TESTING HIV POSITIVE IN PREGNANCY: A STUDY OF WOMEN’S EXPERIENCE AND PERSONAL TESTIMONY FOLLOWING A POSITIVE HUMAN IMMUNODEFICIENCY VIRUS (HIV) ANTIBODY TEST RESULT DURING PREGNANCY

Short Title: Testing HIV Positive in Pregnancy: A Study of Women’s Experiences

A thesis submitted to University of Manchester for the degree of
Doctor of Philosophy in Midwifery

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BY

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ABSTRACT

Midwives recommend antenatal HIV testing in pregnancy for all women. However, limited information is available on the experience of testing HIV positive in pregnancy. This thesis explored women’s experiences of receiving a positive HIV test result following antenatal screening in United Kingdom (UK). Black Africa women have high levels of HIV infection in the UK and notably all participants were African in origin.

The theoretical basis for the study was hermeneutic phenomenology, proposed by Heidegger (1962) and further guided by van Manen (1990), exploring essence and meaning of this lived experience. Thirteen women were recruited and participated in a semi-structured interview. Participants were recruited from two NHS sites, several HIV support organisations and a national advert, in order to obtain diversity of this lived experience.

The emergent phenomenon is transition and transformation of “being,” as women integrated HIV into their lives. As women transformed with the HIV diagnosis they balanced major themes. The major themes consisted of shock and disbelief; anger and turmoil; loss of old self; stigma and confidentiality issues and acceptance and resilience. Primary and secondary themes included: extreme reaction on being given a diagnosis with a cultural belief that they would die; disbelief as the result was unexpected; sadness and loss of their old self; turmoil wanting to terminate the pregnancy; isolation from significant others; breakdown of their relationship and considering suicide and self harm. Most reported the pervasiveness of stigma, and how they managed both this stigma and HIV in their lives; growing resilience was apparent with time. Coping strategies included keeping HIV “secret” and their child or children becoming the prime focus of life, with less importance on self.

This study gives midwives a unique understanding of the complexities for women testing HIV positive and supports Bonanno (2009) and Kübler Ross’ (1969 & 2005) findings on personal loss. Additionally this study provides a unique insight into the phenomenon of transition and transformation for women who tested positive in pregnancy and explores the factors and impact of testing HIV positive. The impact of an HIV diagnosis is culturally difficult for African women and had major implications and challenges for their future life. Midwives are crucial in supporting and improving the experience of women when they test HIV positive.
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DEDICATION, ACKNOWLEDGEMENTS & THANKS

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**LIST OF ABBREVIATIONS**

**AIDS**- Acquired Immune deficiency Syndrome or Acquired Immunodeficiency Syndrome (AIDS)

**BHIWA**- British HIV Association

**DOH**- Department of Health

**HIV**- Human Immunodeficiency Virus or Human Immune deficiency Virus

**LSA**- Local Supervisory Authority

**LSAMO**- Local Supervisory Authority Midwifery Officer

**NAT**- The National AIDS Trust

**NHS**- National Health Service

**NMC**- Nursing and Midwifery Council

**PCT**- Primary Care Trust (former commissioners of care for a locality in England)

**SOM**- Supervisor of Midwives

**SHA**- Strategic Health Authority

**THT**- Terrence Higgins Trust
GLOSSARY OF TERMS

Antenatal HIV testing/screening- a testing or screening programme in pregnancy to detect maternal HIV infection and by treatment improve maternal health and reduce infant transmission of HIV.

Being- a universal concept of Heidegger’s *Hermeneutic Phenomenology*. Not an entity but an ontological analytic. It is to inquire into the nature or meaning of that phenomenon. A fundamental term of human science research process itself.

Being-in-the-world- Heidegger’s phrase refers to the way human beings exist or are involved in the world, such as mother, parent teacher, man woman or child.

Confirmability- the study data is held as being a true representation of the information which participants have provided and not influence or biased by the researcher.

Credibility- the finding of qualitative research is a true representation of the data provided by participants.

CD4- specific immune cell protecting the body from infection that falls as viral load increases and HIV progresses.

CD8- specific immune cell which kills infected CD4 cells that usually rises as viral load increases and HIV progresses.

Dependability- refers to stability (reliability) of the data over time and conditions.

Epistemology- a study of the nature of knowledge, how we understand our world and relates this to theories of what makes up knowledge. It is questioning and understanding how we know what we know.

Essence- inner essential nature of a thing, or true being of a thing, Latin “to be”. The *Whatness* of things.

Hermeneutics- the theory and practice of interpretation and essential element of this study. Greek god-Hermes communicated messages from Zeus

HIV- virus that infect cells of the immune system (See abbreviations)

HIV Test- a blood test for the detection of HIV antibodies.

Human science- this study argues human phenomena (mental, social, historical) differs from the natural world (physical, chemical, behavioural) - Human science require interpretation and understanding whereas natural science require external observation and explanation.
**Lifeworld** - German - *Lebenswelt* - the world of immediate experience, the world as “already there” from Husserl’s (1970) (posthumous) work. Heidegger’s (1962) work - modes of being or ways of being-in-the-world. The world as immediately or directly experienced in the subjectivity of everyday life, as sharply distinguished from the objective “worlds” of the sciences. Which employ the methods of the mathematical sciences of nature; although these sciences originate in the life-world, they are not those of everyday life which this study is interested in. The life-world includes individual, social, perceptual, and practical experiences. The objectivism of science obscures both its origin in the subjective perceptions of the life-world and the life-world itself. In describing and analyzing the life-world, phenomenology attempts to show how the world of theory and science originates from the life-world. It, strives to discover the phenomena of the life-world itself, and attempts to show how the experience of the life-world is possible by analyzing time, space, body, and the very givenness or presentation of experience.

