing on knowledge to others. This intervention could therefore be a promising candidate for further investigation incorporating a more rigorous study design and expanded scope to test its potential effectiveness among larger and more diverse populations.

For the purposes of this pilot study we used internationally certified facilitators, although we recognised that this would be a challenge in terms of resources and sustainability. However, we believed that this was a necessary step to show that the IBSR methodology could be delivered and have the potential to influence self-stigma and other associated states within the urban Zimbabwean setting. Given that the intervention was relatively intensive, both in terms of duration, and its use of trained international facilitators, potential avenues for exploration could now include steps to reduce the length of the intervention, for example to distil it to the ‘minimum unit’ required. To this end, we are currently implementing and testing strategies to transition the intervention from its current ‘high-resource’ model towards one which can be suitably scaled up to reach the wider community, supported by locally-sourced and trained facilitators. Eleven local facilitators have now been trained in this method using a ‘train the trainers’ model, whereby the international facilitators adapted the training to be applicable in a low-resource setting. These steps are aiding in terms of retention of participants, as well as in building local expertise, moving away from reliance on bringing in international staff, and the effect of these changes is currently being investigated by CONNECT ZIST, Trócaire, The Work for Change, and RCSI.

Based on our current findings, we suggest that IBSR: The Work of Byron Katie should be investigated further as a novel, community-based intervention to help overcome the self-stigma that prevents PLHIV from pursuing life opportunities to the fullest extent.

Study limitations

This was a small-scale pilot study which accessed participants from a single urban area in Zimbabwe, and did not contain a control group. As such, the results reported here cannot be generalized to the wider population. Future research in this area should incorporate larger pilot studies that feature a control group, before moving towards judicious use of best-practice methodologies including randomised controlled trials assigning participants either to the self-stigma intervention or an appropriately-considered comparator intervention.

Additionally, social stigma around minority sexual orientations in Zimbabwe precluded our asking participants to disclose their sexual orientations during recruitment, and we did not ask whether they had acquired HIV through heterosexual or same-gender sexual practices. Our findings, therefore, may not necessarily be generalizable across all sexual orientations. The characteristics and effects of stigma that affect different genders and sexualities are likely to vary, and future research should aim to investigate these differences in a sensitive manner, providing valuable insight into the complexities of stigma and self-stigma as they exert their effects on varied populations. This will be especially useful since it is likely that different groups will be responsive to different intervention modalities, therefore building the evidence-base in this area will yield important information for implementers.

We also acknowledge that IBSR is an intensive intervention which requires a significant time investment both from participants and skilled facilitators. In this first instance, we utilised facilitators sourced from outside Zimbabwe due to a lack of local facilitators, and to assure quality. Subsequent work is now focused on building a sustainable intervention that is delivered by a team of trained facilitators sourced from Zimbabwe, with the aim of it becoming fully Zimbabwean-led.

Supporting information

S1 File. Questionnaire administered to participants.

(DOC)

S2 File. Guides for pre- and post-programme Focus Group Discussions and post-programme interviews.

(DOCX)

S3 File. Questionnaire responses (Stata .dta file).

(DTA)

S4 File. Stata .do file of calculations performed.

(DO)

S5 File. List of categories, themes, and sub-themes.

(XLSX)

S6 File. Permission granted by EMH Swiss Medical Publishers to reproduce Fig 1.

(PDF)

S7 File. CONSORT flowchart.

(DOC)

S8 File. TREND checklist.
(PDF)

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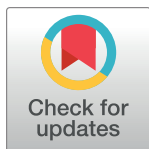
RESEARCH ARTICLE

Exploring the beliefs, experiences and impacts of HIV-related self-stigma amongst adolescents and young adults living with HIV in Harare, Zimbabwe: A qualitative study

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Data Availability Statement: Data cannot be publicly shared due to the interviews revealing HIV status and potentially the HIV status of others, including those in their households. The data has been anonymized and is stored on this project's Figshare account. Upon reasonable request, data can be accessed by contacting the Knowledge and Information Officer, Africaid, 11-12 Stoneridge Way North, Avondale, Harare, Zimbabwe; info@afraid-zvandiri.org; phone: +263 4 335 805.

Abstract

Background

HIV-related self-stigma is a significant barrier to HIV management. However, very little research has explored this phenomenon, particularly in sub-Saharan Africa. This study explored the beliefs, experiences, and impacts of HIV self-stigma amongst adolescents and young adults (AYALHIV) in Harare, Zimbabwe to inform future interventions. It aimed to capture the lived experience of self-stigmatization among AYALHIV and its impact on their social context using Corrigan et al (2009) self-stigma framework of 'awareness', 'agreement', and 'application'.

Methods

Virtual semi-structured key informant interviews were conducted between June and July 2020 with adolescents and young adults (Female = 8; Male = 8) living with HIV (18–24 years) in Harare, Zimbabwe. We conducted the interviews with a purposive sample of AYALHIV enrolled in Africaid's 'Zvandiri' program which provides HIV support services. Interviews were mainly conducted in English and with three in Shona, the main indigenous language. Audio-recorded qualitative data were transcribed, translated into English (where necessary) and deductively coded using Corrigan et al.'s self-stigma framework. The outbreak of SARS-CoV-2 coincided with the commencement of data collection activities, which impacted on both the sample size and a shift from in-person to virtual interviewing methods.

Results

Sixteen respondents (50% male) took part in the interviews. The mean age of respondents was 22 years. All respondents reported HIV-related self-stigma either occasionally or frequently. Three main themes of self-stigmatizing experiences emerged: disclosure,

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relationships, and isolation. These themes were then analyzed within the self-stigma development framework by Corrigan et al. (2009) known as ‘the three As’: awareness, agreement, and application of self-stigmatizing thoughts. Respondents’ experiences of self-stigma reportedly led to poor well-being and decreased mental and physical health. Gendered experiences and coping mechanisms of self-stigma were reported. Data suggested that context is key in the way that HIV is understood and how it then impacts the way people living with HIV (PLHIV) live with, and experience, HIV.

Conclusions

HIV-related negative self-perceptions were described by all respondents in this study, associated with self-stigmatizing beliefs that adversely affected respondents’ quality of life. Study findings supported Corrigan et al.’s framework on how to identify self-stigma and was a useful lens through which to understand HIV-related self-stigma among young people in Harare. Study findings highlight the need for interventions targeting PLHIV and AYALHIV to be context relevant if they are to build individual resilience, while working concurrently with socio-political and systemic approaches that challenge attitudes to HIV at the wider societal levels. Finally, the gendered experiences of self-stigma point to the intersecting layers of self-stigma that are likely to be felt by particularly marginalized populations living with HIV and should be further explored.

Introduction

Stigma is a significant barrier to HIV treatment and management [1, 2]. HIV remains a highly stigmatized condition because of what are considered high risk or taboo behaviors associated with its transmission, such as multiple and concurrent sexual partnerships, homosexual intercourse, drug use and sex work [3–6]. HIV-related stigma can be experienced as social or internalized self-stigma [7]. Social stigma is the outward discrimination towards people living with HIV (PLHIV) [8]. Self-stigma on the other hand, is experiencing negative judgements towards oneself resulting in feelings of worthlessness, shame and emotional distress [9]. For example, a self-stigmatizing thought is, ‘I will never have a future because I am worthless and not good enough.’ There is little research on self-stigma and how it impacts different population groups living with HIV [10]. As a result, this study focuses on the beliefs and experiences of HIV self-stigma amongst young adults living with HIV in Harare, Zimbabwe, an area deeply affected by the HIV/AIDS epidemic.

Corrigan et al. (2009) identify three steps of self-stigmatization [11]. First, one has to have an awareness of a stereotype or negative perception. Then one has to agree with those beliefs, and finally, apply them onto one’s self [11]. This process is described as the three A’s of self-stigmatization, which are awareness, agreement, and application [11].

While social stigma has been the primary focus of HIV stigma research, much less is known about HIV-related self-stigma [10]. Studies have suggested that HIV-related self-stigma can have detrimental physical and mental effects on PLHIV [12]. Research has shown that HIV-related self-stigma can result in non-adherence to HIV medication, lower quality of life and poor mental health [13, 14]. A systematic review found that HIV-related stigma undermined antiretroviral therapy (ART) adherence by compromising general psychological processes (e.g. adaptive coping and social support), and 24/33 (73%) studies reported an association between HIV stigma and ART non-adherence [15].

Researchers found that self-stigma can be experienced almost three times more than social stigma, demonstrating a need to both better understand and address this phenomenon [16]. Data suggest that self-stigma among PLHIV intersects with age, gender and personal experiences [17].

Self-stigma within Zimbabwean/sub-Saharan context

Over 1.4 million people are living with HIV in Zimbabwe and the adult prevalence rate of HIV is 12.7% [18, 19]. Young adults have been identified as a critical population affected by HIV and one third of all new infections in Zimbabwe are currently among people aged 15–24 years old [18, 19]. These young PLHIV can internalize negative stereotypes associated with HIV and experience feelings of isolation, negative self-image, worthlessness and suicidal thoughts [12].

Previous research conducted in Zimbabwe showed that adolescents living with HIV (ALHIV) in Zimbabwe are particularly affected by stigma and self-stigma [20–22]. This report stated that 73% of ALHIV experienced stigma that affected their medication adherence and 47% had virological failure [22]. The stigma experiences reported included abuse, negative self-perception, neglect, social isolation, and discrimination [22]. Additionally, some of the indigenous terms used to identify PLHIV include derogatory terms that translate into “dead one” or “plagued” [23]. This linguistic phenomenon reinforces an unfavorable and hopeless view of HIV [23].

