

***Therapy & HIV positive clients: exploring
aspects that promote psychosocial
adjustment using constructivist grounded
theory***

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Professional Doctorate in Counselling Psychology

by

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Declaration

I hereby declare that the work submitted in this thesis is the result of my own investigation, except where otherwise stated.

Name: 

Date: September 2022

Background/Aim: With the advent of antiretroviral medication Human immunodeficiency virus (HIV) has moved to a chronic disease with life expectancy comparable to a non-infected individual. With antiretroviral medication (ART) individuals with HIV can expect to live longer yet are likely to encounter an increasing diverse array of medical, psychological, social and cultural challenges. Current research links a HIV diagnosis to a theme of adjustment as a positive diagnosis may be accompanied by stigma and has the power to influence and transform individual identities. A HIV positive diagnosis is often accompanied with vulnerability, helplessness and uncertainty with higher incidences of psychological distress such as depression, generalised stress and anxiety. Existing literature has primarily focussed on the efficacy of CBT interventions in relation to HIV. Yet from a pluralistic perspective there is unlikely to be one appropriate ‘model’ as different people are helped by different processes at different times of their diagnosis trajectory.

Design/Method: This grounded theory study explored the experiences via semi structured interviews from a heterogenous group of eight participants aged between 23-47 who have completed a course of therapy in relation to a HIV diagnosis within the previous 2 years.

Results: The data analysis identified that a HIV diagnosis can invariably be accompanied by complex life adjustments as an individual adapts to new experiences of a physical, social, intimate or spiritual nature. Research findings identified two core-categories. The first core category ‘*Process of growth in therapy*’ embodied a process of interpersonal and intrapersonal growth, facilitated within the process of therapy emerging from sub-categories ‘*Processing the diagnosis overwhelm*’ and ‘*Understanding the relationship with the self & HIV*’. A second core-category identified the process of ‘*Therapy as a process of challenging exploration & psychosocial adjustment*’ emerging from sub-categories in ‘*Confronting Stigma*’ and ‘*Exploring, challenging beliefs about the self, world & others*’.

Conclusion: This research is situated within existing literature and how it may provide suggestions for practitioners working with this diverse socio-economic client group. These results may facilitate the efficacy in delivering psychological interventions and help promote an individual’s capacity for psychosocial adjustment in overcoming the challenges in their social and domestic roles living with the stigma associated with HIV.

Keywords: HIV, adjustment, psychosocial, stigma, self-esteem, quality of life, therapeutic relationship, cognitive-behavioural therapy (CBT), psychodynamic, psychoanalytical, grounded theory

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Glossary

Abbreviation

HIV	Human immunodeficiency virus
AIDS	Acquired immunodeficiency syndrome describes potentially life-threatening infections and illnesses that happen when the immune system has been severely damaged by HIV
ART	Anti-retroviral therapy
CD4	Cluster of differentiation 4: these cells are white blood cells called T lymphocytes or T cells that fight infection and play an important role in immune system function
Viral Load	An HIV viral load gives you an idea of how much of the HIV virus is in your body. The test measures the number of HIV copies in a millilitre of blood
GT	Grounded Theory
LMU	London Metropolitan University

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Abstract

With the advent of antiretroviral medication Human immunodeficiency virus (HIV) has moved to a chronic disease definition with life expectancy comparable to a non-infected individual (Van Sigham, 2010). With antiretroviral medication (ART) individuals with HIV can expect to live longer yet are likely to encounter an increasing diverse array of medical, psychological, social and cultural challenges. A HIV positive diagnosis is often accompanied with vulnerability, helplessness and uncertainty with higher incidences of psychological distress such depression, generalised stress and anxiety (Heywood & Lyons, 2016) with depression under diagnosed, under treated and double the risk (Groves et al., 2010). Given the pervasive nature of a HIV diagnosis it is invariably accompanied by stigma and has the power to influence and transform individual identities with a theme of adjustment emerging. Existing literature into psychological therapy has primarily focussed on specific models in particular, cognitive behavioural therapy CBT while qualitative studies have explored the texture of lived experience of a HIV diagnosis (Lawrence & Cross, 2013). There has been little research that explores the processes at play following a HIV diagnosis from the perspective of what impacts psychosocial adjustment within an individual's wider social, cultural and relational factors in relation to psychological intervention. This study explored the experiences of eight participants by exploring their narratives using Charmaz's (2014) Constructivist Grounded Theory Methodology (CGTM). Analysis placed constructivist emphasis on the subjective interrelationship between researcher & participants. *Process of growth in therapy* emerged as one core category accompanied with a core category of *therapy as a challenging exploration and psychosocial adjustment*. The Constructivist Grounded Theory model identified the process of adjustment as participants sought to come to terms with their diagnosis and constructed their new reality of living with HIV in face of stigma and exclusion. The findings are explored in relation to existing psychological theory and may help inform practitioners to better meet clients' needs in working with this specialised social demographic group.

Personal Reflexivity

Qualitative researchers yield a great influence within the research process. Personal reflexivity is a crucial process to understand how my own views, values & assumptions have shaped and formed the research process. Acknowledging how I have impacted the direction of the research, how I engaged with the data collection, how it has been analysed from my own frame and finally how it has been interpreted within existing theory.

A HIV-positive diagnosis can have devastating repercussions. It can provoke a myriad of questions, destroy regular daily life as an individual is confronted with their own sense of mortality. Feelings of worry, vulnerability and despair can surface in as the immediate challenges of a HIV-positive diagnosis sink in. A stigmatised status may accompany this diagnosis when disclosing to a loved one, friends and family. A HIV-positive diagnosis can sometimes force complex life adjustments, with the individual experiencing an overwhelming sense of loss. Financial concerns may result from the inability to work and secondary health issues may impact the ability to fully care for oneself. All of this may irrevocably alter a person's sense of self and negatively impact their identity. Most of these experiences framed my own experience of being diagnosed with HIV.

[REDACTED]
[REDACTED] along with those of watching friends' experience an array of negative emotions in struggling to come to terms with the reality of living with HIV in an unwelcome world with limited treatment options informed the very nature of this research. The psychological support focused on the daily 'here and now' of taking a cocktail of experimental drugs and coping with the associated side effects while balancing the demands of full-time work and the challenges that everyday life had to offer. As I grappled with these changes with the onset of stress and later, depression I was aware that my own individual needs in dealing with the trauma of a diagnosis triggered profound change and left life altering questions were left largely unmet.

This experience was life changing for me on so many different levels and undoubtedly fuels my interest in this area of research within counselling psychology. [REDACTED]

[REDACTED] I experienced profound change on so many different levels - spiritual, emotional, psychological and physical and these all impacted on a sense of self. Yet the psychological support I received arguably fell short of these concerns. [REDACTED]

[REDACTED] The doctoral training course's emphasis on reflexivity has enabled me to think about my own journey, assumptions, values and beliefs, and reflect on my own emotional processing in relation to my diagnosis.

Personal Reflexivity

Navigating a HIV diagnosis - like any other diagnosis - requires a strength and resilience as each person deals with fundamental changes striving to maintain a quality of life in the face of medical treatment with often unforeseen and unpredictable side effects. ■■■■■ ■■■■■ dealing with the stigma attached to the diagnosis with the consequent challenges in adjusting to 'new' sense of self and identity.

Starting on this research project, I worked as a keyworker, then as a therapist within in a drug & alcohol organisation, where I often come across clients living with HIV yet presenting with a diverse array of psychological needs. Armed with CBT focussed interventions initially I attempting to understand clients' distress within a CBT framework. On reflection this was indicative of my first year training where CBT was the main focus and allowed me to feel competent and defend myself against my own vulnerability as first year trainee. Clinically I remained detached from client's emotional struggles and, being less engaged with psychodynamic principles, I may have neglected important key psychodynamic principles such as counter-transference in favour of a treatment protocol.

My own personal journey was facilitated by stellar supervision embracing the humanistic framework and provided me with the validation and assurance not only to sit with my own vulnerability but also to sit with a client's distress. In a real sense I was moving from a 'doing to' to 'sitting with' (Strawbridge & Woolfe, 2010). As I embraced psychodynamic principles I began to appreciate the strength of the core conditions within the therapeutic relationship but also appreciating the role of other therapeutic models on a client's presentation.

This facilitated my own journey of being able to reflect on other therapeutic approaches and to explore subjective lived experience. I started to question clinical cognitive-behavioural approaches and solution focused interventions for individuals presenting with depression, anxiety, PTSD especially for clients who presented with a HIV diagnosis. Rather than pigeon-hole a client into a box I started to formulate and to explore what else a client may value from therapy.

Yet I began to reflect on my own journey and that the psychological 'intervention' I received ■■■■■ was woefully inadequate. With this an understanding that in relation to a HIV diagnosis, with the overt notions of stigma that accompany it, certain aspects of therapy may be more beneficial than others.

Personal Reflexivity

████████████████████ the prospect of a critical literature review appeared a difficult and daunting task. I debated whether selecting this area of research would prove personally and professional too challenging. I discussed ██████████ ██████████ fearing any potential personal & professional repercussions. This itself serves as a poignant reminder of the stigma and fear that an individual diagnosed with HIV is confronted with daily in almost every walk of life.

I am aware that my own preconceptions will have influenced the literature I selected within this very review. In attempting to contain any potential conscious (& unconscious) bias I sought to reflect on the literature selected and whether this was truly representative of the wider social demographics of HIV. For some the fear and stigma embedded within a cultural context may be key aspects of a HIV diagnosis while for others it may represent a complex life adjustments as they grapple with the overwhelming sense of loss in adjusting their identity socially and psychologically.

I continue to remind myself throughout this process, it is these very individuals who will have diverse psychotherapeutic needs to my own that I owe this very research. This reflects an attempt to demonstrate a key value of counselling psychology - a commitment to inclusiveness and acceptance of the uniqueness each client. Giving a voice to those individuals impacted by HIV and what they consider to be the most useful aspects of the therapeutic encounter that promotes a quality of life in their social & domestic roles.

I acknowledge that I am not neutral in relation to this research. As a part of an ongoing process I attempt to remain open to other aspects and ideas during the research process by documenting my idea and thoughts and keeping a reflexive journal. Some of these may provide a reflexive framework during the data analysis. It is hoped this approach will foster a reflective stance as a researcher and hold me accountable to this this process during data collection, analysis and emerging theory.

1. Introduction

"HIV does not make people dangerous to know. So you can shake their hands and give them a hug - heaven knows they need it" (Princess Diana, National AIDS Trust, April 1991).

This quote is taken from an era when a positive human immunodeficiency virus (HIV) diagnosis carried with it the stigma of negative attitudes, prejudice and the essence of physical and psychological suffering. Princess Diana was among the first high profile figures to publicly challenge negative public attitudes and acknowledge the distress of living with HIV. Thankfully a lot has changed since then. Advances in antiretroviral treatment (ART) has transformed HIV into a manageable disease with improvement in treatment outcomes and increased life expectancies (Porter, 2000) with an individual entering HIV care today attracting a life expectancy nearing that of a non-infected individual (Van Sigham, 2010).

Notwithstanding advances in treatment for HIV there were 1.5 million new HIV infections in 2020 (UNAIDS, 2021). HIV is currently an incurable chronic infectious disease and ART poses multiple challenges for a patient including stigma, an untenable pill burden with multiple side effects and the threat of viral resistance in non-compliance (Buell et al., 2016). Living with a HIV-positive diagnosis is associated with higher incidences of psychological distress such depression, generalised stress, anxiety (Heywood & Lyons, 2016) and even PTSD (Nightingale et al., 2010). Depression for this demographic group is under diagnosed, under treated and double the risk (Groves et al., 2010; Heywood & Lyons, 2016).

Viewed within this context Princess Diana's quote is no less relevant today than when it was delivered back in the height of the AIDS pandemic. While a positive HIV diagnosis is no longer a death sentence the advances in medical science have arguably not been met by the psychological needs of this demographic group. With advances in ART individuals with HIV can expect to live longer yet are likely to encounter a diverse array of medical, psychological, social and cultural challenges.

This thesis sought to develop an understanding of the process of psychosocial adjustment individuals may have experienced through the narratives and perspectives of those who have been diagnosed and received psychological therapy in relation to a HIV diagnosis. The experience of therapy following a HIV diagnosis and related research within this field has historically been framed within specific modalities. Given the pervasive nature of HIV on almost every facet of a person's life it may well be that an individual living with HIV may have different needs at different times of the diagnosis trajectory and may place value on other aspects of the therapeutic encounter beyond the therapeutic modality which is delivered.

The aim of this thesis was to examine emotional processes and identify factors impacting the process of psychosocial adjustment following a HIV diagnosis and what of these were considered helpful following psychological therapy. The objective of this study was to explore experiences and identify psychological processes rather than interventions based on diagnostic classification and treatment of targeted symptoms using targeted therapeutic models. This research makes use of a constructivist grounded theory methodology (CGTM) moving away from the more pathologised frameworks. Psychic trauma can accompany a HIV diagnosis and may interplay with complex interactions between social attitudes, personal lived experience and the construction of internal schemas of the self. As such, this study aims to examine narratives using a constructivist grounded theory approach (Charmaz, 2006). This paper adopts a psychodynamic lens primarily from an object relations perspective to highlight the intrapsychic mechanisms that may be involved at a relational, social and developmental level.

This thesis includes a critical literature review, examining a broad range of existing research on the efficacy of psychotherapeutic models following a HIV diagnosis particularly those studies seeking to measure and/or identify the processes associated with psychosocial adjustment. The literature review employed an organised structure of key search terms, keywords and phrases (HIV, psychosocial, adjustment, stigma, cognitive-behavioural) and selection was based on relevance to the research aims and objectives. Within the methodology section, constructivist grounded theory method (CTGM) is outlined along with the epistemological position and the analytical process employed within the process of coding through to theoretical construction. The results section presents theoretical categories which were developed using the analytic processes including researcher reflections to demonstrate the constructed meaning of this grounded

theory investigation. The discussion frames results within psychological theory adopting a psychodynamic lens, the clinical implications and identifies scope for further research.

2. Literature Review

2.1 HIV Distress

Human immunodeficiency virus (HIV) is a virus that destroys the white (T-Helper) blood cells in the immune system and makes copies of itself reducing an individual's immune system. The World Health Organisation (WHO) suggests that the effects of having HIV '*extend beyond the physical well-being to the psycho-social-spiritual-environmental*' as a positive diagnosis can accompany complex life adjustments, with an overwhelming sense of loss and stress as these adjustments take place (Skevington & Saxena, 2003, as cited in Miller & Willig, 2012, p2).

Current literature highlights a significant relationship between HIV, anxiety disorders and depression (Israelski et al., 2007; Heywood & Lyons, 2016) but exact levels of distress vary and are difficult to calculate. Explanations for this have been linked to the diverse physiological symptoms of HIV such as fatigue, nausea, chills/sweats, dizziness, peripheral neuropathy, memory impairment, diarrhoea and sleep difficulties (Gonzalez et al., 2012). These symptoms co-occur with medication side effects and can compound HIV symptoms and related distress. Current literature supports a relationship between HIV and generalised stress, PTSD, negative emotional states and emotional dysregulation (Brandt et al., 2013; Boarts et al., 2006). These mental health issues have been linked to physiological disease progression, lack of adherence to antiretroviral medication and increased risk taking behaviours all of which further contribute to a diminished quality of life (Sherbourne et al., 2000).

Healthcare professionals primarily focus the medical aspects of the disease - the viral load and the CD4 count. Yet Flowers et al. (2011) suggest current health care provision within the UK focuses increasingly on HIV antibody testing there is an increasing need to reduce the psychosocial costs associated with a HIV-positive diagnosis. Indeed one author argues that '*psychosocial adjustment*' is as important as the status of the disease in determining '*the quality of an illness experience*' (Derogatis & Derogatis, 1990, as cited in Rousaud et

al., 2007, p213). Yet psychosocial in itself was defined broadly within the literature. What sets HIV apart from other diseases is that it continues to be a highly stigmatised condition and is often considered a death sentence in certain parts of the world.

2.2 HIV Related Stigma

Rousand et al., (2007) define psychosocial as the capacity to perform social and domestic roles so as to meet the challenges of everyday living without emotional distress or physical disability. A HIV-positive diagnosis may accompany an overwhelming sense of loss and stress this can impact a sense of self. Yet it is the uniqueness of the psychosocial experience makes it difficult to define. As a group HIV has historically faced ostracism, discrimination and even violence since the first cases were reported in 1981 (Herek et al., 2013). Studies largely from the US and Canada have identified psychological problems associated with HIV stigma such as depression, hopelessness, anxiety, low self-esteem and perceived lack of social support (Dowshen et al., 2009; Wagner et al., 2010).

Goffman (1963) argued that stigma is an '*undesired differentness*' that positions individuals apart from '*normal*' society (1963, as cited in Herek et al., 2013, p5). Stigmas can be directly observable or concealable. Individuals with concealable stigmas face very different social challenges compared with individuals with observable stigmas as they work to manage interactions carefully to ensure concealment and avoid being discredited from the non-stigmatised majority. The effects of stigma condition the individual to believe there are potentially negative consequences to any status disclosure and a HIV positive individual will live in constant fear of these.

Research suggests HIV related stigma is a social phenomenon where a person is considered to possess a discrediting attribute and thus deemed tainted, spoiled or flawed by others (Goffman, 1963). A HIV-positive diagnosis is invariably set against a backdrop of gender, race/ethnicity, sexual orientation, social class and religion. An individual is more likely to experience both a combination of felt-stigma (the knowledge and motivation to avoid stigma) along with self-stigma - where stigmatised individuals internalise public attitudes and subsequently feel devalued often reacting with anger and indifference in accepting it's validity (Corrigan & Watson, 2002) and stigma is internalised. Research suggests stigma is prevalent in marginalised groups - initially gay men, illicit drug users (Scrambler, 2003, as cited in Liamputtong, 2013) and HIV-positive individuals.

Individuals with HIV are often perceived as threatening and different to the general public (Zhou, 2007, as cited in Liamputtong, 2013). Discrimination on the basis of HIV invariably interacts and compounds other social prejudices including homophobia, sexism, and racism (Aggleton, & Parker, 2002, as cited in Liamputtong, 2013).

A negative attitude towards the self is associated with internalised stigma as it lowers self-esteem and confidence increasing an individual's susceptibility to depression and anxiety (Herek, 2007, as cited in Herek et al., 2013). One study (Stutterheim et al., 2009) identified that stigma is more damaging in family settings, social settings and healthcare. Stigmatisation by the family was found particularly distressing as families are not chosen an important source of unconditional love and support (Stutterheim et al., 2009). Consequently, potential perceived rejection within family and/or relationships along with associated identity changes are likely to be challenges presented within the therapeutic space. The need to belong is threatened and in many cases rejection acts to promote social isolation.

Stigma ultimately links a person's identity to a heightened sense of vulnerability, helplessness and uncertainty. When this is compounded by the stigma related to membership of other minority group(s) the effects of stigma can be distressing and contribute to a reduced quality of life. This may explain why research links a HIV diagnosis to a transition as it has the power to influence and transform individual identities (Lawrence and Cross, 2013). Status disclosure is a contentious issue as not least as the transmission of HIV is often associated with risky sexual behaviours that promote a blame culture. A HIV-positive diagnosis irrevocably alters a person's relationship as a mother/father/daughter/son or partner. A fear of infection often promotes the need for a distinction between "us" and "them" (Joffe, 1999, p23). With a HIV diagnosis, locations of the 'other' and 'the self' are negotiated as individuals integrate this into their identity.

Negative reactions from others compounded with negative media portrayals of mental health may act to lower an individual's self-esteem (Corrigan, 1994). Research suggests that social stigma acts as a risk factor for those diagnosed with HIV and decreases self-esteem (Masoudnia & Chenaninasab, 2016) particularly in relation to identity (Flowers et al., 2011). Closely linked to this is the notion of sexual self-esteem. This is defined as a 'value that one places on oneself as a sexual being, including sexual identity' (Mayers et al., 2003, p207) and this includes perceptions of sexual acceptability.

Research suggests that a separate self-stigmatisation process exists, specifically associated with seeking therapy. Understanding the psychological impact of stigma in relation to HIV has clear implications for working therapeutically with HIV-positive clients. Clients continue to evaluate their decision to seek therapy after their decision to seek help. Exploring the role of stigma and how it may impact them following engagement, integrating this into the process of creating a therapeutic alliance has been found as beneficial to promote commitment to the therapeutic process. Given the role of internalised stigma and the self-stigmatisation process there is arguably an increased emphasis on the role of the therapeutic relationship within this client group. Given this study explores the helpful factors within psychotherapy that may help to promote psychosocial adjustment in relation to a HIV diagnosis the inclusion of the therapeutic relationship, how it is defined, its variables that contribute to therapeutic relationship merited its inclusion within this literature review.

2.3 Role of the Therapeutic Relationship

Beyond the impact of stigma, the strength of the therapeutic alliance is been cited as the best predictor of treatment outcome and makes more of a valuable contribution than therapist technique or model alone (Orlinsky et al., 1994; Wampold, 2001).

This has led to a growing emphasis on an effective therapeutic relationship defined as a range of variables irrespective of therapeutic modality and the (targeted) presentation. Yet how the therapeutic relationship is viewed depends largely on how a modality views the aetiology of psychological distress.

Humanistic therapy considers '*the therapeutic relationship... is the critical variable, not what the therapist says or does*' (Corey, 1982 as cited in Peltier, 2001, p66). An important component to the formation of a strong therapeutic alliance are the 'core conditions' of empathy, respect and genuineness as Rogers (1951) viewed psychological distress as a failure of caretakers to offer unconditional positive regard therefore inhibiting the search for a genuine self. Rogerian therapy places emphasis on the client's own subjective lived experience as the client has '*vast resources for self-understanding, for altering his or her self-concept, attitudes and self-directed behavior*' (Rogers, 1986, p158). Clients who feel

understood, safe and hopeful are more likely to disclose painful affects and risk thinking, feeling and acting in less maladaptive ways. In developing trust in the therapeutic relationship clients are less likely to introject the values of others through conditions of worth obtained in early life and move to a more internal locus of evaluation (Rogers, 1959) in trusting and valuing their introjected values and self-concept. The humanistic therapist enables the client to understand his/her own thoughts as '*the individual knows his own personality and problems far better than the therapist ever can*' (Farber, 2004, p115). However, a client must *feel* the core conditions and given that these may be experienced differently dependent on social and cultural differences as well as variations in individual psychodynamics. A criticism of the person-centred approach is that it is '*clinically speculative*' as it relies on the therapist '*to spend a considerable period of time waiting for a breakthrough to be made*' (Glassman & Hadad, 2007, p320). In offering unconditional positive regard a client may be lead to believe that negative patterns of behaviour are effective if they avoid uncomfortable or upsetting areas thereby encouraging a continuation of certain damaging psychological constructs within the clients' personality. Duncan et al. (1992) argue that it is not simply adequate to offer the core conditions but these must be matched to the client's (rather than the therapist's) definitions of empathy, respect and genuineness.

Borden (1994) offers a formulation of the working alliance and focuses on the client as active in the change process. Borden (1994) advocates comprises of three factors - a mutual agreement of bond, goals and methods. Borden (1994) openly challenged Roger's notion that the therapeutic alliance required no formal processes. Therapist goal setting from the humanistic perspective, would interfere with the therapeutic process as the client takes responsibility for the content of therapy.

The psychoanalytical approach views the patient in active terms and agrees that the therapist take charge and set treatment goals and tasks. Yet Borden (1994, p15) critiqued the psychodynamic approach as '*the radical reorganisation of personality... and the modifications in parameters of the associative task*' were not parts the alliance-building process. The psychoanalytical object relations school regards the working alliance as a container for the tension where a patient seeks to reconcile their wish for fusion with others and to be part of a whole while integrating this with their need to feel a uniqueness as a lifelong developmental task. This introduces the notion of the therapeutic relationship as a container for emotional learning and facilitating the development of new insight. This

borrowed from prominent psychoanalysts as 'holding' (Winnicott, 1960) and 'containing' (Bion, 1962). Winnicott (1960) regarded holding as a developmental stage in which the mother and child are one entity, as yet undifferentiated within the infant's consciousness. The purpose of holding is to allow a child to be completely unconscious of his requirement for a separate individual. Bion's (1962) theory of containing stems from the notion that an infant may project onto its mother feelings of frustration, anger and fear. The mother attempts to contain these negative projected feelings, while embodying (and demonstrating) a secure emotional base while modelling it back in a more manageable self-soothing state.

The therapeutic relationship with clients then becomes a place where the painful and destructive feelings of the client can be expressed and acted out because they are held safe, where the most painful and destructive feeling of a client can be expressed and acted out. The psychodynamic aim is to enable the client to arrive at an understanding of the meaning and origins of behaviour. The therapist may frustrate any unconscious desires of the patient and instead offers an interpretation of what has taken place between them.

Existential psychotherapists argue that an authentic encounter between patient and therapist in itself is therapeutic (Yalom, 1980). The value of existential psychotherapy is the value it places in relating authentically 'assisting people to come to terms with the dilemmas of living' (Van Deurzen-Smith, 1988, as cited in Milton, 1994, p.vii) and caution in that any specific model the client can experience a split as only one aspect of themselves is related to or engaged with (Milton, 1994). This is tempered by literature that repeatedly suggests that the average client tends to benefit from psychotherapy regardless of the form of psychotherapy (Shapiro, 1983; Safran, 1993). In a key study by Lambert (1992) the therapeutic relationship, technique, client variables along with placebo or expectation of change were all significant factors in positive outcomes. Either way, there is considerable variation in the contribution of a therapeutic alliance to a positive therapeutic outcome.

While psychodynamic and humanistic therapists tend to view the therapeutic relationship as a space where emotional issues are expressed and used as a source of healing Trower et al. (2011, p49) suggest it is the cognitive-behavioural therapist's '*job to set up and maintain the working alliance*'. This entails creating a bond, identifying problems and goals and creating a cognitive conceptualisation. The therapeutic relationship is operationalised into the ABC framework - the internal or external adverse event (A), the

cognitions, evaluative beliefs or dysfunctional assumptions (B) and emotional, behavioural and cognitive consequences of the beliefs (C) - along with therapist and client steps. The cognitive-behavioural therapist uses the framework as '*a clear guide*' (Trower et al., 2011, p49) while the therapist bond is '*collaborative, continuous and underlies all other tasks*' (Trower et al., 2011, p49).

Yet CBT has been criticised for neglecting the role of the therapeutic relationship (Leahy, 2008) along with the risk that the alliance in therapy may be eclipsed by the techniques and protocols. On balance, literature does seem to suggest that the therapeutic alliance does have causal effect on outcome (Klein et al., 2003) and one, if unsurprising conclusion that can drawn is that optimal use of CBT while focusing on the strength of therapeutic relationship may provide optimal treatment.

2.4 Cognitive Behavioural Approaches in treating HIV

A body of literature supports the efficacy of CBT in treating depression and anxiety disorders (Beck, 2005). Yet there is a lack of internationally established treatment guidelines for depression and anxiety in HIV (Olatunji et al., 2006). CBT has found to be very effective for a range of common anxiety disorders in HIV including unipolar depression, GAD, panic disorder, social phobia, post-traumatic stress disorder and childhood depressive and anxiety disorders (Butler et al., 2006). Perhaps unsurprisingly, research into the role of psychological therapy with HIV-positive clients has predominantly focused on CBT. Current literature argues the benefits of CBT on the creation of coping strategies by altering irrational cognitions related to negative psychological states, correctly appraising internal and external stressors and gaining stress management skills (Crepaz et al., 2008). Negative affective states may be more challenging for HIV-positive individuals as they consistently face complex psychological and physical demands of having a highly stigmatised, chronic and life-threatening illness Crepaz et al. (2008).

