A narrative study of how shame features in the lives of women living with HIV

A thesis presented to Dublin City University for the award of Doctor of Philosophy (PhD)

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January 2022

Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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Date: 27 September 2021

Acknowledgements

Multiple individuals and groups have been pivotal in bringing this study to life. Pursuing a PhD is a lonely experience at times, made better by the support of those around me during the past four years. First, I would like to thank my joint supervisors, Dr. Denise Proudfoot and Prof. Anne Matthews for your support. Your patience, kindness and unending encouragement matched with what seemed like unlimited knowledge and advice has made me the researcher I am today and hope to be in the future. I am forever grateful for what I have learned from you both. I offer a special thanks to Dr. Rita Glover who served as my independent panel member for the past four years. Your input and expertise was invaluable for the development of this study and my skills development.

I want to give a special thanks to all of my fellow PhD students whom I met along the way in both the School of Nursing, Psychotherapy and Community Health and to our neighbours in the School of Psychology. In particular, I would like to thank friends and colleagues in H274; Eoghan Scott, Jennifer Okeke, Karen Ward, Hazel Larkin, Lauren McCauley, Aoife McNicholl and Siobhan Woods. It was a pleasure to go through this experience with such kind and uplifting people. In addition, a special thanks to fellow PhD student and HIV activist, Robbie Lawlor for all of our chats. I have learned so much about HIV in Ireland from you, Robbie, and the people of Ireland benefit immensely from your voice.

To Erin and all the staff in HIV Ireland, a sincere thanks to you all for your help in recruitment for this study and accommodating me to conduct my interviews in your offices. Coming into this study, I learned that recruitment was going to be timely and so I very much appreciate your efforts and support in making that happen. Any time I rang, emailed or went into HIV Ireland, your staff were warm and welcoming. I would also like to thank the staff at GOSSH in Limerick, the Sexual Health Centre in Cork, and Positive Life in Northern Ireland for their role in facilitating interviews and recruitment.

Thank you to my Westport girls and dear friends, Eimear, Anna, Clodagh, Niamh and Rachel whom always checked in on and supporting me. You were my five personal cheerleaders throughout this journey, and it always meant a lot when you would take the time to try and understand my work and be aware of my progress and achievements. How lucky I am to have friends like you all.

I could not have completed this PhD without the moral support of my loving family, my parents Noel and Pauline, my sister, Cáit, and my brother, Peter. I am so fortunate and privileged to have grown up with parents and siblings like you; you have shaped me into the person I am today. Moving home to live with my parents for 17 months during COVID-19 restrictions was not how I foresaw my PhD write up going, but I was glad to go home to a safe, comfortable environment during that worrying period. Thank you to my parents, for the endless trips to Lidl and all the other shops to make sure I had everything I needed to work from home, all while running a very busy nursing home. You worked so hard to keep everyone feel safe and secure and your hard work inspired me to keep going on those difficult days during the lockdown.

My partner, Tom, you have lifted me with so much love and encouragement in the last four years. You have kept me going during my lowest days and you have cheered me on endlessly during my triumphs. If our relationship can sustain your cadetship and my PhD simultaneously, we will overcome anything! Completing this PhD meant many sacrifices and difficulties for us and I thank you for your patience and understanding. I am so lucky to have you by my side.

Lastly, but most importantly, I am forever indebted to the twelve women who shared with me their personal stories of living with HIV. This research became a reality because of your valuable contribution and I cannot put into words how much I appreciate you taking the time to travel from different parts of Ireland to meet with me. In our working together, I hope we can make a difference for women all over Ireland who are living with HIV. I dedicate this thesis to you.

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Glossary of Terms

Human Immunodeficiency Virus is a virus that attacks the body immune system. If untreated, the immune system is weakened and becomes susceptible to opportunistic infections.

Acquired Immunodeficiency Syndrome is the most severe stage of HIV infection. It is classified by having a CD4 cell count of less than 200 cells/mm.

Antiretroviral Treatment treats HIV infections by stopping the virus from replicating in the body, allowing for the immune system to replenish itself.

Pre-Exposure Prophylaxis is a drug taken to prevent the contraction of HIV.

Post-Exposure Prophylaxis is a drug taken upon potential exposure to HIV to prevent seroconversion.

Direct Provision is a reception system for people seeking international protection in Ireland. People seeking international protection are housed in communal settings. People seeking international protection are required to stay in the accommodation until their application for asylum is processed, which could be several years.

Health Service Executive (HSE) is Ireland's publicly funded healthcare system.

Health Protection Surveillance Centre (HPSC) is the national specialist agency for the surveillance for infectious disease in Ireland.

Irish Refugee Council is a registered charity that provides support and services to people seeking international protection in Ireland.

Doras is a non-government organisation who work to promote and protect the rights of migrants living in Ireland.

Acronyms

AIDS: Acquired Immunodeficiency Syndrome

CD4: Cluster of Differentiation 4 (T-cell count)

EATG: European AIDS Treatment Group

HAART/ART: High Active Antiretroviral Therapy/ Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

HRQoL: Health Related Quality of Life

HRT: Hormone Replacement Therapy

IPA: Interpretative Phenomenological Approach

MSM: Men who have Sex with Men

MTCT: Mother to Child Transmission

NGO: Non-Government Organisation

PEP: Post Exposure Prophylaxis

PLHIV: People living with HIV

PREP: Pre-exposure Prophylaxis

PWID: People Who Inject Drugs

SSA: Sub-Saharan Africa

STI: Sexually Transmitted Disease

SWS: Swiss Consensus Statement

TasP: Treatment as Prevention

U=U: Undetectable = Unstransmittable

UNAIDS: Joint United Nations Programme for HIV/AIDS

WLHIV: Women living with HIV

Abstract

Name: Ellie Marley
Title: A narrative study of how shame features in the lives of women living with HIV

Once classed as a devastating virus that resulted in a guaranteed premature death, HIV can be treated successfully with lifelong medication and importantly its transmissibility is eliminated for individuals on effective medication. However, the psychosocial burden of HIV remains for many and despite this advancement in biomedical treatment, HIV remains a highly stigmatised virus and condition.

This study explores how shame features in the experiences of women living with HIV in Ireland. There is an absence of women's narratives in the overall discourse on HIV in Ireland, therefore little is known about their lives. Research on shame tells us that prolonged unacknowledged shame can impact on mental well-being if unaddressed.

The study's sample comprised twelve women living with HIV who were based in Ireland. Their narratives based on semi-structured interviews have been analysed using Clandinin and Connelly's (2000) three-dimensional narrative inquiry tool, which explores from the interactional, chronological and situational elements of a story. A cross-case analysis was adopted to explore dominant themes across the twelve narratives.

Findings from this study portray how shame stemmed from an absence of a woman centred HIV narrative and the ongoing presence of stigmatising HIV discourse. Shame featured as three dimensions of the exposed self: anticipated exposure, exposure avoidance and felt exposure. Finally, many of the participants managed to grow through their HIV-related shame and move past it by discovering a shared experience with other women, to reduce emotional isolation.

This study concludes that HIV-related shame can have negative implications for women's health and general well-being, thus compromising women's ability to live well with HIV. HIV-related shame must be addressed with the appropriate intervention. The study contributes to the development of a women-centred HIV discourse. This can help increase visibility of WLHIV and enable potential mitigation of the onset of HIV-related shame, which is crucial in this era of HIV normalisation.

1. Introduction

1.1 Background

In the forty years since its discovery, HIV maintains its position as one of the most challenging global epidemics. The global efforts to end HIV/AIDS by 2030 are ambitious and unfortunately, despite significant progress, targets are not being met to eradicate this virus. The 90-90-90 target was established in 2016 at the United Nations General Assembly's Political Declaration to Ending AIDS. It set out to ensure 90% of those living with HIV know their status, that 90% of people who know their HIV status are on treatment, and that 90% of people who are on treatment have undetectable viral loads by 2020 (UNAIDS 2014). However, societal issues such as stigma, discrimination and criminalisation have been identified as some of the most significant barriers for accessing HIV testing and treatment, especially in key populations such as men who have sex with men, sex workers and people who inject drugs (Wang et al. 2021; Sullivan et al. 2020; Ekstrand, Bharat and Srinivasan 2018). This renders stigma as one of the key factors as to why the 90-90-90 target was not reached in 2020. Furthermore, the stigma, negative judgement and prejudice towards people living with HIV (PLHIV) is one of the biggest barriers to eradicating the virus as it is leading to a reluctance to test due to the fear of knowing one's status, poor adherence to medication, and un-safe sex due to the stigmatization of condom negotiation in some circumstances (Hutchinson and Dhairyawan 2017). These issues strongly impact on the health and well-being of women living with HIV (WLHIV) globally.

Aside from the fact that the stigmatization of PLHIV is a public health issue, the effect of social stigma on PLHIV has detrimental outcomes for the mental health of PLHIV (Nobre et al. 2018; Rice et al. 2018; Sikstrom, 2018; Cuca et al. 2017; Hutchinson, Dhairyawan, 2017; Sangaramoorthy, Jamison and Dyer, 2017; Bennet, 2016; Brion, Mark and Drabkin, 2014). Stigma for PLHIV has always been a feature (of the virus and condition) due to widespread scaremongering and moralising in the early days of HIV globally and in Ireland, particularly how the Irish and British media communicated about HIV (Murphy et al. 2016). This quickly established a narrative that PLHIV were driving the epidemic.

However, in the last two decades, HIV medication has undergone extraordinary medical advances, rendering HIV almost invisible, although not cured, in those infected (Rodger et al. 2016, 2018). The stigmatising discourse that PLHIV are infectious, disease vectors, spreading a 'deadly' virus was once strongly associated with being HIV positive, but is now considered generally obsolete for anyone living with HIV who is fully adherent to their medication. However, while the biomedical aspect of HIV is improving for the better, the social stigma of HIV remains. With the persistence of the societal stigma of HIV, PLHIV are predisposed to feeling shame about their HIV status.

1.2 Human Immunodeficiency Virus

HIV is a retrovirus that, once contracted, depletes CD4 cells in the immune system. CD4 cells are responsible for protecting the body against pathogens, or disease-causing microorganisms. Once the virus embeds itself in the immune system, it begins to replicate, gradually decreasing the CD4 count. As HIV depletes CD4 cells, opportunistic infections can occur. Once the CD4 cell count is below 250 (a healthy CD4 count is between 1,500 to 2,000), a diagnosis of AIDS, acquired immunodeficiency syndrome, is given. HIV is transmitted through anal or vaginal sex, injecting drug use, vertical transmission from mother to child (during childbirth or via breast-milk), and blood-to-blood contact.

1.3 Treatment and Prevention of HIV

While it is not curable, treatment is available to reduce the viral load in the immune system, allowing the CD4 cell count to rise, and regular function of the immune system is maintained. For individuals who believe they have been exposed to HIV, a post-exposure prophylaxis (PEP) is available to take in a 72-hour window following an encounter. Pre-exposure prophylaxis (PREP) can be taken in pill form once a day to prevent HIV acquisition. However, when PLHIV take their medication effectively, viral load can become so low that it is impossible for HIV to be transmitted through unprotected sex. This phenomenon is known as “Undetectable = Untransmittable” or “U=U”, and will be discussed in more detail further on (see section 2.3: Normalisation and HIV).

1.4 HIV Globally

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the global organisation leading experts towards the eradication of HIV/AIDS and is the primary source of global figures of HIV/AIDS. UNAIDS (2021) report that 79.3 million people have been estimated to be infected with HIV since the epidemic began 40 years ago, and as of 2020, 37.7 million people around the globe are estimated to be currently living with HIV. In 2020 alone, records indicate that 1.5 million new diagnoses of HIV occurred, as well as around 680,000 deaths from HIV-related (and/or AIDS-related) conditions. The greatest prevalence of HIV/AIDS is in sub-Saharan Africa and primarily in Southern, Central, West and East African countries, accounting for two-thirds of current cases. Asia and the Pacific make up the second highest proportion of people living with HIV with 5.8 million cases, whereas North America and Western Europe has an estimate of 2.2 million cases of PLHIV. Making up the majority of PLHIV, 20.1 million women around the globe are estimated to be living with HIV, with the highest prevalence of WLHIV living in African countries. Research with WLHIV around the world covers prevention of vertical transmission (mother-to-child transmission) (Cohn et al. 2016; Gumede-Moyo et al. 2017; Pinetti et al. 2015), pregnancy (Peyronnet et al. 2019; Macdonald et al. 2015), gender based violence (Jewkes et al. 2010; Stockman, Lucea, Campbell, 2013; Meyer, Springer and Altice, 2011), sex work (Shannon et al. 2015; Poteat et al. 2015; Decker et al. 2015), stigma and discrimination (Nobre et al. 2018; Rice et al. 2018; Sangaramoorthy, Jamison and Dyer, 2017) and people who inject drugs (Theall et al. 2016; Blankenship et al. 2016). Although women represent over fifty percent of people living with HIV, there is a shortage of research that focuses on how living with HIV affects them (Terrence Higgins Trust, 2018). Below is a table (Table 1) outlining the global figures for HIV from 2020, taken from a 2021 UNAIDS report.

Table 1: Global Estimated Figures (UNAIDS 2021)

People Living with HIV	37.7 million
People Diagnosed since beginning of epidemic	79.3 million
People with a New diagnosis in 2020	1.5 million
People who Died of HIV-related conditions in 2020	680,000
PLHIV with Access to ART	27.5 million
WLHIV	20.1 million
PLHIV in Western Europe and North America	2.2 million
PLHIV in SSA	25.3 million

1.5 HIV in Ireland

Within the Health Service Executive, the Health Protection Surveillance Centre (HPSC) is Ireland’s primary source of factual information and statistical data on HIV. Gathering data on all mandatory infectious disease notifications in Ireland, they issue reports weekly, monthly and annually on HIV, and all sexually transmitted diseases. The HPSC (2019) issued an epidemiological report indicating that as of December 2017, 9344 people have been diagnosed with HIV since records began however; the exact number of people living with HIV in Ireland is unknown as this figure does not account for deaths and migration. Provisional data for 2020 suggest that a further 452 people received a positive HIV diagnosis (HSPC 2021). Ireland's 2020 statistics of HIV positive notifications are reflective of the COVID-19 pandemic restrictions in which access to HIV services (including testing) were limited. For reference, 535 HIV diagnoses were documented in 2019. It is acknowledged that not everyone in Ireland who is living with HIV is aware of their status or has been diagnosed. High prevalence groups in Ireland include men who have sex with men (MSM). Migrant women make up the highest prevalence group of those who are heterosexual, due to, but not exclusively, antenatal testing (HPSC 2019). Below is a table (Table 2) outlining the figures of HIV in Ireland in 2018. The most recent annual epidemiological report for HIV issued by the HPSC was published in 2019. No epidemiological report for HIV has been issued for 2019 and 2020 due to the COVID-19 pandemic; however, weekly statutory notifications of HIV and STI statistics are available.

Table 2: HPSC Estimated Figures for HIV in Ireland: 2018

People Diagnosed since beginning of epidemic	9,344
People Living with HIV	7,200
People with a New diagnosis in 2017	492
People with a New diagnosis in 2018	523
People who Died of HIV/AIDS-related conditions in 2017	5 (CSO Vital Statistics. Report) 4 men, 1 women
WLHIV	111

1.6. Defining Shame

As this study aims to explore the emotion of shame in the narratives of women living with HIV, I present my understanding and position on shame. Shame in this study is explored through a sociological lens, while acknowledging that it is a concept made up of sociological, psychological, biological and cultural elements. Drawing on the work of Cooley (1902) and Scheff (2000), shame is defined in this study as the self-conscious emotion that develops upon seeing oneself judged negatively in the eyes of another and that view is internalised onto the self. In his groundbreaking work on modernity and the civilizing process, Elias (1939) developed modern understandings of shame in society by uncovering a significant decrease in the threshold of shame in modern societies. Elias (1939) concludes that central to our modernity in society was a significant increase in the prevalence of shame relating to social etiquette (bodily functions, sexuality, table manners). Essentially, the more civilised we have become, the greater the possibility to feel shame in social encounters. However, much shame that exists in high prevalence across society is hidden (Elias 1939; Kaufmann 1989; Scheff 2003,). It is important to differentiate between shame that is considered functional and shame that is problematic. Having a 'sense of shame' is the driving source within individuals as members of society which allows for the maintenance of social cohesion, so that as we consider what other people think about us, we consider the risk of possible shame (Scheff 2003, Goffman 1959). On the other hand, problematic shame, the focus of this research, is more negatively influential on one's experiences in that it has the capacity to lead to an array of problems in people's lives (Dolezal and Lyons 2017).

Varying but connected definitions of shame exist in the fields of sociology, psychology and psychotherapy. Brené Brown (2006) defines shame in the development of Shame Resilience Theory as "an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance" (p.45). Due to the fact that we are social beings by inheritance, shame can act as a signal to a threat to our survival. As the social bonds individuals form with people around them are threatened, shame is an instinct that highlights a threat to such bonds (Lewis 1971).

Identifying and referring to shame directly is important for one's understanding and managing of shame (Lewis 1971), an important point considering that shame is often overlooked, unrecognised or masked as another emotion. Shame is often used interchangeably or conflated with guilt, however, the two emotions have distinct differences. Guilt is specific and close to the surface relating to specific acts done or not done. Lazare (1987) posits that sudden shame results from a sudden or chronic awareness of deficiency of the self, or a goal not reached. In shame, the response is to hide and disappear, where as with guilt, the response is often to make amends. The other (person, group) is often the source of real or imagined scorn, contempt or ridicule in shameful situations, however, with guilt the other is hurt or suffering. Interestingly, there are circumstances where feeling guilty can lead to feeling ashamed. Guilt is often produced when someone hurts others, but because women more so than their male counterparts, are generally socialised not to harm others, they may feel shame due to the cultural violation from which their guilt developed (Ferguson et al. 2000).

Shame in women most often relates to a perceived violation of well-entrenched expectations of social and cultural norms for one's gender and feminine identity (Ferguson et al. 2000). When women believe that they have failed to live up to the standards society sets out for their gender, it can be shame-inducing (Weiss 2010). In terms of what is shame-inducing for women, such events are considered as unique as the individuals themselves. However, Brown (2006) compiled common areas within which shame arose most commonly among women. Brown (2006) described how women's vulnerability to shame was associated with 'unwanted identities' to these topics, including body image, mother hood, sexuality, and more.

Shame is and can be a powerful and influential emotion that has the capacity to impact on aspects of one's life, including one's health. It has previously been argued that shame should be considered a determinant of health in light of WHO's health determinants, which include a range of social, biological, behaviour, educational, socio-economic and environmental factors that have the capacity to influence individual and population health (Dolezal and Lyons 2017). While shame can influence our behaviour, it must therefore be considered as possibly impactful on health and health outcomes. In terms of stigmatised conditions such as HIV, shame can have serious implications on one's life in the diagnosis, treatment and management of HIV, which largely stems from HIV stigma (Hutchinson and Dhairyawan 2017) and associated shame.

1.6.1 Underpinning Theories of Shame

The Looking Glass Self (Cooley 1902)

The definition of shame adopted in this study stems from the underpinning theory, the looking glass self theory, developed by Charles Cooley (1902). Although Cooley's (1902) theory of shame in individuals is dated, its core message remains important to current sociological understanding of shame. Cooley states that the social origin of the self is made up of the self's intersection with other people, explaining that there can be no sense of 'I' without a sense of you, them, or another. Cooley's (1902) theory of the looking glass self, depicts the process of self-reflection made up of three core principles. The first is that we imagine our appearance in the eyes of another person. Next, we imagine the other person to make a judgement on their appearance, based on what they see. Finally, a self-feeling such as pride or shame is developed based on the imagination of the judgement made. Cooley (1902) drew the original concept of his theory from the following couplet;

Each to each a looking glass

Reflects the other that doth pass (p. 152)

An important clarification within the theory of the looking glass self is that the development of the self-feeling such as pride or shame does not occur merely from the mechanical reflection itself but from one's interpretation of their reflection perceived, known as self-concept (Hensley 1996). Further, Cooley adds how the value that is placed on the character of the individual holding the looking glass is crucial to the development of the self-definition. Our mental construction of how we appear to others depends on the esteem in which we hold the individual who is holding the glass.

Shame and the social bond (Scheff, 2000)

From a review of existing work of sociologists, Scheff suggests that shame is the premier social emotion (Scheff 2000). Scheff's theory adopts the sociological definition of shame as opposed to the psychological definition (awareness of an inconsistency between the ideal and actual self), and proposed that shame cannot be understood within a framework that is individualist and does not consider 'the other' (Scheff 2003). The underscoring idea behind shame and the social bond theorises that shame is generated by a threat to a social bond that tethers the self to another, resulting an onset of emotional reactions including embarrassment and shyness, self-consciousness and rejection. If shame does result from a threat to the social bond, as informed by Helen Lewis (1971), Scheff argues that it is the most social of the emotions (Scheff 2000). Building on the work of Lewis (1971) who proposed that while shame resulted from a threat of disconnection to a social bond, shame can also results from actions within one's internal monologue, without an actual interaction taking place. Scheff (2000) also draws on the work of Cooley's (1902) looking glass self. Scheff's (2000) theory of shame and the social bond adds to the sociological understanding of shame in that people interpret and react to the reflected appraisals from others in social interactions as well as from wider society.

1.7 Position statement

1.7.1 Study conceptualisation

In the following position statement I will map the conceptualisation of this study, as well as my positionality as a researcher, researching this topic as an 'outsider within'. Throughout this study process, I engaged in epistemological and personal reflexivity to ensure trustworthiness, transparency and rigour.

The conceptualisation of this study was born from my undergraduate and postgraduate education in sociology, immunology and global health. My education led me to become increasingly familiar with and knowledgeable from a theoretical perspective, about the lived experience of HIV. Having worked previously with an Irish Non-Governmental Organisation (NGO) who carried out qualitative research with people living with HIV in countries in the global south, I became increasingly interested in qualitative research with PLHIV. Coming into this study I was keenly interested in the intersection of how HIV was lived and coped with in the face of stigma and as a treatable chronic condition, and this was a question that I aimed to explore further. I developed an interest in the social construction of health and illness, particularly stigmatised health conditions and how their social construction can affect the lives of those who live with them. I came into the study with an understanding of the stigmatised nature of HIV as a condition, and it was from there that I aimed the study would grow.

Early on in this study, I read and examined potential gaps in the field. Outside of an academic exercise, I read a book about shame and women and I explored whether this was a potential topic to be explored for my doctoral thesis. Due to the sensitive nature of the emotion as a topic, I pondered the notion that such a research question could cause offence. However, it is commonly accepted in psychological and sociological work on shame, that shame is a universal, common emotion that the majority of the human race had evolved to experience routinely in interactions. I aimed to explore how WLHIV experienced such shame, as many studies have explored the multiple dimensions of HIV stigma, yet not shame. Establishing a research question that has not been explored previously, warranted an exploration using qualitative methods, as well as relevance to the experiences of the participants.

1.7.2 Positionality

I entered into this study with multiple roles as researcher and co-constructor in this study: a white woman, Irish, doctoral student and apprentice researcher, HIV advocate and ally. I acknowledged that I view the world through a lens of privilege without navigating major barriers daily in my life. Indeed, I noted similarities and differences between the participants and me. From a gender and culture dimension, I was predominantly similar to the participants in this study. Encounters involved women talking to women, and I felt that I could appreciate and understand some of the stories involving shame that women shared, because in part, I understood what it was to feel shame as a woman, but not shame as an HIV positive woman. The majority (eight) of women interviewed were white, the majority (7) were Irish and we came from the same, or similar, cultural backgrounds. This meant that I picked up our common language use and phrasing without difficulty and I could interpret cultural meaning behind certain aspects of their stories, something I could not always do with migrant women. Throughout the research process, I had to consider my position as a predominantly outsider researcher, researching a sensitive topic. Consequently, I self-reflected on how this might affect the data co-constructed between the participants and me.

The foremost difference between the participants and I was that I am not living with HIV. Instead, I approached this study as an advocate and ally for the HIV community, in particular for women living with HIV. Although I am not living with HIV, only to a certain extent can I appreciate the challenges faced as WLHIV, from a theoretical and intellectual perspective. In considering how my position may have influenced the context of each interview, I interpreted each willing participant who met with me as someone who wanted to share their story. Some women voiced how they appreciated the opportunity to share their story, some women's participation was based on wanting to see change for women living with HIV and recognised participation in studies was a potentially effective way to do so.

Regarding racial and ethnic diversities, three of the participants interviewed were black African women and so were of different racial and ethnic background to me, a white, Irish woman. One woman was an Irish citizen and two women were seeking international protection and living in direct provision accommodation at the time of their interview with me. I considered during the arrangement of our interviews and in the interview spaces themselves, how might my position as a white researcher who is not living with HIV might impact on the space in which the data, and subsequently findings, would be co-constructed. I informed all participants that they were in control of the interview, that they could dictate what we did and did not speak about (while following an interview guide) and where and when the interview took place. Between the participants and I, we mutually understood that I could never fully understand their position as black women and women living with HIV, however, given that I positioned myself as an ally towards women living with HIV, they appeared keen to tell me their story *because* I was a white woman. Their concern around confidentiality was possibly put at ease because they understood I had no engagement with their communities from whom they kept their HIV status hidden. It is possible that my position as a white researcher added an extra layer of requirement for confidentiality to their storytelling experience.

As most women were older than me, I wondered how this would affect the researcher-participant relationship: Would they trust me with their stories to represent them truly and fairly, as some women spoke of experiences before I was even born? Would they consider someone older, more professional and more capable? However, I consider myself to be able to talk to anyone of any age as long as they are willing to converse. My childhood, teens and early twenties were spent talking to older people, the residents of the nursing home my parents run. My much younger self used to sit and speak with older men and women and ask them about their day, their lives, and their stories vastly different from my own. I make no comparison with elderly nursing home residents and the women living with HIV in this study, but I recognise how important the qualities of a good qualitative researcher, such as compassion, empathy, sensitivity and listening, are the building blocks for any relationship, that would in turn produce rapport, trust and honesty in the data gathered. Given this, I deem the employment of these qualities above all else.

1.8 Rationale for the study

To date, there has been very little qualitative research carried out with women living with HIV in Ireland. The rate of new positive cases of HIV in Ireland has increased steadily in the last number of years. Equally, women are living longer with HIV meaning overall that cumulatively more women are living with HIV as fewer people are dying from AIDS related conditions due to the success of HAART. HIV can often have no effects on the physical body, with the exception of side effects of ART (Kerchberger et al. 2020). Due to such success, HIV has been increasingly viewed as a normalised, chronic condition (Mazanderani and Paparini 2015). However, the effects of HIV extend beyond the boundaries of the physiological body. Due to the social construction of HIV over the last 40 years, it remains a highly stigmatised condition, and this is known to be detrimental to the well-being of people living with HIV (Beuthin, Bruce and Sheilds 2015; Moyer and Hardon 2014; Walker 2019; Beniot, et al. 2014; Grodensky et al. 2015; Orza et al. 2015). Given this evidence, more research is needed to explore such effects on individuals who live with HIV.

More recently, qualitative studies with women have focused increasingly on psychosocial issues of living with HIV, in particular stigma and the stigmatisation of WLHIV. In settings similar to Ireland such as the UK and throughout Europe and Canada, it is understood that stigma, in its multiple dimensions (Earnshaw et al. 2013) affect and influence women's experiences of living with HIV. However, there is currently very little understanding of how shame, the painful self-conscious emotion when we see ourselves judged negatively by another - and the emotional correlate of stigma - is felt by women who live with HIV. Shame is considered to be the master emotion of everyday life (Scheff 2000), and the premier social emotion due the high prevalence of shame and anticipated shame in social interactions and the potential impact it can have on our social selves. When left unaddressed, in a chronic state, shame can feel like psychological imprisonment (Hutchinson and Dhairyawan 2017). The research question in this study considered how women living with HIV interpret HIV stigma, whether and how that contributes to HIV related shame, and how such shame manifests. Underpinned by theories of shame including the looking glass self (Cooley 1902) and shame and the social bond (Scheff 2000), this present study aims to extend the body of knowledge around the psychosocial implications of an HIV diagnosis among women by exploring how they experience HIV-related shame.

1.9 Research question

This study's research question is: "How does shame feature in the narratives of women living with HIV?"

The study's aim was to:

- Explore how shame features in the narratives of women living with HIV based in Ireland.

1.10 Structure of the thesis

This thesis comprises six chapters. This present chapter introduced the thesis by providing a background of HIV and shame as it relates to the context of this study, and the rationale for this study. In Chapter Two, I present a critical review of existing literature relating to psychosocial issues surrounding WLHIV. Chapter Two identifies and contextualises the research question within broader issues of living with HIV, such as the normalisation of HIV, WLHIV and ageing and sex, to further establish the rationale for this research. In Chapter Three, I present the study's adopted methodology, narrative inquiry. This chapter is divided into two sections; a detailed description and justification for the adoption of a narrative approach and analytical framework. The second section of Chapter Three provides in-depth detail of the research process including data collection and data analysis. This section is concluded with an insight into my own reflexivity journey. Chapter Four reports the study's findings, which is divided into three sections and includes significant micro-narratives and the accompanying analytical text, to represent the three phases of how shame features in the experiences of women living with HIV. In Chapter Five, I critically discuss the study's findings as they relate to existing studies. The concluding chapter, Chapter Six, summarises the key findings of the study and their significance to the field of interest, the study’s strengths and limitations, and the implications for healthcare, education and future research.

2. Literature Review

2.1 Introduction

In this chapter I will examine existing literature regarding HIV and women, as related to HIV normalisation, sex, ageing, stigma and shame. The focus of this literature review is to critique the body of research that informed the study; how the social normalisation of HIV is slow to follow the biomedical normalisation of HIV in Ireland; and how the gap between the social and biomedical normalisation can contribute to shame for WLHIV. The review supports the case that qualitative research examining shame for WLHIV is needed in this current context, in which WLHIV's voices are not adequately facilitated or heard.

The chapter begins by looking into existing research, globally and Irish, in the psychosocial and biomedical fields, carried out with PLHIV. It then enters into the subject of normalisation of HIV, as it relates to the current biomedical advancements in treatment. From here, the research critiqued and focused on stigma as it relates to the lack of mental health support for PLHIV in the emergence of a normalisation era. Finally, this discussion concludes with the argument that shame is an emotional manifestation of stigma, and thus must be examined further. This section provides an in-depth understanding of the various subjects that surround this study and thus, provides a suitable foundation from which to carry out this study.

2.1.1 Search Strategy

I started the search broadly upon beginning the research in October 2017, which was a broad search of qualitative literature with PLHIV and then narrowed this focus to WLHIV to search for recurring topics being explored and their findings. Databases searched were CINAHL, PsychINFO, PubMed, Medline, SAGE Journals Online and Science Direct. Searches for studies were completed regularly throughout the research process until September 2021. The key words used in the searches were: HIV, AIDS, women, female, shame, stigma, qualitative, narrative. Boolean terms 'and' and 'or' were used. Searches included qualitative studies with women on psychological and emotional health and well-being were researched, as were similar studies with both male and female samples. The searches were exclusive to studies in the English language and with adult participants, within the scope of this project. There were 13 publications commonly referred to that formed the main evidence base of the study. These key publications served as the main evidence for this present study and they included qualitative studies with women living with HIV, men and women living with HIV, a review of literature and academic essays. Studies were carried out in Ireland, the United Kingdom, Australia, Canada, and the United States of America. The publications are:

- Walker 2019 (qualitative, men and women, United Kingdom), Proudfoot 2018 (qualitative, women, Ireland), Davtyan 2018 (qualitative, women, United States), Carter 2017 (qualitative, women, Canada), Beuthin, Bruce and Sheilds 2015 (qualitative, men and women, United States), Orza 2015 (mixed methods, women, United Kingdom), Grodensky 2015 (qualitative, women, United States), Perrson 2012 (qualitative, men and women, Australia), Hutchinson and Dhairyaway, 2017 (academic essay), Bennett 2016 (review of literature) Dolezal and Lyons 2017 (academic essay) Brown 2006 (qualitative, women, United States) Lazare 1987 (academic essay).

To establish a gap in the relevant literature and provide justification for the completion of this research, below is a review of literature laid out in three sections. The first section of the chapter provides an overview of research carried out globally and in Ireland with PLHIV and WLHIV. The broad review provides insight in research carried out with PLHIV and establishes the dearth of qualitative research carried out with WLHIV in Ireland.

The next section of the literature review examines the dominant themes that emerged from the qualitative (and some mixed methods) research with WLHIV (and some studies with men and women). The dominant themes researched across these studies were the normalisation of HIV, ageing for WLHIV and WLHIV’s sexual lives. Findings from these studies highlight the psychosocial complexities of living with HIV despite the success of treatment. Most of the studies reviewed were with women, however, some key studies reviewed used a mixed sample and did not provide a gendered perspective on their findings.

To finish, the chapter explores academic literature regarding the central focus of the study’s research question; shame. This includes insight into the ground-breaking work of sociologists and psychologists and their comparative and contrasting views on the emotion. From there, the section examines relevant literature involving shame among women in a range of topics including gender based violence and breastfeeding. The chapter concludes with studies of shame among people living with HIV and shame among WLHIV. Here, the gap in academic literature is highlighted and justification for the study’s aim is provided.

2.2 Research on HIV

Below I present an exploration into the broad area of study on mental health and well-being and PLHIV and WLHIV on a global perspective and the latter half of this section will focus on these issues in an Irish context.

2.2.1 PLHIV, Mental Health and Well-being – Global Context

In developed countries, access to antiretroviral treatment (ART) has allowed for PLHIV to live a healthy life with an average life expectancy, however, there are still a colossal number of PLHIV in resource poor settings who do not have access to this live saving treatment (27.5 million of 37.7 million PLHIV (UNAIDS 2021)). However, research has shown that whether one has access to treatment or not, living with HIV often comes with additional health issues outside of physiological issues that come with living with HIV. It has been widely documented that a HIV positive diagnosis is a traumatic experience for people, with poor mental health and well-being known to occur post-diagnosis (Terrence Higgins Trust, 2018; Brion, Leary and Drabkin, 2014). However, these occurrences do not happen without reason, as this is primarily due to the social stigma attached to HIV. Stemming from widespread negative media messages in the early days of the epidemic, fear and judgement of PLHIV quickly grew across the globe (Murphy 2016). Moreover, this was largely due to those diagnosed with HIV already living with stigmatised identities such as men who have sex with men (MSM), people who inject drugs (PWID), sex workers, or transgender individuals (Sohn, Ross and Wainberg, 2018). Yet, to this day, research has shown that newly diagnosed PLHIV and people who have been living with the virus for years still experience psychological turmoil that living with the virus can bring (Beuthin, Bruce and Sheilds 2015; Moyer and Hardon 2014; Walker 2019; Lawrence and Cross 2013; Flowers 2006, 2010; Carter et al 2017; Tariq, Delpech and Anderson 2016). The onslaught of such issues can affect other aspects of living with HIV such as testing, engaging with healthcare, taking ART to decrease viral load, disclosing the condition to others, establishing relationships and social capital, and general health and well-being of living positively with HIV (Hutchinson and Dhairyawan 2017).

2.2.2 WLHIV, Mental Health and Well-being– Global context

Women's participation in HIV research has commonly been exclusively focused on gaining an understanding around and prevention vertical transmission of HIV. However, increasingly more is becoming knowing about their broader experiences of LHIV. In research on the subjective experiences of women living with HIV, globally, a decrease in mental health and well-being is noted whether women are in a resource poor or developed setting. In Canadian, Australian, US and UK settings, research involving the lived experience of WLHIV indicates a psychological burden of living with HIV, despite having access to medical treatment (Dibb, and Kamalesh 2012, Beniot, et al. 2014; Carter et al. 2014; Grodensky et al. 2015; Orza et al. 2015; Thorpe et al. 2017; Walker, 2019). The recurring themes cited in academic literature about women's experiences of living with HIV are that increased intervention-led support is needed, because globally, there is an absent narrative for women living with HIV to live openly without fear of stigma or judgement. Findings from this study carried out by the Sophia Forum and Terrence Higgins Trust (2018) sought to explore the various experiences of women living with HIV who were based in the UK, given that women are seen to be left out of research and decision-making for design and delivery of HIV related services. Findings from the study described how over half of WLHIV had experience violence due to their status, almost a third of WLHIV avoided/ delayed access to healthcare due to the fear of being stigmatised, and two thirds described inadequate sexual lives (Sophia Forum and Terrence Higgins Trust, 2018).

2.2.3 Research in Ireland with PLHIV

There have been a number of valuable Irish HIV studies. Irish research into HIV has particularly focused on the variety of impacts that HIV has on physiology e.g. platelet function in PLHIV (Satchell et al. 2010), bone mineral density in PLHIV (Mallon 2014, 2010) and looking at cognitive impairment in PLHIV (De Francesco et al. 2016). Irish research has also looked into the impact of ART on the body, and in particular, ART-associated dyslipidemia (Mallon 2011), as well as the ageing population of PLHIV (McGettrick, Alvarez Barco and Mallon 2018). Ireland has also been home to the renowned PARTNER2 study in St. James' Hospital, which recruited sero-discordant partners, to investigate the risk of transmission when the seropositive partner was on effective ART, and was virally suppressed (Rodger et al. 2016, 2019).

Biomedical research with WLHIV in Ireland has primarily focused on reproductive care and prevention of vertical transmission (mother-to-child-transmission (MTCT)), as the majority of women diagnosed are of childbearing age (HPSC 2018). Irish studies with pregnant women have looked at ART resistance in women receiving combination ART during pregnancy (Lyons et al. 2005), reduced rates of vertical transmission in the UK and Ireland from 2000-2006 (Townsend et al. 2008), impaired glucose metabolisms in pregnant WLHIV (Moore et al. 2015), and pregnancy outcomes among women born with HIV (Kenny et al. 2012). Outside the subject of pregnancy and reproductive care for women, there is a scarcity of biomedical research carried out on female-only samples. Organisations such as the European AIDS

Treatment Group (EATG) look to empower women to use their voices in the European response to HIV (EATG 2019). The Metrodora Project is an initiative set up by the EATG, and aims to foster women's participation in research and development in HIV (EATG4Women 2019). Despite the lack of women partaking in biomedical research in Ireland, research from The Terrence Higgins Trust (2018) reported that more research with female participants is needed due to the difference in physiological makeup of males and females and this gap has not yet been fully addressed.

2.2.4 Research in Ireland with PLHIV: Well-being and Quality of life

There has been significantly less research carried out on the experiences of PLHIV, regarding their emotional health and well-being. A number of studies have focused on the psychosocial impact of HIV on one's life, particularly focusing on life post-diagnosis. Murphy and colleagues' (2017, 2015, 2016, 2013) research focuses on the psychological impact of HIV on MSM and gay men. While their research looks in-depth into the subjective experiences of gay men and MSM, in particular sero-status disclosure, stigma, and resilience and post-traumatic growth, it does not focus on the female subjective experience. Ferris-France et al. (2015) study interviewed men and women on the core beliefs around self-stigma. Findings from Ferris-France et al. (2015) have shown some of the core beliefs that contribute to self-stigma in PLHIV are the possible rejection in disclosure, the belief that they can no longer enjoy a healthy sex life, the belief that they are self-worthless and the belief that they are likely to suffer in death. However, this study sample was made up of 10 men and only 6 women, meaning the majority of the data collected is from a male perspective. Recently, Vaughan et al. (2020) published findings from a qualitative study exploring PLHIV who had experienced stigma in a healthcare setting, and found that such experiences affected their engagement in healthcare and overall seeking behaviour. Research exploring social work and HIV in Ireland by Foreman and Ní Raithaille (2016) reported that fear resulting from stigma and discrimination may persist as a barrier for PLHIV to access vital HIV services, including treatment and prevention. Although these studies provide rich qualitative insights to the lived experience of HIV in Ireland, they do not provide a gendered dimension in its analysis.

Nevertheless, it must be acknowledged again that women make up a quarter of HIV positive cases in Ireland, which may account for the fewer numbers in Irish studies. HIV Ireland, a support organisation for PLHIV, released a report in 2016 following the collection of data in two nation-wide surveys, looking at knowledge and attitudes of and towards, PLHIV, as well as a survey looking at experiences of stigma towards PLHIV. This study surveyed 1,013 people who were HIV negative, and 168 people who were living with HIV, however, the report does not provide a breakdown of how many men and women partook in the survey, however, the report highlights that PLHIV are more susceptible to depressive symptoms, and women are even more at risk (HIV Ireland 2017). Melby (2010) completed his doctoral research on the lived experience of HIV in Ireland, exploring the challenges that are faced by PLHIV. With 18% of his sample female, his findings suggested that PLHIV's physical, emotional and sexual functioning were most affected by a positive HIV diagnosis.

A 2016 Irish cohort study looked at the health-related quality of life (HRQoL) and associated factors of PLHIV, in which the sample was 69% male and 21% female. Findings showed that women's mental health was on average, poor, compared to the men studied (George et al. 2016), and the study summarised that providing psychosocial support for PLHIV can increase HRQoL. In a much earlier study, Melby and Murphy (1999) carried out a literature review to establish a theoretical argument on the psychological needs or PLHIV. Their findings from the literature review concluded that the psychological needs of the PLHIV were significantly neglected, and discrimination against PLHIV was evident. Melby and Murphy's (1999) literature review was carried out 22 years ago, yet one could argue that the research in the last number of years indicates that the psychological needs of PLHIV people are still not being met to the extent they need to be. These findings also suggest there is an obvious lack of intervention and support for PLHIV.

2.2.5 Qualitative Research in Ireland with WLHIV

Of the few Irish studies that explored the psychosocial impact of HIV, even fewer have focused on the female subjective experience of living with HIV. While MSM make up an estimated 50% of new diagnoses of HIV in Ireland, it is clear there is a substantial need to consider the needs of MSM and gay men living with HIV. However, women make up a quarter of PLHIV in Ireland, yet there is a significant gap in the research for women's experiences of living with HIV. To date, four studies look at women's experiences of living with HIV (Proudfoot 2018; Kelly et al. 2013; Cairde 2003; Butler and Woods 1992). Two of these studies have focused on mothers (Proudfoot, 2018), women who are pregnant in Northern Ireland (Kelly et al. 2013) and one study has looked at women of ethnic minorities' experiences with HIV (Cairde 2003). Butler and Woods (1992) looked at the experiences of healthcare workers of PLHIV, and also interviewed a small number of WLHIV who were injected drugs or who had contracted HIV from a partner who injected drugs. Findings from Proudfoot (2018) tells us that women who are mothering while HIV positive tend to put the needs of their children before their own in the wake of an HIV diagnosis, and although effective interventions are used throughout pregnancy, participants still worried about vertical transmission. This study also revealed the psychosocial effects of an HIV diagnosis on mothers (Proudfoot 2018). Similarly, findings from Kelly et al. (2013) concluded that the presence of HIV related stigma was a source of anxiety for women, increasing their sense of vulnerability, and in general, threatened the overall experience of pregnancy and care received. Ten years previously, Cairde (2003) carried out research on the experiences of migrant WLHIV in Ireland, from various cultural backgrounds in terms of how these women found accessing healthcare, education, employment, accommodation, etc. The report found that the women involved in this research were dealing with challenges other than their HIV status, such as racism and uncertain migration status, however, they found that they could not enjoy a social life in case it would increase risk of their status being disclosed, indicating that they were worried about stigma.

