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# Our Journey;

# The Participants, the Client and the

# Counselling Psychologist

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# Table of Contents

## Section B: Publishable Article

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**THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:**

# Tables and Figures

**Section A: Research Study**

**Section B: Publishable Article**

# Definition and terms

**Definition of Children, Adolescents and Adulthood**

Defining these individual terms is a complex issue, sometimes dependent upon culture and country. To define adulthood, it is helpful to first define adolescence. Adolescence is the period of transition between childhood and adulthood. To define adolescence, the World Health Organisation (World Health Organisation [WHO], 2013) uses the ages 10-19, the USA between 13-24 and the UK 12-20 years and thus there is considerable overlap. For this study, I have defined adulthood as 20 years and over in line with the WHO and UK. However, when reviewing the literature, it must be held in mind that different studies adopt different definitions to describe adolescents and adults, with some also adopting more ambiguous terms like youth and young people. Therefore, with each study that I discuss I aim to provide the ages of the participants to help alleviate this issue.

**PAHIV**

This research will refer to individuals living with Human Immuno-Deficiency Virus (HIV) since childhood as living with perinatally acquired HIV (PAHIV) whilst acknowledging that some individuals may have acquired HIV through several different transmission routes when babies including breast feeding, vaccinations and medical interventions. Route of transmission may not always be known. I acknowledge these differences however, in line with current literature, PAHIV will be utilised as a generic term. The abbreviation PAHIV+ may also be used to describe these individuals.

**Vertical and Horizontal HIV transmission**

Vertical transmission of HIV from mother to baby may be used synonymously with perinatally acquired HIV. Horizontal HIV transmission is through sexual contact.

**Diagnosis**

Some individuals living with PAHIV might have been told their HIV status long after they were medically identified as having HIV infection. Therefore, when discussing HIV diagnosis for individuals living with PAHIV this is sometimes referred to as disclosure.

**ART**

Antiretroviral therapy (ART) was an early treatment developed for people infected with HIV. Currently the standard treatment in the UK consists of three drugs or more and is called Highly Active Anti-Retroviral Therapy (HAART). Likewise, the term ARV's are also used to describe HIV anti-retroviral therapy. All three definitions may be used interchangeably throughout this research. Treatment is taken to manage the virus as no cure is currently available.

**HCP's**

The term Health Care professionals (HCP's) in this study may include any individual who provides curative, preventive, promotional or rehabilitative health care services to individuals, families or communities in a systematic way. This may include nurses, allied health professionals or psychologists to name but a few.

**Diagnosis/Disclosure**

HIV is diagnosed through taking a blood test specifically looking for the virus. Some adults with PAHIV would have discovered their HIV diagnosis long after they were tested for the virus. PAHIV+ individuals discover their status in variety of ways. This is sometimes called disclosure. It is important to recognise that in the HIV literature the word disclosure is sometime used interchangeably to describe diagnosis and disclosure.

**Mental health problems**

The definition and classification of mental health problems is usually done to facilitate professionals in referring people for the relevant treatment and care. The use of diagnosis is controversial with the concern held that people are all too often described or treated by their label effecting their quality of life. However, in most literature diagnosis is still used as a way of classifying and dividing symptoms into groups. For this research, mental health problems are defined broadly to comprise psychiatric disorders, indicators of more behavioural and emotional problems or more general psychological distress.

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# City, University of London Declaration

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# Preface

This portfolio presents three pieces of work I have completed on my professional journey towards becoming a Counselling Psychologist. It fulfils the requirements of the DPsych Counselling Psychology doctoral level programme at City, University of London and demonstrates my commitment to the scientist-practitioner role. This collection of work honours the personal, subjective experience of individuals, and multi-dimensional approaches to knowing, reflecting a core principle of Counselling Psychology. Whilst this portfolio may seem like an organised, systematic piece of work, compiled of three separate sections, it is important to recognise that what is presented reflects the organic, evolving development of a portfolio made up of three related and interconnected parts. Conceptually this research was born in 2013, developed in 2014, carried out in 2015 and completed in 2017. It has been a long, tiring but rewarding journey.

When I came to pull this portfolio together, I realised for the first time that the overarching theme which had emerged from the research was reflected in the title of the case study I had chosen to include and was originally written in the final year of the taught part of the training. The shared theme which emerged is a 'Journey'. It is this theme which appears to permeate each section of the portfolio and links them together. I shall now attend to each section of the portfolio in turn, providing a brief overview of its evolution, a section on the personal journey I have undertaken, finally concluding with my reflections on becoming a Counselling Psychologist.

Section A presents my research study which is an exploration of how individuals living with perinatally acquired HIV (PAHIV) experience and make sense of reaching adulthood. Having never previously undertaken a qualitative research study before the task was an extremely daunting one. This was eased by the knowledge that this research would be carried out with a focus on individuals living with PAHIV; a familiar cohort I have worked with for over ten years as a health adviser in an NHS Trust Hospital and more recently as a trainee Counselling Psychologists.

Before my Counselling Psychology training began I was involved in setting up the hospital's first outpatient clinic for young people living with PAHIV as they began to reach the age where they needed to transition from paediatric services into adult care. I was acutely aware

that they were the first cohort of individuals with PAHIV to attend our adult service and wanted to make their transitional journey as smooth as possible. I always felt that these individuals had trodden a different path to other young people we saw living with horizontally acquired HIV and wanted to be able to offer them the support they needed.

Shortly before my training began, one of my patients died of a rare side effect after restarting her HIV treatment. She had struggled with adherence to medication and had stopped and started treatment several times. She was only 19, and when I went to visit her in intensive care I remember wondering if anything could have been done differently to support her, which ultimately may have saved her life. I recognise this as a motivating factor to carry out this research. Around this time there was also increasing discussion about the lack of psychological support offered to patients attending our clinic with PAHIV. Support was mainly offered by HIV clinicians, Nurses and Health Advisers who had no previous experience of working with this cohort. When considering the initial research proposal I needed to submit for my application to the DPsych Counselling Psychology programme, this area seemed like the natural choice. Whilst the research question and aim has evolved throughout this process my decision and interest to explore the lived experiences of adults living with PAHIV has never changed.

The journal article in section B presents three themes which emerged from the above research study which I feel may be of importance to a broad range of health care professionals (HCP's) supporting the biopsychosocial needs of PAHIV + individuals. Whilst acknowledging that some of the more psychological findings from this research should be published in a Counselling Psychology Journal in the future, I also feel it is important for a broad range of HCP's to recognise the changing impact of living with PAHIV over time, especially as individuals reach adulthood and their psychological needs evolve and may need to be revisited.  The journal article also provides an insight into the coping strategies individuals may have adopted throughout their lives to manage their difficulties of living with HIV and makes some suggestions for psychological treatment models.

This article focusses on a broader audience because individuals living with PAHIV may not be engaged with Counselling Psychologists or psychological services and may be supported instead by a variety of HCP's. Whilst the participants in this research were all accessing psychosocial support through an HIV charitable organisation, I am aware this type of support is limited in other parts of the UK. This means PAHIV+ individuals may only have contact

with an HIV Physician or Nurse for their medical care, sometimes as little as every six months. This article to the best of my knowledge is the only one in the UK which illuminates the lived experiences of individuals reaching adulthood whilst living with PAHIV. To reach a broad range of HCP's this article is intended for the Journal AIDS Care, Psychological and Socio-medical Aspects of AIDS/HIV. AIDS Care is one of a small number of journals which successfully addresses both the social and psychological aspects of living with HIV infection.

Finally, section C presents a clinical case study. This case study presents an individual with a sexual problem and demonstrates my understanding of how to link the theory and practice of psychodynamic therapy, demonstrating my understanding of this therapeutic model in relation to the client and my ability to work reflexively throughout the therapeutic process. This case study explores the collaborative therapeutic journey between the client and myself and demonstrates my sensitive and thoughtful incorporation of psychological theory and clinical skills. It explores the difficulties encountered on our therapeutic journey, particularly the transference and countertransference relationship, and was probably one of the most challenging cases I experienced throughout my clinical training. Therefore, it received the title 'Our Journey'.

On a personal level this has been an extremely long and demanding journey characterised by an on-going commitment to the rigorous training in clinical practice, doctoral level research, a part time job and a family with two young children. I have learnt how to manage the anxiety which comes from undertaking such a huge task and sit with the feeling of 'not knowing' which frequented me on many occasions both in clinical practice and analysing qualitative data. These experiences have provided me with invaluable learning about myself. I have learnt that all experience is valuable.

I have worked in Sexual Health and HIV services as a health adviser for nearly twenty years. I have also more recently completed a three-year clinical placement as a trainee Counselling Psychologist in an NHS Foundation Trust sexual health and HIV outpatient department, therefore this research is incredibly close to my heart.  During my training and whilst writing this portfolio I have been lucky enough to work therapeutically and as a researcher, with individuals who experience stigmatising conditions which are often difficult to talk about. I feel privileged to have bared witness to the courageous ability of individuals to talk to me about some of the deepest, darkest most difficult experiences of their lives, often never

previously spoken about. Without these individuals, this journey which we have shared would not have been possible and for that I am extremely grateful.

As the writing of this portfolio draws to an end, it feels important to reflect on my identity as a Counselling Psychologist both as a scientist and reflective-practitioner, attempting to understand my relationship to research has been a large part of this journey. Loyal both personally and professionally to the humanistic roots of counselling psychology, I have endeavoured throughout this portfolio to try and understand my client and participants as opposed to search for universal truths. I have done this whilst grappling with the conflict which exists between this and producing a piece of research which is deemed valid and scientific within the broader field of psychological research.

Writing this portfolio has encouraged me to think beyond the confines of the therapy room and recognise that my contribution to the field of counselling psychology should also include research and contributions to the wider society. It is this new understanding of my relationship to research which has helped me to better understand my role as a scientist-practitioner. I recognise that whilst this research sets out to honour the uniqueness of the individual and their subjective experience, which may facilitate a deeper understanding of the client who sits before me, it may only be by influencing policy development and the way in which society sees HIV that we can begin to make a change.

As a Counselling Psychologist, my main objective is to help people live the lives which they themselves desire, enabling their wellbeing and self-actualisation and placing them at the forefront of the therapy. Therefore, this research also provides some suggestions for psychological treatment models. Whilst all sections of the portfolio are informed by psychological theory I have primarily focussed on the subjective experience of individuals, placing them at the forefront of the research and therapy.  This portfolio and its accompanying title therefore acknowledges this journey as a collaborative one.

**Section A**

**Research Study**

*"I never expected to be an adult"*

*An exploration of how individuals living with PAHIV experience and make sense of reaching adulthood.*

# Abstract

Due to highly active anti-retroviral therapy (HAART) becoming available to perinatally acquired HIV positive (PAHIV+) individuals early in their lives, they were given the opportunity to live much longer than those born before them, with many now reaching adulthood. Literature suggests PAHIV positive adults may have faced stressors which increase chances of developing mental health problems for example, familial death, family disruption, stigma and negative environmental characteristics. Additionally, PAHIV+ adults live with the knowledge they have a sexually transmissible infection, even if they have never had sex, suggesting the chance of unique psychological challenges for this cohort. Semi-structured interviews were conducted between May and June 2015 with 8 PAHIV+ participant's (five females, three males) aged 23 – 29 years, who attend an HIV charitable organisation. Interviews were analysed utilising Interpretative Phenomenological Analysis (IPA). This research aimed to illuminate and make sense of PAHIV+ individual's experience of reaching adulthood. One overarching theme; 'Evolving journey' and five super-ordinate themes; 'The changing responsibility of self', 'Reflecting on a difficult childhood', 'The stigma barrier', 'Development of sense of self' and 'Managing uncertainty' were found. An interpretation of the participant's experience is presented in the final analysis. These findings have important implications for all HCP's supporting the psychosocial needs of PAHIV+ adults. Applicability of findings to the field of Counselling Psychology and considerations for future research are considered.

# Introduction 1.0

## 1.1 Overview of chapter

Carrying out this critical literature review has been an on-going and cyclical process. Since initially reviewing the literature in 2013 several papers have been published exploring some of the different experiences of adults living with perinatally acquired human immunodeficiency virus (PAHIV), suggesting a possible growth of interest in the topic area. Therefore, I have continuously revisited this chapter to ensure it includes, to the best of my knowledge, the most recent and relevant published research.

This chapter explores existing literature and ways of conceptualising the experience of people living with PAHIV. I will introduce PAHIV and consider the implications for those living with the condition, with a focus on adulthood followed by a review of literature findings relating to the implications highlighted. I will introduce some of the main voices in the field and focus on any consensus drawn from the years of research in areas of the subject where debate has arisen. How the studies were carried out and any limitations will be critically evaluated. Any opposing positions or areas within the topic which represent a gap in knowledge shall also be explored.

This is a broad subject area with a plethora of literature focusing on PAHIV in children and adolescence. Studies in this section describing the experience of childhood and adolescents are only included in this paper where necessary to provide insight into the past lives of adults living with PAHIV. Studies published within the last five years will be focused on more closely than those published previously. I have made this decision because in the last five years the number of individuals living with PAHIV who have reached adulthood has grown significantly. Therefore, older research is only included where relevant and important in providing a backdrop to this developmental stage. I aim to present only literature relevant to the research topic in an accurate and concise way. While it is important to include some broader topics, I will not be too broad in my peripheral inclusion, to reduce the risk of the more salient points of this review being lost (Cooper, 1988).

Following a general search, a more counselling-psychology-specific-review of the literature was carried out. No published articles focussing on PAHIV were found. This apparent lack of research published in counselling psychology journals focussing on PAHIV and adulthood may reflect that this is a relatively new phenomenon. It may also reflect that psychological research into this cohort has been predominantly grounded in positivism (Christianson,

Lalos, Westman & Johansson, 2007, Bakeera- Kitaka, Nabukeera-Barungi, Nostlinger, Addy & Colebunders, 2008 & Fielden et al. 2006). Due to the paucity of qualitative research in this topic area, those studies found will be given more attention and consideration as they provide a different type of knowledge. Finally, a summary of findings, how this research aims to contribute to the field of Counselling Psychology and an introduction to the current study is discussed.

## 1.2 Background and setting the scene

"We never expected these babies to live. They were certainly not meant to survive adolescence" (Melvin, 2012)

Human Immunodeficiency Virus (HIV) was first recognised in 1981 (Avert UK, 2011) and was described in the literature as something which was predominantly placing gay men and intravenous drug users as the group most 'at risk' (Woodring, Cancelli, Ponterotto & Keitel, 2005). However, cases amongst heterosexual populations in all countries were reported by 1983 (Bor, Miller, & Goldman, 1993) with the first paediatric AIDS patient described in the literature two years after that (Oleske et al., 1983). The number of children and family's HIV has impacted thus grew exponentially (Monahan, 1994; Roth, Siegel & Black, 1994).

Prior to the availability of anti-retroviral treatment (ART) in Europe, half of all children infected with HIV were dead by their tenth birthday (Gray, Newell, Thorne, Peckham & Levy, 2001). In 1996 the introduction of highly active antiretroviral therapy (HAART) meant a significant increase in adult life expectancy in high income countries (Antiretroviral Therapy Cohort Collaboration, 2008; Bhaskaran et al., 2008). Additionally, for children born with perinatally acquired HIV (PAHIV), where HAART was available, a significant reduction in HIV associated morbidity and mortality began (Gibb et al., 2003; Gortmaker et al., 2001; Judd et al., 2007).

By the end of June 2015, a total of 1,934 children had been reported to the Collaborative HIV Paediatric Study (Collaborative HIV Paediatric Study [CHIPS], n.d.), a study consisting of virtually all patients receiving HIV-related care in the United Kingdom (UK) and Ireland from 2006 onwards.  From this number, 110 children had died and 708 had left paediatric care for adult services, transitioning at a median age of 17.5 years. Of the 1,934 children 979 in total remain alive and in active follow up at a clinic in the UK or Ireland, with 53% reported

as female, 50% born in the UK or Ireland, 78% of Black African ethnicity and 48 % of these children attending a clinic in London. Almost all children (93%) were known to have contracted HIV through Mother to Child Transmission (MTCT). Reduced rates of MTCT due to the advent of HAART, HIV antenatal testing, and other interventions has led to the dramatic decline of perinatal HIV transmission in high income countries (Centers for Disease Control and Prevention, 2007).

The number of children reported to CHIPS is thus declining, partly due to fewer new diagnoses and partly due to the number that have transitioned to adult care.  In the year 2000 the median age of children being followed up in CHIPS was 7 years which increased to 17 years by 2014 with the number of children 15 years and over rising from 4% in 2000 to 65% in 2014 (CHIPS, n.d.). These figures illustrate that individuals living with PAHIV in the UK are mostly now older adolescents or young adults.

These individuals are an extraordinary demographic, born during the few years where HAART was not available to reduce the risk of HIV MTCT, but where it became available after they were born, giving them the chance of survival, for some into adulthood. The opportunity to gain experience of working therapeutically with this small cohort will thus remain slim therefore, illuminating their lived experiences may be particularly important to facilitate Counselling Psychologists treating this adult cohort.

These young people infected with HIV as children were originally not expected to reach adulthood thus presenting unique challenges to health care professionals (Boudrea & Fisher, 2012). Whilst treatment outcomes for these individuals has greatly improved, issues similar to those living with other chronic illnesses have been highlighted, including adherence to treatment, quality of life, and disclosure (Melvin, 1999).

PAHIV+ individuals are sometimes described as a "hidden population" (Bell et al., 2003; CHIPS, n.d.; Fielden et al., 2006), or as part of a generation long forgotten, with minimal research exploring the psychological and social impact of living with this condition (Green & Smith, 2004; Thorne et al., 2002). Whilst from a Counselling Psychology perspective I aim to explore more closely the qualitative literature focussing on individuals' subjective experience, and psychological implications of living with PAHIV, the treatment and medical implications for these individuals is also important to contextualise their experience of growing up. I shall therefore briefly discuss the medical background and implications of treatment and adherence, to provide a much-needed backdrop. All research however, is presented holding

in mind the humanistic roots of Counselling Psychology, as I search for an understanding into the lives of PAHIV+ individuals as opposed to humanistic truths (Rafalin, 2010).

PHIV+ adults are at high risk of multiclass antiretroviral drug resistance and treatment failure for a variety of reasons including; early exposure to Anti-retroviral's (ARV's) at birth to prevent possible infection (if mother was aware of HIV diagnosis at birth) (Fogel et al., 2013); previously limited choice of approved paediatric formulations and ARV's for children; and a long history of suboptimal mono and dual therapy regimens (de Mulder et al., 2012; Hansudewechakul et al., 2010) with risk of treatment failures (Sohn & Hazra, 2013). With HIV often diagnosed in infancy and ART introduced, treatment regimens began much earlier than for their horizontally infected peers (Bush-Parker, 2000). We are currently experiencing a new phase in the global HIV paediatric epidemic as children taking HAART reach adulthood.

Increasing non-adherence amongst PAHIV+ youth as they get older has been reported in line with other chronic illnesses (Wiener, Riekert, Ryder & Wood et al., 2004; Koenig, Nesheim & Abramowitz, 2011; Kahana, Rohan, Allison, Frazier & Drotar, 2013; Holmbeck, Bauman, Essner, Kelly, Zebracki, 2010; Agwu & Fairlie, 2013). HAART drug resistance is the main concern with non-adherence to treatment (Koenig, Nesheim & Abramowitz, 2011) compromising drug efficacy and causing treatment to fail. Recent research suggests that PAHIV+ adolescents have poorer health outcomes than HIV infected adults (Bundock, Fidler, Clarke, Holmes-Walker, Farrell, McDonald, Tudor-Williams & Foster, 2011).

Factors which may affect adherence for PAHIV+ adolescents and young people include, cognitive functioning (Laughton, Cornell, Boivin, & Van Rie, 2013) mental health problems (Mellins & Malee, 2013 & Mellins, Tassiopoulos, Malee, Moscicki, Patton, Smith, Usitalo, Allison, Van Dyke, Seage, 2011) and individual behavioural and psychological factors. These may include the perceived level of difficulty in medication routine (Chandwani et al., 2012); depression (Kacanek et al., 2015; Kang, Delzell, Chhabra, & Oberdorfer, 2015; Sheth et al., 2015); substance use (Chandwani et al., 2012); lower treatment self-efficacy (Kang et al., 2015; Rudy, Murphy, Harris, Muenz, & Ellen, 2009); negative treatment outcome expectancies (Rudy et al., 2009); and forgetting to take medication (Chandwani et al., 2012). Side effects have also been identified as an additional reason for poor medication adherence (Macdonell, Naar-King, Murphy, Parsons, & Huszti (2011). Sohn and Hazra

(2013) describe individuals living with PAHIV, infected before their immune systems had been developed as a "highly unique patient subpopulation" (pg. 6), they also suggest a current lack of understanding regarding the consequences of life long HIV and HAART for PAHIV+ individuals. Lindsey, Bosch, Rudy and Flynn (2009) argue that adherence patterns are set in childhood but continue into adulthood. Whilst HIV treatment and good medication adherence is integral to the physical survival of HIV, good psychological health can also reduce problems with adherence (Mellins & Malee, 2013).

## 1.3 Theoretical concepts

From a review of various literature, four main theories have been found which may help conceptualise the experience of adults living with PAHIV; identity, biographical disruption, stigma and Erikson's model of psychosocial stages (Erikson, 1956). Whilst a thorough examination of these theories is beyond the scope of this research, a brief overview of each of them in relation to adults living with PAHIV will be discussed.

### 1.3.1 Identity

Identity theory was discussed by Mead (1934) when he described an individual's identity as consisting of both the 'I' and the 'me'. The 'I' constituting who we are personally, the 'me' as the attitudes towards the self, the perceptions of others and that of the wider society.  Mead (1934) contends that this, along with one's sense of self, which arises from personal and social experiences, constitute our identity. Following this, Erikson (1956) postulated that identity is a process located within the "core of the individual" whilst also located within the "core of one's communal culture" (p. 22). Thus, identity is developed internally within the individual but moulded and altered through an individual's interaction with society.

Young people differ from adults; by definition they still have their youth.  How identity is affected by age has been heavily researched (Myers, 1995). The development of identity in young people was described as a vital task that individuals must undertake (Erikson, 1959; 1980).

Kroger (2004) extends this theory of development beyond childhood and adolescence, suggesting it is an on-going and continuous process throughout life. He postulates that

identity is still in the process of being formed during the transition between childhood and adolescence and is thus incomplete. He suggests if identity has not yet fully developed, a major life event or significant experience during this period could have a serious impact upon the young person. For those discovering they have a lifelong stigmatising illness like HIV in adolescence this could therefore have a profound effect.

How chronic illness impacts identity is explored by Charmaz (1995), she suggests some aspects of an individual's identity may remain the same, whilst other parts can be lost or added. Thus, through this process of redefining your identity, a term coined by Corbin & Strauss (1987) occurs, called partial identity-transformation. This argument suggests that identity can be changed through experiences, as opposed to being fixed. An individual's identity could therefore be disrupted by being told their HIV status, disrupting how they see the past, present and future, whilst also how they see the 'I' and 'me' part of themselves, especially with the stigma attached to HIV.

### 1.3.2 Biographical disruption and critical moments

This 'critical moment' in a young person's biography of discovering their HIV status can also be understood through the conceptual framework of 'Biographical Disruption', a term coined by Bury (1982). Having a chronic illness is characterised by Bury (1982) through suffering, pain and the possibility of death, something which for young people is usually a distant possibility or something which happens to others. Thus, for young people, their plans and expectations for the future may have to be reconsidered as HIV disrupts their sense of autonomy, continuity, control and meaning in life. HIV's potential to radically alter and disrupt a young person's path in life and their future plans is also explored by Hosek, Harper, & Robinson (2002); Tewksbury & McGaughey (1998); Wilson (2007).

Critical moments are described as an important part of a young person's biography and can be either positive or negative; within or outside of one's control, the latter more closely associated with negative critical moments involving events like illness (Thomson et al., 2002). The experience of finding out a HIV diagnosis could therefore be described as a critical moment which is out of a young person's control, with the potential impact far reaching and on-going.

The theoretical concept of biographical disruption has been developed and applied to a few HIV adult studies (Carricaburu & Pierret, 1995; Ciambrone, 2001; Wilson, 2007) and one PhD thesis found which specifically focussed on biographical disruption and young people living with PAHIV (Dorrell, 2009). Dixon-Woods, Young, & Heney (2002) also argue its relevance to children and young people.

### 1.3.3 Stigma

Stigma literature is characterised by a lack of clarification regarding how to define this concept (Link & Phelan, 2001). Some researchers adopt the dictionary's definition as a mark or blemish of one's reputation (Reber, 1995), others reference Goffman's definition of stigma as an undesirable difference that undermines a person's identity (Goffman, 1963). Furthermore, whilst Goffman described stigma as the product of a "relationship between attribute and stereotype" (Goffman, p. 4), many researchers do not include his language of relationships and instead have regarded stigma as an individual attribute that is by default socially undesirable. Researchers have therefore been inclined to ignore the roles of individuals, others and social groups in connecting an attribute to a negative stereotype and deliberately discriminating against its carriers (Link & Phelan, 2001).

The delineation between targets and sources of stigmatisation are therefore obscured by this conceptualisation which fails to distinguish between enacted and felt stigma. This prohibits the recognition that targets and sources of stigma are situated within a social context and that enacted stigma is a way of creating and replicating existing social hierarchies. Parker & Aggleton (2003) suggest, that negotiating or resisting the experience of felt stigma is a way of challenging such hierarchies.

The way individuals respond to stigma has been coined 'self- stigma' (Pryor, Reeder Yeadon & Hesson-McInnis, 2004) and is described to manifest as three primary beliefs; anticipated; enacted; and internalised stigma (Earnshaw & Chaudoir, 2009). Anticipated stigma refers to individuals anticipating social rejection or being the target of discrimination; enacted stigma, involves individuals experiencing direct discrimination; and internalised stigma, where individuals feel self-loathing or shame because of stigma. Scambler (2004) extends this, suggesting there is also 'felt' stigma, the associated shame of living with the attribute and or the fear of being the recipient of enacted stigma. Enacted stigma is also described as the direct experience of discrimination including violence and exclusion toward people living with

HIV (Herek, Capitanio, & Widaman, 2002; Nyblade, 2006). The distinction between enacted and felt stigma is essential in understanding stigma layering (Scambler, 2004), the experience of multiple stigmatising statuses running concurrently, which is largely overlooked in the literature. Stigma related to HIV is also accentuated because it is often 'layered' upon other stigmas linked to drug use, homosexuality and promiscuity.

Goffman (1963) also suggests the experience of stigma differs depending on whether the individual's stigmatised attribute is concealable or not, defining predominantly visible stigma's (gender, race, physical disability etc.) as *discredited* and stigmas predominantly concealable as *discreditable* for example mental illness or HIV. Whilst HIV may be considered a concealable stigma, disease progression causing physical symptoms may reveal visible signs of being HIV+, rendering stigma as *discredited* for those individuals (Stutterheim et al., 2011). Goffman (1963) also described stigma as a type of 'spoiled identity', occurring when an individual or group hold a certain characteristic or attribute which is seen in society by others as an 'undesirable difference'.

### 1.3.4 Erikson's psychosocial stages

Erikson postulated that at each stage of development a crisis occurs. The nature of these crises is described as psychosocial involving the psychological needs of the individual, conflicting with societal needs (Erikson, 1963). A health personality thus results from successful completion of each stage. If a stage is not completed successfully it is suggested that further stages may in turn be more difficult to resolve resulting in an unhealthier personality and sense of self. These stages however can be revisited and reworked at a late time in life.

The conflict in adolescence to be resolved is 'identity vs role confusion', resolution involves synthesising past present and future possibilities into one's clearer sense of self. Adolescents ask themselves the questions Who am I as an individual? What will I do with my life? What are my beliefs about things? Erikson coined this quest to define one's self in adolescence a search for 'identity'. Failure to refine one's sense of self at this stage is suggested to result in confusion regarding who they are.

Prominent issues which might impact PAHIV+ adults will now be discussed, holding in mind the challenges these may also raise for Counselling Psychologists working with this cohort. Whilst presented as individual sections they often overlap and inter-relate. The decision to include and omit certain literature is based on its relevance to my research question and my experience working in the field of HIV.

## 1.4 Review of current literature

### 1.4.1 Psychological impact of living with HIV

Since the HIV epidemic began it has been recognised that individuals living with HIV/AIDS risk significant psychological sequelae (Catalan, Burgess, & Klimes, 1995; Catalan, Meadows, & Douzenis, 2000; Citron, Brouillette, & Beckett, 2005). With the introduction of HAART, psychological morbidity has changed (Catalan et al., 2000) however recent research from Australia (Edmiston, Passmore, Smith, & Petoumenos, 2015) and Canada (Kendall et al., 2014) suggest that HIV's most common co-morbidity remains mental health problems.

Born at a time when HIV treatment was often suboptimal, some PAHIV+ adults may have experienced active neurotropic and neuroinflammatory HIV disease. Neurocognitive deficits and the knock on psychosocial impact of this may include, extensive hospital visits and admissions, potential near death experiences, missed education and missed opportunities to integrate with others socially as well as delayed puberty. The potential impact on the mental health of these individuals as they grow, even with a reconstituted immune system, could reduce their chances of completing school, getting a job, having relationships and living an independent and autonomous life (Wiener, Mellins, Marhefka, & Battles, 2007).

Throughout their childhood and adolescent years PAHIV+ individuals may have faced increasing stressors causing mental health problems including developmental and neurological disabilities related to HIV (Chiriboga, Fleishman, Champion, Gaye-Robinson, & Abrams, 2005; Nozyce et al., 2006), experienced familial death, family disruption, stigma, negative environmental characteristics (Kang, Mellins, Ng, Robinson, & Abrams, 2008; Havens & Mellins, 2008), multiple bereavements and compromised health, both for themselves and family members (Brown, Lourie, & Pao, 2000). Stressors shared with individuals experiencing other chronic illnesses include hospitalisation, ongoing medical

treatment, sheltered life experiences and exposure to pain (Gortmaker, Walker, Weitzman, & Sobol, 1990; Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Wallander & Varni, 1998). Other experiences may include multiple caretaking, transitions growing up due to illness, family disruption or family bereavement and loss (Havens & Mellins, 2008). Additionally, PAHIV+ adults live with the knowledge they have a highly stigmatised and sexually transmissible infection, even if they have never had sex, suggesting the chance of unique psychosocial challenges for this cohort (Mellins & Malee, 2013).

A review of the literature on mental health functioning of PAHIV+ young people (Mellins & Malee (2013), found from 38 papers (the majority from Europe and the United States) that young people experience both emotional and behavioral problems including psychiatric disorders at higher than expected rates for the general population and even other groups at high risk. They also acknowledge that this may not always be attributed to being HIV positive. Both PAHIV+ and PAHIV- cohorts appear to be experiencing similarly high levels of psychiatric problems with some studies showing PAHIV- youth living in HIV affected households, with either similar or sometimes higher rates of mental health problems compared to their positive peers. It seems paediatric HIV infection *per se* may not always be the primary mechanism for such mental health problems. This review also suggests that research to date has focused on identifying risks instead of positive attributes which may help to provide ideas for preventative interventions.  It recommends that developing and evaluating mental health preventions and interventions are needed urgently for mental health to be optimized, for PAHIV+ individuals living in low to middle income countries.

A recent quantitative study examined mental health problems in HIV+ adolescents accessing HIV care in Johannesburg (Woollett, Cluver, Bandeira & Brahmbhatt, 2017). A total of 343 adolescents with either PAHIV or early acquired HIV infection and 4 participants with horizontally acquired HIV infection aged 13-19 accessing 5 clinics for clinical care were recruited. Standardised measures for anxiety, depression, PTSD and suicidality were administered. Using Statistico v13 Bivariate and Multivariate analysis was conducted for all variables.

Findings revealed 27% of the sample was symptomatic for anxiety and depression or PTSD, 24% showed signs of suicidality and 5% reported attempting suicide in the previous month. Suicidality rates in South Africa tend to increase during adolescence due to the accumulation

of adverse childhood events (Cluver, Orkin, Boyes & Sherr, 2015). Living with HIV in adolescence therefore appears to be a predictor for mental health problems. These findings suggest mental health problems need to be identified and efforts to treat adolescents must improve before individuals reach adulthood. Findings may not be generalizable to adolescents in other contexts due to convenience sampling of participants in an urban healthcare setting. These settings provide superior care to adolescents which most do not have access to, thus suggesting problems may be worse than reported in this study. Again, psychological measures across cultures should be interpreted with caution. No HIV negative control group was included in this study to compare the role of mental health problems to. Finally, this study acknowledges that within this context, identifying route of HIV transmission is often hard, thus those identified as being perinatally infected may in fact not have been. The research question this study set out to answer was specifically focussed on investigating the common MHP's experienced by PAHIV+ individuals in Johannesburg; depression, anxiety, PTSD and suicidality. Due to the narrow focus of this question, the study is unable to capture if any other MHP's may exist or any other factors which may contribute to the development and on-going mental health problems experienced within this cohort. Some mental health problems therefore appear evident from these findings but only the ones specifically being investigated. Also, this research doesn't tell us why they are happening or how each participant experiences these problems.

A quantitative study carried out in New York in a sample of PAHIV+ and perinatally HIV-exposed but uninfected (PHEU) youth, examined the co-occurrence of mental health problems, sexual and drug use behaviours and (for the PAHIV+ youth), non-adherence to ART (Mellins et al., 2011). A total of 349 participants were recruited who were enrolled in the Adolescent Master Protocol (AMP) of Paediatric HIV/AIDS Cohort Study (PHACS). AMP is an on-going cohort study which examines the impact of ART and HIV on behavioural, health and neuropsychological outcomes in adolescents and older children. Participants aged between 10-16 years were recruited between 2007 and 2010. A variety of measures were employed to measure the behavioural health risks being investigated including the Behaviour Assessment System for Children, Second Edition (BASC-2) and Adolescent Sexual Behaviour Assessment (ASBA) via an audio-computer assisted self-interview (ACASI). The criteria for at least one behavioural health risk was met by almost half the participants. A total of 28% of participants met the criteria for a mental health problem, 16% for the behavioural risk of sexual activity and substance use. For those sexually active unprotected sex was reported by 50% of PHEU and 65% of PAHIV+ youth. Non-adherence to ART was reported by 34% of the PAHIV+ participants with 45% of these with a detectable

HIV RNA. At least two behavioural health risks were reported by 16% of PAHIV+ and 11% PHEU youth. Being older, not HIV status, was linked with 2 or more behavioural health risks versus none. Detectable viral load and living with their birth mother as opposed to another care giver was found to be linked with co-occurrence of behavioural health risks.

These important findings suggest that both PAIHV+ and PHEU youth have behavioural health risks, which include MHP's; these rise as participants age. It highlights the importance of prevention and treatment efforts to be targeted by service systems. However, this study is difficult to compare to other studies due to the different measures and criteria employed. This is a convenience sample and most participants had been recruited for previous studies. Participants more likely to attend the clinic or better supervised by caregivers may have also been recruited and therefore the number of individuals not adhering to their HIV ART or taking sexual and drug use risks may be underestimated. Limitations include; some demographic differences existing between the two groups and other differences which may not have been accounted for; the mean age of participants was 12 years, thus possibly accounting for lower levels of behavioural risk as they had not yet reached adolescence; and due to the younger age of participant's psychiatric disorders, which typically emerge later in adolescence, may not yet be present in this sample. These participants also reported heterosexual relationships and may not be representative of those in same sex relationships. This young sample size has implications for generalisablity across an older cohort of PAHIV+ individuals who are more likely to experience these behavioural health risks. Further research in an older cohort would also be valuable. This study doesn't identify specific psychosocial mediators in older youth which could be targeted by interventions. This research question only examined certain behavioural health risks, therefore provides no information on other possible behavioural health risks this cohort may encounter.

A multicentre audit revealed the mortality rates of PAHIV+ individuals following transfer from paediatric to adult care services (Fish, Judd, Jungmann, O'Leary & Foster, 2013). This was carried out to establish the number of deaths and associated factors as mortality in young people with PAHIV had not previously been characterised in the UK. Fourteen clinics caring for a total of 248 adults with PAHIV reported a total of 11 deaths. The median age at transfer to adult services was 17, with the median age at death of 21 years. Cause of death was reported as advanced disease (7), Bronchiectasis (1) and suicide (2), with one cause of death missing. Poor adherence to ART had been reported by paediatric care for 9 participants which had continued through into their adult care. A median CD4 count of 24

cells was reported at time of death, 5 patients were currently talking ART but only two had an undetectable viral load. Whilst 8 participants experienced ART resistance, suppressive ART regimens were potentially still available. Overwhelmingly 9 out of the 11 had a mental health diagnosis.