While studies using meta-analysis of CBT are constrained by assumptions of uniformity across study samples as well as the content and expertise of therapists who deliver CBT (Beck, 2005) they do offer an insight into overall efficacy. In a key meta-analytic review by Crepaz et al. (2008) of 19 studies using CBT with people diagnosed with HIV, evidence

supported the efficacy of CBT in demonstrating significant improvements in symptoms of depression, anxiety, anger and stress given but did so cautioning the small trial sizes particularly for anger and stress management. The studies that Crepaz et al. (2008) selected were largely from a North American population. Furthermore 14 of the trials selected did not disclose whether the participants were taking anti-depressant medication. Given that four of the studies selected measured success in a reduction of depression the contribution of CBT is questionable. A further limitation was the absence of long term effectiveness assessment beyond the initial post intervention assessment. Given the pervasive nature of HIV and coping with emotional stress over the course of HIV infection - it is reasonable to expect that without 'booster' CBT there may be a gradual deterioration of CBT practice and skills to effectively assess irrational thoughts and improve coping management skills and prevent relapse. Few studies attempted to address the wider psychosocial issues that impact a HIV-positive diagnosis let alone attempt to measure this.

One study that attempted to address psychosocial improvement (Rousaud et al., 2007) evaluated the efficacy of 16 weeks of group (2 hours) CBT on psychosocial adjustment to HIV. CBT intervention focused on HIV concerns - HIV disclosure, treatment compliance and dealing with adverse side effects. Psychosocial adjustment was measured using the psychosocial Adjustment to Illness Scale (PAIS) that aims to assess functional, emotional and social dimensions of quality of life in seven domains. The cohort included both male and female participants with a diagnosis of psychosocial impairment. The greatest improvement was reported in the social environment domain - the degree to which a participant suffered impairment of social and/or leisure activities as a result of HIV infection. While there were reported improvements in family relations for heterosexual men this was not the case for homosexual/bisexual men who responded that friends/lovers were more helpful. The authors suggested that homosexual/bisexual men avoided HIV disclosure as this would reveal their sexual orientation and prevent possible rejection and discrimination. This study found that participants who had acquired HIV via intravenous drug use did not benefit from CBT interventions 'in the same way' (Rousaud et al., 2007, p239). Interestingly four out of ten participants ranked HIV as fourth priority or lower. Sadly, the study did not divulge the common high priorities and this reflects a severe limitation.

This study sheds light on the fact that HIV in isolation cannot be used as a barometer for what a client may need. Heterosexual men benefited from different aspects of

psychological and social adjustment compared to homosexual/bisexual males while HIV-positive intravenous drug users did not benefit from CBT intervention. As such one is left wondering how CBT address the client's psychosocial needs. Importantly, this study also neglected any post intervention follow up assessment therefore it is debatable if any improvements in psychosocial adjustment to HIV within the social, vocational and family domains were sustained. Finally, participants with a clinical diagnosis of psychosocial impairment recruited for this study would likely be motivated to seek help given the CBT study was run by the psychologist/psychiatrist that also performed the initial diagnosis.

2.5 Opposition to the Cognitive Behavioural Approach

While there is evidence of the efficacy of CBT in treating HIV-positive clients the research is not without methodological flaws. Markowitz et al. (1998) argued that HIV is a significant life event and hypothesised that CBT/IPT is a more effective treatment than an anti-depressant given the high pill burden a positive HIV diagnosis entails (Markowitz et al., 1998,). In a randomised clinical trial Markowitz et al. (1998) studied the efficacy of CBT against interpersonal psychotherapy (IPT), supportive psychotherapy (SP) and supportive psychotherapy (SP) with an anti-depressant (SWI). Participants who scored high on the Hamilton Depression Rating Scale/Beck's Depression Inventory (BDI) were assigned to one of these four groups. Supportive psychotherapy '*resembled the client-centered therapy of Rogers*' (Markowitz et al., 1998, p 453) while IPT is a brief, attachment-focused psychotherapy that focuses on interpersonal problems and symptomatic recovery. All therapists were trained for a year in each modality and used treatment manuals while sessions were audiotaped and blindly assessed to check the model compliance. Interestingly the IPT and SWI groups demonstrated significantly greater improvements on depressive measures than CBT.

Markowitz et al. (1998) explained the greater efficiency of IPT over CBT for HIV-positive clients as IPT connects life events to moods. This enabled the therapy to target what the client cited as important - namely to ability mourn life upheavals with encouraging them to find new life goals and adjustments. There were clear methodological flaws in Markowitz's research namely that IPT/CBT participants received 16 sessions of 50 minutes while the SP and SWI group received between 8-16 sessions of 30-50 minutes '*determined by participant need*' coupled with a small sample size. Participants were overwhelmingly men seeing men (MSM)/bisexual. Interestingly this study recorded the route of HIV transmission. Markowitz et al. (1998) recognised that HIV clients, in suffering multiple bereavements, role disputes and transitions, responded to positive encouragement to '*live out your fantasies*' (Markowitz et al. 1998, p455) and IPT represented a tailored fit of therapy to patient. Criticism was explicitly levied at CBT as it addressed the '*patient's exaggeration of hopeless thoughts*' (p456) which was described as '*dangerous*' (Markowitz et al. 1998, p456) given objectively negative life events such as death/loss. This research suggests there is a limitation of CBT when there are distressing

life events while Markowitz suggested that CBT may be better suited to clients who report few significant life events. Ironically the study by Markowitz et al. (1998) fell foul of many of the criticisms levied at CBT studies - namely that the cohort consisted largely of gay/bisexual males (80%). Moreover, there were no post intervention assessments beyond those at completion so it is questionable whether the efficacies of the IPT and SWI were sustained longer term.

While interpersonal therapy, psychodynamic psychotherapy, and cognitive-behavioural therapy have all demonstrated efficacy with HIV-infected patients narrative therapy has also been found to provide psychological benefits (Zeligman & Barden, 2015) particularly when this is accompanied with addiction issues (Gate-Wolf, 2009). Narrative theory posits that individuals' lives have been both authored by themselves and co-authored by others. The assumption within narrative therapy is that a person's experiential reality is socially constructed (Angus & McLeod, 2004) and a client's story line may contain problems that do not feel authentic to the person's true life experiences. The goal of this approach is to 're-author' old inauthentic story lines revising and giving new meaning while facilitating the client to become the author of their own life in finding alternate ways of viewing their "problem-saturated" story. Narrative therapy consists of a collaborative relationship with four basic principles: (a) externalising the problem, (b) identifying socially constructed messages, (c) focussing on strengths and (d) reauthoring the client's story.

Narrative therapy has been cited as advantageous in that it helps a client position themselves constructively in creating HIV stories, externalising & separating the individual from the disease. The individual takes an active role in writing their story that has a beginning, middle & end and working through their own issues often discovering metaphors for loss & emotional pain in relation to HIV (Arehart-Treichel, 2003).

While research has demonstrated efficacy of particular approaches such as CBT in treating individuals living with HIV it may well be that where significant life events are experienced involving loss, grief and trauma other approaches may target and prove effective in other aspects of an individual's intrapsychic process and interpersonal functioning.

2.6 Psychodynamic Approaches

Psychodynamic literature casts the efficacy of CBT in HIV treatment further into question. Samuels et al. (2011) argue that the association between early childhood trauma and post-traumatic stress disorder (PTSD) with HIV risk behaviours is well documented and indeed this is supported by other authors (Tang, 2020; Samuels et al. 2011) and many are survivors of early childhood may have PTSD. A psychodynamic understanding of the client's history, conflicts and challenges can develop a more profound understanding of the forces that help perpetuate distress and foster a more cohesive, empathic therapeutic approach.

Freud (1920, as cited in Samuels et al., 2011) described the impact of trauma on the "stimulus barrier". In Freud's psychophysiological model, this is a protective shield that describes an essential psychic function - to protect the mental apparatus from external excitations that may overwhelm it and so sustaining the capacity of attention toward the external world intact. This function here is to provide a protective barrier to protect the psychic apparatus against potentially overflowing trauma.

For many suffering PTSD/trauma perennial protection via the stimulus barrier is conspicuously absent and when trust is violated an individual experiencing trauma may result in an overwhelming of the ego. Given a child may not have received parental protection they may well experience difficulty developing their own sense of value of body and self. These individuals may be unable to protect themselves from harm or play out an unconscious compulsion motivated by defensive mastery by turning the passive into active by re-enacting the trauma in order to master it. These strategies are ultimately unsatisfying and often leads to further trauma with increased risk as the individual may seek alternative methods (drugs/substance misuse) to alleviate the pain and suffering which ironically only serve to expose a person to further risk, harm and trauma.

In the US the prevalence of PTSD is 3.5% and this is higher in patients living with HIV (Kessler et al., 2005). Traumatized adults may have problems developing self-love, capacity for self-care as early paradigms of caring and nurturing are either absent or distorted by the significant life events. Samuels et al. (2011) argues - using case studies as examples, the importance of treating trauma/PTSD with the problems of HIV and

treatment adherence by providing a nurturing holding environment (Winnicott, 1960, as cited in Samuels et al., 2011) while working through trauma re-enactment along with any infantile rage and associated guilt. Samuels et al. (2011) acknowledges the difficulty of developing a 'holding environment' with patients with trauma/PTSD as HIV is often accompanied by stigma, negative societal attitudes and discrimination. A successful feature of the psychodynamic perspective is the ability of psychodynamic psychotherapy to reformulate traumatic event(s) making the narrative '*the patient's own to share with "another"*' (Bromberg, 2003 as cited in Samuels et al., 2011, p645). The HIV-positive client needs to feel accepted and can be overly sensitive to fear, discrimination or rejection and given that trust has been violated.

The strength of the psychodynamic therapeutic relationship is the ability to stand the test of the patient's hostility or mistrust as a container for negative transference - as a process in which current emotions and aspects of the self are externalised into the relationship with the therapist. Klein (1952, as cited in Lemma, 2003) outlined the paranoid-schizoid position referring to a constellation of anxieties, defences and internal & external object relations that emerges during infancy and often continue into adulthood. Klein argued that infants suffer anxiety caused by the death instinct, the trauma experienced during birth and further compounded by hunger and frustration. An infant attempts to deal with these experiences, having an rudimentary and unintegrated ego, by using phantasies of splitting, projection and introjection. An infant may therefore 'split' his/her ego into parts and projects out separately his/her feelings of love and hate as separate 'objects' onto separate parts of the mother. The result being that the maternal object is divided into a 'bad' mother – one who is frustrating, persecutory and hated and a 'good' mother – one who is loved and experienced as gratifying.

Using this principle HIV may represents death and this fear of destruction and this must be channelled away from the self. An individual may attempt to protect by splitting, the process where negative representations of HIV may be projected onto other individuals with HIV. A positive diagnosis is something that may happen to 'others'. Individuals invest in social discourses and position themselves in relation to these in order to defend against threats to the self. Eventually these split-off aspects of the self attributed to the 'other' are forced to be incorporated as the HIV-positive person is subject to the same negative social representations of HIV. Psychic trauma is likely to ensue as the person tries to make sense of the disease. As HIV is predominantly acquired via sexual contact and

individual sexual behaviours and how these inform and sustain interpersonal relationships are likely to be explored within the therapeutic space. This is particularly relevant if an individual has attempted to re-enact childhood trauma in an effort to remaster it. An exploration of risky sexual practices may mean sexual feelings may emerge as the HIV-positive individual projects feelings of security and a desire for closeness especially if these were missing in developmental years. The therapeutic space may illicit countertransference in the therapist - the need to father or mother the individual. This may trigger uncomfortable feelings in a therapist in treating a combination of HIV and trauma. However, as Lemma (2003) argues it is the therapist's job not to be liked, but to be helpful.

Conversely an individual's own sexuality may split off as a HIV-positive person associates sex with contamination. Samuels et al. (1991) cautions that an experienced psychodynamic psychotherapist may experience delays in the establishment of trust as defense mechanisms manifest. Defenses may include denial (blocking external events from awareness); displacement (satisfying an impulse with a substitute object); projection (attributing unacceptable thoughts, feelings and motives to others); repression (unconsciously maintaining disturbing or threatening thoughts from becoming conscious and reaction formation (an idea, affect, or desire that is opposite to a feared unconscious impulse). Research suggests an understanding of the phenomenon and function of transference and countertransference is key to the therapeutic change including acknowledgement of any narcissistic defenses including some somatic responses (Athanasiadou & Halewood, 2011).

A careful evaluation and a psychodynamically informed understanding of the patient's trauma history, psychiatric diagnosis and coping mechanisms Samuels et al (2011) suggest are instrumental in reducing risk reduction and promoting care with individuals with HIV. The efficacy of the psychodynamic approach is largely illustrated by case studies with little quantitative research. This approach may be considered as limited if an individual with a HIV-positive diagnosis has not suffered trauma or PTSD. Notwithstanding this, the psychodynamic approach is well placed to offer tangible benefits to HIV treatment particularly from a psychosocial relational perspective.

2.7 Role of Qualitative Research

The limitations of quantitative research reflect the limitations of the randomised controlled trials (RCT) in that they do not allow for an adequate understanding of the multifaceted nature of mental health issues. Authors argue that poor designs limit the way problems, treatments and outcome criteria are defined, understood and treated (Shean, [2014](#)).

Research employing RCT often requires a specific presentation and this is operationalised by a simplified symptom criteria. If participants meet this symptom criteria (i.e. anxiety) it is not uncommon for this to be the symptom of other core issues and the focus of therapy may change. This may be a weakness of CBT with HIV research as a HIV-positive diagnosis can accompany a diverse range of presentations reflecting the diverse array of psychosocial challenges a HIV-positive individual encounters. Sheen ([2014](#)) claims that generally no more than 20% seeking psychotherapy services meet a single symptom criteria and this may be no different in HIV presentations. RCT research often makes the assumption that psychotherapy can be formulated as standardised set of procedures that can be uniformly applied. This potentially biases results in favour of therapies that can be operationalised (Wampold, 2007, as cited in Shean, [2014](#)). In contrast, idiographic therapies emphasise the importance of process variables as a component of therapeutic effectiveness and tailor the therapy to the circumstances of each client.

Miller & Willig ([2012](#)) argue for a bottom-up rather than top down processing to understand the client on their own terms rather than being led by a client's symptoms or diagnosis. Miller & Willig ([2012](#)) found that a client's knowledge, expertise and resources are important when shared with the therapist to gain a better shared understanding of their life and experiences. This research used grounded theory to explore a pluralist approach to therapy and found that clients valued leading the sessions as this allowed the client to be the expert in the room with specific coping strategies and a specific relationship to HIV. This study highlighted the importance of making sense of challenging or difficult parts of their lives that other approaches such as CBT neglected - particularly in respect of past trauma and exploring and making sense of the experience of death and mortality.

2.8 Rationale for Adoption of Psychodynamic Perspective

The efficacy of the psychodynamic approach is largely illustrated by case studies with little quantitative research. Furthermore, the interaction of the psychosocial, physiological and psychological in relation to HIV is problematic and well documented (Crepaz et al., 2008). Much of the existing research on individuals living with HIV is dominated by the efficacy of CBT in relation to psychosocial adjustment. Studies that investigate psychological distress in relation to HIV have often focussed on men having contracted HIV via other men (O'Cleirigh et al., 2003). There is a limited research concerning how people live adaptably with HIV and the most effective therapeutic interventions (Pierret, 2000) particularly from a psychodynamic perspective.

This study primarily adopts a psychodynamic perspective in relation to the psychotherapy following a positive HIV diagnosis. Research suggests that adjustment to HIV can be conceptualised as an ongoing process confronting issues surrounding loss, stigma, uncertainty, sexuality and identity in relation to HIV. The process of addressing the meanings that being HIV-positive holds for the client in therapy and how these can promote acceptance of the illness and cohesiveness of the self can be valuable. There is currently little research on how this process develops in relation to psychotherapy and factors that may contribute to a process of psychosocial adjustment. Given the role of psychosocial factors, ethnic and cultural implications within a HIV diagnosis, the role of prevailing psychosocial attitudes and how clients attempt to resolve their unconscious conflicts, a psychodynamic perspective was considered well placed to explore this aspect. Given the overt role of loss, stigma, sexuality, identity and how these are relationally navigated this study primarily employs object relations theory (Klein, 1923). Object relations is a variation of psychoanalytic theory where the term 'objects' refer to significant others (or parts of a person) with whom a child relates and serves as a template for future interpersonal relationships. Object relations places emphasis on early family interactions – rather than biological drives - emphasising the mother-infant relationship. An object relation involves mental representations of the object as perceived by the self; the self in relation to the object; the relationship between self and object.

Psychoanalytic theory concerns itself with the nature, development and functioning of the human mind, especially in relation to motives and the nature of unconscious mental states and processes. A common critique of the psychoanalytic theory is that it is deterministic

and Freud's argument in favour of biologically-based drives provide fundamental sources of psychological motivation and adopt essentially a realist epistemological position. This may be considered to represent a tension with a constructivist epistemological position adopted within a study such as this. Epistemologically constructivism emphasizes the subjective interrelationship between the researcher and participant, and the co-construction of meaning (Pigeon & Henwood, 1997). Constructivist grounded theory acknowledge the importance of a multiplicity of perspectives and truths and in so doing, CGTM draws attention to the importance of context and the co-construction of meaning. From this frame, Spence (1982) argues that analysis could not discover the historical truth of a patient's life but only constitute a procedure for disclosing it's narrative truth in the eyes of the client. In short, Spence (1982) argued for psychoanalysis as a constructivist enterprise where analysis constitutes a procedure for disclosing the narrative truth in the eyes of the client.

Developments during the 1980s/90s in relation to questions about the 'truth' within psychoanalytic interpretations and the ontology of the mind has revised how the analytic relationship is understood. The view that the analyst retains neutrality and act as a blank screen have been revised to include the individual subjectivity within the analytic relationship (Hoffman, 1983) but rather the analyst has biases and a subjective history that impacts the analytic relationship and therefore psychoanalytical interpretations are subjective and objective neutrality is neither clinically possible or helpful. Gill (1983) and Hoffman (1983) suggests that notions of transference was a '*social conception*' (p127) of transference but rather a response of the client to the analyst. While the concept of object relations theory stems from psychoanalytical theory it has been impacted by the revisions of the analytic relationship presented by constructivist authors such as Gill (1983) and Hoffman (1983) arguing that *what* is known is indeterminate and *how* it is known is through co-construction. It is from this constructivist perspective that psychoanalytic theory – particularly the use of objection relations theory is employed within this study.

2.9 Relevance to Counselling Psychology

Counselling psychology advocates the importance of pluralism in research in terms of epistemology, methodology or interpretation as well as an ethical stance in prioritising the other or ‘otherness’ (Strawbridge & Woolfe et al., 2010). This stance is echoed by (Cooper & McLeod, 2007) who suggest that in practice clients may need, and are helped, by different things at different times. This approach is consistent with the ethos of counselling psychology where helping involves much more than responding to the sickness in a standardised fashion (Strawbridge & Woolfe et al., 2010).

Research into the role of psychological therapy with HIV-positive clients has mainly focused on the efficacy of a single approach. Given the pervasive nature of HIV and individual differences it is feasible that different clients may present different needs at different stages of living with HIV and these needs may not be met by one model. Strawbridge & Woolfe (2010, p7) suggests there is an “*inbuilt bias towards the cognitive-behavioural tradition*” and make the claim that if ‘scientific’ and ‘evidence-based’ are key terms in the claim of counselling psychologist competence it is imperative that conceptions of science, research and evidence are re-evaluated forms in practice and research with their respective limitations.

This study hopes to gain an understanding of how HIV-positive clients attributed factors and processes that promoted psychosocial adjustment (refer [Research Aims](#)) following a diagnosis of HIV. It is hoped this positions counselling psychology to gain a better understanding and develop the skills, techniques, and appropriate interventions to better meet the diverse needs of this particular vulnerable client group. The aim of this research is not only to inform counselling psychology practice but also be of inform other professionals and their own practice within specialist HIV health care provision.

2.9 Summary

The literature presented in this review attempts to capture the challenges of a HIV diagnosis from a psychological perspective and how a HIV diagnosis can be a distressing experience often accompanied by complex life adjustments as an individual adapts the self to new experiences of a physical, social, intimate or spiritual nature. Advances in medical

science have prolonged the life expectancy of a HIV-positive individual creating a diverse set of challenges for HIV-positive clients. These are accompanied by mental health issues including anxiety, depression and stress and are linked to disease progression, symptoms of HIV fatigue, reduction in immune functioning, lack of drug adherence and an increase in risk taking behaviours with a diminished quality of life (Klein et al., 2010; Kalichman & Catz, 2000).

Traditionally specific orientations in psychological treatment such as CBT have proved to be effective particularly in depression and anxiety disorders as CBT creates an environment of hope and choice (Safren et al., 2009). Yet these studies have often been critiqued by some authors as limited given the methodological limitations including the focus on MSM/bisexual male client group, the small sample size, using a wide array outcome measurements while neglecting any subsequent post intervention assessment. While current literature supports CBT as beneficial there are concerns that it does not adequately address the transition that often accompanies a HIV diagnosis particularly in relation to dealing issues of loss, prejudice, mortality, stigma, freedom and isolation.

Current literature argues for the efficacy of other models such as interpersonal, psychodynamic and existential psychotherapy. Proponents of IPT argue the importance of the reciprocal relationships between life events and mood while psychodynamic psychotherapy advocates the importance of a nurturing holding environment (Winnicott, 1960, as cited in Samuels et al., 2011) bringing “*implicit structures into conscious focus*” (Fonagy, 1999, as cited in Samuels et al., 2011, p644). Existential psychotherapists contend the importance of the human situation, shedding light on the client’s social and cultural experience while acknowledging anxieties resulting from notions of death, freedom, meaninglessness and isolation (Yalom, 1980).

There is no ‘one size fits all’ approach in the role of psychological treatment of HIV. From a pluralistic stance, different clients may present different needs at different times. It is debatable if specific models are well placed to meet the diverse needs of this client group. While studies have explored how individuals experience living with HIV few have done so post intervention and even fewer have done so with a view to how the therapeutic encounter is beneficial in specifically in promoting psychosocial improvement in living with HIV.

3. Methodology

3.1 Research Aims

This study was conducted against the backdrop that a ‘physician’ dominated model that appeared to be dominant in treating individuals diagnosed with HIV. Medical advances have progressed the life expectancy and quality of living with HIV yet evidence suggests that those living with HIV are confronted with an array of social and psychological challenges. Framed against a pluralistic assumption that different approaches may be considered more helpful for different clients at different times (Cooper & McLeod, 2007) it may be prudent to explore the needs and wants of the this community rather than what model of therapy delivers the ‘best’ results.

The aim of this study was to what identify helpful factors impacted the process of psychosocial adjustment and what factors were considered helpful following psychological therapy after a positive diagnosis. The objective of this study was to explore participant experiences and identify psychological processes rather than treatment based on diagnostic classification and treatment of targeted symptoms using defined therapeutic models. A emphasis on particular psychological processes in relation to psychosocial adjustment may facilitate therapeutic practitioners when working with this client group.

Psychosocial denotes the psychological and social factors in an individual’s life, for example, relationships, education, age, and employment that relate to their life history (Stubbley & McCroy, 2014) Psychosocial adjustment however can be defined as ‘*the relative degree of harmony between an individual’s needs and the requirements of the environment*’ (Anderson et al., 2002, p32). Generally literature research defined psychosocial adjustment broadly with emphasis on the domains of (1) health care orientation; (2) vocational environment, (3) domestic environment; (4) sexual relations; (5) extended family relationships, (6) social environment; and (7) psychological distress.

Given that psychosocial can be interpreted by participants as having value in diverse areas a broad definition was considered the most appropriate for this study. Psychosocial

adjustment was operationalised as the capacity of an individual to perform social and domestic roles in meeting the challenges of daily life without emotional distress or physical disability. This concept includes interactions between the individual and others in 'roles' as well as with institutions, social groups, communities or tribes that may make up an individual's sociocultural environment. The rationale here is that an individual's role behaviour (parent, spouse, professional) tend to be correlated with judgments about his/her psychosocial adjustment.

The research purpose was to explore plausible psychosocial avenues (i.e. coping, social support, psychological distress) that may have negatively impacted the participant's evaluation of their status and ability to adapt in their social and domestic roles, for example as an employee, spouse and negatively impaired their daily functioning.

3.2 Researcher's Epistemological Stance

The researcher's epistemological assumptions were considered consistent with the social constructivist emphasis on understanding empirical worlds. Finlay and Ballinger (2006) suggest researchers embrace an epistemological stance in which they identify and one that is consistent with one's own values, interests and beliefs in addition to academic or disciplinary demands.

In questioning the existence of an absolute objective reality this researcher adopted a relativist epistemological stance within this study. As an active researcher within this process realities are regarded as social constructions of the mind and notions of an objective reality, truth is best understood as "*relative to a specific conceptual scheme, theoretical framework, paradigm, form of life, society, or culture*" (Bernstein, 1983, p8).

Constructivism is a research paradigm that questions the existence of an objective reality asserting that realities are "*social constructions of the mind*" (Mills et al., 2006, p213) as people attempt to make sense of their experiences within themselves and the world in which they live (Kelly, 1955 as cited in Hayes & Oppenheim, 1997). Reality is constructed through experience and represents a relationship between the self and the world (Hayes and Oppenheim, 1997). With this in mind, a qualitative approach was selected as it was

considered the most appropriate placed methodology to meet this aim and objectives of this study.

The effects of an HIV-positive diagnosis can sometimes force complex life changes, with the individual experiencing a sense of loss and distress as these adjustments take place with a capacity to influence and change identities. This study attempted to gain insight into client's own meaning making process in relation to their own personal experience of therapy following a positive diagnosis as they sought to accommodate to these changes as they constructed meaning and adjusted their behaviours and social interactions within their social and domestic roles.

Historically the researcher within grounded theory has remained a position of “*distinct expert*” (Charmaz, 2000, p513). This is not the case within a constructivist grounded theory approach that positions the author of construction or experience and meaning. Categories and theories do not naturally emerge from the research but that they are constructed by the ‘viewer’ and given meaning within an interactive process (Charmaz, 2000, p524). The researcher brings their own personal, philosophical, theoretical and methodological beliefs to the data and shapes emerging theory and discovered ‘reality’ arises from the interactive process and its temporal, cultural, and structural contexts (Charmaz, 2000, p523). This perspective is seen as attractive as it actively attends to the various ways social reality is constructed culturally, socially and linguistically.. This has particular relevance to a subject that has connotations of stigma where a person, once differentiated is then devalued as the process of devaluation is socially and culturally perpetuated.

3.3 Constructivism & Epistemological Reflexivity

Epistemology is concerned with the theory and generation of knowledge and asks how and what knowledge can we create, what are the assumptions about the world and what is the role of the researcher in the research process. Research emerges from experience, and experience is essentially qualitative in nature. That is, based on qualities which are sensory that are picked up in relation to our environments (Eisner, 2003, as cited in Strawbridge & Woolfe, 2010). The nature of this research adopted a ‘bottom up’ approach to working with theory: the ‘data’ is discovered via an interactive process framed this within a reflexivity and transparency about any perspective I bring to this interactive process.

A HIV diagnosis may accompany stigma and the fear of the changed perception in others and how this this is experienced as a social, psychological and relational context will be '*constructed*' on the basis of how a participant is situated socially, culturally, psychologically and historically. (Charmaz, 2014). Ultimately HIV cannot be understood from looking at the diagnosis in isolation but discovered 'reality' can be understood from exploring it in how an individual makes sense of the diagnosis in temporal, structural and cultural contexts. Researcher & research participant frame an interaction and confer meaning upon it (Charmaz, 2000).

