Professional Doctorate in Counselling Psychology

Doctoral Portfolio

Martina Gerada

School of Psychology
Faculty of Life Sciences and Computing
London Metropolitan University
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Contents

Preface

This doctoral portfolio consists of four sections, each related to the practice of Counselling Psychology (CoP). The first section presents a piece of qualitative research focused on white, European women with HIV and their renegotiation of sexual subjectivity. Sexual subjectivity is defined as a woman's 'experience of herself as a sexual being; her feeling of entitlement to sexual pleasure and sexual safety; her ability to make active sexual choices; and her identity as a sexual being' (Tolman, 2002, p.5-6). This concept has been implicated in women's healthy adult development and explored here in light of adaptation to HIV. The second section is a reflexive essay discussing my personal philosophy of practice and how this shapes my work and professional orientation within CoP. In the third section cognitive behavioural therapy and psychodynamic therapy are compared and contrasted in their application to group therapy, with a special focus on content and process interventions. Finally, the fourth section provides an example of my clinical work with a client in a GP practice as I analyse an excerpt from our therapeutic encounter in a process report.

A unifying theme runs through these pieces of work, one which draws attention to the co-construction of reality and counselling psychologists' role in addressing the interpersonal nature of problems in a non-pathologising manner.

In ***Section A: Research study***, the way that white, European women renegotiate their sexual subjectivity after an HIV-diagnosis is explored through the use of The Listening Guide (Gilligan, Spencer, Weinberg, & Bertsch, 2003), a method of data analysis that focuses on the closeness or distance of participants' utterances to/from dominant discourses in society. It aims to draw out the voices of marginalised or less 'powerful' people in society as cultural discourses of gender, power and politics can work to silence them (Beauboeuf, 2007; Gilligan et al., 2003). As women with HIV, participants often battled with distress that was not directly derived from physically carrying the virus but related to social constructions of HIV/AIDS. Explored through this method, positive change was found in interpersonal support and a personal and social reframing of difficulty. This study is significant to CoP's wider aims of empowerment and social justice (Vera & Speight, 2003; Goodman et al., 2004) as it offers ways of working with women to strengthen identity and personal agency as well as (positively) influencing societal views on people with HIV.

Section B: Reflective essay delves deeper into the notion of co-constructed realities to look at the influence of counselling psychologists as active participants in this process. Through this essay I follow one of the major tenets of CoP, self-reflection (Grant, 2009), to discuss how my experiences and personal beliefs shape my professional orientation to CoP practice. What I discover is a strong affiliation to humanist-existentialist views, alongside a critical appreciation of more structured, directive therapeutic approaches such as cognitive-behavioual therapy. Using the latter as a guide for formulating client difficulties, I remain open to clients' subjective experience and idosyncrasies and place the therapeutic relationship at the centre of my personal theory of change. The essay also discusses my efforts at providing clients with (what is currently considered) best practice for psychological therapy without allowing current socio-political and economic pressures (that shape such considerations) to dictate my professional stance.

In ***Section C: Theoretical essay*** the interpersonal nature of problems and their solutions is made evident through discussion of group therapy from two major theoretical perspectives: cognitive behavioural therapy (CBT) and psychodynamic (PDT) therapy. Besides comparing and contrasting process and content interventions from these two perspectives, this essay highlights how positive change is achieved in, and through, groups. Groups have the capacity for instilling hope, teaching new skills, showcasing adaptive behaviour and offering opportunities for belonging and altruism (Yalom & Leszcz, 1995). In relation to the uniting theme of co-constructed reality, this essay argues that group therapy can offer a safe space where painful experiences, problematic beliefs and unhelpful behaviours can be revisited, sometimes de-constructed and re-constructed, to bring about the needed change. Similarities and differences in CBT and PDT therapists' role in groups are also examined.

The final section, ***Section D: Process Report***, highlights the importance of considering social justice issues when assessing and treating client difficulty. In this report, I reflect on how my personal blind-spots, organisational restrictions and socio-political discrimination negatively affected the therapeutic relationship between myself and a female client who presented with stress over the possibility of an unfair dismissal at work. I discuss how personal schemata related to expressing anger, and dominant beliefs about women's anger, dampened my empathic response to her and curtailed her ability to freely express pain, channelling it instead into defensiveness and aggression (after years of discrimination and veiled injustice). The importance of timely process interventions, where interpersonal dynamics and meta-communication between client and therapist can be explored, becomes evident in this report. Questions about interconnected power-differentials that contribute to client difficulty, and my ability to address them, remain at the end of this process report but they highlight the importance of maintaining a non-pathologising stance advocated for in CoP's emphasis on subjective experience.

Renegotiating the sexual self after an HIV-diagnosis: Listening to white, European women

A dissertation submitted in partial fulfilment of the requirements for the
Professional Doctorate in Counselling Psychology

by

Martina Gerada

Supervised by: Dr Russel Ayling

School of Psychology
Faculty of Life Sciences and Computing
London Metropolitan University
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Abstract

Research in the fields of HIV and female sexuality share a contentious past which centred on prevention and often vilified or victimised women. Psychological research, including that in Counselling Psychology (CoP), has proven more sensitive to women's needs, yet continues to portray the sexual lives of HIV-positive women in a negative light. Despite adopting a philosophy of holism and valuing the creation of social environments that sustain mental well-being, CoP literature is relatively silent on the role of sexuality in women's adaptation to HIV. This qualitative study explores how white, European women with HIV, who have historically been underrepresented in HIV literature, renegotiate their sexual subjectivity, a concept that has been implicated in women's healthy psychological development (Tolman, 2002). Data was analysed using The Listening Guide (Gilligan, 1982; Beauboeuf, 2007), a feminist research tool that focuses on *voice* to investigate social discourses and individual meaning-making in narrative data. Results present six co-occurring voices which describe participants' relationship to Self, HIV and Other. They speak of the continued, significant psychological impact of an HIV-diagnosis, despite advances in medication, which precipitates multiple psychosocial crises related to identity, intimacy and meaning in life. The voice of distress confirms previous research on HIV-trauma and also highlights women's early vulnerability to infection. The voices of resistance, sexual knowing, empowerment, and the generative voice, demonstrate how sexuality is not always a stumbling block to adaptation but can also enable personal growth and psychological healing. The dignified voice speaks of participants' acceptance of the challenges borne of HIV and their ability to preserve the dignity of their lives' circumstances. Clinical implications are discussed in light of counselling psychology's multidisciplinary approach, spanning areas of HIV prevention, social change and individual and group therapy with women living with HIV.

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Glossary

Abbreviations:

AIDS: Auto Immune Deficiency Syndrome

ARVs: Anti-retrovirals

CD4: Cluster of Differentiation 4

CoP: Counselling Psychology

ECDC: European Centre for Disease Prevention and Control

HAART: Highly Active Anti-Retroviral Therapy

HIV: Human Immunodeficiency Virus

PLHIV: People living with HIV

WHO: World Health Organisation

Definition of terms:

- *AIDS:* a condition diagnosed when a person has a CD4 count (see below) lower than 200 cells/mm^3. This means their immune system is very weak because HIV has destroyed a large number of their T-cells (cells that protect against infection). As a result, the person may develop various health problems such as pneumonia, oesophageal candidiasis, cancer, muscle wasting, prolonged fevers, blindness and death. The term is gradually being left for *end-stage HIV* and/or *CDC* (Centres of Disease Control and Prevention) *stage C*.

- *CD4 count*: is a measure of the amount of the CD4 molecule on T-cells that are important in protecting the body from disease (part of the immune system). T-cells are attacked and killed by HIV although they are replaced in the body. If the viral load (see below) is high, the body cannot keep up the production of new cells to replace those killed by HIV. A low CD4 count means that the person has a weak immune system and is more likely to get sick and develop AIDS.

- *HIV-positive*: the diagnosis given to someone who has been tested for HIV and found to have the virus in their bloodstream. CD4 count would usually be between 200 to 250 cells/mm^3. This does not mean that they have AIDS but that they are at a higher risk of opportunistic infections which may lead to AIDS because their immune systems are weak.

- *HIV-negative*: someone who has been tested for HIV and found not to have the virus in their bloodstream. CD4 count is usually between 600 and 1200 cells/mm^3.

- *Positive women:* this phrase describes women who are HIV-positive in a way that seeks to promote empowering discourses around female seropositivity.

- *Sero-concordance*: when both partners in a (sexual) relationship are HIV-positive.

- *Sero-discordance*: when one partner is HIV-positive and the other is HIV-negative.

- *Seropositivity*: the noun denoting the presence of HIV in the bloodstream.

- *Sexuality*: within this research, as indeed in our human understanding of it, the term *sexuality* is seen as eclectic, taken to mean more than sexual identity and practice (although these may play a central role in its expression). Borrowing from Boyce et al. (2007), sexuality is understood as being "bound up with desire, fantasy, bodily expression, power, gender and understanding of self, conceived in practices and sentiments that may be far from socially apparent (or even obviously sexual)" (p.6). Participants were not given this working definition of sexuality but allowed to speak of sexuality in the ways *they* understood it. Nearly all the participants however made reference to notions described here.

- *The Swiss Statement*: a statement released by Swiss experts in January 2008, reporting that HIV-positive individuals who are on effective antiretroviral therapy and who have had an undetectable viral load and no sexually transmitted infections (STIs) for at least six months, are sexually non-infectious.

- *Viral load*: the level of HIV in the bloodstream. The higher the viral load, the more likely it is that the person infected will develop AIDS. Someone with a high viral load is also at a higher risk of passing on the virus through unprotected sex, breastfeeding (in the case of mothers of infants) and exchange of blood through wounds, cuts, transfusions or needles. HIV-medication works to stop the virus from multiplying in the body, therefore lowering the viral load.

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My deepest appreciation goes to my supervisor Dr Russel Ayling whose encouraging words and thoughtful feedback have helped see this project through. He has confirmed to me that a good supervisory relationship is half of the work done.

I would like to thank my family and close friends who have been of constant support. My brother's pep talks, my mother's eye for detail and patient corrections and my father's encouraging words, have all helped to make sure I reach my goal. Special thanks go to Mr Karl Agius who has lived through the worst and the best of this project alongside me. If ever there was a man of patience and unconditional support, it would be him.

Finally and most importantly, I would like to thank the women who participated in this study. They have not only made this project possible, but they have taught me a lot about the process of healing. I hope I have been able to transmit this experience through my writing but like with most things, it was in the meeting, the seeing and the hearing, that this knowledge was understood. I am grateful for this opportunity.

Personal Statement

I ...spent three months in Kenya
I picked up on a lot
I was already interested
I kind of really sparked things off [1]

The path that brought me to develop an interest in HIV is quite unusual. I didn't previously know anyone with HIV/AIDS and had no personal link to the subject. My interest was sparked off when I worked with young men in Kenya on a project for HIV/AIDS prevention. There, I realised how disproportionately the burden of guilt and blame is set on women's shoulders and what a minefield female sexuality can be.

I remember
You asked me
What interested me

I think
I see HIV
I said
Topics that interest me
Sexuality
Guilt
Telling other people,
Being responsible for others
Others at some point having to be responsible for you,

I think,
For me
I view sexuality as being important throughout one's life
You read around,
HIV is there then all of a sudden sexuality disappears
That interests me
You know,
You *had* to view sexuality.

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[1] Extracts of my "I" poems (see 'Method'), created via my responses to participants' questions about why I chose to do this research.

I'm mixing it up
You know?
We're not sexual beings anymore?
You know

My interest in sexuality is a long-standing curiosity, related to a cherished Catholic upbringing that despite offering valuable insights into the human condition, failed to satisfy my desire to understand more about the sexual aspect of my life. Doing research on sexual subjectivity and migration in 2007, and now HIV and sexuality, helped me understand aspects of my own sexuality better, increasing my interest in its importance in mental well-being and health.

In a romanticised and probably unrealistic way, the world of HIV/AIDS brings me closer to the continent of Africa. It keeps alive a dream I have about working in developing countries there and being a part of the vibrancy and intensity which it has shown me. I chose to focus on European women as a way of redirecting my energy to a place I can reach and one that I know better, because as I increasingly realised after returning from Kenya, the greatest changes we can hope to enact must start at home where the intricacies of culture and lifestyle are more known to us. We can then comment on them and insightfully work to better them.

I think
I went to Kenya…

I'm very related,
I'm very related
I'm very interested in aspects of sexuality and identity

I'm interested in how people kind of can continue …to live
I believe
I noticed
I just…thought
I'd like very much to work em with women an-, and HIV,
I'd love to do something like that.
I'm aiming for…
I'll be a Counselling Psychologist
I,
I could work in HIV

Introduction

Over the past fifteen years, advances in HIV-medication have brought about a virtual reclassification of seropositivity. There is still no known cure for HIV but it can now be treated with a strict regimen of different anti-retroviral (ARV) drugs known collectively as highly active anti-retroviral therapy (HAART) or combination therapy[1]. Being diagnosed with HIV in today's Western world marks the advent of a serious chronic health condition but is no longer considered fatal.

Thirty-four million people live with HIV worldwide. 6.6 million are on ARVs (UNAIDS, 2011). In Central and Western Europe the figure stands at 1 million (approx.) with the UK seeing a 50% increase in new cases between 2000 and 2009 (UNAIDS, 2011). However, as HIV prevention and treatment becomes more successful, the spread of the epidemic is decelerated and its effects reversed (UNAIDS, 2010).

Nevertheless, being diagnosed with HIV is considered a traumatic life event that can change the course of one's life. Physical, social, sexual and psychological aspects of the self are threatened by the disease (e.g., Nightingale, Sherr & Hansen, 2010). This is why research into HIV-trauma (e.g., Sherr, Petrak, Melvin & Davey, 1993), post-traumatic stress (e.g., Martin & Kagee, 2010) and, now more recently, post-traumatic growth (e.g., Sherr, Nagra, Kulubya, Catalan, Clucas & Harding, 2011) is becoming increasingly popular. Within the sphere of Counselling Psychology, practitioners and researchers who previously helped people come to terms with their own imminent mortality, or that of loved ones, now face the new challenge of helping people with HIV adapt to an extended life and plan for an unexpected future (e.g., Rabkin & Ferrando, 1997). Society at large is slowly adjusting to the idea of *living well* with HIV (Harding, Liu, Catalan & Sherr, 2011).

Efforts at understanding post-traumatic growth (Tedeschi & Calhoun, 2004) i.e., positive changes that occur following a traumatic life event, have initiated a change in the way psychologists view trauma. Similar to findings in other areas of trauma research (e.g. research with victims of natural disasters), research in HIV-trauma has

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[1] See http://www.avert.org/antiretroviral.htm for more information.

shown that some PLHIV experienced a greater sense of personal strength; a deeper spirituality and appreciation for life; an improvement in important relationships; a change in negative health behaviours; and a reshuffling of life priorities (e.g., Siegal & Schrimshaw, 2000; Goggin et al., 2001; Milam, 2004; Barskova & Oesterreich, 2009; Nostlinger et al., 2010; Dibb & Kamalesh, 2012).

This shift, however, has only just extended to psycho-social research on HIV and sexuality. The literature in this area speaks of sexuality and seropositivity in terms of contagion and risk (e.g., Ehrhardt et al., 1995), dysfunction (e.g., Florence et al., 2004), fear (e.g., Keegan, Lambert & Petrak, 2005), and constriction (Gurevich, Mathieson, Bower & Dhayanandhan, 2007). It speaks of lingering difficulties faced by people with HIV, emphasising problems with disclosure, foreclosed subjectivities and difficulties creating and maintaining relationships. There also exists evidence for positive changes in people's sexual lives post-diagnosis (Hankins et al., 1997; Cranson & Caron, 1998; Kahn, 2000; Keegan, Lambert & Petrak, 2005), but these are framed as minority experiences, mentioned in passing and rarely explored further. Consequently, processes of positive adaptation to a seropositive sexual life remain elusive and misunderstood, complicating the task of working towards positive growth.

In helping people with HIV, mental health professionals are well-equipped with knowledge about what can go wrong, but are far less knowledgeable about successful sexual adaptation. A belief that HIV hits people's sexual life the hardest might make it feel inappropriate and unrealistic to enquire about positive changes in this sphere. Yet to help people adapt healthily to a life with HIV, it is vital to open this area up for exploration.

In re-visiting the concept of sexual renegotiation after seropositivity, I hope to initiate a dialogue that approaches the topic from a place of hope without undermining the real, problematic issues around HIV and sexuality. Inspired by the paradigm shift in HIV post-trauma research and in line with Counselling Psychology principles of empowerment (e.g., Vera & Speight, 2003) and holism (Beatch et al., 2009), this study seeks to understand how sexual subjectivity is renegotiated following a diagnosis of HIV, with special emphasis on what helps or hinders the process of healthy adaptation.

Defining sexual subjectivity

Sexual subjectivity is defined as a person's "experience of herself as a sexual being; her feeling of entitlement to sexual pleasure and sexual safety; her ability to make active sexual choices; and her identity as a sexual being" (Tolman, 2002, p.5-6). It has been used mostly in studies on female sexual development, conceptualised through feminist ideas on sexual equality. Sexual desire lies at the core of sexual subjectivity, moving women from being objects of desire to being the subject of their own sexual lives (Horne, 2005). Sexual subjectivity is considered a crucial element in women's healthy adult development (Martin, 1996; Tolman, 2002), important in the process of developing a stronger sense of self that is fully present in relationship with others and that can act with a sense of agency when relating sexually, or otherwise (Tolman, 2002).

It is important to explore this concept within the realm of HIV/AIDS because, as will be explicated in the following review, HIV can mar each component of sexual subjectivity (mentioned above), leaving women feeling confused, sexless and vulnerable (e.g., Gurevich et al., 2007). The components will be used as markers in this study to explore healthy sexual adaptation.

Focusing on white, European women

Roughly half (47%) of the world's population of people living with HIV (PLHIV) are women (UNAIDS, 2010). In the UK the figure stands at 31% (HPA, 2011). Despite this, the bulk of HIV research has been carried out with homosexual, Caucasian men (e.g., Ross & Ryan, 1995). Early evidence of the growing incidence of HIV in heterosexual women has largely been ignored (Sherr et al., 1993) with mixed-gender studies having relatively small samples of female participants (e.g., Adam & Sears, 1998).

Heterosexual contact is now the highest reported mode of transmission in the WHO European region (45.8%) (ECDC, 2012). Women have been found to be physiologically more vulnerable to infection than men (Iobst & Gandhi, 2009) with the risk of man-to-woman transmission double that of woman-to-man (1 in 1,000 vs. 1 in 2,000). Women are at greater risk because of an unequal exchange of genital secretions during sex and a greater vulnerability to infection between the seventh and tenth day after ovulation due to hormonal effects on the immune system. Some research suggests that HIV develops differently in the female body, therefore current treatment protocols may have different effects on women (Iobst & Gandhi, 2009). In addition, dependency and inequalities of power often impinge on women's ability to negotiate safe sex (e.g., Esplen, 2007), thus gendered research is extremely important.

The majority of studies with all-female participants have been carried out in North America with samples consisting of women of African origin or mixed ethnicity. Contrary to other fields of research, white European women are often under-represented. While ethnically diverse samples aid generalisation of findings and cross-cultural comparisons, the specific needs and experiences of ethnic sub-groups may be overlooked. Evidence from the USA shows that white, middle-class women diagnosed with HIV have greater problems finding and fitting into self-help groups (Ciambrone, 2003) as stark differences in socio-economic backgrounds, ethnicity and migration issues are pertinent variables in feeling comfortable in a group and accessing support.

Little is known about where white, European women with HIV go for support and how they work through their difficulties, especially with sexuality. This gap in knowledge presents an interesting challenge to multicultural competence in counselling psychology (Vera & Speight, 2003). Here, people who are considered mainstream in socio-psychological research (following white, heterosexual men) are an anomaly in the world of HIV/AIDS, not only because they are women (Gurevich et al., 2007), but because they are white and middle class and not expected to have to HIV. In focusing on this sub-group, this study hopes to widen the reach of multicultural competence, from working flexibly with people from ethnic minorities to being sensitive to ethnic majorities' masked isolation.

Methods of literature search

My literature search started at grass roots level whilst on placement at CASCAID (a specialist psychiatric and psychological service for people with HIV/AIDS at the South London and Maudsley Hospital). I read through various HIV/AIDS publications such as BASELINE and Terrence Higgins Trust (THT) and Positively UK magazines. I consulted books available in the library and bought others online.

The vast majority of papers presented in this review were accessed through online databases such as PsychINFO, PsychArticles, EBSCOhost and Google Scholar. I searched for 'HIV/AIDS' and: 'sexuality'; 'female sexuality'; 'women'; 'counselling psychology' and; 'quality of life'. Also, 'sexuality' and: 'chronic illness'; 'identity formation'; 'development' and; 'feminism'. Using the snowballing technique (Langdridge, 2004), I followed up on references and authors of relevant papers from initial search results. I made contact with HIV researchers in the fields of psychology and psychiatry to get their views on current trends in HIV/AIDS research in the UK.

I conducted specific journal searches for 'Counselling Psychology Quarterly' and 'Counselling Psychology review' as well as journals such as 'Feminism and Psychology', 'AIDs Patient Care and STDs', 'Global Public Health' and overseas journals such as 'The Counseling Psychologist', 'Canadian Journal of Human Sexuality' and 'Australian and New Zealand Journal of Psychiatry'. I read approximately 190 articles, excluding book chapters and magazines, and reviewed about a hundred more abstracts.

Research that was excluded from the review related to children and men with HIV/AIDS although the latter was used to inform considerations discussed in the review. Research that was highly medicalised was also set aside, save for papers directly relevant to women's sexual health.

The following review outlines current socio-psychological research in HIV/AIDS, with special emphasis on female sexuality. By critically examining their input in understanding the complex interplay between sexuality and adaptation to HIV, I hope to more clearly define the literature gap I seek to address.

Literature Review

Sexuality in psychological life

> For many years we have all been living…under the spell of an immense curiosity about sex…as if it were essential for us to be able to draw from that little piece of ourselves not only pleasure but knowledge.... (Foucault, 1976 p.77-78)

This quote by Foucault (1976) highlights human beings' fascination with their own sexuality and the importance it has been given over the years. As early as Freud (1905/1955), sexuality has been explored as a key player in healthy adult adjustment. It has been implicated in early attachment relationships and can influence the capacity for intimacy in later life. Whether considered "a positive force warped by a negative civilization [Ellis and Kinsey...] or a negative force in need of social control [Freud...]", it was generally agreed that sexuality had the power "to define who we are as human beings" (Parker, 2009 p.253).

Sexuality's role in intimacy and identity formation inspired much research over the last century (Erikson, 1968; Gilligan, 1982; Tolman, 2002; Ryan, 2007). Feminist scholars, writing about women and girls' psycho-social development, note that a woman's sense of self is heavily tied up with her relational life (e.g., Haug et al., 1987). Sexuality is thus considered pivotal during the years between adolescence and early adulthood but its importance throughout the *entire* lifespan is also evidenced in the research (e.g., Dunn, Croft & Hackett, 1999; Satcher, 2001; Foley, Kope & Sugrue, 2002; Sharpe, 2004).

More recently, sexuality has also been implicated in processes of psychological adjustment to chronic illness (e.g., Verschuren et al., 2010). Addressing sexual and relational issues is now an important component of holistic care, affecting overall quality of life (e.g., Lemieux et al, 2004). These findings hold important implications for the field of HIV as it is increasingly being regarded as a chronic condition.

Many argue that viewing HIV as a chronic condition perpetuates wrong ideas about it being a stable and easily treatable disease. Actually, it can consist of 'dramatic fluctuations in health' (Colvin, 2011 p.4) and significant physical difficulties related to medication side-effects. Such a classification also masks social meanings attached to HIV that disempower people and obstruct adaptation (e.g., Colvin, 2011). However, because of significant advancement in HIV medication, there are physical, social and psychological changes that run alongside such progress, which affect the way people (affected and infected) with HIV view the disease.

Counselling psychology and the changing epidemic

Before ARVs were widely accessible, an HIV diagnosis was seen to catapult people into a developmental crisis as they faced the reality of their own death. The lifespan perspective of Erikson's developmental theory was used to map the psycho-social changes that PLHIV went through. Erikson (1963, 1968), posited that social interactions over a lifetime, shape a person's sense of self (or ego identity). At each life stage, people face a conflict (or developmental challenge) that, if resolved well enough, would lead to ego strength or a sense of mastery, enabling personal growth. If managed poorly, the person is left with a sense of failure or inadequacy that may affect the negotiation of later developmental challenges. Erikson named eight stages of psychosocial development, starting in childhood and ending in old age: trust vs. mistrust; autonomy vs. shame; initiative vs. guilt; industry vs. inferiority; identity vs. role confusion; intimacy vs. isolation; generativity vs. stagnation and; integrity vs. despair. Merriam, Courtenay & Reeves (1997) interviewed a mixed-gender and mixed-ethnicity sample of 18 people diagnosed with HIV/AIDS (CD4 cell count below 500 and not taking HAART) and found that the last three adulthood stages of Erikson's theory occurred at once, regardless of age, as the virus brought on multiple social changes and a greater awareness of death. Post-HAART however, the pertinent questions are: How do PLHIV make sense of this (no longer necessarily) life-threatening but nevertheless life-changing disease? And how can we support their adaptation to a condition that is becoming less physically evident yet is still (potentially) socially disempowering?

Using Erikson's theory, Heiland et al. (2002) explored the reconstruction of identity and meaning in PLHIV after starting combination therapy. They noted a change in social roles and meaningful activities in participants' (gay men of mixed ethnicity) narrated experiences. Before diagnosis, these centred on career, family, friends and romantic partnerships. Following diagnosis, participants experienced a period of crisis where they could not identify any positive social roles e.g., being unemployed or a drug addict. In the resolution stage, following crisis and treatment, participants found meaning through being a friend/family member, a healthy person and a helper. Social roles and meaningful activities acquired at this stage were maintained over time, but the healthy person role decreased whilst an interest in re-establishing roles and activities linked to being a romantic partner and career person increased. While caution is required in generalising from an all-homosexual-male sample, this study points to important changes in identity and self-concept that accompany PLHIV in a post-HAART era and brings them to the attention of counselling psychologists.

The needs of PLHIV have been described as multi-dimensional (Harding, Liu, Catalan & Sherr, 2011). Counselling Psychology (CoP) research that has engaged with the subject of HIV has in fact explored issues of spirituality and coping (Simoni, Mortone & Kerwin, 2002), work and career development (e.g., Maguire et al., 2008), incorporating an HIV/AIDS identity into the self-concept as a way of adapting over time (Baumgartner, 2007) and the importance of developing a shared understanding in therapy (Miller & Willig, 2012). Because CoP has traditionally viewed mental health holistically (Friesen, 1983; Beatch et al., 2009) it has developed into a versatile profession that can meet these varied needs effectively, incorporating sub-disciplines of occupational, multicultural, and health psychology (Chwalisz, 2008). There is thus a strong argument for counselling psychologists to be involved in supporting PLHIV (e.g., Maguire et al., 2008). Finding ways to support individuals "to live socially, economically and emotionally productive lives" (Harding at al., 2011, p.564), is now a major concern for public health policy. Yet sexuality is omitted and even CoP research has remained relatively silent on its continuing importance in the lives of PLHIV.

Relevance and reflexivity

"HIV infection has a detrimental effect on one's erotic and emotional potential…Many people who have to live with HIV need support in order to recover a meaningful emotional and sexual life" (Troussier, 2006 p.155). It is important for counselling psychologists to engage with this issue, to offer clinical care and policy initiatives that are more holistic in their outlook. Viewing the person as a whole (Beatch et al., 2009), CoP understands that health is located as much in the mind as in the body, and is nurtured in community with others (Goodman et al., 2004). Sexuality is important because it is a significant way people connect and communicate.

As a researcher and Counselling Psychologist, my interest lies in issues of identity and self-definition, the ways in which these are understood, maintained and changed over time and circumstance, and their relevance to psychological health. Closely bound to identity, sexuality places a magnifying glass on the ways that human beings relate. It highlights times when people, sometimes necessarily, place boundaries between themselves and the world and how, sometimes, they allow others to permeate through.

According to Ryan (2007) "thought and practice around sexuality constructs our identities [and] our felt options" (p.44). I therefore became interested in how PLHIV re-construct or re-arrange their identities around different options that seropositivity brings and the ways in which avenues for sexual well-being are open or closed to them; especially within a society that valorises sexual pleasure and expression for HIV-negative individuals but goes mum in the face of seropositivity.

Verschuren et al. (2010) state, that qualitative research on the sexual well-being of people with a chronic disease continues to be scarce. Within the field of HIV, discussing sexuality outside the scope of transmission prevention remains contentious and socio-politically charged (e.g., Sherr, Petrak, Melvin & Davey, 1993; Gurevich et al., 2007), leaving the interplay between sexual well-being and psychological adjustment relatively unexplored.

Sexuality and seropositivity

Since the early 1980s, when it became evident that HIV was transmitted sexually, a plethora of studies have explored sexual attitudes, knowledge and practices in an attempt to curb its spread through behavioural change (Obermeyer, 2005). At the helm, biomedical approaches equated sexuality to a biological drive that linked directly to HIV. Post-modern views of sexuality as a malleable entity, shaped by social processes, were suspended in favour of quantification e.g., looking at "frequency of sexual acts, rates of partner exchange [and] patterns of sexual networking" (Boyce et al., 2007, p.9). This approach played a significant role in defining and attempting to control risky behaviours (Boyce et al.,2007), yet was criticised for portraying PLHIV, particularly women, as little more than carriers of disease (e.g., Lawless, Kippax & Crawford, 1996).

Locating women in HIV research

Early studies on the impact of HIV on women tended to tackle non-sexual issues like: stigma (Lawless, Kippax & Crawford, 1996); difficulties in accessing health care (Montoya, Richard, Bell, & Atkinson, 1997); and women's dual, or triple, role as patients and care-givers in families living with HIV i.e., when caring for a partner *and* children with HIV (e.g., Hackl, Samlai, Kelly & Kalichmar, 1997). In these accounts, positive women were often depicted as victims of their illness and of social systems that did not, or could not, meet their needs.

Early sexuality research commonly explored sexual dysfunction (e.g., Brown, Kendall & Ledsky, 1995) and sexual risk-taking (mostly in female drug-users) (e.g., Ehrhardt et al., 1995), portraying women "as incarnations of sexual danger" (Squire, 1993, p.5). Well-meaning research focusing on vertical transmission i.e., mother to child transmission (Sherr, 1991), also overlooked positive women's health and sexual needs, failing to represent them as people in their own right (e.g., Sherr et al.,,1993; Gorna, 1997).

In her provocative work, Gorna (1996) described three discursive portrayals of HIV-positive women: as sexual deviants who deserve the disease they acquired (vamps);

innocent bystanders of male deviance (victims); or beings uninterested in sex (virgins/Madonnas). She also talked about how women have been used to 'heterosexualise' AIDS and to engage heterosexual men in prevention. Attempts at making HIV a respectable disease (as opposed to its roots in 'deviant' or 'queer' homosexual practices), did a disservice both to vulnerable populations and to women According to Gorna, this painted a simplistic and inaccurate picture of female sexuality, seducing research away from truly understanding the issues affecting positive women. In the quote below, Gorna speaks of how, anyone with HIV/AIDS was labelled as 'deviant'. In this way, important, but more subtle, risk factors that led to infection, and continued to put women at risk, (such as power differentials in relational contexts, and meanings attached to sex), were glossed over.

> Those who have been infected with HIV, but who live outside the queer world…who are not poor...not black...never shot drugs (or knew anyone who did)...not lesbian, gay or bisexual (and never known anyone who was) these people become queer when they acquire HIV/AIDS. AIDS is queer coz stigma sticks. (Gorna, 1996, p.4).

A qualitative study by Lekas, Siegel and Schrimshaw (2006) showed that even after over twenty-five years of living globally with the epidemic, "misinformation and irrational fears of contagion" (p.1165) continue to fuel stigma experienced by positive women. Compared to pre-HAART accounts, reported experiences of enacted stigma decreased, however felt stigmatisation (perceived race/gender stereotyping and vicariously-experienced stigma) continued to be a challenge for women in adapting to life with HIV (Lekas et al., 2006). Lawless, Kippax and Crawford (1996) identified (internalised) discourses of being "dirty, diseased and undeserving" (p.1371) in Australian women's accounts of living with HIV and their experience of medical services. Women reported feeling more harshly judged than men for being sexually active.

Such stigmatisation also pervaded research trends in HIV. The vast majority of literature available in Europe is highly medicalised and presents information on positive women in terms of: epidemiology and prognosis (Morlat et al., 1992); disease transmission and progression (Serraino, Franceschi, Dal Maso & La Vecchia, 1995); incidence of pregnancy and live births (De Vincenzi et al., 1997); and prevalence of sexual dysfunction (Florence et al., 2004). It is rare for such studies to move far beyond describing the statistical terrain, and without context, such information may inadvertently add fuel to the proverbial fire, perpetuating stigma. It is only in the last decade that research (mostly in the USA and Canada) began to explore the continued, disrupted or renegotiated sexual lives of women with HIV (e.g., Bova & Durante, 2003; Keegan, Lambert & Petrak, 2005) giving context to the statistics.

In the following sections I shall present research by ethnographers, social workers and nursing professionals, before moving on to psychological studies. Despite overlap in the approach taken to female sexuality, the latter are better-qualified to comment on links between sexual and psychological well-being.

HIV/AIDS and female sexuality

One of the first themes that emerge from literature on female sexuality and HIV/AIDS is women's continued engagement in sexual activity post-diagnosis (e.g., Hankins, Gendron, Tran, Lamping & Lapointe, 1997; Bova, 2000; Lambert, Keegan & Petrak, 2005). A pioneering study carried out by Hankins et al. (1997) pre-empted later studies by Bova (2000), Bova and Durante (2003) and others, and found that the majority of women in their sample (68%) were sexually active post-diagnosis and that "a further 10% intended to have sex in the future" (p.267). Their sample consisted of 161 HIV-positive, Canadian women who were injecting-drug users (IDUs) and non-users of mixed ethnicity. Unlike other researchers at the time, they sought a broadly qualitative understanding of sexual satisfaction, unconventionally distinguishing it from orgasm, whilst also asking more conventional questions about frequency of sex, masturbation, partner type and condom use.

When Bova (2000) presented her findings at the National Conference on Women and HIV/AIDS in Los Angeles in 2000, also suggesting a high rate (90%) of continued sexual activity in women post-diagnosis (and unlike Hankins et al.'s (1997) sample, post-HAART), it was met with shock and confusion by positive women attending the conference (Kahn, 2000). Many expressed no desire for sex, due to fears of transmission or low self-confidence related to medication-induced bodily changes. This reaction was echoed in a later study that looked at desire and sexual practice in Canadian people using combination therapy (Maticka-Tyndale, Adam & Cohen, 2002). Results spoke of "struggles with persistent absence of libido" (p.33) linked to dread in dealing with disclosure, difficulties in negotiating safe sex and problems coping with symptoms of HIV and medication side-effects. This particular study was limited in its ability to comment specifically on women's experiences as the sample consisted of a disproportionately small number of female participants (31:4), yet many other psychological studies (discussed later) showed similar results.

Hankins et al. (1997) also identified difficulties related to fear, guilt and lack of desire but they found that, with 84% of their sample, this largely happened during a period of sexual adjustment (i.e., a period of time when women were not yet comfortable with their sex lives after resuming sexual activity). Authors quoted the median adjustment period (8.5 months) rather than the mean because the data were not equally distributed. There was a higher rate of resumed sexual activity in IDUs when compared to non-users which was assumed to be related to IDUs need to support a drug habit. This points to the interplay of social-economic factors affecting these women. It can be argued that resumed sexual activity, in this case, did not necessarily indicate a healthy, safe or pleasurable practice.

Nursing professionals Bova and Durante (2003) touched upon the issue of socio-economic differences in their study with an all-female, mixed ethnicity sample in the USA. They conducted a quantitative analysis of the relationship between HIV symptoms, illness stage, meaning of illness, quality of life and sexual functioning and found that sexual functioning was related to poverty and sense of oppression, rather than disease progression. Generally, women with better health, who had never used drugs and attributed positive meaning to HIV, were found to have fewer symptoms, a better quality of life and higher levels of sexual functioning.