**Lived meaning** - the way a person experiences and understands his or her world as real or meaningful, it describes those aspects of a situation as experienced by the person in it.

**Method** - is the procedural steps for data collection and data analysis of this research study.

**Methodology** - the philosophical and theoretical influences underpinning this study and the knowledge that is to be determined or a theory developed.

**Narrative** - is the collection and analysis of stories in this study.

**Naturalistic paradigm** - Whilst subjective, it maintains there are multiple interpretations of reality. The goal of the research is to understand how individuals construct reality within their context.

**Ontology** - concerns our views about what constitutes the social world and how as a researcher we study it. So ontological assumptions are the researcher views about the nature of reality and are subjective. It is concerned with what it means to *be*.

**P24 test** - test which detects P24 antigen (from the HIV virus) in the blood.

**Paradigm** - is a view, belief, school of thought which the researcher follows and makes explicit to guide the researcher with acquisition of knowledge.

**Phenomenology** - the study or science of phenomena or the study of essence with the goal to fully describe or interpret the lived experience and therefore answers question of meaning, in understanding an experience from those that have experienced it. Several schools of phenomenology have developed and been refined but simply it may follow a descriptive school of Husserl as the founder of the phenomenological movement or a later interpretive (but also descriptive) approach and follows the Hermeneutic Phenomenological (Interpretative) school of Martin Heidegger. In this study
specifically the later theoretical aspects and analysis developed by Max van Manen (1990) are followed using **Hermeneutic Phenomenological reflection** to determine essential themes.

**Purposive sample**- the participants are drawn from a population known to possess the key characteristic which can inform the research (for this study antenatal screening by midwives and women tested positive to HIV).

**Qualitative approach**- explores opinions, experiences and behaviours from the participant’s point of view by exploring meaning from the participant’s perspective and is inductive and subjective.

**Reflexivity**- integral to this qualitative study, the researcher is self aware but also acknowledges their personal biases and their influences on the research process.

**Subjectivity**- refers to the the subject and his or her perspective, feelings, beliefs, and desires. They are unique to the person experiencing them; the term is usually contrasted with objectivity.

**Thematic analysis**- qualitative data, analysed for themes and meaning from data gained at interview during this study.

**Transferability**- the extent to which this study’s finding can be transferred to other settings or groups.

**Trustworthiness**- ensuring this study represents the truth and encompasses credibility, transferability, dependability and confirmability.

**Viral load test**- the amount of circulating virus (HIV) and indicates viral activity. A blood test which, repeated over time will measure amount of circulating virus and disease progression.

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CHAPTER ONE- INTRODUCING THE THESIS AND RESEARCH STUDY

1.0 INTRODUCTION

This first chapter provides an overview of this thesis and outlines the context and focus of the research. The aims, objectives and research methodology of the study will be outlined, within the structure of the research and within this thesis. In this chapter, I discuss the rationale for the thesis writing style, and present an overview of the thesis chapters, which will, in turn, outline the overall structure of the thesis.

1.1 FOCUS OF THE RESEARCH AND THESIS

This thesis explores the experience of an antenatal HIV positive result and therefore an HIV diagnosis made during pregnancy within the antenatal HIV testing programme in the United Kingdom (UK). Specifically, the research explored the essence and meaning of a women’s immediate reaction of being informed of a positive result and also the longer term impact on the women, their families and support networks, and the effect on the participants’ life-world. By interviewing participants who had undergone this experience, an in-depth exploration of the phenomenon, using a hermeneutic phenomenological approach was made. Interpreting the verbatim text and isolating thematic statements through van Manen’s (1990) hermeneutic phenomenological reflection provided an in-depth understanding of this experience from the women’s perspective. This original midwifery focused research will inform midwifery practice and also make a contribution to the development of antenatal HIV testing. Furthermore, it will contribute to the wider theories and concepts evolving around antenatal testing and other HIV screening programs in the UK. It is important to state that the focus of this thesis is not examining the degree of psychological impact of HIV. The degree of psychological impact has relevance, but was not the purpose of this study. Also,
importantly no psychological measurement tools were used to measure psychological wellbeing. The aim was to explore the essence and meaning of the antenatal HIV testing experience for the women from their own narrative.

Historically, the role of the midwife has evolved and developed in relation to HIV testing in pregnancy. The provision of this screening has been debated in the past, yet the impact of an antenatal positive test result had not specifically been fully explored in the UK when the study was formulated. Therefore, the role of the midwife in this process when a diagnosis was made lacked clarity. Historical factors, service changes, personal opinion and research have influenced the development of HIV testing in pregnancy and led to an increase in women testing and therefore more women receiving a positive result. In 2011, the Health Protection Agency (HPA) (HPA Report 2011) reported that 657,500 pregnant women in the UK were tested for HIV in 2010. The proportion of women accepting the recommended routine antenatal HIV screening test remained high at 96%; this is a remarkable achievement. The Health Protection Agency estimates in 2010 that between 1,200 and 1,300 women with HIV gave birth in the UK, some of which were repeat pregnancies. It is reported that 99% of infants remained unaffected with HIV due to effective antenatal care provision (HPA Report 2011). The decade between 2000 and 2010, 270 newborn infants were infected with HIV. However, 70% of these infected infants were from untested women and the report recommended HIV testing for all pregnant women (HPA Report 2011). London remains the region of highest prevalence (3.8 per 1,000 pregnant women in 2010), particularly among African women (21 per 1,000 population) (HPA Report 2011). Research into how midwives’ view their role in relation to HIV testing suggests that midwives support HIV testing in pregnancy because of health benefits (Low et al 2001). Furthermore, women are also supportive of antenatal HIV testing (Baxter & Bennett 2000). Until recently, there was little understanding of the real life experience and personal impact of receiving a positive HIV result in pregnancy within an antenatal testing programme in the UK. A recent small study (Kelly et al 2012) and my study findings advances understanding of this unique experience; importantly explored from the perspective of childbearing women.
1.2 AIMS AND OBJECTIVES OF THE RESEARCH