Self-stigma contributes to high drop-out rates from HIV treatment and support programs among young people, leading to increased morbidity and mortality [22, 24, 25]. Self-stigma can cause PLHIV to refrain from HIV testing, default on their medication, avoid going to health clinics and experience mental health problems, which increases negative health outcomes [26]. It is particularly critical to address HIV-related self-stigma in sub-Saharan Africa, a region home to 85% of the world’s adolescents living with HIV and the only population with increasing mortality rates [24, 27, 28].

Study focus and rationale

This research explored beliefs, experiences and impacts of HIV-related self-stigma amongst older adolescents and young adults (18–24 years) in Harare, a group with disproportionately poor HIV clinical and psychosocial outcomes [25, 27, 29]. It aimed to understand the experience of self-stigmatization within this population and context through Corrigan’s framework of self-stigma: awareness, agreement, and application. This understanding will help inform self-stigma reduction interventions in Zimbabwe and sub-Saharan Africa more widely. Addressing HIV-related stigma in general and self-stigma in particular, is important for improving AYALHIV’s clinical and psychosocial outcomes [12].

Methods

Design and setting

We conducted this qualitative study with adolescents and young adults living with HIV (AYALHIV) (18–24 years) enrolled in Africaid’s Zvandiri program, in Harare, Zimbabwe. The Zvandiri (meaning ‘As I am’) program provides services, counselling, medication, and support to children, adolescents, and young people living with HIV in Zimbabwe and eight other countries [22, 30]. Zvandiri aims to directly improve the well-being of this population thereby strengthening their engagement with services across the HIV prevention and care cascades [22, 30]. This study used both convenience and purposive sampling to identify respondents as all were participants in the Zvandiri programme and living, as young adults, with HIV. Sixteen respondents were interviewed; 12 (75%) were trained peer supporters known as Community

Adolescent Treatment Supporters (CATS) and 4 were beneficiaries (a term used in Zvandiri for those clients who are not CATS). Purposive sampling guided an equal selection of females ($n = 8$) and males ($n = 8$). Interviews were conducted between June and July 2020. The outbreak of SARS-CoV-2 coincided with the commencement of data collection activities, which impacted on both the sample size and a shift from in-person to virtual interviewing methods.

Theoretical paradigm and positionality

Deductive reasoning using Corrigan et al's (2009) self-stigma framework [11] informed the development of the interview guide (see [S1 File](#)). Questions were grouped by the three A's of self-stigma: awareness, agreement, and application in order to efficiently analyze the potential experiences of self-stigma [11]. The interview guide was designed as a flexible semi-structured guide in order to facilitate the emergence of respondents' lived experiences. Therefore, this research was both deductive and inductive. Deductive analysis was used with the self-stigma framework to determine if respondents actually experienced HIV-related self-stigma. The discussions with the respondents were compared to Corrigan et al's (2009) self-stigma framework [11] in order to have consistency as to what is considered the experience of self-stigma.

However, an inductive and phenomenological approach was also used to determine the themes within this framework of the beliefs and experiences of HIV-related self-stigma as experienced by the respondents. This inductive approach is rooted in the sociological theory of social constructivism; which understands human experiences as socially created and shaped by a person's engagement with their culture and society [31]. This paradigm describes reality as unique for different individuals based on how they make sense of the world through a combination of history, social norms, and community interactions [32]. The social constructivist approach interprets the phenomenon of HIV-related self-stigma from the perspective of the respondents and their unique context which helped to develop the sub themes within Corrigan et al's (2009) three A's of self-stigma: awareness, agreement, and application [11, 32].

As adult researchers, we also employed self-critical epistemological awareness considering how our own perceptions and experiences could potentially influence interpretation of study findings. Our team included Zimbabwean researchers for local and in-depth context, as well as non-Zimbabwean self-stigma experts. We privileged the voices of study respondents and ensured we set aside our own biases to maximise rigour during data analysis, interpretation, and reporting (e.g., through researcher triangulation).

Data collection, processing and analysis

All interviews were led by CR in English in the presence of Africaid's psychologist (VM) who was known to all research respondents. While the psychologist presence may have had some impact on what the respondents revealed, the familiar support provided by the psychologist ensured the safety and security of respondents and provided immediate emotional support if required. Additionally, the psychologist acted as a live translator in the event that any of the respondents needed to respond in Shona. Any translations were time stamped and recorded in the data.

Due to the COVID-19 pandemic, interviews were conducted virtually through the Zoom video conferencing platform because the lead researcher was unable to travel to Harare. With the support of a travel stipend, respondents came to the Africaid facility and participated in the interviews in a private space. Each interview lasted 30–45 minutes and was recorded with respondents' permission. The recorded interviews were transcribed (and the sections in Shona were translated) verbatim into English.

A summary of the discussion was written following each interview. These summaries and weekly analytical meetings amongst the research team informed development of a provisional coding framework. Half of the interviews ($n = 8$) were then independently coded by two researchers (CR, WM) using Corrigan et al's (2009) framework [11]. Discrepancies were resolved through discussion (with EB) until consensus was reached. Any additional codes identified from this first set of transcripts were added to the coding framework. Transcripts were entered into NVivo 12 (QSR International, Melbourne, Australia) and fully coded using the modified coding framework; care was taken to identify any additional emerging codes. Codes were grouped and emerging themes were identified and supported with verbatim quotes. For example a theme was 'agreement' with negative judgements and sub themes included: worthlessness, hopelessness, and negative body image.

Ethical considerations

This study was approved by the Health Policy and Management and Centre for Global Health Research Ethics Committee in the School of Medicine, Trinity College, Dublin (as it was part of a MSc study for CR) and the Medical Research Council of Zimbabwe as the research was being conducted in Zimbabwe (#2604). Africaid provided information leaflets and consent forms to all the respondents at least seven days in advance of interviews. Written and oral informed consent were obtained from all respondents prior to participation. Confidentiality assurances were given during the consent process. Names and other personal identifiers were removed from transcripts before they were analyzed. All information was stored in an approved cloud account that was double password protected and encrypted for protection. Only the lead researcher had access to the account and transcripts unless recorded permission was given to co-researchers. These procedures met the requirements of General Data Protection Regulation (GDPR) in full. Respondents received US\$5 bus fare reimbursements.

Results

Respondent characteristics

The mean age of respondents was 22 years. Most of the respondents 12/16 (75%), were CATS and equal number of male and female respondents (Table 1). The majority of respondents, 14/16 (88%), disclosed that they were born with HIV.

Corrigan's self-stigmatization framework [11] helped to analyse if the respondents actually experienced self-stigma and if so, what self-stigmatizing beliefs they applied onto themselves and the impacts of that. The data indicated that all the respondents experienced self-stigma (the judgements one has towards oneself including beliefs of worthlessness, hopelessness, and self-blame), but it was not felt all the time. Most of the respondents, 10/16 (63%), experienced self-stigma frequently (4 or more times a week) and 6/10 (37%) self-stigmatized only occasionally (once or twice a week). Study findings were grouped into Corrigan's self-stigmatization framework [11] of the three As: awareness, agreement, and application.

Awareness

The respondents were very aware of negative community beliefs through cultural norms and personal experiences. Fourteen of the sixteen (88%) respondents disclosed that they were born with HIV and were informed about their status at a young age. Therefore, they reported that they had endured years of discrimination, stigma and prejudiced community beliefs. Even those who were diagnosed much later, two of the sixteen (12%), were old enough to have an understanding of how others perceived PLHIV. They reported hearing gossip and negative comments

Table 1. Characteristics of respondents in relation to the Zvandiri program (N = 16).

Respondent ID	Age	Female/Male	CATS or Beneficiary
01	24	Female	CATS
02	19	Male	CATS
03	22	Female	Beneficiary
04	22	Male	Beneficiary
05	24	Male	CATS
06	21	Female	CATS
07	18	Female	Beneficiary
08	20	Female	Beneficiary
09	22	Male	CATS
10	24	Male	CATS
11	23	Male	CATS
12	24	Male	CATS
13	24	Female	CATS
14	24	Female	CATS
15	22	Female	CATS
16	21	Male	CATS

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about PLHIV that made the respondents aware of how their community viewed HIV. Misconceptions about HIV perpetuated the fear and judgements their community had towards PLHIV.

This awareness can come from ‘social stigma’, meaning open acts of discrimination towards people living with HIV. Respondents reported experiencing discrimination from friends, family, classmates and community members.

“My Aunt treats me bad when she comes here [Harare]. She doesn’t even want to sit near me, talk to me or even shake hands with me. It makes me feel worthless.”

(Participant 6, Female, CATS)

“Like from that time, they didn’t want to share like a pen or ruler. And other stuff. And I was treated like someone who is always sick”

(Participant 16, Male, CATS)

Awareness did not come exclusively from ‘social stigma’ and several respondents who had kept their status a secret described how they were aware of their community’s negative perception of HIV. They were cognizant of and internalized the mainstream stereotypes about HIV including that PLHIV are unclean, sleeping around, and contagious to touch.

“In the community it is very difficult because they think HIV is an airborne disease or something. That if you play with someone who is HIV positive that you will end up having AIDS or something.”