The research question in this audit set out to identify the cause of death in PAHIV+ individuals who had transitioned to adult services. Findings provide important evidence that this cohort experience serious psychosocial and medical issues which have led to their untimely death, and raises the importance of good mental health support and the need for novel adherence interventions. However, it doesn't tell us why these individuals have experienced these mental health and adherence problems and what this was like for them. Further qualitative research with PAHIV+ individuals who have been close to death but survived would help illuminate this experience.

A recent quantitative study on adolescents aged 13 – 21 years living with PAHIV examined negative life time events (Lewis et al., 2015). Participants with PAHIV reported high levels of negative life events (NLE), on average 10 lifetime negative events were reported with 5 occurring within the last year. The most frequent NLE's reported for both the past year and life time included school problems, community violence and disruption to the family due to illness and death, in line with previous research (Elliott-DeSorbo, Martin, & Wolters, 2009; Martinez, Hosek, & Carleton, 2009; Murphy, Moscicki, Vermund, Muenz, & Adolescent Medicine HIV/AIDS Research Network, 2000). Out of the 166 participants in this study 59.6% were identified as contracting HIV perinatally. PAHIV+ participants were significantly more likely to have problems relating to school compared to their horizontally infected peers, possibly due to frequent illness, hospitalisations, the impact of lifetime treatment and growing up with stigma. In this sample, the prevalence of moderate to severe depression was 13.8%. This was higher than 7.3% prevalence reported for mood disorders in PAHIV+ children and adolescents in a study by Mellins et al., (2009).

There are several limitations of this present study (see Lewis et al., 2015), and again when considering this study in relation to others, these studies are difficult to compare as they are often cross sectional, comprise of different age ranges, ethnicities, genders, route of HIV transmission and differing types of measures for depression and other diagnoses, including self-reported data which may be subject to self-enhancement bias. Participants are often

accessing medical care and have been chosen to participate by care providers, with dropout rates not recorded. Therefore, insights into those not accessing care or those not chosen by their care providers is limited. Again, individuals' subjective experience of living with PAHIV is evidently missing and the importance of deconstructing diagnosis when working with these individuals is highlighted. This research question also examines negative lifetime events only and provides no understanding into the possibility of positive events and resilience.

Daily hassles were also reported frequently within the study, with the most common ones including; trying to get good academic grades, the need for food and uncertainty regarding their plans for the future. These daily hassles caused the greatest levels of depression amongst participants in this study, underlining that daily worry experienced by these young people can also contribute to their overall poor mental health in similar ways to one-off NLE's (Lewis et al., 2015). The importance of not assuming the causes of depression is therefore highlighted and the need for further qualitative research to approach these issues and enhance this quantitative approach is evident.

### 1.4.2 Disclosure

HIV disclosure is a significant issue for all PAHIV positive individuals, closely linked to their psychological well-being and how they manage their condition (Hays et al., 1993; Holt et al., 1998; Levy et al., 1999). Advantages and disadvantages of telling a child they have HIV and at what age this should be done, as well as exploring the impact on their mental health and psychological adjustment is explored across a variety of studies (Lesch et al., 2007; Mellins et al., 2002; Murphy, 2008; Wiener et al., 2007). As children with access to ART have grown up, HIV has changed from an acute terminal illness to a more manageable chronic condition (De Martino et al., 2000; Foster & Lyall, 2005) resulting in them living longer with better health beyond childhood and into adulthood.

With the complexity of contemporary HIV treatment and the requirement of good adherence (Brown et al., 2000; Chesney, 2003; Dorrell & Katz, 2013) to reduce the risk of drug resistance and maximise efficacy (Giacomet et al., 2003; Naar-King et al., 2006; World health Organisation [WHO], 2011), disclosure to young people regarding their HIV status has become more urgent in recent times. Participation in their own decision making, benefits young people both emotionally and physically (Krauss et al., 2013; Naar-King et al., 2006), with carefully planned HIV disclosure positively linked to self-confidence and good social

support, suggested as important for decreased problem behaviour and long term survival (Battles & Wiener, 2002; Ferris et al., 2007; Lam, Naar-King & Wright, 2007).

Disclosure to these individuals has therefore been highlighted by clinicians as increasingly important, making sure they understand their condition and having the correct knowledge as they become more independent, sexually active and more likely to start engaging in behaviours considered to be risky (Ledlie, 2001; Prime, 2004). It is also important to recognise that an individual's understanding of the meaning of disclosure may vary (Siu et al., 2012).

Whilst similarities exist between children with HIV and other chronic illnesses regarding disclosure (Lee & Rotheram-Borus, 2002; Wiener & Battles, 2006; Wiener et al., 2007) compared to children living with cancer and other conditions, children living with HIV are less likely to be told (Lesch et al., 2007). This is attributed to adults' fear of stigma and negative impact on family dynamics (Fielden et al., 2006; Lyon & D'Angelo, 2006). Feeling guilty, the fear of being rejected and blamed, feeling ill-equipped to cope with the emotional impact of disclosure and the potential distress caused to the child were all reported by parents of HIV+ children (Fielden et al., 2006; Wiener et al., 2007). This suggests the existence of complex issues surrounding PAHIV+ adult's past experiences of finding out their HIV diagnosis.

In a recent qualitative study (Dorrell & Katz, 2013) on PAHIV+ individuals, the process of disclosure was found to be a defining moment in their illness trajectory. Findings suggested that whilst some participants were told about their HIV status directly, others found out by accident and of those who were directly informed, a third already thought they suffered from a serious health condition. Others reported guessing or knowing their HIV status before formal disclosure. Participants described feeling worried about their health but failed to initiate conversations with adults regarding their concerns. Participants believed that family members may not have discussed HIV with them, possibly due to their own personal circumstances. This study suggests that participants waited in silence, felt isolated as children and when they did discover their diagnosis, were told to keep quiet because of stigma. These participants were born with HIV at a time when they were not expected to live into adulthood, therefore parents may have developed stories to protect their children, without considering a longer-term view.

This research by Dorrell and Katz (2013) has some limitations. Only one individual researcher carried out the analysis with no peer review, utilising a computer software programme Nvivo. To add rigour to qualitative research it has been suggested that using computer software for data analysis can help (Richards & Richards, 1991). Whilst the search facility in NVivo has been seen to aid accuracy when interrogating the data, one drawback outlined by Brown et al. (1990) is that interrogation of the text in detail is more difficult, due to the way participant's may express similar experiences in different ways, with the use of multiple synonyms, leading to retrieval of only some of the data. Therefore, whilst adding rigour by searching for certain instances that occur, it is suggested that this is done in conjunction with a manual approach which is more thorough (Welsh, 2002), not something identified as happening within this study.

Participants in this study (Dorrell & Katz, 2013) revealed to the researcher that growing up they felt the loudest voice was always heard, and that voice was never theirs. Therefore, the lack of member-checking in this study is questioned. Whilst the level of demographic details provided was good, the age range of the sample (15 – 24 years) appears broad, as there is a considerable difference in terms of developmental stages between these ages, something raised as a possible methodological limitation in another similar study discussed later (Hogwood, Campbell & Butler, 2013) and something important to consider in this current study when attempting to illuminate the experience of 'reaching' adulthood.

The description of the method used to conduct this thematic research was limited, merely describing the use of a Grounded Theory approach until saturation point was reached, with no further methodological details (Dorrell & Katz, 2013). Results, however, are described using literal enumeration. The data collected and analysed for this study was originally collected for one of the authors' PhD thesis discussed briefly earlier (Dorrell, 2009). This original research has not been published but originally caught my eye due to its title 'Growing up with HIV': Exploring the Experiences of the First Generation of Perinatally Infected Young People in the UK'. The research examines the subjective experience of young people finding out their HIV diagnosis with data analysed using thematic analysis. It adopts the concepts of biographical disruption (Bury, 1982) and 'critical moments' (Thomson et al., 2002) to examine how HIV diagnosis affects a young person's biography.

Findings from semi structured interviews of 28 young people aged 15 – 24 years suggest that HIV does disrupt their biography. Participants described how they attempted to make sense of the disruption by creating and maintaining a new identity as they became adults. This process appeared to be strongly influenced by stigma and fear of HIV disclosure, mainly managed through keeping HIV a secret and telling lies. Participants also reported little available support as they often dealt with HIV alone, causing isolation. Whilst this research has not been published, the author suggests that similar studies should be carried out to further understand these issues.

Once aware of their HIV status, PAHIV+ individuals face new challenges including whether to tell others. Two reasons previously identified in the literature regarding why adolescents find disclosing their HIV status so difficult include stigma (Dubois-Arber & Haour-Knipe, 2001; Dubois-Arber, Jeannin & Spencer, 1999) and the lack of acceptance regarding one's own HIV status, and therefore not feeling 'normal' (Suris, Michaud & Viner, 2004).

One qualitative study suggested that as adolescents with PAHIV get older and their cognitive and emotional skills develop, they may increasingly decide to disclose their status (Michaud et al., 2009). Findings from this study explored the level of disclosure and reasons why participants did or did not disclose their status amongst 12 – 20 year olds. Analysed using content analysis, results revealed out of 29 participants', 22 females and 7 males, 19 had disclosed to a good friend, 16 to some teachers and 8 had not disclosed their status to anyone outside the family. Out of the 10 participants' that identified as sexually active, 6 had disclosed to their partner.

Analysis revealed a distinction between passive and active disclosure. Passive disclosure suggested that parents/foster carers either made the decision themselves regarding whether the adolescent should disclose or made the disclosures for them. Active disclosure referred to the adolescent deciding themselves to disclose their HIV status. Increasing autonomy over disclosure appears to occur as the adolescent grows. No variation was found between older and younger adolescents regarding the extent and target of disclosure, however the study did reveal that younger adolescents living with biological parents, who wanted to reveal their HIV status, were dissuaded from doing so due to their parent's fear of stigma.

Whilst the process of disclosure differed between ages, the extent to which individuals decided to disclose their status did not differ between younger and older adolescents, thus not linked to maturation but possibly more related to family circumstances. Foster carers and adoptive parents were reported as often encouraging disclosure, whilst biological parents, especially HIV+ mothers, discouraged their children from disclosure. However, older adolescents displayed more independence regarding who to tell and when. This finding is reflected in a study by Wiener et al. (2000) which suggests that disclosure is avoided by families for fear of not only the negative impact of stigma on their child but for the entire family. The decision by many adolescents not to reveal their status may have therefore been an attempt to protect their family.

A further qualitative study (Sui et al., 2012) examined the concerns, practices and experiences of disclosure in HIV+ adolescents in Uganda, through two focus groups and interviews. This qualitative approach revealed 5 themes; meanings of disclosure, how much to disclose, positive and negative aspects of disclosure (support vs vulnerability), disclosure strategies; and disclosure patterns and perspectives: trust, autonomy and power. Whilst the study does not focus specifically on PAHIV+ individuals, it is possible due to their age, ethnicity and country of birth that some may have been vertically infected. The study provides insight into the lived experience of Black African adolescents aged 15 – 23 years living in Uganda and illuminates their perception of what HIV disclosure means to them. Participants saw disclosure as a broad concept which reaches further than telling someone your HIV status and incorporates a variety of lived experiences. These include the environment and relationship within which the disclosure occurs, suggesting the possibility of individual unique strategies being employed to disclose their status. These strategies were described as joking 'to test the waters' and emotionally preparing those they are about to disclose to, before doing it. This reflects the findings of previous research that disclosure is not a one-off event but a process (Cusick, 1999; Obermeyer, Baijal, & Pegurri, 2011). Other stand out findings included adolescent resentment of third party disclosure regarding their status by others, a longing for themselves to have control over the disclosure of their status, and that HIV should remain a family secret. This is important because one study suggests family secrets are particularly destructive (Cottle, 1980).

Literature suggests that talking about serious illness openly and honestly is beneficial to both the child and the family, emotionally and psychologically and is considered good practice because it reduces lies and secrecy (Bluebond-Langner, 1978, 1990; Chesler, Paris, &

Barbarin, 1986). Good family relationships can be damaged by keeping a diagnosis secret (Dorrell, 2009). Literature suggests better psychosocial outcomes are associated with open communication and disclosure for young people living with HIV and is positively linked with self-confidence and social support (Battles & Weiner, 2002; Rotherham-Borus, Flannery, Rice, & Lester, 2005; Wiener & Battles, 2006), further highlighting the importance of Counselling Psychology provision within this field.

An IPA study exploring the attitudes and opinions of why adolescents (13 – 19 years) with PAHIV do and don't disclose their HIV status was also found, revealing four themes which illuminated their experiences; myths and assumptions, the disclosure dilemma, fear, and lastly, keeping HIV in its place (Hogwood et al., 2013), with all participants facing problems with disclosure at some time. Myths and assumptions, either through direct experience of, or developed from how they imagined others to think about HIV were discussed by all young people as something which prevents disclosure. How they believed others think about HIV was deemed always to be negative, including beliefs about how HIV could be transmitted through toilets seats, being coughed on, kissing, shaking hands and sharing utensils. Participants beliefs had sometimes been evidenced through personal experience.

Because of these myths and assumptions, stigma was experienced not directly but through either hearing other's talk about HIV in the community, school or hearing what others had been through. Understanding and knowledge of cultural attitudes and beliefs also provided participants with this awareness regarding stigma, causing some young people to keep HIV a secret. This lack of knowledge regarding HIV was considered frustrating and the need for better education and awareness of HIV was highlighted, however whilst some young people felt able to educate others and saw this as a chance to challenge these dominant beliefs, others feared this was too risky and may reveal their own status.

Disclosure was described throughout the interviews as causing participants to feel extremely fearful, thus not something they wanted to do. However, some evidence emerged later that disclosure was, in some instances desirable and in others inevitable, but only when the time was right. This 'right time' mainly referred to future jobs, sexual or romantic relationships, getting married and having children, all experiences which growing up and getting older may bring. Expectations that peers may have, by this time, gained a better understanding of HIV also encouraged disclosure. All participants highlighted positives regarding disclosure and

described wanting others to know about their HIV status whilst simultaneously experiencing anxiety regarding how difficult this might be or had been in the past. The main difficulty being uncertainty surrounding how others might react.

When considering who to disclose their HIV status to, the length, quality and nature of the relationship and trust within it was described by most participants as an important factor, particularly in romantic or sexual relationships. A desire to disclose to friends was also described by some as they felt non-disclosure inhibited their friendships and some young people who had already disclosed found it a positive step in strengthening their relationships.

Personal fear of rejection and isolation was identified by all young people interviewed, arising from the myths and assumptions that others hold about HIV and their negative reactions, thus restricting potential disclosure. Disclosure to others, either implicitly or explicitly through attending support groups and clubs, was found to be a positive experience resulting in helpful and unique relationships developed or maintained through shared experiences. This facilitated less isolation and increased acceptance. A fear that disclosure would lead to a loss of control regarding their personal information and the reliance on others to keep their secret was identified by all young people, with much effort afforded to maintain secrecy. Concerns regarding secrecy were also present for those who had previously disclosed their status and did not decline once the disclosure had taken place.

Keeping HIV in its place was the fourth and final theme that emerged from the data in this study. Most participant's accepted HIV as something which was part of them but only a small part of their lives overall and did not feel they had to do things differently to their HIV negative peers. For some, disclosure appeared to be currently less important in their lives, for others they feared that disclosing their HIV status would mean they would be seen differently by others, which would therefore have an impact on the chances of HIV disclosure. Finally, some young people described the desire for a carefree childhood, with the recognition that the future may mean they would have to think about HIV more. Recognition that disclosure may also become more necessary and desirable in the future was also found, however for this adolescent cohort peer acceptance was simply more important during their current developmental stage. This study suggests much conflict in the

decisions regarding whether to disclose, but also the idea that this may change as you get older.

This study, whilst conducted by an individual researcher, was peer reviewed by two separate colleagues to ensure that the themes discovered were grounded in the data and interpreted realistically, which increases the validity and consumer confidence in the research. Sampling was purposive and demographic tables included. Member checking was not carried out. This paper did not provide a detailed explanation of the methodology used and the results appeared to be mainly presented as casual observations, describing participant themes as affecting either 'some' or 'all' participants with, no literal enumeration.

### 1.4.3 Stigma

Psychological research into stigma has historically examined how stigma in society manifests itself within the individual (Major & Obrien, 2005). Over time, chronic exposure to stigma-related stressors may cause the physiological stress system to activate contributing to the accumulation of 'physical costs' on the body (see Ganzel, Morris & Wethington, 2010). These responses to stigma have all been linked to not only poorer physical consequences but poorer mental health outcomes (Hatzenbuehler, Nolen – Hoeksema, & Erickson, 2008; Mak et al., 2009).

Different ways in which stigma can impact an individual are extremely important to consider and understand when working with PAHIV+ individuals, and it must be recognised that those living with chronic health problems may not access the care they need as they anticipate stigma from health workers (Earnshaw & Quinn, 2013). Participants from one qualitative study (Brinsdon, Abel & Desrosiers, 2017) talked about their fears of being discriminated against within health care settings and described both internalised and anticipated stigma. One surprising finding from this study was that some participants managed stigma by not disclosing their status to (HCP's). This finding is concerning as it is argued that for HIV+ individuals to experience optimal wellbeing, disclosure to HCP's is extremely important (Chaudoir, Fisher & Simoni, 2011). PAHIV+ individuals' past negative experiences of stigma in health care settings is an important consideration for Counselling Psychologists working in this field as they are responsible for ensuring clients do not feel stigmatised when accessing therapy. Poor medical adherence, increased drug and alcohol consumption, and poor eating behaviours were also found to be associated with enacted stigma (Pascoe & Smart,

Richman, 2009). People living with mental health problems have also been found to have poorer drug adherence when they experience internalised stigma (Eisenberg, Downs, Golberstein, & Zivin, 2009).

HIV is recognised as a highly stigmatised disease (Lee et al, 2002; Herek et al., 2002). Stigma is specifically targeted at individuals living with the illness and is strongly associated with the ignorance regarding HIV transmission, the severity of the disease, it's transmissible nature and the prejudiced attitudes towards groups in society that are disproportionately affected with the virus (Herek et al, 2002).

HIV stigma can be further conceptualised as a psychosocial stressor comprising either anticipation of negative treatment from others or the self-directed internalisation of negative attitudes held by others (Stuber, Meyer, & Link, 2008). HIV related stigma is specific to those living with the condition and has been defined by socially shared attitudes, actions or beliefs to promote and to perpetuate and devalue those infected or affected with HIV (Herek et al., 2002; Steward et al., 2008; Florom- Smith & De Santis, 2012). HIV related stigma is argued by Parker & Aggleton, (2003) to be a social process of exclusion with particular groups possessing dominant traits of control and power resulting in individual's devaluation.  They urge caution regarding a more individualistic perspective of stigma.

One quantitative study suggests that overt HIV related stigma may be in decline (Herek et al., 2002), however internalised stigma is suggested to still strongly exist causing continued psychological distress and decreased disclosure of HIV status. Furthermore, it suggests problems with long term adjustment and coping with HIV and a reduction in individuals accessing medical care, are all important aspects to consider when working therapeutically with PAHIV+ individuals. As found in adult studies (Smith, Rossetto & Peterson, 2008; Galvan, Davis, Banks & Bing, 2008; Vanable, Carey, Blair & Littlewood, 2006), the stigma experienced by young people because of their HIV status may mean negative implications involving both their physical and mental health (Havens & Mellins, 2008).

It is crucial to understand HIV related stigma in youth, as like other young people with a stigmatised condition, if their HIV status becomes public knowledge they may perceive or experience rejection and discrimination by others, causing them to withdraw (Elkington et al.,

2011; Moses, 2009; Westbrook, Bauman & Sinnar 1992). For those who don't disclose their HIV status they may internalise stigma, through self-blame and shame as they attempt to keep HIV as a secret (Swendeman et al., 2006). Accordingly, Foster, Waeblbrouck, and Peltier (2007), PAHIV+ infected young adults have different pasts and health-care needs, compared to their horizontally infected peers.

Perinatally infected young adults live with a chronic illness from birth and receive medical care from a specialist paediatric medical team, while their horizontally infected peers usually sexually active, receive care in an adult medical setting. Whilst infection routes may differ, PAHIV+ young adults and their horizontally infected peers both face the same stigma associated with HIV (Scambler, 2009). This is outlined by Herek (1999; 2002), who describes how it is often perceived by others that the bearer of HIV infection is responsible for their situation due to the mode of HIV transmission being considered voluntary or avoidable.

Young adults and adolescents living with HIV may also face a set of unique challenges further effecting how HIV related stigma impacts their adherence to care and quality of life (Steward et al., 2008; Harper et al., 2013; Hosek, Harper & Domanico, 2005; Martinez et al., 2012). These unique challenges might be exacerbated by social isolation, stigma and oppression linked to HIV and additionally their sexual orientation identity or sexual behaviour (Herek, Capitanio, & Widaman, 2002; Harper & Schneider, 2003). Being so young and experiencing such strong social stigma may also mean these individuals lack the depth, breadth or quality of support resources needed, which might be available to their uninfected peers. Therefore, young people's internalised stigma, perception of how others see them and lack of social support means they risk increasingly poor psychological health, substance misuse and reduced access to healthcare (Bruce & Harper, 2011; MacDonell et al., 2010; MacDonell et al., 2011; Nugent et al., 2010). This suggests they may also be less likely to access psychological therapy or find it more difficult.

Whilst studies exploring the experiences of stigma in adulthood are abundant (Smith, Rossetto & Peterson, 2008; Galvan, Davis, Banks & Bing, 2008; Vanable, Carey, Blair & Littlewood, 2006) those focussing on adults with PAHIV are not, with no studies on the subjective experiences of PAHIV+ adults and stigma found to date.

One study (Fielden, Chapman, & Cadell, 2011) looked at how adolescents living with PAHIV experience and manage stigma, although their experiences were mediated through HCP's. In this study, stigma was described by HCP's to perpetuate the already existing social exclusion and vulnerability of these young people with silence identified as a tool by which they manage it. Sandelowski, Lambe, and Barrosa (2004) also found silence as a way of managing the stigma and concealment of HIV.

**1.4.4 Romantic and sexual relationships**

PAHIV+ individuals not only manage stigma but also anxiety regarding HIV transmission with fear of emotional pain, loss of sexual spontaneity and freedom and a reduced sense of feeling sexually attractive (Siegel, Schrimhaw & Lekas, 2006), in addition to having to navigate their first sexual/romantic experience with the knowledge they have a sexually transmissible infection. Research into the sexual behaviours of PAHIV+ individuals has been studied, but is beyond the scope of this current research (see Renaud et al., 2013).

Fernet et al. (2011) conducted a mixed method embedded study of 18 PAHIV+ youths who had taken part in a primary qualitative study three years previous. One third of these individuals had now reached 18 years and over. The research aimed to describe youth perspectives, having lived their lives with HIV since birth, on romantic involvement, sexuality, risk management of HIV transmission and partner disclosure. Data was collected utilising self-reported measures, personal accounts and face to face semi structured interviews and analysed using Atlas software. Overall findings revealed HIV infection affected participant's sex lives. Themes arising from the interviews with those who identified as *not sexually active* at the time included; abstaining from romantic relationships and contemplating sexual relations, with the condition that the partner must be informed. For the ten who disclosed they were *sexually active* at the time of interviewing the themes were; protecting one's partner and one's self from rejection, not using a condom is tempting, transgressing, repeating and dealing with risk of losing one's lover.

These findings indicate that whilst fear of HIV transmission is a risk, the emotional risk of rejection is more prominent. Whilst individuals are motivated in initiating relationships, this is fraught with anxiety and fear regarding being rejected by a partner. This is also exasperated by the increasing number of criminal cases brought to court under Canadian Law which was also reflected on by the participants, with the risk of criminal charges of aggravated assault if

they do not disclose their HIV status. Whilst protected sex was reported at first sex by some participants, over half went on to describe future risk taking, including multiple sexual partners, sex under the influence of alcohol and drugs or whilst menstruating. An undetectable viral load and past experiences of HIV not being transmitted to partners fuelled risk taking behaviours as condoms came to represent a barrier to intimacy as opposed to a risk reduction strategy. Perception of risk therefore appears to develop over time and with experience. This research suggests that there is a need to adapt the messages about risk taking depending on the context of individual relationships. This study was undertaken in Canada which has a different criminal justice system and laws pertaining to HIV than the UK which should be held in mind when reflecting on these findings and serves as a reminder to always consider social context and individuals' subjective experiences. The emotional risk of rejection evident here is also mirrored in previous adolescent studies (Fielden et al., 2006; Hosek, Harper & Domanico (2005); Michaud et al., 2009) and may be important to hold in mind when working therapeutically with this cohort.

How individuals living with PAHIV experience intimate relationships has also been researched (Greenhalgh, Evangeli, Frize, Foster, & Fidler, 2013), considering how growing up with HIV has impacted this. Semi structured interviews were carried out with 7 participants aged 18 – 23 years. Three themes emerged from the data which was analysed using IPA; HIV being viewed by partners as linked to AIDS and sexual transmission, discrepancy between young people and their partners' views of HIV, and partner views of risk of HIV transmission. Participants personal experiences of the challenges they had faced in the past regarding HIV including stigma and disclosure appeared strongly linked to how they thought their partners may perceive them. Therefore, participant's main anxieties were regarding the fear of negative attitudes from their partners towards them. Their fear regarding the link between HIV and AIDS/death seemed to reflect participant's personal experiences of HIV education. This may, as suggested by Greenhalgh et al. (2013) be linked to the participant's frame of reference regarding HIV, and their perception of their condition, as all but one of the participants identified black ethnicity. Participants also feared in line with other research (Wiener, Battles, & Wood, 2007) that partners would believe the only route for HIV transmission was unprotected sex.

Participant's described worrying that partners would feel an overwhelming sense of concern regarding HIV transmission and the risk of dying, and decide being in a relationship with someone with HIV was too difficult. Some participants tried to educate their partners but

struggled to convey the seriousness of HIV, whilst simultaneously managing and trying to reduce partner anxieties. A balance of the two when disclosing their HIV status was suggested. This research highlights the complex nature of HIV disclosure within the context of a romantic relationship specifically in an older cohort compared to previous studies.

This research was carried out by an individual researcher but peer reviewed by experts in the field, suggesting overall enhancement of validity within this study. Whilst no member checking occurred, this was reflected on as something which would have been valuable. The description of the method used to analyse the data was limited, however this lack of detailed description across so many studies may be a reflection on the limited word count in journals where qualitative research is being published and not a negative reflection on the ability of researchers *per se.*

Previous research by Frederick et al., (2000) and Ciccarone et al., (2003) involving both adolescents and young adults living with HIV have highlighted the challenges of disclosure in the establishment and maintenance of a sexual relationship. How adolescents and young adults living with PAHIV navigate romantic relationships has been studied by Fair and Albright (2012) with disclosure proving central to participants' ability to initiate and maintain relationships. Findings suggested participant's direct experiences with others was influenced by the pressure they felt to disclose their HIV status. They also described their struggle to manage intimacy, with much anticipated worry impacting their behaviour when dating and having consequences on the outcome of their relationships.

Participants in this study often referred to their HIV status as a "secret" accompanied by the fear of rejection when shared with others. These feelings of rejection also revealed by Fernet et al., (2011) appear to steer many decisions about relationships. Fears appear because of participants past experiences of others' stigmatising attitudes and beliefs toward those living with HIV and in this study, were sometimes linked to participants own past experience of being told their HIV diagnosis. Despite this, most participants still encouraged others in their position to seek a partner. This reflects the importance of close relationships which have been shown to promote emotional and physical wellbeing, in turn reducing the effects of illness (Cohen & Wills, 1985), similar to the benefits of the close relationships in Counselling Psychology, where a strong therapeutic relationship is often considered the vehicle for change (Clarkson, 1999).

Fair and Albright (2012) describe participants as having experienced "unique challenges" (p.752) when embarking on an intimate relationship. Despite these challenges, participants demonstrate the same need for intimacy as other young adults their age. Reported rates of sexual activity in this study (71.4%) are higher than previous studies which involved adolescents (Mellins et al., 2011; Wiener et al., 2007) which may reflect the older sample size with the mean age of 20.7 years. Delaying sexual relationships was also described as a strategy employed to avoid disclosure. For those that did disclose, (40% in this study) which was also found by Dempsey, MacDonell, Naar-King, Lau, & Adolescent Medicine Trials Network for HIV/AIDS Interventions, (2012), disclosure did not always ensure safer sexual practices.

This research was conducted by two authors who independently analysed the data and then came together to form a consensus regarding themes which increase the validity of this study. Whilst purposive sampling was adopted and demographics of participants clearly provided, this study provided limited descriptions of its methodological approach. Interviews were also carried out either over the phone or face to face which may have impacted the interview process. Member sampling was not included and qualitative results with no literal enumeration, mainly employing words like 'many' and 'majority' were used to define how many participants had described certain themes. However, the strong desire and need for intimacy which appears to be increasing as participants grow up were important findings.

With PAHIV+ individuals becoming sexually active and reaching child bearing age, the pro-creational intentions of this cohort are also arising, with one quantitative study of 50 PAHIV+ young people (13 – 24 years) in the United States (US) indicating 70% of participants intended to have their own children (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006). A recent qualitative study of 35 young people aged 15-30 years, identified four primary child-bearing motivations; personal fulfilment, pride, leaving a legacy, and love (Fair & Albright, 2015). An overwhelming 31 out of 35 participants described the intent to have children in the future. Challenges for this cohort included normative concerns regarding the monetary cost of having children and more specific concerns regarding parental disclosure and HIV transmission.

**1.4.5 Transitioning into adult care**

The process of transitioning into adult care from paediatric services for young people living with PAHIV has been well documented in the literature (Fair, Sullivan, Dizney & Stackpole, 2012; Bundock et al., 2011; Foster et al., 2009; Colver et al., 2013), and is defined specifically by the Department of Health (2006), suggesting the importance of addressing medical, psychosocial and educational/vocational needs of adolescents and young adults as they transfer from child to adult health care services.

One quantitative study compared the reported satisfaction surveys of health care experiences of PAHIV+ individuals who attended a transition outpatient service in the UK with young people from a diabetes transition clinic in Australia (Bundock et al.,2011). A total of 21 participants from the UK and 39 from Australia took part. Both groups had a median age of 19 years. An easy transitioning process was reported by 95% PAHIV+ participant's and 87% of Diabetic participants. A positive effect on their health, post transition, was reported by 68% PAHIV+ participant's and 72% of the Australian cohort. Over three quarters of the participants reported; being treated as an individual, being encouraged towards independence and comprehensive management explanations, as "strongly important". The findings suggest transition can be a positive event for young people whether diabetic or living with PAHIV.

This study, whilst questionnaire based and quantitative, provides findings qualitative in nature. Several limitations include; a sample size too small for the quantitative findings to be generalisable and not enough in-depth qualitative finding's to be transferable. Also, patients were not included in the study who were not attending/engaged with these services and not taking ART, who may have had different experiences of transition.

For adolescents living with PAHIV and those reaching adulthood, it is suggested they face the unknown, due to limited data on both the long-term consequences of living with HIV and additionally the long-term effects of the toxicities taking HAART. It is suggested that PAHIV+ individuals not only live with complex psychosocial issues but additionally, complex familial backgrounds, meaning some young people have become carers due to loss or illness of parents. For many PAHIV+ individuals, they live in single parent famiies and/or have experienced multiple care taking transitions and the illness or death of one or both parents (Rotheram-Borus et al., 2002; Bell & Jenkins 1993). Therefore, it is important to consider

that one of the most significant stressors linked to poor mental health outcomes is from the loss of a parent (Rutter, 1966; Kranzler, Shaffer, Wasserman & Davies, 1990).

Evidence demonstrated through a variety of systematic reviews shows that parental HIV is connected to children's psychological problems, such as anxiety, depression and post-traumatic stress (Breuer, Myer, Struthers & Joska, 2001; Sherr & Mueller, 2009; Sherr et al., 2008). Additionally, it is postulated they might have increased risk of neurocognitive impairment which may impact future opportunities (Bundock et al., 2011). Neurocognitive deficits recorded within this population may also affect relationships, education and autonomy (for further discussion see Laughton, Cornell, Boivin, & Van Rie, 2013; Smith et al., 2012; Mintz, Sharer & Civitello, 2012).

PAHIV+ young people face a range of unique physical and psychological challenges as they reach adulthood (Bundock et al., 2011). Cervia (2007) described HIV/AIDS as a disease which involves more potential complexities of transitioning than any other condition. Persson & Newman, (2012) carried out a critical analysis of the transition literature in developed countries and were concerned that the 'voices' that dominate this literature are clinicians and other service providers with an absence of the experiences of the young people themselves. Less well documented is the subjective experience of young people's journey as they transition from adolescence to adulthood. In a database search of Psych info and Psych articles on the 13th December 2016, using the search words *HIV, Adulthood, Adolescents*, in various combinations along with *Counselling Psychology, growing up, experience, perinatal, and vertical* I found no studies exploring the subjective experience of transitioning into adulthood with PAHIV.

### 1.4.6 Studies examining the lived experience of PAHIV

One Swedish, exploratory, qualitative study, using content analysis was found (Rydstrom, Ygge, Tingberg, Naver & Eriksson 2013), focussing on the experience of adulthood with innate or early acquired HIV in Sweden. Five themes revealed; protecting the self from the risk of stigma; to be in control; losses in life; but HIV is not a big deal; and healthcare professionals as an important resource when coping with HIV infection and its consequences. This study, conducted predominantly by a senior nurse, also offered empirical knowledge for health workers facilitating the care and necessary interventions of this increasing population and counselling post interview at participant's request. One ethical

concern regarding this study, was participants meeting the researcher in a coffee shop, which I feel fails to appreciate the sensitivity of the respondent and their confidentiality. This environment risks leaving patients feeling unheard and vulnerable and does not recognise the potential importance of the process to be a helpful and healing one. Also, participant's ability and honesty in answering questions may be restricted within this type of environment.

This current study will be asking a different research question and employ a different approach to analysing the data than Rydstrom et al. (2013). It will focus closely on 'reaching' adulthood, recruiting participants aged 19 and over, much older than the age of 15 which were recruited in the previous study allowing the findings to represent adults as opposed to adolescents, whose experiences may differ due to developmental differences. It will also include participants regardless of the length of time they have been engaged in services as this may be an important part of the experience of reaching adulthood.

Rydstrom et al. (2013) utilised content analysis, which aims to provide from a qualitative data set a quantitative analysis of discrete categories (Brocki & Wearden, 2006). This current study will employ IPA, focussing more closely on the narrative portrayal with the final analysis yielding a detailed interpretative analysis of themes carried out by a trainee Counselling Psychologist, therefore beginning with, but going beyond a standard thematic analysis, offering a more psychologically interpreted approach to answering the research question. Further advantages of adopting IPA will be explored in detail in the methodology chapter.

The lack of current knowledge about PAHIV+ individuals and the need for more knowledge of their 'lived experience' is also discussed in this paper. A stand out finding was that HCP's are an important resource when coping with HIV infection and its consequences with suggestions of context specific support mechanisms for helping deliver optimal care. Boudreau and Fisher (2012) also recognise these young people, now adults with greatly improved life expectancy who were never expected to reach adulthood have been given little attention, as reflected in this review.

Broader literature suggests adults with PAHIV have wide ranging, complex mental health needs (Dickey, Dew, Becker & Kingsley, 1999; Gala et al., 1992; Hedge & Sherr, 1995) and as previously discussed may have faced stressors which increase their chances of future mental health problems. It is important therefore that young people transition into good adult services (Foster et al., 2009) being treated as individuals, which was highlighted as an

important factor during this process (Bundock et al., 2011). Therefore, understanding the life world of these individuals and what it is like to belong to this unique cohort feels incredibly important.

With Rydstrom et al. (2013) focussing their research in Sweden, it is important to gain further insight of this phenomena in the UK population because findings in a UK population will give us new and important information. Living in the UK may be a completely different experience for UK residents' due to demographics, environment, stigma, society, culture, politics, different laws and many other variables. In the UK, we have different laws regarding disclosure of HIV status to sexual partners.

In Sweden law states that anyone with HIV embarking in a sexual relationship must disclose their HIV status, in the UK disclosure only 'must' occur by law if a risk of transmission takes place. Sweden use criminal law in HIV cases more stringently than almost anywhere else in the world ("Sweden's HIV sex law," 2013) which may affect the experience of those interviewed in this study and therefore reveal different experiences than those living in the UK. The first three findings of the Swedish study may have been profoundly affected by this law.