The aim of this research was to explore women’s experiences of an HIV diagnosis in pregnancy from the perspective of the women concerned and to provide deeper insights into the meaning of this experience. Such insights will inform midwifery practice developments and make a contribution to theory development around HIV antenatal testing.

1.2.1 Aim of the Study

To gain understanding and meaning of the personal experiences and the emergent phenomenon of women testing HIV positive in pregnancy within an antenatal testing programme in the United Kingdom.

1.2.2 Objectives of the Study

The objectives were to:

- Gain an in-depth understanding of women’s experiences of testing HIV positive following antenatal blood testing in pregnancy.

- Give women the opportunity to relate their HIV testing experience by personal testimony after an HIV diagnosis in pregnancy.

- Provide a holistic view of the issues of a HIV diagnosis during childbearing by involving women who have been diagnosed in an antenatal HIV testing programme.

- Use the findings to inform current clinical HIV testing practice by midwives and identify potential for a specific clinical care pathway or supportive programme for women diagnosed HIV positive in pregnancy.
Generate further research hypotheses and questions around preconception and antenatal HIV testing and specifically its effect on the African community which has the greatest burden of HIV infection.

1.3 METHODOLOGICAL APPROACH TO THE RESEARCH AND THESIS

My chosen methodology underpinning the study was Heidegger’s (1962) hermeneutic phenomenology, which was used to explore and interpret the meaning of this testing experience. This study utilised in-depth interviews as the method of data collection. Findings were analysed using van Manen’s (1990) hermeneutic phenomenological reflection. Analysis of the transcripts identified four emergent major paired themes and interpretive meanings: initial shock and disbelief; anger and turmoil; loss of old self, stigma with confidentiality issues; acceptance and resilience. A number of subthemes were also apparent such as the influences of partner, family, friends, support workers and HIV specialist midwives; disempowerment verses empowerment and personal resilience and growth.

I propose that women balance these major themes and subthemes in their lives and provide a pivotal balancing model - adapted from Wismont (2000). The phenomenon was one of transition and transformation, which is an adaptive process from “being-in-the-world” without HIV or undiagnosed, to a transformed “being-in-the-world” now living with HIV. The transition process was similar to the model of grief and life change founded by Kübler –Ross (1969 & 2005); my study advances this work, relating it to HIV. The study’s findings also support the work of George Bonanno (2009), natural resilience being the main component in the context of grief and personal trauma or loss.

The sample consisted of thirteen women receiving an HIV positive result during antenatal testing. In-depth interviews provided rich qualitative material which enabled a clear understanding of the HIV testing experience. Many women thought that they were going to die when diagnosed as this is a common finding in Africa (UNI AIDS Report 2010; NAM 2011) but this belief was imported from their country of origin and led to a
significant number having an extreme distress reaction; this is an important facet of this study’s originality and specifically pertinent to the African participants. I had not identified any other study specifically exploring the impact of a positive antenatal HIV testing experience within the context of a UK antenatal screening programme at the study formulation until a recent small study and paper was published in June 2012 by Kelly et al (2012). This was added and explored in the literature review (see Section 2.2.4.1) as the findings were relevant to this thesis. The findings of that study did not influence this thesis as the research, interpretation and writing were already completed. However, due to similar findings reference is made to Kelly et al (2012) in the discussion chapter.
1.4 CENTRING MYSELF IN THE RESEARCH

I recognise that my own subjective values and beliefs could and do have an influence on this study. But, I also believe that this study has become a part of me and feel that I have to put myself in the centre of it. Simply, I will have had an effect and a subjective impact on the process, analysis and interpretation of findings. It would be naive and perhaps dishonest not to acknowledge my role and fail to put myself at the centre of this research. My midwifery background may have influenced the questions posed and the direction of the interviews, even though my main objective was to listen to the stories of women. There will always be a hierarchical relationship between the researcher and the researched (Hunt 2004), but by being open, welcoming and attentive, this may have lessened the effect (Campbell et al 2009). Unintentionally, power relationships, perceived or real, between me and the women in this study may have had some impact. I recognised and accepted that I may be more powerfully positioned when undertaking the interviews and writing up their accounts of the testing experience (Goodrum & Keys 2007; Dickson-Swift 2009). Women may see me as a hierarchical figure and may not have ‘opened up’ fully during the interviews (Campbell et al 2009). Thus, the information and elements of the experience may be missing; a “truthful” account may have been problematic for some women. I took the view that women would tell me what they believed to be important. Participants revealed some very personal data in relation to sexual distrust and sexual practice, suggesting a degree of trust and subsequent honesty.

Women may also have seen me as authoritative and trying to test their morality around HIV or intelligence and knowledge of the subject. I discussed with the women that all of us have different perceptions of events and there are no right and wrong answers to my questions. I encouraged them to speak freely, assuring them that their identities would not be disclosed (Campbell et al 2009). I was a researcher and also a registered midwife which may have had an additional impact. I assured them that I was there as a researcher, but essentially I could not lose my identity as a midwife. As a researcher I needed to learn about women’s experiences to help understand the world from their viewpoint. However, I cannot and did not deny that I am a midwife; this is in my “lived
experience” and I had to recognise that these experiences and views may have impacted on this research study.

