



**The Lived Experience of HIV-positive
Young Adults in Cork, Ireland;
A Qualitative Study**

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Abstract

Background: The number of people diagnosed with HIV in Ireland is increasing. In 2016, 508 new diagnoses were recorded, representing a rate of 10.7 per 100,000 population. Almost half of these diagnoses were in people under the age of 35. National survey findings indicate that people living with HIV in Ireland still experience stigma as a result of their HIV status. The aim of this study is to explore the lived experience of HIV-positive young adults.

Methods: Semi-structured interviews utilising a topic guide of open ended questions were conducted with three HIV-positive young adults, aged 18 to 35 years. Interpretative phenomenological analysis was used to analyse collected data.

Results: This paper highlights the psychological impact of a HIV diagnosis. Participants reported feelings of isolation, suicide ideation, and spending excessive time ruminating on their HIV status, presenting their lives post-diagnosis as distinct from their lives pre-diagnosis. Enacted stigma was encountered in both social and clinical contexts, while internalised and anticipated stigma also proved pervasive. The value of peer support groups was acutely articulated.

Conclusion: This paper suggests that interventions including mental health supports such as counselling must be accessible to people living with HIV, particularly following initial diagnosis. Peer support must also be made available to all people living with HIV. Public awareness campaigns are needed to correct misinformation and challenge HIV-related stigma.

1. Introduction

1.1 Outline of Thesis

Chapter 1 outlines the rationale for the study and its overall aim and objectives. This is expanded upon in Chapter 2, where published literature of relevance is reviewed. Chapter 3 discusses the qualitative study design and methodology while Chapter 4 presents the results from the data analysis. Chapter 5 concludes with these findings examined in the context of existing literature, along with recommendations, and strengths and limitations of the study.

1.2 Rationale & General Aim

As HIV has transitioned from a terminal illness to a chronic illness, the focus of care has also shifted. Effective treatment is now available and when correctly adhered to prevents transmission of the virus (Rodger *et al.*, 2016, Trickey *et al.*, 2017). However there are still many barriers to living well with HIV. For example the prevalence of depression and anxiety among people living with HIV (PLWHIV) is higher than the general population and patients with other chronic illnesses, and HIV-related stigma is strongly associated with psychosocial distress (Lowther *et al.*, 2014). HIV diagnoses are increasing in Ireland, with 508 new cases reported in 2016. Almost half of these cases were in young adults (Health Service Executive, 2017). However there is a dearth of these voices in the literature, so their experiences merit exploration. This exploration can offer service providers a deeper understanding of this demographic and how to best cater to their needs.

1.3 Aims and Objectives

Aim: The aim of this study is to explore the lived experiences of HIV-positive young adults (between 18 and 34 years of age) in Cork, Ireland.

Objectives:

- Explore participants' experiences of living with HIV (LWHIV).
- Explore participants' experiences of stigma, and if identified examine its origin and type.

2. Literature Review

2.1 Living with HIV

Clinical treatment for PLWHIV has improved dramatically over the last thirty years. Studies show that after a year of successful antiretroviral treatment, the life expectancy of PLWHIV is approximately the same as those living without HIV (Trickey *et al.*, 2017). Antiretroviral treatment can also facilitate viral suppression to undetectable levels, meaning there is no risk of sexually transmitting the virus (Centres for Disease Control and Prevention, 2017). The international prospective PARTNER study observed no transmission out of 58,000 condomless sex acts between serodifferent couples where the partner LWHIV is using antiretroviral therapy (Rodger *et al.*, 2016). However, research shows that HIV-related stigma is still a major challenge, one that negatively affects the life and in particular the health outcomes of PLWHIV today (Rueda *et al.*, 2016).

2.2 HIV-related Stigma

The seminal work by Link & Phelan (2001) defined stigma as the “co-occurrence of labelling, stereotyping, separation, status loss, and discrimination” in contexts where power is exercised. It also recognised that stigma has an effect on life chances such as income, education and overall health. Current research broadly conceptualises three main types of HIV-related stigma; enacted, anticipated, and internalised. In this context enacted stigma refers to the experiences of discrimination encountered by PLWHIV (Rueda *et al.*, 2016; Steward *et al.*, 2008). Anticipated stigma refers to an awareness of negative societal perceptions of HIV, and expectation of discrimination/rejection/stereotyping in the event of infection (Golub & Gamarel, 2013; Rueda *et al.*, 2016). Internalised stigma refers to the endorsement of negative beliefs associated with HIV, applying them to oneself when HIV-positive (Steward *et al.*, 2008; Earnshaw *et al.*, 2013).

2.3 Negative HIV-related Stigma Outcomes

A recent report from UNAIDS (2017) outlined how HIV-related stigma deters people from accessing healthcare services, and Sayles *et al.*, (2009) found that PLWHIV reporting high levels of stigma were over four times as likely to report

poor access to care. This presents a clear problem, as timely diagnoses and access to treatment and supports help improve the quality of life of PLWHIV, as well as their life expectancy and infectivity (May, 2016). In a systematic review and meta-analysis of 64 studies, Rueda *et al.*, (2016) found significant associations between stigma and higher rates of depression in PLWHIV, as well as lower rates of adherence to antiretroviral therapy and utilisation of social supports.