One further international qualitative study only written recently examines the lived experience of young adults living with PAHIV (Williams, 2017) Participants were mainly African American, and were recruited from the Children's National Medical Centre in Washington, USA. In depth face to face interviews were carried out with 17 participants, aged 18-24 years old, including 8 males and 9 females. Van Manen's four life world themes; Lived Space, Lived Body, Lived Time and Lived Relations were used to describe the participant's lived experiences. Four Major themes were found; limited social capital, especially when orphaned participants reflected on a life void of parental guidance; incomplete education and unemployment, participants described an idle existence; a harsh life, described as participants facing difficulties meeting their life's milestones; and unanticipated adult issues, where participants described their limited ability to care for themselves and their children. Limitations of this study include the sample recruited from, with the researchers suggesting that if they had interviewed those currently in employment or studying, more positive findings and successful life stories may have been found. This study also used a prescribed framework within which to 'fit' the themes found which suggests a less inductive approach to knowledge generation. Peer review of themes and member checking were carried out in this study increasing its rigour and validity.

**1.5 Methodological reflexivity**

Studies reviewed adopt a plethora of quantitative, qualitative and mixed method designs. Historically research into PAHIV+ individuals has been grounded in positivism but a recent increase in qualitative studies looking at the experiences of these individuals appear to be emerging, alongside a few mixed methods approaches. This variety of methodologies employed to study this cohort all contribute important findings, providing different types of knowledge, each with their own strength and limitations.

The quantitative research reviewed provides a positive approach to social science research, measuring variables precisely and testing hypothesis to see if there are cause and effect explanations. There are many strengths to these quantitative research studies including fast administration and evaluation of tests and results available in a short space of time. The numerical data which is collected with this approach aids comparison between groups of people. Data also allows the researcher to determine how much agreement/disagreement occurs between participants. (Yauch & Steudel, 2003). The quantitative research presented provides us with important figures to suggest that the psychological impact of living with PAHIV is extremely prevalent however due to the different measurements implemented across studies and cultures it often makes them difficult to compare. The strengths of a quantitative approach can also be its weakness. Individual's important characteristics, their identities, perceptions and beliefs cannot be meaningfully reduced to numbers or substantially understood without reference to the context of people's lives (Dudwick, Kuehnast, Jones & Woolcock,2006). For this reason, Dorrell, (2009) suggests further research is needed into the subjective experiences of adults living with PAHIV. This is supported by Persson & Newman (2012), who have also expressed the concern that previous research has been moderated though the voices of HCP's suggesting an absence of the experiences of PAHIV+ individuals themselves. Therefore, this research sets out to fill this gap.

The qualitative studies reviewed here allow issues to be examined in depth and detail. The complexities and subtleties revealed from participant's accounts can sometimes be a limitation with a more positivist approach. A primary strength of the qualitative literature presented is its ability to investigate underlying values, beliefs and assumptions. It is broad and open ended and allows the participant to raise what is important to them. Whilst

qualitative research is not generalisable its findings can be transferred to other settings. The quality of qualitative research relies often on the researchers' skills and can be influenced by the researchers' idiosyncrasies and bias. The assessment of rigor is more difficult to assess, maintain and demonstrate and within the studies reviewed limited word counts in qualitative journals appear to reduce the reader's opportunities to gain a deeper understanding of the methodologies used. Confidentiality and anonymity of participants can also create problems when presenting research findings meaning reduced demographic and other information is often omitted.

With quantitative fulfilling the 'if' and qualitative fulfilling the 'why' of research a few mixed methods studies which combine the two, described by Johnson & Onwuesbuzie, (2014) as the unifying research paradigm have also been reviewed. These mixed method studies adopt the strengths from both quantitative and qualitative approaches whilst attempting to minimize the limitations (Creswell, 2014). This approach can be helpful when a research question is difficult to answer by adopting a single method (Tashakkon & Teddlie, 2010). It also allows for researchers to uncover information that would have otherwise gone unnoticed or been discarded. It is also particularly well suited to research in psychology. Whilst a mixed methods approach can improve validity there are some limitations to this approach; it can be harder to carry out as it is time consuming; and it is costly, due to detailed and complex data collection. Appropriate use of a mixed methods approach can also be challenging to deliver (Bazeley, 2012). Other criticisms include the suggestion that a mixed methods approach lacks substantive focus and purpose.

Literature suggests a wide range of possible past, present and future implications for those living with PAHIV who have now reached adulthood. Past research into PAHIV has mainly focused on a more positivist and quantitative approach, guided and carried out from a medical perspective as opposed to by psychologists. Whilst this provides us with interesting insights and an important backdrop to their history, the number of new qualitative studies published looking at different subjective experiences of those living with PAHIV is extremely exciting and important, especially within the field of Counselling Psychology as their paradigms are closely linked.

Previous studies found which have explored the subjective experiences of PAHIV+ individuals and disclosure (Hogwood et al., 2012; Dorrell & Katz, 2013) and romantic relationship (Greenhalgh et al., 2013) have adopted IPA or Grounded theory and focussed on an older cohort than previously researched which is important, however they still recruit participants with ages that span different developmental stages. This current research intends to focus more closely on adulthood than the previous studies. To date, I have seen no other published studies looking at this phenomenon in the UK giving this research the opportunity to potentially be the first. Therefore, my research question is:

*'How do individuals living with PAHIV experience and make sense of reaching adulthood?'*

### 1.6 Contribution to Counselling Psychology

As touched on above, no studies have been found to date examining PAHIV in counselling psychology journals. A search carried out in the Counselling Psychology Review, found one recent study focussing on the experience of post traumatic growth in individuals diagnosed with HIV (Amos, 2015) and one qualitative study (Lawrence & Cross, 2013) exploring the lived experience of the first ageing cohort living with HIV, a similarly new phenomenon in the field of HIV to this current study. These publications provide in depth understandings of individual experiences of HIV, and offer suggestions for appropriate psychological models when working with these individuals. These studies support the argument that this current research is sufficiently relevant to the field of Counselling Psychology, with the aim of informing both therapeutic practice and extending the forefront of the discipline.

Counselling Psychology recognises clients individual complexities, in particular the relationship that the client has with themselves, between themselves and their world and between themselves and a Counselling Psychologist.

Level three, of the *Standards for psychological support for adults living with HIV* (British Psychological Society, British HIV Association & Medical Foundation for AIDS & Sexual Health, 2011), suggest that psychological support should be delivered by qualified, professionally registered practitioners in counselling and psychological therapies. These standards are not prescriptive with regards to which specific models should be used to treat psychological problems, however they do outline that skilled practitioners with the appropriate training, who have achieved the necessary competencies, should be treating

individuals who require psychological support (Health Care Professions Council (HCPC), 2015; HCPC, 2016; Royal College of Psychiatrists & Royal College of General Practitioners, 2008; Department of Health (DOH), 2004; DH, 2010). Counselling Psychology itself is characterised by a humanistic ideology described by Lane and Corrie (2006) as "…*respect for the personal, subjective experience of the client over and above notions of diagnosis, assessment and treatment*" (p.17) and is therefore extremely well placed to work with PAHIV+ adults.

## 1.7 Introduction to current study

By investigating the phenomenon of what it is like to reach adulthood whilst living with PAHIV, this research may help illuminate the relationship the individual has between themselves and the world as they experience it. This research aims to fill the current gap in the literature. Also by adopting IPA data will be psychologically interpreted which aims to inform Counselling Psychologist's working with this emerging cohort. As outlined, due to the current lack of data regarding the long term complications of living with PAHIV and the toxicities from HAART, these individuals face uncertainty about their future, whilst also living with the knowledge that the disease they live with could potentially be passed to future sexual partners and their own children (Bundock et al., 2011). The evidence to suggest these individuals face wide ranging psychological and psychosocial problems is evident from the literature presented, and the impact of having HIV throughout childhood on neurocognitive functioning is also becoming increasingly apparent, in particular with the increasing burden of poor mental health (Gaughan et al., 2004).  Living with a serious health condition like HIV may negatively impact individuals' lives and how they see themselves. Current literature regarding this and how it impacts their identity is largely focussed on the horizontally infected adult cohort (Heaphy 1996; Tewksbury & McGaughey 1998), which according to Foster, Waeblbrouck, and Peltier (2007), have different pasts and health-care needs.

For these reasons this research intends to allow participants to share their story and for their voices to be heard. This in turn may give the younger generation of teenagers and other adults living with PAHIV a further insight into this phenomenon. It serves to enhance Counselling Psychologist's knowledge base from which to provide and deliver context specific psychological treatment, in turn enhancing client experience, whilst filling a gap in current literature and contributing to future research in this developing area.

# 2.0 Methodology

## 2.1 Introduction to research aim and question

This research explores the lived experience of people living with PAHIV, to make sense of and better understand the nature and texture of their experience of reaching adulthood. The research question is:


***'How do individuals living with PAHIV experience and make sense of reaching adulthood?'***


This chapter provides the reader with an insight into how I attempted to answer this question and includes but not exclusively; the exploration of a qualitative approach to research, my choice of Interpretative Phenomenological Analysis (IPA), my epistemological assumptions, in depth procedural descriptions, personal reflexivity and steps taken to deliver a piece of ethically sound research of a high standard, guided by the frameworks to evaluate the validity of qualitative research as discussed by Yardley (2000).


### 2.1.1 Why a qualitative approach?

Research into adults with PAHIV has been predominantly grounded in positivism (Christianson, Lalos, Westman, 2007; Bakeera- Kitaka, Nabukeera-Barungi, Nostlinger, Addy, Colebunders, 2008; Fielden et al., 2006), utilising quantitative methods. Positivists suggests there is a direct relationship between the world and how we perceive and understand it, asserting that causal relationships between variables can be studied, understood and measured (Denzil & Lincoln, 2000), thus attempting to provide a description of what is 'out there' and to get it right (Willig, 2001), with the emphasis on objectivism and dualism (Ponterrotto, 2005).


This research instead took a qualitative approach by focussing more closely on depth of data rather than breadth, and generated different types of knowledge which is generally context specific and localised. Utilising a qualitative approach allowed for an inductive model of knowledge generation with the attempt of bracketing existing research knowledge, thus allowing for understanding and insight to rise from the data itself. However, a purely

inductive approach wasn't possible when I hold in mind my own role in this process, acknowledging that for data collection and analysis to happen some sort of theoretical lens must be applied (Willig, 2012)

The aim of this research was not to shed light on a particular reality which I believed existed, but to offer an insight into a particular phenomenon. This research attempts to offer insight to individuals trying to understand and make sense of their own experience of PAHIV whilst simultaneously attempting to offer insight to others, especially Counselling Psychologists working with this client group. Therefore, this research did not intend to hold a mirror up to reflect a particular reality, but to provide a space where a particular phenomenon could be explored and reflected on, something which as a trainee Counselling Psychologist resonates closely with me and my therapeutic work. Therefore, to answer my research question, a qualitative approach utilising IPA was employed.

## 2.2 What is IPA?

IPA was developed by Jonathan Smith in the mid 1990's in response to the need for "a qualitative approach to psychology which was grounded in psychology" (Eatough & Smith, 2008, p.180). IPA is an approach to qualitative, experiential and psychological research that draws from phenomenology, hermeneutics and ideography (Smith, Flowers & Larkin, 2009) and offers insight into how a particular person or group make sense of a particular experience (Willig, 2013).

## Phenomenology

IPA's approach is phenomenological because it involves examining in detail a participant's 'life world' (the world as concretely lived) focussing on individual's personal perception of an event or object. Psychologists share phenomenologist's interest in discovering what it is like to be human, what's important to us and what constitutes our lived world.

Edmund Husserl, a German Philosopher, established the school of phenomenology, and famously argued, 'go back to the things themselves', (as cited in Smith et al., 2009) the experiential content of consciousness, the particular. He suggested that knowledge gained in

this way would be knowledge derived of the world as it surfaced through active engagement with it (Willig, 2013).

IPA draws from this theory by focussing on the particular and attempts strongly to focus on particular things in their own right, whilst simultaneously acknowledging obstacles. IPA also recognises such obstacles and sees one of them as the researcher, who brings their own conceptions, which are required to make sense of the participant's personal world, through the activity of interpretation. IPA recognises it is impossible to gain direct insight into another person's 'life world', and that the researcher never has direct access to such experience (Willig, 2013).

The researcher is thus making sense of the participant who is making sense of what is happening for them, this is called a double hermeneutic (Smith & Osborn, 2003). IPA also believes pure experience is not accessible as the researcher is witnessing it after the event has happened; therefore, the researcher attempts to get 'experience close' (Smith et al., 2009).

In Heidegger's major work in *Being in Time* (Heidegger ,1962) he suggests the possibility that any knowledge gained is done through interpretation. Heidegger sees people as always in context with their world with a fundamental part of our makeup being our relatedness to others (Larkin, Watts & Clifton, 2006); he thus contends that people are immersed and embedded in a world of language, culture, objects and relationships, and our 'being in the world' is always temporal, perspectival and in relation to something. Therefore, phenomenological enquiry holds the interpretations of individuals *meaning making processes* at its centre, in line with IPA.

Departing from Heidegger's emphasis on the *worldliness* of our existence, Merleau-Ponty (1962) describes a more embodied nature of how we relate to the world and how this provides us with our own individually situated perspectives of that world. Critically he affords that our bodies form the fundamental understanding of our perception about the world and for IPA researchers moves away from the body as an abstract entity towards a more perceptual one which is extremely important.

Finally, Sartre's work *Being and Nothingness* (Sartre, 1956/1943) extends these ideas to include the context of an individual's social and personal relationships, allowing us to understand our experiences as dependent on the existence, or not, of people, and our relationships to them. Like Sartre's work IPA tends to involve analysis of encounters which involve an interpersonal, embodied, affective or moral nature. This moves us towards a worldlier and more interpretative place, focussing on how we attempt to understand experience through awareness of the complex nature of perspectives and meanings held by individuals, and, that these individuals have a unique relationship with their world (Smith et al., 2009).

**Hermeneutics**

Hermeneutics is the theory of interpretation, which plays a role in the theoretical underpinning of IPA. Schleiermacher (1998), Heidegger (1962) and Gadamer (1990) are three of the most important hermeneutic theorists. Schleiermacher (1998) offers a holistic approach suggesting that through the interpretative process we need to be able to understand the writers not just the text. Gadamer (1990/1960) suggests the author may not naturally hold authority over the meaning of the text; however, he distinguishes between how we understand the meaning of text and how we understand the person, arguing the former more important than the latter.

IPA however does not suggest that our analysis will provide a closer *truth*, but allows us to look beyond what our participants explicitly tell us. This kind of interpretation is justified by Schleiermacher (1998) who believes that the person analysing the text can offer a different perspective.  IPA researchers through detailed analysis, examining connections between transcripts and application of psychological theory, do provide through interpretation what has been coined 'added value' (Smith et al., 2009).

In Heidegger's work *Being and Time* (Heidegger, 1962/1927) he talks about Dasein, describing what he calls "the uniquely situated quality of 'human being" (Smith et., 2009). He diverges from Husserl, away from individual psychological processes towards the questioning of existence and how, through the relationships and activities we are bound up in, we see the world and make meaning from it.

Heidegger (1962) believed when we interpret something, we naturally bring our assumptions with us; the reader, listener or analyser always bringing previous experiences, preconceptions and assumptions with them as they examine the new information or data. Heidegger forces us to re-evaluate the role of bracketing in phenomenological research. His suggestion regarding the relationship between our preconceptions and interpretative work and the different directional ways which these processes can occur, call for a cyclical process of bracketing which may only be partially achieved.

Gadamer (1990/1960) describes this particular process in a similar cyclical way with the phenomenon influencing the interpretation, which may influence one's preconceptions, in turn influencing the interpretation once more. We may hold many simultaneous conceptions contrasting, comparing and modifying these, as part of our sense-making process. When considering the use of interpretation this is a particularly important but neglected area.

**Ideography**

An ideographic approach was taken, which is concerned with the particular, and IPA is committed to this through detail and depth of analysis whilst focussing on particular people, in a particular context, experiencing a particular experiential phenomenon, process, event or relationship (Smith et al, 2009). To understand a particular phenomenon, ideographic qualitative IPA research can, according to Warnock (1987), add something to quantitative research.

**2.3 Why choose IPA?**

IPA has become one of the most commonly used and popular qualitative research methodologies in the field of psychology, with 293 empirical studies published between 1996 and 2008 (Smith, 2011). Patient's illness experience accounted for 24% of the corpus, making it the largest individual category by far. This is not a surprise as the establishment of IPA originated in health psychology, which illness as a topic sits clearly within. The experience of illness usually plays an integral role in concerns and lives of those with the illness, therefore making it an obvious subject for IPA, and IPA an obvious choice to answer this research question. According to Polkinghorne (2005), a primary purpose of qualitative research is "*to describe and clarify experience as it is lived and constituted in awareness*" (p.

137), making it particularly well suited to research in Counselling Psychology as their fundamental paradigms are closely related (Morrow, 2005).

## 2.4 Epistemological and personal reflexivity

The quest for knowledge, what it is and how it is sought is an extremely important one. Epistemology is a branch of philosophy, concerned with the source, nature and various other aspects of knowledge (Howitt, 2010). It concerns itself with the relationship between the 'person trying to know' (the researcher) and the 'person who knows' (research participant) (Ponterrotto, 2005). Psychological research utilises both qualitative and quantitative research methods which provide alternative routes to knowledge, both underpinned by different philosophical positions.

### 2.4.1 Epistemological approaches and assumptions

Qualitative research can be carried out from either a realist, phenomenological or social constructionist epistemological approach as it is not a homogenous field.  This research concerns itself with subjective knowledge of the individual and the analysis of information obtained. Participants exist in the context of their social world, hold their own opinions and views shaped by their experience of being in that world, thus knowledge is within the person who is the focus of this research.

My epistemological stance within this research is characterised by assumptions about what I could know, and how I could know it. Willig (2013) argues that whilst considering the nature of the world at least some assumptions would be made. My choice of research topic, research questions and the type of knowledge I attempt to generate mean I naturally bring some assumptions with me to this research. To assess these assumptions, as suggested by Willig, (2012) I will ask myself the following questions; What type of knowledge will I create? What assumptions do I make about the psychological, material and social world(s) I study? How do I conceptualise my role as the researcher in the process of the research? And what is the relationship between myself and the knowledge I aim to generate?

The type of knowledge I aim to create is about individuals' subjective experience (Smith, 2009). I therefore make assumptions about the world, suggesting that there are as many

worlds as there are individuals (Willig, 2012). The phenomenological paradigm shifts the focus on belief in capturing the 'real' knowable world, to the participant's experience or narrative. This sits comfortably with my own ontology that reality is created by individuals. This phenomenological position argues that experience, whilst always the product of interpretation, thus constructed and flexible, not fixed and determined, is 'real' to the person experiencing it (Landridge, 2007). This also suggests, however, a moderate social constructionist approach suggesting that there is a reality and through the process of perception and communication (Eatough & Smith, 2008) individuals construct their own versions of it. The acceptance that mental states and attributes are real to the person experiencing them (even though unobservable) (Bhaskar, 1975) and the emphasis on the particular context within which individuals make sense of their experience reflects also a critical realist edge (Willig, 2001).

I conceptualised my role of researcher as someone implicated in the analysis (Willlig, 2008) whilst also considering the relationship between myself and the knowledge I aim to generate. Researcher impact will be considered through the process of information gathering, data collection, and approach to questioning participants, interview style and specific responses to answers given. Researcher impact on findings won't be ignored. I acknowledge the difficulty in trying to escape preconceptions, working sensitively and responsibly, whilst attempting to reveal the subject matter of their research on "its own terms" (Larkin et al., 2006, p.108).

Larkin et al. (2006) suggest first person accounts can never truly be achieved. I acknowledge that understanding the experience of my participants involves interpreting their accounts, thus implicated through the process of the hermeneutic circle by providing and recovering meaning whilst attempting to make sense of the participant's account.

The hermeneutic circle concerns itself with the dynamic relationship between the 'part' and the 'whole' on a variety of different levels, with the whole understood by its parts and any parts understood by the whole. Analytically speaking this describes the process of interpretation itself, speaking to its non- linear, dynamic way of thinking. This way of thinking is useful when considering the iterative process of qualitative research. Instead of utilising a step by step approach, analysis of the data involves moving forwards and backwards creating various ways of thinking about it. Therefore, I will think about my research

processes in relation to the hermeneutic circle. I also contextualise the participants' experiences of living with PAHIV as an adult by holding awareness of the social and cultural expectations and norms that currently exist, with the understanding that cultures are also frameworks for meaning making (Much, 1995).

Our experiences and how we understand them are shaped by a variety of relational aspects and through enculturation as explored by Mead (1934) and Bulmer (1969); both proposing that human beings construct their social worlds through inter-subjective interpretative activity. Willig (2008) also argues that IPA has adopted a 'symbolic interactionist' approach as it recognises that an individual's interpretation will inevitably be affected by social processes and human interaction.

### 2.4.2 Descriptive or interpretative?

To answer the question Willig (2012) proposed, I needed to consider whether to take my data at face value or go beyond it. Utilising a purely descriptive approach would capture, represent and clarify the texture and quality of experiences by staying close to the research participants' accounts, believing descriptions can entirely capture and understand the presented phenomenon. Moving beyond the data would enable reflection, not only on the account provided but its wider psychological, cultural, social and even, theoretical meaning (Larkin et al. 2006). The latter approach suggests the addition of a conceptual and critical commentary to the way research participants make sense of their world. When considering my research question and the type of knowledge I sought to find I believed that attempting a pure description of experience impossible, as even through the process of describing something, a certain level of interpretation is always involved. An interpretative approach will therefore be employed.

### 2.4.3 Relativist or realist?

I have adopted a relativist approach to the status of the data because the accounts of research participants aim to tell us something about 'how' the research participant constructs meaning in their lives rather than the participant telling the researcher what is 'really' going on in the world. I have also taken a relativist approach to the analysis of the data as I believe that the findings from this research are not absolute truth claims about a participant's real knowable world. I felt it was impossible to hold a mirror up to the participant and claim that I know what their direct experience is actually like, believing the data to be co constructed by

both the participant and researcher. However, if I was to say that I am a complete relativist I would be abandoning all truth claims about my research, suggesting no real findings can be possible. Therefore, it was important to acknowledge that as a researcher I would be claiming through the process of analysis that I knew something about someone and that I would be tentatively revealing some knowledge that I have uncovered. I therefore recognised there needs to be an acknowledgment (even if somewhat limited) of a realist position to my research.

I therefore explored my research question from a predominantly phenomenological, interpretative epistemological stance focussing on individuals' subjective experiences and meaning-making, whilst simultaneously acknowledging both a moderate social constructionist approach with a critical realist perspective.

## 2.4.4 Personal reflexivity

Reflexivity is extremely important as a Counselling Psychologist in research and clinical work. It was therefore crucial to consider my standpoint and make explicit what I bring to the research, whilst recognising this may still impact the research but enabling me to consider it's influence as discussed by Landridge (2007), who also suggests the increased importance of this to me as a researcher who has not experienced the phenomenon under investigation.

Personal interest coupled with sixteen years' professional experience working with infected and affected individuals with HIV is recognised as a major influence in choosing this research topic. Whilst considering research ideas a few years ago, a PAHIV+ adult who I was working with as a Health Adviser (HA) died. She stopped taking her HIV treatment, and when restarting, encountered severe and life threatening side effects. The striking image of her laying in Intensive Care will live with me forever. I remember wondering what her short experience of life must have been like growing up with PAHIV and whether her life, with the right support could have been any different.

I am aware that my desire to understand these individuals and to in some way give a voice to their experiences may mean that this research is in some way born from my own political position. I have seen the transition of many PAHIV+ adolescents into adult services and I am

acutely aware, in my professional opinion, the need for good specialist psychological support for these adults. My pre-existing relationship with this subject is therefore recognised. I am aware of an on-going desire to improve lives somehow through my research and my training as a Counselling Psychologist. I understand this research should not have this goal; however, these are my motivations, which will not be biases to be eradicated but will inevitably shape the research and its findings. My understanding of participant's thoughts and feelings will undoubtedly be influenced by my own phenomenological viewpoints, for example existing assumptions, conceptions and experiences, as a Counselling Psychologist in training, Health Adviser, Woman and Mother. See Appendix A for an example and extracts from my reflexivity diary, detailing how I may have impacted the data analysis.

## 2.5 Method

### 2.5.1 Sampling considerations

Sampling was consistent with the qualitative paradigm and the orientation of IPA, therefore my sample was selected purposively offering insight into this particular phenomenon of adults living with PAHIV. IPA tends to involve small sample sizes which Smith (2011) suggests is satisfactory for IPA's potential to be recognised. Informed by Smith et al. (2009) participants were chosen that represented a perspective not a population. I was mindful that anecdotally this is an extremely over studied group of individuals due to the small population of those infected with PAHIV. Therefore, recruitment was done sensitively with no pressure placed on individuals to take part. Three men and five women of similar ages, ethnicity and direct experience of living with PAHIV in the UK reflected a homogenous sample.

### 2.5.2 Participants

8 PAHIV+ adults were recruited in line with current recommendations that it is more problematic to meet the commitments of IPA with a sample that is 'too large' rather than 'too small' (Smith et al., 2009). Participants were purposively chosen, over 19 years old (therefore no longer an adolescent (WHO, 2009)), with either PAHIV or early acquired HIV infection from an HIV charitable organisation, which the research question was meaningful to (Smith et al. 2009). I had easy access to recruit there having worked closely with them previously.

This population is small which alone defines the boundaries of a relevant homogenous sample (Smith et al., 2009). All participants recruited were born when medically it was unknown if they would reach adulthood. The sample will exclude participants who don't speak English because with IPA studies participants need to be able to articulate their lived experience.

### 2.5.3 Procedure

Once ethical approval had been granted by City, University of London (see Appendix B) I met with Aaron at 'Unity' who runs the adult support group for PAHIV+ individuals and discussed putting up recruitment posters (Appendix C), the recruitment process including inclusion and exclusion criteria and explained eligibility of participants being over 19, living with PAHIV and being fluent in speaking the English language.

Prior to recruitment commencing Aaron told me he had already spoken to the group and told them about my research, with some already keen to be involved. It was important to hold in mind that participants may feel pressure to participate, and to reduce this, having him as a gate keeper; someone who works very closely with the cohort seemed like a good idea to facilitate a non-coercive and sensitive approach to recruiting participants (Webster, Lewis & Brown, 2014). However, gatekeepers can also be seen as authority figures with power over participants, therefore it was important to ensure through the face to face consenting process at the beginning of each interview that participants knew participation was voluntary and there were no consequences in withdrawing from the study at this stage. Aaron was also aware that sometimes participants may withdraw which is their decision. The right to withdraw was also included in the consent form.

Pressure to participate can also be increased through offering incentives (Webster et al., 2014). Aaron/gatekeeper did ask me if it would be possible to offer participants an incentive as they are an extremely over-researched cohort, who are used to receiving some sort of incentives for their time. After discussion with my research supervisor and ethical considerations explored it was decided that I would offer a £20 high street voucher incentive to participants which has been used in previous research carried out at 'Unity'. This was not used to entice or coerce participants as most were already keen to take part before this incentive was offered, therefore it was offered as a mark of appreciation for their time. I acknowledge that incentives can be used to encourage participation, thus suggesting

pressure to take part however; there is a lack of consensus in the literature regarding appropriateness of providing incentives (Wiles, Heath, Crow & Charles, 2005) with the suggestion that benefits outweigh ethical risks providing these risks are acknowledged and managed appropriately.

Appointments for interviews were made by Aaron for Tuesday evenings during the time individuals would usually attend 'Unity', so they did not have to travel more than they needed to. Participants booked their interviews with Aaron confidentially via email or phone if they did not want others to know they were taking part. The time and date of the interviews was organised between Aaron and the participant with me being informed of this by phone. 'Unity' kindly provided a private, confidential room for the interviews, participants were escorted to me at the beginning of each interview by Aaron. Each participant received the participant information sheet prior to their interview, giving them a chance to read and digest the information. (see Appendix D). Whilst I included some of the potential benefits of taking part in the research, it was also important not to over inflate these benefits (Webster et al., 2014).

### 2.5.4 Data collection

In line with IPA, semi- structured, one to one, face to face, in depth interviews were employed as a method of data collection (Reid, Flowers & Larkin, 2005). IPA argues human lived experience can be understood through the examination of the meaning people impress on it and it is these meanings that my interviews attempted to highlight. These meanings intended to illuminate the embodied, existential and cognitive affective psychological domains (Smith et al. 2009). Therefore, naturalistic first-person accounts of experience were collected.

### 2.6 Interviews and change in research question

IPA is well suited to in-depth interviews because it invites participants to offer detailed and rich accounts of their personal experience, facilitating the elicitation of feelings, thoughts and stories about the phenomenon under investigation (Smith et al., 2009).

Interview questions were created by reading extant literature, drawing from previous specialist knowledge of working in the field of HIV and holding the research question in mind. Main content included asking broad questions about their current lives and what they were doing at the time of interview, helping to develop the relationship between myself and the participant, followed by more specific questions about their experiences as adults living with PAHIV. Interviews were conducted as an open conversation using the interview schedule as a guide and support for myself as a novice interviewer.

Individual in depth, semi structured interviews worked well, providing a safe, private, confidential, one to one space to explore an extremely sensitive topic. My approach to the interviews was friendly and flexible (Rubin & Rubin, 2005), allowing me to build rapport with participants. Experience of working with HIV patients for many years and my recent rigorous training to become a Counselling Psychologist was also helpful. Open ended, non-directive questions were employed to allow participants the opportunity to share their subjective experiences whilst reducing the chance of leading questions and researcher mediation. When developing the interview schedule I was aware that I needed to start with broad, general questions alllowing the parameters of the research topic to be set by the particpant instead of vice versa, reducing the risk that I may impose my own understanding on the particpants account of their understanding of the particular phenomenon (Smith et al., 2009). A balance was struck, between not asking vast amounts of questions whilst also making sure that my topic was talked about enough.

The schedule aimed to provide a plan for foreseen difficulties and in helping phrase difficult questions and introducing difficult topics (Smith, 2003).  The schedule also held information for participants who required referral for psychological support.

**Interview skills**

The skills learnt throughout Counselling Psychology training allowed me to conduct interviews utilising core skills including empathy, unconditional positive regard and congruence. Interviews were not conducted like therapy sessions but aimed to make participants feel more comfortable in sharing their experiences.

**Interview questions**

When deciding on interview questions I considered; an awareness that all questions be foregrounded in something; that by asking certain questions I would be showing what is important to me; how asking someone how they feel assumes that they must feel something; and that particpants may see my questions as a threat if not worded appropriately.

Likewise for the particpant I was aware that when answering my questions they may have used the interview to show me a certain side of themselves, to position themselves a certain way, hold preconceptions of me which may influence how and what they share, interpret the interview situation in different ways and be taking part in the interview for a variety of different reasons.

**Interview schedule**

As I am a novice interviewer and qualitative researcher I tried out the interview schedule on someone who does not have PAHIV and is not part of the research study, in line with the recommendations by Smith and Osbourne (2013). I enlisted the help of a peer who suffers from severe pollen allergy (Hayfever) to be interviewed, recorded and which provided me with some feedback. (see Appendix E for pilot one interview questions).

**Pilot interview: one**

The first interview involved adjusting my interview schedule questions to incorporate their experience of pollen allergy as opposed to PAHIV. I did this by replacing verbally the words HIV with Hayfever . This was done to enable the pilot particpant to think about a health condition which they actually had, and gave me the oppurtinity to hear what my questions sounded like when posed to another. This interview was difficult as many of the questions when adjusted did not work.

The interview did not flow particularly well. Feedback included that questions appeared too abstract, leading and repetitious in content. The interview also felt like the questioning started too abruptly and I felt like I asked too many questions, reducing the chances of an inductive process. The participant also provided other valuable feedback about the experience of being interviewed, whilst I experienced what it was like to ask difficult

questions and reflect on future wording. Considering the feedback, I did some further reading about interviewing and developed a new schedule for pilot interview two (see Appendix F).

## Finalising the interview schedule

Another major consideration when finalising my interview schedule was whether or not I would include a question directly asking what it was like to be part of a 'unique generation'. I discussed this with my resrach superviser because I didn't want to make the assumption that they identified themselves in this way. After much consideration I raised this question with Aaron at 'Unity'. He confirmed that all PAHIV+ individuals in the group I was recruiting from were aware of this, and it was something they had all discussed as a group recently. Therefore I decided to ask this question in the second pilot interview.

## Pilot interview: two

Pilot interview two was carried out utilising the new schedule with a participant recruited for the study. The particpant was aware it was a pilot but also consented to his interview being included as part of the study. This interview was carried out at 'Unity' in the same environment that the other interviews took place. The aim of this pilot was to help identify more closely the best questions to ask, help refine my existing questions and gain important information regarding potential challenges I may face (Willig, 2013). Post interview, this particpant fed back to me his experience of the interview. Overall the feedback was good and provided me with some information regarding the content of the questions and which order to ask them in. (for a detailed list of changes see Appendix G). The question regarding being part of a unique generation was not a concern to the particpant, he understood what it meant and said others would too, therefore I decided to include it within the final schedule draft. After the interview the participant apologised for taking a long time to answer my questions and talking too much. I reasured him that this was fine. Following this feedback I started each interview saying " It's ok to take your time when answering questions, it's your experience I am interested in and that whilst I will ask some questions it's fine to talk away". As a result of the pilot I was able to refine the order of the questions and create a final interview schedule (see Appendix H).

It was hard as a novice researcher to relax into the interview without always holding, to some degree, the interview schedule in mind. I attempted to allow a balance between guiding the particpant and being led, the extent to which I achieved this is difficult to know. When I reflected on my early transcriptions I could see times when I had focussed on my next question instead of encouraging the particpant to continue talking about a valuable area of interest. I attempted to change this in subsequent interviews.

**Interviewing process**

I ensured participants had read the participant information sheet before the beginning of each interview. Consent forms were given and signed before the taping began (Appendix I). Limited demographic information was collected (see Table 1.) to protect participant's anonymity as much as possible, providing a general description of the population. These were chosen because of their perceived importance to the research question.

Table 1. Demographic Characteristics

| Pseudonym | Age Range | Gender | Living arrangements | Ethnicity |
|-----------|-----------|--------|---------------------|-----------|
| Jacob | 26-28 | Male | Lives independently | Black African |
| Emily | 23-25 | Male | Lives with family | Black African |
| Alex | 26-28 | Male | Lives independently | Black African |
| Sam | 23-25 | Female | Lives with family | Mixed |
| Anna | 26-28 | Female | Lives with family | Black African |
| Grace | 23-25 | Female | Lives independently | Black African |
| Abi | 23-25 | Female | Lives independently | Mixed |
| Mia | 23-25 | Female | Lives independently | Black African |

All interviews took place in a private confidential room in 'Unity'. Interviews took place during the summer, meaning windows had to be opened which overlooked a busy street.

Unfortunately, other rooms were not available when these problems arose meaning some interference with recordings did occur. Interviews started with me introducing myself and the research, asking participants to read the participant information sheet if they hadn't already and offering the opportunity to ask any questions. All participants were asked to read and sign each point on the consent form with their initials as I carefully went through it with them making sure consent was fully informed. Each participant was offered a copy of the consent form to keep. Participants were asked specifically if they consented to direct quotes being used from their interviews in the final write up and if they wanted to provide their email addresses so that they could receive the findings of the study. I explained that whilst I would be asking some questions these were just a guide and that their own personal experience was what I was looking for, they could take their time answering the questions and there were no right or wrong answers. This was done to maintain an inductive process and attempted to place them in the position of the expert (Reid et al., 2005). Participants were finally reminded that they could take a break or terminate the interview at any time and the tape was started.

Interviews lasted between thirty-five and ninety minutes. Unfortunately, 2 interviews on one day were cut short because the participants had prior engagements at 'Unity' which I was unaware of at the time, meaning these interviews were interrupted and participants were told that their next appointments were nearly ready. This meant that the interviews were finished slightly prematurely, however both interviews were over an hour long and all questions on the interview schedule were covered. This issue was resolved after discussion with Aaron. All interviews were conducted over 5 visits within the space of 5 weeks, only six weeks after first meeting with Aaron. This meant a steep learning curve for me as a novice interviewer and limited time to reflect between interviews. Thus, all interviews were conducted before transcription took place.

**Post interview**

Post interview debriefing took place giving participants the opportunity to ask questions and reflect on the interview, a debrief sheet was also provided (see Appendix J). Interviews were audio recorded, uploaded to a password protected laptop and transcribed verbatim providing raw data for analysis (Smith, 1996). I made notes in my research diary at the end of each interview which I was able to reflect on when analysing the transcript at a later date, helping me to give meaning to something that was not always overtly obvious through the words of

the participants alone; thus attempting to reduce the assumption that words are more important to how individuals give meaning to something as opposed to gestures, silences or other non-verbal communication.


**Reflecting on the interviews**

Following clarification with Aaron, and participant one, who was also one of my pilot interviewees, I decided to go ahead and ask participant two the question about what it was like to be part of a unique generation to reach adulthood. This participant did not appear to understand the question, even when I explained what I meant. This interview was a particularly difficult one anyway and the participant did need prompting quite regularly and an explanation of some of the other questions I asked was also needed. However, after further discussion with my supervisor I decided that I would remove the 'unique generation' part from the interview schedule to reduce any possible assumptions I was making as a researcher about participants experience in line with the bottom up approach of IPA. This question was replaced with; what is going on in your life right now? This allowed for the experience of being part of a unique generation to arise from the data if it was salient to the participant.