In a different context to the previous studies, Butler and Woods' (1992) study was conducted in an era when HIV could not be treated, and those infected were significantly worse off 29 years ago compared to today. Additionally, another contrast to this study's context was that Ireland was facing poor economic performance in 1992. This is reflected in the study's findings, as Butler and Woods (1992) relayed how carers who were interviewed believed that HIV and AIDS shed light on already existing scarcities in Dublin's health and social services, and women who were contracting HIV in Dublin in 1992 were already living on the margins of society, and already in Dublin's most deprived subgroup.

The previous section has provided an overview of research carried out with PLHIV on a global scale and in an Irish context, as well as the research carried out with WLHIV in a global and Irish context. Narrowing the focus to literature reviewed, the next section will examine the three dominant themes that emerged from the literature reviewed with both women and men living with HIV, which were the normalisation of HIV, ageing among PLHIV and sex among WLHIV. These themes from the literature reviewed provide the foreground of the research question of shame among WLHIV.

2.3 Dominant themes from literature

2.3.1 Normalisation and HIV

In 2017, the Health Protection Surveillance Centre (HPSC) reported an increase in annual positive HIV diagnoses (HSPC 2019). Given that the number of people being detected as HIV positive in a year is gradually increasing (HPSC 2019), the widespread accessibility of antiretroviral treatment in Ireland means an HIV positive diagnosis does not mean a premature death. Therefore, the numbers of PLHIV in Ireland are increasing, as fewer people are becoming ill and dying. Furthermore, the virus can no longer be transmitted sexually from an HIV positive person to an HIV negative person when the individual living with HIV is on effective treatment (Rodger, Cambiano and Bruun 2016), a phenomenon that has more popularly become known as “Undetectable equals Untransmittable”, or “U=U”. St. James’ Hospital is currently involved with the PARTNER2 study, which concluded that zero cases of transmission had occurred after 77000 sexual encounters without condoms took place with 800 gay couples (Rodger et al. 2018). Research like the PARTNER and PARTNER2 (Rodger et al. 2016, 2018) studies have contributed to the dominant biomedical narrative that HIV is now becoming a long-term illness, a condition like any other, and is entering a period of ‘normalisation’. The dominant biomedical discourse is therefore that HIV is now a treatable, manageable illness with which people can live normal lives (Beuthin, Bruce and Sheilds 2015; Moyer and Hardon 2014; Walker 2019). This is a result of the shift in the nature of HIV and what it means to receive an HIV diagnosis (Beuthin, Bruce and Sheilds 2015). Before antiretroviral therapy became widely available for PLHIV in developed countries, HIV was a guaranteed death sentence with a life filled with despair, loss and a painful death. The idea is predominantly used by medical professionals and activists (Mazanderani and Paparini 2015) with the purpose that a narrative can be introduced into the conversation around HIV, that once diagnosed with HIV, one can live a healthy, normal life, with an average life expectancy. Since ART has been widely rolled out in the Global North, the discourse towards HIV is now a linear biomedical, public health discourse that focuses on the curtailment of the virus rather than the lived experience of HIV, and what it means to live with the virus (Walker 2019). A projected benefit for PLHIV from adopting a normalised approach to HIV is that it might eventually facilitate more ‘normal’ conversations around HIV, that would reduce stigma towards the condition, increase testing and increase adherence to ART and ultimately increase physiological health and well-being in PHLIV.

However, without overlooking the extraordinary advances made in HIV research and treatment leading to significant biomedical improvements for PLHIV, medical professionals and activists (Mazanderani and Paparini 2015) have introduced a narrative into the conversation around HIV that once diagnosed with HIV and predominantly use the idea; one can live a healthy, normal life, with an average life expectancy. However, in light of the emerging dominant narrative, research has indicated that although people living with HIV are told by medical professionals that they are able to live a healthy normal life (Jelliman and Porcellato 2017; Mazanderani and Paparini 2015), PLHIV are not always able to subscribe to that narrative, and often face a multitude of issues in light of a positive HIV diagnosis (Mazanderani and Paparini 2015). In Irish research context, both Proudfoot (2018) and Murphy (2016) echoed the significant gap between the biomedical normalisation and social normalization of HIV in their research. Both Proudfoot (2018) and Murphy (2016) platformed their research on this argument, as it gives weight to the increasing argument that attention to mental health issues for PLHIV is needed and lacking. This section will look at the broader aspects of the 'normalisation' idea of HIV following the dominant biomedical discourse, as well aspects such as ageing with HIV and WLHIV's sexual lives.

The dominant circulating biomedical discourse that HIV is becoming normalised has been criticised by those who highlight its limits in terms of the ongoing impact of a diagnosis, treatment and everyday living with HIV (Carter et al 2017; Walker 2019; Tariq, Delpech and Anderson 2016; Beuthin, Bruce and Sheilds 2015; Moyer and Hardon 2014; Lawrence and Cross 2013; Flowers, 2010, 2006). Much of the qualitative academic literature about HIV pays particular attention to the abundance of coinciding issues that occur from an HIV diagnosis, mainly resulting from societal attitudes towards HIV, in both a psycho-social context to a physiological context as is seen in Flowers's (2010, 2006) and Persson's (2015, 2013) research. Mazandari and Paparini (2015) illustrate in their research, based on analysis of 76 interviews carried out in London, how factors such as socio-economic difficulties, concerns about trusting viral undetectability and significantly, stigma and discrimination, were major factors for PLHIV having difficulty with the normalcy of HIV. As a sexually transmitted infection, an HIV diagnosis can leave individuals feeling like disease vectors for a highly stigmatised virus rather than a 'regular' human being who have contracted an illness (Carter et al. 2017). This is further developed by Walker (2019) whose findings reflected narratives of women who do not find themselves attractive, or love themselves because of their status, and question why someone else would too. Additionally, Jelliman and Porcellato's (2017) study based on focus groups with 24 multi-professional HIV specialists indicated that challenges specific to HIV specialists made service delivery difficult. Such findings included a lack of HIV-related public and professional knowledge, stemming from fear and lack of public campaigns, and living with HIV has its own stand-alone features such as violence, the criminalisation of HIV in some settings, and travel restrictions. However, Jelliman and Porcellato's (2017) main theme from this research was that stigma was the greatest factor in what made it a unique long-term condition. This is reflected in resource poor settings also, where in McGrath et al. (2014) longitudinal qualitative study with 949 PLHIV in Uganda concluded that stigma and financial difficulties resulted in issues of care-seeking and a struggle for food and other basic services.

More recently, Sohn, Ross and Wainberg (2018) carried out a survey of Global International Epidemiology Database to Evaluate AIDS in the Asia-Pacific, to identify barriers for PLHIV accessing mental healthcare. Their findings reflected previous studies, echoing stigma, lack of amalgamation of HIV and mental healthcare, and lack of data to drive such a policy change. Additionally, Flowers et al (2006) describe that Black Africans living with HIV in the UK, whom deal with HIV stigma and prejudice, also deal with the abundance of factors that HIV critically impacts on in their lives from family responsibilities and cultural expectations regarding reproduction. This is reflected by other researchers who maintain that HIV is certainly not just a biomedical issue but a major social issue for PLHIV (Beuthin, Bruce and Sheilds 2015; Carter et al 2017; Flowers 2006, 2010; Lawrence and Cross 2013; Moyer and Hardon 2014; Tariq, Delpech and Anderson 2016; Walker 2019).

Importantly, evidence indicates that living with HIV necessitates attention to one’s psychological health alongside one’s biomedical needs. Persson (2016, 2013) echoes this sentiment that an HIV diagnosis is life-changing, drawing attention to the benefits of ART efficacy and its potential to introduce a paradigm shift of one of the most feared illnesses in the world. However, Persson (2013; 2015) is quick to mention in their research that shifting from infectious to non-infectious in the setting of an HIV discourse would not be straightforward. Persson (2013) argues that from the moment a person receives an HIV diagnosis, they must enter into an ‘unequal dialogue’ between their own HIV experience and the dominant HIV discourse (Carricaburu and Pierret 1995; Daniel and Squire 1995). This potentially illegitimates the fears and worries they experience in relation to living with HIV and the uncertainty of the future.

Interestingly, in a study following PLHIVs’ embodied experience of living with HIV (Lawless 1996), a spoiled identity was a common theme. However, as gender partially shaped how the spoiled identity was experienced, Lawless et al (1996) explains that women living with HIV are more likely to have their experience contextualised by cultural stereotypes that framed women as unclean and dirty (Lawless 1996). This is reflected in Carter et al. study (2017) on the problematization of women living with HIV’s sexual lives. This is exacerbated further by

HIV being primarily seen by the public and health officials as either a ‘gay man’s’ or an African disease, which tends to shape public perception, attitudes and public health responses in terms of treatment, and prevention (Persson 2013). Simultaneously, this adds to the conversation in which heterosexual and, in particular women, tend to be over-shadowed and ignored by health professionals (Persson 2013). In Ireland, since recording began, the total number of women diagnosed with HIV is 1858 and the total number of people diagnosed since the same time is 9344 (HPSC 2018) (numbers are most probably higher as these are the most recent data available from the HPSC)). At this rate, a significant proportion of diagnoses are either men or their gender is unidentified, so the danger of women slipping under the radar and being over-shadowed by prevention and treatment campaigns aimed primarily at gay men, Ireland’s highest proportion of PLHIV (HPSC 2018), is probable.

The issue that HIV is socially invisible and/or ignored among both male and female heterosexual populations (Persson 2013), may add to the stigma of being a woman living with HIV and may decrease rates of antiretroviral adherence. Persson (2015) considers treatment – as – prevention (TasP) as a potential pathway for normalised sero-discordant relationships, free from stigma and risk. TasP has the power to ‘un-discipline and de-stigmatise’ (Persson 2015, pg. 392) sero-discordant sexual relationships, (when one partner is living with HIV and the other without) however, it is described in terms of how another risk may unfold in light of this shift in behaviour change. The use of the word ‘un-discipline’ is a striking choice of words in Persson’s (2015) research as it indicates that sero-discordant relationships are not liberated nor are they governed simply by the two individuals in the relationship. Persson (2015) explains that responsible HIV citizenship will be automatically considered for PLHIV and one must be consistently undetectable, or they will be deemed an irresponsible HIV citizen, even an immoral citizen. This brings the questions if a sero-discordant couple in which the HIV positive partner was not undetectable, yet took the appropriate precautions to limit transition, will make them an irresponsible person in the society’s eyes.

Viral undetectability may be relatively straightforward for someone who lives in the Global North with direct access to medication, food to take with that medication, and a clinic that monitors viral loads. Issues may arise for WLHIV who, as mentioned, may find it more difficult due to psycho-social and cultural issues to act on the above. It may also introduce the pressures of condomless sex for sero-discordant couples (Persson 2015), something that may give rise to further issues such as pregnancy and/or additional sexually transmitted infections. However, in

Persson's (2015) previous research, narratives of love, connection, and the consistent manageability and importance of living with HIV are discussed in light of the recent biomedical advances in HIV treatment, indicating positive relationships between the couples themselves, and contradicting the dominant public discourse that HIV sero-discordant couples are fraught with risk and uncleanliness, and are heavily stigmatised. Persson (2015) goes on to highlight that the public discourse of HIV is entwined in risk and infectiousness and a public open discussion around these relationships must be considered.

2.3.2 Ageing for PLHIV

As we set into the 5th decade of the HIV epidemic, there is an increasing prevalence of older people living with HIV due to the success of treating HIV. Older people who are ageing with HIV are gaining increasing attention in health research. Contrasting experiences of ageing with HIV are reported in academic literature. Research findings report anxiety of the unknown around ageing and HIV, and decrease in social support in older people living with HIV, combined with a greater need for social support. In a UK study with a sample of primarily men and one woman (Lawrence and Cross 2013), findings revealed that participants reportedly experience increased HIV stigma with age, and a sense of belonging to the HIV community decreased with age. In studies with female samples, Grodensky et al. (2015) put forward how older women felt their HIV status was shameful because of their age, which affected their sourcing of social connections, resulting in isolation. Furthermore, findings from Warren-Jeanpiere et al. (2017) portrayed that women ageing with HIV need increased social support from their families, healthcare professionals and peers as they grew older. In recent years, the psychosocial implications of ageing with HIV have emerged, however, research also reveals that living with HIV for a longer period of time allows for the development of resilience and increases sense-making of life with HIV. Psaros et al (2015) reveal in a study with women ageing with HIV, that women can experience a change in attitude as they age, and put living with HIV into perspective by comparing it to more serious illness. Similarly, Subramanian et al. (2017) illustrated in their study with women living and ageing with HIV how women can develop resilience over time because of the support they received. Psaros et al. (2015) found that optimism, self-acceptance and strong support systems were beneficial for women ageing with HIV. Literature has revealed the contrasting effects of HIV on the psycho-social experience of ageing with HIV, however, particularly for women, ageing with HIV has implications on the physical body. This too can impact on well-being as people age with HIV.

Living with HIV comes with the uncertainty of ageing with HIV and the longstanding effects that ART has on the body, as Lawrence and Cross 2013; Beuthin, Bruce and Sheilds, 2015; Flowers, 2010, Calvet 2015; Tariq, Delpech and Anderson, 2016, have illustrated in various forms of research. As a person ages, their immune system weakens and although they are taking ART, their bodies may not be as resilient to pathogens as previously (Lawrence and Cross 2013; Beuthin, Bruce and Sheilds, 2015). A Brazilian study (Calvet 2015) has shown that women living with HIV are more likely to experience early natural menopause. WLHIV are more like to enter early natural menopause in their 40s, while entering early menopause may have significant effects on a woman's mental well-being in the context of her identity and her sexuality (Calvet 2015; Tariq, Delpech and Anderson, 2016). This may also limit the chances of older WLHIV having children. It is possible that WLHIV have waited until several years after their HIV diagnosis, waiting to trust their treatment, only to find that they cannot become pregnant. It could also be seen as a recurring biographical disruption, a theoretical term used to describe a break of change in one's life (Alexias, Savvakis and Stratopoulou 2016; Bury 1982). For some women, entering into early menopause may be a reminder of receiving an HIV diagnosis all over again and be difficult to come to terms with the additional burdens of living with HIV. For some women, it may mean they have lost their sense of sexual identity.

Tariq, Delpech and Anderson (2016) have portrayed this to be a scarcely researched area yet likely to be a growing burden of health needs among the growing population in light of the increase of women ageing with HIV, and scope for further research in age-related issues/conditions for older women living with HIV is apparent. Calvet (2015) reiterates this sentiment, concluding that early natural menopause can negatively impact on women's quality of life as well as physiologically, due to a reduction in oestrogen. In light of the above, what is worrying about this is that hormone replacement therapy rates in the United Kingdom are low for WLHIV compared to HIV negative women (Tariq, Delpech and Anderson, 2016). Another area of concern for women is how living with HIV affects their sexual lives.

2.3.3 Sexual lives of WLHIV

As research has indicated, in light of the dominant biomedical discourse of 'normalisation', and thus, ageing women are not only falling short of the HIV prevention and treatment campaigns in the Global North, but the various intersections of their lives that are affected by HIV (such as early menopause) are not as thoroughly researched as their male counterparts. Perhaps this boils down to history of activism and fighting against a stereotype that blamed gay men at the beginning of the AIDS epidemic. Nonetheless, there is no denying that the sexuality and sexual health of WLHIV has been overlooked, and possibly silenced although it is a very important aspect of the lived experience of being a WLHIV (Carter 2017). In Carter et al (2017) review of two decades' worth of studies on WLHIV's sexuality, many studies were shown to narrowly construct sexuality as sexual behaviours and dysfunction relating to illness. Following an HIV diagnosis, women's experience of sexual activity, function, satisfaction, and pleasure is depleted for some time. Lawless (1996) indicates that the sexually transmittable nature of HIV is that makes sexual behaviour highly stigmatised and fraught with panic and fear. In a more recent study, findings from Nevedal and Sankar (2016) illustrated that in a group of older African-Americans (including five women) living with HIV/AIDS, sexual experiences and intimacy were limited due to living with HIV as they perceived their sexuality as damaged and their intimacy constrained. In contrast to the above studies mentioned, Taylor et al. (2017) study of 50 older African American and Latina women, describes how sexual pleasure and a need for intimacy was important to the women in the study as they grew older. An Australian study in which 74 WLHIV were surveyed on their health and well-being, Thorpe et at. (2017) reported that HIV had negatively affected women's sexual and intimate relationships. However, many women also noted the positive affect of ART as they felt more confident engaging in sexual activity while having an undetectably viral load. Furthermore, Thorpe et al. (2017) revealed that just under half of women surveyed had experienced violence, including sexual violence, at the hand of their partner or spouse.

Historically, the dominant discourse for women diagnosed with HIV is contamination and fear (Conrad 1989) and women's sexuality in the context of HIV is shaped primarily by this history (Carter et al 2017). Alice Welborne (2013), agrees when indicating that sexual pleasure for WLHIV has become something scary and taboo due to the level of societal stigmatisation and criminalisation of WLHIV, and that WLHIV are seen as often just a threat to a sexual partner, someone who is sexually deviant (Squire 2003; Persson 2005). Here, again, we see WLHIV framed as a disease vector rather than a woman, a person, who has contracted HIV. The avoidance of sex completely or a loss/ damage to sexuality is hardly surprising for WLHIV (Carter 2017).

2.3.4 Conclusion

Through an examination of past literature concerning the 'normalisation' of HIV in light of the dominant biomedical discourse, it is evident that there are valid arguments against HIV's normalisation in a number of ways. Firstly, the psychosocial aspects of living with HIV, including being a woman who is living with HIV and is a mother, a migrant or in Direct

Provision challenges HIV normalisation. Additionally, the uncertainty of ageing with HIV and the issue of early menopause is a concern for many women; women's sexuality in the context of HIV and significantly, the aspect of intersectionality where HIV affects various personal, social and cultural issues in people's lives. In terms of researching this issue, there is potential for looking into women's perspectives on this in light of their embodied HIV experience framed in the light of the Swiss Consensus Statement (SCS) (Persson 2010). Persson (2013) posed the question as to whether society's perception of a body infected with HIV could be altered and re-inhabited as if it were a regular, non-infectious body, moving away from the idea of the body that was once so significantly marked as being something contagious and dangerous since HIV/ AIDS became apparent. The above research has indicated that living with HIV does not mean living with any other treatable chronic condition for which one solely has to take a pill once a day and forget about it for the rest of the time. HIV is taxing on individuals' mental health due to the stigma placed on the condition by society and even PLHIV themselves. The next section will look at the literature of the emotional manifestation of social stigma, shame, and explore how other psychosocial researchers in a variety of areas, including women and HIV, capture shame.

2.4. Looking at shame through stigma

The subject of HIV-related stigma has been researched across genders, cultures, and in both highly resourced and resource poor settings (Sikstrom 2018; Nevin et al 2019; Nobre et al. 2018; Rice et al. 2018; Sangaramoorthy, Jamison and Dyer, 2017; Cuca et al. 2017; Alomepe et al2016; Karamouzian et al. 2015). Qualitative studies involving a female sample (Arrey 2015) and a mixed sample (Mehdiyar et al. 2020) reveal migrants living with HIV in western countries have concerns around HIV stigma, including self-stigma. In an interview study carried out to investigate stigma mechanisms and well-being among PLHIV, Earnshaw et al. (2013) research highlights the differentiation of stigma mechanisms; anticipated stigma, enacted stigma, and internalized stigma, drawing on the statement that HIV stigma has been widely shown to negatively contribute to the health and well-being of PLHIV (Logie and Gadalla 2009).

Studies with black women in the United States have revealed how these women experience multi-level stigma in various domains in their lives, in multiple settings and contexts (Fletcher et al. 2016; Kemp et al. 2016). Fletcher et al. (2016) provide insight into how the impact of multiple dimensions of stigma on black women in the US has impacted their disclosure decisions and affects their safety in places such as healthcare and work place settings. Following a randomised trial of an intervention to reduce HIV stigma, Kemp et al. (2019) revealed that stigma negatively affects the viral load of black women living with HIV in the US. Ferris-France et al. (2015) qualitative study researching internalized stigma, argues that internalizing stigma manifests as feelings of worthlessness, low self-esteem and shame. While HIV stigma has been widely researched, the manifestations of stigma, such as shame, have not been explored to the same extent. In a quantitative study, Vincent et al. (2017) argues that because shame is the result of internalized stigma, shame, as opposed to stigma, can be addressed and modified in PLHIV through behavioural intervention, thus promoting shame as an important focus for social and behavioural research.

In his work reviewing the presence of shame in social and psychological theory and its accompanying work, Thomas Scheff (2003, 2000) declares shame as a painful subjective emotion that manifests when an individual believes that they are flawed, inferior, or sees themselves as this in the eyes of another person. Scheff (2003) proposed that shame is “the master emotion of everyday life” (p. 6), describing it as the most primitive and universal of all the human emotions, with its presence often unknowingly subtly operating in the healthiest of human interactions (Kaufman 1974). Brown’s (2006) seminal work, based on qualitative interviews with 215 women on shame resilience, echoes Scheff’s (2003, 2000) sentiment on shame, as does Poulson (2004), who drew on Scheff’s (2003) argument, having carried out a review of shame as the ‘master emotion’. Sheff (2003, 2000) and Brown (2006) hold different views however, relating to what constitutes as the opposite of shame. Brown (2006) identified empathy as the opposite of shame, whereas Scheff (2000) declares pride as the opposite of shame in his work on shame in social theory, stating that pride as an emotion equates to the feeling of a secure social bond with another/others, and shame is the emotion that equates to a threat to that bond. Appiah (2010) also reflects this in his philosophical claim, The Honor Code: How Moral Revolutions Happen, in which he argues that our actions are directed by shared forms of social identity, which are instilled into moral norms of a society.

There can be no doubt that shame can lead to a reduction in subjective well-being and prolonged shame can have devastating effects on mental health leading to depression and/or anxiety (Hutchinson, Dhairyawan, 2017; Bennett 2016; Brion, Mark and Drabkin, 2014; Chao, Cheng and Chiou 2011; Persons et al. 2010; Lewis 1987). Brown’s (2006) Shame Resilience Theory proposed that shame is a psycho-social-cultural construct. The psychological component relates to the emotions, thoughts and a person’s behaviour. The social component relates to how people experience shame in an interpersonal context, tying it to relationships and our connections with others. The cultural component relates to the cultural expectations placed on people (specifically women in the case of Brown (2006)), and the real or perceived failure of meeting cultural expectations that can result in shameful thoughts. Scheff (2003) also acknowledges that shame is equally a psychological phenomenon as it is a social one, which is also looked at in Robertson's et al. (2018) quantitative research, informed by information threat theory, who concludes that the true trigger for shame in an individual is the possibility or actual event of being devalued by another.

Kaufman (1974) maintains that shame itself is a taboo subject i.e. society is ashamed about feeling ashamed. Kaufman, (1974) argues that the taboo in shame arose from the lack of language to describe shame. He argues that shame is a 'class' emotion, that embarrassment, shyness and awkwardness derive from. However, concerning the word 'shame', English has a singular definition, whereas in the French or German language for example, two words for shame exist. 'Scham' meaning an everyday, milder shame (shyness, embarrassment) and 'Schande' meaning disgraced shame, eliciting a deeply painful emotional response to breaking a social honour code (Quilty, Conlon and Kennedy 2016). Kaufman's (1974) position indicates that this allows for issues relating to everyday shame to be addressed without causing any offence, however, in the English language, we run the risk of offence because there is no differentiation between disgraced shame and everyday shame. The common vernacular of shame in the English language, a term linked to disgrace, can affect people's interpretation and understanding of the concept of shame, and shame as an emotion (Scheff 2003).

Kaufman's (1989) psychological argument proposes that shame dynamics are part of an interpersonal bridge that connects people, or they would otherwise lead isolated lives. However, in contrast to this sentiment, findings from Chao's (2011) psychological experiment illustrate that prolonged shame is associated with social disengagement and increased tendencies of independence. Conclusions from Kaufman (1974); Retzinger (1995), Brown (2006) and in particular Scheff's (2003) philosophical argument, state that the reason shame is invisible in modern social science is because the taboo around shame has led us to believe that shame does not exist at all. Of course, this idea is informed by the aforementioned work of Elias (1939) that humans have civilised towards an increased shame threshold combined with a decreased acknowledgement and awareness of shame. If shame is as universal and primitive as research has indicated through the years (Brown 2006; Scheff 2003; Kaufman 1974), its presence in HIV research does not reflect this, considering the psychological, social and cultural complexities of the impact of living with the virus.

In a recent effort to differentiate shame from stigma research, Bennett (2016) offers another potential reason for the scarcity of shame as a construct or concern in HIV research. Research acknowledges that literature around HIV in a psychosocial capacity is dominated by stigma, and this is often done without mentioning shame (Hutchinson and Dhairyawan 2017). Bennett (2016) and Hutchinson and Dhairyawan (2017) warn that the misidentifying of shame and stigma's nature can lead to a misunderstanding and failure to adequately address both. As previously mentioned, the stigma framework encapsulated multiple dimensions of stigma; enacted stigma, perceived stigma, and self-stigma (Earnshaw 2013). Shame is an emotion that manifests when someone experiences self/internalized stigma (Ferris-France et al. 2015). Bennett (2016) has pointed out that the scarcity of research carried out on shame in the HIV community is potentially due to shame being subsumed among measures of self-stigma, rather than an established stand-alone area of research in HIV. Additionally, as Bennett (2016) points out, shame is not an ultimate element of stigma, as not everyone who is stigmatised will necessarily internalize that stigma and feel shame. Literature has suggested that expressing self-compassionate thoughts can combat shame, stress and anxiety and contribute to better adjustment to life with HIV (Brion, Leary and Drabkin 2014). Research has also drawn attention to the role of resilience and motivation in PLHIV in which findings showed that practicing resilience to shame was endeavoured by framing positive goals, and using social competence and social skills (Adegoke 2017) while also taking the opportunity to better one's self-care (De Santis 2013).

As mentioned in the thesis introduction, feeling shame is not necessarily entirely harmful, as literature suggests that feeling shame indicates human integrity, can possibly protect individuals from carrying out transgressive behaviour, and allows for appeasing others after a social transgression, perceived or otherwise, as indicated in Matos and Pinto-Gouvei's (2010) quantitative psychological study. Scheff's (2003) philosophical argument maintains that shame serves as a function for society in that it provides an indicator when there is a threat to the social bond. Here, he argues that a threat to the social bond, leading to the breakage of a social bond with another individual, is identified by feelings of shame. Mead's (1934) psychological analysis maintains that humans are a social phenomenon as much as we are biological phenomena and that a threat to our social bodies (as opposed to our physical bodies) elicits shame (Matos and Pinto-Gouvei 2010).

Health-related shame, and shame in the clinical context, have been given some attention in previous years. Over three decades ago, Lazare (1987) published an essay calling for the increased awareness and addressing of shame in clinical encounters, highlighting the negative effects it can have when both the patient and the healthcare professional feel ashamed in clinical encounters. Lazare (1987) brings to light how it is not the norm for healthcare professionals to inquire about the subjective experiences, or well-being, of their patients in that it can be shameful to admit one's shame. Lazare's (1987) essay on shame in clinical encounters, although dated, maintains its relevance to stigmatising health conditions, such as HIV, as pointed out by Hutchinson and Dhairyawan (2017). Building on the work of Lazare (1987), Dolezal and Lyons (2017) offer their observations of the impact of shame on individuals' health by stating that the powerful influence of shame on one's behaviour, can have the potential to impact their health outcomes. As previously stated, HIV-stigma is pointed out as having a negative effect on viral load due to its effect on HAART adherence, however, given the arguments relayed by Dolezal and Lyons (2017), shame must be considered as a target for intervention in such evidence.

In an Irish context, Quilty, Conlon and Kennedy (2015) discuss the key reflections of the Irish abortion regime up to the introduction of the limited abortion legislation in 2013. Such reflections are supported by Appiah's (2010) philosophical argument that our actions are directed and provided with meaning, based on the moral norms of our collective forms of identity that define our moral character, known as honour codes. Appiah (2010) reiterates that violation of such honour codes can produce painful emotions such as shame, and therefore guides our actions so as not to be excluded or punished collectively. The rationale for carrying out research on shame comes from the recognition that PLHIV experience poorer mental health and reduced well-being, not just because they are living with HIV, but due to the social stigma placed on living with HIV, which potentially contributes to experiencing negative emotions, including shame. The rationale for exploring shame for women is due to the cultural and social expectations to which women are held, which may contribute to significant levels of shame. I will discuss this point in the following section.

2.4.1 Women and Shame

Regarding research about women and shame, Brown (2006) argues that women are held to others' expectations all their lives, and categorises 12 shame related issues as the main instigators for eliciting shame in women; appearance and body image, motherhood, family, parenting, money, work, mental and physical health, ageing, religion, being stereotyped, speaking out and surviving trauma. Falling short of these expectations, or a self-perception by the woman herself of falling short, has the power to elicit shame in women, according to Brown (2006), both 'everyday' shame and 'disgraced' shame. Research has also explored shame among women in areas such as gender-based violence (Beck et al. 2011; Weiss 2010), body image (Overstreet, Quinn and Agocha 2010), infertility (Galhardo, Pinto-Gouveia and Cunha 2011), breast feeding (Thompson and Ebisch-Burton 2015), obstetric violence (Shabot and Korem 2018), body weight in pregnancy (Christenson et al. 2018), and abortion (Quilty, Conlon and Kennedy 2015). Shame has been briefly addressed in HIV in more recent years, in a qualitative study that explored the lives of older women living with HIV in the US (Grodenksy 2015). With regard to women living with HIV, the risk of shameful thoughts may be somewhat higher, as they are living with a complex, stigmatised illness (Grodenksy 2015). As previously mentioned, HIV is not considered a deadly virus anymore by medical experts due to the advancements to HIV treatment (Walker 2019; Furlotte and Shwartz 2016). However, literature suggests that although HIV is a treatable illness, the dominant discourse does not take into consideration the psychological and social issues that living with HIV might conjure up (Walker, 2019; Furlotte and Shwartz 2016). An issue might be that the psychological and social issues of living with HIV are increasingly being overlooked in clinical settings, and feelings of fear, concern and uncertainty from people living with HIV may be undermined and overlooked. Clinicians and social workers may not address an issue such as prolonged, unacknowledged shame because the conversation around shame and HIV is not happening in wider society.

2.4.2 HIV and Shame

The literature around HIV-specific shame, while it is limited, suggests that prolonged, unacknowledged shame (Brown 2006) is associated with a reduction in mental health and well-being, leading to mental health issues, e.g. depression, and physical symptoms resulting from a disengagement from treatment (Hutchinson and Dhairyawan 2017; Bennett 2016). Vincent et al. (2017) findings from quantitative tests concluded that HIV related shame correlated with a lower HRQoL, and contributed to depression and loneliness. Furthermore, for women specifically in Vincent et al. (2017) study, social well-being was significantly affected by HIV-related shame. In a review of literature around shame among people living with HIV, Bennett (2016) confirmed that shame and HIV have rarely been examined. Bennett (2016) attributes this issue to the fact that shame has likely been subsumed with measures of internalised stigma.

However, what Bennett (2016) did not acknowledge as a potential contributor to the reason, was Scheff's (2003) argument that shame is not widely acknowledged or explored due to the taboo of discussing shame. Much of the literature's findings of research on HIV and shame, associate shame with poor adjustment in PLHIV, leading to depressive symptoms and poor retention in care. Persons et al. (2010) study shed light on the affect shame has on the health-related quality of life (HRQoL) of PLHIV who experience child abuse, findings from a survey on 247 PLHIV who had experienced childhood sexual abuse indicated that HIV-related shame was a significant predictor in reduced HRQoL of the study's sample, significantly more so than sexual abuse-related shame. However, it is possible in the above study that the factor of a history of child sexual abuse had affected HIV-related shame and HRQoL. In Walker's (2019) study, shame is mentioned in a participant's narrative in response to the argument against the normalisation of HIV. The respondent implies the argument that although HIV is deemed a treatable chronic illness, the psychosocial implications of an HIV diagnosis are unique, it has the potential to elicit shame and other negative emotions. However, Walker (2019) does not address shame in the analysis or discussion of the study's findings, even though shame and guilt are present in the title of Walker's (2019) study, leading one to believe that they are strongly associated with the contemporary experiences of PLHIV in the United Kingdom. As in Person et al. (2010) study, Ho and Goh (2017) describe in their findings how after receiving a positive HIV diagnosis, participants feel an overwhelming sense of shame and describe how they have to reconstruct their lives to enforce normative identities. From a public health perspective of HIV, Hutchinson and Dhairyawan (2017) propose the leading issues that prolonged, unacknowledged shame can lead to in PLHIV. They include shame as a barrier to disclosing one's full sexual history for fear of judgment, as a motivational factor to disengage from healthcare, as a barrier to sexually transmitted disease (STI) testing, as a barrier to the disclosure of HIV to sexual partners or others, and shame as psychological prison for people living with HIV, making their HIV experience ultimately a negative one (Hutchinson and Dhairyawan 2017). The above barriers mentioned are highly important for HIV self-care and Hutchinson and Dhairyawan (2017), claims that shame is a significant attribute steering behaviour in relation to HIV care. Although, Hutchinson and Dhairyawan (2017) approaches the concept of the article from public health diagnosis and treatment perspectives, it is a probability that the knock-on effects could impact on the mental health and well-bring of PLHIV.

2.4.3 Women, Shame and HIV

In the studies presented thus far, the majority of studies utilised samples made up of both men and women. Of the limited number of studies carried out investigating shame in people living with HIV, only two studies had a female-only sample. Grodenksy (2015) involved a qualitative understanding of specific issues that older women living with HIV in the United States face and Lennon-Dearing (2008) explored the benefits of female only support groups. Features of shame were identified in the findings of these studies but the research question of the study did not seek to explore features of shame among their samples. However, findings from both Grodensky et al (2015) and Lennon-Dearing (2008) offer partial relevant insight into aspects of shame among WLHIV. As mentioned, shame has been researched using female only samples in areas such as intimate partner violence (Beck 2011), body image (Overstreet, Quinn and Agocha 2010), infertility (2011) and breastfeeding (Thompson, 2015). However, there appears to be a gap in the literature, with a significant under-representation of women in HIV related research, with the exception of studies relating to mother-to-child transmission. These studies clearly indicate that WLHIV experiences warrant consideration particularly within the psychosocial space. No study to date has sought to understand the impact that shame has on women living with HIV and how this affects their mental and physical well-being. Equally, in an era when ART is widely available and viral undetectability is achievable, keeping PLHIV alive is no longer the sole objective for healthcare professionals. It is critical for healthcare professionals to address the psychological and emotional difficulties to which a PLHIV is vulnerable once they receive a positive diagnosis, and ensure that those difficulties are acknowledged and managed by trained personnel.

If it is that prolonged unacknowledged shame is akin to a psychological imprisonment (Hutchinson and Dhairyawan 2017), this claim warrants an exploration from a female specific perspective. In Brown’s (2006) grounded theory study on shame resilience, the shame web is described as the layered, conflicting and competing socio-cultural expectations to which women are held and they are imposed, enforced and expressed interpretations of who women ‘are supposed to be’ based on their gender, social class, age, race, sexual orientation, etc. Findings from Shabot and Korem (2018) reflect the socio-cultural expectations of motherhood post-birth, highlighting the pressure to be the perfect mother in the moments after birth, which can be shame inducing. These socio-cultural expectations are then reinforced by individuals, groups and media culture. This can be said for WLHIV in Ireland, some of whom are migrants, and within whose country of origin people also hold a similar cultural view of women raised in Ireland. It is reasonable to assume that perhaps if women living with HIV believe that society thinks they are somehow flawed, this may negatively impact them. This study proposes that women, when held to such socio-cultural standards and expectation, upon receiving a positive HIV diagnosis, are at a greater risk of developing shameful thoughts, and aims to understand the concept of how and why this is so.

2.5 Conclusion

In conclusion, I have reviewed insightful publications that relate to the research question and study's sample. HIV remains a difficult condition to live with for many, and how women respond to and deal with being HIV positive has received little attention from researchers. To summarise, I have provided a broad overview of the research carried out with PLHIV and WLHIV on issues of mental health and well-being before reviewing relevant studies in an Irish context. The review revealed a dearth of qualitative studies with WLHIV in Ireland.

Having narrowed the focus of the literature to issues pertaining to women living with HIV, three major themes were identified and further explored; normalisation of HIV, ageing of women and PLHIV and the sexual lives of WLHIV. With successful treatment, people with access to HAART are living physically healthy lives, and importantly, cannot pass HIV on to another person when on effective treatment (Rodger et al. 2018, 2016). Such development is reflected in the literature in the last number of years, as HIV is increasingly viewed as a normal chronic condition, with which one can live a normal healthy life. The concept of 'HIV normalisation' is challenged by some literature, revealing that although HIV is treatable biomedically, it still poses a health issue in other facets of health, due to the dominant discourse of HIV stigma. Key studies with samples made up of women (Proudfoot 2018, Orza 2015) and men and women (Walker 2019; Persson 2012) support that HIV normalisation is not something to which all PLHIV can immediately subscribe to upon diagnosis, although these studies do not explore the presence of shame in the argument against HIV normalisation.

Another common area among PLHIV, paralleled with successful treatment, is the emerging area of study with people ageing with HIV. Relevant studies have sought to explore the psychosocial effects of being an older person or someone ageing with HIV and the results have been contrasting between an increased need for support as people age, and a greater acceptance of HIV as people age (Grodenskey 2015, Beuthin, Bruce and Sheils 2015). An additional success of HAART, particularly due to U=U, is the benefit towards WLHIV's sexual lives. Research has in fact, pointed out the dearth of research involving WLHIV about their sexual lives. Women’s sexual lives are central to their health and well-being and is need of greater attention (Carter et al 2017).

Of the three major themes reviewed from relevant publications, none so far have explored shame among women in any depth. Of the key studies and essays that refer to shame in health and HIV (Hutchinson and Dhairyaway 2017; Dolezal and Lyons 2017; Bennett 2016; Brown 2006; Lazare 1987), it is clear that shame can be harmful for one’s health. However, none of these studies have addressed shame among women with the exception of Brown (2006), although her research does not relate exclusively to health or HIV. I have demonstrated the knowledge gap in the literature, while also arguing for the need to carry out this present study. The evidence from this chapter suggests that a qualitative study exploring shame in the narratives of women living with HIV is a timely and important study to build on the evidence about the psychological and social impact of this diagnosis for women. The review has highlighted the complexities of women’s lives following an HIV diagnosis yet studies have neglected the concept of shame in their analysis, an important social emotion resulting from living with a stigmatised condition such as HIV.

To explore how shame features in the lives of women living with HIV, I adopted a narrative methodology to address this. The next chapter will present the research methodology, narrative inquiry, and describe the research process, data collection and data analysis.

3.1. Methodology

3.1.1 Introduction

In the previous chapter, I argued that shame as an emotion warrants exploration with women living with HIV, considering that prolonged, unacknowledged shame can cause a reduction in well-being. Shame for women has yet to be examined, in depth in the context of HIV, and to best do so I have chosen a qualitative, narrative approach as the means to explore women's subjective realities of experiencing shame as a woman living with HIV. In this chapter, I present the underlying methodological approaches that support the study. I will discuss narrative research approaches, their use in similar studies, and the challenges of adopting a narrative approach. In the second part of the chapter, I discuss sampling, ethics, confidentiality and data collection.

A qualitative approach using semi-structured interviews was adopted to explore how shame features in the narratives of women living with HIV, for a number of reasons. As the phenomenon has yet to be examined in-depth, semi-structured interviews will allow the researcher to access participant's narratives in a rich and contextual form (Tonsing and Barn 2017). The topic at hand is considered a sensitive topic and qualitative research can be recommended for the study of sensitive topics (Elam and Fenton 2003). Crotty (1998) maintains that from an epistemological and ontological point of view, knowledge and reality of matter should only be sought from those who have lived it. A qualitative approach allows participants to speak openly in a manner and pace that suits them, and may give them the opportunity to broach areas that I may not have been aware to ask about. From a sensitivity perspective, in-depth interviews allow participants to feel listened to about a topic that does not have any existing public narratives in Irish society and culture, whilst being in control of what they speak about. Finally, participating in an in-depth interview about a sensitive subject has the potential to be therapeutic, cathartic and healing due to the reflective process that can take place during an interview (Elmir et al. 2011). Narrative inquiry was the adopted qualitative approach, meaning I gathered storied accounts of living with HIV from women based in Ireland.

3.1.2 Narrative Research

This study explored how shame features in the narratives of WLHIV in Ireland. Therefore, this study involved collecting, analysing and sharing multiple stories or personal accounts with the aim of producing narratives of experience related by the accounts of WLHIV (Clandinin 2016).

This study adopted the position that narration is a human sense-making process, an essential element for the construction of lived experience (Casey, Proudfoot and Corbally 2016). It is possible for us to process and understand our own, and others' thought processes and actions, through the collection of and analysis of narratives (Ollerenshaw and Crewswell 2002). Equally, psychologists Schank and Abelson (1995) have contended that human thought-processing is fundamentally a narrative process, while Cortazzi (1993) maintained that narrative is seen by many as of fundamental significance for the mental and social life of an individual. In a narrative approach, the researcher is ultimately concerned with the experience of the narrator and what the experience means to them (Casey, Proudfoot and Corbally 2016). The emphasis on the subjective experience of the narrator stems from Dewey's (1938) philosophical argument that the central lens for understanding a personal experience should be sought through their subjective experience. Although narrative research has been adopted throughout many diverse disciplines, a consensus of what defines narrative research has yet to be reached (Ollerenshaw and Clandinin 2002). However, Clandinin and Connelly (2000) claim that those who intend to carry out narrative research must develop their own construction of the narrative process.

When looking at a phenomenon or event in the past, historical narratives often include facts and data about how information around the subject is known, for example, factual and statistical data provided by the HSE and the HPSC. In parallel to historical truth, narrative truth provides information on an event or phenomenon in the form of a personal story, which can add to the 'black and white' nature of quantitative data too, allowing for a well-rounded picture. Josselson (2011) states that the epistemology of narrative research adheres to the relativity and multiplicity of truths. Narrative researchers' opinions vary in terms of how or if one objectively constructs a reality from the narration of another. However, narrative truth is based primarily, not on a factual record, but on the premise that a constructed account of an experience, and how that experience is understood and recounted by the narrator (Josselson 2011). Accordingly, narrative research for the examination of how people choose to decide what they say to others, and how they connect the various pieces of a story to create a particular experience (Josselson 2011). The narratives that people construct are often centred on a sequence of events that take place over time (Bold 2012), an event being an occurrence that happens to someone, at a certain time, or a certain situation. In this particular study, the key events explored were the experience of their HIV diagnosis, life afterwards, and any circumstances or events where they felt shame due to their positive HIV status. Narrative research sets out to explore a particular phenomenon of interest (Bold 2012), and in the case of this study, the study's primary objective is the exploration of shame. Narrative research has become increasingly popular in health research and knowledge about health and health issues can be learned from women's stories (Durkin, Jackson and Usher 2020; Joyce 2015).