Having high CD4 counts and experiencing better health also emerged in Hankins et al.'s (1997) study as a predictor of sexual activity. This is important in the context of HAART, which helps women maintain a low viral load and a high CD4 count. However, sexual enjoyment was more evident in women with new, regular partners who reported the highest rates of sexual satisfaction and the highest rates of consistent condom use (despite infrequent use in general). Although sexual satisfaction for women in Hankin et al's study, dropped markedly immediately after resuming sexual activity, "it rose to levels higher than those of the pre-test period by the time of the interview" (Hankins et al., 1997, p. 269). Some women explained that before HIV, they took their sexuality for granted, but following a difficult period post-diagnosis, they learned to value their sexual lives more positively. This points to the potential for positive change in women's sexual lives, despite, and perhaps as a result of, HIV.

Indeed, findings of a study in the USA by Cranson and Caron (1998) hint at the possibility of positive changes occurring because of HIV. Authors carried out an in-depth, descriptive analysis of the effects of diagnosis on intimate partner relationships and sexual behaviour in a mixed-gender sample consisting largely of participants who identified as homosexual (52%) and bisexual (14%). They found that some participants reported greater emotional intimacy and became more "choosy" in seeking partners (p.514). Interestingly, although participants also reported a heightened fear of rejection and abandonment, women were found to be better able to foster new relationships post-diagnosis and disclosed their status to potential partners more often than men. The importance of sex in participants' lives was found to be either unchanged or lessened after diagnosis. Unfortunately however, the study did not link this to well-being or adaptation as its aim was the epidemiological understanding and control of HIV as a disease.

In the U.K., Cusick and Rhodes (2000) interviewed 61 HIV-positive drug users and 12 of their partners, to explore issues of sexual safety in relationships. As with the study by Maticka-Tyndale et al. (2002) the majority of the sample was men of different sexual orientations (68%). An oversight in specifying the percentage of gay and bi-sexual women in their sample, but doing so for the men, points to a, possibly unintentional, male-oriented focus that guided the study. Findings showed that difficulties in sustaining safer sex practices with regular partners caused participants to avoid close relationships. Many sought HIV-concordant relationships where unprotected sex was more acceptable and people felt better understood. However, in both concordant and discordant relationships, deciding to have unprotected sex defined the relationship as more intimate and important. Expressing love within a relationship seemed more important that reducing risk. Generally, it was found that heterosexual partners had more difficulty sustaining safer sex practices in long-term relationships than gay men. Authors linked this to power-differentials between men and women and to less exposure to safer sex norms in heterosexual couples. Interestingly, the idea of committing to a shared destiny through risking infection was more commonly voiced by women in this study. This could be interpreted as a gender difference in the priority given to maintaining relationships over self-preservation (Brown & Gilligan, 1992; Gurevich et al., 2007) or viewed as an indication of co-dependence in partners of people who use drugs. The definition of sexual safety used in this study was narrowly based on physical safety and risk reduction. In a later study in the field of psychology, Jarman, Walsh and De Lacey (2005) broaden this definition and talk about the need of psychological protection of self and others (see p.17).

Ethnographic, social work and nursing studies show that few generalisations can be made about positive women's sexual life: Reporting from the same conference where women expressed shock and confusion over reported high rates of resumed sexual activity, Kahn (2000) also speaks about women who felt that HIV made them stronger, more able to refuse sex and to express their sexual needs. For instance, a "politicised sense of self-confidence" (Kahn, 2000, p.4) propelled one woman's sex drive. By challenging gender discourses and taking charge of her life, she was able to fight the guilt and shame associated with HIV. Kahn therefore concludes that empowering experiences seem necessary to help women deal with the "emotional baggage" of HIV (p.3). And as suggested by Bova and Durante (2003), it is not necessarily HIV *itself* that causes dysfunction but meanings and situations attached to it.

Psychological perspectives

It is evident from some studies (e.g., Denis & Hong, 2003) that biomedical views of sexuality have also influenced psychological research into HIV/AIDS and female sexuality. Such studies offer "an ostensible map of sexual life" (Boyce et al., 2007, p.9), for instance, comparing sexual functioning of HIV-positive and HIV-negative women (Denis & Hong, 2003) but often, narrowly focus on physical manifestations of sexual functioning (e.g., frequency of orgasm) and fail to elucidate meanings and situations related to it. Denis and Hong's study fails to discuss the effect of participants' low-level education, relationship status or psycho-social stressors on sexual functioning. It thus holds little relevance to clinical practice.

More in-depth and clinical relevant studies make use of both quantitative and qualitative measures to explore sexual life, joining the dots on important influences on women's experiences. Lambert, Keegan and Petrak (2005) explored the effect of: relationship status; time since diagnosis; CD4 counts and viral load; history of sexual abuse (if present); depression and anxiety, on sex and relationships. In line with previous research, most women (72%) in a sample of mixed ethnicity in the UK, had resumed sexual activity post-diagnosis, but more than half reported impaired enjoyment of sex, infrequent sex, poor communication, sexual dysfunction, higher levels of depression and avoidance of sex (linked to depression). In interviews, women explained how their sex drive had decreased drastically due to fears related to contagion, re-infection and aversion to sexual contact. They felt less sexually confident, more sexually inhibited, and spoke of enjoying and wanting sex less because of the constant burden of negotiating safe sex and medication side-effects. As a result, some chose to be celibate. Many still experienced sexual desire and used masturbation for release or recreational drugs for containment. In considering these findings however, it is important to note that 38% of participants reported symptoms of depression and 41% had a history of sexual abuse. This suggests a complex, non-linear relationship between HIV and sexual difficulty.

By contrast, one participant who had been HIV-positive for a number of years, described a new-found interest and desire for sex after meeting a new partner who made her feel "like a woman" (Lambert at al., 2005, p. 648). This finding links to that of Hankins et al. (1997) where women with new, regular partners reported higher levels of sexual satisfaction.

Most women in Lambert et al.'s (2005) sample seemed to have internalised negative messages about their right to have sex and feared rejection on disclosure which fuelled their avoidance of relationships. However, contrary to their negative expectations, some women continued their relationships even after disclosure. Unique descriptions of disclosure strategies used by women at the start of new relationships emerged from this study and authors concluded that participants expressed the same desire for intimacy in a supportive, accepting and loving relationship of trust as other women.

As mentioned earlier, Jarman, Walsh and De Lacey (2005) looked at the issue of safety in partner relationships by carrying out an in-depth, qualitative study with women in the U.K. The central theme that emerged from the study was women's need for psychological protection on various relational levels i.e., protecting the self from prejudicial responses, protecting others from the psychological burden of HIV and protection from feelings of 'otherness' through intimate partner relationships. Authors noted a conflict between women's need to maintain "more restrictive relational boundaries" (p.540) and the "need to share the emotional impact of HIV and gain support from others" (p.541). Psychological protection through status concealment was preferred by some women but was found to reinforce their sense of isolation and otherness. This concords with earlier findings on the psychological benefits of disclosure i.e., lower levels of distress and depression (Armistead, Morse, Forehand, Morse & Clark, 1999). Authors suggest that an exploration of issues of psychological protection in therapy may help women who are experiencing disclosure difficulties. Unlike other studies, they clearly state the implications of their findings to practice, linking to theory and research on women's psycho-social development. Quoting findings by Gilligan (1982) and Miller (1976), they note how HIV-stigma may alienate women from important, defining relationships in their lives and affect selfhood. Therapeutic providers may thus need to consider more systemic approaches in helping women adjust to HIV.

Within the same time-span, Siegal, Schrimshaw and Lekas (2006) published a paper in the USA exploring women's interest in, and enjoyment of, sex and related feelings of attractiveness. They compared two samples of women, pre- and post-HAART and found that across HAART eras and ethnic groups, women described similar negative effects on pleasure and avoidance as previous research in the UK. Considering earlier findings on sexual relationships (e.g., Keegan, Lambert & Petrak, 2005;

Jarman et. al, 2005), it is interesting to note that the majority of women reporting a loss of sexual interest (and in some cases, feelings of attractiveness), were not in a relationship. This raises questions about a possible link between being *in* a relationship and (as the participant in Kegan et al.'s (2005) study and others in Hankins et al.'s (1997) study, reported) the awakening of a dormant or repressed post-diagnosis sexuality. Also noteworthy is that 46% of participants in Siegal et al.'s (2006) sample had already developed AIDS, with 42% being symptomatic. Authors did not comment on the effects of health and relationship status on sexual difficulties although this has been shown to impact sexual activity and function (Hankins et al., 1997; Bova & Durante, 2003).

Like others, Siegal et al. (2006) considered time since diagnosis, for women in their sample, yet failed to isolate this as a factor in the women who reported diminished sexual interest. Time since diagnosis is an important variable to consider more closely as research on this is contradictory. For example, Brown, Kendall and Ledsky (1995), noted how sexual desire decreased over time for positive women in the military but Hankins et. al (1997) found sexual interest returned after an adjustment period. Interestingly, Siegal et al. present Hankins et al.'s results in a way that emphasises a decrease in sexual satisfaction over time. It is true that 32% of women in Hankins et al.'s study reported such a decrease, however, when looking at the progression of numbers in the three phases of investigation one can see that 42% of women were dissatisfied with sex *before* diagnosis, 57% of women during the adjustment period, and 32% in the month of the interviews. This shows that there was an increase in the number of women who were able to enjoy sex over time.

Fear, protection and pleasure

Psychological studies on positive women's sexual experiences reveal a tumultuous relationship with fear, a deep-seated need for protection and an uncertain path to pleasure. These findings are not too different from other more general studies on female sexuality (e.g., Christian-Smith, 1990; Tolman, 2002). Caught in a world fraught with contradictory messages around sex and sexuality, dealing with fear, protecting the self and others, and seeking and allowing pleasure, seem to be elements of a shared journey for women. Yet here they are magnified by HIV and its bio-psychosocial implications.

Gurevich et al. (2007) highlight a fourth experiential dimension to HIV, constriction/restriction. As part of a larger study on identity renegotiation and disclosure, they used thematic decomposition to analyse qualitative data from interviews with 20 Canadian women conducted between 1994 and 1998. By noting the dominant discourses women used when talking about their lives, authors sought to understand how women's sexuality was transformed by HIV.

Reiterating the findings of Siegal et al. (2006) and others (e.g., Lambert et. al., 2005), Gurevich et al.'s (2007) participants spoke of 'diminished spontaneity' due to the constraints of practicing safe sex and the '(un)natural sex' that pursued. Condoms acted as signifiers of disease and of a self that was unnatural and diseased; they were constructed as objects of interference to love-making, leading to 'diminished intimacy' and 'responsibility imperatives'. These preoccupations with self-regulation and responsibility intruded on women's sexual lives.

Gurevich et al. (2007) described how the theme of 'foreclosed sexual freedom' emerged as participants battled with discourses of female promiscuity (apologetic remarks for sexual appetite) and the end of the sexual revolution (mourning the impossibility of their right to sexual exploration). Authors used 'foreclosed' to mean 'provisional' i.e., something temporary that was bound to change, or changed, as soon as HIV was brought into the picture. The discourse of 'foreclosed power and flirtation' represented how disclosure worked to decrease women's sexual agency. On disclosing, women found they no longer had the power to choose what they wanted to do or who they wanted to be, their positions as current, or potential, lovers were swapped for care-giving recipients or embodiments of the virus. Disclosure was also occasionally found to 'incite violence' although this stands in contrast to studies that have also found it to be a way of protecting women from a sense of otherness (Jarman et.al, 2005) and lowering levels of distress and depression (Armistead, Morse, Forehand, Morse & Clark, 1999).

In response to chronic fears around infecting others, Gurevich et al. (2007) found that women constructed a 'muted or mutated sexuality', learning either to quash sexual feelings or mutate them into a deep need for platonic intimacy. Because of this, their sense of self as sexual beings seemed radically changed and some participants questioned their identity as women.

The major limitation of this study is that, like many others, it only presents an account of *negative* experiences faced by women with HIV. The main thrust of both Siegal et al. (2006) and this study seems to be the "unassimilability of HIV in relation to sexuality" (Gurevich et al., 2007 p. 29). There is nothing to indicate possible successful or satisfactory sexual renegotiation. This could be due to a number of factors, most prominently, the years in which the data were collected. Between 1994 and 1998, HAART was in its infancy and not yet widely used. There is no mention of participants being on medication, only that the majority (65%) suffered mild to moderate symptoms. It is therefore difficult to gauge whether women living in contemporary Europe, where provision of, and adherence to, combination therapy has increased in recent years, would respond in the same way.

Despite claims for the need of interventions "to help [women] regain a sense of themselves as appealing, sensual women who can have gratifying, yet safe, relationships" (Siegal et al., 2006, p. 448), both these studies do little to inform psychologists on how this might be done. Quoting one participant, Gurevich et al. (2007) state "no appropriate models exist for conducting sexual life in this context" (p.29). Women reading Gurevich et al. may believe that the only subjectivities available to them are being unnatural, diseased, recipients of care, walking viruses or having a radically mutated or silenced sexuality. If we assume that discourses construct realities (Potter & Wetherell, 1987), it is important to pay attention to how research purporting to uncover and combat alienating and de-personalising discourses, may inadvertently strengthen them (Greene, Frey & Derelega, 2002). Hollway (1984) discusses how discourse theory and analysis can sometimes create a mechanical repetition of discourses which is not only unable to account for change, but ignores the possibility of personal agency in favour of deterministic analyses of participants' experiences.

In contrast to these findings, contemporary websites, blogs[2] and chat rooms (e.g., the pozfem forum[3]) emphatically remind women, “There is much more to you than just HIV… Don’t let your status rob you of your self-esteem [and] don’t be afraid to have love in your life” (The Well Project, 2010).

The closest that psychological research has come to exploring this, was a study by Squire (2003), examining love for positive women of mixed ethnicity in the UK. Like other researchers before her (e.g., Kirkman, Rosenthal & Smith, 1998), Squire used the narrative genre of romance to examine how people make sense of the dangerous realities of HIV/AIDS within everyday discourses about love, sex and relationships. The romantic narrative was first identified by Frye (1957) and represents ‘the quest for an ideal heterosexual love relationship characterised by mutuality and transcendence’ (Squire, 2003, p.77).

Squire (2003) interviewed 16 HIV-positive women, between 1994 and 1998, who were part of a larger study on support for people infected and affected by HIV. Women in Squire’s sample narrated stories with happy endings, of finding love and support, but also of “love-in-waiting” where the search for “Mr. Right” was “imagined or expected” (p.82). Squire highlights that conventional attributes of suitable partners, such as social and personal compatibility, were insufficient in the world of HIV. Here Mr. Right was someone who knew about HIV; was able to deal with a positive status; able to negotiate sex, disclosure and whether to have children. He was also someone who was able to deal with these issues “without becoming violent or psychopathological” (p.80).

Unlike other studies which largely present a barrage of difficulties for women, Squire (2003) facilitates an understanding of love in the context of HIV. By redefining the love object, she highlighted a story of pragmatism, “concerned with love, but also with other matters such as...medical and social uncertainties of HIV” (p.83). Themes of disclosure difficulties and sexual constraint were presented in a non-pathologising manner within the inevitable struggles of a romantic quest.

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[2] See http://hivpolicyspeakup.wordpress.com/?s=sexuality

[3] The only national network of women living with HIV in the UK established in 2004. The forum is an online space where women can share their experiences, inform others on opportunities of advocacy and activism and pass on any other useful information. See http://www.poz-fem-uk.org/

Nevertheless, Squire's (2003) argument on "non-negotiable" (p.93) sexual desire experienced by positive women seems to fall back into more conventional views on HIV. Squire argued that this desire fell outside discourses of risk (i.e., controlling desires because of the risk of transmission or outwardly rebelling against this constriction) or trust and relationships (i.e., having unprotected sex in perfectly loving, unified relationships), it was not a form of self-destructiveness or self-hatred, nor a wish for greater intimacy but an intransigent product of the constraining conditions of HIV. This is puzzling in light of the non-negotiable, intransigent nature of all desire, regardless of HIV.

Using content and narrative analysis, Squire (2003) also conceptualised romance as experiences of enlightenment and progress. HIV romances were stories of "the quest for a solution to the condition itself...of psychic acceptance and social inclusion…narratives of self-discovery" (p.80) with HIV always at the centre. Stories about relationship difficulties contained "conventionally gendered discourses" (p.87) but romance was often HIV-bound and in some cases, love was HIV-limited e.g., partners staying together because of HIV. Squire conceptualised these romances as being both consolation and constraint, with the self always positioned in resistance to HIV and thus, never free.

Even so, Squire (2003) suggested that stories of romance can empower women to understand, express and live with, both the "gendered and sexualised aspects of the condition" (p.89) as well as the "ludicrous, abject, impossible desires". Sharing these narratives also helped build supportive networks between women where they could "conceptualise wider relationship and reproductive possibilities" (p.73) within the otherwise narrow avenues of HIV and sexuality.

The study's greatest limitation was Squire's (2003) over-use of responses from one participant, whose narrative changed within the time-frame of data collection. Most of the negative experiences quoted, related to this participant's previous unsuccessful relationship, from which she had since moved on. Present positive and past negative narrations were analysed together without considering the effect of time on this participant's adjustment. In addition, Squire uses highly academic language that may be inaccessible to positive women in the general public and may be criticised for maintaining the power-divide between professionals and PLHIV.

Research gap

Biomedical, HIV/AIDS prevention agendas have driven many researchers to focus on the sexual difficulties that women experience. This has helped mobilise much-needed services and further research to help support women with HIV. Nevertheless this narrow (negative) focus has also worked to maintain unhelpful, constricting discourses and has inhibited social change in relation to fear and discrimination against PLHIV. Consequently, knowledge about how women renegotiate a *satisfactory* sexual life following diagnosis is sparse.

Although psychological studies have attempted to give a more balanced view, they often struggled to find enough evidence of positive adaptation. Feminist scholars offer a possible explanation for this. Gilligan (2002) describes how, in response to contradictory messages about their sexuality, women and girls learn to silence their pleasure and their knowledge in order to preserve "their connection with others and also the world at large" (Gilligan, 2002 p.15) e.g., to protect reputation, to maintain friendships. Hollway (1984) speaks of a similar process where men and women take up certain positions in discourses of masculinity and femininity because of a conscious or unconscious investment in that position. Gilligan argues that the impact of derogatory, accusatory or conflicting discourses around women's sexuality is "a shock to the psyche that leads to dissociation" and a silencing of the Self in young girls; likened to the loss of voice experienced in trauma. According to feminist researchers (e.g., Tolman, 2002), dominant discourses are often internalised and can override what women know to be true of themselves and their relationships. Considered queer by association (Gorna, 1996) and fallen from grace (Valencia-Garcia et al., 2008), women with HIV are at the frontline of discourses that want to blame, shame or silence their sexuality. In order to live and function in society (maintain relationships), they may have learnt to internalise these discourses that are then called upon to respond to research questions about their sexuality.

However, according to Beauboeuf (2007), women's experiences "can never be completely contained by a cultural or social discourse" (p. 16) and what women really believe and feel can be discovered on listening more closely. In the midst of constraining and fear-laden discourses, researchers have found women for whom desire and womanhood were rediscovered in relationship (Keegan et al., 2005) and where sexual satisfaction was re-established or even improved after a period of adjustment and with a trusted partner (Hankins et al., 1997). Some women found that disclosure enhanced emotional intimacy in relationships (Cranson and Caron, 1998) and that through living with HIV, they felt stronger and more able to express themselves (Kahn, 2000).

This evidence is fragmented and hidden within studies that speak of HIV and female sexuality in negative terms. In light of this, the current study aims to re-visit the ways in which women, fourteen years after participants in Gurevich et al.'s (2007) and Squire's (2003) studies were interviewed, renegotiate their sexual lives following a positive diagnosis for HIV.

Research question

The study focuses on white, European women with HIV, exploring the renegotiation of sexual subjectivity following diagnosis. The guiding questions are: How does a diagnosis of HIV affect a woman's sense of self as a sexual being? What aspects change, develop or stay the same? What does it mean to experience sexual safety in this circumstance? How is her sense of entitlement to sexual pleasure and her ability to make active sexual choices affected? And how does this influence her ability to form or maintain intimate relationships?

Counselling psychology principles will guide my research process as I attend to what helps or obstructs the renegotiation process. Attending to subjective experience, CoP principles aim to give voice to disenfranchised populations (e.g., Hoshmand, 1989; Chwalisz, 2008; Goodman et al., 2004), not only to inform theory and practice but also, to contribute to changing the fabric of social consciousness.

Method

My ontological beliefs and epistemological standpoint

The epistemological backdrop to this study is largely social constructionist as I do not consider reality to be one or absolute, but multi-faceted and co-constructed (Rudes & Guterman, 2007). I believe that through dialogue, researcher and participant can co-construct an understanding of a phenomenon and enter into a transformative process that produces new perspectives (Gergen, 1985; Hoffman, 1990). This is an ontologically relativist view of reality.

Nevertheless, social constructionism brings to light the idea that social and cultural forces shape what is, and can be, known (Hao-Sheng, 2009). Viewed under this lens, personal agency seems relative, as participants' responses are assumed to be limited by the discourses available to them and by the power they have to negotiate them. On this point, I tend towards more critical realist or contextual constructionist views (Madill, 2000). These acknowledge the impossibility of objective knowledge (knowledge is context-specific and affected by the receiver) yet place pragmatic value in contextual truth obtained through research. Inspired by feminist writings (e.g., Tolman, 2002) I believe a person's account is not merely a product of internalised discourses and social interactions but a complex interplay between these, and an inner, active, agentic self that can take on, move with or contradict these same forces.

Methodology, method and rationale

Qualitative methodologies (generally) are rooted in a philosophy that assumes participants' ability to interpret and speak coherently and reliably of their experience. By regarding participants as reflexive, intentional actors who strive to make sense of their social worlds (Marecek, 2003), they embrace the complexity and subjectivity of individuals' lives. Choosing to utilise a qualitative methodology was thus not only related to its suitability for exploring issues of renegotiation and subjectivity, but also linked to a personal preference for the epistemological stance of qualitative work.

The collaborative nature of qualitative methodologies stands in contrast to quantitative work in allowing more space for individual difference. There is still space for the less-supported truths in qualitative research, which can enable overlooked or undiscovered realities to come to light.

Similarly to the therapeutic encounter, most qualitative methods aim to engage researcher and participants as co-researchers in a process of discovery (Guterman, 1994). With a non-prescriptive style to interviews, they allow participants to speak about what matters to them. In light of the myriad medical opinions, legal and political debates that surround PLHIV, this was considered an important and fitting research stance to take.

These features accord with central tenets of CoP philosophy i.e., a commitment "to engage with subjectivity and intersubjectivity" and "to respect first person accounts as valid in their own terms" (British Psychological Society, 2005, p.1). Qualitative data are effective in bridging the gap between research and practice in CoP as the richness of specific cases and experiences can be used to directly inform therapeutic practice. Close analysis may uncover previously unknown, untapped or overlooked aspects of client strengths and difficulties, which can lead to changes in earlier interpretations: a process known as retrospective generalisation (Eisner, 2003). Therapeutic input and future therapeutic choices can then be adapted to suit current knowledge. Within this study, qualitative enquiry also allows for an exploration of a very personal topic in a safe and containing manner, respecting the psychotherapeutic principles of CoP research (British Psychological Society, 2005; BPS, 2009).

From within the ontological and epistemological spectrum of qualitative enquiry I chose to utilise a relatively uncommon method for analysing narrative data called *The Listening Guide* (Gilligan, Spencer, Weinberg, & Bertsch, 2003). This method is explained in some detail in the section below labelled 'Voice-centred research'.

However a few epistemological points are examined here to compare it to other relevant methods of analysis.

The Listening Guide is a form of narrative analysis. It therefore shares a lot of its epistemological and procedural aims with classical forms of Narrative Analysis. Like Narrative Analysis, it also shares an interest in subjective experience (phenomenology) with Interpretative Phenomenological Analysis (IPA). To different degrees, all three methods agree that language, culture, and discourse create and affect reality but unlike methods such as Discourse Analysis, they believe in "the essentially personal, coherent and real nature of individual subjectivity" (Crossley, 2007, p.133). Discourse analysis on the other hand, does not acknowledge an agentic, reflexive self, because through a radical constructionist view, language is not seen as representing psychological or social reality but rather as constructing it. Therefore there is no true reality to discover; only ways in which realities are constructed through discourse (which is what Discourse Analysis, seeks to find).

Because the aim of this study was not to repeat what previous researchers in HIV and female sexuality have done (e.g., Gurevich et al., 2007) (see Literature Review p.20), Discourse Analysis was not considered a suitable method of analysis. Grounded Theory was also set aside as this study did not seek to develop an explanatory theory of women's sexual renegotiation but simply aimed to understand the way they experienced changes to sexual self and identity whilst living with HIV.

The choice between IPA, classic Narrative Analysis and The Listening Guide rested on subtle differences in the approaches' aims, philosophical positions and methodological procedures. In IPA the main aim is to understand individuals' perspectives, to find out how they are making sense of their personal and social world and/or a particular situation they are facing (Smith & Eatough, 2007). This would have largely suited this study's aims. Nevertheless the emphasis placed on self and identity is more closely matched to the aims of Narrative Analysis (Murray, 2003). In addition, more recent versions of narrative research place greater emphasis on multiple interpretations of a single account, providing a means to challenge dominant narratives. In this way it "offers a framework for promoting personal and social change" (Murray, 2003, p.109) transforming the researcher's role into that of an activist. This resonated more strongly with the way I wished to approach this research from within the field of CoP (see p. 24). The advantage and greater suitability of the Listening Guide over the other methods related to the way it takes into consideration all of these points and is also deeply rooted in feminist concerns about equality and power-sharing in research. This held affinity with strongly-held personal beliefs about equality, and spoke to concerns I had about respectfully and accurately representing my participants through this research.

As The Listening Guide is explained in more detail below, I hope to further clarify the philosophical and procedural differences that have made it stand out as the most suitable approach.

Voice-centred research

The Listening Guide is a feminist research tool that "draws on voice, resonance and relationship as ports of entry into the human psyche" (Gilligan, Spencer, Weinberg & Bertsch, 2003, p.157). This means that it relies heavily on the relationship between researcher and participant during data collection and analysis. The meaning of *voice* in this type of research is two-fold. Primarily, voice is the means through which we speak – we all have 'a voice'. If listened to carefully, the rhythm, pitch, tonality and features of a person's voice can tell of their history and the social and cultural contexts which influence and contain it. 'Voice' is therefore like a "footprint of the psyche" (p.157). The second meaning of voice links to psychoanalytical concepts of a layered consciousness (see 'Epistemological underpinnings' p.29 for more detail). Like the psyche, a person's voice can hold within it multiple layers of meaning, different 'voices', or ways of relating to the world. Voice-centred research is thus based on the premise that a "multiplicity of voices" (Gilligan, Spencer, Wienberg & Bertsch, 2003, p.157) can exist within the same person's narrative as different relational and cultural contexts leave their mark. Background to the method and criticism of its early use are presented in Appendix A.

The aim of voice-centred research is to come to know a person's true thoughts, desires and experiences that may differ from dominant beliefs that pervade society

(Brown, Debold, Tappan, & Gilligan, 1991; Brown & Gilligan, 1991, 1992; Brown, Tappan, Gilligan, Miller & Argyris, 1989). The use of the term 'true' is controversial within the overall (largely) social constructionist view of this study, however it is used here to speak of individuals' inner thoughts, desires or experiences.

Although similar to the way IPA approaches data, some important distinctions exist. Firstly, voices are not the same as themes, extracted in IPA. A voice is a way of relating to the world and is more than a descriptive category which portrays the ideographic meaning of a person's utterances. Secondly, a major feature of The Listening Guide is that although narratives are transcribed, the researcher works mainly with the recordings of interviews rather than with text, as nuanced meanings in tone and pitch of voice are central. Thirdly, the Listening Guide aims to draw out the voices of marginalised or less 'powerful' people in society, particularly women. It tries to understand how people make sense of their experience within broader cultural discourses of gender, power and politics (Beauboeuf, 2007; Gilligan et al., 2003), attempting to uncover truths that may differ from mainstream understandings of a given subject. It therefore takes an active, pseudo-political stance to research, seeking to empower participants and viewing them as insightful co-researchers. This stance is of great relevance to HIV research as discourses of gender, power and politics shape medical and social services and influence the positioning of positive women in society.

Epistemological underpinnings

Voice-centred research draws on four theories (psychoanalytic, relational, literary, and music theory) to produce a multilayered account of the phenomenon being studied. These theories share similar epistemological views: that truth and knowledge are multilayered, affected by cultural, social and relational environments; that the production of knowledge is influenced by the producer and the listener; and that listening for difference can unveil previously untapped perspectives.

With its emphasis on voice as "an instrument of the psyche" (Kiegelmann, 2009, p.9), the Listening Guide is rooted in the psychoanalytic concept of a layered consciousness. Departing from the notion of an 'internalised other' it proposes that social processes and cultural meanings are internalised into conscious and unconscious thoughts and behaviours. By listening to the way people talk about themselves and their experience, one can start to distinguish voice (i.e., true thoughts, desires and experiences) from the cultural discourses that may mask what people know and feel (Gilligan et al., 2003). Attention is therefore placed on participants' experience of their social worlds and its distance from, or proximity to, culturally prescribed narratives (Beauboef, 2007).

The Listening Guide is also based on the theory of postmodern non-unitary subjectivity (Bloom, 1998; Merriam & Caffarella, 1999) i.e., a view of the self as fragmented and multifaceted. Contrary to traditional Western views of a single, coherent and fixed self (Weedon, 1987), it posits the existence of multiple selves, or *voices*, that are "active and continually in the process of production within historical, social and cultural boundaries" (Bloom, 1998, p 4). Accepting the notion of multiplicity does not signify a loss of self or a reification of fragmentation, but offers a way of understanding "the complexities of human identity" (Bloom, 1998, p.6). The Listening Guide borrows from music theory in its use of language to explain the layered texture of meaning it produces. The word 'counterpoint' originally from the Latin meaning for 'point against point', is used to describe how different voices follow one another. Counterpoint involves writing two or more musical lines that sound different and move independently, but which are harmonious when played together. Like counterpoint, voices sometimes meet in unison or move apart; contradicting and complementing, one another as part of the same harmony.

Another key set of assumptions present in this method come from relational psychology (Aron, 1996; Gilligan, 1982; Miller, 1976; Tronick, 1989). This is based on the premise that humans develop in relationship with others and that one's sense of self is inextricably linked to one's social world (Haug et al., 1987; Spencer, 2000). Through this theory, analysis is always placed in relational contexts, paying attention to how gender, culture and even research contexts affect what is known. Being fundamentally a feminist research tool, the Guide "places the social construction of gender at the centre of inquiry" (Cruz, 2003, p.5; Lather, 1992), attending to and examining the interplay between societal representations of gender and sexuality and the actual experiences of individuals (Beauboeuf, 2007). It aims to highlight that the personal can be political and vice versa. It is thus well-suited to the current study where this overlap is seen as particularly powerful and inevitably part of positive women's sexual lives.

The feminist philosophy, woven deep into the fabric of voice-centred research, recognises that, although social change has made gender issues more subtle, they persist on more unconscious levels of thought and behaviour, sometimes making them more difficult to identify and respond to. Through this research, I was vigilant for lingering inequalities between men and women but remained cognisant that gender is not the only denominator of power.

The Listening Guide takes note of the relationship between researcher and participant and the socio-cultural contexts that surround them. Drawing on literary theory, it encourages the researcher to take up two positions; the resisting-listening position (Brown & Gilligan, 1992) and the reader-response position (Gilligan et al., 2003; Morawski, 2001). The first requires trying to free oneself from dominant cultural discourses by listening for signs of "self-silencing or capitulation to debilitating cultural norms and values" (Gilligan et al., 2003, p.30) and then giving voice to a different reality and vision. The second solicits the recognition that the reader is not able to be neutral or objective and thus needs to be reflexive and transparent about her/his own responses. The second position does not negate the first but challenges the belief that we can truly, successfully resist all internalised, pre-conceived ideas about a given situation. Voice-centred research is therefore also social constructionist in its epistemological understanding, requiring the researcher to carefully consider their contribution to meaning-construction within the research (Willig, 2001).

As a researcher in CoP, I am intrigued by the resisting listening response because in a world where carrying HIV can be an experience fraught with doubt, misunderstanding, blame, danger and judgement, it serves as an ideal tool to help sift through widespread and potentially disempowering discourses, to honour the uniqueness and complexity of the human person. This resonates strongly with the principles that guide my profession (BPS, 2005). Although the resisting-listening and reader-response positions seem to mimic the practice of 'bracketing' in qualitative research, they go a step further. Whilst bracketing is the practice of blocking personal or social biases and assumptions about a given phenomenon to understand how it presents itself in the world (Langdridge, 2004), the resisting listening position offers more specific guidance on how to do this by noticing moments of self-censoring i.e., an urge to stay away from taboo issues that may arise during analysis and then resisting them by further exploring the difficult or 'forbidden' questions. In addition, the reader response position does not aim simply to bracket-off the researcher's responses but brings them to light, transparently presenting the process of resonance and relationship that occurs between participants and researcher.

The method's feminist underpinnings also draw attention to power imbalances that exists between the researcher (who designs and directs the study) and the participant, who may feel unable to fully express themselves in the presence of someone with greater social or educational power (Jowett & O'Toole, 2006). The Listening Guide seeks to address this through researcher reflexivity and by encouraging power-sharing e.g., through participant feedback (Willig, 2001).

The Listening Guide Method

The guide lays out four steps for data analysis, aiming to produce a clearly outlined, multilayered interpretation of transcribed data. In acknowledging the relational nature of interpretative work (Tolman, 2002), it discourages the use of the third person to describe procedure. Therefore, rather than anonymising myself and distancing myself from the respondent, I attended to the relationship between us by placing myself directly within the research process.

The first reading is made up of two parts. Firstly, I paid attention to the plot, familiarising myself with the overall stories presented by participants, much in the same way as other forms of Narrative Analysis or IPA would dictate. I listened for repeated words/phrases, recurrent images, metaphors and omissions or breaks in the narratives (interruptions, abrupt changes of subject and/or tone of voice). I took note of these in a column beside the main text. Secondly, I noted my personal responses to participants' stories (Appendix B), recording my first impressions and tracking my intellectual and emotional responses in same column (Brown & Gilligan, 1992). In this reflexive reading (Doucet & Mauthner, 2008) my task was to distinguish my own voice from that of participants before speaking on their behalf, but also to note where I felt connected or distant from what participants were saying i.e., to note resonances between us. This process is similar to what a clinician would do in therapy to be able to listen and connect to the client.

The second reading involved listening for the first-person voice, the "I" statements, within the narratives. By choosing puzzling, or particularly interesting, sections of the transcript e.g., parts that seemed to contradict common assumptions about living with HIV; places where participants seemed to struggle to express themselves; utterances that seemed at odds with the overall story being told, I marked each "I" phrase (subject, verb and any significant accompanying words) and listed them in the order they appeared in the text to create "I"-poems (Appendix C). The poem stanzas were based on natural breaks in the recordings where there was a change of subject or a pause. Often phrases with variations of "I" were also used such as 'me', 'myself', 'my' and also places where participants shifted between 'I', 'we', or 'you', as this can signal varied perceptions of self (Stanley, 1993; 2002). The aim of "I"-poems is to pick up on participants' stream of consciousness as they speak about themselves and the limits of their social world (Gilligan et al., 2003). This can often reveal new meanings to what is explicitly said, "capturing what people know about themselves, often without being aware of communicating it" (Kiegelmann, 2009, p.39). The process also highlights places where the participant "might be emotionally or intellectually struggling to say something" (Doucet & Mauthner, 2008, p.406). Listening to the "I" voice allows the researcher to see how sometimes the desires and wishes of the 'I' (or self) are built around, or validated by, what 'we' (the larger society) do, or 'one' is supposed to do, but it also enables the researcher to note where the 'I' is audibly out of step or in tension with the assumptions and restrictions of a given culture. The limits of their social world may be apparent in the way they are unable to voice their true desires, thoughts or experiences because there is no way to talk about them or it is not allowed.

The second reading and the creation of "I"-poems adds a dimension to the analysis that is unmatched in other methods. This first-person voice is not constructed for the other, or in any way organised to be presented to the other. Neither is it organised *by* the other or by culture. It approximates the unconscious, and thus can give unique insight into participants' true thoughts, desires and inner subjective worlds. This also marks the limits of a social world as it speaks of an experience that is somewhat removed from it.