2.4 HIV in Ireland

HIV diagnosis in Ireland is increasing. 508 new diagnoses were recorded in 2016, representing a rate of 10.7 per 100,000 population, and 5% total increase from 2015. 34% of cases were in people previously diagnosed abroad, of which 86% transferred their care to Ireland. Of the 508 diagnoses, 51% were among men who have sex with men (MSM) which is the highest recorded number of diagnoses in this subgroup since reporting began (Health Service Executive, 2017). As diagnoses continue to rise it is imperative we understand the experiences of PLWHIV and HIV-related stigma in an Irish context.

2.5 HIV-related Stigma in Ireland

It is clear that HIV-related stigma persists in Ireland, and a recent national survey of PLWHIV found that 51% were offended by language used on social media pertaining to HIV, 35% reported that some people do not want to associate with them because of their HIV status, and “a large minority [17%] reported feeling suicidal in the past year due to their status” (compared to ~4% of the general population) (Gardner *et al.*, 2017). This depicts HIV-related stigma as a phenomenon manifesting across multiple social domains in Ireland.

2.6 The Lived Experience of HIV-positive Young Adults

Peltzer *et al.*, (2014) examined the lived experiences of HIV-positive African-American women, aged 18-35, and found they experienced interconnected feelings of isolation and stigma. Arnold *et al.*, (2014) also reported isolation/rejection, further complicated by racism and homophobia in HIV-positive young gay Black men. Suicidal ideation was commonly reported in a study of newly diagnosed HIV-positive MSM in China, aged 18-40 (Li *et al.*, 2017)

where isolation and a culture of heteronormativity contributed to significant levels of distress among participants. Abraham & Jukes (2012) explored the lived experiences and management of stigma in HIV-positive people in Africa, aged 19-39, and found almost all reported anticipated stigma, despite few having experiences that resulted in discrimination or loss of social status. Silva-Suárez *et al.*, (2016) focused on 18-29 year olds with perinatally acquired HIV and their lived experiences within a family context. Although family provided a loving support network for most participants, some also experienced rejection from specific family members.

2.7 Conclusion

In an Irish context, France *et al.*, (2016) has qualitatively explored HIV self-stigma and Patrick *et al.*, (2015) noted the prevalence of internalised stigma in HIV-positive MSM. However no such research has been conducted with a specific focus on HIV-positive young adults. Young adults are living in a changing Ireland that increasingly values social reform, notably becoming the first country in the world to legalise same-sex marriage via referendum in 2015, having decriminalised same-sex activity in 1993 (Murphy, 2016). However it is not clear whether Ireland has made similar strides with regard to stigma and LWHIV. As 47.5% of new HIV diagnoses in Ireland in 2016 were in people under the age of 35 (Health Service Executive, 2017) it is important that we better understand the lived experiences of this demographic. This study subsequently aims to examine the factors which contribute to young adults experience of LWHIV in Ireland, and where stigma is identified its origin and type will be examined. This will be useful in informing and focusing the work of service providers that aim to improve the quality of life of young adults LWHIV.

3. Method

3.1 Literature Search

Table 1: Literature Review Search Strategy

Databases	Key Terms	Inclusion Criteria	Exclusion Criteria
1. Google Scholar 2. EBSCO 3. PubMed	1. "HIV" 2. "lived experience" 3. "stigma"	1. Published 2000-2018 2. Peer-reviewed 3. English language text 4. Qualitative methodology with interviews and/or focus groups with HIV-positive adults under the age of 40 of any gender, socio-economic status and ethnic group	1. Unpublished literature 2. Foreign language text 3. Quantitative method only 4. Published pre-2000

Field searching and Boolean operators used as appropriate.

3.2 Qualitative Study Design

This study uses qualitative research methods to explore the lived experiences of HIV-positive young adults. It provides rich, contextual descriptions of phenomena of interest (Smith & Dunworth, 2003), placing emphasis on understanding the subjective experiences of participants, and the meaning they ascribe to them (Power, 2002). Kotarba (1990) highlighted the importance of qualitative research in understanding the sociobehavioural aspects of HIV, and qualitative research has been shown to contribute significantly to our understanding of HIV/AIDS (Power, 1998).

3.3 Interpretative Phenomenological Analysis

This study utilised interpretative phenomenological analysis (IPA) because it produces rich accounts of lived experience from the perspective of study

participants, and is suitable for exploring complex and emotional phenomena. IPA draws on key components of phenomenology, hermeneutics, and idiography (Smith *et al.*, 2009). Phenomenology focuses on an individual's experience of a phenomenon and the sense they make of their experience, while recognising that it does not exist in isolation but is shaped by culture, society, and history (Eatough & Smith, 2008). Hermeneutics acknowledges that IPA is an explicitly interpretative activity. It recognises that researchers carry their own preconceptions and assumptions but care can be taken to identify these assumptions and a degree of reflexivity employed to ensure their impact is minimised (Smith *et al.*, 2009). Idiography encourages a small sample size, where each individual case is analysed in-depth prior to making generalised assumptions (Pietkiewicz & Smith, 2012).

