The Lived Experience of Adherence to HIV Medication in the Context of Homelessness and Addiction.

A thesis presented to the School of Nursing, Psychotherapy & Community Health DCU, for the award of a Master of Science.

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Master of Science 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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Table of Contents

Declaration ... i

Acknowledgements ... ii

Table of Contents ... iii

List of Tables ... vii

Glossary / Abbreviations ... viii

Abstract ... ix

Chapter 1. Introduction ... 1

- 1.1 A Note on Terminology ... *3*
- 1.2 Thesis Structure ... *3*

Chapter 2. Literature Review ... 5

- 2.1 HIV ... *5*
- 2.2 HIV Disease Aetiology, Signs and Symptoms ... *6*
- 2.3 Psychosocial and Cognitive Impact of HIV/AIDS ... *6*
- 2.4 Social impact: Stigma, Shame and HIV ... *7*
- 2.5 Experience of a HIV diagnosis ... *8*
- 2.6 HIV Medication ... *9*
- 2.7 Adherence ... *10*
- 2.8 Factors Influencing Adherence to HIV medication ... *11*
  - 2.8.1 Physical and Psychological Factors ... 11
  - 2.8.2 Social Factors ... 12
- 2.9 Homelessness and HIV Medication Adherence ... *12*
  - 2.9.1 Homelessness, HIV and Health/Social Care Systems ... 13
  - 2.9.2 Managing HIV in the Context of Homelessness ... 14
  - 2.9.3 Self-Efficacy, Self-Management and Self Sabotage ... 15
- 2.10 Addiction and HIV Medication Adherence ... *15*
- 2.11 Chapter Summary ... *18*

Chapter 3. Methodology ... 19

- 3.1 Introduction ... *19*

3.2 Aims and Objectives of Study *19*

3.3 Research Design *19*

3.3.1 Research Methodology - Narrative Inquiry 20

3.3.2 Riessman's Narrative Framework Approach 21

3.3.3. Rationale for Using Narrative Inquiry in this Study 22

3.4 Research Procedures *23*

3.4.1 Participants and Sample Size 23

3.4.2 Inclusion Criteria 23

3.4.3 Recruitment 24

3.4.4 Interview Process 24

3.5 Ethical Considerations *25*

3.5.1 Consent 25

3.5.2 Participant Vulnerability 25

3.5.3 Participant Vulnerability in Interviews 26

3.5.4 Gendered Understandings 27

3.5.5 Confidentiality and Anonymity 27

3.6 Data Analysis *28*

3.6.1 Case Specific Analysis 28

3.6.2 Thematic Analysis 29

3.6.3 Structural Analysis 29

3.6.4 Dialogic and Performative Analysis 29

3.6.5 Cross Case Analysis 30

3.7 Rigour and Truthfulness in Narrative Inquiry *30*

3.8 Summary *31*

Chapter 4: Individual Narratives- Case Analysis 32

4.1 Frances's Narrative *33*

4.1.1 Summary of Frances's Narrative 37

4.2 Jenny's Narrative *37*

4.2.1 Summary of Jenny's Narrative 41

4.3 Sara's Narrative *42*

4.3.1 Summary of Sara's Narrative 45

4.4 Peter’s Narrative..45

4.4.1 Summary of Peter’s Narrative..47

4.5 Ben’s Narrative 48

4.5.1 Summary of Ben’s Narrative..51

4.6 Arthur’s Narrative 52

4.6.1 Summary of Arthur’s Narrative 55

Chapter 5: Cross Case Analysis and Discussion..57

5.1 Introduction..57

5.2 Diagnosis Experiences 59

5.2.1 ‘And just like that you’re HIV; nothing else.’ - Medical Dismissiveness and Abandonment 59

5.2.2 ‘I think that’s what depressed me more. Not knowing.’ – Information Deficits and Misconceptions 60

5.2.3 ‘You could have caught it off a girl’ – Gender in Diagnosis Experiences............................61

5.3 Transmission Narratives..62

5.3.1 ‘Karma’s a bitch’ - Accountability and HIV Transmission 62

5.4 Experiences of Taking HIV Medication..64

5.4.1‘Horse tranquilisers’ – Physical Effects of ARV Medication 64

5.4.2 ‘It just wasn’t a nice experience. It’s just not nice’ – Attitudes to Taking HIV Medication.64

5.5 Homelessness and HIV Medication Adherence..66

5.5.1‘You’re getting settled, you get uprooted again’ - Tenuous Housing and Privacy Loss........66

5.5.2 ‘My forever home’ – Permanent, Safe Housing as a Support to Adherence........................67

5.6 Addiction and HV Medication Adherence, a Hierarchy in Chaos 68

5.6.1 ‘My first priority was to make myself feel better’ - The Competing Imperative of Addiction 68

5.6.2 ‘We were the junkies to them’ - Stigma among Healthcare Practitioners............................70

5.7 Maintaining Adherence - Performing Adherence Narratives..70

5.7.1 ‘I always take my tablets’ - Preferred Narratives of Adherence 70

5.7.2 ‘We have no complaints about you’ - Performance of the Good Patient/Good Person. 71

5.8 HIV Medication Adherence Support..73

5.8.1 ‘She does her job proper’ - Current Supports to Adherence 73

5.8.2 ‘Addiction in the field experience’ - The Lack of Person Centred, Integrated Care............74

5.8.3 Just to stop, just to be looked after’ - The Balance Between Intensive Support and Autonomy 75

5.8.4 ‘Step by step without falling through the cracks’. What Would Supporting HIV Medication Adherence Look Like?..75

5.9 Chapter Summary..78

Chapter 6: Conclusion...79

6.1 Major Research Conclusions..79

6.1.1 HIV Diagnosis Experiences and Impacts on Treatment Engagement.................................79

6.1.2 Perceptions/Experiences of Transmission and Accountability 79

6.1.3 Homelessness and HIV Medication Adherence...80

6.1.4 Addiction and HIV Medication Adherence...80

6.1.5 Ongoing Adherence and Perceptions of Morality...80

6.1.6 Perceptions of Supports to Adherence 81

6.2 Implications for Practice 81

6.3 Recommendations...82

6.3.1 Practice Recommendations 82

6.3.2 Research Recommendations 82

6.3.3 Policy Recommendations...83

6.4 Limitations and Strengths of the Research..83

References..85

Appendices..104

Appendix 1. Research Poster/ Advertisment...104

Appendix 2. Plain Language Statement 106

Appendix 3. Participant Consent Form 109

Appendix 4. Interview Guide...112

Appendix 5. Interview Questions...115

Appendix 6. Ethical approval...117

Appendix 7. Individual Case Analysis Excerpt 117

Appendix 8. Except from Interview Notes: Arthur, August and September 2021..........................120

Appendix 9. Cross Case Thematic Analysis Table 122

List of Tables

Table 1. Participant Overview..32
Table 2. Cross Case Analysis - Overarching Themes and Subthemes..58

Glossary / Abbreviations

AIDS	Acquired Immunodeficiency Disorder
ART	Antiretroviral Therapy
ARVS	Antiretrovirals
BBVU	Blood Borne Virus Unit
Crack	Crack Cocaine, a highly addictive form of the drug cocaine which has been purified into crystal form, producing a short but intense euphoria. Usually smoked or injected
HAART	Highly Active Antiretroviral Therapy
Heroin	Analgesic addictive drug derived from morphine, often used illicitly as a narcotic producing euphoria. Usually smoked or injected
Hostel	Short term, emergency/ temporary, usually shared accommodation
HIV	Human Immunodeficiency Virus
Injecting drug use	Use of syringes/needles to inject substances
PLWHIV	People living with HIV
PREP	Pre Exposure Prophylaxis
PWUD	People who use drugs
Rough Sleeping	Sleeping outside, usually on the streets
Substance Use	Use of unprescribed drugs or alcohol

Abstract

The Lived Experience of Adherence to HIV Medication in the Context of Homelessness and Addiction

At the end of 2020, The Global Health Observatory estimated that globally there are 37.7 million people living with HIV (WHO, 2022). In Ireland, in 2021 over 6,000 people were estimated to be living with HIV, however this figure has already increased in 2022 with 293 notified cases of HIV in the first six months of 2022, compared to 145 for the same period of 2021 (Health Protection Surveillance Centre 2022). The HPSC 2021 statistics reveal that in 2% of HIV cases, intravenous drug use behaviour was the source of transmission.

Research studies and health strategies emphasize the importance of adherence to HAART (Highly Active Antiretroviral Therapy) to avoid viral replication and personal/public health consequences. However, it is evident that addiction and homelessness can contribute to non-adherence to medical and pharmacological treatment for a range of diseases. Explanations have been put forward in the research including, side effects, stigma/shame, lack of structure/routine, cognitive impairment caused by drug use, lack of motivation/self-worth, lack of facilities to store and take medication.

Adherence to HIV treatment for people who are homeless and in addiction, is further complicated by the required drug regimen which can be complex and difficult to tolerate. This study explores the lived experience of adhering to HIV medication in the context of drug addiction and homelessness, using a qualitative research approach, involving interviews with six people experiencing homelessness and addiction and who are prescribed HIV medication. Individual participant narratives are gathered and analyzed using Riesman's (2008) narrative analysis framework which enables a deep exploration of the stories people tell about their lived experiences. The study findings illuminate how HIV, addiction and homelessness impact on adherence to HAART particularly in relation to diagnosis experiences, stigma and shame as well as the challenges of managing treatment in the context of homelessness and addiction.

It is anticipated that the findings, discussion and potential recommendations from the study will contribute to improved understanding of the needs of this population and more sensitive person centred approaches.

Chapter 1. Introduction

The World Health Organisation (2019) describes HIV as a virus which targets the body's immune system and systematically begins to break it down as the virus progresses. If untreated, HIV may progress to AIDS (acquired immune deficiency syndrome) where the immune system becomes further compromised, leading to systemic immunosuppression and often fatal vulnerability to opportunistic infections and tumours. With advances in medical science and pharmacology, HIV has become a chronic, yet manageable condition when treated with the correct medication, however HIV continues to negatively affect the lives of many people. At the end of 2020, the Global Health Observatory estimated that globally there are 37.7 million people living with HIV (WHO, 2022). 1.5 million people were newly infected with the virus in 2021 and 28.7 million people were accessing HIV medication in 2021. (UNAIDS, 2022).

In Ireland, over 6,000 people are estimated to be living with HIV with 404 new HIV diagnoses in Ireland in 2021, representing a rate of 8.5 per 100,000 population (Health Protection Surveillance Centre, 2022). However, provisional figures from the HPSC show that there were 293 notified cases of HIV in the first six months of 2022, compared to 145 for the same period of 2021 which represents an increase in the number of cases being presented. The HPSC 2021 statistics also reveal intravenous drug use behaviour was the source of transmission in 2% of HIV cases. The risk of acquiring HIV is 35 times higher for people who use drugs. (UNAIDS, 2022).

People experiencing homelessness and drug addiction struggle to maintain medication adherence and engagement with healthcare interventions more generally. (Coe et al., 2015; Diep et al., 2016 and Akindipe et al., 2015). Several research studies identify the inter-relationships between positive HIV status and addiction in terms of co-occurring prevalence (Arnsten et al., 2002, Socias, 2017) and detrimental effects (Wolfe et al., 2010; Stout et al., 2017; Douglas 2018). An Irish study by Kinahan et al., (2016) highlights that people with dual diagnosis of HIV and opiate dependence, experience multiple bio-psychosocial morbidities and have poor HIV and addiction prognosis. Mimiaga et al., (2009) sought to understand the barriers to HIV medication adherence from the perspectives of injecting drug users. Their study concludes that lack of privacy and HIV stigma as well as co-occurring mental health problems and 'forgetting' were ranked highest by respondents as precursors to medication adherence failure. In terms of homelessness and HIV progression/management, Loh, in her 2016 study among homeless drug users in Canada, identified that the duration of homelessness had a correspondingly negative effect on HIV/AIDS outcomes, similarly Sabriya et al., (2013) reported that homelessness was associated with relapse and injection-related risk behavior. Palepu et al., (2011) concur regarding the prevalence of homelessness among HIV-infected injection drug users and also affirm that these complex interactions adversely affect access and adherence to anti-retroviral therapy.

Palepu et al., (2011, p524) further observe that there are ‘limited descriptions of the effect of homelessness on adherence to ART’ in the literature. While research studies have been carried out regarding clinical manifestations and prevalence of co-morbidity as well as rates of HIV medication adherence, there are few qualitative studies containing more in depth explorations which capture the voices and perspectives of those encountering these complexities and challenges. Currently there are calls for public and patient involvement/engagement in research in this area (Brenden et al., 2015, Barker et al., 2018) in order to fully understand lived experience and develop innovative person centered approaches to support HIV treatment adherence in this challenging context. The proposed research aims to fill this gap in the literature and to contribute the voices, knowledge and expertise of persons directly affected to service planning and support initiatives. Research on adherence to BBV medication and treatment is essential for gaining knowledge and insight which in turn can be used to improve treatments aimed at suppressing viral loads. This knowledge also has benefits for healthcare professionals as they engage with clients in the context of homelessness and addiction to support them to achieve adherence.

The broad context of this research study is an Irish homeless service. The overall service, on an annual basis, engages with up to 6.5 thousand people who are homeless or at risk of homelessness (Dublin Simon Community Annual Review, 2021). A range of services are provided, including emergency, short term and longer term accommodation, housing support, welfare rights, education and employment support, addiction support, health support. In 2021, almost 70% of clients accessing the addiction treatment services reported substance use as their primary reason for becoming homeless, with a 23% increase in demand for addiction treatment and primary care services, indicating that addiction support needs are increasing in the homeless population and so too are their health related needs.

The specific research setting is the Blood Borne Virus Unit (BBVU) within the overall homeless service. The Unit was opened in 2010 to address healthcare needs of homeless service users disproportionally impacted by HIV and other blood borne viruses. People typically access this service when they have destabilised in their substance use and disengaged from their infectious disease clinic and thus their HIV medication. I have worked in the organisation’s treatment services for 8 years as a Nurse and Nurse Manager, predominantly working with people in heavy substance use/addiction, who are living with HIV and who are seeking to stabilise on prescribed medication and/or access addiction recovery services.

The experiences of people living with HIV and how they manage this disease in the context of homelessness, addiction and stigma, has always intrigued me. In undergraduate studies I focused on how homeless women living with HIV navigate sexual relationships. It is fitting that my Master’s degree involves further study of the lived experience of people living with HIV who are also dealing with homelessness and addiction. Much of the existing research on HIV medication/ ART adherence is quantitative and there is limited exploration of the lived experience of adherence, especially in the context of substance use and homelessness. This is a client cohort who are living on the margins of society. Lived experience and expertise by experience are paramount to learning and improvement in care provision.

This research has two predominant aims:

1. To explore participant's experiences of adhering to HIV medication in the contexts of personal homelessness and addiction.
2. To gain deeper insight and understanding from participants, concerning challenges and supports to medication adherence in the contexts of personal homelessness and addiction.

The research aims to fill this gap in the literature and to contribute the voices, knowledge and expertise of persons directly affected by service planning and support initiatives.

1.1 A Note on Terminology

Recently, the power and importance of language in positioning individuals and communities has been increasingly understood. We recognise particularly, the stigmatising potential of language used to describe people who use drugs and alcohol. In this thesis, a range of terms are used that reflect the participants preferred terminology as well as the need for clarity of definition. Person first language is used, for example *people who use drugs*, (PWUD) *People living with HIV* (PLWHIV). The term *addiction* is used in the thesis as this is terminology used by study participants regularly and openly. For the purposes of this study, The American Psychological Association definition of addiction is used.

> "Addiction is a state of psychological or physical dependence (or both) on the use of alcohol or other drugs. The term is often used as an equivalent term for substance dependence". (APA, 2015).

Substance use is defined by the NCI as "The use of illegal drugs or the use of prescription or over-the-counter drugs or alcohol for purposes other than those for which they are meant to be used, or in excessive amounts" The term substance use is used predominantly to describe drug and/or alcohol use. The term *drug use* is used in relation to non-alcoholic substances. Substance use does not necessarily equate with addiction, however the term *substance use disorder* is often used as a synonymous term for addiction.

1.2 Thesis Structure

The thesis comprises six chapters. The following chapter, chapter 2, presents the literature review which is broad and multifaceted. The review aims to explore the most up to date and relevant research pertaining to people who are living with HIV, and who may have experience of substance use and homelessness. Literature is examined from the following areas:

1. HIV aetiology, symptoms and experiences of diagnosis and disease management
2. HIV medication, side effects and toxicity
3. Adherence as a concept
4. Adherence to HIV medication; shame, stigma and support
5. Impact of homelessness and social exclusion on HIV medication adherence
6. Addiction and HIV medication adherence

Chapter 3, the methodology chapter, outlines how the rationale for and the process of the research. This chapter presents the research aims and objectives and the chosen research design and methodology; i.e. qualitative research using narrative methodology. Riesman's Narrative framework (2008) is explained. This framework involves gathering and analysing case specific narratives, followed by a cross case thematic analysis involving structural, dialogic and performative analysis. The narratives of 6 study participants gained through semi structured interviews are analysed. Participants were

- Living with HIV
- Resident in the Blood Borne Virus unit at the time of research
- Had experience of substance use
- Had experience of homelessness

This chapter also explores the ethical considerations pertaining to this research such as confidentiality and consent, rigour, trustworthiness. Researcher reflexivity is central to narrative research and this will be explored concerning researcher presence, position, power dynamics and relationships with participants and the attendant impact on the research. Vulnerability of participants and data protection will also be examined.

Chapters 4 and 5 present the findings of the research with an accompanying discussion. Chapter 4 contains the analysis of the individual participant narratives in line with Riesman's (2008) approach. In chapter 5 the findings of the cross case analysis are shared. These overarching findings are contextualised with a discussion of relevant contemporary literature concerning the predominant themes. Finally, the conclusion chapter (chapter 6) summarises the key findings as evident in this research. This chapter identifies the original contribution of findings to research and also the limitations of this research. This chapter outlines the implications of findings for practice, research and policy development and recommendations relevant to these areas are made.

Chapter 2. Literature review

This literature review examines research articles, relevant theory and contemporary health/social care policy pertaining to the lived experience of adherence to HIV medication in the context of homelessness and addiction. For this purpose, the search strategy involved retrieving and analysing peer reviewed research from the following databases; Cochrane, EBSCO, ERIC, Medline, Psych Info, PubMed, Scopus, and Web of Science. The following terms and sources were used as singular terms and in combination for the literature review; HIV, HIV experiences, HIV treatment, ARV medication, adherence, homelessness, addiction. A range of international research studies were retrieved and reference lists from these articles were screened for further relevant sources. Policy sources were accessed from national and international governmental health and social organisations and websites. Theoretical perspectives were gathered from the researchers own book collection as well as libraries and relevant websites.

2.1 HIV

HIV as a health concern first came to public attention in 1981, when the first human case of HIV was discovered and diagnosed in a young homosexual male in Paris. HIV is now known to be the single cause of AIDS, which has been one of the most significant public health pandemics in our history, Sharp et al., (2011). The AIDS pandemic has taken 36.3 million lives and infected 79.3 million people worldwide (UNAIDS, 2020). At the end of 2020, The Global Health Observatory estimated that globally there are 37.7 million people living with HIV (WHO, 2022).Over 6,000 people are estimated to be living with HIV in Ireland with 404 new HIV diagnoses in Ireland in 2021, representing a rate of 8.5 per 100,000 population (Health Protection Surveillance Centre, 2022). However, provisional figures from the HPSC show that there were 293 notified cases of HIV for the first six months of 2022, compared to 145 for the same period of 2021 which represents an increase in the number of cases being presented. The HPSC 2021 statistics reveal that in 2% of HIV cases, intravenous drug use behaviour was the source of transmission.

HIV can be contracted via exposure to bodily fluids (including semen, vaginal fluid, rectal fluid, blood). These fluids must come into contact with a mucous membrane or damaged tissue for transmission to occur. HIV can be transmitted through sex and through the sharing of needles during intravenous drug use. People who inject drugs accounted for 2% of the total diagnoses in Ireland, (HSPC, 2020). HIV can also be transmitted from a mother to an infant in the womb, during child birth or via breastmilk, CDC, (2019).

2.2 HIV Disease Aetiology, Signs and Symptoms

The initial phase of HIV infection is usually referred to as the acute phase: a person in this phase will likely have a high viral load of HIV circulating in their blood. Immunological deterioration begins to occur as early as the acute phase- up to 12 weeks post initial infection with the HIV virus. The symptoms in this phase include; fever, swollen lymph nodes, sore throat, fatigue and headaches, poor/absent appetite. Some people also experience skin rashes and diarrhoea. (Kutzer et al., 2008). The next phase of the HIV infection, the chronic/ latent phase is asymptomatic, characterised by a lowering HIV viral load and a return of the bodies immunological functioning to almost normal levels, thus an increase in the bodies CD4 cells. Although a person may be asymptomatic it is important to note that the HIV virus continues to replicate and infect new cells within the body during this phase. This phase can continue for up to 10 years, sometimes more. Moir et al., (2011) refer to this phase as the body's failure to clear HIV. Following this asymptomatic phase, people who have not initiated HIV treatment will move into the third stage of HIV viral infection to AIDS- this phase is marked by a spike in HIV viral load and a dramatic decline in CD4 cells; and thus the bodies' ability to defend itself. Symptoms will progress and increase in severity as viral load increases and the bodies' immune system (CD4 cells) deplete. This phase is characterised by the emergence of opportunistic infections, such as mycobacterium (non TB) infection of the lung, Tuberculosis (TB), candida infections such as thrush; which could be an oral or systemic infection, and viruses such as the herpes simplex virus. (Hernandez & Middleton, 2013). The symptoms associated with this phase are marked and include; exhaustion, swollen lymph nodes, constant fever, night sweats, oral thrush, genital/anal sores, rashes, significant weight loss, pneumonia and interruption to memory, (Sharkey, 2022). The Centre for Disease Control identify three AIDS defining cancers (the onset of these cancers indicates the progression of HIV to AIDS) – these are Kaposi's sarcoma, cervical cancer and NHL Non –Hodgkin's lymphoma.

2.3 Psychosocial and Cognitive Impact of HIV/AIDS

The psychological and cognitive impacts of living with HIV significant influence treatment attitudes and behaviours and therefore are highly relevant for this research. There is significant evidence in literature to suggest that negative psychological symptoms occur during the initial acute phase of HIV. These symptoms include PTSD, likely linked to the trauma of the initial diagnosis and also depressive and anxiety related symptoms in persons in the acute phase of infection (Ciesla et al., 2001; Familiar et al., 2019). Hellmuth et al., (2017) found that symptoms of depression and anxiety were present frequently during acute infection, and interestingly that the severity of these symptoms correlated with viral load and immunological suppression; in that people with a high viral load and lower CD4 count experienced more depressive and anxiety based symptoms. These studies focus on the initial phases of HIV infection/diagnosis, however Nanni et al., (2015), found that depression was present for people at all stages of HIV infection and in a study by Sebastian et al., (2016) participants noted ongoing extreme worry and fear, despite being engaged in counselling.

In terms of cognitive decline and AIDS related dementia, Shepard & Woods, (2019) found that people with HIV were 5 times more likely to experience cognitive impairment, at a much faster age progression rate than the non HIV affected population. These researchers also note that neurocognitive disorders are associated with poorer day to day functioning, engagement with healthcare and uptake of medication. Further, Janssen et al., (2017) examined cognitive decline and psychological wellbeing in people living with HIV and found that cognitive decline resulted in psychological distress and more frequent use of recreational drugs. These issues could have serious repercussions, notably pertaining to HIV medication adherence. Watkins et al., (2015) outline the symptoms associated with AIDS related dementia, which include; loss of memory, deterioration in ability to concentrate, alterations to one's gait, changes in one's activities of daily living and ability to self-care, loss of inhibition, withdrawal from activities that used to bring pleasure, confusion and disorientation. AIDS related dementia can also lead to associated psychosis. It is important to acknowledge that all of the aforementioned symptoms have a serious potential to interrupt and in some cases halt entirely adherence to HIV medication. It is also possible that these signs and symptoms may be compounded, and also more challenging to detect in a cohort of people who are actively substance misusing.

2.4 Social Impact: Stigma, Shame and HIV

Goffman (1963) described stigma as a 'mark' which signifies that an individual is socially de valued and discredited. He stressed that the relationships and social interactions that surround the 'mark' are how the stigma is constructed. Hutchinson & Dhairyawan, (2017) surmised that HIV related stigma is associated with the perceived relationships between the disease and 'taboo' homosexual and 'promiscuous' sexual practices. Valle et al., (2015) used the Berger HIV Stigma Scale (HSS-21), to examine perceived stigma in a population of people living with HIV in south east Mexico. They outline that the most common routes of HIV transmission are, in their own right, stigmatised if we are to consider for example; injecting drug use, sharing of drugs paraphernalia and unprotected sexual intercourse. People who acquire HIV through these 'risky' behaviours are regarded as non-compliant with a prevailing social or moral code and therefore culpable. As a result, people with HIV are marginalised through fear and ignorance and this often results in feelings of shame, social withdrawal and health/help seeking behaviours. In an exploration of HIV positive people's experiences of shame and stigma in Zimbabwe, Duffy (2005, p.13) found that that 'stigma, suffering, shame, and silence are mutually supporting concepts that challenge health promotion efforts.' This has obvious implications for HIV treatment/medication uptake. Valle et al., (2015) further identify that the social imagery associated with HIV and the fact that it is considered a disease associated with the socially marginalised in society further stigmatises the disease. Social exclusion is defined in literature as the inability to participate in or be involved in the social, cultural or political aspects of a society (Galabuzi, 2006).

Social exclusion can be far reaching, it affects individuals at a very personal level in that it enacts a perceived sense of shame and stigma, it isolates people and increases their risk of loneliness and depression, but it can also affect people in ways in which they never imagined, in that it can influence governments and people in power to make decisions that are not in their favour, are not demonstrative of their experience and only serve to exclude them further. Watson & Kane (2016) identify that the experience of social exclusion results in reduced access to and quality of social support, that it increases the propensity toward high risk health behaviours and can lead to poorer physical and psychological health outcomes. For persons living with HIV and who are homeless this exclusion is only exacerbated. A literature review by Bennett et al., (2016) found that shame was closely linked with more depressive symptoms and poor healthcare service utilization and thus poorer health outcomes for PLWH. Aidala et al., (2007) observed that despite the fact the people living with HIV are burdened with the highest rates of disease, they have inferior contact and engagement with healthcare. Treatment avoidance in PLWHIV was noted in a more recent study conducted in England and Wales (Wiginton et al., 2021). This has obvious implications for both HIV treatment provision and support with adherence.

2.5 Experience of a HIV Diagnosis

The experience of receiving and processing a HIV diagnosis can have a profound influence on a persons's treatment attitudes/acceptance and adherence behaviour (Scherer, 2022). Wolpaw et al., (2013) examined participant experience of a HIV diagnosis through in depth interviews. All participants noted a substantial emotional response which was triggered by a positive HIV diagnosis - feelings of anger, shock and feelings of depression or sadness upon hearing the news of their diagnosis. One respondent noted feelings of suicidality post diagnosis and all of the respondents said that they experienced fear of dying of AIDS. This research also identified a lack of understanding among some participants concerning infection control and transmission and that false positives and false negatives are possible in test results. Wolpaw et al., (2013) note that clear explanation is paramount at diagnosis in order to ensure clear understanding, infection control and treatment engagement among patients. Usman et al., (2018) examined the experience of HIV diagnosis in transgender sex workers in Pakistan, participants felt further stigmatised and marginalised from society as a result of their diagnosis. They also expressed concern pertaining to the physical signs and symptoms of HIV that might expose them as HIV positive. Participants noted feelings of anger, and experiences of loneliness and isolation from within their own community subsequent to diagnosis. These findings indicate that an HIV diagnosis can ignite fear in, and further isolate and stigmatise people.

Okoror et al., (2016) researched the experience of a HIV diagnosis in heterosexual men in Nigeria and note that their experience is under researched. Their study used Wyrod’s (2011) work on gender - what it is to be masculine, and HIV and stigma as a conceptual framework for their research. They describe what they believe it is to be a man in Nigeria; to be masculine, a man must feel that he can provide, and be financially independent. They note that on receipt of a HIV diagnosis men worry that they may no longer be able to experience physical, intimate connection with a woman, may not be able to produce children and that they will no longer be able to provide for their families and thus their perception of what it is to be man is deconstructed. Further, Okoror et al., (2016) identified that these concerns, consequent to diagnosis; impacted on men's sexual behaviour; they engaged in less extramarital sex and utilised protection during sexual intercourse more often. Lynch et al., (2010, p23) surmised that heterosexual HIV positive African men who have been diagnosed with HIV are 'redefining and reconstructing masculinity by refraining from certain aspects of normative masculinity that are seen as jeopardizing their health.' These studies are significant in that they suggest that diagnosis experiences are influenced by sex and gender factors. Notably they indicate that the meaning and interpretation of a diagnosis can impact/ predict future behaviours, including positive behaviours such as safer sex.

2.6 HIV Medication

Antiretroviral (ARV) drugs do not provide a cure for HIV but rather they reduce/suppress the amount of HIV in the blood and halt the destruction of the immune system. In suppression of the HIV Viral load, medication can reduce the risk of transmission, as transmission is less likely to occur in a person whose HIV is virally undetectable (Cihlar & Fordyce, 2016). Margolis et al., (2014) affirm that HIV medication is designed to reduce viral load, to restore immunity, to prevent transmission, avoid resistance, and to improve overall quality of life.

HIV is treated using a combination therapy (consisting of three tablets daily), or by taking a single dose regime, daily. Usual Triple therapy (three tablet) regimens of HIV medication consist of two (NRTI'S) Nucleoside reverse transcriptase inhibitors and one Proton Pump inhibitor. When a person commences HIV medication, they should see a reduction in HIV viral load and an increase in the body's CD4 count. A person whose CD4 count has been low prior to initiating treatment should see and feel a marked improvement in their overall wellbeing. As their immune system rebuilds in strength people should see existing infections clearing and a significant reduction in the emergence of new infections. Weight should begin to increase, feelings of being run down, being generally unwell should improve significantly within a few weeks of treatment with ARVs.

Although the use of HIV medication has positively influenced the lives of people living with HIV, this medication is not without its challenges. Significant drawbacks pertaining to HIV medication are its toxicity, drug side effects and drug to drug interaction, (Margolis et al., 2014). HIV medication may present with side effects of fatigue, gastrointestinal problems such as nausea, vomiting and hyperlipidaemia. Specifically, people on long term protease inhibitors are more likely to develop diabetes and may experience cardiac disease. Margolis et al., (2014) note that associated toxicity with HIV medication at many levels cannot be avoided. They acknowledge that diagnosing associated toxicity can be challenging due to the ambiguity of symptoms such as nausea, vomiting and abdominal pain. It should be acknowledged that in light of the symptoms described above – drug related toxicity as a consequence of taking ARVS cannot be ruled out of the conversation on HIV medication adherence and it should be considered in the prescribing and management of HIV treatment in order to sustain adherence for patients in the long term, (Chesney, 2000).