(Participant 2, Male, CATS)

Agreement

The respondents agreed with several beliefs that underpin HIV stigma and stereotypes. Community beliefs typically include that PLHIV are dying, dirty, immoral, worthless or to blame for their condition [33].

“Yes, I sometimes internalize it, especially when I am alone. I can agree that I am worthless, or I can’t do certain things.”

(Respondent 13, Female, CATS)

While most of the respondents did not outwardly say that they agreed with these negative beliefs and stereotypes about PLHIV, their responses demonstrated that they did agree with and experienced negative judgements towards themselves. This may be a result of internalizing negative cultural beliefs over time and agreeing with them. The respondents agreed with beliefs of worthlessness, hopelessness, and negative body image.

Worthlessness. When respondents were feeling down about their HIV status, they would describe feeling worthless. They reported that these feelings were more intense when they first found out about their status, causing several to become suicidal. Most respondents (88%) had known their HIV status for at least seven years and described that feelings of worthlessness were more prevalent when they first found out their status. However, the belief of worthlessness was still present and impacting their life.

“When I am not positive [towards myself], I just feel I am not worth it. I don’t deserve to be on this planet at all. Because sometimes my family the way they treat me, it makes me feel like I am a burden to them.”

(Respondent 15, Female, CATS)

These feelings of worthlessness have caused suicidal thoughts for many of the respondents. The respondents reported internalizing the belief that PLHIV did not deserve to live. This demonstrates how HIV-related self-stigma can make the respondents feel worthless and confined by their HIV status.

“Honestly, sometimes I wanted to kill myself. I thought why am I living in this world? I don’t have peace, I want peace. And I want freedom to do what I want.”

(Respondent 5, Male, CATS)

“Initially, when I first found out, I wanted to commit suicide.”

(Respondent 7, Female, Beneficiary)

Hopelessness. The respondents described days where they felt no hope for themselves or their future. This despair could be overwhelming and limiting, causing stress and sadness. This feeling of hopelessness was raised more frequently when discussing issues pertaining to interpersonal relationships with friends, romantic partners, and community members.

“Sometimes it makes me feel that there is nothing that I can do which makes me feel very hopeless and worthless and I become very stressed and I start thinking is there ever a time where I can live my life with people who care about me and love me and accept me.”

(Respondent 13, Female, CATS)

A common community belief is that PLHIV are ‘about to die’. When the respondents agreed with this thought, they felt that their destiny was determined and hopeless. This despair could be overwhelming and limiting, causing them stress and sadness. They reported

frequently asking themselves “why me?” They could not rationalize the suffering that their HIV had caused, making them feel hopeless.

“Why only me? Why only me? Why am I the only HIV positive person in the house? Why, why, why, why.”

(Participant 1, Female, CATS)

Negative body image. Common stereotypes of PLHIV in Zimbabwe and elsewhere are that they are ‘unclean’ and able to spread HIV through touch [7, 34]. Although the respondents knew that these misconceptions were not true, they admitted to internalizing the negative beliefs.

“Yeah, from the beginning I felt that I wasn’t worth sitting around people who are HIV negative because I would feel that I was unclean and that I would make them dirty. It has gotten better though.”

(Participant 14, Female, CATS)

These negative perceptions about their body made them feel like they smelled of HIV, should not sit next to people who are HIV negative, and that they could not be loved. This negative body image caused low self-esteem and inhibited the respondents from living their lives freely.

“When I heard that I was HIV positive, it lowered my esteem, I started being reserved. I started disassociating with people. I felt the self-stigma. I could walk and think it is written on the wall; on my forehead you know? I would walk and think it is readable that you are HIV positive. That it can be seen.”

(Respondent 4, Male, Beneficiary)

Application

After becoming aware of and experiencing HIV-related stigma, the respondents reported internalizing negative judgements expressed by members of their community. The application of these beliefs onto experiences in their lives reinforced their self-stigma. The key themes of self-stigmatizing experiences that became evident in the interviews included disclosure difficulties, self-isolation, and relationship complications.

Disclosure. The respondents reported that disclosure was extremely difficult because a lot of trust and time was needed to be able to tell someone about their HIV status. Disclosure is challenging for these respondents because of negative disclosure experiences and their fears of being socially rejected.

“It is difficult to tell people that you are HIV positive because you will struggle to walk in the community, in the neighborhood because people will humiliate you, they will shout at you, say terrible things about you because you are HIV positive.”

(Respondent 9, Male, CATS)

The respondents reported worrying that they would lose their friends if they disclosed their status due to the shame of HIV. Therefore, many respondents kept their HIV a secret, even to the detriment of their health by quitting their medication.

“So, I was shy, I was embarrassed. Like I was still thinking, what will they say if they know I am like this? Will they even accept me? So, I just quit my medication which was quite stupid.”

(Respondent 4, Male, Beneficiary)

“So, my first year in high school, I was a boarder, and that was quite hard. You know you have to take your medication, but you live in a dorm with I think 8 girls and you need that privacy to take your medication. So, I had to quit.”

(Respondent 3, Female, Beneficiary)

Isolation. Isolation and feeling alone was a common theme in the interview responses. Respondents reported being left out by friends and family, feeling like they had no one to talk to, and self-isolating due to their status. This caused self-stigmatization and feelings of loneliness, shame and being silenced.

Respondents endured being left out and separated from other people because of their HIV status and the belief that PLHIV are dirty or dangerous. Misconceptions by others about the virus caused others to exclude the respondents, causing them to feel alone and ‘unclean’.

“My grandma used to say you guys have to sit there, you have to have your own cups, you have to have your own things, you cannot share with others. So, it was so hard for me because always I couldn’t do what other kids could do because I was always being separated from other kids.”

(Respondent 14, Female, CATS)

Experiences of stigma caused so much humiliation that the respondents felt deeply ashamed of their status and would isolate themselves. Respondents reported that their shame would hold them back from socializing with others, making them feel alone and without anyone to talk to.

“It is very painful, and I feel sad and sometimes I cry about it. And sometimes I feel that I shouldn’t even walk in the street or do things”

(Respondent 13, Female, CATS)

“It was really hard because I had no one to talk to. No one to express how I felt and even my own family, they didn’t even understand.”

(Respondent 15, Female, CATS)

Respondents often felt alone because of their HIV status and unable to speak their minds. These feelings were perpetuated through self-stigmatization by believing they were not worthy enough to have a voice.

Relationships. Relationships were a significant source of stress and self-doubt for respondents. As adolescents and young adults, all respondents had either experienced being in a relationship or expressed wanting to date. However, this was complicated by fears of disclosure, experiences of rejection, and the status of their partners.

Respondents reported feeling hopeless about finding love and fearful about disclosing to a potential partner. By believing they were unlovable, respondents reported that they would self-

sabotage relationships by ending or not engaging in them. These feelings generally got better over time as respondents saw other PLHIV engage in relationships.

“She said that in the past she didn’t use to date anyone because she was HIV positive and so she thought that would result in her being rejected.”

(Respondent 13, Female, CATS. Translation from Shona by psychologist)

Many of the respondents had painful experiences of being rejected by a partner due to their HIV status. This led to most of the respondents to choose to date only HIV positive people in order to avoid disclosure. However, several respondents (44%) still expressed a desire to date someone not living with HIV.

“For me it was a big challenge because I was looking for another who was not HIV positive. I wanted someone who was HIV negative to date, but the issue was disclosure.”

(Respondent 12, Male, CATS)

Secondary themes

Secondary themes are reported as important information that came up frequently, but were not as prevalent as the above-described themes. The secondary themes presented are gender differences and coping mechanisms.

Gender differences. The respondents were split evenly on whether they thought men and women experienced HIV-related self-stigma differently. While the interview responses demonstrated that men and women have the same self-stigmatizing beliefs, they suggested that the experiences of self-stigma could be more intense for women due to their already marginalized position in society [35]. Half of the respondents felt that experiences of HIV and self-stigma were worse for women.

“So, if a girl, if she’s positive they will think she is characterless, or she has been sleeping around with a lot of boys. For the boys, if you are HIV positive, it doesn’t really affect him as much.”

(Respondent 1, Female, CATS)

“There is a difference between men and women. . . even if it’s a couple, it is the woman who goes to the facility. So, she is the one who usually is labelled as having HIV or her reputation is usually tarnished in the community because she is HIV positive. Whereas men are usually in hiding and not usually associated with infection even though they are HIV positive”

(Respondent 12, Male, CATS)

Coping strategies. The respondents shared how they were able to better manage their HIV and reduce their negative thoughts. These coping strategies included counselling, support groups, hearing shared experiences, and medication adherence. These interventions and support from Africaid helped ease self-stigmatizing beliefs for the respondents.

“I have had some group counselling with peers, with my primary counsellors at my facility, and some aunties at Zvandiri [Africaid]. They helped me a lot.”

(Respondent 12, Male, CATS)

“And so, when I started seeing others, my peers that were surviving, that were going to school, that were graduating from university I realized that this [stigmatizing thoughts] wasn’t true, that there was hope.”