Many studies have recognised IPA as an appropriate method of study design to examine the experiences of PLWHIV (Flowers *et al.*, 2011, Skinta *et al.*, 2014, Yang *et al.*, 2015, Spiers *et al.*, 2016).

3.4 Sample

IPA values rich, detailed descriptions of experiential phenomena, and as a result purposeful sampling was used. This method is commonly used in qualitative research and involves the selection of information-rich cases to facilitate in-depth study (Patton, 2002). Purposeful sampling aims to yield a more comprehensive understanding of the phenomena of interest - in this case the lived experience of HIV-positive young adults - rather than ensuring the generalisability of findings. Because of this and the idiographic nature of IPA; a small sample size is most appropriate. Three HIV-positive young adults were recruited via the Sexual Health Centre, where staff were informed of the study and its aims and asked to make potential participants aware of same.

3.5 Data Collection

One-to-one, semi-structured interviews (45-90 minutes) were conducted to explore the lived experiences of HIV-positive young adults. Semi-structured interviews - utilising a topic guide of open-ended questions - facilitated the collection of relevant data of appropriate depth, remaining flexible enough to

account for the unique experiences of each participant (Mason, 2002; Silverman, 2017). The topic guide was informed by the research question and literature review. As per the guidelines of IPA, key questions were phrased in an open way that refrained from leading the participant, or making assumptions about their experiences (Smith *et al.*, 2009). A pilot interview was performed with a staff member of the Sexual Health Centre to assess the suitability of this guide. No necessary changes were identified.

Interviews were conducted in a private room in the Sexual Health Centre. Informed consent was obtained from all participants. An information sheet was provided outlining the aims of the study, what participation will involve, how data will be used, and participants rights. A consent form was provided for the participant to sign if they wished to continue with the study. The researcher ensured participants understood their participation was voluntary, and they were free to withdraw with no repercussions at any point prior to the interview and up to two weeks afterwards, whereby their data would be destroyed.

Participants were assigned a pseudonym and made aware that although direct quotes will be used in the written report any identifying information would be removed. Audio recordings and transcripts were kept in a secure location, which only the researcher has access to. Participants can request the audio recording or transcript of their interview, and will be offered a copy of the final report.

3.6 Data Analysis

Data was analysed using IPA. Interviews were transcribed verbatim and re-read multiple times to immerse in the data. Care was taken to ensure the participant was the focus of the analysis; bracketing was used to take note of any assumptions or sense of bias that arose on behalf of the researcher, so that they could be set aside, and later reflected upon.

An initial analysis of the transcripts was used to generate a detailed set of notes on the data. Notes focused on describing the content and the participant's use of language, before taking a more interrogative approach. These notes were used to help further develop emerging themes. Codes and emerging themes were checked by a second researcher to minimise the risk of bias.

Once a set of themes were established the process was repeated for the next case. Emerging themes were bracketed and the described method of analysis systematically adhered to in order to ensure each case could be viewed on its own terms, as per the idiography of IPA.

Once all cases had been analysed in this way, cross-case analysis was performed to search for patterns in the cases.

3.7 Ethical Considerations

Ethical approval for this study was granted by UCC Social Research Ethics Committee.

Given the nature of the research, recalling past experiences had the potential to cause some feelings of distress. Participants were made aware that they can take a break or stop the interview at any time, and offered time to voice any questions/concerns at the end of the interview. A list of supports were provided and a counsellor was available to them at the Sexual Health Centre.

4. Results

4.1 Introduction

Analysis of semi-structured interviews with three HIV-positive young adults was performed and three superordinate themes were identified. These themes were further comprised of nine subordinate themes, as depicted in Table 2. In this chapter each theme will be presented with select supporting extracts from the participants' interviews.

Table 2: Superordinate and Subordinate Themes.

Theme 1: Psychological Impact of HIV Diagnosis
Isolation
Thoughts of Suicide
Rumination
Living a Different Life
Theme 2: Culture of Stigma
Disclosure as a Risk
Intersectionality of Stigma
Value of Education
Theme 3: Significance of Support Services
Validation
Unique and Shared Lived Experience

4.2 Theme 1: Psychological Impact of HIV Diagnosis

This theme highlights the extent to which the participants mental health and emotional wellbeing has been affected by their HIV diagnosis. All the participants adhere to a regimen of antiretroviral medication which they recognise as important in maintaining their physical health, however the psychological impact of coming to terms with and LWHIV has presented its own challenges.

4.2.1 Isolation

Immediately following their diagnosis participants described feelings of complete isolation. This is perhaps best illustrated by Jack's account of receiving his test results.