1.5 WRITING STYLE OF THE THESIS

My former BSc (Hons) and MSc degrees had an academic style which was suited to the objective approach required for the collection of quantitative data. This advanced degree is very different. I will explain and justify the approach in presenting this thesis without separating the text from my own personal experiences with the women in this study. It is appropriate to write in the first person as the chosen methodology underpinning this study is influenced by hermeneutic phenomenological inquiry and the hermeneutic phenomenological reflective analysis and hermeneutic phenomenological writing (van Manen 1990, 2006). Stanley (1992, 1993) and Wertz et al (2011) advocate that the use of the first person can make the author’s position clear within the research, while others view this style as contentious (Okely 1992). I am connected to the research and this thesis; it has been with me for the last four years and our (mine and the participants) horizons are fused in time (Gadamer 1989). Therefore, to try to withdraw myself and commit to being “neutral” is not realistic or achievable; importantly it is not a requirement for the study methodology. Heidegger (1962) and van Manen (1990) allow voices to be heard and fully accept the connection of the researcher with the research, thereby supporting this less formal approach. Whilst I found this style a little ‘alien’ at first, the temptation to revert to traditional academic style was present and remained strong. During this study process, I have learnt to say what I mean in a straightforward way and this, I believe, adds clarity to the text. This chosen methodology cannot be independent of the ontology, epistemology, subjectivity, ethics, politics and social situation of the researcher (Ramazanoglu & Holland 2002) and this I accept. I have integrated the voices of the women throughout this thesis, especially in chapter 4, extracting the essence and meaning that women had of testing HIV positive in their own words. I avoided divorcing myself from the participants by rejecting an academic style of writing that is not reflective of their words. I had one important priority that overrides all others; the women’s narrative and testimonies dominate this thesis. To interpret their words, I have analysed the findings through hermeneutic phenomenological reflection
(van Manen 1990, 2006) following identification of the themes of the research to discover the meaning and essence of the testing experience. This subjective, emotive and emotional experience for me justifies this less traditional style of hermeneutic phenomenological writing (van Manen 1990, 2006). My aim was to provide an honest account of the data received from the women throughout the research process, so my writing style reflects this requirement. It is also important to address the terminology used by women in this thesis. Health professionals use and are encouraged to use antenatal or HIV ‘screening’ (HPA Report 2011), as HIV ‘testing’ often sits within a raft of other antenatal screening procedures; however importantly women in this study use the term HIV ‘test’ or ‘testing’. Women believe that health professionals ‘test’ for the presence of HIV (in fact HIV antibodies). The words ‘test’ or ‘testing’ is therefore the preferred term in this thesis to comply with women’s narratives. The term ‘screening’ will only be used occasionally when addressing health professional issues. Throughout this thesis I may refer to midwives, doctors and birth partners as ‘she’ or ‘he’ for ease of reading, I do not infer that any of these roles should be one gender or the other. I fully accept and absolutely state that any of these roles can be undertaken by a woman or man in today’s multicultural and diverse society.

1.6 STRUCTURE OF THE THESIS

In **CHAPTER TWO**, I investigate and critique the relevant empirical HIV literature related to this study as it contextualises the research. This chapter is divided into two parts. Part one discusses the rationale for the study and literature review strategy, using general and specific search terms. The second part examines HIV and the history of HIV and AIDS, exploring the evolution of HIV testing practice and the impact of HIV on childbearing. I then critically review the literature in relation to HIV and antenatal testing and specifically the experience of testing positive in pregnancy and childbearing. This important section sets the scene for the rest of the thesis. The psychological impact of HIV is an important factor and will be explored, however it is not the prime focus, but reference is made to this important literature. Finally, as an additional search section, a literature review of African experiences of HIV was undertaken as the study’s respondents were all African in origin and this only became apparent after the
participants were recruited. A table of papers used in the literature review is in Appendix 2.

In **CHAPTER THREE**, I discuss the journey I have taken to find a theoretical perspective to underpin this study. I provide a clear rationale for my chosen methodology and present the study design and methods. Ethical considerations and reflexivity are also included in the chapter.

In **CHAPTER FOUR**, I provide the findings of the study and the women’s personal narratives and present the interpretation and meaning with the phenomenon. It will present the interpretative identified themes and examine the immediate and long term impact of the positive HIV result. I reflected and accepted a need to balance the amount of in-depth narrative so that women’s individual voices did not become lost against the uniform chorus of women singing.

In **CHAPTER FIVE**, I explore, analyse and discuss my interpretation of the findings, relating the meaning and phenomenon of this HIV testing lived experience to women’s life world. I provide analysis of this experience using a pivotal balancing model adapted from Wismont (2000) and show how women in this study balanced the major themes in their lives. This gives understanding to the antenatal HIV testing phenomenon of transition and transformation. I explore and propose how a personal loss model, originally proposed by Kübler Ross (1969) and later adapted (2005), is relevant to this study. I also discuss the work of George Bonanno (2009); his theory around natural resilience and how this gives further understanding of antenatal HIV positive testing theory. I discuss the findings in relation to current evidence and contemporary midwifery practice and discuss the practical implications for practice and future research. The strengths and limitations are presented and I also discuss my reflexive research journey. I finally conclude the study and thesis.
1.7 CONCLUSION