As this study aimed to explore and understand how shame features in the lives of women living with HIV, it requires a suitable methodology to adequately address this aim. Research methodology must be correctly suited to the research question and context being studied or the data collected and analysis will likely not be trustworthy, and the research aim will not be met (Bold 2012). I chose a qualitative approach, as the study was exploratory and attempted to gain an understanding of how people made sense of their lives, which numerical data would not adequately do. As this study explores how shame features in the lives of WLHIV, an in-depth inquiry into their lives using narrative research is the chosen qualitative method. The following rationale for selecting narrative research as the study's methodology includes exploring the benefits of narrative research to achieve the study's aim, an overview of other qualitative methodologies, and an exploration into how narrative research has been used in similar studies, both within and outside the topic of HIV.

A narrative approach was deemed most appropriate for this study, as it is acknowledged that narrative research, and the study of collected narratives, is an appropriate process to make sense of a disruptive life event, such as a positive HIV diagnosis (Perrson 2013; Murray 2008). As previously mentioned, an HIV diagnosis remains a significant biographical disruption, where adapting to live with HIV can negatively affect one's psychosocial well-being (Walker, 2019; Alexias, Savvakis and Stratopoulou 2016; Beuthin, Bruce and Sheilds 2015; Bury 1982). Biographical disruption is described as the interruption of one's everyday life structure and expectations for the future due to the onset of illness causing an individual to rethink the trajectory of their lives (Bury 1982). Creswell (2012) defends the benefit of narrative research as having the ability to collect and disseminate people's stories to develop health communication messages to wider social groups. This position is relevant to women living with HIV, as they are considered invisible in society and would benefit from an increase in health communication dissemination to increase visibility (Terrence Higgins Trust 2017), as discussed in Chapter 2. This is further defended by Ollerenshaw and Creswell (2002), as they maintain that narrative research outcomes have the ability to provide voices for whom public, commonly known narratives do not exist. Narrative researchers Carless and Douglas (2017) propose six qualities of narrative research, indicating its significant benefit for use in psychosocial research. They illustrate how narrative research provides an in-depth insight into the narrator's life experience about certain events, such as an HIV diagnosis, allowing the narrator to take control and tell their story the way they want to tell it, so this allows the researcher to gain the narrators subjective response to events. Narrative research allows the narrator to delve into the meaning of the experience of such events, and as such allows the narrator to make sense of the experience during the storytelling process. Throughout a trust and compassion filled interview, narrators have the opportunity to share their thoughts on the dominant narratives that society holds (Carless and Douglas 2017) on HIV. For example, a narrative that exists for people living with HIV is that HIV is stigmatised due to it being a sexually transmitted disease, a result of a careless, unsafe sexual encounter, or perhaps, intravenous drug use. The other existing discourse suggests that HIV is now a perfectly treatable chronic illness that can no longer shorten the lives of infected people, nor is it transferrable through unprotected sex (Rodger et al. 2018, 2016). Narrative interviews allow for the women, who may or may not subscribe to either of the above narratives, to create and co-construct their own narrative, along with the researcher, and challenge the widely held views described above. Accordingly, Carless and Douglas, (2017) relay how narrative research provides a platform where narrators can tell their stories of experiences around issues that are taboo or silenced due to existing dominant narratives, such as speaking about their shame, or their HIV status. It allows the narrator to co-construct their narrative with the guidance of the researcher.

In addition to the above, narrative research sheds light onto the sociocultural context in which a story is shaped, as the dominant discourse held in that socio-cultural context often shapes narratives, be that in subscription or rejection of that narrative (Carless and Douglas 2017). This element of narrative research is highly relevant in the context of HIV, as certain dominant beliefs, such as stigma, have survived despite change in the biomedical narrative around HIV (Walker 2019), meaning stigma towards HIV still survives although the very nature of how the virus affects people has changed due to treatment. These two dominant narratives, which exist side by side in social and clinical contexts (Walker 2019), may or may not be drawn out in the narratives of the study's participants. This means that participants may subscribe to alternative narratives around HIV, or may not subscribe to any single HIV narrative because HIV is not the biggest issue they face on a daily basis. For example, issues such as children, living in Direct Provision accommodation, and/or financial issues may take precedence over HIV in some women's lives.

3.1.2.1 Alternative Research Designs Considered

Before selecting narrative inquiry as the study's methodology, alternative qualitative methodologies were explored, including Interpretative Phenomenological Analysis (IPA) and Grounded Theory methodology. Phenomenology has been widely used in research with people living with HIV. Skinta et al. (2014) researched shame, self-acceptance and disclosure in the lives of gay men living with HIV in San Francisco. Treisman, Jones and Shaw (2014) explored the experiences and coping strategies of African women based in the UK following a diagnosis of HIV during pregnancy. Davis et al. (2016) explored location, safety and (non) strangers in gay men's narratives on hook-up apps. The rich findings from these studies have increased knowledge about the lived experience of PLHIV by adopting an IPA methodological approach. There are similar overlapping features between narrative inquiry and phenomenology, as phenomenology is the study of individuals' lived experience (Stark and Trinidad 2007). However, narrative inquiry, although it too tends to experiences, is interested in exploring the chain of experiences that weave a narrative.

IPA is the phenomenological research approach in which a researcher explores in depth an individual's experience regarding a particular phenomenon, to understand how that person makes sense of experiencing the particular phenomenon (Creswell 2007; Brocki and Weardan 2006). It is widely used within the social and health sciences, as well as in psychological research (Creswell 2007). IPA is the commonly adopted qualitative research methodology across multiple academic fields according to Tuffour (2017), and its primary aims are to look in depth at how people makes sense of life experiences, as well as allowing the researcher to gain a detailed understanding of a recalled account of an experience (Tuffour 2017; Brocki and Weardan (2006). IPA, as a methodology, typically tends to maintain focus on the explanation of a person's experience, their understanding, their views and their perceptions of the experience (Reid, Flowers and Larkin 2005). Additionally, as IPA is phenomenological, it seeks to explore individuals' subjective reports, rather than objective reporting (Flowers, Hart and Marriott 1999). According to Creswell (2007), IPA describes what all research participants that are describing an experience have in common regarding a phenomenon. This is contrasting to narrative research, which aims to collect, reconstruct and re-tell stories. The adoption of narrative research, and not IPA, to explore how shame features in the narratives of women living with HIV come from the recognition of how living with HIV has changed, and still changes, significantly over time. While taking into consideration the medical advancements made to HIV treatment from the 1980s up until the third decade in the 21st century, it also considered how living with HIV can change for the participants from the point of diagnosis, through the adaptation phase and life thereafter. IPA, in theory, could explore how women make sense of their experiences due to both having many overlapping characteristics. However, narrative research allowed the study to capture an ever-developing story in all its major and minor events, and how the participants made sense of the details. When exploring shame, and how one leads to feeling ashamed and what feeling shame can lead to, one of the key details that allowed for this process is exploring where experiences lead to other experiences, which is why it was important to gather and re-story the data in the narrative format. As well as IPA, grounded theory was considered as a potential methodology for this study.

Grounded theory methodology has been adopted in several studies exploring HIV related issues. Madiba and Mokwena (2012) grounded theory study about caregivers’ barriers to disclosing the positive HIV status of children living with HIV who were taking ART in a resource-limited setting in South Africa. Haliemeriam, Kassie and Sisay (2012) developed a theory regarding the sexual lives and fertility desires of HIV sero-discordant couples in long-term relationships in Ethiopia. Solomon et al. (2014) adopted grounded theory to explore ageing with HIV and disabilities, and the uncertainty surrounding these issues.

Grounded theory is a qualitative research design adopted when one looks to produce a generalised explanation of a process, action or interactions that are formed by the perceptions and views of research participants (Creswell 2007; Strauss and Corbin 1994) to develop a theory. The explanation, or theory, that is grounded in the data is systematically gathered from participants and analysed (Creswell 2007; Strauss and Corbin 1994). The theory that evolves through doing research explains processes held in common between participants, in consistent back and forth between analysis and data collection takes place (Stauss and Corbin 1994). Grounded theory unites the theoretical development with the research process, as well implemented a diligent process of checking, refining and defining the theory relating to the data (Charmaz 1996). The aim of this study is not to develop a more objective understanding of the area of study, shame among women living with HIV, by generating a theory. Several theories already inform the study, and so the study’s aim was to gain a deeper understanding of the lived experience by means of generating narratives of shame from stories of women living with HIV based in Ireland.

3.1.3 Narrative Research in HIV populations

Narrative research has been used in several studies relating to HIV in recent years, exploring the lives of people living with HIV. Proudfoot's (2018) narrative research explored the experience of mothering while living with HIV in an Irish context. Owen and Catalan (2012) carried out a narrative inquiry into gay men in London, ageing with HIV, and Greene et al. (2014) used narrative research to gain understanding into how mothers living with HIV managed infant feeding decisions when breastfeeding was the norm. Fewer narrative studies have been carried out with a focus on shame. However, Fallon (2013) explored the narratives of young people, focusing on shame and sexual health, and Dayal, Weaver and Domene (2015) used the narratives of counsellor trainees with eating issues to portray how feeling shame turned to shame resilience. Narrative research has also been incorporated into studies with female only samples in areas such as breast cancer survivors, exercising during pregnancy, and unintended pregnancy (Barakat, et al. 2015; Yazdkhasti et al. 2015; Johnson, Fornander and Rutqvist 2010). While these studies indicate that narrative research can be applied to a variety of subjects, and to shame related to living with HIV, no narrative research to date has explored shame with women living with HIV, as far as I can identify.

Narrative research is not only a research method but it is also a theoretical approach in understanding psychological and sociological phenomena (Carless and Douglas 2017). According to narrative theory (Fisher 1984), humans have always had the capability of telling stories (Murray 2002), and that it is a basic human strategy for coping with and understanding experiences (Brown 2006) as it provides sense-making and coherence overall to their lived experience. When the characters in people's stories are investigated, it can provide us with an understanding of the circumstances and events that are described, but importantly, it can also provide a better understanding of the storyteller as a character and the social context within which the story about the phenomenon in question, is established and constructed (Murray 2002).

3.1.4 Ethical Considerations of Narrative research

Like all qualitative research, narrative inquiry warrants ethical considerations as it implies intruding on participants while they are living their lives and asking them about an issue to which they are connected (Clandinin 2007). This is especially relevant when the topic of discussion is of a sensitive nature (Bold 2012), in the case of this study, the lives of women who are living with HIV. Clandinin (2007) expresses that while an important component of narrative research is that while it is an opportunity to gather data on a certain phenomenon from people's stories, it should be of benefit to the participant. The participant should benefit from them telling their story around their experience, and should ultimately centre on non-maleficence (Bold 2012) meaning that no harm will be done to the participant throughout their engagement in the study. Therefore, for this study's participants, their experience of living with HIV was not exploited for the benefit of collecting data.

Furthermore, Clandinin (2007) illustrates how narrative research involves the research partaking in two different, yet connected role; the first is that they are a professional researcher who is in the role of scholarly student, to accurately, authentically and ethically collect data, while the other is that the researcher becomes is one half of a close personal relationship with their participant. While both roles are equally important, the former being mandatory as a research student, the latter is mandatory to establish trust and rapport throughout the interview process with the participant. Narrative research is said to be established on an interaction within a relationship (Clandinin 2007; Halloway and Freshwater 2007). The greater the level of trust and rapport the participant has with the researcher, the more open they will be during the interview, allowing for greater self-disclosure and greater depth to their life experience will be revealed (Bold 2012). While a purpose of establishing trust and rapport early in the interview process is to allow the participants to become more open and revealing about their experience, another significant purpose of this is to allow the participant to be as comfortable and at ease as possible at that time.

3.1.5 Research on sensitive topics

Research that aims to explore how women living with HIV experience shame is sensitive research, and therefore should be treated accordingly. The exact definition of sensitive research is debatable. In their earlier work, Lee and Renzetti (1990) have argued that any research can be potentially sensitive, depending on the participants and context. Elmir et al. (2011) in their research which explores issues of interviewing people on sensitive topics, draw on the work of Cowles (1988) and Stanley and Sieber (1988), which defines a sensitive topic as one that has the possibility of causing distress to the participant and/or researcher in an emotional, physical or psychological way. In this study, two sensitive topics are explored in depth; shame and HIV. Shame might be considered a sensitive topic because western cultures lack acknowledgment towards it. Most cultures are not accustomed to talking about shame, therefore talking about shame or what makes us feel ashamed, can lead to more shame, according to Scheff (2003) and Kaufman's (1974) philosophical arguments as discussed in the literature review (Chapter 2). Furthermore, Brown (2006) describes in her grounded theory study on shame resilience, how talking about what makes us feel ashamed can lead us to be vulnerable, when we draw upon why a certain issue made us feel ashamed in the first place.

Western culture has been civilised to hide our shame (Kaufman 1974), so to speak about what makes us ashamed may seem somewhat unorthodox, or even uncomfortable. HIV is considered a sensitive issue primarily due to the stigma attached to the condition (Earnshaw 2013), as well as its association with death and illness in history. Living with HIV can be associated with the onset of mental health issues such as depression and anxiety (Hutchinson, Dhairyawan 2017; Bennet 2016; Brion, Leary and Drabkin 2014; Chao, Cheng and Chiou 2011; Persson 2010; Lewis 1987). The diagnosis of HIV in many people is cause for distress (Brion, Leary and Drabkin 2014), and lack of sensitivity in research with PLHIV may contribute to those negative emotions. While HIV may not be a sensitive issue for everyone living with the condition, considering that shame will be explored within the area of HIV, it is treated as a sensitive issue. Due the nature of this study being that of a sensitive one, the researcher is aware and attentive of participants' well-being throughout the interview process. Again, I prioritised each participant's well-being above data collection throughout the entire research process.

3.1.6 Challenges and Criticisms of Narrative Research

There are a number of cited challenges in using narrative methodology in qualitative research (Josselson 2007; Holloway and Freshwater 2007). It was anticipated (in advance of starting the study) that some of these challenges may arise throughout the data collection and analysis phase, and it was therefore important to acknowledge the issues that other narrative researchers have met with and overcome. Firstly, qualitative research is time consuming, in that interview scheduling may take some time, the interviews ranged from 50-100 minutes, and transcription and narrative analysis was the lengthiest process (Savin-Baden and Van Niekerk 2007). As it is the nature of a narrative approach to interview a small number of participants (Creswell 2007, Holloway and Freshwater 2007), this study set out to interview 10-15 participants over a six to nine month period and ultimately interviewed 12 women over a 12 month period. This is considered a lengthy period in which to carry out and transcribe all interviews, and begin the analysis phase of research. Concerning narrative analysis itself, there are few tools/frameworks for the analysis of narrative data and analysing narrative research has its own specific challenges. However, this study has justified its use for the chosen analytical tool. Narrative researchers here describe that it can be difficult to grasp the narrators' understanding and their meaning of an experience (Josselson 2011). This was considered throughout the interview and analytical process of this study. Attempts to alleviate such a challenge involved, when needed, drawing on issues brought up in a participant's narrative, and ensuring that I repeated, reiterated and understood the participant's perception of an issue. During the analysis process, I planned that a critical review and reflection would take place to ensure the participant's understanding and meaning of an issue is clear in their narrative.

Storytelling does not always follow a chronological linear sequence. Josselson (2011) goes on to describe a significant issue in narrative research in that narrators can often organise their story's differently each time they tell them, and to different audiences. This affects the generalisability and transferability of narrative studies; however, this is not a concern for this study, as the study does not aim to generalise or be transferable. However, it is the nature of narrative research for the narratives to be a co-construction of both the narrator and the researcher, as each interview's context will influence the analysis and researcher's interpretation of each account. Squire (2008) additionally posits that the narrative research develops in light of the connection between the narrator and researcher. As it is the job of a narrative researcher to interpret, transform and retell a story, critical reflection on a participant's narrative is important. Narrative researchers must be cognisant not to prioritise dramatic or interesting stories over the 'truth'. Therefore, resisting the temptation to document a story that reflects our own views, opinions and biases must be upheld (Holloway and Freshwater 2007) through the process of implementing reflexivity which requires the research to consider their social position and how that affects the process and outcome of the study (Berger 2015). The understanding and interpretation of a participant's narrative can be affected by the researcher's own history and position in society, which must be considered through the research process (Berger 2015), this is discussed in section 3.3, page 74. In this study, each transcript was critically reviewed several times to ensure this issue did not arise, while also keeping an awareness of this challenge when analysing and reviewing the analysis.

3.1.7 Narrative Analysis

To use the data collected in narrative form in social research, the narratives needed to be analysed and reinterpreted, as they cannot speak for themselves (Riessman 2005). The central feature of narrative analysis is the 're-storying' or 'retelling' of narratives from original raw data to an analysed form to better understand the lived experience (Clandinin and Connelly 2000). The narrative analysis involves the process of transcribing, reading and re-reading the data to identify and understand the primary issues, characters and settings within the narrative (Ollerenshaw and Creswell 2002). Additionally, narrative analysis requires the researcher to ‘re-story’ the narrative by placing it in chronological sequence, as often, when we tell stories, they may not always be in chronological order. The purpose behind this element of narrative analysis allows potential causal links to be identified and provided (Ollerenshaw and Creswell 2002).

The analysis of this study’s narrative accounts was carried out using the three –dimensional narrative inquiry space (see table 3 pp. 55), which is a narrative analytical tool, developed by Clandinin and Connelly (2000), and was formed based on John Dewey’s experiential philosophy (1938, 1934, 1925). Dewey’s (1938, 1934, 1925) philosophy proclaims that to understand someone, we must focus on their experiences, and not only their personal experiences, but also their social experiences and interactions. Referring back to Chapter 1, this section is particularly significant for analysis of shame, given that Scheff (2003) proposed that shame cannot be analysed or understood without looking at the social and interactional elements of a shameful event. Dewey’s philosophy also looks at the continuity of experiences as key to learning about an individual’s experiences, as experiences that occur can lead to the growth of other experiences (Ollerenshaw and Creswell 2002; Dewey, 1938, 1934, 1925).

Therefore, the basis behind the three-dimensional narrative inquiry space comes from the recognition that researchers should not only look to examine an individual’s personal experience, but equally, their interactions with others (Wang and Geale 2015; Clandinin and Connelly 2000). Thus, when using this analytical approach, the researcher analyses the participant’s own personal story as well as their storied experiences involving their interactions with other people in and throughout their lives. This is the first dimension of the research – the interactional, which looks at the personal and social elements. The personal element of the interactional dimension looks inwards to the participant’s internal conditions such as their hopes, feelings and aesthetic responses to a situation. The social element of the interaction dimension looks outward to conditions within their environment where they exist with other people in their narrative. This looks at these people and describes what their intentions, purposes and points of view are within the participant’s narrative. In this present study, women’s accounts were analysed for HIV-related shame in how they personally recounted how they felt and what they believed about living with HIV. Women’s accounts were then analysed with a focus on their sense making of their interpersonal relationships and the social environments in which they lived as HIV positive women. This dimension was of particular relevance in exploring shame, as shame is a social emotion that cannot be fully understood without paying attention to social interactions and women’s sense making of those interactions.

The second dimension of analysis is the continuity or temporality dimension, which looks at the past, present and future elements of the participant's narrative. This involves analysing past experiences of the participant, while equally looking at their current experiences and actions, and what they hope or anticipate their future experiences and actions will be. The third and final dimension of the three-dimensional narrative inquiry space is the situational dimension, in which the researcher considers the participant's landscape or setting in which the story takes place, and how the participant experiences are affected by this setting (Wang and Geale 2015; Clandinin and Connelly 2000). In this dimension the researcher explores what these places represent to the narrator and of what significance they represent to the narrative. Clandinin and Connelly, (2000) developed the three-dimensional narrative inquiry space as a way of conceptualising 'what narrative researchers do'. By exploring shame through the chronological dimension of the framework, analysis revealed the chain of experiences of women's HIV-related shame; its development, its manifestation and its impact, and in its recovery. Analysis of the settings and context of stories within accounts brought the importance of places and settings in shameful experiences into focus. HIV-related shame in women's stories were contextualised by the places in which they occurred, and analysis further drew on women's sense making of such places and their meaning to stories.

Another key characteristic of the three-dimensional narrative inquiry space is to emphasise particular experiences in a participant's narrative, rather than try to explain them (Clandinin and Connelly 2000). Equally, focusing on the different dimensions in the analysis will lead to an overall, broad, holistic lens with which to retell a story, instead of a linear, highly structured approach used on other analytical tools, such as the problematic-solution model (Ollernshaw and Creswell). The three-dimensional narrative inquiry space (Clandinin and Connelly 2000) facilitated the in-depth analysis of shame within women's accounts to provide fresh insight into women's experiences of living with HIV. In section 2 of this chapter, I detail the analytical process, which ultimately led to the study's findings.

Table 3: Three-Dimensional Narrative Approach (Clandinin and Connelly 2000)

Interactional	
Personal	*Look inward to internal conditions, feelings, hopes, aesthetic reactions, moral dispositions*
Social	*Look outward to existential conditions in the environment with other people and their intentions, purposes, assumptions, and points of view*
Continuity	
Past	*Look backward to remembered experiences, feelings, and stories from earlier times*
Present	*Look at current experiences, feelings, and stories relating to actions of an event*
Future	*Look forward to implied and possible experiences and plot lines*
Situation/Place	*Look at context, time, and place situated in a physical landscape or setting with topological and spatial boundaries with characters' intentions, purposes, and different points of view*

3.1.7.1 Alternative narrative analysis considered

Several alternative narrative analytical processes were consulted when deciding on the right tool with which to analyse the study's data. Murray's (2000) framework, structural analysis, thematic analysis and the problematic-solution model are previously used analytical tools used by narrative researchers (Bold 2012; Ollerenshaw and Creswell 2000). Murray's (2000) framework is an experience centred narrative approach which allows for an in-depth exploration into the lived experiences of the narrator regarding a particular experience, through examining the research from multiple perspectives; personal, interpersonal, positional and ideological (Murray 2000). The personal level examines how the narrator described the particular experience in question. The interpersonal element examines the interaction between the narrator and the researcher during the interview, how trust and rapport is established in the interview and how that affects the narrator's level of openness and disclosure of sensitive details. The positional element looks at the social positional differences between the narrator and interviewer, and examines how that affects the narrative account. Finally, the ideological element of the framework examines the social and cultural structure and how they influence and are represented in the narrative (Murray 2008, 2000).

The problematic-solution approach to narrative research is a problem-oriented model that looks at the sequences of events that occur in a narrative with the aim of identifying the problem and thus, the solution (Ollerenshaw and Creswell 2002). The problematic-solution approach emphasises the explaining of events and experiences, unlike the three-dimensional narrative approach, which looks to describe experiences (Ollerenshaw and Creswell 2000). Additionally, the problematic-solution model applies a linear and significantly sequenced approach to analysis (Ollerenshaw and Creswell 2002). The process of structural analysis looks at what a story is about, the orientation of a narrative, a complicated action, the evaluation and the result (Bold 2012).

Thematic analysis (TA) is a qualitative analysis method used to identify, analyse and report patterns, or themes that emerge in one's data set. It organises and categorizes data to illustrate a rich, contextual account of data (Braun and Clarke 2006). Having typically been used in psychology research, TA is used more broadly across research areas in qualitative research, and is used as an analysis tool across different qualitative research methods including grounded theory and IPA (Javadi and Zarea 2012; Boyatiz 1998). However, Braun and Clarke (2006) argue that TA should be considered a research method in its own right. It is considered one of the most commonly used data analysis tools, as well as one the simplest to implement (Javadi and Zarea 2012). That being said, TA is considered an appropriate tool for novice researchers, due to the simplicity of its use and implementation (Javadi and Zarea 2016; Alohjailan 2012). In contrast to the view that TA is considered a simplistic methodology for novice researchers, Nowell, Norris and White (2017) argue that due to the lack of literature on TA, it can cause confusion and hesitation when carrying out a rigorous TA. Nowell, Norris and White (2017) further argue that adopting a TA inhibits students from making claims about language usage in a study and is therefore disadvantaged compared to other qualitative methodologies. TA is implemented through familiarization with the data to begin with, generating initial codes, searching for emerging themes, reviewing these themes, and eventually defining and naming themes (Braun and Clarke 2006).

3.2 Research Process

3.2.1 Research setting

The participants were recruited through an Irish organisation for people living with HIV, namely *HIV Ireland*. This organisation provides support, counselling and advice to people who are living with and/or affected by HIV and AIDS. The organisation is based in Dublin and is widely recognised within the HIV community due to their efforts to reduce the prevalence of HIV through the implementation of effective prevention strategies, sexual health education, and through public awareness for the last thirty years. I believed them to be an appropriate organisation through which to recruit participants. Ethical approval was received from Dublin City University in December 2018 (see Appendix a.). I approached the head of the organisation, explaining my research aims. I explained to the organisation that I would be inviting women who are living with HIV and using their organisation to take part in my research by agreeing to be interviewed. I explained the criteria to be met for participation and I provided a plain language statement (PLS – see Appendix b.) to the organisation's key contact person who disseminated it out to women who fit the criteria. The PLS invited women to partake in the research and explain the research question, its aims and objectives. HIV Ireland requested that I compile a one-page summary about the study and what was involved in taking part in an interview, as this would be uploaded onto a web page for women to observe and engage with on their own terms.

3.2.2 Recruitment through a voluntary organisation

I chose to recruit research participants from a support organisation rather than a hospital setting. This decision arose from the underlying assumption that the hospital setting is associated with diagnosis and illness, whereas an organisation is a place of support and trust to which participants may have reached out to, and therefore individuals may be more comfortable talking about their experiences. Additionally, as hospital appointments take place every six months for PLHIV, recruitment and data collection process would likely be much slower. The voluntary organisation as a facility could be considered more relaxed and comfortable for the participants, than a hospital setting, which may cause the participants to associate the interview with the clinical aspect of their HIV experience. Additionally, as the sample are considered a *seldom heard* group (detailed in section 3.2.4), their pre-existing engagement with the voluntary organisation benefited the recruitment process. However, the study does acknowledge the absence of women whom voluntary organisations have not engaged with, and are potentially marginalised and silenced as women living with HIV, which is detailed in the limitations of the study.

3.2.3 Ethical Considerations

While the ethical considerations for narrative inquiry are detailed in the previous section, 3.1.4, ethical considerations for the research process itself are now outlined. Ethical approval for this study was obtained in December 2018. Several issues were raised by the research ethics advisory committee in reference to permission sought for the use of HIV Ireland's offices for interview, protocol surrounding what should be done with interview documents following each interview, and clarity surrounding the legal limitations of confidentiality during the interview process. I addressed and rectified the issues raised by the research ethical advisory committee and such procedures were adhered to during the data collection process. During the interview process, several ethical considerations were taken when recruiting and interviewing women, in particular when interviewing on features of shame and talking about shame. Primarily, having respect for each participant during the recruitment and interview process, and any follow up interaction that took place was priority. Equally, ensuring the participants that an interview was a safe space to tell their story, however they wish to tell it, at a pace with which they are comfortable. The researcher/participant relationship manifested throughout the interview and impact on the data gathered (Josselson 2007). Ethical considerations also focused on consent, confidentiality, and ensuring that shame was not elicited during the interview process, by asking carefully and strategically worded questions (Bold 2012). Participants were asked to sign an informed consent form, ensuring they fully understand the study's intentions, and my intentions of their participation in the interview. Their understanding included the awareness that although every possible measure will be taken to ensure their confidentiality was to be taken, their participation in the study could increase their risk of their HIV status being identified. The measures that I took to ensure the confidentiality of the participants included not recording their full name, changing any identifying details in the transcripts and using a coded journal to keep track of what details had been swapped. Only I have access to this material and it was kept secured at all times.

In the literature review, shame is referred to as an emotion that is likely to cause offence when queried, as talking about shame has been known to cause shame (Scheff 2003). It was a priority for me that I did not elicit shame in participants during the interview. As it cannot be completely controlled as to whether participants feel shame or not, I took certain steps to ensure the participant was informed on the topic. Prior to being asked about their shame, I explained what shame is in detail to introduce the participants to the subject. The participants were asked to elaborate on their responses, allowing for more depth in each answer. The reasoning behind this process is to make the subject of shame less threatening and offensive than immediately asking them 'do you feel shame as a woman living with HIV'. The study does not assume that a participant would feel shame in relation to their HIV status, but it is anticipated that their personal experiences will be disclosed and shared following a question like the above.

3.2.6 Confidentiality

The confidentiality of the participants was upheld throughout the entire research project. Confidentiality was necessary in this research and had particular significance as this is a small sample within a small population of women. All participants were given a pseudonym for confidentiality purposes; however, they were asked if they wish to give themselves their own pseudonym. I ensured confidentiality as only I have access to the recordings and any notes or materials relating to the research project. My two joint supervisors had access to the interview transcripts. Both hard and soft copies of information such as the audio-recordings, transcripts and written notes were locked in a password-protected computer, with password protected files, and locked in secured filing cabinets to which only I have access. The audio-recorded material was not, nor will it ever be, played in any public forum. As mentioned, when relating back to each narrative, the participants were provided with pseudonyms so that their identity is concealed in the thesis. Any information in their interview that is closely linked to their identity was also changed to another name/place/detail, however, when quoting participants, verification of direct quotation and their contextual correctness always took place. I used a codebook journal to code any identifying information in relation to the participant. The journal was used to keep a record of what authentic information matches with fabricated information. This was useful so that confusion did not occur as to what was authentic and what was fabricated when it comes to including the information in the written thesis, and for the purpose of confidentiality. Only I had access to this journal and it was locked away in a locked office when not in use. It was not removed from my office space in the School of Nursing, Psychotherapy and Community Health in DCU until March 2020 due to unforeseen circumstances, in which I was advised to work from my home due to COVID-19 national restrictions. All information and work relating to this study and the confidentiality of the research participants was locked in a home office space.

3.2.4 Sampling

The sampling strategy used in this study is purposeful sampling, as the sample consisted of women living with HIV in an Irish context. Purposeful sampling is a common approach of qualitative research and a mixed variation sample was adopted to document narratives from a diverse population of women living with HIV (Ritchie *et al.* 2003). Due to the evident under-representation of women in the social science realm and other areas of HIV research (Terrence Higgins Trust 2018; DeJong and Battistin 2015; Logie et al. 2012; Smith et al, 2007), I chose to explore only women's experiences. The sample are considered a *seldom heard* group considering their HIV status and the likely association with stigma (Earnshaw 2015). This was reflected in the time frame it took to recruit participants for the study which was longer than initially anticipated. As I looked to gain insight into how shame features in the lives of women living with HIV, participants must have self-identified as female, have received an HIV positive diagnosis at least three months prior to sampling, and be at least 18 years old. The study attempted to explore multiple understandings of the experience of shame due to their HIV diagnosis, the impact of shame on their lives, and therefore included women from a variety of age categories. The sample included women from countries where HIV has both a high and low prevalence, and in the case of this study, three women were from East African countries, one woman was from Oceania, and eight women were Irish. The purpose behind this was in an attempt to gain variety to the cultural aspects of the narratives collected relating to shame and HIV. This relates back to the point that shame can occur when one feels that they have fallen short of cultural expectations (Brown 2006), which may vary depending on each participant's ethnicity.

The sample size in narrative research could be considered a relatively low number, as it involves the collection of narrator's stories via in-depth interviews (Holloway and Freshwater 2007). Studies using semi-structured interviews as their research method that related to shame and/or HIV were consulted to inform this study's sample size. Of nine studies with sample sizes ranging from four to 35 participants, literature suggests that for the use of narrative research in this study, a sample of up to 20 participants was needed to produce the desired outcome i.e. meet the study's aims. Equally, Reissman (2005) maintains that the use of large numbers in narrative research is inappropriate as there are ‘faceless’ and ‘nameless’ (Riessman 2005, p.6). The final number of participants that were interviewed in this study was 12 participants. Data collection ceased following the twelfth participant, as it was considered that data saturation, the point in the data collection process in which it is considered that no new information can be collected had been met, and a sizable amount of data had been gathered. Additionally, given the overall challenge of recruitment for this study, 12 participants was deemed a sufficient sample size, given that these women fall into a *seldom heard* group. A *seldom heard* group describes ‘a group of people who do not have a collective voice and are often under-represented in consultation or participation activities’ (Social Exclusion Task Force, as cited in Community Network for Manchester 2011, p.16). *Seldom heard* is a term used instead of ‘hard to reach’, as the latter implies that individuals are difficult to engage with on their own accord, rather than various sectors' failure to include their voices on such matters. (Begum 2005)

3.2.5 Informed Consent

Once a potential participant made contact with me or the key contact person regarding the study, they were informed in detail about the study and given the opportunity to read the study’s Plain Language Statement (PLS). The PLS gave details on the exact nature of the study and why it was being carried out. It informed participants of what they were being asked to do and that their participation was voluntary, in which they have the full authority to exit the interview and/or leave study at any stage. It also detailed my limit to confidentiality where incidences of serious harm to self or others become known. The limit to confidentiality was implemented with the acknowledgment that issues may emerge during the interview process because as a researcher, I am aware that each interview took place within a wider social context in which issues relating to harm to the self and/or others can occur. Once a participant decided to participate, they were given another copy of the PLS to read again and a copy of the Informed Consent Form (ICF) to read, ask questions about, and sign (see Appendix c.). Participants were given the opportunity to leave the ICF and PLS at the interview or take it home with them. Before the interview process, I went through the ICF with the participant, and I asked them if they had any questions regarding any detail in relation to the study, interview process, PLS, ICF, etc. I also informed the participants that they were welcome to contact me post-interview if they have any further questions or queries. I repeated this step at the end of the interview. The ICF helped ensure that the participant was aware and understood all of these details prior to engagement in an interview.

3.2.7 Data Collection

As previously described, the data was collected using a narrative approach, meaning the interview was largely controlled by the participant, with me, the researcher, interjecting where appropriate, to either ask another question or probe the participant for clarification or for further expansion of their answer to a question. This means that a semi-structured interview schedule has been drawn up (see Appendix d.) and was referred to in the interview process. The interview schedule was drafted in accordance with the study's aim, thereby asking questions that allowed for the gathering of efficient data to meet the study's aim. In some cases, not all questions from the interview schedule were asked or answered, in circumstances that the interview went on for longer than anticipated, or the participant may not have wanted to discuss a certain topic. As with the nature of narrative approach, I broached on questions and topics that were not on the schedule, but have been brought up by each participant's response.

Prior to starting data collection, I carried out a pilot interview. The function of a pilot interview in this case was to allow me to test the questions that I am asking participants and how they are phrased. The pilot interview determined which questions should be taken out or included prior to data collection. It also functioned as a trial for practical elements such as the use of the digital recorder to ensure it was being used properly and was fit for purpose for the entire time, while also allowing me to practice interview skills and how best to make participants comfortable. I included the data gathered into the study's findings, which I stated to the participant.

The interviews were arranged with the participants based across the country via phone call, text message, and email or through the key contact person in HIV Ireland. Prior to confirming the interview time and date, I confirmed the facility's availability with the voluntary organisation. On the day before each interview, I confirmed with the facility to ensure a private, comfortable space was available. It was anticipated that due to a variety of reasons, participants may not be able to attend the interview on the scheduled day and I had to be prepared for any last minute changes. On the day before each interview, I contacted the participant or the key contact person the participant was in touch with, to confirm that the date and time still suited them. Only on one particular occasion could a participant not attend the interview and rearrangements were made to reschedule, and the interview took place on another date.

3.2.8 Interviews

Recruitment for interviews took place online via newsletter, and via word of mouth through the voluntary organisation from February 4th 2019 and the first interview commenced on February 28th 2019. Recruitment lasted for 12 months with the final interview taking place on February 28th 2020. The account below describes the twelve interviews that have taken place. Each interview lasted between 47 – 100 minutes. After the participant signed the informed consent statement they are asked to fill out a demographic sheet (see Appendix e.). This allowed for the development of a demographic profile of the study's participants. With the permission of the participants, each interview was audio-recorded and notes were taken throughout. Audio recording of the interview allowed for detailed transcription of the interviews and thorough analyses. Note taking during the interview aided in gathering my thought process, and to document potential follow up questions. All twelve participants gave their verbal and written consent to have the interview audio-recorded.

Once recording had started, I clarified with the participant once more that they had read the informed consent statement, and that they understood and agreed with its content. The interviews started with me asking the participant to tell me a little bit about themselves, on where they are from and who is in their family/ whom they live with. It was hoped that through establishing conversation, the participant would become more relaxed into the conversation. Equally, it was important to let the participants know that I did not merely see them as women who are living with HIV, but rather women who were valuable members of society and whose lives are not dominated by HIV. Following this brief introduction, I went on to explore a series of areas relating to HIV in their lives. While each interview took place with the use of a semi-structured interview schedule, each interview went in a different direction depending on what the participant spoke about in relation to the research topic. While the participant's response often led to other relevant points of discussion, there were a number of topics that I aimed to bring up in each interview where possible. To begin exploring HIV in their lives, I asked each woman about how she came to learn about her HIV positive diagnosis and how she felt at the time of the interview compared to at the time of diagnosis. The participants were asked if they felt comfortable to talk to the people around them about their diagnosis, and how they found interacting and trusting the medical professionals in their lives. The participants are asked about the Swiss Consensus Statement, more commonly known as "Undetectable = Untransmittable" / "U=U", and what difference it had made to their lives as living with HIV. The participant was asked to describe their relationships with the people around them since becoming HIV positive, as well as being asked about navigating sexual intimacy and what this looked like in their lives. After asking the participants to speak in depth about HIV in their lives, I asked them if they ever felt shame due to their HIV status, what causes them to feel shame and what did it feel like. Towards the end of the interview, I ask the participant more uplifting questions such as what are the aspirations for the future, what has been the happiest moment HIV has brought into their lives or if they benefited from living with HIV in any way. Finally, they were also asked about their reasoning for choosing to take part in this interview, how they felt the interview went for them, if they had any feedback regarding the questions they were asked and if there was anything they would like to have been asked. The recording was then turned off.

As mentioned previously, due to the nature of narrative research, not all of the above was discussed and there were many other issues talked about that do not relate to HIV. One must assume that HIV is not the only issue the participant faced, and that might cause them shame. Prior to data collection, it was anticipated that participants may become upset or distressed during the interview, given the nature of the research topic. On several occasions, participants became upset during the interview and I immediately asked them if they wanted to take a break. When a participant became upset, I informed them that if they wanted to cease the interview completely or postpone for another time, they were welcome to do so, however, no participant wanted to stop the interview. It was anticipated that not every interview would run smoothly, however, I was prepared to be flexible in my thinking and improvise accordingly. Once the audio-recording was turned off after the interview, participants were offered follow-up counselling with the voluntary organisation, given the opportunity to ask more questions and to follow up if they would like further information regarding the study.

I wrote down my own observations and reflections about each interview once I was on my own. This practice was implemented as a part of the wider process of reflexivity, in which the researcher considered their social position through a process of continued internal and critical self-evaluation, while also recognising and appreciating that the position may affect the process and outcome of the research (Berger 2015). Gouldner (1971) suggests that reflexivity allows for analytical attention to the paid to the researcher's role in the qualitative research process, which is supported by Berger (2015) who states that reflexivity allows for quality control in qualitative research and is a significant factor in upholding such quality. Details of my reflexive journey is featured later on in this chapter in section 3.3.2. Following my own critical self-reflection on each interview experience, I began transcribing the interview in the days following. Before I began transcription, I listened over the recording to write down reflective thoughts that I may not have written down during the interview. I listen back, begin transcribing, and listen once more to make sure the transcription is correct to exact detail.

3.2.9 Data Analysis

Earlier in this chapter, I included a detailed description and rationale of the chosen analytical framework, Clandinin and Connelly's (2000) Three-Dimensional Narrative Inquiry Space (3DNIS). I include a systematic guide to the analytical activity, which includes a broad experience-centred exploration into the presence of shame in women's accounts to establish micro-narratives of shame, the application of the 3DNIS analytical framework to the micro-narratives of shame and a cross-sectional analysis to identify similarities and contrasts across the twelve narrative accounts. Central and pivotal to the analytical exercise was exploring throughout how shame featured in women's accounts, on an individual level and collectively across accounts. The analysis of each account of women's experiences was carried out without the aid of software. Although this was a timely exercise, it necessitated and facilitated a robust familiarity with the data and intimate details of each woman's account. Excerpts from the micro-narratives and their accompanying analysis are presented in more detail in the following chapter, Chapter Four: Findings. The below table, (table 4) provides an overview of the data analytical steps.

Table 4: Overview of analysis

1.	A broad exploration into the presence of shame within each account was carried out.
2.	Micro-narratives (stories within the account) of shame were noted and preliminary codes were assigned.
3.	Micro-narratives were analysed with the Three-Dimensional Narrative Inquiry Space (Clandinin and Connelly (2000); continuity analysis, intersectional analysis and situational analysis, and additional codes were assigned to the micro-narratives.
4.	A cross case analysis of the analysed micro-stories of HIV-related shame in women's accounts was conducted to establish similarities and contrasts among

	women's experiences, and subsequent narrative threads across the accounts. This was completed by compiling and grouping codes to establish narrative subheadings and overarching narrative headings.

3.2.9.1 Identifying Narratives of HIV-related Shame

To facilitate familiarisation of the data, I listened to the interviews noting previously unobserved aspects of the interview to come back to in the transcription and analysis. I then transcribed the audio verbatim. Transcribing the audio interviews myself allowed for initial familiarisation and intimacy with the data. I paid attention to pivotal moments in the interviews, noting how participants told such moments in the stories and if there were a strong emotional presence in the storytelling process. I noted language use, hesitation in their voice, when they laughed and/or cried, when they expressed fear and were annoyed or angry. The notes added context and meaning to the transcribed text. Once I had completed all transcriptions, I started to read and reread each interview, as well as making notes beside the text to capture early thoughts and interpretations I had, consulting with field notes and observations I had made throughout the interview.

Following transcription, I began in the first phase of data analysis, which involved an open coding exercise of all micro-narratives involving shame in the accounts. The presence of shame within women's stories was identified through participant's narration of events in which they felt other people viewing them negatively, in which they felt judged, humiliated, and deeply hurt, uncomfortable due to other people's gaze. This particular process involved a dissection of each account in an exploration for HIV-related shame. Codes were assigned anywhere that I interpreted shame to have appeared in micro-narratives of diagnosis, events around adaptation to living with HIV, sharing their HIV status, navigating relationships, concealing their HIV status, stories of being in healthcare settings, and meeting other women living with HIV. This allowed for a filtering and compressing of accounts to reveal rich data embedded in core experiences of HIV-related shame among women's broader experiences of living with HIV. As I was exclusively exploring a particular concern, shame, this required rigorous examining and re-examining my own interpretations behind the meaning women assigned to experiences of shame. Before assorting the generated codes into greater narrative threads involving a cross case analysis, I analysed each account with the three-dimensional narrative inquiry space to assign particular codes per each dimension to women's accounts.