During the third reading I listened for *contrapuntal* or *relational voices* i.e., "different ways of voicing the relational world" (Taylor, Gilligan & Sullivan, 1995, p.31). By re-reading the transcripts a number of times, I identified multiple facets to the stories being told that spoke to the research questions i.e., I started to listen to the different voices present within each narrative. Relevant theory and literature on female sexual subjectivity and seropositivity helped me to 'turn up the volume' on "voices that are in tune with theoretical expectations and those that are somehow obscured by mainstream constructions of the phenomenon" (Sorsoli & Tolman, 2008, p.502). Distress and trauma are commonly reported in the literature, therefore I first listened for voices related to this. The musical metaphor of counterpoint helps conceptualise how 'turning up the volume' may be done by paying closer attention to voices that may be 'softer' or less obvious than others because they do not conform to mainstream understanding of a phenomenon and are thus harder to hear. It is hoped that theory used to identify relevant voices, is later informed and sometimes modified, by what emerges from the narratives.

When identified in one narrative, I created a marker or initial description for each voice, then listened for them in other interview-transcripts. After listening for the same voice in different interviews, I assessed whether its definition made sense or adequately explained a meaningful aspect of the text. Sometimes I listened again to fine-tune it to nuances picked up from different women's narratives. At first I identified three contrapuntal voices that spoke to the research question, then I reviewed important aspects that emerged from earlier listenings and either added them to existing voices or listened for them as a separate voice. Six voices were identified through this process.

I marked each voice with a different coloured font on a separate worksheet to create a trail of evidence (Brown et al., 1989) (Appendix D). Different colours provided visual evidence for the interplay of different voices i.e., how they moved together or overlapped. Unlike other qualitative methods such as Grounded Theory or IPA (according to descriptions by Smith & Eatough, 2007), the Listening Guide allows for multiple coding of the same text - transcripts are read through a separate time for each contrapuntal voice, therefore a single statement is often found to hold multiple meanings and marked several times.

During the fourth reading, I sought to identify how the first-person voice for each participant, from the second reading, related to the contrapuntal voices extracted in the third. I searched for alignment between the voices, asking myself the following questions: Is the self voice in agreement with, or contradictory to, the various voices identified? How do the voices relate to one another or appear in the text? How do they speak to the research question? And what evidence is my interpretation based on?

Finally, I pulled this information together to create a description of what I learnt about each participant (see Appendix E). However, in the following chapter, I presented them in a way that would respect their anonymity by speaking more generally about the women's voices as a group rather than individually.

Reflexivity, validity and power-sharing

From a social constructionist viewpoint, sound qualitative research should demonstrate participants' constructions of reality whilst presenting an accurate account of the co-construction that inevitably occurs *between* researcher and participant.

The Listening Guide is designed to guide the researcher in their interpretations; to note personal resonance with the participant's voice but also to pay attention to social and cultural resonances that may emphasise or mask what they are trying to express (Gilligan et al., 2003). It puts great emphasis on the researcher's self-reflection guiding them to reflect on, and reveal, themselves in their research.

Validity and reflexivity are intricately linked throughout data analysis. Tracing my closeness (connectedness) and distance (disconnection) from each participant in the first reading, allowed me to note how I may be blinded or biased in my interpretations. Presenting these considerations transparently and coherently helped the study gain validity, creating a comprehensible trail of evidence (Yardley, 2000; see Appendix B). In this first reading I considered how my actions (tone of voice, non-verbal expressions), characteristics (young, adult female with negative/unknown serostatus) and position as researcher may have affected participants' responses. I also noted my social location to each participant (Mauthner & Doucet, 1998): defined as similarities in gender, ethnicity and social class that linked us and differences in culture, background, religion, experience and understanding that distinguished us. Making cultural and power differentials explicit, allowed greater transparency in the analytic process. Furthermore, a second trail of evidence was created in the third and fourth readings which connected my interpretations to the original transcriptions (see Appendix D).

Inter-rater reliability, within the epistemological framework of this research, does not require that the same interpretations be made by an independent person but rather, that another person can follow in my interpretive footsteps because of the transparent way in which the analysis was conducted and presented. Feedback on my work from colleagues working in the field of HIV and from my research supervisor confirmed this.

Due to the interpretive nature of the research, sharing power was crucial for data validity. This was done by seeking participants' collaboration in the final stages of research. Following initial (individual) interviews, participants were invited to discuss my interpretations as a group. I was curious to hear the women's views on the analysis and whether they thought it was an accurate representation of their personal worlds (Sorsoli & Tolman, 2008). I presented the different voices alongside women's "I" poems in an anonymous and generalised fashion. A more detailed and individualised discussion of voices and "I" poems would have made a further claim for validity and power-sharing but it would have also required that I take on a more psycho-therapeutic role with participants which would have been inappropriate in this setting. Reisman (1993) advises against a complete abdication of the researcher's intellectual independence during this process. Consequently, the feedback collected was not used for analysis in the same way as individual interviews, but incorporated into the discussion of results. The Listening Guide generally uses individual interviews as the main data collection strategy, nevertheless seeking respondent validation is consistent with its feminist tradition of co-research and the sharing of power (Wilkinson, 1998). Participant feedback helped the study gain credibility through a shared understanding whilst a group format was used to foster a sense of 'collective agency' amongst participants (Tilley, 1998). Feminist research suggests that through groups, women share resilience, power and compassion, and encourage one another to act on their strengths in meeting future challenges (Williams & Ayres, 2007; Mkandawire-Valhmu & Stevens, 2010). It was hoped that this research would facilitate such an experience.

Research design

Qualitative data were collected through semi-structured, individual interviews with six participants and analysed using The Listening Guide (Gilligan, Spencer, Weinberg, & Bertsch, 2003). A follow-up participant feedback group was conducted to examine and strengthen the validity of findings and to create a space for participants to meet (Brooks, 2000; Legard, Keegan, & Ward, 2003).

The participants

Six, white European women aged between 27 and 51 who had been living with HIV for a minimum of two years, agreed to participate in this study following my contact with them through Positively UK[4] and BASELINE[5]. I used both convenience sampling (Ritchie, Lewis, & Elam, 2003) and snowballing (Creswell, 2002) as recruitment procedures because the sensitive nature of the topic made it difficult to recruit participants from the general public. It could be suggested that being

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[4] Previously known as Positively Women, this London-based charity offers peer-support to women, men and youth with HIV /AIDS across the UK

[5] An NGO that publishes a free monthly magazine distributed to over 200 HIV clinics and community support groups in the UK.

affiliated with an organisation (albeit loosely) or knowing a third person who introduced the possibility of participation on my behalf, helped tackle issues of trust and credibility that may have otherwise deterred people from participating.

The number of participants was decided according to guidelines for small scale qualitative research (Langdridge, 2004) as well as availability of participants. Focusing on a few cases enabled me to take into consideration broader cultural concepts and complex inter-relational patterns (Camic, Rhodes & Yardley, 2003) that might have been at play.

A time-span of a minimum of two years post-diagnosis was chosen because anything short of this was considered too soon for women to have started to adjust to changes related to seropositivity. This decision was made following various conversations I had with psychologists working in the field and with managers of organisations that support people with HIV (e.g., Positively UK; Hope Gate Trust; Terrence Higgins Trust; Positive East).

The decision to recruit white, European women was informed by a gap in the literature on HIV/AIDS and female sexuality (see 'Introduction') and inspired by feminist perspectives on equality and minority representation.

To take part in the study, participants must have previously been in therapy or attended a support group to ensure they had experience of discussing issues related to their HIV status. It was assumed that this would act as a protective factor against any distress created by the interview. The possible effect of this inclusion criterion on analysis results is discussed in the final chapter (p.100)

All participants held regular jobs and were active in the community. None reported being on psychiatric medication nor considered themselves to be suffering from mental health difficulties. This was confirmed through informal conversations I had with participants prior to the interviews where I briefly assessed their mental state.

Two participants were on anti-retroviral medication; the others had low/undetectable viral loads and high CD4 counts and therefore did not require HAART. Three of the women identified as heterosexual, two had relationships with men and women but did not identify as bi-sexual, and one participant was questioning her sexual identity despite living as a heterosexual. All six women had contracted HIV through sexual intercourse in heterosexual relationships. More detailed participant descriptions can be found in Appendix E.

Materials

An initial information sheet (Appendix F) and consent form (Appendix G) were used to inform participants about the study and gather informed consent. A semi-structured interview schedule (Appendix H) was used for data collection. Open-ended questions asked in the interview centred on the topics of: personal experiences of sexuality and intimacy generally; past and current experiences with HIV in relation to sexuality and intimacy; entitlement to sexual safety and pleasure and; identity as a sexual being. Specific questions about the effects of therapy or support groups on women's experiences post-diagnosis were omitted. Instead, women were asked general questions on the process/ experiences they went through since diagnosis and what they think contributed to change, if they felt there was any. This ensured that participants were left free to mention what *they* felt was important. Follow-up or clarifying questions were asked if participants then made reference to these sources of support. Interviews were recorded using a digital recorder. A debriefing sheet (Appendix I) was handed to all participants at the end of each interview (see 'Ethics' for rationale).

Procedure

Potential participants were approached through Positively UK and BASELINE via emails sent by the organisation, containing information about the study and my contact details. Interested parties contacted me directly via email. A time and venue for the individual interviews were arranged, depending on participants' availability and preference. Confidentiality was upheld by ensuring that the venue was private enough for participants to speak freely without disturbance. When meeting at participants' private residences, I ensured my own safety by letting a trusted person know where I was and the estimated length of the interview. I also made plans to call them afterwards to indicate that I had left safely.

On meeting, participants were reminded of the study's aim and given the opportunity to ask questions in order to gain fully-informed consent. They read and signed the consent form before commencing the interview, which lasted about an hour.

After the interview, participants were encouraged to voice any queries or concerns about the research. They were given a debriefing sheet with my contact information and that of my supervisor should they have required further clarifications about the study. It also contained information on immediate and longer-term access to counselling services that participants could contact if needed (see 'Ethics').

Interviews were later transcribed and analysed using the Listening Guide (Gilligan et. al, 2003). After an initial analysis, participants were invited to take part in a participant feedback group (held at Positively UK). Feedback was not transcribed or analysed but included in the discussion of results.

Ethics

The study was conducted according to the British Psychological Society's (BPS) ethical guidelines (2005) and approved by the Research Ethics Review Panel (RERP) for the Psychology Department at the London Metropolitan University (Appendix J). Ethical approval for recruiting participants was also granted by Positively UK as a collaborating organisation.

To safeguard anonymity, participants were given pseudonyms. The same was done for people and places mentioned during the interviews This excluded Positively UK and Baseline who agreed to being mentioned as participating organisations. Participants were advised that to protect confidentiality, recordings would be used for the sole purpose of this study and would be accessible only to myself and my research supervisor. Participants were made aware that data collected for this research could later be published in psychological journals and articles issued by Positively UK or BASELINE. They were also reminded that they could withdraw from the study until three weeks after the interviews. After this, data analysis would have progressed making it difficult to separate an individual's contribution from the larger analysis. If participants had chosen to withdraw during the set time, interview recordings would have been deleted and transcriptions destroyed. None of the participants withdrew.

Transcribed data were kept separate from the consent forms to ensure anonymity. The former were stored electronically in a password protected file on my personal laptop whilst the latter were stored in a locked drawer.

Recruitment criteria, together with an informal assessment of the mental state of participants (see 'The Participants') ensured as far as possible, that despite being considered a vulnerable population due to their HIV-status, participants were well-adjusted and mentally healthy individuals, able to discuss such a personal and potentially sensitive topic in a manageable way. To monitor any unanticipated negative effects from the interview, debriefing occurred afterwards (Appendix I). And a distress protocol was prepared (see Appendix K).

While attempting to create an environment of mutual respect and safety, participants were made aware that the scope of research differed from that of therapy and the researcher would not give professional feedback on personal issues discussed. Participants were nevertheless encouraged to contact me or my supervisor should they have any questions or comments related to the study, or to withdraw their participation.

Analysis

The voices that emerged from the third reading will be presented here alongside the women's "I" poems. This will provide a multi-layered presentation, faithful to the complexity in renegotiating one's sexual life following a positive diagnosis for HIV.

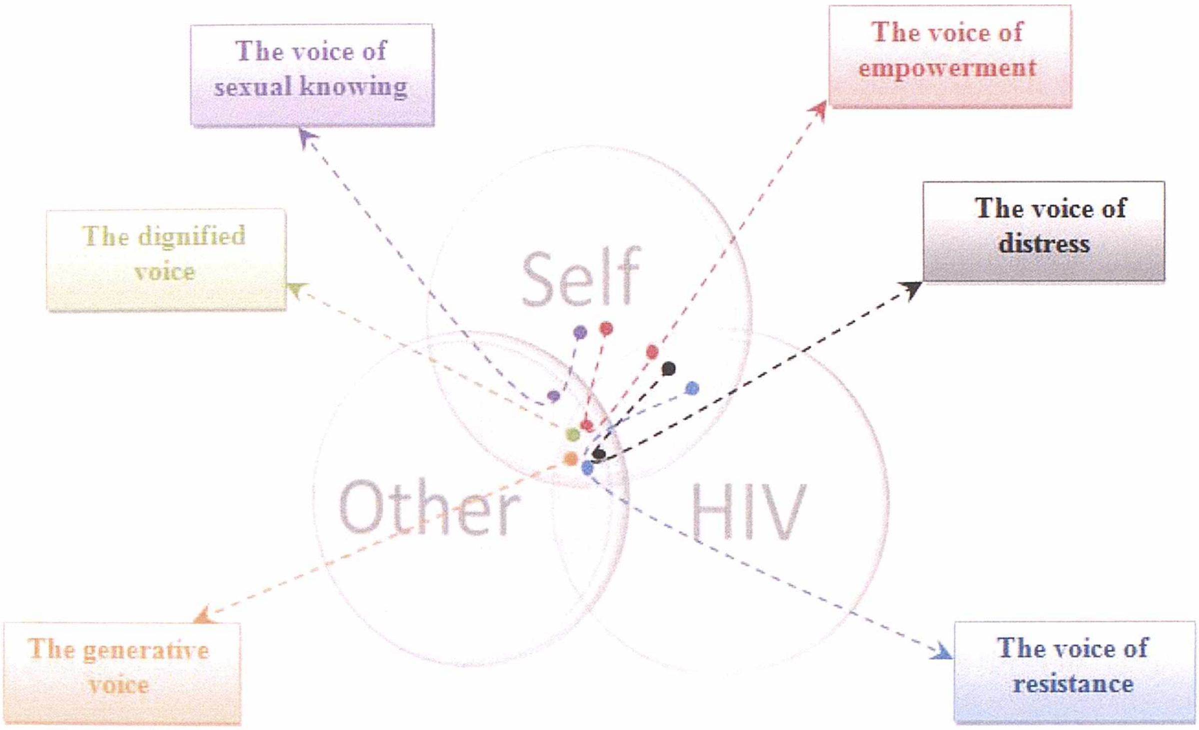
Six voices were extracted from the women's narratives:

1. The voice of distress
2. The voice of resistance
3. The voice of sexual knowing
4. The voice of empowerment
5. The generative voice
6. The dignified voice

The order in which the voices are presented can be interpreted as a renegotiation pathway where the initial distress and trauma experienced after diagnosis, slowly transform into resistance and push-back survival instincts as the women learn to listen to their sexual selves more, understand themselves better, and inhabit a place of greater empowerment and dignity. Presenting this process as a linear one however, is neither useful nor accurate. Using the analogy of sound, it is more helpful to think of the voices as being present simultaneously, with some voices heard more loudly and clearly in different women's narratives, at different points in time.

Taking inspiration from HIV literature and analysis results, I have conceptualised women's renegotiation of sexual subjectivity as a four-dimensional process. The six voices spoke of relational ties that the 'Self' created and maintained, with itself, with 'HIV', with 'Others' and between 'Self' *with* 'HIV' *and* 'Others' (see Figure 1. below). As the voices moved within these four dimensions, they were heard either to contradict or to correspond to one another as contrapuntal pairs.

Figure 1:



The voice of distress was heard at the intersection between Self and HIV and Self, HIV and Other. *The voice of resistance* touched upon the same relational ties but countered the voice of distress. *The voice of sexual knowing* was heard to be cultivated within the Self and expressed when Self related to Other. *The voice of empowerment* touched upon three dimensions, Self relating to Self, Self relating to HIV and Self (with HIV) relating to others. It often followed the voice of resistance in countering the voice of distress within the narratives (depicted on either side of the voice of distress). It was also often in synchrony with the other three voices. *The generative voice* developed from a relationship between Self with HIV and Other. *The dignified voice* emerged when Self with HIV was made known to Other. The movement and overlap of voices will be explained further as each voice is presented below.

The model, pathways and voices can be understood and interpreted in many different ways. I present here, *my* efforts at listening to Dona, Vanessa, Kate, Andrea, Tasha and Jenny (pseudonyms) as they shared with me their understanding and experience of sexuality and HIV. To assure participant anonymity, pseudonyms were not used to identify different women's individual responses. Line numbers were kept as evidence to link quotes to the transcribed text, without jeopardising anonymity. In the transcribed text "[…]"marks places where spoken material has been omitted for the sake of clarity in presentation; "…" denotes a pause in participants' speech or narrative; whereas "…" at the beginning and end of a quote shows that it was extracted from a longer sentence.

1. *The voice of distress*

Incredibly nuanced and multifaceted, the voice of distress spoke of the relationship between Self and HIV, and Self, HIV and Other. It could be heard as whispers and loud cries at different stages of the women's lives, sometimes present in silences surrounding their sexual lives *before* infection and echoing across the empty space of disconnection following the trauma of diagnosis.

1.1 *An early vulnerability*

This is an aspect of the voice of distress, through which four of the women spoke about a personal vulnerability that they could link back to being infected with HIV. It is important because it highlights early signs of this voice that may have gone unnoticed, thus creating vulnerability to infection.

> …as a young woman I had a lot of insecurity [...] the fact that I could be sexually available made me feel wanted...and made me feel…accepted…but it was, you know, it didn't really allow for….maybe the closeness that I was really looking for...(48, 52)

> …in the past, sex has been a bit of an escape for me when em…like if I haven't wanted to deal with certain things…the way, I would feel better would be by…meeting someone and having sex with them...(31)

Participants seemed to describe an instrumental use of their sexuality to satisfy deeper needs which they were “ill-equipped” (49) to recognise and respond to. One older participant, who had addressed these issues in therapy, recognised that this vulnerability coalesced with societal forces to place her younger self in a precarious position.

> [I] was living in a society which, sex-ified and objectified young women a lot and I think that the mixture, of this willingness of exploring eh... sexuality and eh maybe some, you know, issues with self-esteem and depression, made me very vulnerable (46)

Other participants highlighted other factors that may have affected their initial vulnerability. One woman spoke of naivety, linked to a conservative upbringing, where sexual exploration was prohibited. Another, mentioned lack of information, as sexual fears in her youth related to pregnancy, not disease. She also spoke about a daughter’s desire for a guiding maternal figure that was absent from her life.

1.2 *The romantic veil that somehow disappears*

Whether it was naivety, lack of information and parental direction, or an inner sense of insecurity that brought these women to encounter HIV, it was the sense of disillusionment, a loss of innocence, that accompanied them following diagnosis. ‘The romantic veil that somehow disappears’ (71) is the way one participant described the distressing effect of HIV on sexuality.

> …something that should have been very natural, like two people being together in a sexual way […] didn't, didn't turn out to be, right for me…(93)

> I was never told by my parents that sex was something sinful but it was something to be enjoyed and I think...when I was younger […] I wanted to enjoy it but eh... unfortunately this sexual freedom that my parents were encouraging […] wasn't happening... in ...an equal world or wasn't happening in a world that...was really free (46)

For some, disillusionment was a realisation that sex was not only about romance but also about physical practicality and safety. For others, the dream of sexual liberation, promised by earlier generations, was still being fought for, never fully conquered. Disillusionment came on strongly and painfully for one woman who was diagnosed in the aftermath of her marital separation. Experiences of disillusionment also happened on very personal levels, where women discovered that knowledge did not necessarily translate into personal power or self-esteem.

> The fact that, you know…that you went to university and you read Marxism and you know about Virginia Wolfe and […] all the feminist authors doesn't mean that when you are in a, in a relationship with a man that you are gonna be able to behave in the way that you have been, taught to think… […] there is almost a disconnect between your intellectual self and what you are like when you are with this desire and this need to be, to be close to somebody, to be close to a man(49-50)

At times disillusionment was strongly tied-in with regret.

> …if I'd […] had more conversations with [my lesbian friend] instead of just having this ideal of, of male and female and not looking at my own sexuality [...] then maybe I wouldn't have been in this situation now (83)

1.3 *Trauma and disconnection*

The voice of distress could be heard loud and clear when the women spoke about first receiving their diagnosis. Finding out they were HIV-positive was a traumatic event which radically changed the women’s lives and perspectives.

> …I mean, just…my whole world got turned upside down (35)

> …when I was told that I was HIV positive, I thought I would die very quickly, a horrible death (66)

The trauma experienced however was most evident in stories of disconnection. The first point of disconnection occurred within the self on encountering HIV.

> [I] just completely, kind of em…eh…shut down… ...for two years and I was just kind of on auto-pilot really (91)

This feeling of disconnection from the self was most clearly heard in the following "I" poem, where a dialogue between a self that is recognised (I) and a self that is less personal, more distant (You), marked a separation within this woman's psyche.

> You know,
> I cannot
> You know
> You have this thing in your body
> You know...
>
> Your enemy inside you…?
> I don't know
>
> I think
> Your body becomes your enemy…?
>
> You have this kind of, this feeling of disconnection,
> You're not really sure who you are anymore
>
> …
>
> I...
> I cannot see this HIV
> You know
> I cannot,
> I haven't really experienced
> I have access
>
> You know
> You know,
> I think…
> I think...health-wise
> I've been okay.
>
> You know,
> I don't know.

Another form of disconnection was “denial” (102). One woman ignored the possibility of having HIV for years to protect her family from repercussions of the news. Another seemed to experience disconnection on two levels. The first was conscious and easily accessible.

> …we had a couple of years I think where we were completely in denial both of us, em about em... ... about our HIV. Completely in denial (102)

The second was more sub-conscious, emerging in her “I” poems (Appendix C, point *3*). When talking about life with HIV, she clearly shifted from “I” to “we” indicating that the experience of being HIV-positive was tightly bound to her (seropositive) husband. Seemingly marking a connection, this shift signalled a loss of self, a discontinuation of an earlier, separate self.

Disconnection was also present in relationships with others when HIV was involved. Silence and disconnection initially befell one participant’s marriage when she discovered her husband had given her HIV. Other times, the women did not experience disconnection directly because of HIV but because of their lovers’ reaction to it.

> A lot of my relationships broke down and then at the end of it I had, you know, very abusive, very violent reactions from my partners…I've been accused of being a killer, I've been accused of being this…you know really…you know, horrible, horrible, violent […] I feel the rest of the world, is my, is an enemy (203, 205, 209)

> It made me feel really sad…I was quite depressed (laughs nervously) when, when I was with him…emmm… I think…I felt angry, very angry sometimes, that, he didn't wanna listen or that he didn't want to understand. (121)

Feeling disconnected because of others’ reaction to HIV and the resultant sexual constraints, became “an identity issue” (135) for one participant. Without being able to connect sexually with the other, she felt “useless” (111), irrelevant, as if one kind of disconnection (from other), caused a disappearance of the self. Another participant echoed this.

> I'm just
> I am not…
> I'm not…
> I am not
> I think
>
> You are just pushed...
> You're outs-,
> You're outside
> I don't know,
> I just feel
>
> You have HIV,
> You've done something
> You are ...a bad person
>
> I think
>
> I think,
> You have a relationship
> You,
>
> You as a woman with HIV,
> You must be… a junkie
> You know…
>
> (213, 215, 217, 219)

When either, or both, of these forms of disconnection were experienced (within the Self because of HIV and/or between Self with HIV and Other), women were unable to safely interpret others' motives. Many could not imagine being accepted by others and were left deeply confused when others wanted to connect with them. Acceptance was seen as a foreign, unrecognisable occurrence, an unimaginable "gift" (129) for some.

> Why would somebody want to be with me after that? Why would somebody be, in danger or put themselves in such danger all the time? But it, it's because for me it is very difficult to put myself in somebody, uh, who, somebody who's not, um, uh, positive, uh, in their position I can't see it (129)

The women described lacking trust in others and consequently some lived this by lowering their expectations.

> I think with a lot of positive people uh […] our trust has been […] misused? Or…broken […] and I think it's difficult to, or at least it was difficult for me em… … …to want to trust somebody…again (91, 95)

Sometimes, even when encouraged to elaborate, the women were unable to finish their sentences or collapsed their explanations into phrases like, "there are so many layers, it's a bit difficult to explain..." (187) or, "it's complicated" (54).

> I think it's difficult to...even express that. You know, it's like something that once you…and it's strange to experience something like that, you know, quite young... (181)

This trailing off of voice may have signalled an experience difficult to process (disconnection from self) and hard to convey (disconnection from other).

1.4 *The gremlin on my shoulder*

The voice of distress spoke of an internal and interpersonal battle fought against guilt, anger, shame, fear and isolation. This is the ugly side of HIV. One participant described the voice of distress as 'a gremlin' that would speak out what she tried to hide.

> I used to think about the gremlin on my shoulder
> I was first diagnosed
> I just had this,
> I couldn't tell,
> I mean,
> I told my sister
> I couldn't,
> I didn't feel up to telling anybody else
>
> I used to think about this gremlin …just sitting there
> I would introduce myself
> 'Hello, I'm …'
> I,

You know
I felt like this gremlin…was just sitting there saying
'And I'm HIV positive also'
I was having to tell it to shut up
(81, 83, 85)

Other participants spoke of their experience of guilt and shame and an almost unbearable fear of rejection and isolation.

> I had this guilt inside coz I hadn't been able to tell to the partners and […] I would have to leave, you know, coz I couldn't imagine telling them (91)

> …rejection... ...would fill me with...dread and fear and this feeling like... ...it was too painful to live with it? (95)

1.5 A blanked out sexuality

The voice of distress also spoke of the pain women feel when the diagnosis threatens the legitimacy of their sexuality. This section speaks of the ways in which women experienced an overshadowing of their sexuality.

I see it and think
Who you are as a sexual being
You're no longer…
I don't know
(67, 69)

Some women internalised this experience whereas others attributed it to a societal phenomenon which they externalised and (as demonstrated later) resisted.

I think
It's automatically assumed that we should be asexual.
You know
Our sexuality just gets blanked out
You know,
Sexuality just kind of gets ripped out of you?
(17)

Whether externalised or internalised, this phenomenon was experienced as a loss of control over one's "sense of self" (379) because one's sexuality becomes "everybody else's property". The voice of resistance (see below) was first heard, as women took a stand against this blanking out of their sexuality.

2. *The voice of resistance*

This voice touched upon the same relational ties as the voice of distress but countered it, mediating the relationship between distress and empowerment. It could also be interpreted as a voice of resilience, contradiction, rebellion or sexual agency but 'resistance' represents its constant presence, the way it was sometimes pushed back by distress but never really overthrown. It was heard at the intersection between self, HIV and others, as the women resisted societal expectations of HIV-positive women, wanting to change society's misperceptions of PLHIV. In a pseudo-rebellious manner, women also resisted internalisation of societal messages and defended what *they* knew to be true of themselves.

2.1 *I am not my HIV*

Articulated most clearly and assertively by three women, this concept was found in all the women's narratives.

> I'm (age below thirty)…
> I…wouldn't … necessarily describe myself in relationship to HIV
> I don't think it represents me…
> It is part of me, but, it isn't what I am.
>
> I wouldn't say that
> When I talk about myself
>
> I think
> I'm a ...young woman,
> I was very young
> I was diagnosed with HIV.
> I had to…work my way around it
>
> I consider myself just a normal person
> I love

> I come from (a European country)
> I was diagnosed
>
> (5-19)

In resistance to HIV taking over, this participant is paradoxically forced to put HIV first to then organically integrate it into her self-description. Similarly, she initiated a seroconcordant relationship through an online dating site for PLHIV, putting HIV first to then minimise its influence on her life.

> …people who like dancing, meet at a dance club and they start from there, people who like chess, um, yeah meet there and they have a basis for their thing so...em, that's what brought us together…but that doesn't define our relationship (179)

Seeking normality and being "a fully-functional person" (171) was important and often mentioned by participants.

> HIV is a virus […] a woman with HIV is […] I'm just like everybody else. I am not… ...I'm not…you know, a Martian (laughs), I am not from another planet (213)

> My life it's normal,
> Our sex life is normal,
> Our intimacy is normal now
>
> (124)

Due to a conservative upbringing, this woman (quoted directly above) demonstrated a particularly intense preoccupation with normality. HIV presented the ultimate test for her and pushing it aside to reclaim a more balanced life took time and even involved resisting medical advice.

> We decided...if we were to get on in this relationship I think we just have to lead what we class as a normal life em, even though, the doctors were advising us otherwise, we made the conscious decision…[to have sex without condoms](101)

Listening to the voice of resistance was important for these women to find themselves again and to protect themselves from discrimination or stereotyping. It helped one participant manage the disproportionate importance given to HIV in her serodiscordant relationships.

> …the problem with disclosing HIV very early on in a…relationship is that sometimes HIV takes the centre of stage and it's like, instead…of a person really evaluating me as, who I am, […] sometimes it's like all they can think about is this bloody HIV! (108)

2.2 *It is my right to be a sexual person*

The voice of resistance speaks out against the notion that positive women should stop having or wanting sex. Occasionally, this was like an existential knee-jerk reaction to the heightened perception of death brought on by the HIV.

> My first feelings weren't
> 'Oh I'm gonna give up sex …'
> I really felt
> I was,
> I felt like it was important to have sex
> I had very little to live
> I didn't want to live the very little I had left without sex
> (77)

Other times, it was an assertive articulation of their right to a sexual life. .

> I should have a sexual life
> I could have
> I did.
> (80)

This aspect of the voice of resistance that asserts positive women's "right to have intimacy" and "be a sexual person"(47, 49) was not easy to hold on to because "sex doesn't happen on your own unless you're masturbating" (105). Consequently, much of the women's sexual lives seemed to exist "in spite of" (40, 77, 80) difficult interpersonal and social negotiations involving HIV.

> In spite of having...a life-threatening, sexually- acquired (laughs)...condition, I still feel that, you know, sexuality is a ... ...should be a great source of joy and connection between human beings (40)

The change from the definite ‘is’, to a more tentative ‘should’, statement gives away the difficulty this participant sometimes finds in living out her sexuality serenely.

2.3 *Fighting internalisation*

The voice of resistance was crucial in defending against possible internalisations of social and cultural stereotypes about HIV, which in turn could fuel negative beliefs about the self.

> I feel that… I shouldn’t….I shouldn't feel like I am…u…useless… (111)

It was instrumental in averting the sense of personal annihilation that came when lovers rejected or blamed women because of HIV, and stopped the internalisation of guilt and blame.

> I had to fight a lot with them, for them, to make them understand…that, you know, “it's not my responsibility to tell you I've got HIV, because otherwise you wouldn't have slept with me[…] and then[…] what if I didn't know? […] it is your own responsibility to make sure that you are safe” (167,171,175)

The voice of resistance also roused the educator role; by fighting internalisations of blame, the women were able to teach partners and others about sexual agency and responsibility. This fight against the internalisation of blame is potentially made even harder in light of legislation on the criminalisation of HIV transmission (see Appendix L).

2.4 *Contradicting stereotypes*

Through the voice of resistance the women spoke out against inaccurate representations of their lives. Most commonly, women attempted to counter stereotypical ideas about ill-health, unhappiness and isolation.

> It's…the way people treat HIV that is the problem more than the bio-medical issues of having HIV…(69)

> I mean, HIV,
> I'm really lucky,
> I'm really fit and well,
> I got a CD4 count of (high), undetectable viral load.
> I was
> I'm just disgustingly healthy.
>
> I've probably got a better life-expectancy than quite a few other women of my age,
> I should think.
> (99, 101)

The phrase 'disgustingly healthy' (99, 101) seems to used by this participant in quite a rebellious manner in that her good health flew in the face of all disease-related stereotypes or expectations about people with HIV. Another participant's use of the phrase 'for real' (below) was meant to emphasise the importance of the sero-discordant relationships she had, challenging stereotypes of promiscuity on the part of people with HIV.

> …there are people out there who really don't believe that somebody negative would want to be with somebody positive but that wasn't my case coz I had these two, eh, examples of fulfilling relationships that had been long-term relationships not just, you know, meeting somebody and that's it. No they weren't flings, they were…for real (157,159).

One participant clearly stated that she did not hate HIV, yet her "I" poem (below) shows hesitation, as if it were too controversial to say that. We can see the clash between society's expectations of PLHIV and this participant's experience of herself. Her voice is hesitant at first but then loudly and clearly contradicts those expectations.

> I think,
> I think…
> People talk about, HIV
> People would expect
> You,
> You have really bad experiences
> You know
> You have a lot of issues
> I,
> I don't know
> You're like a sad and miserable person
> You know,
>
> ...
>
> I think
> People don't expect
> People don't understand...
> I've told some people
> They think I'm crazy.
> They think, 'god you've got HIV!'
> 'You should be crying round the corner'
>
> People looking at me pitiful...
> I think, 'No!'
> 'Why…would I be crying...?'
> I am a very positive person
> (271,273,275)

In asserting what is true to them and contradicting common beliefs, the women (once again) fended off harmful internalisations. Sometimes they also needed to defend against harmful beliefs perpetuated from inside the world of HIV. One participant found herself resisting other positive women's assertions that HIV made them feel dirty: "I never…felt dirty" (321). She also resisted the idea that not having children was an irreparable loss for a woman.

> I don't see myself um, so much of a victim of this […] my partner um, has two kids […] he is not, yeah willing to have other kids and that's good for me so I'm, I'm safe (laughs) let's say, I don't, I don't consider it an issue (249).

Nevertheless, her use of the word ‘safe’ hinted at an awareness that resistance could easily be overpowered by distress if social and relational pressures around her maternity changed.

In her “I” poem, another women attempted to dispel two universal assumptions about PLHIV; fear of disclosure and death.

> I'm not scared of it…
> I think,
> You know,
> I may be more open…
> I say more what I think?
>
> I maybe haven’t done as much
> I'm doing now
> I think
> I'm more, more genuine now than…I was before.
>
> I'm not worried,
> I'm not worried really
> I might die soon
> I know
> I go for my check-ups
> I look after myself
> I can live long.
> (179,181,183)

The women resisted other non-HIV-specific stereotypes e.g., Catholic influences that often juxtaposed sexuality and sin; objectifying influences of a society in which sex is “based on pornography” (167) and; negative appraisals of women’s desire for connection and companionship, often mistaken for weakness or desperation.

> I define myself in terms of being with somebody. Yeah, rather than uh, an individual so uh, my need to...be with a person […] to me it’s vital to, to...to share... uh, life ...with a person (297)

Some women also felt that they defied culturally prescribed notions of beauty and femininity; they did not conform, yet felt confident about their appearance and attractiveness and had positive experiences around them.

> I know I don't look like one of those models in the papers but […] I think […] you know, that sex is good, that the body is good, you know, that there is no shame (166)

> …society is always bombarding me with images of young, skinny, unattainable women and eh, a sex that is based on pornography and, and it's just very shallow. I think […] is that all there is? Is this all we have to achieve? (167)

> …I'm not a sex goddess [laughs] I'm not! But I am a person who… appreciates, uh, intimacy and uh…mmmm…yeah. That's, that's how I describe myself (221-223).

2.5 *Tolerating ambivalence*

As the women contended with personal and societal distress about HIV, they also learnt to hold the tension brought on by contradictory thoughts and emotions created by the virus. At times, confident articulations dropped a tone as women expressed ambivalence about certain issues. However, they resisted falling into distress. For instance, the bond of companionship created between one woman and her (seropositive) partner thanks to HIV, also represented a form of captivity for her.

> We almost feel like we have a bond… …whether that's a good thing or a bad thing I'm…some days I'm not sure […] you feel like your arms are tied together at all times (124,144)

Sometimes, confidence, in articulating their right to non-disclosure and shared responsibility for safe sex, waned as women admitted to waiting "to see how it goes" (197). The same was true about the idea of pregnancy. The tone and speed of speech betrayed one participant's attempt at nonchalance about the conception method.