Constructivism showcases knowledge of empirical worlds adopting a middle ground between postmodernism and positivism. It assumes a relativism of multiple social realities, strives for interpretative understanding of subjects' meanings and represents a reflection of how reality is constructed as an interactive process (Charmaz, 2000). In adopting a constructivist stance in this research relativity and subjectivity are brought into the interpretative frame and the active role of the researcher in what is attributed to the study participants . As a researcher I am interpreting data and acknowledging I am also culturally and socially positioned and holding preconceptions. Engaging in reflexivity enables the researcher to reflect upon biases and assumptions (McLeod, 2001) and challenge these in gaining an awareness on potential interpretative biases of meanings and experiences. The reflexive stance is pivotal to the a researcher's credibility and to ensure rigour within the methodology. To ensure transparency and credibility within the reflexive process reflections are documented throughout the analytical process.

3.4 Constructivist Grounded Theory Method (CGTM)

Grounded theory is diverse with three main versions. The traditional version (Glaser, 1978), the evolved version (Strauss and Corbin, 1998) and the constructivist version proposed by Charmaz (2014). In the traditional approach (Glaser, 1978) a literature review is carried out *after* the participant data is collected and given this research forms part of a doctoral thesis the literature review was carried out *prior* to conducting the research and therefore inconsistent with the Glaser & Strauss model. The evolved grounded theory (Strauss & Corbin, 1998) employs axial coding. Charmaz (2014, as cited in Mills et al., 2006) argues that axial coding constrains the construction of theory in terms of imposing

codes and may distance the theory from the diversity of experience. This would impact the phenomena of participants' experiences of living with HIV and how they may have experienced any psychosocial adjustment. For this reason the Glaser & Strauss version of grounded theory was rejected.

The version of grounded theory selected for this thesis was the CGTM version proposed by Charmaz (2014). This version endorses a literature review in advance of the participant data collection and adopts a more flexible iterative approach to coding. This version also endorses the role of the researcher by moving back and forth between the data and the analysis. Charmaz (2014, p. 254) claims that, "*data do not provide a window on reality; rather the discovered reality arises from the interactive process between the researcher and participants*". The ontological position of the CGTM approach is consistent with the ethos of pluralistic stance of this research: recognising the existence and validity of a variety of beliefs, values, realities, and identities and that that there is no objective reality but rather there are multiple realities.

3.5 Rationale for Constructivist Grounded Theory (CGTM)

Qualitative methods considered for this study ranged from Interpretative Phenomenological Analysis, Discursive Psychological approach and Thematic Analysis.

This research considered Interpretative Phenomenological Analysis (IPA) however this methodology concerns itself with the ways in which people make sense of the world in regards to a particular phenomenon (Smith & Eatough, 2006) such as living with a positive HIV diagnosis. While IPA is well positioned to explore and document the quality and texture of an individual's subjective lived experience of a HIV diagnosis it would not progress beyond this and attempt to explain any adjustment a person may make in response to a positive diagnosis and how a therapeutic encounter may facilitate this. This research aimed to explore aspects that promote psychosocial adjustment as defined by the participant - what enabled them to adapt in their social and domestic roles. IPA was considered limited as it requires a homogeneous participant sample (Willig, 2013) and this would have limited the diversity and difference this research aimed to give voice to.

Given the role of stigma in relation to a positive HIV diagnosis the discursive approach was considered. The discursive psychological approach focuses on how language is constructed, its functions and consequences as people negotiate their meanings in culturally constituted discourses. The discursive psychological approach concerns itself with the construction and negotiation of psychological concepts and processes and how a person adopts a subject position to perform social actions, including how they construct versions of reality (Potter and Wetherell, 1987). The discursive psychological approach has been criticised in adopting a narrow behaviourist focus in exploring observable linguistic behaviours and arguably neglects subjectivity and internalised states. Given that this research aimed to explore the psychological processes experienced following a HIV-positive diagnosis, an individual's sense of self may be impacted following a positive HIV diagnosis. The discursive approach was considered limited due to its inability to identify individual cognitions and subjective emotional states and account for why individuals pursue particular objectives. This would have been unhelpful in identifying processes that individuals cited as promoting psychosocial improvement. While there is some debate in grounded theory as to whether the focus is on individual experience or social processes, Willig (2008) argues that both forge a more propound understanding of the psychosocial dynamics. This is consistent Goffman's (1963) observation that stigma connotes an

“*undesired differentness*” that impacts an individual’s experience and sets them apart from “*normal*” society (Goffman, 1963, as cited in Herek et al., 2013, p5).

CGTM has its roots in early sociological thought, pragmatism and more recently symbolic interactionism. Charmaz (2000) was the first researcher to argue for a CGTM approach in recognising the mutual creation of knowledge by the researcher and the relativism of multiple social realities. Constructivist grounded theory methodology (CGTM) can be underpinned by a relativist position in positioning the researcher as a part of the research process rather than separate from it (Charmaz, 2000).

CGTM as outlined by Charmaz (2014) positions the researcher close to the participants in keeping their words intact within the process of analysis and keeping a participants’ presence throughout. CGTM places emphasis on action and process and the emergence of meaning in asking questions about what people are doing and trying to accomplish, how exactly they are going about it and how people understand what is going on. CGTM was considered the most appropriate methodological approach not only as it is both the process of category identification and integration - a method, as well as a product, a theory. Categories are identified (events, processes, occurrences) and relationships are made between categories. CGTM was considered well suited for discovering the participants’ core concern as “*narrative constructions*” (Maines, 1993, as cited in Charmaz, 2000, p514) via interviews then generating a theory accounting for the processing of the problem or concern. Namely, how participants experienced the process of therapy in response to a HIV diagnosis and what they described as helpful in this process and how therapy contributed to [any] psychosocial adjustment. In effect the constructivist researcher gains multiple views of the participants’ subjective lived experience of the phenomenon under investigation and this understanding – along with any theory of processes - is considered as reconstructive (Charmaz, 2006).

A CGTM approach was consistent with adopting heterogeneous participant sample and this reflects the aim of this research to understand the variety of ways that diverse participants identify aspects of the therapeutic processes as helpful in facilitating a psychosocial adjustment. This ground up approach sits well with the grounded theory approach, that data collection is undertaken with no hypothesis.

3.5.1 Rationale for constructivist semi structured interviews

Interviewing is the most widely used tool for collecting data in qualitative research (Green & Thorogood, 2014). Charmaz (2006) argues that constructivist grounded theorist attend to the situation and construction of the interview, how the participant constructs his/her story, attends to the interviewer-participant relationship as well as the explicit content of the interview. Face to face interviews were therefore considered crucial conduit for accessing potentially rich data. Given the sensitive nature of the subject matter it was a platform to develop an interaction, to foster exploration, facilitate emergent understanding while legitimising the participant's status and validating their experience. Given the function of constructivist grounded theory is to build concepts and theory from the ground up interviewing within grounded theory can never be standardised or formulaic. Bluff (2005) suggests that interviews can be semi-structured when the process of theory building facilitates the researcher to refine emerging concepts and build theoretical categories to explain the phenomenon under study. From the researcher's perspective, semi-structured interviews allowed the participant to tell *their* story without the researcher preconceiving the content, or projecting values or assumptions that may impact the interview direction. During the course of data collection and analysis, as patterns were identified in the data, the interview schedule and research questions evolved in line with the discovery of new data and development of the emergent theory.

Influence on research design & methodological decisions

While my own personal interests and background informed this research I was careful to remain open to that participants' experiences of a diagnosis and staying open different experiences that may have been very different to my own. In reflecting on this, I was keen to document this within a research journal asking myself questions such as 'What do I know? How do I know what I know? What shapes my views & how has this impacted my perspective?' These questions were periodically asked to ensure a robust reflective process throughout each stage and allowed me to identify preconceptions and how these influenced my role as the researcher. Explaining and documenting my rationale as to way I considered grounded theory the most appropriate methodology facilitated more clarity. Reflection on a methodology that was consistent with my research question was an important consideration and ensured it provided a good 'fit' with my ontological and epistemological position and led to the adoption of a constructivist grounded theory approach.

3.5.2 Rationale for abbreviated version of CGTM

Charmaz (2000) argues that grounded theory strategies need not to be either prescriptive or rigid or prescriptive but rather focus on meaning while furthering interpretive understanding.

This research was conducted alongside the practical limitations of participant recruitment imposed during the COVID pandemic. HIV services quickly moved to online and/or telephone based support. Service provision was stretched due to COVID restrictions and there were concerns in providing participant access to a researcher given that HIV positive service users are considered a vulnerable client group. Ethical concerns about providing a researcher access to a potentially vulnerable client group made recruitment challenging - especially to those who were recently diagnosed and female participants in particular, expressed concerns regarding anonymity and/or confidentiality. This coupled with a research deadline limited the researcher's ability to employ a full CGTM and an abbreviated version of grounded theory was selected (Willig, 2013). As Pigeon and Henwood (2005) argue an abbreviated version should only be used where there are recourse constraints.

It is important to differentiate between the full version of the CGTM model that requires data collection to be driven by emerging theory and progressively focused on data collection and the abbreviated model. The full CGTM version requires the researcher to move from data analysis to data collection from different data sources (focus groups, participant observation and diaries) to achieve full theoretical sampling and exhaust theoretical saturation. The abbreviated version works solely with the original data – the interview transcripts of eight participants were analysed followed the principles of coding and constant comparative analysis. The researcher did not benefit from departure of the original data set to potentially broaden and refine the data analysis. Coding and constant comparative analysis, methodological and theoretical saturation was implemented within, and limited to, the original interview transcripts.

3.6 Grounded Theory Principles of Analysis

3.6.1 Coding

Grounded theory coding suggests Charmaz (2014) is an interactive method and generates the “bones” of analysis Charmaz (2014, p113) suggests that coding as a “*pivotal link*” between data collection and developing an emergent theory to explain the data. Grounded theory emphasises what is occurring in the data as codes take together nascent theory and provides further direction for data gathering working towards generalisable theoretical statements. Initial coding attempts to identify action and process and therefore heavy emphasis is placed on use of the gerund moving away from static labels i.e. leader becomes leading. Initial line by line codes are provisional, comparative and grounded in the data while maintaining an open stance open to other analytic possibilities. Careful coding at stage argues Charmaz (2014) helps the researcher refrain from projecting your motives, fears or unresolved personal issues to your data collection.

Focused coding processes and refines the data by assessing and selecting the most prevalent and significant codes with most analytic power to “sift, sort, synthesise and analyse” large amounts of data (Charmaz, 2014, p138). Focused coding advances the theoretical direction by applying concepts to the existing data and looking for relationships between the data. The researcher is recognised as instrumental in deciding what the codes say and interpreting their meanings. The researcher bring his/her own analytic skills and perspective and applies focused coding to the development of tentative, process-focused categories making analytic connections between associated initial codes. For example, the initial codes ‘explaining rationale for prioritising self’, ‘experiencing shift in social self since diagnosis’ and ‘prioritising self & close friends’ were seen as examples of participants ‘adjusting value constructs’ and became the category code for these. As Willig (2014) suggests grounded theory categories emerge from the data, they are not mutually exclusive and “*evolve throughout the research process*” (p, 209).

As categories and subcategories began to surface the researcher moved towards creating an interrelated theory. For example, the themes of *Managing Pain Medication* and *Developing Drug Coping Strategies* were seen as linked to subcategory of *Navigating the Medication Regime*. This subcategory was seen as informing how the self related not only

to medication but became to be symbolic of how the individual *Understood the relationship with the self & HIV* and this became a category that also linked to other subcategories such as *shifting value constructs*. Grounded theory engages with constant comparative analysis and moves back and forth between the identification of similarities and differences emerging categories. Once instances of a phenomenon have been identified within a category any associated differences are then isolated and form subcategories. With each new category or idea, a concept begs a fresh look at the data to elaborate or revise the original construct. This interaction is regarded as theoretical sensitivity where the researcher refer back to the source data.

The reflexive process - interview & coding strategies

Engaging in reflexivity throughout the research process including the interviews as I listed to digital recordings during early transcriptions allowed me the opportunity to refine my interview style. My interview style evolved and improved with practice and with practice I was aware of my confidence in conducting an interview - allowing the interviewee to take the lead rather than being constrained by the interview schedule. This more relational style created a relaxed space and facilitated a more relational interview experience. I felt this contributed to building rapport and establishing trust while supporting the interviewee's ability to narrate their experiences on their own terms.

While interviewing participants and listening to their accounts, some of the material was upsetting to hear. There was moments that resonated with my own experiences and I was not only reminded about my own personal journey but also about containing my own emotional instinctive responses while playing an active role in how participant's constructed their own unbridged versions. I reflected on my own personal biases in a journal after each interview, specifically those biases that might interfere with my ability to respond with sensitivity and openness. My own experiences for example, in taking early medication was fraught with issues and I was aware of the relationship between how antiretroviral medication facilitates a life expectancy nearing that of a non-infected individual and provided some participants with a new lease of life yet for others it only served to reinforce the stigma accompanied with intolerable side effects. To avoid imposing my own bias on the data I committed myself to learning how participants justified alternative understandings. I committed to reading about the role of medication in HIV and how the landscape of HIV medication research has moved away from increased efficacy to increased tolerance. This was an important step in avoiding any biasing aspect of my background from influencing the participant as I was aware the participant may feel judged if they disclosed that medication had a transformative effect on their psychosocial adjustment & quality of life and this contrasted with my own personal experience. In committing to appreciating alternative perspectives I hoped would minimise researcher influence on participant interactions and I believe to subsequent data interpretation and analysis.

3.6.2 Theoretical sampling & saturation

Theoretical sampling is a pivotal part of formal theory development and used to further develop emerging categories and refine existing ones. Theoretical sampling was used to develop category properties by exploring any gaps within the data. The use of memos within the reflexive process helped engage the researcher to any missing or incomplete theory. Participants whose voices were not part of emerging categories provided a rationale to seek to define and refine how participants constructed their realities for alternative emerging categories.

Theoretical saturation is achieved when gathering fresh data does not yield any new categories or provide any new theoretical insights. Grounded theory commands saturation to apply to categories (Charmaz, 2014) arguing that theoretical sampling is conducted until no new emergent properties or until there is no further theory development. To achieve this aim the interview schedule was amended to reflect revised category questions that emerged from previous interviews and these were applied to the remaining four interviews until no additional category properties emerged. This impacted the model to include a new refined category ([Appendix L](#)). The researcher was aware that uncritical or unanalytic treatment of the data may, as Charmaz (2006) suggests, have resulted in early saturation of the data.

3.6.3 Clustering

Clustering is a flexible, creative and visual technique to understand and organise the data. Charmaz (2014) recommends clustering as a process to understand relationships as it is an image of how the research fits together. Clustering was used as Charmaz (2014) recommends it as a strategy for making writing less onerous for those who dread it as it enables the researcher to establish a sense of control in the ‘chaos’ of the analytic process in sifting and sorting. The clustering utilised within this research employed the ‘nucleus’ method proposed by Charmaz. A main nucleus process was selected from the focused coding and then placed in the centre, the researcher then returned to the data and identified

what the emerging properties of that nucleus were. The smaller processes were then listed as smaller subclusters under the nucleus process keeping related emergent properties and processes within that subcluster. Connections were then with branches to the other nucleus processes (Appendix N). Clustering analysis helped with making sense of the data, asking questions of it, and establishing relationships between processes.

3.6.4 *Memo-writing*

As Charmaz (2000) acknowledges memo writing is the intermediate step between coding and the first draft of the completed analysis. Memos were adopted to provoke new ways of looking at the data and an interactive space to capture thoughts, ideas, data and perspectives. Memos initially developed the focused codes and comparing them to variety of categories. The categories were often rewritten or changed to reflect and process of questioning the data 'fit' to categories and the wider process or function at play. Memos facilitated the researcher to make comparisons and connections with related analytic constructs and maintain focus on the research question in hand. Memos also provided the researcher with an opportunity to engage in critical reflexivity and question assumptions. Reflexivity memos recorded during the data analysis provided the basis for the researcher.

The reflexive process – memo writing

Memo writing was an essential part of my reflexive process. The researcher used the guidance suggested by Charmaz (2014) on memo writing to maintain the focus and direct the research process. Using memos helped identify action processes rather than isolated topics and how they fitted in wider functional processes. Ironically this process itself enabled myself, as the researcher, to limit data 'overwhelm' by focusing on how an action code functioned, exploring the code properties and helped define processes. Memos also facilitated research development in that it allowed space to grapple with the data, helped define the analytic journey, facilitated refining categories and their relationships and to develop a sense of control, autonomy and skill in analysing the data. Memo writing also helped acknowledge my assumptions, biases and beliefs and interrogate assumptions through the use of supervision enabling me to step back and sit with participants in their narratives.

3.6.5 Participant Sample

Participant recruitment in grounded theory is purposive and determined by the action or activity being researched (Frost, 2010). In this research the psychosocial adjustment was primarily participant defined but guidance was provided in terms of how a participant was better able to navigate everyday social and domestic roles in response to psychological therapy.

A heterogeneous sample size of eight adult participants were recruited to represent a diverse demographic sample of varying ages, social and cultural backgrounds and sexual orientations. All participants were adults confirmed that they had received psychological therapy in response to a HIV diagnosis within the previous 2 years. For ease of communication and transcription participants were required to converse fluently in English and have received a minimum of 6 sessions of psychological therapy with a good recollection of the processes on how a positive HIV diagnosis may have impacted them. Semi-structured interviews were employed with an interview schedule ([Appendix F](#)). An exclusion criterion was applied such as nonstabilised axis-I disorders where clients have been prescribed psychopharmacological treatment (i.e. mood disorder with a risk of suicide), mental disorders, substance misuse, symptomatic non-HIV related disease, and significant cognitive impairment.

[Table 1](#) illustrates the participant sample recruited for this study.

Table 1. A demographic sample table of eight participants

Participant	Name (pseudo)	Age	Gender	Ethnicity	Sexual Orientation	Provider
1	Brian	34	Male	White Other	Gay	HIV Service
2	Faisal	27	Male	Asian British	Bisexual	HIV Service
3	Wilomena	26	Female	Black African	Heterosexual	Student Services, University
4	Steve	31	Male	White British	Gay	CMHT Privately funded
5	Eduardo	23	Male	White Other	Gay	HIV Service
6	Samantha	33	Female	White British	Heterosexual	IAPT Service
7	Sam	29	Female	Black British	Heterosexual	HIV Service
8	Karl	47	Male	White British	Gay	HIV Service

3.6.6 Recruitment

To identify and target potential interest a participant advertisement ([Appendix B](#)) was placed in specialist HIV counselling services and social media platforms (Facebook, Instagram). Participants who expressed an interest in this research were provided an information sheet ([Appendix D](#)) and asked to confirm they met the inclusion criteria. Given the nature of the research may well be distressing for some participants in guidance with the BPS Code of Human Research Ethics (BPS, [2021](#)) steps were taken to minimise the potential risk that may be associated in discussing a potentially sensitive topic ([Appendix H](#)).

Participants meeting the inclusion criteria were invited to a face to face interview with the researcher at a mutually convenient time. At the interview stage participants were briefed on the nature of the research and completed a demographic information form ([Appendix C](#)). An interview schedule ([Appendix F](#)) was used to guide a semi-structured interview of approximately 60 minutes duration. The questions within the interview schedule reflected aspects of HIV diagnosis in relation to adjustment and focused on the process in relation to therapy. Appropriate interview locations were private, accessible to the participant either at the University or within the counselling service where the participants attended.

3.6.7 Ethical Considerations

Ethical approval for this research was obtained by LMU Research Ethics Review Panel ([Appendix A](#)). The impact of therapy and the adjustment a person may make in response to a HIV diagnosis is potentially a sensitive area and may involve some degree of distress. The BPS Code of Human Research Ethics (BPS, [2021](#)) argues for sensitivity to potential impact of interventions to the possibility of individual distress. Due to possibility of reliving trauma in relation to either the original diagnosis or personal related material participants were reassured of a distress protocol ([Appendix H](#)) and reassured of their right to take a break or to terminate the interview.

Participants were reassured of confidentiality via the information sheet ([Appendix D](#)) and the informed consent ([Appendix E](#)) and any identifying details will be anonymised

throughout the research. No deception was involved. Participants were informed that this study formed part of a doctoral thesis and in the event they no longer wished for their data to be used in the study, they were able to withdraw either during the interview or up to 4 weeks following the interview. Participants were also advised that a copy of the completed thesis will be available in the LMU library and the British Library (<https://ethos.bl.uk/Logon.do>). All sensitive material including participant consent forms and related material were securely digitally stored with the hardcopies held in a locked filing cabinet. All participants were advised that interviews were audio-recorded and stored securely on an encrypted file on a password protected laptop and only accessible to the researcher. All participants were offered a debrief following the interview and offered access to the completed research. In line with the BPS (2018) guidelines, all participant information, recordings and transcripts will be deleted and destroyed after five years.

3.6.8 Interview Structure

The researcher used semi-structured interviews with an interview schedule (Appendix F). All interviews took place either at the service the participant attended or in a study room at the LMU. Semi structured interviews are compatible with several methodologies, easier to arrange and are essentially non-directive. The researcher used the interview questions to conduct semi-structured interviews asking open questions focusing on process and action placing emphasis on a participant's psychosocial adjustment in relation to therapy following a positive HIV diagnosis. A detailed and comprehensive participant account was coaxed by asking the interviewee to '*state the obvious*' (Willig, 2013, p103) giving an explicit voice to otherwise implicit assumptions.

Constructivist grounded theorists attend to the construction and the interview situation, how a research participant constructs their story along with pauses attending to the interviewer-participant relationship as well as the explicit spoken narrative of the interview (Charmaz, 2014). The researcher in attending to the interviewer-interviewee relationship also attempted to attend to non-verbal communication including voice, tone, pitch and tempo.

The reflexive process – insider/outsider perspectives

Researchers have extensively explored issues around shared identities (Aiello & Nero, 2019) sometimes referred to as insider/outsider perspectives. As Parashar (2019) argues the status of a researcher as insider or outsider plays an important role when conducting a research study, ranging from data collection to interpretation of the research itself. Potential biases may impact the research owing the position of the researcher and highlighting any plausible impact is central to the integrity of any study such as this. My identity as a researcher appeared to reach and sit on both sides (insider and outsider) to the research participants. On one hand I openly acknowledged [REDACTED] familiarity with issues that impacted newly diagnosed men having had similar experiences. I was aware of the challenges that accompanied a diagnosis ranging from medication compliance and side effects to disclosure issues and the stigma related to a diagnosis. This position made it easy for me to have an open and honest discussion with participants. My insider knowledge made for easier flow as medical terminology and medication brand names did not need to be elaborated. It permitted license to ask frank and questions and using an insider perspective & I was able to identify and emphasise with participants while gaining privileged access to their inner lived experience. [REDACTED] [REDACTED] not only may have made participants more comfortable in participating and may have provided the opportunity to develop rapport and build trust by offering reassurances, validating experiences and highlighting participant strengths.

It contributed to an openness with participants plausibly contributing to frank congruent and authentic disclosure. Yet at the same time I was also an outsider to some I interviewed. [REDACTED] there were limitations in terms of gender, ethnicity and sexual orientation. As a post graduate researcher some may have also perceived me as white, middle class and therefore removed from the financial struggles that accompanies a HIV diagnosis. This from a socioeconomic perspective, may have positioned me as an outside in relation to those participants who have struggled financially. I was aware of my 'researcher persona' (Chesney, 2001) particularly as when I may have been perceived as an outsider in attending to my own identity, how this may have been projected and influenced what participants decide to share and the data constructed. As a novice researcher with little interviewing experience I found drawing on past experience in attempting to reduce the interviewer/participant distance helpful in creating a safe, empathic space where participants felt safe enough to share their experiences.

A heterogenous sample group was required for this study yet some of the participants may have regarded me as an outsider on the basis of ethnicity, class, gender, religion or sexual orientation. Some research suggests that the influence of gender within participant interviews is dependent on participating women's perceived sense of skill of dealing with men (Reinharz & Chase, 2002) and this source of difference can be reduced if the male interviewer downplays his gender. Given that the researcher identified as gay may have helped facilitate more disclosure accompanied with framing the interview as relaxed -checking in with the participant and matching the communication style and the pace of the participant.

The discussion of issues involving sex & sexual relations is often considered taboo yet two of the participants identified as black British with one identifying as Black African. [REDACTED]

[REDACTED] our different ethnic backgrounds may have represented a barrier. The insider-outsider divide was perhaps most acute while interviewing a female black British participant where the only thing we shared was a common HIV status. I drew on my training in working with difference and diversity in acknowledging differences and making it explicit that I had not lived through her diagnosis and every individual journey is unique particularly taking into account a black African culture where discussions of sex and sexually transmitted diseases are taboo. These differences – and how they were handled within the interview – did not appear to have reduced rapport or willingness to disclose to an 'outsider'. It appeared that my curiosity as a white, middle class, male researcher fostered genuine interest and motivation to recount their own unique lived experiences in relation to HIV and therapy set against different cultural and social attitudes.

3.6.9 *Validity of research*

The search for validity rests on the assumption that it is possible to replicate good research and that a measurement will yield the same results under different conditions. As Charmaz (2014) suggests “*the criteria for evaluating research depend on who forms them and what purposes her or she invokes*” (p337) acknowledging the active role of the researcher in the process of emergent theory. Yardley (2000) suggested a set of useful characteristics that can be applied to ensure standards for qualitative research: sensitivity to context, commitment & rigour, transparency & coherence and impact & importance.

3.6.10 *Sensitivity to context*

A researcher’s sensitivity to study context is based on the researcher’s ability to balance their attitude to the theory, the existing literature and the data collected. In this grounded theory research the literature review was completed in advance of the data collection and in so doing can yield knowledge along with exceptions and assumptions. As Charmaz (2014) concedes, this may also taint a researcher’s perception and interpretation. To avoid this pitfall, the researcher attempted to limit any assumptions related to prior knowledge acquired either from personal experience or from the literature search to assure that emergent theory acquired from interview data was grounded in theory. The researcher attempted to apply theoretical sensitivity (Strauss and Corbin, 1998) to ensure that the research results emerged from participant’s accounts rather than a reflection or projection of the researcher’s own preconceptions. Constant process comparison was applied (what, where, how, why and by whom) to question and facilitate a deeper understanding.

3.6.11 *Commitment and rigour*

The importance of systematic and thorough data collection, analysis and reporting (Yardley, 2000) was achieved through recruiting an adequate heterogeneous sample size to yield “*an in-depth interview study of lasting significance*” (Charmaz, 2014, p108). The credibility of this study was augmented by seeking the input of a number of sources (Mays & Pope, 1995) including the input of a clinical supervisor and a chartered psychologist to critically examine the analytical process. Quotations were used in the data analysis to demonstrate how subcategories contributed to category formation. Grounded theory

research also cites the capacity of reflexivity at differing points as key within the research process (Mauthner & Doucet, 2003) and to this end reflective comments have been added throughout.

3.6.12 Transparency and Coherence

The requirement for transparency in this study was achieved in providing details of how the research and grounded theory analysis conducted. To ensure transparency interview extracts are included within the data analysis and the process of identifying categories and subcategories are included in the appendices. The reflective process was considered a crucial aspect of transparency and in meeting the requirement for coherence in constantly questioning the methods and analysis employed as fit for purpose.

The researcher also sought ‘independent auditing’ to check that identified categories and subcategories was credible and reflective of the data collected (Smith, 2001) to critically examine participant accounts against the researcher’s grounded theory analysis. The study strove to maintain a consistency between the research question, the appropriateness of the methodology with the researcher’s epistemological position as Yardley (2000) suggests this is key to achieve coherence.

3.6.13 Impact and Importance

These are a requirement for judging research quality and one that Yardley (2000) suggests can be measured by the contribution of research to the relevant chosen field. This research expands on the critical literature review in adding to the theoretical knowledge of HIV in exploring the efficacy of therapy following a positive HIV diagnosis in relation to psychosocial processes. The research hopes to facilitate practitioners’ understanding, appreciation and theoretical knowledge in relation to individuals living with HIV in order to better meet client needs of this specialised group.