One participant that was recruited for me was a French speaker. Whilst he spoke English, it was not his first language. This was out of my control, only meeting him as he entered the room to be interviewed. I struggled at times to understand him, often having to ask him to repeat himself. At the end of the interview I thanked him and gained consent to contact him if I needed any clarification post interview. He happily obliged. The implications of this will be discussed further in the discussion; however, if I was to carry out future research I would aim to be more involved in the screening of participants.


Another participant that I interviewed was visually impaired and disabled, unable to use her hands. Again, I was not aware of this until she entered the interview room. Implications arose about how she would sign the consent form. I read out the details of the consent form and she gave verbal consent to be interviewed, Aaron agreed then signed the consent form on her behalf with her permission. I decided to read the participant information sheet and debrief sheet out to her before and after the interview. During the interview, the participant expressed concern regarding telling me about her disability on tape for fear of being

identified. I reassured her regarding confidentiality. Again, the implications of this will be visited more closely in the discussion.

**Change in research question**

My initial research question at the beginning of the study was 'How do individuals living with PAHIV experience and make sense of being part of a unique generation to reach adulthood?' The words 'unique generation' are used in literature and this is something which I felt sure participants would be aware of. As this was not something which participant two identified with and following the removal of it as a question in the interview schedule I decided to also remove it from the research question.  The research question therefore changed to 'How do individuals living with PAHIV experience and make sense of reaching adulthood?' This removed the assumption that participants identified with this, in line with a bottom up IPA approach.

**2.7 Analytic procedure**

**Transcription**

Transcription and analysis took a long time to complete; I started in September 2015 and finished in July 2016. This was due to strong demands of the final year of my doctoral training, work commitments and managing a young family, alongside the quality of some of the tapes due to noise, the language, varying accents, the speed at which they spoke and the fact that English was not one of the participant's first language. Once each tape was transcribed it was formatted into a word document. Transcripts were printed on A4 paper, landscape with line numbers attached to each line of text.

**Steps of Analysis**

IPA boasts a well-established procedure for analysing this type of experiential qualitative data (Smith & Osborne, 2003) and was used because it has been proven to be an effective method in the exploration of underexplored topics including sexual health and HIV (Flowers, Duncan & Knussen, 2003; Flowers, Davis, Larkin, Church & Marriot, 2011; Brocki & Wearden, 2006).

IPA has no prescribed single method to analyse the data. The analytic focus directed towards participants attempting to makes sense of their own experience is described by Smith (2003) as an iterative and inductive cycle. Due to IPA's ideographic commitment I analysed the first case in detail, then the next and so on. Smith et al. (2009) suggests the researcher is inevitably influenced by the findings of the first transcript and in some ways changed due to the hermeneutic aspect of IPA which I can concur with.

**Step one: reading and re-reading of the transcript**

Analysis began with the reading and re reading of the text with the meaning of the word becoming clearer in the context of the sentence and vice versa. Hermeneutics recognises this, as Smith et al. (2009) describes where parts can only be understood from an understanding of a whole and a whole can only be understood from an understanding of the parts.

**Step two: initial noting**

Wide ranging unfocused notes were made by hand, including any questions, comments on language, summary statements, descriptive labels and absences (Willig, 2013). Different colour pens were used to define descriptive (Blue), linguistic (Red) and conceptual (Black) comments and written in the right-hand margin of the transcript (Smith et al., 2009). Using the colour codes enabled me to be disciplined in covering the text from all three aspects.

When making my conceptual comments, I considered Eatough and Smith's (2008) suggestion of two levels of interpretation; a descriptive and empathic level, allowing at first the researcher to enter the participant's world and then to critically interrogate the participants accounts to gain further insight into nature, meaning and origin, going beyond their words and understanding. I hoped this would enrich the research whilst giving ethical consideration to the imposition of meaning and giving/denying of a voice to research participants (Willig, 2013). Reflexivity was also addressed making careful distinction between participant's comments and researchers' interpretation of them.

This approach to analysis aided the process of allowing new and novel ideas to emerge. Where new themes emerged, they were checked against the original transcript and where appropriate, previous elicited themes were modified or became master themes or sub-

themes as Smith and Osborn (2003) suggest "…*aiming to respect the convergences and divergences in the data*" (p. 73).

Smith et al. (1999) state that "*analysis requires close interaction between analyst and text: the analyst seeks to comprehend the presented account whilst concurrently making use of his or her own 'interpretative resources'*" (p. 223), so in this way there was a need to become immersed in the data collected, attempting to move from the descriptive to the interpretative (Brocki & Wearden, 2006). Peer review of the themes also took place by my research supervisor. An *interpretation* of the participant's experience is what is presented in the final analysis, Willig (2013).

**Step three: development of emergent themes**

Identification and labelling of emergent themes were recorded in the opposite margin from the initial noting. This attempted to reduce the vast volume of data whilst simultaneously maintaining its complexity through mapping out the connections, patterns and interrelationships between the initial exploratory notes. An analytic shift was then necessary as I began working primarily with the initial noting as opposed to the transcript, always making sure it was tightly linked to the transcript.

Identifying emergent themes from analysing the exploratory comments meant focussing on a local level at certain parts of the transcript whilst simultaneously remembering what was learnt from the initial noting process. The breaking up of the participant's narrative at this stage felt incredibly uncomfortable.  I was also aware that unlike the stages that came before it I was struggling with giving myself a more centralized role in interpreting and organizing the data. Recognition of this process as one of the manifestations of the hermeneutic circle helped alleviate my anxiety to some extent, conscious that the resulting analyses would result from the collaboration between the participant and myself. I then reflected on the initial noting and comments attached to the piece of transcript, attempting to produce a pithy and concise statement which reflected the importance of what I had written. Themes attempted to reflect the psychological essence of the particular piece containing enough particularity to ground it and enough abstraction to be conceptual. Emergent themes were developed from both the original thoughts and words coupled with my interpretation. These themes aimed to capture an understanding (see Appendix K for transcript example).

**Step four: connections across emergent themes**

With all emergent themes for the entire transcript written in the left-hand margin of the transcript as they arose, thus in chronological order, I began to look at how these emergent themes may fit together. I then printed all emergent themes and cut them up so each theme was represented on a separate piece of paper. These pieces of paper were then laid on the floor enabling me to move them around further. This enabled me to explore 'spatial representations' (Smith, 2009, p.96) of the relationship between the emergent themes. Any themes with similar understanding were placed together. Some themes appeared to naturally pull others towards them like magnets. Opposing understandings were represented by placing them at different ends of the floor. This process worked well.

Any emergent themes that I thought could be disregarded, which included only a few for some participant's and none for others, were kept safe as I was aware that further analysis of other transcripts may mean that I would want to return to them for re-evaluation. Connections between emergent themes were looked at employing abstraction, subsumption, polarisation, numeration and function (Smith et al., 2009). These strategies are not mutually exclusive and I employed the ones that worked best for me with the material I was engaging with. Emergent themes were then grouped together and given 'Major Theme' names which best captured their essence of the participant's experience. Notes were made in my research diary at the end of this stage of analysis including how I conducted the process and any thoughts I had.

A summary table was developed to display themes. Quotations were used to illustrate the way themes were mobilized (Willig, 2013) and linguistic changes made when necessary (Sandelowski, 1994). Initial summary tables (see Appendix L for an example) contained major themes with some themes from earlier stages removed, if not well represented in the text and marginal to the phenomenon. Awareness was given to the fact that as a researcher I was making these decisions based on my interests and orientations. I needed to make sure summary tables reflected meanings that structured the participant's accounts as opposed to recording what I, as a researcher, believed to be an acceptable amount of clusters/themes (Willig, 2013). All quotes were accompanied by line numbers so they could be easily located.

**Step five: moving to the next case**

Moving to the next transcript I repeated steps 1 – 4, attempting to do justice to each participant's subjective experience by treating each case on its own terms. Therefore, whilst working on the second case I attempted to 'bracket' the emerging ideas from the first, keeping close to the commitment of ideography in IPA research. I was acutely aware that this was difficult and effectively my 'fore-structures' had been changed. My awareness helped me to attempt, with each new case to allow new themes to emerge. This continued for all subsequent transcripts.

**Step six: patterns across cases**

Looking at patterns across cases was conducted by lying out on the floor, all eight summary tables. I then asked myself the questions suggested by Smith et al. (2009); "What connections are there across cases? How does a theme in one case help illuminate a different case? Which themes are the most potent?" (p.101). these questions were written down to remind me of them throughout this part of the analysis process. Each participant's summary table was printed on a different colour card, and I noted down which colour belonged to which participant. I then cut them up into individual themes and stuck them to a large window; this enabled me to explore the 'spatial representations', but this time across all participants. I used a window which allowed me to leave the pieces of paper up there because I knew that this part of the analysis could take several days. This stage enabled the analysis to be developed to a more theoretical level, where major themes for individual cases in addition reflect higher order concepts (super-ordinate themes) across the cases. It was important at this final stage of analysis to not only present these shared higher order qualities but also to point out how participants constitute unique idiosyncratic instances. Results of super-ordinate themes and nested themes were displayed using an Excel spread sheet, the different colours representing the different participants as explained in the key (see Appendix M for an example).

**Writing up analysis/results**

Analysis write up aimed to show the reader what I had found by providing "a convincing account of the nature and quality of the participants' experience of the phenomenon under investigation" (Willig, 2013, p.92). This was done through a substantial, clear, full narrative account containing transcript extracts supported by descriptions of the data and detailed analytic interpretations. This provided a summary of overall findings to begin with, followed

by a list of super-ordinate themes and a diagram to help the reader see clearly what was found. This was followed by a list of the subthemes nested within the super-ordinate themes. Each super-ordinate theme was then written up in sequence, starting with a short introduction outlining what it was, followed by examples in detail of how it applied to the participant accounts. The write up involved drawing from all accumulated materials so far; research diary, themes, extracts, initial noting and a substantial number of quotes from the transcripts. Quotes are provided with the intention of providing a transparent evidentiary base. Each quote was labelled with the participant's pseudonym helping the reader to follow the participant's story through the analysis. These were coupled with page and line numbers from the transcript where they could be found. The final narrative aimed to represent and capture the raw extracts from participant accounts intertwined with analytic commentary from myself, fulfilling both the "I and the P of IPA" (Smith et al., 2009, p.110).

I wrote the analysis chapter the day after I completed my analysis whilst fresh in my mind, revisiting it thereafter to add detail. As I wrote this section some themes loomed larger and were more illuminating, others faded away, in particular an overarching theme emerged, appearing to permeate and connect all super-ordinate themes. The line between analysis and write up was blurred and cyclical with all claims grounded in the participant's accounts.

**Measuring recurrence**

A final table measuring recurrence across cases was created. This was recommended by Smith (2009) to help enhance validity of findings. A decision was made that for a super-ordinate theme to be classified as recurrent it should be present in all participant interviews, for subthemes this was at least a half. I was however mindful that the level of theming and commenting would influence the degree of recurrence and allowance for the degree of variation within that recurrence would still exist. A continuous negotiation of the relationship between commonality and individuality and convergence and divergence in keeping with IPA was undertaken.

**Levels of interpretation**

Throughout analysis I held the concerns expressed by Hefferon and Gil-Rodriguez (2011) in mind, that often student IPA research is conducted in a more thematic way than the interpretive way intended for good IPA. I made sure I chose my research question in

advance of my methodology to avoid engaging in the process backwards, thus reducing the chances of generating myself problems in the execution of this research as discussed by Barker, Pistrang & Elliot (2002) and Punch (2000). Accessing good research supervision throughout the analytic stages of my research was also of paramount importance.

As suggested by Reid et al. (2005) in IPA less is more. Eight participants were therefore chosen to allow greater depth of analysis and a focus on interpretation given the time constraints of this research and to avoid the risk of shallow descriptive analysis of participants. Recommendation for professional doctorates ranges between four and ten participants (Smith et al., 2009) therefore I was in line with this and felt able to provide a good depth to my interpretations within the data set.

**Other considerations during analysis**

Non-verbal communication was also an important part of the analysis. Merleau-Ponty (1962) argued "The body is the vehicle of being in the world" (p.82), Finlay (2006) agrees, suggesting the researcher should reflexively attend to their own bodies and their participants as well as what they verbalise. He suggests three distinct yet connected layers of attending to the body and embodiment including embodied self-awareness, bodily empathy and embodied inter-subjectivity. Therefore, whilst immersed in the interview process I attempted to simultaneously reflect and hold awareness for important non-verbal, bodily communication to reduce the risk of missing something extremely important. Through coding the transcripts, I was looking largely for overt meaning however the real challenge was giving meaning to things that were not expressed through language. This meaning I was attempting to capture, as reflected by Finlay (2006) may also have laid in my own reactions and responses to what the participant was telling me. As a Counselling Psychologist in training this is something I felt well placed to do. On reflection, however, I could have also asked participants about certain silences during the interviews and explored what they meant. This may have allowed me to get closer to the participant's experience.

**2.8 Ethics**

At the heart of any ethical practice is the avoidance of harm. Ethical guidelines will be closely followed throughout this research serving to make clear the conditions under which this psychological research is acceptable. I understand as a trainee Counselling Psychologist

that we have a moral and legal responsibility towards our participants and owe a great deal to those who agree to take part in our research and make it possible. Participants will be treated with the utmost respect and with the highest standard of consideration (British Psychological Society [BPS], 2014). Brinkmann and Kvale (2008) suggest awareness of ethical dilemmas as they surface throughout the research using professional and ethical judgement to adopt ethical research behaviour throughout.

'Unity' does not have an ethical committee; therefore, this research will be guided by City, University of London, BPS (BPS, 2006) and Health Care Professions Council (Health Care Professions Council [HCPC], 2016) ethical guidelines. The BPS ethical principles for conducting research with human participants will be followed closely (BPS,2006) to make reasoned judgements, with the research guided by the four main principles of; respect for the autonomy and dignity of persons, scientific value, social responsibility, maximising benefit and minimising harm.

## Confidentiality

Raw data obtained from participants remained strictly confidential. Internal confidentiality also known as deductive disclosure was also considered. This occurs when the traits of groups or individuals cause them to be identified in research (Sieber, 1992); this is more of a risk with qualitative research which provides rich participant accounts. I attended to this by reducing the demographic data provided, anonymising data, using pseudonyms and intentionally reducing and concealing information thought to risk participant's confidentiality. (Damianakis & Woodford, 2012) and by choosing which extract to use carefully. Pseudonyms were derived from an internet search of common names. Anonymised data was shared only with my research supervisor and university peers for peer review during data analysis.

## Consent

Informed, written consent was gained at the beginning of all interviews before any data collection took place. Explicit written consent was obtained from participants for the use of direct quotes in the final published thesis. Privacy and confidentiality was upheld but participants were informed that confidentiality might be broken if they disclose risk to themselves, to others, children at risk or illegal or terrorist acts (BPS, 2014). All participants were over 19 years old, therefore able to fully consent themselves to the research.

Participants were not individuals I have supported psychologically whilst working as a HA or trainee Counselling Psychologist.

**Deception**

Participants were not deliberately deceived through the process of this research. I sought to give as much information to participants about the research as possible, any aims of the research that were withheld before the interview were revealed at the debrief stage. Participants were fully informed of the research procedure through an interview schedule (with no methodological reason to conceal this) with some omission regarding key concepts that may influence or bias the focus of participants' narratives (Willig, 2013). Participants were fully informed regarding the aims of the research once data collection was complete. If participants wished to receive a final summary of results, they were able to by indicating this and providing an email address on the consent form. Participants can access any publications arising from this research.

**Analysis**

Ethical consideration was given to the imposition of meaning during the analysis stage with the interpretative nature of the analysis recognising that higher-level interpretations of the data risk participants being denied/given a voice (Willig, 2013) see also Larkin et al. (2006) and Willig, (2012) for further discussion on the ethics of interpreting data.

**Participant protection**

My intention throughout the research was not to increase participant's probability of harm or cause any undue risk, however I was conscious that some questions might illuminate issues that could potentially cause distress to participants, no more so however than in a therapeutic situation. I was confident my skills as a trainee Counselling Psychologist, coupled with the physical setting of 'Unity' where participants were already emotionally well supported, with instant provision available if the need arose for direct access to psychological support, was adequate in preventing participants from undue harm. I held responsibility to contain distress and alleviate any undesirable effects from the consequences of this research.

Participants were recruited from a small group of individuals who all knew each other which brought its own issues regarding confidentiality. This was discussed with each participant at the beginning of the interview. Participants were made aware that others may notice they were taking part simply by seeing them come in the room or leave the group they were attending to be interviewed. Participants were given the option at this point to not continue if they held concerns. No participants expressed concern that others may know they were talking part.

## Right to withdraw

Participation was strictly voluntary, at the point of recruitment I recognised that I could be seen by potential participants as in a position of power and no pressure to take part or remain in the process was asserted by myself, with the right to withdraw up until data aggregation, without explanation. Due to time constraints, I needed to place a limit on data withdrawal; this was made explicit to participants on their participant information sheet and consent form (BPS, 2014). I explained, withdrawal at any time of the research would not cause any impact to present or future care (Smith et al. 2009).

## Psychological support and debriefing

Participants were made aware that 'Unity' could offer direct access to psychological support if needed post interview and thereafter. Contact details for psychological support were also given on the participant information and debrief sheet. Post interview debriefing provided the opportunity for participants to ask questions and reflect on the interview and information given, providing them a complete understanding of the research they participated in. I was also prepared to inform participants if I had any concerns regarding their physical and psychological health and discuss after the interviews if any questions or concerns arose from the interviews which they wanted to discuss.

## Researcher safety

On-going personal therapy and supervision were utilised for psychological support during this research process. Panic alarms in each room, a fully occupied building, and staff members aware of who I was with and for how long, were all in place to optimise my safety.

**Resources**

Financial cost involved; personal travel expenses and incentives, 2 x £10 shopping vouchers for each participant (See Appendix N). Personal costs included: printing, photocopying and reading materials, e.g. books and journals. Other costs included time spent in meetings with Aaron at "Unity", recruiting, interviewing, transcribing and analysing data. A digital recording device to record interviews and a laptop to upload the interviews and transcribe the data I already possessed.

**2.9 Validity and quality of IPA**

As a novice researcher IPA was certainly attractive in terms of its flexibility, accessibility and applicability (Larkin et al., 2006). However, this flexibility brought concerns regarding rigour. Validity and quality in qualitative research has always been a contentious subject (Smith, 2011). Frameworks to evaluate the validity of qualitative research written by Yardley (2000, 2008), Elliot et al (1999) and Smith (2011) were adopted, to facilitate my quest in undertaking 'Good IPA' (Smith, 2011). Guidelines suggested by Yardley (2000) were used to facilitate my discussion regarding the quality and validity of this research study (see Discussion chapter), and are not prescriptive or rigid rules but open to flexible interpretation, providing me the opportunity to fit them specifically to my research study.

Good IPA recognised by Smith (2011) ,although not exhaustive, include; extended participant narratives, most themes supported/evidenced by extracts from at least fifty per cent of participants, interesting interpretations of the data integrated with extant literature, nuanced and rich accounts of participants making sense of a particular phenomenon, analysis managing the collective experience and individual meaning in a balanced way and themes only judged as recurrent if they appear in half of the transcript at a minimum, with only these then presented.

Good quality IPA and its goals are not about attempting generalisation of results, but rather, group to group transferability of findings. Smith et al. (2009) suggests that the reader of the research can "assess the evidence in relation to their existing professional and experiential knowledge" (p.4) arguing theoretical generalisability. Broad limitations of qualitative methodology which I also considered have been discussed by Silverman (2006), Rawson (1999) and more specifically regarding IPA by Willig (2008).

# 3.0 Analysis

## 3.1 Introduction

Presented within this chapter are the findings from semi structured interviews carried out with eight participants. These were analysed using IPA to explore the experiences of individuals reaching adulthood with PAHIV. The themes presented in this section aim to shine a light and illuminate the diverse and complex nature of these individual's subjective experience, providing a rich and multidimensional insight into their lived experience. To answer the research question, the researcher's interpretation of the participant's interpretation of their experience is what is presented in this analysis. One overarching theme of an 'Evolving journey' which permeates five super-ordinate interconnected themes emerged from the analysis, as illustrated in Figure 1.



Figure 1. Diagram of Themes

Analysis revealed the first super-ordinate theme 'the changing responsibility of self' to be a theme unanimously experienced by all participants. It has no subthemes and stands alone in its own right. The other four super-ordinate themes have further subthemes, see below:

**1. The changing responsibility of self**


**2. Reflecting on a difficult childhood**

a. Diagnosis changed self

b. Problems in the family caused by stigma and cultural difference

c. Anger and blame towards parents for HIV status

d. Secrecy and isolation in family

e. Numerous struggles at an early age


**3. The stigma barrier**

a. A secret life

b. Perception of self by others

c. 'Keep reducing stigma bit by bit'

d. Negotiating a sexual relationship with HIV even if you've never had sex

e. 'Biggest killer of HIV'


**4. Development of sense of self**

a. Purpose and achievement gives a focus

b. Trying to make sense of self

c. Learning through experience

d. Support and therapy


**5. Managing uncertainty**

a. 'I choose to focus on better things'

b. 'Russian Roulette'

c. Disclosure as a risk

d. A need for control

e. Acceptance?


All participants expressed super-ordinate themes 1 – 5, except for super-ordinate theme 4 which was expressed by the majority (7 out of 8) of participants. Each individual subtheme was not necessarily expressed by every participant. Please see Appendix O for a table of appearance of each participant.

Each super-ordinate theme will be explored independently and through exploration of the subthemes, utilising quotes directly and verbatim from the participant's transcripts. All names and identifying details of participants have either been changed or omitted and the use of pseudonyms has been adopted. Each quote will be named using the pseudonym and the page number followed by the line number from the transcript where the quote can be found (e.g. Bob, 10: 81). Finally, I will discuss the overarching theme and explain its relationship to the five super-ordinate interconnected themes as I summarise the chapter.

### 3.2 Super-ordinate theme one: The changing responsibility of self

All participants described a changing responsibility of self. Participant accounts describe how their responsibilities have changed over time, for some this was a burden, for others more a duty. Mia describes how responsibility has changed as she has grown up:

> "…as a child y'know you're someone else's responsibility, as an adult you literally have the reality of like y'know, wow, oh my days..." (Mia, 102:581).

Mia describes being looked after well as a child, her use of the words 'oh my days' illustrate the realisation of the magnitude of responsibility she has for herself as an adult. Alex also feels this huge responsibility as he is living in alone, completely responsible for himself possibly for the first time in his life:

> "…even in my first week of Uni I was actually fight some Cancer so in some way you kind of have the responsibility to know what thing you should do and the consequences" (Alex, 8:52).

Not only does have Alex have responsibility for himself as an adult he describes the huge responsibility of managing a cancer diagnosis and accessing the appropriate care and treatment during his Fresher's week. He reflects shortly after this extract that the negative impact of HIV is that as you get older you have to start to worry about 'tomorrow'. This may mark the end of living in the moment for Alex and the beginning of adulthood and responsibility where you have to also think about the future.

Grace remembers clearly the realisation that she was ultimately responsible for herself when she could no longer rely on her mother for help:

"I will never forget ringing her on the phone and I said somethings not right you need to help me find someone else (referring to a carer) and she didn't, for whatever reason maybe she didn't understand maybe she was too busy but I really really needed someone then I really really did…" (Grace, 45:253).

Grace's need for help is emphasised by the repetition of the word 'really'. She makes excuses for her mother's lack of help possibly to protect herself from the painful feelings of being let down. She continues to say after this extract that from this point on she had to 'grow up', becoming responsible for herself.

Sam, Jacob, Anna and Abi, half of all participants describe as adults that they feel a responsibility to others. Sam describes being a member of 'Unity' and how as an adult he has become a coordinator. His role is looking after the young people who he 'used to be':

"…completely different focus, umm and that focus not being…on me... but for other people, empowering and helping people" (Sam, 1:56)

Jacob reported something similar:

"…the fact that we're unique is kind of a responsibility that we should share our stories at least or share and be able to support people who are in the next generation…" (Jacob, 79:512).

Jacob describes feeling responsible for others because of his unique situation; this suggests that he recognises he is in a special position to be able to help others. He also repeats 'share' twice which may help to emphasise the importance he may place on others sharing their stories, possibly something which may have helped him in the past or on reflection he would have found helpful. This responsibility he feels as part of a unique cohort may also reflect his sense of purpose and how he makes meaning out of being HIV positive a theme explored previously.

Anna wants to be a therapist and is considering her training path, she describes having her own therapy and how helpful it has been and how now it's her turn to help others:

"I'm starting funny enough starting in counselling since September" (Anna, 17:88)

Anna may find this funny because she is being interviewed by me (a trainee counselling psychologist) but it is also possible she finds it funny as it is something she has relied heavily upon for herself in the past. As she goes on to describe after this extract how useful she found therapy this may be the reason she has decided to take on the responsibility of helping others in the future.

Abi reflects on being part of the first generation of individuals to have reached adulthood with PAHIV, appearing unsure whether she thinks this is 'necessarily great or good' she understands that she is part of it nevertheless and with this comes a sense of responsibility for others:

> "…it's like being part of like, something, but not something that's necessarily great or good but something that you can't help be a part of it, but, if you can…be an example to others to show that you…you can basically live and survive and live a healthy life then why not?" (Abi, 36:317)

Emily finds responsibility a more positive aspect of adulthood. She describes how her mum always told her when to take her medication and how restrictive this was for her when younger. She couldn't go places on her own in case she forgot her medication however as an adult she is now responsible for her own medication:

> "…it was fun just to leave the house, go to like a group um, like a youth sleepover and actually grow to look after myself…" (Emily, 32:178).

Emily appears to enjoy the responsibility of remembering to take her own medication possibly as it gave her some independence. The word 'grow' may suggest this is something which has developed over time.

## 3.3 Super-ordinate theme two: Reflecting on a difficult childhood

Participants described their experiences of adulthood often through the process of reflecting on the past. Throughout the analysis, despite the interviews initially being focussed on the participant's current experiences as an adult there was a strong recurrent theme of talking about the past. All participants reflected on their difficulties in childhood, for most the struggle growing up in a family which they imply as an almost different culture to their own. They all reflect heavily on the past which may suggest its overwhelming impact, which still exists today.

Participants describe poor communication with their parents when younger especially about HIV and allude to being culturally and generationally different to them. Here Sam highlights this experience:

> "So we, we talk more and we communicate more, but it's still erm...it's still a bit of taboo, a bit taboo at home, in terms of how open my parents can be and then them kind of...err....they communicate well with each other but I think they struggle to communicate with me because it...because of the length of time from when I found out about my status to kind of now and then they were struggling to kind o'... be able to express themselves, as openly as I'm able to express myself with them because of the gap, the generation gap and then, and what their experiences are (intake of breath) of HIV in Africa and Zimbabwe" (Sam, 37:341).

Sam reflects on his relationship with his parents and the generational and cultural gap between them and himself. This may be Sam's way of rationalising why his parents don't understand him which defends against painful feelings of disconnection. Whilst Sam describes communication improving over time his use of the word 'taboo' suggests that within the family there is a social custom which prohibits or restricts him from discussing HIV more openly. Sam's recognition that his parents communicate well with each other and less with him may suggest that he feels like an 'outsider' in his relationship with his parents. Sam describes always having lived with HIV but not always knowing. Emily also reflects this experience:

> "I just remember when I was younger I didn't even know about my status and I didn't know why I was taking medicine…" (Emily,22:116).

Emily describes being told her HIV status in year 8. She describes how after her diagnosis she educated herself about HIV, learnt about its history and how it came to be so stigmatised. She was also able to reflect and understand why she had been taking medicine. Emily reflects deeply on the process of becoming educated about HIV. Emily's focus on talking about the practical things she did may have been her way of avoiding the emotional impact of HIV at the time or her way of avoiding telling me, the researcher, about the emotional impact. Emily's use of the word 'even' may allude to her extreme surprise that she was not told sooner about her HIV diagnosis suggesting a possible resentment towards her parents that this was kept from her for so long.

**3.3.1 Diagnosis changed self**

Four participants described diagnosis as a life changing moment. Jacob recalls his HIV diagnosis and describes an initial terrifying lack of hope for the future:

> "There was no future when I was younger, definitely no future, it's like I wanted, yeah that's the main difference, when I was younger I felt there was no future, now I'm older than I was, I just feel there is a future" (Jacob, 38:244).

Jacob's fear about the future appears to be something which was located in the past as he specifically says this is how he felt when younger. His use of the word 'definitely' indicates how sure he felt at the time. Jacob further describes how it took a 'while' for him to realise he had 'more to come in life'.   Following his diagnosis Jacob tells me there was a period of time where he could not believe he had a future, concerned predominantly about how long the HIV treatment would keep him alive and whether one day he would become resistant to it.

Mia adopts the use of a hypothetical story about her own children (whom are not yet conceived) to possibly describe her own childhood experience of HIV diagnosis:

> "I wanna be open with them so it's not like a thing where they're you know in the dark cos I think that was me" (Mia, 178:1045).

A few moments later Mia begins to talk in the first person:

> "I wanna (inaudible) understand that you know I have to go hospital and stuff but I was never told until nine, which is a good age but it still didn't register for me" (Mia, 180:1053).

This extract about her 'children' begins as a hypothetical story. The degradation of the pronoun use (from 'them' to 'me' to 'I') may suggest the personal relevance of the story for Mia and may be used to tell her story in a safe and less emotional way. Mia was told her diagnosis at the age of 9, she uses the word 'register' and later 'get to grips with it' suggesting that whilst she had the knowledge of her HIV status she did not really grasp it with understanding.

Whilst many participants described finding out about their HIV status as a shock they also recognised it as a way of making sense of their lives; a theme presented later in this chapter. Grace describes this beautifully:

"When they told me, I was positive, it was like a jigsaw puzzle had started to fit together because it then made sense and that was really weird because most people say that their lives fell apart when they found out they were HIV positive, mine actually made sense" (Grace, 70:396).

Grace uses the metaphor of a puzzle which provided me with an even stronger image in my mind of her experience and may be used by Grace to help her understand her response to her diagnosis. Grace tells me 'most people say that their lives fell apart when they found out they were HIV positive', leaving me wondering who most people are. Grace may be trying to tell me she is different, possibly stronger than others, she may also be alluding to the idea that she feels there is a particular way you should react to an HIV diagnosis. Grace also reflected afterwards how her diagnosis not only helped her make sense of her own life up until that point but also helped a friend who she disclosed to understand her better too and strengthen their relationship. This reflection puts another positive spin on her diagnosis and extends the positivity to her friend, reinforcing the positive aspects of her diagnosis. This positive outlook may have helped facilitate Grace's ability to cope.

For some participants discovering their HIV diagnosis also meant the status of their parents or mother being revealed. Jacob told me:

"I found out about her diagnosis the day I found out about mine and she said it did bring us closer together but like, I still don't want talk about it at first I don't want it to be like I get home an yeah 'You taking your medication?' 'Yeah how about you?' it's like not really the conversation I really wanted, just wanted to be like any other kid…" (Jacob, 42:272).

Jacobs's language of 'her' and 'she' portray a woman as opposed to his mother. This detached speak may be indicative of the feelings of detachment he felt from his mother back then. This is also evidenced when he talks about his mother feeling closer to him through diagnosis with him implying otherwise. His use of a role play within this extract highlights Jacob's disdain for his mother trying to develop a closer relationship with him through their shared HIV status. Jacobs behaviour in this extract reflects upon a 'day' when this all happened which may reflect a particular moment in time which stands out as memorable for him.

**3.3.2 Problems in the family caused by stigma and cultural difference**

This subtheme was expressed by the majority of participants. Alex was given his HIV diagnosis at the age of 15 by his Doctor:

> "Dr told me I was HIV I didn't cry I obviously because of the African society it's very not to cry so I've got to man up" (Alex, 6:38).

I can't imagine for Alex how difficult this must have been. Alex's account appears to define him in a gender specific way emphasising his role as a man but also as an African man. Alex tells me twice that he didn't cry suggesting that whilst he may have wanted to, cultural expectations prevented him. This extract illuminates the strength of cultural norms and expectations placed upon Alex in his childhood. Africa, was highlighted as a place that heavily stigmatises HIV:

> "'there's a big stigma, especially in Uganda, and like related to HIV and that is why, from my parents' generation especially they wouldn't disclose their status, that not even to family members" (Sam, 33:307).

Sam describes stigma as something which is located 'out there' in the world, doing this may help him detach from the personal impact this has on his life. He attempts to normalise HIV by describing it as something that is very normal in Africa. This may help him to make sense of his parent's behaviour within the family and help him understand why he experienced such secrecy and isolation in childhood. Grace echoes this experience:

> "I know there's family members, ver, very close who say things like 'Mmm, How do they, would they live with somebody who's positive, that's crazy, how could they do that? That's just weird' (Grace, 61:344).

In this extract Grace mimics her African Aunts who she was very close to. Her use of their voices illuminates what she hears when they speak around her. Describing the idea of living with people with HIV as weird and crazy allows us insight into how Grace experiences stigma within her own family.

After a drunken family party, Grace can't remember, but fears she disclosed her HIV status, she has not heard from them since and doesn't ever think she will again which she describes as extremely rejecting and hurtful.

### 3.3.3 Anger and blame towards parents for their HIV status

A strong feeling of anger towards their mother or parents when they were younger was explicitly described by four of the participants, with many blaming them for their HIV status as illustrated by Emily:

"…blamed my parents for giving me this condition" (Emily, 54:304).

Emily begins by using the past tense when she talks about blame towards her parents which initially suggest strong blame was something in the past, something which has changed over time. Later Emily describes blaming herself 'too much' and finally states 'we can either keep blaming ourselves or just move on…' Emily's use of the word 'we' may be indicative of her speaking collectively about both herself and her parents or have been adopted in the more formal context of referring to herself. This list of who is to blame feels like a process that Emily may have gone through, by trying to let go of the blame Emily may be attempting to try and accept her diagnosis. Her lack of current acceptance may be represented by the way she refers to her 'condition' instead of HIV.

Grace also talked candidly about her anger towards her mother when she was younger:

"There's nothing I can do about the fact that your mother didn't check you when you were younger" (Grace, 31:173).

Grace begins this extract describing her situation personally but then moves to a more detached narrative by describing her mother as if she was someone else's. This may infer that she is unable to comprehend that her own mother would not check her for HIV. This extract also highlights Grace's perceived lack of control over having HIV infection, placing the full responsibility with her mother. Grace is not able to entertain the idea that her mother may not have known her own HIV status when Grace was born, something which was extremely common in the early days of Mother to Child HIV transmission.

Grace's strong words are coupled with the understanding as an adult that rather than holding such anger and blame for her mother like Emily, it is simply easier 'letting things go'. Grace goes on to describe she cannot change her situation and that it is just 'really unlucky'. By letting things go Grace says she is able to 'take control' suggesting that she may have adopted these strategies as a way of coping.

Sam sums up nicely most participant's experiences of being angry when younger with HIV:

"Yeah, from when I was younger I didn't know what I was doing, I was just, I was angry at a lot of things, I was angry at parents, I was angry at the world, I was a...angry with, at knowing that I had to take a tablet a day for the rest of my life" (Sam, 37:341).

### 3.3.4 Secrecy and isolation within the family

Secrecy and isolation was talked about by 4 participants and alluded to by all. Sam reflects on his childhood and how he kept his emotions and feelings a secret whilst simultaneously isolating himself from family and friends:

"...compared to before where I wouldn't communicate any of my thoughts and then I'd isolate myself and then I'd, so I'd be holding in the emotions, I'd physically be away from everybody and then I wouldn't talk ab...talk about any of that until a week later wh...and... wh...until I arrived at the 'Unity' building" (Sam, 35:325).

As Sam says 'holding in' I imagine a 'container' within which he attempted to conceal his emotions in. His isolation punctuated by his physical withdrawal from others. The 'Unity' building appears to represent a safe space where Sam can release his true feelings. Jacob also describes being able to be himself at 'Unity':

"…once in between these walls I'm, I become myself, I became myself and um soon as I'm out it's like, I felt like I'm lying…" (Jacob, 11: 70).

Jacob describes being in between 'walls' at 'Unity', analogous with a protective space within which his secrets could be shared safely, a space for the real Jacob. As soon as he leaves the safety he must lie once more. 'Unity' has been described by many of the participants as an extremely important safe and non-judgemental environment in which they feel strongly supported, almost like a surrogate family providing them with the nurturing, open environment they lack at home. For some it is the only place they don't feel isolated and able to be themselves, not having to keep their HIV a secret.