3.9.2.2 Continuity Analysis

In line with the 3DNIS's continuity element, I restructured each filtered and compressed narrative in chronological order. In participant's originally structured accounts, participants did not tell their stories chronologically but instead moved between the past, present and future tenses regularly throughout as we discussed various aspects of living with HIV. I began each interview by asking women to tell me about themselves. Some women began their accounts years before their HIV diagnosis, while other women began their story by talking about their lives in the present. Establishing where women's stories start and how they progressed allowed me to identify how participant's experiences grew and led to other experiences, central to the philosophy behind the 3DNIS (Dewey, 1938a; 1938b; 1935). The factors driving women's HIV-related shame were identified and the process and trajectory of HIV-related shame began to emerge. As women told their stories about their experiences, they situated themselves in a timeframe, either their past, present or future. In some cases, certain micro-narratives transcended across time, which too, carried meaning. Such incidences included concealing their diagnosis or challenges faced in continuously navigating the decisions around sharing their HIV status with others, or navigating healthcare settings as HIV positive women. The chronology of micro-narratives identified how women's diagnosis led to women's adaptation to life with HIV, to making sense of the challenges and triumphs that faced since their diagnosis. Emerging in the continuity analysis were women's reflections on their past, which demonstrated a journey of sense making of their experiences. This holds particular relevance to HIV as there is a shift in the condition's timeline when it transformed from a deadly illness to a chronic condition.

3.2.9.3 Interactional Analysis

Once the accounts were reorganised chronologically and analysed to explore the continuity of shame, I re-read through the micro-narratives of HIV-related shame to complete the interactional analysis of accounts. The first level of interactional analysis involved exploring the participant's personal experience of HIV-related shame in their story. Shame is already a deeply personal experience. So personal that it was considered an incredibly isolating experience and the personal analysis of women's HIV-related shame focused on how they made sense of and spoke about shame affecting their experiences. As women expressed how they saw other people judge them negatively for their HIV positive status, concerns of fear, anger, and loneliness coincided with the personal experience of shame for women.

The second level of interactional analysis considered the outward social environment of their story, social discourse, and the relationships they had with the primary characters that featured in their stories. Naturally, women's stories featured their relationships with loved ones, friends, and other people who make up their life story. It too features their relationship with the society in which they are shaped and how they viewed the world around them in which they exist. Within the micro-narratives of HIV-related shame, women spoke of how they viewed themselves through the eyes of other people. The feature of other people's gaze in the individual or broader sense in women's experiences was pivotal in the development and sustenance of HIV-related shame. Equally, the value placed on the individual's gaze was considered as women relayed an experience. For example, some mothers felt greater levels of shame in the eyes of their children than they did anyone else because the risk to their bond with the children was crucial for their well-being. Women's micro-narratives of shame were contemplated through their broader social environment in which they lived in how such environments could contribute to, exacerbate or heal their shame.

3.2.9.3 Situational Analysis

Next, the narrative analysis of accounts focused on the situational elements of the story, which tended to where the stories within their accounts took place and key contextual detail of the stories. Women attended to places, geography, spatial detail, and context, which was important for their storytelling process. An event, and the implications for HIV-related shame, may be completely dependent on where the story unfolds, rather than what actually happens. This was most notable in stories set in Direct Provision (DP) accommodation, or in healthcare settings, particularly HIV clinics. In these women's stories, places carried significant meaning as to the HIV-related shame experienced. A woman living in DP accommodation routinely navigated her surroundings for her roommates so that they do not see her take her HAART. Her experience of HIV-related shame was largely due to her living situation, in which she routinely examines her spatial surroundings. Similarly in healthcare settings; a woman sitting in an HIV clinic may experience HIV-related shame as the threat of another seeing her there, as her presence as a HIV clinic may result in unwanted disclosure of her HIV status.

3.2.9.4 Cross Sectional Analysis

Once the accounts were filtered and reduced following their analysis using the 3DNIS framework, the next point of analysis focused on how shame featured across the twelve analysed accounts. The presence of shame within each account was considered as it developed and diminished across time, how it featured in the personal and interpersonal dimensions of accounts, and in particular places and contexts. The micro-narratives of how shame featured in each account was compiled to draw out similarities and contrast in women's HIV-related shame. Codes developed and assigned from each account were brought together and compiled based on the meaning I had assigned to them in my interpretation. I reviewed and adjusted the codes, and assembled the data that applied to each code to establish preliminary sub-headings. I grouped the sub-headings and developed the findings in major stages. Three narrative threads with sub-narrative headings were identified as the process in which shame features across the twelve narrative cases (see Appendix i).

3.3. Validity and Rigour

To establish and maintain quality and rigour in narrative research, issues of trustworthiness and reflexivity must be considered and addressed to persuade readers of the study's credibility and relevance (Loh 2013; Reissman 2008).

3.3.1 Trustworthiness

Regarding the credibility and validity of narrative research, trustworthiness is pivotal to its establishment (Reissman 2008). Several techniques such as member-checking and audience validation were adopted to develop trustworthiness throughout the research process. Lincoln and Guba (1985) recommend member checking by providing the study's participant with a summary of their accounts, and defines it as one of the most critical steps for a study's credibility. This is considered an opportunity for researcher's analysis to be expanded or elaborated on, potentially enriching the data and thus included in the overall analysis (Bloor 2001). However, narrative researchers have conflicting views as to this strategy stating that in member checking, participants may not be able to recognise a story they wish to see in the data analysed, as re-storied accounts takes a different form the original transcripts (Czarniawska 2004; Sandelowski 1996). In considering this, Loh (2013) recommends 'member checking' rather than 'member validation', as this takes into account that participants are not involved in the analysis of the data, however, representation of their stories should be accurate.

To uphold the ethical standards of narrative research, participants should be allowed to review the data, the researcher's interpretation of their accounts, and make comments (Loh 2013). With this in mind, following data analysis, I reached out to participants, offering them their analysed narrative should they wish to read it. Most participants accepted my offer, a small number did not respond, and one participant declined as she anticipated it would be emotionally difficult for her to relive. One participant responded to provide clarification on matters of chronicity, in which the timeline of some events were out of sequence. Furthermore, for validation throughout the data collection process, during each interview, I paid particular attention to verifying my understanding of participants' accounts by clarifying details of stories told and thoughts shared.

Peer validation aids in the verification of my interpretations of the study's data, which can further establish trustworthiness. Loh (2013) recommends researchers seek validation from experts in the field of study by gaining their views of the analysed data. I sought out peer validation from my academic supervisors, one of whom is an expert in narrative research with experience researching with WLHIV, and one of whom is an expert in nursing research, involving maternal and global health. In reviewing and giving insight into my analysis of each narrative account and the cross-case analysis, their expertise provide valuable insights to the data analysis process further developing my analysis of the data. The final technique to ensure trustworthiness in this study is the process audience validations by demonstrating the relevance of the study's findings to the wider field of study. In this case, the process of gaining validations from primary individuals who will be reading and possibly impacted by this study. Over the course of this study, I have presented the research in its early and later stages at national and international conferences on HIV and narrative inquiry. Furthermore, I was invited to present the preliminary findings from the study to a conference ran exclusively for and by people living with HIV in Ireland. Conference attendees were able to provide feed-back on my interpretation of the findings. As well as establishing trustworthiness of the study throughout the research process, I also engaged in reflexivity and this will be presented in the following section.

3.3.2 Reflexivity

To facilitate transparency and enhance the study's rigour, I engaged in reflexivity throughout the study. In the generation of knowledge by means of qualitative methods, reflexivity is considered a crucial process for researchers to engage with (Berger 2015). Because qualitative research occurs between two or more people, in a certain time and place, all qualitative research is contextual (Dodgson 2019). Equally, researching a sensitive issue such as shame among a group of seldom heard voices, necessitates continuous critical reflexivity (Adeagbo 2021). This allowed me to examine my own values, beliefs, biases and previous experiences in ways that may benefit or hinder the collection, interpretation and analysis of the data. While I detail my positionality in this study in the introduction to this thesis, I state how I do not have any personal connections to the experiences of women living with HIV, and so I do not have prior personal insight into the subject. However, when I started this research, my academic and professional background had largely informed my beliefs and understanding of women living with HIV in an Irish context. To maintain self-supervision, I kept a reflexive journal to keep track of my decisions, thoughts and reactions throughout the research process. Below, I include excerpts from my research journal to give readers insight into my thoughts about the research journey.

3.3.2.1 Reflexivity in Data collection

> *"Today I was informed by the HIV Ireland staff member that a woman declined to be interviewed because she was too ashamed to do so. The magnitude of hearing such a response to the study reinforced to me the importance of these women's stories in this study" (Reflexive Journal – April 2020)*

Semi-structured interviews were used to facilitate data collection. As a novice researcher I was nervous yet eager to meet each participant. I appreciated the interviewing process in the sense that I was actively involved in data collection for my study, as the opportunity to sit and actively listen to women's stories of living with HIV was a humbling privilege, not just as a researcher but also on a basic human level. Stories of women living with HIV in an Irish context are seldom documented and so I tried to address this by listening to women with great curiosity and genuine interest and care. I was keen to conduct the interviews because I expected the interviews to be interesting, thought provoking and emotionally moving, which they all were. I realise that it probably isn't helpful to have such high expectations of the data collection process but I cannot deny that my sense of excitement as a researcher was a reflection of the amount of time spent thinking about this study and its potential outcome and ultimate potential impact on people's lives. From my perspective as a researcher, I appreciated that it was a different experience for the participants, to share the intimate and sensitive details of their lives with a stranger. Taking that into consideration, I was often nervous about how women would perceive me, knowing that the research would be impacted if I misspoke or came across poorly. In a sense, I noted that I faced potential academic shame. Because I held myself to a high standard as a PhD student, I felt that if I misspoke or made mistakes and I believed the participants judged me negatively for my performance, I might feel a failure as a PhD student. From the outset of every interview, from connecting with women over the phone, email or text message, I aimed to establish rapport. The participant could decide the location of the interview in a neutral venue. In practice, in the majority of incidents, I offered them a location and they accepted.

Early on, I positioned myself as an HIV ally and advocate. I felt the need to speak softly and warmly, and to approach them confidently yet modestly and gratefully. I found myself wanting these women to understand that I only have the best intentions for their participation in my study because that was my reality in my position as an outsider researcher to the HIV community. However, in another sense I was not strictly an outsider, as I was completing this study under the supervision of experts in nursing, one of whom completed their doctoral research with WLHIV. Prior to each interview, I felt it important for both myself and the participants if we sat and spoke casually for several moments prior to the interview. I wanted the participant to get a sense of me as a person, a fellow woman, and not just as a researcher. I didn't share a great deal of personal information about myself with participants, however, a small number of participants were curious to know about my reasoning for carrying out this study and I explained my academic background and personal interests in the field of study. I approach this study as an outsider in the sense that I was researching an experience in which I have no lived experience, as I am not living with HIV. However, I am familiar with the subject area of the lived experience of HIV on an academic level and have read heavily around the topic. I asked women about the types of terms they would like to use because prior to interviewing as I had become aware that the term 'disclosure' as it relates to one's HIV status was deemed an increasingly problematic term. Although I wasn't absolutely sure that participants would deem it problematic, as an outsider with no personal connections to women in Ireland living with HIV, I erred on the side of caution and for the duration of the interviews, I used the term ‘shared their HIV status’. It was only on the 7th interview when a participant happened to bring up voluntarily that she didn’t appreciate the term ‘disclose’ because it made her feel like she had something to hide, and she had nothing to hide. I realised as an outsider that if I have any trepidation about terms and language use in the interviews, I must always consult with the participants and confirm their preference of terminology.

Throughout data collection, engaging in reflexivity benefitted my development as an interviewer and qualitative researcher, as it allowed me to think critically about my thoughts and feelings about the interview process. I noted following my first interview the following:

> *“For my first interview, I very much enjoyed it. I felt nervous often because I was aware that sometimes my interviewing technique was a little off, and I think this might be because I was a little overwhelmed. Sometimes I would be quick to explain a question or reiterate myself if I found that she was taking some time to answer. Sometimes I didn’t allow a pause after a question for too long because it was a worry that possibly she didn’t quite get where I was coming from?” (Reflexivity Journal – February 2019)*

I acknowledged early on the data collection that I needed to trust and believe in myself more during the interviews, or this would impact negatively on the data collected. Balancing the interview between allowing for thoughtful pauses during moments of silence, against knowing when to respond to a participant, was something that I deemed of great importance. I found this difficult in early interviews and noted it in my journaling. I combatted this concern by advising women at the start of their interview that I aimed not to interject much unless I had questions or follow-up questions, and that this was not a sign of judgement or disagreement.

> *“I found it hard not to console her as much as might have in a situation outside of an interview. In some of the things she would say, I feel as though she was looking for validation, or maybe a cue that that was the right thing to say, and it is hard not to reassure them that they are doing well, give advice when it is sought, or agree with them when they make a statement about a situation. As she was telling me about events that were quite uncommon, and what someone might even consider*

> *traumatic, it was hard not to do this, and I was paranoid that she might think I was shaming/judging her. I wanted to let her know that I supported her, I wanted to tell her that everything she was feeling was appropriate for her situation and not to feel bad about it. Yet, my role as a researcher does not recommend such, although it crept in from time to time. It is hard to sit there, nod my head, and not respond with agreement or conversation without coming across as a little harsh, considering the sensitivity of the topic. (Reflexivity Journal - March 2019)*

Looking back on the data collection phase of the study, I found this to be the most rewarding phase of the study. While the interviews served the function of data collection for the study, I found myself regularly acknowledging the privileged position I was in to listen to these stories. Each interview was much more than a means to the end goal of the study, they were unique and moving encounters that will stay with me long after this research is completed.

> *'Exactly one year to the date since my first interview, I have completed my final interview for this study. I am relieved I have managed to gather this many accounts and I am looking forward to exploring each one. However, I am left with a tinge of sadness that, for now, I no longer get to sit with women and have such meaningful, interesting conversations. I have greatly enjoyed gathering their stories and, if time allowed, I would gather many more. In reflection of today's interview, I am pleased with how far I have come in my capacity to interview. I reflect back on my first several interviews, and compare my progress." (Reflexivity journal - February 2020)*

3.3.2.2 Reflexivity in Data Analysis

I could not write reflexively about the study's data analysis without discussing the context in which it took place, during the COVID-19 global pandemic. Qualitative analysis is messy, time consuming, can be emotionally demanding and sometimes stressful. Removing myself for the norms and comfort of an academic environment, and change in normal life routine impacted the flow in which I progressed in the depths of narrative analysis. I reminded myself how fortunate I was to have gathered my final interview in the weeks prior to the implementation of countrywide restrictions and nothing but my own mentality was standing in my way. However, given the depth of thought and consideration the study's transcripts required to ensure the appropriate level of analysis, this was a personally and academically challenging period of the study due to the on-going global pandemic. Thus, I felt apprehensive about devouring the volume of data I had gathered. I was intimidated and routinely experienced self-doubt in my ability to draw conclusions from the deep personal experiences that did not belong to me. Although an arduous process from beginning to end, I found myself routinely engrossed in narrative analysis as I relived the interviews and participants' accounts over and over in my mind.

Qualitative research must be transparent about the choices made throughout the data collection and analysis process to enhance rigour and trustworthiness (Davis 2020). I started the narrative analytical process by reading each interview thoroughly, memoing notes throughout. Throughout this process, reflexivity aided me to become self-critical of the lens in which I interpreted the data I had in front of me. I do not live with HIV and therefore could not relate to the experiences of living with HIV depicted in the accounts gathered. That being said, I could not be fully objective in my analysis, as the accounts were co-constructed between the participants and I, and so I make transparent my own biographical context, as per the introductory chapter, which would ultimately influence how the data was interpreted. This means in a sense that I left a part of me in the findings by way of my own personal philosophy and such, the interpretation of the data is uniquely constructive and not strictly objective.

The self-reflection and self-examination of our unconscious bias is of great importance in gathering, interpreting and analysing data (Dodgson 2019). Buetow (2019) warns how failing to do so can result in qualitative researchers making cognitive errors by focusing on what we want and expect to see and place greater value on these aspects of the data, over other elements, due to how they align with our pre-existing beliefs. In considering my biases and personal history, the personal lens in which I interpreted women’s shame in their accounts was under constant critical reflection. Coming into this study, I mention I position myself as an ally and advocate for women living with HIV. Through my intellectual learning, I understand women living with HIV to be a stigmatised group, and their stories of living with HIV to be somewhat silenced. Taking this into consideration, in both the data collection and analysis, I continually had to be mindful not to over-empathise with women to compensate for the potential stigma and judgement of others. By doing so, I risked clouding my interpretation of participants’ accounts. One major element of this was engaging in routine reflection in examining my interpretation of how women felt and experienced HIV-related shame. Some women spoke directly how something made them feel ashamed and others alluded to it by speaking openly about how they worried or thought negatively about what others might think of them in light of their HIV. I was careful not to over analyse micronarratives as potentially more shameful that they are just to deliver on the studies objectives. To combat this through data analysis, I reviewed narratives of shame against empirical literature and theoretical underpinnings of shame. Reflecting upon these decisions brought to light how every qualitative researcher sees the world differently through our pre-existing beliefs, and no two people would interpret these stories identically. These unique findings emerged from a relationship between the researcher, me, and the participants, within a specific context.

3.3.2.3 Reflexivity in the Discussion

> *'Right now, it is difficult to look back over the last 3.5 years and see how far I've come. This discussion chapter is currently a black hole; I feel as though I am staring into an empty dark space. This has been an anxious few weeks for me, as I have no idea what I am doing or what crucial context is going to fill the pages. Broken down into smaller segments of work, this will be manageable, and so I start by bringing forward what I have learned from the study so far and begin there. I look forward to the moment that I look back to this journal and I can truly recognise how far I have come' (Reflexivity Journal - March 2021)*

I was initially reluctant to include autobiographical journal entries that depicted such dour moments in this study, yet writing my thoughts about the discussion chapter was vital for my understanding and development as a researcher. So much of this thesis, coincidentally, is made up of moments of pride and shame. Prior to developing and writing the discussion chapter, I was temporarily paralysed by the fear of having to assert the findings from this study into the wider field of research. Having very little opportunities to discuss my research and its progress outside of conversations with my supervision team (due to COVID-19 restrictions), I had concerns that my academic peers would doubt my study's contribution. This may not be an unusual feeling at that point in the process but the isolation and doubts I felt were symptomatic of the situation I found myself in while writing up my study. However, I realised that I had become over familiar with my findings to the point where I did not fully believe they were original to my study, as I had spent so long pondering them during the analysis. Overwhelmed and overcome by self-doubt and sustained imposter-syndrome, I took a moment to reflect on how far I had come on my journey as an apprentice researcher. Looking back, the discussion chapter was an engaging chapter to write. It was encouraging for me to see how my findings compared and contrasted with the existing studies that informed the development of this study, and I felt this solidified my position as a qualitative researcher.

3.4 Conclusion

This chapter has detailed the study's adopted methodology and research process. I have presented a theoretical argument for adopting a narrative inquiry approach, as well as a brief exploration into alternative research designs. Narrative inquiry was the selected approach for this study as it provided women the opportunity to share and make sense of their stories, in particular, a possibly disruptive life event. Equally, narrative inquiry is an appropriate research method to amplify the voices of seldom-heard groups. Referring to the ethical implications of narrative research, as this is a sensitive topic being studied, I made sure to establish trust and rapport with all research participants while ensuring not to exploit participants for the benefit of data collection. My approach to using narrative inquiry in sensitive research involved the use of Clandinin and Connelly's (2020) three-dimensional narrative inquiry space analytical framework. I provided insights into the study's research process, including the research settings, which was in HIV Ireland and venues associated with HIV Ireland, ethical considerations include receiving ethical approval for the study, informed consent and confidentiality. I recruited participants through a voluntary organisation as it facilitated timely data collection, meaning the majority of research participants had some form of peer support. In writing reflexively about the research process, I demonstrate continuous critical reflection throughout the research process. In completing this study through my personal lens, I aimed to give readers insight into how my role as the researcher brought about these study's findings. Overall, I demonstrated my approach to this study and the process in which it was carried out.

Chapter 4: Findings

4.1 Introduction

This following chapter presents the findings from this study. The chapter is presented in three sections; each section comprises themes developed from personal narratives of participant's shame. Section one presents the HIV discourse that informed women's sense making of their diagnosis and its contribution to HIV-related shame. Section two presents the women's experiences of HIV-related shame and section three describes the women's experiences of moving beyond HIV-related shame and developing self-acceptance. Table 5 below details the study's participants' profiles and table 7 outlines the layout of the chapter, including which participants' interviews excerpts were chosen to illustrate each sub-section. Each section includes an excerpt from a participant's interview transcript in which they describe their personal experience. A table (table 6) including four eras of HIV treatment and prognosis, was drawn up to provide context of each narrative text, outlines the era in which the participant was diagnosed and the era when the illustrated excerpt took place.

The level of HIV-related shame experienced by each participant was varied. Eight participants described HIV-related shame as a part of their present, with some participants experiencing greater levels of HIV-related shame than others did. Four participants described HIV-related shame as a part of their past but not their present and provided insight into their past shame and moving beyond feeling HIV-related shame.

Table 5. Participant Profile

Name	Age Range	Years Diagnosed	Children	Marital/ Relationship Status	Nationality/ Immigration Status
Julie	50s	8	Y (3)	Widow	East Africa (seeking international protection)
Donna	40s	12	Y (3)	Single	East Africa (has 'leave to remain')
Rachel	30s	11	Y (2)	Single	Irish

Grainne	40s	10	Y (2)	Married	Irish
Angie	50s	3	Y (2)	Married	East Africa (Irish citizen)
Olivia	50s	9	Y (2)	Single	Irish
Ruth	40s	6	Y (1)	Single	Irish
Maebh	50s	18	Y (2)	Partnership	Irish
Jenny	20s	11	N	Single	East Africa / Irish
Marie	60s	27	Y (2)	Single	Oceanian
Linda	60s	22	Y (1)	Single	Irish (NI)
Sophie	50s	23	Y (1)	Partnership	Irish

4.1.2 Overview of women's accounts

In interviewing twelve women about their experience of living with HIV, women whose stories are not often documented, themes beyond the topic of shame were listened to.

Eleven of the twelve women interviewed were mothers. Some had children prior to being diagnosed with HIV, others had children after their diagnosis, however, none of the women were diagnosed during pregnancy. One woman was attempting IVF when she learned of her diagnosis and her journey was postponed for some years. Women's children were central to most of their stories as they strongly identified as mothers above other aspects of identity such as being a spouse, a sibling or a daughter. Women who were diagnosed after having their children were gravely concerned at how their HIV positive status would impact on their children's lives. Many felt guilty for this. Women who had their children post-diagnosis described closely monitored but manageable pregnancies.

The profile of the women interview demonstrated an older population, with over 50% of women interviewed over the age of 50. The older women on this group, Marie and Linda, were in their late sixties and were diagnosed with HIV quite early on in the epidemic, with no access to HIV treatment. Both women were told they likely only had a short number of years to live and this featured strongly earlier in their accounts. Both women had to give up their jobs and had small children to look after at the time, exacerbating the experience. The older population of women in the study demonstrated the ageing population of WLHIV and the success of treatment. Equally, the study involved the participation of a young woman in her mid-twenties, Jenny, who lived a different life to most of the other women due to her younger age. Attending school, university and navigating romantic relationships in her youth were all aspects of life Jenny had to navigate as a teenager and young adult living with HIV. Her account provided an important contrast to the other women in the study by illustrating a narrative of a young woman living with HIV in Ireland. This highlights that modern perspectives of HIV in Ireland today are made up of experiences of people across ages.

Table 6: Eras of HIV

Pre-HAART era 1980 – 1995	**HAART 1 era 1995 – 2005**	**HAART 2 era 2005 – 2017**	**U=U era 2017 – 2021**
AZT (zidovudine) prescribed Pre HAART Multimorbidity and poor life expectancy Risk of vertical transmission (VT)	HAART prescribed CD4<350 Improved disease outcome Good to normal life expectancy Reduced to no risk of VT in pregnancy	HAART prescribed at diagnosis (2010) Normal life expectancy No risk of VT in pregnancy	U=U (HSE approved 2020) PreP HAART prescribed at diagnosis Normal life expectancy No risk of VT in pregnancy
<u>Woman diagnosed in this era</u> Marie Linda	Maebh Sophie	Olivia Ruth Jenny Julie Donna Rachel Grainne	Angie

Table 7: Outline of sections and the participants represented

Section 1 Origin of shame	Absence of a women centred HIV narrative - Grainne - Olivia	Shame as an external force - Maebh - Rachel	
Section 2 Shame as exposure	Anticipated exposure - Angie - Sophie	Exposure avoidance - Linda - Julie	Felt exposure - Donna - Jenny
Section 3 Growing through shame	Discovering a shared experience - Julie - Ruth	A change in perspective - Olivia	In a position to help - Maebh - Marie

4.2 Section 1: The introduction of HIV-related shame

This first section describes why and how shame took shape in the stories of women living with HIV. In Chapter two, shame was defined as a painful subjective emotion that manifests when an individual believes that they are flawed, inferior, or sees themselves as this in the eyes of another person (Scheff 2003). These findings illustrate how women developed HIV-related shame due to the lack of discourse around women and HIV thus resulting in emotional isolation following their diagnosis. It also explores how the presence of unhelpful stigmatising discourses relating to HIV have been a source of shame for women, fearing that their stories may be perceived in light of such discourse. Findings reflect the interactional element of the three dimensional narrative structure, which explores the personal and social elements of a person's story. This study adopts the term 'discourse' to refer to commonly spoken and written communication and social meaning that have largely shaped societal understandings of HIV at certain times.

4.2.1 The absence of a woman-centred HIV narrative

Most women in the study described a sense of isolation following their diagnoses. The loneliness and isolation described appeared to stem from not knowing women who were living with HIV, and not seeing themselves represented in an encouraging way in the HIV experiences they witnessed around them. Participants were asked what they knew about

HIV prior to their own diagnosis and participants who were born and raised in Ireland often referred to common stereotypes, describing how in the early period of their diagnosis they understood HIV to be a condition that affected gay men, African people and drug users. Grainne's excerpt below reflects such a response, as she describes her lack of knowledge of HIV at the time of diagnosis, which contributed to her shock upon diagnosis;

> G: 'What do you mean I have to go out to this place, what is it?' I thought – OK. It could be Chlamydia, it could be something - Gonorrhoea, something like that, I don't know! Probably in the back of my mind I was thinking, maybe it is the worse-case scenario, maybe it is that? But had a very sleepless night that night.. I knew because I had an appointment straight away, which is rare in the HSE. So myself and my husband were directed to, 'the corridor of doom' as I call it. Which is (laughing) the STI clinic out in [hospital name] and went out there and met Dr. [name] who was there at the time, who interviewed us, or interviewed us – we had appointments with her separately. She told me the bad news first and that there'd be a follow up test. I was completely in shock because, I don't fit the stereotype, I'm not gay, I'm not African, I was living in a bubble of all this. I had rarely heard about it except for.. Freddie Mercury, ehh, stuff like that, red ribbon in December, charity stuff. But it didn't impact my life in any way. So, yeah, I was in a bad way.'
>
> (Grainne: diagnosed in HAART 2 era, quote relates to HAART 2 era)

The context of the above excerpt is Grainne's recollection at being called for her appointment where she would learn her HIV positive diagnosis. Grainne's recollection from ten years ago positions herself as not knowing what was going to happen, which highlights the unexpected nature of the diagnosis. She is expressing how seldom she thought of HIV prior to learning her HIV positive status that it didn't enter her mind that day to think of it. Grainne's use of terms such as '*worse-case scenario'* and '*that*' as terms to describe HIV point to her possible discomfort in retelling the story, as she rarely made eye-contact during this portion of the interview. Her pace is steady yet her tone is uneasy and agitated as she describes a difficult memory, sighing deeply throughout this except. Positioning HIV as the worst diagnosis to receive out of all STIs suggests Grainne's knowledge of HIV was informed by outdated discourse of no treatment, illness and death. Following her diagnosis with *'the bad news',* Grainne recalls a profound sense of shock, repeating her position as being uninformed that she could be infected with HIV. Grainne's reaction to her diagnosis was informed by commonly referred to people living with HIV; gay men, Africans and Freddie Mercury. In making sense of her diagnosis and of HIV, there was an evident absence of white, heterosexual women within the sense making. As Grainne identified as a white, heterosexual woman, this appeared to contribute to the onset of isolation in her experience.

Furthermore, older white Irish women, like Olivia, were aware of the media campaigns warning people of HIV/AIDS in the 1980s and 1990s, referring to the popular tombstone advert.

> O: 'It was like, how will ever again will I have a relationship with anybody, how do I live my life with this? How can I be a woman with this?'
>
> E: 'Why did you think like that?'
>
> O: 'Because of the only thing I remember about it was the shame campaign years ago, dya know, like the lesions, you can't be with anybody, ehh, it's such a hateful disease, like I mean all the terminology was very hateful, very strong and everything, right?'
>
> (Olivia: diagnosed in HAART 2 era, quote relates to HAART 2 era)

Like Grainne, Olivia had only an outdated era of HIV to refer to as she made sense of her diagnosis, although both narratives took place in a time where HIV was treatable and viral undetectability could be achieved. In describing her thoughts about HIV among women, Olivia's reflection is filled with despair and sorrow, as though she is sad for the woman she was in that period. In recounting the memory, her tone is panicked. Olivia appeared to internalise the discriminatory media messages she once saw when she was younger, as she looked to the future and questioned how her sense of womanhood would be impacted on by a HIV positive diagnosis. Olivia's excerpt is situated following a breakup between Olivia and her ex-partner shortly following both of their HIV positive diagnoses. Prior to this, Olivia described not needing to think about what HIV would mean for her life going forward because as far as she was concerned, it did not matter as long as she was with her partner. Now that Olivia had to navigate life as a single woman living with HIV, her outlook on the future could not picture a life where women can live happily with HIV.

As women who witnessed HIV affecting groups of people with whom they did not identify, most interpreted their diagnosis to be somewhat abnormal. This seemed to often affect how women thought about sharing their diagnosis with others as they came to terms with their diagnosis, as it appeared that women were concerned with how the news would be interpreted given that they did not consider this to be a common problem for women. Some women also felt that they were at a loss for who to turn to for support, as they were not made aware of what support was available, further compounding their belief that HIV was not something women ordinarily needed to reach out for support. The women in this study were all aware that other women were diagnosed with HIV in Ireland and elsewhere, however, in their stories they were struck by an absence of women's stories in the overall HIV discourse, which left them with a sense of isolation. This appeared to contribute to their emotional isolation and the onset of HIV-related shame until they discovered other women living with HIV and established a shared experience. This will be discussed later in section 4.3 of this chapter. While there was a notable absence of encouraging women-centred HIV discourse from women's accounts, the presence of stigmatising discourse of HIV was deemed unhelpful to how women made sense of and adjusted to their diagnosis. Compounding the lack of women-centred HIV discourse, women further noted that their awareness of stigma also drove them to feel shame.

4.2.2 Stigma as an external force of shame

Some women in the study cited HIV-related shame as something that manifested from an experience of overt disapproval in the form of enacted stigma. However, all of the women's stories relayed how their shame manifested from their awareness of stigmatising HIV-discourse that related to issues of morality and HIV as a contagion. Women often referred to the stigmatising social discourse surrounding HIV as a source of shame, as an external force put on them from society's ideals. Women referred to two dominant strands of stigmatising HIV discourse within the overall HIV discourse. The first relates to perceptions of people living with HIV as somehow morally inferior and non-deserving of empathy due to their deviant behaviour and the second relates to HIV as a contagion to be feared due to the outcome of sickness and death. With both strands of HIV discourse circulating in society, some women noted their concern of how the presence of such discourse could potentially inform people's beliefs about women living with HIV. Women referred to the possibility that their identities and lives would be held up against such discourse, therefore, these acted as an external force that kept women silent about their own experiences.

4.2.2.1 Discourse of women with HIV as sexually immoral

The first strand of HIV discourse women mentioned as harmful to them, was the association between HIV and immoral behaviour, and in the case of many women, the immoral behaviour relates to women's sexual behaviour. Many of the women acknowledged in their stories how their HIV status could possibly call in question their morality or the perceived lack thereof, in relation to their sexual behaviour as women. Irish born women commonly referred to this discourse, suggesting they perceived a societal intolerance for women's expression of sexuality. As HIV is classified as a sexually transmitted infection, women possibly considered their HIV status to be linked with sexual behaviour although not every woman contracted HIV via sexual activity. Some women were conscious that their HIV status would suggest they engaged in high-risk sexual activity or having many multiple partners. Rachel is a single mother of two children in her 30s and experienced deep HIV-related shame, compares her circumstances with a friend's;

> R: "It was also her finding out that she has Hep B that prompted me as well, because if she can get something (pause) and she's been doin' nothin'! She's a Muslim woman, she's been married for years, and it was something that was carried on from her mum. She was born with it and never knew. D'ya know, it was nothing that she'd done. But em, I just thought 'if it can happen… if she can have anything, sure why can't you, you've been irresponsible'. D'ya know?
>
> E: 'So do you see a difference there from her getting Hep B from her mother, compared to you getting it through sex?'
>
> R: 'Well I see an aspect of blame when it comes to me, yeah. You know, it wasn't her fault that she ended up with hep B and I'm not saying it's anybody's fault, y'know and I'm not saying I would like, I am my own worst critic. D'ya know it's not that I would judge anybody else but it's that, you'd initially think, oh they've been a bit … a bit, d'ya know what I mean?'

> (Rachel: diagnosed in the HAART 1 era, quote relates to the blue U=U)

While a number of women in the study acknowledged that their HIV positive status might have them perceived as immoral due to its association to sex, Rachel's account assigned herself the role of a self-perceived immoral person. Speaking in a matter-of-fact matter, the overt comparison Rachel makes between her route of transmission via sexually activity and that of her friend, who contracted HIV through vertical transmission, suggests a deeply internalised shame she holds against how she came to contract HIV. In painting her friend with entirely different characteristics to her own in terms of religion, marriage, sexual habits, Rachel is drawing an obvious differentiation between her and her friend. Rachel positioned her friend in a socially desirable situation in comparison to her own, marriage, religious, monogamous, which she highlights when Rachel positions her friend as being entirely unaccountable for her HIV status. Rachel, on the other hand, views herself as entirely accountable for contracting HIV. Rachel's tone in describing her friends is rather light and empathic yet transforms to self-criticism in referring to herself. Her view of herself is a product of deeply stigmatising discourse that positions people who become infected through methods such as vertical transmission, medical procedures, or sexual assault etc. as innocent victims of HIV and those who contract HIV through sexual acts or intravenous drugs, etc. have done so through their own volition. Rachel emphasises her point with conviction by verbally emphasising '*it's nothing that she's done'.* As Rachel is narrating the above account, it unfolds that she situates her and her friend's positions, as though society is judging them both, whereby Rachel would be judged for her actions, her friend could not be.

Across many women's stories, there was an obvious distaste at how HIV's link to sex, high-risk sexual activity and having many sexual partners was present in discourse of women and HIV. This strand of HIV discourse mentioned by several of the women points to the internalisation of how women are often judged for their sexual behaviour by the society in which they live, and how the generation of shame is often used as an emotional tool for controlling women's sexual behaviour.

4.2.2.2. Discourse of people with HIV as viral contagion

The second strand of stigmatising HIV discourse referred to PLHIV as dangerous contagious agents. Women perceived the threat of HIV within that discourse as a reason to conceal their HIV status. The fear outlined by a number of women was that they would be seen as vectors of and spreading HIV in which individuals would ultimately see them as dangerous or disgusting. While women typically cited such an outcome as something that would cause them discomfort, they considered it as possibly affecting the relationships they had with the people around them. Maebh, a grandmother, diagnosed in 2002/2003, who has been living with HIV for seventeen years at the time of interview, had concerns about how her grandchildren’s mother would be with Maebh holding her child.

> M: ‘Nobody talks about it really now.. But when my son’s girlfriend got pregnant – they’re married now – it was a really hard time because I thought… will she.. like, I had a dream that I saw people on a beach, actually it wasn’t a dream I was really on holidays. There was a grandmother with all the grandchildren. And I remember thinking ‘oh my god, what if his wife doesn’t want me to touch the kids?’ I mean people would bathe… like you don’t know do you? Next thing – oh my hands are clean, y’know? And now, there’s no problem with either of them but I did have to say like – was it shame, I don’t know what it was emm.. it was a real worry that she would be – not my son – but she would be funny with me near her child.
>
> E: Really?
>
> M: Yeah it was weird for me..
>
> E: And so, did you have a conversation with her?
>
> M: I.. I said it to her , I don’t know what I said but she looked really awkward because he’s not a girl who would talk about her feelings and.. and I don’t know what I said but I was really passionate saying it but I just remember she was like ‘Oh jesus!’ (laughs) So.. it was never a problem, I held the child any time so.. with both my sons and their wives.. but it really was.. and I knew it didn’t make sense because I knew I couldn’t pass anything to the child, that it wasn’t real.. and then I came back from counselling and that’s what I’m saying like, it’s different times..
>
> (Maebh: diagnosed in HAART 1 era, quote relates to the HAART 2 era)

Maebh relayed the account above as someone who seemed tormented by the idea that she could be a threat, or viewed as a threat, to her infant grandchildren. Maebh balanced her painful memory, with an understanding tone for the situation she potentially saw unfolding, even though her daughter-in-law made no indication that Maebh was a threat. As a mother who raised small children herself, Maebh appears to characterise her daughter-in-law as being a cautious mother who, like Maebh, would look out for any potential threat to her young child. The thought of her possibly being seen as dangerous bound Maebh in a position of temporary powerlessness and inferiority and her daughter in a position of power and superiority, as Maebh saw her as possibly keeping her grandchild away from her in protection. While knowing she could not infect a young child by being near them or holding them, Maebh's focus on her hands as being possible sources of infection indicates an internalisation of HIV discourse, possibly due to what she believed to be at risk. However, Maebh portrays courage in the face of anticipated shame in approaching her daughter-in-law, addressing her fears to her. Maebh's identity as a mother and grandmother unfolds strongly as she relays her account above, in that the thought of not being able to hold or be near her grandchild because of her HIV weighed strongly on her.

In concluding section one, there are multiple factors that have emerged from women's stories as contributing to the development of varying degrees of HIV related shame since their HIV diagnosis. The majority of the women interviewed were shocked to learn they were HIV positive, shock that appeared to result from a prior-held belief that HIV was not something that would ever have to deal with, however, not all women felt this way following their diagnosis. The shock upon their HIV diagnosis points to the absence of open discussion of experiences of people living with HIV here in Ireland and in other countries where women received their diagnosis. In contrast to the absence of what might be considered helpful and encouraging discourse, most women acknowledged the presence of unhelpful and potentially damaging discourse. This section focused on the origin of shame in their stories, the next section will explore the varying ways women experienced HIV-related shame by means of exposure.

4.3 Section 2: The Shame Experience: Undesired Exposure

Section 2 Shame as exposure	Anticipated exposure	Exposure avoidance	Felt exposure
	- Angie - Sophie	- Linda - Julie	- Donna - Jenny

The last section explored factors that contributed to the development of HIV-related shame, the presence and absence of discourse around women and HIV and now the discussion will focus on how shame is experienced by women across their stories. It unfolded during the twelve interviews that at some point during their experience, HIV was a source of insecurity for women, something they wanted to hide from the lives they showed to others or else they were otherwise exposed to potential social disapproval. This was suggested as something that emanated from the stigmatising HIV discourse in section 1.

> ‘That’s when I felt the shame. I felt it. I felt like I wasn’t wearing any clothes on me, you understand what I’m trying to say – I felt like I’m naked.’ Julie, describing shame as exposure.

In portraying their shame-experience, the term ‘exposure’ is referred to throughout this section as the term captures the experience of another witnessing an unacceptable part of the self, as it was anticipated, avoided and felt. Tangney (1995) asserts how feeling shame involves feeling exposed, which Julie describes above as feeling people can see parts of her that she would ideally cover up and hide. To be exposed, points to a lack of concealment, an absence of protection and for potential social disapproval. To be exposed was intricate to the undesired experience of shame. Shame was not exclusively expressed from the point of view of situations where women felt ashamed. Women also spoke about anticipating HIV-related exposure, and adopting mechanisms to avoid exposure, which was understood as an attempt to control their shame. These findings detail how anticipated exposure, exposure avoidance and felt exposure collectively made up how shame was experienced by women. While it is considered healthy and normal behaviour to want to avoid painful exposure in the eyes of an individual or society, the continued anticipation and avoidance of undesired exposure of HIV recalled by women lead to significant amounts of stress, sacrifice and maintained silence in their lives.

4.3.1 Anticipated undesired exposure

When all twelve women told of how they adapted to life following their diagnosis, at some point each of them described anticipating exposure that they believed would result in shame because of their HIV status. The prevalence of anticipated exposure varied across women's stories, dominating the lives of most women but seldom an issue in others. As time went on and women adapted to life with HIV, the frequency of women anticipating exposure during interactions appeared less and less, however for most women, it remains. Most participants referred to the exposure of their HIV positive status to others as what drove them to anticipate exposure. It was evident across women's stories that if they anticipated any possibility for shame and discomfort, they protected themselves from such exposure.

Participants acknowledged that stigma is associated with an HIV diagnosis. The thought of how HIV was viewed by others led women to believe that they would be somehow viewed poorly due to their HIV status. Many women held beliefs that the vast majority of people in their lives and in society in general, would not understand that HIV is a manageable condition. Some women assumed that sharing their HIV diagnosis with another, or group of people would result in a response of scrutiny and judgement and would not demonstrate empathy or compassion. What stood out from women's descriptions of anticipated exposure was that it could be avoided and it could protect their social relationships. Women's assumptions that they would be perceived negatively in the eyes of people, groups or communities around them demonstrated the value of these relationships to participants, and their need to protect themselves from social isolation. Sophie was diagnosed in the late 1990s and described her fear of her partner's family learning her HIV status when she was in the hospital giving birth.