(Respondent 13, Female, CATS)

Discussion

Corrigan et al. (2009) defined self-stigmatization as a process in which a person becomes aware of negative stereotypes, finds that they agree with those judgements, and applies the stigmatized beliefs onto themselves [11]. The data was analyzed using this framework and the results of this study clearly report feelings, experiences, and beliefs that are consistent with Corrigan’s definition of self-stigma. Respondents reported the beliefs and feelings of worthlessness, hopelessness, and negative body image. These negative self-perceptions were reinforced by the self-stigmatizing experiences of disclosure difficulties, isolation, and dating complications. Respondents all expressed having frequent (4 or more times a week) or occasional (once or twice a week) negative feelings towards themselves because of their HIV status.

All respondents were aware of the harmful stereotypes ascribed to PLHIV. They heard negative comments, witnessed intolerance, and endured personal humiliation as a direct result of their HIV status. There are several societal beliefs and cultural factors that made the respondents aware of HIV stigma. The negative association between HIV and the lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) community and the fact that acts of homosexuality are illegal in Zimbabwe adds additional stress and fear to PLHIV when disclosing their HIV status to friends, family, or partners-regardless of their sexuality [23]. Despite most of the respondents being born with HIV, they still felt blamed for living with HIV and were associated with ‘immoral’ behaviors such as multiple sexual partners or drug use. Additionally, the respondents reported that being called in Shona the equivalent of “dead one” or “plagued one” led them to believe that their lives were hopeless. These stereotypes perpetuate negative conceptions of HIV and reinforced adverse cultural norms that the respondents internalized.

Not only were the respondents aware of the societal stereotypes of PLHIV, but they also agreed with many of the underlying beliefs associated with them. These negative self-perceptions included beliefs of worthlessness, hopelessness, and negative body image. These beliefs caused the respondents to feel limited in their agency to live their lives the way they wanted. However, the respondents explained that these beliefs were more intense when they first found out their diagnosis. Self-stigmatizing thoughts can decrease over time with proper interventions and are not a static experience. Most of the respondents had known their status for at least seven years. Therefore, it would be interesting to investigate further how self-stigmatizing beliefs vary with length of time knowing one’s HIV status and mode of transmission.

Believing that their lives were worthless and hopeless caused many of the respondents to experience depression or suicidal thoughts. This led to emotional distress which resulted in poor adherence to anti-retroviral regimens. When they believed their lives were no longer worthwhile or feared they would be severely judged, the respondents decided to stop taking their medication. Without medication, the respondents experienced an increased viral count, causing extreme weight loss, and increased susceptibility to AIDS-related illnesses [36]. Additionally, these beliefs deeply impacted their ability to easily connect with friends or family, inhibiting them from a support network.

Interestingly, while the respondents felt hopeless in their personal relationships and ability to be accepted by their community, they generally did not feel hopeless when talking about

their career. Corrigan et al. (2009) explained that self-stigma can deter people from going after their dreams and careers due to feelings of worthlessness and hopelessness. However, in this study, most of the respondents explained that attending counselling sessions and seeing other PLHIV who had thriving careers were sources of inspiration and encouragement. Research has shown that support groups are a useful resource for facilitating self-acceptance and restoring the confidence that may be lost once one is diagnosed with a highly stigmatized infection such as HIV [20, 37]. This supports the transformative effects of support groups, however, these groups must also address self-stigmatizing beliefs that respondents' experience.

The respondents each spoke of several experiences in which they were aware of negative self-judgments including disclosure of their HIV status and dating with interpersonal relationships of paramount importance to this age group. As young adults, peer acceptance is extremely important for support and determining self-worth [38]. It is an age where young people are trying to find their individuality, yet also desire community acceptance [38]. Study respondents reported that living with HIV created a tension between the need to be themselves while also maintaining social and community acceptance.

Respondents felt that by disclosing their HIV status, they would not be accepted by their community. This realization caused stress and fear in trying to decide whether to disclose to friends or family. Several of the respondents were still in school, a place that commonly facilitates gossip and social exclusion towards PLHIV [39]. This caused most of the respondents to avoid disclosing their HIV status to anyone. However, the burden of this secret made many of the respondents feel shameful and stressed, leading them to avoid engagements with friends, skip doctor's appointments, and stop taking their medication. This caused both physical and emotional health problems for the respondents and likely explains the high rates of virological failure seen in this group [22, 27].

By not disclosing or talking to anyone about their HIV, the respondents described an intense loneliness and isolation. It often was not that the respondents had literally no one to talk to. Instead, their self-stigmatizing beliefs made them feel so shameful and worthless that they were unable to initiate needed conversations for support. These feelings caused the respondents to self-isolate and pull away from friends, family, and social gatherings. Studies have shown that PLHIV silence themselves to avoid conflict, judgement, and to conform to societal standards [40, 41]. However, the respondents reported that the burden of living with the secret of their HIV status was extremely overwhelming to handle alone [41].

The respondents were 18–24 years old, an age range where dating and relationships are often important and a priority [42]. This was clear because the topic was discussed at length in the interviews. However, as important as relationships were to them, dating also caused stress and complications for the respondents. Their self-stigmatizing beliefs made them feel hopeless to find a partner that would ever accept them. This was immensely saddening and discouraging for respondents who wished to start a family. Past rejection, abuse, and stigma caused low self-confidence and fear when trying to date or disclose to a partner. Studies have shown that anxiety and shame before or during disclosure in relationships are common for young adults with HIV [43, 44]. Therefore, when the respondents self-stigmatized, their shame normally caused them to end the relationship before they had to face disclosure. Beliefs of worthlessness and shame were most closely tied to dating and interpersonal relationships, indicating the importance of this topic.

Respondents who did decide to date, often found it easiest to date someone who also had HIV. This helped them to avoid the disclosure process and feel less ashamed. However, several of the respondents (44%) admitted to wishing they were dating someone who was HIV negative. This suggests deep rooted judgements towards themselves and HIV, because they could not even fully accept someone who shared in their same condition. There is little literature on

this phenomenon with PLHIV and dating, however, this stigmatization towards one's own group has been seen in other marginalized communities, such as those in the LGBTQ community and people with mental illnesses [45, 46]. These studies linked that those who experienced self-stigma could also stigmatize others within their group due to the negative beliefs they hold about their group identity [45, 46]. Therefore, further research should investigate the complicated experiences of self-stigma and dating in this age group due to its importance and influence on the respondents.

This study had a gender balance of 50% men and 50% women. Both sexes reported very similar beliefs and experiences of HIV-related self-stigma. They shared the same feelings of worthlessness, hopelessness and negative body image when dating, disclosing their status and feeling isolated. Yet, both men and women in the study felt that society was harsher and more discriminatory towards HIV positive women than men. Half of the women ($n = 4$) discussed the possibility that the increased prejudice they experienced as women caused them to self-stigmatize more often and more intensely than men. A study undertaken by Duffy (2005) concluded that women with HIV were more discriminated and more frequently blamed for spreading HIV in Zimbabwe than men [47]. Reidpath et al. (2005) explain that by holding two stigmatized identities in society, such as being woman and a person living with HIV, one can experience layered or additive stigma, which can increase the frequency and intensity of self-stigma [5]. This was only reported amongst half of women and we did not have quantitative scales to measure self-stigma intensity. Therefore, gender differences should be further explored as a potentially impactful aspect of self-stigma with a larger group of respondents.

Taking these findings into consideration for future interventions is critical in addressing HIV-related stigma. Study respondents were already receiving counselling and engaged in support groups. Additionally, most of the respondents were CATS which meant that they had training and on-going supervision in the provision of counselling which has been found to alleviate feelings of hopelessness, worthlessness, feeling unloved, isolation, depression and suicidality. That all of the respondents still reported self-stigmatizing beliefs despite the support highlights the need to specifically address self-stigma within the Zvandiri program (now in nine countries) and to remain mindful of CATS' own support needs. Previous research suggested a reduction in stigma among ALHIV supported by CATS [48] and further suggested that engagement with CATS improves self-acceptance, self-worth and confidence [20, 49, 50]. Innovative strategies to both enhance and sustain this transformative effect should continue to be explored.

Importantly, our study suggests that context is hugely key in the way that HIV is understood and then impacts the way that PLHIV live with, and experience, HIV. This is especially salient in the colloquial references to PLHIV which condemn these individuals some kind of "half-life". As such, interventions that support PLHIV in general and AYALHIV in particular, need to be context-relevant if they are going to impact on self-stigma at all. Additionally, interventions should be systemically applied (i.e. policy and politics need to change attitudes at societal, community, household levels while HIV services build individual resilience in the meantime). It will be important to work across the entire socioecological framework since individuals are embedded within larger social systems and multiple levels of influence not only exist but are also interactive and reinforcing [51].

Of note, our team is currently piloting a peer-led intervention to support AYALHIV in Zimbabwe on the journey from self-stigma to self-worth using a combination of inquiry-based stress reduction, music, art and creative expression (all have been previously run separately and successfully by the team) [13, 21, 52, 53]. Addressing and reducing self-stigma will likely enhance AYALHIV's confidence to take medication, disclose their status safely, and take

appropriate healthcare measures [13]. The spiral effect will be the much-desired improvement in AYALHIV's clinical and psychosocial outcomes [15, 22, 30].

Strengths and limitations

As a qualitative study, this research reports in-depth accounts and analysis of the lived experiences of HIV self-stigma. The interviews helped create a rich description of the thoughts and beliefs that PLHIV experience about themselves. Since there are very few studies on HIV self-stigma, this study makes a valuable contribution to the understanding of this important issue and provides an opportunity for Africaid's Zvandiri programme and other HIV support interventions to specifically address the impacts of self-stigma.