Secrecy appears to permeate many of the participant's family's life. Emily describes not being allowed to know her parent's birthday's because it is seen as dishonouring, illustrating how in her culture certain things are extremely secretive. I begin to better understand Emily's predicament and how openness is inherently difficult within her family's culture. She goes on to say:

"We don't really talk about HIV I'm not sure why um yeah I think because it's become a habit where we can't tell anyone so we just grew up with it" (Emily, 9:46).

As an adult Emily told me that she is able to talk about opinions of HIV with her parents if it comes up on the news but not to the extent where she can say 'how it makes me feel'.

### 3.3.5 Numerous struggles at an early age

Four participants described numerous struggles at an early age, with their accounts highlighting the extreme physical, psychological and emotional struggles they experienced at an incredibly young age. Abi explicitly demonstrates this:

"I feel like the worst has happened to me in life already, like...I lost my parents at a young age umm...I found out that I'm HIV at a young age, also I've been homeless before, erm...don't, but don't really like have...much family. I've got like one more sister...erm...I've had a lot of horrible things happen when I was younger and I'm not even 25 yet, so I feel like I'm sort of built to face things…" (Abi, 50:447).

Abi appears to describe these events with a positive twist suggesting at the beginning that the worst has happened and at the end she feels 'sort of built to face things'. The words 'sort of' may suggest that this is not necessarily the case. Perhaps also this extract implies some type of searching and questioning why this all happened to her.

Anna talks about the emotional impact of HIV in childhood and adolescence describing 'holding a lot in' which resulted in her appearing out of control to others:

"I was a, I was what you call a case study when I was younger, I was jus, I don't know, I was wild I was reckless and everything I jus, I didn't care… I don't know, I think I just thought about myself" (Anna, 53:286).

Describing herself as a case study Anna elicits the idea that her behaviour could fill a whole report, illustrating the enormity of her 'reckless' behaviour. Anna's difficulty to articulate how she is feeling in this particular extract may reflect her struggle through childhood further. Anna's lack of care about others and egocentric/hedonistic existence at this time may have been an important way for her to seek some sort of pleasure in life, an important part of putting herself first at such a difficult time whilst possibly experiencing denial.

**3.4 Super-ordinate theme three: 'The stigma barrier**

The profound effect of stigma was described by all participants. Stigma appears to have a direct impact upon the lives of each participant, including the way in which they can make friends, have loving relationships with others but also how they see themselves and their difference. Sam questions why stigma is so prevalent and describes its damaging effect on relationships:

"Why is there such a stigma attached to HIV and... ehh.. ...an... why is that stigma always, not always but most of the time attached to particular minority groups or, or, or kind of, used as a, as a, kind of, used as a barrier between people" (Sam, 48:447).

Sam suggests stigma is attached to particular minority groups. This reflects not only Sam's experience of stigma in relation to HIV but also towards himself as belonging to an ethnic minority group. Jacob shares Sam's pain of experiencing stigma as a child:

"I couldn't tell anyone and I thought about many stigmas and many um many things, many stories, I read about all the stories about HIV in the paper (inaudible) an then listen to people in the playground laugh about it an I'm just there quietly trying to chuckle along…" (Jacob, 74:474).

To place this reflection into context, the type of knowledge Jacob describes people having when he was a child in the playground is nicely described at the beginning of the transcript:

"…my mum told me that I've got HIV and obviously my knowledge of it was, was just um Mark Fowler story in EastEnders…" (Jacob, 5:27)

This example highlights not only how long ago Jacob was born but also where people were getting their knowledge from. This lack of knowledge about HIV which still exists today continues to fuel stigma about HIV. Sam also describes stigma as something which occurs due to poor education and knowledge:

"HIV is seen as this...curse, th ...this disease and it's an absolute taboo"
(Sam, 52:485).

Shortly before this excerpt Sam described how his parents were given the wrong information about HIV and how they passed it on to him. Describing HIV as a curse suggests it is seen as an evil force and great misfortune and may provide some insight into why HIV is so highly stigmatised in African culture.

### 3.4.1 A secret life

Living a secret life was talked about by four participants but secrecy appeared implicitly evident in all participant's accounts including those illustrated in the previous sub theme: Secrecy and isolation within the family. Jacob told me that his HIV status was kept a secret from his younger sister, she did not know what was going on and describes HIV as something simply not spoken about:

> " …she living in a house oblivious (Jacob's Sister) so it's just that little secret in the house, and then just coming , so coming to 'Unity' where I could share stuff but, it's like 'Unity' was like this kind of affair it's like I don't know, I kind of sneak away and then , I'm opening up and then I go back to school to my mates or go back home and then I'm hiding the lie" (Jacob, 44:284).

Secrecy is highlighted here by Jacob's use of the word affair and how he feels he 'sneaks' around. This stigma continues as the participants grow and they begin to live lives outside the immediate family.

Jacob told me that now that he is older more people know about his HIV status including his friends and siblings. Whilst trying to say he no longer hides this secret away from others Jacob tells me:

> "I'm not hiding away, I'm not hiding that secret from myself, um from others I mean" (Jacob, 45:290).

His slip of the tongue may suggest that whilst Jacob was keeping HIV a secret from others when younger he may have also been hiding it from himself in the form of denial.

Alex also describes his secret life at university, his friends' question why his house is so tidy and he doesn't feel able to tell them it's because he worries about catching diseases. Alex hides his medication and sometimes doesn't take it if he is out at a party with his friends. Alex lies to them and tells them he can't drink alcohol because he has to get up the next day

but it's actually because he needs to stick to his treatment regimen, he says he lies to 'protect' himself and leads a double life:

> "…lead a double life" (Alex, 12:79).

### 3.4.2 Perception of self by others

Half the participants described concerns regarding perception of self by others. Mia illustrates her concern that people will assume her HIV was contracted through sexual transmission:

> "I didn't sleep with anybody, prior to ending up with my status" (Mia, 89:506).

Mia talks about sexual relationships and how others can just jump into bed with people but she can't. She feels that she is unable to explain to partners that she has HIV because she has never had sex. This also means having a conversation where her family's HIV status would need to be revealed.

Others fear they are seen as different or unfavourably because they have HIV as recounted by Abi:

> "I don't want them to use it a...against me to make me feel like I'm less than them" (Abi, 19:170).

This extract conjures up images of HIV being a weapon, something to be used to harm someone, Abi suggests here that having HIV makes her feel inferior and different to HIV negative individuals. Abi also describes pity and people's attitudes changing towards her illuminating further reason why some participants didn't want to tell people their status:

> "…problem is being able to be comfortable to tell people and knowing that things aren't going to change if you tell them" (Abi, 13:113).

Alex agrees with Abi:

> "…I don't want them to kind of feel sorry for me that's one of the things (inaudible) because people know like you have XYZ and they feel sorry for you, for me I just want to be treated as a normal human being" (Alex, 31:209).

Alex does not want pity, his desire to be treated as 'normal', suggests in contrast that he may experience others treating him as 'abnormal' and therefore different because he is living with HIV.  The concept of normalcy was referred to regularly during interviews across all participants as they yearned to not be seen as different.

### 3.4.3 'Keep reducing stigma bit by bit'

Two of the eight participants described wanting to educate others about HIV. Sam says:

> "…it's just the lack of knowledge and I've got like so many different ideas I don't know how to articulate or an ah, umm...it's just being part of this generation, it feels like we need to make sure that people are knowledgeable about exactly what HIV is, in comparison to what AIDS" (Sam, 49:451).

Sam repeats 'knowledge' in this extract which emphasises the importance he feels others knowledge of HIV is. It suggests that society's lack of knowledge is a huge problem for Sam. This need for others to be better educated about HIV and by extension less judgmental may reflect Sam's personal desire to live in a less stigmatised society.  Alex extends this idea by describing his life no longer being about him but about others, he jokes about becoming a voice for people with HIV:

> "I feel like an Ambassador for HIV" (Alex, 63:424).

He also describes what this would mean for him:

> "…it's kind of like a privilege you stand up in a way like you stand up for something you believe and that something you believe is you can show the people a different angle of what I think should be done and what I think they should believe" (Alex, 65:437).

Alex is directly describing how he wants to change people's beliefs about HIV and show people a different perspective. Through changing society's perspective on HIV this may for Alex reduce some difficulties he experiences because of stigma. As he repeats 'stand-up' I wonder if he wishes he could one day stand tall and proud to be HIV positive.

Alex' humour in the above extract as he describes wanting to be an 'Ambassador for HIV' may indicate a nervous disposition which also surrounds him. Despite wanting to share his knowledge of HIV, there is also a part of him which is scared. Giving people information about HIV means his HIV status may no longer remain confidential, his fears are demonstrated below:

"some people say something about HIV or something horrible I just kind of ignore them, make like I didn't hear nothing but for me I think (inaudible) ignorance of these people but one of the reasons is I'm scared that I might give something with passion but when I give passion some people ask you why? so from that day I fear (inaudible) because I'm HIV and you cannot tell but sometimes like you just prefer to listen to them speak but inside you are actually dying" (Alex, 18:121).

As Alex speaks I can hear he is angry, his anger directed at the ignorance of others but possibly also towards himself as he feels impotent in being able to correct and educate them for fear of risking disclosure of his own HIV status. This illustrates the individual but also wider struggle with reducing the stigma of HIV. A vicious circle exists of wanting more education for others to reduce stigma, but needing stigma to be reduced significantly in order to feel safe enough to educate others and not fear disclosing your status.

**3.4.4 Negotiating a sexual relationship with HIV even if you have never had sex**.
The universally described negative impact of HIV on sexual relationships appeared in all participant accounts. Some described never having a sexual partner, some only partners that were positive, two described having a sero-discordant sexual relationship. Fear around sexual relationships includes the personal risk of rejection and the risk to others of passing on HIV as described by Jacob:

"…never forgive myself if I infected anyone else" (Jacob, 25:162).

Jacob describes this as his biggest worry when it comes to sexual relationships. He describes blocking previous attempts at relationships because of this fear. Following this extract Jacob repeats twice that he would never forgive himself if he passed on HIV to a partner. This emphasises his fear but may also suggest his contempt for his mother, the source of his own HIV infection and how negative he feels about having HIV.

Abi suggested that a sexual relationship may never be possible because of HIV:

> "I now don't know if I can ever have a relationship with anyone without them...um freaking out, that I'm positive" (Abi, 58:331).

The use of the words 'freaking out' in this excerpt suggest the extreme reaction that Abi anticipates from a future partner if she was ever to disclose her HIV status. Another participant Sam describes complete emotional disconnection from anyone to protect himself from ever having to disclose his status:

> "I was fearful of having the conversation. If I got emotionally attached to somebody I'd have to tell them I'm HIV positive" (Sam, 38:353).

Sam describes the function of emotionally disengaging from others as a way of protecting himself.

### 3.4.5 'Biggest killer of HIV'

Societies continued perception of HIV and the impact of stigma on those living with HIV was described by three participants and is poignantly illustrated by Jacob:

> "There's still a lot of stigma I still think that's the biggest killer of HIV um, people living with HIV" (Jacob, 81:514).

Jacob metaphorically describes stigma as the biggest killer of people with HIV, suggesting that stigma is more likely to kill you as opposed to HIV itself; this illustrates its centrality and enormity for Jacob.

Grace describes stigma as something that she will never get away from:

> "I've got this positive label on me, really who's gonna be in love now with me?" (Grace, 104:595).

The use of the word 'label' intimates that Grace has been stamped and marked with HIV, like stigma, a mark of disgrace, something that she will be unable to change or shift and something which makes her sadly unlovable.

**3.5 Super-ordinate theme four: Development of sense of self**

Development suggests evolution and growth, something which all participants described in their interviews; in particular, their development of sense of self stood out. An individual's sense of self can be defined as the way in which individuals think about and view their own beliefs, traits and purpose within the world, something which is always changing. This involves dynamically both the 'inner' and 'outer' self.

**3.5.1 Purpose and achievement gives a focus**

The majority of participants described achievement as an extremely important part of their lives. Having goals to work towards especially regarding building a family and getting a job appears to provide a sense of purpose and accomplishment. Emily describes wanting to be able to do in life what 'most people' do, getting her own home, children and job, when asked what this would be like for her to have these things this is what Emily said:

> "…I think it'll be a sense of accomplishment and, that I managed to get this far and it doesn't matter what you go through or your status, you could still achieve what you want to achieve and there are some people out there that have already done that, despite their status and yeah I think it's a sense of accomplishment and just giving other people that hope as well that they can make it as well" (Emily: 48:270).

Emily's extract illuminates the fact that Emily may not have previously thought she would ever have these things. She repeats the words 'achieve' and 'accomplishment' emphasising the enormity of importance it holds for her. Emily appears to be somewhat surprised that others with HIV could achieve their goals and this is highlighted by her use of the word 'despite'. However, Emily appears to find hope in the stories of others achievements. As Emily describes wanting what 'most people' have she eludes to the idea she that wishes for the same opportunities as others. Through endeavouring to achieve these things Emily's life holds an important purpose and may help develop her self-esteem and self-image. At the end of the extract Emily also describes giving other people hope. This is echoed by Sam who sees helping others as his purpose in life.

> "It would mean that I've (sighs) served a purpose in a way like as in my journey has served a purpose, it wasn't just for me, 'cause it, it doesn't feel validated if it's just for me 'cause then I've kind of kept this tool and I've not allowed other people to access that for themselves and help them learn that, erm... so it would be validating to know that it's not just, it wasn't just a coincidence that I was able to kind of start thinking the

way that I do or feeling the way that I do that other people are able to experience that I can help them, the system to do that" (Sam 14:122).

Sam's brief sigh suggests a possible longing for his life to feel like it serves a purpose. The importance of purpose in his life is emphasised through his use of this word twice in close succession. This is followed by the declaration that without helping others, his life would ultimately not feel validated. If Sam can see himself as someone who can help others and make a difference it may help him develop his self-image.

### 3.5.2 Trying to make sense of the self

In this first extract Grace begins to question some of her recent reasons for drinking excessively:

> "…am I drinking because of her (Mother)? Or am I drinking because I'm positive? Or am I drinking because I'm disabled? Or am I drinking because I haven't got erm, a love interest in my life…" (Grace, 18:97).

Grace asks herself many difficult questions one after the other. By asking herself these questions she may be alluding to the idea that knowing the answers may somehow help her to better understand herself. Finally, towards the end of the transcript Grace describes trying to understand why she gets so angry with her carers for not bringing her shower chair when she needs it.  She has come to realise through personal reflection her lack of independence, and control over life is the real reason for her anger towards the carers:

> "…maybe the shower chair represents the fact that I can't control my life…"
> (Grace, 98:559).

Grace later reflects on this saying she is just trying her best to be in control of what she can. In this moment, she is able to make sense of her anger which may help her to cope with it better in the future. Mia also has many unanswered questions:

> "…you know sometimes I have questions and I think there's no one really I prefer to speak about this other than my mum and then the moment I started to learn more about her and she was yeah, it made sense…" (Mia, 228:1340).

Mia's wish to ask her mum questions demonstrates her desire to try and understand more about her past. At the end of this extract Mia describes finding out more about her mother

(who has passed away) which she says helps her to 'make sense' of things.  What makes sense for Mia is unfortunately not explored any further within this transcript.

Making sense of the self for others led to questions regarding why they are still alive:

> "I used to get thinking like, why not me? Or I just think I am next" (Mia, 36:193).

Mia attempts to understand herself through exploring her mother's history reminds me of the therapeutic, psychodynamic approach which suggests our behaviour and feelings as adults (including psychological problems) are rooted in our childhood experiences, especially our relationships with caregivers. Having lost two close friends growing up because of HIV, Anna describes struggling to make sense of how she is still alive; demonstrated by the questions she asks herself. Anna goes on to explain after this extract that dwelling on things can make her 'depressed' and its best to keep 'moving forwards'.  Anna's need to keep moving forward suggests she wishes to try and leave something behind, for Anna trying to make sense of these unanswerable questions may be too difficult to face. Grace has also lost friends and tries to make sense of how she is alive:

> "…it's not that I wanna die or anything like that, it's just that if we take it with Science then I'm supposed to not be on this earth" (Grace, 82: 466)

Grace attempts to make sense of her situation by comparing herself to her friends who have died. Grace describes that if we use the knowledge that science has previously provided us with she should be dead. This illuminates Grace's experience of living beyond medical expectation, something difficult to make sense of.

### 3.5.3 Learning through experience

Seven participants described learning through experience. Anna describes never thinking before she acted when younger. In adulthood, Anna has learnt to manage herself differently, weighing up pros and cons and deciding which paths to take in certain situations. If her decisions do go wrong she doesn't focus on 'regret' but instead calls it:

> "…a learning experience" (Anna, 52: 278).

Anna describes learning from previous experiences as a helpful tool which is echoed by Mia:

"I think when you learn things for yourself it sticks more because you've had to remember it yourself, whereas when someone tells you something ...(pause) it's not the same" (Mia, 17:89).

Anna describes something which cannot be taught, the art of developing your own skills to cope. Mia uses the word 'sticks' which illustrates that if you learn something yourself it is more likely to stay with you. As Mia pauses I wonder if in the past she has experienced many people telling her what to do which has not been helpful.

### 3.5.4 Support and therapy

Notably all participants were attending 'Unity' a charitable organisation which provides support. Not surprisingly therefore the importance of good support was described by the majority of participants and alluded to by all, with many stating 'Unity' as one of the most important sources of support available to them.  'Unity' aims to facilitate and develop self-image, self-esteem and identity and with this kind of support, appears to have helped participants make sense of their situation and lives.

"I'm trying to think where I would be as a person if I didn't have the support system like 'Unity'" (Jacob, 19:123).

Grace agrees and describes what it is that is most helpful about such a charity:

"I don't have to come here and talk about being HIV positive, I can come here and talk about other things and then if I wanna talk about being positive I can do that without being judged" (Grace, 123:703).

Grace is describing a space which is non-judgemental and an open forum to speak about whatever she likes, whether it's related to HIV or not. This non-judgmental environment helps develop confidence and self-esteem. By suggesting the importance of being able to speak about all things apart from just HIV I wonder if Grace may be alluding to the fact that other services or professionals always think you need to talk about HIV to be helpful which you don't. This is something I have heard many times anecdotally in the past.  Mia describes nicely how 'Unity' helps her:

"you come here and I speak to other people and they go through the same stuff and it makes me think oh!.." (Mia, 60:339).

Shortly before this extract Mia had been feeling dehydrated and fatigued and described having no idea why. Through attending 'Unity' and speaking to others in a similar situation she was able to recognise that some of her symptoms were experienced by others. Talking to others helped her normalise what was going on and make sense of it. Mia's use of the word 'oh' followed by a pause suggests that she was surprised by what she heard and that what she heard was something new, suddenly something she thought previously to be living alone with and difficult to understand became easier.

## 3.6 Super-ordinate theme five: Managing uncertainty

> "I never expected to be an adult…" (Jacob, 89:567).

This extract reflects the belief held by not only Jacob when he was younger but also the entire medical discipline. At the time the participants were born, medical professionals did not believe PAHIV+ children would reach adulthood, and with no current medical evidence to guide and inform us of how long they will live in the future, these individuals have to manage the uncertainty of physically surviving with HIV coupled with the ongoing psychological impact of this uncertainty, something they have all lived with for many years. It is therefore not surprising that all participant accounts illuminate this uncertainty. Participant accounts also suggest they have developed ways to manage this uncertainty, whether consciously or unconsciously.

### 3.6.1 'I choose to focus on better things'

Mia describes how she often feels upset and trapped by her life but chooses to think positively:

> "… you know there's quite a few days feel upset, you know like it's not, don't get it twisted, my life is very … cos I choose to focus on better things, I have a good life…" (Mia, 161:942).

This extract illustrates how Mia often feels upset. Telling me not to get it twisted may suggest she does not want me to get things the round the wrong way, it may be important to Mia to portray a positive image of herself to others. Mia then switches to telling me that her life is good and that she chooses to focus on the positives, this may be her way of coping with such difficulties. Emily also focusses on the positives despite living through such negative times:

"I have heard stories of people who are like my age, some of them couldn't make it, like they passed away at the same age as me, um, when I was younger, but um, it just encouraged me to look after myself more and just to remind myself that life is, you have to, enjoy what you have…" (Emily, 36:200).

Emily may use social comparison to try and make her situation easier to bare. By comparing herself to others in less fortunate situations this enables her to create a more positive outlook and use these experiences as a way of motivating herself. As she describes having to remind herself to 'enjoy what you have' I wonder how much enjoyment in life she really experiences, a thought supported by the use of such a cliché. Sam describes how HIV has changed his path in a positive way, he wanted to be a footballer when younger but describes giving up one 'dream' and discovering another:

"I look back at it I don't feel as though it's a wasted opportunity I feel as though it's something that made me a bit stronger and it's because I was HIV positive" (Sam, 64:599).

Sam reflects on his younger years and how he initially 'gave up' his dreams. His use of the words 'wasted opportunity' may allude to how he used to feel about his life with HIV. As an adult, he describes a more positive way of thinking, going on to describe 'an entirely new him'.

### 3.6.2 'Russian Roulette'

Nearly all participants talk about the loss of someone close in their lifetime, mainly friends and family, including parents. This loss of others, often at such a young age, along with the uncertainty of how long medication will keep them alive, lead the majority of participants to question how long they had to live.  Anna describes this uncertainty:

"…HIV is like a, a domino effect where one goes down and the rest all go down (inaudible) and because the time they passed was very close, so it's like was a two-year gap so I'm just thinking, Am I gonna be the next one in two years?" (Anna, 29: 155).

Anna uses the analogy of a domino effect to illustrate her fear that once one person has died that she knows the next will follow in short succession, shorty followed by her. The way Anna is thinking is reminiscent of what is often described in later stages of life when people

experience the multiple losses of friends and family and begin to wonder when their time will come. Grace describes her future as a game of 'Russian Roulette':

> "…you're always sometimes looking back and you're looking back because you're thinking to yourself 'Is this the day?' I've live through this for quite a while…am I just playing Russian roulette …" (Grace, 31:14).

Grace questions how long she will live and describes it as a lethal game of chance; this may suggest that she feels lucky to still be alive whilst uncertain how much longer for. Another reason highlighted by Abi and Anna for feeling uncertain about their future is the loss of their parents at such a young age:

> "…my mum died in her twenties from it so I just think that I'd get past certain age (inaudible) ok she dies, she died at 29 and I just think I still now think 'Will I make it past twenty nine?'" (Anna, 25:132).

Anna compares herself to her mother using her death to benchmark her own longevity. Abi describes a similar process:

> "…one of my biggest fears, has always been, if I have children, then I'm gonna end up dying like my parents did" (Abi, 26:235).

Abi's fear of dying when her children are still young may reflect her own traumatic childhood as she describes the loss of her father when she was five and her mother when she was nine. Abi fears that if she has children and she dies that they will be left alone to deal with HIV and would hear their status from someone else. She fears that they won't even remember her. This fear about the future may reflect what actually happened to Abi as a child.

### 3.6.3 Disclosure is like 'Giving away a secret'

Disclosing your HIV status involves risk and uncertainty: the risk of rejection and the risk and uncertainty of your HIV status becoming public knowledge. The majority of participants held the view that disclosure could be both a positive and negative experience. Sam describes disclosing his status to his friends when he was 15 years old and how this process involved these divergent ways of thinking:

"…it felt like there was a lot of, from that point on there was a lot of... from that point on there was a lot of development that came out of it,…erm, because (intake of breath) you kind of... you...you're putting yourself out there, you're leaving yourself vulnerable and you're allowing people into your world and into your zone and to understand (intake of breath) all of the turmoil and all of the chaos and all of the, all of the fear that you are experiencing or have been experiencing and then once they're aware of that oh well at least what the, what the cause was that, then...all other pieces of information sometimes piece together to make sense for them but then also for you...it's...it feels really erm... cleansing because you're able then to have different conversations" (Sam, 19:175).

Sam describes the dichotomy faced with disclosing your status; the vulnerability that you risk because you don't know how others will respond and the positive aspects of a disclosure if things go well. The hesitations and stuttering in the extract suggest that this was difficult for Sam to articulate possibly due to the emotive nature of what he was telling me. Sam describes the extent of the risk by the using of the words 'putting yourself out there' and 'leaving yourself vulnerable'. Describing disclosure as letting people into your world suggests that two worlds may exist for Sam which echoes the 'double life' experienced by Alex in a previous excerpt.

Anna describes disclosure as a largely uncertain process:

"You got that one conversation like to just, go well or go really badly"
(Anna, 86:469).

The use of the word 'really' in this excerpt may suggest that a bad outcome feels more likely for Anna. Anna goes on to describe a past disclosure to a partner which went well at the time, however when they broke up she went through 'hell' as he wanted to tell people about her HIV status resulting in her having to seek legal advice and closing down her social media accounts.

### 3.6.4 A need for control
The majority of participants described a lack of control over their health due to its uncertain and unpredictable nature:

"...it's either I'm really healthy or I'm unwell" (Mia, 7:34).

Mia describes the two extremes of her health; the use of the word 'really' appears to accentuate the distance between the two polar opposites. This may suggest her health never feeling balanced or within her control. Anna also described her health as unpredictable which has a huge impact on her career progression as she has recently had to spend time in and out of hospital appointments:

"yeah, obviously with being...with my health it can be unpredictable at times, so at times when I do get ill it kind of puts a dampener on things" (Anna, 15:79).

Anna appears to avoid using the word HIV at the beginning of this extract instead choosing to use the word health. It may suggest that it is easier to cope with a lack of control over your health as opposed to HIV. Mia also describes her health as unpredictable:

"I was fine last week and now its just be , they, they, they might have to do surgery and its like, what on earth, what?" (Mia, 103:586).

Mia reflects on the way her health can change so much in such a small space of time demonstrating its unpredictable nature and her lack of control over it.

Below, Abi describes the multitude of things she has little or no control over, something which she would desperately like. This extract also encapsulates the uncertainty about her life expectancy mirrored in other themes presented within this chapter:

"I wouldn't have to worry about getting in a relationship, I wouldn't have to worry about telling people about my status and having...and possibly worrying that they come up to you and say...(inaudible), oh, I wouldn't have to worry about not being myself around people, I wouldn't have to worry about people using my status against me or telling other people, I wouldn't, erm...I would...wouldn't worry about taking medication every day, or what would happen if I don't take it, I wouldn't worry about, what if my medication stopped working one day, what if...the...there's no medication that helps me anymore, what if I catch like a really, really bi...a...big infection that I can't fight off, just things like that" (Abi, 52:466).

Worry appears to be the main concern within this extract. For Abi it may be easier to list all the things that she wouldn't have to worry about if HIV negative as opposed to all the things she does have to worry about being HIV positive. This list of worries summarises well the magnitude of problems faced by most participants.

### 3.6.5 Acceptance?

Alex describes how he feels he has accepted his HIV positive status:

> "…because for me HIV is now part of me…" (Alex, 32:214).

The way Alex describes HIV being 'part' of him suggests a more integrated self with HIV, an acceptance and welcoming of it. Jacob also describes HIV being within him:

> "I've now conquered this great thing within me and it's still gonna be within me but it's, just take my meds it's like brush my teeth every day and then, then carry on with life" (Jacob, 20:129).

He describes HIV as a 'great' thing he has overcome illustrating its magnitude and defeat. He also describes it as 'within' him suggesting it is now a part of him. As he describes his daily tasks, using brushing his teeth to demonstrate mindless routine, this may illustrate that he has accepted HIV in the same way you accept that teeth just have to be brushed.

Two participants experience of acceptance of HIV diverged greatly from this, Grace describes the struggle of finding a partner, uncertainty regarding ever having children and how sexual intercourse will never be great because HIV is always in the 'back of your mind'. Grace poignantly illuminates how she feels about having HIV:

> "I hate being positive, it's not fair, it's not fair…(29 second pause)" (Grace, 107:617).

The long pause following Grace's words produce a torrent of tears, her sadness filling the room. In the silence, I feel her pain, pass her a tissue and wait, giving her space. Grace then wipes her eyes and laughs saying 'that's it'. Grace may use humour to move away from her painful feelings. Abi sometimes wishes she didn't have HIV either, she sees her friends complain about their problems which feels insignificant when she thinks about herself:

> "'I just think oh I wish I had that problem instead, like, I wish I could like just swap lives for like a day or two, it would be a breeze for me" (Abi, 51:459).

Abi later reflects on what she has said:

> "…at the end of the day I feel happy being who I am, I wouldn't want to be anyone else …but (laughs) there are things we'd all like to change…" (Abi, 53:476).

Abi's use of the word 'but' followed by a short laugh and the idea that we all have things we'd like to change, suggest she may not have accepted her HIV but speaks like this as a way of coping.

**3.7 Overarching theme: Evolving journey**

Within each super-ordinate theme presented above, participants experiences appeared to have changed over time, as they both explicitly and implicitly describe what appears to be an 'Evolving journey'. Grace, like the other participants alluded to how life was a journey:

> "I can see myself actually getting to grips with 'this is life this is how it is' instead of lying in my bed feeling sorry for myself, umm yeah, cos that's how it was before, it was it was tough" (Grace, 2:7).

Grace describes seeing herself as different in the future, a self with a firmer hold on life. This difference is accentuated by her comparison to herself in the past. This extract nicely reflects how far Grace has come on her Journey. Grace also explicitly reflects on her life as a journey:

> "…I've been able to um pick myself up and, and myself you know, do it my way and umm get there but it, it's, it's always a journey, I think that's' the problem, people think that there's a, there's an answer to something, like a 'one tick' answer and then everything will be fine and that's just not life" (Grace, 2:12)

Grace also describes 'getting there' which illustrates her sense of movement towards a new place.

**3.8 Summary**

My interpretation of the participant's interpretation of their experiences of reaching adulthood whilst living with PAHIV has been captured here through the interpretative phenomenological analysis of transcripts from eight participant interviews. All participants provided me with their moving, sometimes distressing stories from which this data has emerged. Whilst the analysis reveals five separate super-ordinate themes characterising the experience of

reaching adulthood with PAHIV the interconnectedness between them must not be ignored. The experience of reaching adulthood appears to be strongly characterised by participant's experience of stigma which can be seen to permeate all other super-ordinate themes, especially found as participants reflected on a difficult childhood and the impact of stigma on their development of sense of self. Stigma was talked about when participants described the fear of disclosing their HIV status in relationships and discussed further by some as they talk about their responsibility as an adult to reduce stigma amongst their peers and in society.

As participants were asked about their adult life they all did this by reflecting on their life experiences from childhood, through their teens and into their twenties. Within each super-ordinate theme, there appears to be a suggestion of change over time, therefore in the attempt to illuminate what it is like to reach adulthood with PAHIV what has also emerged is each participant's individual 'Evolving journey' which had led them to this point in time. These participants, who identify as having experienced wide ranging and often challenging life events from an extremely young age, have learnt from this journey, through experience, how to manage their lives in the best way they can. Therefore, an evolving journey is a central organising feature of the five super-ordinate themes. The overarching theme and each independent super-ordinate theme helps shine a light on the next and should not be considered in isolation.

### 3.9 Analysis reflexivity

Whilst carrying out the analysis I have been challenged to make some important decisions. Please see Appendix P for my analysis reflexivity diary which provides insight into why I have arranged the themes in this way and why I think they now make sense placed where they are. Illustrated is some of the most important questions I asked myself, followed by my thinking process and finally my resolve. This is not an exhaustive list of questions I asked myself and I am not suggesting that there is a right or wrong way to answer my questions rather; my intention is to provide the reader with some insight behind my thinking.

# 4.0 Discussion

This chapter reviews the findings from this study in relation to the research aims and question. As the analysis chapter provides a detailed description of the findings from this study, instead of reflecting on each individual theme I will consider the research findings in relation to existing literature, theories and concepts. I will provide an overview of the psychological implications of living with PAHIV and some suggestions regarding psychological models of therapy for working therapeutically with these individuals. Clinical implications and considerations for Counselling Psychology followed by some suggestions for future research and a brief conclusion will draw this research to a close.

## 4.1 Research aims and summary of results

This research intended to illuminate PAHIV+ individuals subjective experience of reaching adulthood, a unique medical phenomenon for those living with HIV since birth. The objectives of this research were met as the young adults directly shared their stories and had their voices heard through in depth semi structured interviews. As discussed in the methodology chapter this research was undertaken for various reasons including to provide an insight into this phenomenon for others living with PAHIV; especially those who are younger or have little or limited contact with others living with PAHIV. Whilst also developing the knowledge base for Counselling Psychologists from which to deliver context specific, individualised psychological treatment, thus enhancing client experience. Participants recruited were between 23-28 years old providing an insight into an older cohort than previously found in any other qualitative studies looking at the experience of PAHIV+ individuals in adulthood. Five super-ordinate themes characterising this experience emerged from the data: 'The changing responsibility of self', 'Reflecting on a difficult childhood', 'The stigma barrier', 'Development of sense of self' and 'Managing uncertainty'. One overarching theme which permeates and connects these is an: Evolving journey.

Findings suggest that although this research was focussed on participant's subjective experience of reaching adulthood, what emerged, was that participants make sense of this by reflecting on their past, how their experiences have changed over time and what they learnt either implicitly or explicitly along the way. Therefore, an 'Evolving journey', appears to strongly characterise the way participants currently experience and make sense of reaching adulthood.

**4.2 Discussion of findings in context**

This current study revealed four similar themes to the five found by Rydstrom, Ygge, Tingberg, Navar & Eriksson, (2013) in their landmark study, discussed in the introduction. Both studies, conducted several years apart, with participants of different ages, living in different countries, with different laws, appear to reveal that participants share many similar experiences, suggesting validity of findings.

Both studies suggest participants want to protect themselves from stigma, have more control over their lives, have experienced loss, and described the right support as an extremely important aspect to coping with the consequences of living with PAHIV. Whilst the fifth theme reported by Rydstrom et al. (2013) 'HIV is not a big deal' was not found in this current study, participants did talk about accepting their HIV and thinking positively about their status. As this study adopted IPA instead of content analysis and data was psychologically interpreted, by myself, a trainee Counselling Psychologist, it allowed me to extend participants accounts to suggest acceptance of their HIV and positive thinking may have been adopted as coping strategies to manage the uncertainty of living with PAHIV. This therefore raises the question; Do the participants in the previous study experience living with PAHIV as 'not a big deal' or do they adopt this as a way of coping psychologically with the difficulties they face? Likewise, the theme 'a need for control' found in this current study, which appears similar to the theme 'to be in control' found previously (Rydstrom et al., 2013) has also been psychologically interpreted and suggests participants 'need control' in order to manage uncertainty. Therefore, whilst there appear to be similarities in participant's experiences across both studies, by going beyond the data and psychologically interpreting it, this current study extends some of these previous findings.

In line with previous research, some participants in this study described their HIV status being kept from them for too long when younger (Lesch et al., 2007); possibly due to parent's fear regarding enacted stigma on the family (Fielden et al., 2006; Lyon & D'Angelo, 2006). Some participants in this study, when told their HIV status, described it as a defining moment in their illness trajectory in line with findings from Dorrell and Katz (2013). Other findings from this current study were backed up by previous research including; numerous struggles at an early age (Lewis et al., 2015), family disruption due to illness and death (Elliott-DeSorbo et al., 2009; Martinez, Hosek, & Carleton, 2009), that disclosure could be both a positive and negative experience, with participant's wanting more control over

disclosure of their status (Sui et al., 2012) and that disclosure was not a one off event but a process (Cusick, 1999; Obermeyer, Baijal, & Pegurri, 2011). Further findings from this current study reflected in the literature, revealed fear around sexual relationships especially passing on HIV, personal risk of rejection (Fielden et al., 2006; Hosek, Harper & Domanico, 2000; Michaud et al., 2009), and fear regarding the uncertainty they face in the future (Lewis et al., 2015). Participants fear about the future and how long they will live may reflect the medical concerns that PAHIV+ individuals are at high risk of experiencing multiclass ARV drug resistance and thus treatment failure in the future (Fogel et al., 2013).

This current study suggests, in line with previous research that fear of stigma can lead to; fear of rejection by others if HIV status is discovered (Fernet et al., 2011; Fair & Albright, 2012); a lack of HIV disclosure causing individuals to become socially isolated; and fear of being treated differently by friends, family and wider society (Flowers et al., (2006). Also in line with previous research, participants' fear regarding disclosure, how others might perceive them, the uncertainty regarding how others might react and consequently keeping HIV secret (Hogwood, Campbell & Butler, 2013) were also found.

Findings from this study are also reflected in some very recent international literature (Williams, 2017; Woollett, Cluver, Hatcher & Brahmbhatt, 2016). Williams' (2017) qualitative study discussed earlier described participants' experiences of adulthood as characterised by isolation, secrecy, stigma, unpredictable health, uncertainty regarding disclosure, anger at parents, secrecy within the family and the desire to think more positively in the future, all found in this current study. This suggests the qualitative findings from this study may be transferable across a variety of cohorts across different countries.