2.7 Adherence

In order to explore experiences and perceptions of adherence, we first need to define and examine the concept of adherence. Chakrabarti (2014, p. 30) proposes that adherence refers to a process, in which 'appropriate treatment is decided after a proper discussion with the patient.' Other terms that have been used in association with adherence are 'compliance' and 'concordance.' Compliance refers to a patient complying with the clinician's treatment recommendations (Panesar, 2012). There is a power dynamic involved in the concept of compliance wherein the clinician is regarded as expert and the patient is expected to follow and benefit from this expert knowledge and treatment. Chakrabarti (2014) notes that the term adherence has replaced compliance and that adherence takes into account the relationship between the client and the clinician, as opposed to compliance; which infers that a patient must 'comply' with the instructions of the clinician. In moving from the term compliance to adherence, (Chakrabarti, 2014, p. 33) adherence is defined as a 'continuum of behaviours'… from fully non adherent, to partially non adherent, to adherent.' This is particularly relevant when applied to the respondents in this research as levels of adherence, or the 'continuum' of adherence may vary from respondent to respondent.

Concordance is defined as an agreement between clinician and patient, whereby the patient is an active participant, the desires and wishes of the client are central to this process (Marinker, 2007). Khair (2014) further advocates a move from concepts of compliance and adherence to more concordant mechanisms of prescribing whereby the patient is an active participant in their own lives, making decisions and taking responsibility concerning whether, how and when, and in what way they choose to take their medication. A move from compliance to concordance should be the goal for all clients initiating or recommencing HIV medication in order to promote long term adherence and patient engagement in treatment.

In this research, there is recognition that, due to biopsychosocial and addiction challenges, not all service users have the ability or opportunity to achieve concordance. On the other hand, the concept of compliance denies the potential for agency and autonomy among this population. Therefore, the most fitting concept for this service user group is that of adherence, wherein an appropriate treatment regimen is decided as a result of discussion between the client and clinician and the client has choices as to whether or not to adhere to the regimen and is facilitated and supported as far as possible to manage the ARV treatment in ways that suit their lifestyle and needs (Chakrabarti, 2014). Chakrabarti (2014) emphasises further that the patient should not be held primarily responsible for non- adherence. This is a move away from the notion of compliance that infers that if a patient does not comply, that they have done wrong or are at fault. It challenges the concept of responsibility and proposes that within adherence both the patient and the clinician are responsible for whether a prescribed medication regimen is adhered to or not. Khair (2014) suggests that we should be engaging patients in 'mutually acceptable' treatment regimens that are agreed between the prescribing clinician, healthcare practitioners and the patient. In a concept analysis of adherence, (Lyu & Zhang, 2019 p. 85) conclude that adherence is a 'phenomenon that is essential for healthcare providers and creates an opportunity to develop interventions to improve patient outcomes.' Gaining insight into what influences client adherence allows for the development of strategies to support clients to be engaged with and adhere to their treatment regimen.

2.8 Factors Influencing Adherence to HIV Medication

2.8.1 Physical and Psychological Factors

This research aims to explore the lived experience of people living with HIV (PLWH) in trying to adhere to their HIV medication and in turn how to best support people to adhere to their medication. Adherence to medication can be complex and laced with apprehension and fear for many people. Fear of the disease, fear of the unknown and apprehension regarding the medications that they have been prescribed. Non adherence to medication can be associated with disease denial and fear of stigma (Skovdal, 2011). Non adherence can be as a result of a busy or chaotic lifestyle whereby a person is simply unable to stick to a repeat regimen of medications (O' Carroll & Wainwright 2019; Park et al., 1999). For some people the experience of taking medication is negative; people experience side effects that are simply intolerable and this too can impact whether a person is likely to adhere to a regimen or not (Godin et al., 2005).

Lacob et al., (2017) explore HIV medication specific factors that may influence adherence. These include; the selected ARV drug: including side effects, frequency and time limitations potentially associated with same. Side effects and the need to take this medication daily, and ideally around a similar time each day, in itself can be a barrier to adherence for some patients on ARV. In a study by Miamiga et al., (2010), participants noted medication related side effects such as nausea, diarrhoea, headaches and stomach aches, as negatively influencing adherence. Some study participants also believed that certain ARV medication (e.g. that manufactured in specific countries) worsened HIV/AIDS symptoms and/or created extreme side effects including epilepsy. Patient beliefs have a significant impact on whether or not a person will initiate or adhere to their medication, (Horne, 2020).

Miamiga et al., (2010) in their focus groups also identified what respondents perceive as 'facilitators to adherence'- which include: prompts or reminders to take medication, support from family, community or friends. Respondents identified opiate substitution treatment (OST) such as methadone for instance as a facilitator of adherence. They also identified that wanting better health was also facilitative of adherence. Lacob et al., (2017) examined the role of the patient in likelihood of adherence; the understanding of the patient and the willingness of the patient to engage with their HIV diagnosis/status and reduce their viral loads are all factors that may determine adherence. They discuss the ability of the patient to accept HIV medication; its advantages and disadvantages. Importantly, factors that are both supportive and challenging to ARV medication adherence should be taken into consideration in the development of interventions and supports for people who are homeless and who use drugs (Vlasnik et al., 2005). It is essential that the person who is taking the treatment is involved in this process. Importantly, Lacob et al., (2017) also identify '*doctor devotion'* as an important component in adherence to HIV medication. ‘Doctor devotion’ refers to time spent with the patient, education and the relationship between the doctor and the patient; whether it is based on trust and whether the patient’s decisions and thoughts are respected. This may be particularly pertinent in relation to patients living with HIV where stigma and shame are common experiences.

2.8.2 Social Factors

Hutchinson & Dhairyawan (2017) identify five ways in which shame can influence HIV treatment and outcomes. In relation to treatment and adherence specifically, they surmise that shame may act as a barrier to accessing medical care, treatment, and testing and that it makes people want to ‘withdraw from and hide form the world’ (p.225). They note that this factor makes living with HIV a very negative, isolated and dark experience. Shame as a barrier to help seeking and adherence was also found in studies by Konkle-Parker et al., (2008); Lowther et al., (2016) and Steward, et al., (2018). Vanable & Sweeney (2016) suggest that stigma and shame may perpetuate mental health difficulties in some people and that this in turn could lead to challenges in self-care and desire to build or maintain optimum health. Rintamakie et al., (2006) found that for people living with HIV, social stigma was a predicator for medication adherence. On analysis they found that people that considered social stigma a high concern were 3.3 times more likely to be non-adherent to HIV medication than those who did not consider social stigma a prioritised concern. Interestingly they also noted that people concerned with social stigma had lower understanding of the HIV disease process and were 2.5 times less likely to be able to define or understand the meaning of a CD4 count.

Lacob et al., (2017) point to social and family background as a potentially predetermining factor to adherence. They propose that a person’s social supports, whether in the form of family, community or social supports (groups, community programmes etc.) may impact on adherence either positively or negatively. They note the possibility that family/ community could reject or discriminate against the person; and that community/ family may impact on whether or not a person adheres to HIV medication. Lacob et al., (2017) also explore social challenges to adherence rates and find that social isolation can be a major contributing factor to poor adherence to HIV medications. Social isolation in HIV positive clients is further compounded by enacted stigma and shame associated with HIV and can lead to depression. This is an important consideration when one considers the additional social exclusion and stigma which occurs in homelessness and addiction.

2.9 Homelessness and HIV Medication Adherence

Homelessness as a phenomenon and an experience is difficult to classify and many definitions have been advanced. For the purposes of this study, the definition used is the ETHOS (European Typology of Homelessness and Housing Exclusion) typology devised by FEANTSA. ETHOS identifies four types of homelessness and housing exclusion: roofless (without any shelter, sleeping rough); homeless (with a temporary place to sleep, in institutions or shelters); living in insecure housing (due to insecure tenancies, eviction, and domestic violence) and living in inadequate housing (in caravans on illegal campsites, unfit housing, and extreme overcrowding). Global Statistics pertaining to homelessness remain challenging to ascertain due to varying definitions of homelessness within Europe and globally as well as difficulties in gathering reliable, stable data among an often transient population. In July of 2022, Homeless figures in Ireland reached a record high of 10,568 adults and children (Department of Housing, July 2022). The Irish Government's recent housing policy *Housing For All*, (Department of Housing, Local Government and Heritage, 2021). acknowledges that in Ireland today 'too many people are experiencing homelessness or are unable to access appropriate housing' O Reilly et al., in their research in 2015 note that respondents who were homeless listed substance use; drugs, alcohol and family issues as their primary reason for becoming homeless.

2.9.1 Homelessness, HIV and Health/Social Care Systems

Watson & Kane (2016) identify homelessness and the experience of poverty as 'extreme forms' of social exclusion. People who are homeless have a significantly higher mortality rate and a much shorter life expectancy than the general population (Ivers et al., 2019). This is due in part to high risk or health impairing lifestyle behaviours, however there is no doubt that homeless populations experience marginalisation and discrimination in appropriate health and social care provision; 30.2% of homeless deaths occur due to treatable illnesses (Aldridge et al., (2019). Homeless people typically have increased rates of mental health issues (Perry & Craig, 2015), addiction (O'Carroll et al., 2021), chronic illness (Luchenski et al., 2018), and dual diagnoses (O Reilly et al., 2015). Additionally, homeless people are exposed to barriers while trying to access healthcare services due to having no permanent address, stigma and discrimination, mental physical health/ addiction issues and lack of knowledge/support regarding help seeking processes (Elwell-Sutton et al., 2016; Wilson & Astley, 2016; Parsell et al., 2019; Hodson & Glennerster, 2020). This in itself will significantly impact on whether or not a person will be able to access or indeed adhere to HIV treatment.

People who are homeless are disproportionally negatively affected by HIV (Morrison, 2009). O Reilly et al., (2015) estimated the prevalence HIV in the homeless community in Dublin as 3.6%. Kidder et al., (2007) found that homeless individuals were far more likely to have stopped taking their ARVS than non-homeless populations. Alarmingly in this study some participants said that they had been told to stop taking their ARVs by their doctors as the doctors predicted that these patients would become resistant to them through non-adherence anyway. Krusi et al., (2010) examined the social determinants of HIV medication adherence and propose that homelessness and addiction are still dealt with at a moral level in many countries and that this moral approach is a determinant of social exclusion. They argue that homeless people and people who use drugs are deemed to be violating the norms of society and are discriminated against and excluded from society as a result of this perceived deviation. They identified that exclusion and discrimination negatively influences treatment access, provision and adherence as well as influencing opinion and government decisions relating to prioritisation and spend for medical and social care. Conversely, Krusi et al., (2010) found that good social connection and support and a positive relationship with healthcare workers correlated with better HIV medication adherence.

2.9.2 Managing HIV in the Context of Homelessness

People living with HIV (PLHIV) identify housing as their most prominent need. They prioritise this need above social, medical services and employment. PLWHIV further identify a lack of suitable accommodation as a barrier to access health care and as a causative factor of their suboptimal health (Maulsby et al., 2017). This is in line with Maslow's (1947) theory of a hierarchy of needs, whereby a person has needs that are a priority and necessary to support their very existence, such as food and shelter. Persons who are homeless may prioritise finding shelter before they will prioritise for instance going to an appointment, or finding a suitable place to store their HIV medication. Greenwood et al., (2013) assert that until an individual has a stable place to call home, and unless their basic safety and security needs are met, he or she will be unable to successfully address other complex challenges, such as mental health or substance use. This will have implications in the consideration of strategies to improve adherence to HIV medication in this cohort of people. The Irish Government's recent housing policy *Housing For All*, (Department of Housing, Local Government and Heritage, 2021) contains many action to address housing supply, however there is little acknowledgement or housing prioritisation for homeless people with complex health care needs.

Douaihy (2005) identifies a range of practical barriers to ART adherence among people who are homeless and/or sleeping rough including; limited access to food/regular mealtimes, cooking facilities and clean fresh water, a lack of a routine, and a chaotic lifestyle. Kidder et al., (2007) noted that most respondents who had stopped taking their HIV medication had done so because they had ended up back on the streets. Loh, in her 2016 study among homeless drug users in Canada, identified that the duration of homelessness had a correspondingly negative effect on HIV/AIDS outcomes. People who are homeless may have nowhere safe to store their HIV medication which is often prescribed in large quantities given the requirement to take 3 tablets per day. In a qualitative study Miamiga et al., (2010) participants stated that having to take medications at specific times and with food restrictions was both complicated and challenging. Douaihy (2005) also found that people who are homeless have reduced privacy and private space. Similarly, Vanable & Sweeney (2016) noted that people who have to take to their medication at inopportune times and at times in public experience fear of inadvertent disclosure resulting in delayed or skipped doses and thus compromising adherence.

Norton et al., (2010) identified challenges to ARV adherence due to ingestion, side effects and lifestyle. Some study participants said that simply they found the tablets difficult to swallow and that they tasted bad. Some said that they found it difficult to incorporate medication regimens into their daily lives; they said that they struggled to take their medications when they were feeling unwell, both physically and emotionally. Kalichman et al., (2015) found that food insecurity and hunger correlate with poor ARV adherence and that this is because ARV medication is often prescribed to be taken with food and because of the side effects associated with taking ARVS on an empty stomach such as digestive issues like nausea, vomiting, reflux and heartburn. In a study examining medication adherence in homeless and housed people; Kidder et al., (2007) highlighted that certain side effects associated with HIV such as diarrhoea may be much more challenging for persons who are homeless. In Dublin city centre the numbers of public toilets that can be accessed by homeless individuals have dropped significantly (Finnian, 2019).

2.9.3 Self-Efficacy, Self-Management and Self Sabotage

In a study focusing on non-adherence to medication in homeless people, Coe et al., (2015) found that 36.4% of respondents had adherence issues. They highlight that actually 74.5% of adherence issues rested with the patient and that inability to self-manage, in particular to self-manage medications was the primary reason for non-adherence. This finding that an inability to self-manage is a barrier to adherence is consistent with a study conducted by Lyu & Zhang (2019), which identifies self-efficacy and self-determination as necessities for individuals trying to adhere to medication. Bandura's (1997) theory of self-efficacy supports the idea that in order to cope and function under stressful circumstances and in adversity a person requires a sense of self efficacy, and a belief that one's own actions can produce an effective or positive result. Bagby (2015) further argues that in the context of homelessness, a person would require a particularly 'resilient' (p.48) form of self-efficacy in order to withstand the constant barriers and 'likely repeated failures' associated with homelessness. Similarly, Vandemark (2007) found that homelessness and displacement limit a person's sense of self-management in engaging with healthcare services and appointments.

In addition to challenges to self-management in the frequent chaos of homelessness, Powell & Maguire (2017) argue that some people in homelessness may engage in high HIV risk behaviours such as unprotected risk sexual behaviours and practices and intravenous substance use involving needle sharing. Similar findings were presented by Cervantes & Agosto (2018). Wenzel et al., (2017) conducted a study to ascertain if high risk behaviours deteriorated overtime when people eventually accessed stable accommodation. They found that while there was an increase in sexual behaviour in more stable accommodation, there was a reduction in some high-risk behaviours such as condom-less sex and multiple partners. However, they also found that exposure to HIV prevention programmes dropped in the 12 months that people were suitably housed, as did uptake in PREP treatment (Pre exposure Prophylaxis) for HIV. This would indicate that housing alone is not sufficient to reduce HIV risk behaviour and increase prevention exposure/ uptake.

2.10 Addiction and HIV Medication Adherence

People with addictions/substance use disorders frequently struggle to remain adherent and to engage with medication and treatment for health. (Weiss, 2004; Podymow et al., 2006; Coe et al., 2015; Starks et al., 2020). This has ramifications for all health-related conditions and the management of health for people who are homeless and or use substances.

The DSM 5 (2013) outline 11 criteria that characterise addiction/substance use disorder. These include; using more substances than planned or for longer than intended, an inability to stop taking the substance, experiencing intense cravings/ urges to use a substance, requiring more of the substance to achieve a desired effect, development of withdrawal symptoms, prioritising the access and use of substances, neglecting other life responsibilities such as work, family, or financial commitments, continuous use of a substance despite negative relationship/ family, health, mental health consequences and the use of substances in risky, dangerous settings.

Addiction theory is multifaceted and complex, it is an area of research that is often contentious and widely debated. West (2001) outlines theories and models of addiction, and posits that these theories can be organised under five umbrella terms:

1. The broad approach to addiction, linked to behavioural/ cognitive and social theory, examples include: the disease model of addiction and Substance dependence as a compulsive behaviour.
2. The stimuli and a predisposition to addiction theories; focus on the significance of the substances used and their effects which are often desirable and can perpetuate addiction.
3. Theories supporting the individual and a proclivity toward addiction; suggest that certain individuals may be more susceptible to drugs/ stimuli whether this is psychologically, socially or even biochemically.
4. Environmental and social conditions that promote or inhibit addiction. These theories examine social, environmental factors such as poverty, lack of opportunity that may make addiction more likely.

West (2001) describes a fifth group of addiction theories that transverse the aforementioned theoretical perspectives, these theories focus on relapse and recovery. Relapse and recovery has received much debate and scrutiny, yet the definition of recovery, the process of recovery and a person’s propensity, or likelihood to recover from addiction, remains one of the most significant questions in addictions research today.

Robinson et al., (2003) define addiction as a compulsive pattern including drug-seeking and drug-taking behaviour that takes place at the expense of most other activities. It is inferred in Robinson’s definition that within this pattern, the substance becomes the priority. All other activities such as attending to health and wellbeing lose priority. The compulsive pattern suggests that a person in addiction is stuck in this repetitive motion and that they are compelled to continue; all the while everything else in their lives is removed. Substance use in itself has a detrimental effect on a person’s brain function related to motivation, pleasure and also cognitive function. This will have significant impact on a person’s ability to take or remember to take their medication. The Brain disease model of addiction posited by theorists such as Volkow (2000) and Robinson (2003) has come under much scrutiny and debate, with theorists arguing that the brain disease model, although indisputable, is limiting as it portrays individuals as lacking free will and lacking in decision making capacity.

The United Nations World Drug report (2021) states that between 2010 and 2018 the global number of people using drugs in the past year increased by 22% from 226 million people to 274, of these 274 million people; it is estimated that 36 million suffer from a drug use disorder. This is defined as drug use that is harmful to the point where as person might experience drug dependence and or require treatment.

Several studies correlate low prescribed medication adherence levels among people with addiction issues (Hinkin et al., 2007; Palepu et al., 2008; Schneider et al., 2012 and Kadar et al., 2015). Harmful substance use strongly correlates with ARV non adherence (Kadar et al., 2015) and disease progression, increased HIV viral load and early morbidity in persons living with HIV (Schneider et al., 2012; Kadar et al., 2015). An Irish study by Kinahan et al., (2016) asserts that people with dual diagnosis of HIV and opiate dependence, experience multiple bio-psychosocial morbidities and have poor HIV and addiction prognosis. Interestingly, alcohol use was found to have a more negative effect on ARV adherence than other substances and being male was strongly associated with poorer adherence. Kadar et al., (2015) highlight that persons who miss HIV medication doses are more likely to disengage from treatment and become non-adherent in the long term.

In a qualitative study conducted by Miamiga et al., (2010) in Ukraine, a country where up to 33% of intravenous drug users are living with HIV, respondents provided a variety of reasons as to why they did not adhere to HIV medication including dependence on opiate based substances and the complexity of most ARV drug regimens, ARV related side effects, forgetting to take their medication and the presence of a concurrent mental health disorder. Interestingly, Lacob et al., (2017) highlight that research studies between 2005 and 2014 demonstrated significantly higher adherence in patients with a once-daily fixed-dose (single tablet regimen) compared to any other treatment regimen.

In relation to the effect of opiate dependence on adherence to ARVS, respondents in the study by Miamiga et al., (2010), highlighted that the primary concern or need of someone who is addicted to opiates, is where and how they will secure their next ‘fix’ or substance of choice. This is in accord with previous study findings whereby persons in addiction are stuck in a repetitive cycle of seeking, finding and taking substances. It is also illustrative of Maslow’s (1947) hierarchy of needs theory in that the need for a ‘fix’ supersedes all other needs for persons in addiction. One respondent proposed that ‘*People who take street drugs are busy thinking about where to get drugs, how to get drugs and do not have time to take ART’ (*Miamiga et al., 2010, p.5). There is a requirement for HIV medication to be closely monitored particularly in the initial stages of treatment – this too can pose a limitation to people who use substances, in terms of maintaining adherence. Attendance at medical appointments will be challenging for a person who is substance misusing. Side effects and contraindications go un-noted and unresolved and thus disengagement and non-adherence are more likely.

2.11 Chapter Summary

This chapter explored literature relevant to the experience of people who are homeless, who use substances and who are living with HIV and the associated complexities of trying to adhere to HIV medication in these contexts Literature was examined pertaining to HIV, its history since its first presentation in a human in 1981, the disease progression, and signs and symptoms. Literature exploring diagnosis experience was examined, and it was found that this is a significant, traumatic event for those receiving same. Issues pertaining to HIV medication, side effects and medication compliance/ adherence were also explored. It was noted that aside from the physiological side effects there are psychological and social barriers to adherence for people. Finally, this literature review investigated the complexities of addiction and homelessness and how these two factors uniquely affect a person’s ability to adhere. There was a significant amount of research on medication adherence and the experience of substance addiction and homelessness. However, few studies have researched the impact of homelessness *and* addiction on HIV medication adherence.

Chapter 3. Methodology

3.1 Introduction

This chapter outlines the aims and objectives of this research and describes the qualitative research design and well as the study methodology; narrative inquiry. The rationale for the choice of design and methods is articulated and the process of the research is described. The chapter also outlines ethical considerations and potential limitations to this research.

3.2 Aims and Objectives of the Study

The experience of people who are prescribed HIV, ARV medication, who are homeless and are living with addiction has not been widely explored in research. Additionally, research on medication adherence predominantly employs quantitative methods. Therefore this research aimed

- To explore participant's lived experiences of adhering to HIV medication in the contexts of personal homelessness and addiction
- To develop understanding and knowledge concerning challenges and supports to medication adherence in the contexts of personal homelessness and addiction

The objectives of the study were to

- Recruit 5 – 7 participants who had contemporaneous experience of being prescribed HIV medication while navigating substance use and homelessness
- Using narrative methodology carry our semi-structured interviews with participants to gather narratives of experience

- Analyse the data using Riessman's (2008) narrative inquiry framework to develop understanding and knowledge concerning challenges and supports to medication adherence in the contexts of personal homelessness and addiction

3.3 Research Design

As the research aims and objectives called for a focused exploration of human experience and perceptions, qualitative methodology was best suited to this purpose. Qualitative research focuses on lived experiences and the subjective meanings and understandings that are associated with these phenomena. Qualitative research has been variously defined and described, however Aspers & Corte, (2019 p142) helpfully outline some of the predominant characteristics of this approach

> “Qualitative research is multimethod in focus, involving an interpretative, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.”

3.3.1 Research Methodology - Narrative Inquiry

This research was concerned with the personal lived experiences of those who were trying to manage the challenges of complex circumstances. Many scholars argue that human beings across time and cultures narrate and configure lived experience through the formulation of stories. The articulation and sharing of these stories enables meaning through individual reflection and discursive processes. (Riessman, 2008) notes that through narratives people edit their ‘remembered pasts’ in order to ‘square with their identities in the present’, (p. 379) and that by examining their past experience people can make sense of it. Narratives are present in many forms; they can be communicated orally, visually, or they can be written. Riessman & Quinney (2005) highlight that narratives serve different purposes for different people; and argue that they can be used to ‘remember, to argue, to justify, to persuade, to engage, to entertain and even to mislead an audience’ (p.395). Narrative researchers are interested in examining the stories that people tell about lived experience and their interpretations of these phenomena (Polkinghorne, 1988). This concern with interpretation of lived experience locates narrative methodology with a qualitative phenomenological framework (Geale, 2015).

Narrative inquiry has developed as a research methodology over the last fifty years, influenced by such disciplines as psychology (Bruner, 1986; Polkinghorne, 1988), anthropology (Ochs and Capps, 1996), socio-linguistics (Labov & Waletsky, 1967), sociology (Hickson, 2016), social action (Bell, 1988), education (Connelly & Clandinin, 1990) and healthcare, medicine and illness (Charon, 2006; Casey, Proudfoot, & Corbally, (2016). Bell (2002) and others (Sandelowski, 1991; Frank, 1995) suggest that narrative inquiry emerged in response to biomedicine’s focus on disease processes and quantitative, empirical research and consequent neglect of patient experience. Frank (2001 p. 358) suggests that illness stories challenge listeners to question the privileged status of biomedical formulations of disease and treatment which result in the ‘erasure of suffering from illness.’

A large body of literature attests to the value of narrative inquiry as a way of understanding people’s first-hand accounts of their illness experiences (Andrews *et al.*, 2013; Wang & Geale, 2015; Haydon *et al.*, 2018) and the importance of incorporating these understandings into effective and sensitive care provision (Riessman, 2002; Greenhalgh, 2016). People who experience illness can generate understanding and meaning by revealing or sharing illness narratives, (Kleinman, 2020). Frank (1995) identified narrative types in illness narratives; for example, the quest narrative (where the person’s narrative reveals a searching for meaning in the illness experience) the restitution narrative (where a person is able to find meaning in the illness experience and can articulate a sustaining narrative) and the chaos narrative (illustrating ongoing trauma and difficulty in reclaiming a sustaining explanatory narrative).

3.3.2 Riessman's Narrative Framework Approach

Riessman's (2008) approach provides a framework and a structure to the researcher. Riessman outlines clear methods of analysis and processes to make sense of data. Riessman's approach is multifaceted and detailed. Riessman's (2008) takes into consideration that a story is told at a specific time, is influenced by personal, socio-political, relational and environment circumstances and that the role of the narrator and the identity they assume within the narrative all contribute to and shape the construction of the story. Bruner (1986) refers to the 'dual landscapes' of Narrative, one being the landscape of action (the plot and the makeup of the story) and the other being the landscape of consciousness; referring to the psychological state of the story teller. Therefore, a narrative can never be posited as fact or definitive truth- its truth is in the telling, in the moment and in the space of the telling, influenced by context, culture and social circumstance.

Research participants choose which stories to share and which to omit. There is a recognition in Riessman's (2008) framework of the relational process between the research participant and researcher involving a range of communication and power dynamics that will influence the production of the narrative. Thus the researcher is implicated in "the scenes of storytelling" (Gubrium & Holstein, 2009 p. 250). Riessman (2015) claims that this characteristic is inevitable in all research and that researcher reflexivity makes these processes visible. In this research I acknowledge and examine my role as a female nurse practitioner who is the manager of the healthcare environment where the participants are service users. As far as possible in the research, the emphasis was placed on the story of the participant; although I was conscious of my position, participation and presence in the dialogue, the narrative approach allowed for the expression of the participant's story in the context of their current circumstances and environment.

Riessman's (2008) approach acknowledges co-constructionism in the narrative interview research phases in particular. Riessman (2008) proposes that the narrator develops a self specifically for the listener. At the same time the listener is already listening with their own beliefs, values and preconceptions. In this regard the narrative is already being co-constructed. In much of her discourse surrounding narrative, Riessman speaks of the importance of listening. She signals that the development of this skill is imperative for all researchers. She specifies that as researchers we want to listen in an 'emotionally attentive and engaged way' (Riessman, 2008 p. 26). She further acknowledges that in the listening we expose ourselves: our own identities and preconceptions (p. 27). There is co-constructionism in the listening. Riessman (2008) notes significantly that the narrative approach is a 'dialogic relationship' that allows for 'greater communication equality.'

In her approach to narrative, Riessman (2008) advises that researchers collect field notes and observational notes that can be used to develop richer analysis and findings. She advises 'careful and sensitive transcription' methods Riessman p.26 (2008). She notes that reliance on transcription alone is not sufficient to convey experience. While reflecting on her research with Indian women and the issue of fertility; Riessman (2008) notes that in the transcription of one interview parts of the respondent begin to disappear- her position in society and parts of her personality which are expressed visually also disappear. She recommends the use of observation and incorporating long term relationship dynamic into the transcription and also the use of imagery in some instances to improve the quality of narrative detail, (Riessman, 2008).

3.3.3. Rationale for Using Narrative Inquiry in this Study

The service users who access the Blood Borne Virus Unit in which this research was conducted are very much living in the present, they live chaotic lifestyles and a lot of them are living in the cycle of addiction, getting drugs, taking drugs and planning how they will access their next drugs. There is little time for personal reflection or exploration. The services that these clients access are busy, staff to client ratios are maintained at minimal levels; the time to listen and the time to extract meaning from narrative has been diminished. This research seeks to give opportunity to clients to share their stories, and to derive meaning from the sharing of their stories. Through narrative research and inquiry, the researcher gains insight into a person's unique situation, their knowledge and their experience (Barabasch, 2018). In order to understand adherence and challenges to adherence, access to participant stories, perceptions and motivations opens up a conversation, a story about why people make the decisions they do. Narrative inquiry methodology has been used in a range of studies of HIV experience (Plummer, 1995; Squire, 2013). For example, in recent research, Scorgie, et al., (2021) researched narrative sexual histories and perceptions of HIV risk among young women taking PrEP in southern Africa, Shepherd (2022) used narrative frameworks of Plummer (1995) and Frank (1995) to analyse published stories by UK women concerning their HIV experiences. Researchers have also adopted narrative inquiry to examine experiences of homelessness (Williams & Stickley 2010; Toolis & Hammack 2015), and addiction (Hammer et al., 2012; Sharma 2015 and Niyazi et al., 2019).

Narrative inquiry was chosen over a range of other qualitative inquiry methods because this approach recognises that the stories that people tell are always contingent on intrapersonal and interpersonal dynamics (Squire et al., 2014). They are always partial and shifting, influenced by time and memory. These characteristics struck me as resonant with the circumstances of the research participant group whose lives are constantly shifting and their perceptions and articulation of their lived experience is often partial, chaotic and non-linear. Many qualitative approaches assume an order in the telling of experience and that this can then be faithfully represented through coding processes and thematic analysis. While these processes are useful, narrative inquiry enables a deeper level of appreciation and analysis of not just the content but also the context of storied lived experience. Trahar (2013) claims that narrative inquiry gives life to voices that frequently remain silent. Client experience of medication management in the context of homelessness and addiction has for too long been overlooked. Narrative research allows the nurse researcher access to the participant's subjective experience within the context of their social world, a world for participants in this research that is heavily influenced by homelessness and addiction.