In this thesis I have given a platform for women’s voices to be heard. Interpretation has given in-depth understanding to the phenomenon of testing HIV positive in pregnancy. The original knowledge gained, should impact on the development of contemporary midwifery practice.
CHAPTER TWO- EMPIRICAL REVIEW OF THE HIV AND HIV TESTING LITERATURE

2.0 INTRODUCTION

This study explored women’s experiences of receiving a positive HIV result following antenatal HIV screening in the UK. This comprehensive literature review focused on antenatal HIV testing; the review comprises a general search around HIV and antenatal HIV screening worldwide and a specific search to examine the impact and experience of women testing HIV positive during childbearing. After the study, narrative data were analysed, a search was undertaken to examine the African experience of HIV, as all participating women were sub-Saharan African in origin. This literature is discussed later in this chapter. This study is a qualitative phenomenological study and therefore a systematic review of the literature was not a requirement (Hickson 2008). I did, however undertake a comprehensive review to explore the originality of the proposed research and the topic in-depth, to gain understanding and insight into antenatal HIV testing; the impact on women was an important focus. My midwifery experience informed my view that this positive result would have a major impact on not just the women themselves, but her wider families, social circle and wider community. It was also necessary to see if antenatal testing policy had evolved further and if any substantial contributions to this specific area of midwifery practice had occurred, since the completion of my Master of Science degree in 2006. This current study has a different methodology and focus of inquiry from my previous study (Lingen-Stallard 2006), which surveyed women’s views on HIV pre-test information prior to women undergoing antenatal HIV testing. This literature review gave me impetus to see what happens next for a woman, after she receives an HIV positive result. Any search strategy needs to be transparent and reproducible (Hickson 2008) and by adapting the principles of a formal review, this assisted me with this process.

In part one of this chapter I explain the search strategy, process and methods used to review the relevant HIV literature. In part two, I explore the impact of HIV in
childbearing and critically analyse the results of the search to set the scene for this study.

Hickson (2008) maintains that when undertaking a phenomenological study, a formal literature review is often not required before data is collected, but further states that it may be of value to gain an understanding of the topic, themes and the study’s originality. Hickson (2008) maintains that formal literature reviews may be harmful prior to data collection and the researcher needs to exercise caution; the researcher may be less open to new ideas, being unduly influenced by the views of others. However, I argue that an inadequate literature review may be detrimental to the research. Without a literature review, one may not comprehend all relevant issues related to the topic. Relevant issues may be missed when engaging with participants and/or interpreting their narratives. I am already familiar with the body of HIV evidence and will not bracket this prior experience; this is not a requirement in the chosen methodology. I am of the view that reviewing the HIV literature did not harm data collection and in all probability enhanced the process.

2.1 PART ONE- SEARCH PROCESS

This section will explore, discuss and critique the review search process.

2.1.1 Rationale for Research

HIV infections are now commonly diagnosed in pregnancy with black African women having the greatest burden of infection in pregnancy due to high levels of infection in migrants to Europe and the United Kingdom (De Cock & Low 1997; Kennedy 2003; Southgate et al 2008; Giravdon et al 2009; HPA Report 2011).

In the UK, the Department of Health (DOH) (DOH 1999, 2003) instructs midwives to recommend HIV testing in pregnancy and encourages women to accept and undertake testing for HIV antibodies in pregnancy. Women need to be tested for HIV before a definitive diagnosis can be made and effective treatment given to reduce HIV transmission to the unborn infant (DOH 1994, 1996, 1999, 2003, 2004a).
Antiretroviral drug therapy has had a major impact on HIV disease management and HIV positive pregnant women have benefited from drug treatments which has led to a decrease in transmission rates to their unborn infant (NAM 2010; HPA Report 2011). These health benefits can only be accessed by antenatal testing and diagnosis (Jones et al 1998; Adler 2001a, 2001b; Kennedy 2003; Giravdon et al 2009; NAM 2010).

Mercey (1998), Mercey & Nichol (1998) Boyd et al (1999a, 1999b) and Baxter & Bennett (2000) maintain pregnant women must be offered HIV testing as a routine screening procedure integrated within antenatal care to detect and treat maternal HIV infection and reduce infant transmission rates. A survey of maternity units in the UK in 1997 noted that HIV testing in pregnancy had expanded greatly (Ruby & Siney 1997). Midwives are a key component in offering HIV testing and Kennedy (2003) maintains women should be informed of a positive result by the midwife taking blood but with further peer support if required. Studies have inquired about women’s views about the acceptability of the antenatal HIV test in pregnancy (Duffy et al 1998a, 1998b; Simpson et al 1998, 1999), women’s support for HIV testing (Boyd et al 1999b), and pre-test information giving (Sherr et al 2000, 2001; Roth et al 2003; Lingen-Stallard 2006). However, specific research exploring an antenatal HIV positive result in pregnancy in the UK is minimal and Kelly et al (2012) was published after the completion of these study findings. In order to protect the integrity and independence of the interpreted findings of my study, Kelly et al’s (2012) study findings will not be referred to or used in the finding chapter. However, it will be utilised in the discussion section. A small number of papers were of relevance with testing HIV positive in pregnancy and the literature revealed women’s in-depth testing experiences in a mandatory antenatal HIV testing in the United States of America (USA) (Simpson & Forsyth 2007). The mothering experience of HIV positive women with their children were also explored by studies (Ingram & Hutchinson 1999, 2000; Kirshenbaum et al 2004; Sanders 2008) and a metasynthesis was also undertaken of HIV positive mothering (Sandelowski & Barroso 2003). More women are now diagnosed with HIV in the UK, due to the mass screening in pregnancy (NAM 2011) and the important experience of receiving a positive HIV result following antenatal testing was not fully explored. This study addresses this research need, by exploring the phenomenon and essence and meaning of this antenatal HIV testing experience for women in the UK.
2.1.2 Search Strategy