Positive findings permeate this current study's analysis chapter, suggesting for some participants they are experiencing post traumatic growth. Findings suggest some participants have developed resilience and a determination to help others, coping strategies to manage the psychological impact of living with PAHIV, ways of adapting over time throughout their 'evolving journey' by learning from experience, developing their sense of self and accessing the right support and managing the changing responsibilities that growing up with HIV has brought them. These findings are reflected in a recent qualitative study carried out across HIV clinics in Johannesburg, South Africa aimed to identify elements of resilience amongst a

group of PAHIV+ adolescents (Woollett, Cluver, Hatcher & Brahmbhatt, 2016). Twenty-five in depth interviews were conducted with 15 females and 10 males, 13-19-year-old PAHIV+ adolescents. Data was analysed in NVIVO 10 with coding carried out utilising a thematic approach. A high level of resilience was described despite marked stressors in the adolescents' lives. Resilience was characterised by a set of beliefs, including a belief in fate and because of their adversity, the recognition of their own personal strength. Robust self-esteem, actively taking responsibility for themselves and pragmatic acceptance were all evident. Other findings included an appreciation of challenges they had been through which was a measure of their personal resilience which validated their ability to cope and a pragmatic acceptance about their lives and their diagnosis. Respondents talked about needing to take responsibility for their own lives and health, discussed the 'desire to support and help others, in particular their peers with PAHIV and to educate others about HIV infection, treatment and care. One participant described wanting to tell South African people that HIV is not a death sentence, which resonates with Alex in this study who described himself as an 'Ambassador for HIV'. These findings of post traumatic growth in PAHIV+ individuals are also highlighted in a paper by Sherr, Nagra, Kulubya, Catalan, Clucas & Harding, (2011).

As discussed by Sherr, Cluver, Betancourt, Kellerman, Richter & Desmond (2014), it is extremely important to highlight these positive outcomes and demonstrate that despite the adversity faced by PAHIV+ adults, some have developed resilience and coping strategies to manage their condition, something which should be developed and promoted for all PAHIV+ infected people. Development of both peer support and family based interventions promoting resilience in adolescents have already begun to reveal some promising findings (Rotherum-Borus, Stein & Lester, 2006; Kumakech, Cantor-Graae, Maling & Bajunirwe, 2009; Funck-Brentano, Dalban, Veber, Quartier, Hefez, Costagliola & Blanche, 2005).

The findings from these studies and their implications for international research and practice must be considered. Whilst these studies discussed have been carried out as far away as USA and South Africa where cultural and societal differences exist, many findings remain similar. This may in part be due to many participants recruited coming from similar black ethnic backgrounds. Nevertheless, these similarities suggest findings from this current study can be transferable across a variety of settings and helpful for all HCP's working with this cohort. Likewise, the psychological models of therapy suggested from this study, to support individuals living with uncertainty, stigma and issues regarding the acceptance of their HIV

status can also be considered. The coping strategies adopted by some participants in this study may also help inform the current work being done to improve resilience amongst PAHIV+ adolescents (Sherr et al., 2014).

Unexpected findings, not reflected in the literature on PAHIV+ adults, following my searches included participant's cultural differences within the family, their desire to actively reduce stigma in society and amongst peers, purpose and achievement gives them a focus, on-going attempts at trying to make sense of themselves, how they have learned through experience and how their responsibility of self has changed in adulthood. Some participants talked about being unique which meant they felt a responsibility to share their stories and support others younger than them in the next generation. Also, not previously found was participants fears that their lives may be cut short because they had lost peers their age or because their parents had died at similar ages to which they were fast approaching. Additionally, this research unexpectedly revealed the overarching theme of an 'An evolving journey' which will now be discussed further in relation to existing literature, theories and concepts.

## 4.3 Discussion of findings in relation to existing theoretical models

### 'Evolving journey'

Many different theoretical models can be adopted to discuss the overarching theme of an 'Evolving journey' found from this study, including but not exclusively, Marcia, 1966, Piaget 1972 and Erikson, 1959. Fair and Albright (2012) suggest that Erikson's model of psychosocial stages (Erikson, 1959), (see Appendix Q), is something which HCP's and guardians should use to conceptualise the life cycle of PAHIV individuals, because they are reaching adulthood. I feel that the findings from this current study can be best explained by adopting this psychosocial model. Due to some of the limitations of this model, a further developmental model at the end of this section will also be discussed in relation to my findings (Shonkoff, & Garner (2011).

Erikson describes adolescence as involving the resolution of the task 'identity vs role confusion'. He suggested that this stage should be resolved for individuals to experience a healthy personality in young adulthood. This task is described as at a time when teenagers are refining their sense of self, through testing out different roles and integrating these to

develop a single identity. If this fails, confusion ensues regarding who they think they are. The testing out of these roles for the participants in this study may have been complicated by being told their HIV diagnosis. An HIV diagnosis may have forced participants to revisit earlier stages, as Erikson's model suggests an individual's vulnerability and possible sense of guilt, shame and doubt and mistrust in adulthood could be rooted in previous unresolved conflicts.

Post diagnosis, participants had to face the challenge of coming to grips with what HIV meant to them and their identity, a new 'HIV positive self' which they had to integrate and possibly try out in different situations. A diagnosis of HIV could therefore be considered something which may cause 'role confusion'. This new self was described by some participant's as not being a 'self' they could show anyone. They had to develop, within the family and amongst peers who did not know their status, a pretend 'HIV negative self'. Most participants described being encouraged to keep their HIV diagnosis a secret by their parents due to fear of stigma. Most were forbidden to disclose their status to anyone, thus forcing them to act out the role of being HIV negative amongst friends and even family members. This was an extremely difficult task and is particularly well illustrated by Jacob in the analysis chapter when he describes being one person when he attends 'Unity' and another when he leaves the building and meets his school friends. For Jacob this was the only place he could openly 'try out' his new 'HIV positive self' in a safe, non-judgemental environment. Jacob's struggle may have been compounded by lack of resolution (as discussed by Erikson) at previous stages for example shame, doubt and guilt in childhood.

For Grace, finding out her HIV diagnosis meant everything fell into place like a 'jigsaw puzzle'. This may suggest that for Grace her HIV positive 'self' could finally be realised and understood as part of her identity and why she was attending multiple hospital visits and taking medication. This may be an example of Erikson's model (1963) which suggests role confusion can be resolved through gradual restructuring of a self-definition which brings together the different selves towards a consistent and contented sense of who you are, your identity. This unification of one's identity may also have been evident in Alex's interview, as he described HIV as part of him, and Jacob's interview when he described HIV as something which he had conquered, but remains within him.

Erikson (1963), agrees his theory does not always work in this way. For some adolescence, he suggests identity is formed early, through adopting parental expectations and values, with traditional cultures sometimes telling adolescents who they are, as opposed to allowing them to discover this for themselves (Myers, 1995). As many participants described their parents expecting them to keep their HIV a secret when younger I wonder what impact this may have had on the formation of their identity, and whether it caused them to have conflicting identities which may be what is reflected in the analysis when Alex described living a 'double life', something which Sam also alluded to.

Suggested by Erikson's stages, young adulthood begins at approximately 20 and ends in early 40's, the task to be resolved is called 'Intimacy vs Isolation'. He contends that young adults need to explore and establish intimate relationships and increase their capacity for intimate love (Erikson, 1994) and if this is not resolved, social isolation occurs. Intimate relationships were talked about by most participants suggesting they are an extremely important part of reaching adulthood.

Anna's negative experiences of disclosing her HIV, put her off any further disclosures thus isolating herself from the prospect of a future intimate relationship. This appears to resonate with the 'Intimacy vs Isolation' stage. All participants appeared to be thinking about an intimate relationship either now or in the future, their fear of this not happening (or being 'resolved' and being left alone) was highlighted by Grace. Grace described struggling to find a partner, she feared being left alone and isolated as reflected in the model. Grace's struggle may suggest previous unresolved conflicts particularly around early childhood for example 'Trust vs Mistrust'.

Mia described her changing responsibility of self over the years, from being the sole responsibility of someone else, to having full responsibility of looking after herself. This is echoed by Alex and Grace who have also come to realise that they are now responsible adults.  This responsibility appears to extend to helping others. Jacob, Anna and Abi talked about feeling responsible as adults to help others, with Jacob suggesting as part of a unique cohort he should be supporting the next generation. Whilst still in their 20's this sense of feeling responsible and wanting to contribute to the lives of others appears to resonate with Erikson's model of Middle adulthood. In Erikson's model (Erikson, 1959) this happens

between the ages of 40 – 65, considerably older than the participants in this study, a task described as 'generativity vs stagnation'. This task is described as something which middle aged people go through as they find the need to contribute through family or work to the world they live in and if this is not achieved a lack of purpose will ensue. This stage also talks about a lack of purpose if tasks are not resolved. "Purpose and achievement" was a sub theme found in this study. Having purpose was described as extremely important to Emily who talked about building a family and getting a good job. Sam suggested it was important his journey 'had served a purpose', with his use of past tense, suggesting it already had. Therefore, participants' accounts not only suggest that participants might revisit and rework previous conflicts, especially those not satisfactorily resolved in the past, but, in the face of death may move more rapidly through the remaining stages of development to resolve those too, a finding which is reflected in a previous paper by Merriam, Courtenay & Reeves (1997).

Loss of parents and peers along their journey was described by some participants. As adults, some participants questioned their future and own mortality, which doesn't resonate anywhere within Erikson's model, but may reflect participants reaching the later stages earlier in their life. Whilst I feel this model helps conceptualise the development of the participants within this study, their subjective experiences also illuminate how this order may have been disrupted. Erikson's stages are separate and assume you travel through them in one direction, only passing to the next once the previous is resolved. The findings of this study suggest that, for some, perhaps this process is more fluid than described by Erikson. More flexibility would allow the opportunity for a more back and forth process of development and the opportunity to return to certain stages and 'resolve' them later in life.

Whilst the findings from this study relate well to Erikson's model, this psychosocial model does not suggest the causes of development and the types of experiences individuals must have to successfully resolve each conflict. There is no universal mechanism for the resolution of each crisis described in this model.

Developmental causes of adult diseases have been previously explored by Shonkoff, Boyce & McEwen, (2009). Shonkoff & Garner, (2011) went on to develop a ecobiodevelopmental (EBD) framework which aimed to promote health and prevent disease throughout the

lifespan. Their framework extends and illuminates how early childhood experiences and environmental factors can leave a lasting impression on the genetic predispositions that affect long term health and emerging brain architecture. The model suggests that early childhood adverse experiences and stressful events, can cause poorer health outcomes caused by either cumulative damage over time or through the biological embedding of such adversities throughout critical developmental periods. The model also examines toxic stress and its disruptive impact. It suggests early adversity is linked to later impairments including behaviour, learning, physical and psychological well-being.

The findings from this current study, especially the superordinate theme 'Reflecting on a difficult childhood' illuminates participants' early adverse experiences of living with secrecy and isolation, numerous struggles, poor relationships with parents, parental loss and an unexpected HIV diagnosis which resonate strongly with this model. According to this model, these findings should be considered as a reason why PAHIV+ individuals experience psychological problems as they grow up. The idea that adult disease can be caused by developmental disorders offers a transformational approach (Shonkoff, et al., 2009) and suggests the findings from this study should be considered for future prevention and interventions for children born with PAHIV both in the UK and internationally.

**'Managing uncertainty'**

To facilitate the understanding of chronic illness, which HIV has been described as for over two decades (Chu & Selwyn, 2011; Matic, Lazarus, & Donaghoe, 2006; Nokes, 1991) many theoretical frameworks and models exist. These include psychosocial, biopsychosocial and biomedical models (Walker, Jackson, & Littlejohn, 2004). They include amongst others, the shifting perspectives model of chronic illness (Paterson, 2001), the uncertainty in illness theory (Mishel, 1988; 1990) and the chronic illness trajectory (Corbin & Strauss, 1991; Alonzo & Reynolds, 1995). Whilst it can be helpful to categorise and suggest phases of chronic conditions, it is equally important to acknowledge significant differences between conditions and the ensuing impact on an individual's life (Newman, Steed, & Mulligan, 2004).

Throughout this research I was struck by the levels of uncertainty participants described living with. Weitz (1989) suggested uncertainty amongst HIV+ individuals are derived through extensive and unpredictable physical and mental health problems related to the condition, the novelty of the condition and the speed at which the illness and the information

surrounding it changes, whilst this research is outdated, participants in this study were all born shortly after the time this research was published. This current study suggests individuals living with PAHIV experience uncertainty for a variety of reasons including ambiguous symptom patterns, complex changing treatments, and fear of rejection regarding their HIV status. These types of uncertainty have been connected to poor psychological adjustment and negative perceptions of quality of life (Weitz, 1989).

Brashers, Neidig, Reynolds & Haas, (1998) developed a theoretical framework to explain the uncertainty surrounding HIV. Their conceptualisation has been developed through analysis of the existing literature on uncertainty and HIV, and previous concepts by Mischel (1988, 1990) alongside the illness trajectory views of Corbin & Strauss (1998) and Alonzo & Reynolds (1995). Brashers et al. (1998) developed this model because they believed a gap existed, failing to explain the experience of uncertainty in illness across the HIV trajectory. I have chosen to discuss this model because change in uncertainty over time appears particularly pertinent for this cohort, having lived with PAHIV for so long, over different developmental stages, born at a time when information about the disease and life expectancy was changing.

As individuals move through the HIV illness trajectory certain areas of uncertainty may increase or decrease in salience, thus with every phase of the illness psychosocial needs may change (Brashers et al. 1998). This change was illustrated through participant interviews, with childhood characterised by the uncertainty of not knowing how long their treatment would work and how long they would live, and adulthood characterised by new uncertainties, including when they would be ill next, what reaction they would experience if they disclosed their HIV status and whether they would ever meet someone and have children. Brashers et al. (1998) paper "Uncertainty across the HIV trajectory" and their biopsychosocial model; describe four different stages; At Risk, Diagnosis, Latent and Manifest. I will introduce each stage and discuss briefly in relation to the research findings.

The 'At-Risk' stage does not include any reference to those living with PAHIV from birth, however it does outline individuals' perception of risk to HIV and suggests that individuals may perceive themselves to be at risk because they belong to a high-risk group or because they had relationships with those who had died. Whilst the model's reference to

'relationships', may have meant sexual relationships, I would argue that some participants in this study witnessed family members dying and may have suspected HIV. As children, due to Global media coverage at that time, participants may have been aware they belonged to a high-risk group, perceiving themselves at risk.

The 'Diagnosis Phase' suggests uncertainty may develop due to the ambiguity and complexity of an HIV diagnosis. Participants lack of knowledge regarding HIV when diagnosed was reflected in the interviews. Emily described educating herself and Jacob got his knowledge from the Mark Fowler story line in EastEnders. Jacob described his diagnosis as terrifying; he lacked hope and became uncertain about the future, especially how long HIV treatment would keep him alive; as an adult, his uncertainty towards the future has changed, which may reflect improved medication and increased knowledge of HIV. Participant's limited HIV knowledge as children and the uncertainty they experienced as a result was illuminated by this study and fits the biopsychosocial model as described by Brashers et al. (1998).

The 'Latent Phase' is characterised within this model as a period where HIV is asymptomatic, concealable and generally less disruptive. However internal disruption of distress and anxiety may covertly exist (Alonzo & Reynolds 1995).

Mia and Anna described some asymptomatic periods, but these were punctuated by periods of illness, described as unpredictable and a cause for uncertainty. Some participants described phases in their lives when they felt well and 'normal', which brought new concerns regarding uncertainty, including meeting a partner and considering HIV disclosure. Deciding who they should or shouldn't tell (Greene & Serovich, 1996) and how others may react (Gaskins & Brown, 1992; Gordon & Schontz, 1990) are described in the model as common at this phase.

Uncertainty during the latent phase is suggested to be caused by a lack of 'event familiarity', and event congruence. Lack of event familiarity for some participants may have occurred as they started to experience new events linked to their HIV diagnosis, for example hospital

appointments, increased encounters with HCP's, increased doctor consultations and confusing clinical language, all of which may have caused confusion at a young age.

The latent phase also suggests that a lack of social support can cause uncertainty. Mia described attending 'Unity' and discovering others were having similar symptoms to her. This may have helped to reduce the uncertainty she felt regarding her health, helping her to normalise her concerns.

Increasing uncertainty in the latent phase may also be caused by a lack of event congruence (Mishel, 1988). Distress can be caused due to the unpredictable nature of HIV infection and not knowing when and if sickness will occur (Gaskins & Brown 1992). Mia talked about the unpredictable nature of her illness, how one minute she can be totally fine and the next, she needs surgery.

During this latent phase, the model suggests individuals begin to think about what plans they should make for the future. As discussed, how participants viewed the future appeared to have changed over time. Participants were born before the introduction of HAART and may have developed renewed hope over the years that the treatment for HIV would bring them good health, career, a family of their own and longevity of life. This renewed hope however is often tempered, as illustrated, with new concerns and uncertainties.

Finally, the model suggests you reach the manifest stage, consisting of symptomatic HIV infection, accompanied by unpredictable symptoms causing much uncertainty regarding health status. With the onset of every new symptom it is suggested that the individual will interpret and attribute meaning to the illness event. Because symptoms can be caused for a variety of reasons and individuals may lack 'event familiarity', ambiguity may ensue causing uncertainty. The model also reflects that uncertainty can be caused due to the unknown long term effects of being on HIV treatment. Whilst this model was developed many years ago and HIV treatment has significantly improved, the uncertainty described by this model is particularly well highlighted in this research by the theme 'lack of control' which falls within the super-ordinate theme 'managing uncertainty'. The lack of control described by participants mainly involved the unpredictable nature of HIV infection. Abi described

uncertainty regarding longevity of HIV treatment, poor health, and contracting an infection she couldn't fight

.

Whilst the phases in this model are linear and described as occurring in succession, I would suggest for participants in this study the latent and manifest phases have considerable overlap. This overlap is mainly demonstrated through participant's descriptions of a health condition which they have limited control over due to its unpredictable and uncertain nature, with symptoms coming and going unpredictably, as opposed to asymptomatic, then symptomatic periods occurring in a linear fashion.

Whilst this model has helped me to conceptualise the experience of uncertainty for individuals reaching adulthood with PAHIV, it does not explicitly include uncertainty regarding the future and life expectancy, which the participants within this study talked about. As HAART has become available and survival has dramatically increased, some participants felt that a future was now possible, in line with 'Lazarus Syndrome' (King, 1997). Nevertheless, uncertainty regarding long-term prognosis still appeared to emerge from participant accounts.

Some participants described periods of good health, which brought unexpected new stressors to negotiate. These findings reflect those reported by Brashers et al. (1998), with HIV+ participants describing an improvement in their physical health as an unexpected stressor, which makes them renegotiate their future orientation, feelings of hope, social identities and roles, interpersonal relations and quality of life.

HIV+ individuals who are now experiencing more effective HIV treatment (Gallo, 1996) by default will live for longer, with the many uncertainties that HIV infection brings. Uncertainty is considered a long-lasting and persistent cause of psychological distress (Brashers et al. 1998) and, as reflected by the participants in this current study, the causes of such uncertainty appear to change over time. Stressors like uncertainty have also been shown to negatively impact immune functioning (Jemmott & Locke, 1984), therefore, it is suggested that interventions to manage uncertainty may play an important role in the holistic care of individuals living with PAHIV (Brashers et al. 1998).

**'The stigma barrier'**

The pervasive effects of stigma related to HIV were described by King (1989), at the beginning of the epidemic, when he said the stigmatisation of HIV had a much bigger impact than the physical disorder. Participant's accounts in this study appear to reflect this. The way Jacob describes stigma as "the biggest killer of HIV um, people living with HIV", appears to echo what King is saying, that stigma is worse than the disease itself, it supersedes it.

Herek (1999) suggests transmissible conditions have greater stigma attached to them. Stigma is also strongly linked to the ignorance which exists regarding how HIV is contracted (Herek et al., 2002). The impact of stigma is reflected in the findings of this study when Abi says she doesn't think she could ever have a sexual relationship without someone "freaking out" that she is positive. A further problem encountered by Mia is that by explaining how she contracted HIV she also naturally implicates her family's HIV status. Participant's fear of how others may perceive them and their family might be explained by Goffman's concept of a 'spoiled identity' (Goffman, 1963) which he would suggest occurs because they fear people within their society perceiving them to have 'undesirable difference'. This fear of participant's identity being ruined by HIV disclosure makes telling others their HIV status a difficult decision.  Abi described her fear of being seen by others as "different" or "unfavourable"', she describes feeling inferior and different to her negative peers, suggesting HIV has 'spoiled' how she thinks others may see her.

In line with wider literature, stigma was described by participants in this study as both 'felt' and 'enacted' (Scambler, 2004). Participants in this current study described experiencing 'felt stigma', the fear of encountering stigma (Scambler 2004; Scambler & Hopkins 1986) from a potential or new sexual partner, possibly because intimate relationships are often sought after in adulthood (Erikson, 1950) the cohort from which participants were recruited. For some participants, this fear meant they wouldn't disclose their status to others. Sam described portraying himself to others as HIV negative, this behaviour is described by Goffman (1963) as 'passing', as the individual attempts to conceal their stigmatising attribute.

In this current study 'enacted stigma' appeared to be described less than 'felt' stigma', in line with Herek et al. 2002 who suggest it is in decline.  However, I contend, the experience of less 'enacted stigma' by participant's, may be a result of the strategies employed by them to reduce their chances of this experience.

The main strategy to protect themselves from enacted stigma appears to be non-disclosure. Non-disclosure of HIV as a way of avoiding 'enacted stigma' appeared in several participant's accounts, as they described their HIV status as a secret they had to keep. This strategy was described by participants as being adopted by their parents when participants were children which may suggest a type of learnt behaviour. Sam described his parents' generation as never disclosing their status, not even to other family members. Parental secrecy was possibly their way of attempting to protect the entire family from a 'spoiled identity' (Goffman, 1963).

Stigma was also reflected on from an African perspective as a 'curse', something which some participants described as a myth believed by their parents. Five participants described experiencing the effects of stigma and cultural differences within the family, Sam suggested this may be because his family had experienced the stigma associated with HIV first hand in Africa, before coming to the UK. Keeping silent about HIV therefore reduced their chances as a family of experiencing 'enacted stigma' and a 'spoiled identity' (Goffman, 1963). As adults, some participants appeared to have adopted this strategy of silence for themselves, as a way of avoiding stigma and rejection from sexual partners. This fear of rejection was found in one study as driving many decisions regarding HIV disclosure (Fernet et al., 2011).

Silence, as a tool by which to manage stigma, has been described in previous literature (Fielden, Chapman, Cadell, 2011; Sandelowski, Lambe, & Barrosa, 2004). HCP's hold fears that young people may adopt silence as a way of initially helping their social survival (Fielden et al. 2011), but fear it will result in future resistance to disclosing their status, thus perpetuating the silence within which they live. This was reflected to some degree in the findings from this current study in the subtheme 'A secret life' discussed in the analysis chapter. Whilst disclosing their HIV status appeared a huge risk for participants regarding fear of 'enacted stigma', literature suggests that individuals who don't disclose their HIV may have other problems as a result of internalising stigma (Swendeman, Rotheram-Borus, Comulada, Weiss & Ramos, 2006). Therefore, whilst no participants overtly described internalised stigma, participants who described a lack of HIV disclosure may consequently be experiencing this internalisation. This is of concern, because evidence suggests that for optimal wellbeing disclosure is important (Chaudoir, Fisher & Simoni, 2011), with the decision to not disclose, found to lead to increased psychological distress and a sense of isolation. (Chesney & Smith, 1999).

Literature suggests that PAHIV+ adults have different pasts and health care needs than their horizontally infected peers, but share the same stigma associated with HIV (Scambler,

2009). Herek, (1999) contended that HIV is considered as more stigmatising because it is sexually transmissible, perceived to be a condition which individuals have control and choice over in terms of their behaviour, and considered voluntary and avoidable. Whilst PAHIV+ individuals may share the same stigma associated with HIV they must also manage the assumptions by others that their HIV was contracted through sex. This is illuminated by Mia as she described her fear that if she told people she had HIV they would think she had caught it through unprotected sex. This may also highlight Mia's own prejudice towards HIV contracted through sexual intercourse and how she may see it as more stigmatising than her own HIV, contracted perinatally. It may also illuminate that she feels her HIV status is not her 'fault'. This was something described by Grace in her interview when she said it was not her fault her mother didn't check her for HIV. Whilst PAHIV+ individuals may not be responsible for their HIV status *per se* it appears that these participants feel this may contribute to how others see them. HIV is often synonymous with promiscuity and being from certain ethnic minority groups and this has also led me to consider the added impact of stigma layering PAHIV+ individuals may experience (see Scambler, 2004).

This current study, revealed that two participants wanted to educate others about HIV now they have reached adulthood in line with previous studies (Rydstrom et al., 2013; Hogwood et al.,2013). Sam talked about being part of a "generation" that needs to provide others with the correct knowledge about HIV. Alex described himself as an "ambassador for HIV", giving his life to others and becoming a voice for the people. This type of behaviour has been described as activism, possibly adopted to transform their "spoiled identity" into a "project identity" (Castells, 1999), changing their personal identity and searching for social transformation.

Whilst this section has predominantly focussed on the negative aspects of stigma it feels important to note that some participant's experiences of HIV disclosure diverged, in line with current literature (Fielden et al., 2011) and for some they did not experience the stigma they had feared; this was illustrated by Sam in the analysis chapter when he describes a lot of "development' coming from a positive disclosure".

I want to finish this part of the discussion by acknowledging the individual differences of each participant which took part in this study and remember that whilst by the nature of a discussion similarities are often drawn, the shared themes that arose should not take away the importance of attempting to understand how each participant experienced them on an individual level.

**4.4 Validity, quality and limitations of current study**

**Validity and quality**

Four key dimensions proposed by Yardley (2000) helped to assess this research; 'Sensitivity to context', 'Commitment and rigour', 'Transparency and coherence' and 'Impact and importance'. I shall discuss each of these in turn.

I initially reviewed the extant literature focussing closely on the phenomenon under investigation. This provided me with understandings already created by previous researchers in similar areas, and the context from which to consider my own research. Having worked in an NHS HIV outpatient department for over 15 years, I was already acutely aware of the clinical context of this study, however it was important to also explore and understand the current theoretical and conceptual ideas within this field. This helped develop my knowledge of some of the complex arguments and different perspectives currently adopted, with the view to providing myself as the researcher with the academic tools to facilitate an extensive and deep analysis, whilst simultaneously acknowledging that theory can influence interpretation, and that the analysis must be 'manifestly sensitive' to the data. This was notably employed within this study as I questioned any unexpected findings which conflicted with my prior understanding of the topic, not just making note of them but actively pursuing and examining them until satisfied they were adequately accounted for.

Awareness was given to the socio-cultural setting of the study and the impact of my own personal and professional characteristics, for example my gender or status as a HCP. As a HCP, I was acutely aware of the importance in addressing the power balance during the research process. This was done by using the term 'participants' not subjects, and promoting a more powerful and active role within the research for participants, overtly suggesting at the beginning of each interview that participants were the experts on themselves and at the end that it had been a privilege for me to share their stories. My commitment to this research is evidenced through prolonged engagement with this research topic, from both my clinical experience and as a researcher. Throughout the research process I have been guided by both professional and ethical guidelines as laid out in the methodology to ensure commitment to the wellbeing of participants at all times. I have endeavoured to develop strong skills and competency in the methods adopted for this research. I have also immersed myself within the relevant data. Evidence for competency regarding the method is

predominantly found in the methodology chapter and the engagement and immersion with the data through the rigorous process of interviewing, transcribing and analysing of the data myself.

The analysis chapter provides evidence of rigour by demonstrating the completed data set and analysis. Analysis focussed in depth on each individual case, making sure all themes were grounded to the original transcripts. Rigour also included to the best of my ability, strong interpretations which addressed all complexities and variations I observed. These interpretations were informed by my knowledge of psychodynamic theory but led by intuition and imagination. The way they articulated their emotive accounts in such deep and open ways, I feel the quality of the data was extremely rich. I considered interviewing more participants, generating more data, however in keeping with IPA's ideographic approach, I decided depth and rigour of analysis for less participants were more important.

Triangulation of analysis was conducted to attain a rounded understanding of the topic under investigation, in two ways; first, regular meetings occurred with either my supervisor or interim supervisor at different stages of the research process. This involved explaining to them the process I had been through to arrive at my themes, and them asking questions and providing feedback. Feedback was also given regarding the labelling of some themes in the final stages of analysis. Whilst both supervisors did not go through the process of fully engaging with the transcripts, they could provide me two different outsider perspectives from Counselling Psychologists both interested in health but less familiar with the extant literature on HIV, which was extremely valuable. Unfortunately, member checking was not done and this is something which could have contributed to the findings in this study. However, member checks are not straightforward validity checks and demand increased time on the participant's commitment to the study and are part of a process of error reduction, which may have generated further data which would have needed to be analysed and interpreted (Pope & Mays, 2006). Within the time constraints of this research this would have been difficult.

Transparency is clearly demonstrated throughout this thesis. Evidence in the methodology chapter details every aspect of data collection, explains the rules followed to code the transcripts and provides examples of transcripts analysed. The analysis chapter demonstrates transparency by presenting direct examples from the transcripts and a section on why I made certain decisions. Reflexivity sections are provided throughout the thesis

displaying transparency, and include assumptions brought to the research, my thoughts, feelings and decisions made. This is aimed at providing the reader with some context regarding myself as the researcher, as the analysis is digested. Coherence is evidenced within this research through the 'fit' between research question and method used to investigate this phenomenon explained in detail within the methodology chapter.

This research has always aimed to be useful, its importance and impact remaining central at all times throughout the process. This research is intended to provide findings which can be implemented into clinical practice (Swanson, Durham & Albright, 1997), particularly for Counselling Psychologists psychologically treating this cohort. Whilst this research may be seen as esoteric, with the cohort of adults living with PAHIV in the UK so small, I would argue the insights provided are not only invaluable to those working in the field, but the ideas generated from the findings may eventually have a wider impact. This impact may hopefully be seen by both adults living with PAHIV, children who will eventually be adults living with PAHIV, but also of potential use in future discussion regarding services needed for these individuals or other young people growing up with such an uncertain and stigmatising illness, especially in more remote parts of the country. I believe the results from this study may also be important to 'Unity' where I recruited participants from, at a time when evidence for funding is needed more than ever. Finally, I hope articles from this research study will be published in HIV, Health and Psychology journals, promoting the field of Counselling Psychology and in turn improving clinical practice and quality of care delivered to clients and patients alike.

Representing participants accounts during the analysis process was an overwhelming responsibility. It was this responsibility that forced me to work iteratively, interrogatively and closely with the transcripts, producing themes which are reflective of participant's accounts. After writing the analysis chapter and representing the themes with quotes from participants accounts I felt satisfied I had hopefully achieved this. For the most part I closely followed the guidelines laid out by Smith et al., (2009) as I am a novice researcher, in not only IPA but all qualitative methods. This did not however impede my ability to work flexibly throughout the process with the excellent advice of an experienced supervisor.

Literal numeration was held in mind through providing tables of appearance for each subtheme, and explaining where possible how many participants had talked about each subtheme. However, I also paid attention to some individual utterances which I feel played an important role in the analysis. I justify this as, according to Willig, (2013) the significance of a theme is not always demonstrated through numeration.

Researcher impact was monitored closely through a reflexivity diary. Data collection and analysis may have been affected by my age, gender, ethnicity and other personal and professional experiences of the research subject and where I am positioned within the research is also recognised.

Potential impact of the physical location of interviews ('Unity'), an HIV charitable organisation which promotes psychological wellbeing and holistic biopsychosocial support to the individuals interviewed, may have impacted some of the findings, including the 'Learning from experience' and 'support and therapy' sub themes. I recognise that data analysis may have been influenced by my psychological training, for example interpreting the data to reveal some coping strategies, which PAHIV+ individuals may have adopted to cope psychologically with uncertainty, for example the sub themes 'I choose to focus on better things' and 'Acceptance?' I recognise that uncertainty is something which I personally struggle with and which may have influenced the finding and naming of the superordinate theme 'Managing uncertainty'.

Participants were also aware I worked for a local NHS Trust and knew I was training to be a Counselling Psychologist, which may have impacted the type of things they shared with me. I am aware that having worked in this field for many years I may have overlooked or omitted certain questions that I could have asked participants because I already thought I knew something about them, likewise they may have omitted certain details of their experience assuming I knew certain things about them and their condition. My level of knowledge regarding HIV may have also influenced the type of questions I felt comfortable asking which I feel was a positive attribute to this study. I have also trained in the theory and practice of psychodynamic therapy which may have impacted the way in which I have analysed the data.

Whilst IPA aims to gain insight into the world of the participant, it is recognised that this understanding is gained through the researcher engaging and interpreting the account of the participant, therefore necessarily implicating the researcher in the analysis. Analysis is thus implicated two-fold; phenomenologically, aiming to represent the participant's world view and interpretatively, dependant on the conceptions and standpoints of the researcher, thus a reflexive attitude from myself as the researcher was essential (Willig 2013).

As a researcher, I also recognise that my own views of the world, and the relationship and interaction between myself and the research participants may have impacted the research. Instead of bracketing off these assumptions, I used them to aid and advance my understanding. I do recognise that without developing any initial categories of meaning and modifying them throughout the process of interacting with the data, knowledge would not be possible (Willig, 2013).

An important point to also consider was the process that I went through as I considered whether to ask participants about what it was like to be part of a unique generation. On reflection, this was a personal assumption, supported by others, but ultimately belonging to myself that this would be an important part of the participant's experience; one that they were aware of. Whilst from a medical perspective these individuals are the first generation of PAHIV+ individuals to reach adulthood (Persson & Newman, 2012) this was not something which emerged as particularly important to the participants in this study. This finding supports the decision to omit the question and recognises the importance of not entering an IPA study with these types of assumptions.

Finally, I am acutely aware despite attempting not to be, that I was looking for the negative impact of PAHIV in individuals as they reached adulthood, and how this research could somehow add something to their lives. Throughout the analysis stage it was important to reflect on this. I worked iteratively, going back and forth to each transcript, as much as possible bracketing any negative assumptions and worked hard to make sure that I had looked at them from different angles, challenged coding and themes and changing where necessary, if I believed they were influencing my work. Some changes following peer review from my supervisor were also made.

A reflective research diary capturing these reflections throughout the interview and analysis stages is in Appendix A. This diary helped me track my assumptions and preconceptions, but also to see how things changed and evolved throughout the research process.

**Limitations of current study**

All participants who took part in this study were recruited from the same HIV charitable organisation. Some were training as peer mentors and life coaches. These participants' experiences may differ significantly from individuals who are not linked in with support services, or those from NHS settings, outside London, in other parts of the country. Participants keen to tell their stories may have been recruited first for this study. Findings may therefore be different than if less motivated individuals or those less willing to articulate their stories had been recruited.

Due to the nature of qualitative research these findings cannot be considered generalisable, however this research did intend to create this type of knowledge. Only participants who identified as Black African or Black Mixed ethnicity participated in this study which may be a further limitation. Whilst this is reflective of the demographics of individuals disproportionately affected by PAHIV living in the UK it may not tell us about the experiences of being from a different cultural background. Beyond the scope of this research, but an extremely important consideration, is the impact of African culture on these individuals' experiences, especially of stigma. (see Joffe, 1995). The findings from this study regarding participants' experiences of stigma for example may differ to individuals in other countries with other cultures and social contexts. This limitation is reflected in many of the research papers reviewed for this thesis, with participants mainly of Black African ethnicity. Many studies are also carried out by White British, American or Canadian researchers. Therefore, my own British identity, culture and experiences which I bring to the research may present some limitations to the study.

This study employed a relatively homogenous sample as suggested by Smith, Flowers and Larkin (2009). However, it is important to reflect that a further limitation to this study is sample size. Only 8 participants were recruited for this study, 3 males and 5 females. Therefore, this research only illuminated the voices of a limited few. There were potentially more participants available to recruit, but time was also a limitation in carrying out this

research. I also acknowledge the study's findings may reflect the experiences of those who volunteered first, who may have been more motivated to share their experiences. The voices of those less willing or less able to articulate their experiences is ultimately not heard. Marginally more females than males took part in the study providing more female dominated findings despite no apparent gender differences being found.

This research was conducted from single interviews. Further interviews with each participant may have helped to develop the findings found from the initial interview. Therefore, I acknowledge this may be a limitation to the current study and may be helpful to future research studies. Flowers (2008) suggests that planned multiple contacts can offer the chance to probe and develop material from an initial meeting, building a trusting relationship, where participants feel comfortable with increased disclosure. However, he also cautions that one danger of such multiple contacts is the focus can turn away from an open examination of lived experience at that time, and instead be dominated by "follow up" on issues raised previously.