There were some limitations to this study. CR, a non-Zimbabwean, led the interviews in English which may have made it difficult for respondents to connect with the researcher, in addition to creating a power imbalance [54]. A few of the respondents chose to respond to certain questions in Shona, which was translated live by the Zimbabwean psychologist (VM) present. Live translations have the potential to not capture all that was originally said or to be accidentally misinterpreted [55].

Due to the COVID-19 pandemic, availability of respondents was limited; therefore, twelve of the sixteen respondents were CATS. CATS have been trained to help young people living with HIV and teach them coping mechanisms, so this type of training and knowledge about HIV may have had an impact on their responses. The CATS training and increased access to HIV resources could alter their beliefs and therefore potentially report lower levels of self-stigma than other PLHIV. This limits the generalizability of the results of the study because most young PLHIV do not have as easy access to HIV resources as the CATS do. However, the fact that CATS still reported HIV-related self-stigma despite their training and experience as peer counsellors indicates that self-stigma is still a pervasive and unaddressed issue.

COVID-19 also caused the interviews to be online over video call rather than in person. In person interviews are generally regarded as the preferred method for talking about sensitive issues, such as HIV, so that the respondent feels more comfortable [56]. Therefore, doing these interviews online could have inhibited the respondents from opening up as much as they may have wanted to about their HIV experiences. Despite these limitations, we still hope that we managed to elicit important self-stigma information that will inform stigma-reduction interventions.

Conclusions

This study explored the beliefs, experiences, and impacts of HIV-related self-stigma amongst young adults living with HIV in Harare. The results of this study are critical to our understanding of how adolescents and young adults in Harare, Zimbabwe experience HIV-related self-stigma and will inform Africaid's Zvandiri programme and other HIV support intervention's efforts to address the impacts of self-stigma. Coping strategies for self-stigma that were helpful for the respondents should be incorporated into existing and future HIV interventions by addressing self-stigmatizing thoughts in counselling, support groups, inquiry-based stress reduction, art, meditation, and mindfulness techniques. This will help young adults struggling with HIV-related self-stigma to recognize their self-judgements and constructively change the way they view themselves. Additionally, engaging more young people in interventions that challenge self-stigma can help PLHIV build a community and support network that is clearly needed amongst this age group. By promoting awareness of self-stigma, PLHIV may be empowered to challenge the perspectives of others, attend social gatherings, talk to their partner about their HIV status, and proactively engage with HIV support services.

Supporting information

S1 File. Interview guide.
(DOCX)

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Wakakosha “You are Worth it”: reported impact of a community-based, peer-led HIV self-stigma intervention to improve self-worth and wellbeing among young people living with HIV in Zimbabwe

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Introduction: Self-stigma—negative self-judgements or core beliefs—can result in feelings of shame, worthlessness and self-blame, and impacts social interaction, mental health and health service utilization among people living with HIV (PLHIV). Few interventions target self-stigma among PLHIV and, to our knowledge, none until now for adolescents and young people LHIV (AYPLHIV) in sub-Saharan Africa. We present qualitative findings on the perceived impact of a self-stigma intervention (*Wakakosha*, “You are Worth it”).

Methods: The *Wakakosha* intervention adopted inquiry-based stress reduction (IBSR) at its core—a unique way of identifying and questioning deeply rooted self-stigma, combined with mindfulness, meditation and creativity. The intervention consisted of 16 × 3 hour group sessions. Supporting the intervention was a 156-page activity journal. We utilized a qualitative enquiry to explore the perceived impact of the intervention at various time points between November 2021 and November 2022, with 62 participants ($n = 32$ female). Discussions explored experiences of being involved in the intervention and any reports on changes in relation to self-stigma and shame. Additionally, we reviewed intervention documentation and creative elements. A thematic analysis guided generation of themes across all data sources.

Results: Both intervention participants and coaches described the transformative effect of the intervention, detailing their experiences before and after. Main themes that emerged were positive changes around: self-confidence, self-agency, sense of purpose/meaning, body positivity, improved communication and

personal/family relationships and, forgiveness. The intervention also transferred a set of practical skills on self-inquiry, mindfulness, meditation and creativity that continued to be used in participants' daily lives.

Conclusion: The *Wakakosha* intervention, using IBSR supported by music, creativity, writing and mindfulness techniques, showed potential for reducing self-stigma and improving self-worth among AYPLHIV. It also transferred practical skills to intervention participants and peer coaches, building their capacity to support others and deal with life challenges beyond HIV. The next phase is to continue supporting the young people to ensure fidelity as the peer coaches deliver the intervention to others. Study results indicate that culturally and practically, interventions to reduce self-stigma and/or improve self-worth operate at various levels and need to be designed and assessed at each level.

KEYWORDS

HIV, inquiry-based stress reduction (IBSR), self-stigma, intervention, self-worth, wellbeing, young people, internalized stigma

Introduction

More than four decades into the global HIV pandemic, stigma remains a major barrier to HIV treatment, management and care (1–7). Goffman described stigma as, “an attribute that is significantly discrediting” which, in the view of others, serves to reduce the person who possesses it (8). Goffman also importantly identified stigma as a complex and multi-dimensional phenomenon (8). The internalization of stigma leads to what Goffman called “spoiled identity” or self-stigma (8, 9). HIV-related self-stigma is experiencing negative judgements towards oneself resulting in feelings of shame, worthlessness, self-blame and, emotional distress (10).

Self-stigma can result in non-adherence to HIV medication, lower quality of life and poor mental health (10, 11). A systematic review found that HIV-related stigma undermined antiretroviral therapy (ART) adherence by compromising general psychological processes (e.g., adaptive coping and social support), and 24/33 (73%) studies reported an association between HIV stigma and ART non-adherence (12). Multiple and intersecting drivers of stigma (HIV, orphaning, ill health, poverty) make adolescents and young people living with HIV (AYPLHIV) particularly vulnerable (13). Self-stigma contributes to AYPLHIV's high rates of attrition from HIV treatment and care, treatment failure, morbidity and mortality (14–16). In sub-Saharan Africa, home to 85% of adolescents living with HIV globally, adolescents are the only population with increasing mortality rates (14, 17, 18).

While most stigma initiatives focus on averting discrimination (also known as enacted stigma) (9), the phenomenon of self-stigma is much less understood (11, 19). However, approaches that target self-stigma likely benefit psychological function and wellbeing of people living with HIV (PLHIV) in general and AYPLHIV, specifically (19). As many AYPLHIV were perinatally infected, they experience a great deal of self-stigma and shame throughout their young lives, including as a result of taboos about being sexually active (19). Of note, research suggests that self-stigma is experienced by PLHIV to a far greater extent than stigma received from the broader community (11, 20).

Self-stigma occurs at the individual level, but also influences interpersonal relationships, community participation and engagement and, ability to access rights and health services (11). We previously

presented a framework comprising three interacting groups of factors (self, social, contextual) which influence the development and perpetuation of self-stigma (11). Further, the socio-ecological model provides a useful framework for understanding how health and wellbeing are influenced by multiple factors at various levels (individual, interpersonal, community, societal) (9, 21). However, few programs or interventions exist at the individual level and, to eliminate HIV stigma, it is necessary to work at multiple levels, including the individual, community and wider society (9, 22).

With reference to Zimbabwe, previous research has shown that AYPLHIV are particularly affected by stigma and self-stigma (13, 16, 23). Seventy-three per cent reported stigma and this affected their medication adherence; 47% had virological failure (16). In another study, AYPLHIV felt that because they were HIV positive, life was not worth living and described deliberately missing their medication so that they could eventually die (13). Further, in a study exploring the experience and manifestation of depression in AYPLHIV, adolescents attributed their experiences of depression to a sense of “being different from others”, both due to their HIV status and the impact HIV has had on their life circumstances (23). In the current study's formative research with AYPLHIV (2021), all participants reported HIV-related self-stigma either occasionally or frequently and experiences of self-stigma reportedly led to poor wellbeing and decreased mental and physical health (19). At baseline, the Zvandiri-friendship bench trial of a community adolescent treatment supporters-delivered problem-solving therapy found 62% of adolescents LHIV at risk of common mental disorder. Intervention data confirmed recurring themes of low self-worth, shame and worthlessness (24).

Based on previous findings on the high prevalence and negative impact of self-stigma in AYPLHIV, coupled with the absence of individual-level interventions to address self-stigma (11, 22, 25), we developed an intervention to be layered within an existing program, Zvandiri. The Zvandiri (meaning “As I am”) program,¹ recommended in 2013 by the World Health Organization as a best

¹ www.zvandiri.org

TABLE 1 Wakakosha session overview.

Session#	Session title
1	Self-stigma, emotions and me
2	The power of thinking
3	Introducing inquiry
4	Judgements about HIV
5	What others think of me
6	How HIV limits me
7	Deepening inquiry
8	ARVs and my story
9	My body
10	My body and sex
11	Forgiveness
12	Deepening inquiry
13	Shame and guilt
14	Relationships and fear of disclosure
15	Death and dying
16	My future

practice program (26), is a theoretically grounded, multicomponent, peer-led, differentiated service delivery model for children, AYPLHIV in Zimbabwe and adopted/adapted in 11 other countries (16, 27, 28). The program's effectiveness in supporting improved HIV outcomes was recently demonstrated in the Zvandiri trial (adjusted prevalence ratio of virological failure or death 0.58, 95% CI 0.36–0.94; $p=0.03$) (16). Zvandiri aims to directly improve AYPLHIV's wellbeing and strengthen their engagement with services across the HIV treatment and care cascades, including through peer counselling, community outreach, digital health and support groups (27).