> I always think, you know, having children wouldn't be a problem…em, because once you have, you know, you've found that person who wants to do it with you, you can do it at home, you know, there's like, there's the syringes,

> you inject the...semen through your womb, heh whatever. I don't really know how it works but... em (253)

The voice of resistance enabled the women to hold their ground against forces that threatened to take over their sense of self (even internal pressures of doubt or insecurity). Resistance also allowed for voices *other* than distress to speak out and be heard.

3. *The voice of sexual knowing*

This voice spoke of two relational dimensions: an intrapersonal sense of what sexuality is and is for; and an interpersonal negotiation about how this may play out. The name came from a participant's description of knowing what she knows about sexuality "on instinct" (40).

3.1 *Sexuality is core*

Five of the six women described sexuality as being central to their existence, "an essential element [...] without which [they] don't see life itself" (65). Sexuality is also essentialised and made universal in a way that transcends gender.

> We are all sexual beings…and that's just a fundamental part of our…make-up...our psyche... and to pretend otherwise is actually denying ourselves a part of our…real understanding of our existence (75, 77, 79)

In moments where this voice was overpowered by distress women experienced a form of existential crisis, feeling "useless" (111) when they could not express themselves sexually or satisfy their partner's needs. Being diagnosed following a marital separation catapulted one participant into a midlife crisis which was resolved through rediscovering her ability to have a healthy, stable sexual relationship. She said of sexuality "...yeah it just makes me feel alive you know?" (335) and "I've got a, quite a bit of fantasy…I'm definitely not dead…" (287).

3.2 *Pleasure, connection and the self*

Through this voice, all participants spoke about pleasure and their sustained ability to connect sexually to themselves and others. In the following "I" poem, the woman's sense of self was consistent and clear, in tune with her bodily senses and with 'other' who stimulates these senses.

> I…
> I like sex
> I like,
> I like feeling sexy
> I like… being intimate
> I like being touched,
> I like touching…
>
> I like,
> I like the pleasure it gives me
> (85)

Echoing this, another woman stated that sex has "always been very satisfying" (323). Pleasure came by engaging a different faculty of the mind (imagination) and relaxing, or trusting.

> Maybe it's related to imagination a lot? Coz […] to me, sex is very much in, in the mind […] it is very physical too but if I'm not relaxed and I don't have the right uh, um, state of mind let's say[…] I'm not able to, um, fully, yeah, appreciate and explore (229, 231)

Being able to enjoy sex also related to early beliefs e.g., "sex is good, that the body is good […] there is no shame" (166). Such beliefs dissipated fearful or self-conscious thoughts allowing physical connection.

> …it's almost as though it allows me to be…in a dimension, in a presence that should, should disengage me from my mind and from, this flow of thoughts (140)

Again, the use of 'should' indicated that although initiated within the Self, this voice always had to be negotiated in relationship with the other, with HIV as an adjunct. Sometimes, the way partners reacted to HIV affected how the women felt about sex and pleasure but also, about themselves and the way they dealt with rejection.

I've got mixed feelings

I've gone through different experiences sexually
I've had partners where… they have been, have felt very comfortable
I've had partners where… they've been really, really scared

…

I feel really strong
I think about that partner
I think
You know,
'You'll find someone who wants to be with you for who you are.'

I think about the other guy
'You need to remain strong.'

…

It's, it's like a, a bit of an identity issue
(101, 103, 129, 133,135)

Other times, women described sexual pleasure in less complicated terms, focusing on physical satisfaction.

I'm just horny
I'm not
I'm not a lovey-dovey
I want that it's exciting
I definitely don't want a routine
(275)

I just think about my pleasure
I concentrate on that
I don't have a partner
I'm not in love
I think about sex,
(217)

The importance of experiencing sexual pleasure linked to a unique form of self-expression that some women emphasised but all alluded to. Orgasm was described as "an incredible […] emotional relief" (215).

> The orgasm somehow needs to…happen to trigger that […] crying and that sort of pent up emotion and…and…a sense of pain and…coming out but healing (219, 221).

Women used sexuality and their sexual relationship with regular partners to heal themselves from the trauma of loss following diagnosis. Through pleasure one participant was able to connect to her pain and express it.

3.3 *The instrumentalisation of sexuality*

Talking about their experience of sex and sexuality, participants often spoke in a voice that resembled sexual knowing but which led to unfortunate or undesirable circumstances e.g., using sexual pleasure to escape difficulties and then contracting HIV. I have referred to this instrumentalisation earlier as being a form of vulnerability (see *the voice of distress*). However, in different readings of the same text, a more intended, self-knowledgeable facet to this emerged. I therefore present it here again under the voice of sexual knowing (see lines 52 and 31 in *an early vulnerability*). Through this voice women reached a new awareness of self which sometimes surprised or confused them. Becoming aware of her misuse of sexuality, confused one participant, who shifted from definite terms in her "I" poem, to a space where thinking and feeling left her not knowing.

I haven't used it the right way
I've been sleeping with people
I didn't feel anything…

I don't know
I do...
I do like having sex
I…
I don't know
I think
I feel…

I…
I don't know
(87- 97)

Another "I" poem (shown in Appendix C, point *1*) demonstrated how one participant, who stopped to listen to her voice of sexual knowing, realised she needed to question herself more and make some changes to her life. Her desire to regain a sense of normality seemed to have precipitated a form of (hetero-)sexual identity foreclosure that left her unsure of who she really was as a sexual being.

3.4 *Sexual fluidity*

Four of the women spoke about their experience, and/or awareness of the possibility, of being attracted to both sexes. Two women reported having had sexual relationships with both men and women following diagnosis. It was unclear as to why this happened post-diagnosis (and with one women, whether it also happened before diagnosis) but at different points in the interview both women spoke about having been in violent or abusive relationships with men. It is speculated that an openness and attraction for both sexes already existed in these women but may have been acted on in response to a need for protection; both from further potentially abusive relationships with men, and from risk of onward transmission or re-infection (as risk is reduced in female homosexual activity).

Sexuality was described as "how you…perceive yourself, within your sexual relationship" (15), understood as being defined and redefined in relationships where sexual expression took place. One participant stated that although bisexuality was always a plausible option, she hadn't "found...the right woman ever to be…lesbian or bisexual with" (255).

The possibility of bisexuality came later in life for another woman. When she was younger, lack of knowledge about different lifestyles, but also fear of falling outside the norm, pushed her to silence her voice of sexual knowing. Following diagnosis, she came in contact with a number of LGBT organisations and now describes herself as being "very drawn to other sexualities" (51) and curious about her own.

> I'm probably more curious now
> I would
> I would consider,
> I probably would consider now a same-sex relationship
> I wouldn't have done
> I would never have thought about it.
> I probably would now.

4. *The voice of empowerment*

Positioned in response to the voice of distress, this voice is just as complex and multifaceted. It describes the changes, experiences and coping mechanisms that the women negotiated within themselves, in relation to HIV and between self, HIV and other.

4.1 *Intimate recognition*

Nearly all the women, to different degrees, described a shift from distress to empowerment, a change that five women linked to being intimately recognised by another i.e., having an outsider (seronegative individual) look beyond their positive status, to see and understand the woman, the person, behind it.

> What changed was somebody coming into my life, it wasn't a conscious decision, it was…uh, this person happened to be there and, um, mmm, we developed a relationship […] to my surprise, umm, he wasn't...scared at all uh, he was concerned (129).

> I could talk
> I,
> I didn't want to
> I think,
>
> We knew
> We were friends
> We were able
> I told him
> We…(got informed)
> We (actually went)
> I think that is what contributed
> (135,137,143)

On meeting her partner, this participant suddenly saw the possibility of a sexual relationship despite HIV. The phrase 'to my surprise' (above) seems to mark the presence of the voice of distress (mistrust) and the shift to the voice of empowerment through intimate recognition. Her hesitation and fear were replaced by an ability to act. She gained strength moving from "I" to "we". Through relationship, women also found new power to accept and cope with their diagnosis.

> …the support that I had from this… guy, […] has influenced a lot, the way I feel about sex even being HIV-positive […] he, he gives me hope (143,145,147)

The women spoke of different sources of support.

> …my doctor is really good […] I remember him talking to me about HIV and... telling me, "if you still feel like having sex, go out there and have sex […] just use a condom" […] and I think this... this helped me a lot because [...] I express myself a lot through my sexuality? Emmm... …so that, that meant a lot to me (77)

One woman slowly moved away from distress through a supportive relationship with a nurse at an HIV clinic, whilst another, did so through the mutually and persistently supportive relationship she shared with her seronegative husband.

4.2 *Protecting the self*

The negotiation process described by the voice of empowerment, included women's realisation of the importance of self-protection; not only that they *needed* to protect themselves (in reaction to distress) but that they *could* i.e., an informed and empowered action towards self-preservation.

In relation to disclosure and fear of rejection, the women used different self-protective methods. During one-night stands, some often "didn't say anything" (105) about HIV but insisted on using condoms. In different situations, early disclosure was used.

> I always disclosed before I got involved with somebody seriously […] I thought if I wait for too long, I'm so infatuated with that person that it's hard for me. […] Better I know from the beginning em, if he can take it or not (61, 233,235)

Another woman used self-talk to protect herself, together with a delayed disclosure strategy to give herself a chance at finding a companion.

> I thought, "Right! You can't control…these things because they don't depend on you". […] The moment they get in contact with your fluids, on purpose, after you've asked them to use a condom! It is their own responsibility (159,163)

> If I tell them that "oh, you know, I've got HIV" it's, it's easier for them to just turn around…em and leave me standing there. Em…whereas if you know that person em…better… …it's more difficult to turn your back on them… (191, 193)

Internet dating sites for PLHIV was another self-protective strategy that women used to check on people before meeting them. Dating another HIV-positive person was a conscious, self-protective decision for one woman because the sense of guilt and responsibility in previous sero-discordant relationships disallowed her to be herself.

> I am much more relaxed about it because em, in this relationship […] the fear uh factor, uh the fear of infecting the other person uh is no longer there […] I think uh em, it's, it's a way for me to feel more sure of myself and...express sexuality different[ly] (75,77).

When stating that she felt her (seronegative) ex-partners deserved a "fear-free relationship" (165), it may have been that she also felt the same about herself.

4.3 *Awakening*

The experience of HIV helped three women arrive at a greater awareness of themselves as sexual beings. “HIV [was] like a magnifying lens” (185) forcing them to look at themselves more closely.

> …it opens your eyes, being diagnosed HIV positive [...] to lots and lots of other things… that I would not have considered or even noticed... (65)
>
> It makes you much more aware of, eh, who you are as a sexual being because you're no longer just, mmm….I don't know, sexuality becomes much more, uh, physical in a way, when HIV is involved (69)
>
> I kind of had to look […] ask some very hard questions... about how I was relating to men, how I was relating to sex... (48, 54,56).

Awakening was not an easy process and greater awareness, not always welcome. This is why the voices of empowerment and distress are conceptualised as contrapuntal voices. Awakening resulted from an existential shock brought on by HIV and empowerment came from being able to embrace the crisis and take advantage of the clarity that can result.

> I think that this fear and ex-, extreme awareness of death and em, the-im- how impermanent life is, is also one of the biggest blessings that HIV gives you because at that point, when you face death, then you really need to embrace life you know, so, you know, it's the blessing and it's the curse of HIV (183).
>
> …it makes you look at your vulnerability quite, closely but…(sighs)… …I'm happy for that. You know, I feel like you know, why are we here if I cannot look at myself…you know, in the fa-? I think HIV has allowed me, you know I had... to take away the veil, I think I just had to, take a very good look at myself in the good and the bad… (193)

The result was personal growth; a better understanding of one's vulnerability, a greater openness to express fears and personal issues and; a sense that HIV sits at "the core of those experiences" (257).

4.4 *Making active choices*

Waking up to one's self seemed to precipitate a necessity to actively take charge of one's life. The happiness and fear-free relationship enjoyed by one participant, resulted from a "conscious decision" (149) to be with someone positive. Making this decision held great importance in her narrative because, twice in the past, she had felt disempowered by others taking decisions for her: by the partner who infected her and the two seronegative partners who accepted her. Despite benefitting from the love and acceptance of the latter partners, not feeling in control of that reality, made her uncomfortable.

> …people have, have felt attracted by me, in a sense that I wasn't very much, I didn't feel like I'm controlling it and when HIV really, uh, entered and after two relationships with two people who were negative, I thought, I don't wanna go through that again... (353)

Considering other women's narratives, I wonder whether what she did not want to experience again, was feeling indebted to someone who had more power in the relationship because of being seronegative.

In reaction to the immobilising effects of taboo and silence around HIV another participant "made a choice" (93) to go public with her status, claiming power back to herself in this way.

> …having taken this kind of... ...personal and political action […] by saying well, you know, "I don't care I'm gonna tell everybody I have HIV", I kind of turned everything on its head (95, 97)

Other active choices taken by participants were: reclaiming their sexual life following a period of celibacy and; working to nurture intimacy within their marriage after HIV.

4.5 *Putting HIV in the background*

The voice of empowerment (together with resistance) helped women negotiate ways to prevent HIV from completely overrunning their lives. Paradoxically, this sometimes required placing HIV at the forefront of their public or family lives (mentioned earlier).

> Everybody in my family knows…and it's not really an issue [...] even at work, [...] all my friends knew. It was just like, a part of me like, as if I, got a mole or whatever (29, 31, 37)

Bringing HIV to the foreground, making it known and visible, enabled this participant and her friends and family to accept it as part of her self – like one would with a mole on the skin.

Disengaging from actively countering HIV and no longer being in confrontation with it, also enabled women to put it aside and reclaim power over their lives.

> ...my life was a red ribbon. It was an AIDS ribbon […] everything revolved around it [...] now [...] my life is like a jigsaw and only one part of that jigsaw is red. That one tiny part em...is my HIV. Everything else is the other things that I do in my life (118)

> We've moved on…em and it's about us, not… em…proving that we are…normal (202)

Sometimes, comparing HIV to more acceptable social phenomena helped make sense of things and reduce HIV's power to isolate.

> …people who are single parents for example? [...] as soon as [potential dates] know that they have children, […] they're not interested anymore. So I compare myself a bit like that (233, 235)

Comparing herself to single parents does two, paradoxical things for this participant; it normalises the experience of having something, or being someone, that others may not easily accept, but it also highlights the same difference which it is trying to normalise i.e., it emphasises that which sets her outside the social norm. This shows a complex interplay between 'background-ing' and 'foreground-ing' HIV that women may need to contend with.

Another strategy used by the women to manage the potentially disempowering effects of having HIV was viewing it as "a health issue" (237). Thanks to advances in medical treatment, but also to a shift in their belief system, coping with HIV became a practical thing and (potentially) less of a psychological burden.

> I always have to think, okay, I have to prioritise and make it as, yeah, simple as possible, so that, I have that energy that I need to, uh invest in my relationship (239)

4.6 *Reframing difficulties*

Participants demonstrated two more adaptive strategies that were not directly spoken about. One was the way they reframed difficult situations e.g., disclosure was seen as an opportunity to be more genuine or a test to partners' commitment or interest. The other, was the use of irony or humour to lighten difficult realities of living with HIV e.g., being ironic about the number of relationships she had or joking about the process of adaptation.

> In the past year, most of the people...eh...this *crowd* of people I had a relationship with (laughs) (110)

> It's not like I have, you know, reached an enlightenment (laughs) it's a, it's a work in progress (laughs) (195)

4.7 *Feeling stronger*

The core of the voice of empowerment is a sense of increased mental strength, an ability to withstand and adaptively cope with the physical and psychosocial difficulties brought on by HIV.

> I tell somebody that I'm HIV positive and he says he doesn't want to be with me, and it's okay, I survive (laughs softly). I realise I can live with it (95)

> I think I've become much stronger, I've become much stronger, thanks to the support, thanks to the you know, political involvement, thanks to, I think just getting older as well (97)

Feeling stronger, for this participant, was also related to age. Reaching midlife changed her priorities, making certain sexual choices easier for her. Reproductive choices no longer plagued her as they did in earlier adulthood and she felt less sexualised by society. Interestingly, this gave her greater control over her sexuality which was no longer dictated by social standards of youth and beauty. Thus, feeling stronger eventually also led to increased sexual confidence as a woman with HIV.

Another participant became more selective in choosing partners after finding scope and meaning through HIV-activism and a sense of pride and empowerment from adversities overcome.

> It made me...see… …how, how, far you can get like, how strong...as a person, you are, and, you know, you may fall down but, you know, the rising up[…] when you've fallen down. […] like I feel very proud of myself? (255,257)

One woman's renegotiation of an increase sense of power emerges beautifully in her "I" poem.

> I think
> I am…

> I feel very comfortable in my sexuality,
> I feel very lucky
> I've grown to feel,
> You know
> I can,
> I can talk about vaginas and…orgasms
> I remember
> I used to feel soo embarrassed
> I'm just used to it
> I just feel really lucky
> I just feel very kind of... at ease in myself and in my body
> (249, 251)

No longer bound to proving her virility following a period of insecurity and crises, another participant rediscovered a similar ease of being, within a new, stable relationship. Her use of the word 'proper' and the phrase 'how it's supposed to be' seem to mark the continued (and shared desire) for normality mentioned by other women and discussed earlier.

> Now I think, I'm secure, you know like, I don't have to prove anything to myself anymore em…it's just nice and…comforting and you know a proper relationship again, how it's supposed to be…(173)

Feeling stronger also enabled the women to accept love in their lives. One participant shared her dilemma in agreeing to have unprotected sex with her husband, following results of an undetectable viral load.

> …say, there are two partners and one of them is on kidney dialysis and the other partner actually wants to give them, donate, one of the kidneys. And the partner who needs the kidney is saying, "No, no I don't want to do that to you" and the other partner is saying, "but I love you, I want you to get better so I want to...out of my love for you I want to donate this kidney to you". [My consultant], as an advisor, has said, "well, you know... don't you feel it's acceptable to accept your partner's love?" [...] And so I said, "okay, right. I can understand that so alright, I can accept my partner's love" (165,167)

Empowerment fed off, and bred, a propensity for different forms of self-expression in the women. One participant noticed herself becoming more genuine and outspoken and another overcame a fear of disclosure through writing (see Appendix C, point *2*). Becoming more genuine may also be linked to a form of greater authenticity that came with feeling more confident in themselves. As an agglomeration of different coping mechanisms, the voice of empowerment enabled the women to reclaim power and express themselves in ways helpful and meaningful to them.

5. *The generative voice*

Feeling empowered in themselves and their relationships seemed to fuel, in the women, a desire to share their knowledge of HIV. The generative voice speaks of how participants seemed to skip to a late adulthood stage (as described by Erikson, 1963; 1968) and work for the benefit of the next generation. This voice thus speaks of the relational dimension of Self, HIV and (HIV-positive) others.

5.1 *Participation*

Generativity was firstly demonstrated through women's reasons for participating in this study.

> ...to help people who are just starting off, you know, are just newly diagnosed [...] just to, uh, give out some of my experience [...] and how I see it and maybe eh, this little bit will uh, be important in the larger perspective like in a PHD or a study... (47, 51)

> … because I will speak to you, you will speak to ten other people, people will read your dissertation and they will speak to ten other people and that way we're going to get the message out…(9)

The generative voice was one that wanted to change things for others, to speak out and be heard. According to the participants, "the only way for that to happen is [for them] to be involved" (36).

5.2 *Finding reciprocity*

Participants linked their desire to help others, to the experience of having themselves been helped. Similar to *intimate recognition*, the difference is that the people offering recognition are HIV-positive. They thus offered a different *quality* of recognition and understanding.

> ...meeting other positive women, who, em, had basically decided that, who wanted to turn themselves round and sort themselves out after a diagnosis [...] It just gave me a really strong kind of, starting point for…rebuilding that sense of self-worth and em, you know, restoring my sense of, it is my right to be a sexual person(45,47)

> I was...therefore starting to feel able to, kind of…put things back…somehow for other people? Because they'd been really supportive to me? (93)

In positive women's groups, participants found others who had faith in them and, as one woman stated, who showed her a way through the toughest time in her life. This resulted in a strong sense of group identification.

> ...that sense of identity, through the HIV, is something which…has been yeah, it's an incredible gift to have been…given that sense of…community (293, 295).

Another woman described a similar experience in her seroconcordant marriage. Her husband was "somebody who understands" (182). When this sense of reciprocal support was not available, the women sought it out. However, because they specifically sought out positive *women*, they were unsuccessful at times.

> I think it would be em, a nice thing to have like eh... ...a place where women can meet and talk about sexuality because I think there are always men there, I know a lot […] of women, they don't feel free to talk…(361)

Women-only support groups exist but are quite rare (less than a dozen can be found through a simple internet search). The majority are located in London (e.g., Positively UK has four different women's groups meeting at their premises). However, as one participant reported, these not easily accessible to women living outside London.

5.3 *Being an advocate*

Throughout the narratives, the generative voice could sometimes be heard moving alongside the voice of resistance. As the women gained confidence through contact with HIV-positive role-models and living their lives in a more genuine way (see *Contradicting stereotypes*) they also started to speak out about socio-political issues affecting women with HIV. They expressed concern over: potentially complicating effects of the Swiss Statement; criminalisation of PLHIV; and taboo around conceiving. What started off as a personal experience of resistance, evolved into a wish to take a political stand and become advocates for themselves and others.

> I started questioning a lot of... ...of this em...silence around HIV and, and also this...... this kind of idea [...] this culture of being ashamed, you know, being in this....continuous hiding (93)

I became infected
I was
I thought
I wanna do something
I wanna, change people's lives

…

Why can't we talk about it?
Your neighbours
Your brothers and sisters
Why don't you talk about it?
Why are you so scared about it?

I understood
I was meant to
(65, 67)

In understanding things for themselves, nearly all of the women actively spoke out for others and challenged the silence around how women can adapt positively to HIV. They advocated for more support through women-only groups and one participant spoke about the importance of individual support.

> ...maybe, at first the one-to-one support is more important than a group [...] because you first have to come to terms with it and only [then] can you go into a group (421,423)

This counteracts what other women said about positive outcomes of being in a group but it presents an important point: reminding us that as individuals, people may require different forms of help.

Advocacy seemed to add meaning to the women's lives, justifying existence in the same way that generativity does in midlife. As seen from the younger participants who were still in their twenties, this psycho-social task was not age-bound in the case of HIV.

6. *The dignified voice*

This is the voice *best* able to hold the tensions created by HIV. Through it, participants were able to acknowledge the difficulties of living with HIV and the importance of making those difficulties known (self with HIV and other), without allowing this reality or information to push them into a position of victimisation or pity. It is an assertion of an intrinsic right to respect and ethical treatment: dignity.

6.1 *Acknowledging difficulty*

The women's dignified voice did not hide behind false hope or wallow in despair but spoke sincerely about how life was harder with HIV.

> ...because you ask those questions, it doesn't mean that, you suddenly become strong and assertive and now that you also have HIV and you are able to kind

> of, turn those relationships around. In a way, it becomes even more difficult... (58)

> …it's very hard to find somebody anyway, but when you add up something like, this, it's just its like […] I could have chosen from all the apples in the world but now I have only this little tree here... (233)

> I think it takes a lot of courage, to have to disclose to […] somebody you, you, you haven't known for a very long time (341)

Besides psycho-social hurdles, there are also physical difficulties that need to be dealt with.

> HIV is so complicated in terms of, energy levels and so many things that I want to do especially because I'm here in a new environment and I always have to think, okay, I have to prioritise […] because it's one thing when, when you're tired coz you're […] a work-aholic in a city like London […] But when you have, I don't know, diet problems or, uh, it just, you're, you're very tired because [of] your treatment for example obviously uh your […] relationship would be affected (239,241)

Even in cases where a non-detectable viral load and a loving partner made an enjoyable sexual life more possible, the dignified voice reminds significant others that thoughts about HIV still need to be acknowledged or addressed and that women's subjective reality needs to be respected.

> …to be honest, I still don't feel a hundred percent happy with [having unprotected sex], because there's always that ongoing lingering thing about well…you know [...] what if suddenly, my viral load were to kick in again…?(171, 173)

6.2 *Searching for the middle ground*

The dignified voice often followed the voices of empowerment and distress in participants' narratives, as if playing a similar melody an octave lower or higher respectively, to negotiate a middle ground. The participant who felt empowered by her choice to start a relationship with an HIV-positive man, qualified her newfound freedom.

> ...it's not like "wow!" There is this huge liberation all of a sudden. Em, "we can do absolutely anything!" Because it's not the case [...But] we're very much into each other and um, mmm...I don't know how much HIV really um, weighs in the whole, equation (187)

It seemed important for these contrapuntal voices to exist in this way for women to effectively communicate their need, or wish, for understanding, without being disempowered by pity.

> Now that I have HIV…well it's not like I am less vulnerable, I'm even more vulnerable because HIV makes you even more vulnerable […] but then [...] you know, I think any difficulty gives you an opportunity (187)

The voice of distress was heard chasing closely after the voice of dignity when some women brought up the issue of having children. They veered away from falling into distress by repeatedly searching for the middle ground.

> If I hadn't had HIV, I would have definitely had…several children…quite a large family… …and…I missed out on that…but, I do have […] children and…I do have an incredibly lovely partner so… em… …but yeah I mean when I look around at my friends now and… I mean, you know, I'm so lucky that I have what I have but I look around at my friends now and you know, they're starting to have grandchildren.. .and em...that still feels quite hard... …it makes me want to cry…heh…but yeah, I'm just really lucky that I've… you know, had children at all (297, 299, 303)

The issue of pregnancy seemed to vary in importance for participants: two women, who already had children, never mentioned it; the two younger participants seemed more at ease with the options available to them i.e., not having children or getting special medical care to conceive and give birth. All four women who spoke about pregnancy, however, demonstrated the same contrapuntal pairing between the voices of distress and dignity.

The dignified voice enabled women to negotiate a less taboo-ridden social standing, subtly changing the way people view HIV by being honest but not fatalistic.

> …there's also the fear of losing the person next to you […] yeah, compromise immune system does mean uh…that...yeah he might...have this rather than other …but I don't see it as um, I think I, I don't know, negative people would have the same problem maybe…(251, 253)

> 45% of people in the UK have a long-term health condition […] Em they have to diet, you know, certain things, I mean I have to be careful but, other than that it doesn't affect my life… (132).

Discussion

This study sought to explore how women with HIV renegotiate their sexual subjectivity two or more years post-diagnosis. Sexual subjectivity was defined as a woman's "experience of herself as a sexual being, her feeling of entitlement to sexual pleasure and sexual safety, her ability to make active sexual choices, and her identity as a sexual being"(Tolman, 2002, p.5-6). In light of earlier research on seropositive women and sexuality, this study's wider aim was to listen again and listen for difference, focusing particularly on the construct of sexual subjectivity and using Counselling Psychology principles to do so.

The account presented in this study, moves beyond the constriction and limiting discourses reported by Gurevich et al. (2007). Participants voiced relational realities other than diminished, foreclosed or muted/mutated ones. They did not shy away from talking about difficulties they experience. In fact the voice of distress was one of the strongest and most far-reaching of the voices. However, through the Listening Guide, more positive and adaptive voices were allowed to emerge: the voices of empowerment and resistance, which were just as powerful as that of distress; and sexual knowing, generativity and dignity, which open new paths for understanding sexuality and HIV. The significance of these findings therefore lies in their ability to articulate previously unnamed dimensions of experience and inspire new possibilities.

Renegotiating sexual subjectivity

Self as a sexual being

As in previous literature, HIV was seen to have devastating effects on women's sense of self as sexual beings. Yet, the presence of voices other than that of distress indicated that (sexual) selfhood was not experienced as an unchangeable entity that was broken or ruined by HIV, but rather as something that could be renegotiated in relationship with self, other and HIV (as a personal and social construct, and a physical entity).

The process of renegotiation depended heavily on self-other relationships that women had before and after diagnosis. Findings (see p.44 and p.68) showed that post-diagnosis, women re-evaluated the way they *used to* relate sexually as HIV placed a magnifying lens to those experiences. Renegotiation was therefore retrospective, as well as prospective. Sexual relationships *post*-diagnosis then delineated the extent to which women saw themselves as contagious and dangerous, or accepted and acceptable. If they found lovers who continued to desire them following disclosure, they felt hopeful, experiencing their sexual self as alive, expressive and listened to. However, if lovers shunned them because of HIV, this bred despair and an experience of the sexual self as obsolete. Therefore, sexual subjectivity was not affected simply by the physical presence of the virus, but by the co-constructed meaning of HIV within their (intimate/sexual) relationships as Bova and Durante (2003) argue. Having at least one positive experience post-diagnosis seemed to act as a protective factor that renewed hope and helped women regain strength when subsequently faced with rejection or disappointment.

Sometimes, despite being in seemingly accepting relationships, a sense of self as dangerous or contagious persisted (see p. 67, quote 75, 77; and to a lesser extent p. 78 quote 171,173). Lekas, Siegal and Schrimshaw (2006) refer to this as felt (internalised) stigma, whilst Gurevich et al. (2007) take it to signify a transformation to a diseased and unnatural subjectivity. Felt stigma might have been unintentionally and implicitly maintained in relationships through projection of fear and blame (from partners) and projective identification (from women). The same might have occurred on a societal level when stigma was experienced vicariously through others (friends, family or even strangers) who were discriminated against. As these authors note, such an experience can present a challenge to adaptation, yet participants in this study demonstrated a conscious move away from inhabiting diseased or unnatural subject positions (evidenced in the voices of resistance and empowerment). Gurevich et al. (2007) seem to have overlooked, or underestimated, the ways in which women manage to edge themselves out of constricting, discourse-enabled realities related to HIV. It could be that advances in medication or societal changes that were not present at the time of their data collection e.g., dating sites for PLHIV, have enabled new adaptive strategies that they could not detect. Alternatively, they simply were not listening for difference.

For participants who, similarly to Hankins et al.'s (1997) study, reported a (temporary) drop in sexual activity immediately following diagnosis, it was interesting to note the similarities and contrasts to Gurevich et al. (2007)'s conceptualisation of a muted/mutated sexuality. Silencing sexuality may seem the obvious choice for those who, sometimes unknowingly, present HIV as a form of punishment for promiscuity or poetic justice for a deviant lifestyle as discussed by Greene, Frey and Derlega (2002). However, most participants viewed celibacy as a legitimate subject position that did not represent an absence of sexuality, an incomplete self or a permanent mutation of their sexual selves. It was simply conceptualised as a state of sexual non-(inter)action that was later left for a different, more (inter)active subject position.

This and other similarly adaptive views were often negotiated in supportive peer groups. As mentioned by Squire (2003), romantic (or sexual) possibility was collectively constructed through listening to others. Shame was dissipated and pleasure legitimised through adaptive behaviours modelled by other positive women. Haug et al. (1987) argued that storytelling has the power to overcome shame related to the inadequacy of life because it allows women to give an account of what was actually done. Relationships with HIV consultants and other medical staff could also affect renegotiation positively when medical advice was based on an understanding of the women's personal needs and life contexts.

Entitlement to pleasure and safety

In contrast to most other research findings (e.g., Siegal, Schrimshaw & Lekas, 2006), participants demonstrated a keen sense of entitlement to sexual pleasure and to shared responsibility for sexual safety. As in Hankins et al. (1997), enjoying sex was a way of fully living life in the face of death.

It is interesting to note the discursive function of women's assertion that sexuality (and sexual pleasure) was a fundamental right (see 'voice of resistance'). Boyce et al. (2007) discuss how such claims have been important in HIV-activism and sexuality politics, but run the risk of presenting sexuality as a "fixed attribute of the self" (p.29), existing outside social construction. Echoing early work by Gagnon and

Simon (1973) they argue that sexuality is not stable, but scripted i.e., it is guided by cultural, interpersonal and intrapsychic instructions or rules (scripts), and is accounted for in different ways which may or may not relate to how it is enacted. This epistemological issue is core to this study. Researchers like Gurevich et al. approach sexuality as something purely socially constructed, where discourses create subjectivities and realities. Through the listening guide, this study attempted to embrace a more critical realist view, which still acknowledges the power of sexual scripts in shaping reality, but also pays attention to personal agency and a resilient sense of choice that women have in selecting the discourses that shape their realities. Therefore, although titles like 'the voice of sexual knowing' or assertions about sex being a right, may seem void to strict social constructionists, both I as the researcher, and the women as participants, chose to use these terms to influence what shapes the reality of women with HIV.

Sexual pleasure and safety are not easy to come by in the world of HIV. Therefore it is important to talk about the active role that women have taken to attain these; oftentimes by engaging in personal and political struggles. One such struggle was participants' call for partners to be responsible for their own sexual health/safety. If this were the case, "responsibility imperatives", that take away from women's sexual enjoyment (Gurevich et al., 2007, p.9), could be lessened. Women, who regularly attended support groups, were more involved in advocacy work or were better informed, demonstrated a greater sense of entitlement to sexual safety and pleasure.

To many of the participants, experiencing sexual pleasure in the context of HIV meant being alive (see 'the voice of sexual knowing'), hence its importance. 'Sexual knowing' was not meant to signify an a priori knowledge, immune to social construction but it stands in contrast to instances in the narratives, where women did *not* know (e.g., being unable to speak of their experiences in 'Trauma and disconnection'). When the voice of sexual knowing was heard, women appeared free from guilt, fear, shame or confusion. From within this voice, pleasure played an important role in marking out new paths for self-expression, enabling women to heal through relationship; recognise instances when they misused their sexuality (instrumentalisation); and acknowledge the fluid nature of their desire and attraction.

The continued ability to experience sexual pleasure also helped women fight unhelpful internalised sexual scripts. The toughest script to resist was that of sexual spontaneity discussed by Dune and Shuttleworth (2009) i.e., the belief/expectation that sex is only pleasurable if spontaneous. Because partners had to negotiate sexual safety on a very practical level due to HIV, they often experienced a loss in spontaneity (mentioned by Gurevich et al., 2007) which sometimes led to sexual difficulties. When women attributed this to a personal failure to fulfil sexual expectations (as prescribed by the internalised script), the result was frequently distress (Dune & Shuttleworth, 2009). In situations where partners shared responsibility for condom-use and ably communicated sexual preferences or discomforts, distress abated and sexual scripts could be altered.

It was evident that the concept of sexual safety was not only about physical health (e.g., avoiding viral transmission or risk of re-infection) but also included emotional safety (Jarman, Walsh and De Lacey, 2005) (see 'voice of sexual knowing' p.61 and 'voice of empowerment' p.65-66, 67). Trust, absence of fear, support, understanding and excitement were important elements that contributed to sexual adaptation. In light of HIV, sexual safety also encompassed circumventing possible violent reactions from partners after disclosure or at the end of a relationship.

The timing of disclosure was an important aspect in securing both safety and pleasure in relationships. Disclosing quite early, sometimes, ensured emotional safety by testing others' reaction before getting attached. Late disclosure, alternatively, helped secure pleasure by assuring that potential partners were not scared off by HIV or consumed by thoughts about it, taking energy away from the relationship or sexual encounter. Late disclosure however, also put women at risk of violent reactions if (for various reasons) they had to disclose *after* being sexually involved.

Making active sexual choices

Deciding when, how and whether to disclose, was one of the active sexual choices women needed to make as a result of their diagnosis. However, making choices that affected their sexual lives went beyond status disclosure or condom negotiation as is sometimes depicted in the literature (e.g., Hankins et al., 1997; Lambert, Keegan & Petrak, 2005). Women initiated a positive transformation of sexual subjectivity by deciding to engage with the questions that HIV brought up. They went to support groups, read books, sought out personal therapy or used a combination of the three to find the recognition, companionship and information they needed to face the issues unearthed, or created, by HIV. These actions acted as precursors to important decisions that, directly and indirectly, affected their sexual lives. Personal decisions were moved by: curiosity; trust; a greater sense of safety; and a desire and need for self-protection. They affected their sexual lives directly. In contrast, political stands that women took (e.g., being open about their status, campaigning, lobbying), were moved by resistance or rebellion and had an indirect effect on their sexual subjectivity. When women were able to draw power from participating in socio-political environments, this sometimes translated into personal strength in more intimate spheres (see 'the voice of empowerment' p.72 quote 97).