Interviews were carried out in the summer months and the interview room was extremely warm. Windows therefore were opened and overlooked busy streets. Unaware of it at the time, this contributed to intermittently high levels of background noise which obscured some of the content of the interview tapes which made transcription of a couple of interviews more challenging.

I am aware that I bring to the research my own assumptions. Whilst my general knowledge of HIV infection may have helped me understand better what participants told me, particularly in relation to HIV treatment and disease progression this could also be a limitation of the study. Whilst I attempted to remain in a 'not knowing' position to ensure I made as few assumptions about what participants were telling me as possible, for example questioning what they meant by treatment resistance, rather than assuming I knew, it is possible however that due to my existing knowledge, I may not have asked participants to elaborate as much as someone with less HIV knowledge. Participants may in turn have answered questions in a certain way or omitted certain details to their accounts because they thought I held enough knowledge.

Some demographic information was not collected which may have been useful to contextualise participants' experience including; religion, sexuality, country of birth, and more general information regarding their father's HIV status, how long they had lived in the UK, age they discovered their diagnosis, how long their parents had been living with HIV and if/when they had experienced the loss of parents. However, I was aware this is a very small cohort, and the more information I gathered the more identifiable participants may have become, therefore protecting their anonymity was paramount. This was ultimately a difficult balance.

## Limitations of IPA

Reasons for choosing IPA have been extensively explored in the methodology chapter, therefore this section will now focus on some of its limitations outlined by Willig (2013). Several of the practical and conceptual limitations Willig highlights involve the role of language, how suitable the accounts are, and finally explanation versus description. I shall discuss each of these in turn and how they relate to my analysis.

This research collected data through interviews, therefore participants communicated their experiences through language. Language therefore was the tool by which they used to capture and share their actual experiences which assumes that participants have the necessary tools to be able to do this. Willig (2013) argues that language therefore constructs instead of describes reality. This suggests the words we choose when describing a specific experience construct a certain version of that experience. Therefore, language does not just give expression to experiences but adds meaning to the words, making it impossible to gain direct access to someone else's experience. To put into context, this suggests interview transcripts from my interviews inform me regarding how participants 'talk' about a specific experience in a specific context as opposed to the 'experience itself', they add meaning. This is however in line with the social constructionist perspective, and for this study the meanings that participants attach to their accounts are seen as an important part of the analysis.

The texture of experience is also of concern to phenomenological study. IPA does not claim to find individuals opinions, rather to find the experiences and meanings placed upon the particular phenomenon. As participants' descriptions of their experience is what phenomenology, as a social scientific research method relies on, this brings up some further

important questions; To what degree do participants accounts provide suitable data to be analysed phenomenologically? How well can participants articulate and share the quality of their experiences? and Is it possible for individuals to utilise language which enables them to describe their emotional and physical experiences in a nuanced way? This may have been a concern during this study because individuals could be deemed quite young to be able to talk about their emotions, thoughts and feelings. It is a sensitive and emotive topic area and participants' cognitive development had the potential to be impaired or delayed as a consequence of HIV infection. Nevertheless, I feel participants were well positioned to speak and articulate their experiences because this is something they do at ''Unity'. Interviews provided rich moving accounts from participants as a result.

Some participants may have found articulating their accounts easier than others, in particular one participant where English was not his first language. Nevertheless, once I analysed the transcript I could see how rich the data was, and how valuable his shared experience was within this study. If I had not included him, his valuable 'voice' would not have been heard. Likewise, one participant who was disabled told me that she did not want to talk about certain aspects of her life because she did not want to become identifiable. Whilst I reassured her that I would maintain her confidentiality at all costs, this may have resulted in her sharing a more restricted account of her experience.   I feel that all interviews, despite their differing levels of language sophistication offered valuable insights into this particular phenomenon.


Finally, Willig (2013) addresses the issue of explanation versus description. As IPA intends to better understand 'how' participants experience the world, with the focus on how they 'perceive' reality (Kvale 1996), it does not, she contends, attend to the reason 'why experiences happen or differ between individuals', thus describing as opposed to explaining individuals lived experiences. This disregard for the origin or cause of a particular experience, Willig argues, limits our understanding of an individual's experience.   I would argue that because IPA adopts a conceptual as well as descriptive approach to analysis that researchers can in fact take participants' accounts beyond just description.  I contend, as a Counselling Psychologist in training that gaining insight into an individual's subjective experience is extremely important, both in IPA research and in the therapeutic setting; in the same way that IPA adopts an interpretative approach in research, as a practitioner these interpretations can be used to further understand our clients subjective experience beyond just a description. Perhaps only once we know how people experience things can we begin to look at why.

**4.5 Clinical implications and considerations for Counselling Psychology**

Loyal to its humanistic roots Counselling Psychology endeavours to search for understanding as opposed to looking for universal truths; primarily focussing on the individual, their subjective experience and particularly acknowledging difference (Rafalin, 2010). As a nearly qualified Counselling Psychologist my aim is to support individuals, valuing and acknowledging their differences, showing appreciation of their unique and subjective experiences and facilitating change that individuals identify as important to them. This focus on individual difference which I shall take forward into my therapeutic practice can also be seen to permeate the research presented here. I believe my epistemological stance resonates closely with IPA and I hope that the findings of this research can provide some important clinical considerations for the future.

First and foremost, it is important to remember that whilst there are themes presented within the analysis chapter, the value, I believe, is in the quotes from the participants and how they illuminate both similarities and differences. It is these quotes which give voice and illuminate participants subjective experiences. Whilst feeling compelled to list all important findings which could implicate future clinical practice, which I am sure is evident from this research, I do strongly believe that for all HCP's working with PAHIV+ adults, including Counselling Psychologists, if they take anything away from this research, it should be the importance of working with the individual. Participants in this study, who have reached adulthood, have all been, and continue to be, on their own personal journey.

As I become a scientist-practitioner, I am aware of the tension which exists between suggesting that complex, individual experiences influence the human psyche, and human beings can never truly be understood and the next section of this thesis which explores some models of working with these individuals which are evidence based, suggesting they are reliable, official sources of knowledge facilitating us to develop solutions for clients which are helpful and consistent (Bury & Strauss, 2006). Therefore, my suggestions are tentative and exploratory as opposed to prescriptive and concrete.

**4.5.1 Psychological theories**

This research has highlighted some of the issues which may impact adults living with PAHIV psychologically, including difficult childhood experiences, complex family histories, stigma, fear of rejection and living with multiple uncertainties. How some participants attempt to cope also appeared to emerge from the data revealing the importance of support and therapy, positive thinking and for a couple of participants, acceptance of their HIV status. Several therapeutic models, whilst not an exhaustive list, may be useful to consider when working with some of these issues including, Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), Cognitive Behavioural Therapy Targeting Intolerance of Uncertainty (CBT-IU; Robichaud, 2013) and a psychodynamic approach, in particular object relations theory (Klein, 1946; Bion, 1962a, 1962b, 1967; Winnicott, 1964). It is beyond the scope of this research to discuss these models in depth, however I shall briefly introduce each one and explain why I feel they may be worth considering when working with this cohort.

**ACT**

ACT, whilst loyal to its behavioural roots, focusses instead on thoughts and feelings in the current moment, accepting hostile internal states and holding the belief that thoughts connected to the self are linked to an individual's learning history, rehearsal and internal reinforcement.  Rather than attempting to help people to control and change their thoughts, feelings etc. particularly previously unwanted ones, which is the focus of traditional Cognitive Behavioral Therapy (CBT), ACT focusses on encouraging people to just notice, accept and embrace them.

ACT has been found to have utility over established psychotherapeutic models for improving outcomes in long term chronic illness (Angiola & Bowen, 2013; Graham et al., 2015; Hadlandsmyth et al., 2013; Whittingham, 2014) and therefore makes it an important consideration when working with PAHIV+ adults. For example, distress and negative illness beliefs may be realistic with HIV at certain times, therefore ACT's attention towards instigating valued behaviours whilst simultaneously accepting these feelings and thoughts may be more effective as opposed to trying to alter them, like existing CBT models do (Graham et al., 2015). Some have contended that non adherence to HIV medication (Moitra, Herbert, & Forman, 2001) are connected to avoidance of HIV related feelings and thoughts

for example shame and fear. Thus, ACT may be particularly effective in HIV adherence due to its emphasis on encouraging acceptance in the service of meaningful behaviour.

ACT also focusses on shame, fear and identification within a stigmatised group, which acts as a barrier to living life in line with one's own values, and is one of only several theory based approaches, proven to be an effective anti-stigma intervention across a variety of conditions (Luoma, Kohlenberg, Hayes, Bunting, & Rye, 2008). This is an especially important finding in relation to the results from this study which suggest that participants experience strong self-stigma which is currently impacting many aspects of their lives. Finally, I would like to reflect on 'acceptance' as an alternative to 'experiential avoidance' and how two participants in this study described accepting HIV as part of them. This model may therefore suggest they have begun accepting this aspect of themselves, without attempting to change it, reducing their chances of ongoing psychological harm. Further research into the efficacy of ACT for PAHIV+ individuals would be extremely interesting and an important way to help explore and reduce psychological problems.

## CBT-IU

CBT refers to a group of interventions which share the basic ideas that psychological distress and mental disorders are maintained by cognitive factors, with maladaptive cognitions adding to the maintenance of behavioural problems and emotional distress (Beck, 1970; Ellis, 1962). Becks model suggests these maladaptive cognitions involve schemas and general beliefs about the world, the self and the future, creating automatic and specific thoughts in certain situations (Hofmann, Asnaani, Vonk, Sawyer, & Fang, 2012). Several disorder specific models have been developed since these earlier formulations. Whilst protocols may diverge for specific treatment techniques they all maintain the same core model and broad approach to treatment. One study I found specifically adapted a course of CBT to psychologically treat women living with HIV in Africa (Tshabalala & Visser, 2011). This was a mixed method study utilising qualitative interviews, from which themes were derived and used to develop a specific CBT intervention. This was then implemented and evaluated, revealing a decrease in depression, negative coping and internalised stigma and increased self-esteem and positive coping when compared to the control group (Tshabalala, & Visser, 2011).

Other CBT models for example the CBT-IU aims to target intolerance of uncertainty. The CBT-IU protocol (Robichaud, 2013) which focusses on; intolerance of uncertainty; positive beliefs about the function of worry; negative problem orientation; and cognitive avoidance, may also be an interesting model to explore with PAHIV+ individuals following the emergence of 'managing uncertainty' as a super-ordinate theme in this current study. Whilst this model has been mainly developed to treat people with diagnosed generalised anxiety disorder (GAD), its focus on the intolerance of uncertainty, may be able to help PAHIV+ individuals, who identified not only the uncertainty they experience regarding HIV disclosure, how long their treatment will last and how long they have left to live, but how this uncertainty has changed over time. Given the dynamic and ever changing nature of topics participants in this study described worrying about, traditional CBT which focusses on the content of worry, and encourages individuals to re-evaluate the severity and chance of feared events happening, may essentially involve chasing a moving target. CBT-IU focusses on uncertainty as the underlying theme of threat. Once individuals stop fearing and avoiding uncertain events, excessive worrying should be lessened (Robichaud, 2013).

**Psychodynamic theory**

Finally, I will briefly discuss object relations theories (Klein, 1946; 1952; Bion, 1962a, 1962b, 1967; Winnicott, 1964), which propose that relationships with others form the most necessary and fundamental parts of human life. It suggests the interpersonal patterns developed in infancy with care-givers shape how individuals relate to others in their adult life. Therefore, as all participants reflected on a difficult childhood, and some described difficult relationships with their parents, including parental loss, it is possible that their early relationships could have been less than adequate, causing possible relational difficulties in adulthood. This whistle stop tour of psychological models brings me finally to reflect on working with PAHIV+ individuals as a Counselling Psychologist. Counselling Psychologists are trained to work in a variety of models and are therefore well place to provide psychological treatment to these individuals. Whilst specific models have been developed to treat specific disorders I hope that these models have also demonstrated the importance of tailoring therapy to the individual. Using the themes from this current study to develop context specific psychological treatments for PAHIV+ individuals is an important consideration for the future.

### 4.5.2 'Unity' and social justice

Participants described "Unity" as somewhere they could go and talk about anything, in a non-judgmental way; this did not however have to be specifically about HIV, something extremely important as a HCP to bear in mind. Individual therapy was described by participants as an important support, alongside the organisation which appeared to represent a 'family', a safe place, where participants could be themselves. Somewhere they could go and speak to their peers and share their experiences, which often helped them realise that others have similar problems. Therefore, from this research I would suggest a non-judgemental, holistic approach for these individuals where possible to support their psychosocial needs. However, whilst this has been the reality for the participants in this study who live in a big city, access to such resources may be limited further afield. This organisation is currently providing skype peer support which may help bridge this current gap and provide individuals with increased access to the support they need and deserve.

Social justice suggests a "vision of society in which the distribution of resources is equitable and all members are physically and psychologically safe and secure" (Bell, 1997, p.3). Social justice within the field of Counselling Psychology means that our professional activities should focus, not only on the individual clients in our therapy rooms, but also on changing societal values, policies, practices and structures, to actively support access for marginalised groups, to get the tools they need for their own self-development (Goodman et al., 2004). Counselling Psychologists should therefore aim to expand their services and skills, extending these to social action, advocacy and preventative interventions (Speight & Vera, 2004). Therapy via skype is something Counselling Psychologists should therefore consider.


Finally, practitioners should recognise the 'Evolving journey' PAHIV+ individuals are experiencing and the changing impact of HIV for them over the lifespan. They should recognise that HIV disclosure is a complex, on-going process, not a one-off event, and uncertainty and fear may be influenced by their past experiences of stigma and how this was managed within the family. The positive aspects of disclosure must also be considered due to the psychological benefits as discussed. Practitioners must also consider that uncertainty for individuals may change over time and with each new asymptomatic phase or stage of development new uncertainties may arise. This uncertainty can cause mental health problems (Lewis et al, 2015) and is a further consideration for Counselling Psychologists treating these individuals. The development of good psychological health can also reduce

adherence problems (Mellins and Malee, 2013) meaning counselling psychologists are well place to not only facilitate psychological wellbeing but physical health also.

## 4.6 Future research

A major accomplishment of the current era is the significant reduction of HIV mother to child transmission (MTCT; Coutsoudis et al., 2013). With the attempts of UNAIDS to practically eliminate PAHIV (Joint United Nations Programme on HIV/AIDS, 2013), the number of PAHIV+ individual's clinicians and HCP's will see, will reduce further in the future and the cohort will continue to age.

With many PAHIV+ adults reaching adulthood they will inevitably begin to have children of their own. A previous quantitative study has suggested that a large percentage of PAHIV+ individuals, when asked regarding their procreational intentions, expressed the wish to have children (Ezeanolue et al., 2006). One female in this current study already had a child, and some participants described thinking about having children in the future. With evidence to suggest that children who are *affected* by HIV may be an area of concern (Sherr, Croome, Castaneda & Bradshaw, 2014), understanding the subjective experiences of PAHIV + adults with children, would therefore be of interest for future research. Following this it may also be interesting to explore the experiences of male and female participants separately to see if any similarities and differences occur between genders.

Some participants in this study described their struggle to understand their parents, especially when they were younger. Research suggests that parents of children born with HIV may have experienced many struggles in the past research (Fielden et al., 2006; Wiener, Mellins, Marhefka & Battles, 2007) therefore the subjective experience of the parents of PAHIV+ individuals may therefore be another area which could benefit from further research. Illuminating these parental lived experiences may help provide further contextualised support for the whole family. It would also be interesting to explore the experience of those who have not accessed support such as those in this current study.

Research carried out recruiting PAHIV individuals from ethnicities other than Black African, and research conducted by researchers from backgrounds other than White British,

American or Canadian researchers should be considered in future research. It may also be interesting to consider the different religious backgrounds of PAHIV+ individuals and the impact this may have on their experiences of reaching adulthood with PAHIV.  Whilst recruitment of these individuals from other ethnic backgrounds may be particularly challenging due to their small numbers in the UK, it would be interesting and important to carry out further research in this area to see if there are any similarities or differences that emerge. Whilst these differences are a possibility, and would be extremely interesting for future research to investigate it was not the aim of this current study to create generalisable findings.

Finally, it would be interesting to revisit this cohort throughout the lifespan to understand further their lived experiences as they continue their 'Evolving journey', especially because the long term psychological effects of living with PAHIV is currently unknown.

## 4.7 Reflexivity

This training and research has been an incredibly long journey, one of uncertainty and not knowing. This research has taught me to sit with the uncertainty of whether I am good enough. I am aware that I find uncertainty a negative aspect of my life and how this negativity may have impacted the way in which I have analysed and discussed the findings. I have made every attempt to bracket this where possible. I also admit that as I set out on this journey I thought that I may find 'problems' things that I could help 'fix'. What I have discovered is something far more important, these participants evolving journeys are inspiring, the adversity they have faced, the resilience they have shown and the challenges they have conquered, have taught me, that nothing is impossible. In the darkest moments of this research, I have focussed on their strength and this has helped me through. In a strange way, they ended up helping me.

## 4.8 Conclusion

This research highlights the complex nature of living with PAHIV in adulthood. Participants have reached adulthood, and make sense of this by reflecting on their past. They describe an 'Evolving journey', characterised by a developing sense of self and the changing impact of responsibility, stigma and uncertainty that living with HIV infection brings. Due to the changing nature of these individuals' experiences over time a continual revisiting of their social and psychological needs is evident. These findings have provided interesting and

important clinical implications for HCP's and Counselling Psychologists, with some suggestions for future treatment interventions and research explored. This research has; given voice to the participants in this study; allowed these voices of a small cohort who are experts in their experience to be heard and provided the opportunity for others to hear their voices. Finally, for Jacob this research has provided him with the chance to share his experience in the hope that someday, the way people negatively view HIV will change:

"I feel the only way it will change is hearing, hearing a story or hearing from someone who has gone through it" (Jacob, 82:52).

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# Appendices

## Appendix A: Reflexivity diary extracts and example

**May 2015**

Thinking about my research question…Is the unique generation thing a major assumption I have made? Is it more of a medical term to define them as being medically unique? Maybe because I have worked within the medical environment this is something I have picked up on? For some reason I feel like they all know this……but maybe not. I will discuss with Fran and see what she thinks.

So after much deliberation and discussion with Fran I decided to ask Aaron at 'Unity', he says categorically that they are all aware of this so I think i will ask one participant in the pilot interview and see what they say about it.

Participant one did describe being part of a unique generation and also felt this was something everyone was aware of so I will include it. Post interview I wondered what type of impact I had on the interview and what he told me. I also wondered if he knew others who had offered to participate and wondered if they would talk to each other about what the interview was like, what impact may this have on the research? Also once published or available for public viewing I must make participants as non-identifiable as possible not just to outsiders but also to each other.

**July 2015**

Thought of the day…do people make sense of difficult situations or experiences by in turn, unconsciously trying to help others worse off than themselves? Some participants are becoming life coaches and peer mentors; I am training to be a Counselling Psychologist…is there are parallel?

Thinking about Counselling Psychologists and whether they stigmatise people with HIV, especially if they are uneducated in this area. How are HCP's perceived regarding this, how

am I persevered as a HCP by participants? How will this influence the interview? Does stigma stay the same of change as we grow?

**September 2015**

Started thinking about layers of the self, public and private, true and false selfs. Whilst having lived with HIV for your whole life you didn't always know… so there is a point when your life changes with this new knowledge but you always had HIV. This is a very different experience to being diagnosed with horizontal HIV. This is first time I had really thought the fact that their diagnosis was possibly new to them but not to their parents or medical staff who already knew, a position as a health adviser working in HIV that I have occupied. I wonder how much medical professional think about this when support5ing people with PAHIV…

Went running and thought about interview 2, this participant described suffering from a mental health condition which I am not going to divulge but I thought about this and how her childhood and the abandonment/loss she had experienced characterised her early years and may contribute to her mental health problems. She then discovered her HIV diagnoses and experienced the loss of a self she once thought she knew. A possible loss of identity. She then described that the worst had happened and I wondered if adulthood is a time for acceptance feeling more comfortable in your own skin. I also reflected on therapy as a place that she had found intimacy and closeness with another and the importance of this for her. I think I also feel the same about therapy and this may impact the way I interpret participant's experiences of therapy. Things to consider: is loss and gain a theme? Loss in childhood of parents etc, gain in adulthood closeness to therapist and nothing can be worse than childhood? Becoming a therapist allows me to have intimate therapeutic relationships, does becoming a life coach do this for some participants. You become the helper not the helped.

In interview two I asked what would you tell a younger you (advice)? Say 5 years ago, I didn't realise that at the time maybe they hadn't known their HIV status, therefore some may be relatively newly diagnosed which is important to consider when working with this cohort therapeutically but also when analysing the transcripts that I may have assumed they had known for longer.

I have also noticed that when participants describe a feeling of safety about being alone I also feel safe in spending time alone. The research is also helping me to reflect on myself. A kind of cyclical process!

Always important at the end of an interview to discuss anything that the participants may have said that might be incorrect. This has arisen because one participant described not being able to have children because she is positive and it felt important to explore this with her. I feel I have an ethical/moral responsibility.

I noticed on moodle that I have written to Fran in the submission box PSD207 that I removed the interview question regarding being part of a unique generation because even though 'Unity' have told me participants know, to what level this awareness is at is unknown and it is important not to make assumptions.

I have realised that I often make sense of difficult situations/ experiences by comparing myself to others normally looking at others that are less fortunate than me to make me feel better. I wonder if this experience may impact how I analyse the data and must hold this in mind.

I was also thinking about adulthood and how I define it for myself, It really does feel impossible to do and the word 'journey' springs to mind as I consider the transition from adolescent to adulthood. I reflect on how PAHIV individuals all share HIV but their journeys living with it are all so unique and individual. This is a very important thing to consider whilst carrying out this research.

This got me thinking about my own preconceptions: I assume that it is important to know what reaching adulthood is like for these individuals. That five years ago participants would have been aware of their status That living with HIV is difficult There will be few positive to living with PAHIV All these assumptions are important to recognise throughout the research process.

**October 2015**

Trying to vary the ways in which I look at a transcript, be imaginative and think about ways in which they may avoid pain, the ways they see/think/feel about others and reflect on the way I also do this in my life to help aid bracketing. I have come to realise through therapy that going to university (twice) and studying hard may be my way of avoiding pain or being vulnerable and I must be aware of this when I analyse participant accounts especially as most have been to Uni. Going to University for them will hold different meanings to each participant.

Struggling with analysis and decided to go for a run. During my run I started thinking about my past and how through personal therapy I have been able to understand my past and parents a little more. When one of my participants talked about how finding out she had HIV made sense to her and helped her to understand her past rather than it being a life changing event, I found myself being able to understand what she meant a little more, by recognising this in myself I am able to hold awareness of this and bracket it whilst I stay close to her experience.

Today I have been thinking about my own childhood losses and how these impacted me. I have also been thinking about the uncertainty of the research process and how sitting with the not knowing is something I find very difficult. I feel that whilst this is first and foremost a difficulty I am having with carrying out qualitative research, I am also aware that this is also something I am learning to sit with in the therapy room with clients and also something I am working on in personal therapy. I have found it hard today doing some analysis and sometimes I find myself thinking that it is something I need 'to do' rather than letting it flow over me, again a bit like life. This process is therefore a great personal learning experience for me.

When thinking about how some of my participants have been training to become life coaches and some have in the past worked in the caring profession I started to reflect on how therapy and therapeutic relationships are something that some people may only experience in their capacity as a health care worker and I was wondering if this may have been an unconscious drive of mine to become a Counselling Psychologist? I have become the helper to defend against being the helped? Also becoming a member at ''Unity'' for some participants appears to be important to them because they feel a sense of belonging. I

remember feeling this when I joined an antenatal class when I had my children and the positive impact sharing an experience had for me. I had to try and make sure during analysis that I was aware of my own experience and the impact that this could have on how I interpreted the data. Another thing that struck me during today was how many of these individuals have fought the odds to live through this and how as a child growing up I felt that my life was a struggle and a battle to be fought.

I noticed today in personal therapy that I avoid feelings of sadness by focussing on the next thing I need to do, so by focussing on others I don't have to focus on myself. This helped me reflect on my participant who focusses all his energies on helping and education others with HIV and when interpreting the data this was something I needed to be aware of, to make sure it was his experience not mine.

**November 2015**

Today I took my son to a writing festival. Whilst authors got up on stage and told their stories of how they became writers I realised that I too have a story and that my story, my experience of working in HIV for many years is extremely important to be aware of as I think about my participants and analyse my data. I became aware of my own political view and how I have always wanted to improve their quality of life and psychological health.

Today I was interpreting data and many things came to mind. I became aware that the way I may interpret the data could be affected by aspects of myself I had never considered before, for example being a mother, a Health Adviser for over 10 years and my training as a Counselling Psychologist especially in psychodynamic theory. I have ultimately heard the stories of many HIV patients in the past either through seminars or patient groups or in the therapy room. I started to worry that I may have so many previous experiences of working with this cohort that maybe I would miss things because they assume that I know or that I don't ask certain questions because I assume I know something already. Alternatively, I may be well placed to ask difficult and personal questions because of my experience in this field.

Today I started thinking about why I decided to interview participant's at 'Unity' instead of the local NHS Hospital where I currently work. Three main reasons arose. Firstly, I was worried about the length of time NHS ethics would take and time constraints for this research are

huge. There were also two other qualitative studies taking place in the HIV clinic I work in and this is already an over studied cohort therefore I felt it best not to carry out further research at this time. Finally, I would not have been able to recruit anyone that I had previously seen as a patient or in therapy due to conflict of interest therefore reducing my recruitment opportunities.

**July 2016**

I have been thinking about how I am a white western women interpreting Black African peoples experience of living with PAHIV and I feel like I need to know more about their culture. Am I missing stuff that is cultural or religious possibly?

**August 2016**

I realise that I has previously assumed that living with PAHIV into adulthood would get harder because of fear regarding life expectancy however it seems that for many life has got easier in a way (Transcript 4 line 120).

On holiday and talking to a friend who has Chrons disease and nearly died a few years ago. He says he thinks about the future not the past, other things have become more important to him, for example work is now less important than family. This makes me think about the impact of living with a chronic illness and how becoming symptomatic and experiencing near death experiences can disrupt your plans and make you re-evaluate your life.

**September 2016**

Running on George's birthday. Realised that when I am analysing the data I think very psychodynamic and need to consider the impact of this on the research. As I run I want to stop but because it's so good for my back I keep going. I wonder if keeping healthy because you HIV keep you going? Then I realise that I also believe that just because it's good for you doesn't mean it's easy, sometimes you needed wider reasons to do it!!

Analysis a transcript at work I begin to think about specialist HIV services, when I choose my themes they may be influenced by where I work and there is some conflict within me

between what to present…Medical vs Psychological aspects of HIV. This is important to reflect on.

**October 2016**

Final analysis stage begins. Feeling unwell and kids of school sick. Not a great start. Initially seemed quite easy. All themes naturally fell into place:

- Future
- Health
- Disclosure/stigma/others
- Childhood
- Growing up/learning from experience
- Coping
- Giving something back
- HIV is a burden
-

I wonder if they all fall in to past present and future super-ordinate themes at this point. Is there something about purpose? When younger – little purpose as they thought, they would die, now older they see more purpose in life? Or is it about others? Is it about having someone to share life, problems, love and worries with….or is this just how I feel? Today at the farm for Alberts birthday I saw an owl called Coco, his owner was talking to us and told me that if she doesn't see him nearly every day he gets depressed. Apparently, owls can die of broken hearts. This got me thinking about the isolation experienced but those living with HIV and the impact of this on intimate and close relationships. Or is it about existence and dying. Do we as humans exist solely to be close with other? I think for me this is extremely important and may influence how I think about HIV as a barrier. Were they young and thought they would die, they are now survivors and a future is possible…..Is it about a journey...childhood, diagnosis, growing up and the future.

Meeting with Fran regarding themes. There appears to be something about a journey which permeates all participants' accounts which both Fran and I could see. May be an 'overarching theme' to be considered.

Collapsed themes again moved the 'educating others' from a theme on their own to 'a need for control' After reflecting back on an interview where I had written 'Is he looking for external control as he has little internal control' a feeling I had in the room at the time. I also thought it could go in 'reducing difference' but thought long and hard about the psychological reasons for educating others.

**Diary Example**

Emergent themes into table Nº 5.

Most difficult one yet due to disability.

Impact of previous analysis difficult to shift eg coping strategies section.

Unsure if disclosure is a group on its own or should be split into the groups its had the impact on?

Also not sure about the carers part — is her main concern about carers tied up in lack of control → yes I think it is!

Do I talk about health or impact of aging over heat

- experience of adulthood suggests the latter.

## Reflexivity trans 5

Whilst typing up emergent themes table I add a theme about loss & her friends dying in their 20's. I reflect back to a pt I lost few years ago and

wonder if this research is an unconscious attempt to help Mes in a way I failed her?

## Appendix B: Ethical approval



Psychology Research Ethics Committee

School of Social Sciences

 City University London

London EC1R 0JD

13 March 2015

Dear Simone Ruddick,

Reference: PSYCH(P/F) 14/15 126

Project title: The Experience of Adulthood Whilst Living with Perinatally Acquired HIV

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

Recruit a new category of participants

Change, or add to, the research method employed

Collect additional types of data

Change the researchers involved in the project

Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee ███████████████████, in the event of any of the following:

Adverse events

Breaches of confidentiality

Safeguarding issues relating to children and vulnerable adults

Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Erika Suchanova                     Katy Tapper

Departmental Administrator                     Chair

Email:███████████████          Email:███████████████

CITY UNIVERSITY LONDON

Psychology Department

What is eligible for light touch review?

| Does your research involve any of the following? | Yes | No |
|---|---|---|
| Persons under the age of 18 | | x |
| Vulnerable adults (e.g. with psychological difficulties) | x | |
| Use of deception | | x |
| Questions about potentially sensitive topics | x | |
| Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid') | | x |
| Potential for psychological stress, anxiety, humiliation or pain | x | |
| Questions about illegal activities | | x |
| Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs) | | x |
| Potential for adverse impact on employment or social standing | | X |
| The collection of human tissue, blood or other biological samples | | X |
| Access to potentially sensitive data via a third party (e.g. employee data) | | X |
| Access to personal records or confidential information | | X |
| Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants. | | x |

If you have answered 'No' to all the above, your application is probably eligible for light touch review. We aim to review it within 7 days of submission.

If you have answered 'Yes' to <u>any</u> of the questions listed above, your application is NOT eligible for light touch review and will need to be reviewed at the next Psychology Department Ethics Committee meeting*. These meet on the first Wednesday of every month (with the exception of

August). You will need to submit your application at least 2 weeks in advance of the meeting you would like it considered at.

Please submit all applications to ██████████████████

*NB. If the research is considered very high risk, or the committee does not feel it has the necessary expertise to review the application, you will need to complete a Senate Ethics Application which will need to be reviewed by the Senate Research Ethics Committee. Similarly, if your research is supported by external funding (e.g. ESRC) it may also need to be submitted to the Senate Research Ethics Committee ██████████████████████.

*If you are unsure about your answers to any of the above questions, please contact the Chair of the Psychology Ethics Committee, Katy Tapper ██████████████████████.*

CITY UNIVERSITY
LONDON

Psychology Department Standard Ethics Application Form:

Undergraduate, Taught Masters and Professional Doctorate Students

This form should be completed in full. Please ensure you include the accompanying documentation listed in question 19.

| Does your research involve any of the following?<br><br>*For each item, please place a 'x' in the appropriate column* | Yes | No |
|---|---|---|
| Persons under the age of 18 | | no |
| Vulnerable adults (e.g. with psychological difficulties) | yes | |
| Use of deception | | no |
| Questions about potentially sensitive topics | yes | |
| Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid') | | no |
| Potential for psychological stress, anxiety, humiliation or pain | yes | |
| Questions about illegal activities | | no |
| Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs) | | no |
| Potential for adverse impact on employment or social standing | | no |
| The collection of human tissue, blood or other biological samples | | no |
| Access to potentially sensitive data via a third party (e.g. employee data) | | no |
| Access to personal records or confidential information | | no |
| Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants. | | no |

If you answered 'no' to <u>all</u> the above questions your application may be eligible for light touch review. You should send your application to your supervisor who will approve it and send it to a second reviewer. Once the second reviewer has approved your application they will submit it to ▇▇▇▇▇▇▇▇▇▇▇▇ and you will be issued with an ethics approval code. <u>You cannot start your research until you have received this code.</u>

If you answered 'yes' to any of the questions, your application is NOT eligible for light touch review and will need to be reviewed at the next Psychology Department Research Ethics Committee meeting. You should send your application to your supervisor who will approve it and send it to ███████████████. The committee meetings take place on the first Wednesday of every month (with the exception of August). Your application should be submitted at least 2 weeks in advance of the meeting you would like it considered at. We aim to send you a response within 7 days. Note that you may be asked to revise and resubmit your application so should ensure you allow for sufficient time when scheduling your research. Once your application has been approved you will be issued with an ethics approval code. You cannot start your research until you have received this code.

| Which of the following describes the main applicant? <br><br> *Please place a 'x' in the appropriate space* | |
| --- | --- |
| Undergraduate student | |
| Taught postgraduate student | |
| Professional doctorate student | x |
| Research student | |
| Staff (applying for own research) | |
| Staff (applying for research conducted as part of a lab class) | |

| 1. Name of applicant(s). |
| --- |
| Simone Ruddick |
| 2. Email(s). |

| |
|---|
| ███████████████ |

| 3. Project title. |
|---|

The Experience of Adulthood Whilst Living with Perinatally Acquired HIV

| 4. Provide a lay summary of the background and aims of the research. (No more than 400 words.) |
|---|

Literature suggests PAHIV+ adults may have faced stressors which increase chances of developing mental health problems, familial death, family disruption, stigma and negative environmental characteristics. Additionally PAHIV+ adults live with the knowledge they have a sexually transmissible infection, even if they have never had sex, suggesting the chance of unique psychological challenges for this cohort. This cohort is also unique due to the development of HIV antiretroviral treatment which became available to these individuals giving them the opportunity to live much longer than those born before them.

This research aims to investigate a small group of people living with PAHIV and hopes to illuminate and makes sense of their individual experience of being part of this unique cohort who have now reached adulthood. Semistructured interviews will be carried out with 8 adults living with PAHIV who currently attend a London based HIV organisation. Interviews will be analysed utilising Interpretative Phenomenological Analysis (IPA). The benefits of this study are hopefully two fold. Participants will get the opportunity to meet with a Counselling Psychologists and tell their story the way it is for them, whilst the field of Counselling Psychology gains potential insight into the participant's life world, enhancing their knowledge base and potentially facilitating the psychological treatment of these individuals in the future.

5. Provide a summary of the design and methodology.

This research aims to explore the lived experience of people living with PAHIV or early acquired infection and serves to make sense and better understand the nature and texture of their experience of being the first of a unique generation to reach adulthood.

This study employs IPA because it offers insight into how a particular person or group make sense of a particular experience. An ideographic approach will be taken which is concerned with the particular and IPA is committed to this through detail and depth of analysis whilst focussing on particular people, in a particular context, experiencing a particular experiential phenomenon, process, event or relationship.

This research aims to investigate 8 PAHIV+ young adults who attend an HIV London based organisation. Participants will be purposively chosen, aged over 19 and have early acquired or PAHIV. This sample will exclude

participants who do not speak English because with IPA studies participants need to be able to articulate their livid experience.

Eligible participants will be identified via liaison with the head of operations. Participants will be identified by looking at current age and diagnosis and those due to attend the organisation soonest will be identified and approached regarding the study. A written information sheet will be handed to participants before the interview giving time to read and digest the information.

If verbal consent is given I will call them offering an appointment to come for an interview, this will take place at the organisation, during a normal visit if they prefer.  The interviews will take place in a room which will offer privacy. The organisation will be able to provide the appropriate psychological support if the need arises. The time and date of the interview will be negotiated between myself and the participant.

6. Provide details of all the methods of data collection you will employ (e.g., questionnaires, reaction times, skin conductance, audiorecorded interviews).

Participants will be interviewed between 45 – 90 minutes, utilising a semi structured questionnaire. Interviews will be audio-recorded and data will be collected, transcribed and analysed using IPA.

Basic demographic data will also be collected

All data will be anonymised to protect participant confidentiality.

7. Is there any possibility of a participant disclosing any issues of concern during the course of the research? (e.g. emotional, psychological, health or educational.) Is there any possibility of the researcher identifying such issues? If so, please describe the procedures that are in place for the appropriate referral of the participant.