Evaluations have illustrated peer-support groups' potential in significantly transforming AYPLHIV's perception of HIV as a debilitating infection which they are experiencing in isolation, to a manageable condition (13, 28, 29). A key function of peer-support groups is that they nurture self-acceptance and enhance self-esteem through connectedness with others who have shared lived experiences (13, 28, 29). However, support groups do not intentionally address self-stigma and as a result, may not necessarily ameliorate it (19). Further, while young people do well in support groups, they continue to struggle outside the group setting (13, 29). A specific intervention addressing self-stigma is likely to additionally support AYPLHIV to deal with life challenges outside of peer-support groups. Informed by our formative study (19) and our previous work on self-stigma in Zimbabwe (10), we co-developed and piloted a culturally appropriate, locally informed intervention for AYPLHIV (18–24 years) to address self-stigma. Specifically, the intervention sought to increase self-worth and wellbeing by reducing self-stigma among AYPLHIV in Zimbabwe. This paper reports on findings from a qualitative study that explored the perceived impact of this intervention on self-stigma. For this pilot intervention, involving a relatively small sample, a qualitative exploration of nuanced and detailed accounts was most appropriate to provide a deeper understanding of any changes, how the intervention worked and what could be improved (see discussion).

Materials and methods

Study design: intervention overview

We sought to adapt and optimize an innovation we previously piloted among adults living with HIV in Zimbabwe—inquiry-based stress reduction (IBSR): the work of Byron Katie (10). IBSR is a unique way of identifying and questioning thoughts that cause shame, anger, fear and violence. Working with beliefs is imperative as self-stigma is deeply rooted in a person's belief system. The beliefs that underlie shame, guilt, worthlessness and blame can be questioned with IBSR; allowing for new perspectives, insights and options that are kinder, more peaceful and empowering.² IBSR provides an opportunity to discover a new and kinder way of living within oneself and the world—no matter what is happening. It uniquely combines in-depth inquiry of stressful thoughts with the process of cognitive diffusion and mindfulness. The evidence base for IBSR is growing and effectiveness has been shown on stressful beliefs in relation to cancer, HIV and among high school teachers (30–32).

The “Wakakosha: You are Worth it” project was a partnership between Zvandiri, Beyond Stigma and others. Local coaches, previously trained in IBSR, themselves adults LHIV, co-delivered the intervention together with an internationally IBSR-trained facilitator and an international creativity coach. In brief, the *Wakakosha* intervention aimed to equip AYPLHIV (aged 18–24 years) in the use of IBSR/self-inquiry to manage stressful beliefs, reduce self-stigma and grow their sense of self-worth and wellbeing. Following formative research in 2021 (19), a pilot 1 day workshop was held with 12 AYPLHIV and feedback systematically collected. The intervention was then fully designed based on the formative research, the pilot workshop and, drawing on previous self-stigma interventions designed for adults LHIV and survivors of gender-based violence (10). Principles underpinning the intervention included youth-centered, do no harm, flexible and adaptable, safeguard confidentiality, respect, non-discrimination, inclusive of key populations, playful and promoting best practice.

The *Wakakosha* intervention curriculum was designed (by NF and VM) to start with several universal stressful thoughts about being HIV positive and from there, to work systematically through more acute self-stigmatizing core beliefs at a deeper level each week. Introductory sessions on thinking, identifying and feeling emotions were also provided before progressing to the deeper issues in the curriculum. During the process, participants were encouraged to identify, and inquire about, their stressful thoughts regarding shame, HIV status, disclosure to others, sexuality, judgements of self/others, the body, illness and death. Overall, the intervention aimed to improve management of specific emotional and psychological symptoms (relating to self-worth, stress, anxiety, depression, fears). The intervention consisted of 16 × 3 hour group sessions which included individual and pair work (Table 1).

Each session contained a mix of theory, meditation, group and individual experiences of IBSR, music reflection and sharing of insights, with time for singing and songs carefully matched to a session's themes to enhance learning and healing (see Figure 1). Supporting the

² See www.beyondstigma.org for description of IBSR methodology.



FIGURE 1
Wakakosha creativity example.

intervention was a 156-page activity journal that contained worksheets, exercises and homework. Techniques such as journaling, box-breathing, podcasts, letter writing, poetry and drawing were used throughout. The intervention was first designed to be delivered as a 6 days residential face-to-face camp. Due to COVID-19, a hybrid of online and face-to-face was adapted and delivered over 16 weeks, with weekly homework and practice sessions supported by WhatsApp.

Wakakosha intervention implementation

Thirty Zvandiri Community Adolescent Treatment Supporters (CATS) were initially recruited in 2021 to receive the intervention delivered by trained adult coaches (local and international). CATS are 18–24 years-olds LHIV, trained, mentored and supported to deliver structured support groups, counselling and tailored community-based adherence support to their peers (16, 28). From this group, 15 were identified to be subsequently trained as peer coaches, and attended a residential face-to-face, six-day immersive Training of Trainers in early 2022. Then a new group of 30 CATS was recruited and participated in the second delivery of *Wakakosha*, a 10 days face-to-face intervention (5 h per day), this time delivered mainly by peer coaches (supported by adult coaches). Each day of the training and/or intervention was evaluated, and feedback used real-time to adapt and ensure the curriculum was meeting the young people where they were. Towards the end, participants produced a song and recorded a music video which showed their experiences of the program and what happens when self-stigma is addressed. They also produced a podcast series through which they shared their own letters and poems about the body and forgiveness (available: <https://www.beyondstigma.org/videos>).

Study design: qualitative evaluation

Study participants and research activities

A qualitative enquiry explored the perceived impact of the *Wakakosha* intervention at various time points. Firstly, in November 2021, a focus group discussion (FGD) was held with 12 of the 30 CATS who were the first to receive the intervention. Another 12 CATS took part in in-depth interviews (IDIs) between November 2021 and February 2022. Additionally, 12 of the 15 CATS recently trained as peer coaches took part in a FGD in March 2022. In addition, 24 of the 30 CATS recently trained by peer coaches took part in two separate FGDs in November 2022. We also conducted key informant interviews (KIIs) with 2 of the 4 adult coaches who had facilitated the intervention sessions (Table 2). Further, we analyzed intervention activities (e.g., letters to self or body, activity journals and daily evaluations).

Qualitative data collection and processing

Individual interviews and FGDs explored experiences of being involved, any changes in relation to self-stigma and shame (including examples of increased self-worth, examples of doing things they would not have done before, for instance: dressing better, enrolling for a course, approaching someone with confidence, self-agency, self-esteem, self-love) (see sample interview questions in Table 3).

All discussions were led by two experienced Zimbabwean researchers (WM and ON) in private spaces and lasted approximately 30 min (individual interviews) and 1.5 h (FGD). All discussions were conducted in Shona, the participants' language. With the participants' permission, the discussions were audio-recorded. The recorded

TABLE 2 Summary of qualitative data collection.

Date	Participant category	Method	Number
November 2021	First set of CATS	FGDx1	12 (<i>n</i> = 6 female)
November 2021–February 2022	First set of CATS	IDIx12	12 (<i>n</i> = 6 female)
March 2022	Peer coaches	FGDx1	12 (<i>n</i> = 6 female)
November 2022	Second set of CATS (trained by peer coaches)	FGDx2	24 (<i>n</i> = 12 female)
November 2022	Adult local coaches	KIIx2	02 (<i>n</i> = 2 female)

TABLE 3 Sample interview questions for intervention participants by domain of interest.

Domain	Sample interview question
Overall experiences in program	Tell me about your experience in Wakakosha program. What did you like and dislike about the program?
Changes in thinking about self and HIV	What changed or stayed the same about how you think about yourself and HIV after taking part in this program?
Changes in self-stigma and shame	What changed or stayed the same about self-stigma and shame after taking part in this program?
Intervention components	Which components worked well or did not work well?
Intervention delivery	What do you think about the way the program was delivered? What worked well and what did not work?
Program recommendations	If the course were to be offered elsewhere, what should be maintained or changed? Why?

interviews were transcribed and translated verbatim into English. Interviewers (WM and ON) reviewed all transcripts to confirm their accuracy. A summary was written for each individual interview or FGD.

Qualitative data analysis and validation

Half of the interviews (*n* = 6) were thematically coded by two researchers (WM and ON), using deductive and inductive approaches by creating a coding framework based on the topic guides and adding codes iteratively (33). WM, ON, and EB met regularly to develop a common understanding of the codes and their application and, to discuss emerging patterns. These deliberations achieved *credibility* (ensuring researchers' representation of themes fit with participants' views) and *confirmability* (ensuring interpretations were clearly

derived from the data) (34). Researchers used memoing to consolidate emerging themes and as a reflexivity tool, whereby they kept a “self-critical” account of the research process and reflected on potential biases to enhance findings' *dependability* (34).

Any additional codes identified from this first set of transcripts were added to the coding framework. Transcripts were entered into NVivo 14 (QSR International, Melbourne, Australia) and fully coded using the modified coding framework; care was taken to identify any additional emerging codes. Codes were grouped and emerging themes were identified and supported with verbatim quotes. A workshop was held with three peer coaches (SM, MK, and TD) and two adult coaches (SV and MC) to review research findings and contribute to manuscript writing.