Identity as a sexual being

Sexual identity showed an interesting relationship to HIV. Women who had bisexual experiences spoke of how, the possibility always existed in their minds yet they only acted on it (sometime) following their diagnosis. This aspect of sexual fluidity remained unclear and requires further exploration. Others, who had never thought of bisexuality or homosexuality before, were introduced to such possibilities through the world of HIV as discussed by Gorna (1996). This raised new questions about their own sexual identity which some were unable to answer but remained curious about.

Women who had had relationships with both men and women did not identify as lesbian or bisexual but affiliated themselves with proponents of queer theory i.e., steering clear from labels and embracing the mutability of their sexuality (Moon, 2008).

In describing themselves sexually, women gave responses that might be expected from any portion of the population (e.g., being open; giving; lazy; passionate). HIV was not included in these descriptions. At different times however, women made sure to describe themselves as *not* their HIV. Perhaps, having their sexuality always framed in terms of HIV (in medical spheres, mainstream research and even in conversation with me), they wanted to draw a line between that which could be studied and scrutinised in relation to HIV, and that which was *theirs*. The main message was that HIV was not the entirety of their being. However, as discussed by Squire (2003), positioning the self in resistance to HIV ('I am not my HIV') signified a subject position that was paradoxically, inextricably defined by it.

Ego development and HIV trauma

Through the voice of distress this study's findings clearly confirm research on the traumatic effects of an HIV diagnosis (e.g., Nightingale, Sherr & Hansen, 2010). Echoing Gurevich et al. (2007), participants talked about feeling disconnected from the self and alienated from others, with fear, discrimination and constriction regulating this divide. In the midst of this, it is interesting to note the effect of HIV trauma on the women's developmental trajectories and renegotiation processes. There is commonality in content between findings in the current study and stage theories, such as those put forward by Erikson (1963; 1968), Kübler-Ross (1969) and Baumgartner (2007), however the concept of stages, and stage-like progression, is questioned through these findings.

Despite its relatively restrictive, binary view of development, Erikson's (1963,1968) theory offers a lifespan perspective that covers the various ages of participants in this study. It also has been used previously in HIV research (Merriam, Courtenay & Reeves, 1997) and is thus a good point of reference for discussing findings.

Similarly to Merriam, Courtenay and Reeves (1997), participants in this study were seen to re-visit and/or fast-forward through the four adulthood stages of psycho-social development as described by Erikson(1963,1968). Being diagnosed in midlife or young adulthood made little difference to how the women were catapulted into the psychosocial challenge of *identity versus role confusion*. As suggested in Gilligan (1982; 2002) and Tolman's (2002) work on female sexuality, a woman's sense of identity is strongly tied up with her relationships. Consequently, for those women whose diagnosis signified a threat to, or a loss of, relationships (e.g., a lover's rejection or induced miscarriage), there was also a loss of self or confusion about one's identity. The fall into identity confusion was evidenced through the voice of distress (see 'Trauma and disconnection') as women spoke of a self that was dispersed or subsumed within HIV. As discussed by Gilligan (1982; 2002) and Tolman (2002) shifts from an "I" voice to "we" or "you" can be indicative of this. Incomplete, faded-out sentences and inarticulation may also be markers of the loss of voice mentioned in Gilligan's work on relational trauma. The women became unable to see their true selves, and therefore found it hard to speak of their experience.

The initial shock and diffusion of identity is well documented in literature on HIV and identity (e.g., Baumgartner, 2007). Research by Baumgartner (2007) shows a similar pattern to the negotiation pathways mentioned in this study: initial shock or denial; immersion into the world of HIV/AIDS; life re-evaluation; integration of the HIV-identity; and decentralisation. There is also some overlap with other models documenting the processes people go through when faced with significant life changes or losses (e.g., Kübler-Ross, 1969). In relation to Kübler-Ross' model there is slight overlap in terms of early periods of denial, later depression and eventual acceptance. However, Baumgartner's study pays particular attention to the incorporation of an HIV/AIDS identity over time and is thus more directly relevant here. Baumgartner identified two turning points or transitions within her model. The first, moved people out of denial into immersion e.g., needing treatment for an HIV/AIDS-related opportunistic infection. Following this, people tended to become immersed in the world of HIV where an HIV-identity became central. Learning and teaching about HIV was common, and involvement in the HIV community, frequent. This overlaps with findings presented in the generative voice. The second turning point occurred post-immersion, and was usually related to medical success in viral load management and effective life-extending medication. At this point people tended to spend less time focusing on their health and took up activities unrelated to HIV. Here there is overlap with the voice of empowerment ('Putting HIV in the background') and possibly also the dignified voice.

Even in the current study, re-negotiating the psychosocial challenge of identity vs. role confusion required that women search for, and commit to, a new identity as

HIV-positive women. Findings (e.g., 'the generative voice') reconfirm that being around other positive women greatly enabled this process (e.g., Dozier, 1997). Messages about sex and sexuality cultivated in groups, affected women's sexual subjectivity by bolstering or weakening their sense of entitlement to sexual pleasure and safety. Personal agency could be seen to work in this process, as the women did not simply mimic others but sometimes defined themselves in contrast to other positive women's ideas ('voice of resistance').

Within this developmental challenge, the women gained a sense of *fidelity* (the developmental virtue obtained at this stage) in three ways: by embracing an HIV-identity; becoming more committed to themselves and their needs; and by adapting disclosure strategies to test the fidelity of others e.g., use of early disclosure (Derelega & Winstead 2004). The latter two processes were articulated by the voice of empowerment under 'Feeling stronger', 'Protecting the self' and 'Reframing difficulties', and related specifically to the women's sexual lives.

Within the generative voice under 'Finding reciprocity' and 'Becoming an advocate' one can see elements of what Baumgartner (2007) described as the stage of immersion i.e., involvement in an HIV-community, an HIV-identity becoming central, and learning and teaching others about HIV. Being immersed in the world of HIV gave meaning and purpose to one woman's life. However, the generative voice was also heard in women who could be considered further along Baumgartner's stages, for example, in 'I am not my HIV' some women indicated a decentralisation of their HIV-identity, yet continued to value a shared sense of being positive women. Sharing identity through HIV was a significant aspect of the generative voice because it compelled participants to support other positive women, even when, in their own lives, they were 'putting HIV in the background'.

The value of conceptualising such relational processes as *voices,* rather than stages, becomes clearer here: voices can co-occur, and in not following a linear pattern, they can better represent life. Most psychological models follow stage-like progressions, and despite allowing for overlap and retrograde movements between stages, they do not allow for a *co-existence* of stages or experiences. Because of this difference, it is difficult to juxtapose current findings and HIV literature without to-ing and fro-ing between the idea of co-occurring voices and stages of negotiation, yet this is done to be able to discuss similarities in content.

In this regard it can be said that the next Eriksonian stage of *intimacy versus isolation* was heard mostly through the voice of sexual knowing, with the voices of resistance and empowerment providing momentum for change. Gaining confidence from a renegotiated sense of identity enabled some women to begin confronting their HIV-induced fear of intimacy. Acquiring HIV sexually, whilst in a committed (heterosexual) relationship, caused some women to suffer a loss of trust due to betrayal (sexual infidelity or deliberate non-disclosure), which jeopardised their ability to be intimate with another for some time post-diagnosis (e.g., Hankins et al., 1997). Some had (protected) casual sex but did not want to be intimate with men, and those who entered into significant (serodiscordant) relationships, struggled to fully enjoy intimacy because an exaggerated sense of responsibility kept them feeling isolated within these relationships (e.g., Gurevich et al., 2007).

Renegotiating this psycho-social stage and being able to fully enjoy sexual intimacy (indeed, to find love, the virtue attached to this stage), sometimes required women to take a decision on the type of partner they would make themselves available to. As Squire (2003) noted, the qualities of Mr. Right were redefined in light of HIV. Because achieving intimacy is a joint endeavour, it required a partner who was not fazed by taboos surrounding the condition. The desire to be close to someone could have been "muted/mutated" by HIV (Gurevich et al., 2007 p.24) but women in this study found ways around it e.g., by using dating sites for PLHIV.

It is possible to interpret participants' stories of intimacy as being "HIV-limited" as described by Squire (2003, p.86), yet this would only perpetuate discourses of restriction, consolidating the idea that the women were captive to something that they were actually learning to live around. 'I am not my HIV' and 'Putting HIV in the background' are aspects of the women's voices of resistance and empowerment that clearly speak of this. None denied that HIV sat at the heart of their experiences; however this is different to saying that it limited them. Many in fact, referred to HIV as an opportunity, a reason to look at their sexual selves and their relationships more closely and make amends to self-defeating behaviours (Nostlinger et al., 2010).

Listening to the voice of sexual knowing (their desire, curiosity and need to *feel* alive) helped women overcome the fear of intimacy. One woman gave up casual relationships for something more meaningful and was slowly learning to love someone again (See Appendix L for a comment on this section). Another narrative represented the ideal romance described by Squire (2003), a story about struggle and tragedy (induced miscarriage) but with love prevailing in the end. Successfully re-negotiating intimacy came by slowly getting back in touch with their sexual selves and then allowing love and trust to guide their decisions on sexual intimacy. Both these examples stand in direct contrast to findings by Gurevich et al. (2007) that speak of diminished erotic possibilities and associated diminished intimacy.

In some relationships, love and sexual intimacy became more important than the need for (absolute) viral security (Cusick & Rhodes, 2000). The self-interested risk-avoidance that couples may have had, immediately following diagnosis, was replaced by an (informed) decision to have unprotected sex. Taking this decision in agreement with, or against, medical advice however, seemed to affect the sense of otherness experienced by couples. Going against medical advice intensified the experience of otherness for one woman and prematurely consolidated her (seroconcordant) relationship (Jarman, Walsch & De Lacey, 2005). Echoing Squire's (2003) description of a pragmatic love, this participant described her relationship as both "consolation" and "constraint" (p.89). The difficulty in successfully renegotiating intimacy was tied to an intensified fear of isolation due to the HIV. Avoiding isolation and responding to the need for (sexual) normality may have led to a premature union between this participant and her partner, keeping her from exploring other sexual avenues.

For women who did not talk about sexuality in terms of love, negotiations of the seventh psychosocial stage (*generativity vs. stagnation*) were more apparent. The generative voice was inspired by the women's negotiation of this stage. Regardless of age, all the women showed healthy engagement with this psychosocial challenge, gaining meaning through caring for others (e.g., advocating against desexualising messages around women and HIV; running support groups) and in some cases replacing the desire to have many children with a global community of friends and colleagues involved in HIV.

In their research, Merriam, Courtenay and Reeves (1997) describe the movement of a group of HIV-positive people through the four psychosocial stages of adulthood, including the last stage of *integrity vs. despair*. Their sample consisted of participants whose CD4 counts were under 500 and for whom anti-retrovirals were not yet available. Because the sample of women in the current study was significantly healthier (higher CD4 counts) and not in any real danger of developing AIDS, I did not think that the last stage would be relevant. However, my findings showed that the dignified voice was an articulation of negotiations of this very stage. Erikson (1963) writes "ego integrity is the acceptance of one's one and only life cycle... that permitted no substitutions [...] the possessor of integrity is ready to defend the dignity of his own life style" (p. 168). In light of this, the women's ability to accept both the good and the bad of a life with HIV, their acknowledgment of the role HIV has played in their personal growth, and statements they made about not fearing death, point to the successful way in which they have already begun to engage with this developmental challenge.

Although encouraging, such a finding indicates that advances in HIV medicine (that now manage HIV like a chronic illness), do not reduce the psychological impact of the disease. An HIV-diagnosis is still experienced as a life-threatening event which can mobilise the negotiation of all four stages of adult development. These are normative stages that sometimes overlap and re-occur at different points in life, yet facing all four at once may be overwhelming and highly disruptive for newly diagnosed men and women.

As Siegal at al. (2006) have noted, women's ability to adjust psycho-sexually to HIV is not directly linked to having better health due to successful medication regimes. Issues of trust, emotional hurt and past betrayal persist beyond good physical health and prevent women from engaging in and enjoying sexual relationships. Participants in this sample had all received some form of psychological support (peer or professional) besides (some) also being on HAART (Implications discussed in 'Limitations and reflexive critique' p.100). Being, and staying, physically healthy was an important aspect of successfully reclaiming their sexual lives but it also depended on: having someone to talk to that understood and knew about HIV; being seen as more than just their HIV; being around other positive women who inspired ways of living well with the virus; finding ways to take charge of their sexual lives; and teaching others to do the same.

Implications for Counselling Psychology

The voice of distress and HIV prevention

Although the aim of revisiting the topic of sexuality and HIV was to find ways of supporting women already living with HIV, the voice of distress offers interesting avenues for HIV/AIDS prevention that are worth expanding on.

Findings on early vulnerability and disillusionment (see voice of distress) demonstrate how being ill-equipped to face certain intrapersonal and interpersonal challenges in young adulthood left some women vulnerable to infection. Being educated and knowledgeable about gender issues, power relations and even sexual health did not translate into personal power. Vulnerability related to a lack of psychological (or other) resources required to meet those challenges, resulting in the use of sexuality as a compensatory strategy.

Amaro (1995) offers some insight into possible reasons for the disconnection between education or knowledge and personal agency. Whilst arguing for the need to develop new models of HIV sexual risk reduction, she highlights that a woman's power in specific relationships is not only dependant on what she knows or has been taught, but also on her and her partner's adherence to traditional gender roles. This is not only affected by their attitudes, beliefs and values regarding the role of women and men, but also by the level of comfort in *contradicting* tradition. At a young age and in cultures with strong patriarchal traditions, participants of this study may not have had sufficient power to adequately negotiate situations of sexual risk.

Amaro (1995) also emphasises the importance of 'connection to others' in women's lives and sense of self, highlighting its effect on risk behaviour. This could help explain the use of sexuality as a compensatory strategy. Amaro argues that: the degree of mutuality in the relationship; the anticipated level of threat to connection through conflict about safer sex; as well as the skills, and level of comfort, in dealing with conflict, all have an effect on women's exposure to sexual risk. Thus, women might use sex to *maintain* connection, and avoid anything that they fear, or anticipate may cause disruption. Although it did not emerge in the interviews or analysis, Amaro also speaks of fear of violence and abuse as being another reason why women might put themselves at risk of sexual infection.

It is also important to consider how family discord and parent-adolescent conflict may push young women to seek connection elsewhere by initiating (early) sexual relationships (e.g., Flewelling & Bauman, 1990; de Graaf, van de Schoot, Woertman, Hawk, & Meeus, 2012). At a young age they may not yet have the (psycho-social) resources to manage such relationships safely.

The implication of the finding on early vulnerability supports recent literature on the need for systemic approaches to HIV-prevention strategies. Boyce et al. (2007) argue that the different societal and subjective meanings of sexuality, as well as its "symbolic value" (p.1), need to be considered in HIV-prevention programs. As Kirkman et al. (1998) point out; some of the reasons why adolescent girls have unprotected sex are built around, and fuelled by, the romantic narrative. Unprotected sex is a way of demonstrating love and trust; one's virginity is offered as a gift; and never doubting a partner's 'safety' is seen a form of trust. Willig (1997) also talks about how people can sometimes consciously take risks to prove their trust in others. Methods based on safe-sex education therefore simply do not suffice. More effective approaches need to incorporate the countless reasons why people have sex (e.g., love, money, self-esteem, escapism) in more honest and open discussions about sexuality. Werner and Bower (1982) argue that traditional health education approaches, aimed to bring about behaviour or attitude change by acting *upon* people (teaching/indoctrinating), are not as effective as participatory education where, through open communication, *people* are encouraged to act upon the world to bring about change. Participants clearly stated that they generally lacked such open discussions while growing up and greatly desired them before and *after* acquiring HIV. Boyce et al. also recommend more "sex positive approaches" (p.15) to prevention programmes, where pleasure is given precedence over messages of fear and risk and where safety becomes an (important and recognised) aspect of pleasure.

This crucial symbiosis between safety and pleasure was absent in the ways some participants were taught to think about sex.

In CoP there is great scope for delivering more systemic, individually-tailored sex education. Its principles, which place subjectivity at the heart of intervention, could help create environments where women and girls are supported in listening to their own voices, enabling them to develop sexual self-knowledge and a greater sense of sexual agency. Through personal therapy, and group work, counselling psychologists could encourage open discussions about personal meanings attached to sex/sexuality and together with their clients, explore the social influences that hinder, or encourage, helpful (or unhelpful) thoughts and/or behaviours related to sexuality.

Life groups could be set up in community centres, sixth forms and universities, and also offered as adjuncts (or alternatives) to individual (private) therapy. Initially coordinated by a psychologist they could then develop into peer-led groups. Thus, counselling psychologists would get involved in their communities, empower individuals through *self*-knowledge (rather than just knowledge) and work towards goals of social justice i.e., contributing to environments that *support* mental health and well-being (Goodman et al., 2004).

Harding (2005) presents a similar venture to life groups that Reeves (2005) and her colleagues set up for women of colour/indigenous women who were either HIV-positive or ‘at risk’ groups in the USA. *Transformational work*, as they describe it, moves beyond transferring skills/knowledge related to HIV but focuses on psychological work addressing self-esteem, self-image, trauma, dependency, co-dependency, personal autonomy and decision-making. The goal is “to understand the issues for HIV risk and care, from personal and social perspectives” (Reeves, 2005, p.113).

The secondary aim of a life group would be to create a network of support that can counter the value that society places on sexualised females. Having lived in a Catholic country, I also recognise the need to address beliefs that reduce the importance of sex to procreation. As seen in this study, the healing power of one’s sexuality is not limited to an ability to procreate. Listening to the voice of sexual knowing helped women regain a sense of themselves in the world. They equated sexual expression with feeling alive and, for one woman, sex offered a channel of expression for grief over loss. Supporting and helping women understand the positive power of their sexuality is something that religious institutions continue to fall short of. The role of Counselling Psychologists can be crucial in this respect because the non-judgmental, gently inquisitive attitude that supports our work can create an environment safe enough to explore these issues, whether we are working with HIV-positive or HIV-negative people. Also, Life groups need not only be for women. Mixed-gender groups would stand a better chance of reaching the goal by bringing into the picture men's role and responsibility (e.g., Amaro, 1995; Boyce et. al, 2007).

In time, this could mean incorporating more than just safety into the idea of an enjoyed sexuality, and speaking instead, of a sexuality that can heal. Such a paradigm shift would not only strengthen prevention efforts but also hold value for helping women renegotiate their sexual subjectivity post-diagnosis.

Voices for change

This study's most prominent contribution to the field of CoP is its influence on individual/group therapy with positive clients. In conceptualising post-diagnosis experiences as 'voices' with different decibel strengths, rather than as set stages, it offers a framework for counselling psychologists to work with the entirety of the human person. If an HIV-positive client presents as highly distressed, experiencing and expressing shame, guilt, avoidance or acting out, it does not mean that the entirety of their being is in this state. The voice of distress may be the loudest and strongest at that time, but therapists and clients can work together to listen for other co-occurring voices. This could help offset the strength of the voice of distress, without ignoring or denying it. Over time, the client can be supported in listening to more empowering or adaptive aspects of the self. From such a new perspective clients are also 'given permission' to return to that voice when times are hard, expressing and exploring it without undermining stronger parts of themselves.

The more far-reaching implication of this study is the *different* way in which it portrays positive women. Not only does it bring hope for a possible paradigm shift in people's understanding of living with HIV, but also starts to create a much-needed, affirmative role-model for newly diagnosed women. In doing so, it speaks to more general principles of CoP research that aim to ameliorate people's lives systemically. In line with Chwalisz's (2008) comments on the need for counselling psychologists to draw on positive psychology principles, this study has succeeded in identifying some adaptive responses that women with HIV endorse to renegotiate their sexual lives. It is important to speak of successful adaptation and make these stories known because they act as examples for others. In Foucauldian understanding, discourse shapes sexuality. It is thus important to be careful where we focus our attention and what discourses we (sometimes unknowingly) strengthen (Greene, Frey & Derlega, 2002). As counselling psychologists we can move beyond focusing on medical or clinical difficulties and be the voice for a different take on HIV, not blindly or foolishly ignoring difficulty or psychological pain but being inspired by people who are managing to move beyond it, and using such examples in our clinical work.

These findings also emphasise the importance of exposing ideas about sexuality and HIV that hinder positive women's adaptation. As seen in the voice of resistance, women sometimes fought an inner battle with dominant discourses or sexual scripts that they internalised even before diagnosis. The need to collaboratively re-write such scripts is an important implication for working with seroconcordant/discordant couples. It is also a useful area to explore with single women to help protect them from internalising blame in casual encounters. The model presented in Figure 1 (p. 43) can be used to identify the relational plane on which to focus intervention.

This type of introspection and belief-challenging is also an important exercise for therapists and other health professionals working with PLHIV, as personal biases can work to subtly hinder clients' adaptation. Apart from being relevant to individual client-work, it also applies to how the condition is presented to the outside world. Professionals act as expert representatives of HIV, therefore their role in educating the public is crucial. Changing fear-laden messages to coping ideas, indirectly helps support positive people in their intimate/personal lives through systemic change.

Counselling psychologists and others working in fields of HIV, health and sex education can teach the (non-positive) public about HIV in numerous ways. A few examples are: creating sex education curricula that include sections on being in relationship with HIV-positive persons; offering specialised sexual education services to seronegative partners and/or serodiscordant couples and; using waiting rooms in counselling services (that are not HIV-specific) as showcases for information on living well with HIV, so that the larger public can access such information. The United Kingdom National Guideline on Safer Sex Advice (Clutterbuck et al., 2011) provides important practical information that can be used for this purpose. It discusses issues related to sexual safety for PLHIV such as when to start ART, condom use (e.g., size, type) and practices of serosorting (i.e., having sex only with people of perceived or declared similar serostatus) in a very simple and straightforward manner.

Speaking to the focus of this study, there is a need to move away from persevering societal beliefs of women as *Virgins, vamps and victims* (Gorna, 1996). It is part of the ethos of CoP that professionals and researchers work towards creating an environment that sustains mental health and well-being (Goodman et al., 2004). For women with HIV this would mean interacting in a society that is less hostile and more knowledgeable on matters related to sex and HIV, enabling them to sometimes step out of the role of sex educators within their relationships and focus on being partners and lovers. This is a wish that women clearly expressed in their narratives.

By making reference to Merriam et al. (1997)'s research on ego development, this study reminds psychologists working with PLHIV to note the various psychosocial challenges that clients may unknowingly and simultaneously be struggling with. Working collaboratively with clients to uncover them, whilst using psycho-education on developmental stages to frame discussions, may help give a context to people's experiences.

Although this study linked the renegotiation of stages to positive women's sexual lives, the voices of empowerment, generativity and dignity draw on various dimensions of existence: family ties, friendships, laws and policies, medical advancements. Acknowledging this during therapeutic work is very important as systemic issues may work to facilitate or inhibit healthy adaptation. Helping clients see what is, and is not, in their power to change may be important to lessen the sense of guilt or disempowerment that they may be experiencing. A sexual focus could nevertheless, be useful for professionals working with people to whom the virus was sexually transmitted.

Another direct therapeutic implication of findings is the importance of paying attention to foreclosed/premature unions between seroconcordant couples. Such unions may be protective at times and distressful in others. Clients may need to be supported through periods of re-evaluation of their circumstances that may or may not lead to decisions to leave the relationship.

In addressing issues of sexual safety it is important to explore and support the idiosyncratic ways in which women understand and negotiate sexual safety (e.g., emotional safety, avoiding violence), whilst also discussing potential risks.

Findings showed that offering group therapy or setting up life groups would be a valued service for women with HIV. Many expressed the desire for a space where they could talk openly and safely about sexual issues with other women. This was not always possible in support groups where rapport-building was usually negatively affected by different socio-economic needs (Ciambrone, 2003) and a varied, irregular attendance. In Ciambrone's study, when the majority of women attending a group had difficult socio-economic circumstances (e.g., financial difficulties or issues related to migration) these monopolised group discussions, pushing other, less pressing issues, to the side. White, middle-class women often felt their issues were less important and therefore contributed less to group discussions and sometimes, also dropped out. A more formal therapeutic setting such as a closed group (Yalom & Lesczc, 2005) could address such issues: an initial assessment would help assign people to different groups depending on their circumstances, needs and expectations; and compulsory regular attendance (i.e., having participants commit to attending regularly and informing the group to when, and why, they could not attend) could ensure that there was more structure and predictability to the group that could foster greater trust and openness between members.

As Chwalisz (2008) remarks and as is demonstrated here, the role that counselling psychologists can take in working with PLHIV is varied and includes interventions on an individual, group and societal level. Working on psycho-sexual issues is never divorced from health and/or psycho-social concerns. Therefore integrating sub-disciplines is important. Additionally, the therapeutic implications presented here hold relevance to working with people with different chronic illnesses, in particular, the empowering concept of co-occurring voices.

Limitations and reflexive critique

This study presents two controversial elements that can be considered both limitations and key features to the insight acquired. The first was that the majority of participants were involved in HIV activism. According to Greene et al. (2002) and Brashers, Haas, Neigid and Rintamaki (2000), activists were more likely to use problem-focused coping over emotion-focused coping, had more knowledge about HIV treatment and enjoyed a well-integrated social network, all of which aided adaptation to HIV. Therefore, the sample necessarily limited the degree to which the findings may be generalised to all women living with HIV. Nevertheless, such a bias gave voice to adaptive behaviours and successful renegotiations in positive women's sexual lives, offering helpful information (role-modelling) that holds relevance outside the world of activism.

Findings may also have been affected by the inclusion criteria related to women's prior experience of therapy and/or support groups (see p. 38). This decision was taken to ensure the wellbeing of participants: it offered protection against distress that may have arisen in the interview had there been no prior experience of talking about HIV and sexuality. This (ethical) decision may have coloured results in that fewer unresolved issues may have emerged during the interviews, yet, as mentioned above, the intentionally precise sample also enabled stories of adaptation and well-being to emerge.

The second controversial feature was the way in which *specific* voices, inspired by existing literature or contemporary knowledge, are listened for in the Listening

Guide (see p.34). I first listened for the voice of distress which is widely written about in HIV research, followed by the voice of resistance and that of empowerment which are hinted at in various studies. The emergence of the other voices occurred once the first three were extracted and set aside. They were less directly informed by literature but related well to psychological theory. This method enabled a good balance between expanding previously conceived (but underdeveloped) notions and allowing new ones to emerge. In some ways it limits what can be heard and only allows in-depth analysis of a certain range of voices. Nevertheless it also regulates personal bias as listening is informed by relevant theory and literature.

One limitation that emerged at the end of the study, related to the voice of sexual knowing. As some women remarked during the feedback meeting, this voice had the potential to be stronger and more nuanced, had there been greater familiarity between us to be able to explore it more deeply. Due to restrictions in time and resources, I only conducted one interview with each participant and a follow-up participant-feedback group. Participants felt that multiple meetings (at least two) might have engendered greater comfort and familiarity between us, allowing for more in-depth discussions in relation to this voice. A second interview may have also given me the opportunity to overcome a personal hesitation about exploring the issue of onward transmission of HIV more openly (see p. 106)

In distinguishing white, European, HIV-positive women from the rest of the HIV population, the study marks ethnicity and gender as differentiating criteria. Outside socio-political and economic settings however, this distinction may be considered superficial. In fact, one participant commented that, in her experience, socio-economic status affected peer-group inclusion/exclusion more often than ethnicity. It might therefore be short-sighted to limit the applicability of findings to this one population sub-group. Gender, however, continues to be a defining variable according to participants. The study's guiding questions seem to suggest or assume that being 'a woman' is something specific, a predefined experience linked to gender or bio-genetic make-up. Although it is probably true that similarities in (physical or psycho-social) experience draw a group of people together under this label, it is also true that women are different and the experience of womanhood varied to say the least (e.g., homosexual, transgender women). I cannot hope, nor do I wish, to subsume that experience into the narrow parameters set out by this research. Consequentially, the wording used may be considered a limitation.

Methodological considerations

Investigating the research question through different qualitative means e.g., Interpretative Phenomenological Analysis (IPA) or Grounded theory might have yielded different but not dissimilar results. The advantage of the Listening Guide (LG) over IPA is the direct clinical applicability of working with voices. The LG also offers greater insight into participants' consciousness through "I" poems, making it ideal for research on identity. IPA and other theme-focused analyses narrow down on the content of transcribed text, potentially overlooking hidden meanings in the spoken word e.g., tone changes and breaks in speech. Utilising video as well as audio could help improve LG protocol by adding non-verbal cues to interpretations.

Using grounded theory could have served to further develop a relational theory of HIV and sexual renegotiation. It would have also allowed the incorporation of numerous non-research based influences on the theorisation of the subject e.g., informal conversations, internet-based support chats, newspaper articles etc.

A quantitative approach to this study would not have been possible without pre-conceived notions on successful renegotiation. However, in a mixed-methodology study, measures of sexual subjectivity using an inventory (Horne & Zimmer-Gembeck, 2006) might have helped shed light on aspects of sexual subjectivity that were stronger or better negotiated than others in light of HIV.

The research process

Power-sharing has shaped the research process throughout. At recruitment, Positively UK required that I write a tailored proposal to be approved before any information was shared with its members (see Appendix M for the policy). Aiming to balance power, the organisation did not simply accommodate my research needs but asked that I write an article or aurally present my findings in return. Passing this pseudo-test allowed a more trusting and collaborative relationship to develop between myself and the women recruited from this organisation.

Interview venues were chosen by participants, which, in some cases, may have affected the depth of responses e.g., women interviewed at work or in a public place remained more guarded than others. In general however, participants fed back (during debriefing) that they felt safe and comfortable talking to me, perceiving me as an *informed* professional who would not judge them.

In approaching the transcribed data for analysis, my own questions about HIV and sexuality surfaced. The most pressing was *'How do you stay positive in the face of something so potentially negative... in the most intimate aspect of your life?'* This personal question guided my interrogation of the texts and pushed me to listen for ways in which women coped. On a personal level I desired to find hope in women's narratives, something that would ease my dis-ease about what I had read about HIV/AIDS. Politically, I felt it was important to find ways to shift discourses of distress and disempowerment that did little to inform therapeutic practice. As a researcher, I followed the gap in the research and listened for affirmative transformation amidst obvious distress and difficult changes brought about by HIV.

Reflecting on the process of analysis, it is interesting to note how findings met my expectations or otherwise. My greatest and most daunting expectation was to hear about the "unassimilability of HIV in relation to sexuality" (Gurevich et al., 2007 p. 29). I anticipated hearing stories of dread and despair (see also 'My voice in the research' below). Instead, women told stories of resilience and empowerment, in a resilient and empowered manner. Their determination to resist, and even overthrow disempowering and desexualising messages around HIV, was immediately evident in the interviews. The notion of a fluid sexuality was another unexpected finding. It was interesting to see how exposure to the world of HIV helped women question and/or know their sexual selves better. I was also surprised at the insightful and self-compassionate way some participants spoke about their early vulnerability: they did not use language related to promiscuity or self-blame but demonstrated an understanding of the social and emotional precursors of their actions. It is possible that this was the influence of therapy and/or support groups at play. The issue of motherhood, as it emerged in the findings, was both weaker and stronger than expected. Participants spoke about it less, and less often, than I anticipated but for women who were diagnosed before HAART and who lost a child, or were never mothers because of lack of medical options, it seemed a burning issue.

During the feedback group, participants reacted well to the analysis' results, supporting the claims made and showing a keen interest in the idea of co-existing voices. They offered insights that informed my discussion of clinical implications (e.g., using voices in therapy) and limitations (e.g., multiple interviews to further explore the voice of sexual knowing). I did not transcribe or analyse our conversations in the same way as the individual interviews. This allowed me to maintain intellectual independence (Reisman, 1993) over interpretations made at the analysis stage, whilst remaining true to the collaborative spirit intended by including their feedback in my discussion of results. Sharing power was not only ethical but also strengthened my confidence in the study's validity. It provided greater depth to my inquiry, highlighting aspects of the subject that might otherwise have been less accessible to me (Freeman et al. 2001, van Eik & Baum 2003, Duggleby 2005).

Suggestions for future research

One largely speculative and highly sensitive area that could be explored further is why women tended to have, or thought about having, bisexual experiences *after* being diagnosed with HIV. Despite being a thorny issue to explore, it could provide unique insight into female sexuality post-diagnosis.

Another area that could not be sufficiently expanded on in this study was the impact of mother-daughter relationships (or more generally parent-child relationships) in positive women's conception of sexuality. When asked about how sexuality featured in their lives, all participants spoke about their families of origin and the majority talked about their mothers. This was also the case in previous research I have done on sexual subjectivity and migration. As was demonstrated in this study, it is not only sociocultural, economic or biological contexts that make women vulnerable to HIV but also psychological factors that push them to use sexuality to compensate for needs of closeness and acceptance. Thus, this could be an interesting avenue for HIV-prevention research.

Accessing a different population of HIV-positive women to compare responses with could help expand the applicability of current findings. Only two (of six) participants were on HAART and because participants' responses did not differ greatly, this issue was not discussed any further. However, it might be important to explore how voices might change in a sample of participants who need to be started on medication.

The age-old question about whether the resilience shown by these women was due to circumstances such as support from loved ones/peers or whether it was down to personality traits might also be a valid area for future research. However, I believe that the value of such research would depend on whether it would help people live better with the condition.

Finally, it would be interesting to see a project, similar to participatory action research, which took the Listening Guide and tested it as a form of collaborative, narrative therapy. This has been done with other feminist research tools e.g. Haug et al.'s (1987) memory work. Teaching participants about the method and then having them *collaboratively* identify voices in their own recorded and transcribed narratives could make for an interesting take on power-sharing in research and in therapeutic encounters. It could help create a more empowering form of therapy where women learn to identify their own streams of consciousness and use them to inform therapeutic work.

My voice in the research

Finding my voice in this study was a difficult task because harsh facts about HIV/AIDS consistently drowned it out. The bulk of information about HIV is daunting and sometimes just brutal[6]. In most media portrayals and prevention campaigns, there is no space, no hope for life after diagnosis. Academic research

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[6] See http://www.youtube.com/watch?v=e4ZBzMOV9Js or search 'MTV AIDS shot'.

does not offer much solace either. I remember writing in my reflective diary (Appendix N), 'It is all about death!' and in that I noticed a parallel between my experience as a researcher engaging in this project and what it might be like for women who enter this world through diagnosis.

My reaction was rebellion. Not because I knew any better, as I had no direct experience of HIV/AIDS, but my personal belief, 'you're not dead until you're dead', was a strong driver in the conceptualisation of this study. Reports on medication successes bolstered my conviction.

In truth, I have come across women who share my rebellious belief and are witness to its verity. They confirmed to me that it is okay to explore concepts that counter mainstream beliefs and it was on meeting *them* that I managed to hear my own voice again. I was then able to monitor its influence on data analysis and made sure to stay close to the women's actual spoken words (through multiple listenings) to portray their experiences accurately.

The biggest obstacle for me was daring to say that maybe it was okay for women with HIV to be sexually active. The fact that they are, is well-known in research but it seems to be a condemned reality in (most) parts of the world. In the Catholic society where I grew up, suggesting it is deplorable. I had to speak directly to this taboo, explaining myself to friends and family, pushing the boundaries of what is culturally acceptable. However, the internalisation of this sociocultural belief often created panic in me because 'what if positive women themselves agreed that this was a futile and invalid area of research?' This was the gremlin on *my* shoulder.

The second set of taboos I had to face was the idea of positive women having unprotected sex and the possibility of them having passed on the virus. In both these cases I struggled with my own judgemental, castigating beliefs, managing to suspend thoughts about the first but completely avoiding the latter. Participants may have shared my discomfort as we discussed unprotected sex in some detail but did not broach the subject of transmission. This is a substantial limitation of the study that might have been resolved through multiple interviews as an increased familiarity might have enabled more honest discussions of such controversial issues.

At different points during this project I noted my varying desire to be distant or close to participants. At first, I felt I needed to approach HIV-positive women as an HIV-*negative* woman. I made it a point to define myself, to myself, as negative and even went to get tested. This action was motivated by fear - an intense discomfort about entering the world of chronic illness and a reaction to the terror that built up in me after reading so much about HIV/AIDS. On some level I justified this to myself as being good practice, addressing my fears before going on with the project, but in reality it was a form of defence. From Gorna's (1996) perspective, I was protecting myself from being queer by association. The contradictory result of such an action was fascinating. On the one hand, it created the safe distance I wanted, but on the other, it allowed me to follow in the (physical and emotional) paths participants might have taken just before diagnosis.