Reflexivity within the research

As reflexivity has become increasingly popular in legitimising qualitative research a common pitfall, argues Gentles et al. (2014) is where researchers fail to specify their own understandings, positions and approaches. Hall and Callery (2001, as cited in Gentles, 2014, p257) suggested 'attending to the effects of the researcher-participant interactions on the construction of data' yet other authors (Mallory, 2001) take a wider view of reflexivity as not only focusing on the researcher-participant relationship during data collection but also the effects of this interaction on analysis. Mruck and Mey (2007) highlight the congruence of a constructivist approach to symbolic-interactionism and propose reflexivity in all stages of the research process and that reflexivity during the writing process as the most interesting and useful.

*As a researcher the participant responses were monitored on many levels, subsequently responding to interpretations of what is going on during the interview particularly taking into account the extent the *insider/outsider* perspective in relation to the participant. The general objective aim of the reflexive process is to increase transparency and trustworthiness of the research and as Hall and Callery (2001, as cited in Gentles, 2014) point out in grounded theory reflexivity exists as theoretical sensitivity emphasises the reflexive use of self in the process of developing the research questions & subsequent analysis. Reflexivity as consistent with a constructivist stance is regarded as an advantageous process.*

With this in mind it is important to pay attention to the varying type of researcher interactions including specifying the researcher's position on reflexivity adopted for this research, outlining the justification and decision for how reflexivity was engaged within this study and summarising the reflexive observations and considerations that were developed during the course of the study.

Framed within this reflexive process, first person singular is used to reflect the agency of the researcher, the first person plural is used when a supervisor shared an important role in specific decision making. Broadly reflexivity in this study was divided into how, as the researcher, I may have impacted participants during the data collection, how participants may have impacted on me, decisions made that may have impacted the research analysis and how the research impacted on myself given it is the researcher's emerging constructions of concepts that shape both process and product (Charmaz, 2014).

4. Data Analysis

4.1 Grounded Theory Model

Grounded theory was considered a good fit to the research question it is a *process* of category identification and integration and a *process* of developing theory. Grounded theory employed within this research primarily sought to identify and understand what aspects of therapy help facilitate psychosocial adjustment as a *process* with individuals diagnosed with HIV.

In so doing, this research seeks to i) support those working with this specialised group in being able to identify therapeutic processes and/or factors that facilitate psychosocial adjustment; ii) provide a diagnosis trajectory framework for those diagnosed with HIV; iii) provide a diagnosis trajectory and framework for working with and meeting the needs of this specialised client group.

While diverse and complex in nature, participant accounts provided an emergent theoretical framework presented in [Figure 1](#). Core category of '*Process of growth*' and '*Therapy as challenging exploration*' encompasses four categories and 12 related subcategories that emerged from participant accounts of their experience of therapy in relation to a HIV diagnosis.

4.2 Presenting the Results

4.2.1 Use of Quotations

Quotations are displayed in italics. Where the researcher omitted a portion of a participant's narrative [...] this only employed where a portion of a participant's narrative combines to other supporting portions of the transcript. Minor hesitations and utterances such as "*erm*" have been removed to aid clarity. Pseudonyms were used throughout for all names, places and services and essential factors are disguised to maintain confidentiality.

4.2.2 *Researcher Reflections*

Some versions of grounded theory have been critiqued due to limitations of researcher reflexivity. Original grounded theory suggests that theory emerges from the data with limited acknowledgement of the role of the researcher who is a conduit in the emerging theory. This research was conducted using Charmaz (2014) version of grounded theory employing a social constructionist theoretical perspective. Within this epistemology implicit is that the emerging theory may represent one truth - rather than the only truth - from the researcher's perspective. Given the active role of the researcher in identifying emergent theory the researcher has included reflections to frame interpretations and provide alternative perspectives.

4.2.3 *Overview Core Categories*

An overarching concept among participant narratives was a process of moving from a sense of overwhelm following a HIV diagnosis and grappling with negative emotions to a sense of personal growth marked by new value constructs, beliefs and meaning making while overcoming intrapersonal and interpersonal hurdles associated with the stigma attached to their diagnosis.

From the analysis two core-categories and four categories with 12 related subcategories were identified which captured the participants' experiences of therapy following a positive HIV diagnosis (Table 2). The categories appeared to mark a transition as participants moved through a chronic illness trajectory each concept interlinked to the next. The schematic (Figure 1) captures how the interlinked processes in how participants seek to navigate, understand and transition in response to a positive HIV diagnosis. The way that participants navigate each 'stage' of the illness trajectory they are confronted with different aspects of living with HIV, adopt different strategies and adjust their value beliefs which fosters a process of growth. The ongoing process is illustrated by each gear as it captures the participants' progressive journey as they engage in therapy, with each step functioning to provide a platform for the next as they confront living with a chronic illness.

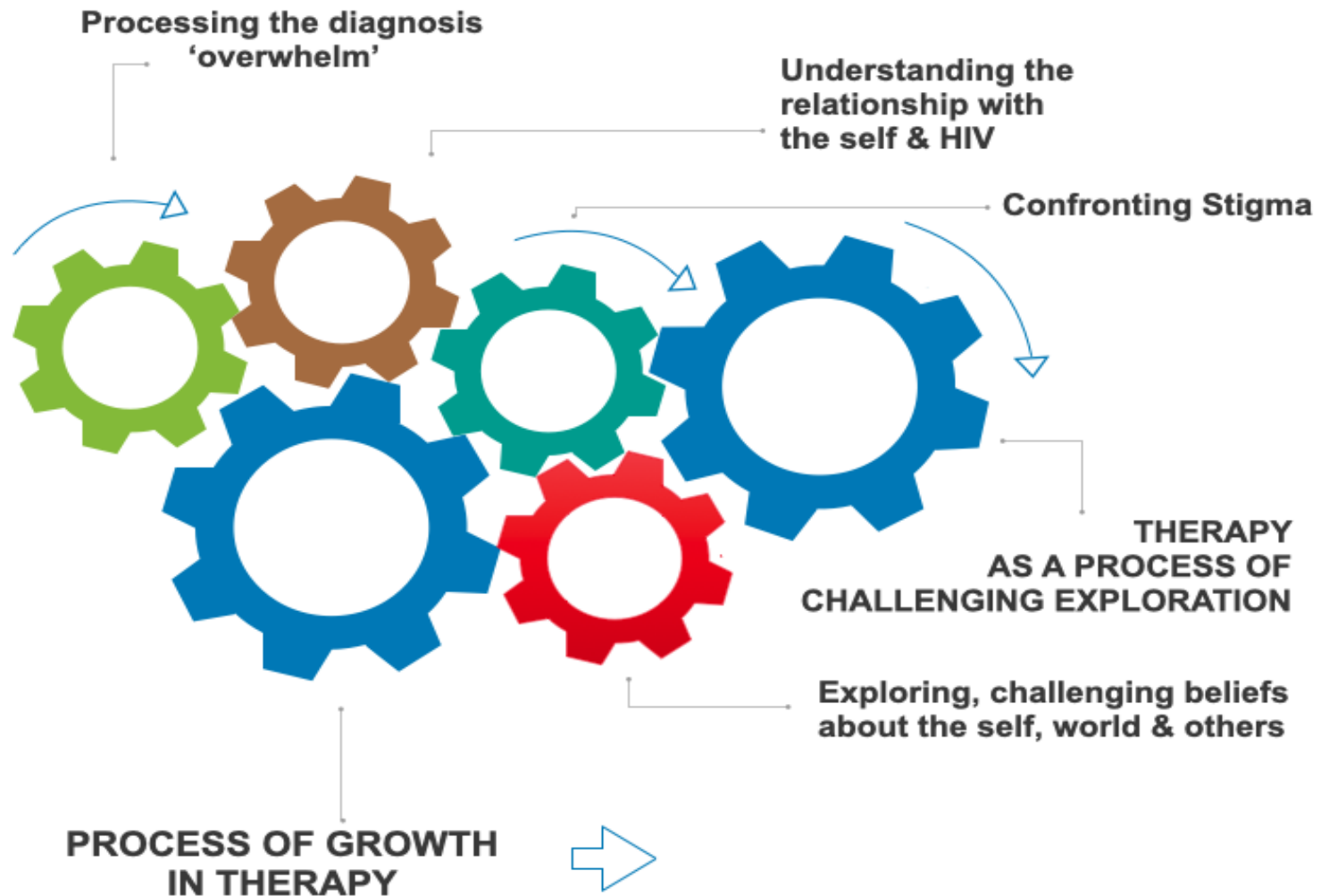
Within the core category *Process of growth in therapy* participants described progressing from *Processing the diagnosis 'overwhelm'* to *Understanding their relationship with the self & HIV*.

Within other core category of *Therapy as a process of challenging exploration & psychosocial adjustment* participants continued on their journey by *Confronting stigma* and as they continued the process of integrating HIV into their identity and gaining an increased self-acceptance through *Exploring and challenging their beliefs about the self, the world and others*.

4.2.4 Table 2. *Table demonstrating categories and sub-categories*

<i>Core Category</i>	<i>Category</i>	<i>Subcategory</i>
Process of growth in therapy	Processing the diagnosis 'overwhelm'	Experiencing negative emotions
		Acknowledging denial
		Exploring loss & proportioning blame
	Understanding the relationship with the self & HIV	Confronting mortality
		Navigating the medication regime
		Shifting value constructs
Therapy as a process of challenging exploration & psychosocial adjustment	Confronting stigma	Sabotaging the self
		Constructing medication strategies
		Managing rejection
	Exploring, challenging beliefs about the self, world & others	Navigating disclosure & implementing boundaries
		Adjusting value beliefs
		Qualities of therapeutic process

4.2.5 Figure 1. Schematic demonstrating categories & how they relate to core categories through the diagnosis trajectory



4.3 Core Category: *Process of Growth in Therapy*

4.3.1 Category: *Processing the diagnosis 'overwhelm'*

Participants used the therapeutic space initially *Experiencing negative emotions* while *Acknowledging denial* before progressing to *Exploring the loss & proportioning blame* in relation to relationships, their perceived health and sense of identity. In in this process participant narratives all described *Confronting mortality* in addressing existential notions of death in relation to their recent diagnosis.

4.3.1.1 *Experiencing negative emotions*

All participants expressed a common narrative in experiencing an initially negative emotions following a positive HIV diagnosis ranging from denial to shock, disbelief, panic and confusion and hopelessness as they struggled to come to terms with their diagnosis:

*"...it was very emotional at the time. It was too much to handle, I couldn't believe it. And I think I cried during the first session [...] it was too emotional for me to - to get over it.
[Faisal, 38]*

Faisal captures disbelief and uncertainty and appears to indicate some denial and this prevailed in other participant accounts.

For many participants the initial overwhelm was compounded by other comorbid medical conditions augmenting uncertainty and vulnerability. Many participants questioned their capacity to cope with the unpredictability of managing life with poor perceptions of health. This uncertainty underpinned a concept of loss of control triggering a sense of vulnerability:

*"I was feeling very overwhelmed, and the life I wasn't going to cope being this sick. I'm in the real world. I didn't understand how I was going to take care of myself. I thought I was going to be street homeless, sick, no energy, poorly, constantly with flu."
[Brian, 81]*

This overwhelm appeared to be augmented by disbelief, fear and shame with perceived uncertainty over their health and future was this appeared a primary motivator to seek therapy. While uncertainty was constructed by participants differently most centred around negative perceptions surrounding quality of life and poor psychological adjustment. As result, participants often described spiralling into depression and anxiety with an array of negative emotions. The therapeutic space was initially used to make sense and come to terms with their new status and finding meaning:

“I was desperate. I was really like, what am I gonna do with my life? I didn’t even want to work or to study. I didn’t want to do anything cos what was the point if I was gonna die anyway? We are all going to die, you know, but [...] so soon, why?”
[Eduardo, 27]

4.3.1.2 Acknowledging denial

Denial can function to avoid a threat to the psyche and help unconsciously manage negative emotions. Questioning the validity of the diagnosis appeared a common feature:

“There was a nurse in there and he said well ‘Your result came back pass positive’ and I was like How? That surely can’t be right?! I don’t have lots of sex. Immediately I thought it was a mistake.”
[Wilomena, 28]

Participants often reflected on their world as meaningless with overwhelming emotions. Denial and shock appeared to facilitate participants to cope with the overwhelm and make immediate day to day survival possible. Denial appeared to help participants to pace their feelings of somehow being spoiled along with the impact of shame and stigma related to a HIV diagnosis.

The primary function of therapy appeared to be a space to process the diagnosis. A positive HIV diagnosis conjured negative metaphors in all participants as they drew on social constructions of the disease fearing the body being invaded by a ‘dirty’ virus. With the threat of being infected with HIV participants appeared to position themselves in relation to these social discourses in an attempt to defend against the threat of HIV infection possibly as a destructive threat to the self. Wilomena appeared to question the validity of

the result appearing to defend herself against the vulnerability and risk of a HIV diagnosis as HIV as something happening to others.

Reflective comment: I was keen to engage in a participant's perspective and meaning making given the sensitive subject matter to gain an insight into their process. I was mindful to stay bounded in focusing on their account making and experiences as a participant may relive and be unwittingly retraumatized. Aware of not wanting to open a 'can of worms' yet eager to hear their process of dealing with a positive HIV diagnosis I was mindful to tread carefully and adapt to a participant's relational style. It was also crucial to reflect on my role as the researcher as active in the research process both during the interview and subsequently in selecting emerging categories. Maintaining an awareness in containing my own emotional responses as these may be very different to the participants particularly in relation when societal and cultural factors are taking into account.

The need for an emotional release, to explore negative emotions, make sense of their positive HIV status and identify immediate coping strategies could be viewed as an attempt grapple with the psychological and sociological phenomena associated with a diagnosis. This was invariably evident where participants lacked familiarity with HIV with systems of care that are ambiguous or complex.

4.3.1.3 Exploring loss & proportioning blame

Loss was a concept that weaved throughout each participant narrative and was mediated by relational, societal and cultural factors. A common narrative of a positive diagnosis stemmed from an infection via a partner and subsequent the loss of a relationship:

*“at the time I was mourning my partner, and he was in very tearful situation where he has caught it, and he was ill but at the same time, he had unprotected sex and passed it onto me and he felt very responsible”
[Steve, 7]*

Steve's notion of loss was framed within his perceived loss of his health and the loss of his relationship. Steve reflected on 'mourning' his partner conjuring notions of death. The experience of HIV itself can be a metaphor of death but one that stemmed from a loving trusting relationship appeared to create an array of negative emotions stemming from anger to betrayal, blame shame and regret. The dynamic of an infection via a partner was unexpected but nonetheless, impacted a participant's subjective experience of loss with a partner's diagnosis often preceding their own and impacting their ability to seek timely medical treatment. Participants saw themselves as being complicit in that process:

"We were looking quite ill and Gavin [partner] was continuing to be resistant to taking medication and I just followed his lead. Everything he did I just followed his lead. Typical. I was just like a child, you know and it was easier to focus on him and trying to attend to his needs and, and - and being in denial and forgetting that I was positive so such a point that both of us were both that unwell that we had developed - Kaposi's sarcoma- the black lesions? So we had Kaposi's sarcoma."
[Steve, 15-17]

A concept emerges here of how a partner's positive HIV diagnosis can overwhelm an individual's own capacity to deal with and prioritise treatment. Steve's language appears to acknowledge a loss of identity within the dynamics of his relationship and he struggled to cope acknowledging "being in denial":

"when I've accessed therapy we've looked at that concept of sacrificing myself or forgetting about myself and focusing on Chris [partner] in some respects but it was partly me in denial, it was easier to focus on him than to deal with myself."
[Steve, 32]

Steve's reflection "I was just like a child" appears to signify following his partner's lead. Yet on closer examination this reference could also be inferred to make reference to a childlike ego - one that is young and underdeveloped in total compliance. It may also allude to a loss of self in "sacrificing myself" in focusing on his partner's needs that are deemed as more important. This could be framed as an defense as Steve seeks to protect his ego. HIV can be viewed as an omnipotent threat to the self in representing death and destruction and in facing this stark reality with positive diagnosis may be met with an existential crisis.

Reflective comment: In examining the diverse ways that the participants made use of their psychological mechanisms in relation to a HIV positive diagnosis I noted of the role of the ego and how participants appeared to employ various strategies to defend it. I also noted the influence of social context in an individual's experience of HIV and how this interplayed with an individual's ability to process and adjust their self-concept. In taking a systemic view of the individual and how they were positioned in relation to wider protective and risk factors and now that informed psychological theory.

A concept surfaced stemming from within a relationship denial with loss on different levels: loss of health as opportunistic infections ravaged an already impaired immune system, loss of relationships and a HIV diagnosis as damaging to the sense of self resulting in a loss of self-esteem.

4.3.1.4 Confronting mortality

A sense of mortality while a prevalent concept in most accounts appeared to be influenced by both cultural and societal factors and a common concept in participant narratives:

"I think it really shocked me after receiving the diagnosis. What was the reason? Okay, and why did this happen? You know, and then I started to put a lot of blame on top of me like, what is going to happen? Am I going to die quickly? [...] What are the consequences of what I have?"
[Faisal, 17-19]

Faisal contemplates the consequences of his diagnosis and psychological and emotional strain is palpable shouldering blame and responsibility. Participants invariably explored loss and recriminations following a HIV diagnosis and the therapeutic space became the sole place to explore this:

"I have contact with my family but my mother I could never tell them - that is the issue coming from an Asian community [...] the shame it would bring on her family and the community. It would be enormous."
[Faisal, 41]

Faisal reflects on the Asian collectivist culture where stigma and shame from HIV impacts the 'family & community'. This conflicts with the individualised Western notions of stigma where the individual is the object of shame. Faisal's perception of his diagnosis and informs a sense of obligation to protect his wider community. The researcher pondered the psychological burden of having to contain this diagnosis for fear of disapproval from the family and wider community. This account marked a divergence from other participants in acknowledging the impact of culture within a HIV diagnosis.

Reflective comment: Participant narratives surrounding concept of loss made me reflect on value of bereavement models - such as the stages of grief - to a HIV diagnosis within this grounded theory framework. I started to question the role of emotions in relation loss, identity and self-concept and the extent these were influenced by culture and religion. It created an awareness of how interpersonal & intrapersonal factors interplayed in dealing with a HIV diagnosis and the role of denial and avoidance as primary defense mechanisms in navigating loss.

4.3.2 Category: *Understanding the relationship with the self & HIV*

This category emerged as participants continued their journey in *Navigating the medication regime* they began *Shifting value constructs* by slowly integrating HIV into their identity. A related construct of *Sabotaging the self* surfaced where participants adopted strategies to negotiate HIV relationally, emotionally and culturally.

4.3.2.1 Navigating the medication regime

This category encompassed ranging from the emotional and physical distress from starting ART following a positive HIV diagnosis to developing adaptive coping strategies faced with the negative perceptions of quality of life. The researcher used the 'in vivo' term *regime* used by one of the participants as it aptly illustrates the concepts of discipline and control set against the concept of uncertainty across the HIV illness experience. While ART facilitated a longer, healthy life it accompanied side effects:

“There’s been a lot of side effects of taking the medication. Sometimes, headaches, palpitations and you know when, when the medication impacts places for weeks and weeks and then your body gets used to it...”
[Faisal, 72]

Reflective comment: I observed similarities in participant narratives in regard to the perception of ART medication both as a reassurance against HIV yet also reaffirming an individual’s HIV status and uncertainty in relation to care provision and disease progression. The concept of uncertainty appears to create a tension against having a personal sense of control. This paradox is discussed in relation to grounded theory in the Discussion section. I considered how an individual’s construction of HIV informed their adoption & adherence to medication particularly as participants were diagnosed at different stages of the chronic illness trajectory.

Complex changing treatments, ambiguous symptoms and negative perceptions of social response were all seen to mediate a participant’s attitude to uncertainty. Brian echoed that psychotherapy provided reassurance yet medication initially reaffirmed his HIV status:

“I had the assurance that it was about 2 or 3 weeks before there was a kind of balancing - or balancing out of like very strong, absolute nausea, panic attacks, nightmares - crazy, crazy nightmares - you know? [...] the therapist here who gave me really, really positive reinforcement feedback.”
[Brain, 155]

The management of uncertainty appeared to be an important function of therapy with the benefits of a therapist familiar with HIV as a chronic illness trajectory, medication side effects and the ability to create a meaningful with medication.

4.3.2.2 Shifting value constructs

Participants described making adjustments in their value constructs in response to living with HIV, facilitated within the process of therapy. These adjustments comprises of concepts of exploring the diagnosis beyond medication, changes to participants’ value

beliefs as they moved towards increased acceptance of HIV and a related increased self-acceptance.

A concept emerged of participants making changes in their perspectives marking a change in attitude and behaviour. Therapy appeared crucial for Steve to gain an understanding of what factors were contributing to his self-destructive behaviours:

“I think more initially he [therapist] picked up on the wrong things that I was saying cos a lot of my issues stem around alcohol if I’m being self-destructive I feel like it stems from issues related to my understanding and management of my HIV [...] I think he thought that I had daddy issues. Maybe I do but I thought more of the drinking was socially related to that and thinking who will love me, who’d want to be with me, who will invest in somebody who’s got HIV.”
[Steve, 141-143]

Steve appeared to regard himself as somehow defective and unlovable and this impacted his relationships with other men and informed his coping strategies in drinking as a protective measure. Adjustments to participants’ value constructs often appeared to be prompted by emotional pain. Brian describes taking a more appreciative perspective after ‘*hitting rock bottom*’:

“It’s almost liked I’ve been - forced to like, you know, like some people would say a rock bottom situation where I’ve been forced to like, appreciate my health more, like it’s a massive, huge, psychological paradigm shift before I probably taking it for granted and abused it”
[Brian, 184]

Brian’s reflects on confronting the repercussions of his past behaviours and moving to an appreciation of health rather than ‘*abusing it*’ appearing to adopt a more compassionate view of himself:

“I had really unrealistic expectations of how it [health] should be and how it should look and felt pressurised to like be... have you know, be perfect and have the best lifestyle and like, it’s about like staying well as opposed to staying perfect”
[Brian, 182]

Exploring this within the confines of therapy, Brian acknowledged making amends with his past and adopting - paradoxically - an increased capacity for self-acceptance in ‘*staying well*’ rather than ‘*staying perfect*’. Perhaps following a positive diagnosis Brian felt that

perfection is unobtainable, and in so doing, settles for being authentic with his real self, discarding the need to meet the perceptions of others. For Brian the HIV diagnosis appears to have promoted a shift in his value beliefs rejecting societal expectations and this facilitated being able to adopt a more compassionate and accepting view of himself. For some participants acceptance was tempered by the perception of control and autonomy:

“I don ’t accept the fact that something has invaded my body and I don ’t have control over that but I am at peace with the fact that I can live with it in some sort of harmony because I am supported by great doctors you know?”
[Steve, 320]

Steve describes the anguish of having his body ‘invaded’ and the loss of control implicit with his diagnosis. Working towards being ‘*at peace*’ with HIV and finding a positive way of relating to HIV Steve appears to recognise that a toxic relationship with HIV is detrimental.

Reflective comment: While unpacking the ways that participants related to HIV I was aware of the different ways that participants made sense of their relationship with HIV and how they navigated this is a process in relation to their internal and external worlds. A HIV positive diagnosis invariably appeared to be accompanied by growth as participants transitioned to adopting more compassionate and accepting view of themselves in relation to HIV. I reflected on how this ‘shift’ mirrored aspects of Acceptance & Commitment Therapy (ACT) and how this informs adjustment.

4.3.2.3 Sabotaging the self

Exploring how HIV impacts an individual’s sense of self in relation to defenses appeared to be a concept:

“Yes, we did discuss protecting the self. Interestingly not fully protecting the self, but rather than because I went through a process where I was sabotaging situations because I was scared of rejection related to HIV as well.”
[Samantha, 184]

The saboteur that Samantha describes here could be interpreted as a function of an aggressive and persecutory ego as Samantha seeks to defend herself against perceived rejection. This could also be viewed as an internalisation of an external conflict where Samantha fears societal retaliation due to the stigma attached to a woman living with HIV. The act of sabotaging may have been employed to protect the ego from the persecution that HIV may trigger.

Reflective comment: In situations where participants sabotaged I pondered the function of the ego in Samantha's relationship with HIV. From an object-relations perspective Samantha may perceive HIV as an active relationship. Samantha's attempt to protect her ego led me ponder the role of attachment style in an individual's relationship with HIV. Sabotaging relationships can be associated with an avoidant attachment style leading me to question the impact of attachment. An internal working model is the cognitive framework that comprises of mental representations for understanding the world, self & others and based on a relationship with a primary caregiver. Participant narratives and the use of language allowed me to gain insight in a participant's world but also gave some insight into a participant's internal working model and how that may inform a own relationship with HIV.

Within the therapeutic space, participants demonstrated a similar path in making positive changes in their value constructs in adapting a more positive relationship with the self & HIV to better overcome relational challenges they faced.

4.4 Core-Category: *Therapy as a process of challenging exploration & psychosocial adjustment*

4.4.1 Category: Confronting Stigma

This category reflected the therapeutic process of exploring, confronting and overcoming stigma attached to HIV. In so doing participants described *Constructing medication strategies* to conceal their HIV status. Participants appeared active agents in *Managing*

rejection and in developing coping strategies they drew on *Navigating disclosure & implementing boundaries* in an attempt to buffer themselves against stigma. This appeared to have a protective function.

4.4.1.1 Constructing medication strategies

A prevalent concept was the psychological impact of taking ART medication. While ART has provided a reassurance of a life expectancy framed against the perception of adequate healthcare provision it served to reinforce an individual's HIV status and promoting feelings of shame, guilt and rejection and appeared to inform a person's identity. Taking medication publicly was therefore cited as initially challenging for most as they feared revealing their status:

“you're still objectified somehow either strongly or mildly [...] if I do need to like, open up my bottle of Truvada or cos it's morning time, you know and I'm on the tube, I won't. I'll wait until I'm, you know, on the street.”
[Brian 100-103]

This narrative belies Brian's perceived perception of being '*objectified*' and something he reflects is '*a bit much*' perceiving negative judgment and feeling overwhelmed at the prospect of taking medication publicly:

“it's irrational, I understand that. It's an emotive response, you know, you just think oh this that giant blue bill that everyone probably knows what it is.”
[Brian, 113]

Brian may be demonstrating an internalised stigma that he is projecting onto others. Appearing to wrestle with the conflict between the irrational and rational parts of his psyche. With the initial fear surrounding taking medication publicly the onset of shame was fairly universal in participant accounts, individual coping strategies varied:

“Well that's just, you know - the family, they are curious 'Why are you taking that pill? What is that? You know? I just keep placing them in vitamin pots.”
[Eduardo, 105]

Concealing the medication and his HIV status appeared a defensive strategy to protect Eduardo from the perceived shame and guilt from his family. A protective strategy that

Wilomena employed initially was avoiding social contact in not taking her medication publicly:

“the first month of my treatment I lost some friends, I mean, not friends. I don't think they were really my friends [...] because I didn't really know how to manage taking my pills and being out - out in , in the social world. If they would invite me to a dinner or whatever I would decline. So they got fed up at some point”
[Wilomena, 296-297]

Such is the power of the shame and perceived stigma that Wilomena chose to distance herself socially and in that process experienced additional loss and social isolation.

Reflective comment: Nonverbal communication often portrayed the gravity with which participants relived their experiences in retelling their own unique stories. Participants frequently avoided eye contact, folded their arms or lowered their voice when they recalled their experiences in taking medication and encountered stigma, shame and guilt in the early days of their diagnosis. This may have been due to the uncomfortable emotions that arose from reflecting on their medication concealment strategies but I wondered how much was due to that fact that they were telling me and feeling shamed perhaps recognising how their measures may have been seen as extreme in the here-and-now of the interview. The way non-verbal communication was employed and presented as inconsistent with a participant's narrative also provided cues about an individual's defense strategies & provided a protective function in creating a 'reality' that reduced psychological conflict.