Results

Between November 2021 and November 2022, sixty young people LHIV, aged 18–24 years took part in the research. Of these, 30 (50%) were female. We also held discussions with two of the four female adult coaches (see Table 2).

Overall, both intervention participants and coaches described the transformative effect of the *Wakakosha* intervention, detailing their experiences before and after. The main themes that emerged were the existence of previous self-stigmatization and the move to positive changes around: self-confidence and self-agency, sense of purpose and meaning in life, body positivity, improved communication and personal/family relationships, self-forgiveness and forgiveness of others. These themes are described in detail below.

Transitioning from previous self-stigmatization

Participants described how they experienced self-stigma, including negative self-judgements, prior to enrolling onto *Wakakosha*. One participant noted that there were “...*certain things that might happen. Simply because you are HIV positive you will begin to personalize issues...* ‘So this person did not see me when I was passing by...Has she heard something about me?’ You might be assuming that someone has ignored you, yet this is all in your mind...” (Male 23 years, FGD). Participants also described instances of negative self-judgement. “...*Telling yourself that you cannot do this because of your (HIV) status*” (Female 23 years, FGD).

Participants described effects of these self-stigmatization experiences including self-isolation and depression. “*When I was home and we had visitors, I would shut myself in a room because I am HIV positive...I was worried that visitors would see me and guess my status. I was worried that family members would disclose my status to others. So, you are always alone in your room, and this causes so much stress because you are always assuming several issues*” (Female 20 years, FGD). One participant described how similar distressing experiences triggered perpetual suicidal thoughts. “*I was only thinking about death...It was better for me to die as there was no reason for me to continue living. My relationships were difficult and there were also challenges at home because of my (HIV) status*” (Female 19 years, IDI). Prior to the intervention, participants not only *agreed* with stereotypes or negative perceptions about

themselves but *applied* them too, including the belief that they could not amount to anything.

Experiences after the intervention

Self-confidence and self-agency

Intervention participants described gaining various skills including self-confidence. This often prompted them to pursue previously “impossible” goals such as enrolling for academic and professional courses. “*I encouraged her, and she enrolled for a teacher training course*” (adult coach, KII). Another participant reported pursuing a career as a nurse aide. Some participants reported renewed self-agency. A participant who had inherited a piece of land but was not using it productively due to self-stigma-induced loss of self-agency reclaimed it and started farming, remarking that, “*I would tell myself that there was no way I could farm that whole piece of land...If I had not attended Wakakosha I would have surrendered the land to someone else*” (Female 24 years, FGD).

Sense of purpose and meaning in life

After the intervention, participants affirmed a new sense of purpose in their lives as reflected by one who noted that, “*After the training I learnt that there is nothing I cannot do, and I can do it*” (Male 21 years, FGD). More so, the intervention inspired a sense of self-worth and purpose in the participants, with some rediscovering their entrepreneurial passions. Another participant labelled themselves “a jack of all trades” attesting to a renewed entrepreneurial drive and passion for new vocations, stating that, “*I am now involved in five things...welding, plumbing, art, building and fashion*” (Male 23 years, FGD).

Body positivity

Because of self-stigma, participants, especially female ones, developed negative attitudes towards their bodies as evidenced by reports of having previously been ashamed of, and neglecting, their own bodies. A participant remarked that, “*I used to hate my body, and I would say, ‘I do not want my body because I am tiny. I do not want my skin because it is too dark’*” (Female 20 years, FGD). Yet another participant narrated, “*I would ask myself why I was not gaining weight...my body was too thin. When I looked at other girls with bigger body structures, I would ask myself why I could not also get there*” (Female 23 years, FGD). Participants further acknowledged different ways in which they mistreated their bodies, with one admitting to their body that they, “*hurt you (body) terribly by not caring well and starving you because of my self-stigma...*” (Dear Me Podcast #4), while others engaged in alcohol and drug abuse as well as deliberate self-poisoning in a bid to kill themselves (Dear Me Podcast #8, #13).

Such thoughts, however, changed upon completing *Wakakosha*. Noteworthy was the body positivity message that the intervention inculcated in participants, motivating them to reevaluate their beliefs and attitudes towards their bodies and embracing body positive routines. One participant remarked that, “*It was only after Wakakosha when I realized that I should be proud of my body because my face has not been reacting to the drugs that I am taking*” (Female 23 years, IDI). More so, a recurring message in the Dear Me Podcasts is that of participants committing to taking better care of their bodies through

eating healthy, quitting alcohol and drug abuse as well as improved hygiene (see Dear Me Podcast #11, #12, #13).

Improved communication and personal/family relationships

Participants also reported improved communication and personal relationships. As participants were relatively young (18–24 years), forming relationships was one of their key considerations. Nearly all described previously struggling to come to terms with their emerging sexuality in the context of a life threatening, sexually transmissible infection. “*I would tell myself that ‘I am HIV positive; I cannot date someone who is HIV negative’*” (Female 22 years, FGD). Even when they were now in relationships, participants would worry about family size and “curtailed” longevity. “*I was stressed. When I gave birth, my sister-in-law said ‘You should not have another child because you are going to die soon. Who will take care of your children?’ So, I had told myself that it is fine to just have one child. I held on to those words...*” (Female 21 years, FGD).

Post intervention, participants reported improved personal and family relationships. Most participants reported previously being bitter and angry towards their parents, relatives, and other members of the community. One participant reported that after the intervention relations thawed between him and his father, admitting that “*...now (after the intervention) I have realized that I am now more humane, I am no longer exchanging (harsh) words and I now respect him...*” Another participant was elated with how his love life had improved, stating that, “*My love life is now great. Yesterday was a wow for me. We were coming from church, and she invited me for dinner. It was excellent. My love life is now great*” (Male 22 years, FGD).

Self-forgiveness and forgiveness of others

Many participants reported positive changes in self-forgiveness and in forgiveness of parents for passing on HIV. Most were bitter towards their parents but through the intervention, they were able to forgive and erase the negative thoughts, “*Even to my dad, I used to believe he was stigmatizing me when I was young...he did not visit me. So, I just wrote a letter to both asking for forgiveness. I learnt about forgiveness because I was very bitter towards my parents about being the only child who was born with HIV in my family*” (Male 18 years, IDI). Through the intervention’s transformative effect, participants also learnt self-forgiveness as evidenced in the powerful messages of forgiveness in the Dear Me Podcast series. Participants also asked for forgiveness for having put their bodies on the line by starving themselves and abusing alcohol (Dear Me Podcast #5, #13) while others forgave themselves for ignorantly indulging in risky sexual escapades (Dear Me Podcast #6, #11).

A male participant described how the *Wakakosha* intervention had helped him find closure. “*So, I wrote a letter (as part of intervention activities) to both of them (deceased parents) asking for forgiveness...*” (Male 22 years, IDI). He went on to describe what he did next. “*One weekend I travelled to the rural areas, bought flowers, and went to their graves and ‘said’ to them ‘I am very sorry for not forgiving you all along...’ I then placed the flowers on their grave*” (Male 22 years, IDI). Another male participant stated, “*I wrote a letter to my mother asking for forgiveness. I was angry due to my status, saying ‘I am HIV positive because you were careless. You were careless with your life, and you gave birth to me fully aware of your status.’ So, I wrote the letter asking for forgiveness because I was ignorant*” (Male 19 years, IDI).

Some letters were addressed to surviving relatives. “...She was blaming her uncle (father’s young brother) for ill-treating her after her father’s death. But after doing the session, she realized that this uncle did all he could to provide for her and her siblings. For example, he paid their school fees. She wrote an “amendment letter.” She was now saying that she has actually realized that her uncle was not a bad person. He was actually a good person for taking care of her. As an uncle, he was not obliged to look after her when her parents passed on. So she realized that she had to thank him” (peer coach, IDI).

Experiences about the approach/process

Both intervention participants and coaches (facilitators) described an overwhelming transformative effect of the intervention. CATS described for example, how they often spend time and effort offering peers support around adherence and overall wellbeing support, and rarely get the opportunity to introspect. Despite their mentorship, training, and support, they reported feeling unable to address personal challenges including self-stigma. One CATS summed up this shortcoming through a local proverb “N’anga haizvirapi” (A traditional healer cannot treat themselves) (Female 24 years, IDI), an expression which underscores that CATS need support too. “Also, it helps us the CATS. Yes, we might be trained but, in some instances, you will be focused on other people. But with Wakakosha you are also focusing on yourself” (Male 24 years, IDI).

Participants described in detail the new skills they had acquired. “We were taught that if there are challenges, we should not see these as permanent. We should have positive and not negative thoughts only. For example, when faced with a situation, we could only view it from the negative side, without looking at the positive side. Through this program (Wakakosha) I was taught to look at both sides and then think about how I can overcome the problems that I am facing” (Male 23 years, IDI). As with other participants, he found this problem-solving skill quite empowering.

CATS were also equipped with vital skills they now use to help their peers. I have skills that I am using on other people. There is one called box breathing. We would do this box breath whenever we were starting sessions. You would close your eyes and breath in and out... breath in and out. I normally use this when I am with a client who is disturbed and is facing some challenges. Maybe he is not calm...I can also ask them to give me their emotions from 1–10. By so doing, you will realize that I am feeling this emotion because of this and that. We will then start the counselling session (Male 24 years, IDI).