Jack: "You go up to a clinic and you come in, the doctor sits you down in this room and she goes "oh we have your results back we tested you three times for HIV you came back three times as being positive". And inside that small room I just felt like you're on your own, no one wants to know you, and your life has fallen apart".

The positive test result is a catastrophic event and Jack assumes a position of isolation that is not dissuaded by the presence of a doctor. Despite later disclosing to supportive family members this possibility is not considered and rejection seems inevitable.

Isolation was also self-employed in efforts to prevent compounding the difficulty of LWHIV.

Noah: "Sometimes I just keep myself out of people, and just maybe keep myself alone and just be in a certain place the way I can just think and meditate."

Jack: "You feel like you're isolating you feel like you're alone, and you feel the best for you is basically to go into this isolation period and what you want to do is like lock yourself away and that's it."

For Noah and Jack, isolating themselves affords protection against the complicated nature of interpersonal relationships while they are coming to terms with their diagnosis during a time of emotional fragility. This also informs the decision making process with regard to disclosure and will be discussed in section 4.3.1.

For Sophie, the threat of lifelong isolation following her HIV diagnosis proved significant. Recognising this potential harm was the motivating factor in seeking help from a support group.

Sophie: "If you don't go [to the support group] you're gonna be on your own forever."

4.2.2 Thoughts of Suicide

Participants reported extreme emotional distress following their diagnosis. LWHIV proved overwhelming to an extent where suicide was considered a plausible route to escaping this distress, highlighting the severity with which a diagnosis has the potential to negatively affect the mental health of a person.

All participants initially viewed premature death as an inevitable consequence of their diagnosis.

Sophie: "[I] feel like throwing myself into the river. Just straight over like. Like my life was over I didn't know that you get all this medication and now it's undetectable, I didn't know any of that stuff, so I was just like my life is over like it's just gonna kill me, 'cause I had no idea."

Sophie's lack of education with regard to HIV treatment resulted in feelings of hopelessness that contributed to suicidal ideation.

Sophie mentioned on a number of occasions that she wished she had known to bring someone to the clinic when receiving her HIV diagnosis. The diagnosis was a shock, and without the emotional support of a family member or friend she felt particularly vulnerable.

Sophie: "I went on my own and I literally just ran, and I was just walking past and I was like will I just throw myself into the river and end it, nobody will ever need to know. And then I was like can I do it and I was like no I really can't do it. So they could like ring and say something did show up, bring somebody with you."

Noah's diagnosis resulted in feelings of anger, which he internalised and manifested in self-destructive behaviours. Despite recognising the benefits of antiretroviral therapy, he stopped taking his medication for two weeks when feelings of hopelessness meant planning for the future seemed redundant.

Noah: "At that time I was just thinking of killing myself. I didn't want anything like, I mean honestly, in that time it's like, I stopped taking my medication for two weeks. I didn't take any of my-I just stopped like. The reason I did that is because I was just angry at myself and angry at my life and I just wanted to end my life."

LWHIV also proved emotionally overwhelming for Jack, prompting him to question if it would be easier to end his life than to continue living with the lifelong burden of his diagnosis. Ultimately he was dissuaded by thoughts of family and friends, motivated by his valued relationships with them.

Jack: "Your family would be suffering very much because they have lost a son or a daughter because you were only thinking of yourself and your only outlook was, you go off and kill yourself, because you can't deal with it. And I was thinking an awful lot of that for a very long time, that I'm gonna end my life because I can't deal with this anymore."

4.2.3 Rumination

Participants spent excessive time ruminating on their HIV status, be that questioning their own role and the role of others in their diagnosis, or forecasting potential complications and other difficulties post-diagnosis.

Jack recognises the harm that this rumination caused him, discussing how it contributed to his depression and isolation. However it only is only in hindsight that the futile nature of this torment became clear.

Jack: "I was with depression for a very very long time, 'cause you're just sitting at home going why did it happen to me how did it happen to me and you're like there's no point thinking ifs and whys and who was it with, because it's very hard. But that's what I was like for a long time."

Sophie similarly recognised the unnecessary burden in dwelling on unanswered questions regarding her contraction of HIV, acknowledging this rumination as a barrier to moving forward with her life.

Sophie: "It's just tiring like I want answers that I can't get, that I'm never ever gonna get as long as I live."

Sophie: "I need these answers that I know I can't get and it's still in my head that you're never gonna get these answers so just put it to the back of your head and move on."

Noah struggled the most with this rumination, finding himself so frequently consumed by thoughts of his HIV status that it results in acute psychological distress, impeding his ability to function in day-to-day life.

Noah: "I think about it [HIV status] every day, even sometimes I don't sleep at night, I think about it, I think how am I gonna survive, maybe am I gonna reach the age of 60 or 70 or whatever, when am I gonna die like, so it's something that keeps on coming into my brain and you know, I don't function very well."