Shame and guilt associated with taking ART appeared to be an initial phase within the HIV trajectory. As time passed, participant's described being more at ease:

“I would get alarms and I was very shy and shameful about taking them in public but it's not the case anymore like now it's a bit like I'm on a train and I need to take my pills, I take them.”
[Wilomena, 110]

Wilomena's narrative demonstrates a process of overcoming the perceived stigma attached to taking medication publicly moving from being “*shy & shameful*” progressing to a defiant “*I take them*”. This demonstrates a progressive shift in her sense of self and how

she progressively constructs her identity in relation to HIV. It could be argued that HIV stigma hinders self-esteem and maintaining a valued sense of self. Navigating the thorny issue of disclosure by exploring plausible identifying factors such as medication and how these impact a client's sense of self and their attainment of goals was described as an implicit function within the therapeutic space.

4.4.1.2 Managing rejection

Feelings of shame and guilt were strongly linked to the perception of humiliation and rejection. The stigma a participant appeared to perceive informed the extent they disclosed their status and exploring rejection within therapeutic domain was cited as key to the process of overcoming it:

*“I must say it was really insightful. He [therapist] was definitely more interested in my experiences contributing to my self destructive behaviours so looking at really, yeah like my identity, my attachment maybe with my HIV? What that means for me, how do I introduce that to other people.”
[Steve, 116]*

For Steve exploration of his identity and attachment style with HIV to understand possible “destructive behaviours” and how they relate to HIV:

*“So if I was anticipating rejection it's because I would sabotage the situation so it that it would just end rather than get in to that point. Does that make sense? Never really focusing on introducing yourself and saying it but it just more looking at how can you protect yourself if it is a negative rejection, you know?”
[Steve, 186]*

Here the therapeutic exploration appears to have targeted how Steve's status may have contributed to feelings of inferiority within relationships, and fearing the humiliation of rejection sabotage was employed defensively. Given Steve's history of contracting HIV via an open relationship this researcher wondered if this may represent an attempt to take control by making defeat manageable rather than face the destructive force of rejection. Steve reflects on HIV as an part of his identity that he actively relates to:

“I was always scared of how other people would see me with it [HIV] [...] it was the first time that I felt like an individual living with HIV by myself and then that's when it really came in with the therapy - my relationship

with my HIV [...] this particular therapist as well, was really positive in just making me feel that the HIV isn't all of me like it's part of me.”
[Steve, 120]

Steve appeared initially to incorporate HIV into his self-concept negatively impacting his self-esteem and seeking to reject before being rejected and in so doing protecting his ego. The perception of being rejected has implications with HIV and stigma and while this strategy was functional for Steve this strategy unwittingly left him feeling isolated and unworthy of love. The therapeutic function appears to have been to change way the Steve related to HIV in changing his perception and attitude towards it. Steve reflects “*isn't all of me like it's part of me*” suggests that a HIV diagnosis initially overwhelmed his sense of self. Reducing HIV into a component part of his identity facilitated Steve to relate to others beyond that of being a HIV positive gay male living a more socially adaptive and fulfilling life.

All participants ascribed to shameful feelings when initially diagnosed with HIV invariably positioning themselves as inferior due their infectious status. In exploring Steve's “*attachment*” with HIV it resonated with the researcher that HIV may represent an internalised object of shame with which participants - and in particular, Steve - actively related. When participant's needs for acceptance, respect, and positive regard were frustrated HIV may have represented as an internalised ‘bad’ object and relating to it in this way may have only perpetuated to an internal state of fear and suspicion. Changing this way of relating to HIV to a more secure emotional base appeared to be key area of growth for Steve and featured in other participant accounts.

Reflective comment: Do all individuals experience an adjustment in relation to HIV? On ponding process: the idea of a transition or adjustment in relation to a HIV diagnosis was a debatable concept. I strived to maintain an open outlook in my interview schedule. Yet, as participants progressed through the trajectory of HIV diagnosis they all disclosed navigating a difficult relationship with HIV and by proxy, their relationship with themselves in navigating internalised and enacted stigma. Their transition was functional - in shifting participants' value constructs surrounding HIV they experienced less shame and guilt. As stigma is socially and culturally constructed it shaped participant's self-concept & their boundaries while helping them adapt their relational style.

4.4.1.3 Navigating disclosure & implementing boundaries

A common concept in participants' narratives was grappling with the tension between disclosure and non-disclosure or as one participant reflected between "privacy and shame". Renegotiating interpersonal boundaries with the self and others as a protective function was described by participants as a helpful feature of therapy.

Participants described feeling of shame was often cited as compounded by an obligation to disclose. Addressing this within the therapeutic space with a practitioner familiar with HIV and the ethics surrounding HIV disclosure was deemed as "*a revelation*":

"it was actually quite a revelation for me as I'd been in the previous mind set of [...] feeling like you are compelled to disclose, you could make people sick, you would be found to be a liar - you know the moral/ethical"
[Brian, 121-123]

This psychological burden was echoed by Steve:

"the plans were we were not going to tell any of them [family] and it's like, living a lie, you know and having to pretend at party events or like, because I was getting chemotherapy, you know?"
[Steve, 20]

Participants recounted a tension between disclosure and non-disclosure. When a participant opted to exert their right to privacy this was invariably accompanied with a psychological burden in "*living a lie*". Disclosure as an interpersonal experience was fraught with shame, and fear of being "*ostracised or challenged or labelled or rejected*" [Steve, 103]. This appears to reflect the prevailing social attitudes of HIV and clear boundaries as a protective measure were maintained by all participants to ensure a sense of safety.

Boundaries were initially a source of confusion and grappling with the conflict was associated with non-disclosure:

"I was interested - overly interested in people who were new or HIV positive, almost being quite deceitful in trying to understand their still relate to them privately but not tell them about my status- it didn't feel great"
[Steve, 69]

This may represent a potential defense in the form of a reaction formation, feeling threatened and holding feelings of hostility and resentment towards a virus that ‘*has invaded my body*’ sought to befriend HIV positive individuals yet within the safety of keeping his own status concealed. Steve reflects on the tension here ‘*of being deceitful*’ seemed to mask a resentment “*it didn’t feel great*” perhaps reflecting on guilt and shame over the sense of deception.

In an attempt to understand the psychological mechanisms at play there appeared to be a process where participants became adjusted to disclosing their status as a defensive strategy:

“it started with my friends and then I started telling guys that I was dating and those dating it’s difficult cos it was that ‘When do I wait to tell them? I dealt with that in therapy. Yes because I got a lot of rejection, and some of the rejection was quite negative.’”
[Steve, 171]

Rejection following disclosure was described as a fairly typical experience and the participants used the therapeutic space to explore this and gain an understanding of privacy versus secrecy - the cost/benefits of disclosure appeared an essential component of developing the relational self. The limitations on avoiding disclosure was reflected by Steve:

“I’m done with the whole, meet guys go in - 3 or 4 dates let them see me so that they see me and then when I tell them that I’m positive they’ll understand [...] I went on several dates too, they’d like me, and maybe I’d introduce that but like before anything sexual happens but then sometimes I got told that I was deceitful that I was manipulating.”
[Steve, 175]

This experience appears to inform Steve’s approach in disclosing his HIV status:

“I tried another approach that’s basically telling guys straight from day one -before I met them and that actually worked a lot better. It’s just means you need to be brave quite quick and jump into the deep end”
[Steve, 182]

Early disclosure was therefore adopted as a protective strategy against the pain of being rejected later. Participants described perceived rejection in relation to sexual relationships as particularly problematic. This provided an barrier to disclosure:

“If I tell a guy you’re positive there’s the feeling that it’ll change the way he sees you - like a victim or he’ll pity you. I can’t handle that so I just don’t go there”
[Brian, 198]

Being seen as a ‘victim’ links to shame as it appears to pollute an individual’s sense of identity. Many of the participants reported a loss of libido as an initial side effect from taking medication but reporting that dealing with the emotional impact of HIV took psychological precedence. As participants progressed through the chronic illness trajectory many described sexual inhibition:

“I haven’t really had much sexual interest since my diagnosis really... I’d like to meet that special person but it’s a pipe dream [...] Trust is a real issue - as you can imagine if I tell them I’m positive they usually ghost me & I’m left feeling terrible - as if I’ve done something”
[Samantha, 199-200]

For those which participants who experienced infection via sexual intercourse within the confines of a relationship the researcher queried the loss of sexual interest post diagnosis. If HIV is regarded as ‘dirty’ or ‘toxic’ and a danger to the self, this may be projected onto the act of sex itself as dangerous and dirty and somehow spoiled. This notion fits well with the constructionist view of identity as result of an interactive process of social labelling and self-identification.

For participants in revealing their HIV status they experienced considerable rejection and ‘ghosting’. Samantha’s rejection seems to elude to a change in how she sees herself as a sexual being informed by others’ rejection. A diagnosis may impact an individual’s identity and self-concept as they perceived themselves as ‘infectious’ as Samantha acknowledges - the ‘fantasy’ is possibly destroyed and along with feelings of guilt and shame, her sexual self.

Samantha reflected on the paradox of contracting HIV within the context of a relationship and almost touches on it by asserting “*trust is a real issue*”. The researcher probed the extent to which the context of an infection borne from a relationship played a formative effect on a participants to initiate, engage and sustain a new relationships and navigate the thorny issue of trust post diagnosis against the backdrop of stigma and shame. A diagnosis can often be traumatic and in Samantha’s case, the ego may have fragmented: a progressed

(developed) part of the ego may act as a ‘caretaker’ for a regressed ego (taken to an earlier stage of development). As a protective measure the caretaking ego may view potential relationships as representative of further trauma.

Reflective comment: I was struck here with Steve’s use of ‘pretend’ and how it may represent an active false self that may be used to protect his hidden true [positive] self. It also occurred to me that by accommodating to others’ expectations in the hope of a meaningful connection removes the authenticity of a real connection ultimately producing less authentic and satisfying relationship. While there are similarities & differences in participant’s narratives to status disclosure but each reflected on a journey of discovery albeit mediated by social and cultural constraints.

Cultural attitudes was an explicit societal limitation in navigating disclosure:

*“my parents that are difficult. They’re from a difficult culture, a different community so you would struggle, you know, being brought up in Britain holding British values it’s a different type of mindset you know? Massive cultural difference [...] even if it’s happening people simply in that community do not talk about sex - do not talk about anything to do with sex in general, are like it’s all taboo.”
[Faisal, 50-58]*

The sense that here is that Faisal feels the subject of sex or HIV could not be approached either culturally or generationally as a first generation Asian male and provides a context for why Faisal chose not to disclose his status. There is a sense of cultural ‘citizenship’ whereby Faisal is confronted by Western cultural notions regarding HIV yet also maintaining an Asian cultural identity, is subject to a second divergent layer of cultural stigma regarding HIV.

Reflective Comment: Narratives from ethnic minority participants provoked an acute awareness of the individual and how there exists a complex interaction between internal schemas in relation to HIV, personal experience and prevailing social and cultural attitudes. Drawing on the paranoid-schizoid position described earlier the researcher

pondered the extent to which splitting occurred as a defense to protect the wider community where positive participants may adopt a defensive position as locating themselves as 'bad' object post infection and the wider community as the 'good' uninfected object. This distinction locates the risk in the participants to protect from the vulnerability of shame, blame and guilt from their wider ethnic community yet accompanies further burdening and distress.

4.4.2 Category: *Exploring, challenging beliefs about self, world & others*

Confronted by the notion of mortality in receiving a HIV diagnosis adjusting value beliefs was cited as instrumental in gaining an increased autonomy, self-efficacy and self-acceptance. Participant described aspects of therapy and the therapeutic relationship as promoting psychosocial adjustment and those formed *Qualities of the therapeutic process*.

4.4.2.1 Adjusting value beliefs

The way participants constructed HIV appeared to inform their attitudes, and this in turn appeared to inform their behaviours. In Faisal's case the introduction of hope represented the potential to lead "*a fulfilling life*" and motivation to challenge his own thoughts and emotions and improved psychosocial functioning:

"therapy's provided me [...] the positive thinking positive rather than thinking negative about it. I think at first when I started therapy it was very very negative, very negative. I think even today I might get a lot of negative thoughts & train what can be the positive concept. What is the worst that can happen? Therapy has helped me to change my emotions to be able to adapt straggles to get on with life."
[Faisal, 64]

While Faisal appears better able to sit with the unpredictability of life. Uncertainty was recognised as a problematic aspect of living with HIV. Participants reflected on identifying the sources of uncertainty and challenging negative perceptions of quality of life and poor psychological adjustment. Faisal's capacity to be able to cognitively restructure his thoughts and be better able to "*change my emotions*" demonstrated an adjustment in his worldview. Ascribing meaning to the diagnosis framed within uncertainty appeared to

facilitate acceptance yet acceptance was defined differently by participants at different stages of the illness trajectory. The ability to better understand and manage HIV was initially a therapeutic goal but moved into a more generalised acceptance for other participants:

“even though the talking therapy I was influenced - was connected to HIV and managing it and, it’s nevertheless it has this integrative knock on effect on other things. You talk about self-acceptance with HIV but it’s often, sort of simmered down to just good old generalised stuff acceptance, you know?!”
[Brian, 211]

Working through the diagnosis trajectory was accompanied by a process of self-acceptance having a “*knock on effect*” signifying a shift in Brian’s value beliefs about the self, the world and others cultivating a more accepting authentic relationship with others:

“before my diagnosis I felt pressurised by society to be out there to be seen, to [...] to achieve, to meet society’s standards I’ve been adjusting I feel like I’m - it’s not really important to me at all anymore. I’ve got no interest in it. I don’t really feel compelled to put the effort in to sort of, please other people, to like put myself out there to be seen to be social. I feel calm and accepting of that. It feels comfortable, it feels right.”
[Brain, 208-209]

Brian seemed to demonstrate an increased internal locus of evaluation. This is referred to the extent we trust and value our view of self. Brian appeared to reject external societal pressures in favouring congruence and a more authentic relationship with himself in accepting his status and sexuality.

Participants often declared an increased sense of self-efficacy and autonomy yet how this was expressed and measured by participants varied. For Steve this meant finding a voice:

“I used to be very silent - I would stay in the corner I didn’t have voice. I was scared HIV consumed me. I’m not scared to speak out and tell somebody. I just went through this experience. I honestly I think it was always there it just was just my environment and setting and people I was with who were holding me back.”
[Steve, 277]

Steve positioned himself as inhibited due to ‘*environment and setting*’ rather than internal causes and this suggests the extent to which social and environmental factors has the potential to mediate an individual’s ability to live a fulfilling life with HIV.

The image Steve offers of being ‘*consumed*’ by HIV conjures up the notion of being devoured and the negative image of death against the positive image of life. There appears to be here an explicit threat of death anxiety with the feeling of the intrusion of HIV as an ‘*end of life*’ and with it a helplessness that appears to inform an individual’s core concept of a HIV diagnosis. This could also be viewed as an existential threat to the self with the vulnerability that the self will no longer be able to hold itself together and death anxiety triggers passivity and impaired mental functioning. Steve appears to have shifted from state of helplessness to a position with increased autonomy, one where he finds a voice and is an active participant in his relationships with others.

4.4.2.3 *Qualities of the therapeutic process*

This category aims to capture therapeutic factors that participants cited as helpful as they progressed through therapy *and* those that were cited as facilitating a participant’s psychosocial adjustment in living a fulfilled meaningful life following a positive diagnosis.

For many the process of therapy appeared to be augmented by the ability of the therapist to be an active listener with the capacity to establish an emotional connection:

“So I was kind of like of really living for that once a week session where I felt like someone I was speaking to someone who was hearing me.”
[Brian, 106]

For Steve his previous negative experience of a therapeutic relationship lacking a connection appeared to inform a decision to seek a therapist familiar with HIV and one that would *not* include CBT:

“Like, it was as if I’d a problem something like [insomnia] rather than realising what stage I was in the transition and the journey of HIV if that makes sense? So, the when I saw the CBT therapist that approach is not useful when you’re in the first year - 18 - 2 years - whenever of the diagnosis.”
[Steve, 289]

Steve describes a strong therapeutic relationship as meaningful in pursuing the personal goals of addressing inner conflicts. Control in selecting the therapist, the therapeutic goals and the length of therapy was deemed important:

“I genuinely feel through that going to therapy to try & address some of my inner conflicts and challenging mine has really helped. That’s been really useful. Very, very useful. I don’t know if it was because it was on my terms but... and I had a lot of involvement in it but it was definitely looking at somebody who again the therapeutic relationship was really important it was open ended, you know, I controlled how many sessions I wanted.”
[Steve, 279]

A prevalent concept within participants’ accounts was a loss of control in facing the uncertainty of a positive diagnosis against health uncertainty. Steve’s need to select the therapeutic model, negotiating the therapeutic goals while controlling the number of sessions may have provided him perhaps with a reassurance to compensate against the uncertainty of associated in confronting a HIV diagnosis. The need to exert control within the therapeutic process could be interpreted here as a defense against vulnerability and uncertainty. The capacity of the therapist to provide a safe space appeared instrumental. Feeling safe with therapy that is ‘containing’ was described as key:

“You need a relationship that this containing and holding and that will see you through that process because at that point I still didn’t have a clue who I was. I think I did carry with me as great sense of shame, fear, guilt, self-loathing because of the HIV. I knew he was very much more psychodynamic so I was getting the impression he was going to go to all that like - all that daddy issue stuff and I was just like, right! Maybe there is - but he was able to make me secure in doing it.”
[Steve, 151]

While Steve appeared well versed in therapeutic models and he highlighted the ability of the therapist to become ‘a container’ - taking into their own self the client’s unwanted thoughts or feelings. The container for Steve appeared to be a holding space for emotions but arguably also where fragments of the self were projected onto the relationship with the therapist. Faisal also reflected on this process:

“I started therapy it was very difficult to engage with him cos he was very difficult to relate to, like, I would off on a tangent, like being negative, he would be like, ‘come back to the table, sit back in the chair ‘You can’t leave here’ [...] I was pretty angry with the diagnosis ‘Why me?’ and then my wife, my family and even some friends. I know inevitably some of it got directed at him [therapist] & I did feel a bit bad about that.”
[Faisal, 243]

The strength of the therapeutic relationship appeared to be the ability to withstand the test of client anger and hostility. Faisal appears to recognise how he shifted from the therapist “being difficult to relate to” to attributing “there’s a connection there”:

“I think he’s done an okay job because for me to come back to the service [...] to continue and it would show, you know, there’s a connection there that we’re slowly working towards so it’s been challenging it’s been a very emotional journey.”
[Faisal, 232]

The capacity of the therapist to work through these negative emotions including client ‘hostility’ may suggest that HIV, as a potential representation of death and destruction and therefore toxic, must be channelled away from the self.

“When a good man is hurt, all who would be called good must suffer with him” (Euripides (484 BC - 406 BC)

5. Discussion

This chapter aims to evaluate the results in relation to the original research aims and objectives and place them within current literature and psychological theory. Clinical implications and considerations for counselling psychology in working with this client group will be explored before exploring the potential limitations of the research and recommendations for future research.

5.1 Overview of the Research Findings

This research aims to identify the what participants cited as helpful aspects of therapy in response to a HIV diagnosis. All participants engaged in therapy in relation to a HIV positive diagnosis within the previous two years and described this as contributing to their ability to better meet challenges of day to day living. This research sought pay particular attention to the complex and interrelated processes for participants after receiving a positive HIV diagnosis and following their decision to engage in therapy, what they identified as helpful aspects in promoting their ability live meaningful, adaptive and functional lives in their social and domestic roles.

5.2 Core Category: Process of growth in therapy

5.2.1 *Processing the diagnosis ‘overwhelm’*

This category reflected a participant’s HIV diagnosis can overwhelm an individual’s own capacity to deal with it. Participants unequivocally expressed negative emotions in relation to a positive HIV diagnosis ranging from disbelief, shock, fear, anxiety, depression and helplessness with an augmented sense of uncertainty and this is supported by others studies (Flowers, 2011). In contrast to studies that explored the impact of HIV generally this study found that it was important to locate what an individual was experiencing framed within

the chronic illness trajectory as the relevance of HIV to identity is understood to change across time and this is echoed in other research (Flowers et al., 2015). Within the initial phase following diagnosis participants described a lack of capacity to cope with perceptions of poor quality of life, complex treatments, ambiguous ART symptoms set against the fear of an ostracising social responses.

The availability of social support appeared to inform and impact participants' perceptions of uncertainty and this is consistent with research by Brashers et al. (1995) in recognising uncertainty as problematic aspect across the chronic disease trajectory as many of the participants struggled to achieve a personal sense of control.. Mishel (1995) defines uncertainty in HIV as an individual's inability to ascribe meaning to the illness when outcomes are unpredictable. An initial function of therapy within the overwhelm phase was making sense of a diagnosis set against the complexity and ambiguity HIV diagnosis and primarily providing a nurturing holding environment (Winnicott, 1960, as cited in Samuels et al., 2011).

In receiving a diagnosis it was not uncommon for participants to be confronted with an increased awareness of their own mortality in comments such as "*what's the point if I'm gonna die?*" and "*Am I going to die quickly?*". Participants often cited feeling disbelief and could be interpreted as a denial in being paralyzed with shock or numbness as individual's faced an existential crisis. This has support in literature (Flowers et al., 2011: Kubler-Ross, 1997) who identified individuals struggled to adjust to their HIV positive diagnosis and identified themes relating to crisis, loss and challenges and described in integrating HIV, a sense of damaged identity. From an existential standpoint Milton (1964) suggests that HIV be considered within the context of the *givens of existence* (Yalom, 1980) namely Death, Freedom, Meaninglessness and Isolation. Participants reflected on their notion of death as a HIV diagnosis confronted a sense of their own mortality forcing them to explore the freedoms that they enjoy against how this is impacted once the effects of HIV are felt. Famously, Jung commented "*Meaning makes a great many things endurable - perhaps everything*" (Jung, 1965, p340) and this appeared to be the case as participants grappled to make sense of their infection namely stemming from sexual contact, often from the confines of a relationship marked by trust and love. The immediacy of the stigma associated with HIV appeared to impact participants as the therapeutic space became a platform to disclose as participants described struggling with the rejection and isolation and a fear of being ostracised in relationships.

Participants appeared to make a conscious decision to locate meaning in their diagnosis attempting to make sense of their loss. Negative perceptions related to a reduced quality of life from loss of [good] health, loss of social support, loss of identity associated with being HIV negative and a loss of hope for the future. As one participant reflected “*who’d want to be with me, who will invest in somebody who’s got HIV?*” [Steve, 141-143] A related concept related to loss was the loss of relationships. Five of the participants described loss due to HIV infection from the confines of a loving relationship and the sense of responsibility and betrayal related to this and the eventual relationship breakdown as each wrestled with themes of trust and betrayal. Denial occurred here as concept as participants often overwhelmed a participant’s capacity to seek treatment or they negated their own needs for seeking treatment by prioritising on the needs of their partner. Denial surfaced as participants sought to answer the question “*How did this happen?*” as they questioned their reality. Importantly, the ‘reality’ of denial and how it surfaced within participant narratives varied. One participant chose to retest disputing the validity of the HIV result. Another participant described continuing with life without medical intervention focussing on the needs of his partner.

Denial appeared to be functional in that they attempted to cope and make day to day survival possible while pacing the feeling of grief. Framed within the stages of grief (Kubler-Ross, 1997) posits that denial as primary defense mechanism to help pace the feelings of grief. This places a case for negative emotions as a psyche protective mechanism asserting that as denial fades it is slowly replaced by the reality of the diagnosis. The stages of grief consisting of denial, anger, bargaining, depression and acceptance with grief seeing as a healing process and this is broadly applicable to HIV within a chronic illness trajectory. As participants experienced denial they appeared in many ways to be starting a healing process and moving towards accepting the reality of the loss. Exploring this and attributing meaning to it was an essential first step for most participants following an initial overwhelm. Anticipatory grief appeared to be pertinent as Kubler-Ross suggests, this is a preparation for the beginning of the end but in the eyes of the participants the end of a ‘normal’ healthy life in receiving a positive HIV diagnosis. Framed within the early stages of mourning, participants maintained grief in preparation for the final ‘*separation from the world*’ (Kubler-Ross, 1997, p.1) perhaps due to the stigma and social repercussions they began to position themselves as the ‘other’ in being diagnosed HIV positive and somehow set apart from mainstream society.

5.2.2 Understanding the relationship with the self & HIV

A function of therapy cited by many participants was exploring and understanding their ambiguous relationship with HIV. On the one hand participants experienced a linear, biomedical treatment that offered a prognosis of life expectancy nearing that of a non-infected individual (Van Sigham, 2010) yet the stark reality of taking ART medication, set against the uncertainty of a chronic illness trajectory (McCorkle & Pasacreta, 2001) as participants grappled with stigma, shame, guilt while questioning their sense of self.

Once participants navigated an initial ‘overwhelm’ as denial dissipated participants were confronted by the stark reality in confronting feelings of distress and anxiety grief and loss and grappling with a new reality. A dilemma appeared to surface as taking ART: it is essential for HIV progression management yet it augmented feelings of shame, guilt and loss. Frye et al. (2009) suggest HIV related loss represents a threat to social existence and identity. Research findings here go some way to support this as participants acknowledged a dichotomy between the empowerment and control taking ART offered set against the uncertainty of HIV care provision & identity adjustment. All individuals participating in this study were put on challenging ART regimes following their diagnosis (an early intervention strategy in line with North American treatment protocols) managing short/mid-term side effects, while navigating new personal and professional relationships and negotiating thorny issues around HIV disclosure.

Control emerged as a concept as a positive diagnosis and the resulting prognosis to be unsettling, confusing and full of uncertainty on the other hand therapeutic reinforcement encouraged an emerging sense of adjustment and self-acceptance. An individual’s beliefs about their controllability of what happens to them has been identified is a core element of how they navigate the world (Shapiro et al, 1996). Locus on control is a concept with roots originally in social learning theory and posits that individuals are more likely to change their behaviour following a (positive or negative) reinforcement than are people with a belief in external control. Participants generally acknowledged to a more internal locus of evaluation in their narratives and this appears consistent with research that state individuals with increased external locus of control report higher levels of psychological distress

(Petrosky & Birkimer, 1991) and increased defense mechanisms (Joffe & Naditch, 1977, as cited in Marks, 1998).

Participants related their capacity for increased autonomy from structured rather than unstructured therapy with many reflecting that weekly events often eclipsed important aspects relating to their identity and relationship with HIV. These were often set against the backdrop of distress and difficulty in managing their daily emotions and psychosocial functioning while navigating social roles of partner, employee, student or as son/daughter. The results in this study lend support that the period immediately following a positive HIV diagnosis is accompanied with a vulnerability to depression (Ciesla & Roberts, 2001) and therapeutic support during this time was perceived to be 'invaluable' in exploring relational aspects of HIV and the impact on their social functioning and identity.

Psychosocial adjustment was defined by participants as achieved by more meaningful relationships in their social roles of friend, partner, or colleague. Participants explored their attitudes and beliefs in relation to HIV and in so doing, were better able to locate HIV as a component part of their identity rather than feeling that HIV defined them. Much of this process appeared to be the capacity to make amends with the past. Many participants expressed recriminations as a result of their diagnosis attributing blame for shortcomings in contracting HIV. Unpacking this within the confines of therapy was cited as crucial to emerging sense of adjustment and self-acceptance. Self-acceptance was described as highly dependent on the perceptions of acceptance from significant relationships and from this, relational therapeutic models fared most favourably with therapeutic outcomes.