After meeting the participants, my need for separateness disappeared and instead I felt a deep desire to belong. I caught myself wishing I had HIV to be able to share in their sense of community. In retrospect I realise that this was partly motivated by a sense of inadequacy and an assumption that having HIV would give me more authority to speak of these issues. I believe that this desire for closeness helped me understand my participants better, whilst my underlying sense of inadequacy kept me on my toes.

During the feedback-group, I asked participants how they felt about speaking to a woman of unknown serostatus. They reported that within the research set-up they could sense that I was "a goodie", that I was "on their side", so it did not matter because they felt that I would not judge. As a CoP practitioner, getting to a point where clients/participants feel supported in this way, especially when their experience is often one of marginalisation and prejudice, felt like a success. As a CoP researcher however, I wondered to what extent my being "a goodie" stopped me from broaching more difficult topics with them and to what extent they felt they needed to censor their responses to keep me "on their side". This experience of transference and counter-transference illuminates potential traps that practitioners working with PLHIV may easily fall into.

As I exit this project I find that I am neither a stranger nor a member in the world of HIV but I believe I have found a middle ground from which to speak about it. I am honoured by the trust my participants placed in me and I hope I have done it justice.

Conclusion

This study has put forward new ways of thinking about the sexual subjectivity of women living with HIV. Participants demonstrated various ways in which they have learnt to live *around* constricting and unhelpful discourses related to their sexuality. The voice of distress, that marked well-documented experiences of trauma, stigmatisation and loss, was shown to exist alongside the voices of resistance, empowerment, sexual knowing, generativity and dignity. These voices spoke of experiences that women came across, but also sought out, which enabled them to renegotiate important aspects of their sexual selves and lives. It was evident that, despite advances in medication, being infected with HIV was still a traumatic experience that precipitated significant changes in identity, intimacy and meaning in life. Women questioned and renegotiated meanings around their sexuality on four relational planes: within themselves, in relation to HIV, in relation to others, and between themselves *with* HIV in relation to others. The co-construction of new meaning through supportive relationships stood out as a key element of adaptation.

This study highlighted the continuing importance of sexuality in positive women's lives, recognising it as an integral part of the healing process as described by participants. The existence and recognition of different ways of being or relating to the world (i.e. multiple, co-occurring voices) inspire ways of working with positive women that uphold the CoP principles of holism and subjective experience. The notion of co-existing voices also challenges earlier stage-theories of adaptation, offering a framework for working with the entirety of the human person and their experience. Finally the study offered practical ways in which both prevention work and post-diagnosis support can be led by counselling psychologists who see the value in bringing more systemic change to society, so that we can speak more often about a sexuality that is not only safe and pleasurable but that can also heal.

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Appendix A

Method

Background and criticism to the Listening Guide

The Listening Guide was first developed in 1982 by Carol Gilligan during her studies on identity and moral development. Gilligan (1982) noticed that the way in which female participants spoke about identity, morality and relationships differed from mainstream psychological theory of the time. She noticed that women's and girls' (sometimes subtly and sometimes largely) different ways of perceiving, understanding and thinking about their social worlds was not being picked up in research. Despite being spoken about, in theory based on generalised research findings, women were not often the subjects of research.

Through the use of voice-centred methodology, Gilligan (1982) and others were able to focus on the largely overlooked and distorted experiences of women in different areas of social life ranging from anger among girls (Brown, 1998); sexual desire in female adolescents (Tolman 2002); women experiencing workplace transitions (Balan, 2005); and strength in black women (Beauboef, 2007). Although mostly used with female participants, this method has also been used to explore adolescent girls' and boys' friendships (Way, 1998), heterosexual couples' attempts to share housework and childcare (Doucet, 1995) and is increasingly being used to explore experiences of neglected or otherwise "voice-less" groups in society.

There has been some strong criticism of Gilligan's original work, with debates on the reliability of her findings and the consequences of her assertion on gender differences, especially in educational settings (Jaffee & Hyde, 2000; Hyde, 2005; Barnett & Rivers, 2004). Yet even her critics appreciate the larger point she contributed to research, "that if psychological theories of human development intend to represent lived experience, then they must be constructed with the diversity of such experience in mind" (Jaffee & Hyde, 2000, p.721). Voice-centred research contributed towards a paradigm shift, one which allowed women to take up a place of equality in socio-psychological research and which also understood that social change required a shift in structure on a political and a theoretical level, as the possibility of different ways of being came to the fore (Kiegelmann, 2009).

Appendix B

Method

Sample extract of first reading of interview with Tasha

		Familiarising myself with the text	My initial response
M	Okay,so Tasha, would you like to tell me a bit about yourself coz I …don't know much. These are my papers for, hehe, em, the schedule. Em, how would you describe yourself? Who is… Tasha?		I feel quite nervous. This is my first interview and I find it difficult to shift from therapist to researcher
T	Hehe, hmm yeah it's a very difficult question of course…em…ffff… I'm 29…		
M	Mhmm…		
T	Eh, I…wouldn't eh necessarily describe myself in relationship to HIV because I don't think it represents me…	HIV does not represent me	
M	Mhm		
T	So eh, it is part of me, but, it isn't what I am.	It isn't what I am	Interested… sense something different to literature. I like these statements - they give me a sense that she is empowered and resisting dominant discourses that want to engulf her person into the condition of HIV
M	Mhm		
T	So, I wouldn't say that that is the first information about me when I talk about myself so, um, I think I'm a …young woman interested in… travelling and knowing.. people um and uh, um, somehow, uh, my life uum, um, has, uh become very, uh complicated at a certain point uh when I was very young. That is ten years ago, uh, when I was diagnosed with HIV.	Life became complicated	
M	Mhm.		
T	Uh and starting from that um, I had to…work my way around it	Working her way around it	
M	Mm.		
T	Um, otherwise um, I consider myself just a normal person with various interests. I love to write, read eh, travel, know new people and uh, basically, um, explore everything that life uh, offers me.		

Sample extract of first reading of interview with Andrea

A	I don't know, you never know unless you're in the situation but hehehe		Maybe she senses my discomfort because she also laughs nervously at the end of each statement
M	Okay. Em...so in relation to HIV and s-s- and sex... or sexuality I gues but sex mhmm... how, so that is how you felt, back then it was, people supported you in a sense and said, 'go ahead, don't, don't let this stop you from having sex'...		
A	Yeah.		
M	How about now? How do you feel...that relationship maybe is? Has it changed?		
A	Eh... I think that's a ...after two years em, I've got, sometimes I've got mixed feelings about it. Em... because I've gone through, different experiences sexually em... like, I've had partners where... have been, have felt very comfortable or maybe, not at the beginning but they've been willing to learn about it.	mixed feelings - comfortable - willing to learn	
M	Mhmm		
A	Em... and then I've had partners where... they've been really, really scared and they, you know, to the point where they don't even wanna...kiss me, for expample. So, I think... it depends on the mentality of the people for me. It makes me feel ...one way or another and at the end I always think well, you have to be strong, you know, you know, you know who you are, you know how HIV is transmitted, you know what is safe and what isn't em...so that to me is very important that, that I know, where I stand.	scared - strong,,, you know,,,	I am touched by her resilience in this extract
M	Mhmm		I realise how different our world views are - I would speak in terms of love but for her, being recognised as sexy and having people want to have sex with her is so important to her self-concept and self-expression that true 'love' or loyality is seen in the men who would still have sex with her
A	But at the same time... you know... sex doesn't happen on your own, unless you're masterbating heheheh but em, so... because I've encountered different reactions with my partners... em, but, I, I have, one of my sexual partners for example, I've known him for four years... and when he learnt about my diagnosis, he was very shocked em... but he's always been very supportive...	sex doesn't happen on your own	
M	Mmm..		
A	He's always been there and he hasn't stopped having sex with me so, every time... I find myself being disappointed by... like someone I may be interested in or you know, someone I want to start a relationship with and, and the reason why it doesn't go further is that I have HIV?	He's never stopped having sex with me	
M	Mmm.		
A	I always think about this... sexual partner and that gives me strength.	sexual partner gives me strength	Her voice cracks at this point - still a painful reality for her
M	Mmm.		
A	Em...so I feel that... I shouldn't.. I shouldn't feel like I am...u...useless...I mean, I, I was on and off with... a guy for a year, about a year and em...he had real issues about that fact that I have HIV...	useless...	Rushes through saying that as if ashamed for it to stand alone without explanation
M	Mmm		

Appendix C

Method

Extracts from women's "I" poems

1. *Participant talks about herself as a sexual being.*

This is something she seems to find hard to do despite her generally confident attitude. The "I" poem shows her stream of consciousness as she progressively comes to the realisation that she has ignored her sexual self for a long time and sees value in changing this for herself.

How do I describe…myself…… to myself?
How would...How would I?
I'm not to be honest.
I look

I have quite a passionate nature…
How do I describe my sexuality to myself? …
I just see myself as normal
I just see myself and my sexuality... normal.

I suppose to be honest,
I...

Who? How would I?
I probably

I suppose
I've…
I've not taken time out
…

My sexuality
I've not thought about
My sexuality…
My life
I think about that
I… can't think of anything
I can't think
I will.
I need to just sit down
I'll

I'll think

I suppose,
I've…not wanted to deal

I think
I've not wanted to deal
I need to … look at myself
For me…
I speak
For me
Me …
My life
I wouldn't have done.

I think
I'd like to see…

I haven't even considered myself
If I can have something to give
I just need to go away and think
(216-246)

… … …

2. *Extract demonstrating a successful struggle for self-expression.*

This "I" poem captures a potential adaptive coping mechanism that this participant makes use of. In real life her articles are public and therefore she does disclose, she does tell, but it is also an indirect route to self-expression that offers some distance, some safety until she is ready to show, tell and discuss things with her partner. It could easily be extrapolated to coping mechanisms such as writing a diary or a letter that offers perspective until one is ready to share one's thoughts and feelings with significant others .

I wrote an article

For me
I mean,
I've written
I was thinking
I didn't tell
I didn't want to,
I still didn't want to

I wrote about it

I wrote an article
I did
I showed him
I wrote it up
I showed it to him

I wrote an article
(137 - 161)

………

3. Extract demonstrating disconnection from self following diagnosis.

When talking about life with HIV, this participant immediately shifted from "I" to "we" indicating how the self with HIV is bonded to this other person and through it they are one.

We didn't
I didn't
We didn't…
We hardly spoke

We tried,
We were told to
We tried
We did
I think
We decided
If we were to get on in this relationship
I think
We just have to
We made the conscious decision
We were,
We were going to die together.
We thought
We'll just get on with it

Appendix D

Method

Sample extract of the third and fourth readings from Dona's interview

D	Em… … … now… … … yeah and that…after I got diagnosed, *after those three years of silence…em… I had to just, try it again… em… it was very difficult for me to… get involved again for the first time after being together with my …husband for twenty years…*	three years of silence…	**Her sexual voice/ The voice of distress/ The empowered voice**	The sexual voice pushes to be heard beyond the distress
M	Mhm..			
D	**Eh, eh and, and then…yeah, that was quite hard. Em, well not quite hard, it was… awful hehehe.**	quite hard - awful		
M	Mmm.			
D	Em… … but then…yeah, I had a time when…em… … I wasn't loose but I just… … to, to like feel that I'm normal em… I had to have…se- different encounters…	to feel that I'm normal	**Her sexual voice/The voice of distress**	
M	Mmm.			
D	Mmm.Yeah and now, since one and a half years I'm stable, you know like, it's like a nice thing again? You know like eh, eh… (sighs)… it's not to prove to myself that I can still have it. I think my age also, plays a, a, a role now.	to prove to myself - age		
M	Mmm.			
D	There were times when eh em… yeah when I was heading towards fifty, emm, that I got, I got involved with men quite a bit younger…and I think em…that was also, now I can see it, to prove to myself that em, you know people still want me, men still want me.		**Her sexual voice/The voice of distress**	
M	Mmm.			
D	And now I think, I'm secure, you know like, I don't have to prove anything to myself anymore em… it's just nice and …comforting and you know a proper relationship again, how it's supposed to be…	prove anything to myself	**The empowered voice/ The voice of sexual knowing**	
M	Mmm, okay em…shifting now on, maybe a bit more specifically to HIV…			
D	Mhmm…			
M	…what thoughts of images comes to mind when you speak about HIV, when I …mention that? So same question but …now related to HIV. What comes to mind?			
D	(Sighs) in relation to sexuality? …Or?			
M	Maybe in general?			
D	In general… … em, the stigma? Here. Em… I don't really… I'm not scared of it… I think, for everything there's a reason em… … … good eh, you know like, bad times they always gave me something good as well?	stigma here (UK) I'm not scared of it	**The voice of resistance/ The voice of empowerment**	
M	Mhmm.			
D	Eh, they changed me and the HIV did as well, you know, I may be more open… eh to people now and I say more what I think?	more open, say more		

Sample extract of the third and fourth readings from Tasha's interview

		Familiarising myself with the text	Voices emerging in third reading	Interpreted in light of 'I' voice
T	...so, uh, that would be one negative aspect but I don't see myself um, so much of a victim of this and my partner um, has two kids from um, uh, uh, some later, further, some other relationship and he is not, yeah willing to have other kids and that's good for me *so I'm I'm safe hehehee let's say,* I don't, I don't consider it an issue. But em, in other terms it just, the worst thing about it is this, it's that it's there, you know, it's there as a constant uh, in, everything that you do, uh, because um...I'm gonna be very, I don't know, uh practical...in, giving an example. For example, I'm on a new um, um, um, medication, for, I've been on it for uh two weeks now and I have to take it at night uh and I have very strange symtoms, sometimes and um, uh, not just my sleep pattern but also sex was uh um effected by it so right now I'm expecting things to be uh, better because they say those side effects would wear off...	I don't see myself so much a victim of this...	The voice of resistance/The dignified voice/ The empowered voice (practical)	Her voice goes lower in tone... maybe this sort of resistance might be hiding a desire of hers of maybe a desire to have the option open to her too like it is for most women
M	Mmm.	HIV it's a constant.		
T	...in time for example. So that would be worst thing about it. The fact that, uh, it is there and of course um, there's also the fear of losing the person next to you. Okay?	Sexual problems also a health issue - practical.		
M	Mm.	Fear of losing the person next to you... if you cannot manage effects of HIV medication on sexual appetite		The dignified does not deny difficulty but puts perspective to situations that might be pitied.
T	...because, yeah maybe, yeah, compromise immune system does mean uh...that... yeah he might... have this rather than other ...but I don't see it as um, I think I, I don't know, negative people would have the same problem maybe coz, you never know. But for us, I think it is a little bit more, yeah, it would be a little bit more, important		The voice of resistance / The dignified voice	If she does not listen to this voice, HIV could come and affect other, important areas of her life
M	Mmm.			
T	Yeah.			
M	And what would you say is the good thing, or...?			
T	Ffff...the good thing is, em... for me HIV was, uh, something that made me grow as a person... so... um. I always think that...... I wouldn't have been this person that I am now without the experiences that I've been through and HIV was, a very important part of those experiences, somehow the core of those experiences. So, the good part about it and especially related to sexuality, is that it...um, made me aware, and um, understand myself in ways that, probably uh, without it, I wouldn't have been able to, to see and...	Something that made me grow as a person.	Voice of empowerment (acceptance & growth)	

Appendix E

Method

Description of participants

In presenting the women who took part in this study I have been mindful to omit any easily identifiable details. I have generalised information about their age and their country of origin, exchanging names of places for larger geographical areas and deliberately excluded information on their occupation and level of education. What I do present in more detail is the interplay of the different voices as they emerged in each woman's narrative.

Tasha was a woman in her late twenties from South-Eastern Europe who had been living and travelling in different parts of Europe for two years. She had been diagnosed ten years earlier and was in a monogamous relationship with an HIV-positive man at the time of the interview.

Tasha's narrative demonstrated how the voice of distress, particularly aspects of disillusionment, guilt and shame, shattered an initial innocence surrounding her sexual life. Through 'intimate recognition' Tasha was able to start to renegotiate her sexual life as the voices of resistance and empowerment were heard in unison, drawing strength from one another. In her descriptions on 'finding reciprocity', Tasha's generative voice was heard, bolstered by the voices of empowerment and resistance. The voice of sexual knowing emerged late in Tasha's narrative: although shy and somewhat understated it was steady and passionate, holding the same timbre as her dignified voice.

Vanessa, a woman in her mid-forties from Southern Europe, had been living in the UK for eighteen years and diagnosed HIV-positive for fourteen. She was single when I met her.

The most prominent of Vanessa's voices was that of empowerment. It coloured the way Vanessa spoke about everything; the time before HIV, her distress and disappointment after infection and her understanding of what was needed to turn things around. Interestingly, the voice of resistance was heavily tied up with Vanessa's generative voice and both fed off empowerment *and* distress. The dignified voice was the result of this convergence of voices, where each of the voices was expressed in a balanced manner. The voice of sexual knowing was present early in Vanessa's narrative but often came head-to-head with the voice of distress in her lifetime.

Andrea's experience was similar. Also single, Andrea was a Southern European woman in her late twenties. She had been living in London for seven years and was diagnosed two years prior to the interview.

Andrea's sexual voice was loud and demonstrative. By her own admission, it was often used to drown out the voice of distress. This was a strategy she used before infection. After infection however, Andrea's sexual voice allowed her to gain new insight and greater maturity so that the 'instrumentalisation of sexuality' became evident to her. Through the voice of empowerment she attempted to change the way she related to others sexually. However, because of HIV, the voice of distress and sexual knowing were often at loggerheads. The voices of generativity and dignity were present, but not often heard in Andrea's narrative and it was the voice of resistance instead that was more common.

Dona was in her early fifties. She was born in Central Europe but had lived all of her married life in Africa. After the breakdown of her marriage, she moved back to Central Europe where she was diagnosed with HIV. Dona had been living in the UK for two years when we met and was in a relationship with an HIV-positive man.

Empowerment, generativity and dignity were the voices most often heard in Dona's narrative. The voice of distress was also clearly identifiable when she spoke of the period just before and just after diagnosis. However, the tone of her narrative was mostly set around these other three voices. Her voice of resistance was less articulated than other women's and usually surfaced from within the voices of dignity or empowerment. Her sexual voice, on the other hand, was unexpectedly frank and quite powerful. It excluded the possibility of 'sexual fluidity' but strongly brought in the element of pleasure.

Jen was a British woman in her late forties who had lived in the UK all of her life. Divorced and re-married to an HIV-positive partner, it was her second husband who unknowingly gave her HIV. They had been living with HIV for over two years (unspecified) when I met her.

In Jen's narrative, empowerment was the most silent of the voices; dignity and resistance in the form of 'searching for the middle ground' and 'tolerating ambivalence' were heard instead. The voice of distress was balanced out by aspects of the voice of empowerment, mostly 'intimate recognition' and 'putting HIV in the background' however Jen resisted listening to the voice of sexual knowing that, for other women, had fuelled empowerment. Although her sexual voice was heard in some instances, she held back on it because in many ways it was tied up with distress (related to questions about her sexual identity). Jen's major source of empowerment was her generative voice through which she gained strength and perspective.

Kate was a British woman in her early fifties who worked and lived in different parts of Africa as a young woman. She was diagnosed over ten years prior to our meeting. Before being diagnosed, Kate was pregnant with her seronegative partner's child but because of HIV she was advised to terminate the pregnancy. She and her partner later married.

The two most powerful of Kate's voices were the voice of distress and the voice of sexual knowing. Through the second, she was able to listen to and placate the first. Paradoxically, from within both of these, Kate found her voice of empowerment. Like Vanessa, Kate's voice of resistance was tightly bound up with generativity and both these voices were fuelled by empowerment and dignity. The voice of dignity and the voice of distress could be heard in counterpoint to one another at certain points in her narrative.

Appendix F

Information sheet

My name is Martina Gerada. I am a post-graduate student at the London Metropolitan University reading for a Professional Doctorate in Counselling Psychology. As part of my degree I am conducting a research project on female sexuality and HIV.

My interest lies in the process women go through in adjusting to a positive diagnosis of HIV with particular focus on their sexual lives and sexual identities.

How, if at all, does a diagnosis of HIV affect a woman's sense of self as a sexual being? What aspects of her sexuality change, develop or remain the same? Does the passage of time after diagnosis play a part in this? And how do aspects of sexuality such as pleasure, intimacy and safety feature in all this?

This is the type of questions that will be asked if you choose to take part in the study. The interview questions are meant as a guide to help and encourage you to expand on your own thoughts, reflections and experiences regarding this topic.

Women recruited for the study should be **over 18 years of age**; preferably **diagnosed with HIV at least 2-3 years ago** and **have attended therapy or self-help groups in the past**. This is necessary to help protect participants who might otherwise be exploring sensitive issues for the first time in a research situation. Despite being a safe, confidential and mutually respectful environment, this type of interview cannot provide answers to personal questions or offer psychological support.

The interviews will last approximately an hour and take place at a time and location convenient to you. They will be conducted in a manner that **will protect your confidentiality and anonymity**. Sessions will need to be audio-taped for later transcription, but all information gathered will be held in strict confidence, only I and my research supervisor will have access to the recordings. Anonymity will be respected as all participants will be given pseudonyms (different names) when data is transcribed. Participation is entirely voluntary and there will be no penalty on withdrawal. Even after giving written consent **you will have the right to withdraw from the study up until three weeks after the interview should you wish.**

This research project has been approved by the Ethical Board at the London Metropolitan University.

If you would like to take part and require more information please send an email to martinagerada@yahoo.com. Your contribution will be greatly appreciated as research on HIV and sexuality has been largely silent on women's experiences. On completion of the study you will receive a summary of findings and any relevant information.

In taking part in this study you are contributing to a discussion about female sexuality that recognises its importance to women's lives and identities especially in an age where HIV in the Western world is a chronic but manageable condition.

Thank you for your time and I hope to hear from you soon.

Regards,
Martina Gerada
Trainee Counselling Psychologist

Supervised by Dr. Elena Gil-Rodriguez
Email: e.gil-rodriguez@londonmet.ac.uk[1]

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[1] My supervisor was later changed. Participants were informed of this and given updated information when invited to attend the participant feedback group.

Appendix G

Consent Form

Dear participant,

Thank you for agreeing to take part in this study. By signing this form you are confirming your consent to participate and showing that you understand that:

- The session (lasting approximately 60-90 minutes) will be audio-recorded for later transcription and analysis by the researcher: (Martina Gerada).

- The recordings will be used for the purpose of this study and will only be heard by the researcher (Martina Gerada) and her research supervisor (Dr Elena Gil-Rodriguez) to protect confidentiality.

- Anonymity will be maintained through the allocation of pseudonyms during transcription and throughout the rest of the study.

- Audio-recordings will be stored under secure conditions and destroyed at the end of the examination process for this research project.

- Data collected will be used for this research study with the possibility of publication in psychological journals or presentation to scientific bodies.

- The research will be conducted according to the Code of Conduct and Ethical Principles of the British Psychological Society.

- Participation is voluntary and you are free to withdraw from the study up until *three weeks* from the interview date in which case data will be removed and destroyed.

Signature: Date:

If you have any questions of require any clarification about the consent form or the study in general please feel free to ask directly or contact myself or my supervisor on the contact information provided below.

Researcher: Martina Gerada
Email: martinagerada@yahoo.com
Mobile: 07518137128

Supervisor: Dr Elena Gil-Rodriguez
Email: e.gil-rodriguez@londonmet.ac.uk
Telephone: 020 7320 2331

Appendix H

Interview Schedule

[Introduction to the study, signing of consent forms and clarification of queries]

Can you tell me a bit about yourself? Who is ...?

What was your reaction when you first read about this research?

Why did you agree to come here today?

What are your expectations of the interview*?*

Sexuality (generally)

What thoughts or images come to mind when you think about sexuality and intimacy?

Do you think HIV has an effect on this?

If so, how/in what way?

Self as a sexual being

How would you say sexuality has featured in your life thus far?

(Is it/was it an important part of your life?)

HIV and sexuality

What thoughts or images come to mind when you think of HIV?

When it came to sex and intimacy, how did you feel when you were first diagnosed with HIV?

How do you feel now? Has it changed?

(What do you think has contributed to this change?)

(Can you tell me more about this process?)

What happens nowadays when you are interested in/sexually attracted to someone?

How does it compare to before your diagnosis?

Can you tell me more about why?

How does it compare to just after your diagnosis?

Entitlement to sexual safety and sexual pleasure

What is important to you when it comes to being sexual/having sex with someone?

What thoughts or images run through your head as you are engaging with someone sexually?

Identity as a sexual being

How would you describe yourself (to yourself) sexually? (Who, what, how am I sexually?)

What do you feel has contributed to this image/idea of yourself?

What does having HIV mean to you (with regards to your sexuality)?

What is the worst thing about having HIV in terms of your sexuality?

What is good/positive about it in terms of your sexuality?

Do you have any other thoughts or reflection about the topic that you would like to share with me?

Were you expecting me to ask anything that I didn't ask today?

Is there anything you would like to ask me?

Appendix I

Debriefing sheet

Dear participant,

Thank you for taking part in this research project. Your contribution is very much appreciated.

If you have any questions regarding the research or wish to withdraw your consent to participate (over the next three weeks[*]) you may contact me via email at martinagerada@yahoo.com or by mobile phone on 07518137128.

If you prefer to speak to my supervisor you can contact her at the following address:
Dr Elena Gil-Rodriguez
School of Psychology
Faculty of Life Sciences,
London Metropolitan University
Calcutta House
1, Old Castle Street,
London, E1 7NT
Telephone: 020 7320 2331
Email: e.gil-rodriguez@londonmet.ac.uk

Later in the analysis stage of research, I might contact you again to ask your feedback on emerging results of the research. This is a usual part of the particular research method I am adopting, however it isn't compulsory, therefore please let me know if you feel you do not wish to be contacted about this.

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[*] The three-week limit is necessary due to restrictions in time for collecting and analysing data for the completion of the study.

Once the research is complete I would be able to send you a copy of the study or a summary of the findings if you are interested in having it. Please let me know if you would be interested.

Finally, if as a result of participating in this study you have experienced or are experiencing any difficult feelings that you would like to address I have provided you with the contact information of organisations that may offer you some support.

Samaritans:	Provides 24-hour confidential emotional support for those experiencing feelings of distress or despair Telephone: 0845 790 90 90 Website: www.samaritans.org.uk
Careline:	Provides confidential crisis telephone counselling. Careline maintains an extensive information system which contains details of other agencies and support groups throughout the country and can refer callers to a specific agency when required. Telephone: 0845 122 8622 Website: www.carelineuk.org
BACP	The British Association for Counselling and Psychotherapy website offers a list of qualified counselling psychologists and psychotherapists around the UK. You can follow the 'Find a Therapist' link to find a therapist in your area. Telephone: 0870 443 5252 Website: www.bacp.co.uk

Appendix K

Distress Protocol

This protocol has been devised to deal with the possibility that some participants may become distressed and/or agitated during their involvement in my research into HIV and sexuality. This is a very sensitive and personal topic that may bring up unresolved issues or create some distress for participants.

There follows below a three step protocol detailing signs of distress that I, the researcher, will look out for, as well as action to take at each stage. This protocol is modelled on one by Chris Cocking (2008), a grade 5 qualified Mental Health Nurse registered with the NMC, who has experience in monitoring and managing situations where distress occurs. It is not expected that extreme distress will occur, nor that the relevant action will become necessary. This is because most of the participants with HIV would have been recruited from self-help groups where such topics would have already been discussed and also, participants would preferably have gone through a course of personal therapy before being recruited for this study. However the protocol would be used in the unlikely case of emergency.

Mild distress:

Signs to look out for:

1) Tearfulness
2) Voice becomes choked with emotion/ difficulty speaking
3) Participant becomes distracted/ restless

Action to take:

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

Severe distress:

Signs to look out for:

1) Crying, inability to speak coherently
2) Symptoms of panic such as shaking, feeling of unease/nausea, hyperventilation

And/ or

3) Severe agitation, verbal (or physical) aggression

Action to take:

1) The researcher will intervene to terminate the interview/experiment.
2) The debrief will begin immediately
3) Relaxation techniques will be suggested to regulate breathing/ reduce agitation
4) The researcher will recognize participants' distress, and reassure that their experiences are normal reactions to difficult events
5) 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
6) Details of counselling/therapeutic services available will be offered to participants

And/or

7) Maintain safety of participant and researcher

8) If the researcher has concerns for the participant's or others' safety, he will inform them that she has a duty to inform any existing contacts they have with the voluntary organisation or mental health services, such as their G

Appendix L

Discussion

The added burden of criminalisation

In light of new legislation on the criminalisation of people with HIV (mostly in the U.S and Canada), all of these aspects of sexual renegotiation related to intimacy vs. isolation are again catapulted into confusion and distress. Fighting the internalisation of blame also becomes harder as one has to contend with the very real and hard consequences of a legal system that wants to assign blame.

> *Charges are being laid against people living with HIV who are alleged to have put their sexual partners at risk for HIV during sexual intercourse. The allegations, over 1000 already in the U.S., allege that the person having HIV did not tell the partner of his or her status, even though in many cases they were wearing condoms and /or had an undetectable viral load. And these are cases of consensual sex. Of course we do not want to see predators on the streets. But the stories I have heard are of people living with HIV who have been doing what they understood they should to protect their partners and/or were telling partners of their status before having sex. Yet, when things go sour in the relationship, or for whatever reason, the partner charges them with assault, attempted murder and in many U.S. States can actually rely on specific HIV criminal laws. People are sent to jail for years when there was no harm done and no criminal intent whatsoever.* (L. Binder, 27 July 2012, opendemocracy)

The personal is made political in a very disempowering and threatening manner as civil society barges in to HIV-positive people's lives to potentially eradicate the hard work done towards healthy psychological adaptation.

> *It is a terrible irony that we have come to a place where the medications we fought for will allow us to live a relatively normal quality of life, and now we are going to go to jail for doing so* (L. Binder, 27 July 2012, opendemocracy)

Under such threats of criminalisation, seeking partners on online groups for people with HIV becomes a prison not an adaptive opportunity and attempting to trust partners again becomes twice as hard and triple the risk (emotional risk, physical risk of re-/infection and risk of prosecution). Thus, constriction and limiting discourses (Gurevich et al., 2007) continue to lurk dangerously under the surface. It is our duty as Counselling Psychologists (Goodman et al., 2004), and generally as people working in mental health, to pre-empt the negative influences of such legislation and speak out to encourage less disruptive ways of protecting public health.

In light of this, it is not surprising that the possibility of onward transmission remained taboo even within this study. Dominant discourses of fear affected both me as a researcher and the women as participants. It worked to silence my professional curiosity for fear of losing my ability to remain impartial and kept the women from saying anything "wrong" about this subject – all showed the "right amount" of hesitation about unprotected sex. Only one participant mentioned the issue of criminalisation. Speaking from within her generative voice she called it "appalling".

In the U.S. HIV-positive people can be prosecuted for intentional and reckless transmission as well as for accidental transmission *and* exposure where transmission has not occurred. In the UK the situation is different. In their official guidelines, The Crown Prosecution Service (2011) only mentions intentional and reckless transmission as grounds for prosecution and closely defines these terms. Prosecution on the grounds of recklessness is initiated if it can be proven that a person foresaw that their partner might contract HIV via unprotected sexual activity but still went on to take that risk. Reasonableness of taking such a risk is also considered e.g. low risk of transmission because of a low viral load. Around 24 people in England, Scotland and Wales have been found guilty of intentional or reckless transmission of HIV thus far.

Appendix M

Positively UK Research Policy

POSITIVELY WOMEN
living with HIV ... changing lives

Policy on Cooperation in Social and Medical Research:

Positively Women receives many requests from medical and social researchers and their students for assistance in their research into the experiences of HIV positive women in the UK, particularly those from the African continent. The increased research attention is welcome if the results are to be used to increase services and resources and reduce stigma for service users and other HIV positive people and their communities.

However, multiple research requests targeting similar audiences could result in a small population being over-researched, and increasing research collaborations could lead to a drain on Positively Women's resources.

Positively Women has a responsibility to ensure that any research project it participates in will in no way exploit the participants.

Positively Women will therefore work with partner agencies and individuals who wish to access staff, volunteers or service users for research only **under the following conditions**:

1. The research is reasonable, sensitive to the needs and feelings of the participants, and takes into account issues such as confidentiality
2. Participation is done voluntarily and with full and explicit consent of the participants
3. The research will lead to direct and demonstrable improvements in the lives, conditions or opportunities of people living with HIV
4. Researchers undertake to present findings in an accessible form to the research subjects
5. Research follows stringent ethical standards as set out in the Helsinki Declaration
6. The research is being conducted by a reputable agency
7. Positively Women has the staff capacity to undertake such collaboration.

As a general rule, PW will not work with individuals working on research for higher degree purposes.

PW will always ask for people taking part in interviews to be given a fee and cover for additional costs e.g. childcare, although this may not always be a pre-condition. Positively Women does not support interviews taking place at interviewee's homes.

Where PW has agreed to collaborate, the following assistance can be given:

1. Advertising the research, but individuals will not be approached.

2. Positively Women's premises can be made available to researchers to conduct interviews, etc., provided it does not interfere with service provision & any costs are covered

In circumstances where a researcher or agency works collaboratively with PW and meetings are held at PW's premises, PW will contact people direct to inform them of the research and procedures for participation.

Where researchers and agencies are working independently PW will request service users to contact the researcher/agency direct; PW will not forward service user's personal details to researchers not seek permission from the service user to do so.

Appendix N

Extracts from reflective diary

04/07/2011

My god it's all about death! All the adverts, information slides, presentations, clips on AIDS/HIV on youtube are about death. The most shocking one is on youtube and called MTV AIDS(shot). It's shocking – people in love, happy, having sex, making love then the guy in each picture, points a gun at the woman's head and kills her!

17/07/2011

This dissertation is going to take me on a journey into the world of chronic illness; a place I know I don't want to go and I know it on a visceral, psychic level - strange how that parallels the human desire to stay alive.

14/03/2011

I finally understood the concept of contrapuntal voices and it came through Beethoven. His Piano Sonata No. 14 in C sharp minor to be precise. Contrapuntal voices: two hands, playing the same piece, at the same time but saying very different things. One slow, dying, low, the other alive, hopeful, living, despite the low one, and then the one chooses to join the other and slows down, remaining bright, remaining treble but moving towards a stop – but at points the bass also joins the treble, always supporting it in time and sometimes answering, asserting, wanting to assert its presence. The other hears and follows, they move together, one lowers itself, goes higher to assert itself – stays alive, plays its part so that at the end, as base wins over or simply remains, it is not a loss but a coming together, an amalgamation.

Section B:

Reflective Essay

PYP152C

Developing a personal philosophy and orientation to counselling psychology practice

According to a review of studies looking into therapists' preferred models of counselling by Quenk and Quenk (1996), 'no significant relationship [was found] between personality and theoretical orientation'. This finding comes as a welcome surprise as I approach the end of my final year of training, especially in light of difficulties I have encountered in practicing cognitive behavioural therapy (CBT).

While CBT appeals to my more rational and scientifically-minded self, both I and my supervisors find that I tend to take on a more humanistic stance with clients and struggle with performing the sometimes prescriptive tasks of a cognitive behavioural therapist. This seems to be due to a personal belief system about change which is somewhat at odds with the basic tenants of manualised treatments such as CBT. According to Horton (2000) and others, a personal belief system consists of a person's values, their cultural identity (Bernard & Goodyear, 1992), their worldview and their developmental stage in the lifespan (Egan & Cowen, 1979). Using these as markers I hope to delineate the personal philosophies that underpin who I am becoming as a therapist and to better understand how these, link to my current training and practice of counselling psychology.

My belief system and emerging dilemmas

I was born into a family who had, what I understand to be, three distinct powerful forces at play that influenced who I am and the contradictions I sometimes grapple with. On the one hand there was the strong religious influence that came from my mother's family - not the dogmatic type of religion but rather a sincere faith and appreciation for all things spiritual and ethereal about our existence. On the other hand there were the intellectual, culturally-enamoured travellers of my father's side of the family – open-minded people yet very rational and (somewhat) emotionally-stunted. Although my mother and father did not completely play out the roles doled out by their respective families, their life choices brought to bear the third great influence in my life; the realisation that truth is co-constructed at best and unattainable at worst. Thus, my belief about this world is that it is transitory, we are here on a journey and will eventually move on to something else; my love for the world is in its diversity, in the vastness of knowledge (empirical or otherwise) and experience it can offer and; my understanding is that this is *my* truth and like mine, are many other truths that have been constructed and lived-by. And thus, despite my love for knowledge and information, I separate myself from positivist schools of thought and lean more towards a social constructionist position. This is how I approach my life and my practice as a counselling psychologist.