3.4 Research Procedures

3.4.1 Participants and Sample Size

Participants in this research were recruited through convenience sampling in the Blood Borne virus Unit. In narrative research, participants are frequently known to the researcher and consideration of the dynamics of these relationships and their influence on the narrative forms part of the research process. The sample size in this research was small in order to be able to capture and analyse in depth interviews with few rather than scant information from many. Riessman (2008, p6) notes that narrative is not a suitable methodology to use in the research of ‘large numbers of nameless faceless individuals.’ Riesman’s (2008) narrative approach is more suited to smaller participant numbers. The proposed sample size was maintained at 6 which has been recommended in qualitative research in general (Smith, Flowers & Larkin, 2009). Sample size for this study was maintained at six in consideration of the possibility that participants in the sample group could disengage from the process due to perhaps early discharge, illness, drug use etc. The people accessing the Blood Borne Virus Unit (BBVU) at the time of the study were aged between 20 and 55 with a 65% male and 35% female gender mix, therefore all participants were over 18 years. Participants needed to be currently prescribed medication for HIV and be classified as homeless by the service. Despite being heavy substance users, many service users do not have a clinical diagnosis of addiction, however it was evident that the study participants had long standing drug use with attendant complications and all self-identified as being addicted to drugs. Although mental and physical health issues were common among the participants, again these were long standing issues and the health of each potential participant was reviewed through discussion with the health care team and participants in light of their capacity to participate in the research.

3.4.2 Inclusion Criteria

Inclusion criteria for this research were as follows:

- Service users accessing treatment from the BBVU
- Service users over the age of 18
- Service users who were currently prescribed medication for HIV
- Service users who fulfilled the service criteria as being homeless
- Service users who self-identified as having problems with substance use/addiction
- Service users who had at the time adequate mental and physical health to consent and participate in the study (this was identified through discussion with the health care team and participants).

3.4.3 Recruitment

Participants were recruited using recruitment posters located in a prominent position on the Blood Borne Virus Unit. The poster provided details of the study, inclusion criteria, and what participation would involve (See Appendix 1). Information regarding the study was also conveyed to service users via staff in the unit. Additionally, a generic information session concerning the research was conducted by the researcher in the BBVU and interested service users were invited to contact the researcher personally on the unit, by phone, email or via unit staff if they wished to participate. Upon contact with the researcher, potential participants were provided with an information sheet (see Appendix 2) outlining the details of the study, inclusion criteria, the requirement that interviews are recorded, their right to withdraw from the study until the point of data analysis, and measures that would be taken by the researcher to ensure participant anonymity. Interview times and locations were then arranged with the service users who continued to participate. In this research 6 participants volunteered to participate and they consented to being interviewed.

3.4.4 Interview Process

Interviews began with a review of the plain language statement (Appendix 2) and ensuring that participants understood the nature of the research, their participation and rights. Written consent was obtained prior to commencing each interview. Interviews took place within the unit for privacy reasons and space requirements. These interviews took place during waves of COVID-19 and social distancing and mask requirements were in place.

Riessman (2008) advocates allowing space for a more participative, relational way of interviewing, which both reflects and respects participant's ways of making meaning in their lives. For the purposes of this research 6 interviews were conducted. The questions were direct but in line with narrative interviewing style they allowed significant scope to the participant to tell their story in their own preferred style (Riessman 2008). I used active listening skills and prompts to draw out areas of perceived significance, for example; a participant mentioning having to move hostels and taking HIV medication. Narrative elements were further encouraged through prompts such as 'can you give me an example of that?' – see (appendix 4) Interview Guide. In line with active listening I encouraged and engaged with the participants using non-verbal ques such as smiling and nodding. The interviews were recorded using a digital recording device which enabled recordings to be safely and securely uploaded to an encrypted laptop.

When interviews were concluded each participant had an opportunity to reflect on the interview and how they were feeling. I checked, prior to leaving the room, that participants felt comfortable to continue their day's activities. The next steps in the research process were explained to the participants. Participants were reminded of the available supports on the Blood Borne Virus Unit (such as counselling, nursing one to one support) should they require same.

Riessman (2008) highlights the importance of sensitive listening to the interview recordings paying particular attention to pauses in the narration as well as participant emphasis. She also advises maintaining reflective notes during the interview and these were maintained in this research for all 6 interviews. During the transcription phase I was meticulous and maintained notes on utterances and pauses: in line with in- interview reflective notes and what was audible on recordings.

3.5 Ethical Considerations

3.5.1 Consent

Ethical approval for this research was granted from DCU Ethics Committee. Research participants were provided with participant information sheets. These were read through with some participants who had literacy issues.

A consent form (Appendix 3) was provided to each research participant and was read through with each individual to ensure that same was understood. Written and verbal consent were obtained when signing the consent form. Verbal consent was again clarified prior to each interview. Participants were reminded at these two time points that they had the option to opt out of the research study at any time prior to analysis.

3.5.2 Participant Vulnerability

Many of the clients attending the BBVU have experienced trauma, some may at times experience diminished cognitive ability secondary to illicit drug use. Clients entering the BBV Unit at Dublin Simon community have an array of complex physical and mental health needs: Physically, they may present with opportunistic infections or general health deterioration due to drug use and poor diet, nutrition. People who inject drugs may also have significant wound care needs. There may be concurrent mental health diagnoses; such as depression, anxiety, schizophrenia or drug induced psychosis. These vulnerabilities were taken into consideration when developing the inclusion criteria and in selecting the sample group. Mental health and physical health concerns were taken into consideration and clients were not included if either had deteriorated or rendered them unsuitable to participate. This was checked with the nursing staff prior to selection and again prior to interview. Fundamentally, participants were provided with full and accessible information about the study at all stages, had opportunities to ask questions.

During the research process I held a dual position as project researcher as well as being the Nurse manager of the BBVU. This dual role is common in practitioner research (Berry, 2016) and requires ongoing reflexivity and vigilance around power dynamics (Goldstein, 2017). There was a risk that service users may have felt unduly influenced to participate in this research or to ‘say the right thing,’ to please or to incur favour. Service users may have also felt obliged to participate because they may have believed that to not participate would impact negatively on the care that they received on the

BBVU. Participants were informed at recruitment stage, at consent stage and at pre and post interview follow up of their right to withdraw from this research. It was also made clear to them that disengagement from the study would have no impact on their care or treatment on the BBVU. During the research process, I was constantly observing participant psychological comfort levels and any hesitancy around participation.

3.5.3 Participant Vulnerability in Interviews

I was conscious that participants may have the potential to become upset during interview and was prepared to pause or stop the interview if necessary, to facilitate some breathing space, reschedule or discuss the participant's ongoing engagement in the study. My training and experience in emergency psychological first aid and in working with vulnerable adults in trauma informed interventions allow me to interact with this sample population in a way that is sensitive and therapeutically informed. My background and this training supported me to envisage and avert/mange any potential ethical dilemmas and enabled me to promote and preserve participant safety. All participants had a good level of psychological support available to them during the study period and their time in the BBVU, namely the service staff and a specialised, service specific counselling service. Each participant was be made aware of this during the consent phase of the research. No adverse consequences were experienced by study participants and extra support was not required.

The fact that I, as the researcher may have had long standing existing professional relationships with some of these clients could not be ignored and was evidenced and taken into consideration during the interview process. I have developed close relationships with clients, over the years working in BBVU. They have shared with me, at times; their deepest fears, traumas, their greatest achievements and their failures. For some clients I have had to discharge them from the service due to challenging behaviour or high risk substance use. Interestingly, these prior relationships were also acknowledged by some participants

> 'there was times I came in here, I mean you, you know that ehm I mean this is like, I mean this is probably like my 9th admission in here like and like without, without ehm, without (the Service), and without Respite I would be fuckin dead like times and times over' – Frances

In some interviews, our past experience together did shape and impact the interview to some degree. These relationships are acknowledged and incorporated into narrative inquiry processes through the premises of dialogical narrative co-construction. However, the researcher has an ethical and procedural responsibility to ensure that the participant narrative is not compromised. This is achieved by ongoing vigilance of relational dynamics and researcher reflexivity (Ellis & Bochner, 2000). The nuances of existing relationships were documented in interview notes and were taken into consideration and explored at analysis stage. I considered potential biases attributed to my position as lead researcher. My knowledge and experience working in the fields of addiction and HIV and my pre-existing relationships with respondents could all impact the outcomes of this research. In particular I was conscious of this at interview stage and ensured that questions asked were limited and uniform across respondents. I also endeavoured to limit my interactions within each interview so as to not influence the flow of personal narrative, but also as I was conscious that I myself have strong opinions and thoughts on much of the content that was explored in this research. I endeavoured to accept, identify and highlight the nuances that emerged during interview in interview notes and on reflection post interview.

3.5.4 Gendered Understandings

In this research there are potential sex/ gender dimensions to be considered. The aims, objectives and processes of this research were developed as gender neutral; however, the results of the research could be differentiated/ influenced by gender; for instance, the difference between the needs and priorities of the men and women, the perceived social roles of men and women. Arnsten, in her 2002 research concerning the impact of active drug use on anti-retroviral therapy adherence and viral suppression in HIV- infected drug users noted that women who had depression displayed lower levels of adherence than women without depression, however there was no link between depression and adherence observed in male respondents. This is significant and indicates that a variance does exist in the lived experience of men and women and potentially in their experiences of adherence to HIV medication. Additionally, I was aware of my position as a female researcher and my own gender based ways of understanding and perceiving phenomena.

It was therefore necessary that consideration be given to gender, in the selection of research methodology; interview style and questions, and in the data collection and analysis. Questioning styles were examined to ensure that they were gender neutral and/ or gender inclusive. I engaged in ongoing reflection regarding my own responses in interview and my processes of analytic judgements. Similarly support from supervisors was sought to ensure that there was no gender bias in the data analysis process. Tannenbaum et al., (2016) warn against gender bias in formulating research recommendations or implications for practice. Gender is important in decision making, dissemination, engaging stakeholders, and influences preference in the uptake of interventions. It is clear that if this research does not consider and account for gender differentials from the proposal phase up to the dissemination phase, clients could be excluded from the benefits of the outcomes, recommendations and proposed interventions.

3.5.5 Confidentiality and Anonymity

The confidentiality and anonymity of participants and their data was a primary consideration. Interviews were conducted in private rooms within the service. Participants were made aware, prior to engaging in the research, of the use of their data in terms of storage and dissemination. Anonymity was discussed and information pertaining to the use of their data in line with GDPR requirements was included in information provided to the participants; both verbally and in written form (See information sheet appendix 2).

As the sample size was small and due to the nature and detail of narrative analysis it was not possible to guarantee complete confidentiality and anonymity and the participants were advised of this throughout the research process and in consent. The following strategies were employed to try to preserve anonymity and promote confidentiality as much as possible: Interviews were recorded on a secure digital recorder and were deleted directly after transcriptions. Data was cleaned directly after transcription in order to remove any identifying information which was then replaced with pseudonyms. All identifying information was stored separately from raw data. The data was stored as per GDPR requirements in a password encrypted file on laptop (also encrypted) securely at the researcher's office. Only I and my supervisor had access to raw data. Pseudonyms were used for participant names. All remaining information in both hard and soft copy will be securely and permanently destroyed five years after completing the study to allow for publication.

This research was conducted with the service users in the BBVU as I had direct access to this hard to reach group and have gained their trust through therapeutic work. The study population were in patients in a safe and therapeutic environment with staff and support wrapped around them.

Vulnerabilities outlined above were taken into consideration and various strategies were put in place to support clients. As previously mentioned the value of this research for this particular cohort could be significant, this is a particularly under researched population and therefore this is a justifiable piece of research.

3.6 Data Analysis

The purpose of narrative analysis is not just to reveal the individual story (content) but also to consider the meaning of the individual's story in the world (context) and the narrative processes by which the person makes meaning (construction). Riessman (2008) refers to this as the 'what' and the 'how' of stories. This involves paying close attention to both the content of what is narrated, how the narrator tells or performs the story, how they position themselves and others and the relational/contextual circumstances of the telling and the audience. Therefore, Riessman's approach to narrative analysis focuses on four dimensions: the case specific nature of narrative; thematic analysis; structural analysis and performative/dialogic analysis. These dimensions are explained below. I also conducted a cross case analysis of the six interviews as recommended by Riessman (2008) in order to gain a sense of common and unique findings across participant narratives.

3.6.1 Case Specific Analysis

Many narrative researchers, including Riessman, emphasise the importance of exploring the person's whole narrative as far as possible. This involves engaging the person in detailed explanation and narration of life events and perspectives. In this research individual narratives were studied, summarised and elements pertinent to Riesman's four dimensions were highlighted, see Appendix 7. Similarly, narrative analysis involves examining that person's stories within their own life context or in their own case. In the presentation of the narrative analysis and findings, extended segments of the person's narrative are set out with accompanying analysis. This differs to the more common presentation of traditional qualitative research which describes themes first with short exemplary quotes from the participant responses.

3.6.2 Thematic Analysis

Within each participant narrative or case, a thematic analysis was carried out. Riessman (2008) refers to thematic analysis as the 'what' of the narrative; what messages the narrator is trying to convey via the story. Thematic analysis involved examining the recordings, transcripts and field notes for areas of particular significance, repetition or emotional charge. I was alert for particular pre-occupations or recurring experiences. The participants' perceptions and contexts of their experiences was also important in the thematic analysis. From this process, particular significant themes were established within each unique narrative case. See appendix 7 for a data analysis extract in this regard.

3.6.3 Structural Analysis

In line with Riessman's (2008) approach, each narrative was also analysed concerning the 'how' of the story. This involved examination of the structure of the narrative for example language and metaphors used and whether the story telling is linear or nonlinear. Langer (1991) discusses the lack of linearity in the telling of traumatic events. He recounts interviews with Holocaust survivors whose stories were rarely linear and dance from time to time and place to place. Martinez (2020) examined migrant histories and identified that their narratives were often non-linear reflecting their migratory experience, which very often does not align with expected linear histories. The narratives provided by the respondents in this research are narratives of trauma: the trauma of homelessness, substance use and of living with HIV in this context. Riesman (2008) regards the structural element of analysis as similar to the study of a piece of music. Riesman's structural analysis allows the researcher to examine the make-up, the detail of each individual's narrative. In the structural analysis of the narrative the researcher identifies defining or turning moments of the story, the undulation of the story; where it might begin and where it ends. See appendix 7 for a data analysis extract in this regard.

3.6.4 Dialogic and Performative Analysis

Many narrative researchers and theorists highlight the dialogic nature of storytelling and story sharing (Naumer, Fisher & Dervin 2008; Fisher, 2008; Smith & Sparks, 2008; Fisher, 2011). Meaning is created through articulating our stories to and with an audience. The responses of the audience/listeners further shapes individual and socially agreed meanings of experience. Sharing narratives through dialogue involves performance; performativity is interactional, between story teller and audience – often a dance between the two (Riessman, 2008). For example, we often perform our gender identities in everyday interactions. The portrayal of self through one's story is known as identity performance (Goffman, 1959). Performative and dialogic research acknowledges that stories are not just told, they are performed; the narrator *creates* their position within the narrative. It acknowledges that people negotiate how they want to be seen in the world through the stories they construct and tell (Riessman, 2008). Dialogic and performative analysis recognises that language is constructed and interpreted between speaker and listener and in this way acknowledges that the researcher is not a passive participant in the process but has influence and is an active part of the process. See appendix 7 for a data analysis extract in this regard.

3.6.5 Cross Case Analysis

After analysing the individual six cases, I carried out a cross case analysis. The purpose of this was to further examine any similar experiences or meanings that were common across the six narrative cases and to explore where there were areas of difference. Riessman's (2008) cross case analysis approach was used for this purpose. This involved examining the findings of the individual cases and undertaking a further thematic analysis, arriving at common, overarching themes that were apparent in some or all narratives as well as idiosyncratic or unique experiences (see Appendix 9).

3.7 Rigour and Truthfulness in Narrative Inquiry

In this research I was mindful of factors potentially influencing the interactive and analytic research processes; for example, my position as the service manager and how this may affect the identified performances/narrative sharing of all involved. Power dynamics may result in some stories being omitted or reframed and my own personal knowledge of the participant back stories and histories could also influence my interpretation and analysis of the stories told at interview. In addition, I was conscious that I was coming to this research influenced by a range of theories, knowledge and pre-conceptions. According to Aspers & Corte, (2019, p153)

> "Theory and previous research cannot be escaped or bracketed. According to hermeneutic principles all scientific work is grounded in the lifeworld, and as social scientists we can thus never fully bracket our pre-understanding."

These considerations are well recognised and accepted by narrative researchers as part of the research process (Burman 1997; Finlay 2002; Loh, 2013). The researcher does not claim to have accessed a 'true' story but rather a story performed to a particular audience at a particular point in time as a narrator is trying to make sense of lived experience. The researcher also signals that their interpretation is dependent on these dynamic influences. This awareness is conveyed in the analysis through reflexive researcher comments on some interpretations, (see Appendices 8 and 9). Riessman (2008, p.191) proposes that in analysis the researcher must convince the reader that their interpretation is 'plausible and reasonable.' In this research I have endeavoured to prove rigour and trustworthiness from initial ethical approval to the analysis and findings of my research. Initially in gathering data, the recording procedures and records were the primary source of evidence. These were complimented by robust note keeping: interview and reflective notes.

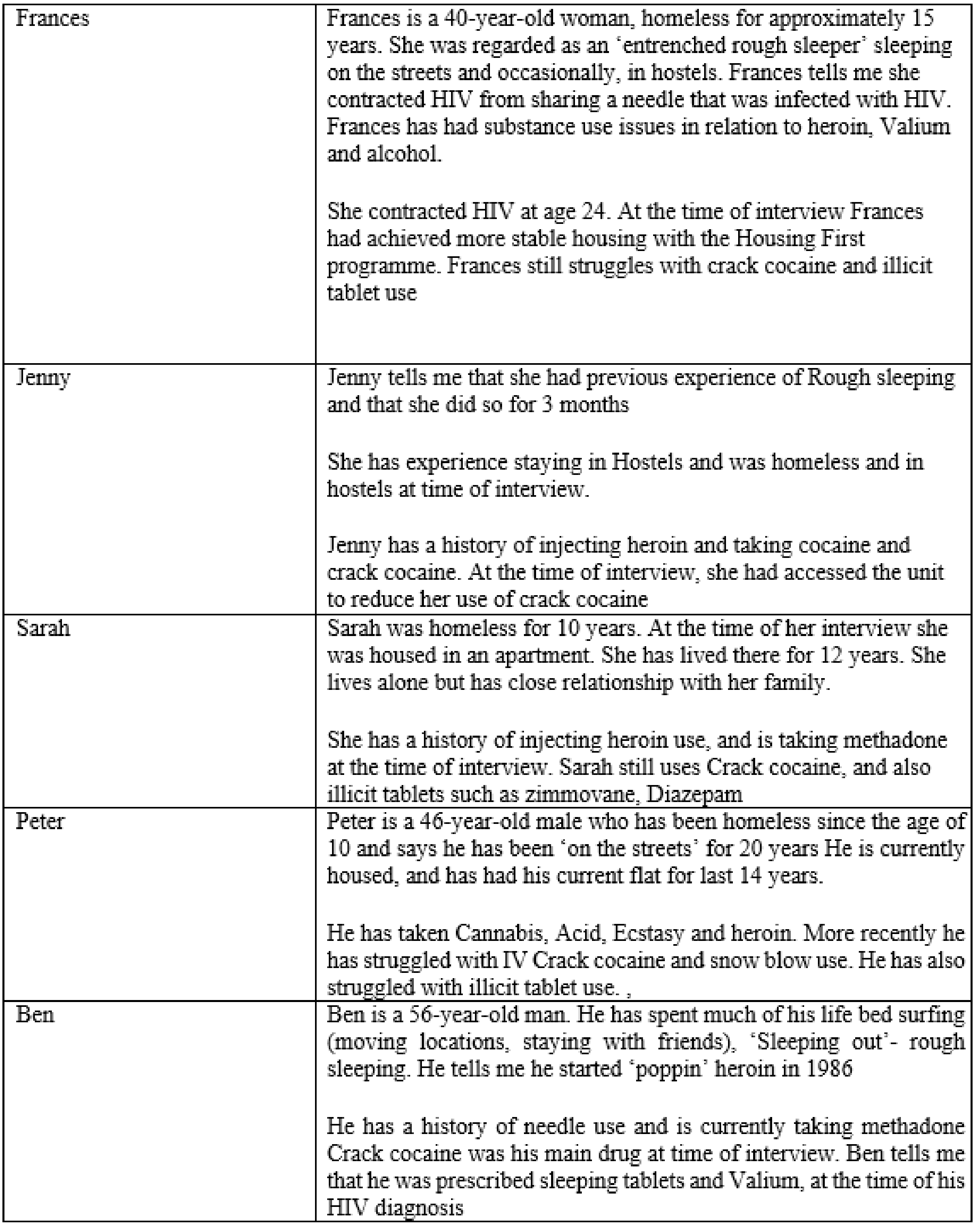
3.8 Summary

This chapter described the research methodology chosen for this study. It outlined the aims of the study and the rationale for choosing a narrative methodology. Further, the research procedure and Riessman's (2008) narrative framework were described in detail. The chapter outlined emergent ethical issues in this research such as the vulnerable participant group, interviewing processes, confidentiality as well as issues of rigour and trustworthiness in narrative inquiry.

Chapter 4: Individual Narratives- Case Analysis

In the following chapter, the individual narratives of the six research participants are presented.

Table 1. Participant Overview



Frances	Frances is a 40-year-old woman, homeless for approximately 15 years. She was regarded as an 'entrenched rough sleeper' sleeping on the streets and occasionally, in hostels. Frances tells me she contracted HIV from sharing a needle that was infected with HIV. Frances has had substance use issues in relation to heroin, Valium and alcohol. She contracted HIV at age 24. At the time of interview Frances had achieved more stable housing with the Housing First programme. Frances still struggles with crack cocaine and illicit tablet use
Jenny	Jenny tells me that she had previous experience of Rough sleeping and that she did so for 3 months She has experience staying in Hostels and was homeless and in hostels at time of interview. Jenny has a history of injecting heroin and taking cocaine and crack cocaine. At the time of interview, she had accessed the unit to reduce her use of crack cocaine
Sarah	Sarah was homeless for 10 years. At the time of her interview she was housed in an apartment. She has lived there for 12 years. She lives alone but has close relationship with her family. She has a history of injecting heroin use, and is taking methadone at the time of interview. Sarah still uses Crack cocaine, and also illicit tablets such as zimmovane, Diazepam
Peter	Peter is a 46-year-old male who has been homeless since the age of 10 and says he has been 'on the streets' for 20 years He is currently housed, and has had his current flat for last 14 years. He has taken Cannabis, Acid, Ecstasy and heroin. More recently he has struggled with IV Crack cocaine and snow blow use. He has also struggled with illicit tablet use. ,
Ben	Ben is a 56-year-old man. He has spent much of his life bed surfing (moving locations, staying with friends), 'Sleeping out'- rough sleeping. He tells me he started 'poppin' heroin in 1986 He has a history of needle use and is currently taking methadone Crack cocaine was his main drug at time of interview. Ben tells me that he was prescribed sleeping tablets and Valium, at the time of his HIV diagnosis

4.1 Frances's Narrative

Frances has been attending the BBV unit for a number of years and we know each other well. We grew up in the same area and realised several years back that we were in the same school and would have attended together at one point in time. Frances's story is one of domestic violence and trauma and alcoholism that began at a very young age. She began using drugs such as heroin at a young age. Frances tends not to stay in the one place for too long but rather keeps moving from one place to another. She has lived her life in this manner since she left home. This sense of her wandering is prevalent throughout her narrative. She presents as a bright and vibrant young woman, full of life and of hope. I hold a lot of her history, gathered from many years of conversation. I was reminded of this as I transcribed her interview; of the value of other people's stories and histories; and my own responsibility as a practitioner and a researcher to attend to and honour their meanings in my re-presentation. The interview session with Frances took place in her bedroom at the BBV during a recent admission for drug and ARV stabilisation.

Frances moves between the bed and chair throughout the interview. She doesn't settle in the same spot for long. Frances begins her story with a vivid account of how she became HIV positive.

> *I was HIV positive when I was 24, I'm now 40. I was at Connolly station there was a guy that I didn't know sleeping in a sleeping bag and I said to him… 'can you score me gear?' and he was like 'oh yeah.' He only had one works, one barrel, one spike* [one syringe and one needle] *and he insisted on going first, he swore on his kids, his family he had nothing. Now I'd briefly been in England, locked up. I did a lot of running around at that time, and I'd had a full NCT, they do all your bloods so I knew that I'd hepatitis but I knew I had no HIV. I hadn't used from then to this date, so when he gave me the barrel it was pink, I stuck it into me… I ended up overdosing, funnily enough, and ended up in hospital, gave myself a little bit of a fright and I said 'fuck it I'm going back down to my partner.' I got pregnant and I get my full bloods done and the doctor comes in real nonchalantly and says 'we have good news and bad news, Ms O' Reilly, your Hep C is dormant but you have HIV.' I personally thought that I'd murdered myself, I thought I'd killed him* [her partner]. *I thought I'd killed the baby, I knew NOTHING (Frances' emphasis) about HIV.*

Frances tells the story of how she contracted HIV in some detail. She knows exactly the occasion that this event occurred and the person from whom she contracted the virus. She recounts using the needle and syringe and vividly describes the contents of the syringe as *'pink'*. Frances says '*I stuck it into me*.' There is a sense of inevitability when Frances says this, in that she knew it was pink, she knew there was blood in the syringe, but she knew she was going to use it anyway. Here, the desire for Frances to use drugs overrides evident risks.

A sense of transience is present in Frances's narrative. Pre – diagnosis Frances is engaged in what she later referred to as 'Geographics', 'running around' from place to place. Similarly, traumatic experiences are described in a transient, passing fashion, and are somewhat minimised for example '*very briefly been in England and been locked up, I did a lot of running around at that time,'…. 'so I knew that I'd hepatitis* *and that it was dormant'. 'I ended up overdosing, funnily enough and ended up in hospital, kind of gave myself a little bit of a fright.'…. 'So within all of that I got pregnant and I go to get my full bloods done….'* There is a dismissive, inconsequential tone in Frances' listing of these traumatic events. I wondered at the time whether this was a performance of bravado or stoicism or whether chaos and trauma is so embedded in Frances' life that she has become habituated to it.

Interestingly, Frances's reaction and account of her HIV diagnosis is different. Frances notes that the doctor conveys this to her '*real nonchalantly'…* '*we have good news and bad news ….*' The energy and animation of Frances' narrative as she describes her diagnosis is markedly different; *'I, personally thought that I'd murdered myself, I thought I'd killed him* [her partner], *I thought I'd killed the baby.'* Here her detached, dismissive tone is replaced by one of drama, distress and guilt. The HIV diagnosis has impacted her in ways that incarceration, Hep C and pregnancy have not. I wondered if Frances expected these major life events to be part of her life as an IV drug user however she may not have anticipated HIV; she was not prepared for this, as part of her life narrative *'I knew NOTHING about HIV'.*

Frances describes further her perception and experience of diagnosis.

> *I'd been told I didn't have to be on medication, I had get checked every now and then, sure of course an addict, that's living in chaos, is not going to go and get checked. I ended up getting taken into hospital and they'd told me that it had almost progressed to AIDS, 3 years had gone past, they put me on medication. They were like horse tablets, I didn't enjoy takin them, they could be very hard on your stomach, for a using addict to take a really hard medication like that, didn't sit with me. I didn't stay compliant for very long. I walked in to this clinic - everybody looked like they were dying and I was like, 'that's not me.'*
>
> *The doctors were very strict and like you have to be here at this time otherwise we are not going to give you your medication and you'll die, there was no empathy and they looked, from my side of the fence as if they looked down on us, especially the non-gays coz y'know we were the junkies to them…they would use ye, as a number, they would very rarely make eye contact, they would stick their heads in their notes.*
>
> *I didn't have a very good or positive experience regarding that. I just felt like fuck them, better off taking my chances. I went once in a blue moon to collect meds, didn't stay compliant. The doctors were rigid, ridiculously so, if you're living a chaotic lifestyle, you're homeless, you wake up in the morning, I'm going to be honest, my first priority was to make me-self feel well, don't mind going to get medication, that I feel like I don't need in the first place. So most of the time I wouldn't.*

Here, Frances articulates her expectation that a using drug addict is not going to go and get their HIV checked; drug users are unlikely to engage because of the chaotic nature of their lifestyle. Frances positions her own non adherent behaviour as indicative of addicts in general. It may be that Frances has internalised/is performing a societal 'low expectation' discourse frequently employed in the context of addiction; that drug users like herself are predestined to not engage with HIV care because drug users don't get checked. There a sense of pre-determination rather than self-determination. We see this lack of agency when Frances says that she was 'taken to hospital', as if plucked off the streets. Frances did not decide or chose to go to hospital because she knew she needed care. She was taken there. From a practical perspective Frances describes what it was like to take the medication and how she 'didn't enjoy it'. This is an interesting turn of phrase which suggests that perhaps Frances believes that drugs are to be enjoyed; that there should be a tangible gain (such as enjoyment) in taking medication. Frances is frank when she says that when she wakes up, her priority is to make herself feel better, and to do this she uses drugs. Frances describes the challenges of taking HIV medication; they were like *'horse tablets'*, too *'hard'* on her stomach and that it didn't sit well with a *'using addict'* to be taking something so hard on her stomach, likely because it would make her sick. It seems it doesn't make sense to Frances to be taking a drug that doesn't make her feel good.

Frances recalls attending a London clinic to start treatment; she describes not fitting in; - everyone in the clinic *'looked like they were dying'*. Frances's sense of isolation and exclusion is compounded by her experience with doctors here. She describes them as strict and says that they lacked *'empathy'*. Notably she says she felt that they looked down on her, as a *'non – gay'*, intimating that drug users were treated as *'less than'* in this clinic. In this portion of her narrative it seems clear that she felt alienated almost instantly from the very place that was supposed to be treating her. Frances self-reports that she is a person who takes off, leaves when things become uncomfortable. The implications of the experience she describes, for further engagement and subsequent treatment would be catastrophic for Frances. In this clinic there is nothing to anchor her; no sense of belonging, of comfort, of safety.

The following section of Frances's narrative is in contrast to her experience of HIV treatment in London. Frances talks about her experience of treatment in a local Dublin hospital and in a respite service. Her narrative is one of perceived acceptance and inclusion, she talks about her experiences here with fondness.