Participants acknowledged creating, adapting and sustaining a relationship with HIV having to make psychological and social adjustments. This process is temporal requiring both intrapersonal and interpersonal adjustments. The therapist, especially if they possessed experience of the issues surrounding HIV such as ethics surround disclosure in relationships, were active agents in this this adaptive process in reflecting, mirroring and providing constant affirmation and endorsement allowing participants to feel more 'normal' and regulate negative affect through reframing and therapist modelling. These findings reflect those of Flowers et al. (2011) in that although HIV is an unique subjective experience, the significance is relational as participants sought to adjust psychologically, socially and culturally in changing the notion of HIV from a 'death' sentence to a 'life' sentence (Flowers et al., 2001, p669).

5.3 Core Category: Therapy as a process of challenging exploration & psychosocial adjustment

Within the therapeutic space participants explored the damaging impact of HIV and stigma on their identity and locating HIV to a component part of their identity was deemed functional to maintain and integrated and coherent sense of self-esteem and facilitated intrapersonal, interpersonal and psychosocial adjustment.

5.3.1 *Confronting Stigma*

Evident across every participant narrative was the perception of stigma as HIV represents “*an attribute that is significantly discrediting*” (Goffman, 1968, as cited in Smith et al., 1989). Yet a HIV diagnosis was perceived to go beyond this in being able to spoil an identity in the eyes of others (Roeleder et al., 2015). As participants moved from the acute phase to the more stable phase (McCorkle & Pasacreta, 2001) in consistent with Corbin and Strauss chronic illness trajectory framework participants identified factors that facilitated or hindered their attainment of goals. As all participants described the notion of stigma as central to their self-concept and their self-esteem and therefore an obstacle for a coherent integrated self.

Participants initially explored their relationship with HIV and many participants encountered difficulties in taking ART. ART reinforced the notion of being infected and confronted individuals with notions of disease, disgust and shame with implications of immoral behaviour. Indeed this is consistent with research that HIV is a virus heavily associated as a product and punishment of the immorality surrounding gay sexual behaviour (Mahajan, 2008). Goffman (1963) acknowledged stigma as fundamentally relational and framed against this, HIV represents a complex interaction between social and cultural attitudes. Participants described feeling ‘objectified’ and ‘stigmatised’ with shame, guilt and blame pervading participant narratives with taking medication cited as particularly challenging. However, these findings did not support research that found little relationship between taking ART medication and psychological distress (Siegal & Lekas, 2002). Participants invariably adopted the subject position of the ‘other’ with having HIV and thus feared being labelled as ‘dirty’ or a ‘danger’ due to perceptions of immoral

behaviour with connotations of promiscuity and/or a hedonistic lifestyle reacted to a prevailing *stereotype threat*. Exploring these perceptions within the safety of the therapeutic space was cited as instrumental where participants engaged with pervading social constructs of HIV in relation to felt stigma (Herek et al., [2013](#)).

Confronted with society's devaluation of them participants appeared to apply coping strategies by internalising the stigma in accepting its validity and participants appeared to devalue themselves. Participants appeared to adjust their identity to accommodate HIV and experiencing enacted stigma many of the participants reported feeling a heightened sense of vulnerability and powerlessness and motivated to maintain continual vigilance primarily in relation to disclosure. Primary interventions within the therapeutic domain that were cited as helpful was the participants' capacity to process stigma using the strength of the therapeutic relationship overcoming notions of shame, guilt and blame. Exploring shame based participant experiences where the authentic (HIV positive) self was rejected, participants often resorted to projecting an external false (HIV negative) self (Winnicott, [1965](#)). In most cases participants who experienced shame required a safe enough nurturing holding environment (Winnicott, 1960, as cited in Samuels et al., [2011](#)) to explore their shame based experiences where their feelings can be contained and validated by empathetic therapists. Many participants in confronting HIV and working through feelings of shame, blame and guilt explored the repercussions of living a 'deceptive' incongruent life and questioned the validity of this in finding these produced less congruent authentic, and rewarding, relationships. The value of processing shame in therapeutic work is well documented (Kaufman, [1989](#)) and this research in relation to HIV is no exception.

Given the relational aspect of HIV problems in participant's cultural, social, professional and domestic domains many participants initially queried who would want a relationship with someone as HIV positive. This process of internalisation appeared to be consistent with research suggesting that stigmatised individuals may react to society's devaluation of them with anger, indifference, or internalisation of the stigma (Corrigan & Watson, [2002](#)). Participants reported reacting with self-stigma in manifesting negative attitudes towards the self with low self-esteem and self-worth. Research supports the relationship between self-stigma and psychological difficulties (Corrigan et al., [2006](#)). Key to an emerging sense of adjustment and acceptance appeared to be participants capacity to overcome both felt and internalised stigma. The contradiction here is that acceptance is strongly dependent on the perceptions of acceptors from other people and initiating and navigating disclosure

strategies within negotiated boundaries with the self and others surfaced frequently in participant accounts.

The capacity of the therapist to target a participants' internal worlds and their perceptions of imaginary signs and symbols while exploring internalised stigma was described as crucial in exploring notions of legitimacy and vulnerability. The process of challenging negative attitudes towards aspects of the self, as a domain specific form of low self-esteem, altered participants notions of their self-concept.

5.3.2 Exploring, challenging beliefs about the self, world & others

A positive HIV diagnosis is associated with poor self-esteem and feelings of shame and guilt (Manhas, 2014) and HIV-related stigma has been demonstrated to contribute to psychological distress over and above health status and HIV-related symptoms (Stutterheim et al., 2009). Internalised stigma can be linked to global self-esteem (Herek et al., 2013) and associated with socially avoidant behaviours thus reducing the risk of enacted stigma yet increasing isolation and reducing social support. Targeting social integration yet navigating this on their own terms while mindful of navigating risk in relation to the self, the world and others was an identified therapeutic goal in almost every participant narrative.

For participants therapy was described as instrumental in presenting as authentic in significant relationships. A hurdle every participant to overcome was the thorny issue of disclosure. Most participants described painful experiences of rejection when disclosing their status with some electing not even to disclose to immediate family and loved ones. Much of their experiences related to rejection from the wider (gay) community (participants who identified as gay) particularly within the confines of sexual relationships. Some participants described feeling obliged to disclose due to perceptions of ethical and moral compass and feeling this tension, felt distressed and culpable of deception. Often the therapeutic space, with a skilled and knowledgeable therapist to help make informed decisions on disclosure framed within boundaries of trust, shame and privacy was cited as empowering. A shift was evident as participants described being initially cautious in disclosing their HIV status feeling empowered to disclose more freely or on their own terms. Some participants viewed this as a defensive strategy as negative reactions could be encountered before emotional investment occurred thus protecting themselves reducing the emotional impact of rejection. Identifying strategies for stigma management was therapeutically a key area of development yet one that was cited as the most challenging. Participants identified the trust in the therapeutic relationship as an agent for change in giving them courage to disclose to friends and/or family. This area was strongly associated with the psychodynamic/psychoanalytical models not least an embodied experience HIV impacts individual reality and personal significance is often relational. The role of the ego, understanding defense mechanisms along with a participants' potential for projective

identification and splitting all facilitated participants to understand and adapt to their social and domestic roles. This is discussed more fully in [Psychodynamic Perspectives](#).

Stigma management encompassed Goffman's (1963) theory regarding impression management including pervasive self-monitoring and the concealment of one's sexual identity including difficulty with intimacy and this supports other research in this area (Skinta et al., 2014). Research suggests that this is not uncommon and individuals may mistrust the intentions of others and intimate relationships and avoid exposing themselves and this may evoke further shame and feelings of inadequacy (Lansky, 2005).

To some extent this may explain why participants described a reduced sexual self as they grappled with a positive diagnosis. Relatively little research has been done on sexual health and wellbeing of individuals living with HIV and sexual self-esteem (SSE) has been found to include aspects of past and current experiences and guide a person's sexual behaviours (Anderson, 1996, as cited in Rohleder et al., 2015). For the participants who identified as gay disclosing their status particularly within the confines of a sexual relationship, although rarely explicitly acknowledged, appeared to trigger feelings of shame, inferiority and vulnerability. These may have related to previous experiences of coming out as gay and interconnected with internalised homophobia and the interconnection between HIV and gay sexuality has been highlighted in previous research (Jaspal & Lopes, 2020).

SSE has been found to be key for sexual assertiveness with the ability to communicate sexual needs and initiate sex (Ménard & Offman, 2009). Yet participants reflected on a destruction of the sexual self locating the 'hazard' of HIV within themselves and a potential threat to their partner. This was particularly evident in the narratives of the women and indeed an explanatory perspective is offered by research by Gurevich et al. (2007) who found that women may feel a need to discipline their sexual desires and in so doing experienced less sexual spontaneity. The therapeutic space was described an area where the role of the therapist was fostering a participant's sexual identity enabling them to locate HIV as a component part of their sexual identity. Locating hope for the future was an integral part of the therapeutic process as some described their HIV diagnosis as traumatic either as an experience or relationally as they lost partners, friends and even jobs due to their diagnosis and/or ill-health. Processing this loss and finding meaning and hope living a fulfilled life with HIV in their respective roles were key aspects every participant showcased as instrumental in their reintegration into mainstream society.

5.4 Psychodynamic perspectives

Advances in ART have evolved a HIV diagnosis has changed from being ‘*a death sentence to a life sentence*’ (Flowers et al, 2011, p1387) and still has the capacity to stigmatise and spoil an identity (Goffman, 1963). Themes such as stigma, fear of discrimination and identity are all central to the experience of a diagnosis. An individual’s capacity for acceptance in a HIV diagnosis can be considered as relational as a diagnosis is a complex interaction between social attitudes, interpersonal experience, and internal schema of the self (Roeleder et al., 2015).

The origins of psychodynamic theory can be attributed to Freud’s psychoanalytic theory with it’s emphasis on unconscious conflict and meaning. While the model has evolved into diverse approaches all models place emphasis of the intrapersonal, developmental and relational process. As a relational model, psychoanalysis as a discipline and method can provides a unparalleled framework of working with individuals to provide a more informed understanding of practices and experiences of social exclusion as both internal and external conflicts are more toxic and less available for integration than while they remain unconscious.

5.4.1 Freudian Concepts

Classical Freudian therapy focuses on the nature and consequences of conflicts resulting from primarily sexual and aggressive wishes originating in childhood. Conflict between impulse and defence is therefore seen as the focus of therapy. Contemporary Freudians have moved away from reducing everything to drives - internally generated biological forces that seek discharge - to being increasingly concerned with a variety of motives for the use of defences and for the construction and development of fantasies and transference (Sandler, 1983).

A HIV diagnosis can potentially be a traumatic event as an individual is confronted with negative imagery of death, destruction and disease. Yet for Freud (1920, as cited in Sugerma, 2016) it was not possible to conceive of one’s own death other than a derivative of the castration complex. Freud argued for a psychic representation or primitive image which emerge as a series of interactions between attachment & separation; movement &

stasis; integrity and disintegration. Symbolically death can be framed as representing ultimate separation, stasis and disintegration.

Denial, as seen in some participant responses following a diagnosis, can be interpreted psychoanalytically as a defense against the notion of death. In the absence of a denial Lifton (1982) argued an individual experiencing a life-threatening trauma is subject to an intrusion of the ‘*death imprint*’, an image-feeling of threat or end of life. The sense of invulnerability (or denial that death is real) is irrevocably shattered. Taken within this context a HIV diagnosis may be perceived as a psychic trauma coming together of a real threat to the self, accompanied with residual anxiety represented by threats stemming from separation, stasis and disintegration. Separation as the person may feel disconnected from relationships and mainstream society, disintegration as the experience may have impaired a person’s ability to adequately repress the knowledge of death that permits healthy functioning which ends all movement and vitality resulting in helplessness – ultimate stasis. Many of the participants interviewed within this study expressed remorse, guilt and self-condemnation. A plausible psychodynamic interpretation is the concept of failed enactment as participants failed to prevent the infection, while experiencing an overwhelming sense of vulnerability.

5.4.2 Self-Psychology Perspectives

Self psychology addresses the suffering some individuals experience as a result of difficulties in regulating self-esteem. Kohut (Baker & Baker, 1987) argued that a certain amount of self-esteem is essential for normal personality functioning and made important contributions to understanding the self. Kohut (1971) suggested that the self has traces of the grandiose omnipotent self and the ‘idealized parental imago’ - the intrinsic need to view another as omnipotent, the need to feel close to and supported by a powerful, beautiful, all knowing Other.

As a child, the caring self is experienced as a merged Internal (self) and External (mother object) and seeks to individuate from the mother. This is achieved through a process of mirroring which Winnicott (1965) suggested is the opportunity for the child to see him/herself reflected in and responded to in the mother’s face. Both Kohut (1971) and Winnicott (1965) argued for the power of mirroring as a first experience that can impact a felt sense of being attached, loved and is instrumental in the development of the self. As

the self seeks to individuate from the mother via mirroring, the self experiences affirmation where primitive narcissistic fantasies of being omnipotent and the centre of the world are affirmed and experienced as positive narcissism - that of the grandiose self. Yet often mothers fall short of ideal parenting the self may experience parental limitations and the child experience negative narcissism, feelings of shame, inferiority, worthlessness and guilt.

Kohut (1971) suggested that individuals maintain their self-esteem through the use of other people within relationships. These are referred to as 'self-objects' - other people who are not seen as separate but those with agency and intentionality that are internalised and keep the self from falling apart. These self-objects are internalised in such a way that they are endowed with fantasy with psychic and emotional energy, both libidinal (energy created by survival and sexual instincts) and aggressive related to both innate and genetic individual characteristics.

As the self matures pride in the self in his/her increasing physical and mental powers are often humbled by the reality of limitations in the real world. The experience of a HIV diagnosis can be traumatic relationally as the individual is confronted with the loss of perceived good health, aspirations of the future, and relationships. This impacts an individual's self-esteem and narcissistic structures can be severely injured triggering what Kohut coined narcissistic rage, shame and helplessness. All participant narratives within this study expressed some of these in relation to their hostility initially towards HIV. Attachment is regarded as a key foundation for a sense trust, invulnerability and self-esteem and deficiencies in this nurturing process may lead to a dominance of negative imagery characterised by separation, disintegration and stasis against positive imagery of attachment, integrity and movement (Bowlby, 1969). Individuals can be seen to have a 'psychological balance sheet' of both negative and positive biographical assets and these have important implications for an individual's sense of self and associated resilience. Working with individuals with a HIV diagnosis set against themes of narcissistic injury may experience vulnerability, mistrust and appear helpless with a damaged sense of autonomy. Shame and guilt may be set against an individual's own perceived shortcomings it is important to be aware that individuals living with HIV may resent the perceived power of the therapist and potentially regard them as threatening.

5.4.3 Object relations theory

Object relations theory is a psychodynamic school of thought that focuses on relationships as being key to personality development than individual drives originating from various theorists including Klein (1923), Fairbairn (1952) and Donald Winnicott (1960). Object relations perspective argues that personality structure is formed in infancy out of the internalised interactions between the child and significant others and emphasises the origins of the self lie in self-other interchanges where one comes to sense their existence as both a separate and interdependent being. Klein placed emphasis on the role of a person's subjective experience and a central tenet of this theory is the function of phantasy.

Introjection is based on a concept on unconscious phantasy or incorporation – taking something into oneself while projection is based on the notion of expulsion or expelling something away from oneself. The notions of projection and introjection act on a primitive level taking in and spitting out various feeling or states of mind that would otherwise cause internal conflict. The internal world is also considered to be populated by internal objects – a version of a person that is filtered through projective or introjective processes that distort the 'real' person. Klein (1923) suggested internal objects progressed developmentally from concrete or physically present to represented as symbolically either in words or forms (Hinshelwood, 1989).

From an object relations perspective a new-born is regarded as ill-equipped to deal with the complexity of human emotional experience. An adaptive function within the early years a baby manages emotional experiences in black & white terms –a subjective experience of frustration may be attributed to an active attack from a persecuting external agent regarded as a 'bad' object while feelings of being taken care of with pleasure or satiation is regarded as stemming from a 'good' object. This function can be applied to an immature ego as it seeks to defend itself by projection destructive impulses out into the world, which becomes bad and persecuting. The very process of splitting and projection contributes to an internal state of fear and suspicion triggering paranoid anxieties referred to as the paranoid-schizoid position. The paranoid-schizoid position places human aggression and destructive-ness at the core of our psyche.

Joffe (1999, as cited in Roeleder, 2007) suggests a psychoanalytic framework for understanding HIV and how locating the risk in others serves as a defense against vulnerability. Klein (1952, as cited in Lemma, 2003) suggests via the paranoid-schizoid position how good experiences are taken into the self while bad experiences are projected

outward particularly in times of stress. HIV as with other transmissible diseases, is accompanied by fear of infection representing metaphors for death, destruction and punishment with the perception of HIV as a threat must be channelled away from the self. Society manages the fear and disgust associated with HIV in creating a distinction between those at risk of HIV and those who are not, creating an 'us' & 'them' dichotomy. In an attempt to protect the self, splitting occurs where negative representations of HIV may be projected onto 'bad' others with HIV in an attempt to 'unburden' the self and preserve themselves as the 'good' uninfected object. In receiving a positive diagnosis locations of the 'self' and 'other' are reversed positioning the individual in having to renegotiate a new identity. This supports research in this study as participants sought to integrate HIV into their identity, locating it as a component part rather than being defined by HIV as the 'bad' object.

Some participants recounted how their interest in sex, or a severely reduced libido was observed following a positive diagnosis. This is consistent with research that Cartwright and Cassidy (2002) who posit that following the psychic trauma stemming from a positive diagnosis activate primitive defense mechanisms as parts of a person's sexuality are split off as sex is associated with being a source of contamination and has a projective function. This theme was evident in participant narratives particularly where infection was situated within a relationship. Social notions of HIV may have become incorporated into the self and the other.

Participants acknowledged the role of denial as defensive mechanism in their capacity to deal with the impact of a positive diagnosis. delaying their start in seeking medication, or those receiving a positive diagnosis within the confines of a relationship prioritising their partner's needs over their own. Locating HIV as the risk in their partner, the 'other' these participants defended against their own vulnerability as they attempted to adjust and make sense of the implications of the disease. The impact of a positive diagnosis was often accompanied by a period of helplessness and indeed this was a feature of many of these participant narratives. Taken within the context of these participants narratives, individuals may have experienced feelings of guilt and self-condemnation following a positive diagnosis with a perception of failure in taking care of themselves. HIV may accompany a metaphor of death and punishment with a perceived aggressive invasion into the body, can be experienced as overwhelming and provoke unconscious castration fears, along with

shattering the notion of being omnipotent and invulnerably and destroying an individual's sense of autonomy.

Psychodynamic and psychoanalytical perspectives can offer an alternate lens through which to understand by providing meaning to experiences through interpretation. HIV can be seen as a complex interaction of the social, cultural attitudes that interact with constructs of the self and intrapersonal experience. This positions the psychodynamic model as well placed to make a valuable contribution in providing individuals with hope in therapy, a more integrated social identity, and coherent self-esteem in striving for a fulling and meaningful life with HIV.

5.5 Narrative therapy & HIV

Given the unique challenges to living with HIV set against societal and internalised stigma narrative therapy may offer a helpful approach in transforming a client's dominant problem-saturated narrative of HIV into a meaningful story of one's disorder and life that promotes recovery. The impact of stigma was a salient narrative within participant accounts. Garte-Wolf (2011) found evidence that using narrative therapy (for substance misuse) clients with HIV enabled clients to share their stories in a space free of stigmatisation. Research further suggests that mainstream societal messages regarding HIV increase the likelihood of client's engaging in self-blame and shame and this exacerbates psychosocial distress (Swendeman et al., 2006) and internalising society's negative views can make an individual more vulnerable to rejection (Lee et al., 2002). Narrative therapy enables the client to deconstruct socially constructed messages regarding stigma and shame (McLean & Marini, 2008) in seeking ways that permit the client to reauthor socially constructed stories to be inclusive of strength and empowerment.

Traditional therapeutic approaches have historically attributed mental health issues to diagnosis pathology and as such interventions have also targeted modifying certain behaviours. Narrative therapy offers the advantage of working collaboratively with the a client in externalising the problem i.e separating the problem from the client's history. This is particularly helpful in working with individuals where there may be a strong cultural connotation to a HIV diagnosis and/or status. This not only locates problems outside the confines of the 'person' and on individual pathology but a useful strategy for where an individual's complex life experiences may not fit neatly into defined diagnostic criteria. Individuals may be able to see their diagnosis as something they are living with opposed to something that defines them. Eliciting culturally constructed messages to assist in the externalisation process such as "*How do you think HIV controls your life?*" to facilitate how the notion that HIV does not define them but is a part of them. This was a reflection from one participant that appeared to mark a departure in recognising the impact of stigmatising message may have on notions of personal inadequacy. Lambie & Milsom (2010) suggest that once a problem has been externalised an individual may feel more trusting to share as they increase their acceptance, question the validity of attributing HIV to personal limitations.

Identifying socially constructed messages and understanding their impact on emotions such as shame and self-esteem is crucial particularly as this may impact disclosure. This is consistent with research that suggests individuals living with HIV elect not to disclose their HIV status until symptoms are present or concealing their disease becomes too challenging (Serovich et al., 2005). Many of the participants in this study expressed a clear rationale for refraining their HIV disclosure to direct family for fear of shame, rejection, stigma to fearing the negative impact of their status on a third party. Identification of these socially constructed messages and how these may have been internalised and inform emotions, self-esteem and self-worth appeared to be a feature within participant narratives and an area that narrative therapy targets.

Individuals who are living with HIV, particularly following a recent diagnosis, may present as more prone to focussing on the negative aspects of the diagnosis, the perceived weaknesses and rather than any positive aspects such as early intervention and the capacity to actively manage disease progression. Narrative therapy takes a strengths based approach focussing on identifying area where an individual may struggle, highlighting exceptions to challenges. The assumption that the client is the expert on their own lives (Dybicz, 2011) to install hope and build positive expectations which support change shifting from a problem saturated narrative to one of empowerment.

The process of externalising the problem, exploring ways that their narrative has been socially constructed and identifying an individual's own strengths positions a person to reauthor their own unique story. Narrative therapy may have good application for drawing on cognitive constructs by installing the belief that change occurs when individuals are able to change their schemas through differentiation and integration. Differentiation relates to creating alternate narratives through the reauthoring process while integration occurs when clients integrate these into their new lives (Angus & McLeod, 2004).

Clients who identify a loss of control within their lives as a result of a HIV diagnosis, those who identify psychosocial or cultural stressors such as layered stigma as primary challenges to adapt to a quality of life in their social or domestic roles may find narrative therapy a strengths based approach that allows life to be viewed in a less problem saturated, empowered way.

5.6 Implications for Counselling Psychology

This study aims to identify the diverse aspects of therapy that individuals found helpful in promoting psychosocial adjustment following a positive HIV diagnosis. This research would appear to mirror previous research in so far that what participant's appeared to experienced can be framed within the chronic illness trajectory particularly as (McCorkle & Pasacreta, 2001) as the relevance of HIV to identity is understood to change across time (Flowers et al., 2015). This finding appears to add weight to the importance of pluralism both with research but also practice in recognizing that HIV positive clients may present with different needs and helped by different therapeutic interventions at different times (Cooper & McLeod, 2007).

This research echoes previous research on how individuals experience a positive diagnosis and how HIV is integrated into a spoiled self (Goffman, 1963) following a period of overwhelm and loss, with a resulting sense of a damaged identify (Flowers et al., 2011) and negative self-esteem (Herek et al., 2013) as participants sought to overcome notions of stigma. Individuals sought to renegotiate their identity with HIV confronting existential concerns as they grappled with this process of adaption in overcoming both enacted and internalised stigma. The therapeutic domain became a platform for most individuals to challenge, explore and confront relational notions of the self, others and the world.

HIV as a chronic illness

Individuals within this study recounted in receiving a diagnosis of HIV there is still no cure for (beyond the two cases reported from stem cell therapy (Warren, 2019) and reflected on being confronted on notions of death following with associated loss of hope and meaning that invariably accompanies a positive diagnosis. The use of bereavement counselling due to the chronic nature of a diagnosis has been advocated by some and does bear broad relevance to the stages proposed by Kuber-Ross (1969) of denial, anger, bargaining, depression and acceptance. The use of this model appeared to be particularly useful within the initial diagnosis when individuals grapple with denial and overwhelm and they attempt to assimilate HIV into their identity. Yet the stage model proposed by Kuber-Ross has levied some criticism as being rigid (Bowlby,1986) and as HIV has moved from being considered a terminal to a chronic illness it is important to frame a diagnosis beyond death

as individuals seek to adjust psychologically, socially and culturally moving from HIV as a 'death' sentence to a 'life' sentence (Flowers et al., 2001, p669).

HIV can invariably be accompanied by depression and anxiety and these can suddenly impact an individual's own sense of mortality and autonomy with a perceived loss of power and control. A sense of a mind-body relationship was described by participants as they reflected on being invaded and attacked by HIV with intrusive changes often augmented by medication side effects with the anticipation of sexual and social rejection (Van Dyk, 2008; Eller et al. 2013). Creating autonomy and an internal locus of evaluation appeared particularly effective framed within a person-centred approach as this facilitated a person to feel understood. This study appeared to demonstrate that moving to an internal locus of control using the strength of the therapeutic relationship as an agent for change was associated with greater mental health benefits, and interventions that increased capacity for increased internal locus of control accompanied by Rogerian core conditions can be helpful especially when working with a culturally diverse population. Counselling psychologists working pluralistically are well placed to make a valuable contribution to this client group yet it is important to locus of evaluation is just one aspect of an individual's belief system and one that this is socially and culturally acculturated.

Participant narratives overwhelmingly described the intense, psychological distress associated with a HIV diagnosis and the related social adjustments but as Flowers (2011) suggests, the distress stemming from the diagnosis and the accompanying process of adjustment are not singular but unfolding in a temporal, relational and societal contexts. An individual's diagnosis can be framed both within the chronic illness trajectory as well as being *socially* and *relationally* constructed. Central to an individual's experience of adjustment to HIV is an individual's understanding of stigma, discrimination, identity related distress and interpersonal relationships. The importance of overcoming socially mediated shame, the exclusion of being positioned as the 'other' that is feared and ostracised. A relational model such as psychodynamic or psychoanalytic therapy was cited as having much to offer individuals living HIV (Rohleder, 2015; Joffe, 1999). The notion of the therapeutic relationship as a container for emotional learning in facilitating the development of new insight (Strupp, 1969, as cited in McLeod, 2008), becoming a place where the painful and destructive feelings of the individual can be expressed and acted out because they are held safe and secure. By establishing a working alliance, working through defended and/or split off aspects of self, working through shame based experiences and

giving meaning to experiences through interpretation fosters an individual to (re)locate meaning in their life. In processing the 'psychic trauma' making sense of this socially and establishing ways of coping many of which are relationally situated. As Flowers et al. (2011) argue stigma is a function of value and meaning attributed to social positions and identities. Renegotiating this within the confines of therapy, establishing boundaries and self-care, adopting a to new social identity, promoting self-esteem and repairing a self damaged by being positioned within society as the other are all key aspects of the therapeutic process that foster individual growth. In considering therapeutic interventions counselling psychologists would do well to pay close attention to relational aspects between clients and their diagnosis and facilitate those clients living with chronic and diseases to establish more relational ways of communicating (Kleinman, 1988).

This study has demonstrated that while individuals diagnosed with HIV may be situated within chronic illness trajectory there was a sense of divergent illness trajectories that were broadly based and an implicit limitation of this study was the relatively young age of the participant sample. Framing a diagnosis both within the illness trajectory and an individual's identity with a client's stage of life may foster a greater shared understanding of how HIV is experienced psychologically and emotionally. Not only does this position counselling psychologists to change how HIV is perceived in mainstream discourse but alerts professionals to the how HIV is primarily socially, culturally and relationally mediated and these are unique challenges of an client as they progress through life. It is hoped this type of research helps counselling psychologist practitioners not only meet the diverse needs of this specialist client group but also positions them to better fill the psychological needs left by advances in ART medication. It is hoped that research of this nature highlights the complex presentation that a client with HIV may present and the importance of training and support working within this client group. Reflective examination of our own biases, preconceptions is fundamental to avoid the risk of repeating dysfunctional relationship patterns and risk perpetuating further harm to a client.