There is a possibility that participants may raise issues of concern to me during the research interview. As a Trainee Counselling Psychologist, I have the skills to be able to identify this and refer to the appropriate services. As the research is being carried out in the setting of a organisation that has been developed to support such individuals I would be referring them to in-house support which may be delivered by a psychologist or counsellor.

8. Location of data collection. (If any part of your research takes place outside England/Wales please also describe how you have identified and complied with all local requirements concerning ethical approval and research governance.)

N/A

9. Details of participants (e.g. age, gender, exclusion/inclusion criteria). Please justify any exclusion criteria.

Participants will be over 19, any gender and must have PAHIV. This sample will exclude participants who do not speak English because with IPA studies participants need to be able to articulate their livid experience.

10. How will participants be selected and recruited? Who will select and recruit participants?

Participants will be selected and recruited through liaison with the

Organisation's operations Aaron. A group is held monthly for support to young adults and this will be where I can recruit participants from.

11. Provide details of any incentives participants will receive for taking part.

12. Will informed consent be obtained from all participants? If not, please provide a justification. (Note that a copy of your consent form should be included with your application, see question 19.)

Yes

13. How will you brief and debrief participants? (Note that copies of your information sheet and debrief should be included with your application, see question 19.)

To brief participants they will be given a participant information sheet before they attend the interview, this will give them time to read and digest the information. When participants arrive for the interview they will have the opportunity to ask any questions they may have and given a copy of the interview schedule. Post interview a debrief sheet will be given and again a chance to reflect on the interview and ask any questions.

14. What potential risks to the participants do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.

The biggest potential risk that I foresee is that this research may bring up issues for participants that they find distressing. This will be managed at the time by myself as a Trainee Counselling Psychologist and then appropriate psychological support will be offered post interview.

I don't foresee any health and safety risks.

Extreme care will be taken over confidentiality when transcribing and presenting the data collected. Pseudonyms will replace real names including names written on transcripts ensuring participants remain completely anonymous. Voice recordings will be encrypted, securely stored and destroyed when no longer required for research purposes.

Participation will be strictly voluntary with the right to withdraw up until the point the data is aggregated without explanation. Withdrawal from the study at any point will not impact present or future care (Smith et al, 2009). All participants will be over 19 years old. I will be consciously aware that some of my questions may illuminate issues that participants may not have previously considered.

Interviewing individuals that are already well supported by a specialist HIV organisation aims to reduce the risk in two ways. Firstly these are already well supported individuals and secondly they have direct access to ongoing support and referral for counselling.

Participants will be fully informed of the research procedure through an interview schedule (with no methodological reason to conceal this) with some omission regarding key concepts that may influence or bias the focus of participants' narratives (Willig, 2013). Written consent will be needed before data collection takes place. Participants will be fully informed regarding the aims of the research once data collection is complete, debriefed after the interviews with the opportunity to ask questions, have access to any publications arising from the research and be aware and have access to psychological support during, throughout, post interview and thereafter if needed. Participants will also have the opportunity to be followed up for psychological support from the organisation. Contact details for further follow up psychological support will be given post interview.

If direct quotes are to be used specific permission will be asked for by participants involved and written consent from them obtained

15. What potential risks to the researchers do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.

I will be interviewing these young adults in a private room with an emergency alarm, it is a safe and secure environment and I will not be alone in the building. I will not be interviewing any participants who I already know or have worked with in any capacity before. For any psychological issues that may arise for myself throughout these interviews I have my own personal therapist.

16. What methods will you use to ensure participants' confidentiality and anonymity? (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)

*Please place an 'X' in all appropriate spaces*

| Complete anonymity of participants (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.) | |
|---|---|
| Anonymised sample or data (i.e. an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.) | |

| De-identified samples or data (i.e. a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.) | x |
|---|---|

| Participants being referred to by pseudonym in any publication arising from the research | x |
|---|---|
| Any other method of protecting the privacy of participants (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only.) *Please provide further details below.* | x |

Before data becomes anonymous only I will have access to the data. Once data has been anonymised, data may be seen by my supervisor and other Counselling Psychology trainees during the process of analysis.

Interviews will be recorded on an encrypted digital hand held device.

Interviews will be deleted once they have been transcribed.

There will be no future use of your personal information

Records will be kept in a locked filing cabinet. Raw data will be stored for three years and then destroyed.

| 17. Which of the following methods of data storage will you employ? |  |
|---|---|

*Please place an 'X' in all appropriate spaces*

| Data will be kept in a locked filing cabinet | x |
|---|---|
| Data and identifiers will be kept in separate, locked filing cabinets | x |
| Access to computer files will be available by password only | x |
| Hard data storage at City University London |  |
| Hard data storage at another site. *Please provide further details below.* |  |

| 18. Who will have access to the data? | |
|---|---|
| *Please place an 'X' in the appropriate space* | |
| Only researchers named in this application form | |
| People other than those named in this application form.  *Please provide further details below of who will have access and for what purpose.* | x |
| Before data becomes anonymous only I will have access to the data. Once data has been anonymized, data may be seen by my supervisor and other Counselling Psychology trainees during the analysis of research process | |

19. Attachments checklist. *Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.

*Please place an 'X' in all appropriate spaces*

| | Attached | Not applicable |
|---|---|---|
| *Text for study advertisement | x | |
| *Participant information sheet | x | |
| *Participant consent form | x | |
| Questionnaires to be employed | x | |
| Debrief | x | |
| Others (please specify, e.g. topic guide for interview, confirmation letter from external organisation) | | |

| 20. Information for insurance purposes. |
|---|

(a) Please provide a brief abstract describing the project

Children with PAHIV are living into adulthood for the first time. A unique generation of people are facing this new phenomenon. There is a paucity of research in this area highlighting the experience of these particular individuals. This qualitative study will aim to illuminate the lived experience of individuals who are the first of a unique generation to reach adulthood whilst living with perinatally acquired HIV, through interviews with 8 young adults utilising semi structured open ended questions. The mental health needs of this population are diverse and possibly unique. This research hopes to enhance Counselling

Psychologist's knowledge base from which to provide and deliver context specific psychological treatment, in turn enhancing client experience, whist contributing to future research in the development of this area.

*Please place an 'X' in all appropriate spaces*

| (b) Does the research involve any of the following: | Yes | No |
|---|---|---|
| Children under the age of 5 years? | | x |
| Pregnant women? | | x |
| Clinical trials / intervention testing? | | x |
| Over 5,000 participants? | | x |
| | | |
| (c) Is any part of the research taking place outside of the UK? | | x |

If you have answered 'no' to all the above questions, please go to

section 21.

If you have answered 'yes' to any of the above questions you will need to check that the university's insurance will cover your research. You should do this by submitting this application to anna.ramberg.1@city.ac.uk, before applying for ethics approval. Please initial below to confirm that you have done this.

I have received confirmation that this research will be covered by the university's insurance.

Name    …………………………………………….

Date……………………………

| 21. Information for reporting purposes. | | |
|---|---|---|
| *Please place an 'X' in all appropriate spaces* | | |
| (a) Does the research involve any of the following: | Yes | No |
| Persons under the age of 18 years? | | x |
| Vulnerable adults? | x | |
| Participant recruitment outside England and Wales? | | x |
| | | |
| (b) Has the research received external funding? | | x |
| 22. Declarations by applicant(s) | | |
| *Please confirm each of the statements below by placing an 'X' in the appropriate space* | | |

| I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct. | x |
| I accept the responsibility for the conduct of the procedures set out in the attached application. | x |
| I have attempted to identify all risks related to the research that may arise in conducting the project. | x |
| I understand that no research work involving human participants or data can commence until ethical approval has been given. | x |

| | Signature (Please type name) | Date |
|---|---|---|
| Student(s) | | |
| Supervisor | | |

## Appendix C: Recruitment poster

**CITY UNIVERSITY LONDON**

Department of Psychology City University London

 PARTICIPANTS NEEDED FOR RESEARCH IN

'The Experience of Adulthood Whilst Living with Perinatally Acquired HIV'

We are looking for volunteers to take part in a study focussing on what adulthood is like whilst living with perinatally acquired HIV

You would be asked to: meet confidentially with a Trainee Counselling Psychologist during a normal visit to ''Unity'' and answer some questions about what your personal experience of adulthood is like.

Your participation would involve one session lasting approximately 45-90 minutes.

For more information about this study, or to take part,

please contact: Simone Ruddick ▇▇▇▇▇▇▇▇▇▇▇▇▇ ▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇ or Dr Fran Smith, City University on 020 7040 8162, ▇▇▇▇▇▇▇▇▇▇▇▇

This study has been reviewed by, and received ethics clearance

through the Psychology Department Research Ethics Committee, City University London. Ethics approval number *[ PSYCH(P/F) 14/15 126]*

If you would like to complain about any aspect of the study, please contact the Secretary to the University's

Senate Research Ethics Committee on ▇▇▇▇▇▇▇▇ or via email: ▇▇▇▇▇▇▇▇▇▇▇

**Appendix D: Participant Information Sheet**



Title of the study: The Experience of Adulthood Whilst Living with Perinatally Acquired HIV (PAHIV)

My name is Simone Ruddick and I am currently training to be a Counselling Psychologist at City University. I would like to invite you to take part in a research study that is close to my heart. I have worked at a London NHS Hospital since 2004 and was involved in setting up and developing the young person's transition clinic for HIV adolescents moving from pediatric to adult services. My interest has always been in the best possible care for all patients, in particular supporting individual's psychological needs. With many of you now getting older I have been wondering what it must be like to be a young adult living with HIV to reach this stage of your life and how in particular psychological services can best support individuals.

Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you want to take part.

What is the purpose of the study?

This study aims to look at what it is like to be living as an adult with perinatally acquired HIV as there is currently little information available. This research aims to change that by conducting a one off meeting which may last approximately 45 - 90 minutes with 8 young adults who currently attend ''Unity''.

Why have I been invited?

You have been invited to take part in this study because you are an adult, who attends

''Unity'' and acquired HIV early in life. Approximately 8 participants will be recruited in total.

Do I have to take part?

Participation in this research is strictly voluntary. You do not have to participate in all of the research for example answering a particular question if you do not want to. If you do wish to take part and at a later date change your mind you can withdraw up until the point the data is aggregated. This will not affect any future access to the organisation for support or disadvantage you under any circumstances. It is your choice whether or not to take part. You will be asked to sign a consent form if you do decide to.

What will happen if I take part?

Participation will take place where possible during your normal visit to the organisation. It should only take between 45 – 90 minutes of your time.

You will only need to meet with me once which will involve an introduction to the research, the interview and debrief at the end.

Whilst I will collect some demographic information from you at the beginning of the interview this will all be held confidentially and the interviews will be anonymous. The interview will consist of several semi structured interviews which will give you the opportunity to tell your story.

There will only be you and myself in the room.

This is a qualitative piece of research.

Interviews will take place in a private room at ''Unity''.

Expenses and Payments (if applicable)

As this interview will take place during a normal visit travel expenses will not be paid.

I am hoping that this research may be able to offer individuals an opportunity to share their stories which may be of therapeutic benefit to themselves, future young adults and the field of counseling psychology.

What do I have to do?

All I will need you to do is dedicate a short amount of time to speaking with me during your normal visit in a relaxed environment about your life as an adult.

What are the possible disadvantages and risks of taking part?

Whilst interview questions aim to be sensitive, there is always the chance that during the interview issues of a delicate nature may arise when you tell me about your life. Whilst I am a Trainee Counselling Psychologist and will be able to help you with these feelings at the time, there will also be the opportunity for follow up psychological support after the interview has finished or at a later date if you wish to engage further with counselling support or a psychology referral here at ''Unity''.

What are the possible benefits of taking part?

One of the possible benefits in taking part in this process is the opportunity to meet with a Trainee Counselling Psychologist. Having a space to sit and reflect on what is happening in your life right now may be of therapeutic benefit, it is also an opportunity to be heard in a non-judgmental way. This is your opportunity to tell your story the way it is. Findings from this research may in turn benefit the younger generation of teenagers and young people living with PAHIV who might be curious to know what adulthood might look like for them in the future

Secondly in order to best support patients psychological needs now and in the future there is a strong benefit for Counselling Psychologists and other health care professionals to have the best understanding they can of their clients or patients. Whilst I am aware that you are part of a heavily studied group of service users at ''Unity'' I am also aware that there is no research that I have found to date hearing about adults experiences of living with PAHIV.

What will happen when the research study stops?

Participants will be fully informed regarding the aims of the research once data collection is complete.

Will my taking part in the study be kept confidential?

Before data becomes anonymous only I will have access to the data.

Once data has been anonymised data may be seen by  my supervisor and other Counselling

Psychology trainees during the analysis of research process

Interviews will be audio recorded on an encrypted digital hand held device.

Interviews will be deleted once they have been transcribed.

There will be no future use of your personal information

Records will be kept in a locked filing cabinet. Raw data will be stored for three years and then destroyed.

What will happen to the results of the research study?

The thesis will be published and placed in the university library for viewing for the next 5 years, I will reserve the right to publish extracts from this thesis. You will have access to any publications arising from the research. Anonymity will be maintained at every level. If you wish to receive a summary of

the final results please indicate in the box provided on the consent form and provide your current email address.

What will happen if I don't want to carry on with the study?

You have the right to withdraw from the study up until the point the data is aggregated without penalty or explanation.

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone ███████████. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is *[insert project title here]*

You could also write to the Secretary at:

Anna Ramberg

Secretary to Senate Research Ethics Committee

Research Office, E214

City University London

Northampton Square

London

EC1V 0HB

Email: ████████████████████

Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee, approval number *[insert approval number here]*

Further information and contact details

Please feel free to contact either Simone Ruddick or Abi Nolan if you would like a psychology referral to talk through any difficult issue that may arise from the interview, or for any other information regarding the study you can contact

Simone Ruddick on email: simone.ruddick.1@city.ac.uk, Abi Nolan on email: Abi@bodyandsoulorganisation.org or Dr Fran Smith, Psychology Department, City University on 020 7040 8162 or email: █████████████████

Thank you for taking the time to read this information sheet.

## Appendix E: Interview schedule pilot one (Hay fever)

If an alien walked through your front door and you had to describe to them what it means to be an adult right now living with (Hay fever) what would you say?

Have you been aware growing up that you are one of the oldest people living with Hayfever from birth or early childhood?

If yes in what ways?

Is this something you think about?

Can you tell me a bit more about this please?

If no 'How does it feel that I have just told you this?'

Can you describe ways in which adulthood for you may be different from how the younger generation living with (Hay fever) may experience it in the future? Or are they the same?

Can you tell me what you think might be same/different about your adult life compared to others around you, e.g. family, friends, colleagues?

What might be different about the way you look at the future compared to others younger than you living with (Hay fever) PAHIV? Or is this the same? Can you tell me more about this?

How does knowing you are one of a few young people to reach adulthood with (Hay fever) feel?

How do you imagine children and adolescents born with (Hay fever), younger than you, the future generations will feel as adults? What would be the same/different to your experiences?

Imagine you went to meet younger people living with (Hay fever) to explain to them what it is like for you living as an adult. Can you tell me how you would explain this to them?

No one can predict the future, no one knows how long they are going to live, can you tell me how being born with (Hay fever) and now being an adult affects how you think about the future? If at all?

If a younger you (maybe around the time you found out about your diagnosis) walked through the door and wanted to ask you to describe what it is like to be ( insert age they are now)  and still living with (Hay fever) , what would you say?

Can you imagine any differences between how adulthood is for you compared to how it might be for future generations growing up with (Hay fever)?

-        Are there similarities?

General prompts throughout

Can you tell me a bit more about that?

What do you mean by '?'?

I'm curious to know how that made you feel.

I'm curious to know what you think about that.

**Appendix F: Interview schedule pilot two**

1. How does living with HIV as a _ _ year old impact on your life right now?

Home, work, friends, relationships, career, education

Would this be similar or different of you didn't have HIV


2. What is it like to live with HIV at the age you are now?

What is harder/ easier?

What does this mean for you?


3. I am aware that sometimes yourself and others your age having lived with HIV since you were young are often identified as the 'first generation' and I was wondering what that is like for you?

What is it like being identified as part of this group?

What's it like being one of the oldest?

What does it mean for you?

What do you think about that?

How does that feel?


4. I am aware that there is a lot of existing emotional support available out there for you and I was wondering at this point in your life what works best for you?

What is your experience of this support?

Good/bad

What could be better or more useful?

What would you change?


5. What is it like for you when you think about the future?

Is this different from how you saw it in the past?

What is similar/different

Harder/easier


6. If you could speak to your younger self, for example to a younger you 5 years ago what advice would you give yourself?

What would you say to yourself?

Why would you give this advice?

Prompts

Can you put a word to that?

Can you tell me a bit more about that?

Could you explain that in a little more detail?

What makes you say it like that?

## Appendix G: Interview schedule final and revised

1. Five minute introduction to the interview and the chance to ask questions 2. 45- 90 minute interview which will be digitally audio recorded 3. Debrief at the end of the interview , opportunity to ask questions and reflect

Questions Guide

1. What is going on in your life right now?

How does HIV impact on this?

What is harder/ easier right now?

What does this mean for you right now?

2. How does living with HIV as a _ _ year old impact on your life right now?

Home, work, friends, relationships, career, education

Would this be similar or different of you didn't have HIV

3. I am aware that you have lived with HIV since you were young and I was wondering what that is like for you?

What is it like being identified as part of this group?

What's it like being one of the oldest?

What does it mean for you?

What do you think about that?

How does that feel?

4. I am aware that there is a lot of existing emotional support available out there for you and I was wondering at this point in your life what works best for you?

What is your experience of this support?

Good/bad

What could be better or more useful?

What would you change?

5.      What is it like for you when you think about the future?

Is this different from how you saw it in the past?

What is similar/different

Harder/easier


6. If you could speak to your younger self, for example to a younger you 5 years ago what advice would you give yourself?

What would you say to yourself?

Why would you give this advice?


General prompts throughout

Can you tell me a bit more about that?

What do you mean by '?'?

I'm curious to know how that made you feel?

I'm curious to know what you think about that? -          Can you put a word to that?

Can you tell me a bit more about that?

Could you explain that in a little more detail?

What makes you say it like that?

Tell me what you were thinking?

How did you feel?

Why now?

For further details regarding future psychological support please contact


Simone Ruddick:  ███████████████

════════════════════
████████████████████

## Appendix H: Changes and reflections after pilot interview two

Change question 1 to a softer question as it was too hard to start with

Realised question 1 and 2 are similar so merge them

Adding 'right now' to my prompts to remind participant's that we are talking about the here and now

Add prompts:  Tell me what you were thinking? How did you feel? Why now?

## Appendix I: Consent form



Consent Form

Title of Study: The Experience of Adulthood Whilst Living with Perinatally Acquired HIV

Please read and initial the boxes below.

| 1. | I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.<br><br>I understand this will involve:<br><br>be interviewed by the researcher allow the interview to be digitally audiotaped | |
| --- | --- | --- |
| 2. | This information will be held and processed for the following purpose(s):<br><br>For my research thesis which will be published and held in the library at City University for up to 5 years. I reserve the right to publish further articles from this research<br><br>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. | |
| | Names will be replace with pseudonyms to protect my identity from being made public. | |

| 3. | I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw up until the stage of the project up until the data is aggregated. Withdrawal from the study will not result in you being penalized or disadvantaged in any way. | |
|---|---|---|
| *4.* | I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998. | |
| 5. | I agree to take part in the above study. | |
| 6. | I agree to direct quotes from what I have said to be used in the final publication of the thesis. | |
| 7. | I wish to receive a summary of the results when this research is complete and provide my current email address below. Email address_____ | |

Name of Participant          _____

Signature          _____

Date          _____

Name of Researcher consenting Participant_____

Signature          _____

Date          _____

When completed, 1 copy for participant; 1 copy for researcher file.

## Appendix J: Debrief sheet



The Experience of Adulthood Whilst Living with Perinatally Acquired HIV

This qualitative research aims to illuminate the lived experience of individuals in early adulthood living with perinatally acquired.

DEBRIEF INFORMATION

Thank you for taking part in this study! Now that it's finished we'd like to explain the rationale behind the work.

This research was carried out to try and better understand what it is like to be someone who was born with HIV or acquired it early in life and has now entered adulthood. By asking you the questions that I did I was hoping to gain a better understanding of your own unique individual experience of what this is like for you. The reason for doing this is to hopefully help better inform Counselling Psychologists who are working with adults who are in this situation.

If for any reason this research has raised your concerns or you would like a psychology referral to talk through any issues raised by this interview please feel free to contact either myself or the head of operations at ''Unity'' Abi Nolan.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

*Simone Ruddick (simone.ruddick.1@city.ac.uk)*

*Dr Fran Smith (fran.smith.1@city.ac.uk)*

*Abi Nolan (Abi@bodyandsoulorganisation.org)*

Ethics approval code: *[Insert ethics approval code here.]*

# Appendix K: Example of a coded transcript

thought I kind of felt like "oh", it was..it wasn't really a relief it

*Handwritten codes:* Disclosure not a relief / Surprised. / Judges others as she might judge honey? / Surprise that disclosure went well

was just like I kind of thought "wow" erm, y'know, (inaudible)

*Handwritten codes:* Surprised.

just took it, that he took that really well.

*Handwritten codes:* Surprised how well he took it.

I. How did that feel?

*Handwritten code:* Stigma.

R. Just, I, I don't know, I still haven't placed a feeling on it,

*Handwritten codes:* Emotionally inept? Is she going to? Will she fall again? / Difficult to know how she felt confused? / ...ing feelings positive disclosure

because I'd..I just..if someone, I, if..if I met someone else

*Handwritten codes:* There's the way would react neg? Stigma? / Future set way meet someone she.

| | |
|---|---|
| 7 | and they didn't react like that I would have been just like |
| 8 | "oh", y'know because I still have that same feeling, 'cause it |
| 9 | was y'know, he took it almost too good, but at the same time |
| 0 | it was just like, y'know, it's given me that....I think it's given |
| 1 | me, my, that focus, because y'know I have, I have got that |
| 2 | reason to, to, to say that "alright, cool, I have, I have got |

*Handwritten annotations (right margin):*

If someone was to react negatively to her disclosure.

Surprised? disbelief. Feels massive it they are [?] about themselves

Fundamentally doesn't feel loveable / good enough and can't believe that with HIV its possible — impact on his sense of experience? a gift of experience?

A new focus. / direction?

A positive disclosure has given her a reason to believe in

*Handwritten annotations (left margin):*

Disbelief someone could accept her HIV.

...ure disclosure is new direction to self.

something else" y'know where somebody else can just jump

into a relationship with (inaudible) ok, y'know I haven't got

anything and it's emotional 'cause like with me, I didn't have,

I didn't sleep with anybody, prior to ending up with my status,

not saying that's the only way but I'm saying you know, I

didn't, d'you know what I mean, I didn't sleep with

HIV from PPHIV.

needs to give other answer. – elders saying PPHIV reduce stigma?

talks to self. – tells self-its ok.

Has to explain because more as well as HIV.

stranger to HIV

caring. They care if you have PPHIV or HIV if you're not a head.

In a sexual rel they want to know something different.

active – loaded to negative connotations.

Feels she needs to explain PPHIV

difference between HIV and sexually aquired

(a stigma)

(9) somebody, y'know, it was from (transmission?), so it's just

(10) like, "ok" so it's even having to explain that, because

(11) somebody that doesn't know that like I said with telling a

(12) friend, they're responsible with "oh my gosh are you ok?" ,

(13) with someone that you're going to be intimate with, they

(14) wanna know is it because you know, you've been sleeping

## Appendix L: Example of summary tables

Summary Table 1.0 Emergent Themes: transcript two

| Major Theme 1: Social Comparison | Key Words/ Quotes | Page/Line no's |
|---|---|---|
| Emergent Themes: | | |
| 1. Health | '..people always think HIV is the worst but..' | Pg 31 line 276 |
| 2. the and Self Others | ''I just think oh I wish I had that problem instead, like, I wish I could like just swap lives for like a day or two, it would be a breeze for me' 'I don't want them to use it a..against me to make me feel like I'm less than them' | Pg51 line 459 Pg 19 line 170 - 171 |
| 3. Perception | '..problem is being able to be comfortable to tell people and knowing that things aren't going to change if you tell them' 'I feel like if I tell certain friends things wouldn't be the same' | Pg 13 line 114 Pg 14 Line 120 |
| 4. Time | 'its because I don't know anyone that's been born with it and like who's either like 50' 'we're like the first generation kind of people' 'it's crazy' | Pg 34 line 303305 Pg 35line 313 |

| Major Theme 2:<br><br>The Self | Key Words/ Quotes | Page/Line no's |
|---|---|---|
| Emergent Themes | | |
| 1.<br><br>Isolation/Secrecy | 'I wasn't (?) told'<br><br>'left out' x 2 | Pg 11 Line 91<br><br>Pg 6 |
| 2. Adjustment | 'finally getting into my adult life even though you start being an adult at eighteen'<br><br>'..to not base your opinion of yourself on other people's opinions of you, or other people's perceptions of you' | Pg 22 line 197<br><br><br>Pg 47 line 423 -<br><br>424 |
| 3. Identity | 'these days I'm having, making more of like erm, trying to decide, like, who I want to be and settle into myself and things like that' | Pg 16 line 141 |
| 4. Hidden Self | 'I wouldn't have to worry about people using my status against me or telling other people' | Pg 52 line 466 |

| 5.        Self-Acceptance/Denial | 'completely fine' actually quite fine' | Pg 8 lines 66-69 |
|---|---|---|
| | 'I made it into a bigger thing than it was' | Pg 8 63 |
| | 'the only thing different about me and someone who's not positive I'd say is..i cat..i catch colds so easily' | Pg 21 line190 – 191 |
| | 'at the end of the day I feel happy being who I am, I wouldn't want to be anyone else...but (laughs) there are things we'd all like to change...but I don't think, I don't think it would be easier, its just what you're used to...yeah it's just what you're used to' 'I felt a bit stigmatised but not, not directly' | Pg 53 – 54 line 476 - 481 |
| | '..a lot of people, if I was to tell them that I | Pg 7 line55-56 |
| | found out that I was HIV positive then, they would think "your life must have changed the day you found out", but actually it hasn't' | Pg11 line 92 - 94 |
| 6. comparing self to younger self | 'I just felt like every other child' | P21 line 186 |

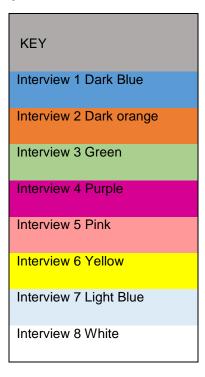| Major Theme 3: Relational | Key Words/ Quotes | Page/Line no's |
|---|---|---|
| Emergent Themes | | |
| 1. Sexual partners | 'I'm        terrified        to       ever       tell           someone      I'm...positive' | Pg 18 line 157 |
| 2. Friends | '99% of my friends don't know' | Pg 12 line 108 |

| 3. Therapy | Confidentiality. 'its like my diary, its like a person th..that I can tell things to, confidentially but also ….give me an | Pg 38 line335 – 336 |
| --- | --- | --- |
| | outlook with it, like the bigger picture' 'I cant see my life without therapy' | Pg 37 line 327 |
| 4. Having Children | 'one of my biggest fears, has always been, if I have children, then I'm gonna end up dying like my parents did' | Pg 26 line 235 - 237 |

| Major Theme 4: Life Experience | Key Words/ Quotes | Page/Line no's |
| --- | --- | --- |
| 1. Childhood | 'I lost my parents at a young age' | Pg 50 line 448 |
| | Trauma and Fear of abandonment | Pg 42 line 371 |
| | 'because I relate to all of them' | |
| 2. Living/Surviving | 'I've had a lot of horrible things happen when I was younger and I'm not even 25 | Pg 50 line 450 – 452 |

| | yet, so I feel like I'm sort of built to face things' | |
| --- | --- | --- |
| | 'it's actually quite a big thing that people my age are the people that are born with HIV and are living with it' | Pg35 line 307308 |
| | 'you can basically live and survive' | Pg 36 line 319 |

| 3. Future | ' I do think differently about it now' | Pg 30 line 264 |
| | 'HIV is so manageable' | Pg 32 line 282 Pg 33 line 291 |
| | 'I mean nobody really knows what age they're gonna live up to' | |
| | 'next few years' | Pg 23 line 201 |
| | 'what if I like find the one and I wanna get married' | Pg 12 line 103 |
| 4. Self-worth | 'if you can…be an example to others' | Pg 36 Line 318-319 |
| 5. Adulthood | 'I've somehow lived to be 23 years, I'm going to be 24 this year, well, it can't all be that bad because, I feel like the worst has happened to me in life already..' | Pg 50 line 446 |

## Appendix M: Example of final results table

| KEY |
|---|
| Interview 1 Dark Blue |
| Interview 2 Dark orange |
| Interview 3 Green |
| Interview 4 Purple |
| Interview 5 Pink |
| Interview 6 Yellow |
| Interview 7 Light Blue |
| Interview 8 White |

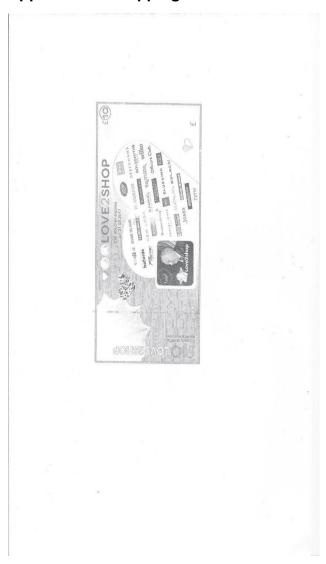| The changing responsibility of self |
|---|
| Has been supporting the family as well as the self |
| responsibility in adulthood increases |
| more control and more responsibilities in adulthood |
| a responsibility to educate and look after self once diagnosed with HIV |
| responsibility changes as you grow up |
| recognition we are ultimately responsible for ourselves |
| feels responsible to help others in similar situations |
| Responsibility feels like a burden |
| health impacts self physically but is also a huge responsibility |
| becoming an example to others is important to self |
| wants to be a counsellor and give something back to others |
| understands others difficult journeys and wants to help them because you know what its like |

**Appendix N: Shopping Voucher**

**Appendix O: Table of appearance of each participant.**

**Super-ordinate theme two: Reflecting on a difficult childhood**

| Subtheme | Diagnosis changed self | Difficult family life | Anger and blame towards family | Secrecy and isolation in family | Numerous struggles at an early age |
|---|---|---|---|---|---|
| Sam | No | Yes | Yes | Yes | No |
| Abi | No | No | No | Yes | Yes |
| Emily | Yes | Yes | Yes | Yes | No |
| Jacob | Yes | Yes | No | Yes | Yes |
| Grace | Yes | No | No | No | No |
| Alex | No | Yes | Yes | No | Yes |
| Mia | Yes | Yes | Yes | No | No |
| Anna | No | No | No | No | Yes |

**Super-ordinate theme three: The stigma barrier**

| Subtheme | A secret life | Perception of self by others | Negotiating sexual relationships | 'Biggest killer of HIV' |
|---|---|---|---|---|
| Sam | No | Yes | Yes | No |
| Abi | Yes | Yes | Yes | No |
| Emily | No | No | Yes | No |
| Jacob | Yes | No | Yes | Yes |
| Grace | No | No | Yes | Yes |
| Alex | Yes | Yes | Yes | Yes |
| Mia | No | Yes | Yes | No |
| Anna | No | No | Yes | No |

## Super-ordinate theme four: Managing uncertainty

| Subtheme | 'I choose to focus on better things' | 'Russian Roulette' | Disclosure as a risk | A need for control | Acceptance |
|---|---|---|---|---|---|
| Sam | Yes | No | Yes | No | No |
| Abi | Yes | Yes | No | Yes | Yes |
| Emily | Yes | Yes | Yes | No | No |
| Jacob | No | No | No | No | Yes |
| Grace | No | Yes | Yes | Yes | Yes |
| Alex | Yes | Yes | No | Yes | Yes |
| Mia | Yes | No | Yes | Yes | No |
| Anna | Yes | Yes | Yes | Yes | Yes |

**Super-ordinate theme five: Development of sense of self**

| Subtheme | Purpose and achievement gives a focus | Trying to make sense of self | learning through experience | Support and therapy |
|---|---|---|---|---|
| Sam | Yes | No | Yes | No |
| Abi | No | Yes | Yes | No |
| Emily | Yes | No | Yes | Yes |
| Jacob | Yes | Yes | Yes | Yes |
| Grace | Yes | Yes | No | Yes |
| Alex | No | No | Yes | No |
| Mia | No | Yes | Yes | Yes |
| Anna | Yes | Yes | Yes | Yes |

**Appendix P: Analysis Reflexivity Diary**

**Question 1:** Why is secrecy identified as a subtheme in both 'Reflecting on a difficult childhood' and 'Stigmatisation of HIV as a barrier to the relationships we have with ourselves and others', rather than presenting them together as one?

**Thinking process:** Secrecy, specifically experienced within the family was described by half of all participants. The secrecy that they describe is not just about HIV and stigma but is also rooted within the culture they were raised. It was also closely linked to isolation. The experience of secrecy relating to stigma and described by three different participants felt like a different and important experience to highlight.

**Resolve:** I feel that this difference may have been lost if they had been presented as one theme, therefore I shall leave them as two separate but obviously interconnected themes.

During the writing up of the analysis some themes did collapse into others. Initially 'Health is unpredictable' was a subtheme under the super-ordinate theme 'managing uncertainty'

**Question 2:** Should the theme 'Health is unpredictable' be a standalone subtheme? What is happening psychologically for these participants?

**Thinking process:** Participants described the importance of being healthy and how feeling healthy means you can cope better. Others described heath as unpredictable, impacting hugely on their lives. Trying to keep yourself healthy with an unpredictable illness suggested to me that participants may be trying to grasp what little control they had over their health.

This may ultimately suggest a fear of losing control.

**Resolve:** I decided therefore that this subtheme would be moved and collapsed into 'Need for Control' subtheme under the super-ordinate theme 'managing uncertainty'.

# Appendix Q Erikson's model of psychosocial stages

| Stage | Basic Conflict | Important Events | Outcome |
| --- | --- | --- | --- |
| Infancy (birth to 18 months) | Trust vs. Mistrust | Feeding | Children develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust. |
| Early Childhood (2 to 3 years) | Autonomy vs. Shame and Doubt | Toilet Training | Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy, failure results in feelings of shame and doubt. |
| Preschool (3 to 5 years) | Initiative vs. Guilt | Exploration | Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt. |
| School Age (6 to 11 years) | Industry vs. Inferiority | School | Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority. |
| Adolescence (12 to 18 years) | Identity vs. Role Confusion | Social Relationships | Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self. |
| Young Adulthood (19 to 40 years) | Intimacy vs. Isolation | Relationships | Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, while failure results in loneliness and isolation. |
| Middle Adulthood (40 to 65 years) | Generativity vs. Stagnation | Work and Parenthood | Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, while failure results in shallow involvement in the world. |
| Maturity (65 to death) | Ego Integrity vs. Despair | Reflection on Life | Older adults need to look back on life and feel a sense of fulfillment. Success at this stage leads to feelings of wisdom, while failure results in regret, bitterness, and despair. |

# Section B

# Publishable Article

## *"I never expected to be an adult"*

## *An exploration of how individuals living with PAHIV experience make sense of reaching adulthood.*

*\*This article will be submitted for publishing following the journals own guidelines (see Appendix A) however, some formatting changes have been made in keeping with the thesis guidelines. Apart from formatting, all AIDS CARE Journal article guidelines have been followed.*

*\*Names, places and certain biographical/personal identifying details have been changed or omitted throughout to preserve confidentiality.*

**Section C**


**Clinical Case Study**


*"Our Journey"*

**Working with Transference and Countertransference**

The Professional Practice Component of this thesis has been

removed for confidentiality purposes.


It can be consulted by Psychology researchers on application at

the Library of City, University of London.

# Appendices

## Appendix A

DPsych Counselling Psychology

CITY UNIVERSITY
LONDON

| Placement Supervisor's Confirmation |
|---|
| I confirm that ▮▮▮▮▮▮▮▮▮▮▮▮▮▮ (trainee's name) has completed<br>Form CTI, page 1, and obtained the client's signed consent to the recording and use for academic assignments of their therapeutic sessions. |
| Placement Supervisor's ▮▮▮▮▮▮▮▮▮▮▮▮▮ Name:<br><br>I G<br>Placement Supervisor's ▮▮▮▮▮▮▮▮  Date: \_\_\_ 2  Signature: |

Complete page 1 and show to the supervisor who is supervising your work with this client. Ask your supervisor to complete page 2 to confirm that you have obtained the client's permission to record the session and to use it for your academic assignments.

To ensure full anonymity of the client, page 2 only must be submitted with your case study/ process report. and the client's name must not appear anywhere on the form.

Page 1 must not be submitted, and should be retained with the client's notes within the agency/ placement setting.

CT1 Form