> *I just always felt more of an affinity with the doctor, she was female and ... she took an interest in me… She could see somethin' in me that I couldn't see in myself. I looked up to her, she would take time with me. She treated me like a human being. Today she has a walk in clinic; there for people that are non- compliant, or people that are living in homelessness or in addiction. It's so gravely important to have places like this, without respite I would be fuckin' dead like times over. I remember coming through those doors, on my knees, very little weight on me, strung out to the back bone, and without that bit of time, just to stop just to be looked after; I mean fed, warm bed, people that actually give a fuck people that want to make a difference… I feel like crying, honestly people that care, its invaluable ...It's the safe space that we don't have on the outside, its being known, and being understood and not being judged. It's a place for not only my body but my fuckin soul to like take a breath.*

In this section Frances talks about her affinity to her doctor *'I just always felt more of an affinity with the doctor, she was female and ... She took an interest in me… She could see somethin' in me that I couldn't see in myself.'* Frances feels comfortable, as if she belongs here. This is what is important to Frances to be able to relate to others and have them relate to her. This is in stark contrast to Frances's experience in London which is depicted as alien and excluding. Frances continues to describe an Irish HIV care system that is inclusive and flexible: she talks about drop in clinics that suit the needs of the people that they serve. Frances moves to her experience in the respite unit; a safe place where the basic needs often neglected in drug use are being met – food, warmth and a place for her *'soul to take a breath'.* Here she is accepted, even when she has been extremely chaotic. It seems it is the feeling of unconditional acceptance that is important to Frances. Frances becomes emotional during this portion of the interview and the meaning of her words and the emotion of them become evident. I wondered was Frances emotional because she so rarely feels this care and acceptance. This feeling of acceptance and belonging is at the core of what is meaningful to Frances. It is for this that she continues to move and search. I wonder if this is because this sense of belonging, to a family for instance had been so disrupted and removed for Frances from an early age.

I ask Frances about what her ideal service to support PLWH who are homeless and who use drugs would look like.

> *It would be tailored to the person; the person that's ready to get clean, a door to door situation; the opportunity to go from here to somewhere else. They have that step by step by step without falling through the cracks. For the person that wants to get clean, but doesn't know, provide the information give them a taste of CA/ NA and a place for them to go to after here; the option of long term. In an ideal world we have a place for them to find a forever home …My forever home, unfortunately, will not be my forever home, because my circumstances are different. I have an addiction support worker; her intention is fantastic, she does not have the life experience or the addiction in the field experience to understand; that you're walking past your home and someone says are you looking for a tray of pills or rock, you're having a shitty day it's not easy, to say no, the inherent problem is location. You're talkin' about entrenched rough sleepers that have had serious addiction problems, you can't just fuck them into the middle of town, and expect everthin' to be cool. I have my little flat but God if you could pick it up take it somewhere else it would be ideal'.*
>
> *A Doctor was talking about the testing bus and going out to people that genuinely are sleepin' on the streets, that are positive, and givin' them their medication., I know that sounds like people be like oh my God that's ridiculous, but It actually for a fact sometimes is the only way, to be at a specific place twice a week, on a bus. I know hopefully, were going to have the jab soon. They are going be just so important, towards getting people healthy and non-detectable.*

Frances makes valuable contributions here in regards to what she believes is needed in services for PLWHIV who use drugs and who may be homeless. It is likely that these solutions have developed from Frances's own experience. She remarks on the necessity of addiction life experience in order to support people in addiction. She emphasises the importance of pathways and preventing people from slipping through the cracks. She remarks on the need for low threshold services, long term care for people who want to stop using drugs but do not know how. Frances suggests that in some instances and for some people the only solution is the bus – a low threshold approach that seeks people out and gives treatment; people in transit, people who are difficult to pin down - Nomads. Notably, she feels that people might perceive this idea as ridiculous, possibly a draconian measure or perhaps that society might perceive drug users as undeserving of this level of support. Frances' meaning is not clear here.

Frances identifies that she has a home, a home that she says is not safe, and will never be because the location is unsuitable. Even at home she does not feel like she belongs, she does not feel safe. We see the nomadic theme in Frances's narrative emerge again. Frances tells me that she will again, move on. Her search for safety comfort and acceptance will continue.

4.1.1 Summary of Frances's Narrative

Early in Frances's narrative we see her overriding desire to use substances. We see that this desire precedes any risk. We are also exposed to the impact of substance use in this narrative; and its degrading effect on self- agency. Frances seems to have become immersed in a pre-ordained narrative that is based on what she perceives to be the life trajectory of a using drug addict. It seems at times that Frances is detached from many of the traumatic experiences that she describes in her narrative: overdosing, finding out that she has become pregnant. Frances's reaction to her HIV diagnosis is different, there is a dramatic sense of distress and guilt. Was Frances prepared for HIV in the trajectory of her own life? Was this part of her own envisaged biographical script?

In Frances narrative we are witness to two contrasting, yet powerful experiences of HIV treatment. We see one experience in London that is isolating, excluding and discriminating for Frances; she was made to feel less than, insignificant. We see too an experience of treatment in Dublin where Frances is seen, included and cared for. Frances provides valuable insight into the care provision that might suit the needs of PLWHIV who are also dealing with addiction and homelessness. But even here we get a sense from Frances that she will be judged by society for even conceiving of the idea that people who use drugs would be deserving of such a level of support. Perhaps Frances believes that she herself is undeserving of support and care. It is unclear as to whether this ongoing sense of exclusion and judgement has developed from experience for Frances or whether it has been constructed and realised as part of her pre-ordained narrative

Frances's nomadic pursuit of acceptance and care is a persistent instability in her life. She has no anchor to this world, she has no sense of safety even within the bounds of her own home. Frances moves from people and places where she does not feel accepted. Her experience with care providers in relation to her HIV and her substance use is significantly linked to her propensity to adhere or engage with a treatment regime. In the midst of this transience and movement of seeking safety, adherence to and engagement with HIV medication is not always Frances's main priority.

4.2 Jenny's Narrative

Jenny comes from a home where domestic violence and alcohol addiction were prevalent. Of her eight sisters, six of them developed substance use problems. Jenny became pregnant with her first son, at 16 and began using drugs at 18 starting with IV heroin. Jenny was diagnosed with HIV at approximately the age of 21 or 22.

Jenny and I have a good relationship, in that we can talk with ease. At the time of the interview Jenny had been transferred to us from a 6-month stay hostel. Jenny appears relaxed and comfortable in her surroundings. I ask her which area she would like to talk about first; in relation to her experiences of taking HIV medication. Jenny starts the interview by recounting the experience of her HIV diagnosis.

> *My HIV diagnosis was told to me at the hospital. I still remember I went in with an abscess and I was in a ward downstairs and a doctor came in and I was told in a way, 'Oh, yeah, by the way, you have HIV', and he just walked away, that's the way I was told. That's exactly the way I was told. 'If your surgery goes okay, you'll be able to go home in a day or two,' and like, 'I have nowhere to go.' 'That's not my problem.' 'Can I see a social worker?' I walked out of that hospital with nowhere to go and after being told I had HIV. That's the way, 'By the way, you have HIV,' and I was, like, 'Oh, and how long have I got to live?' ... and they just walked away. That's the way I was told.*

Here Jenny recalls her HIV diagnosis; she depicts the doctor as uncaring and dismissive in tone. *'oh yeah, by the way'*. It feels in these words; as if the diagnosis does not matter. There is a sense that Jenny is lost, alone after hearing her diagnosis, and is grappling to find support. There is a sense of abandonment when she says *'they just walked away,'* For Jenny this is a cataclysmic event, diminished by the inconsequential delivery of a diagnosis. It appears that Jenny has received no information or encouragement to attend further services or treatment.

Despite her experience Jenny proudly informs me that '*You know, it was a good three to five years before I got sick.'* On developing pneumonia, she was prescribed HIV medication.

> *The first medication didn't agree with me, remember you had to keep it in the fridge. I think I started with six or seven tablets at that time, 18, 19 years ago. I kept vomiting. I felt like I'm getting the medication, so I must be nearly dying. I even remember asking the doctor, 'How long have I got left now?' Because I never read into it... He said, 'This is the medication to stop you from getting AIDS'. And I said, 'What do you mean? I have AIDS?' He goes, 'no you haven't. You have HIV.' I said, "Yeah, but that is AIDS," because I was so, you know. But no, he explained it to me and then I kept to the tablet routine and to my appointments and then it was undetectable for a couple of years. Then I felt good. I felt alive again, I got side effects from the medication. It was hard because I knew when I take these tablets ... I'd be in the toilet vomiting, but that would be only one vomit and then that would be it. But that only lasted for a week. I lost my hair. It started falling out. Yeah. I had hair down to here, thick hair, and I lost it. I didn't lose it quickly, it just went thin, Yeah. I got very conscious. I had to keep on wearing hats.*

In this excerpt it is clear that there are some gaps in Jenny's knowledge around HIV. She had confused HIV and AIDS and had believed she was dying. It seems that Jenny lived with this belief for some time without medical explanation which must have been frightening and distressing. This later interaction, however, subsequent to diagnosis, seems to have been more positive for Jenny, she felt empowered to seek information and this may have supported her adherence to treatment; *'he explained it to me and then I kept to the tablet routine and to my appointments and then it was undetectable for a couple of* *years. Then I felt good. I felt alive again.*' She maintained adherence despite significant side effects (nausea and hair loss). However, for Jenny, trying to adhere to HIV medication in the context of homelessness was much more challenging.

> *If you are homeless, it's hard, even if you're taking your medicine, because you have to leave it in a locker because they are HIV meds, people that are on methadone, we have to put them in the locker, most people that are on methadone live in hostels, you know. I must have been in about 40 hostels in Ireland. It was always a six-month hostel, and then when you're getting settled in, you're uprooted again…the things I've lost…. I've lost everything; personal things that I'll never get back again. You have to get people to open your locker and they're seeing what you're taking. It is hard, even if you're doing great on your meds, it's hard. I found it hard, that's why I didn't take my meds, because I didn't really want people…. because people that were working in most of the hostels I had known -they used drugs with me in the past and now they were homeless workers. They knew I had HIV. It was just the stigma, that they looked down and yet they used to use with me. There would be people there beside you and getting their meds too, and they'd be saying, 'What tabs are they?' and I'd have to explain, 'They're my HIV tablets.'*

Jenny takes us into the world of hostel living in Dublin. She describes the chaos of this environment and says that she was constantly being uprooted and losing things – things she will never get back. Here she conveys a sense of transience and constantly feeling unsettled. She explains clearly the routine for getting medication in the hostels: having to get it from a locker, with other people present. She depicts a lack of privacy and confidentiality. Significantly she mentions the stigma and the feeling of people looking down on her, particularly those who were former drug using companions and now working in homelessness services. The sense of shame and altered power dynamics are strongly evident here. This experience of chaos, breach of privacy and stigma seems to have caused significant emotional distress for Jenny, which seems to outweigh the physical side effects of taking HIV medication.

A further major impact on Jenny's HIV medication adherence was her drug use. Here she describes further the challenges of taking HIV medication in context of her transient accommodation and escalating drug use

> *I used to feel healthy, get into a place, a six-month hostel, and then I'd have to move. I'd stop my medication I would feel good for a couple of months, I'd be smoking rock and then I'd hit rock bottom, I'd start getting sick. I don't know how I'm still here…. I've been in some states. I've lost so much weight I had to just buy clothes from children's departments. It was the drugs that was killing the times of the appointments, getting there. If I knew there was a rock, two rocks …I'd jump up and get there, it's just mad, like the drugs just took over my head. When I'm hectic, it's just more like I'm not concentrating on that HIV treatment. That treatment should be more a priority than what I am concentrating on going out to get my next rock. But, no, I would leave that and fly out and get my next rock. There'd be some days I wouldn't even put water on my face, I'd be just straight out the door*

Jenny describes being up and down in terms of feeling good. She says that she would access stable accommodation and start to feel good, but this would lead to drug use and Jenny would find herself once again at 'rock bottom' which is an interesting choice of word given her addiction to 'rock.' Jenny's narrative here is one of a repetitive cycle, led by and consumed by access to substances- namely Crack cocaine. She describes how her drug use was all encompassing and significantly impacted her ability to engage with appointments and thus treatment. Drugs are personified and given agency '*It was the drugs that was killing the times of the appointments'……* '*drugs just took over my head.*' Jenny acknowledges that her HIV treatment should be her priority, however this imperative cannot compete with her all-consuming need for crack cocaine.

Jenny is very clear as to what would help her to adhere to her HIV medication, to Jenny it is simple; her keyworker in her hostel, can give her, her medication.

> *What would have supported me to take my meds was; I asked my key worker to give them to me every day. 'We haven't got the policy to do that'. I asked, 'Could you do it on the sly?' 'Oh, no.' 'Can you come up and tell me?' 'It's not for me to say. It's for you to take.' I said, 'Listen, I know that. I'd take it but I'm hectic.' 'I don't have to tell you to take your meds, you're a grown adult.' That's what I got. I am a very bad person for not taking my medication and it's like it could be in that drawer, I'd be just too lazy to take it. It's mad. But when I'm stable and when I'm good I take it. But if I'm hectic, I won't.*
>
> *No one supported me. No. Not even the key worker. I don't want to go back to the hostel because I won't go back. I'd rather get a tent and go to Phoenix Park. I've never got a chance of a home. I'd be on my own and I could put my cups, my plates, my medication here, and open my medication and put it beside my methadone. I could just have my medical press in the bathroom when you're getting ready, your methadone in there, your HIV treatment or whatever else you're on, and take it all in the bathroom…*

Jenny interprets the keyworkers refusal to dispense her medication as a lack of support. I surmise that this keyworker likely cannot dispense medication, and believes that dispensing is not an empowering, sustainable approach to medication management. There appears to be a power struggle at play here. The keyworker wants Jenny to be empowered to take her own medication. But Jenny does not seem to believe that she has the power herself, to take them. Jenny once again alludes to feeling dismissed and diminished *'you're a grown adult'*. It appears that for Jenny, it its incomprehensible as to why this key worker will not just give her the medication. I considered at this point in her narrative; the link between Jenny's possible lack of self-belief, diminished sense of personal agency and her experience of being dismissed and of her feelings being diminished.

Jenny provides key insights into her own potential barriers to adherence in this narrative where she clearly states that when she is *'hectic'* she will not take her medication. Notably she says *'I am a bad person for not taking my medication.'* This suggests that there is a question of morality for Jenny connected with whether or not she takes her medication. Yet Jenny makes the point that there are times when she will just not take her medication. There is a real sense of apathy when Jenny explains this to me; 'they *could be in the drawer there and I would just be too lazy to take them.'* Again Jenny makes a moral judgement of herself as lazy. She follows this up with '*when I am stable I take them.'* This indicates that when Jenny is using substances she is more apathetic towards taking her HIV medication.

In her dreams of having her own home however, Jenny performs herself as an agentic person; organising her medication in a *'medical press'* and taking it in her own bathroom. This picture of domestic simplicity is in stark contrast to Jenny's earlier description of having to queue up at her locker to get her medication in the hostels, and indicates again that a lack of privacy, stigma, shame and the chaos of the hostel environment negatively impact Jenny's ability to adhere to medication. Throughout her narrative, in the midst of chaos and trauma, there are also signifiers of her yearning for stability and routine

> *I was clean for four years, in London, and I know I have the hunger and I have the taste of being clean, and I want that. I had the nice good living, I had the money every day, I had a nice home. You know, every day my friend rang up, 'Do you want to go for coffee?' Yeah, because I had money. I wasn't making excuses up because I had to spend it all on a rock. It was great, fantastic. I used to go out clubbing at the weekend and everything.*

In sharing her desire for sobriety and recovery, Jenny says that she has a *'hunger'* for it. Jenny seems familiar with recovery; she has experienced it before, however there is a profound sense of struggle for Jenny as she relays the many attempts she has made to get recovery when her body was willing but her head wasn't. It seems as if Jenny is in a battle between addiction and sobriety. There is a yearning in how Jenny describes the simplicity of sobriety; going out for coffee, even clubbing. Jenny appears to have choices and options in recovery. Choices that are strikingly absent in her narrative of addiction.

4.2.1 Summary of Jenny's Narrative

Jenny's diagnosis and initial engagement with HIV care was a negative one. We see the implications of this in Jenny's sense of abandonment and isolation and we see it too in her lack of knowledge. On commencement of medication Jenny's experience was more positive and she felt empowered to seek information and ask questions. Jenny says that following this she was adherent for a period of time and felt alive.

In Jenny's experience living in hostels we see issues of privacy and stigma arise. Jenny's life is intermittently uprooted when her stay comes to an end which negatively impacts her ability to adhere. In stark contrast Jenny describes living in a home; where her medications are accessible and private, safe in her bathroom cabinet. Yet, there is a struggle, a doubt for Jenny as to whether she really can take her medications consistently. Jenny knows that at times the drugs have taken precedence for her over her medications and there have been times where she just hasn't taken them.

Finally, we are witness to Jenny's constant battle. The battle between addiction and recovery, the life she depicts of recovery and the choices and options it reveals, is in stark contrast to the automated, closed cycle of addiction that Jenny conveys. Jenny's desire for recovery appears present and strong, but the cycle of crack addiction continues for Jenny to *'take over everything.'* Jenny returned to emergency accommodation after this interview was completed.

4.3 Sara's Narrative

Sara is a 52-year-old woman who has a long history of substance use and periods of homelessness. However, Sara has been housed in a flat since her HIV diagnosis. Sara tells me that addiction is 'horrible.' She tells me how 'ridiculous' drug use is, making someone else rich. She doesn't know where it all started, she supposes she just wanted to be part of the gang.

Sara describes being diagnosed with HIV after a dental procedure where she had teeth extracted.

> *When I was diagnosed, I was homeless. I went to the hospital, and the woman walks in to me and says, 'Do you know you're HIV positive?' Got no counselling, nothing...a total shock. It was horrible, to hear that you're HIV, just like that, 'You're HIV,' that's all, nothing else. It was blunt. Not, 'How do you think you contracted it?' No explanation, no nothing, so I think that's what depressed me more. Not knowing. I didn't know much about it. Then trying to tell my family that, because I always had a clean needle, always. When I lived in a flat I lived with these people, ex-addicts, they'd knock down and say 'Aww Sara, you always have a clean one,' [needle] which I always did, I was always careful, but to my knowledge someone switched it, he's six feet under now so karma's a bitch. I know it was him…… It was horrible. I'd be the type of person that'd say, 'You can't use this because I am HIV positive.' Whereas others wouldn't tell you that they had it. I'd rather tell because I wouldn't like to give it to somebody the way I was given it.*

Sara conveys the unexpected nature of her diagnosis and her sense of lack of support at the time. Sara is shocked at her diagnosis given that she always used a clean needle. Sara wants me to know that she was always careful, she was known for having clean needles. I sense that Sara might be conveying the message that she didn't deserve to contract HIV because she always used clean paraphernalia. Sara believes that a chance encounter where someone deliberately switched paraphernalia, was the event in which she contracted the virus. Her narrative focuses on casualty of circumstance, and the unscrupulous behaviour of others. Sara does not see herself or her drug use behaviour as implicated in her HIV positive status. She wants me to know that she is careful not to transmit her HIV to others. She is an active participant in the protection of others. Sara goes on to describe her subsequent HIV treatment and her perceptions and experiences of this.

> *You're taking four or five different tablets, like bleeding horse tranquilizers. You're getting used to them and they're making you very sick, until they find the right combination to go with your body. It just wasn't a nice experience. It's just not nice.*
>
> *I hated taking them. Because to me taking them makes it true, now I have got it, so I have to take them. It's not a flu, it's something. I'm on two tablets now, because I have come off them so many times, they are sickening. I'd fall asleep after I'd take them. It's just like a heavy load on you. I have to eat something with them.*
>
> *I did worry about not taking my medication, but then the drugs then would block it out. Then there would be times that I'd sit there and I'd say, 'I have to start taking them,' because of the kids and all. I'd say, 'Ah, now, I'm going to take them,' so I'll have a sleep for an hour and then I'll wake up and feel better. At least I know then that's that day over. It's just not a nice feeling, knowing that you're taking these things to keep you alive. If you're told you're going to die if you don't take this. It's like everything else, you have to do it.*

Here Sara describes her complex and ambivalent relationship with HIV medication. The physical challenges and effects are identified; the size of the tablets, the effects on her digestive system and making her drowsy. Sara indicates that the burden of taking them is a *'heavy load'.* There are also psychological challenges to taking HIV medication. For Sara, this appears as symbolic; taking HIV medication means that her diagnosis was real '*makes it true, now I have got it, so I have to take them. It's not a flu, it's something,'* medication is a repetitive reminder of this circumstance. Sara has come off her medication at times and says that the drugs would block out her worries about not taking her HIV medication. However, interestingly, she resumed taking her medication '*because of the kids and all'* and the knowledge that she will die if she doesn't take her medication. The struggle between denial, guilt and the imperative of maintaining health is strongly narrated here and is also reflected in Sara's initial use of the distancing *'you'* to her use of the more personal *'I'* as the narrative segment continues. In her next section of her narrative, Sara makes interesting comparisons between her drugs of abuse and her prescribed HIV medication

> *It is hard, you can't be motivated until you get this fucking thing into your body, it's a demon, and you have to put that demon first before anything else. It's horrible. It's the worst experience of my life, you lose everything; you fight with your family…some people steal from their family. I don't. Never, I'm not trying to wear a halo. My mother will tell you, 'Sara won't steal from you, she'll ask you for it.'…But you'll try and protect your kids in any way you can.*
>
> *You're taking that and then your grandkids are saying, 'Nanny, where is your medicine'? You have to take it. 'I'll pour it out for you, Nanny.' And you're trying to say, 'Oh, no, baby, you can't take that because that's for Nanny to make Nanny better.' There's bad ways of telling her and there's a good way in telling her, 'No, you don't take that, that's just for Nanny to get better, but you're not allowed to take it. You can hold it and I'll tell you how many to count out for Nanny,' try and educate her in the same way. But she's only five, but just like, 'Nanny has to take two of them, because if Nanny doesn't then she gets pain in her belly.'*

Sara describes the desire to use drugs as a *'demon inside your body.'* She says that you have to put that demon before anything else. Sara continues with a narrative around her drug use, which she has constructed perhaps with the purpose of conveying that even though addiction is horrible, she has maintained her values. Sara does not steal. She wants me as the listener to know that her mother would say *'Sara won't steal from you; she will ask you for it.'* Sara immediately follows this account with a description of taking her prescribed medication in front of her grandchildren and how she has shielded them from the reality of her situation; she tells them she has to take them or she will get a *'pain in her belly.'* Sara reveals an interesting dynamic here whereby she is protecting her granddaughter, but involving her in her medication routine simultaneously. Sara is educating her granddaughter on the importance of taking her medications (methadone and ARVs) but protecting her from the reality of why she is taking them. Interestingly her grandchildren are evidently a support to her also in the management of her mediation and she says that they will often prompt her to take them. Sara has constructed a very safe, inclusive image here of family life. But the reality of medications, and why she is taking these remains hidden. There is a contrast here in Sara's narrative between the innocence and safety of the situation she describes and the secrecy and shame of the medications she is taking and why she is taking them.

In the next portion of her narrative Sara moves onto talking about supports that she has had over the years in relation to both her HIV and her addiction.

> *I didn't have to carry them with me every day. I was lucky in that way. I had my mother with me too. My support was good. I could follow it up. Any disadvantages were through my own fault; being pissed off, being greedy, wanting more. The staff are great, you'll have your one-to-one with them, lying to them will get you nowhere, you just tell them, 'I feel like shit today, I feel like I need it today,' so then they can talk you out of it, they try their best. I'm not wearing a halo; I can be a fucker at times too; we're all the same. The crack has everybody fucked up big time. It's totally different. I'm a people person, I get on with everybody, I have my values and my pride and my principles. I won't ask for anything, unless I have the money for it.*
>
> *My family… I don't hide anything from them. If I'm on stuff, I tell them I'm on it, if I need to go to meetings or anything like that, they are there for me. We're a close family. They're all we have, at the end of the day. My daughter rings every day now and says, 'Mum, have you taken your medication?' I've had letters saying that my CD4 count is too low, and my viral count needs to go back up higher and that has scared me, so it's because of that mainly that I do take them now all the time really. There was a time where I thought, 'Ah, fuck it,' but I don't now.*

When Sara talks here about engaging with drugs services she says that by engaging with them they can *'talk you out of'* presumably using substances. Here Sara demonstrates a sense of passivity whereby only the intervention of a drugs worker, can stop her drug use. Sara is clear of her power of choice to engage with supports, but less sure of this power of choice when it comes to decisions around drug use. I wonder how Sara's perception of choice affects how she takes her HIV medication. Does Sara feel that unless her family prompt her or witness her taking her medication that inevitably she may choose not to take them?

We see the emergence of the 'good person' narrative and it is reinforced again; yet Sara does contradict herself. She is self-deprecating when she says frankly *'I'm not wearing a halo,'* she infers here that her lack of a halo is as a result of the crack epidemic, not Sara. Sara then conveys how she is unlike other drug users; she is honest, she has her *'values'* her *'pride'* and her *'principles.'* Sara doesn't steal and she doesn't hide anything from her family. There is a sense in Sara's narrative that she may struggles with both the personas that she presents to me. At one level Sara is a person who has strong beliefs values and indeed has pride. On the other hand, Sara has been in active addiction and this may have pulled her into places where this sense of herself, her pride and her values has been challenged and perhaps eroded. In this narrative there is a clear link between Sara's knowledge of HIV and adherence to HIV medication and engagement with services. Sara says that letters she has received outlining that her CD4 count is low have prompted her to engage. She refers to staff at the infectious disease clinic as *'guys'*, which suggests that she has a good and informal rapport with staff there. For Sara knowledge and a good rapport with staff providing care have been positive in her adherence.

4.3.1 Summary of Sara's Narrative

Sara tells me in the beginning that she contracted HIV, when a man switched the needle she was using. This suggests that the moral responsibility and the blame for her diagnosis sits with this man. She says her diagnosis was abrupt and that she left with no knowledge. Undoubtedly Sara has a lot of support from her family, her daughter reminds her to take her medication. We see later that knowledge and rapport with care providers are influencers of adherence for Sara.

Sarah describes her HIV medication as *'sickening,' 'horse tranquilizers,'* and a reminder of circumstance, of the fact that she has HIV. Sara describes a sense of ritual and routine when she takes her medication. She says taking her tablets is a heavy load and that she sleeps after she takes them.

Sarah describes using drugs as a *'demon'* inside your body. There is a strong sense at that times Sara is not aligned to the idea of being in addiction, she despises its associations of criminality and deceit. She emphasises in her narrative, that she has removed herself from these associations. She is different; she does not steal, she has her values and her pride and she does not use or share dirty/ used paraphernalia.

This morally decent persona is bolstered / reinforced by the fact that she has maintained connection to her family of origin and her children. The shame of her diagnosis and drug use is hidden from view.

There is a sense of struggle throughout her narrative the struggle between the good morally right persona, the person who adheres to her medication and the drug using persona, the one who does not wear a halo, and who does not take her medication unless she satiates the demon inside.

4.4 Peter's Narrative

Peter is 46-years old. He tells me that he became homeless at the age of 10 and does not mention family at all during our interview. Peter tells me he has a significant history of poly substance use that includes; weed, ecstasy, acid, heroin, cocaine, crack and snow blow. He says he has been a drug addict all his life, but he has not injected over the last few years. He stopped injecting because he almost lost his leg. Peter has had his own bedsit for the last 14 years. He wanted to take part in this research to help someone like him and others, especially so that doctors can learn from his experience. Peter believes that this is important. Our interview feels formal and I sense Peter is nervous, his breathing is quick. He begins his story by telling me how he contracted the HIV virus.

> *I was with a girl… I ended up being with another girl, I went to use a condom and she says, 'No, I don't want you to use one,' and I didn't. I ended up finding out that I caught HIV. She was the only one that I've slept with. I never used with anybody or anything like that. Now she's saying that she had cancer, but she had hair down to her arse, and she had cancer three times, which I find hard to believe. So I reckon I caught it off her. I haven't actually put it to her. But I reckon that's how I caught it.*

> *I found it very hard at the beginning. I did a little bit of counselling but, I couldn't really talk about it. I learnt to live with it myself. Any other girl that I've met I wouldn't sleep with them without telling them that I had HIV, even if I was using a condom I still wouldn't sleep with them until I'd told them. A lot of girls would say, 'Okay, you've been truthful with me', so I'd explain it to them how it works, with your CD4 count and undetectable and what does that mean, and I'd say to them, 'If you want to talk to a doctor, there's no problem there. You can come with me to the clinic and you can ask any questions you want,' and most girls turn round and say, 'Listen, it's fine, it's grand, I'll be with you, it's cool, you've been honest with me, and I like that.' But, I've had people who are not very nice to me because I have it. I'm not ashamed of having HIV. I don't go around saying that I'm proud of it, but I don't hide it. If I was ever using around anybody, I'd say, 'Nobody touch nothing belonging to me. I have HIV, don't touch water, don't touch anything, just leave my stuff alone.'*

Peter's story of how he contracted HIV is interesting. He says that he contracted the HIV virus via sexual intercourse. He says he has never confronted the girl he believes he '*caught it*' from. I know as a nurse, working in the area of HIV for the last 10 years; that transmission of HIV from a female to a male, via a single sexual encounter is unlikely. Analysis conducted by Boily et al., (2009) on the sexual transmission of HIV from female to male partners identifies that the risk per sexual act is 0.04%. Knowing this, I wondered at the time of the interview whether Peter believed that he had contracted HIV from this low risk exposure. He claims that '*She was the only one that I've slept with'* and '*I never used with anybody or anything like that'* so it is difficult to establish where transmission may have occurred. Maybe it was more comfortable for Peter to accept sexual intercourse as the mode of how he contracted the virus. I also considered that perhaps there could be relief for Peter in sharing the blame for his diagnosis with this sexual partner. Perhaps this was easier too. Perhaps Peter was performing this narrative as a way of coping with his diagnosis. Peter wanted me to know however, that he discloses to his partners; that he is an honest, accountable and responsible person. He wanted me to know that he is safe; that he is knowledgeable and informed about HIV. In telling me about how he prevents others from contracting his HIV, Peter emphasises how careful he is with the equipment that he uses to inject drugs. Again Peter is performing for me this safe accountable honest person. It was interesting then, that when discussing how he contracted HIV himself, his emphasis is solely on sexual transmission. It seems that here might be an avoidance here for Peter because to connect the two is to acknowledge that he may have had a role to play himself, in becoming HIV positive. In his next narrative section Peter tells me about how he manages his medication.