Rescher (1993, as cited in Cooper & McLeod, 2007) all understanding is dependent on experience as human beings will have a range of experiences. Therefore the 'normal' human condition is dissensus rather than consensus. From the perspective of this researcher in understanding the construction of HIV it was critical to view the individual pluralistically a commitment to 'inclusiveness towards otherness' (Cooper & McLeod, 2007, p136) in embracing other worldviews. Ironically this position is pitched against

mainstream discourse where HIV is invariably located in the 'other' (Joffe, 1999) and in adopting a pluralistic stance counselling psychology works towards inclusion in respecting otherness and inclusiveness. This research does not aim to identify a consensus or single pathway through which change occurs but rather a process through which an client will progress through which will position clinical practice to better support HIV positive client identify goals, tasks and methods in pursuit of a meaningful, fulfilling relationships for the future.

5.7 Evaluation and suggestions for future research

Care was taken to conduct this research in compliance with the code of human research ethics (BPS, 2021) and good practice guidelines (BPS, 2017). However, no research however would be complete without acknowledging and addressing a study's limitations and areas for potential future research. Charmaz suggests credibility, originality, resonance usefulness as helpful criteria in evaluating a grounded theory study (Charmaz, 2014).

This study comprised exploring the individual psychosocial adjustment in relation to therapy following a positive HIV diagnosis from a heterogenous group of participants. This permitted a valuable insight into what participants identified helpful aspects of therapy that facilitated their own psychosocial adjustment. Participants recounted aspects of therapy that they considered beneficial in their own capacity to adapt and live more fulfilling life and this was done independently from the model of therapy and/or intervention received. The origins of this research rose from the pluralistic assumption that different clients may present with different needs at different times and therefore emphasis within this practice-based research has been placed on the centrality of the therapist-client collaborative relationship. From a pluralistic perspective there is no single pathway or single process through which change occurs and moving away from the efficacy of a particular chosen model or intervention is arguably a strength of this study.

The heterogenous participant sample recruited for this study aimed to draw a sample from a cross-section of individuals diagnosed with HIV within the preceding 2 years. Participants' lived experience of their initial diagnosis and related psychotherapy along with any intrapersonal and interpersonal adjustments were recent, and individual recollections were emotive. Yet this can also be regarded as a study limitation. If

individuals are placed within a trajectory of chronic illness in relation to tasks and goals (Corbin & Strauss, 2020) and an individual's psychosocial adjustment in relation to HIV is linked to this trajectory, then it is plausible that an individual's capacity to meaningfully live a fulfilling life in their social and domestic roles will continue to adapt and evolve beyond the 2 year window following their initial diagnosis. Future research would do well to explore the efficacy and impact of therapy as a longer term process on an individual's capacity to live a meaningful life with HIV in their social and domestic roles particularly if HIV is regarded as moving from "*death sentence to a life sentence*" (Flowers et al, 2011, p1387). This research focussed on participants who were diagnosed within a two year window. There may also be divergent illness trajectories according to the length of time since diagnosis especially given that older participants report more significant challenges in living with HIV. Future research would do well to explore this.

Recruitment limitations compounded by constraints placed on HIV service provision during COVID thwarted this researcher's attempt to solicit a wider demographic sample group. HIV services quickly moved to online and/or telephone based support. Service provision was already stretched due to COVID restrictions and there were concerns in providing access to a researcher during this period & logistical issues in cascading the research details to those participants who met the inclusion criteria. Service users are considered a vulnerable client group and this is especially so for those recently diagnosed. Ethical concerns about providing a researcher access to a potentially vulnerable client group made recruitment challenging. Given the stigma attached to HIV, soliciting research interest was also challenging as participants – especially those who were recently diagnosed and female participants in particular, expressed concerns regarding research anonymity and confidentiality.

Perhaps a further limitation of this research was the inclusion of one participant who was aged over 34 years. The research findings must therefore be framed within this constraint particularly given that recent data cites a reduction in individuals between the ages of 15-24 years of age testing positive for HIV (Collins, 2020) with a gender imbalance favouring males. That said, this study aimed to recruit participants from a wide cultural and ethnic groups and arguably, given the limited sample size, this study achieved a level of diversity. Yet it is important to remember that qualitative studies do not aim for robust comparative analysis and future research may wish to explore the interplay of psychosocial factors with differently defined socio-ethnic participant samples.

Exploring the participant profiles and while they did reflect difference and diversity in the research sample all brought their own stories of loss, transitions, stigma with diverse psychosocial stressors and as such may have found a HIV diagnosis particularly challenging. Yet individuals bring their own agenda to research (Raheim et al., 2016) and while all the participants identified with a difficult journey those who expressed interest yet due to confidentiality, covid or logistical concerns did not participate may have had diverse experiences from those included in this study.

5.8 Conclusion

The medical model of HIV disease management promotes the view that HIV is normalised and moved from a terminal to chronic disease definition. Yet research indicates that from a psychosocial perspective for those individuals in this study diagnosed within two years, there is little evidence of normalisation and identity related distress remains critical to participant's experiences of a HIV diagnosis and this impacted their capacity to process and make identity related adjustments. While HIV may have moved from a '*death sentence*' notions of mortality still exist compounded with navigating complex medication regimes with diverse side effects.

Stigma plays a critical role in shaping an individual's reactions to a diagnosis. Participant narratives provided an insight into how a positive HIV diagnosis is fraught with diverse notions of stigma and alters an individual's sense of self and through assimilating HIV an emergent sense of adjustment and self-acceptance is fostered. Much of the psychological work participants related was in addressing both enacted and self-stigma in challenging the legitimacy and societal messages and with it, their sense of vulnerability. Sutterheim et al. (2009) highlights the role of interactions with family members and health care professionals and key areas for intervention. This research would go further in highlighting the need to provide a greater emphasis on a person's role(s) in relation to their psychosocial domains.

This study used constructivist grounded theory to explore the helpful aspects of therapy that promoted psychosocial adjustment in individuals living with HIV. Two core categories emerged: *process of growth in therapy* and *therapy as a process of challenging exploration & psychosocial adjustment*.

Both the core categories selected were considered consistent with the constructivist perspective that we do not discover reality as something out there or hidden in ourselves but rather we invent it (Watzlawick, 1984). Confronted by with a HIV diagnosis, participants appeared active in the *process of growth in therapy* & development was seen as facilitated within the context of psychotherapy as they constructed their own versions of reality through individual experience. While each participant may have defined growth differently each appeared to process an initial ‘overwhelm’ phase and they all sought to understand their individual relationship with HIV. How that relationship was defined varied as did how each progressed through the *process of therapy as a challenging exploration & psychosocial adjustment*. Within each core category there was scope for each participant to construct their *own* version of what *process of growth in therapy* signified and how *therapy [was] a process of challenging exploration & psychosocial adjustment*. Emphasis was placed on participants own constructions of psychosocial adjustment and how it was measured varied by individual.

Living with HIV can be an embodied experience and is can be regarded as relational and temporal processes framed within social and cultural contexts. It is hoped that this qualitative research adds to the body of existing psychological literature and facilitate counselling psychologists when working with this diverse socio-demographic population.

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Appendices

Appendix A: Ethics Approval Confirmation

 **Angela Loulopoulou**
Ethics cleared
To: Sean Snow, Cc: Catherine Athanasiadou-Lewis

2 March 2018 at 10:44
[Details](#)

Dear Sean,

The Head of Research has approved your Ethics Proposal form. You can proceed with recruitment and data collection.

Kind Regards,

Angela

—

Dr Angela Ioanna Loulopoulou, PhD; AFBPs; FHEA

Principal Lecturer in Counselling Psychology
Programme Director of the Professional Doctorate in Counselling Psychology
School of Social Sciences
Chair of Subject Standards Board for PG Psychology
Chair of Review Ethics Committee for PG Psychology

Office hours 9.30-17.00 Tuesday to Thursday

Please email me if you would like an appointment.

Contact address:

London Metropolitan University
Room TB-20
Tower Building
166-220 Holloway Road
London N7 8DB
Tel: 0207 133 2667

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Appendix B Recruitment Research Poster

January 2019



LONDON
METROPOLITAN
UNIVERSITY

Department of Psychology

- Are you an adult (18 years +) ?
- Have you been diagnosed HIV positive in the last 2 years?
- Have you received therapy in the last 2 years?



PARTICIPANTS REQUIRED FOR RESEARCH

Volunteers are sought (age 18+) for research on a study that explores 'How do clients living with HIV experience psychological adjustment in the context of psychotherapy?'

You would be asked to participate in a 1:1 interview and talk about how therapy has contributed to your ability to cope with the challenges of daily life in living with HIV in social and/ domestic roles.

Your participation would involve one session no longer than 1 hour.

In order to preserve your confidentiality all names and identifying features will be anonymised.

For more information about this study, or to take part, please contact:

Researcher : Sean Snow

Tel : 07592 849 XXX

E-mail: SES0424@my.londonmet.ac.uk



Supervisor

Dr Catherine Athanasiadou-Lewis

E-mail:

c.athanasiadoulewis@londonmet.ac.uk

Appendix C Demographic Information Sheet

Gender: Are you

- Male
- Female
- Non-binary

Age: What is your age?

- 12-24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65 + years

What is your ethnic background?

- White British
- White European
- White Other
- Asian / Asian British
- Black African/Caribbean
- Other Ethnic (i.e. Arab)

What is the highest degree or level of education you have completed?

- Nursery school to 8th grade
- Partial secondary school, no GCSE
- Secondary school GCSE
- Some university credit, no degree
- Trade/technical/vocational training
- Bachelor's degree
- Master's degree
- Other

What is your marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated

Are you currently:

- Employed
- Self-employed
- Unemployed
- Homemaker
- Student
- Retired

When were you diagnosed with HIV?

- the previous 6 months
- the previous year
- Within 2 years

Have you received therapy in response to a HIV diagnosis with

- the previous 6 months
- the previous year
- Within 2 years

To the best of your knowledge, which of the following what best describes the therapy you received?

- Person-centred
- Cognitive-behavioural therapy
- Acceptance and Commitment therapy
- Dialectical Behaviour Therapy
- Psychoanalytical/Psychodynamic therapy
- Schema therapy
- Integrative therapy (more than one model)
- Unknown

What type of service did you receive your therapy?

- NHS - Community Mental Health Team (CMHT)
- NHS - IAPT Service
- Specialised HIV Counselling Service
- University / Higher education setting
- Other

Appendix D Information Sheet

To whom it may concern

I am a counselling psychologist in training at London Metropolitan University and currently conducting supervised doctoral research into how people living with HIV experience psychosocial adjustment in the context of psychotherapy.

What is the background of the research?

The medical advances of treating HIV have progressed at a fast pace. Research suggests an individual entering HIV health care today may have a life expectancy nearing that of a HIV-negative individual. Yet advances in medical science have arguably not been matched by the psychological needs of this particular group given the complexity of living with HIV and the associated problems such as depression, hopelessness, anxiety, low self-esteem and perceived lack of social support.

In conducting this research I am hoping to gain a better understanding of other individuals' experiences of a HIV-positive diagnosis, the challenges this presents and an HIV-positive person's needs from therapy. I hope this not only gives a voice to individuals affected by HIV but I also hope that it establishes what therapeutic processes or therapeutic aspects that are considered most helpful in promoting a quality of life in dealing with the psychological and social challenges of living with HIV.

Is participation voluntary?

This study is looking for individuals who would be interested in helping in this study's endeavour in sharing your own experiences. By participating in an interview lasting approximately 60-90 minutes selected anonymised data from your interview will be used for a published supervised doctoral research project.

Participation is discretionary and without obligation: you are free to withdraw at any time from 4 weeks from the interview date. This interview will *not* affect any ongoing healthcare or the provision of anti-retroviral therapy.

What is involved?

The interview will be approx 1 hour long on your experiences of therapy that contributed to the ability to live a fulfilled life day to day life following a positive diagnosis.

What will happen with the information collected?

While the interview will be digitally audio recorded and transcribed, it will be strictly confidential and securely, digitally stored. All recorded interviews will be destroyed on completion of the research.

What do I need to be aware of taking part?

This information brief aims to inform you about the nature of the research but also serves to help to prepare you. The area of HIV is a sensitive and like any diagnosis, HIV can be a distressing experience. Discussing this material may evoke some upsetting and difficult emotions. It is therefore important that any participation is subject to the fact you are aged at least 18 years and have been diagnosed HIV-positive within the 2 years with psychotherapy having been received in relation to this HIV-positive diagnosis within this time.

What if there is a problem?

Time will be set aside at the end of the interview to discuss any issues that may have arisen for you and should you require any further information or support services, this will also be provided.

Should you feel that a concern develops during the research process or you wish to register a formal complaint please contact my research supervisor, Dr Catherine Athanasiadou-Lewis at c.athanasiadoulewis@londonmet.ac.uk.

If you are interested in discussing this research further or registering your interest, please feel free to contact me ses0424@my.londonmet.ac.uk or on 07592 849 XXX.

Thank you for your time

Kind regards

Sean Snow
Researcher

Appendix E Informed Consent

Please ensure you read this carefully

Title: Therapy & HIV positive clients: a grounded theory analysis exploring aspects that promote psychosocial adjustment

Interview Format: In this research you will be presented with a number of questions regarding your own experience of therapy in relation to a HIV positive diagnosis. This interview will be digitally audit recorded.

- I confirm that that I have read the accompanying information sheet detailing this research and had the opportunity to ask any questions.
- I understand the nature of the research and interview procedure.
- I understand I am free to withdraw from this study without prejudice and with no obligation to provide any further information. This will not affect your right and/or access to other services. Should I wish to withdraw this must be done within 4 weeks of the actual interview date via email or telephone using the contact details provided.
- I understand that participation in this study is anonymous and voluntary.
- While the interview will be digitally recorded, a pseudonym will be used throughout the final interview transcript and all information that may promote any identification (i.e. address, friend's names) will be changed to ensure confidentiality.
- I understand that this research forms part of a supervised Doctoral research project and the results of this will be accessible to others when completed and that excerpts from my interview (less any identifying information) may be used within the research.
- I understand that I may find this interview upsetting and that it may evoke a number of difficult and distressing feelings for me. I will be offered support and the opportunity to discuss these feelings at length post interview with the researcher. The researcher will also give information on further support should this be required.
- I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be provided in the debriefing form.

- I understand that although the data will be anonymised and securely digitally stored, all data will be securely destroyed once the study has been completed.

Participant signature: _____

Researcher signature: _____

Print name: _____

Print name: _____

Date: _____

Date: _____

Appendix F Interview Schedule

These questions form the basis of a semi-structured interview. Questions are organised into groups that related to the research aims. Not all questions may be asked but selected according to how the interview develops taking account of the participant's own concerns and the session content.

Impact of medication on lived experience of living with HIV

- How do you experience and evaluate the effects of medication? How did it impact you?
 - ➔ If so, how has this contributed to any challenges?

Identifying a client's psychosocial adjustment in relation to HIV

- What was your experience of being diagnosed positive?
- How do you feel this impacted you?
 - ➔ How does this differ from how you experience your HIV diagnosis now?
 - ➔ How do you feel you have adapted? What was the process of adaptation?
 - ➔ How has this impacted your sense of self?
 - ➔ What aspects of the self changed if any?
- How do you feel this has impacted your ability to meet the demands of everyday life?
 - ➔ How do you feel therapy contributed to living more meaningfully with HIV?

Therapeutic factors that enabled change

- How did you feel you have experienced psychological therapy?
- What concerns did you have initially?
- How would you describe any changes or transitions that have occurred during therapy?
- How would you describe the contribution of the therapy to your understanding and ability to deal with living with HIV?
- Is there anything that you have rather have benefitted from instead?

The process of change

- What personal significance do you give to your diagnosis now?
 - ➔ How has therapy contributed to this understanding?
- Has there been any personal significance?
- Is there anything else that you would like to add?

Later interview questions added due to theoretical sampling:

How do you view HIV now in relation to how when you were diagnosed?

- What challenges did you experience in relation to HIV and how were these dealt with in therapy?
 - ➔ How did you experience stigma in relation to HIV?
 - ➔ How did therapy contribute to overcoming any challenges/notions of stigma attached to HIV to living a more fulfilled day to day life?
 - ➔ How would you describe the process of exploring this within therapy?
 - ➔ What factors do you feel helped with overcoming this?
- How did you feel this impacted your ability to initiate and sustain relationships?

Relationship with HIV

- In what has your relationship changed as a result of therapy?
 - ➔ What contributed to this change?
 - ➔ How would you describe therapy in relation to this change?

Appendix G Debrief Sheet

Title: Therapy & HIV positive clients: a grounded theory analysis exploring aspects that promote psychosocial adjustment

Thank you for taking part in this study. This research forms part of a doctoral research on the therapeutic features are deemed helpful in promoting psychosocial adjustment in people living with HIV infection.: The interview you have provided will be transcribed, analysed and parts used to form a doctoral research study.

You are welcome to contact the researcher concerning this. While researcher has clinical experience of dealing with distress and the impact of HIV there may be more appropriate services to meet your specific needs. The researcher along with a research supervisor will identify these for you.

Confidentiality: The information you have provided will be used for this study only. The recording will be transcribed and analysed and will be used for doctoral thesis write up and possible publication. Any information provided is confidential, and no information that could lead to the identification of any persons will be disclosed in any reports or to any other party or organisation.

Contact: Please feel free to get in contact with me should you have any questions or concerns about the study. If you wish to withdraw from the research, please contact me within one month of your interview. If you said you were happy to be contacted again after this interview you may be contacted again for clarification or be invited for a second interview. I can be contacted on: 07592 849 XXX or SES0424@my.londonmet.ac.uk. Emails will be checked regularly.

Complaints: If you have any complaints regarding any aspect of the interview process during this study, please contact my research supervisor Dr Catherine Athanasiadou-Lewis on 0207 133 XXXX or c.athanasiadoulewis@londonmet.ac.uk.

Occasionally in talking about a stressful event such as a diagnosis a person can relive some of the emotions and feel as if they 're-live' the experience. This can be helpful as it facilitates emotional processing. However, we can often find this we are overwhelmed with the impact of past events and struggle to emotionally process them adequately. If this occurs, please do not hesitate to contact someone for some support:

Connect Services
Terrence Higgins Trust Counselling Services
314-320 Grays Inn Road
London WC1X 8DP
Phone: +44 (0)20 7812 1777
THT Direct: 0845 122 100
Email: counselling@tht.org.uk

London Friend
86 Caledonian Road
London
N1 9DN
+44 (0)20 7833 1674
Email: office@londonfriend.org.uk

NAZ Sexual Health for Everyone
30 Blacks Rd
London
W6 9DT
Phone: +44 (0) 020 8741 1879
Email: manolee@naz.org.uk

Positively UK
345 City Road
London EC1V 1LR
Phone: +44 (0) 020 7713 0444
Email: sstrachan@positivelyuk.org

Citizens Advice Camden HIV Advice Service
(welfare benefits, debt management, housing, community care, employment, immigration)
88-91 Troutbeck
Albany Street
London
NW1 4EJ
Email: help@camdencabservice.org.uk
Phone: 44 (0)20 7380 8270

Royal Free Hospital Psychology Unit in HIV Medicine
Royal Free Hospital
Pond Street
London
NW3 2QG
Web: www.royalfree.org.uk
Phone: +44 (0)20 7941 1800

56 Dean Street
Soho
London
W1D 6AQ
Email: 56deanstreet@chelwest.nhs.uk
Phone: +44 (0)20 3315 6699

Please contact your GP should you find yourself considering harm to yourself or others. In the event that this occurs outside of office hours please contact NHS 111 where a referral will be made to your local mental health team. In the event of an emergency, please contact your local primary care service walk-in centre or emergency department.

Should you elect to withdraw your details from this study it should be done within 4 weeks of the interview date as it may not be always possible at a later stage. If you are interested

in the results of the study, or if you have any questions about this study, including if you wish to withdraw, please contact me at SES0424@my.londonmet.ac.uk.

If you have any further queries, please do not hesitate to contact me.

Appendix H LMU Distress Protocol

Protocol to follow if participants become distressed during participation in the study:

Occasionally in talking about a stressful event such as a HIV diagnosis an individual may relive some of the emotions and discussing distressing events evokes the possibility that they be (re)traumatised. This protocol (Cocking, 2008) presents a framework should some participants become distressed and/or agitated during their involvement in the research study. If distress presents during an individual's participation in this study, the researcher, Sean Snow is a counselling psychologist in training at London Metropolitan University and has experience in managing potentially distressing situations. Participants will be reminded that they may elect to stop the interview at any time and may choose not to answer certain questions should they find them distressing. A three-step protocol detailed below outlines signs of distress that the researcher will monitor both during and after the interview. Appropriate action is detailed at each stage. It is not expected that extreme distress will occur or that these actions will become necessary but that working with people following a chronic diagnosis such as HIV should be considered vulnerable.v

Mild distress

Signs to look out for:

- Tearfulness
- Voice becomes choked with emotion/ difficulty speaking
- Participant becomes distracted/ restless

Action to take:

- Ask participant if they are happy to continue
- Offer them time to pause and compose themselves
- Remind them they can stop at any time they wish if they become too distressed

Severe distress

Signs to look out for:

- Uncontrolled crying/ wailing, inability to talk coherently
- Panic attack- e.g. hyperventilation, shaking, fear of impending heart attack
- Intrusive thoughts of the traumatic event- e.g. flashbacks

Action to take:

- The researcher will intervene to terminate the interview.
- The debrief will begin immediately
- Relaxation techniques will be suggested to regulate breathing and reduce agitation

- The researcher will recognize participants' distress, and reassure that their experiences are normal reactions
- If any unresolved issues arise during the interview, accept and validate their distress, but suggest that they discuss with mental health professionals and remind participants that this is not designed as a therapeutic interaction
- Details of counselling/therapeutic services available will be offered to participants in the debrief.

Extreme distress:

Signs to look out for:

- Severe agitation and possible verbal or physical aggression
- In very extreme cases possible psychotic breakdown where the participant relives the traumatic incident and begins to lose touch with reality

Action to take:

- Maintain safety of participant and researcher
- If the researcher has concerns for the participant's or others' safety, he will inform them that he has a duty to inform any existing contacts they have with mental health services, such as a Community Psychiatric Nurse (CPN) or their GP.

If the researcher believes that either the participant or someone else is in urgent need of care, then he will suggest that they present themselves to the local A&E Department and/or contact 111.

Appendix I Iterative process of grounded theory steps

The following provided a structure of how the researcher moved through the process of analysis starting from the raw data through to the phases of coding and creation of categories. The analytic focus on actions and processes with the questions being asked 'What was the participant trying to achieve here?' and this objective informed how theory was constructed.

Interviews transcribed from encrypted audio files into Apple Pages. Line-by-line coding was applied to each line of the interview transcript. Relationships between initial codes were explored with the most significant initial codes becoming emergent focused codes.

Further exploration of the relationships between focused codes led to these emergent focused codes to hold sub category status.

Sub-categories that were found to be interrelated was used in a clustering exercise to produce an interrelated map of the research to inform categories.

The categories and core categories that were identified are organised in a table. This led to the generation of a cohesive grounded theory with direct quotations taken from participant accounts.

The pages that follow show an example, edited to demonstrate the steps above.

Appendix J Participant interview extract – a worked example of initial & focussed coding

	A	B	C	D
247	Line	Transcript	Initial Coding	Focused Coding
248	188	P: You really just think- just now I feel like to be well in the moment is to make sure that I've had enough care is to metabolise the ARVs and make sure I have them at the same time every day, make sure I get my appointment.	Explaining 'well in the moment'	Prioritising self-care
249	189	P: Erm and make sure I don't too get too depressed and make sure, yeah, you know what I mean? It's like a more... a softer way of living so yeah, I guess so, that's a good way of [inaudible] [chuckle]	Prioritising self-care	
250	190	I: Well, it sounds to me there's two components and then there's physical health which the antiretroviral therapy to take care of and there's also the mental health actually the two are currently linked to some degree but my own option is that the antiretrovirals - the antiretroviral therapy you know, takes care of your physical health but actually - I think there's psychological aspect of being diagnosed has fallen behind		
251	191	P: Yeah		
252	192	I: And the supportive ,and you can't exemplify it, you had great care physically		
253	193	P: I think my case was very unique so I feel like - I'm pretty sure millions who've not have not that that experience of going straight into a HIV specialist	Acknowledging unique HIV treatment	Acknowledging unique experience
254	194	I: Humm		
255	195	P: 12 weeks psychotherapy		
256	196	I: Humm		
257	197	P: the support cause as well as somewhere to come at any time with a key worker and a, erm, newly diagnosed course. So yeah, I think that's - and I wouldn't have known that Positive East existed if the hospital hadn't told me, I just - you know?	Explaining unique treatment experience	
258	198	I: So you mentioned about the changes in yourself becoming a bit more comfortable in who you are?		
259	199	P: Yeah, that's a simple way of putting it! [chuckles]		Increased self-acceptance
260	200	I: In a simple version of you living in the moment is what you say?		
261	201	P: Yeah!		