Within this overarching framework, there are also other more culturally-bound values that I hold, which inevitably influence my practice. Working in this field has pushed me to name and monitor their involvement in my work[1]. Perhaps this is what attracted, and still attracts, me to the discipline. Counselling psychology encourages (and some would argue, requires) a deeper understanding of oneself (Grant, 2009). It facilitates a process of growth in me as I sift through the difficult experiences of my life. It provides a sense of purpose through its emphasis on understanding and reaching out to others, and in its attempt at making a positive difference.

Maybe because I am a young adult in training and also because of my religious upbringing, I believe that the meaning and purpose of life is 'becoming' rather than 'doing' or 'being'. However, I also believe that each has its place and time in the course of one's lifespan. In my experience, people come to therapy during different phases of their life and it is my duty as a therapist to help them figure out which one it is – do they need to do something differently; do they need to learn to just 'be'[2]; or do they need to come to a realisation that will help them along in their journey of becoming? [3]

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[1] For instance in working with seropositive gay men, I have had to confront the power of my moral standings around sex, health and intimacy to be able to genuinely be with my clients.

[2] A form of acceptance advocated for by third wave cognitive therapies like mindfulness techniques (Kabat-Zinn, Lipworth & Burney, 1985; Segal, Teasdale & Williams, 2002) and less directly, components of Acceptance and Commitment Therapy (CAT) (Hayes, Strosahl & Wilson, 2003).

[3] In tune with more existential/humanistic schools of thought (Corey, 2005).

My issue at practicing pure CBT is that most times it assumes that people must ‘do’ to bring about change[4]. The therapist too can get caught up in the ‘doing’ of therapy - ideally ‘with’ the client but sometimes ‘for’ the client - rather than remaining attuned to client needs. The concept of ‘client needs’ is in itself a tricky one as sometimes what a client needs might go beyond verbalised goals.

In my training thus far, supervision has been crucial in curbing my tendency to ‘do’ too much in situations where processes of change required different forms of therapeutic interventions. Sometimes it was required of me to sit back and to stop offering alternatives to a client whose apparent enthusiasm at setting goals obscured a recurring behavioural pattern in which her own needs and desires were buried in attempt to please others. This inevitably led to persistent low-moods and lack of motivation. From a schema theory perspective, both of us played out our respective schemas[5]: she was approval-seeking and subjugating her own needs whilst I was engaged in the performance of cognitive behavioural techniques which activated my unrelenting standards schema (Young, Klosko & Weishaar, 2003). Good supervision and a well thought-out formulation helped me become aware of this. I was able to shift into a less directive mode in therapy allowing her the space to express and explore the underlying causes of her unhappiness.

In another instance a client who had just lost two close friends wanted help ‘getting organised’ and motivating herself to study. In the course of therapy it became evident that what she needed from therapy was quite different from her initial goals and related more to accepting her loss and being contained through the grieving process (Lendrum & Syme, 1992).

Often, I find that CBT speaks a language in which difficulty equates to a problem that can be solved through setting goals. In some ways this is a very positive and empowering message when compared to endless repetitions of frustrated childhood

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[4] Protocol CBT interventions for anxiety and depression for instance involve collecting evidence for new patterns of thought, carrying out behavioural experiments and record-keeping (Beck et. al, 1979; Padesky & Greenberger, 1995).

[5] A schema is a cognitive structure through which we filter information to be able to understand our world (Beck et al., 1979). Young’s definition (1990, 1999) refers to schema primarily developed in childhood - consisting of cognitions, emotions, memories and sensations - that are triggered and played out in certain situations.

needs spoken of in psychodynamic theory (Huprich, 2009). However, I do believe that just as realities are constructed, therapy can be a place where difficulties are de-constructed and given new meaning through the process of the therapeutic encounter.

I was brought up to believe that people are basically good[6] and that given the right conditions they are able to make healthy choices, to heal and move towards their true potential. I see that my role as a fellow human being is to reach out to that 'trustworthy, positive centre' (Rogers, 1987) and make genuine connections.

I therefore consider myself a humanist at heart. However, in the course of my training I became increasingly aware of the difficulties in understanding what constitutes 'the right conditions' for change in different clients – does it mean simply offering support and empathy; does it consist of challenging thoughts and modifying behaviours; is it about enabling new experiences? [7].

The previously-mentioned positive other schema (Beck et al., 1990) has served me well in my work with clients as it sets the stage for the core conditions of empathy, unconditional positive regard and genuineness (Rogers, 1957) - conditions which have been proven to facilitate change. However these have also been shown to be neither entirely necessary nor sufficient for effective therapy (Gelso and Carter, 1985).

In addition to evidence present in the literature, this has also shown up in my own practice. For instance, in working with clients who suffer from depression/low self-esteem I often find that being empathic and understanding is not enough for change. Utilising knowledge of the links between biological factors, behaviours, cognitions and emotions, and using the cognitive- behavioural techniques devised to mobilise them, is crucial (Butler, Chapman, Forman & Beck, 2006)

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[6] A positive Other Schema (Beck et al, 1990).

[7] And again on what level (emotional, behavioural, cognitive, and spiritual) and where (within the therapeutic relationship or in the external world) should the new experience be located?

In thinking about my personal beliefs I soon become aware of how my own schemas may fight for survival[8] and affect the way I conduct therapy in the way I struggle to take on a more directive stance when needed. Consequently, I move into thinking about concepts of psychological theory. It seems as if I shift in and out of the different layers of the four-tiered model of integration described by Bond (1995) and expanded on by Horton (2000)[9]. When thinking about the model's deepest layer, 'personal philosophy', I quickly shift into the level of 'formal theory' which houses what I know about human learning and development. This makes it hard to separate what I believe in, from what I know about beliefs, making cognitive theory a sort of meta-belief.

Some may argue that this is an ideal stance from which to practice counselling psychology because it precludes any value judgements; it understands that every belief is valid given a certain context. The resulting emphasis on individuality of meaning, and interest in understanding context, echoes the guiding principles of counselling psychology (Division of Counselling Psychology, 2005) and also ties into a social constructionist view-point. Seen in this light CBT and humanistic therapies share common ground despite having different theories of change.

Nevertheless the dilemma (or challenge) in trying to incorporate these seemingly opposing approaches (CBT being considered interventionist and person-centred/humanist therapy non-interventionist) into my clinical theory[10] and the methods (skills and strategies) used to implement them, remains.

Developing an integrative stance to clinical theory

As my personal belief system and formal theory start to find common strands through which to link, CBT currently dominates, with some resistance, on the level

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[8] Schema maintenance is the way in which information that matches schema content is more easily accepted, attended to and assimilated (Beck et al., 1979)

[9] The model identifies a surface layer of 'skills and strategies' used in face-to-face interactions: a second layer of 'clinical theory' that houses therapeutic concepts of change: the third layer is 'formal theory' which is the therapists' held beliefs and training about what makes for normal and abnormal behaviour in human development: and finally, underpinning it all, is the personal belief system or philosophy.

[10] The guiding concepts about change that define my practice (Horton 2000)

of clinical theory. Within my practise I tend to use a cognitive behavioural framework as a basis for understanding and formulating my clients' difficulties. A sound yet fluid formulation then guides the techniques (active or otherwise) that I choose to adopt, together with supervisory discussions and a constant tuning-in to interpersonal processes in therapy. Guiding the latter is a psychodynamic understanding of processes of transference and counter-transference (Huprich, 2009) but also simply the noting of clients' non-verbal communication to situations in-session.

Working in short-term therapy placement settings (6-8 sessions) often forces me to take on a stronger interventionist stance than I feel comfortable with; thus constantly challenging my beliefs about the processes of change and the time they require.

An idea which I have found helpful in this regard is that therapy is simply one of the catalysts for change in a person's life. Thus the change I sometimes hope to see in a client might not occur during our time together. This lifts the pressure of grandiose ideas about saving people which I might have had on entering this profession. It allows me to focus on clients' presenting problems and longer-term solutions even in light of short-term therapy.

An illustration of this is an experience I had with a client who had long-standing issues around decision-making and a fear of growing old. She presented to therapy confused about IVF[11] treatment in light of early-onset menopause. She was angry at the medical professionals for not offering enough support and direction. Because of previous experience I was aware of the potential risk of being drawn into feeling responsible for her decision. I was immediately overwhelmed by what I felt contributed to her problem and what could potentially be worked on. Supervision helped me to accept that I would not see her through this decision but could help her understand her desires and motives better. I was able to communicate this to her, she agreed on this goal so we worked together on exploring and defining what was of value in her life.

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[11] In Vitro Fertilisation

In working with this client I was able to adapt and incorporate concepts from ACT (Acceptance and Commitment Therapy). Starting from a cognitive-behavioural formulation built around thought-behaviour records, we were then able to move on to an exploration of the values that currently guided her. In helping her identify and sift through these values she was able to see which ones she wanted to hold true to and which others belonged to a culture that she thought she had left behind or which belonged to dominant discourses around femininity and motherhood which she could not prescribe to. As a result, she was better able to accept her current situation and make a commitment to speak more openly about her fears with her partner who was very supportive.

In this case my supervisor's advice helped free me from personal constraints of what I call my 'saviour complex' but it also gave me permission to move away from a strict model of CBT and to vary the techniques I used. I was still working within a broad CBT framework but was able to work creatively with newly acquired knowledge from other approaches. According to Cooper (2008) 'with more complex clients, the skill lies in being flexible within a cognitive therapy framework, whilst guarding against becoming solely supportive' (p. 290).

During my training I notice that I have mostly struggled with following strict protocol and applying it consistently across different client presentations. According to Miller, Hubble and Duncan (2007) the former is not so much a problem as is the latter. They articulate that the making of an effective therapist does not depend on the applied orientation or techniques used but rather on determining one's baseline of effectiveness and then practicing (through repetition) just beyond one's known ability. This idea is similar to Vygotsky's concept zone of proximal development[12] (1978) – an idea also used with clients in Cognitive Analytic Therapy (Ryle, 1990).

Therefore it would make sense for me to identify areas that I have grown proficient/confident in and then set goals to extend my practice just beyond my current abilities. This is something I feel I have been repeatedly encouraged to do in my training but something that I am only now starting to implement consciously.

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[12] It is the difference in what a learner can do without help and what they still require instruction in.

Through supervision it has become clear that I have developed a propensity for building good therapeutic relationships with clients[13]. According to Orlinsky et al. (1994) this augurs well, as the therapeutic bond or alliance, strongly shows up in evidence that links process and outcome measures. I also have a good grasp of the main tenants of CBT however there remains a gap between my thinking about a client's difficulties and the execution of the model's clinical interventions. Whether this is due to fears around adequate performance or an internal resistance towards manualised treatment I cannot be entirely sure.

I am wary of current political and economical trends that create 'off-the-shelf' manualised treatments for specific disorders with the implicit expectation that they should be delivered as quickly and as efficiently as possible. I struggle to accept this narrow appraisal of evidence-based practice and endorse a more pluralistic stance towards theoretical paradigms. I fully agree with Holmes et al. (2006) when he writes, 'an evidence-based, empirical world view is dangerously reductive insofar as it negates the personal and interpersonal significance and meaning of a world that is first and foremost a *relational world*, and not a fixed set of objects (p. 183).

It is interesting to note that there exists research that shows that whilst manual-based training does increase therapists' technical skills it can deter from the development of therapists' alliance skills (Castonguay, Goldfried, Wiser, Raue, & Hayes, in press; Henry et al., 1993). Fostering an awareness of self and other, remains crucial to the formation of a strong therapeutic relationship which most expert therapists agree is a prerequisite for change (Horvath and Greenberg, 1994).

Bridging the gap

In dealing with these dilemmas and philosophical debates I am always acutely aware of my duty towards my clients. Although providing, what is currently considered, 'best practice' will always be debatable, it is my duty as a trainee to learn the recommended model enough to serve me as a tool. I know, however, that being in

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[13] Of course, this depends on clients' willingness to engage however I am generally able to find a way to connect.

training or being a practitioner does little to halt the constant learning process. Therefore it is also important to recognise one's clinical limitations and refer on when another approach may seem more suitable to clients' presentations.

Currently, cognitive-behavioural theory acts as an overarching framework for my work. It helps me identify the dimension in which change might most benefit my client (emotional, behavioural or cognitive). I still struggle with implementation but find that I am increasingly able to draw from different theories of change (such as ACT and person-centred) to inform my work. In considering future developments for my practice, I am intrigued by third-wave cognitive therapies. Because of their emphasis on experiential components for change, they seem to hold a more holistic view of the human condition which I prescribe to.

Cummings and Lucchese's (1978) argue that situational factors play a significant role in therapists' choice of orientation. This resonates with me as I feel I have fallen into a CBT quite inadvertently because it is the recently preferred, and increasingly widespread, approach. Nevertheless, I recognise its usefulness both generally and in my work. In line with current trends (Garfield & Kurtz, 1977; Jensen, Bergin, & Greaves, 1990; D. Smith, 1982; Norcross & Newman, 1992; Norcross & Prochaska, 1988), I also see myself moving past a strict allegiance to a specific model and towards an increasingly integrative practice.

I have chosen the profession of counselling psychology for this reason. Because in a world that has become increasingly manualised, machine-driven, fast-paced and timed, it is able to take onboard new methods that make sense in such a world, yet it continues to acknowledge the humanist-existentialist nature of its work. In my view, it recognises the uniqueness of each human person whilst also noting the patterns that connect. It understands that the time we take to see beyond recurrent thoughts, anxieties, low moods, harmful behaviours, persistently difficult emotions; and make connections, is not only time well-spent but the healing process that needs to happen.

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Section C:

Theoretical Essay

PYP048C

With reference to two theoretical models, compare and contrast process and content interventions in working with a group. Use clinical examples to illustrate the theory.

Introduction

In this essay I will attempt to distinguish between content and process interventions in cognitive-behavioural group therapy (G-CBT) and psychodynamic group therapy (G-PDT) delineating differences and similarities in their theory and practice.

As a counselling psychology trainee the little experience I had of group therapy has been that of a novice practised largely in cognitive-behavioural therapy, entering a group-setting with a psycho-dynamically trained co-therapist. In this context, I found myself considering the precise question of this essay i.e. comparing and contrasting what I know, to what I observed; weighing one approach up with another. I will use this experience to frame my considerations of the two approaches in light of their respective emphases on content and process issues.

What are content and process?

In CBT it is not unusual to dissect therapeutic work into component parts of content and process interventions. It will be argued that the same cannot easily be said about psychodynamic therapy where these seem more conceptually interwoven.

Content usually refers to the active, collaborative work that clients and therapist/s do (White & Freeman, 2000) i.e. psycho-education on presenting problem/s; data collection through thought-behaviour records (G-CBT); activity-planning and goal-setting. Content interventions could be described as collaboratively building a context around group members' symptoms/problems: taking into consideration thoughts, emotions, behaviours, real-life consequences and situations whilst also noting early/earlier, experiences in the clients' lives that have fostered particular ways of being.

Process, on the other hand, is something that occurs in the 'here-and-now'. It reflects the nature of interpersonal relationships between group members, including the therapist (Yalom, 2005). Process interventions are not focused on clients' verbal utterances but look at *why* clients might have said what they said. It rests on the assumption that there are multiple layers of communicated information that pass between interacting individuals and that taking note of when it was said and how it was said helps to uncover its deeper meaning/scope.

Process interventions are a form of metacommunication i.e. encourage speaking about communication. Tone of voice, non-verbal expressions and the emotional weighting of utterances are noted to help increase clients' awareness of how they relate. This may not be immediately accessible when focusing only on content.

Set in there here-and-now, process interventions draw on real-life examples of clients' interpersonal worlds that may mirror what happens outside the group. A client/group is immersed in the experience: emotions, thoughts and behaviours (CBT perspective) are all immediately available to the conscious mind when they are pointed out. If the timing and nature of the intervention is right i.e. the client feels contained/safe in the group and is open/willing (not heavily defended, in psychodynamic language), then integration and new learning are more likely to happen. Yalom and Leszcz (2005) in fact, speak of process as 'the power source of the group' (p.150).

As alluded to earlier, PDT seems to hold a less distinct separation between content and process interventions. In my understanding, process lies at the heart of every psychodynamic interpretation, question or comment so that there exists no focus on content without an underlying attempt at drawing out process issues.

Interventions in G-PDT aim to make the unconscious, conscious. The unconscious can be thought of as unprocessed emotional memories or ingrained behavioural repertoires related to unmet childhood needs, unresolved conflicts or past interpersonal traumas that have not been made sense of, worked through, or (in CBT language) integrated by the conscious mind. The aim is to wean clients out of their blind-spots using the group as a space where process issues can emerge through transference[14]. Although the role of transference is controversial in brief G-PDT (Henry, Strupp, Schacht, & Gaston, 1994), it remains a valid way of understanding G-PDT. Within a group setting, "reality and immediacy heighten transference experience" (Behr & Hearst, 2005, p.6). Unconscious conflicts emerge and old/ingrained ways of relating are *transferred* onto group members and/or the therapist. Transference is "…held by the group, eventually modified… and used as [a] reality-adapted, new [experience] of the self in relation to others" (Behr & Hearst, 2005, p.6).

In this context, the distinction between content and process appears blurred as content is used to elicit process and has little use alone. In my view, the move from manifest (what is seen/heard - content) to latent (underlying communication – process) is intrinsic to PDT. It seems evident that groups are approached in significantly different ways in G-PDT and G-CBT, having different starting points.

Forming the group

Historically CBT was adapted to groups to "increase the efficiency of delivering CBT to individual clients, not to tap the unique benefits inherent in [groups]…" (Yalom & Leszcz, 2005, p.512). Process issues where not at the forefront of forming and running CBT groups. The main aim was to provide psycho-education on specific issues and train clients in cognitive-behavioural skills to better manage their symptoms.

Nowadays short-term psychodynamic groups share a lot with G-CBT because of the nature of brief therapy e.g. identifying specific goals, focusing on goal attainment and real-life application of new learning. However, theoretical aims behind G-PDT remain to develop a relationship where needs can be expressed through transference (Behr & Hearst, 2005). The focus becomes more interpersonal than intrapersonal however.

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[14] The unconscious redirection of feelings from one person (usually from one's past) to another person in the present.

The theoretically ideal group in G-PDT would have the "widest possible span of personalities and diagnoses" (Behr & Hearst, 2005, p.39), this increases the possibility for group member empathy, mirroring, and transference experiences.

Differing in focus, G-CBT usually seeks to bring together a homogenous group i.e. people presenting with similar problems e.g. anxiety and/or depression; specific phobias. The group meets for a limited period of time to work on a pre-defined problem e.g. G-CBT for panic disorder. On starting the group, clients are clear on what it's for and further information is given at the first session. This is what I expected when I was first asked to co-conduct a group.

Case example

The group, set at a university counselling service, was meant as a slow open group[15] *where three members started and were expected to be joined by others later during the group's life. Besides attending the same university, members held very little else in common, presenting with different problems and cultural backgrounds. Because it was not a closed or homogenous group, there was little sense of cohesion on first meeting. The sense of safety and quick move to deep exploration available to homogenous groups (Behr & Hearst, 2005), was not available here.*

Not having been involved in any pre-group preparations, I was not aware of what clients had been told about the group and its aims. Expecting that information to be given immediately exposed my knowledge bias and general preference for more structured therapies. My psychodynamic colleague could not answer the question about the aim/nature of the group: in his understanding, his role was simply to create and maintain a space (Van der Kleij, 1983) - what the group was, or was for, would emerge as the space got inhabited by what the members brought (content in psychodynamic language) and their inter-relational dynamics (process).

This stance was extremely anxiety-provoking for me. I struggled not to offer reassurance or explore clients' expectations; to somehow give structure to the

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[15] Initially open to new members then closes when a specific number join (Behr & Hearst, 2005).

session. Because of my background in CBT, I saw my role as co-therapist differently to what is normally expected in G-PDT. I viewed myself as a facilitator, charged with welcoming the group and engaging them in collaboratively setting a group agenda. I also believed that a more content-oriented stance could have helped clients feel more secure within the group at the start.

Watske et al. (2008) found that cognitive-behavioural therapists generally tend to be more supportive and empathetic in their approach to group work in comparison with psychodynamic therapists who are more interpretative and confrontational. This may reflect a difference in their initial (and continued) emphasis on content or process issues respectively. In my opinion an excessive (early) focus on process may elicit a defensive stance from clients whereas more content-oriented beginnings nurture collaborative, open attitudes leading to safer-feeling explorations of process. It is the careful balance between the two interventions, in my view, that enables a good working relationship to develop with clients.

According to Keijsers, Schaap and Hoogduin (2000), although therapeutic bond is essential in both approaches, the psychoanalytic principles of neutrality and abstinence (used to elicit transference) initially cause G-PDT therapists to be experienced as less supportive and empathetic.

The therapist's role

Set between the influential roles of 'technical expert' (teaching new skills and understanding motivations of behaviour) and 'model-setting participant' (modelling empathic, non-judgemental interpersonal responses) (Behr & Hearst, 2005), the task of every group therapist is to slowly move away from the first and endorse the latter.

In CBT this is handled by emphasising the clients' responsibility for change e.g. through assigning individual homework tasks, and by remaining transparent through explaining the reasoning behind specific content-interventions e.g. the importance of homework; the reasons behind identifying automatic negative thinking. This content-oriented stance of CBT therapists as psycho-educators retains a 'technical-expert' flavour, however as the group learn the necessary techniques, this role eventually becomes redundant.

Process interventions in G-CBT also retain a certain transparency. They are not heavily interpretative in nature but simply bring clients' attention to thoughts, behaviours or emotions that happen in the here-and-now e.g. what went through your mind just now? How are you feeling at the moment? What do you think this is related to? In this way CBT therapists model ways of being reflexive.

In G-PDT the therapist travels a similar route i.e. gradually disengaging clients from omniscient/omnipotent (expert) fantasies that may initially have and start an acculturation of the group to the analytic process (model) until the analytic task is taken over by the members.

The group psychoanalyst uses his/her position of power to hold the transferential space. In brief therapy s/he may initially use warm-up or turn-taking techniques (Behr & Hearst, 2005), introduce some psycho-educational material (Lotz & Jensen, 2006; Yalom & Leszcz, 1995) (content) and end by rounding-off or evaluation. However input from the therapist is generally kept to a minimum because the therapist is meant as a transference object. The less 'visible' s/he is the more space there is for unconscious projections to be cast onto him/her and later utilised in, carefully-considered process interventions.

Becoming aware of this difference, helped ease my anxiety in later sessions. Although theoretical rationale backed my co-therapists' behaviour, there was still some discomfort at the lack of transparency about 'how the therapy works' – something which in CBT is central to collaborative relationship-building.

It seems that implicit (generally) to a psychotherapeutic stance is the facilitation of client regression[16] with the aim of uncovering difficulties that can slowly be brought to the awareness of the adult mind. In brief G-PDT the focus on the past is undoubtedly minimised and the emphasis on regression greatly restricted (Henry,

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[16] Returning to an earlier or less developed psychological state.

Strupp, Schacht & Gaston, 1994). Nevertheless, it still stands in contrast to CBT that tends to call on the more adult side of clients to collaboratively make sense of difficulties.

In a sense the CBT therapist stands beside clients/groups to guide and support. The G-PDT therapist, with a more abstinent/neutral stance, stands more as a mirror to the group. On the one hand, s/he "is penetrated and influenced by the group processes" (Behr & Hearst 2005, p.103) as a group member but on the other s/he must remain outside these processes, maintaining the "free-floating attention needed to monitor them" (p.103) and reflecting them back when opportune.

I could immediately sense a shift in my usual role as I sat at the first session. I was outside my comfort zone due to theoretical differences and the co-therapy set-up, however there was a lager dynamic at play that made me acutely aware of 'sitting on the fence' i.e. feeling that at any point I would rather just be a group member or retreat to a space that belonged only to therapists in individual therapy – a space I realised did not exist in group therapy.

In co-therapy groups there is a tendency to split the two therapists into good and bad, kind or stern, maternal and paternal. *This split happened almost immediately in this group. Because of my absence at the assessment stage, one group member singled me out as the intruder. I was the bad, unwanted therapist. She resented me and rebelliously questioned my presence. My role in that case was to be that blank screen on which she could transfer her feelings. By holding it within the group and not responding reactively, we were able to use it in a later process intervention that helped identify this client's interpersonal conflict. Nevertheless it was a very uncomfortable experience and sitting on the fence required a careful balance between responding to content issues (listening and responding to her concerns) and paying attention to process (carefully pointing to the potential deeper meaning of her communication).*

The group in action

As mentioned earlier, the 'here-and-now' retains centre-stage in group therapy and is where most psychotherapeutic work is done. Yalom and Leszcz (1995) speak of the here-and-now as having two tiers which are generically tantamount to content and process interventions. Tier one includes feelings elicited and expressed in the group, self-disclosure, catharsis, feedback and socialising techniques. Tier two is about recognising, examining and understanding process issues.

On one occasion a member of the group, A., shared her frustration and annoyance at a situations where 'people showed no respect' and took her for granted. The group sat listening to her account, offering polite, supportive remarks but this did nothing to ease her frustration. My co-therapist then wondered if A. was expressing emotions related to the previous week when group was cancelled because of lack of attendance: this lead to a discussion about commitment and betrayal in personal relationships.

The group was able to offer empathy and support whilst also holding the projections that one member brought. Underlying process issues related to betrayal and anger were then gently fed back to the group to bridge the manifest content of the group's interaction with the group's process relationships (Ogden, 1979).

In the study by Watske et al. (2008) essential process components of G-CBT and G-PDT were compared under clinically representative conditions. As in the example above, G-PDT therapists focused more on interactional and dynamic aspects of therapeutic work using interventions like interpretation, clarification and confrontation focusing on relationships and emotional recognition. In numerous studies, G-PDT focused on patients' affect significantly more than G-CBT (Blagys & Hilsenroth, 2000). G-CBT therapists used more cognitive, behavioural and psycho-educational strategies to encourage self-efficacy rather than emotional expression (Watske, 2008).

Tackling the previous scenario from a CBT perspective would have involved eliciting A's automatic thoughts about the situation brought together with related feelings *and behaviours (content). The group would then help her to make links to previous experiences that left her feeling unappreciated. Ways in which she could change her behaviour to protect and bolster her sense of self-worth would be discussed. The intervention related to the previously cancelled session could also have been brought up. A. would be allowed to express her emotions but also encouraged to make links to related dysfunctional thoughts/assumptions and to reality-check these with the group. Feelings and reactions of the group would be explored as they occurred in the here-and-now (process).*

Similarities can be drawn in that content is used to elicit process issues available in the here-and-now in both approaches, however CBT is characterized by a more active exploration, it involves a level of structuring of a client's experience and is usually more directive (Watske, 2008) – especially at the beginning, until clients can apply cognitive-behavioural techniques independently.

Therapeutic change in groups

Yalom and Leszcz (1995) list eleven factors that affect change in groups, applicable both to G-CBT and G-PDT. The instillation of hope and sense of universality/shared experience are strong factors in homogenous groups for both therapies. With its focus on problem-solving and didactic instruction CBT may seem to hold a more hopeful, future-oriented stance. However, immense hope can be found in PDT that enables the identification and expression of deep-seated pain that previously had no shape or form.

Imparting information also supports change. Content-oriented, structural groups e.g. behaviour-shaping groups or communication skills groups use direct suggestion to help people who have reached an impasse to learn new skills in dealing with challenging situations e.g. G-CBT for young parents.

Groups offer opportunities for altruism and developing socialising skills. These can be experienced both through content and process discussions e.g. psychodynamic groups encourage open feedback about interpersonal exchanges i.e. process discussions which help clients learn about their own contribution to interpersonal problems. Then, content discussions are opportunities for mutual support and empathy.

The therapy group resembles a family - containing authority figures, peers/siblings, strong emotions of intimacy and hostility. Group process interventions can act as a corrective recapitulation of the original family-group, healing old wounds. E.g. in CBT core beliefs around lack of worth, and/or unlovability can be challenged and replaced by a sense of belonging and care (group cohesiveness).

Groups offer spaces to learn about others (interrelatedness), express feelings (catharsis) and imitate adaptive behaviour. The existential need for meaningful relatedness is never outgrown and with good rapport and cohesiveness, personal reflection and exploration initiate change.

How do G-CBT and G-PDT lead to change? And do their methods differ?

Although classic psychoanalysis emphasises the role of unconscious motivations, and CBT has historically placed more emphasis on content rather than process, brief forms of G-PDT and G-CBT have grown considerably closer.

Both these approaches aim to increase clients' awareness of what their behaviour is like; how it makes others feel; how it shapes others' opinions of them; and how it influences their opinion of themselves. They may do this using different therapeutic language but both lead clients to question whether they are satisfied with the world they have helped create (Yalom & Leszcz, 1995). Both, I believe, ask a fundamental question about will and responsibility.

Counselling psychology remains aware of socio-economic and political pressures that can disempower clients from bringing the necessary change. However, in as much as they can, both approaches aim to increase clients' sense of mastery.

In G-PDT process interventions reframe symptoms in an interpersonal context. They draw out and demythologise fears around expression of emotion and bring the self back in relation to others, thus moving away from passivity and isolation that undermine mastery.

The message CBT gives to clients is that life is manageable. This is echoed in its structured and goal-oriented nature. It fosters the idea that there is some control we can have over our moods and behaviours and that with some support for new learning, insight and effort we can get to where we'd like to be.

The message is therefore two-fold; there is no danger in change and change is possible (Yalom & Leszcz, 1995). As therapeutic change occurs, the group moves from content to process more naturally. In CBT clients move from describing situations or reacting in the group, to making links between thoughts, emotions and behaviours, reflecting on, and challenging, them in light of interpersonal interactions. In PDT, members move from narrative to reflective discussions (Schlapobersky, 1994) linking phenomena to reach greater awareness on the origin and meaning of interchanges.

In conclusion

It has been argued that G-CBT and G-PDT differ in the emphasis they place on content and process interventions and their conceptual separation. The shared therapeutic aim of mastery is sought after in different ways, with G-CBT being considered more technique/content-focused. As groups progress, process discussions become more frequent in both therapies due to similar intents at modelling greater client/group reflexivity. Change occurs *within* individuals *through* the group as larger existential issues around isolation and illness are inevitably eased through both approaches.

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Section D:

Process Report

PYP047C

Process Report

Introduction

I present the case of a bi-racial, British woman in her mid-thirties seen in primary care. Referred due to work stress, she had no psychiatric diagnosis yet on first meeting her I recognised some difficult personality traits. I immediately felt uncomfortable in her presence but could not articulate why. I experienced her as contemptuous, aggressive and intensely guarded.

Her distress over work elicited important questions about power/discrimination in clients' lives and how they are dealt with, or not, in our profession. The way she presented challenged how I usually conduct therapy and I found her one of the most difficult clients to sit with.

In this report I critically evaluate my work with Anna (pseudonym). Being far from the best example of my clinical work, I purposefully chose to reflect on this case as I approach the end of my training. The clear difficulties I had in meeting this client on a collaborative working-plane allowed me to reflect on my personal blind-spots but also comment on organisational restrictions and socio-political discrimination that, together with the client's personality, contributed to a very imperfect therapeutic journey.

Context & Referral

At the GP surgery clients are referred by in-house GPs. Anna's referral stated that she suffered from reduced appetite, insomnia and anhedonia due to a possible unfair dismissal at work. The expectation for treatment was to help her manage stress and reduce symptoms.

Trainees see up to six clients a day for an average of six sessions. In this context therapy tends to be directive and there is little scope for accommodating clients' idiosyncratic propensities for trust and relationship-building.

Working in this context has often felt strained for me. My therapeutic style tends to be less directive because of a personal ethos that holds time (and idiosyncratic timing) to be central to the process of change. In the current economic/financial situation however, learning to work flexibly within restraint becomes both the challenge and the art of the therapist.

The therapeutic model generally offered at the practice is CBT however supervisors encourage adopting other approaches if/when necessary. I expected to use CBT with Anna however it seemed neither appropriate, nor possible, when in-session with her. A schema model (Young, Klosko & Weishaar, 2003) guided my understanding/formulation but sessions took on a much more person-centred nature. I struggled to offer what she requested from therapy i.e. a safe space to talk about work-issues, due to counter-transferential reactions to her anger. I use the anger model by Cox, Stabb and Bruckner (1999) to better understand anger and its role in women's lives – both for my client and myself.

Client information

Anna is the eldest of three siblings born to non-British parents - first-generation migrants who suffered abuse and racial discrimination throughout Anna's childhood. Anna is the first in her family to have a pension and a steady income.

She grew up with her grandparents, becoming their carer until their death a year ago. Her mother left when Anna was still a teenager to work for a women's rights group abroad. Her father developed a degenerative condition and lives in a care home.

She has two children (under age seven) with her partner, a manual labourer who works on commission. There is a history of (mutual) violence in the relationship however things had reportedly improved after recent couple therapy. Anna has a degree, is a government employee and a union representative. She has no substance-abuse history and is not on any medication. In her late teens Anna was diagnosed with dyslexia.

Assessment

Initial interview

On entering, Anna immediately agreed to record sessions stating that they might be useful for her upcoming employment tribunal case. She vividly described how she felt unfairly treated at work when her manager did not make reasonable adjustments to cater for her dyslexia. A series of events escalated to a tribunal case[17]. During this time Anna suffered from psychosomatic symptoms diagnosed by the GP.

In our second session, after consulting with my supervisor who strongly discouraged sessions be used in this way, I re-iterated the scope of recordings clarifying that they were for teaching purposes only. She understood and agreed to this, requesting however that she get a copy of recordings as was her right.

This set the stage for our therapy, an uncomfortable tit-for-tat. She was 'helping' with my training requirements but unlike all other clients, she asked for something back. Although we agreed on the recordings' terms of usage, there remained a certain discomfort around her intentions and general agenda for therapy, generating a sense of mistrust between us.

This gives a context to the uncharacteristic lack of empathy I felt for this client. In the course of therapy, it was always incredibly difficult to get her to talk about herself. Most sessions were taken up by, what I experienced as, ferocious descriptions of discriminatory incidents at work. I wondered whether she simply wanted to record her version of happenings rather than engage in the therapeutic process i.e. building a trusting relationship through which to explore difficulties and gain insight.

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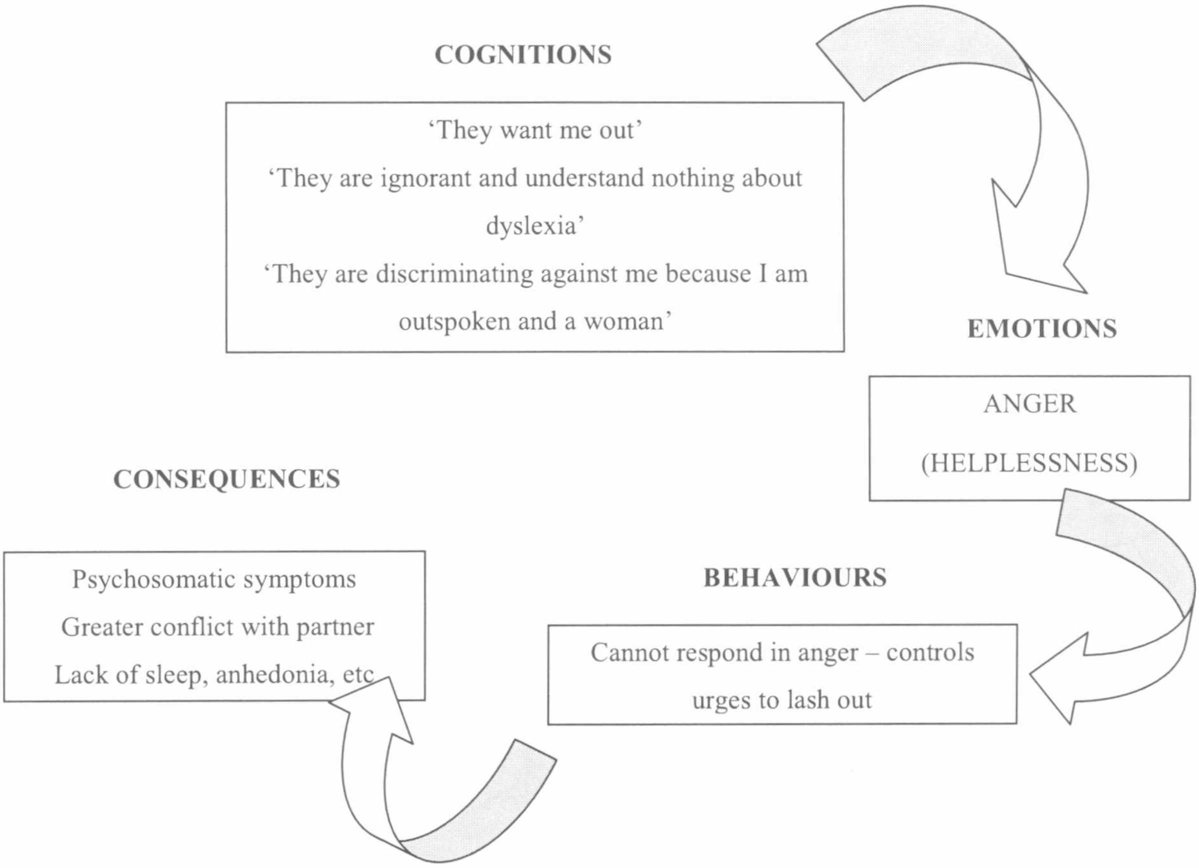
[17] Details are not described to protect confidentiality.