> *I haven't had any really support with taking my medication I'd bring my support worker with me when I go to the hospital. I have a lot of appointments through other illnesses. So I like him with me. I don't remember everything, I can talk to him and he'd tell me what I'm forgetting. When I take my tablets, I give them in to methadone Clinic and they give them out to me. If I had them at home, I probably wouldn't take them because that's what happened to me before, and my CD4 count just crashed. I was intravenously using cocaine and snow blow and that was more important to me than taking the ARVs. I didn't care. Once I had my drugs, I was happy.*
>
> *My support worker came knocking at my door one day to see was I alive or dead, because I hadn't been to the clinic in weeks and he brought me back to the clinic. My support worker is my right arm. He has saved my life, basically. And myself, you know, copping on after a*

> *while, ‘Listen, you’re not taking your HIVs, you should take them. Get your life back together’ ...*
>
> *There'd be nothing stopping me, takin me tablets only myself. When I was on drugs, I didn't care. The drugs were more important, money for my drugs was more important than dealing with my HIV. My CD4 count went down to 5 at one time and to 2 another time. I was lucky I was brought back up again. If that would have been in the ‘80s, I would have been dead. So, basically, I have no real support with taking them. I think the clinics should have pulled me up on it, and said, ‘Listen, you’re not getting your meds anymore, you're not going to the hospital,’ and them encouraging me to do it.*

It is important to note that Peter has utilized the services of the BBVU for the past 7 years, its primary purpose as a service is to support people to re-engage with their HIV medication. Peter gets his HIV medication dispensed to him from his methadone clinic. He feels that if he had the tablets at home he wouldn’t take them. He has a support worker in this clinic who reminds him and accompanies him to appointments. Yet, Peter tells me that he hasn’t had any real support. He repeats this sentiment yet it is followed by accounts where people have helped him. Peter appears torn between his portrayal of himself as a competent, engaged patient and the fact that throughout his life he has been supported, and has required support. Significantly Peter describes a time when he was chaotic; using crack cocaine and snow blow. He tells me he had stopped attending his methadone clinic and thus taking his HIV medication. However, a call from his support worker to his door incentivised Peter back into attendance. I probed Peter further about this lapse in attendance, I asked him if he had been worried about not taking his medication, he told me that at the time it had been irrelevant, the drugs were more important. Here we see that the desire to use illicit substances far outweighs the desire to take HIV medication. Peter also indicates that although, predominantly he does attend his hospital appointments, if he was chaotic and on drugs he was unlikely to attend.

4.4.1 Summary of Peter’s Narrative

Peter shares a clear narrative of transmission via sexual intercourse. There is a sense that the woman in this narrative is vilified as a person of contagion. I considered it unusual that as an older male, Peter was able to talk about sex openly with me. Peter does not connect his drug use to his HIV diagnosis in his narrative except to say that he has *‘never used after anybody.’* There seems to be an avoidance to acknowledge the impact that Peter’s drug use could have had on his health, on his life. There is a sense too that Peter is putting distance between himself and perhaps the sense of blame in this narrative in how he portrays the woman he was seeing. Peter performs in this narrative an honest, safe, competent determined person. He is honest with his partners and shares with them his knowledge on HIV. He says that he can do anything if he puts his mind to it. There is contradiction in Peter’s narrative between the performances of a careful competent person; protecting his partners from his HIV and the person Peter alludes to as chaotic in his drug use. There is a sense that the chaotic side of Peter’s life is hidden from me to some degree in his narrative and I feel that he is not quite illustrating to me the full extent of this chaos and the impact it has on his life.

Peter does not acknowledge the level of support he has been afforded in order to stay adherent and engaged with medical care. It is possible that he does not perceive the interventions that have occurred as support or supportive. Although in demonstrating gratitude; Peter says that his support worker has saved his life, he still reiterates that he has never had any real support. Peter in his narrative, sways between the portrayal of his determined, competent self and the hidden more chaotic self that requires significant support to maintain adherence to ARV medication.

4.5 Ben's Narrative

Ben is a 56-year-old male. He has been attending the BBVU Unit since it opened in 2010. He has attended regularly at least twice per year and I know him well as a client. Ben's accommodation status has always been ambiguous and it has always been a challenge to get him to access suitable accommodation on discharge. In interview, Ben also clearly recalls his HIV diagnosis

> *In 1988 I felt a bit unwell and me sister said 'I've an appointment for me doctor, come up with me and he might see you'. But what [the doctor] shouldn't have done was called me in with me sister and said 'I've something to tell ye,' it hit me like a tonne a bricks, but I knew, I gave a test three weeks ago I said, now he's gonna tell me I've something, I knew. I was with a girl, I loved the girl, right. She has a kid for me, he hasn't got it, she had it, she told me, I could have used a condom but I didn't and I would never say to her if I met her on the streets 'Only for you, I wouldn't have had HIV,' coz it's me own fault, if I didn't want to get HIV I would have used a condom but I DIDN'T. But every girl I was with since, I tell them what I have, every girl doesn't care and mostly any girl that I was with had the virus and I knew they had the virus. So I didn't mind because both of us have it, but the Doctor said; 'just be careful, use a condom, now and again because the woman is more open than the man.' He said 'a woman is more open, ye can get it more from a woman,' but I thought it was like gay people; men doin' men, but he said 'well mostly in that circumstance yeah'… No but it was hard. I said to my sister, 'you're the only one that knows.' When I was diagnosed with HIV, straight away; 'I'll start ye on Valium.' Tablets I was never on in my life. If I had gone up 2 weeks before and asked him I'd be told no, but the minute I was told I was HIV; he said 'do you need relaxers?' Now I'm 40 years on them, so I can't come off them, they are a very hard thing to come off.*

Ben was called into the doctor's office with his sister and she was present when he was diagnosed. Ben was not given the option to receive this diagnosis in private. Ben can recount vividly the time where he believes he contracted the HIV virus, he knows the woman, but tells me he doesn't blame her. Ben takes responsibility for the fact that he did not wear a condom. Interestingly Ben remembers that the doctor had said to him that a woman is '*more open'* – anatomically, he appears to take from this remark that men are more susceptible to the virus than women. Ben takes responsibility for not wearing a condom but suggests that he was vulnerable anyway, because he is more likely to get it from a woman. This didn't really make sense to me at the time of the interview, and I wondered how many misinterpretations or misunderstandings have patients taken away from diagnosis- a time of huge shock and distress for most, as Ben says like being *'hit by a bus.'* What interpretations do patients take away in order to cope with diagnosis? Was it easier for Ben to take away that he was vulnerable and that this woman gave him HIV? Or was this simply just a misinterpretation.

Ben concludes by telling me that at diagnosis, the informing doctor prescribed him sleeping tablets and Valium, Ben notes that had he asked for these medications prior to diagnosis he would have been denied. Ben tells me that he has been on these tablets for 40 years. This to me was poignant and harrowing. I imagined that this doctor had likely prescribed these medications to Ben to help him to cope and to function with this diagnosis. Forty years later Ben is still alive, but addicted to them in a time where street tablets such as benzodiazepine and Z drug sleepers are one of the most commonly abused substances that we see in services. In conveying his story, Ben stresses his willingness to adhere to ARV medication.

> *I always take my tablets, and why? I give them to my clinic. I think, if I was at home and I had my tablets, I don't think I'd take those tablets. I always take me tablets, don't miss them, at all… always. The minute I get them I bring them straight to the clinic. And the next day I might go in and she'd say to me, 'Were ye in the hospital yesterday where are your tablets? Will you just bring them in will ye?' and I'll bring them in the next morning and say 'There ya are.' She'd say, 'that's why we have no complaints about you.' Even the hospital said it the other day; 'We are just worried cause it went up three or something,' they said 'it's really nothing but we're wondering because Ben told us he is taking his tablets every day, he goes the clinic 7 days a week and he gets them every single morning in the clinic.'And they tell you to have breakfast beforehand. I don't have to have anything. I take me tablets on an empty stomach every morning… well as I said I never missed the hospital…. well my mother never missed Mass.*

Importantly, Ben confirms that he hands his medication over to his methadone clinic and that they, specifically the pharmacist, make sure that he takes his medication, by prompting, encouraging and reminding him to do so. Ben is conveying to me in this narrative that he is well thought of in services, that he has a good rapport with staff. Ben is performing the role of the good patient. He always adheres to his medication, and he can even take his tablets on an empty stomach. It is noteworthy that in this narrative Ben equates that fact that he always takes his medication to the fact that his mother always went to mass. Indicating perhaps that Ben believes that to take his medication is good and right. It is unclear in Ben's narrative, how he manages to attend regular HIV Clinic appointments and if or how he has been supported to do same.

In the next section of narrative, it becomes clear that addiction does interrupt Ben's adherence to regimen to some degree.

> *I don't take heroin now, Crack is my main thing. I think it's the main population of Dublin now is on crack, and anyone will do anything for it, sure I seen young girls, Jesus…. Offerin, for a bitta rock and it's horrible…. like a girl can give her body away for a twenty-pound rock, they give it for fuckin anything. It's not a drug that ye can get strung out on, people say it's a mental drug, mental thoughts go through your head, Eavanna, mental thoughts like I had thoughts of doing that like a couple of weeks ago (gesticulates, cutting wrists). I done it a bit but, then I moved down a bit and was like 'what am I doing?' I've grandkids, I wouldn't want them to see that or me daughter seeing it, I said 'I'd be kill't' (killed by family). I said stop that Ben and get them thoughts out of your head'. But it was the Crack... I'd never let me addiction get in the way of it* [medication] *… Right, so I missed my Triple*

> *therapy, I'd had it bad with this Crack business for a month and it was the worst month in my life, I thought I was dying, I thought I'd got COVID…. Thought I got every disease, right. The minute I started back, it was the doctor said to me 'go back on your treatment.' I went back on me treatment and after a week and a half I felt like a brand new person again and I do wonder 'why can people, not just take them.'*

Ben begins this section of his narrative by describing the desperate measures that people will go to, to get Crack. He also notes that crack has brought him to desperate places where he has self-harmed. At this point Ben completely contradicts his initial narrative and tells me that at one point he was so *'bad on the crack'* that he stopped taking his medication; he describes thinking he was dying, and that he had contracted *'every disease'*. Ben however concludes this section wondering why some people can't just take their medication. This indicates that Ben is not connected to or acknowledging that what he has just described, when he was *'bad on the crack,'* is non- adherence. To Ben this was exceptional and this was the crack – it is understandable why he didn't take his medication, he thought he was dying. Here Ben may be transferring blame for his non adherence from himself to *'the crack,'* while also justifying the non – adherence. This was an interruption in his performance as the good patient. I probed Ben at the time of interview, as to whether he felt getting his ARVs at the methadone clinic supported his adherence in general, even when he was taking Crack cocaine. He told me that as a system for adherence it *'worked perfect.'*

I asked Ben about his experience of homelessness and its impact if any on his medication adherence.

> *Homeless, bed surfing like someone will get me one night someone will get you another night, but it's horrible. I'd like to have my own little place. Anywhere. This is all about homeless people, because Doctors are telling me 'it's all homeless people that's not getting their treatment,' right. But I'd say; 'if you're homeless, right, you don't get take aways, then why can't ye not just go to your clinic go get your medication and go to your clinic, give it to the clinic the way I do and get them every morning?'*

Ben intimates that he is bed surfing and considers himself homeless, but does not elaborate. When telling me that homeless people are not getting their treatment; he refers to them as *'they'* and *'you'* and again cannot understand why *'you can't just... go get your medication.'* Ben believes that he is not one of *these* people, he seems disassociated with homelessness and people that do not adhere to medication.

Later in our interview I asked Ben about what had supported him over the years in regards to his drug use and taking his medication.

> *I have support, family, but it's horrible coz me daughter has 2 young kids and I don't like bearing on her. The community drug team, they were very good to me, the hospital, they were very good to me. Even if I go to me Granny's, and my aunt sees me: 'did ye have anything to eat?' Come round and she'd make me anything I want …she is very, very good to me in that way, what with meals wise, givin' me things. If she knew I was sleeping out she'd make toasted sandwich, steak and kidney pie. Everyone in the flats always says it; 'for a person that's homeless, that stays out, you're always spotless clean.' Me daughter gets me clothes all the time.*

> *I wouldn't mind doing 12 weeks here and then if they said ye can continue for another, just try to get a little flat, … I am homeless, down as homeless, but I feel very sorry for people that is homeless, that's not even getting their treatment. I go to the HIV Clinic. The doctor, she's a heart of gold she makes me day. I just go to see her, coz she makes me laugh,* she *has a smile from the time ye go into her to the time you're finished. I would say to people: 'do ye get that rock first thing in the morning?' A rock is more important for them, 'twenty-pound, get a rock but when ye smoke it, come with me to the hospital and you'll get yer Triple therapy, ye ring the methadone clinic get them dispensed every day.' The pharmacist said 'I don't trust you havin' your tablets at home, because I don't think that you would take them every day, on drink and being on Crack.' I said, 'I don't think so myself either.'*

Ben talks about various community supports; his local drugs team and the support he has received in his HIV clinic. Ben talks of a complex yet supportive relationship with his Aunt and his Daughter. He says that his Aunt still gives him meals if he calls over and that his daughter makes sure that he always looks well. We see here that Ben is homeless but he is not like other homeless people. Ben pities homeless people. Ben is always *'spotless clean.'* Significantly and perhaps with only the voice of experience Ben tells me that in order to support others to attend clinics to get their medication, he would let them smoke their crack cocaine first*, 'get a rock but when ye smoke it, come with me to the hospital.'* In my interview notes at the time, I reflected that this was a low threshold, harm reduction approach of sorts. We see that Ben is likely aware that he needs a level of support to adhere to his HIV medication, and that if he did not have them dispensed to him at his methadone clinic he probably would not be adherent.

4.5.1 Summary of Ben's Narrative

Ben's diagnosis was not confidential, which he still remembers with some distress. It appears that some of the information he received at that time may have been incorrect or misinterpreted; for example, the emphasis on transmission through sex where women are anatomically *'more open'* and therefore more contagious, and his own belief that only gay men contracted HIV. He takes responsibility for how he says he contracted the virus; he didn't wear a condom. It is poignant that he is still addicted, forty years later, to tablets he was prescribed at this time and infers that he is still paying the price for this today.

For Ben, taking ARV medication is what a good, well liked patient does. He equates this adherence to going to mass. Ben believes that he is a good patient. However, this performance of good/adherent patient is challenged by his account of not taking his ARV when he was *'bad'* on crack-cocaine. He describes feelings of suicidality and poor mental health. Ben is sorry for people who are homeless, although he himself is homeless. He is not like them. Homeless people struggle to take their medication. Ben believes the solution to this is that they should, like him, simply get their medication at their methadone clinic. Ben feels that he has been supported; by community drug teams, by his HIV clinic where the staff are warm and they smile. Ben portrays himself as a good patient there. When asked what he thinks would support others to take their medication Ben says if they want a rock, that he will get them the rock, but that they will have to attend the hospital with him afterwards. Ben is acknowledging that crack is the priority for these clients but that if we meet this need the client is more likely to engage with treatment and or services.

4.6 Arthur's Narrative

Arthur is a 46-year-old male. He was diagnosed with HIV 4 years ago. Arthur is currently staying in a 6-month bed in a hostel in the city centre. Arthur and I have a good relationship and he has stayed on the unit many times despite his recent diagnosis, he often presents as heavily drug affected throughout his admission. He has maintained a relationship with family, in particular his mother, and his children. While staying in the Unit he has been able to attend his daughter's first communion.

Arthur begins our interview by telling me about his experiences in homelessness.

> *I was homeless for about 20 years. On the streets, sleeping bag or a few jackets. Most of the time, I would just walk around all night, doing burglaries here and there, which wasn't helping, because I was getting nicked. I had charges about that thick. I robbed shops and factories mostly. I used to do butchers. I only got a hostel there a few months ago. I hate the place. I hate it.*
>
> *I started off smoking grass, but I didn't like it because I used to get paranoid. I switched from grass to acid, which didn't agree with me either. I used to get paranoid on that. So, I switched from acid to ecstasy, which I liked because I was getting a buzz out of it, the dancing buzz. I liked them. It made me get up and dance. I would feel good about myself. But I gave them up as well. Then I went from ecstasy to heroin for a comedown. I started smoking heroin, one or two bags, for the comedown. But then eventually, I started using. That's how I lost all my veins, so I started using my groin. Luckily, I never got an abscess. My blood flow is still grand. I can still get it if I want it, but I have no interest in drugs anymore. That is why I am here. I never took crack. I was strung out to bits on tablets. I used to take three trays of tablets a day, but I got myself down to a tray before I came in here. It's just a habit. If I want to stop something, I will do it.*

Arthur doesn't give much time to homelessness in his narrative, considering the experience spans 20 years. His telling of it however conveys a sense of prolonged wandering in loneliness and darkness. For Arthur drugs fixed something in him; something that was missing. There is a sense of impulsivity in this narrative. Arthur moves from substance to substance in the pursuit of the feel good. But, he says that eventually he '*started using'*. This seems to indicate that at this point Arthur became addicted and the drugs no longer worked, no longer made him feel good. Arthur demonstrates the lengths he would go to, to use drugs: his legs, his groin. But at the end of this narrative we see a flash of determination: '*It's just a habit. If I want to stop something, I will do it.'* I wondered if this choice was as simple as Arthur described it.

Arthur tells me that he found out that he was HIV positive when he was admitted to hospital with a collapsed lung. His experience of receiving the diagnosis appears to have been kind and compassionate.

> *A doctor came to me and went, 'I have a bit of bad news for you.' I went, 'What is it this time?' He went, 'I'm sorry to tell you, but you have HIV.' I was going, 'What? but I never used after anybody.' He said, 'You could have caught it off a girl. Loads of people catch it*

> *off girls-that have been around the block.' So, I found out that I did catch it off a girl, but she is dead now. If I got my hands on her at the time, I would have strangled her. She knew she had it, but she never told me. If she told me, I would have been able to do something about it. I would have been able to put a condom on, but she never told me. I was actually shocked when the doctor told me……About four years ago. It's horrible.*
>
> *When my ma found out that I had HIV, she was saying, 'How the heck did you get that?' She was going through birds' names that I was with. She said, 'You could have caught it off her, you could have caught it off her. You could have caught it off her, you could have caught it off her.' I was struggling enough that I said, 'Ma, just forget about it. I have it. They are going to get rid of it. They are giving me tablets to get rid of it. It will be gone in no time.' The day I told her that it was lying dormant, that they can't find it, she was delighted. She even said to my Da, 'No, his HIV is gone. They can't find it in the hospital.' You would think I was after losing it. [Laughing] No, it was the way she said it to my da. 'No, his HIV is lying dormant. They can't find it in his blood.' My dad was delighted as well.*

Arthur tells me that his immediate reaction to his diagnosis was to inform the doctor that he hadn't shared paraphernalia. He tells me that the doctor informed him that he could have *'caught it'* from a girl, that a lot of people were catching it from girls that had '*been around the block'*. During the interview I was momentarily horrified, I did wonder if the doctor had in fact said this to him. I concluded that this is what Arthur remembers. This was the preferred narrative of contagion. Arthur tells me that he found out that he did '*catch it off a girl'* and that she is dead now. He said that if he had known at the time he would have worn a condom. He says that when he disclosed to his mother that he had HIV that they had gone through a list of women, from whom he could have contracted the virus. There is a strong sense in this narrative that by vilifying one of Arthur's sexual partners as the perpetrator of his HIV transmission there is relief for Arthur and also for his mother. This is something that has happened to Arthur, he is a victim here. Arthur momentarily alludes to personal responsibility when he tells me in hindsight that he would have worn a condom, but he is clear that this would have occurred only if he had known. Hence the responsibility and blame lies firmly with the perpetrator – Arthur's sexual partner.

Arthur on describing telling his parents about his HIV status, tells a funny anecdote; he says that when he told them that his virus was dormant (presumably undetectable) that his father had said '*No, his HIV is gone. They can't find it in the hospital.'* Arthur said it was *'as if he was after losing it.'* I remember in the interview picturing Arthur and his parents running around a hospital looking for his HIV. Arthur and I both laughed at this point and it was light relief from our earlier conversation about his diagnosis. I considered as Arthur was telling me about his experience of contracting the HIV virus, that in 2015 (approximately 4 years ago) there was a significant outbreak of new HIV infections within the drug using population. This outbreak was linked to the use of a short acting stimulant called snow blow. There is no acknowledgement of a link between Arthur's drug use and his diagnosis of HIV in Arthur's narrative except when Arthur says in response to his diagnosis that he '*never used after anybody'* This perhaps signifies that Arthur is in denial about the consequences and the connection between his drug use and his HIV.

Arthur emphasises his adherence to HIV medication.

> *Yes. I take my medication every day of the week. It wasn't a bother to me. I had no problem at all. I have not missed one day of my medication…Ever. I collect them from the ID clinic and bring them down and drop them into the methadone clinic. That is grand. The swallowing. At least I am not choking on them or anything. Everything is grand with my HIV. It is actually lying dormant at the moment. You can't find it. I did the Hepatitis-C medication. That's lying dormant as well, I haven't got it. They can't find it. They can't find my Hepatitis-C either. I was taking three tablets, for about twelve weeks and I flew through it. I wasn't thinking. If you stop and think, you would be saying to yourself, 'Why do I need to take this?' But you need to take them to make it better. As I'm saying, I haven't missed the one. The way I look at it, Eavanna, it's important to me. Only for that, I would be dead. That is why the hospital told me to stop drinking, I just stopped. I have no problem with drinking anymore. The last time I was here, I was mad into drink. I haven't touched it since the last time I was here.*
>
> *I don't care if it makes me sick, once it keeps me alive…Then I've got my D10 turned into five D2s. I don't know why, I just think it's a lot stronger, taking five 2s instead of taking one 10. I would break them in my mouth. I take one, bite it in half, take two, bite it in half, take three, bite it in half, take four, bite it in half, take five, bite it in half, and then just drink a drop of water. Then I would say, 'Where's my methadone?' That's the way it works on me.*

Arthur tells me that he has no problem taking his medication; that he can swallow them. He tells me that taking his medication is important to him because it keeps him alive, and that he doesn't care if the medication makes him sick – which indicates that he might have some issues taking same. He tells me that the hospital had told him to stop drinking, perhaps Arthur's alcohol use has disrupted his HIV medication previously, though this is not certain. Arthur describes ritualistically taking his prescribed benzodiazepine medication. He says that he takes 10 mg of Diazepam but that he has to have same broken up into 5 x 2mg tablets, believing that they are stronger this way. He says that he takes each one and bites it in half. Arthur has adjusted his regimen in such a way because he believes it makes them stronger- will increase their potency and thus have a more pleasing effect. This indicates that even when taking medication that is being dispensed to him, Arthur is taking them in his own way, in order to get the maximum effect that he desires. He has reconfigured his regimen to suit his own needs, suggesting a retained personal control over a process that is very controlled.

Arthur tells me that he doesn't get any support. He then goes on to describe some support resources.

> *I am not getting any support. The only people that have come to see me are my mother, and probably my son or daughter have come up once or twice with her. But the main support I have is my mother, and my keyworker. She is good. She does her job proper. I used to drop in and see the doctor, and see the nurses, for a bit of support. I said, 'Where can I go and what can I do?' They gave me a few names, and addresses, and all. But I never bothered to go. I would rather just come to here.*
>
> *I nearly lasted six weeks the last time, but as usual, I fucked up. I fell asleep on some girl's shoulder. The GAs* [General Assistants] *at the clinic, I think they should be saying to them, 'Make sure you take your HIV medication this morning.' That would push them towards taking it. They [the GA's] are always there. I think they should make you take it there and*

> *then, in front of them… If I caught people not taking it, or flushing it down the toilet, I would snap at them. I would say, 'What are you doing, flushing them down the toilet, or not taking them? You're supposed to be taking them, not throwing them away.' My ma rings me. I give my ma all my appointments, and she rings and says, 'You have to go to hospital this morning.' 'Yes, what time? 'Right, half ten.' Well, I have time to run down, get my medication, and then straight up I go.*

Arthur's mother is very involved in his care and has been a persistent advocate and support to him. Arthur tells me he often drops in to see this keyworker, the nurses and doctors, and that he has asked them for other community supports. He says though that he hasn't bothered to access these. There seems to be some ambivalence in Arthur's narrative around personal autonomy, acknowledging the need for support and requesting/availing of support. He initially portrays himself as taking his ARV medication every day independently without need for support, yet this is challenged here by his comment '*I nearly lasted six weeks the last time, but as usual, I fucked up'* as well as his description of the level of support he requests and receives. However, simultaneously Arthur protests that he is not getting support or that when he gets it, he does not avail of it. This indicates that someone may in fact be supported and still perceive themselves as very much unsupported or of not requiring support. There is a notable struggle for Arthur between perceived and actual support, between a lack of support and a lack of his own engagement with support. Arthur performs two identities here a person who is unsupported and a person who does not engage with support.

When asked what he thinks would support people who are homeless and on drugs to take their HIV medication Arthur bestows a lot of power and responsibility on the GA's (General assistants) in the methadone clinics and advocates quite a controlling response by these practitioners '*I think they should make you take it there and then, in front of them.'* Arthur can't understand why people wouldn't take their medication he says that it is easy and if he caught anyone flushing it down the toilet he would take a firm no, nonsense approach. I wondered during the interview if people were actually flushing their HIV or Hepatitis C medication down the toilet.

4.6.1 Summary of Arthur's Narrative

Arthur started to take substances at a young age, perhaps as a form of self-medication. He didn't feel good about himself and for a while the drugs used to fix that. His years of substance use have not however been without consequence. Arthur believes that he contracted HIV through sexual intercourse with a woman who had been 'around the block.' There is a sense of vilification associated with this woman that brings perhaps a relief to Arthur; his diagnosis is not his fault. This sentiment may also be shared by Arthur's mother.

Arthur stresses that he is and always has been adherent to his medication, however he also refers to frequent lapses in his sobriety/self-care, therefore his level of ARV adherence is not clear. He has ritualistic methods of taking his prescribed benzodiazepines, he believes that these methods yield a more gratifying, positive effect; he remains invested in the effects of mood altering substances. He describes loosely the negative effects associated with taking HIV treatment. I think about the delayed gratification when taking HIV medication- they have no immediate effects, bar the associated, reported negative side effects (nausea, vomiting etc.) I wonder about Arthur's likelihood to adhere to a substance that does not provide the immediate gratification that he describes initially in his narrative; like the drugs that made him '*want to get up and dance.'*

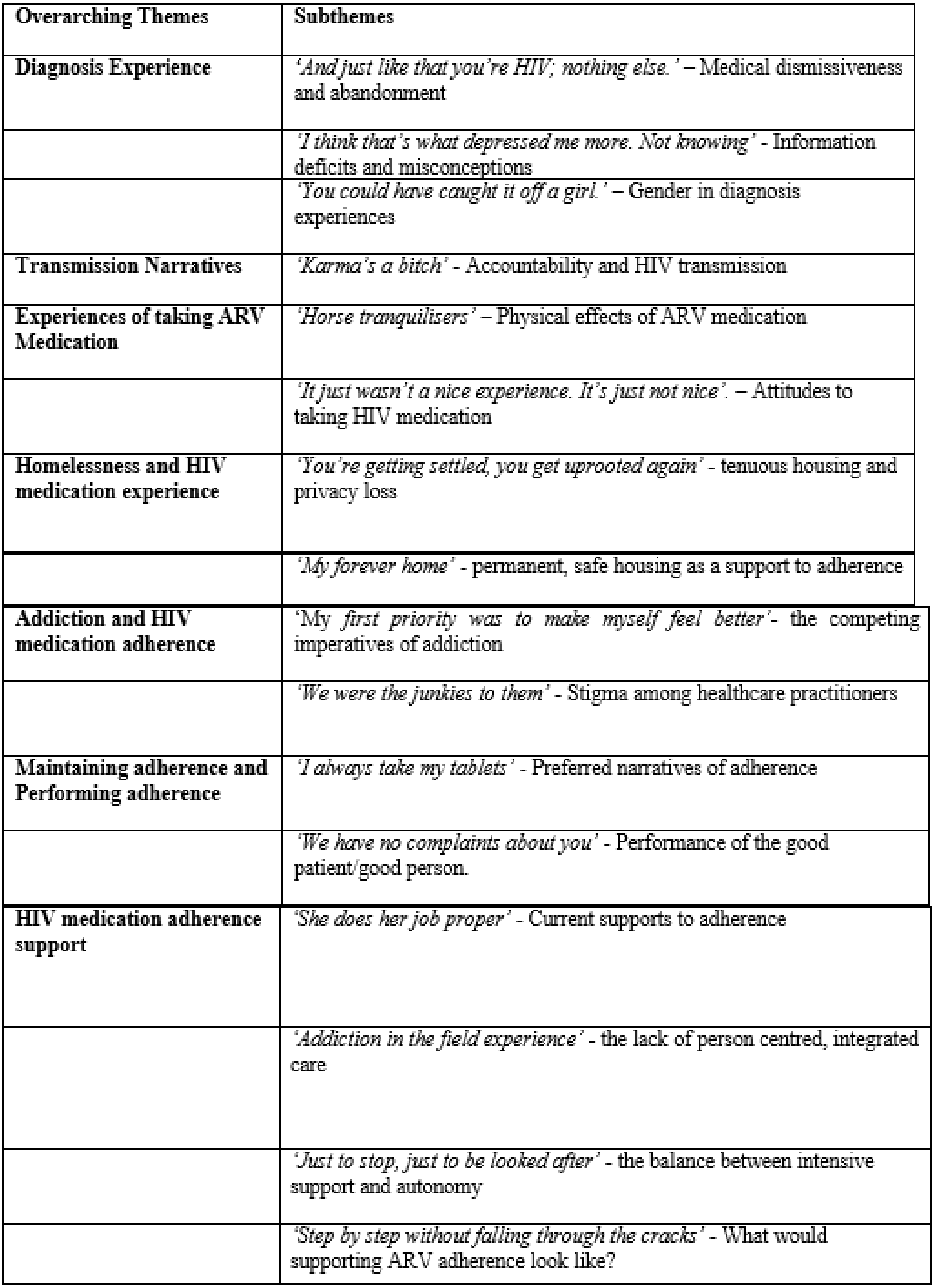
Arthur also appears ambivalent regarding his need and desire for support and his need to maintain a narrative of independence and not requiring support.

Chapter 5: Cross Case Analysis and Discussion

5.1 Introduction

This chapter presents a cross case thematic analysis, conducted across the six participant narratives presented in earlier chapters. Riessman (2008, p11) refers to narrative analysis as the interpretation of texts presented in a 'storied form.' She affirms that this analysis is not merely about content, but is an exploration of intention and language, the 'how and the why' (p.11) of narrative. Narrative analysis considers how a narrative is constructed and sequenced, to generate meaning. It considers the audience for whom narratives have been created and the purpose; 'what has the story accomplished?' (p.11). An in-depth exploration of all six narratives was conducted. Using Riessman's (2008) framework, narratives were summarised and coded. Common themes, phrases and language were identified. These commonalities were documented, categorised and arranged into emergent themes. This process resulted in the generation of overarching themes and subthemes which represent the overall study findings. These cross-case themes are summarised in table 2 and explored with reference to relevant research literature in the accompanying discussion.

Table 2. Cross Case Analysis Overarching Themes and Subthemes



Overarching Themes	**Subthemes**
Diagnosis Experience	*'And just like that you're HIV; nothing else.'* – Medical dismissiveness and abandonment
	'I think that's what depressed me more. Not knowing' - Information deficits and misconceptions
	'You could have caught it off a girl.' – Gender in diagnosis experiences
Transmission Narratives	*'Karma's a bitch'* - Accountability and HIV transmission
Experiences of taking ARV Medication	*'Horse tranquilisers'* – Physical effects of ARV medication
	'It just wasn't a nice experience. It's just not nice'. – Attitudes to taking HIV medication
Homelessness and HIV medication experience	*'You're getting settled, you get uprooted again'* - tenuous housing and privacy loss
	'My forever home' - permanent, safe housing as a support to adherence
Addiction and HIV medication adherence	'My *first priority was to make myself feel better'*- the competing imperatives of addiction
	'We were the junkies to them' - Stigma among healthcare practitioners
Maintaining adherence and Performing adherence	*'I always take my tablets'* - Preferred narratives of adherence
	'We have no complaints about you' - Performance of the good patient/good person.
HIV medication adherence support	*'She does her job proper'* - Current supports to adherence
	'Addiction in the field experience' - the lack of person centred, integrated care
	'Just to stop, just to be looked after' - the balance between intensive support and autonomy
	'Step by step without falling through the cracks' - What would supporting ARV adherence look like?