> S: All of his sisters were coming to see this new baby and I just thought 'what the hell do I do if they ask?' And I just thought 'say nothing'. 'I have no idea why, this is just the room they gave me!' End of story, I just played dumb. I didn't know how else to handle it, and so, that's the only thing I remember. There was one other stress, I'll just tell you that, one of Paul's sisters, Paul has 10 sisters – about 7 of them are in the medical world and one of them was working in (local) hospital doing above all things – she was the blood analyst. I was saying to Paul, all the time, like we have got to go and talk to – I can't remember her name – about this because my

> bloods cannot go to your sister. And Cora's bloods cannot go to your sister. So anyways, it was talked about it was – (Doctor's name) I think was her name – she said yeah we'll look after that don't worry, they will be sure and divert them, they will get special… whatever.. attention. And I'm assuming they did because Deirdre never changed in any way with me, and she'd pop up to see me on her days.. y'know, and lunch hour and that, for the few days I was there and all the rest of it. It was weird.. the whole thing was secretive, fearful and stressful.
>
> E: And would this be a fear of people finding out?
>
> S: Yeah!
>
> E: And what would that fear of finding out mean to you?
>
> S: Well, first of all that they would not really like me or support me, or judge me, or…. Ara think I was a slut or what my past might have meant to them but also because for Paul's family, they would have been very protective of him"
>
> (Sophie: Diagnosed in the HAART 1 era, quote relates to the HAART 1 era)

When Sophie recounts the above excerpt from 16 years ago, her tone was stressed and urgent, throughout, as she is brought back to her birthing experience as a WLHIV. Looking back on her days in hospital giving birth to her daughter, Sophie told the story as if this was the one time in her life that she truly feared her HIV status could become known to people she absolutely wanted to keep it from, her partner's 10 sisters. Sophie spoke of various incidents, or a '*stress'* as she referred to them as, she feared at the time might be the incident that would lead to the reveal that Sophie was living with HIV. The location of this excerpt added to the sense of powerlessness she had throughout the situation. Sophie's recollection of being placed in an isolated room, although she acknowledged that this is for her benefit, caused her to be annoyed at hospital staff as she appears to have felt forced to think of a lie to her partner's family as to why she was in a room by herself. In this sense the location of the story exacerbated the anticipated undesired exposure. In repeating the story in her interview, Sophie indicated this still bothered her, as if the hospital staff had to keep her away from the women who were not HIV positive. Realising that her daughter's blood could possibly be analysed by her partner's sister, Sophie recognised another threat of exposure and indicated a transference of power to her doctor to rectify it. In this part of this vivid narrative, Sophie positioned the sister (who worked as a blood analyst) as a threat to her concealed HIV status. An emphasis was placed on the number of sisters that Sophie's partner had, as well as how protective they were of him, suggesting the exposure that Sophie anticipated was a fear that she could be ganged up on by ten sisters who did not think she was good enough for him due to her HIV status.

In contrast to Sophie narrative excerpt above, Angie describes anticipated exposure in her account below. Unlike Sophie's account, Angie refers to anticipated exposure in the presence of strangers and the possibility that someone might recognise her at the clinic. Angie narrates a HIV-related exposure in the eyes of other people living with HIV, rather than a connection;

> A: So if you're going through that door, and you're a black woman, definitely you're not going to maxillofacial stuff – come on. They are definitely going upstairs to the ID clinic. And definitely, if it's not STIs, then it's HIV. And that's it. Because that's all that's in that building. So you go in, sometimes you'll find loads of people sitting.. in that waiting area. Waiting to go… to… the maxillofacial stuff. And you have to go one step up to the STI clinic. When you get to the top of the steps, there is a door on the left, there is a door. And it's got a small little window, a little tinted window. And there's a – I know exactly what's there! – and there's a sanitiser gel. So you walk – before you open that door, your heart is racing, who's on the other side? And that's all… who's on the other side? Do I know them? Do they know me? Now. (place name) is a very small city. So, I get up there, I squeeze the gel, buying time, gaining momentum, gaining the strength to open that door. And when you open the door, I scan from here – before I can even take a step – I scan from here, all the way to the end because it's a long corridor and chairs are on one side. So you have to walk past everyone to the middle of this long hall, that's where the office is. That's where you go to present yourself, say your name, and that's where they tick off and find your file. But it's that corridor – so everyone, we all call it the corridor of doom.
>
> (Angie: diagnosed in U=U era, quote relates to the U=U era)

In the above excerpt, Angie tells her story of routine anticipated exposure that she experienced each time she attends her HIV clinic. It was clear from the way Angie retells this routine that every detail remains in her memory, suggesting that she was on high alert of her surroundings, especially when she acknowledges how well she can describe the clinic's interior. Her tone is particularly calm and paced in comparison to the event that she is describing. Angie situates her narrative at the intersection of a clinic for a non-stigmatised medical specialty, maxillofacial, and a stigmatised speciality, STIs and HIV care, introducing her race into the story as how people must assume that she is there for HIV treatment, and race is not something Angie can conceal. While Angie described this routine during her interview, she spoke it in a calm, matter-of-fact tone, as if reading systematic instructions. What is interesting in this excerpt is how Angie moves back and forth between the use of the first person to the second person, by her use of 'you' and 'I' interchangeably. This is possibly Angie, in describing to her audience this difficult process, a way of her trying to get her audience, the interviewer, to understand through her recollection of this routine event, what it is like for her. Equally, it is possible that instead of consistently using 'I' throughout her excerpt, Angie is distancing herself from the recollection of the event, in which she knows she is uncomfortable.

It is evident in this section that some women appear to anticipate the worst-case scenario so they can prepare themselves and try to avoid it or its impact, echoing Robertson's and colleagues (2018) who argue that the possibility of being devalued by another is a significant trigger for shame. Anticipating a shameful encounter appeared to be a way women controlled and ultimately avoided feeling exposed. Experiences of exposure avoidance appeared regularly in women's stories, narrated as both unique events and as a prolonged mechanism.

4.3.2 Avoiding Undesired Exposure

When women relayed in their stories the various circumstances in which they believed they were going to feel exposed due to living with HIV, adopted strategies to avoid such exposure often followed. Women described shame avoidance as a mechanism they adopted throughout their diagnosis to prevent people seeing them in a way they didn't want to be seen. While exposure avoidance is considered healthy social behaviour, its significance for the women in this study saw it result in major sacrifices in life, and continuous secrecy and silence.

For some women in the study, to adopt behaviour that resulted in shame avoidance, was conveyed as taking control in a unique event or routinely so that they would not experience

HIV-related exposure, and that was something they were accepting of. In contrasting stories, women conveys their shame avoidance had resulted in sacrifice. Women talked about their awareness that silence and sacrifice was price to pay to ensure that they would lessen any potential exposure of their HIV status. By adopting mechanisms to mitigate the possibility of exposure, women described a safety in their silence, as opposed to talking about their HIV. The rationale to avoid such exposure by means of adopting avoidance mechanisms, suggests that women believed exposure relating to their HIV status would fracture the social bond held with that person, group, or community.

This avoidance of shame exposure was seen across various spaces in women's accounts. Below are two accounts from Linda and Julie, who illustrated their experience of attempting to manage prolonged shame avoidance through narratives of relationships and intimacy, and in direct provision centres. In these circumstances, the avoidance of feeling exposure added to their own shame.

Linda, is in her 60's and is a mother of one daughter and never had an intimate relationship following her HIV diagnosis;

> L: I haven't had any sexual relationship since.. and that was part of it. A choice I probably made, because I wouldn't have wanted to tell someone in a relationship, about being HIV positive.
>
> E: What would have been the reasons behind that?
>
> L: Em, well fear of rejection, fear of em, y'know, them abusing your confidentiality.. y'know, what you have disclosed. Em, that you'd be vulnerable in terms of things like y'know, abuse, whether physical, psychological, emotional, whatever. And also, I suppose, in the early years, it was that. I wouldn't have, y'know, I.. y'know.. I could have the constellation of not having passed it on to anybody else.
>
> E: That's interesting.. so you're actively not getting involved into intimate relationships, that's directly related to HIV?
>
> L: Yeah.. yeah.. yeah..
>
> E: And is there any regret there at all, or is that how you've liked it looking back?

> L: Em.. I suppose, you, , I… I had a daughter to deal with. I had a daughter for y'know, companionship and doing things with, em, but I think you do miss that em, y'know, that you do have someone to share the, y'know, just do the.. y'know go to the pictures with, go out or whatever, y'know. Em, and I.. that, em.. I y'know, I have missed that bit. I don't have a confident that I would say.. y'know, that I would say y'know, that you would.. em.. that you would bare your soul to. (pause..) so that's probably one of the things that I think is. Yeah..
>
> (Linda: diagnosed in pre-HAART era, quote relates to the U=U era)

Detailing her reasons for abstaining from intimate relationships for over thirty years, Linda appears to have made a significant sacrifice in her life as a way of ensuring she would not have to tell anyone about her HIV status. In the thirty years Linda has been living with HIV, she describes this avoidance of exposure starting from a context when HIV was potentially deadly right up to the point of her interview. Linda portrays her sacrifice as a necessity, paying a high price for a valuable gain, indicating just how much the concealment of her HIV status means for her well-being. In telling the above excerpt, it is clear Linda has made peace with her decisions. She appears to have focused on bringing up her daughter instead of having a relationship. However her reflection, points to feeling the absence of intimate companionship in her life indicating her realisation of what she has given up in her attempts to conceal her HIV status. Her portrayal of her life over the past thirty years, holding back from deep emotional connections, demonstrates Linda scaling her life back to minimal exposure to limit any risk to exposure to HIV-related shame.

In a different context, Julie who is living in DP practices exposure avoidance by how she manages her medication.

> J: To open that box, I have to see whether she is not around,
>
> E: Who is she?
>
> J: My roommate. And you know the container for the medication, they make noise. It was still very hard, nothing changed for me. I had to put them again in the tissue, put them under the pillow, that was the life. Until I was transferred to [place name], where I'm now staying. I tried to say to the manager 'Can I have my own room?' He says 'why? Why do you want your own room?' That's when I said 'oh god – let

> me just share with him' but I didn't want to. Because I wanted my space, I told him. He said 'you can't do that'. It really affected me. I stayed there, we were two in the room. Then came another later, we are now three. So I had to default my medication at times, because I couldn't take them. Because of the shame.
>
> (Julie: diagnosed in the HAART 2 era, quote relates to the U=U era)

Julie's story primarily takes place in the context of DP, where unlike other participants; she is required to share a room with another woman, which is the norm in these settings. The setting in which Julie's except takes place adds context to the meaning she places on the story. In explaining the nature of her living circumstance, Julie is visibly frustrated as she tells her story, sighing heavily and is tense. When referring to direct provision in her interview, Julie's story largely revolves around consistently keeping her status from anyone in the centre who doesn't know her HIV status. To Julie, should her HIV status become known to another person in the centre, she is insistent that she would be judged heavily, marginalised and discriminated against in the centre. Julie's employment of exposure avoidance tactics to ensure her HIV status remains concealed is mandatory in her eyes. However, unlike other participants, the exposure avoidance tactics Julie felt forced to employ can affect her physical health as well as mental well-being. In describing what she must forego to achieve exposure avoidance, Julie is stressed, as she knows her doctor does not recommend defaulting her medication. Julie acknowledged that the exposure avoidance mechanisms she endures daily are made worse by living in direct provision. Seeing as Julie is required by law to live in the circumstances she lives in, her narrative speaks to a sense of feeling trapped and burdened by the fear of exposure. In contrast to participant's who can conceal their HIV status behind the doors of their homes, Julie's experience as a WLHIV in direct provision in Ireland affects how she controls the concealment of her HIV status. It represents and distinguishes the experiences of migrants in Ireland living in direct provision, an issue that has shaped how they experience living with HIV in Ireland. Furthermore, her position in direct provision places her in an unstable and uncontrolled environment for taking her medication every day, as highlighted in her excerpt.

Anticipation and avoidance of undesired exposure resulted from an experience in which women weighed up the level of risk to exposure and ultimately decided to avoid particular actions, such as relationships or taking medication, indicating how anticipating and avoiding undesired exposure can shape women's experiences as they live with HIV and affect their health. However, several women recounted narratives of the exposure of their HIV status, the painful feeling of being unprotected and exposed to unwanted social disapproval. The next section will present the finding; feeling undesired exposure, in which women describe circumstances in which their HIV-related shame was exposed to others.

4.3.3 Feeling undesired exposure

Stories of felt exposure relating to a woman's HIV status were not as common across women's stories in comparison to stories of anticipated and avoidance of exposure. This may be the very effect or outcome of successful exposure avoidance tactics employed by women. Women relayed experiences of feeling inferior in the eyes of another due to stigmatising HIV discourse When women referred to exposure avoidance, it came from a place of necessity and safety. However, when women narrated stories of felt exposure, they were often performed with difficulty, with some participants becoming visibly upset upon recollection. In their interviews, some women spoke of how they believed the person they were interacting with saw them, almost to confirm within themselves that that was how the individual saw them due to their HIV status. This is evident in both Donna and Jenny's stories below. Sometimes this exposure was felt when women interpreted a person to be overtly judging them, and other times women described events where essentially no indication that judgement is described, yet they still felt painful exposure. During our conversations, some women made sense of these uncomfortable moments as times in which they not only felt ashamed but also believed they were made feel ashamed by the actions of another In Donna's story below, her experience of felt exposure resulted from an overt experience with enacted stigma when she was travelling through an airport;

> D: They put me in the system that I'm HIV positive. So the immigration officer in [city name], when he took my fingerprints, then he was like 'So why didn't you tell me that you were HIV positive? Do you know that I have a wife and kids?' Whereby.. I can't..' I'm like to him 'How will I transfer this to you because I'm not even in contact with you in any blood, or in any sexual way? Why are you saying that to me? He was like 'Yeah, you were supposed to tell me that you are HIV positive. I was holding you' You see that thing.. it nearly crushed me like.. to zero. Because… I told everybody, I told Dr. [name] , I told the…the.. the.. the social workers and, that thing really, really got to me because it took long and every time I was sleeping I would.. you know? Sometimes I dream about that and I used to cry

> a lot about that because I didn't expect somebody who is well educated, who is someone I can run to, to ask for protection and this person will mock you in that way.
>
> E: That's terrible. So that experience has really stayed with you?
>
> D: Yeah.. yeah, it has stayed with me. Even now it's been there, I've been going for counselling, I'm still going there for counselling, that thing.. I used to.. cry a lot. I wanted that man to come and apologise to me, just to say sorry.. (upset) because, even now I'm still ashamed, even.. you'know? It's still in me, that anger is still in me, like, why did that man say that.
>
> (Donna: Diagnosed in HAART 2 era, quote relates to the HAART 2 era)

In an event that took place less than five years ago, the retelling of her interaction with an immigration officer was a difficult story for Donna to narrate. Firstly, the overt nature of the judgement and disgust Donna endured in the airport appeared to cause her trauma in the way that has remained with her. The unexpected nature of the interaction appeared to compound the level of felt exposure Donna experienced, frozen in shock at a mandatory meeting for immigration; Donna had no option but to remain at the encounter. As this interaction took place in an airport, Donna may not likely have been willing to share her HIV status with the man in this scenario, as there was no clear reason for him to be informed. Donna's description of the event as it unfolded was similar to that of a verbal attack; she attempted to protect herself from further exposure and humiliation by correcting the man that he was wrongly informed in what he was saying. Given that the event took place in an era where HIV treatment is at its most advanced, the immigrations officer's use of stigmatising discourse to try defend himself from the threat he witnessed in Donna is alarming. As Donna spoke about this in her interview, she began to cry. Donna positioned herself in the context of the story to be a victim of a hero turned villain. Having characterised an immigration officer as a protector and someone she can turn to if she needs help, his actions quickly transitioned him into someone who hurt Donna due to the way he made her feel painfully exposed and self-conscious. Like Julie, Donna's experience of being a migrant helped shape this experience. Because of her position as a non-Irish citizen at the time of the event, she was required to engage with the immigration officer which led to the unfolding of the above event. This puts into context the structural issues that migrant women face with regard to controlling the concealment of their HIV status, and added stress of facing the possibility of feeling undesired exposure.

While Donna experienced felt exposure due to overt communication of another's judgement, other incidents of felt exposure occurred from more subtle interpretations of judgement. Reflecting on this, Jenny, a young woman in her 20s, relays an incident she felt exposed by the judging gaze of a health professional who she interpreted as questioning her sex life as a woman living with HIV;

> J: I used – (pause).. kinda like.. not that they'd ask me, but when they found out that I was HIV - actually I did experience stigma from them. Like, just kind… 'oh..' It wasn't, kinda, it wasn't even what they said, it was how they said it, and the tone they said it in, and you knew straight away that they, were making a judgement about it and, y'know, they ask you how many sexual partners you've had? I dunno, I think I was doing an STI check, like, whatever, and I told them, and they were like – as if to be like – oh you know, really? And you have that condition?
>
> E: How did that make you feel – do you remember what your thoughts were?
>
> J: I just.. yeah.. I felt really, like, judged to be honest and just really.. yeah, shame. I felt really, a lot of shame because, as if to be like 'because you have HIV, you shouldn't be' – not sleeping around but you shouldn't be like.. that's kind of the feeling I got from them.. they made me feel really small. Like really, really small, and just kind of like…
>
> (Jenny: diagnosed in HAART 2 era, excerpt takes place in U=U era)

Although Jenny had held onto this memory since it happened, it wasn't until she was asked to talk about her experience with healthcare professionals that she characterised herself as a victim of stigma, indicated by her pauses, hesitancy and the back and forth nature of her account. An added element of this account is that, in attending a sexual health screening, Jenny was seeking out non-judgemental services for something she cannot do herself but instead requires a healthcare professional. It is understood from the excerpt that the healthcare professionals didn't verbalise to Jenny that she shouldn't have casual sex because of her HIV, however, that was how she interpreted the message as Jenny points to the doctor's tone and hesitation after she informed them she was HIV positive. Jenny articulates the doctors purpose in this story is to shame her into changing her behaviour, as from a medical perspective, they see her as a viral vector that should not be having sex even though this story takes place in an era of recognised viral undetectability. In the context of Jenny's overall story, she portrayed doctors and other health professionals as supportive individuals. However, the purpose of this account is to illustrate that Jenny has encountered doctors who she feels don't see her beyond someone living with HIV, a harsh reality she has come to learn growing up with HIV. In performing the narrative, Jenny's tone of voice transformed to become softer and quieter than had been previously. Reflecting on this incident in her story, Jenny realised that she was hurt and that she felt such painful exposure at the hands of a health professional and in telling the story, Jenny sounded sad for herself.

In concluding section two, in portraying their accounts of living with HIV, experiences of shame were evident in women's past and present. The shame experience, presented as feeling exposed, highlights the profound stress, worry and fear women felt at the thought of themselves exposed to shame. In avoiding such exposure to HIV-related shame, women endured sacrifice and hardship, affecting their social lives and physical bodies through their endeavours to keep their HIV status concealed to avoid exposure. These findings are similarly put forward in Hutchinson and Dhairyawan's (2017) philosophical argument for the research of shame along stigma in qualitative HIV research. Finally, women described the psychological and emotional pain caused by the experience of feeling exposed to another, resulting in feelings of inferiority due to their HIV positive status. At the time of the interview, a number of women's narratives (2) remained centred in a HIV-related shame experience. However, in contrast to experiences of shame revealed in the findings in section two, it was evidently important for women to share the progress of their journey living with HIV, as detailed in section three.

4.4 Section 3: Growing through shame

<u>Section 3</u> Growing through shame	The power of shared experience - Julie - Ruth	A change in perspective - Olivia - Jenny	In a position to help - Maebh - Marie

This section will illustrate how discovering a shared experience among other women living with HIV, as well as therapy and counselling, lead to a reduction in the overall HIV-related shame experienced (anticipation, avoidance and felt exposure) due to a reduction in emotional isolation and change in perspective about their HIV.

However, it is important to note that while most (11) women in the study had engaged in some form of support, the majority of participants appeared to remain in shame based practices, such as anticipated exposure and exposure avoidance in their stories, although to a much lesser degree compared to their past. Throughout their interviews, when women were speaking in the past tense about an experience of HIV-related shame, they often returned to the present, clarifying how they do not feel quite like that anymore, or no longer have those experiences, as if to counteract the recollection of the discomfort of challenging times in their lives.

4.4.1 A Shared Experience

Women described multiple different ways in which they came in touch with other women living with HIV. Of the twelve participants, ten women had engaged in a social group for WLHIV, PLHIV or CLHIV at some point in their lives. Although not every woman in the study had connected with other women living with HIV, every participant referred to the importance of having another person to talk to, who truly understands their set of circumstances. The need for peer support is understandable because of the emotional and psychosocial burden living with HIV can bring. Ruth is from a rural area but finds virtual connection with other women valuable;

> E: How do you find the social support.. yano [you know], a group of peers..
>
> R: It’s awkward because.. I live in *place name* [laughs] yano? But it’s awkward for any – like there’s another girl like she lives in *place name* so it’s just awkward for everybody. But the Whatsapp group is great and people just dip in and out as

> they want to, yano that kind of way? So we know somebody's there, yano, it's knowing that there's other people there is enough sometimes, dya [do you] know that way? You kind of need it at different times but em… Yeah it's good but then…as I go on with this, sometimes I'm like, I dunno, I don't even know how to word it – should we be gone past the whole thing of 'somebody with HIV needs a support group' dya know what I mean, like.. Should it even be that thing anymore that you need a support group for? Dya know?
>
> (Ruth: diagnosed in HAART 2 era, quote relates to the U=U era)

Ruth situates her narrative in terms of her own geographical proximity to the rest of the group. At this point, Ruth praises the availability of a virtual platform for the social group. Ruth expands on this by indicating that this is how she avails of support from the WhatsApp group, '*to know that there's other people there, is enough sometimes'*. She is not alone, she knows there are other women living with HIV that she can identify with. The casual and informal nature, *'just dip in and out'*, that Ruth positions the group in her life suggests she does not rely on it heavily in the present. In contrast with other participants, Ruth's perspective on the social group changes when she questions its overall purpose. The tone and structure of sentences within her excerpt indicate Ruth's ambivalence and hesitancy in her narration. Given Ruth's growth within her own narrative, her questioning of the social groups function, points to how she sees the future of her own HIV experience and that of other women's HIV experience. Through her narrative, Ruth indicates her hope that women, including herself, won't experience emotional isolation that leads them in search of a social support group.

Collectively, women expressed similar reasons across their stories as to why they reached out for support; in search of relief for emotional isolation and to meet with other women who might understand their unique situation. For most women, they described that until they met with other WLHIV, with the exception of healthcare workers, women felt unable to openly discuss their HIV- related issues with the people in their lives.

This is relevant to Julie's portrayal of the role that the social group plays in her live, within the context of living in DP;

> E: What was it like to have a social worker – was that beneficial?

> J: Of course it was, because he was the one who referred me here to say you can find people here, you can find a family, where by you can be expressing yourself, asking questions, sharing, socializing.
>
> E: Your community with other…with other women living with HIV is like a family?
>
> J: (nods) Especially for me because I am benefitting a lot – because I've got no one here. If I have a problem, I know who to ring, who to talk to, yeah… if I'm too stressed
>
> (Julie: diagnosed in HAART 2 era, quote relates to the U=U era)

The narrative above describes how Julie edged out of unwanted isolation and towards a community. Julie, more so than other participants in the study, expressed a deep appreciation towards the function of social groups in her life. This appreciation comes from a place of sourced relief whenever Julie attends social groups, as she weighs this group up against the context of DP. The above narrative is situated in both the past and present, in which Julie positions herself prior to attending the group; in isolation and without support she is presented with hope and inviting possibilities. In portraying the narrative, Julie directly refers to her social group as family in her present. In using the term *'family'* Julie is not only expressing her hope of close knit social and emotional support, but in using it in her present, she appears to have achieved it. Moving on, Julie paints a comparison, a back and forth narrative between the comfort and safety of her '*family',* against the isolation in direct provision, '*I've got no one here'.* Here in her narrative, Julie positions the isolation living in direct provision above that of HIV, pointing to the benefits that social support has been for her experience in DP as much as HIV support.

When telling their stories of engaging socially with other WLHIV, most women did not directly associate their engagement with shame reduction. However, through establishing connection and a shared understanding with women they identified with, the connection made between women appeared to challenge the shame many women experienced. A narrative unfolded portraying a group of women bonded together through solidarity.

4.4.2 A change in perspective

Over time, the women's outlook on being HIV positive changed and it was evident in their accounts that some believed that they were not defined by their status. This mainly featured in how women spoke about themselves and in how they appeared to other people. Some women felt that if they were to be judged or stigmatised at this point in their lives, they would see that as a poor trait on the other person's behalf, not on their own, suggesting a sort of reverberation of shame. Alternatively women shared how, in comparison to their past self in which they were almost imprisoned by the burden of their shame, they now can't imagine themselves caring about what others think of them, and see HIV as being a part of them. Oliva grew to accept and appreciate her status as described below.

> O: I was driving home that Sunday evening, and I was driving away and all of a sudden this cartoon thing came into my head and it was.. I call him 'Bunkee' – carbuncle, right? It's attached here (points), right, but it started off and I drew it all out and if I could get somebody to animate for me it would be brilliant. And what it was, it started out as this thing latched itself to me … and I couldn't get rid of it.. eventually could.. and I was saying what is wrong, what are all the pains for and everything and it turned out it was the HIV, right? But this is.. the expression was angry, it was an ugly thing, it was the ugliest thing I've ever seen… ah.. it was absolutely angry, it was draining everything out of me, the more angry it got, the worse it drained me and the more I fought it to get rid of it, pull it off, tear it away, the more it destroyed – you know. This thing was – there was a dynamic going on, there was a whole clutter of bits in between, but do you know how I remember getting to this stage? In my head with this story right, all of a sudden it got to the stage where it was like …. a kind of a truce was called. I don't know what it.. right? And now it's got to the state where .. then the story got to the stage where ..em.. 'you alright there bud?' dya know? You have to live too kind of a thing, right? You've had to find somewhere to live and.. alright. Thank you for finding me and you've taking me on an amazing journey – just do me a favour, just keep your fuckin' head down and don't show your ugliness when people don't know what you are. But I said, when people are around you're more than welcome to pop your head up, say hello, but I'll say it in a good way, I don't want to be dragged through the shit like I did before. I actually created kind of a …and now it is a …pause… it's

> like emm.. yano a little dog cuddles at ya, kind of a feeling… I've attached that kind of a feeling because that gave me.
>
> (Olivia: diagnosed in HAART 2 era, quote relates to the U=U era)

The story Olivia shares above depicts a journey of how she grew to accept her HIV. The context in which the story occurs is as a thought in Olivia's mind one evening as she was driving in her car. Olivia was living with HIV for around 6 years at this point in her life. The story contains two characters, her past and present self and the character she assigns to her HIV. As Olivia tells the story, she introduces an unknown character in cartoon form called 'Bunkee', described as a sort of parasite that has been causing her pain and illness, her tone and depiction of this character is animated with disgust and contempt. This early section of the story appears to represent Olivia's life prior to her diagnosis following a series of illnesses that lead to an HIV diagnosis. From there, Olivia introduces a battle narrative, a back and forth struggle depicted by Olivia trying to remove 'Bunkee' but his resistance only harms her further. This segment of the narrative appears to reflect the years following her diagnosis, a physically, mentally and emotionally challenging time in Olivia's life. However, at this point in the narrative Olivia's mannerism and tone changes to become soft, as she introduces a drastic shift in her and 'Bunkee's' relationship, by way of a '*truce'*. This unexpected change in Olivia's perception of 'Bunkee' came from a place of empathy and newfound understanding for a living thing trying to survive, in the same way that Olivia battled to survive HIV. Eventually, in Olivia's portrayal she is caring and warm towards 'Bunkee'. She has animated 'Bunkee' with a name, a function and purpose in her life. The function of Olivia's narrative above depicts a journey from hostility towards her HIV, to the acknowledgement that as treatment is currently, she will never be without HIV, to finally welcoming for 'Bunkee's' presence in her life.

Olivia's development in how she sees HIV as no longer something that bothers her, is reflected across other participants' narratives. Below, Jenny reflects on her past self's view on living with HIV, finding her negative perception of HIV almost comical;

> J: Because before I would have been so nervous to tell someone, like.. and I'd cry, every time I'd cry, and I'd be like 'Look, I have to tell you something' and I'd be like.. and I'd be CRYING. And.. now I'm like.. why - this is just who I am, like it's

> just like saying ‘Oh I have curly hair’ Y’know it’s just like.. (laughs), It’s just something I have now.
>
> (Jenny: diagnosed in HAART 2 era, quote relates to the U=U era)

Jenny gives insight into how she used to view herself as a young woman with HIV, compared to how she sees herself now. When Jenny described how she would cry in telling people she was living with HIV, her reflection upon such memory was that of disbelief as she emphasised the word ‘*crying’* for effect. In doing so, Jenny looks back, questioning why she was upset, by giving context to her current feelings HIV, that is a part of who she is. Equally, Jenny’s story of growth in her attitude towards her HIV doesn’t only give insight into how she feels about her HIV, but indicates a growth in how she sees other people see her, and that is that she is completely unapologetic for who she is.

Growth and development often occurred due to emotional and psychological support gained from HIV-related social groups and professional help. This led women to develop a change in perspective about how they see themselves and how they see other people see them. This suggests that when women tended not see HIV as a negative attribute about themselves any longer, they didn’t anticipate individuals around them to either, a change in perspective provided some relief to HIV-related shame.

4.4.3 In a position to help

While speaking about their lives in their current contexts, some women spoke of how they did not need the support of the social group in their lives so much anymore. These women spoke of how social support groups had served its purpose in their lives and now they saw themselves as being in a position to help women who were newly diagnosed. Maebh, who has lived with HIV for many years, expressed a wish to emotionally and socially support women who are newly diagnosed with HIV.

> M: I’m emm.. in a really good place now at the moment so I don’t think I really need the group.. emm.. I’d like to think that I’m there for other people – like that girl now – the girl whose in the group and recently she told this guy and he didn’t want to know so she’s heard no more from him, and she’s young and she’s only been diagnosed a year and you know.. it’s really hard for her.

> E: Ok so you are in more of a peer support position right now?
>
> M: I'd like to be doing more of that I think yeah.. I don't really need the group for anything .. I don't.. I did years ago definitely, I don't know.
>
> E: So social support plays an important role in your life?
>
> M: Now it does, it didn't when I was diagnosed. I lived in England, I was very isolated and I was bringing up my kids on my own. But now, I'm in a good place and ehh.. yeah I.. I mean when they start up in the hospital now and have the groups, I will really like to be there for someone to come in. When I was here (sexual health centre), people would come in and they're newly diagnosed and they'd say, 'you're the only person that I met' and y'know, it's a huge thing and I could have done with that .. and I'm glad they are seeing it up in the hospital now.
>
> (Maebh: diagnosed in HAART 1 era, quote relates to the U=U era)

In the telling of her hope for the future, Maebh's account reveals a woman who has faced challenges living with HIV and because of her experience, wishes to help others avoid the same. The continuity of Maebh's narrative transitions between past, present and future, which enables her to situate her story, giving context to her present, and future by detailing her past experience. By referring to the isolation she experienced, Maebh provides cause for joining the social group later in her experience. Maebh allocates the social group as being a significant benefit in her adaptation to her diagnosis, but going back to early in the narrative, is when she believed she needed the social group the most. Pointing to this absence in her past, Maebh channels empathy and understanding with people newly diagnosed with HIV, as if she foresees how their experience will play out given her own struggle. With this in mind, Maebh looks to the future to take action to help people like her. Maebh's thinking is supported by several others in their narratives, women who have been through challenges because of their HIV diagnosis. Challenges that they believe could have been addressed and negated had they the opportunity to connect with someone who had been.

While women were keen to express their wish to support other women with HIV, in a unique experience, Marie, who's been living with HIV for circa thirty years, described a different approach, by sharing her HIV status with her younger university classmates and people she meets on her travels.

> M: Em, I've told one of them. There is one of them who lives in the same building as me; we walk home together quite a lot in the evening. So, I told her one night and she went 'Oh! Oh, Ok' but I always think that I should tell young people because otherwise it's invisible? Y'know that's like..
>
> E: Yeah, see it as an opportunity to educate, y'know to tell somebody about U=U or that sort?
>
> M: Yeah, yeah, it's kind of, to a lot of them it just doesn't exist. Like I remember – a couple.. a couple.. I remember saying 'I remember ' – well actually one fella said to me once that – I was working with this one fella once and he said to me 'Oh what makes you think you've got HIV?' (laughing) I said 'Aw God, I don't know how many blood tests I've had' (laughing), and he was sort of 'what??' Yeah, yeah its sort it – and another one said to me something about 'I've never met anyone with HIV – wow! First time – wow! You don't look any different?' Yeah I suppose yeah, I do like to – I do sort of tend to – anyone under 30, I tend to drop it on them (laughs).
>
> (Marie: diagnosed in pre-HAART era, quote relates to the U=U era)

Marie's account depicts an evident contrast in comparison with other narratives in the study. Her performance of the narrative is light-hearted and humorous as she relays the multiple experiences she's had sharing her HIV with young people in recent years, reciting the multiple responses she's received while laughing. Marie alludes to anticipating shock from those she shares her status with, yet prioritises their awareness over how they might perceive her after the fact. Marie's basis for her decision to share her HIV status stems from a perceived obligation to educate others, coming from an acknowledgement that HIV is not often talked about among the young people she interacts with and believes it should be. Given such, Marie positions herself as an older, experienced educator with the ability to inform the younger generation in the hope that HIV will be more openly discussed.

Summarising section 3 of the findings, when reflecting on their lives prior to the support they received, women mostly classified their experience as difficult. That being said, women were keen to share the progress of their journey in terms of growth. In the establishment of solidarity via social and peer support, women escaped emotional isolation and developed a new perspective on how they viewed their HIV status within themselves and to other people. This growth was experienced as self-compassion and gratitude across the narratives, antidotes to HIV-related shame. Similar findings were portrayed in Briony, Leary and Drabkin (2014) and Brown, (2006). Women alluded to the absence of speaking with another woman living with HIV in the early stages of their diagnosis as something that might have prevented the onset of shame in adaptation to life with HIV. Reflecting on this, participants were keen to take action to limit women enduring the emotional burden of HIV-related shame. Taking action came from a budding intolerance some of the women expressed due to the lack of a women centred HIV narrative. Therefore, while the study recognises through the personal accounts of women that living with HIV can be an incredibly challenging journey, it highlights the need to amplify the stories of resilience, perseverance, and encouragement that came about when the right supports were in place.

4. 5 Conclusion

This chapter presents the findings from twelve narrative interviews of women living with HIV with particular emphasis on the role shame has had in their HIV experiences. Specific to these findings is a portrayal of how shame featured across women's narratives, in particular the onset and development of shame, how it was experienced and how it was grown through. There were three distinct ways in how shame shaped these women's lives following their diagnoses. For some, shame was very much part of their adjustment to their diagnosis, how they lived after, with HIV directly affecting aspects of their lives as WLHIV. There were accounts of specific shame related experiences in some accounts and how shame was dealt with and contained due to peer support. For some women a change of perspective about their HIV facilitated them to live with it but not letting it dominate their daily lives. Additionally, another significant narrative thread portrayed the desire to help other women in an attempt to lessen or prevent potential shame associated with being an HIV positive woman.

The following chapter draws together the study's findings by utilising and drawing on appropriate theoretical perspectives and previous research to demonstrate how the study contributes to broader body of knowledge of the experiences of WLHIV with a specific emphasis on HIV related shame.

Chapter 5: Discussion

5.1 Introduction

In this present study, I explored through the means of narrative inquiry and analysis, the shame experienced by a group of women living with HIV. To the best of my knowledge, this is the first qualitative study to explore shame in the narratives of women living with HIV. The study's findings relate to women's development of HIV related shame because of the lack of a women-centred HIV-discourse and their awareness of HIV stigma. Women experienced HIV-related shame in which they anticipated, avoided and felt an undesired exposure of the self at various moments during their accounts. Lastly, HIV-related shame was reduced and sometimes eliminated with the discovery of a shared experience and change in perspective in being a HIV positive woman, which led some women to help other WLHIV.

I will now discuss the study's findings within the context of relevant existing research, and I discuss the relevant theoretical underpinnings throughout. The findings are discussed from across three dimensions; *1) the development of HIV-related shame, 2) shame depicted as undesired exposure of the flawed self,* and *3) growing through HIV-related shame.*

5.2.1 Shame in becoming a HIV positive woman

These women each described a reconstruction of themselves following their HIV positive diagnosis, informed by the absence of women's stories with which they could engage, and with the awareness and experience of stigmatising HIV discourse for others. Following diagnosis, these women struggled to comprehend a sense of self as a HIV positive woman. Within their narratives, their diagnosis appeared to matter deeply to all women in terms of how it was going to affect their lives physically, emotionally, psychologically and socially. In looking towards the future, women commonly questioned how they were going to live their lives as a women living with HIV. This following section will discuss the finding 'the development of HIV related shame', alongside empirical literature and is underpinned by the relevant theoretical perspectives. The stage will be discussed under the headings *1)Shame in isolation,* which will be broken down into two concerns *i)the presence of outdated discourse* and *ii)the absence of a women-centred HIV discourse* and *2)Stigma as the external force of shame,* which in turn relates to two main concerns, *i)being viewed as a threatening contagion ii)being viewed as sexually immoral.*

5.2.1.1 Shame in Isolation: HIV stereotypes and outdated discourse

When women spoke about what they knew about HIV prior to their diagnosis, the information they drew on as they began to understand how HIV, would shape their sense making of living with HIV. Given the information they drew on in light of their diagnoses, all of the women in the study undoubtedly positioned an HIV diagnosis as an unwanted identity trait. A pivotal study by Ferguson, Eyre and Ashbaker (2000) posits that a quintessential factor in one developing a shame reaction is having an unwanted identity, a characteristic that has the capacity to compromise their self-ideals (Crozier 1998). Ferguson et al. (2000) argue that women are more prone to shame compared to men due to the potential to violate deep-routed expectations that women 'should' behave in a certain way that conforms to feminine identity and ideals. If women subscribe to certain expectations yet believe that they have violated them, their acquisition of an unwanted identity may give rise to feeling shame. From women's accounts, the stigmatising discourse that persists around HIV has denoted it to be a strongly undesired health condition, which possibly has contributed to varying degrees of shame.

The dominant discourse of HIV at the time of their diagnoses (over a 30 year time period) positioned 'other' groups of individuals as 'people living with HIV', and not groups of people with whom these women could strongly identify. This finding builds on research from Proudfoot (2017), Walshe et al. (2012), and Stevens and Hildebrandt (2006) whom, in their research with women living with HIV in Ireland and the United States, illustrated women's shock and surprise at their diagnosis as they believed they did not fit a 'profile' of those who become HIV positive. This pattern among women's accounts gave rise to a sense of isolation in the circumstances in which they found themselves, positioning themselves as a sole figure disconnected from other people living with HIV. Women's assumptions about who was living with HIV in Ireland likely contributed to the unexpected nature of their HIV diagnosis and their response of shock. For some women, upon presenting with symptoms to a healthcare setting, their HIV took months to diagnose, further reinforcing the belief that heterosexual women were not at the forefront of groups diagnosed with HIV in Ireland. In Ireland, gay and bisexual men who have sex with men make up the most diagnoses annually here in Ireland (HPSC 2018), with rates of HIV greater than ever. Dominant HIV discourse has been heavily associated HIV as a 'gay man's disease' in the past (Persson and Newman 2008), however, females make up the majority of people living with HIV around the world (WHO 2019). Some participants in the study spoke about the strong association that they believed people in society generally made between gay men and HIV, more so than with women, and that people were more in tune with the representation of gay men in research and the visibility of their stories, in comparison to women and their stories.

5.2.1.2 The absence of women-centred HIV discourse

When participants learned of their own diagnosis, they began to make sense of what an HIV diagnosis meant. Of the factors that informed their sense making of being a woman living with HIV, one of them was that they did not identify with people who they believed were at risk for HIV, resulting in an onset of isolation in their newfound experience. Women's depiction of how they could not engage with women's stories of HIV in the initial sense making of their diagnosis was an interesting finding. Given this, the struggle that followed, coming to terms with their diagnosis as women, was an isolating process. In shame resilience theory, Brown (2006) argues that the lack of critical awareness towards a shameful situation can result in one's inability to deconstruct and contextualise an issue. The employment of critical awareness stems from skills that enable one to connect their own social and cultural expectations that can shape their response to an experience.

For this study's participants, isolation developed in not having another woman, or other women, to talk to in that crucial phase of beginning to reconstruct their identity. This was compounded by their lack the awareness of female centred HIV discourse to guide them. Brown (2006) argued that normalising an experience can occur from deconstructing and contextualising an experience, and has the capacity to reduce the feeling that one is isolated in their experience. In her study with over 200 women, Brown (2006) had discovered that when critical awareness is lacking, women were unable to deconstruct and contextualise the issue causing them shame. This resulted in women individualising the issue, rather than linking their experience in with the larger context, and perceived it as a personal flaw that only they experience. In the context of this study, most women individualised the position as women living with HIV among other groups of people, reinforcing the idea that they were alone in their experience. Kralik, Brown and Koch (2001) support this idea in their study with women who have been diagnosed with a long term or chronic illness. Although Kralik et al. (2001) do not refer to shame, their study holds relevance to this study as they describe feelings of loneliness and isolation following the life changing event of a chronic illness. This was accompanied by conflict around the relationship with the self before their diagnosis and identity as a woman living with an illness, and vulnerability due to lack of relevant information and facing the uncertainty of what their diagnosis meant for their lives.

The alienation and isolation experienced by women lead many to not share their diagnosis widely. This was compounded by the lack of visibility of other women with HIV in Ireland, and was a common factor that drove HIV-related shame. Women's interpretation of their HIV positive diagnosis was described in isolation, rather than recognising there were other women living with HIV in Ireland and around the world. In most cases it was some time before women engaged in peer and/or social support in which they met other women living with HIV, and one woman interviewed who experienced a high level of HIV-related shame, had never engaged in any peer and/or social support. As in this study, research from Proudfoot (2017), Walshe et al. (2012), and Stevens and Hildebrandt (2006) portrayed women's shock and surprise upon learning their HIV status because they believed they did not believe they fit the 'stereotype' of someone living with HIV. This means that women are not commonly included in HIV discourse and that there is a low level of awareness of women living with HIV, especially in an Irish context. The current study further highlights how the absence of female centred HIV discourse can affect women's adaptation to living with HIV and the development of shame, due to the onset of perceived isolation in their experience following diagnosis.

Undoubtedly, given the acquisition of an unwanted identity and the uncertainty an HIV diagnosis brought into their lives, Bury's (1982) theory of Biographical Disruption is relevant to the finding, 'the development of HIV-related shame'. Biographical disruption (Bury 1982) refers to the disruptions of everyday life due to the onset of chronic illness, and as such was not the case for most women in this study who were diagnosed with access to HAART, core elements of the theory can be applied to these findings. Bury declares an element of biographical disruption as, 'Disruption of explanatory systems normally used by people, such as the fundamental rethinking of the person's biography and self-concept is involved' (Bury 1982 pp.169), which considered the uncertainty that women faced in light of their diagnosis. Although most participant's experience biographical disruption in that they believed that their HIV diagnosis would result in serious illness, the biographically disruptive nature of an HIV diagnosis extended beyond the biomedical disruption anticipated in the management of a chronic illness. HIV diagnosis was life changing for all women given the psychosocial complexities of living with HIV, resulting in further biographical disruption. In the context of this study, women's sense of self as women, including their sense of motherhood, were fundamentally threatened upon HIV diagnosis, resulting in future uncertainty. Upon diagnosis, women faced the liminality of when their understanding of HIV as a deadly virus to avoid at all cost merged with the reality of HAART and living with HIV for the rest of their lives. This study echoes existing research in that it too highlights women's shock at being diagnosed with HIV. Additionally, this present study extends understanding of women's experience of diagnosis and post-diagnosis as being a critical period of the development of HIV-related shame due to the absence of a progressive women-centred discourse with which they could engage.