4.2.4 Living a Different Life

Participants presented their lives post-diagnosis as distinct from their lives pre-diagnosis. The impact of their diagnosis was strongly felt when realising aspects of their lives they previously took for granted no longer felt secure.

Noah: *“I’m just living a life but, the life that I used to have before is not the one that I’m living right now.”*

Noah: *“Everything has changed like, like I said my life is not the same. I just feel like maybe I’m dead and maybe I’m dying soon or something, you know.”*

Noah: *“[if you are being] disconnected, or maybe people are talking about you, you know, it ruins your life, you don’t live the life that you’re supposed to live.”*

These extracts illuminate the sense of grief Noah feels for the life he lived pre-diagnosis. Both his present and future feel lost, living a life he has been given as opposed to a life he has made for himself. This feeling of powerlessness and lack of autonomy is further compounded by the isolation and stigma of LWHIV.

Sophie too feels the future she took for granted has now been lost as a result of her diagnosis. She no longer sees herself represented in the family unit, forcing her to question the prospect of motherhood. This uncertainty hinders her ability to feel hopeful about her future.

Sophie: *“It’s like, I keep saying ‘oh I’ll have kids someday’, but I don’t know. Like all the people I’ve met and all that stuff, you’ve never, I’ve never seen any young girl my age that has it [HIV], that has a family. They’re all like older, like older women.”*

Sophie: *“It’s just hard like, not knowing will I ever be in a relationship again.”*

4.3 Theme 2: Culture of Stigma

This theme highlights the multitude of ways in which the participants experienced HIV-related stigma. Anticipated, enacted, and internalised stigma was experienced in a variety of settings, often inextricably linked, and framed as an inescapable consequence of LWHIV.

4.3.1 Disclosure as a Risk

For participants disclosure was a balance of probabilities between the risk of stigma and the reward of support. Anticipated stigma made participants fearful of potential backlash, which given their already vulnerable emotional state they were anxious to avoid. Noah in particular was very distressed following his diagnosis, and as a result concluded the risk of disclosure was too great.

Noah: "So I just feel like if I tell people, if I tell even my friends about it, it's gonna like ruin my life like, you know, things will be worse than maybe how it is now. So it's better for me to just think about it myself."

Noah had also witnessed enacted stigma prior to his diagnosis, and non-disclosure offered a way of protecting himself from similar discrimination.

Noah: "I don't wanna like be the same as how [the HIV-positive] people were feeling at that time, I don't wanna like involve myself in that kinda situation you know, because maybe I'm gonna like kill myself."

Internalised stigma persists as it cannot be as easily avoided via non-disclosure.

Noah: "It's just only in me now. It's like now I'm hating myself."

Sophie: "I went home and I literally just had a shower because I felt dirty and I just didn't feel clean."

Risk of rejection was at the forefront of the participants' minds, the experience feeling dehumanising and a complete disregard of their personhood. This informed participants' decision to not disclose as acceptance could not be guaranteed.

Jack: "It's a horrible thing to have, and when people are rejecting you it's the worse thing that ever happened to you."

Jack: "You feel like you're, that you're someone who has leprosy, it's like ... you're thrown to the side and they don't want to know about you no more".

This also further highlights the significance of the social impact of LWHIV.

Participants decided to disclose when they reached a threshold of emotional distress whereby the risk to their health as a result of isolation outweighed the risk of rejection. LWHIV can be a burden to cope with alone and disclosure serves as a coping mechanism to remove some of that burden.

Jack: "You're very trapped in yourself, it's like you were screaming in the inside but no one was hearing you and that's what was happening with me. You're going around with your head to the ground you feel like everybody is looking at you, you're very very paranoid. And once I started disclosing my status to people I was like, it was a weight being lifted off my shoulders, and it made me happier."

Sophie: "Cause I was feeling depressed and suicidal I was like I'm either gonna hold it back to myself and battle and keep it to myself and it'll get worse and worse, or else I can just [describes disclosure]"

4.3.2 Intersectionality of Stigma

Participants' experiences of HIV-related stigma were shaped by other aspects of their lived experience, predominately gender and sexuality.

Jack, a gay man, perceived his HIV status to be particularly "taboo" within the gay community. Given the historical significance of HIV in the gay community and the shared social identity of its members, Jack perhaps expected some amount of solidarity. Instead, he has experienced enacted stigma in the form of social rejection.

Jack: "To this day and age now if you go out in the gay scene anywhere, you go to a future partner 'I'm HIV-positive', the first

thing they're going to do is 'oh no, I can't be friends with you, I can't go out with you'. They're terrified because they don't want to be seen that they're friends with someone who has this illness."

Noah also identifies as a gay man, and as a result has been rejected by his parents. This means he cannot disclose his HIV status to them and avail of valuable familial support.

Noah: "When I got this infection it was something very hard for me even to explain to them because I am already in a situation whereby like they don't wanna talk to me."