Presenting problems

Most evidently Anna was seethingly angry at her employer and therapy provided a safe space to vent her anger. Diagrammatically[18]:



COGNITIONS

'They want me out'
'They are ignorant and understand nothing about dyslexia'
'They are discriminating against me because I am outspoken and a woman'

EMOTIONS

ANGER
(HELPLESSNESS)

BEHAVIOURS

Cannot respond in anger – controls urges to lash out

CONSEQUENCES

Psychosomatic symptoms
Greater conflict with partner
Lack of sleep, anhedonia, etc

Anna insightfully reported that work-difficulties had affected her relationship with her partner from whom she got little emotional support. Anna felt less able to enjoy time with her children and described herself as their carer (as opposed to their mother).

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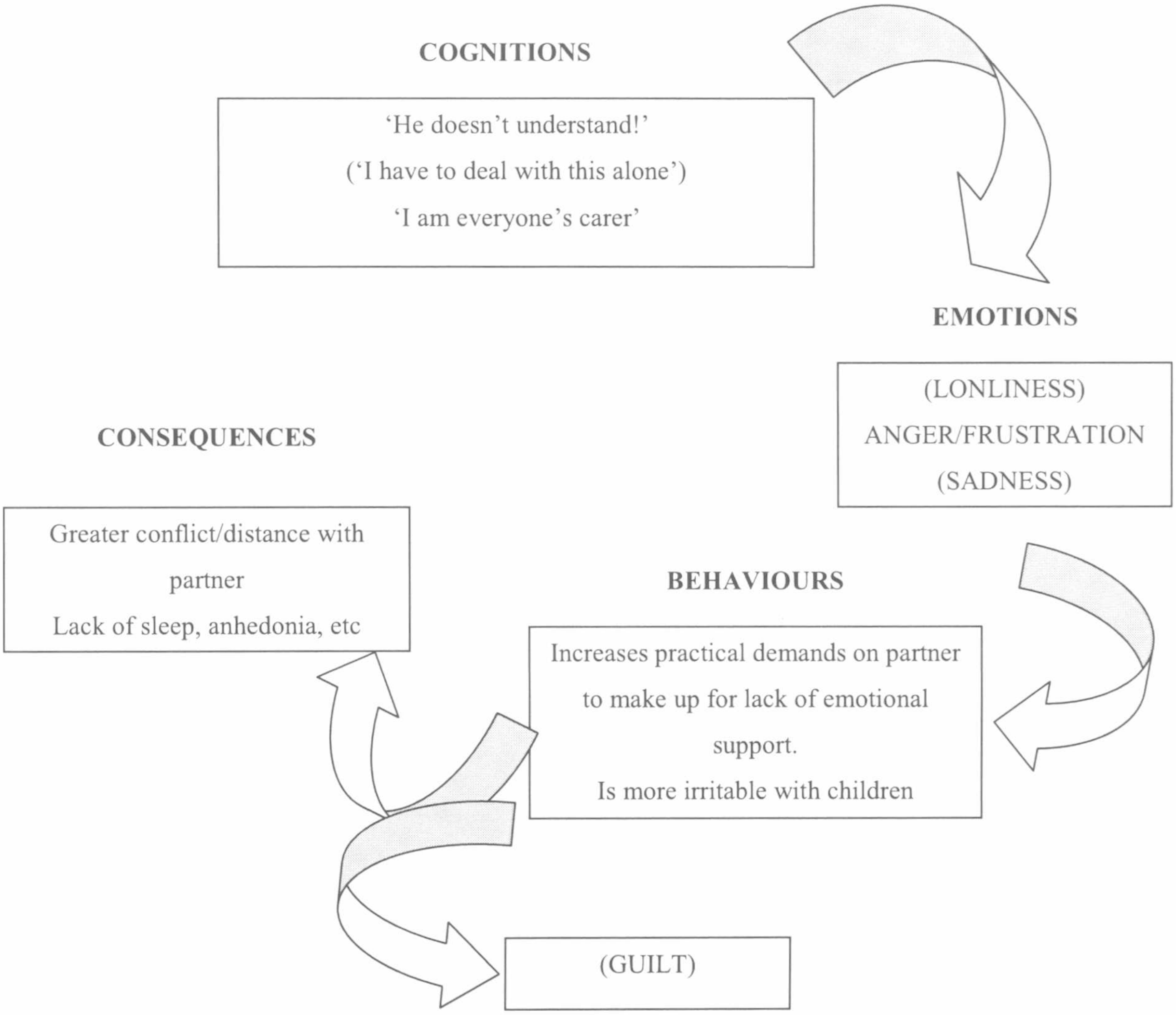
[18] Writing in brackets is information inferred by me.



Briefly discussed in assessment, the recent loss of both Anna's grandparents and possible unresolved bereavement issues (Kübler-Ross, 1969) might also have contributed to her anger. Anna had originally requested bereavement therapy (elsewhere) but work issues had taken over (see formulation).

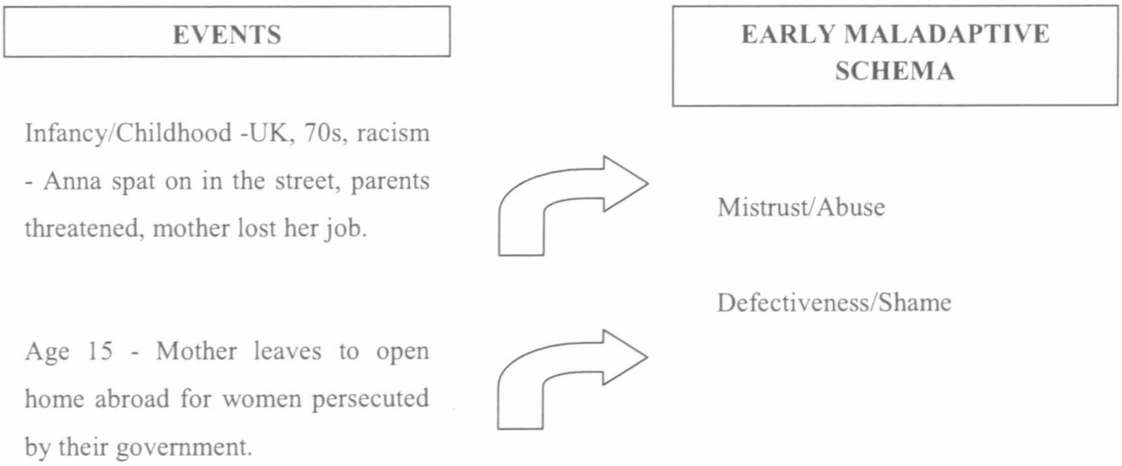
She reported that exercise and art had helped her manage stress, suggesting that (probably for various reasons) Anna got little emotional support from significant others (see formulation).

Formulation

Drawing on schema theory I pieced together fragments of a personal history that Anna shared with me and my own experience of her in the room.

Events in her young life may have contributed to the formation of early maladaptive schemata together with issues of self-esteem (defectiveness/shame) linked to experiences of racial discrimination and mistrust towards a society that caused her family pain.

Predisposition:



EVENTS

Infancy/Childhood -UK, 70s, racism - Anna spat on in the street, parents threatened, mother lost her job.

Age 15 - Mother leaves to open home abroad for women persecuted by their government.

EARLY MALADAPTIVE SCHEMA

Mistrust/Abuse

Defectiveness/Shame

Growing up Anna learnt about self-sacrifice through her mother – "voluntarily meeting the needs of others at the expense of one's own gratification" (Young, Klosko & Weishaar, 2003 p.16). Having no choice over her mother's departure might suggest a subjugation of her own emotions/needs for those "less fortunate".

I hypothesise that Anna's confrontational and guarded nature may be explained by the coping styles developed in response to these situations. She was a very independent woman whose partner was often unable to meet her emotional needs (mistrust/abuse, abandonment schema surrender). She developed a hyper-vigilance and sensitivity to discriminatory behaviour (mistrust schema surrender) which she reacted to by becoming an advocate for others – turning helplessness and anger into a (positive) form of rebellion. Rebellion also links to an over-compensatory response to the hypothesised subjugation schema. With regards to self-sacrifice, she often went out of her way to help others but resented it when not immediately appreciated (schema overcompensation) (Young, Klosko & Weishaar, 2003). This was evident when she talked about caring for her dying grandparents, or her partner and children.

From a schema mode perspective (Young et al., 2003) Anna seemed to function in three modes – Angry Child (venting anger at unfair treatment)[19], Detached Protector (largely shutting off her emotions from others, including me, not to seem vulnerable) and Demanding Parent (feeling high levels of responsibility for others and putting pressure on herself for their care[20] –dying grandparents, neighbours, co-workers).

Seemingly, Anna functioned well before. Her anger/rebellion at unfair treatment usually occurred in other people's defence and was therefore 'honourable'. People were often thankful for her help, keeping her self-sacrificing resentment at bay. However in the presenting situation, Anna came in the line of fire. Old maladaptive schemas were activated but respective coping responses were less effective at helping her avoid painful schema-related emotions.

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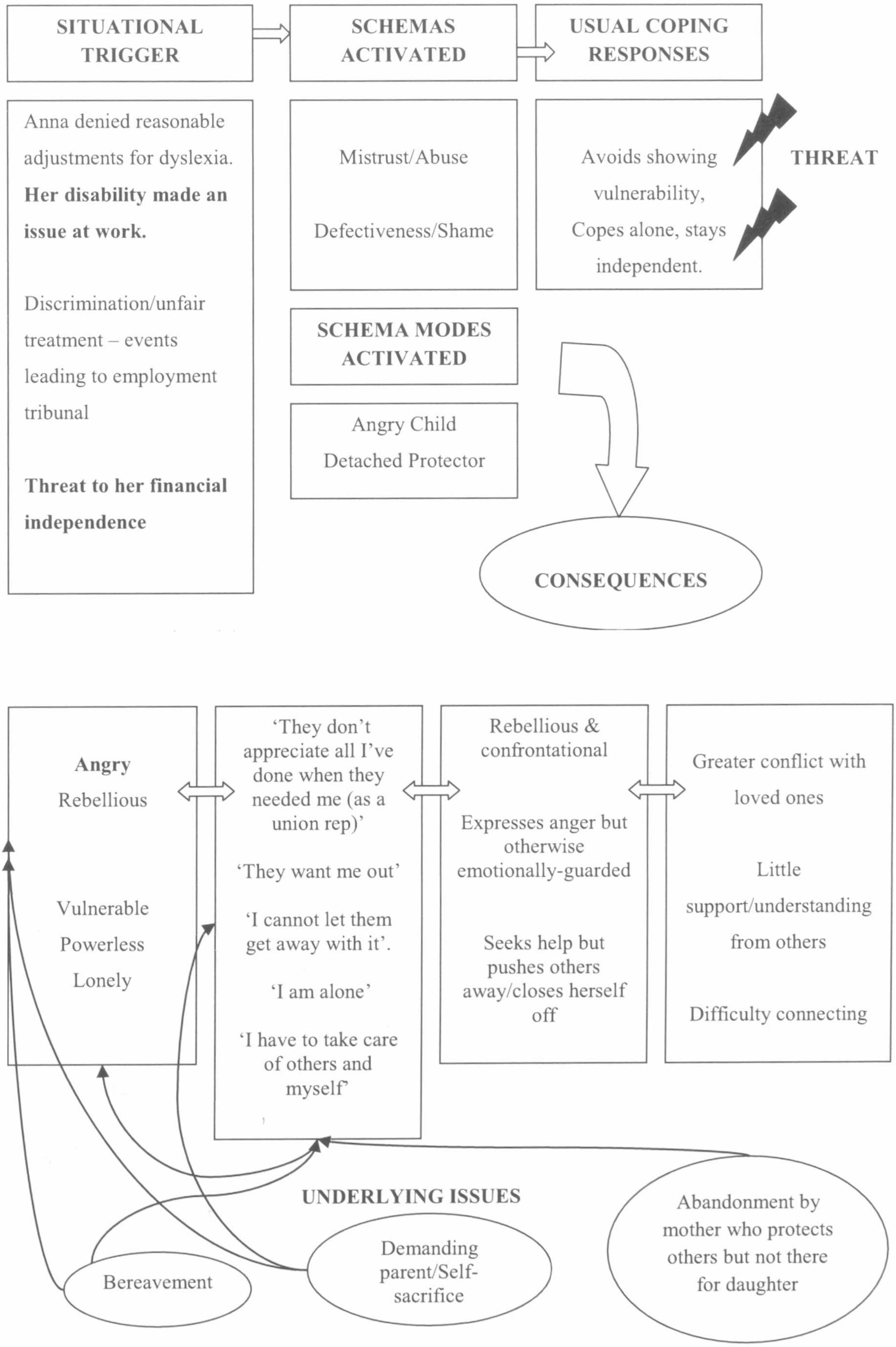
[19] Related to Abandonment, Mistrust/Abuse, Defectiveness and Subjugation schemata.

[20] Related self-sacrifice schema.

Precipitation & Perpetuation:



SITUATIONAL TRIGGER

Anna denied reasonable adjustments for dyslexia. **Her disability made an issue at work.**

Discrimination/unfair treatment – events leading to employment tribunal

Threat to her financial independence

SCHEMAS ACTIVATED

Mistrust/Abuse

Defectiveness/Shame

SCHEMA MODES ACTIVATED

Angry Child

Detached Protector

USUAL COPING RESPONSES

Avoids showing vulnerability, Copes alone, stays independent.

THREAT

CONSEQUENCES

Angry

Rebellious

Vulnerable

Powerless

Lonely

'They don't appreciate all I've done when they needed me (as a union rep)'

'They want me out'

'I cannot let them get away with it'.

'I am alone'

'I have to take care of others and myself'

Rebellious & confrontational

Expresses anger but otherwise emotionally-guarded

Seeks help but pushes others away/closes herself off

Greater conflict with loved ones

Little support/understanding from others

Difficulty connecting

UNDERLYING ISSUES

Bereavement

Demanding parent/Self-sacrifice

Abandonment by mother who protects others but not there for daughter

Her (financial) independence was threatened and her usual emotionally-guarded response disallowed people to give support, being either blocked out by her anger or unaware of her pain.

A similar dynamic took place between us - I felt blocked out by her anger and struggled to empathise with her. As Brescolli and Uhlmann (2008) discuss, I fell into the social-stereotyped view that deems anger an internally-caused state in women. Whereas in men it is attributed to external events (a frustrating situation), in women it signals "an angry person", "being out of control" (Plant, Hyde, Keltner & Devine, 2000). To my retrospective dismay, I thought precisely this of Anna at first.

However, I also struggled to understand my counter-transferential aversion towards her anger. Cox, Stabb and Bruckner (1999) speak of four ways in which anger in women is diverted[21] (Suppression, Segmentation, Internalisation, Externalisation). I recognised in myself a tendency to *segment* anger i.e. having an unconscious desire to avoid it and claiming to dislike anger in others (Cox & St.Clair, 2005).

Literature on women's anger strengthened my initial formulation. In self-sacrificing Anna seemed to have *internalised* (Cox at al., 1999) anger she might have felt towards her mother for leaving or her grandparents for the unintentional burden placed on her in their old age. By avoiding direct anger-expression and placing others' needs before hers, Anna never could receive validation for her feelings, creating guilt around her anger and affecting her self-esteem.

Thomas (2005) found that women's anger 'is squarely grounded in interpersonal interactions [where] people deny women power/resources, treat them unjustly, or behave irresponsibly toward them' (p.504). Anna experienced all three in this situation. Her anger was justifiable by any reasonable standard yet realising this made *me* feel powerless. As a counselling psychologist I am trained to deal with dysfunctional thoughts, aid behavioural change but I do not feel equipped to

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[21] Anger diversion is an internal, socialized way in which women escape full conscious knowledge and/or direct use/expression of their anger (Cox&St.Clair, 2005).

(directly) tackle issues of social justice despite its implicit role in our professional ethos.

In addition, I recognised in Anna what Thomas (1993) describes as 'trait anger' (a personality-based proneness to anger). It is positively correlated with faulty cognitions, higher perceived stress, insufficient social support, depression and somatic symptoms, whilst being inversely correlated with self-esteem. Therefore standing by the story of injustice was not an automatic stance to take. Recognising these traits in Anna stopped me from colluding with her account of events.

Interventions focused on increasing her self-esteem whilst allowing a discussion of anger-producing events in a supportive/empathetic environment (Thomas, 2005). The formulation was only partly shared with Anna e.g. links between anger and self-esteem were not directly discussed but used to guide interactions. Conversely, the link between Anna's history and advocacy work was openly discussed.

Intervention

Overview

In the first two sessions Anna spoke minimally about her life outside work despite my subtle encouragement. Albeit a generally guarded manner, Anna's affect intensified/changed when discussing her role as a mother (though offering no explanation when gently probed - abandonment?) and when describing how people at work constantly challenged who she was (defectiveness?).

After an initial formulation, I hoped to help Anna expand the range of expressed emotion and people she directed it towards, to try and gain perspective on what might have aggravated issues at work.

In the segment presented, Anna herself brought up issues of self-esteem. Previously, session three consisted of a crescendo of anger/frustration about work. She then fleetingly mentioned that she and her partner decided to separate. Every attempt to get her to expand on this was misunderstood, seemingly redirecting her frustration at me. Instead of offering empathic responses about the work situation, I asked about a detail in the story and missed a chance to connect to her. I probably tried to bypass her anger which generally left me feeling attacked/powerless. As she accused her boss of not understanding, I felt that she was also accusing me. I did, in fact, 'miss' her repeatedly in this session.

On-going evaluation

20:01

<table>
<tr><td>Client:</td><td>Realistically, my options are go to work, sit on my hands any time my manager comes within hitting distance! Listen to what he's got to <i>say</i> and respond to it in an <i>email</i>… if I don't think that I can actually respond to him verbally <i>without</i> disclosing my annoyance… and <i>upset</i>! Because he clearly does not <i>understand</i> the <i>fact</i> that I have been deprived of my dignity at work!</td></tr>
<tr><td>Therapist:</td><td>Mhmm…</td></tr>
<tr><td colspan="2"><i>Annoyed at this point, I was unsure of how to react. I took a step back within myself to note my personalization of her anger. There was a mixture of transferential and counter-transferential material – she vented her anger on me as I became "her employer" eliciting in me a desire to escape.</i></td></tr>
<tr><td>Client:</td><td><i>That</i>! Just went like that for him (moves her hand over her head). I've <i>explained</i> it to him! I've articulated it…! (voice breaks slightly and client has tears in her eyes) Those people present in the <i>room</i> …understood what I said! Therefore, the problem is, with his difficulty of dealing with…the fact that he is instrumental … in not affording me my right to dignity at work! (She begins to cry through her anger) He's <i>not</i> acknowledged the part that he has played!</td></tr>
<tr><td colspan="2"><i>This was when I saw her as a victim: her crying enabled me to soften to her. I fell into the stereotypical expectation that women's pain be demonstrated through tears. It is also a reaction I am more comfortable with and recognize</i></td></tr>
</table>

<table>
<tr><td colspan="2"><i>in myself (segmentation of anger).</i>

<i>My response (below) however, remained guarded, practical. She was speaking emotionally and I attempted to draw her into a more rational/cognitive state partly to protect myself from her and partly because I thought discussing emotional regulation strategies would help protect her family (as she requested). Mistakenly, I never verbally acknowledged the pain I saw so her feelings remained invalidated. I wondered if similar interactions occurred with significant others.</i></td></tr>
<tr><td>Therapist:</td><td>How are you going to cope with all that emotion? What are you going to do with it?</td></tr>
<tr><td>Client:</td><td>I'm gonna paint! … (crying softly) That's what I've always done. (sniffs)
(Noise in the background due to construction works carried out at the practice)…… I'm gonna go to work, do what I've got to do …and…I will paint! (Unidentified word)…thing. It doesn't require a babysitter! Doesn't require me to <i>go</i> anywhere! (Works continue) …. (She cries softly) … … (Client sighs)… (Sniffs three times)… and I went to a …funeral on Monday … (cries and sniffs) …and had I not gone back to work I would have had to go to another one today but…</td></tr>
<tr><td colspan="2"><i>The noise was distracting and seemed to add more distance between us.</i></td></tr>
<tr><td>Therapist:</td><td>(softly) Who's funeral?</td></tr>
<tr><td>Client:</td><td>(Sniffs)… Claire[22], a friend of the family and then on Monday was my neighbour's funeral…</td></tr>
<tr><td>Therapist:</td><td>Mmmm….did that bring up anything…for you?</td></tr>
<tr><td colspan="2"><i>I didn't want to make assumptions that this was painful for her. I also wanted to see if it would start a discussion about her grandparents.</i>
<i>Things had come to a head – employment tribunal, separation, neighbours' death – making it difficult for me to know where to enter; I wanted her to guide me.</i></td></tr>
<tr><td>Client:</td><td>Yes! …(sniffs) (door slams outside) …(sniffs) we'd only been</td></tr>
</table>

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[22] Pseudonym

<table>
<tr><td></td><td>neighbours let’s say for seven years coz compared to the other neighbours who’s known each other much longer… I had appreciated (chokes up) …em, when she’d been…a secret cheer leader for me …and she encouraged me to continue to be a union rep! …</td></tr>
<tr><td>Therapist:</td><td>Mmmm….</td></tr>
<tr><td colspan="2"><i>My non-verbal behaviour softened. I finally felt able to empathise with her.</i></td></tr>
<tr><td>Client:</td><td>… … … … … (Sniffs)… … … … … … (Sighs) … … … … … … …</td></tr>
<tr><td>Therapist:</td><td>… … Lots of difficult emotions…(I pass her the tissues)</td></tr>
<tr><td>Client:</td><td>Sorry? (blows her nose)</td></tr>
<tr><td>Therapist:</td><td>I said, there are lots of difficult emotions…</td></tr>
<tr><td colspan="2"><i>When I was able to reach out to her, she missed what I said. Frustrated, I repeated myself – feeling that it was important for her to hear - but I became guarded again.</i></td></tr>
<tr><td>Client:</td><td>Oh yeah (sighs)</td></tr>
<tr><td>Therapist:</td><td>You’re dealing with a lot of difficult ones…</td></tr>
<tr><td>Client:</td><td>(Blows her nose) …. (Sighs)… (Sniffs)… (Takes a tissue, sniffs)… … can I ask <i>you</i> some questions?</td></tr>
<tr><td>Therapist:</td><td>Mmm!</td></tr>
<tr><td colspan="2"><i>I immediately felt uncomfortable, expecting a probing, counteractive question. I realised I felt vulnerable around her and was mistrustful of her. Again I wondered whether this was a form of transference or projective identification.</i></td></tr>
<tr><td>Client:</td><td>What is the first thing you think of when you think of me?</td></tr>
<tr><td colspan="2"><i>There was a frailty/innocence to the question that I did not expect (defectiveness). It was also ironic since I had been struggling with what I thought of her from the start.</i></td></tr>
<tr><td>Therapist:</td><td>… Okay before I answer these questions…</td></tr>
<tr><td>Client:</td><td>(sniffs)</td></tr>
<tr><td>Therapist:</td><td>…is there a reason …<i>why</i> you’re asking these things…or, or…I know…</td></tr>
<tr><td colspan="2"><i>I usually find redirecting a question to a client cliché and somewhat</i></td></tr>
</table>

defensive, yet I appreciate its value in process interventions. Despite a clumsy attempt, I held my position as a therapist enough to enable a deeper exploration of the question.	
Client:	Yeah! So I can get an objective view from someone else about what are the things that are… apparent…to people that I interact with that are positive…
Therapist:	…Mmm…and is there a reason why you're looking for this information?
Client:	(indignant tone) Because I feel I need it! …Because! I've gone back to work…alright, I haven't spent a lot of time there but I know, that to spend that much time in an environment where……you're not………valued…
Attempting to use the downward arrow technique, I wanted to ask why she felt she needed it. However her tone of voice signaled to tread with caution. I would have pushed had our relationship been 'safer'. Nevertheless, my non-verbals asked the question for me and she obliged.	
Therapist:	Mmm….
Client:	…by… everyone…those have authority over you…are not, supportive…
Therapist:	Mmm…
Client:	…you need more of that outside of your life at *work, if* that is your environment at work! And I've asked this question to quite a few people recently and…it's been great. It's been quite an affirming thing that other people see things in me that I might not recognize…!
My dilemma: on one hand I thought this was reasonable – constantly being criticised at work can affect self-esteem. What seemed odd was that she had to ask people for validation/praise/support in this 'artificial' way–was it not available in normal interactions with people? Why?	
Therapist:	Mmm…
Client:	(Sniffs) and…they've almost always been positive!
Therapist:	Mmmm, but as you said, at work it's not everyone who doesn't like you or…has problems with you or…

<table>
<tr><td colspan="2">I was testing whether she was over-generalising or filtering out positive feedback. In retrospect I realise that this question * drew us into a poorly constructed intervention aimed at exploring her relationship with authority figures which was relevant to formulation but premature and badly timed. I should have explored why she actively needed to seek support/validation from people. What circumstances/personal attributes might stop people from spontaneously offering this? (Detached Protector mode?)</td></tr>
<tr><td>Client:</td><td>No, it’s not everyone! It’s not! I’ve got some very good friends at work!</td></tr>
<tr><td>Therapist:</td><td>Mmm…</td></tr>
<tr><td>Client:</td><td>I’ve had people contact me whilst I’ve been off of work…!</td></tr>
<tr><td>Therapist:</td><td>Mmm…</td></tr>
<tr><td>Client:</td><td>…That have supported me! That have…said to me, ‘oh, I can’t wait till you get back to work, we’re gonna have a lunch together’.</td></tr>
<tr><td>Therapist:</td><td>Mmm…</td></tr>
<tr><td>Client:</td><td>You know, very positive things!</td></tr>
<tr><td>Therapist:</td><td>But at the same time, that seems …maybe more difficult to bring to the surface when someone in authority is telling you, or giving you the message that there’s something wrong…</td></tr>
<tr><td colspan="2">Statement rather than question: a repeated mistake I make throughout the session yet an unusual one for my therapeutic style. I held my ground with her in this way signaling a possible resistance/rebellion on my part – a counteraction to her negative energy.</td></tr>
<tr><td>Client:</td><td>Yeah! That you’re sick!</td></tr>
<tr><td>Therapist:</td><td>Mmm...but why is it that, that …?</td></tr>
<tr><td>Client:</td><td>You’re sick! You’re not promotable! You’re challenging! I don’t like it! Well, sorry!!</td></tr>
<tr><td>Therapist:</td><td>Mmm…and I’m sure that’s…. (exhales) I mean…</td></tr>
<tr><td>Client:</td><td>Yeah!</td></tr>
<tr><td>Therapist:</td><td>Difficult to hear is an understatement…(she speaks over me)</td></tr>
<tr><td colspan="2">Feeling exasperated as she spoke over me, I realized that again I was not adequately validating what she was trying to express.</td></tr>
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<tr><td>Client:</td><td>There are lots of challenges in life…!</td></tr>
<tr><td>Therapist:</td><td>Mmm… (tentatively) but again, in an environment like that, is it something about having… an authority say that to you?… when you weigh it up against, you know, people who actually do, love and care for you…?</td></tr>
<tr><td colspan="2"><i>I insisted on making my point and despite my frustration, I made it as calmly and empathically as I could.</i></td></tr>
<tr><td>Client:</td><td>Is there…sorry, can you clarify the question?</td></tr>
<tr><td>Therapist:</td><td>In the sense…</td></tr>
<tr><td>Client:</td><td>(sniffs)</td></tr>
<tr><td>Therapist:</td><td>…it seems as if, because it is coming from an authority, like a boss, somehow it outweighs… other positive feedback that you're getting.</td></tr>
<tr><td colspan="2"><i>Again, she did not understand/pay attention to me. My frustration mounted. The question then turned into a statement.</i></td></tr>
<tr><td>Client:</td><td>It doesn't outweigh it! It's just very……if you, if you try to keep your life in balance, and you've got this constant thing when you're at work of somebody telling you, you're ill, you're, you're not promotable, you're not this! You're not <i>that</i>!!</td></tr>
<tr><td>Therapist:</td><td>Mhmmm…</td></tr>
<tr><td colspan="2"><i>I realized here that this was not the direction I wanted us to take (see * above). Her frustration towards me mounted so I took a step back.</i></td></tr>
<tr><td>Client:</td><td>You get that, that, that… that accumulates but if you've got all these other positive things to outweigh it, then…it's very easy to set that aside and not, take on, somebody…. I'm mean I'm quite…I'm usually very robust…</td></tr>
<tr><td>Therapist:</td><td>Mmm…</td></tr>
<tr><td>Client:</td><td>…in myself and my self-esteem to <i>know</i> that if somebody, you know, if somebody wants to be critical or make a comment to me and they say, 'oh, you know, you might find this critical, however…I'm gonna make this observation about you…that's fine!</td></tr>
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<tr><td>Therapist:</td><td>Mhmm…</td></tr>
<tr><td>Client:</td><td>Everyone is entitled to do that…regardless of their authority, their job hat, whatever!</td></tr>
<tr><td colspan="2"><i>I probed to try understand why this situation was outside of what she could manage.</i></td></tr>
<tr><td>Therapist:</td><td>But…?</td></tr>
<tr><td>Client:</td><td>…I have my right to challenge that view! I have the right to hold my <i>own</i> view!</td></tr>
<tr><td colspan="2"><i>Seemingly in a more rational/secure mind-set now - one where what her bosses said need not be internalized or hold so much power over her - however if this were sustainable, she needn't ask others for validation. Detached protector mode seems secure but is internally vulnerable.</i></td></tr>
<tr><td>Therapist:</td><td>And what is your view of yourself?</td></tr>
<tr><td>Client:</td><td>My view of myself is that I'm a very capable…easygoing! Very often, easygoing… flexible, person! The feedback that I get from a lot of <i>people</i> is…that, 'oh I always found you very supportive and if you've not been able to or, if you think that, what I need advice or help from is not from you, you're very good at signposting people'. And I'm like, 'oh right!' 'Oh great, that's fine, I, you know?'</td></tr>
<tr><td colspan="2"><i>I should have asked what it meant to her being in this situation. Through my formulation I predicted that her advocacy role worked to boost her self-esteem when people were thankful, but I wanted to help her explore what was happening on a more intimate level now that she was in a vulnerable position and needed support.</i></td></tr>
<tr><td>Therapist:</td><td>Mmm…but however that's a practical thing in a way, you're talking there about, again that kind of em…advocative side of you, in a sense.</td></tr>
<tr><td>Client:</td><td>Yes advocative…yeah the advocacy role that I naturally…</td></tr>
<tr><td>Therapist:</td><td>Mmm…</td></tr>
<tr><td>Client:</td><td>…tend to lean to…</td></tr>
<tr><td>Therapist:</td><td>What about kind of more, maybe closer to home…(she speaks over me) with relationships</td></tr>
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<tr><td>**Client:**</td><td>I’ve had to be an advocate for myself!</td></tr>
<tr><td colspan="2">*Again she talked over me, disallowing me to enter. We were on different wavelengths – she was talking solely about work and did not allow for a deeper exploration (timing?resistance?).*</td></tr>
<tr><td>**Therapist:**</td><td>Mmmm</td></tr>
<tr><td>**Client:**</td><td>I have constantly had to be an advocate for myself! Coz I don’t except other people’s labels about me!</td></tr>
<tr><td>**Therapist:**</td><td>Mmm…</td></tr>
<tr><td colspan="2">*I wonder if she was (unconsciously) disallowing me to understand or label her.*</td></tr>
<tr><td>**Client:**</td><td>That’s their view, that’d fine! It doesn’t mean that I have to assume… … or lower my expectations because of what…somebody else’s expectations are!</td></tr>
<tr><td>**Therapist:**</td><td>And that’s…as you said, you know, quite a strong stance you take, you’re quite a fighter in that sense.</td></tr>
<tr><td colspan="2">*Despite the struggle to keep track of what was going on between us I was able to stop and offer some validation.*</td></tr>
<tr><td>**Client:**</td><td>Yeah!</td></tr>
<tr><td>**Therapist:**</td><td>Em…but quite tiring no? Keeping up that…</td></tr>
<tr><td colspan="2">*I might have been talking about myself here although I meant it for her too.*</td></tr>
<tr><td>**Client:**</td><td>Well I don’t feel like I have to fight for everything all the time! But, if it’s dignity and respect at work! Yes I will! Whether it’s for myself or someone else! And that is one of the things that I’ve had to learn, is that, yes I can do it for other people but I can also do it for myself!</td></tr>
<tr><td colspan="2">*Detached Protector mode disallowing entry so I tried to probe.*</td></tr>
<tr><td>**Therapist:**</td><td>Mhmmm…although you’re paying quite a price for it…</td></tr>
<tr><td colspan="2">*Simultaneously I wondered if I was colluding with a system that wanted to shut her up – that initial impulse in me that also wanted to label her; as mad (personality disordered, difficult) or bad (angry female trouble-maker). I recognised that the argument that fighting for your rights is tiring/comes at a price has been used to shut women and minorities up for centuries.*</td></tr>
<tr><td>**Client:**</td><td>Yeah!</td></tr>
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<tr><td>Therapist:</td><td>Mmm… so when you ask me that question…what do think of me or what comes to mind when you think…</td></tr>
<tr><td>Client:</td><td>What is the first thing you think of when you think of me?</td></tr>
<tr><td>Therapist:</td><td>If I had to ask that to you…about yourself, what is the first thing you think about when you think about you? What would that be?</td></tr>
<tr><td colspan="2"><i>Recollecting my thoughts, I brought us back to the original point i.e. attempting to help Anna find strength within herself, know herself apart from derogatory voices.</i></td></tr>
<tr><td>Client:</td><td>Eh… …. … easygoing…</td></tr>
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Evaluation & Endings

What this session (and therapy) lacked was an open discussion of process issues. This could have potentially deepened trust in our relationship and helped Anna gain insight into interpersonal interactions outside therapy. Notwithstanding my positive experience with other clients, it always felt premature and potentially dangerous here.

Despite an ongoing struggle between us, Anna opened up to me more as we explored her questions. She shared personal information that shaped the formulation presented. Anna left the session with a clear focus - her family. In the following session she reported that she and her partner were not separating. She also appeared calmer and more self-confident.

Reflections

The strongest theme in my work with Anna was power – the power her employer had over her, the destructive power of discrimination, the power of her anger over my therapeutic stance and the uncomfortable (albeit consented to) power I have in being able to write about her in this way.

I specifically chose not to expand on diagnostic possibilities of her presentation because I still cannot be sure where the problem lay – was there a personality issue or was her anger circumstantial, related both to her social past/present? Am I, in trying to 'reduce symptoms' shutting her up, maintaining societal status quo or am I helping her protect what matters in a painfully imperfect world? Is there a difference?

These are questions that will only surface more often as I am launched into the real world. What I have learnt from this experience is that using time wisely, and bravely, in therapy is essential. This may mean growing bolder in my process interventions, discussing both interpersonal and societal issues with clients (where possible) and definitely making use of trustworthy, insightful supervision.

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