5.2.2 The external force of HIV-related stigma

Many women positioned the shame they felt as externally imposed by the stigmatisation of HIV perpetuated by ongoing societal discourse around HIV. The development of shame among WLHIV as driven by stigma was not an unexpected finding. The common stigmatising discourse that women drew on following their diagnosis and in the adaptation to HIV, was regarding myths of sexual deviance and the contagious HIV positive body. Most women in the study believed their HIV status was a potential source of negative judgement in either their past or their present. Considering that participants described these myths as the stigmatising discourse that drove their shame, this finding is consistent with studies with WLHIV regarding anticipated and enacted stigma in Western and African contexts (Davtyan 2016; MackAlomepe et al. 2016; Fletcher et al. 2016; Grodenskey 2015; Lawless et al. 1996).

Goffman (1963) in his seminal account of stigma and the management of spoiled identity, adopts the term stigma as it was originally used by the Greeks; 'bodily signs designed to expose something unusual and bad about the moral status of an individual' (p.1), and he describes stigma himself as 'an attribute that is deeply discrediting'(p.3). Goffman's work on stigma informs how these women constructed their diagnosis with HIV. They developed a reconstruction of their identity to include their HIV status, which most women interpreted to be a heavily stigmatised condition based on its associated to what society considered 'immoral behaviour'. With this point in mind, women's interpretation of societal HIV stigma led their positive HIV status to become a label they did not want.

Women's accounts revealed an imagined, anticipated and experienced reality of being stigmatised due to the unwanted identities other's might assume of them by extension of their HIV positive status; identities of being a contagion and sexually immoral. Some women believed these identities applied to them, other women did not. However, the majority of women interpreted the discourse they commonly associated with HIV, as a reason not to speak openly about their status. Importantly, whether this discourse is currently the dominant discourse related to HIV in Ireland, this is how many of the women interpreted it to be, forcing shame on them via stigma.

5.2.2.1 Being viewed as a contagion

The idea that some women might be viewed as a contagion was present in this study's narratives which referred to experiences during pre-HAART and post HAART era, and in the context of U=U. Although these women knew they were not a risk to others, they acknowledged others' perceptions of them, although they were based on common misconceptions. Women found these misconceptions frustrating but were tolerable of them, indicating a sense of powerlessness in their positions.

Women spoke of the ignorance of others, their lack of understanding and thus having to explain to people about their common misconceptions about HIV. This often meant that women were concerned that people would be afraid of them. Interestingly, although they knew that the information they thought people held about HIV was incorrect and unfounded, the thought that they could be viewed as a dangerous contagion to others, was for some women, enough to conceal their status. It is apparent that women considered others to be afraid of them. In this incidence, women's emotional responses to stigma; shame, was reinforcing that people may fear them. This was notable in the accounts of migrant women who lived in DP centres, in which women described fellow residents to be particularly discriminatory to people living with HIV.

This finding corroborate findings from Persson's (2013) study, which explored how the historical discourse on HIV has informed the transition from infectious to non-infectious bodies, in the context of viral undetectability in sexual relationships (Persson 2015; 2013). Persson (2013) argues that the mainstream media's public visibility of a HIV positive body that demonstrates hyper-infectivity, decay and death, has 'haunted' people living with HIV resulting in tension between the current normalised biomedical discourse of HIV as a treatable chronic illness and the fearful historical discourse. Although Persson's (2015) notion of infectivity related to sexual activity, such an issue is relevant to this finding. These accounts indicate that while they subscribe to the notion that they are non-infectious and certainly not contagious, it is the concern of *the other* and what they believe that can partially contribute to their shame.

The fear of being viewed as a contagion is described in others studies with WLHIV. Alomepe et al. (2016) echoed these findings in their study with women living with HIV in Cameroon, whose participants described feeling judged following experiences of enacted stigma. In their study with older women living with HIV in the USA Grodensky et al. (2015) found women did not feel comfortable sharing their HIV status with others in case they would be viewed as infectious for being HIV positive. Fletcher and colleagues' (2016) research also reported how African American WLHIV were aware of how their family members and others within their social network held concerns about the possibility of transmission and subsequently avoided physical contact with women, including having them use disposable utensils in their company. The emotional responses to stigma in the above studies is absent, with the exception of Grodensky et al. (2015) although their study positions shame as a concept viewed by the other, rather than the emotion felt by participants. Efforts and suggestions to improve the lives of these women mostly fall on the need to dismantle and break down societal stigma, rather than addressing the emotional response of shame that experiencing stigma may elicit. Considered the recent nature of these studies, it stresses the persistence of unique emotional challenges for WLHIV.

5.2.2.2 Being viewed as sexually immoral

As well as believing that individuals might believe their HIV infection to be contagious, women were also concerned at what others might assume about their sexual history given their HIV positive status. Women (two) who did not contract HIV via sexual activity noted this also, suggesting women might be concerned about how their sexual history might be viewed in light of their HIV positive status. This finding revealed a cultural dimension to the shame women developed in their response to stigmatising discourse of HIV. For example, all Irish born women referenced how they were concerned that their HIV status might associate them with sexually deviant or sexually immoral behaviour. As mentioned earlier in Chapter 2, Ireland's cultural history of policing women's sexual bodies in ingrained in the national identity of the country due to the lengthy period in which the Catholic Church set the precedent for societal norms and behaviours for women to be 'good' and 'virtuous' (Fischer 2016). Punitive measures of marginalisation and institutionalization were put in place for women who did not conform to these norms. With Ireland's cultural history of punishing and shaming women for their sexual behaviour, it is possible that women feared the association between HIV and sexual immorality because of this history.

Although women in this study had concerns about terms such as ‘slut’ or ‘slapper’ due to their HIV positive status, the majority did not believe it to be true about themselves. Most women expressed their frustration over the powerlessness that this stigmatising discourse brought them and remained silenced. Hutchinson and Dhairyawan (2017) argue that one does not need to believe they do or did anything wrong to feel shame. A small number of women in this study, however, expressed an internalisation of this particular stigmatising discourse. The finding, being viewed as sexually immoral, is upheld by previously published qualitative research with WLHIV. In a much earlier study, Lawless, Kippax and Crawford (1996) explored the positioning of HIV positive women in Australia 25 years ago, and their findings depicted how participants felt that that their healthcare providers assumed them to be sexually deviant or promiscuous because they have acquired HIV. The dated nature of this study tells of how persistent stigmatising HIV discourse has been across decades. Likewise, in a more recent study with African American and Latino WLHIV, Davtyan et al. (2016) uncovered how participants were conscious that inaccurate assumptions about WLHIV’s engagement in socially deviant sexual behaviour facilitated their own acquisition of HIV. Similarly to this current study, Davtyan’s et al. (2016) participants positioned the misconception of WLHIV and sexual deviance as commonly held by ignorant and uneducated individuals with which women felt that they had to keep their HIV status from. This study reflects previous studies’ findings in that participants in this study were conscious that they would be misconceived as sexually deviant, and did not want that identity. A subtle differentiation, however, is that in this study, a number of participants who contributed to this finding internalised the stigmatising discourse around sex and HIV, resulting in the belief that they had facilitated their own HIV acquisition, as though they had violated the cultural standard of sexual activity set out for them as women. This particular finding is similar to work by Grodensky et al. (2015), who researched with older women living with HIV in the US. However, with a sample of exclusively older women (aged 50 and older) in Grodensky et al. (2015) study, the current study suggests that, and how, shame can arise following the internalisation of stigmatising discourse across ages.

It is important to unpack the undesirable nature of being perceived as a woman who has had many sexual partners, and what this meant for participants who felt this way. It points to the long-existing double standards in many societies related to women who have multiple sexual partners in comparison to men, a sexist narrative that positions women as devalued, and men as ultra-masculine for their sexual conquests. Through the rise of feminism in western society, women are slowly becoming more sexually liberal, challenging sexist narratives of double-standards. However subtleties of these narratives persist across cultures as is evident from participants' accounts, revealing another gendered dimension of this finding.

The external force of HIV stigma is further considered in light of Cooley's (1902) theory of the 'looking glass self', a theory that informs how shame developed in women in this study. The looking glass self proposes that we imagine how we appear to other people, or another person. We then imagine the other's judgement of us, be it a positive or negative judgement. Once we interpret how we appear to another, typically a self-feeling, either pride or shame can arise, depending on how we see ourselves reflected from the perception of another. In this light, women saw or imagined that other individuals, communities and society view and judge them negatively because of their HIV status, giving rise to the emotional response of shame. In the context of this study, women saw themselves negatively in eyes of others due to the stigmatisation of HIV, believing people might view them as sexually deviant or they are capable of spreading HIV and causing harm to others.

The terms stigma, internalised, perceived and enacted stigma (Earnshaw and Chaudoir 2009) have dominated literature to describe the concerns of participants who fear that their HIV status might be perceived negatively by others, meaning their actions and experiences are shaped by this belief. However, to date few studies with women living with HIV have explored the emotion shame, in-depth from a psycho-sociological perspective as this study does. This study argues that it is feeling shame around their HIV status and therefore, the willingness to avoid exposure of their unwanted identity. Therefore, as the findings from studies using these terms are presented from an alternative position, this study provides an alternative and arguably more direct position on the impact of shame rather than stigma on women living with HIV. Women's development of HIV-related shame was primarily due to the stigmatising discourse they believed was enforced on HIV-positive women, and a lack of encouraging discourse with which they could engage. In the next section, the chapter will discuss how, through narrative analysis, women experienced shame through undesired exposure.

5.3. Shame as undesired exposure

This section of the chapter will discuss the finding ‘Undesired Exposure’. Having previously considered how HIV-related shame developed in women’s accounts, I will now critically discuss how it can take shape in women’s lives as they navigate life with HIV. This issue will be discussed in three parts; anticipating undesired exposure, avoiding undesired exposure, felt undesired exposure. The term exposure as it relates to HIV, is primarily used to describe the circumstances in which someone has potentially encountered HIV infection that might result in HIV acquisition. The interpretation of the term as it relates to potential HIV infection does not relate to the findings in this study. To feel shame, an individual is likely, but not always, to believe that they have violated some sort of social or cultural norm, and the term ‘exposure’ as referred to by the participants in this study, implies that this apparent violation could become known to others. Exposure does not refer merely to their HIV status becoming known, it is the painful recognition that someone can see them bare and uncovered, meaning they may be open and vulnerable to judgement and potential criticism.

5.3.1 Anticipating a threat to the social bond

As women drew upon their awareness of stigmatising HIV discourse, the study’s findings reiterate how women did now want to be held against such discourse. Being held against such stigmatising discourse, women feared being perceived as women who violated cultural and social norms. Due to this awareness, women expressed their expectations that if they were known to be HIV positive, this would have a negative outcome for their social self. Wrapped up in these beliefs, women anticipated that people would not understand HIV, and that people would judge them and ultimately, that undesired exposure would result in a breakdown of relationships and damage their social network due to being shunned and ostracized. While the majority of women in the study did not interpret their HIV positive status to be inappropriate or immoral, they anticipated their HIV status would not be understood or accepted by others at some point during their HIV experience. Therefore it was impactful that most acknowledged others may not feel the same, because most ideals of the self are social rather than individual (Scheff 2000), meaning their behaviours and actions sometimes catered to the view of the external other rather than themselves.

The settings and context in which participants anticipated undesired exposure is interesting and appeared to be of great significance to women’s sense of exposure. Such settings included healthcare settings, DP centres and in the women's own communities. In clinical and healthcare settings, not only has shame been cited as a powerful influence in how one experiences their condition, but it also can have a force within clinical encounters (Dolezal and Lyons 2017; Lazare 1987), meaning shame may play a part in enacted or avoided health behaviours. In healthcare setting, women's concerns involved feeling exposed in front of staff or other clinic attendees who may or may not have also been HIV positive, indicating that the healthcare setting potentially becomes a high-risk environment for exposure for some women. Women's concerns over undesired exposure in a clinical setting likely related to being seen in a HIV or sexual health clinic and associating that to being HIV positive. In other healthcare settings outside of HIV, sexual health or infectious diseases, some women also anticipated exposure from healthcare professionals. Some women perceived that many people see HIV as uncommon among women in Ireland and there might be a lack of understanding of their circumstances from the healthcare professionals. Although approached from the angle of stigmatising behaviour, this is reflected in Vaughan et al. (2020) recent study involving the experiences of stigma in healthcare settings among people living with HIV in Ireland, which indicated how participants commonly anticipated stigma in healthcare settings, although in said study, incidents of enacted stigma were noted. Vaughan et al. (2020) argues that healthcare professionals who are empathic and show an appreciation for patients in potentially emotionally difficult circumstances could contribute to the reduction in women's anticipation of undesired exposure in clinical settings. This would seem to have resonance here, as displaying sensitivity and empathy towards women in healthcare settings can possibly reduce an avenue of stress for women and not contribute further to undesired exposure. This is relevant to the debated biomedical normalisation of HIV, as healthcare professionals more recently see HIV is a treatable chronic illness, and tend not to address and may minimise the psychosocial burden of the condition in these encounters.

The anticipation of exposure in front of others who are also living with HIV was an interesting finding. One might assume that to someone else living with HIV, they could not be judged for having the same condition. In contrast, the study's findings portrayed accounts of migrant women who were weary of being seen at an HIV clinic, especially meeting people from their own country. The anticipation of exposure among people from women's own cultural background, whether they are HIV positive or not, has emerged in other studies (Mehdiya 2020; Arrey 2015). Building on existing research, this concern also related to the women living in DP accommodation who were extremely concerned about concealing their HIV status. These participants framed the context of living with HIV as migrant and black women, which adds an additional element to their anticipation of exposure. Consequently, in examining this finding through an intersectional lens (Crenshaw 1994), it is evident how these women's race and migrant status intersect with their experience of living with HIV. Intersectionality was put forward by feminists of colour and challenges our understanding of stand-alone identities by illustrating the intersection and interactions of social formations such as race, gender, age, class, ethnicity, sexual orientation and more (Crenshaw 1991). In that sense, applying Crenshaw's (1991) intersectional lens to this finding brings to light how being a HIV positive woman, and being a black woman and/or migrant women are not mutually exclusive, as their experiences as women living with HIV has been shaped by their black and migrant identity and vice versa. Specifically, there is an added wariness about potential exposure due to the colour of their skin, and the circumstances in which they live (DP accommodation) because they are migrants. Intersectional concerns are particularly relevant in DP centres, as women's awareness and vigilance put them in the position of considering when and where they take their ART, and even to the dietary choices made, to great precision, which is a unique perspective from this study. While this is not a comparative study, the study notes that black women's experiences of keeping their HIV status from people of their own cultural and ethnic background was more pronounced than that of the white participants.

The presentation of vigilance throughout various contexts of women's accounts appears to have contributed to levels of anxiety, as women appeared routinely aware of possibly feeling undesired exposure over which they had little control. This is considered in light of Goffman's (1971) argument that we are innately concerned about how we appear to and are viewed by others, that we constantly aim to present the best version of ourselves, and in doing so, are continuously anticipating shame.

Scheff's (2000) theory of shame and the social bond can provide greater insight into this finding. It becomes apparent that when women anticipated undesired exposure related to their HIV status, they were signalled by a threat to their social bond with an individual or group. Scheff's (2000) sociological theory of shame builds on the work of Charles Cooley's (1902) 'looking glass self' theory and Helen Lewis (1971), theorizing that when we feel shame, it is due as a cognitive response in anticipating a disconnection of a social bond with another. This response is due to our innate fear of disconnection from another due to being misunderstood, which could result in the isolation, something that is deeply discomforting to most humans (Lewis 1971). In healthcare settings, DP centres, and elsewhere, women are, in a chronic and acute sense, met with the threat of disconnection from another at the thought of their HIV status portraying them as immoral or unaccepting, and that is fear igniting.

This is the first study of its kind to explore the response of shame among women living with HIV, while other research has explored the related social process, stigma. The finding of this study about anticipated undesired exposure is partially reflected in Manijeh et al. (2020) and Arrey et al. (2015), who carried out studies with migrant women in western countries on their experiences of living with HIV and the fear of disclosure, depicting anticipated stigma as a significant contributor to non-disclosure. A notable distinction between this study and those mentioned is that this unique finding emerged in the context of DP centres in Ireland, where these women's sense of anticipating exposure is not limited to social or healthcare settings but further arise in their living situations which are communal. Neither of these studies, in exploring stigma, examine its potential contribution to shame as determinant of health behaviours, although it could be argued that the participants' decision to not-disclose is driven by their emotional response of shame and not wanting to be viewed as HIV positive, due to the cultural stigma of HIV as laid by the authors. As previously mentioned in Chapter 2, perhaps shame is overlooked in these studies or it is not deemed appropriate, relevant or worthy of exploration, or it is possibly too difficult to address. While Manijeh et al. (2020) and Arrey et al. (2015) recommend discussions with healthcare providers around disclosure, this study recommends that such discussion should include conversations that address and unpack potential shame, as it is a possible determinant of disclosure or non-disclosure, as disclosure is a social and interpersonal experience.

Although shame has been scarcely explored in the context of HIV, it has been explored in other areas relating to women. For example, in a study with victims of sexual abuse, Weiss (2010) analysed gender specifically in relation to the anticipated exposure for women and why they didn't want to report their abuse. The study cites not wanting to be viewed as the deserving victim, a disgraced victim or the defamed victim and although the study is quite dated, it illustrates the pervasive nature of shame among tabooed topics, and how powerful it can be to silence. There are subtle although important distinctions between anticipating exposure and anticipated/perceived stigma. Exposure points to the lifting of the veil of security in concealment and when this is removed, women become vulnerable to the painful self-consciousness of stigma and negative judgement, because of how they see themselves in the eyes of people who stigmatised them. I argue that while stigma has been shown to damage women’s health, the impactful emotional response of shame following exposure, may be more readily addressed through intervention, meaning people living with HIV can gain control over their shame but cannot control how others stigmatise them.

As women shared their experiences involving anticipating undesired exposure, narratives of avoiding undesired exposure often followed. The next section will discuss the finding avoiding undesired exposure, which sees sacrifice and silence throughout women’s HIV experience as a result of tactics to avoid undesired exposure.

5.3.2. Avoidance of undesired exposure

The avoidance of undesired exposure in response to potential exposure emerged as a thread throughout women’s accounts of their past and present experiences. This is significant in a context where HIV is completely treatable, is non-threatening to one’s life while on treatment and is untransmittable while someone has an undetectable viral load. Women did not want to be known as HIV positive and some went to great lengths to conceal their HIV positive status from people around them. Avoidance of undesired exposure suggests a perceived sense of control, yet simultaneously, took away aspects of freedom as a woman living with HIV. HIV disease management has been primarily focused on the biomedical perspective regarding ART treatment and adherence. However, the women in this study illustrated another dimension of dealing with their HIV; the management of avoiding undesired exposure. In other terms, most women in this study prioritised keeping their HIV positive status from becoming known, alongside their biomedical treatment of keeping their viral load down. When considering adaptation to and living well with HIV, shame in the form of avoidance of undesired exposure can impede and deter women’s potential to live well with HIV.

This finding confirms shame is a potential determinant of health in how one experiences a stigmatised medical condition. Dolezal and Lyons (2017) argue that shame should be treated as a social determinant of health because it has the position to control one’s health behaviour and could possibly contribute to negative disease outcome. Hutchinson and Dhairyawan (2017) agree in the context of HIV, asserting that if one explores stigmatising experience among PLHIV, they too must explore the shame such an experience might elicit.

In maintaining avoidance of undesired exposure, women made sacrifices in their lives and remained silent about their experience of living with HIV because they wanted to avoid any potential undesired exposure of their HIV status. This finding proposes that shame influenced women's HIV experience in the social and physical sense to prevent avoidance of the exposed self, providing an important opportunity to advance the understanding of the role shame has in the experiences of WLHIV.

Considering that most women did not want to feel undesired exposure of themselves by means of opening up about their HIV status, avoiding such exposure could provide these women with a sense of security and control. Given the stress women felt while anticipating undesired exposure, avoiding such exposure could temporarily release women of such stress and anxiety. Therefore, women sometimes applied positivity towards exposure avoidance. The inconspicuous nature of living with HIV in the era of ART and undetectability meant they could largely conceal their HIV status unless they chose to share it with someone. This bodes well for women who were keen to avoid undesired exposure to a certain degree. Importantly, by not sharing their HIV status or details of their HIV status, this was a key method to prevent themselves from being judged negatively and discriminated against but it had additional consequences. The social support that comes from sharing one's HIV status is widely considered beneficial to health outcomes (Brener et al. 2020; Kamen et at. 2016; Cederbaum et al. 2017) but was not an option for some, or most, of these participants.

Many women in this study described making sacrifices that involved relationship decision-making as a method to prevent undesired exposure. One woman made the decision to avoid having an intimate relationship with anyone who wasn't living with HIV as she couldn't face the potential rejection from someone who was HIV negative. Another woman actively avoided relationships completely out of fear of rejection or possible intimate partner violence because of her HIV status. This finding is in agreement with other research including migrant and non-migrant women (Mehdijar at al. 202; Thorpe et al., 2017; Davtyan et al. 2016). Some women in relationships pointed to the low self-esteem they experienced as HIV positive women in sero-discordant relationships with men, feeling obliged to overlook problematic behaviour they experience, which affected their power in the relationship. Similarly, Altschuler and Rhee (2015) conclude that a woman's self-esteem can play an important role in the power she holds in sexual decision-making. This suggests that women's low self-esteem resulted in them feeling as though they did not have the right to speak up in their relationships because of their HIV status and this finding highlights the gendered aspect of this study. The avoidance of undesired exposure can mean that for some women, shame can potentially impact women's agency in intimate relationships.

For those who were trying to avoid exposure by others, they had to take steps to conceal their daily medication regimens. Women spoke about feeling they were unable to take their medication in front of others to mitigate any association with HIV treatment, pointing to the biomedical sacrifice endured to avoid undesired exposure. This was a concerning and significant finding relevant to the women in the study who lived in DP centres and were required to sleep in a shared space with other migrant women. Again, this underscores how women who are residing in DP accommodation were vulnerable to additional complexities of managing their HIV due to a lack of privacy, which is compounded by issues that non-refugee women didn’t have to consider. Implications for such an outcome can impact on women’s physical health, as the WHO (2020), CDC (2020), HSE (2020) recommends full adherence to ART as much as possible, and to take it at the same time every day. This is recommended by health officials and they warn, if doses are missed, the virus gains the opportunity to multiply, potentially weakening the immune system resulting in possible sickness (CDC 2020). Women to whom this occurred pointed to their frustration of having to skip a dose of ART, yet positioned it as necessary to protect themselves, suggesting in this case that shame is a determinant of their HIV management in the biomedical sense and can be harmful. Women’s sacrifice to avoid undesired exposure pointed to the high value they placed on HIV concealment and the length they would go to ensure its upholding. Little research has been carried out with PLHIV or WLHIV in the DP system in Ireland and this research provides some understanding into the complexity of life for those who are HIV positive living within the DP system. However, more research is needed to uncover how PLHIV in DP manage their HIV and their health and well-being and suggests further exploration of the psychosocial effects with particular reference to how shame and stigma can impact on the management of health conditions in these settings.

Due to lack of disclosure to family and friends, when some women refrained from bringing their families and friends into their HIV experience to avoid undesired exposure, they were potentially losing out on beneficial social support. In the context of a manageable health condition, while keeping a secret about their health, women were largely unable to share with others and discuss the impact the condition has on their life and their overall HIV experience. Regarding stigmatising identities, Weiss, Quinn and Williams (2016) argue that the more social support someone has predicts greater health outcomes, and poorer health outcomes when this social support is lacking. While some women shared their status with few people, other women were comfortable with a limited number of friends or family knowing their HIV status but not widely, regarding their health status as no one's business. A small number of women indicated their desire to speak publicly about their experience as women living with HIV, however, did not feel ready to do so. Montiero et al. (2018) posit in their study with pregnant women living with HIV in Brazil, that the sustained silence around people living with HIV is partially perpetuating the structural and psychological mechanisms that can result in HIV stigma. Currently the low visibility and representation of women living with HIV in Ireland, as pointed out earlier this chapter, was possibly impacting on women's adaptation to diagnosis. While this study recognises that it is not the duty of women living with HIV to speak publicly about their HIV positive status to address the issue of awareness of HIV among women, this could have a positive impact on women who are newly diagnosed through the development of an empowering women-centred HIV discourse. The experience of shame via avoidance of undesired exposure appeared to be almost normalised by many women in the study throughout their past and present. This normalisation of such avoidance was characterised by frustration, but was tolerated, suggesting there are few other option available to them but to engage in avoidance tactics.

The avoidance of undesired exposure is reflected in a number of studies exploring stigma among WLHIV, indicating a widespread perceived need to withhold one's status from others for significant periods among other women living with HIV outside of this study. The finding emerged in studies in African and Western contexts and among young and older cohorts. Grodensky et al. (2015) study with older women based in the United States, reported how all 15 participants in their study restricted their social interactions, asserting that they didn't want others to learn about their HIV status. Similarly, another study in the United States with women of colour, Davtyan et al. (2016) study revealed that women who experienced stigma in healthcare settings resulted in women feeling precluded from engaging in necessary healthcare intervention. While Davtyan et al. (2016) suggest that women disengaged from medical interventions because of stigma, this study proposes that another element of this process is the shame that stigma could elicit that drove women to no longer wish to engage in healthcare.

Findings from recently published work by Mackworth-Young et al. (2020) illustrated tactics to prevent inadvertent HIV disclosure employed by young women living with HIV in Zambia. Interestingly Mackworth-Young et al. (2020) approach their work from a position of participant's having agency and control over their HIV status by using secrecy, fabricated stories and hiding their ART due to their fear and anxiety in response to HIV stigma. While they make the valid point that HIV disclosure is not always a viable option for women in resource poor settings, to advocate for secrecy and silence as a barrier against stigma is certainly thought provoking in the context of this study. Reflecting this current study's findings, such revelations could also be viewed by women as feeling trapped and silenced by one's HIV status, leaving one unable to talk about their HIV experience with others. Mackworth-Young and colleagues (2020) do not mention shame anywhere in their publication as a potential emotional response to HIV stigma that possibly yields such secrecy and hiding experienced by their participants.

Avoiding exposure to others is considered with reference to Relational Cultural Theory. Relational Cultural Theory (Baker-Miller 1976), a female centred psychological theory, theorizes how women yearn for connection throughout their lives and grow towards and through these connections. Baker-Miller (1976) goes on to state how mutual empathy and empowerment facilitate these growth-fostering connections developed between people. In applying Relational Cultural Theory to this finding, women recognised the importance of the various relationships in their lives and if a threat to their social bond becomes apparent, the avoidance of undesired exposure can protect and maintain these relationships. The dreaded fear and breakdown of relationships appears enough for women to keep their HIV status a secret, as such isolation could contribute to great suffering as relational cultural theory posits. Equally, however, the withholding of one's HIV status can impede the connection between two individuals due to secrecy and hiding affecting a woman's well-being.

Within many societies, women are aware from an early age of the social and cultural expectations placed on them that they believe they have to live up to (Brown 2006), as pointed out in section 1 of this chapter. Public portrayal of falling short of these expectations and feeling exposed is shame triggering. This study has indicated that to avoid such painful self-consciousness and feeling ashamed, these women's yearning to protect themselves can manifest in unhealthy and harmful behaviour, for example, social withdrawal and defaulting HAART. The next part of this stage of the finding will discuss ‘felt undesired exposure’, which details women’s interpretation of the negative impact of incidences where they felt exposure relating to their HIV status.

5.3.3 Felt Undesired Exposure

In this study, social interactions involving felt undesired exposure occurred when women believed another person socially disapproved of their character for violating a social or cultural norm. This type of interaction has been described previously using the term ‘enacted’ or ‘perceived’ stigma (Earnshaw et al. 2013). However, in this study, depictions of felt undesired exposure did not always include overt or even covert disapproval. Some stories involved subtle interactions with non-verbal cues shared, while other women felt undesired exposure based on the covert nature of the judgement placed upon them. This finding draws on the theory of ‘the looking glass self’ (Cooley 1902), as women saw themselves be perceived and judged negatively by another, regardless of whether the individual was providing them with verbal or non-verbal social cues, and felt shame in response to the interaction. For example, Donna saw herself negatively in the eyes of the immigration officer she met with who told her that he didn’t want her touching him, directly informing her that due to her HIV positive status, he was judging her negatively. On the other hand, during an informal conversation with her nurse taking her blood, when Rachel learned that she and her nurse were from the same town, Rachel suddenly felt undesired exposure because someone from her hometown knew her HIV status, something she worked hard to conceal. Often unexpected, the presence of felt undesired exposure suggests the presence of acute shame in a woman’s account in comparison to chronic shame displayed in sections 5.3.1 and 5.3.2.

Rather than examining the stigmatising nature of the relayed encounters, this study shows the manifestation of shame in encounters resulting in undesired exposure. This study focuses on the encounter as well as emphasising the influence such an encounter can have on one’s emotional well-being. Importantly, not all women who felt undesired exposure in this study described encounters as stigmatising. This study posits that interactions contributing to poor well-being in WLHIV are not limited to stigmatising encounters. In a healthcare setting for example, although a healthcare professional may consider themselves respectful and empathetic, a patient’s shame may still influence the outcome of an encounter. Hutchinson and Dhairyawan (2017) state that by simply pointing out to a patient that they do not need to feel shame about an issue will not yield fruitful results for one’s shame, rather, they recommend the patient identify the genesis of their HIV-related shame and gain an understanding of how they frame such messaging in their lives. Drawing out encoded beliefs and thoughts to the forefront of one's consciousness, they argue, could help in the deconstruction of their HIV related shame (Hutchinson and Dhairyawan 2017; Lazare 1987; Brown 2006).

In relaying the encounters in which women felt undesirable exposure, it appeared a power differentiation was at play. In the narrative finding of felt undesired exposure, the individuals who they felt exposed in front of those who were positioned as morally superior to them, whether that was overtly put to them as in Donna's story, or interpreted as such like in Jenny's story. Although these women did not know these people personally nor would they have been important social bonds, the finding suggests it didn't make the felt exposure a less painful experience. Feeling as though they were being viewed as lesser than by another was heavily impactful in these women's lives, in particular when the encounter was with someone in a position of power. For example, in Jenny's encounter with a physician, the patient-physician encounter was compromised following the physician's comments regarding Jenny's sexual activity as a HIV positive woman. In his essay regarding shame in the clinical encounter, Lazare (1987) argues that physicians will more often than not fail to motivate and encourage patients to better their health behaviours when they purposefully use shame and humiliation tactics. Considering Lazare's (1987) point, it could be argued in Jenny's excerpt that the physician's execution of their objective did not yield the intended results but instead lead to felt undesired exposure where Jenny felt poorly judged for being sexually active, resulting in an overall negative encounter.

The painful nature of feeling undesirably exposed in an encounter can have a lasting impact. It can reinforce to women that they are lesser-than the individual with whom they have the encounter and lead to disengagement from social or healthcare settings. Particularly regarding healthcare settings, felt exposure can lead to disengagement in one's healthcare in an attempt to facilitate avoidance of undesired exposure. In this circumstance, felt exposure in healthcare settings can result in shame becoming an invisible barrier to women living with HIV accessing the appropriate healthcare services (Dolezal and Lyons 2017).

Existing publications have largely explored encounters such those as mentioned above solely from the perspective of stigma (Vaughan et al. 2020; Kemp et al. 2019; Cuca et al. 2017; Davtyan et al. 2016; Fletcher et al. 2016; Pelzter et al. 2016). While these studies shed crucial light on the stigmatisation of PLHIV, they neglect to report the emotional impact of stigma, i.e. shame, as this study does. Furthermore, this current study proposes that in looking at shame within these interactions, a stigmatising encounter did not always need to occur for women to feel exposed as some women felt undesired exposure by others simply learning something about them, highlighting the depth of their HIV-related shame. This reveals the additional benefit of directing intervention and addressing HIV-related shame as well as stigma. The final section of this chapter will now discuss the finding ‘Growing through HIV-related shame’.

5.4.1 Growing through HIV-related shame

The final part of this chapter involves a critical discussion of the finding ‘Growing through HIV related shame’. While collecting stories largely filled with trauma, hardship and emotional turmoil, the presence of uplifting and encouraging accounts shed light on the progress made by women over the many years they lived with HIV. Mainly, hearing from and meeting other women who were living with HIV appeared to add to women’s well-being. I apply the lens of Brown’s (2006) Shame Resilience Theory (SRT) to support this discussion of women’s growth, towards shame reduction.

5.4.2 Discovering a Shared Experience

STR (Brown 2006) provides women with the crucial knowledge that there are other women living a similar experience to them. This is important in the context where there is very little public discourse about HIV among women in Ireland outside of the HIV community. Prior to diagnosis, most women are outside of the HIV community. As shame can grow quickly if one believes they experience a social violation on their own, to know that they are like others can provide relief to that situation. The process of reaching out and engaging with another person about their living with HIV points to a willingness to make oneself vulnerable to connection, and yearning to move beyond feeling HIV-related shame. This is meaningful and is a significant contribution of this research as it ties in with the commonality across participants that upon diagnosis, they found it challenging to relate to people who they knew to be living with HIV. In their seminal work with self-help groups, Gussow and Tracy (1976), maintain that such groups provide a valuable resource to people with chronic illnesses, as they attend to the gap in the health service between the networks of agencies and healthcare practitioners. Self-help groups in the form of group or individual peer support can address issues among women living with HIV than healthcare professionals or people within their social networks who are not living with HIV cannot.

The benefits of discovering a shared experience through either group peer support, individual peer support, or informal engagement with other women living with HIV were plenty. Particularly in the context of HIV, people can make significant progress in positive coping and adaptation to HIV in intimate and humanized settings, more so than clinical or medical settings (Nkosi and Rosenblatt 2019). It provides women with the knowledge and awareness that they are not alone, other women whom they could identify with are living with HIV and are a source of comfort knowing that they are not alone. It offered the opportunity to share their story in a safe space where they would not be judged, where women likely would understand their problems, and be met with empathy and understanding. It offered the chance to establish a meaningful connection with others and discuss issues exclusively pertaining to WLHIV such as motherhood, sex and relationships, menopause. Paudel and Baral (2015) note similar findings in their review of literature in which they conclude that social support groups are among the most effective intervention in managing stigma and were identified as being of fundamental importance for women upon diagnosis. This study, however, adds to the body of qualitative research involving WLHIV's engagement in peer support, by demonstrating how group and individual peer support can be utilized to target shame reduction.

Considering the environment in which women living in DP accommodation lived, they appeared to value their participation in the social group as it allowed for face-to-face interpersonal communication with women living with HIV. While other participants in the study had family members, friends, partners or even therapists whom they could talk about their HIV with when necessary, women living in DP indicated not having such social resources given their low level of social capital. Furthermore, the type of accommodation in which women live as individuals seeking international protection, points to the unique need women living in DP have for HIV peer support groups. In feeling unable to talk openly about their HIV status where they live, having a social support group provided these women with opportunities to share their story and discuss their problems that they could otherwise not do in the DP centre due to the avoidance of undesired exposure. Subramanian et al. (2017) reported similar findings in their study of resilience in low-income African American women living with HIV, revealing that often the only source of social support for refugees was support groups for WLHIV as they lacked a social support system in the US. While Subramanian's et al. (2017) findings link back to this study, the context of which participants in this study lived with HIV adds another element to their accessing of social support groups as they felt unable to talk about HIV in their homes. The importance of peer support groups for HIV-related shame among WLHIV living in DP is a significant finding from this study.

In the narrative thread, ‘discovering a shared experience’, women mentioned briefly the potential benefit they could gain from online support groups, or online forums specifically for WLHIV, of which there is currently none in Ireland. A small number of participants mentioned they would appreciate the ease of access to an online forum for women over a women’s social group. Possible reasons for this preference include being geographically disadvantaged and/or lack of time due to mothering and professional roles. Moreover, considering the influence of shame in women’s experiences, studies have noted the benefits towards anonymity that online forums can provide over face-to-face interaction (Mo and Coulson 2013; Oh and Lee 2012; Peterson 2009). However, there appears to be very little research carried out to date exploring the benefits of online forums for women living with HIV.

In applying Brown’s (2006) SRT to the finding ‘discovering a shared experience’, it allows us to view the benefits of ‘discovering a shared experience’ through the lens of shame and shame reduction. Brown’s (2006) STR posits that one’s ability to employ shame resilience depends on their position on the shame resilience continuum; acknowledgement of personal vulnerability, critical awareness, reaching out, and speaking shame. This finding is viewed through the ‘reaching out’ continuum which, when employed, enables women to develop mutually empathetic relationships with other WLHIV. When building a support network, women were able to identify their shared experience that they have largely lived with in isolation which was, in the case of this study, living with HIV in what felt like a male dominated HIV community. This connection is crucial for women to demystify key characteristics of shame. Central to the benefit of employing SRT’s reaching out category was the recognition that often women’s most private struggles were experienced by other women too, leading them to feel less alone.

Noting the benefit that engaging in social support groups and peer support that had been brought to women’s lives, this particular finding aligns with those of existing studies with women living with HIV (McLeish and Redshaw 2016; Warren-Jeanpiere et al. 2015; Orza et al. 2015). One publication noted shame reduction as a potential benefit of women living with HIV who engage in support groups (Lennon-Dearing 2008). The finding ‘discovering a shared experience' extends the research carried out by Lennon-Dearing (2008), whose study revealed that women's engagement with gender-specific HIV support groups contributed to lowered feelings of HIV-related shame. However, while Lennon-Dearing (2008) acknowledges that shame is reduced following engagement with social support groups, this study provides an in-depth qualitative view into the function of peer social groups for shame reduction as well as relevant theoretical insight. Furthermore, although their study was published 13 years ago, it demonstrates the continued need for the provision of support groups and peer support for women living with HIV to address and reduce negative feelings about the self, such as shame. In comparison, this study's context takes place in a more advanced era of HIV treatment, yet maintains the importance and benefit of providing various levels of group and individual peer support to women. Given such, this study puts forward that informal and formal emotional and informative support by women who are also living with HIV can contribute to reducing feelings of isolation, thus, shame reduction by discovering a shared experience with other women. The following section will discuss the narrative thread 'Change in perspective'.

5.4.3 Change in perspective

In the overall context of this study, the unfolding of the narrative thread 'change in perspective' was encouraging and noteworthy. As women recounted their stories across years of living with HIV, some accounts steered towards a change in their attitude towards being HIV positive. The significance of this finding comes from the recognition that HIV is treatable but not curable and that all of the women in this study felt HIV contributed negatively to their lives causing varying degrees of HIV-related shame. So, to express a shift in how they felt about their HIV status via deconstructing HIV as it relates to their lives as a shameful health issue carries meaning. Importantly, this has changed how they consider how others might have viewed their HIV status.

Women's change in perspective about what it meant to be HIV positive appeared to happen for a number of reasons. Women's adaptation to HIV overtime led to an acceptance of the self and thus, a diminished concern to how they appeared to others. In contrast, however, a small number of women in the study continued to struggle emotionally, women whom lived with HIV for over ten years. This suggests that time alone is not a predictor of positive adaptation, which contrasts with studies such as Beauthin, Bruce and Sheilds (2015) and Psaros et al. (2015). Another beneficial factor in women's lives as they adapted to life with HIV was the support they received over the years. As well as discovering a shared experience with other women, receiving support from family, friends and trained professionals, reinforced to women over time that their precious social bonds would not be broken because of their HIV status. This suggests the acceptance by others contributed to their own self-acceptance as WLHIV. Importantly, women who displayed a change in perspective towards their living with HIV appeared to deconstruct HIV in their lives as it contributed to their shame thus normalising it, suggesting the presence of shame resilience. For these women, HIV faded into the background of their lives; it no longer took up as much space in their lives and their thoughts, pointing to a gradual minimisation of HIV in how it influenced their lives.

Guided by Brown's (2006) SRT, when the critical awareness continuum is applied to a women's positive perspective change towards her HIV, it provides an added level of understanding of how such a process can result in, and equally, result from a reduction in HIV-related shame. In this category of Brown's (2006) STR, "the critical awareness continuum represents both the level of awareness a woman has about the sociocultural forces that shape her experiences and her ability to critically assess her personal experiences in the context of those forces" (Brown 2006, pp. 48). For example, a participant demonstrated critical awareness around HIV acquisition by stating that although she had unprotected sex, something that she understands to be heavily stigmatised for her as a woman, in Western cultures having unprotected sex is a relatively common among men and women who are not living with HIV. Thus, leading her to the conclusion that her HIV acquisition wasn't inconceivable and deserving of stigma and judgement she felt she received at times. As portrayed in this study, participants sometimes compared their lives with HIV to normal, non-threatening forms, such as Jenny's comparison to her curly hair or Olivia's transformative narrative, which included the personified image of a cartoon version of HIV. Constructing HIV as a normalised chronic condition appeared to somewhat contribute to women's sense of HIV-related shame reduction. However, this current study does not consider HIV is a normalised condition, as these findings exist in a context where women passionately expressed the hardship that an HIV diagnosis introduced into their lives.

The finding 'a change in perspective' aligns with existing research exploring women's progression to positive perspective change towards their HIV. The majority of research in which findings revealed acceptance of HIV over time appear to be carried out with older women (Albright and Fair 2018; Subramanian et al. 2017; Psaros et al. 2015, Teti et al.

2015). In this study, ageing with HIV did not always indicate progression in their perspective of living with HIV, while some of the youngest participants, Jenny, a woman in her 20s and Ruth, a woman in her early 40s demonstrated an encouraging change in perspective. Considering this finding as it relates to younger people was present in two of the four accounts of women under 50, it does not add great significance to the finding. That being said, as we enter into an era where younger people are living with HIV for many years, possibly due to being born with HIV, it is important to consider their positive adaptation to HIV, as it is not a phenomenon exclusive to older people ageing with HIV.

The majority of studies that have explored positive changes in women’s perspective and outlook of living with HIV have been carried out with older women, however, this study has shown, in a limited way, how women across ages have shown to positively adapt to HIV overtime. Moreover, this is the first study to link younger, as well as older women’s change in perspective about their HIV status to HIV-related shame reduction. This study builds on existing studies by demonstrating how a change in attitude and management of one’s HIV status can lead to shame reduction through the development of self-acceptance and the ability to deconstruct HIV as a relatively normalised condition. The next and final part of this chapter considers another positive element that emerged from women’s accounts; a willingness to help newly diagnosed women.

5.4.5 In a position to help

As women moved through their accounts, it was encouraging to see features of growth across their accounts in wanting to help others, particularly women newly diagnosed. Whether they provided peer support or spread awareness of HIV among family and friends, women channelled the lessons learned through their own experiences in an attempt to make changes for others. It further indicated the women’s own growth towards empowerment and shame reduction, as they were in a position to support women emotionally and with information.