	A	B	C	D
262	202	I: Erm, rather than you striving for perfection		
263	203	P: Hummm		
264	204	I: And having unrealistic expectations about your health and life		
265	205	P: And meeting other's people's needs and expectations, you know, I mean	Rejecting expectations of others	Rejecting expectations
266	206	I: How do you think that relates to other people around you? So has there been a shift in yourself and how has that impacted the relationships you've had?		
267	207	P: Erm, that's a good question I must say, like before my diagnosis I was a lot more social and a lot more - I pressurised myself - or I felt pressurised by society to be out there to be seen, to have - to be, erm, to achieve, to - erm, you know, meet society's standards.	Explaining pre diagnosis need to meet social pressures	Adjusting value constructs
268	208	P: I think we all have that and I included to cultivate friendships and cultivate popularity and I feel like since my diagnosis since being getting well and I'm not bedridden and I've been adjusting I feel like I'm, it's not really important to me at all anymore.	Experiencing shift in social self since diagnosis	
269	209	P: I've got no interest in it. The consequence is that I spend too much time on myself I don't really feel compelled to put the effort in to sort of, please other people, to erm, to like put myself out there to be seen to be social. You know, make efforts to like impress and meet people and like entertain them and be friendly with them.	Explaining rationale for prioritising self	
270	210	P: Erm, I feel like, erm, you have - definitely not against social - being social, I just feel like it's completely lost it's importance to me.	Explaining shift in social self	
271	211	P: I feel quite satisfied for now to spend time on my own or spend time here or spend time with a couple of close friends who I sometimes see when they have time because you know people work and they have families and they have social lives so it's	Prioritising self & close friends	Adjusting value constructs
272	212	P: - you can be ships in the night you can see each other very rarely even if you're close friends and I'm sort of like, okay with that. I don't have any - I feel calm and accepting of that. It feels comfortable, it feels right	Accepting of new social network	

	A	B	C	D
273	213	I: It sounds like you're more accepting of yourself and more accepting of the relations you have with other people?		
274	214	P: Yeah, I would like better relationships with people who is more - people with more integrity, people who are closer, and you can really relax. and say anything and they'll come and see you and not like competition over who's more valuable, who got more time - whose time is more valuable. Who got- you know who can fit -do you what I mean? It's this weird, it's kind of that kind of thing. It's more sincere , erm, yeah.	Explaining preference for sincere relationships	Adjusting value constructs
275	215	P: So, and probably I wouldn't be - feel so, I think it's not a stretch to gage that in, the freedom in my mental health is, you know, is consequence of- is has had - is a result of the,	Connecting to HIV	
276	216	P: erm, the uh, talking therapy that I've been having here, you know, even though the talking therapy I was influenced - was connected to HIV and managing it and, erm, it's nevertheless it has this integrative knock on effect on other things. You talk about self-acceptance with HIV but it's often, sort of simmered down to just good old generalised stuff acceptance, you know ?![Chuckles]	Processing of acceptance	Gaining acceptance
277	217	I: Yeah! I guess - a contact diagnosis -		
278	218	P: So I think it's the same thing but you wouldn't have - maybe it's - you know what mean, it came together as a package		
279	219	I: Uh, huh		
280	220	P: which was very - er, if you're talking about improved mental health in general, in life then that's - I feel like I've had that from having that I'm busy working on that, having that experience and can you know, I mean benefiting from it.	Benefitting from improved mental health	Gaining from acceptance
281	221	I: It sounds like it's worked out quite well for you. Is there anything that you would have rather have liked to have had inst- it doesn't sounds like it. Is there anything that you would have had instead or additionally?		
282	222	P: Yeah, that's also a very good question. And it comes back to when we first started chatting and you were telling me about the CBT and I was thinking most people don't know - they don't have point of comparison - they don't have the experience to say like 'Oh, I don't know if this is right for me because there's other things that are probably better'. Erm	Ability to make informed therapeutic decisions	Making informed therapeutic choices

	A	B	C	D
283	223	I: I suppose what I mean there in therapy is there anything that was not addressed that maybe could have been addressed. Or stuff that could have been looked at, erm...		
284	224	P: Yeah, probably. I mean it's - you only have to - that the hour goes very quickly! Very quickly and sometimes you just, you have, erm, like eight RVs related things on your mind that you've made a mental note to talk about but the sessions roll over and it doesn't -	Therapy moving quickly	
285	225	P: there's no time - it's gets by the wayside, you start linking to, you know, sort of, snowball or go with the topic that comes up something that happened in the week or a relationship or whatever.	Issues getting sidelined by current life events	
286	226	P: Achievement and it takes up all the time so erm, yeah, the only thing I can think of is this sort of, erm, if I was gonna like have it perfectly I would have it bit more, being more led, structured, let's deal with your mental health with regards to your HIV diagnosis and your, and your living with that	Preferring structured therapy	Preferring structured therapy
287	227	P: because as much as I appreciate it, I ended up being very integrative and covered a lot of bases and I must have needed that or I feel like I've benefited from it. I feel like that we kind of like, forgot or got side tracked, and I didn't know we were - it's retrospective - it's an retrospective observation since you ask.	Benefitting from integrative approach	
288	228	I: Sure. So you saying that here and now, things that happened during the week kind of came into the room and eclipsed		
289	229	P: Yeah!		Current events eclipsing key themes
290	230	I: on the stuff		
291	231	P: Yeah, the emotional issues the past issues his childhood issues, things have happened during the week, erm, tasks you know, accomplishments that were were trying to be supportive and achieving.	Explaining range of issues	
292	232	P: That just took up - I mean I guess, you know, my case is quite specific cos at the same time I was like struggling with recovering from that other illness and struggling with like being homeless and struggling with like just, you know, with my partner dumping me for being positive.	Struggling with rejection & positive diagnosis	Acknowledging unique experience

Appendix K - Extract of coding table (line-by-line codes, focused codes, categories and core categories)

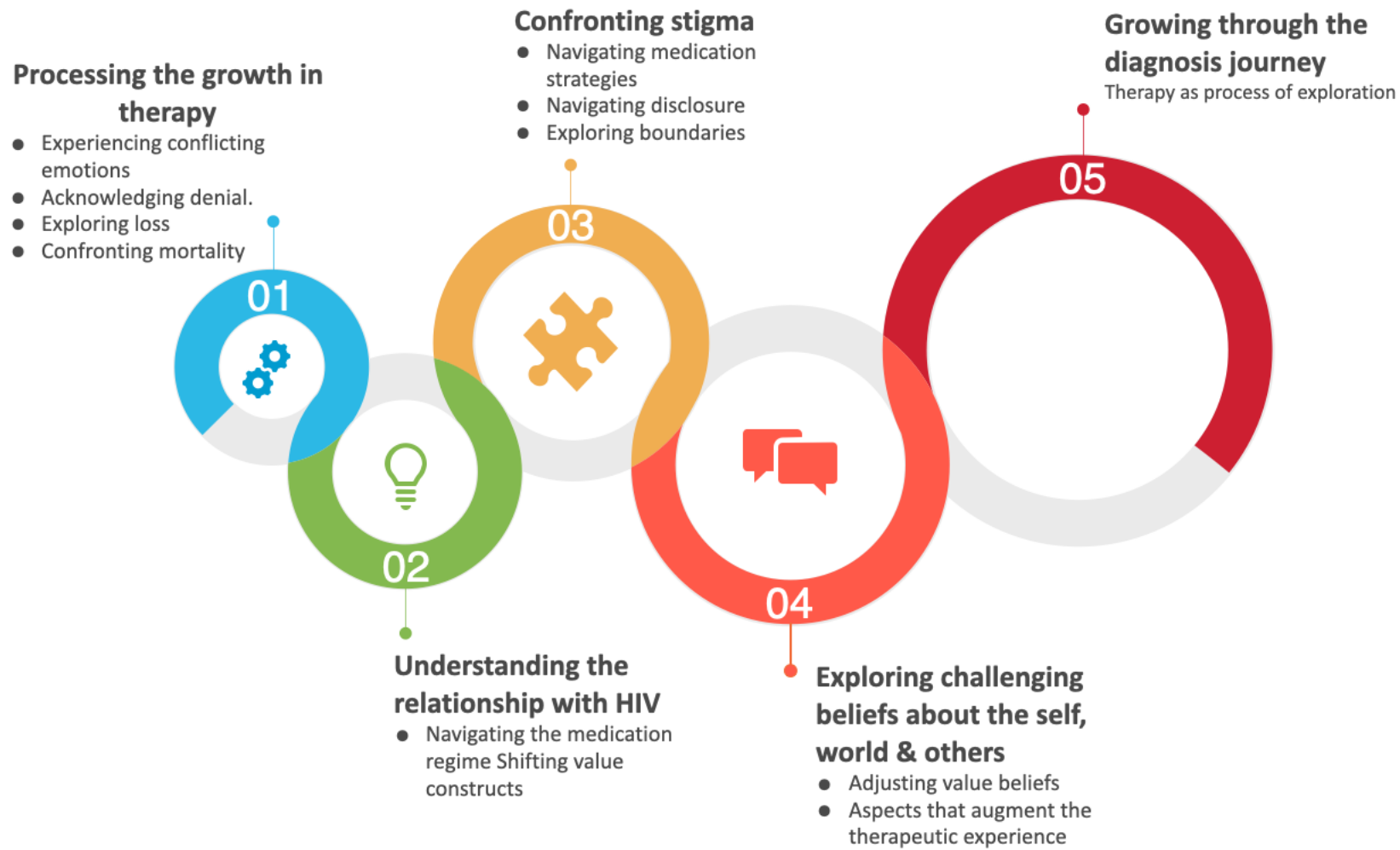
Core Category	Category	Sub-category	Focused code	Line by line code	Quote
	Processing the diagnosis overwhelm	1. Experiencing conflicting emotions	Acknowledging uncertainty & overwhelm Feeling overwhelm Experiencing overwhelming emotions	Overwhelmed with burden of care Experiencing fluctuating emotions Loosing emotional control	[Brian] I was feeling very overwhelmed, and the life I wasn't going to cope being this sick. I'm in the real world. I didn't understand how I was going to take care of myself. I thought I was going to be street homeless, sick, no energy, poorly, constantly with flu [Brain] Yeah, definitely. I was up and down. I was really, erm, [6 sec] I was just not coping. I was depressed, very hysterical, very reactive [Steve] I went to the Uni and just couldn't keep up with the demands and I just started crying in front of like, some admin person - told the whole world almost my situation - just like blurted it out
		2. Acknowledging denial	Acknowledging role of denial	Sacrificing self needs for relationship	[Steve] it was just a really difficult time, erm, yeah, and when I've accessed therapy before we've looked at that concept of sacrificing myself or forgetting about myself and focussing on Steve [pseudonym] in some respects but erm, its not all bad in Steve it was partly me in denial, it was easier to focus on him than to deal with myself
		3. Exploring loss & proportioning blame	Experiencing loss Processing the diagnosis	Witnessing partner's deterioration Facing recriminating self	[Brian] a very dysfunctional relationship and he took it very, very badly and refused to get treatment and started taking lots of drugs and partying and getting more ill, and erm, we broke up - or he broke with me [Faisal] I think it's actually a shock just to receive a diagnosis of that - of that complex nature. It's always questionable like erm, to your self, like - what did I do? How did it happen? In the back of mind I keep saying to myself did I do this or was the cause of this? If that's the cause that's my punishment.

Core Category	Category	Sub-category	Focused code	Line by line code	Quote
		4. Confronting mortality	Trying to gain a voice Confronting own mortality Confronting own mortality Confronting own mortality	Requesting medication Confronting notion of death Being confronted by notion of death Being confronted by notion of death	[Brian] I was constantly probing them through my morphine as 'well I'm going to get RV!?' [laughs] you know? and I genuinely felt just that I was - I quite stereotypically just my life was over I felt was going to die [Steve] Because again I was like - I was still so young and I had so many dreams and aspirations and I just, I just I think my understanding for me was that it was as death sentence I had no idea what to expect and I just was, you know... [Steve] I think again, like I said, it's [inaudible] stereotypical but I just to just death sentence and die erm, it was quite difficult. Erm and I remember just sitting talking - the nurse was trying to like contain me and respond to me and asking me,
	Understanding the relationship with the self & HIV	5. Navigating the medication regime	Managing the pain Managing medication side effects	Receiving pain relief Experiencing medication side effects	[Brian] like given intravenous morphine on a drip for the whole time I was there - so it's all a blur.. [Faisal] In the medications there's been a lot of side effects of taking the medication. Sometimes, headaches, palpitations and you know when, erm, when the medication impacts places for weeks
		6. Shifting value constructs	Shifting perspectives Adjusting value constructs Adjusting value beliefs	Post diagnosis psychological shift Explaining preference for sincere relationships Gaining positivity	[Brian] it's the shift has been to be a bit more appreciative and chilled and relaxed and and erm, in the moment I think that's probably what I'm trying to say. [Brian] Yeah, I would like better relationships with people who is more - people with more integrity, people who are closer, and you can really relax. and say anything and they'll come and see you and not like competition over who's more valuable, who got more time - whose time is more valuable. [Faisal] that what's therapy's provided me. It's given me the positive thinking positive rather than thinking negative about it. I think at first when I started therapy it was very very negative, very negative.

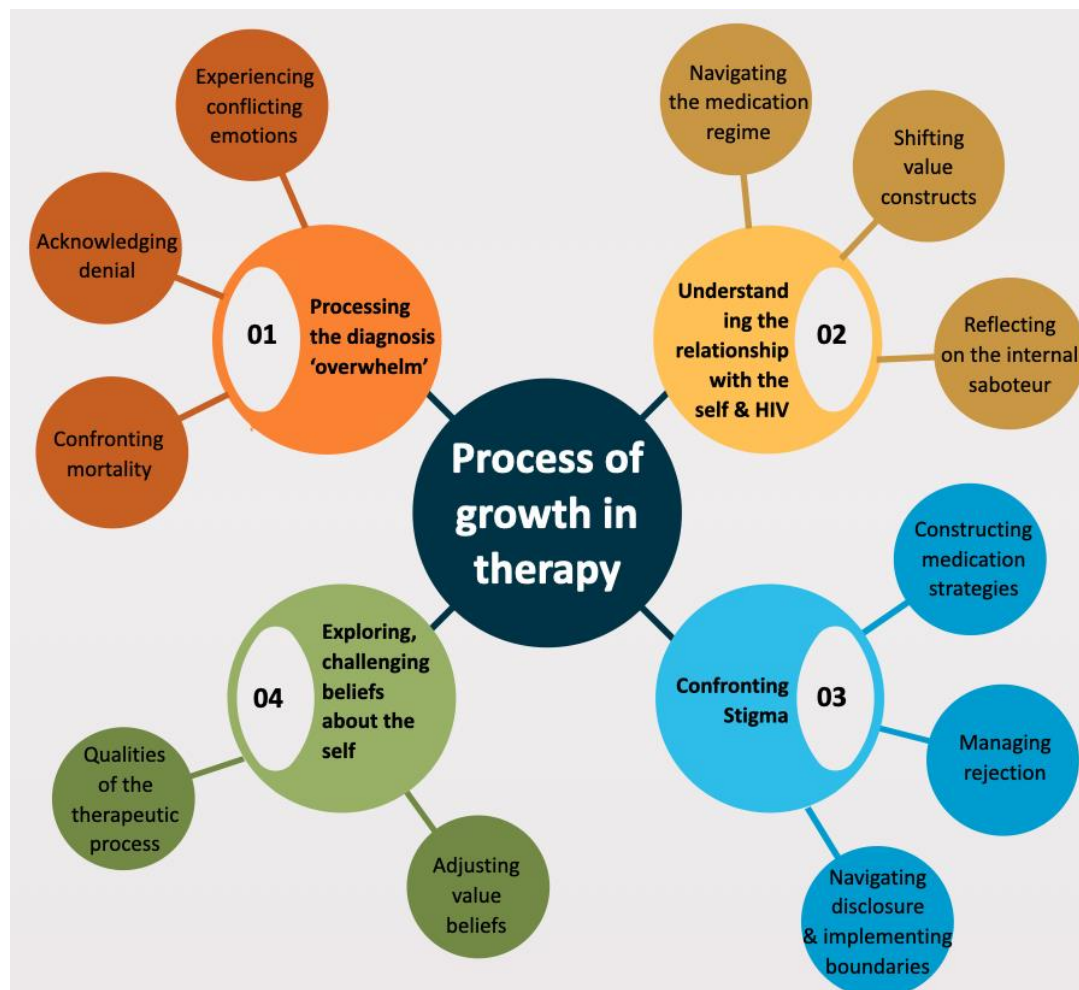
Core Category	Category	Sub-category	Focused code	Line by line code	Quote
Process of growth in therapy		7. Reflecting on the internal saboteur	Employing rejection as a defence Explaining destructive behaviours in relation to HIV Recognising sabotage in rejecting	Explaining role of avoidance Rejecting before being rejected Exploring attachment style in relation to HIV Explaining function of rejecting	[Steve] I mean, that's almost like a blessing in disguise as well cos I could separate myself from the situation And I thought that was like health in some respects switching off and avoiding but actually, it , you know, it really wasn't effective in any respect [Steve] I was felt I would be rejected. Humm, I was almost rejecting them before they would get to me because of stuff like that ,erm, and it was though processes and experiences like that that lead me to like initially seek therapy myself [Steve] he was definitely more interested in my experiences contributing to my self destructive behaviours yeah like my identity [Steve] Yes, we did discuss protecting the self. Interestingly not fully protecting the self, but rather than because I went through a process where I was sabotaging situations because I was scared of rejection related to HIV as well.
	Confronting stigma	8. Constructing medication strategies	Accepting stigma related to HIV Confronting notions of stigma Managing stigma & shame Experiencing stigma & shame	Shame taking meds under scrutiny Experiencing shame Struggling with stigma & shame Experiencing shame	[Brian] We don't, I know. I, for example, if I do need to like, open up my bottle of Truvada or [inaudible] cos it's morning time, you know, erm, and I'm on the tube, I won't. I'll wait until I'm, you know, on the street. [Brian] It was really really difficult because you really struggle with the feeling of shame. Like you are - have done something wrong [Brian] you know, like the things we talked about when we first started talking about that I struggled with, you know, feeling like there's a stigma that I still struggle I still managing the secrecy and the flush of shame if anyone does ask you about it [Steve] I think I did carry with me as great sense of shame, fear, guilt, self-loathing because of the HIV

Core Category	Category	Sub-category	Focused code	Line by line code	Quote
		9. Managing rejection	Dealing with rejection Exploring boundaries to manage rejection	Receiving rejection Disclosing status upfront	[Steve] Erm, I dealt with that in therapy. Yes because I got a lot of rejection erm, and some of the rejection was quite negative. [Steve] Erm, and then I tried another approach that's basically telling guys straight from day one -before I met them and that actually worked a lot better
		10. Navigating disclosure & Implementing boundaries	Accepting choice in disclosure Expressing choice in disclosure Feeling empowered through non-disclosure Acknowledging non-disclosure burden	Accepting disclosure autonomy Explaining rationale Feeling less judged & more accepted Acknowledging difficulty in disclosure	[Brain] I just didn't think - I think when you - yeah! It suddenly was informed and I processed and accepted that I had a choice. [Brain] So erm, yeah, he was like if you're adhering to medication blah de-blah, de-blah, if you're undetectable, you've no moral/ethical/legal obligation to ever... it's up to you. It's your choice. [Brain] absolutely for now I still feel empowered by my choice to have non-disclosure. I feel more equal, more, erm, you now - more less judged, more accepted. So I practice that at that stage, I do non-disclosure [Steve] all I can say is that I felt like a child - an adult child, you know, dealing with this massive diagnosis and not being able to tell anybody, and not knowing how to tell anybody especially where I lived
Therapy as a process of challenging exploration	Exploring, challenging beliefs about the self, world & others	11. Adjusting value beliefs	Exploring & understanding diagnosis Process of self-acceptance	Process of accepting & understanding Feeling more a peace with authentic self	[Brain] I think I'm still in the process of exploring and, erm, accepting and understanding and erm, wanting to be well psychologically about it and wanting to do well physically with it. [Brain] you know, a high standards and erm, since the diagnosis and with the supportive therapy I feel much more at peace with just being exactly how I am and as healthy as I am today and you know what I mean
		12. Qualities of therapeutic process	Qualities of therapeutic relationship	Experiencing therapeutic support	I think the mediations made me stable but therapy has made me just get on with it but I do have to say it's very er, to receive a diagnosis of that - of HIV - is very, erm, personal-centred and he's very individual to one individual

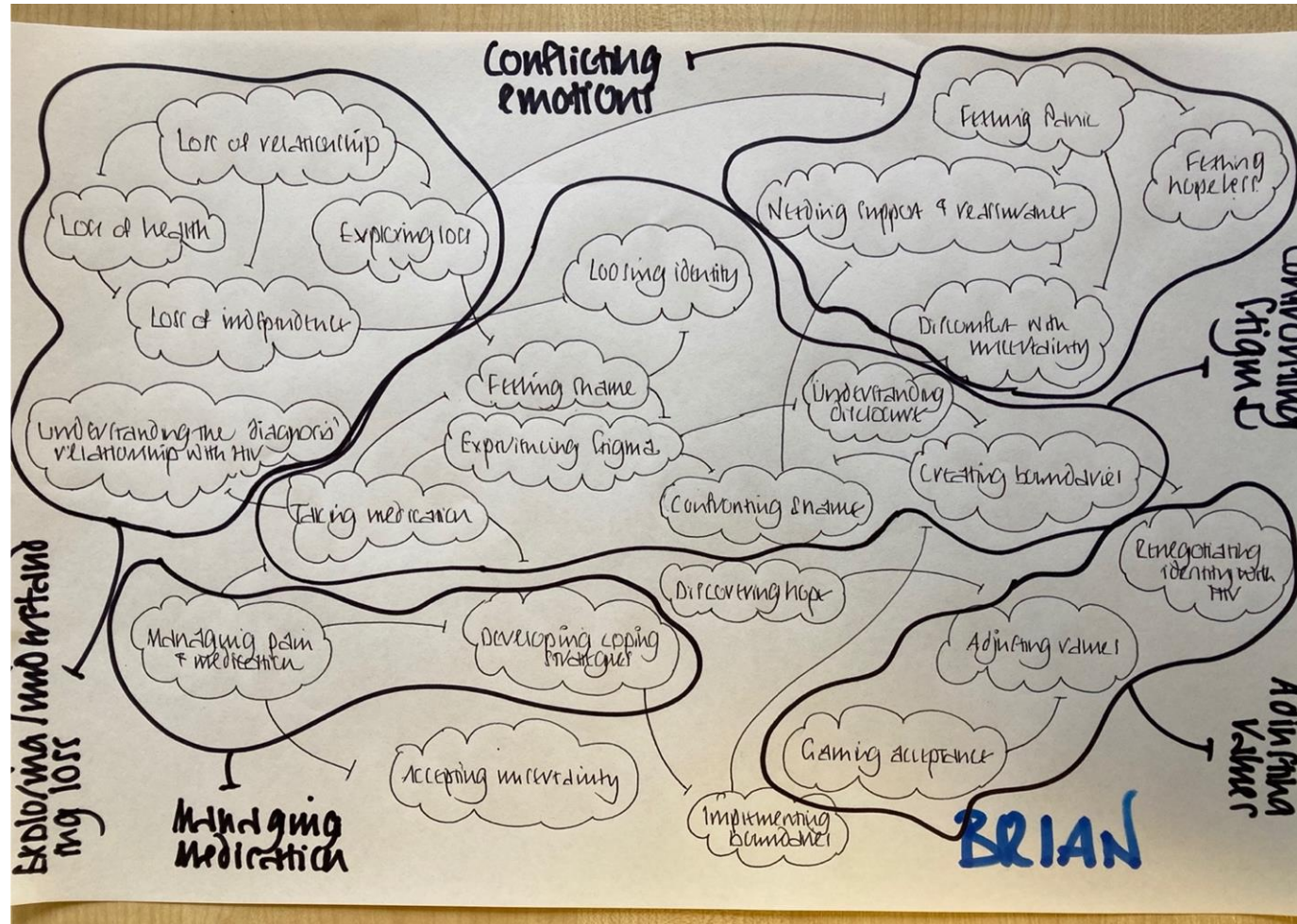
Appendix L - Initial schematic demonstrating the interlinked categories & how they interconnected with the single core category (10/10/20)

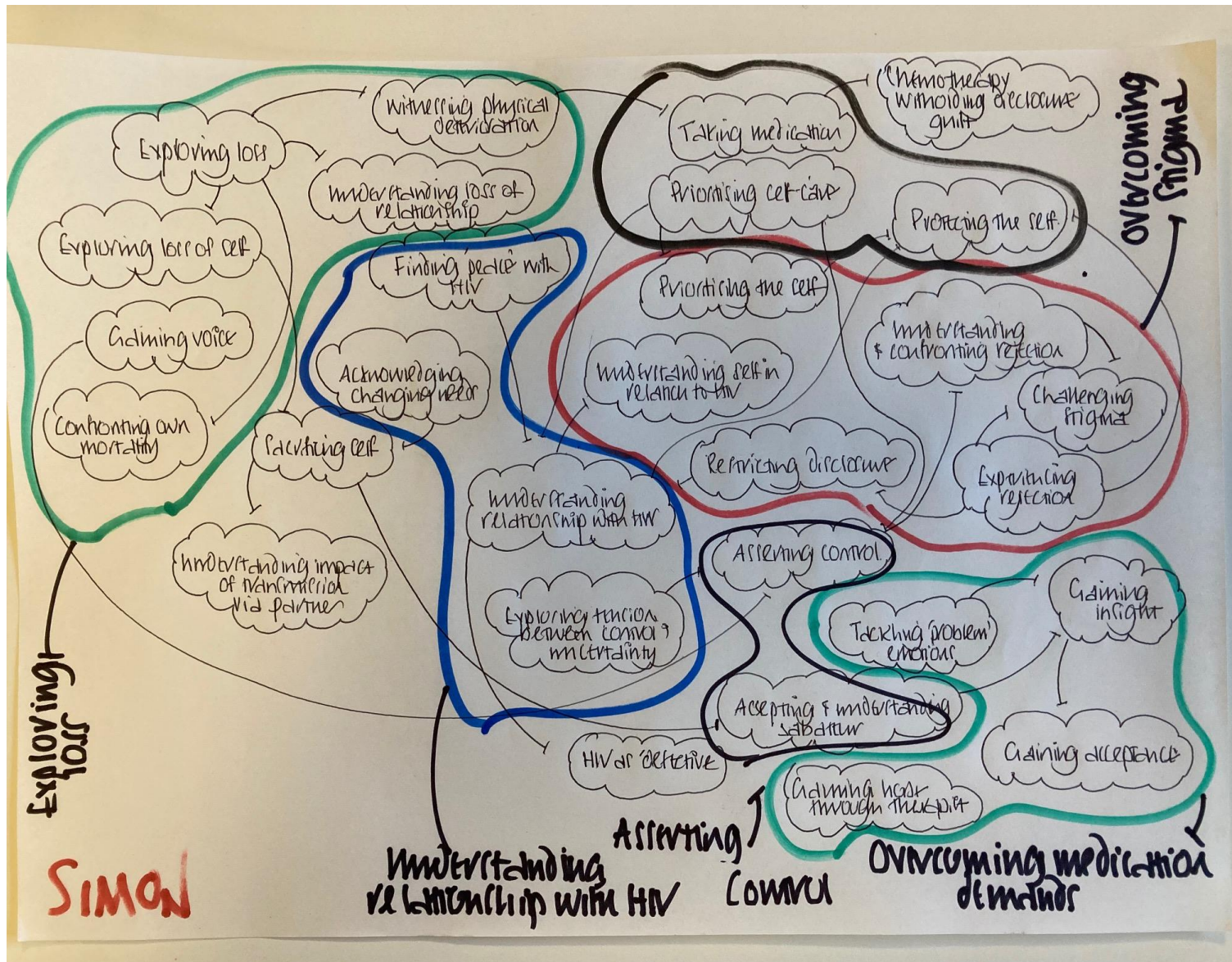


Appendix M - Initial schematic demonstrating the interlinked categories & how they interconnected with the addition of an additional subcategory of *Reflecting on the internal saboteur* post theoretical sampling (05/07/21)



Appendix N Example extract – worked examples of clustering





Appendix O Related journal article

Abstract

With the advent of antiretroviral medication Human immunodeficiency virus (HIV) has moved to a chronic disease with life expectancy comparable to a non-infected individual. While a positive HIV diagnosis is no longer considered a death sentence it is debatable if advances in medical science have been met by the psychological needs of this demographic group. With antiretroviral medication (ART) individuals with HIV can expect to live longer yet are likely to encounter an increasing diverse array of medical, psychological, social and cultural challenges. Current research links a HIV diagnosis to a theme of adjustment as a positive diagnosis may be accompanied by stigma and has the power to influence and transform individual identities. A HIV positive diagnosis is often accompanied with vulnerability, helplessness and uncertainty with higher incidences of psychological distress such as depression, generalised stress and anxiety. Existing literature has primarily focussed on the efficacy of CBT interventions in relation to HIV. Yet from a pluralistic perspective there is unlikely to be one appropriate 'model' as different people are helped by different processes at different times. This grounded theory study explored the experiences via semi structured interviews from eight recently diagnosed individuals focussing on helpful aspects of therapy that participants cited as helpful in facilitating their own psychological and psychosocial adjustment. This study identified that a HIV diagnosis can invariably be accompanied by complex life adjustments as an individual adapts to new experiences of a physical, social, intimate or spiritual nature. This research findings identified two core-categories. The first core category embodied a process of interpersonal and intrapersonal growth, facilitated by the therapeutic space that comprised of: processing the 'diagnosis' overwhelm; understanding the relationship with the self & HIV and confronting stigma. A second core-category identified therapy as a conduit for exploring, challenging beliefs about the self, world and others. These findings are situated within existing literature and how they may augment efficacy in psychological treatment of HIV-positive individuals in promoting an individual's psychosocial adjustment in helping a client overcome the associated challenges of life in their social and domestic roles living with HIV. The research findings are explored with specific implications to implications for counselling psychology.

Keywords: HIV, adjustment, psychosocial, stigma, self-esteem, quality of life, therapeutic relationship, cognitive-behavioural therapy (CBT), psychodynamic, psychoanalytical, grounded theory