While Jack does disclose his status to an ultimately supportive mother, the stress of disclosure is compounded by the recent disclosure of his sexuality. Narratives of guilt and shame meant he too feared rejection from his parents.

Jack: "It [his HIV status] was the final nail in the coffin as they say, it was like rubbing salt into the wound."

As a young adult Jack expected his peers to be educated about HIV, given the availability and accessibility of reliable health promotion material. However he noticed his youth afforded him no protection against HIV-related stigma as *"people of my age are actually people who are actually having the stigma"*. This deconstructs binary narratives of old conservatism versus youth progressivism.

Sophie contracted HIV via sexual contact and reported feeling the culture of sex negativity in Ireland informed their HIV-related stigma. She felt her sexual activity would be harshly judged and people would incorrectly presume to know her sexual history. Uncomfortable, Sophie employed non-disclosure as a method of stigma avoidance.

Sophie: "[On why she chooses non-disclosure] I'm afraid that people will just think of me in a different way, than what people think of me now. They'll be like 'oh stay away from her, how the fuck did she get that' d'you know what I mean? Like 'she's sleeping with everybody' when I was only with the one person for years."

4.3.3 Value of Education

Participants strongly believed that the stigma they faced as a result of their HIV status was culturally entrenched due to a lack of education.

Participants found HIV and AIDS were synonymously used terms, though they rejected any association with AIDS, finding it increased their risk of enacted stigma. While this misconception mostly stemmed from ignorance, AIDS was also weaponised as a form of stigmatising language. This caused great offense as it invalidated the struggles of participants. Using their difficult and at times traumatic experiences for jokes felt deeply disrespectful.

Sophie: "Like when they hear HIV they automatically say 'oh she [has] AIDS' d'you know that kinda way, it's just natural. That's my only fear really like."

Jack: "But the word AIDS is not something to be joking about, because like, it's bad enough having the stigma but then you're having people making a joke out of this. And they're just making a mockery of it."

Participants frequently noted that misinformation regarding the transmission of HIV is particularly damaging, fuelling enacted stigma by othering PLWHIV. This dehumanisation proved acutely frustrating.

Jack: "And that's what annoys me the most, you're just wondering why are people having this ideology, why are they so ignorant. Why can't you just broaden your mind and go first of all you can't catch it by touching or kissing or by touching a cup or sitting down by their seat."

Participants knew very little about HIV prior to their diagnosis. They discussed the value in educating younger generations about HIV, which likely reflected the education they wish they had received prior to their own diagnosis.

Sophie: "The younger generation they need to know."

Jack: "You're actually giving information to these people [students] who won't get caught like people like me."

Their lived experience of HIV has inevitably deepened their appreciation for HIV education and prevention, though stigma is still a barrier for PLWHIV who wish to be advocates.

Noah: "If people come out on that TV and say it [that they are HIV positive], at the end they get discriminated."

4.4 Theme 3: Significance of Support Services

Given the psychological impact of diagnosis and experiences of stigma described in section 4.2 and 4.3, it is evident that LWHIV requires a holistic approach, caring for the whole person – both body and mind – in order to fully embrace wellness. It is imperative that support services facilitate this goal. This theme highlights the impact that support services (or lack thereof) can have on the experience of LWHIV.

4.4.1 Validation

It is vital that PLWHIV feel validated by their health care providers. HIV is a chronic illness that requires lifelong support, and it is evident that the quality of these supports mattered deeply to participants.

When seeking support following his diagnosis Jack felt completely dismissed by clinical staff. Comparing his experience to being left in the “wilderness” he evokes the sense of abandonment he felt. Being subjected to enacted stigma in a clinical setting in the form of victim blaming discouraged him from engaging any further with these services. As a vulnerable teenager Jack felt his care was not prioritised, and as a result this experience damaged his trust in the health service.

Jack: "I d'you know was saying to her [doctor] I'm HIV-positive and she kinda turns around to me she goes it's your own problem get over it."

Jack: "I'm like yes I know it was my own fault, but, a doctor should not be telling someone at the age of 17 it's your own fault, I'm like going d'you know completely just rub it into my face again."

Jack: "You've no empathy inside the hospitals, you go in there, when I went in there there was no empathy, absolutely nothing at all."

Noah's experience was similarly impactful, but on the opposite end of the spectrum. His visits to the doctor or clinic are a reliable system of support. Unable to disclose to friends or family, he feels relief in having a safe space where he can openly discuss his experience (feel "free") and access supports. Doctors offer reassurance, encouragement and information that he cannot access anywhere else, and so visiting the hospital always proves a positive and valued experience.

Noah: "HIV [-positive people] they are more like free like whenever they go to the hospital and when the doctor is trying to I mean advise you or maybe tell you things or maybe tell you something else that will, I mean, change everything the way you think about it. It helps us, it helps a lot."

Noah: "I'm so happy like if I go there. Of course some times when I go to hospital I feel like maybe I have bad pressure or something like that, but when I go there and I see him and he talks to me and he says 'how are you feeling oh no oh this time around your bloods are okay yeah this and that okay so are you taking your medication yeah continue and you'll be fine' there are so many things he says, he talks to you and encourages you".