Existing studies have reported how WLHIV and PLHIV have found value in providing peer support to others. In a study with older women living with HIV, Psaros et al. (2015) reported how participants liked to attend support groups to help women who were newly diagnosed, and felt it important to educate friends and family about prevention. This study’s finding, ‘in a position to help’, also aligns with findings from both an Irish based study carried out with both men and women, Ferris-France et al. (2015) and a UK study with black African mothers and pregnant women living with HIV (McLeish and Redshaw 2016). Both studies conveyed benefits of providing peer support, which included a gained sense of self-worth from providing peer support to others, and the transformative nature of volunteering for their own self-esteem and self-confidence. Extending on these studies, participants in this study channelled their own lack of peer support in the early period following their diagnosis with HIV, recalling the isolation they felt and not wanting other women to feel the same. This points to the possible benefit women gain from providing support to other women living with HIV, by attempting to contribute to the change the trajectory of shame and fear that women often experience following an HIV diagnosis. The finding, 'in a position to help', suggests that some felt empowered to contribute to the uplifting women-centred HIV discourse that was missing from their lives following their own diagnosis. Importantly, women's participation in this study further demonstrated their keenness to contribute to a women-centred HIV discourse in Ireland.

The benefits to women who provide social support to other women outside of the context of pregnancy and motherhood are not greatly known. Marino, Simoni and Bordeaux Silverstein (2007) put forward benefits to providing peer support in promoting ART adherence for PLHIV, although the dated nature of this study is not entirely relevant in the current era of HIV, where emotional and psychological issues are increasingly weighed up against the biomedical normalisation of HIV. On the topic of peer support for mental health, benefits to providing peer support show increased mental health and well-being, in addition to improved social functioning and perception of one's own health condition (Burke et al. 2018; Johnson et al. 2014). Research has largely focused on the benefit of peer support for the recipient (Positively UK 2017; French et al. 2017; Peters et al. 2017; Richter et al. 2014). However, although this study touches briefly on the subject, perhaps a better understanding of how peer support benefits and impacts peer support workers is warranted, given the growing number of HIV diagnoses year on year in Ireland among women. If women feel good about themselves living with HIV, they may be able to share their progression with other women, which highlights the importance of shame reduction for the implementation of peer support workers. Women living with HIV who have overcome challenges relating to shame and stigma can offer various forms of support for women who are in the early stages of adjusting to an HIV diagnosis. In essence, this study demonstrates how in overcoming their own HIV-related shame, women felt empowered to contribute to dismantling shame and stigma by using their own experiences to educate within and outside the HIV community.

5.5 Conclusion

The study explored shame narratives of women living with HIV. The findings, presented and discussed in three stages, reveal how the development, manifestation and influence of HIV-related shame can and do compromise a woman's ability to live well with HIV. The first stage of the study's findings revealed how shame developed in women's accounts. The lack of female centred HIV discourse upon diagnosis combined with awareness of stigmatising HIV discourse contributed to the development of HIV-related shame among women, due to feeling isolated and stigmatised. Thus, it is shown here the harm that the absence of a female-centred HIV-discourse inflicts or the dominant narrative surrounding HIV as a disease of gay men. The study has shown how women diagnosed with HIV can feel isolated as they can struggle to connect with broader pre-conceived notions of what it means to be a HIV positive woman, due to the lack of empowering female-centred HIV discourse. The development of HIV-related shame can be linked to women's perceived sense of the violation of female cultural expectations and norms. Women's awareness of their HIV status being possibly viewed as sexual promiscuous by others was a significant finding from this study and it underscores the gendered aspect of shame in these women's accounts. From the critical discussion of the first stage of the study's findings, the accounts in this study demonstrate how the development and persistence of HIV-related shame contrasts with the dominant biomedical discourse of HIV being a normalised chronic illness.

One of the more significant findings to emerge from this study was how HIV-related shame can influence women's experience of living with HIV. By underpinning this finding to the theoretical perspectives of 'the looking glass self', 'shame and the social bond' and 'cultural relational theory', their application strengthened and informed the meaning of this finding. Shame, as experienced through the medium of undesired exposure, indicates the multiple ways in which women can experience HIV-related shame. Women's accounts tell of how experiences of undesired exposure can negatively impact one's well-being, and potentially affect their HIV experience going forward. As more research focuses on living well and living longer with HIV, women's depiction of chronic anticipated and avoided undesired exposure of the self highlights the challenges of such. HIV-related shame can act as a potential determinant of health and health outcomes, given how shame via undesired exposure can, in part, have an effect on women's emotional, psychological, social and physical health. Furthermore, women's stories illustrate that when shame is endured and unaddressed, it can have consequences for their health and lives such as limiting relationships or restricting their ART around others. This particular finding was significant as it demonstrated that when considering management of their HIV, women managed undesired exposure of the self in parallel with their biomedical management of HIV. Additionally, women's narratives of anticipating and avoiding undesired exposure contain gendered aspects, as cultural expectations of women, in part, differ to that of men. This was demonstrated so, by topics such as sex and relationships, motherhood and pregnancy.

The present study features encouraging and uplifting stories as women progressed and adapted to life with HIV. Importantly, shame, as a process among WLHIV, can be addressed and moved through. Women's stories highlight the beneficial roles of the shared experience and peer support can play in the deconstruction of HIV as a socially life-ruining condition, which are key factors in shame reduction. Importantly, women can develop empowerment, empathy and courage and women used their developed skills to support other women. HIV-related shame among women needs to be addressed with the appropriate interventions. Addressing HIV-related shame builds on the need for HIV-stigma reduction. Without minimising the importance and necessity of stigma reduction, shame reduction and resilience can be tackled and maintained internally, and yet managing the external nature of HIV-related stigma and judgement can be more challenging to control. This study, informed by the stories of twelve women living with HIV based in Ireland, demonstrates that shame did impact on their lives post-diagnosis by revealing the role and effects of HIV-related shame.

Chapter 6: Conclusion

6.1 Introduction

This chapter highlights the study's key findings and contribution to knowledge. I will discuss the strengths and limitations of the study and their potential impacts and offer implications for future research based on this study's findings. Finally, the potential implications the study may have for healthcare practice and education are presented.

6.1.1 Contribution to literature and theoretical understandings of shame

This is the first study to explore shame in the experiences of women living with HIV in Ireland and thus sheds light on the lived experiences of women living with HIV against the backdrop of HIV-related stigma. The study reveals the importance of engaging with emotion in the face of stigma, and ultimately lends to a greater understanding of women's experiences in this era of normalisation in which the psychosocial burden of HIV is often deemed more challenging than managing HIV physically. This study is the first to identify accounts of shame among women's experiences of living with HIV, rather than referring to them as effects of HIV stigma. As per Lewis (1971), it is pivotal to identify and name shame in people's accounts and not mask it as another emotion or process, as this will prevent shame from being addressed and targeted in interventions.

A unique contribution of the study was that HIV-related shame developed as women struggled to connect with an empowering and encouraging female-centred discourse around HIV. Existing studies (Proudfoot 2017; Walshe et al. 2012; Hildebrandt 2006) proposed that women experienced shock and disbelief upon diagnosis due to believing that they did not fit a 'profile' of someone who could become HIV positive. However, this study extends the understanding of women's post-diagnosis experiences to include a disconnect between their experiences of women living with HIV with the dominant discourse around HIV. This resulted in women feeling isolated post-diagnosis and unable to practice critical awareness around their condition, which contributes to feelings of shame.

The study contributes to existing knowledge by way of the finding 'experiencing undesired exposure'. Previous studies with women living with HIV (Mackworth-Young et al. 2020; Manijeh et al. 2020; Davtyan et al. 2020) have stated that women's concealment of their HIV status is largely due to the anticipation and avoidance of HIV stigma, yet they do not include the emotional response of HIV-related shame as this study does. By exploring shame as the emotional response to HIV stigma, as well as women's awareness that HIV is a stigmatised condition, these insights add to existing knowledge by suggesting that shame as anticipated and avoided undesired exposure of the self can result in fear, stress and potentially harmful avoidance strategies. This positions HIV-related shame as a potential determinant of mental and physical health and contributes to existing knowledge that shame as well as stigma can be harmful for WLHIV if unacknowledged and unaddressed and affect their lives after diagnosis.

The finding ‘growing through HIV-related shame’ contributes to existing knowledge as it reports how peer-support in the era of HIV-normalisation can reduce HIV-related shame. This finding extends existing research by Lennon-Dearing (2008) who proposed that peer support reduced feelings of shame among women living with HIV, however, this was prior to the era of HIV-normalisation and viral undetectability. This study extends the argument put forward by Lennon-Dearing (2008) by demonstrating that peer-support is important for shame reduction in this current context of HIV-normalisation. Additionally, the study’s findings of a positive adaptation to HIV diagnosis among women extends research by Subramanian et al. (2017); Beauthin, Bruce and Sheilds (2015) and Psaros (2015). Findings from these studies were based on samples of older women due to them living with HIV for longer. While this study confirms previous studies’ findings, it also adds to the body of knowledge in that both younger and older women experienced positive adaptation to their HIV status, due to the deconstruction and normalisation of the HIV, minimising its impact on their lives. That positive adaptation to HIV is not exclusive to older women is a significant finding. Young people who were born with HIV are now coming into and have reached adulthood, and so positive adaptation to HIV being possible across ages is significant.

6.1.2 Gendered aspects of shame

Women’s experiences of HIV are shaped by the broader sexual and sociocultural norms due to the fact they deemed an HIV diagnosis to be a violation of these norms, or they perceive others to see them as so. HIV-stigma is often perpetuated by a discourse of HIV as a condition contracted by transgressive behaviour, of which women in this study were aware, thus rendering an HIV-diagnosis shame-inducing. This study uniquely puts forward that women’s interpretation of an HIV-diagnosis can be different from men’s and other genders’, as the societal expectations of women and the challenges they pose can impact how women come to feel HIV-related shame. For example, women’s concerns over being viewed as sexually immoral was informed by their awareness of HIV-stigma but was contextualised by the social expectation of women to be sexually conservative based on cultural gender norms for women. Furthermore, in avoiding the exposure of their perceived violation of such gendered sociocultural norms, women went to great lengths to ensure their HIV status remained concealed.

Informed by Brown’s (2006) Shame Resilience Theory which examines the cultural expectations of women as shame triggers, women’s experiences of living with HIV are considered the context of broader societal issues with which women are faced; sexuality, motherhood, body image, ageism, race, work, religion, and mental and physical health. Living with HIV, a heavily stigmatised condition in the context of broad sociocultural expectations, mean that women’s experiences of HIV can be intensified and complicated when they are held against such expectations, meaning that shame can often develop and manifest. Given the sociocultural expectations placed upon women, this research suggests an HIV diagnosis was a catalyst in feeling though one has fallen short of, or believes others will see them as having fallen short of such expectations, which can result in shame.

6.1.3 Contribution to Theory

The study provides further insights into the theories ‘the looking glass self’ (Cooley 1902) and shame and the social bond (Scheff 2000). By applying Cooley’s (1902) ‘the looking glass self’ theory to this study, it reveals how the reflection in looking glass can be warped by the sociocultural norms and expectations that women live against and potentially determines women’s perception of how they are viewed by others, ultimately shaping their experiences as women living with HIV. Additionally, the study builds on Scheff’s (2000) ‘shame and the social bond’ in which he declares that shame derives from a perceived threat to the social self in a similar way. This present study extends Scheff’s (2000) theory in illustrating that a threat of disconnection from another human, resulting in isolation and loneliness, is informed by women’s self-perception potentially having violated the norms women are held too, when they received an HIV diagnosis and for years after. Furthermore, in drawing on Scheff’s (2000) theory to this study, it tells of how responses to threats to our social bonds can be harmful to women in the context of maintaining concealment of their HIV status and thus, shame, it is unacknowledged and unaddressed form, can be harmful.

6.2 Key findings: HIV-related shame among women in an Irish context

This study used narrative inquiry to explore shame among women living with HIV in an Irish context. In adopting the chosen analytical framework for this study, the analysis provides greater understanding of the trajectory and processes of shame across women's accounts. Furthermore, the study offers a qualitative perspective of women's contemporary experiences living with HIV in this era of the biomedical normalisation of HIV.

HIV-related shame can, and in this study did, negatively influence women's experience of living with HIV. Furthermore, the study indicates that when shame is endured and unaddressed, it can have implications for a woman's well-being. The development of HIV-related shame can be linked to women's perceived sense of the violation of female cultural expectations, including the fear of being seen as sexually immoral. Ireland has a complex history of punitive measures for women who were deemed sexually immoral and this legacy is evident in this study's findings. The study provides fresh insights into women's adaptation to living with HIV in that women found the lack of an encouraging female centred HIV-discourse upon diagnosis to be isolating and resulting in the belief among both African and Irish women, that they would be perceived as violating cultural norms for women. The study raises the importance of such encouraging discourse for women's adaptation to life with HIV, as its absence can be shame inducing for women.

Shame can act as a strong determinant of health, given how shame, via undesired exposure, can, in part, have an effect on women's emotional, psychological, social and physical health. Unaddressed HIV-related shame inhibited women's ability to live freely with HIV, as it appeared to have various forms of control over their actions as HIV positive women. Chronic, unaddressed HIV-related shame can compromise a woman's ability to live well with HIV. The study offers a limited but important perspective of HIV-related shame as experienced by women living in DP. When considering women's management of their HIV, women prioritised managing undesired exposure of the self alongside their biomedical management of HIV. Women's living environments, such as for women living in DP's communal settings, can compound women's HIV-related shame. Women who experienced HIV-related shame deemed privacy to be of crucial importance to avoid the undesired exposure of their HIV. The development and experience of HIV related shame contains gendered aspects, as cultural expectations of women, in part, differ to that of men. This was demonstrated so, by topics such as sex and relationships, motherhood and pregnancy.

The study offers fresh insights into women's growth beyond HIV-related shame, and concludes that HIV-related shame among women needs to be addressed with the appropriate interventions. Addressing HIV-related shame builds on the need for HIV-stigma reduction. Without minimising the importance and necessity of stigma reduction, shame reduction and resilience can be tackled and maintained internally, and yet managing the external nature of HIV-related stigma and judgement can be more challenging to control. Importantly, shame among WLHIV, can be addressed and moved through in women across ages. Women can benefit from connection and empathy regarding their HIV positive status from their social connections, peer support and healthcare workers within and outside of HIV care.

6.3 Strengths and limitations of the study

6.3.1 Strengths

This research supports and extends previous studies examined in the literature review. However, this study's intention was to study the impact of shame on the lives of WLHIV in Ireland from the onset. The adoption of a narrative approach in this study allowed for in-depth understanding of their lives and the meaning they applied to their experiences, through the narratives they shared during the interviews. The area of study under exploration, shame among women living with HIV, was largely unexplored and a narrative exploration has provided nuanced contextualised insights, as narrative inquiry can amplify stories that are otherwise silent (Wang and Geale 2015). Narrative research has been adopted successfully in previous studies to explore women's experiences of living with HIV, yet this is the first study to explore shame within women's narratives. The lack of women centred discourse in an Irish context is somewhat addressed in the gathering of women's stories of living with HIV for this present study. When women participated in this study, they contributed to a woman-centred HIV discourse by sharing their stories and their experiences. In the context where women's stories of living with HIV are considered invisible and even intolerable in public discourse, this study was a safe space to lend their story.

Through adopting a narrative approach, the study gave women the opportunity to tell their stories how they wanted and emphasise key experiences, which is necessary in gathering accounts from seldom-heard voices. A key strength of narrative inquiry is that in storytelling, people can often make sense of their experiences in how they construct and deliver a narrative response. Additionally, given the sensitivity of the research, there are benefits from adopting the narrative process, which allows for the gathering of largely untold, unheard stories. The study was strengthened by the adoption of the three-dimensional narrative inquiry space (Clandinin and Connelly 2000). The dimensions of the framework provided the appropriate tool for the analysis of shame, such as women's interactions with the people in their stories and their wider social environment. The stories gathered spanned over many years in tandem with the constantly developing HIV treatment field, and through narrative analysis, illuminated how shame evolved, was lived with and in some cases, overcome. I approached this study from the perspective of an outsider, as someone who is not living with HIV; I sat with each woman as a learner and the participant as the expert. The rich data from these women's narratives, using selected theoretical viewpoints adds to the literature on contemporary female HIV experiences.

There was variety in the participants' geographical locations across Ireland. The findings are drawn from accounts of women living in counties in the North, South, East and West of Ireland. This offered perspectives from experiences from women living in both rural and urban settings in Ireland. Living with a stigmatising condition with which one feels shame, can be contextualised by where they live, even on a small island such as Ireland. In women's accounts, the variety of geographical location presented itself in how women came to be diagnosed, their experiences accessing service provision and concealing their diagnosis. Living with HIV in a rural community differed when compared to an urban community in which living in an urban community with HIV was noted by a number of participants as being more desirable due to the lowered probability of being known in the community (as one might be in a rural area). As the data was made up of accounts of women who lived all across the Island of Ireland, the findings, although are not generalizable, are representative of women who lived in various counties. Furthermore, the accounts consisted of stories of women who lived with HIV for a wide range of years, spanning from three years to twenty-seven years, as well as a wide range of ages from mid-twenties to late sixties. This range of ages and years lived with HIV among the study's participants meant the data was compiled of experiences of living with HIV from over two decades ago as well as more recent experiences. This provides the study with a trajectory of living with HIV as the nature of living with it developed alongside, as well as providing understanding into how women across ages experience HIV related shame.

6.3.2 Limitations

There are limitations to this study that should be taken into consideration when interpreting its findings. Limitations concerning this present study include being an outsider researcher, participant recruitment and sample, study design and although not a concern for qualitative research, the issue of generalizability. This section will attempt to look at these limitations, their potential impacts, and how they were addressed throughout the study process. The limitations are laid out below to facilitate transparency and to increase the authenticity of the study.

My position of being an outsider researcher brings limitations to the study. I entered into this study in the position of an outsider as I am not living with HIV, I did not have experience working with people living with HIV prior to this study and I was not well known within the HIV community. However, I have worked in global health and have studied HIV and stigma, and other aspects of women's experiences academically and in my work. For this research, as I was an outsider with no experience of living with HIV, nor experience working with PLHIV, everything I would come to know about shame among WLHIV would be derived from the twelve narrative interviews conducted. Therefore, the study was potentially impacted on because I asked women to talk to me, a stranger, about a potentially highly sensitive area of their life. Issues of trust on behalf of the participants should be considered, as sharing such sensitive details with a stranger in a one-off hour meeting could be challenging. This possibly affected the data collected. I tried to take whatever steps I could to build that trust, given my position and role.

Firstly, I did not recruit participants myself; in most cases, HIV Ireland's key contract person recruited through an All-Ireland network of PLHIV. This meant that upon interview, the extent of our communication was emailing or text message, and in few cases, a phone call. Although the women decided on their own accord that they wanted to share their story of living with HIV with me, the context in which the interviews were set up and arranged, meant that I needed to establish rapport and build a comfortable environment for women. It was pivotal for me as a researcher that participants felt safe with me as someone listening to a sensitive, highly personal story within a one to two hour period. Of course, I respect that it is possibly quite a challenge to talk about something that may be considered painful or challenging in their life with a stranger they have just met. This posed a challenge for me ahead of the interview, as given the sensitive nature of the research topic, the data gathered depended on the rapport and trust established between the researcher and participant. This was not something I could always control; however, I always employed measures to prevent my position of being an outsider from inhibiting me to build relationships with participants ahead of each interview. This involved first and foremost positioning myself as an advocate and ally for WLHIV from the outset of our meeting, sharing details about myself and why I was researching this particular topic, and engaging in some open conversation unrelated to the topic, prior to starting.

I was limited in my capacity as I came from a different cultural and racial background to three of the participants. Three participants originally came from East African countries, with two living in the direct provision system. These women made clear to me during their interviews that they felt comfortable talking to a white, Irish person about their HIV status over someone from their own country. This is positioned as me being far less likely to communicate their HIV status to people from their home countries. Yet, there are limitations in gathering and analysing accounts of women who originate from different countries than I. I acknowledge the issue of power differentiation in the study's reflexivity, by ensuring all women that they understand that they have control during the interview and that I was there to listen to and learn from them, in a non-judgemental capacity. In qualitative research, the researcher typically holds most of the power in an interview, posing the research question, using an interview guide and often decides when the interview is over (Karnieli-Miller et al. 2009). There is power held by the participants during interviews also, seeing as their responses can equally guide the interview and they can cease the interview at any moment. However, not all power differentiation between white researchers and black, marginalised women can be addressed with reassurance of my advocacy, and this may have affected the co-construction of their account. Furthermore, due to differences in our cultural backgrounds, there may have been details or aspects of women's accounts that had cultural significance that I overlooked, or possibly had drawn an alternative conclusion from that someone from the same cultural background might have drawn. However, to address this potential barrier, I confirmed with women routinely throughout their interviews that I understood to the best of my ability what women were speaking about.

All the women, except one, had engaged with a voluntary organisation in which they were in receipt of support of some form. Therefore, the stories from this sample of women do not represent women who did not engage in support. This is important given how the study has demonstrated how support has shown to impact shame. I did not recruit participants from clinical settings as well as voluntary organisations as it was taken into consideration that the structure of a voluntary organisation would aid the recruitment process and be facilitative. I made the decision to not be directly associated with clinical care, as participants and researcher relationships, and data collected, may have been influenced by participants experiences in healthcare settings as noted in Chapter 3. However, this means that because the sample included only one participant (this participant had partial peer-support) who was not engaged in a voluntary support organisation, it did not feature the voices of Ireland's most marginalised women living with HIV. Ultimately, however, in designing the study, I took into the consideration the relatively low-prevalence of women living with HIV in Ireland, and that a voluntary support organisation would facilitate timely recruitment. Equally, completing the interviews in the facilities provided by *HIV Ireland* and the associated organisations meant that on-site support could be provided to women in times of distress, however, this was not needed at any point.

The study was not co-designed with women living with HIV, and therefore, those most impacted by the study's outcomes did not inform the research question and design. Given my position as an outsider researcher who considers WLHIV to be the experts regarding the experience of living with HIV, the study is limited by their lack of participation in the design of the study. A notable benefit of having research participants involved in the research process includes increased relevance and applicability of the study's outcome (Tomlinson et al. 2019). As a doctoral student, my skills, knowledge and experience compounded by time and financial boundaries meant that I did not consider public-patient involvement in the study early on in the design stage. However, the study was designed and carried out without the involvement of women living with HIV, one of Ireland's primary HIV support organisations, HIV Ireland were consulted on the study and research question during the design stage, although organisation members who were consulted were not living with HIV. Having agreed it was a worthwhile study with which HIV Ireland would engage, the organisation supported recruitment for the study. Additionally, although this is not a feminist study in the emancipatory sense, I am a feminist and as that is at the forefront of my actions throughout this research process, this study I sought to increase women's visibility in HIV research.

Finally, the study is limited in its capacity to generalize, though this is deliberate and implicit in its design. The study's sample is relatively small; however, is an appropriate sample for an in-depth narrative study. The study did not set out to generalise the findings and this must be taken into consideration when interpreting the findings. Based on this study, perhaps a quantitative study exploring shame among women living with HIV across Ireland would provide additional understanding, as elaborated below.

6.4 Implications

6.4.1 Implications for future research

This study and its findings have highlighted the need for further research, including the following:

- *Qualitative research exploring living with a stigmatised condition or identity in the Irish Direct Provision service:*

  This present study has shed light on the challenges of living in direct provision as women living with HIV. The nature of accommodation in direct provision is that it is communal living, and individuals may have to share bedrooms and other small spaces with their children and others seeking international protection. The lack of privacy while dealing with a stigmatised medical condition has problematic outcomes, and warrants further research and action. Although the Irish government has promised that the current direct provision system will cease to exist come the end of 2024, it is still unclear how people seeking international protection will be housed, or if the target will be met. Taking the challenges seen in this study into consideration, further exploration into the challenges faced and how they are navigated by those living with a stigmatised health condition. There is also the issue of stigmatised sexual identities, and these issues need to be explored in two separate studies, or how they overlap for some people. Issues of insider-outsider researcher positionality would need to be considered in the study design, given the potential for different cultural backgrounds of researcher and participants.

- *Experiences of PLHIV as volunteer peer support workers (VPSW):*

  This present study revealed the importance of formal and informal peer-support for shame reduction and overall well-being among WLHIV. If Ireland is to establish a robust, structured peer support network for PLHIV involving a greater number of VPSW, further exploration into the role of the peer support volunteer is needed considering the growing number of PLHIV in Ireland. Given this, action research exploring the advantages and disadvantages (regarding role, impact and other aspects) of being a VPSW could shed light on ways to increase the number of VPSWs in Ireland. A potential action research study design might include inviting men and women living with HIV to participate in the research to be trained by HIV organisations to become a VPSW. The study would engage with participants prior, during and following their training and volunteering as VPSW to gather accounts of progress and experience as a VPSW worker. By gathering both male and female perspectives, research could explore gendered dimensions of VPSW.

- *The impact that COVID-19 on PLHIV in Ireland who engage with HIV support services:*
  The study was partially carried out during the COVID-19 pandemic. The findings, which demonstrated the importance of peer-support and group-support for HIV positive women, are juxtaposed by the reality in which social support groups for PLHIV could not take place across the last 18 months. As it is considered that social groups moved online to continue on peer-support, there is potential scope for research to be carried out to explore how social support is provided and received by PLHIV. Participants in this present study noted the disadvantage of living in a rural area as a member of a social group. Perhaps a patient-public involvement design, with peer researchers, could explore via focus groups, PLHIV's experiences during the COVID-19 countrywide lockdown, in which life for many dramatically changed. Equally, research could explore how virtual social groups could be enhanced and improved upon in the future to facilitate individuals who are not geographically suited to attending in person social groups.

6.4.2 Implications for Practice

Healthcare practitioners: Healthcare professionals can, in their own capacity, reduce or add to HIV-related shame. Shame can influence clinical encounters, especially when healthcare workers make or ask stigmatising and insensitive questions and comments, particularly during this era of HIV-normalisation. It is vital for women to feel safe and secure in their healthcare environments, without HIV-related shame, to ensure that women remain engaged in their treatment. This alone will not be sufficient for WLHIV to deconstruct and address/reduce their HIV related shame. It will likely be helpful for women to know that healthcare workers view them as they would an individual with a non-stigmatising health condition, without minimising the impact that life with HIV can have on one’s life.

In clinical encounters, healthcare workers must not dwell on the route of HIV acquisition, nor equally, brush over the emotional and psychological effects of HIV in priority of women’s physical health. It is of great importance that healthcare workers be aware of how their actions or language use might elicit HIV-related shame in a clinical encounter. It is possible that some women will automatically assume that they will be viewed badly because of their HIV status, which could affect or interrupt their engagement in healthcare visits. In some cases, healthcare professionals may be the only people that women see who know their HIV status, so the importance of empathy and non-judgemental communication about their HIV status cannot be overstated. Healthcare workers dealing with women living with HIV must play an active role in promoting women’s shame reduction. This is addressed below in ‘implications for education’.

Another recommendation for healthcare is that women are supported from the point of diagnosis and the months following that, regarding their emotional and psychological health. The gender aspect of women’s experiences need acknowledgment. In this era of biomedical HIV-normalisation, it is crucial for people newly diagnosed with HIV to not have their emotional and mental health overlooked by healthcare providers, simply because HIV is now fully treatable. Currently, social workers primarily engage with women in the early stages of their diagnosis to support in the adaptation to treatment and adaptation to life with HIV, as well as engaging women with support networks, although not every woman in this study was afforded such support. Learnings from this study confirm the importance of guiding women who are newly diagnosed and potentially dealing with trauma, towards effective social and peer support, as well as counselling and therapeutic measures to prevent shame development, or help them towards shame resilience. This action should be taken as soon as possible following diagnosis as it would be most beneficial for women’s emotional health, so HIV-related shame does become a norm of living with HIV as they adapt to their diagnosis.

Furthermore, women’s adaptation to their HIV positive diagnosis may benefit from meeting other women living with HIV early on their diagnosis, given the benefits that peer support can bring. The trauma and isolation of an HIV diagnosis can lead to poor mental health and well-being, and rather than leaving women to source their own peer-support, working closely with women who are newly diagnosed, to ensure they have all available resources made accessible to them during a very troubling time, is crucial. Foreman and Ní Rathaille (2016) found that the role of social workers for PLHIV in an Irish context has changed as pre- and post-HIV test counselling no longer occurs as often as they once did, given the changing nature of HIV. This is possibly in response to the biomedical discourse of normalisation of HIV, although this study challenges such discourse. Social workers play a pivotal role in women’s HIV diagnosis adaptation and with a steady increase in HIV positive diagnosis over the last number of years, a greater availability of social work referrals for PLHIV is required. Given such, a funding increase should be allocated for the suitable availability of HIV social workers to avoid delay or absence of referrals of women and others living with HIV to social care workers.

HIV and Sexual Health Organisations: HIV-related shame can pose as a challenge for women to reach out for help, especially in chronic shame. Having online information support for and about women is needed. Given the lack of awareness that there are Irish based women living with HIV, websites of Ireland leading HIV organisations ideally should consult with WLHIV to ask their needs regarding the creation of web pages aimed at education and supporting WLHIV, women newly diagnosed, and women looking to support other women. Alternatively, this online information could be introduced into existing Irish HIV and sexual health websites. WLHIV across Ireland would benefit from such a website, which should offer contact details for accessing support, anonymous testimonies of women living well and healthy with HIV, and information about dealing with shame and stigma.

Direct Provision: Another implication from this study concerns people seeking international protection who are living with HIV in direct provision accommodation. The study revealed how privacy is pivotal for HAART adherence in communal living settings such as direct provision, yet is sometimes not afforded to PLHIV in the accommodation. HIV organisations and healthcare professionals treating PLHIV need to work with management and social workers in direct provision so that they are more involved in a supportive capacity of migrants living with HIV, of course, without risk of unwanted disclosure of the individual’s HIV status. Organisations such as HIV Ireland, the Irish Refugee Council, Doras, and MASI (Movement of Asylum Seekers Ireland) could deliver a framework to direct provision centres around the country, who are likely to accommodate and will accommodate in the future, PLHIV, to facilitate provisions to ensure privacy and discretion without risk to PLHIV.

6.4.3 Implications for Education

Healthcare workers: A concern that emerged from this study was the number of healthcare workers in clinical encounters who were apparently not up to date with relevant HIV clinical advancements. This is most likely due to the relatively low-prevalence of HIV in Ireland, and while many healthcare workers may learn about HIV in training, they may not meet WLHIV regularly, or ever at all. Although healthcare workers may pose intrusive questions and comments as merely curiosity, healthcare professionals should be educated on how to deal with patients or service users with stigmatising conditions such as HIV. Based on this study’s findings, it would be beneficial for WLHIV if their healthcare providers outside of HIV care were educated on the complexities of living with HIV, as well as become up-to-date on the advancements in HIV medication, U=U and PreP. This holds particular relevance to HIV, as health outcomes, treatment and viral undetectability have enhanced significantly in the last number of years. This study recommends for the Department of Health to develop a task force, made up of people living with and without HIV working with HIV organisations (HIV Ireland; Sexual Health West; the Sexual Health Centre Cork; Gender, Orientation, Sexual Health and HIV (GOSHH) Centre Limerick) whose sole purpose is to educate healthcare providers about HIV and other stigmatising conditions. By establishing a curriculum for dealing with women living with HIV in healthcare settings, healthcare workers must be educated to develop their understanding of shame and become invested in shame reduction in clinical encounters. Healthcare professionals must attend to the emotional health of WLHIV as well as their physical health by becoming familiar with recognising shame –based behaviours and referring women on for further health intervention; counselling and psychotherapy. The curriculum should also train healthcare professionals to become aware of their biases and judgement towards PLHIV regarding outdated HIV clinical information could have a negative effect.

Women living with HIV: It is important that women are given opportunities to gain the skills to cope and deal with the negative emotions that arise from an HIV diagnosis, in particular shame which may lead to anxiety and depression, and reduce well-being. Such skills could be developed in routine shame-resilience and empowerment workshops, led and run by qualified mental health professionals and women living with HIV, delivered in line with other supports offered by HIV Ireland, other NGOs and the HSE. Such workshops may act as intervention-based workshops for the reduction of shame among women. Learnings from this study indicate the provision of peer-lead social support for WLHIV, as this has shown to be helpful in reducing HIV-related shame due to enhanced critical awareness of their condition. As mentioned in Chapter 5, critical awareness is described as a woman's level of awareness of the sociocultural forces that shape her experience and her ability to explore her experiences in light of those forces (Brown 2006). While this was shown to happen gradually over time, this study recommends a goal-orientated workshop to solely focus on this process for WLHIV, led by trained peer support workers. Encouraging women's shame reduction and resilience would mean adopting Brown's (2006) shame resilience theory into a workshop format and would include; women's development of a critical awareness by enhancing their broader understanding of women's experiences of living with HIV and simultaneously, targeting and deconstructing the core issues that informed their HIV related shame. This would occur in line with acknowledging their personal vulnerability as a woman living with HIV and speaking openly and comprehensively about the core issues or messages that drive their HIV-related shame (norms and expectations for women and how they intersect with their interpretation of HIV stigma) in the context of a safe workshop space. With regards to this study's implications for the lives of WLHIV in Ireland, it adds to the discourse of HIV in Ireland by underscoring HIV positive women's lives. It is aimed that women living with HIV who have little or no support, or who are struggling with their HIV status will learn that they are not alone in their experience.

6.5 Reflexivity

As the research and thesis conclude, I reflect on the overall qualitative research process in knowledge production regarding the role of shame in women's contemporary experiences of living with HIV. The nature of narrative research is categorised by my construction of data alongside participants and thus, I am too a part of this research. My decisions based on my view of the world were central to the outcome of this study, which leaves readers with one aspect of reality, a truth as interpreted by me through the stories of the participants, unique to the context of this study.

Throughout this research process, I have navigated the balance between my power and responsibility as the researcher, in which I sometimes felt I intruded on the lives of WLHIV, and my vulnerability and negative emotions of being a student. The emotional and mental experiences of a researcher completing a PhD are significant to the construction of the meaning of knowledge produced (Vince 2020). Many positive and negative emotions have unfolded as I progressed through this study; joy, enthusiasm, excitement, while alongside the positive emotions were stress, anxiety, fear, and loneliness. Central to this experience was a deep exploration into my own shame as a woman, and as a female academic, and what I have learned about myself will benefit me for years to come. I knew coming into this study that I would face significant challenges, I was not ignorant of the magnitude of work to be done to achieve a doctorate. However, I did not factor in a global pandemic. While there were multiple moments during the last 18 months in which I struggled deeply, I grounded myself by realising the privileged position I was in, and how I should never take my education for granted.

As I progressed, my motivation behind my initial engagement in this study has changed and developed. What was previously an academic endeavour for professional development, the experience transformed into a deeply personal journey. I have dedicated four years to this study, which I believe is a testament to the passion I have for the subject. It has been a privilege to learn from these women. Having spent a great deal of time pondering and considering such in-depth, personal and sensitive stories, I think it would be difficult to quantify how much these women's stories have taught me about the complexities of life.

6.6 Conclusion

This study has identified, through narrative inquiry, the importance of understanding shame in the accounts of women who are living with HIV. HIV-related shame, the negative self-conscious emotion felt when women believed others to view them negatively because of their HIV status, certainly does feature in these women's accounts. By identifying and exploring the HIV-related shame in these women's accounts, this research extends understanding of the lived experience of women who live with HIV in an Irish context. The silent and insidious development of shame as a response to dominant HIV-stigmatising discourse was apparent across women's accounts and in some cases, was unaddressed and persisted for many years. The women's narratives have given insight into the need for an encouraging women-centred HIV discourse in Ireland. Importantly, this study identifies shame as a potential determinant of HIV-related health outcomes for women, as the anticipation and avoidance of undesired exposure proved damaging for women's overall well-being.

The study further illustrates that HIV-related shame can be addressed and overcome by deconstructing the core messages informing women's shameful internal dialogue with an empathetic and understanding audience. The key findings from this research, which adds to the limited body of knowledge around shame among PLHIV, will guide professionals who work with WLHIV, such as healthcare professionals, those working in support of people living with HIV, in understanding and supporting women throughout their HIV experience. As I complete my thesis, my final commentary on my work is demonstrated by a particularly thought provoking quote from my study. No woman living with HIV should feel like Julie did when she talked about the risk of undesired exposure. She said *"I felt like I wasn't wearing any clothes on me, you understand what I'm trying to say – I felt like I'm naked."* This is why HIV-related shame needs to be addressed for all women living with HIV.

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Appendices

Appendix a) Ethical Approval

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Ms. Ellie Marley,

School of Nursing and Health Sciences

3rd December 2018

REC Reference: **DCUREC/2018/203**

Proposal Title: Do women living with HIV have to deal with shame? An exploration of how shame features in the narratives of women living with HIV

Applicant(s): Ms. Ellie Marley, Dr Denis Proudfoot, Professor Anne Matthews,

Dear Colleagues,

Further to full committee review, the DCU Research Ethics Committee approves this research proposal.
Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

Donal O' Gorman

Dr Dónal O'Gorman
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

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Appendix b) Plain Language Statement

Plain Language Statement

1. **Introduction to the Research Study:**
    - Study title: ***Do women living with HIV have to deal with shame? An exploration of how shame features in the narratives of women living with HIV.***
    - Ph.D. student Ellie Marley, Assistant Professor, Dr. Denise Proudfoot and Prof. Anne Matthews from the School of Nursing and Human Sciences in DCU are carrying out the research.
    - Ellie Marley can be contacted at: ellie.marley3@mail.dcu.ie

2. **Details of Study:**
   This study is being carried out to interview women who are living with HIV (WLHIV), to find out if and how they experience shame in their lives due to the condition. It is not expected that women living with HIV do or should feel shame, but it is believed that social stigma of HIV is causing feelings of shame in women. 507 people were diagnosed with HIV in 2017, and one in four living with HIV are women, yet there is very little research being carried on women (with the exception of pregnancy). Therefore, little is known about life in Ireland as a woman in living with HIV. The aim of this research is to give a voice to Irish-based women who have previously not been able to tell their story, and contribute to the fight of ending the stigma against HIV.

3. **Details of Study Participation:**
   Participants will be invited to attend at least one interview face-to-face by the lead researcher who is a PhD student. The interviews will take place between October 2018 and Summer 2019. The interviews will not take longer than 90 minutes. If the participant wishes to carry on the interview, a follow up interview can be scheduled. The researcher may request a follow-up interview with some participants. The interviews will be audio-recorded for the purpose of gathering data and recalling information when transcribing the interviews, however, should a participant wish not to have their interview audio-recorded, their participation will still be facilitated.

4. **Potential Risk to participants arising from research involvement:**
   There is a possibility that participants may become upset, distressed or agitated during the interview, as you will be asked to talk about your HIV story and more specifically, times when they have felt shame. If the circumstance arises, the participant will be given the opportunity to cease or postpone the interview, and will be provided with information to access support from the appropriate organisations.

5. **Benefits (direct or indirect) to Participants:**
   It is intended that the outcome of this study will be to document the stories of women living with HIV and how shame features in their lives. It will also help inform the implementation of policy and interventions that will attempt to support and improves the well-being of women living with HIV.

6. **Protecting Confidentiality:**
All efforts will be made to ensure the confidentiality of the participants is protected. Participants names will be protected and a pseudonym will be given to each participant, and all other identifying details will be changed. Only the lead researcher will be analysing the collected data (the digitally recorded interviews which will be transcribed into typed documents). The researcher will secure all interview materials, including transcripts and notes, where they will not be accessed by anyone other than the lead researcher. Should the researcher become aware of serious harm to others or self, from the participant, they will be obliged to inform the authorities and confidentiality will no longer be upheld.

7. **Data Destruction:**
Five years after the study ends, the data recorded and stored will be destroyed.

8. **Voluntary Participation:**
The participant is ensured that they may withdraw from the interview or research study at any point prior to data analysis, and doing so will bring no risk to the participant.

9. **Additional Information:**
It is intended that this research study will be carried out with 20-25 Irish-based women living with HIV for a least 3 months.

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary,

Dublin City University Research Ethics Committee,

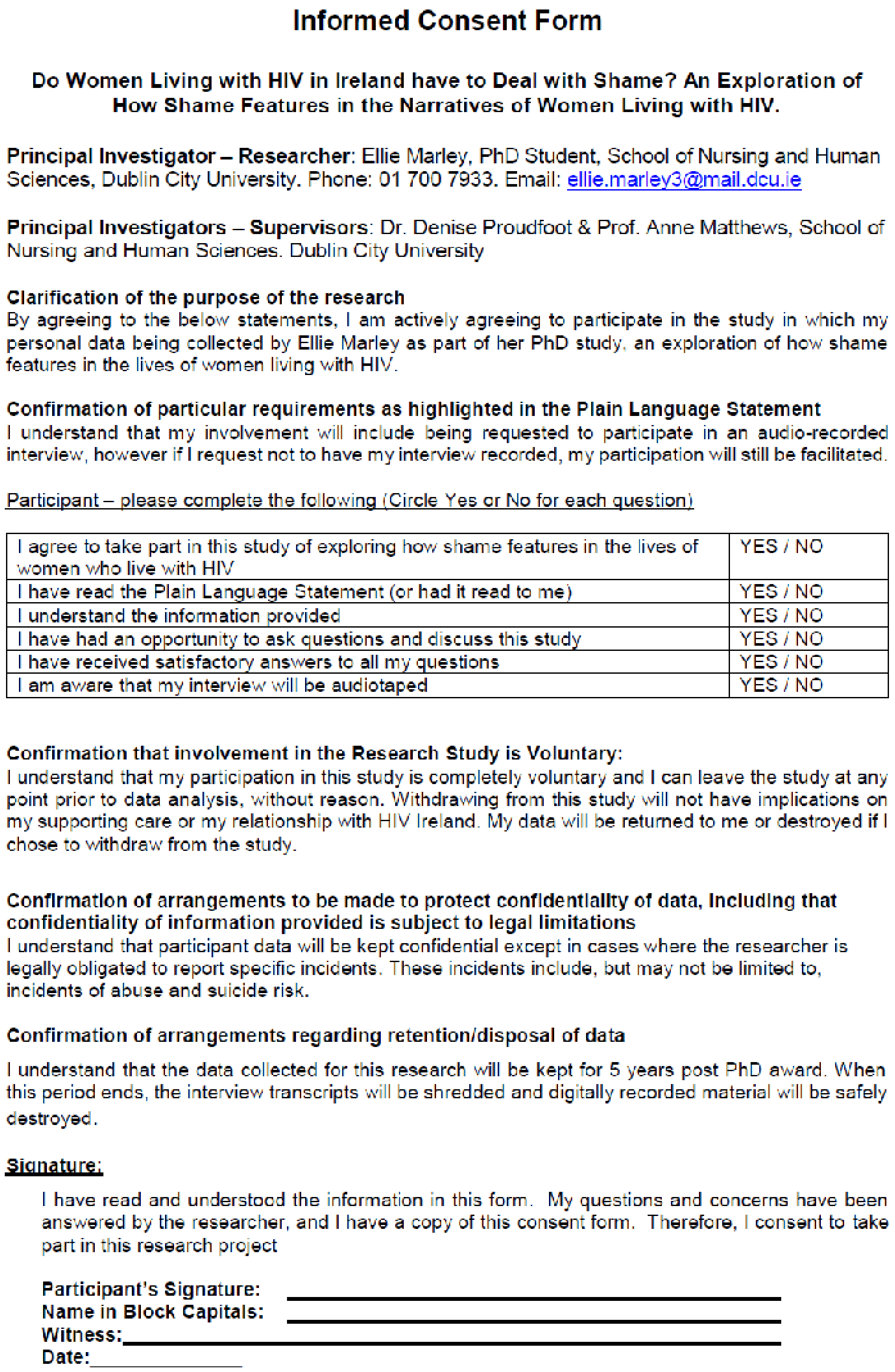
c/o Research and Innovation Support,

Dublin City University,

Dublin 9.