5.2 Diagnosis Experiences

The experience and perception of HIV diagnosis is critical to a person's sense making process and ability to incorporate HIV into a life narrative. In a study by Wolpaw et al., (2013) participants spoke of feelings of anger, shock fear of dying and feelings of depression or sadness upon hearing the news of their HIV diagnosis. The explanations, emotional support, dignity and respect afforded by the practitioner relaying the diagnosis is hugely impactful and influences the future trajectory of the patient's perceptions of the disease and engagement with treatment. All but one participant in this research shared their experience of their HIV diagnosis; each of them recalled the experience vividly. The detail in which they relayed their experience of diagnosis illustrates that this for them was a significant event, and pivotal moment in their lives. Their experience of diagnosis in general, was not a positive one.

5.2.1 'And just like that you're HIV; nothing else.' - Medical Dismissiveness and Abandonment

Three participants; Frances, Jenny and Sara describe their diagnoses experiences as involving practitioners who appeared *'nonchalant'* and dismissive in communication concerning their diagnosis. There is a sense that in the experience of participants, their diagnosis is insignificant to the informing doctor *"Oh, yeah, by the way, you have HIV,"* and *'he just walked away, that's the way I was told.'* The diagnoses are quick, flippant, and dismissive. Sarah expresses shock at her diagnosis and felt unsupported at the time *'and just like that you're HIV, nothing else.'* Ben highlights that the way in which he received his diagnosis was a significant confidentiality breach; he was unprepared and he was informed that he was HIV positive in the presence of his sister. Ben's negative experience is compounded in hindsight by the fact that he was prescribed *'relaxers'* (diazepam) and sleeping tablets in response to this diagnosis, which he feels led to his addiction. Arthur is the only respondent whose diagnosis seems to have had a sense of compassion or empathy, his doctor told him *'I have a bit of bad news for you'.... 'I'm sorry to tell you, but you have HIV.'* Peter did not reference diagnosis in his narrative, he instead related his beliefs about contracting the virus.

For Jenny, Sara and Frances there is also a strong sense of abandonment associated with their diagnoses, which is apparent in the language they use: '*I walked out of that hospital with nowhere to go and after being told I had HIV'.* Jenny says that the doctor '*just walked away'* several times in her narrative and Sara says that at the time she *'Got no counselling, nothing. It was horrible, to hear that;' ... 'no explanation, no nothing.'* The lack of support experienced is emphasised in the repetition of words such as '*nothing', 'nowhere.*'

Given that the majority of people interviewed in this research received their diagnosis in the late eighties and nineties, during the height of the AIDs epidemic, it is not surprising that at the time they felt dismissed. Rutledge (2011) acknowledges that stigma among healthcare providers was at its peak in the late eighties and nineties due to a fear of occupational transmission. Rutledge (2011) acknowledges further that this fear of transmission was an antecedent of HIV related stigma. More recent, subsequent research suggests that HIV related stigma remains present in healthcare settings with instances of overt and covert privacy breaches of health information by healthcare workers (Shacham et al., 2015; Dapahh et al., 2016). Mosek et al., (2005) in their study exploring narratives of drug users living with HIV found that healthcare providers were biased and provided inadequate care to drug users due to a prejudice that they perhaps did this to themselves. This moral judgement of PWUDs, the belief that they deserved their HIV and the presumption that they would be unable to adhere or engage; is likely to impact significantly their adherence or engagement potential. It is possible, in this research that the above factors contributed to people's perception of their diagnosis experience and so too to their potential to adhere to treatment in the future.

5.2.2 'I think that's what depressed me more. Not knowing.' – Information Deficits and Misconceptions

Wolpaw et al., (2013) highlight that patient's understanding at the time of diagnosis is most important in order to prevent further transmission during this virulent time. In the narratives of Jenny, Frances and Sara, there is a sense that upon diagnosis, they did not gain information, understanding or reassurance concerning their HIV disease and potential outcomes. Jenny left her diagnostic appointment with a fear of impending death*, 'how long have I got to live? ... and they just walked away.'* Later, on commencement on medication, Jenny reflects that she had no knowledge or information regarding HIV at that time. '*I even remember asking the doctor, how long have I got left now? Because I never read into it…'* Sara says that her diagnosis was similarly abrupt and non-discursive; *'It was blunt. Not, how do you think you contracted it? No explanation, no nothing, so I think that's what depressed me more. Not knowing. I didn't know much about it.'* Sara goes as far as to say that the lack of explanation or information at the time of her diagnosis was more depressing than the diagnosis itself. Frances says too, that she knew nothing about HIV at the time of diagnosis and for her she felt like a murderer, that she had murdered herself, her unborn child and her partner. Similarly, Gourlay et al., (2014) in their study of women and prevention of mother to child transmission in Tanzania found that 'distrust, level of communication and disrespect' influenced engagement and interactions with HIV prevention services.

In a study on the diagnosis experience of people with HIV, Hult (2009) respondents said that they were too shocked to comprehend anything that was said in their appointment thereafter. This suggests that a persons' ability to receive and comprehend information provided at diagnosis may be compromised. However, the participants in this study were clear that they did not receive adequate information at time of diagnosis. They shared a knowledge deficit that resulted in unnecessary fear and stress; fear of dying, and of contagion. This lack of knowledge and fear around HIV may impact attitudes to treatment and adherence.

5.2.3 'You could have caught it off a girl' – Gender in Diagnosis Experiences

The influence of gender in HIV diagnosis, treatment, patient engagement, and public/healthcare attitudes is increasingly recognised in research (Asiedu & Myers-Bowman, 2014; Hutton, 2021) and was also a feature of this study. In contrast to negative diagnosis experiences of the women in the study, the males generally recounted more engaged encounters with healthcare professionals. Despite the fact that his diagnosis was not confidential, Ben relates that his doctor spent time with him discussing how he potentially contracted the virus. Similarly, Arthur, whose diagnosis communication seems to have been compassionate, also says that his doctor spent time discussing how he may have contracted HIV.

The content of the diagnosis discussion also appears to be infused with gender stereotypes. Significantly, both Ben and Arthur recount being told that they may have contracted HIV via sexual intercourse; a female has *given* them HIV. Ben recalls the doctor indicating that women are more likely to transmit HIV. '*The Doctor said; "just be careful, use a condom, because the woman is more open than the man, ye can get it more from a woman."* Similarly, Arthur related that his doctor told him that he may have contracted HIV via sexual intercourse with a particular type of woman '*He said, "You could have caught it off a girl. Loads of people catch it off girls that have been around the block."* No reference to the men's IV drug use is present in the narration of the doctor's advice. This shifting of focus to more a socially acceptable transmission narrative is supported in a study on gendered HIV experiences in Ghana. The researchers (Asiedu & Myers-Bowman, 2014, p704) contend that "when men in male-dominated cultures are blamed …. it is with an underlying assumption that the misbehaviour is to be expected and tolerated." In the BBV narratives, there is a sense of female vilification, associated with the female anatomy and alleged female promiscuity. Kilty & Bogosavljevic, (2019) in their Canadian based study, highlight that sensationalist media (covering HIV non-disclosure cases) contributes to the stigmatisation of women living with HIV by characterising them as promiscuous, oversexualised predators.

Ben and Arthurs's diagnosis narratives also raise questions as to how/what diagnosis information was delivered and how this was interpreted and used by the men to make sense of this traumatic life experience. Were Ben and Arthur really told that they were more susceptible to contracting HIV from women or that they likely contracted it from a promiscuous female? Or is this how they have configured their narratives of the diagnosis event? Is this how Ben and Arthur chose to remember what they were told about their HIV diagnosis? Okoror et al., (2016) identify that there is limited documented research on the experience of men who receive a HIV diagnosis in Nigeria as opposed to women – where there is a body of research available.

As previously discussed, the female participants; Frances, Sara and Jenny narrate a more emotionally negative diagnosis experience with feelings of being abandoned and dismissed. The women appear to have internalised the shock and self-blame of the diagnosis, narrating fears of their own deaths and causing the deaths of others through transmission. International research suggests that women may have a different lived experience of HIV due to their unequal social and economic status in society and they have higher rates of depression and anxiety. Furthermore globally more women have been diagnosed with HIV/AIDS and are more likely to be stigmatized than men (Asiedu & Myers-Bowman, 2014).

5.3 Transmission Narratives

The participant's reflections as to how they contracted HIV also provide some insight as to their perceptions of risk taking behaviour as well as their sense of personal agency and responsibility. These are important characteristics which also relate to treatment engagement and medication adherence.

5.3.1 'Karma's a bitch' - Accountability and HIV Transmission

Research participants vividly recounted narratives pinpointing how they contracted HIV. That these experiences/ explanations are recalled and put forward with such certainty indicates the power of constructing a specific narrative to sustain preferred realities. Frances and Sara specifically connect their HIV transmission to IV drug use, while the three male participants Peter, Arthur and Ben connect transmission to sexual intercourse. Jenny, the third female participant, did not share how she believed she contracted HIV at interview. Frances's narrative pinpoints the specific occasion in which she says she contracted HIV, where she shared a needle and a syringe that was *'pink'*. She recalls this scenario clearly. Sara believes that she contracted HIV because a man switched her needle, '*I was always careful, but to my knowledge someone switched it, he's six feet under now so karma's a bitch.'* Similarly, to Frances, Sara knew the exact occasion in which transmission occurred. It is notable that for the three female participants in this research there is no mention of the possibility of sexual HIV transmission. Sexual partners and sexual transmission are never alluded to in relation to the transmission of HIV. This is striking as both Jenny and Frances shared their experience of sex work to support their addiction, so it is clear that these women were engaged in sexual activity as they were too, in injecting activity.

In contrast, Peter, Ben and Arthur all perceived that they contracted HIV via sexual intercourse. This is interesting given their shared history of IV drug use. For Ben and Arthur, this narrative of sexual transmission was supported, or possibly initiated, by their diagnosing doctors, as previously described. There is a sense in both of these narratives that the female is being vilified as the 'giver' of HIV, removing some elements of fault and accountability perhaps from Arthur and Ben. Peter, like Ben and Arthur, claimed that he knew that he *'caught'* HIV from a girl. *'She was the only one that I've slept with. I never used with anybody or anything like that.'* Peter acknowledged that transmission via shared paraphernalia is possible *'I never used with anybody,'* however he was firm in his conviction that he contracted his HIV via sexual intercourse because this woman was the only one that he has slept with.

Given that all participants in the research were IV drug users and all sexually active, it is worth questioning why for the men in this research there is a sense of certainty that their HIV was transmitted via sexual intercourse, despite their shared history of IV drug use and yet for the female participants, intercourse as a mode of transmission is not considered at all. I had reflected in my interview notes that the men in this research were comfortable in talking to me as a female researcher about sex. Yet for the women it seemed that to discuss sex or sexual practice was uncomfortable, perhaps still taboo, or possibly related to the trauma of sex work and therefore, silenced. It is possible that for the females in this research there is more perceived shame and stigma attached to the possibility of sexual transmission, than to transmission as a result of intravenous drug use. Hutchinson & Dhairyawan (2017) and Valle et al., (2015) highlight that HIV related stigma is associated with the perceived relationships between the disease and 'taboo' homosexual and 'promiscuous' sexual practices. Similarly, and yet in contrast for the males in this study, it is possible that they are potentially more comfortable with the narrative of transmission via sexual intercourse, than with the narrative of perceived irresponsible intravenous drug use practices. Much research has been conducted on the 'sexual double standard' pervasive in society; where by male sexual conduct relating to promiscuity or multiple partners is still more acceptable than that of their female counterparts (Milhausen & Herold, 1999; Carey, Senn, Seward, et al., 2010; Panteá, Farvid Braun & Rowney, 2017). It may be that this double standard is at play for participants in these narratives of HIV transmission.

For all of the participants in this study, accountability appears inextricably linked to their story of transmission. There is an attempt to remove or share the responsibility of transmission. For Ben, Arthur and Peter, the transference of accountability is evident in the language they use: they *'caught' it* from a girl. They were vulnerable to infection. Arthur's narrative, describes the woman he was with, as having been *'around the block.'* Her activities; being around the block vilify her as a transmitter. However, Ben and Arthur do acknowledge that they made the choice not to wear condoms. Frances, does not deny personal responsibility in her narrative she says clearly that she was aware of the risk, the needle *'was pink'* but she used anyway. However, this is qualified by her statement that the person she used with *'swore blind… that he had nothin'*- he assured her that he was safe. Sara, in contrast denies accountability because in her case; she believes the needle was *'switched'* without her knowledge. Similarly, in Sara's narrative, there is a perpetrator of transmission. Krusi et al., (2016) explored responsibility and high risk behaviours in relation to HIV transmission. Six participants were interviewed, strikingly all participants rejected the narrative of transmission via their own high risk behaviour, the study found that all participants removed themselves from blame and personal culpability, focusing instead on wider demographical issues, so as to 'to fashion themselves as deserving HIV citizens' (Krusi et al., 2016, p. 68). In contrast, a study by Usman et al., (2018) presents a more complex picture of accountability for high risk behaviour. Notably fourteen out of sixteen respondents said that they had continued to have sex for money post a HIV diagnosis, twelve out of sixteen respondents reported informing their clients of their HIV status. Three out of sixteen experienced anger and rage as a result of their HIV diagnosis and stated that they continued to engage in unprotected sex post a diagnosis because of this unresolved anger and rage that they were experiencing.

The narratives of transmission in this research predominantly appear to separate the narrator from culpability; either through the swapping of a needle, or via sexual intercourse with a woman who did not disclose her status. For participants in this research there is no outright denial of personal accountability in contracting HIV. However, all participants perceive accountability as not theirs alone, there are people and circumstances in their narratives that share this accountability. This is perhaps a coping mechanism, as responsibility shared is a burden shared. Perhaps the shared responsibility for such a life altering diagnosis, a diagnosis laced with such shame and stigma is easier to bear. Personal responsibility is also an important factor in medication adherence. In a study examining the adherence of low income persons with multiple co- morbidities it was noted that self- discipline and a sense of personal responsibility were positive motivators of adherence to medication, Shiraz et al., (2011).

5.4 Experiences of Taking HIV medication

The experiences of being prescribed, taking and managing HIV medication are complex and have significant implications for adherence. Participants' narratives concerning their experiences of HIV medication varied. Some participants focused on the practicalities of medication management while others focused more on the deeper, more emotive associations with taking medication.

5.4.1 'Horse tranquilisers' – Physical Effects of ARV Medication

Sara and Frances talked about the side effects of taking medication. They referred to the large size of the antiretroviral tablets as *'Horse tranquilisers /horse tablets.'* Arthur also reported that at some point he may have found his medication difficult to swallow. Frances said that it didn't feel right taking something so hard on her stomach. Sara, Jenny and Frances all reported that at some stage the medication made them feel sick. Jenny's hair fell out and Jenny also described the original complexities in storing and taking the medication *'The first medication didn't agree with me, remember you had to keep it in the fridge. I think I started with six or seven tablets at that time, 18, 19 years ago. I kept vomiting.'* Jenny also mentions the ordeal of persisting with ARV regimens *'until they find the right combination to go with your body.'* Mills et al., (2006) acknowledge that ARV adherence is a lifelong commitment and that adherence to the medication is required to achieve optimal treatment efficacy. In their study of adverse drug reactions Li et al., (2017) report on the visible side effects of Anti-retroviral therapy; these include body changes including rashes, sweating, weight gain, weight loss and hair loss. These factors for some respondents resulted in treatment *'vacations'* (Li et al., p. 4), and in some cases absolute disengagement from medication regimen. Rao et al., (2007) also correlate severe side effects with poor ART adherence.

5.4.2 'It just wasn't a nice experience. It's just not nice' – Attitudes to Taking HIV Medication

It was evident from the narratives, that the psychological ramifications of taking HIV medication had the potential to impact participant adherence. The psychological burden of taking HIV medication is described in a very tangible way by Sara, in that the weight of the HIV diagnosis became palpable and exhausting when she took her HIV medication '*taking them makes it true, now I have got it'* and was of such magnitude that she had to sleep after she had taken her tablets. Similarly, participants in the study by Li et al., (2017) reported that the side effects and taking the medication was a reminder to them that they were sick. It is important to note that pharmacologically, ARVs have been known to contribute directly to neurological and psychological disturbance. Cespedes et al., (2006) refer to these side effects as neuropsychiatric side effects, they include; insomnia, depression and suicidality, anxiety and irritability. Cespedes et al., (2006) note that these factors can influence ARV adherence.

Sara and Frances emphasise the lack of enjoyment in taking ARV medication. Frances says '*I didn't enjoy takin them ...for a using addict to take a really hard medication like that, didn't sit with me*.' Similarly, Sarah frequently signifies that taking ARV medication is not a pleasant experience. '*It just wasn't a nice experience. It's just not nice. .... It's just not a nice feeling, knowing that you're taking these things to keep you alive.'* This attitude really struck me at the time of interview; I noted the complex ambiguities between taking prescribed medication and taking mind/mood altering drugs. Frances sees ARV as a *'really hard'* medication but does not identify the associated damage of being *'a using addict.'* I wondered whether Frances and Sara were accustomed to anticipating all drug use as pleasant. This impression was also reinforced by Arthur's description of his ritualised practice of taking his prescribed diazepam in tiny doses to gain maximum effect. If so, getting used to taking ARV medication, which had no mind/mood altering effects may also have affected adherence.

Fogarty et al., (2002) acknowledge that there are certain traits linked to HIV treatment that make adherence less likely, they acknowledge that regimens are long in duration; for life, they are given often at a time where a patient might not even be symptomatic, and notably that the 'treatment payoff' (p.94), that of delayed disease progression, may only be felt at some stage perhaps in the future. This is interesting in the context of this research. As noted previously for participants in this research there is an expectation of reward 'payoff' likely related to drug use; participants took substances to *'feel better,'* or because they made them *'want to dance.'* There is evidence to suggest that neural pathways in the brains of substance users alter as a result of this pay off, the positive stimuli associated with drug use. This reward stimulus which turns 'substance misuse into an automatic compulsive behaviour' (Volkow et al., 2010, p.1). In ARV adherence there is an absence of reward stimulus or payoff for a person whose brain has become habituated to same. How likely is this person; preoccupied with the compulsion of substance use to take a medication for which there is often no palpable reward. The perceived lack of, or delayed reward stimulus associated to ART and the fact that participants in this research through addiction have become habituated to same; suggest that the motivation to adhere to ART in this cohort may be limited.

Sara's statement '*It's like everything else, you have to do it'* suggests a resignation regarding the need to take medication. This attitude is not present among the men in the study who seem to be less ambivalent about the need to take ARV's and are more pragmatic in their response. For example, Arthur comments

> *They are giving me tablets to get rid of it. It will be gone in no time. Yes. I take my medication every day of the week...I flew through it. I wasn't thinking. If you stop and think, you would be saying to yourself, 'Why do I need to take this?' But you need to take them to make it better.*

This study also found notable differences in patterns of non- adherence between men and women and differences in reasons provided for non-adherence, between and men and women, with the female participants disclosing their struggles with adherence more readily than the males. A large study on adherence, conducted by Thunander et al., (2012) noted that women tended to be less adherent to medication than men, a finding supported by other studies (Granger et al., 2009; Chan, Shrank & Cutler 2010; Puskas et al., 2011). Asiedu & Myers-Bowman (2014) also highlight the relationships between gender, poverty and adherence in that men are more likely to have the economic means to afford basic necessities as well as their medications and treatment related needs. Courtenay (2000) reported that gender significantly impacts overall HIV health related outcomes. This indicates a need to recognise gender in the promotion of medication adherence.

5.5 Homelessness and HIV Medication Adherence

Lack of stable and predictable living accommodation has profound impacts on a whole range of biopsychosocial functioning and activities of daily living, including engagement with medical treatment. For persons living with HIV and who are homeless, these impacts are further exacerbated (Powell & Maguire, 2017; Lyu & Zhang, 2019). In a study examining health status, health care use, medication use, and medication adherence among homeless and housed PLWH, Kidder et al., (2007) found that homeless respondents had lower CD4 immune-cell counts, were more likely to have disengaged from ARV medications, and overall were less adherent to ARV regimens. They found that people who were homeless with HIV were more likely to have substance use issues, were more likely to have difficulty in accessing health care and overall, that their physical and mental health was poorer than that of housed individuals.

PLWH further identify a lack of suitable accommodation as a barrier to access health care and as a causative factor of their suboptimal health (Maulsby et al., 2017). In the interviews, participants were encouraged to share narratives concerning their experiences of homelessness and simultaneously managing HIV medication.

5.5.1 'You're getting settled, you get uprooted again' - Tenuous Housing and Privacy Loss

Although the impact of homelessness on medication adherence is recognised in research and the impact was evident to some extent in this study, two of the six participants were housed (Sara and Peter) at the time of the study so current homelessness was not strongly impactful on their ARV adherence. Arthur didn't allude to the impact of homelessness on his adherence at all, except to say that he hated the hostel in which he was living. Ben’s narrative reveals the generalising and stigmatising responses of doctors who had told him that homeless people do not take their medication. Ben’s solution to this is that homeless service users should do as he does and get their HIV medication dispensed to them at their methadone clinic.

Frances and Jenny provided the most insight into homelessness and adherence in this research. From the beginning of her narrative Frances portrayed herself as a person who moves from location to location and place to place, in the search for stability, acceptance and inclusion. This nomadic lifestyle is unstable and is not conducive to routine and reliability in regards to adherence. Similar to Frances’s portrayal of this moving nomad, Jenny too says that the necessary transition from hostel to hostel every 6 months was very disruptive. *‘It was always a six-month hostel, and then when you’re getting settled in, you’re uprooted again…. The things I've lost…. I've lost everything.’* Watson & Kane (2016) identify that the experience of social exclusion results in reduced access to and quality of social support, that it increases the propensity toward high risk health behaviours and can lead to poorer physical and psychological health outcomes.

Jenny’s narrative provided a unique insight to her experience of homelessness, living in hostels in Dublin’s inner city. Jenny described the challenges to confidentiality and dignity in trying to take medication in a hostel. The lack of privacy in receiving her medication was a source of shame and distress; ‘*There would be people there beside you and getting their meds too, and they’d be saying, “What tabs are they?” and I’d have to explain, “They’re my HIV tablets.”* Similarly, a study by Walley et al., (2008) found that people who are homeless often don’t have a routine, they often don’t have a place to store or keep their medication, and they are disproportionately affected by issues pertaining to privacy and stigma. For Jenny, this shame was further compounded by the fact that she has used drugs previously with staff now working in hostels and they were now dispensing her HIV medication; *‘they used with me. They smoked with me and now they're working there.’* This experience contributed to self-stigma and a sense that others were looking down on her. This risk to confidentiality and dignity is potentially a significant barrier to adherence. Coe et al., (2015) identify self-efficacy and self-determination as necessities for individuals trying to adhere to medication. Bagby (2015) further argues that in the context of homelessness, a person would require a particularly ‘resilient’ form of self-efficacy in order to withstand the constant, barriers and ‘likely repeated failures’ associated with homelessness.

5.5.2 ‘My forever home’ – Permanent, Safe Housing as a Support to Adherence

Ben, like other study participants, identifies the impact that a stable home can have on adherence.

> *Homeless, bed surfing like, someone will get me one night, someone will get you another night, but it’s horrible. I’d like to have my own little place. Anywhere.*

The perceptions of the research participants in relation to the positive influences of a stable safe home is supported by relevant research. Leaver et al., (2007) identify that affordable and sustainable accommodation correlates with better health outcomes and adherence to treatment. However, the location of the home is also important. Significantly, Frances reflected that the home in which she had been placed *'will not be my forever home,'* because that home was not safe; if she was having a bad day and someone offered her '*a tray of tablets,'* that sometimes, it would be very hard to say no. The location of her home was unsafe, because it was a threat to her stability, her sobriety and so too to her ability to remain adherent. Surrat et al., (2015) found that neighbourhood disorder often experienced in lower income areas is an environmental influencer of adherence. They find that this disorder whether drug use or crime, acts as a divergent from ARV adherence. Jenny also poignantly describes her desire for privacy, dignity, physical and psychological safety in a home where medication adherence is part of her routine

> *'I've never got a chance of a home. I'd be on my own and I could put my cups, my plates, my medication here, and open my medication and put it beside my methadone. I could just have my medical press in the bathroom when you're getting ready, your methadone in there, your HIV treatment or whatever else you're on, and take it all in the bathroom.'*

5.6 Addiction and HIV medication adherence, a hierarchy in chaos

Addiction is well recognised as an influencing factor on health and health care engagement. According to Gonzalez et al., (2011), 40–74% of people living with HIV report comorbid substance use or related disorders. Gonzalez et al., (2011, p.223) further acknowledge that substance use in people who are living with HIV can lead to 'maladaptive management' of their HIV. The individual narratives revealed that addiction has impacted the lives of all of the participants in this research in varying, significant ways and in relation to ARV medication in particular. Jenny further elaborated that her use of street drugs made it impossible to attend or stick to appointment times. Typically, participants would say that their adherence dis-improved when they were *'bad on the crack'* or their substance of choice. This is significant because it indicates that for all participants the chaos generated from substance use has impacted their adherence. Arthur is the only participant who did not perceive that his substance use may have impacted negatively on his ability to adhere to HIV treatment, however, he did acknowledge that he was told at his infectious disease clinic to stop drinking.

5.6.1 'My first priority was to make myself feel better' - The Competing Imperative of Addiction

Frances indicated that she felt that she didn't need to take her HIV medication. Rather, she described her need for street drugs *'to make myself feel better.'* The need for the treatment of addiction with substances, took precedence over the need for treatment of HIV with medication for most participants. Jenny said *'When I'm hectic, it's just more like I'm not concentrating on that HIV treatment.'* Peter notes that for him intravenously using cocaine and snow blow *'was more important…than taking the ARVs. I didn't care.'* Sara perceived addiction as being like a demon and that '*you have to put that demon first before anything else.'* Jenny echoed this sentiment when she said *'There'd be some days I wouldn't even* *put water on my face, I'd be just straight out the door.'* For a significant proportion of respondents in this research the need to take substances far outweighed for them the need to take their HIV medication. In some cases, participants personified the power of drugs to subvert their treatment, affording drugs an agency that was absent in their own lives. For example, Jenny's comment that '*It was the drugs that was killing the times of the appointments, getting there'* and Sara's reflection *'I did worry about not taking my medication, but then the drugs then would block it out.'* Substance use is associated with immediate gratification; an instant remedy (Heshmat, 2015). Heshmat, (2015) also views addiction as a diminished capacity to choose and that addicted individuals assign lower values to delayed rewards than to immediate ones. This has obvious and severe implications for propensity to adhere to medications.

Participants in this research used poly substances; including crack cocaine, benzodiazepines, heroin methadone and more. It has been affirmed in recent research that adhering to HIV medication prevents transmission of the HIV virus and also prolongs life and health. Participants in this research acknowledged that it was difficult to remain compliant to medication when using drugs, and in some cases made it impossible to stick to or engage with appointments. The side effects of illicit substances (used by participants in this research) such as Crack Cocaine, Benzodiazepines, are likely to further impede adherence to prescribed medication such as HIV drugs. Side effects associated with Benzodiazepine use; include but are not limited to drowsiness, sedation, poor concentration and memory loss. A study by McGowan et al., (2011) involving participants who were both IV and non IV drug users identified that substance use was significantly related to decreased receipt of ART and less time on ART overall. Metsch et al., (2009) identified that cocaine use and heavy alcohol use was associated with never having attended a HIV care facility, and thus never receiving ART. Paulillo et al., (2017) found that alcohol use in general was associated with missed ARV doses. Conen at al., (2015) found that opiate use correlates with an absence in initiation with treatment and poor/ non adherence. These are striking observations that acknowledge that not only the preoccupation of addiction, but the side effects of substance use whether alcohol, benzodiazepines or cocaine, severely impact people's ability to adhere to medication. Notably what these findings also support is that drug users not only find it challenging to adhere to or stay adherent to medication, but that drug use impacts their ability to initiate or engage even with health care or HIV treatment services.

Several of the participants in this research alluded to disengagement with HIV treatment in times of increased drug use, namely crack cocaine. This is significant as it implies that although not abstinent, participants had experienced times of relative addiction stability, perhaps with less associated chaos, where they were able to adhere to their HIV medication. Further research is warranted on respondents reported addiction stability. A health led approach to addiction as reflected in Ireland's national drugs strategy; Reducing Harm, supporting recovery (2017- 2026), (Department of Health) is necessary. Promoting and sustaining stability is imperative to improving engagement in care and treatment. The types of substances used by individuals need to be considered in relation to medication adherence.

5.6.2 ‘We were the junkies to them’ - Stigma among Healthcare Practitioners

In addition to the chaos of addiction, the stigmatising attitudes and inflexible practices of some practitioners relative to addiction, also affected ARV medication adherence. These negative responses were evident in the earlier findings regarding diagnosis, however marginalising attitudes and low expectations were identified by some participants as prevalent throughout their treatment and contributing to treatment disengagement. According to Frances

> *There was no empathy and they looked, from my side of the fence as if they looked down on us, especially the non-gays coz y'know we were the junkies to them… I just felt like fuck them, better off taking my chances. I went once in a blue moon to collect meds, didn't stay compliant. The doctors were rigid, ridiculously so, if you're living a chaotic lifestyle, you're homeless.*

Sadly, Frances has internalised this self-stigma which limits her possibilities of recovery. This is evident in her narrative when she reflected that *‘as a using drug addict’* she *‘didn't stay complaint for very long.’* A narrative study by Mosek et al., (2005) suggests that healthcare providers often assume that drug using patients could never adhere to the ARV treatment regimen. Similarly, in a study of narratives of diagnosis experience by Hult, (2009), respondents felt that healthcare providers judged them, with one respondent citing *‘well this shouldn't be a surprise. We discussed your high risk behaviours,’* as the response of a HCP to their HIV diagnosis.