This suggests standards of delivery of care have either improved since Jack was diagnosed, or are inconsistent and dependant on the care provider themselves.

4.4.2 Unique and Shared Lived Experience

All participants spoke very favourably of their peer support group. This group offers a safe space for PLWHIV to share their experiences and both give and receive support, fostering a sense of community built on mutual respect and understanding. Participants valued socialising with peers because their shared experience of LWHIV meant they could empathise and relate to one another in

ways that even supportive and well-intentioned friends or family members could not.

Sophie: "The people in the group, we text like if I've a problem, or you could text them and they know what you're going through, cause my [immediate family] they don't know what I'm going through, because they've never been through it."

Peers also serve as role models to younger or more recently diagnosed PLWHIV. Noah feels powerless and fears for his future, but seeing PLWHIV into old age offers him hope and encouragement. Their advice is valued.

Noah: "There are some people in the group who lived with HIV for over 60 years so you get some advices from them like they will tell you how they have lived I mean to that age. So, yeah, it helps like when you see them they say 'oh you know look at me I do this I go to the gym I do that' so it's something like when you see them when you talk you get encouragement like yeah maybe I will live again."

Having lived with HIV for a number of years Jack finds sharing his experience with other PLWHIV rewarding, hoping to offer advice and support that will allow them to have a better experience than he did.

Jack: "You can give them the help you can give them the assistance, and they won't be on their own like I was when I [was diagnosed]."

5. Discussion

5.1 Introduction

The aim of this study was to explore the lived experiences of HIV-positive young adults in Cork, Ireland. Through semi-structured interviews three superordinate themes were identified, which will be discussed in this chapter in relation to existing literature. Recommendations, and strengths and limitations of the study will also be outlined.

5.2 Psychological Impact of HIV Diagnosis

A main finding of this study is the extent of the psychological impact of HIV diagnosis. Participants reported feelings of isolation, often isolating themselves as a method of stigma avoidance. Peltzer *et al.*, (2014) and Arnold *et al.*, (2014) similarly reported young HIV-positive African American women and Black gay men isolating themselves to minimise the threat of stigma, while a study by Webel *et al.*, (2014) found that younger PLWHIV were significantly more isolated than older PLWHIV. This suggests there is merit in targeting interventions to combat isolation in young adults.

Suicide ideation was reported by all participants. Their diagnosis resulted in extreme emotional distress and significantly impacted their mental health. This resonates with national survey findings that a large minority of PLWHIV in Ireland felt suicidal in the past year due to their HIV status (Gardner *et al.*, 2017). Suicidal ideation has long been associated with HIV diagnoses (Kelly *et al.*, 1998, Siegel & Meyer, 1999) and evidently still affects PLWHIV to this day (Schadé *et al.*, 2013; Li *et al.*, 2017). This highlights the importance of screening for suicide risk in PLWHIV, particularly after their initial diagnosis.

Repetitive negative thoughts or rumination also featured prominently in the accounts of participants. These are positively correlated with depression and anxiety (Segerstrom *et al.*, 2000) and participants themselves recognised the extent of harm this rumination caused them. Where excessive worrying and rumination is reduced so too are the symptom levels of anxiety and depression (Topper *et al.*, 2017) and so PLWHIV should be actively supported in the healthy

emotional processing of their diagnosis. Similar to Leyva-Moral *et al.*, (2015) participants expressed a loss of autonomy as their future felt irreversibly changed by this diagnosis. It is important that service providers empower PLWHIV with the education and resources to adapt to this new life.

5.3 Culture of Stigma

Non-disclosure was often employed by the participants as a method of stigma avoidance. Their experiences of anticipated, internalised, or enacted stigma meant that they were afraid to disclose their status and compound the already difficult reality of LWHIV. As is the case in this study, Derlega *et al.*, (2004) proposed PLWHIV with a high degree of anticipated stigma may be less likely to disclose their status for fear of social rejection. Some participants also reported experiencing depression, which Murphy *et al.*, (2018) says can be positively predicted by internalised and enacted stigma. Stigma is associated with an increase in depressive symptoms among PLWHIV (Vanable *et al.*, 2006) and so it is clear that interventions to promote the mental health of PLWHIV should be complimented by interventions to reduce societal stigma.

Experiences of stigma were shaped by other facets of participants' identities, namely gender and sexuality. Participants who identified as gay men experienced stigma as a result of their sexual orientation, and one felt further marginalised for his HIV status within the gay community. HIV-related stigma has previously been documented in the gay community by Smith *et al.*, (2012). This merits consideration as Ferlatte *et al.*, (2017) found that experiencing multiple forms of stigma was associated with a significantly increased risk of suicide ideation and attempt. Participants did not feel supported by the gay community in their experience of LWHIV, as previously suggested by Murphy *et al.*, (2015). There is a lack of literature exploring the lived experiences of women LWHIV in Ireland and so this is a potential area for future research.