Tel 01-7008000

Appendix c) Informed Consent Form



Informed Consent Form

Do Women Living with HIV in Ireland have to Deal with Shame? An Exploration of How Shame Features in the Narratives of Women Living with HIV.

Principal Investigator – Researcher: Ellie Marley, PhD Student, School of Nursing and Human Sciences, Dublin City University. Phone: 01 700 7933. Email: ellie.marley3@mail.dcu.ie

Principal Investigators – Supervisors: Dr. Denise Proudfoot & Prof. Anne Matthews, School of Nursing and Human Sciences. Dublin City University

Clarification of the purpose of the research
By agreeing to the below statements, I am actively agreeing to participate in the study in which my personal data being collected by Ellie Marley as part of her PhD study, an exploration of how shame features in the lives of women living with HIV.

Confirmation of particular requirements as highlighted in the Plain Language Statement
I understand that my involvement will include being requested to participate in an audio-recorded interview, however if I request not to have my interview recorded, my participation will still be facilitated.

Participant – please complete the following (Circle Yes or No for each question)

I agree to take part in this study of exploring how shame features in the lives of women who live with HIV	YES / NO
I have read the Plain Language Statement (or had it read to me)	YES / NO
I understand the information provided	YES / NO
I have had an opportunity to ask questions and discuss this study	YES / NO
I have received satisfactory answers to all my questions	YES / NO
I am aware that my interview will be audiotaped	YES / NO

Confirmation that involvement in the Research Study is Voluntary:
I understand that my participation in this study is completely voluntary and I can leave the study at any point prior to data analysis, without reason. Withdrawing from this study will not have implications on my supporting care or my relationship with HIV Ireland. My data will be returned to me or destroyed if I chose to withdraw from the study.

Confirmation of arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations
I understand that participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

Confirmation of arrangements regarding retention/disposal of data

I understand that the data collected for this research will be kept for 5 years post PhD award. When this period ends, the interview transcripts will be shredded and digitally recorded material will be safely destroyed.

Signature:

I have read and understood the information in this form. My questions and concerns have been answered by the researcher, and I have a copy of this consent form. Therefore, I consent to take part in this research project

Participant's Signature: ____________________
Name in Block Capitals: ____________________
Witness:____________________
Date:______________

Appendix d) Narrative Interview Guide

Narrative Interview Guide:

To initiate the interview, a short conversation will ensue around the person's life, where they will be asked relatively comfortable, everyday types of questions about themselves, easing them into the interview experience.

- Where are you from? (explore answer)
- Whom do you live with? Who are your family? (explore answer)
-

After a brief period, the interviewer will attempt to steer the interview back around to the below questions. As this is a guide, it is not anticipated that all questions will be asked.

1) How did you find out about your diagnosis?
    - Can you tell me about your reaction to hearing this? Can you tell me about your emotions at the time, and what your initial thoughts were?
    - Do you still feel the same about the diagnosis?
    - What did you know about HIV at the time of your diagnosis?

2) Do you experience shame because you are a woman living with HIV?
    - If so, in what context do you experience shame? Family/Children/Physical Intimacy/Employment
    - Have you ever felt bad, or ashamed in a healthcare setting because you live with HIV?

3) Do you feel like you would like to talk more about HIV to someone but cannot, because of feeling ashamed?
    - Have you told anyone that you are living with HIV?
    - (If narrator hasn't disclosed to many?) What do you imagine your reaction be if the people closest to you found out you were living with HIV? Children/parents/close friends/ partners.

4) How has it been having to take medication for HIV?
    - Do you have to hide this from anyone?

5) Are you in a relationship with anyone at the minute? Sexually?
    - What is your perspective on the phenomenon that if you are virally undetectable, you cannot pass HIV on through sex?
    - How would you feel about telling a sexual partner about you living with HIV?

6) Do you ever feel like living with HIV has affected your happiness?
    - Can you tell me somehow you have benefited from receiving your diagnosis?

Closing question:

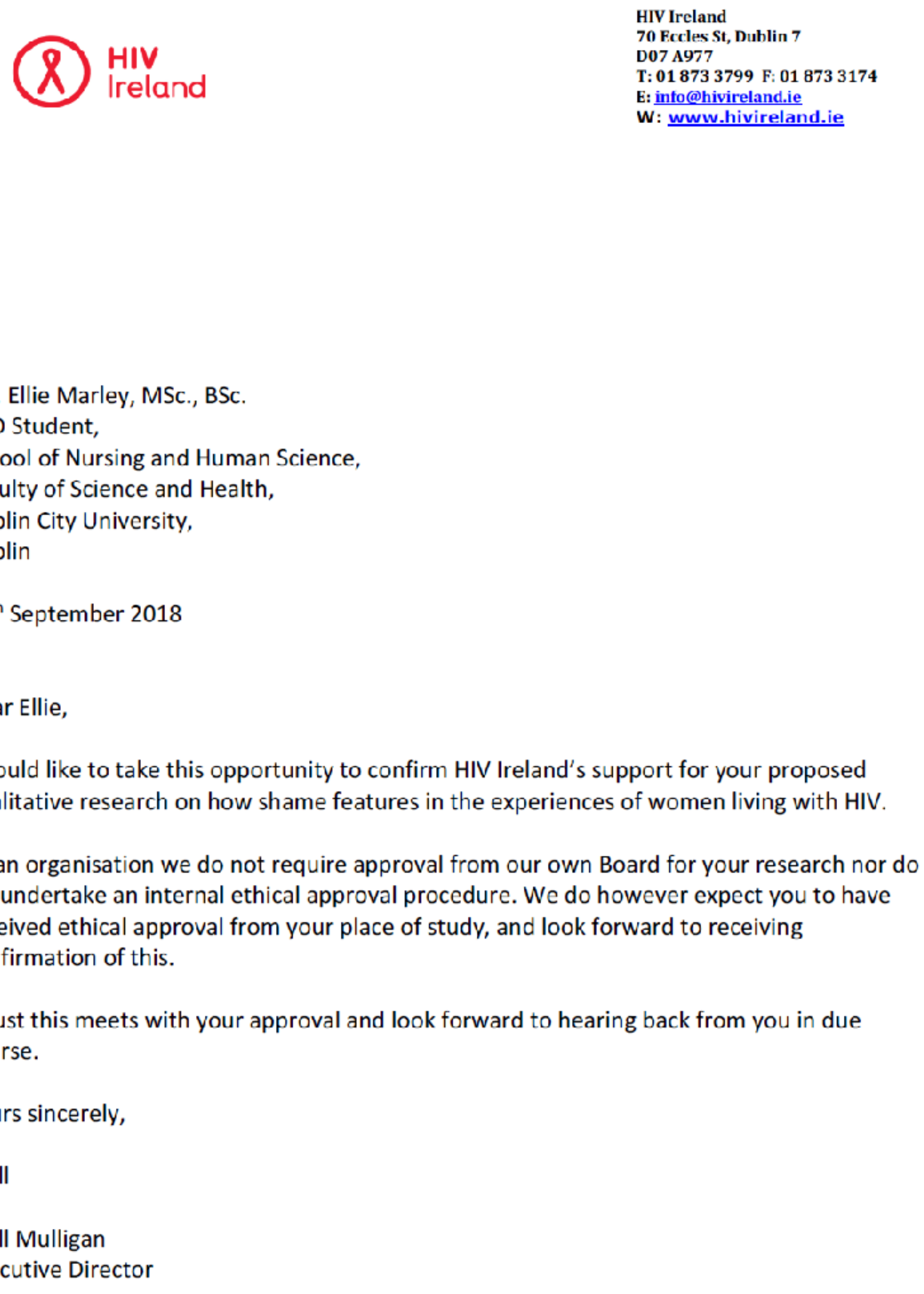
- Why did you decided to part-take in this research?
- What did you make of this experience?
- If you could change anything for women living with HIV, what would you change?

Appendix e) Participant Profile

Participant Profile:

Age range (tick beside)	18-25 26-35 36-45 46-55 55 and above
Nationality	
Place of Birth	
Children	YES / NO Number: ______________ Age/s:
Relationship Status (tick beside)	Single In a relationship Married
Level of Education (tick beside)	Primary Secondary Third Level
Occupation	
Immigration Status	

Appendix f) Letter of approval from HIV Ireland: Recruitment



HIV Ireland
70 Eccles St, Dublin 7
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Ms. Ellie Marley, MSc., BSc.
PhD Student,
School of Nursing and Human Science,
Faculty of Science and Health,
Dublin City University,
Dublin

25th September 2018

Dear Ellie,

I would like to take this opportunity to confirm HIV Ireland's support for your proposed qualitative research on how shame features in the experiences of women living with HIV.

As an organisation we do not require approval from our own Board for your research nor do we undertake an internal ethical approval procedure. We do however expect you to have received ethical approval from your place of study, and look forward to receiving confirmation of this.

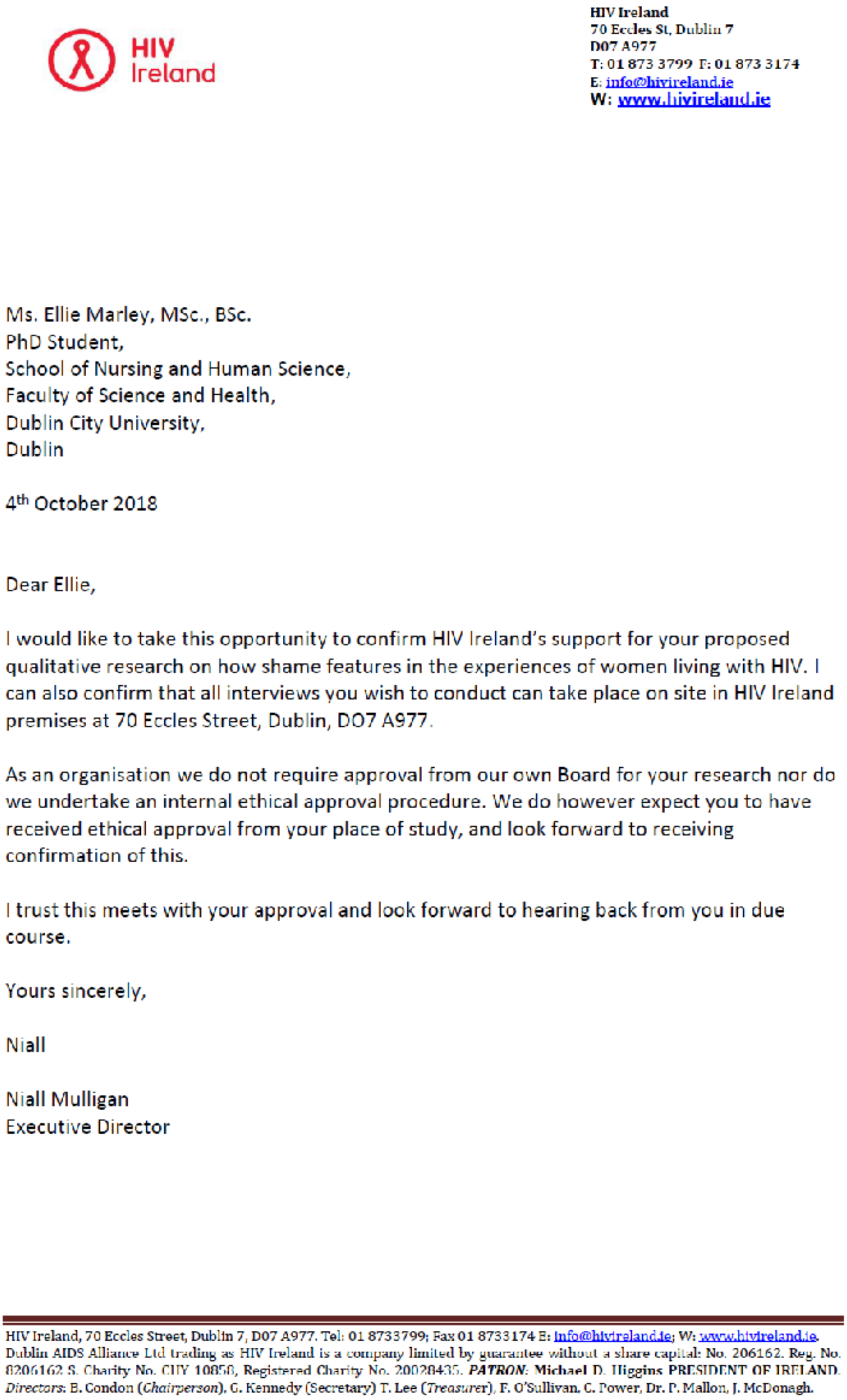
I trust this meets with your approval and look forward to hearing back from you in due course.

Yours sincerely,

Niall

Niall Mulligan
Executive Director

Appendix g) Letter of approval from HIV Ireland: Facilitating Interviews



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Ms. Ellie Marley, MSc., BSc.
PhD Student,
School of Nursing and Human Science,
Faculty of Science and Health,
Dublin City University,
Dublin

4th October 2018

Dear Ellie,

I would like to take this opportunity to confirm HIV Ireland's support for your proposed qualitative research on how shame features in the experiences of women living with HIV. I can also confirm that all interviews you wish to conduct can take place on site in HIV Ireland premises at 70 Eccles Street, Dublin, DO7 A977.

As an organisation we do not require approval from our own Board for your research nor do we undertake an internal ethical approval procedure. We do however expect you to have received ethical approval from your place of study, and look forward to receiving confirmation of this.

I trust this meets with your approval and look forward to hearing back from you in due course.

Yours sincerely,

Niall

Niall Mulligan
Executive Director

HIV Ireland, 70 Eccles Street, Dublin 7, D07 A977. Tel: 01 8733799; Fax 01 8733174 E: info@hivireland.ie; W: www.hivireland.ie.
Dublin AIDS Alliance Ltd trading as HIV Ireland is a company limited by guarantee without a share capital: No. 206162. Reg. No. 8206162 S. Charity No. CHY 10858, Registered Charity No. 20028435. ***PATRON:*** **Michael D. Higgins PRESIDENT OF IRELAND.**
Directors: B. Condon (*Chairperson*), G. Kennedy (Secretary) T. Lee (*Treasurer*), F. O'Sullivan, C. Power, Dr. P. Mallon, J. McDonagh.

Appendix h) Summary of Narrative Analysis: 3DNIS

*Pseudonyms allocated

Julie*, 50s. From East Africa

Dimension	**Shame in the account**
Interactional	Julie recognises that her HIV status was a source of shame for her due to the heightened cultural taboo of living with HIV in her east African country. Upon moving to Ireland, she feels freer in herself compared to her country of origin. Julie often spoke about the fear she held in other's learning her HIV status, particularly if people from a similar cultural background were to find out, expanding that she would be ostracised. Because Julie lives in DP accommodation, she feels quite lonely and down without her children. It is difficult for her not to be able to openly discuss living with HIV in her living circumstances but she passionately expressed that she would not do so. Julie is highly vigilant of the people around her direct provision, in particular her room-mate, as she does not want this woman to see her take any type of medication. This is a source of agitation for Julie. Regarding intimate relationships, Julie does not feel comfortable engaging in a sexual relationship with anyone who is not living with HIV. This is because she believes that another person living with HIV would not view her badly because they are both in the same situation.
Chronological	Julie was diagnosed with HIV which living in East Africa, which she felt unable to accept and was devastated by the diagnosis. Following her diagnosis, Julie's husband also tested positive and died by suicide. Julie's family were subject to ridicule in the wake of her husband death in which people assumed that her died by suicide because he was HIV positive, this assuming she was HIV positive too. Julie then moved to Ireland without her children to seek international protection, and struggled to adapt to life in DP due to barriers in taking her medication. She is constantly worried she will be caught taking medicines, and believes that if people see her taking tablets, they will assume they are for HIV. Currently, Julie meets with a group of women living with HIV where she can talk freely about her issues and share her experience with others. Overtime she became empowerment and practices self-love. Children are very supportive of her and call her regularly to make sure she is taking her HIV. Going forward Julie hopes to work with other people living with HIV by supporting newly diagnosis individuals, as she recognises the shame one might feel when diagnosed with HIV.

Situational	Much of the shame in Julie's story takes place in her DP accommodation and in health care settings. Not having any privacy appears harmful to Julie as it impedes on her management of HIV. She describes having to place her tablets under her pillow so she can sneak them at night, always looking around her in case people are looking when she is taking her medication and having to be vigilant about what food she eats in case people realise her diet is suited to taking HAART (which it is). Sometimes she will skip her medication if she cannot have privacy. In health care settings, Julie discusses a near accidental disclosure of her HIV status to her friends when a healthcare worker spoke to her about her HIV medication while her friends were beside her. Julie was conscious for some time following that her friends could search the name of the medication on the internet and learn she was taking HAART. Julie is considerate of other aspects of attending health care settings, explaining how she doesn't like having to tell health care workers that she is taking HAART. She assumes that when they ask her medication history, it is to discriminate against her.

Donna*, 40s. From East Africa

Dimension	**Shame in the account**
Interactional	HIV-related shame in Donna's account featured strongly Donna's account. She expressed HIV-related shame through feeling she is unfairly treated and it is anger inducing in the circumstances she has dealt with. Shame manifests as frustration and sadness resulting in Donna often wishing she had never contracted HIV. Donna's shame is in response to her perspective and understanding of how other people view HIV. She holds trepidation regarding people from a similar cultural background learning her HIV status. Due to a number of experiences, Donna anticipates being judged negatively and feeling badly about her HIV status. On a number of occasions, Donna's peers have negatively judged and ostracised her when they learned her HIV status. Donna decided she would not share her HIV status with anyone not living with HIV going forward, as the judgement is painful for her to deal with.
Chronological	Early on in her diagnosis, Donna unable to accept her diagnosis possibly because she believed HIV to be a stigmatising condition. Moving to Ireland and into DP, Donna's experience as an HIV positive woman when she moved into the communal living setting. She considers how others in the accommodation would treat her should they learn of her HIV status. Particular experiences of HIV stigma resulting in HIV-related shame has resulted in her not sharing her HIV-status to anyone who is not living with HIV and Donna stated that she will maintain this going forward. Donna credits meeting other women in the social group and prayer for helping her cope with HIV-related shame, however, she still

	deals with a significant level of HIV-related shame. In Donna's insight to her hopes for the future, she intends to complete her nursing degree. She has a young daughter living with her in DP and Donna's aim for the future was to find secure accommodation for her and daughter to live.
Situational	In Donna's church, she experienced HIV stigma when her fellow church attendees ostracised her for being HIV positive and she departed from the church. What was a safe space for Donna, a sanctuary and place of worship became a place where she saw others view her poorly. Donna shared another experience in the airport in Ireland in which she experienced enacted stigma, resulting in her feeling humiliated, angry and hurt. The shame of this experience in the airport stayed with Donna for many years and impacted her decision making around sharing her status. Living with HIV in the DP accommodation was central to Donna's experience of HIV-related shame. Consideration for her surroundings and physical environment intersected with her interpersonal dimension as she feared her HIV status becoming known.

Rachel*, 30s. From Ireland

Dimension	**Shame in the account**
Interactional	Rachel's HIV-related shame is deep, chronic and impactful. From a personal perspective, she viewed her contraction of HIV as a very negative aspect of her life. It has caused her a great deal of hardship in how she navigates her life. Upon diagnosis, Rachel was momentarily suicidal. Her HIV diagnosis did not align with her morals and because of how poorly she viewed HIV, Rachel could not bring herself to say the acronym HIV at the start of the interview. Rachel is insecure in herself as a HIV positive women, which stems back to her constant worry about what will happen should someone learn her HIV status. HIV-related shame impacts her experience in how she believes how others might see her as a HIV positive woman. Based on how she views HIV, she believes that others will view her poorly and judge her for being HIV positive. Rachel considers how her relationship with her children could be affected if other's were to find out about her HIV status. In navigating intimate relationships, the thoughts of sharing her HIV with another person is a risk for Rachel. Rachel has very little support for her HIV and does not share her status with other unless necessary (healthcare, research, etc.).
Chronological	Rachel found adjustment to her HIV status to be a significant challenge, although she describes having her daughter in her life made it worth living. Rachel go into a serious relationship some years later and had a second child, however, that relationship broke down. Rachel credits her perseverance, despite the psychosocial burden of living with HIV, is due to her children. Rachel maintains that her children will never learn about her HIV status, nor will anyone else in her town, to protect them. The longer that Rachel

	lives with HIV without support, her HIV-related shame is sustained over time. As time went on, Rachel spoke about ‘getting on’ with her life and has learned to appreciate the uplifting aspects that HIV has brought into her life such as adopting a healthy diet and exercise regime. The absence of support provision for her emotional health means Rachel still does not talk about her HIV with anyone in her life, with the exception of one individual.
Situational	The situation dimension of Rachel’s HIV-related shame revealed that she did not date anyone in her home town out of fear that if the relationship did not work out, the individual may share her status with others in her hometown. This is in consideration for her work life as Rachel believes that if people were to learn about her HIV in her town, her job would be in jeopardy because she works with children. Furthermore, Rachel’s HIV-related shame emerged in a clinical environment in which she learned that a nurse she spoke with was also from her hometown. Rachel expressed a deep fear that she will see this woman in her hometown and knows that Rachel is HIV positive.

Grainne*, 40s. From Ireland

Dimension	**Shame in the account**
Interactional	Grainne described being mortified following her diagnosis. She felt suicidal for a short time early on in her diagnosis but no longer feels that way. Grainne felt isolated and alone although she was married and had family around her. Grainne expressed fear early on in her diagnosis about what might happen should her family and friends learn about her diagnosis. Grainne was married at the time of her diagnosis but wanted her husband to leave her. She feels she does not have the right to initiate sex in their relationship thus is unhappy with her sex life. Regarding her family and friends, Grainne believes without doubt that she and her family would be shunned should they learn about her HIV status. Grainne’s awareness of societal HIV stigma in the environment in which she lives has left her feeling annoyed and frustrated at people’s ignorance around HIV.
Chronological	In the chronological dimension, it is evident that Grainne’s HIV-related shame persists throughout her account. Fear and worry of what was to come of life as a HIV positive women accentuated her struggle to accept her diagnosis in the early stages of account. At the time of Grainne’s diagnosis, she and her husband were due to try IVF treatment but were denied this in Ireland because of her HIV status. This was another burden of Grainne’s diagnosis, which she felt forced to keep silent. Grainne credits counselling as a being a ‘life-saver’ as the years went by. Grainne accessed IVF abroad and became pregnant, giving birth in an Irish hospital, which she

	found very stressful. She feared visitors looking at her medical chart or them possibly overhearing something relating to HIV. Grainne was further displeased in the hospital setting when midwives asked her how she contracted HIV. Currently, Grainne described being in a much better place but she maintains that she and her husband have decided that they will never tell anyone, who doesn't need to know, about her HIV status. Grainne expressed fears about the future that should she become forgetful or 'doddery', she may inadvertently share her HIV status with someone.
Situational	In the situational dimension, Grainne's HIV-related shame manifests in a number of settings. While in social settings, such as family dinners, etc., Grainne is reluctant to take her ART in front of others as she expressed concerns that they might ask what she is taking. Grainne's account referred to the 'Corridor of Doom' in her HIV clinic. She referrers to the corridor by this name because the setting is deemed unwelcoming and should someone see her there, her presence may inadvertently reveal her HIV status.

Angie*, 50s. From East Africa

Dimension	**Shame in the account**
Interactional -	In the personal dimension, Angie's shame is presented as fear and anxiety over her HIV status when she thinks of her HIV status becoming known. Upon diagnosis, Angie questioned what she had done, and how that will affect her future. Angie ponders how others will view her as a HIV positive woman. She considers this from the perspective of her husband and daughters, as well as people from her home country. Angie, as an East African woman, is awareness of the taboo of HIV (as a contagion/ moral issue) in the country that she comes from and is weary of how that will affect her future.
Chronological	Angie reacted well to received her HIV positive diagnosis. Her main concern was that she finally discovered what was making her sick and now that she had answers, she could be treated. The first thing Angie did following her diagnosis was call her mother, as she too lives with HIV. Angie mothers reassured her that she would be able to live a normal and healthy life as a woman living with HIV. This was helpful to Angie and possibly, knowing her mother was living with HIV prevented any major onset of HIV-related shame. As Angie adapted to her diagnosis, HIV-related shame was not something that featured in her day-to-day experience of living with HIV, but strongly featured in her bi-annual visits to her HIV clinic. Angie describes a weekly build-up of getting herself emotionally and psychologically ready to attend the clinic, her main concern is who she will see and more importantly, who will see her. As mentioned, Angie does not want to be seen by people from her home country as being HIV positive, although they might be HIV positive too. Currently, Angie's is focused on working with local staff members in the HSE about treating PLHIV, but she does not

	share her HIV status in this training. In the future, she hopes to speak publicly about her HIV status, suggesting she is achieving HIV-shame reduction.
Situational	The presence of shame features strongly in the situational dimension of Angie's account, which is particularly characterised upon attending her HIV clinic. Angie believes that her entering the building where the HIV clinic is as a black woman, signals to others that she is HIV positive. Although there is another clinic in the building for separate medical services, Angie believes that other would assume she must be attending for HIV treatment because she is a black woman. Angie's underlying understanding of this assumption stems from the belief that people in her vicinity commonly associate HIV with black people.

Olivia*, 50s. From Ireland

Dimension	**Shame in the account**
Interactional	Olivia revealed that her HIV meant she lost who she was as a woman, as to her it meant the loss of femininity. She no longer had respect for herself upon being diagnosed with HIV, feeling unattractive, ugly and repellent. She further believed that she failed as a mother. Olivia felt shame in the eyes of the man who infected her with HIV. She recalls the intensely painful moment he left here to be with someone and believed this was because of how he viewed her. She believed this for many years until she met him and he informed her that he could not look at her because how ashamed he felt at giving her HIV. Olivia had thought she failed as a mother in the eyes of her children, that they would view her poorly and it affect their relationship if they learned she was HIV positive. In the time that she concealed her status from them, Olivia's relationship with her children suffered and this affected the family dynamics. In reflection of societal standards of being a woman in Ireland, she felt that as a HIV positive woman, she failed to reach this standard, as she could not imagine what it would be like to live as a woman with HIV in Ireland.
Chronological	Olivia was diagnosed with her partner whom she contracted HIV from. She reflects on the diagnosis as being grateful she had him with her, and that it was a difficult yet manageable time. Moving on several months, Olivia's life came crashing down when her partner left her for someone else. It was at this point Olivia entered the most challenging phase of her HIV experience, in which she started to realise how devastating HIV would be for her. She couldn't bring herself to share her status with people for some time. Her identity as a woman and mother was compromised as Olivia couldn't envisage what her life would be like as a WLHIV. Olivia reached out to a local support agency for counselling and began to navigate the negative thoughts she had around her diagnosis. A

	significant turning point for Olivia's HIV-shame reduction was telling her children she was HIV positive. What she imagined could result in the breakdown in their relationship was strengthened by their empathy and support. Olivia described a poignant moment in her account in which she imagined her HIV to be a small animal that she initially found threatening and ugly, but soon grew to become fond of the little creature. The creature in Olivia's narrative was her HIV and represented a turning point in which she stopped feeling resentment towards living with HIV and began to embrace it. Olivia, like Angie, too would like to speak publicly about living with HIV in the future.
Situational	Like other participants, HIV-related shame in the situational dimension of Olivia's account manifested in the HIV clinic she attended. Olivia referred to her HIV clinic as 'the corridor of doom' (as Grainne did) because sitting in the corridor made her feel ashamed of having HIV. This, according to Olivia, was because the corridor was unwelcoming, outdated, and unpleasant place to sit waiting for treatment.

Ruth*, 40s. From Ireland

Dimension	**Shame in the account**
Interactional	Ruth expressed frustration and discontent at the lack of the awareness or visibility of women living with HIV in Ireland, and perhaps this stems from her feeling somewhat unable to speak openly about living with HIV due to fear of negative judgement. On the other hand, she gave a normalised portrayal of herself as a HIV positive woman, and was satisfied in her life with regards to how people viewed her, explaining that she did not care how people thought of her. Considering her son, Ruth was more vigilant about people learning her HIV status because she believed it could affect him negatively. Additionally, Ruth didn't want her son to know she is living with HIV. Ruth displays concerns about her son knowing her HIV status because of the assumptions he could make about her sexual activity, which is something Ruth does not want. When Ruth spoke about the town in which she lives, she described it as a place full of ignorance towards PLHIV. This didn't appear to cause Ruth to actively hide her HIV status from people, however, she explained that she would know who to tell and who not to tell, indicating an aspect of vigilance.
Chronological	Ruth is five years diagnosed and at the time of her interview felt that she was back to her old pre-diagnosis self. The relatively low level of HIV-related shame did not hold Ruth back from living her life. Early on in her story Ruth describes how she felt 'embarrassed'

	at the fact she had contracted HIV. Later in Ruth's story, she took a case against a major company for discrimination, which she won. The empowerment Ruth described from this appeared to give her courage. Approaching an HIV service support organisation several years ago, Ruth knew there would be other women like her and looked to reach out. Upon forming a women's group, allowing her to share her experience with other women in a similar position. Ruth still hasn't told her son she is living with HIV but explained how that could change as she grows. For her future, Ruth hopes to see an increased awareness and visibility of women living with HIV across Ireland.
Situational	In a healthcare setting, Ruth was shocked and angry when more than one health care provider asked her how she contracted HIV. Knowing that it was none of their business, Ruth refused to divulge but the experience has caused her to consider the 'small-mindedness' of the town in which she lives. Ruth is considerate of the fact that in living in an rural part of Ireland, she is not always able to see other women from the HIV positive women's group. However, having social media has been a benefit to Ruth as it is a convenient want to keep contact when she needs to.

Maebh*, 50s. From Ireland

Dimension	**Shame in the account**
Interactional	Maebh is living with HIV for almost 20 years and describes living very well with HIV. In the early part of her diagnosis, Maebh hid her HIV status from the people around her following the shock of her diagnosis. Maebh remember that HIV was not something she could related to women upon diagnosis, which was a challenge in her adaption. Maebh described feeling 'dirty' at one point in her account, and on several other occasions, had 'irrational' concerns that she could possibly infect others. She had particular concern through her hands. In keeping her HIV status from others, something Maebh felt deceitful in that although she knew she didn't have to share her medical information with people, perhaps they would be different with her had she told them she was living with HIV. However, for the people in her life who matter, Maebh cannot imagine now, how she could be stigmatised. Maebh kept her HIV status from the people around her for some time, possibly to avoid any negative judgement given the stigma of contracting HIV. However, as mentioned, currently she doesn't believe she would be stigmatised from the people she knows and cares about. Maebh describes times in her life when she was very concerned about how people would view her as HIV positive, particularly in terms of the danger she might pose. This is

	particularly to when her son's partner was pregnant and Maebh worried that the mother would not allow Maebh near the baby because it might be dangerous. Another aspect to the interpersonal dimension of shame in Maebh's account is her providing support to other women newly diagnosed with HIV, in an attempt to prevent the outcome of adaptation to HIV that she had.
Chronological	Maebh struggled to adapt to life with HIV, describing she engaged in destructive behaviour in the early months, as a distraction. Moving back to Ireland, Maebh became involved with a sexual health organisation that delivered HIV services. Here she availed of counselling and began to heal. Now Maebh likes to be there for younger women or women newly diagnosed so that they have someone who living with HIV to talk to, who had been through the experience themselves. She hopes to set up a system in her local hospital where people can avail of onsite support in the hospital.
Situational	The situational dimension of Maebh's account takes place in England and Ireland. Early in Maebh's account when she was coping with the adaption to her HIV diagnosis, Maebh felt the emotional and psychological support in her clinic in England was very helpful. Upon moving back to Ireland, Maebh felt that the Irish Health system lacked those services, this impacted on her as she felt somewhat isolation and had to go out searching for such services. Having experienced the health service as only treating her HIV, the virus, and not the emotional burden on the condition, she hopes to see greater emphasis on that side of treatment going forward.

Jenny*, 20s. From Ireland

Dimension	**Shame in the account**
Interactional	Jenny learned she was HIV positive as a teenager. She remembers feeling that as though her life wouldn't change and she would still feel the same. However, growing up Jenny felt different from her peers as she was mixed race in a predominantly white town. Once Jenny received her diagnosis, she felt different all over again. As Jenny matured, her thoughts of feeling different from her peers transformed into feeling unique and special, which is something that HIV has given to her. Jenny is considerate of who she shares her HIV status with, maintaining that if she decides not to tell someone, it is a reflection of them and not her. Jenny has felt shame in navigating intimate relationships, in that she felt that if men showed interest in her, she should be grateful because she is a HIV positive woman, placing her in an inferior position in her relationships.

Chronological	Jenny has been living with HIV for around ten years and when she learned of her diagnosis, she remembers feeling numb and that she thought she would die. In adapting to life with HIV, Jenny has the support of her parents and CHIVA in the U.K. In attending CHIVA, Jenny experienced growth and development as a young person living with HIV. However, Jenny felt that on return home, Ireland's support services were not comparable. As Jenny grew older, she navigating who to share her status with and decided to share her HIV status with friends. She learned who was supportive of her and who was not as Jenny revealed a number of highly stigmatising events that had a strong impact on her. The more Jenny came up against and overcame challenges relating to HIV, her attitude towards living with HIV changed. She now considered HIV to be a part her normal life, as normal as any other characteristic in her life, given that that is how it impacts her. Jenny has aspirations to engage in HIV activism to create change for young people living with HIV, a decision which stems from her own experience in which she benefitted from CHIVA but isolation in Ireland was to her detriment.
Situational	Being one of the only mixed race people living in her town, Jenny believes that if she were to speak openly to others about her HIV status, some would see her as more likely that her white peers to be HIV positive, as if it were somewhat expected. As Jenny considers how many people know her in her town, she imagines that were she living in a more urban setting, she could speak more freely about her HIV status without being known. Going to CHIVA in the U.K. helped Jenny adapt to HIV growing up as she got to meet people in a similar situation and share her experience with others. Upon return to Ireland, Jenny felt that she missed the supportive aspect of CHIVA in which she could feel like herself as a young person living with HIV. Back in Ireland, Jenny felt different once again.

Marie*, 60's. Oceania

Dimension	**Shame in the account**
Interactional -	Marie felt a great deal of shock and denial about her HIV diagnosis and she could not make sense of the event. Her negative experience of diagnosis was compounded by her feeling ignored in trying to get answers to her questions. Early on in her diagnosis, Marie wanted to keep her diagnosis a secret and so she and her husband did not tell people. Currently, she holds no issue with people knowing and actively will share it with people where possibly to

	raise awareness. Her attitude is that if people don't see her as a HIV positive woman, HIV will remain invisible. For much of her living with HIV, Marie's ex-partner was in her life but she reveals that he did not want her sharing her status with other people, Marie expanded by stating she believed he didn't want people knowing his partner was HIV positive, in that he dealt with HIV-related shame. Given the circumstanced behind her HIV acquisition (infected with HIV during routine medical procedure), Marie's interaction with the health service in her country were rather unpleasant as they believed she had falsified or exaggerated the event. Marie describes being made feel as though she was a burden to the health system in seeking the truth about her HIV acquisition.
Chronological	Marie was diagnosed 31 years ago at a time when there was no treatment for HIV and was told she was going to die. She describes this a difficult time for her partner and children, and because they didn't want to tell people about Marie's HIV, her family were quite closed off. Marie remembers losing some friends when they heard about her diagnosis, because their families did not want them associating with Marie. Although Marie's partner expressed discontent on the occasion that she would tell someone, when Marie and her partner split up some years later, she was freer to tell people. She did when it suited her and it benefitted her. She did not let the judgement of others hold her back from sharing her story. Currently Marie lives in Ireland and makes sure to tells the young people she meets that she is living with HIV to raise awareness and educate them.
Situational	Much of Marie's story takes place between her Oceania country and Ireland. She recalls how back in her Oceania country that women were seldom heard among the voices of people living with HIV and that awareness around HIV was about men. She felt that this contributed to a social isolation in these women, in that they didn't often meet or support each other, however, she herself was doing well. In her home country, Marie desperately tried to explain to her health service that she believed she contracted HIV during a medication procedure, however , she was told they thought was lying, that she was crazy, etc. Eventually when they realised this was the truth, she was still overlooking as a HIV positive woman because the majority of people living with HIV where she is from are gay men. Upon moving to Ireland, Marie looks to meet with social groups here, which she found and met up with. As mentioned, as she was attending a third level education course, Marie had the opportunity to tell young people in Ireland about HIV. She stated that she likes to tell people who are under the age of 30, as they are most likely to be without judgement or have a prejudicial view about people living with HIV.

Linda*, 60s. Ireland

Dimension	**Shame in the account**
Interactional	Linda was embarrassed to have contracted HIV over 30 years ago, as to her, it signalled that she had had sex outside of marriage and that was source of shame for her. Linda held a lot fear around her diagnosis, at the fact that she was dying and at the thought of people in her life finding out she had tested positive for HIV. Linda felt isolated for many years living with HIV because for a long time, she didn’t know any other women who were HIV positive, and this appeared to contribute to a degree to loneliness. Linda expressed frustration and sadness at the ignorance that still exists around HIV and she feels it better to live in secret with HIV rather than tell people. Because she doesn’t want to share her HIV status unnecessarily, Linda has never engaged in a sexual relationship to avoid sharing her status and being rejected.
Chronological	Linda was diagnosed at a time when there was no treatment for HIV and so felt quite a lot of fear regarding her impending death. However, due to the stigmatising nature of HIV, Linda had to deal with that primarily in silence and isolation. During this time, Linda gave up work so that no one would learn her HIV status. As more treatment became available, and Linda’s condition became less threatening. Still, Linda has concealed her HIV status for her daughter, as she feared that should people in her vicinity learn her HIV status that her daughter would discriminated against for being Linda’s daughter. Furthermore, she stayed away from intimate relationships since here diagnosis so she wouldn’t have to share her status to a sexual partner and face rejection. Currently, Linda works with other people living with HIV providing peer support as she believes it is helpful to have other people to talk to and get advice from because such advice is not available to people via mainstream health information. For Linda, she would like to see greater sexual education for younger people to reduce HIV stigma and equip them with knowledge that would limit HIV transmission.
Situational	In health care settings, Linda has experienced stigmatisation due to the fact she is HIV positive ahead of having medical procedures. She understood that health care workers thought she might be a threat to other patients in the health care setting. In the environment she was in, Linda felt it was difficult to confront the situation because she wasn’t sure if she was being stigmatised against and she didn’t want to draw further attention to herself. In Linda town/city where she lives, she considers that if her HIV status were to become known in the area she would be forced to move due to the negative response she could incur. As a woman in her HIV support centre, Linda is often assumed to be a member of

	staff who isn't living with HIV, rather than a female service user and peer support worker, highlighting the lack of awareness of WLHIV.

Sophie*, 50s. From Ireland.

Dimension	**Shame in the account**
Interactional	Sophie felt anger at the shame put on her by other people's stigmatising views of HIV. In diagnosis, Sophie felt shock and disbelief, as she never saw women like her deal with HIV, just gay men. She alluded to feeling shame due to the guilt she had over her daughter's health condition, which she believed was due to her taking HAART during pregnancy. Alongside anger, Sophie expressed fear at the thoughts of others learning her HIV status. Sophie felt that if people were to learn about her living with HIV, they would assume she had engaged in high risk sexual behaviour, or that she had a multitude of sexual partners in her past. Broadly, Sophie believes the stigma upheld by Irish society is causing women to feel silent and that they do not have the right to speak openly or candidly about living with HIV.
Chronological	Sophie, who was diagnosed over 20 years ago, recalls adapting to life with HIV as massively challenging. She shared her HIV positive diagnosis with her close friends who were very supportive but she recalls not associating people like her, heterosexual white women as being HIV positive. Difficult adaptation due to fear of judgement. Attending and volunteering at a social support organisation, Sophie met other women and began to feel less alone in her situation. Several years following her diagnosis, Sophie unexpectedly became pregnant and held significant concerns over the health of her child, however, she was HIV negative. Sophie recalls her experience giving birth as massively stressful as she was constantly worried that her HIV status would become known in the hospital setting. Sophie invested in counselling for herself and has tackled some of her HIV-related shame. Currently, Sophie is still private about her HIV status but the majority of people in her who are important to her know her HIV status. Sophie still feels the burden of HIV stigma driving her silence. Because of the shame she feels due to societal stigma, Sophie hopes for a major shift in societal attitudes towards people living with HIV.
Situational	While Sophie was giving in birth in the hospital she described a situation of fear and panic at the thought of her partner's family learning she was HIV positive. The setting is significant to the story as her medical information is known by a number of staff in the setting, and could potentially become known to her partner's family.

Appendix i) Establishing overarching narratives

Narrative theme	**Initial Codes**	**Micro-narratives**	**Overarching narrative title**
The nature of all the diagnosis stories were unexpected and shocking. Following diagnosis, most women did not know other women who went through what they were experiencing. In sense-making, awareness of the persistence of HIV-stigma relating to women's sexual morality and the infectious nature of HIV was shame inducing.	Isolation Information held about HIV Looking to relate De-valued by sexual activity Blame Noted fear of HIV (by others) Perceived self-affliction	The lack of a female-centred HIV discourse HIV-stigma driving shame	The Development of HIV-related shame
In adaption to and living with HIV, shame was experience in multiple dimensions. Perceived threats to their social bonds due to be negatively evaluated, strategies to avoid such breakage to a bond, and feeling such breakage were all experienced.	Vigilance Feeling vulnerable Control Secrecy Sacrifice Believed negative evaluation Anger Regret	Anticipating undesired exposure Avoiding undesired exposure Felt undesired exposure	Undesired exposure as HIV-related shame
As women met other women living with HIV, they began to feel a reduce sense of isolation in their experience. For some women this contributed to a	Empathy and understanding Relating to others Learning from others	Discovering a shared experience	Growing through HIV-related shame

change in attitude about what being HIV positive meant to them. In wanting to create change for the future, some women felt strongly about supporting newly diagnosed women. These women did not need support for themselves but recognised the benefit of such a resource for others.	Shift in priorities Normalised HIV No longer in need of HIV support Acting for change Empowered	A change in perspective In a position to help	