5.7 Maintaining Adherence - Performing Adherence Narratives

The previous sections presented findings regarding participants' attitudes to taking HIV medication as well as the life contexts of homeless and addiction which could challenge adherence. It is also important to analyse attitudes and behaviours concerning ongoing adherence in the longer term. The narrative accounts revealed some interesting perceptions regarding how participants positioned/performed themselves as long term HIV medication users

5.7.1 ‘I always take my tablets’ - Preferred Narratives of Adherence

Interestingly, Peter, Arthur and Ben initially, in interview; performed absolute adherence: saying *‘I take me tablets every day’, ‘I never miss a day.’* Each of them began by assuring me as the listener that they absolutely, always take their medication. Hurwitz et al., (2004) in reference to performance narratives suggest that they are the process of acting out illness, and that often for the people performing they are ‘healing dramas’ (p.73). They further note that performance narratives are rarely narrative accounts of the past rather an exercise in the shaping of the present; ‘living narratives’ (p.74). In narrative storytelling people are not passive in the scenes that they create, as human beings and by our very nature people shape and control the scene. Hurwitz et al further acknowledge that these ‘healing dramas’ can evoke for patients the possibility of healing and of hope, even in the face of a dire prognosis. It seemed that in these performative narratives Peter Arthur and Ben were performing for me perhaps the patient or the person that they wanted to be. A person who is regimental about their tablets, totally adherent, a person who is healing and has hope. For Ben and Peter, it is as if their initial instinct is to perform adherence, but in doing so they come to the realisation within their own narrative that there have been times that their absolute adherence has wavered. Ben and Peter told me that specifically Crack had impacted on their ability to adhere and that they stopped taking their HIV medication, when their crack use had escalated. Ben, Arthur and Peter conveyed this interference with adherence as momentary, a blip- subsequent to their addiction. For them it was not a genuine disruption or break in adherence, it was a once off, a consequence of Crack Cocaine. It is possible too that my position as researcher could have influenced this portrayal of adherence, given that I am the manager of this unit that supports people to engage/ reengage with HIV medication and that Ben Arthur and Peter have been attending this unit for over 7 years, while I have been a nurse and a manager.

Frances, Jenny and Sara did not appear as adamant about portraying their ongoing adherence to HIV medication. There was more transparency in their narratives of adherence. Sara told me clearly that she had *'come off them many times'.* They did not seem to share the same necessity as their male counterparts; to convince me of their adherence to HIV medication. Jenny says *'It is hard, even if you're doing great on your meds, it's hard. I found it hard, that's why I didn't take my meds.'* There was a sense that Jenny, Sara and Frances were more up front, perhaps more real about their non-adherence. This is another interesting gender variation.

5.7.2 'We have no complaints about you' - Performance of the Good Patient/Good Person.

Several of the participants in their narrative performed the 'good patient role', the patient who is known by and well liked in health care settings. This 'good patient' role is prevalent in illness narratives. Campbell, et al., (2015) state that 'patients negotiate their relationships with health care staff to enable them to access good service and to ease their clinical experience'. These authors suggest that patients do this through the performance of the 'good patient' and this performance of the good patient is the only way a patient can enact any control/ power in an interaction with healthcare providers. Good patients are deemed compliant, docile, clean, and obedient (Khahil, 2009). Strikingly, Chadwick (2017) found that even in the midst of active labour women were enacting the performance of a 'good patient' so as to garner control and ease their clinical experience.

In this research, the 'good patient' narrative was performed in three distinct ways; performance of adherence, performance of being informed and knowledgeable about HIV, and performance of being a well-liked person in the healthcare service. The performance of adherence has already been described and was clear in Ben and Arthur's narratives in their repetition of phrases such as *'I always take my meds'*, *'never missed a dose'*, and *'I'd never let me addiction get in the way of it.'* Their performance of the good patient was further supported when they both reported that they couldn't understand why people would not take their medication. We witnessed the performance of being informed and knowledgeable in Peter's narrative when he described telling his other drug users and sexual partners that he was HIV positive, sharing relevant information with them and inviting them to come to the HIV clinic with him for further information. Similarly, Sara performs an educator role in relaying selected information to her grandchildren regarding her medication. Ben also describes how he encourages other drug users to engage in treatment by facilitating their drug use as an incentive.

We see the performance of being well liked in Ben's narrative when he claims that by his bringing in his ARV medication the staff member says *'There ya are…. that's why we have no complaints about you'.* He quotes the hospital staff comments *'Even the hospital said it the other day; "we are just worried because it went up three or something," they said "it's really nothing but we're wondering because Ben told us he is taking his tablets every day, he goes the clinic 7 days a week and he gets them every single morning in the clinic."* Being recognised as responsible and honourable even in the midst of the chaos of addiction is important to many of the participants; Sara highlights that she is known for always having clean needles, that she is always honest with staff '*lying to them will get you nowhere*' and that she would never steal from her family. Ben also stresses the importance of being a responsible family member; both he and Sara highlight that holding prestige and dignity within the family is a powerful motivator for maintaining stability and adherence.

For some of the respondents there was also a moral component associated with whether or not they take their HIV medication. Ben equated taking his medication to being akin to his mother going to Mass. Jenny indicated in her narrative, that sometimes she would just be too lazy to take her tablets. Peter reflected that the only thing stopping him from taking his medication was himself. For Sara too, there was a sense that the sleep she takes after her medication is a reward and she describes that she almost feels relief when she wakes and she has taken them '*Ah, now, I'm going to take them, so I'll have a sleep for an hour and then I'll wake up and feel better. At least I know then that's that day over.'*

There was a sense from these narratives that the participants associated taking medication with being a good person, whereas not taking their prescribed medication as a moral failing. This sense was encapsulated by Jenny when she said *'I am a very bad person for not taking my medication…. But when I'm stable and when I'm good I take it. But if I'm hectic, I won't.'*

In recent years we have moved from the notion of medication compliance to the concept of adherence: a mutual agreement between prescriber and patient, where the patient is imbued with control, autonomy and choice (Hawking et al., 2020). However, according to these authors, the adherence model has not yet permeated into practice. In analysing narratives of medication adherence they found that 'narratives about medicine-taking aligned with wider discourses of being a good patient through references to being adherent' (Hawking et al., 2020 p2320).

Morality, the good patient and the portrayal of oneself as a good person are all connected in the narratives in this research. People living with HIV because of its associated transmission routes have been and in some cases are considered still to be immoral or to have committed some immoral act; unprotected sex or drug use with needles. We have explored in this research the associated stigma that is connected to this sense of amorality. We see the struggle between the good person and the immoral person in Sara's narrative as she plays the role of educator but shields her grandchild from why she is taking her HIV medication and her methadone. She is shielding her grandchild from her own perceived immorality; her drug use and her HIV. Therefore, it is not surprising that participants in this research associate morality and being a good person with taking their HIV medication, and with attending their appointments. This is also what is consistently being asked of them by HCPs. In the construction of the good patient narrative participants can disassociate from the amorality connected to their drug use and HIV status, and portray themselves as the good patient.

5.8 HIV Medication Adherence Support

Given the obvious challenges to ARV medication adherence among people who are homeless and who use street dugs, it was important to seek study participants' perspectives and experiences of support in this regard. Narratives revealed some interesting perceptions regarding perceived need for support, views/experiences regarding the quality of support received and expectations of what ARV adherence support should involve.

5.8.1 'She does her job proper' - Current Supports to Adherence

All participants verbalised the need for support with some aspect of their ARV medication regime. However, their narratives regarding their perceptions of and engagement with this support varied. As previously outlined, most participants experienced a lack of supportive information provision and psychological support at initial diagnosis. In terms of ongoing support with adherence participants identified two main sources of support; family and service staff. Family support was particularly valuable for Sara, Ben and Arthur with family members prompting them to take medication, reminding/accompanying to hospital appointments, assistance with activities of daily living and psychological support. This support was valued by these participants and seen as protective against relapse. Service staff, including individual keyworkers, HIV clinic staff, methadone clinic staff, dispensing staff, and doctors were identified as playing a role in ARV support. Perceptions of the quality of this support were largely positive. '*The staff are great, you'll have your one-to-one with them, lying to them will get you nowhere, you just tell them, "I feel like shit today, I feel like I need it today," so then they can talk you out of it, they try their best'* (Sara).' Peter mentions that he received initial counselling, that the doctor at the HIV is informative and supportive and that his key worker attends appointments with him and monitors his hospital attendance and ARV adherence. Similarly, Ben highlighted the adherence support he received from the pharmacist in the methadone clinic and the welcoming support from his doctor in the HIV clinic. Arthur said of his keyworker '*She is good. She does her job proper'* and that *'when the hospital told me to stop drinking, I just stopped. I have no problem with drinking anymore.'*

5.8.2 ‘Addiction in the field experience’ - The Lack of Person Centred, Integrated Care

Some participants identified what they saw as limitations to support. For example, Frances said of her addiction support worker *‘her intention is fantastic, she does not have the life experience or the addiction in the field experience to understand.’* This suggests the importance for Frances of support from a peer who understands the struggles of addiction. Frances also highlighted what she perceived as inflexible attitudes and practices of doctors in clinic appointment times.

It became apparent in this research that the three male participants were having their HIV medication dispensed to them from their methadone clinics. This means that these clients bring their HIV medication from their infectious disease clinic and give it to the pharmacist at their methadone clinic, who then dispenses this to them on a daily basis with their methadone. This has potential to influence adherence positively. Conen at al., (2015) and Miamiga et al., (2010) confirm the benefits of combining treatment for both opiate addiction and HIV to reduce associated adherence barriers. Farrell et al., (2005) noted that adherence to ARVs improved for individuals in the first 4 weeks of methadone maintenance therapy, the stabilisation phase. Similarly, Palepu et al., (2006) found that methadone maintenance resulted in a reduction in opiate use and greater uptake of and adherence to HARRT. Gowling et al., (2013) recommend mitigating the risk of HIV infection, progression and transmission by the use of a combination of needle exchange, HIV treatment and opiate substitution treatment (OST).

However, none of the female participants interviewed were receiving their HIV medication at their methadone clinics. This is significant given the challenges and responsibility for storing and taking their HIV medication (often a 4 week supply), once they receive it from their infectious disease clinics. This warrants further investigation as to the criteria for engaging in this service and its effectiveness as a model of HAART adherence promotion in people who are addicted and, or homeless. Care provision in Ireland for PWUDS and who are living with HIV is disjointed. This was evident for half of the respondents in this research; having to attend different locations, appointments and settings to meet their often complex and high health needs. It is also unclear as to whether this is established practice or a system that has developed overtime to suit the needs of individuals attending these clinics. This is a likely deterrent of adherence and of continuous engagement. Furthermore, the utilisation of methadone clinics for the provision of ARVS seems to be under researched in Ireland. In a study on PWUDS attending General Practices for their OST in Ireland Cullen et al., (2009) acknowledged that the majority of these attendees had high comorbidity burdens and often had chronic disease or illness. The article proposes a primary care approach and further research, on the utilisation of healthcare for this population.

5.8.3 Just to stop, just to be looked after' - The Balance between Intensive Support and Autonomy

One of the many interesting findings in the narratives is that although participants identify a range of supports and acknowledge these as useful, some participants simultaneously maintained that they were getting no support. Notably when asked if they were supported Peter and Arthur immediately responded with *'I haven't had any real support with my medication'* and '*I am not getting any support,'* respectively. They repeated statements relating to being unsupported throughout their narratives. Peter said he was unsupported and then immediately explained the various ways in which his support worker had supported him. Similarly, Arthur expressed that he was predominantly alone and unsupported and then described the support he received from his family. This was quite remarkable and raises questions about the participants' perceptions and expectations of desired ARV support.

Sara was disappointed and frustrated that her keyworker would not administer her ARV drugs to her every day, particularly when she was at risk of non-adherence through being *'hectic'* on street drugs. The keyworkers refusal to take control over Sara's ARV administration was interpreted by Sara, not as a means of promoting her independence but rather as a lack of support. The desire for another to take responsibility for ensuring ARV adherence, especially during periods of relapse was common in the narratives. According to Frances, '*sure of course an addict, that's living in chaos, is not going to go and get checked.'* Peter said *'There'd be nothing stopping me, takin me tablets, only myself.'* Peter describes how his keyworker came knocking on his door to see if he was dead or alive when he had relapsed into heavy drug use and was not attending clinic*. 'My CD4 count went down to 5 at one time and to 2 another time. I was lucky I was brought back up again'.* The keyworker brought him back to the clinic. Frances also highlighted the fundamental need for externally enforced interruption to drug use, safety, provision for basic bodily needs and comfort when in relapse '*without that bit of time, just to stop just to be looked after; I mean fed, warm bed.'* Again there is a sense that support means active intervention in relapse, taking over control, saving people, bringing them back from the brink. Miamiga et al., (2010) in their focus groups also identified what respondents perceive as 'facilitators to adherence'- which include: prompts or reminders to take medication, support from family, community or support from friends.

5.8.4 'Step by step without falling through the cracks'. What Would Supporting HIV Medication Adherence Look Like?

Despite the complexities in the perception and experiences of support, the participants in this study were able and keen to share their opinions on what would support people living with HIV, who are homeless and may be in addiction to take their HIV medication.

Respondents suggested very intensive, almost paternalistic support mechanisms; such has having a nurse to give them medications and take them to hospital appointments, perhaps a mobile van that could find people on the streets to test and to provide medication. Frances describes this latter assertive measure as possibly a *'ridiculous'* level of support but she is clear that sometimes that *'is the only way'.* Ben, Peter and Arthur all agreed that getting HIV medication at methadone clinics is a solution for clients who are homeless and trying to remain adherent to medication. They all advocate for a simple no nonsense approach to encouraging adherence. Interestingly, Lacob et al., (2017) highlight that research studies between 2005 and 2014 demonstrated significantly higher adherence in patients with a once-daily fixed-dose (single tablet regimen) compared to any other treatment regimen. Arthur and Peter both believe in a more proactive approach from the clinics, involving the general assistant staff, '*I think they should make you take it there and then, in front of them'* (Arthur). Ben takes this proactive engagement a step further when he says that if a person's priority is to get Crack, he would support this endeavour, but only on the basis that they must attend a hospital appointment thereafter. This illustrates that Ben believes a harm reduction approach could further support people to engage with HIV medication. He addresses the urgency of addiction, but almost uses this as a bartering tool to encourage ARV adherence and service engagement.

It is challenging to consider these high threshold support models in a society where healthcare is in motion toward empowerment, autonomy and control for the person who is accessing it. It does appear from narratives in this research that participants want both, someone to support them and to guide them in their health care, but also the autonomy and control to engage in same themselves. Some participants in this research noted that they, themselves, were the only people who could ensure adherence to medication, intimating too, a perceived personal responsibility and efficacy. Miamiga et al., (2010) identified that wanting better health was facilitative of adherence. Lacob et al., (2017) examined the role of the patient in likelihood of adherence; the understanding and willingness of the patient to engage with their HIV diagnosis/status and reduce their viral loads are all factors that may determine adherence.

Importantly, the participants in this research have experienced periods of street drug stability; where they were able to adhere to their medication and engage with treatment. These periods of relative stability warrant further investigation to establish a) how they were achieved and b) if and how these periods could be supported/ maintained. In an article focusing on enhancing adherence, Farrell et al., (2009) acknowledge that initiatives focusing on medication adherence alone, have proved to be limited and in the long run; unsuccessful. Furthermore, they agree that HIV medication and adherence should be 'contextualised within overall care.' Farrell et al., (2009) examine a motivational interviewing style of interaction between healthcare provider and patient, and exemplify that some studies have seen positive results on the use of MI in HIV care engagement. They assert that it is the 'spirit' of motivational interviewing that encourages a 'respectful way of being with patients,' patients are viewed as experts in their own lives and the provider's role is to create a collaborative therapeutic environment within which to conduct an 'interview' (Farrell et al., 2009, p.70). This method of care is equitable, and allows for autonomy. Farrell et al., (2009) call for care that is contextualised, and care that acknowledges the recipient as a whole person.

Participants also identified supports that were more holistic and sustaining to them across their life situations. The importance of family love and support has already been discussed. Lacob et al., (2017) point to social and family background as a potentially predetermining factor to adherence. They propose that the social supports that a person has whether in the form of family, community or social supports (groups, community programmes etc.) may impact on adherence either positively or negatively. The persistence of family and some service staff over time and through a range of difficulties was also identified in this study. Nabunya et al., (2020) acknowledge that the family is a crucial and valuable microsystem that supports individuals emotionally to achieve optimal HIV medication adherence.

Respect, dignity and privacy were noted as absent in diagnosis experiences and therefore important. The unconditional positive regard of practitioners was highlighted. Arthur remembered the warmth and welcome of his doctor and Frances commented on her sense of connection with her doctor. '*She could see somethin' in me that I couldn't see in myself. I looked up to her, she would take time with me. She treated me like a human being.'* Beach et al., (2006) in examining whether the quality of the patient-provider relationship was associated with better adherence and health outcomes for patients living with HIV found that patients who reported that their care provider 'knows' them were more likely to be adherent to their HIV treatment. They found that the patient's sense of being known as a person significantly correlated with ARV adherence and also undetectable HIV viral loads, indicating a sustained viral suppression. Lacob et al., (2017) also identify 'doctor devotion' as an important component in adherence to HIV medication. 'Doctor devotion' refers to time spent with the patient, education and the relationship between the doctor and the patient; whether it is based on trust and whether the patient's decisions and thoughts are respected.

Frances emphasised the supportive role of walk in clinics and respite services for people *'strung out to the back bone…. a safe space that we don't have on the outside, its being known, and being understood and not being judged. It's a place for not only my body but my fuckin soul to like take a breath.'* For those who are ready to engage with treatment and ARV adherence, support should be *'tailored to the person'* and *'step by step by step without falling through the cracks.'*

For Jenny, Frances and Ben the solutions are simple yet difficult to come by; gaining safe and stable accommodation away from neighbourhoods where drug use is rampant. Jenny reflects that if she had her own home, a place to keep her medications, this could support her to take them. Her poignant illustration of domesticity is uncomplicated by addiction and the transience of homelessness. As previously outlined, housing provision on its own may not be sufficient to support ARV adherence, however housing with additional support can be effective. Hawkins et al., (2010) assessed the impact of a Housing First approach on the viral loads of homeless people with HIV. This Housing First approach utilised a harm reduction model incorporating low threshold accommodation. The Viral load in 69 % of participants in that study dropped to undetectable, a rate that is much lower than in the homeless population in general. Significantly, in this study researchers found two reasons for viral load decrease:

1. People's increased sense of safety and stability in accessing housing resulted in more emphasis and energy to place on adherence to medication and healthcare, and 2. The sense of community, and living among people who had a shared history of homeless and HIV was conductive to normalising their experience and providing participants with the sense that if others could do it (achieve an undetectable viral load) so too could they.

5.9 Chapter Summary

This chapter, through cross case analysis and accompanying discussion, explored the emergent overarching themes and subthemes in this research. Commonalities and contrasting ideas were examined across the six narratives. While narratives initially seemed unique and distinct there were striking similarities in the shared lived experience of the people living with HIV, while also dealing with addiction and periods of homelessness. Participant lived experience at diagnosis, a negative experience for many, was examined. These poignant narratives revealed negative and demeaning experience for the majority of respondents which influenced subsequent adherence perceptions and behaviours. Participant beliefs about HIV transmission revealed some original findings regarding potential gendered perceptions and responses as well as complex struggles between shame, responsibility and blame, emotions which also underpin attitudes to treatment adherence. Participant experience of substance use was explored and it was noted that addiction and the effects of substances have impacted participant adherence. It was acknowledged that issues of loss of dignity, agency, privacy and confidentiality are present for PLWHIV in the Irish homeless system. Participants in this study simultaneously described receiving significant support while also feeling unsupported. This is an intriguing finding which warrants further research. Participants performed the role of the adherent, good patient, and it was posited that this performance, for participants was necessary to garner control and hope in their treatment and in their own lives. Finally, participants in this research acknowledged that ultimately, they have the control over whether or not they take their medication. However, participants also affirmed that in order to do this, they need varying levels of support; particularly intensive support when drug use is escalating and compromising ARV treatment, and a safe and stable place to live.

Chapter 6: Conclusion

This research explored the lived experience of adherence to their HIV medication in the context of homelessness and addiction. Palepu et al., (2011, p.524) observe that there are ‘limited descriptions of the effect of homelessness on adherence to ART’ in literature. While there is research regarding clinical manifestations, prevalence, co-morbidity, as well as rates of HIV medication adherence, there are few qualitative studies containing more in-depth explorations; which capture the voices and perspectives of those encountering these complexities and challenges. Currently there are calls for public and patient involvement/ engagement in research in this area (Brenden et al., 2015; Barker et al., 2018) in order to fully understand lived experience and develop innovative person-centred approaches to HIV treatment and adherence in this challenging context. This research is unique in that it is an exploration of the lived experience of adherence to HIV medication. This research is also a multifaceted exploration of experience; exploring not only adherence to HIV medication, but the contextual experiences of homelessness and addiction.

6.1 Major Research Conclusions

6.1.1 HIV Diagnosis Experiences and Impacts on Treatment Engagement

Evidence from this research demonstrates that people who use services remember the interactions that they have with healthcare providers and staff. Narratives of diagnosis experiences in the study reveal participant feelings of being stigmatised, devalued and dismissed by healthcare staff and of their leaving the diagnosis context with knowledge gaps, misconceptions and fears. Gender imbalances seem to feature in both the process of diagnosis interventions and in the diagnosis content; with females feeling demoralised in the diagnosis experience as well as being stereotyped as the HIV ‘carriers’ in the diagnosing doctors discussions with the males. Stigma, bias and sub-optimal health/social care for marginalised and HIV populations are evident in international research, however these narratives provide deeper insights into the nature and experiences of these issues at diagnosis. Recognition of gender influences in HIV experiences, perception and treatment is only recently emerging in research and this qualitative study illuminates the characteristic of this phenomenon in more depth. Negative interactions such as those experienced at diagnosis, had lasting impact on the study participants, influencing their self-perception, sense of agency as well as their motivation to adhere to medication and engage with health care.

6.1.2 Perceptions/Experiences of Transmission and Accountability

It was important for study participants to account for their HIV transmission and this resulted in the configuration of explanatory narratives that served to confer meaning or to protect them from the shame, distress and guilt of HIV related consequences. In these explanatory narratives, accountability for HIV transmission was moved partially or totally to other people or circumstances; again this had a gendered dimension with males supressing their IV drug risks and attributing transmission to sexual intercourse with promiscuous females, and females supressing their sexual behaviour and attributing transmission to IV drug use often at the hands of males. Participant beliefs about accountability also have relevance for their accountability for medication adherence and treatment engagement. These are complex and interesting findings which warrant further exploration.

6.1.3 Homelessness and HIV Medication Adherence

The findings indicate that homelessness had a destabilising and chaotic effect on participants' HIV medication adherence, particularly in relation to challenges in maintaining privacy, confidentiality and dignity while receiving and taking medication. Participants felt shamed by staff and other homeless service users. Not having a safe and constant place to call home adversely affected not just storage of medication but also participants sense of routine, security and self-agency which are important factors in self-care and treatment engagement. High risk neighbourhoods also challenged efforts at substance use reduction, treatment adherence and recovery.

6.1.4 Addiction and HIV Medication Adherence

Participants in this research invariably prioritised street drug use over HIV medication adherence. The immediate gratification associated with substance use and the use of illicit substances as self-medication, cannot be underestimated. Side effects and slower recognition/evidence of therapeutic effects of HIV medication also accounted for this prioritisation. The detrimental effects of substance use and addiction on concentration, cognition, executive functioning skills was a major challenge. Participants highlighted that when they were in phases of heavy substance use, any available energy was spent in raising money to buy drugs, finding a supplier and using drugs. This left little time for HIV related treatment needs. However, participants also indicated that in periods of drug stability, they had been able to adhere to medication. This suggests that drug stabilisation, contributes to improved treatment adherence among people who use drugs. It is possible that abstinence is not required in order to achieve and maintain adherence to HIV medication, but that through drug stability, adherence can be achieved. It was noted that care provision for PLWHIV, who use drugs and have experience with homelessness is disjointed and challenging to access. Several studies echo this experience and endorse a more collaborative holistic approach to individual care, some acknowledge that addiction treatment in conjunction with HIV treatment has yielded positive results.

6.1.5 Ongoing Adherence and Perceptions of Morality

In their narratives, participants were keen to present themselves as having moral worth which they exemplified as taking responsibility for their substance use and ARV treatment. This could be a reaction to the stigma and shame associated with HIV risk behaviours and an attempt to transform the narrative of perceived deviance to one of adherence. Participants described themselves as either ‘good’ when they are successfully managing their level of substance use and their adherence to ARV medication or ‘bad’ when self- management of drug use/adherence to HIV medication has deteriorated. Similarly, the desire to be regarded as a ‘good’ patient is evident in the narratives. In this research, the ‘good patient’ narrative was performed in three distinct ways; performance of adherence, performance of being informed and knowledgeable about HIV and performance of being a well-liked person in the healthcare service. These responses are interesting and contribute to understandings of how adherence can be supported

6.1.6 Perceptions of Supports to Adherence

There was some complexity in participants’ perceptions of the support they received and desired with some people not identifying/acknowledging family and health service interventions as support mechanisms. It seems that there is a disparity between actual and perceived support. Participants have experienced negative interactions with care providers and services so this may have affected their perceptions of support received. Another factor is the varying levels of support desired, depending on emerging challenges and crisis points. Participants highlighted their desire for intensive, almost paternalistic support when drug use is escalating and compromising ARV treatment and a lower level of support in times of relative stability and adherence. There is a strong sense in this research that participants want autonomy and to be empowered in their health care, but that simultaneously there are times when they desire higher levels of support, where healthcare professionals take more control of patient welfare through direct interventions. This is an interesting finding when one considers the possibilities of moving from adherence to concordance.

6.2 Implications for Practice

This research raises many implications for practice. Participant narratives provide useful insights regarding practitioner roles and behaviours at diagnosis and ongoing encounters. There are many examples of dehumanising and disempowering interactions with little reassurance, empathy or client centred information given. Stigma and bias were prevalent in relation to drug use HIV status and gender. These experiences, remembered long after the events, had traumatic effects on participants, engendering further shame and distress. Some examples of caring practice were also remembered and identified. Thus practitioners need to be cognisant that their interactions and interventions shape patient’s narratives of experience, the sense thy make of these and the formation of their own self- concept as a result. Additionally, practitioners’ positive and negative expectations of service user outcomes and adherence levels will invariably transmit to the service user and may influence adherence behaviour. Participants narrated their abilities and desires to achieve adherence, particularly in periods of relative stability in drug use; further adherence support work could be done in this regard through integrated case management between housing and healthcare.

6.3 Recommendations

Narrative research studies do not customarily make recommendations as the research aim is to illuminate lived experience and how participants' make meaning of these events. Also, with small participant numbers and the acknowledgement of a range of intrapersonal and interpersonal influences on the story related, narrative research does not claim to be generalizable. However, given the scarcity of research on ARV adherence in the context of substance use and homelessness as well as the direct recommendations from research participants analysed in their narratives, some recommendations are made here

6.3.1 Practice Recommendations

1. The diagnosis of a life altering /long term/ chronic illness is significant and frequently traumatic. Exceptional communication and interpersonal skills are required in this instance: appropriate training and experience is necessary for any clinician assuming this role. Further, all efforts should be made to ensure that the person receiving this diagnosis is supported by a family member/ advocate.
2. A review of training and ongoing supervision regarding bias, stigma, dignity and confidentiality in care interventions should be undertaken with practitioners working in services related to drug use, homelessness and HIV with attendant professional development as required.
3. Education and training in HIV disease and management in the context of drug use and homelessness should be prioritized among practitioners working in these areas
4. Adherence support interventions need to be flexible, varied and client centred depending on the capacity/engagement level and preferences of client at any given time
5. Adherence support interventions need to be strengths based and trauma informed.
6. Interagency communication and case management needs to be improved between HIV, addiction and homelessness services. This would include joint addiction and HIV walk in clinics, respite services, housing with support (for example Housing First model). Service user engagement and empowerment should be maximised in periods of relative stability in drug use/housing contexts.
7. Safe and stable housing wherein the person can establish/maintain routine and recovery with support as required

6.3.2 Research Recommendations

1. The relationships between diagnosis experiences and ongoing ARV adherence among this population needs to be explored further, both quantitatively and qualitatively.
2. The influence of gender, both in disease transmission and the perceptions/behaviours of those with HIV as well as treatment processes and outcomes, requires further research.

3. Additional research is required on specific factors that support as well as hinder ARV adherence among this population; for example family, personal beliefs, specific housing arrangements, particular treatment approaches.
4. Research is required on the experience of stabilisation in this cohort, its effects on ARV adherence and how to support and sustain drug stabilisation

6.3.3 Policy Recommendations

1. Housing policy needs to take into consideration the needs of people who use substances and who are endeavouring to enter and sustain recovery from substance use. These people will require ongoing, substantial support.
2. The location in which people are housed can have significant impact on health and recovery outcomes; this needs to be acknowledged when placing individuals with substance use issues or people who are living with chronic illness.
3. Housing and healthcare policy needs to reflect the principles of integrated care to a greater extent in order to facilitate more cohesive support for those who have HIV, homelessness and substance use support needs

6.4 Limitations and Strengths of the Research

The mall sample size (six participants) might be considered a possible limitation of this research. However, the findings from the in-depth narrative analysis reveal a wealth of information and insights, directly from those affected, which are rarely found in wider or larger scale studies. Some of these nuanced or previously unvoiced perceptions will, hopefully, help to develop understanding and empathy among practitioners regarding the human emotions and challenges experienced by these participants. The unique findings will also stimulate further, possibly larger scale research regarding gender influences and factors/conditions that support adherence among this cohort.

My position as the Nurse Manager of the unit in which this research took place and my role as the lead researcher had to be considered during this process. The nuances of existing relationships were documented in interview notes (Appendix 8) and were taken into consideration and explored at analysis stage. I have developed close relationships with clients, over the years working in BBVU. At times, I have had to discharge them from the service due to challenging behaviour or high risk substance use. I was conscious that I am also a character in their life narratives whose care may shape their perceptions and narratives of adherence. The impact of this existing relationship was not as significant in the narrative interviews as I had predicted. However, it is possible that the participant narrative performative may have been influenced by my presence/position and the participant/service user desire for to be seen as a ‘good’ therefore ‘adherent’ patient. These performative dynamics are recognised and accepted in narrative research and researcher reflexivity and transparency regarding these influences is integral to the conduct of narrative inquiry. Many of the participants also revealed deeply human experiences of shame, fallibility and non-adherence which were striking in their honesty, generosity and insight.

This research allowed for a unique exploration into the lived experience of people living with HIV, who use drugs and have experience of homelessness. This is a population of people whose voices are rarely heard, and are rarely acknowledged. There was a sense in every interview that clients felt privileged to be listened to and privileged to be heard. When I started transcribing the first narrative it was I who felt privileged to have held a piece of this person's life, of their story and to be able to share it. In a world where we have become focused and orientated towards data and performance indicators, it is important not to lose sight of the value and significance of peoples' stories and experience. It is imperative that we continue to listen to, to share and to learn from the experience and wisdom of the people who use our services.

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Appendices

Appendix 1. Research Poster/ Advertisment

WOULD YOU LIKE TO BE INVOLVED WITH NEW RESEARCH TAKING PLACE IN THE DUBLIN SIMON COMMUNITY BLOOD BORNE VIRUS UNIT?