Participants perceived the public to be uneducated with regard to HIV transmission and infection, further contributing to stigma in the form of offensive language, stereotyping, and othering of PLWHIV. This is unsurprising given that almost a quarter of respondents in a national survey of HIV knowledge and attitudes in Ireland mistakenly believed HIV could be transmitted via kissing.

However where Gardner *et al.*, (2017) found younger people were more likely to be accepting of PLWHIV than older people, one participant in our study reported experiencing the opposite. Given the assumption those more educated about HIV report lower rates of HIV stigma (Balfour *et al.*, 2010; Li *et al.*, 2010) it would be worthwhile targeting HIV education interventions to young people in Ireland, for example through secondary schools.

5.4 Significance of Support Services

Interactions with health care providers had a profound effect on participants, and it was important that they felt validated and cared for. One participant encountered enacted stigma in a healthcare setting as they were dismissed and blamed for their diagnosis by their doctor, an understandably upsetting experience. Other studies have shown that stigma still persists in healthcare settings (Ekstrand *et al.*, 2013; Chambers *et al.*, 2015) and can negatively impact a person's access to and quality of care (Kinsler *et al.*, 2007). It is clear then that education is needed for clinical staff as well as the general public to help combat HIV-related stigma. In a national survey of PLWHIV in Ireland 18% reported their HIV status had been accidentally disclosed in a hospital setting, and so institutional guidelines and practices that may enable stigma should also be considered (Gardner *et al.*, 2017).

The ability to share their lived experiences and both give and receive support from other PLWHIV was highly valued by participants. Peers offered advice and served as role models for those struggling to adjust to LWHIV. A study by Bateganya *et al.*, (2015) concluded that support groups for PLWHIV are associated with reduced mortality and morbidity, increased retention in care, and overall improved quality of life, and so it is important that this peer support is accessible to PLWHIV in Ireland.

5.5 Strengths & Limitations

A strength of this study is its qualitative design, eliciting rich accounts of lived experience from young PLWHIV. This insight is particularly valuable given the lack of phenomenological research giving voice to this demographic in Ireland. The use of IPA in this study is clearly described to enhance transparency, while

codes and emergent themes were reviewed by a second researcher to ensure consensus and minimise bias.

The participants in this study were recruited using purposeful sampling through the Sexual Health Centre, so it is possible that the findings may differ for PLWHIV not seeking support from this service. Three participants is an appropriate sample size for a study using IPA (Smith *et al.*, 2009) and as this study aimed to explore the depth - as opposed to the breadth - of the experiences of LWHIV, its results are not generalisable. However comparisons with existing literature suggest that they are not isolated.

5.6 Recommendations

Peer support should be accessible to all PLWHIV and service providers should ensure the emotional wellbeing of clients is appropriately cared for.

There is a clear need for HIV education in Ireland, as people still uphold damaging misinformation regarding HIV and its transmission. Public health campaigns should dispel common misconceptions to help reduce stigma and create a cultural context whereby PLWHIV are comfortable disclosing and seeking appropriate supports. Educational campaigns should ensure they are targeting young adults, while secondary schools may be considered as an appropriate avenue for providing accessible and comprehensive HIV education to adolescents. While just over half of new HIV diagnoses in 2016 were reported in MSM (Health Service Executive, 2017), HIV-related stigma also persists within the gay community. As such HIV awareness and education campaigns must engage this demographic.

Stigma in healthcare settings should also be considered. This has not yet been explored in Ireland and so is a potential area of future research.

5.7 Conclusion

Qualitative research exploring the lived experiences of HIV-positive young adults is scarce. Where age is an inclusion criteria the majority either describes children and adolescents (Li *et al.*, 2010; Hodgson *et al.*, 2012; Siu *et al.*, 2012, Mburu *et al.*,

2014) or people 50 years and older (Foster & Gaskins, 2009; Emlet *et al.*, 2011; Wallach & Brotman, 2013; Rosenfeld *et al.*, 2014). This study explored the lived experiences of HIV-positive young adults in Ireland and found that they suffered a significant level of psychological distress as a result of their HIV status. The experience was characterised by isolation, rumination, and suicide ideation as participants struggled to come to terms with their new and marginalised identity. It is important that support services acknowledge the complex and personal nature of this experience and actively promote not just the physical but emotional wellbeing of their clients. The pervasive nature of anticipated stigma was most strongly felt, and played a crucial role in non-disclosure. In this study great importance was placed on relationships with clinical staff, and where enacted stigma was experienced in this setting it deterred clients from further engagement with services. This was framed in contrast to peer support groups. Here PLWHIV create their own safe spaces to acknowledge and support one another, free from judgment or reproach, highlighting the importance of feeling respected and valid. As HIV diagnoses continue to increase in Ireland it is vital that PLWHIV have access to these supports, and that public health campaigns educate the public to help tackle HIV-related stigma.

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