The principles of a formal systematic review may assist the researcher in achieving a comprehensive formal literature review and locate relevant literature (Sackett et al 2000; Hickson 2008). The research using a qualitative phenomenological approach aimed to explore women’s experience and personal testimony after being diagnosed HIV positive in pregnancy following antenatal screening. Within the scientific hierarchy of research for this qualitative study, rigour is still required and it is my opinion that exploration of the relevant literature and its impact was helpful for the understanding of this study. Relevant literature on the topic, irrespective of findings, needs to be included to reduce the potential bias; a systematic approach assisted the search strategy and literature review process (Sackett et al 2000). In summary, a review of the literature, when undertaken needs to be high quality to be of value.

2.1.3 General Search Terms for Literature Review

To gain understanding of HIV, AIDS and antenatal HIV testing, to include its evolution, history and social impact, less specific search terms were used to expand the search. These included the terms antenatal HIV screening or testing in pregnancy as Europe and the UK test for HIV in pregnancy. However, this study is specifically about women’s real life subjective experiences of receiving a positive HIV diagnosis in an antenatal testing or screening programme in the UK and required more specific search terms.

2.1.4 The Research Question or Phenomenon of Interest

The study explored and questioned women’s experiences and personal testimony when diagnosed HIV positive in an antenatal testing programme within the UK. This aspect required a specific search to assess that the proposed research is original (Hickson 2008) and enable contextualisation of findings within the existing evidential base.
2.1.5 Specific Search Terms from Research Questions or Phenomenon

Sackett et al (2000) proposes analysis of the research questions or phenomenon, which are divided into three domains of; population, intervention and outcome. The modified PICO framework, also uses Patient/Population, Intervention, but has the addition of Comparison/Context and then Outcome (PICO). Comparison (such as which treatment is most effective) was not required for this study. Context is important as HIV testing/screening occurs in the UK and is included. These helped identify the key or search term words and components used in this search strategy (Sackett et al 2000). The following specific terms were identified and (see Appendix 1- Table 1) included women's or women, experiences or experience of an HIV or AIDS diagnosis after antenatal or pregnancy screening or testing. These key words with other terms assisted in specifically targeting the literature to antenatal HIV testing issues for women with the diagnosis of HIV in pregnancy. Other general terms were later used (see 2.1.12 - further terms) such as resilience, attitudes; perceptions and coping to widen the search and combine with the specific search terms later (see Appendix 1- Table 1- Specific Search Terms).

2.1.6 Search Process for Specific and General Search

Online databases were searched (see Appendix 1-Table 3) firstly for the general search terms which later included the psychological HIV literature when the search was expanded (see expanded search section 2.1.12.1). A specific search was also undertaken (see Appendix 1-Table 1) to explore the antenatal HIV test experiences for women testing HIV positive but the specific search produced minimal pertinent literature until one recent UK paper was published in June 2012 by Kelly et al (2012). These searches were repeated a number of times in 2010/11/12 and lastly in March 2013, prior to final thesis submission. The African literature was added after the analysis of the findings and is discussed later (see section -2.2.5). National and local reports, policy and guidelines were also accessed and consulted. Local searches included reports from Strategic Health Authority NHS London (Southside, London), local and hospital HIV and screening guidelines and recommendations. HIV support charity’s literature was
also reviewed and this included literature and information from, National AIDS Trust (NAT), Positively UK (formally Positively Women), Crusaid now merged with the Terrence Higgins Trust, Body Positive, and the African support group Body and Soul. Unpublished literature is included if justified and relevant. Repeated searches in May 2012 revealed one additional relevant paper (Sherr et al 2011) and July 2012 revealed a small study by Kelly et al (2012) with a small number of others for additional inclusion.

2.1.7 Journals Consulted

Bowling (2002) maintains that once relevant papers are identified, the supplied references in that paper are reviewed for further primary sources. Hand and computer searches were undertaken with a number of relevant journals with a year date commencing 1981 to the present date which is illustrated in the Appendix 1 (see Appendix 1-Table 2).

2.1.8 Databases Accessed for Search

A number of medical, nursing and midwifery databases were accessed (see Appendix 1-Table 3 & 4) and specific HIV information sites examined (see Appendix 1-Table 5) for relevant information with search engines used (see Appendix 1-Table 6).

2.1.9 Limits to Specific and General Searches

Papers range from 1981 when HIV and AIDS was first reported (Shepherd 1994; Kennedy 2003) to the present date, to gain an historical perspective of antenatal HIV testing. The general and specific searches were initially limited to abstracts written in English from Europe, North America, New Zealand or Australia and later Africa.