This research project is called - ***The lived experience of adherence to HIV medication in the context of Addiction and Homelessness.*** The purpose of the research is to learn more about how being homeless and living with addiction affects how people manage their HIV medication. Not much research has been done in this area so it is important to hear the stories, experiences and views of people in these situations so that service staff can have a better understanding of some of the issues involved.

My name is Eavanna Maloney and I am the Nurse Manager of the Blood Borne Virus Unit DSC. I have been granted funding from the Irish Research Council to do this research. The research project will be part of my Masters in Science degree at Dublin City University (DCU). My supervisor in DCU is Briege Casey and my supervisor in DSC is Majella Darcy.

What is involved?

I am looking for up to eight volunteers who would like to tell me the story of their experiences of trying to manage their HIV medication while they are homeless and experiencing addiction. The volunteers will be asked to take part in a one to one interview with me (Eavanna) in a private room of the BBVU lasting 40 minutes to one hour. The interview will be recorded on a password protected mobile device, but the recording will be erased as soon as it is typed up and all personal details e.g. your name, information that might identify you will be deleted form the files and I will use codes or false names instead.

Participation in this project is completely voluntary. You should not feel any pressure to volunteer just because you are using the BBVU the service and or/you know Eavanna, the researcher. Whether you choose to volunteer or not, the service you receive will remain the same. You can also change your mind and opt out of the research at any time, even during the interview.

Because we want to ensure that the most relevant information is collected on this topic and that all involved feel respected and safe, there are some participation guidelines. You may be able to participate in this project if you are living with HIV, are experiencing homelessness and addiction and you are in good enough physical and mental health to take part in an interview with the researcher. You may not be able to participate in this project if you don't experience the issues we are exploring (i.e HIV, Homelessness, Addiction) or if you are currently not well enough to participate in a researcher interview.

A general information session providing more details about this useful research will be held ________________in the group room, BBV stabilisation Respite Unit.

Your stories/experience and opinions matter; they are valued by Dublin Simon Community and can have a huge impact on how we support clients living with HIV. If you would like to participate, or you would like further Information: please contact Eavanna Maloney –Nurse Manager: BBV Stabilisation Respite Unit. eavannamaloney@dubsimon.ie Phone: or your Key worker can make contact for you.

Thanks, Eavanna

Appendix 2. Plain Language Statement

Research Title: *The lived experience of adherence to HIV medication in context of addiction and homelessness.*

Researcher: Eavanna Maloney, Nurse Manager, Blood Borne Virus Unit email eavannamaloney@dubsimon.ie phone 086 045328808.

Supervisors: Dr.Briege Casey, School of Nursing and Human sciences, Dublin City University, email, briege.casey@dcu.ie phone 01-7008521, Majella Darcy, Head of Treatment and Enterprise, Dublin Simon Community, email majelladarcy@dubsimon.ie

This research project is being funded by the Irish Research Council, Post graduate Employment based partnership. The employment partner is Dublin Simon Community (DSC) and the research will be carried out in the DSC Blood Borne Virus Unit (BBVU). The research project will be part of my Masters in Science degree at Dublin City University (DCU)

Purpose of the research:

The purpose of the research is to learn more about how being homeless and living with addiction affects how people take their HIV medication. Not much research has been done in this area, yet it is known that people who experience addiction and homelessness can struggle with managing their HIV medication. It is important to hear the stories, experiences and views of people in these situations so that service staff can have a better understanding of some of the issues involved.

What does participation involve?

Your participation will involve a one to one interview with the researcher, Eavanna, lasting approximately 40 minutes to one-hour long. The interview which will take place in a private room at the BBVU. You will be asked to read and sign a consent form which confirms your willingness to partake in the study. The interview will contain several questions regarding the story of your experiences managing HIV medication while experiencing homelessness and addiction issues and will be recorded on a digital audio device. You can opt out of the research process if you change your mind, even if this is during the interview.

Participation in this project is completely voluntary. You should not feel any pressure to volunteer just because you are using the BBVU the service and or/you know Eavanna, the researcher. Whether you choose to volunteer or not, the service you receive will remain the same. You can also change your mind and opt out of the interview at any time, even during the interview.

Because we want to ensure that the most relevant information is collected on this topic and that all involved feel respected and safe, there are some participation guidelines. You may be able to participate in this project if you are living with HIV, are experiencing homelessness and addiction and you are in good enough physical and mental health to participate in an interview with the researcher. You may not be able to participate in this project if you don't experience the issues we are exploring (i.e HIV, Homelessness, Addiction) or if you are currently not well enough to participate in a researcher interview.

How will my privacy be protected?

The interview recording will be erased as soon as it is typed up and all personal details e.g. your name, information that might identify you will be deleted form the files and codes or false names will be used instead. The list of participant names will be stored separately on a secure computer which is protected by passwords and encryption While every effort will be made to protect your anonymity, due to the small number of interviews being carried out and the use of direct quotation when writing up the research study, anonymity cannot be totally guaranteed, and it is possible that you could be identified. However, the researcher will take all measures to ensure that anonymity and confidentially is preserved to the highest degree possible.

Potential benefits

There are no direct benefits provided by the study, however it is hoped that taking part will provide a space for you to voice your own experiences and opinions. This may be helpful to you in making sense of these experiences. People in situations of homelessness while experiencing HIV and addiction, often feel ignored or shamed and that they are not heard. We hope that you will find taking part in the research a way of making your voice heard and that you feel pride in making a useful contribution to the knowledge and sensitivity of service treatment staff in DSC, Ireland and beyond.

Potential risks

There may be a risk that you could become distressed when thinking about/remembering sad or painful experiences. The researcher (Eavanna) is very skilled at making you feel more comfortable should this happen. There are a range of supports available; including BBVU staff or counselling services in DSC or externally and you will be supported to access these if necessary.

Limits of confidentiality

Confidentiality cannot be maintained in the event of a disclosure of information which involves a risk to you, another person or a child protection issue (Children First guidelines will be adhered to).

Do I have the right to withdraw from this study?

The choice to participate in this study is completely voluntary. You are free to withdraw from the study up to the point of data analysis.

How will my information (data) be used and disposed of?

Interview data will be typed up from the audio recordings, the audio recordings will then be deleted. The researcher will study the anonymous information and look for common experiences or experiences that are important for the research results. All information will be stored securely on the researcher's password protected laptop. Any paper material (e.g. consent forms) will be stored in a locked filing cabinet at the researcher's home office. All of the data collected will be stored for a period of five years following completion of the Masters programme. After this period of time, the researcher will securely dispose of all digital or paper materials.

How will I find out what happens with the project?

The researcher, Eavanna will do a presentation in the BBVU and in DSC in relation to the results of the study. In this presentation, great care will be taken that no-one involved is personally identifiable. The results will also be presented at conferences and in journals in Ireland and abroad so that people who plan services and who work in this area can be better informed and prepared. If you wish to be informed about the results of this study, a summary information sheet can be provided to you.

If you have any questions regarding the research please contact the researcher: Eavanna Maloney by by email at eavannamaloney@dubsimon.ie phone 086 0453288 or alternatively the research supervisor: Dr. Briege Casey email: briege.casey@dcu.ie phone 01700 8521. If you 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, email rec@dcu.ie phone 01-7008000

Appendix 3. Participant Consent Form

Research Title: *The lived experience of adherence to HIV medication in context of addiction and homelessness.*

Researcher: Eavanna Maloney, Nurse Manager, Blood Borne Virus Respite stabilization Unit, email eavannamaloney@dubsimon.ie phone: 086 0453288

Supervisors: Dr.Briege Casey, School of Nursing and Human sciences, Dublin City University, briege.casey@dcu.ie phone 01-7008521, Majella Darcy, Head of Treatment and Enterprise, Dublin Simon Community, email majelladarcy@dublinsimon.ie

This research project is being funded by the Irish Research Council, Post graduate Employment based partnership. The employment partner is Dublin Simon Community (DSC) and the research will be carried out in the DSC Blood Borne Virus Unit (BBVU). The research project will be part of the researcher's (Eavanna Maloney) Masters in Science degree at Dublin City University (DCU)

Participant Consent Form

The purpose of the research is to learn more about how being homeless and living with addiction affects how people manage their HIV medication. Not much research has been done in this area. It is important to hear the stories, experiences and views of people in these situations so that service staff can have a better understanding of some of the issues involved. If you agree to take part in the research project, you will be interviewed and asked a series of questions in relation to your experiences.

Participant- Please complete the following (circle yes or no for each question):

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 audio-taped Yes/No

I am aware that my choice to participate in this study is completely voluntary and that I am free to withdraw for any reason up to the point of data analysis. Yes/No

Confidentiality and Disposal of Data

My data will be kept secure at all times, and my name will not be divulged to anyone. My name will be anonymised to protect my identity. However, given the small number of participants and the fact that direct quotes will be used in analysis of the study findings, I am aware that my anonymity cannot be fully guaranteed. I am aware that this study will be subject to legal limitations of confidentiality, which have been explained to me. I understand that all information gathered during the research will be securely deleted and shredded five years after the completion of this Masters study in accordance with DCU guidelines.

Yes/No

My Participation and Consent

I understand that my participation in this research involves telling my story and talking about my experiences of living with HIV and taking HIV medication, being homeless and dealing with addiction. I understand that my participation in this research is voluntary and that I can withdraw from this study at any time, without explanation or repercussion. I understand that there will be no penalty should I chose to withdraw from this research, and that my withdrawal will have no impact on the care I receive while resident on the BBV stabilization unit.

Yes/No

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

Signature

Participants Signature: ___________________________________

Name in Block Capitals: __________________________________

Researcher: ____

Date: _______________________

Appendix 4. Interview Guide

DCU

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Dublin Simon Community

Research Title: *The lived experience of adherence to HIV medication in context of addiction and homelessness.*

Background/Demographic Questions:

1) Age, Gender
2) Living arrangements – type of abode, living alone or with others? Homeless? How long? Sleeping rough? If so, how long?
3) Level of community support – family? Staff? Other?
4) Addiction/substance use issue – how long? What substances and level/severity of use/addiction?
5) Level/nature/quality of support for addiction issues
6) HIV diagnosis. When diagnosed? Effects/symptoms of HIV experienced
7) HIV medications and medical support

Interview Questions:

1. **Why did you decide to take part in the research?**

2. **Tell me about how you became aware that you had HIV, what was that like for you?**

3. **Tell me about the time when you were first prescribed HIV medication**

3a How did you feel about it at that time?

a) Did you think your HIV medication was important to your health? Say more
b) Did you have any emotional responses regarding the need to take HIV medication Say more?
c) Did you feel motivated to take your HIV medication? Say more
d) Did you feel under pressure to take the HIV medication? Say more
e) What did you think would happen if you didn't take your medication? Did you worry about that?

3b How do you feel about it now?

a) Difficulties swallowing
b) Side effects
c) Remembering doses times
d) Not having knowledge/confidence about it
e) Storing
f) Finding a place to take it/embarrassment
g) Not enough support

4. **Can you tell me about your experience of managing your HIV medication, while you are/were homeless?**

Prompts:

a) Was/is your ability to manage your medication affected by being homeless? Say more
b) What was/is that like for you?
c) What kind of problems / challenges do/did you face?
d) What was/is helpful in managing your medication while homeless

5. **Can you tell me about your experience of trying to manage your HIV medication while you are or have been in addiction?**

Prompts:

a) Was/is your ability to manage your medication affected by your addiction/substance use issues? Say more
b) What was/is that like for you?
c) What kind of problems / challenges do/did you face?
d) What was/is helpful in managing your medication while having substance use issues

Interview pause check - in

Are you ok to continue talking to me about all of this?

You have discussed with me what it was like taking your HIV medication while you were homeless and experiencing substance use issues. You have said that it was xx, xx and xx.

6. **Are there other factors in your life aside from being homeless and dealing with addiction that make it difficult to take your HIV medication? Say more**

Prompts:

a) *Can you tell me more about that?*
b) *In what way does that make it more difficult*
c) *What kind of problems / challenges do/did you face?*

7. **Can you tell me what would have supported you to take you medication at that time when you were homeless and dealing with addiction?**

Prompts

a) *Was there a person who could have supported you? How could they have supported you?*
b) *Was there a service that could have supported you?*
c) *If you could have chosen anything / or anyone in the world to support you to take your medication at that time? Who or what would that have been? What would it have looked like?*
d) *Describe it to me?*

8. **If you could create the 'dream' service or support to help people with HIV who are homeless and in addiction what would that be?**

Prompts:

a) *Think big!*

Appendix 5. Interview Questions.

Research Title: *The lived experience of adherence to HIV medication in context of addiction and homelessness.*

Background/Demographic Questions:

1) Age, Gender
2) Living arrangements – type of abode, living alone or with others? Homeless? How long? Sleeping rough? If so, how long?
3) Level of community support – family? Staff? Other?
4) Addiction/substance use issue – how long? What substances and level/severity of use/addiction?
5) Level/nature/quality of support for addiction issues
6) HIV diagnosis. When diagnosed? Effects/symptoms of HIV experienced
7) HIV medications and medical support

Interview Questions:

1. **Why did you decide to take part in the research?**

2. **Tell me about how you became aware that you had HIV, what was that like for you?**

3. **Tell me about the time when you were first prescribed HIV medication? 3a How did you feel about it at the time?**

   3b How do you feel about it now?

4. **Can you tell me about your experience of managing your HIV medication, while you are/were homeless?**

5. **Can you tell me about your experience of trying to manage your HIV medication while you are or have been in addiction?**

6. **Are there other factors in your life aside from being homeless and dealing with addiction that make it difficult to take your HIV medication?**

7. **Can you tell me what would have supported you to take you medication at that time when you were homeless and dealing with addiction?**

8. **If you could create the ‘dream’ service or support to help people with HIV who are homeless and in addiction what would that be?**

Appendix 6. Ethical Approval

Dr Briege Casey School of Nursing and Human Science 16th September 2019.

REC Reference: DCUREC/2019/148 Proposal Title: The lived experience of adherence to HIV medication in the context of Addiction and Homelessness; a qualitative study of a Blood Borne Virus Unit.

Applicant(s): Dr Briege Casey

Dear Briege, 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,

Mark Philbin

Dr Mark Philbin Interim Chairperson DCU Research Ethics Committee

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Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

Research & Innovation Support
Dublin City University,

Appendix 7. Individual Case Analysis Excerpt

Interview 2: Jenny

Key: Performativity

Context

Structure and Language - symbols/metaphors

Drug use

Homelessness

HIV

Medication adherence

Throughout my life, the first season of the drugs, I think there were three seasons of drugs, three categories of drugs: your first season, your second season, your third season. The first season of my drug use was heroin. And then I went on to a methadone clinic, and then I'm still taking heroin, still taking heroin. Then my second season was cocaine, IV. I went to actually start walking the streets to feed that cocaine habit because it was a £300 pounds a day cocaine habit. I was walking the streets day and night, me and my mate, and we would make like, the first £300 we would make, and that's £300 pound each, so we'd make that £300 within an hour, that was back then because it was more expensive. We'd make £600 between the two of us, and then she used to drive, we'd drive, we'd get the coke, we'd use the coke, then get ready in different clothes, we'd have it in the car, go back down, get another £300.

And then the third season was the crack, when I went to live in London, and that is hectic. I stopped taking heroin and I stopped taking… well, it is cocaine, but it's smokable and it's just as bad as cocaine, as using it, like, you know. That is the root of all evil, you know what I mean? That was my downfall, is the crack. It's just taking over, it's taking over everything.

….but it was just the drugs that was killing the times of the appointments, getting there. If I knew there was a rock, two rocks to go and meet my dealer over there, I'd jump up and get there, but to go and get… It's just mad, like the drugs just took over my head. I just want to stop now. I just want to get up like normal and, you know what I mean. There'd be some days I wouldn't even put water on my face, I'd be just straight out the door.

The first medication didn't agree with me. I kept vomiting. So I was on there, I can't remember, it's so far back. But I was on the one with the fridge; remember you had to keep it in the fridge. And I was on another two. I think I started with six or seven tablets at that time

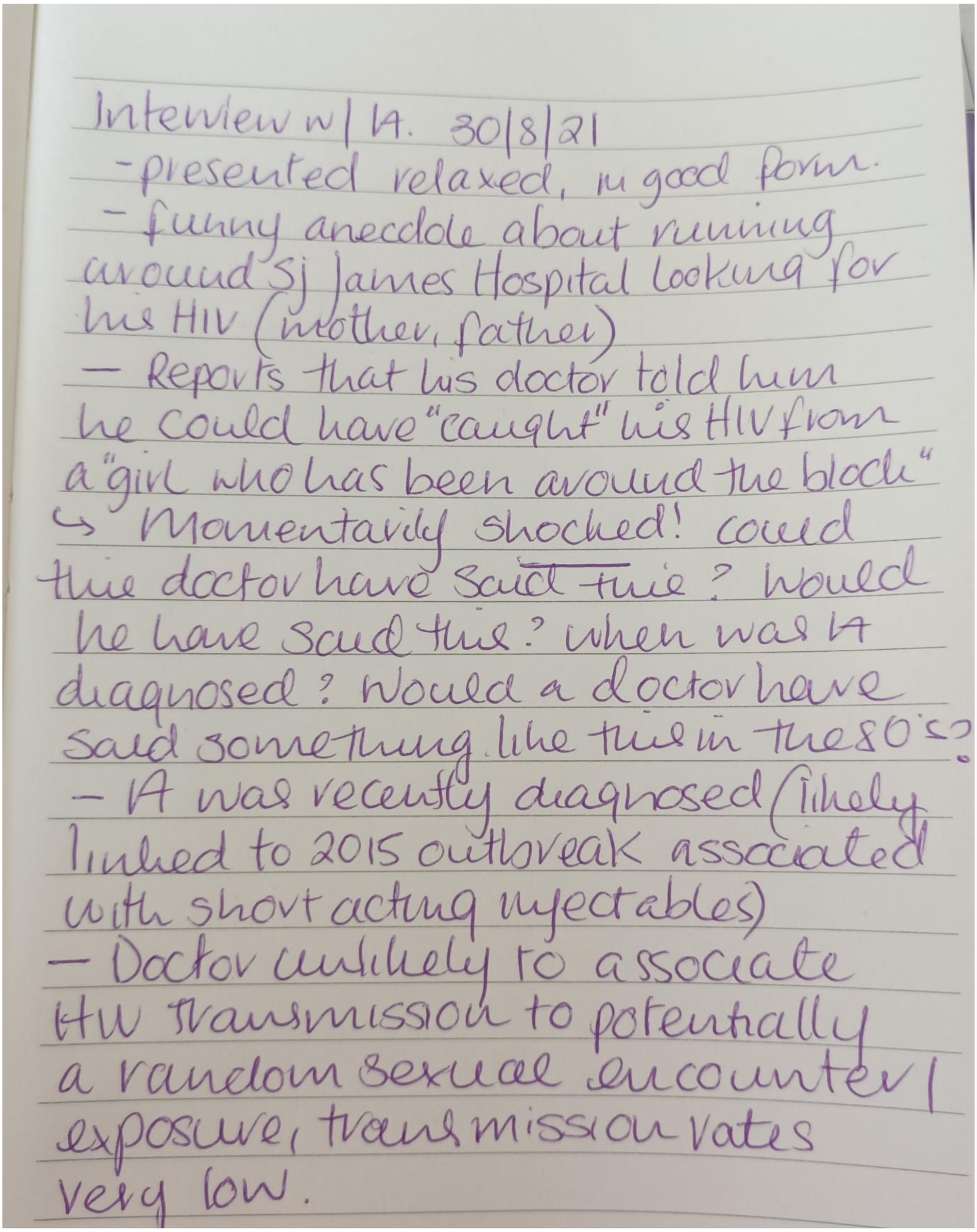
I would get into a place, a six-month hostel, and then I'd have to move after the six months, then I'd stop my medication and I would feel good for a couple of months, I'd be smoking rock and then I'd hit rock bottom, I'd start getting sick. I don't know how I'm still here speaking to yourself because I've came into hospital in some states. I've been in some states. I've lost so much weight I had to just buy clothes from children's departments. You know, it's just, I don't know.

They were talking about bringing this injection thing out for people because I am a very bad person for not taking my medication and it's like it could be in that drawer, I'd be just too lazy to take it. It's mad. But when I'm stable and when I'm good I take it. But if I'm hectic, I won't. When I'm hectic? It's just more like I'm not concentrating on that HIV treatment. That treatment should be more a priority than what I am concentrating on going out to get my next rock. But, no, I would leave that and fly out and get my next rock. I've often sold my treatment tablets to the black people to sell on because they can't get it because it's so expensive. One time I got £500 for selling my medication, to a Nigerian person. Yeah, I did. I suppose you've heard those stories before, but I did. Yeah, I did, and it was only the one, and the reason why I sold him it was because I hadn't been taking the last ones and I had them.

I felt like I'm getting the medication, so I must be nearly dying. I must be nearly dying. I must be dying, like. I even remember asking the doctor, "How long have I got left now?" Because I'm starting the medication, because I never read into it and never took nothing. He said, "This is the medication to stop you from going to get AIDS." And I said, "What do you mean? I have AIDS?" He goes, "no you haven't. You have HIV." I said, "Yeah, but that is AIDS," because I was so, you know. But no, he explained it to me and then I kept to the tablet routine and to my appointments and then it was undetectable for a couple of years. Then I felt good. I felt alive again,

The side effects that I got was I lost my hair. My hair started falling out. Yeah. I had hair down to here, thick hair, and I lost it. I didn't lose it quickly, it just went thin, and that was only… and then the first week I just got sick. That was it, and then weeks after that, I was grand. It was hard because I knew when I take these tablets half an hour or not even half an hour, I'd be in the toilet vomiting, but that would be only one vomit and then that would be it. But that only lasted for a week. I know some people are different, but mine only lasted a week. Yeah. I got very conscious. I had to keep on wearing hats then.

Appendix 8. Except from Interview Notes: Arthur, August and September 2021

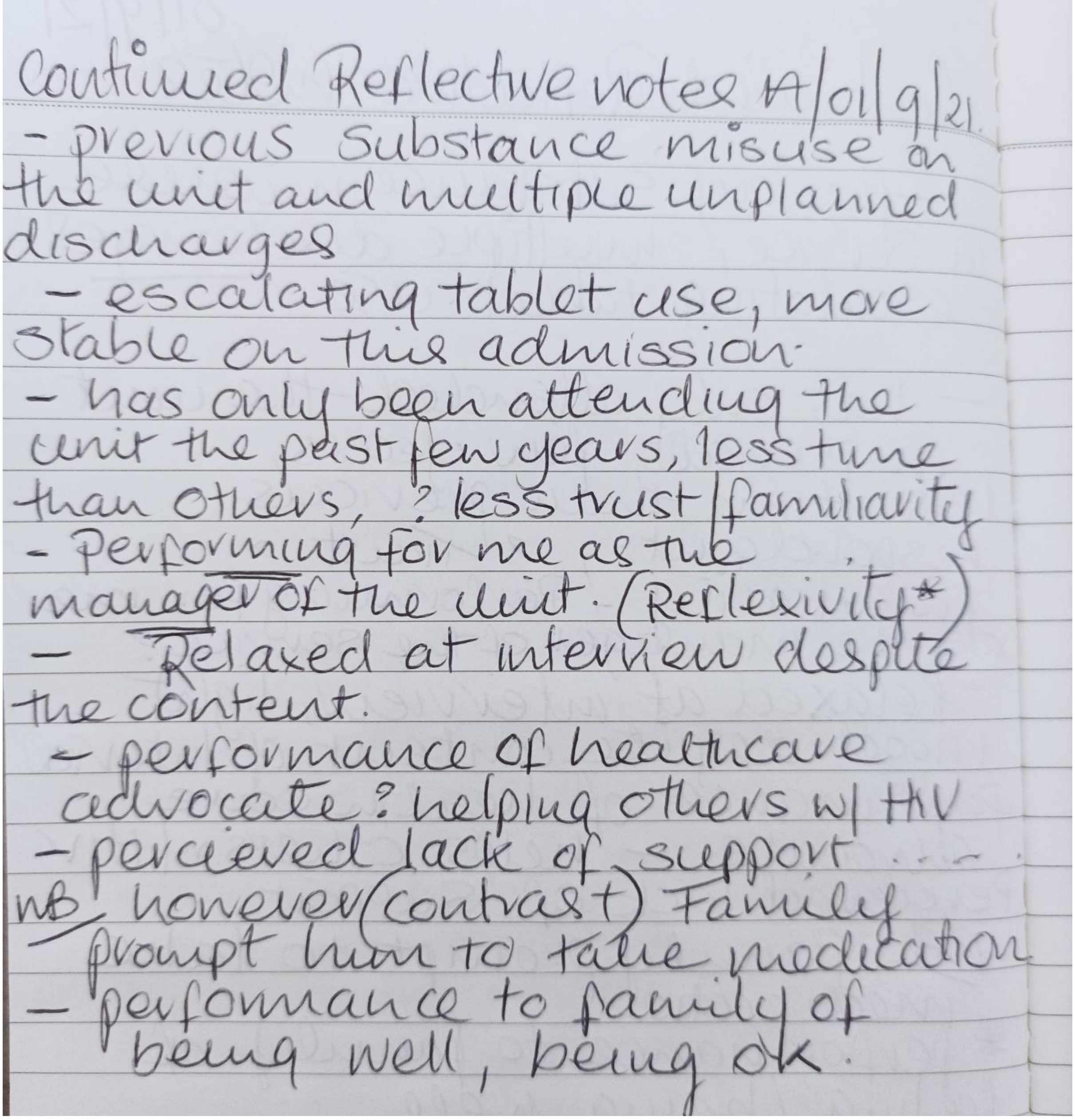


Interview w/ 14. 30/8/21

- presented relaxed, in good form.
- funny anecdote about running around Sj James Hospital looking for his HIV (mother, father)
- Reports that his doctor told him he could have "caught" his HIV from a "girl who has been around the block"

↳ Momentarily shocked! could this doctor have said this? Would he have said this? when was 14 diagnosed? Would a doctor have said something like this in the 80's?

- 14 was recently diagnosed (likely linked to 2015 outbreak associated with short acting injectables)
- Doctor unlikely to associate HIV transmission to potentially a random sexual encounter/exposure, transmission rates very low.



Continued Reflective notes 14/01/9/21.

- previous substance misuse on the unit and multiple unplanned discharges
- escalating tablet use, more stable on this admission.
- has only been attending the unit the past few years, less time than others, ? less trust/familiarity
- Performing for me as the manager of the unit. (Reflexivity*)
- Relaxed at interview despite the content.
- performance of healthcare advocate ? helping others w/ HIV
- percieved lack of support ...

nB however (contrast) Family prompt him to take medication

- performance to family of being well, being ok.

Appendix 9. Cross Case Thematic Analysis Table

	Frances	**Jenny**	**Sara**	**Peter**	**Ben**	**Arthur**
Overarching Themes						
1. Diagnosis	✓ Nonchalant diagnosis	✓ Nonchalant and dismissive	✓ a total shock / unsupported	X talks about transmission	✓ Breach of privacy at Diagnosis: prescription of sleeping tablets and relaxers	X compassionate and that the doctor took time with him 'ye might have caught it off a girl'.
2. Addiction	✓ Links drug use to Transmission Expectations of the life of a drug user Drugs first	✓ cycle consumed by the need to get Crack Drugs first Does not want to be associated with drug use	✓ A demon inside your body Drugs first	✓Intermittently Drugs first 'the drugs were more important'	✓ 'bad on the crack' feelings of suicidality and depression	✓Intermittently
3. Medication	✓Big horse tablets, didn't sit right with using drug addict hard on your stomach Drugs and reward didn't like them	✓Hair falling out, sick	✓Sleeping after taking tablets; 'horse tranquilisers, make you sick, 'it means its real that you have HIV	**X**	✓Equates medication to going to mass	✓Ritualistic, manipulating regimen, he can swallow them doesn't mind if they make him sick
4. Contagion / Transmission Narrative	✓Transmission via needles	**X** Does not discuss or disclose transmission route	✓Refers to transmission risk needles	✓Transmission via Sex Girl with Cancer	✓Transmission Via sex girl he was with	✓Transmission via sex from girls list of women Diagnosed in 2015. But alludes to the risk of sharing needles
5. Homelessness	✓Hostels, rough sleeping, Movement; when things are uncomfortable, lack of safety	✓Movement uprooted lack of privacy feelings of stigma and shame	✓Housed since diagnosis, has experience of homelessness	✓Housed 14 years homeless since age of 10	✓Feels sorry for homeless, he is not like other homeless, ambiguity as to housing status,	✓Isolating, lonely, crime – doesn't give the topic much time in his narrative

	Frances	**Jenny**	**Sara**	**Peter**	**Ben**	**Arthur**
Overarching Themes						
					registered as homeless	
6. Non adherence	✓Being stigmatised, excluded, strict, rigid services, staff with no compassion and empathy Transient lifestyle, necessity to keep moving	✓Being uprooted, crack cocaine, lack of privacy and associated stigma and shame	✓ When 'hectic', apathy, not bothered, 'they could be in drawer' and Sara wouldn't take them, a bad person for not taking meds	✓Chaotic Drug use IV use of Crack cocaine and the drugs were more important	✓Chaotic Drug use Can't fathom why others wouldn't adhere *'bad'* on crack-cocaine. He describes feelings of suicidality and poor mental health.	✓Chaotic drug use, likely disrupted by alcohol use
7. Adherence	✓Feeling safe and supported Sense of belonging	✓Dispensing of medication would support adherence, lack of own self- belief in ability to adhere on her own	✓Knowledge, adherence and engagement with care are connected. Family support and prompts	✓Plays the role of the good adherent patient methadone clinics	✓Plays the role of the good adherent patient equates adherence to going to mass methadone clinics	✓Plays the role of the good adherent patient Family support and prompt methadone clinics
8. Support	Named services , Staff who have experience of addiction, safe space to call home	X	Family support and prompting re. medication	Support worker supports adherence, frequently says he wasn't supported, nurse to go with	Family, methadone clinics	Family support and prompting to take medication Methadone clinics,

	Frances	**Jenny**	**Sara**	**Peter**	**Ben**	**Arthur**
Overarching Themes						
				clients to collect meds		
Subthemes	**Frances**	**Jenny**	**Sara**	**Peter**	**Ben**	**Arthur**
Stigma	✓ and experienced in services	✓ felt in hostels	**X**	**X**	Says that people say he always looks well 'for a homeless person, he is not like other homeless people	**X**
Shame	Says she is not afraid of people knowing, says she has been in situations where people have said 'she is the one with the virus'.	**X**	Sara talks about taking her medication in front of grandchild, ? hidden shame , medication to make her 'tummy feel better'.	Says he is not ashamed, doesn't care who knows, if very up front in disclosing to sexual partners		**X**
Confidentiality	**X**	✓Breached in hostels	**X**	**X**	✓Breached at diagnosis	**X**