Commenting on the activity journal, a participant stated “...In the ‘journal,’ there were some ‘exercises,’ and these were part of homework. You would ask yourself through the sheets the emotions that you were going through on that particular day. You would then circle. From there, you would then start doing an inquiry using that yellow card that contained the four questions and the turnaround prompts. And then stressful thoughts that caused you to be in that emotional state will begin to emerge. And then at the end of the day you will be in a different emotion” (Male 22 years, IDI).

The acquired skill sets were not only helpful to intervention participants but also others. “So, the skills that I am using on other people include inquiry and the yellow card. Out there, there are peers who might be having stressful thoughts. Sometimes when I contact a client, I will end up using that yellow card” (Male 23 years, IDI). Another participant highlighted how components of the intervention can be used beyond self-stigma situations, noting that, “...When I go

home and I start doing this with my aunt (55 years old), asking her to turn around her thoughts. Holding the yellow card and asking her about her thoughts on that issue. I will then ask her to do the turnaround thoughts... turn around to yourself. At the end of the day, she will start laughing asking if these were the activities we were doing, and I would say ‘Yes’” (Male 22 years, IDI). Overall, participants felt the skills they learned could be applied beyond self-stigma into their everyday lives, in particular the ability to solve problems.

Lastly, participants reported how creativity (music, drawing, poetry) helped them engage in challenging topics on self-stigma, thus promoting awareness and healing. “The singing helped us easily share our feelings whether sad, happy or angry” (Female 18 years, FGD) (creativity component of this intervention to be reported separately).

Delivery challenges and recommendations

As already noted during the description of intervention delivery, due to COVID-19, some sessions had to be delivered online, which had its own challenges. Participants articulated some of the challenges. “...Going forward, we will prefer face to face mentoring. There are instances when things are said, and you have to express your emotions... If it is online, no one can see what is going on. If you are discussing face to face, you can express your emotions and then you receive counselling” (Male 21 years, FGD). A local adult coach weighed in, “Especially when we were still doing this from home (online), it was worse. It was okay when we were coming to Zvandiri because they have a strong network connection. But from home, you could see the young people complaining that there is no power and this affects network connectivity. Therefore, I did not like the online program at all, especially during the first days when everything was to be done online” (adult coach, KII). Implementing an online intervention within a context characterized by erratic power supply, limited internet connectivity and exorbitant data charges involves “scaling a mountain.”

Some recommendations centered around ensuring intervention materials taken home do not result in inadvertent HIV status disclosure. “I would like to go back to (activity) journals. Those are for us participants who are attending the meetings. However, there is over emphasis on HIV. Yes, it’s good but I might be staying at a home where relatives and friends come. Maybe I have not yet disclosed to them. Through this CATS program, we have disclosed, and we are now used to this. But some people might be affected when they are going around with that ‘book, and someone opens the ‘book,’ they will see text which reads, ‘Because of HIV...’ If only they could find other words to talk about HIV in a way other people will not know HIV is being discussed” (Male 24 years, FGD). These concerns should be taken into consideration going forward.

Discussion

We qualitatively explored the perceived impact of “Wakakosha: You are Worth it,” a culturally appropriate, locally informed intervention for AYPLHIV to address self-stigma. The evaluation revealed that the Wakakosha intervention effected positive changes on many aspects of self-stigma including self-judgements, self-worth, sense of purpose, self-agency in career and education, body image, self-forgiveness and forgiveness of others and improved communication with family and significant others. It also transferred a set of practical skills on self-inquiry, mindfulness, meditation and

creativity that continued to be used in participants' daily lives. We previously noted how interventions to support PLHIV in dealing with self-stigma, particularly at the level of core beliefs, are lacking (11, 22, 25). Interventions such as *Wakakosha*, tailored to the context of HIV self-stigma and using knowledge of underlying core beliefs, may better equip participants with the psychosocial tools and strategies to mitigate self-stigma.

The emerging field of positive health perceives health as a state of wellbeing, not an illness and can be defined as an approach to health that recognizes factors that drive disease and illness and focuses on the processes that underpin good health and wellbeing (35–39). From our study findings, we can see many aspects of positive health emerging and being strengthened (e.g., gaining self-confidence, a new sense of purpose in life, a sense of self-worth, self-agency and purpose). These and other findings (39, 40) buttress calls for positive mental health interventions for AYPLHIV that are anchored upon the need to improve and evaluate human strengths and capabilities as enshrined in positive outcomes such as self-esteem, self-worth and flourishing (35–37).

In addition, what emerged from our study were also a number of cultural and contextual insights into positive health, namely the culture of discussing feelings and emotions, spirituality, and individual versus collective agency. In relation to feelings and emotions, in Zimbabwe, as in other sub-Saharan settings, culturally speaking or articulating feelings and emotions is uncommon (28). Importantly, the intervention reportedly had a positive psychosocial effect on males who in this context are less able to discuss or express emotional concerns, largely due to hegemonic masculinity where males are socialized around toughness and concealing emotions (41, 42). Cultural sensitivity in ways of doing this needed to be incorporated into the training.

What also emerges is the strong collectivist culture in Zimbabwe and thus the wellbeing of others is as, if not more, important for positive health. In positive psychology, as noted by Wong (43), there has been some inclusion of altruism (44) and compassion (45), but “there are cultural differences in the balancing act between *me* and *we*. ... we need to emphasize positive motivations, processes, activities, and outcomes for both individuals and groups” (Wong, 2011, p. 72). For an individual in Zimbabwe, as in most of sub-Saharan Africa, self-acceptance is bound up with acceptance within one's community. Hence, for the AYPLHIV, it was difficult for them to separate themselves from the diminished status of their parents due to HIV infection, increasing the potency of the shame and self-stigmatizing beliefs they had about themselves and their parents. These difficulties of separating the self from others also strengthens the value of community and opinions of others regarding morality and HIV acquisition, which in turn fuels shame, self-stigma and the acceptance of social stigma and discrimination as well-deserved punishment for sexual deviance (13, 19). Therefore, addressing self-stigma at individual and communal levels helps to defuse disempowering narratives in the individual first and this cascades to the community.

Participants reported changes at the household/family level as a result of the intervention. A potential limitation of this study was that we did not directly collect data at this level. In keeping with the socio-ecological model (21), as per the information reported by respondents, it is likely that a successful intervention at the individual level will have

a positive impact at household/family level. Future explorations should explore changes beyond the individual more systematically.

Increasing attention continues to be paid to community-based peer-support programs as a mechanism to improve clinical outcomes and wellbeing (28). While the predominate focus of research on peer support for AYPLHIV has focused on the potential benefits to those receiving peer support (26), there is also growing recognition of the essential need to focus on the health and wellbeing of the peer supporters themselves (46). This study demonstrates that peer supporters themselves also benefit from the various intervention activities. Ensuring support and ongoing mentoring for the peer coaches is key to the ongoing success of this and other interventions (28). As part of *Wakakosha*, an online Toolkit has been produced and will be tested to provide this support to the peer coaches going forward.

Creativity clearly played a supportive role in the absorption, emotional processing and deepening of positive changes around self-stigma and shame, variables which are difficult to openly discuss without causing or triggering deep hurt or stressful thoughts around experiences within oneself and with others. Our team has previously used creativity on other difficult topics, including to explore experience and manifestation of depression in ALHIV (23). Further exploration is needed to specifically measure and assess the impact of creativity on self-stigma and shame among AYPLHIV.

Our assessment was intentionally qualitative as though we could have used some quantifiable measures of program impact, these have a number of drawbacks. Firstly, they limit the number of domains that can be assessed; most of the outcomes as described above would not have been captured by standard measurement scales. Secondly, it is not possible with measurement scales to interpret differences in mean scores in terms of the lived experience of the participants. For example, a change in mean score over a group of participants does not tell us what proportion of participants materially benefitted. Comparing scales across different cultures has been likened to comparing chopsticks with forks if appropriate adjustments in scales are not incorporated (47). Lastly, the qualitative approach respects the agency of the participants. Participants entered the program with their own individual hopes and aspirations. These were captured in an early activity called “This is Me” embedded in the curriculum. We took the decision to assess the program relative to these individually valued outcomes rather than against universal ones.

Another limitation is that, as participants were already Zvandiri CATS with potentially lower self-stigma levels, the overall positive impact found here may not necessarily reflect what would occur in for example, CATS clients. Future initiatives should evaluate impact of the intervention when it is offered to CATS' clients and AYPLHIV outside of the Zvandiri program. In addition, despite confidentiality assurances, participants may have felt obligated to largely report positive experiences whilst downplaying negative ones.

Conclusion

This intervention shows potential for reducing self-stigma and improving self-worth among AYPLHIV. The next phase of this intervention will be to continue training and supporting the young

people to ensure fidelity and provide quality support as the peer coaches deliver the intervention to others. Ongoing support and mentoring for the peer coaches will take time and resources, particularly in the first few years of gaining traction for a new methodology such as IBSR. As this is a cognitive and mindfulness-based methodology, careful supervision and ongoing individual practice is important. Future research and evaluation should carefully consider spirituality and the communal view of positive health more broadly when looking at self-stigma and self-worth. It should also be cognizant of the cultural context and consider using the socio-ecological framework to reflect the various levels affected - the individual, family and wider society.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by Medical Research Council of Zimbabwe (#2604). The patients/participants provided their written informed consent to participate in this study.

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Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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