2.1.10 Search Results

The last search in March 2013 is presented (see figure 1) and includes all the combined search results and later African papers. The total number of antenatal HIV testing abstracts retrieved after searching was 470 but with the above limits to search, 138 that
were deemed possibly relevant. These also include midwives views and midwives support of antenatal HIV testing and the integration of HIV testing in routine antenatal care. All 139 abstracts were read that were potentially relevant but 77 were discarded as they would not contribute to the study aim. In total, sixty two papers relevant to antenatal HIV testing and HIV diagnosis were fully retrieved. Fifty five research studies were included as they were pertinent to HIV testing in pregnancy and/or the experience of testing positive. Only one Randomised Controlled Trial (RCT) was identified (Simpson et al 1998) which examined user acceptability and satisfaction of HIV testing. One U.SA study explored mandatory antenatal HIV testing and positive results (Simpson & Forsyth 2007). A number of studies examined women’s experience of mothering after HIV diagnosis and were relevant (Ingram & Hutchinson 1999, 2000; Kirshenbaum et al 2004; Sanders 2008). Sandelowski & Barroso (2003) produced a metasummary and metasynthesis of 56 qualitative HIV studies, which explored the theme of motherhood and the focus, was on “HIV positive mothering”. Sherr et al (2011) published a systematic review of the psychological HIV literature and examined resilience and personal growth after a HIV diagnosis and whilst not based on antenatal HIV testing, was of relevance to this study and its later findings. The final combined search results (figure 1) and table in appendix (2) includes all papers in the review. The majority of papers explored HIV and childbearing issues, but relatively few of an antenatal HIV diagnosis in pregnancy until June 2012 with one UK paper by Kelly et al (2012). The later addition of the African literature around HIV testing issues are included but reviewed as a defined section of this literature review. The search for the African papers followed the same principles as this search but actively sourced them from the African setting.
Fig 1-Flow Chart (March 2013) of General and Specific Search Results of Empirical Literature Search Strategy on HIV and Antenatal HIV Testing via Databases. (Includes African Papers)

Step 1. 470 Abstracts retrieved and reviewed from all databases accessed (138 after limits to UK, USA, Europe & later African)

331 abstracts discarded as not relevant to topic or Non UK, EU, USA or review.

Step 2. 139 Abstracts possibly relevant to antenatal HIV testing and experience of testing

77 abstracts discarded as reliance on medication, treatment and pregnancy affects

Step 3. 62 Articles, papers and reports fully retrieved read and critically reviewed

17 discarded as repeating same result or same paper and/or over reliant on personal views or commentary and issues with methodology of paper limited or poor

Total of 55 ARTICLES included the literature review on antenatal HIV testing and/or experience of HIV testing

Includes One RCT paper on Antenatal HIV Testing

Includes 3 papers on Experience of HIV positive mothering and one on mandatory testing in USA

Includes later 2011 paper published on HIV resilience And one later UK paper June 2012 on HIV diagnosis in pregnancy
2.1.11 Lack of Information on Specific Search

One USA study by Simpson & Forsyth (2007) in a state mandatory antenatal testing program was identified. A number of papers focused on mothering, stigma and reproduction (Ingram & Hutchinson 1999, 2000). Sandelowski & Barroso’s (2003) metasummary explored the HIV positive mothering experience and whilst of interest and in many aspects pertinent, this was not the focus of this study. Sanders (2008), specifically examined women’s experience of a pregnancy when previously diagnosed HIV positive and whilst it has some similarities with the current study, it differs as participants were already diagnosed HIV positive before becoming pregnant. No study was identified that specifically questioned women’s experience of being diagnosed HIV positive in an antenatal screening programme in the UK until a short period prior to submission of this thesis and this was added (Kelly et al 2012) (see section 2.2.4.1). It later became apparent, due to the lack of information on the specific search, that an expanded search was required. The lack of specific UK information was disappointing, but highlights the importance of this current research.

2.1.12 Allied Expanded Searches

To offset the lack of specific data, and to add to the general search of HIV testing, a further expanded search included HIV terms with care, support, psychological, mental health, reproduction, impact of an diagnosis, stigma, coping, resilience, knowledge, opinion, uptake, attitudes, beliefs and perceptions. This widened the search and was undertaken to ensure relevant papers were not missed but the focus remained the antenatal testing HIV positive experience.

2.1.13 Total Number of Relevant Papers

The full list of relevant HIV testing papers and studies (March 2013) included in the review are in appendix (see Appendix 2). Bowling (2003) proposes a check box for assessing the relevance and quality of each reviewed study or paper which was adapted to HIV antenatal testing topic (see Appendix 3). All identified studies and papers were scrutinised and analysed against this check box criteria. Furthermore, each paper was
assessed using the hierarchy of evidence for a systematic review model, which was helpful in grading the level of research evidence (Sackett et al 2000) (see Appendix 4).

2.1.14 Other Sources

I have developed HIV expertise in my career. My written work includes a BSc (Hons) 1996 study on midwives attitudes to HIV testing; major aspects of this work informed a study by Low et al (2001), in which I was a co-author. My earlier Master’s degree dissertation on women’s views on HIV test information (2006) is relevant, as its content is pertinent to antenatal HIV testing and pre-test HIV information; the search located a number of studies and papers from that dissertation. However, the search for this study had a different emphasis and was specifically searching for sources which included women’s experience of testing positive. Local reports and HIV testing policy were often not available in the published literature and were accessed from the local NHS trust or via the strategic health authority (SHA at NHS London). The NAM (National AIDS Manuel) proved useful and also published updated studies and key findings via registration and weekly email. Local HIV networks and national HIV charities were useful for obtaining information on HIV testing programs and HIV testing availability.

I have used published expert opinion in this review, as required, as my personal experience of the development of antenatal testing is supported by Kennedy’s (2003) claim, that expert opinion has often driven the antenatal HIV screening program. This claim is further justified as De Cock and Johnson (1998) argued, without formal evidence of the need to normalise antenatal testing and not see it as distinct or exceptional and this “normalisation” testing policy was implemented without formal evidence. However, later success was claimed as the maternal uptake testing rate increased after this policy change. This will be explored later in the review.

The national research register was accessed 20/5/2010 prior to study formulation and this revealed one PhD study examining if HIV positive women felt midwives had prepared them for a positive diagnosis. Despite Email contact with the author to explore the study further, no response was obtained. A search of PhD thesis titles in UK did not elicit any relevant studies.
2.2 PART TWO– HIV AND HIV TESTING LITERATURE REVIEW FINDINGS

2.2.0 INTRODUCTION

The aim of this review was to critique and understand the relevant HIV literature. Importantly, I wished to tell a story of HIV that pertains to childbearing women and HIV testing, by following the principles of van Manen’s (1990, 2006) phenomenological reflection and phenomenological writing to convey meaning (explored in Chapter 3-Methods and Methodology 3.1).

Part Two is divided into five sections and uses the current literature to explore the topic of HIV by unfolding, developing and critique of the literature. Section one presents a history and background of the virus, exploring HIV, the HIV test and its impact. Section two reviews and critiques the relevant findings in relation to childbearing and care and the treatment implications for women and infants.

Section three is pertinent and explores and critiques the impact and development of antenatal HIV testing. Section four explores the fundamental experiences of a positive result in pregnancy and its effects on women, infants, families and communities. This section also draws on other communities affected by HIV and explores this experience as required. Section five examines the African experience of HIV and HIV testing as a distinct review and was added later as all the respondents were African and reported marked cultural beliefs and stigma imported from their home countries.
2.2.1 SECTION ONE- HIV AND AIDS UNFOLDS

This section is concerned with the history and background of HIV and the transmission, rates of infection and development of HIV.

2.2.1.1 History and Background of AIDS and HIV

The first case of Acquired Immune Deficiency Syndrome (AIDS) was reported in 1981 and the virus (HIV) was later isolated by Luc Montagnier in 1983 (Shepherd 1994). Robert Gallo also claimed to have isolated the virus and it became apparent that both discoveries were the same (Adler 2001a; Kennedy 2003). The virus was formally known by different names and in 1986 was renamed the Human Immunodeficiency Virus or Human Immune deficiency Virus (HIV). The isolation of the virus led to the development of an antibody test in 1985, which enabled the screening of individuals for antibodies to the virus (Adler 2001a, 2001b). The HIV antibody test is accurate and sensitive, but specifically indicates exposure to the virus (Mercey & Gibb 1999; Adler 2001a, 2001b). However, false positive and false negative results were reported especially in the early years of HIV testing and although rare, with the advent of confirmatory viral load testing, are very uncommon findings today (NAM 2010, 2011).

HIV testing does not detect the presence of the HIV virus; it detects HIV antibodies which is the body’s immune response when exposed to the virus (Adler 2001a, 2001b). HIV types 1 & 2 antibodies are sought during antenatal screening. HIV 1 is the focus of this study and of greater concern as it has greater prevalence and virulence and more health damaging than HIV 2 (Adler 2001a, 2001b; Kennedy 2003; NAM 2008). The antibody test is unable to inform if the infection remains active or give any indication on the state of immune function. This specific aspect requires further medical investigation to examine HIV disease progression and subsequent damage to the immune function by the virus.

The rates of infection, detection and diagnosis of HIV 1 (referred as HIV in thesis from this point) vary in the UK (DOH 2003, 2004; NAM 2010; HPA Report 2011). Greater London has the highest levels of HIV and specifically, Lambeth, Southwark and
Lewisham with 11% of the total HIV infected population of the UK residing here (HPA Report 2011). Other urban areas with large numbers of ethnically and socially diverse populations also have a disproportionately higher number of HIV infections. Further statistics reveal gay men, African and black populations had the greatest burden of HIV infection in 2004 and this trend continues (Lambeth, Southwark & Lewisham SHA 2004; Southgate et al 2008; HPA Report 2011). Specifically black African women are increasingly diagnosed HIV positive with the majority diagnosed in pregnancy since the introduction of national antenatal screening (De Cock & Low 1997; Nicoll et al 1998; DOH 2003; Lambeth, Southwark & Lewisham SHA Report 2004; Southgate et al 2008; HPA Report 2011).

Worldwide, the numbers of individuals infected with HIV are at unprecedented levels and are presently estimated at 60-80 million, with poorer nation states having pandemic levels of infections (UNAID Report 2010). This is compounded by poor nations being unable to access the expensive medication and often being reliant on experimental or charity led treatment programs which leaves a large pool of untreated infection in a population (NAM 2010; UNAID Report 2010). In sub-Saharan African nations, social structure is threatened as communities are being decimated by HIV infection (Southgate et al 2008; NAM 2010).

In the UK, individuals are encouraged to test for the presence of HIV antibodies and if diagnosed with HIV are able to access effective treatments and care (NAM 2008, 2010). Treatment reduces both mortality and morbidity and by reducing the pool of HIV infection also lowers infectivity risk in the population (NAM 2010). This in turn has led to the development universal antenatal testing and also targeted screening of “at risk populations” such as gay and sub-Saharan African men.

2.2.1.2 HIV Pregnancy Rates in UK

HIV rates in pregnancy range between 3 in 1000 outside of London to 10 in 1000 within Greater London (NAM 2010, 2011; HPA Report 2011). Sub-Saharan Black African women have the greatest levels of HIV infection with 47 cases per 1000 pregnancies (NAM 2011; HPA Report 2011). The HPA Report (2011) is reliant on accurate
reporting of infections but interestingly the incidence of women going on to have further pregnancies after an HIV diagnosis has increased. Women’s childbearing confidence has grown as HIV treatment has provided excellent health outcomes for mothers and infants (NAM 2012).

2.2.1.3 What is HIV?

HIV is a blood borne retroviral infection, which is most often sexually acquired. This sexual transmission route can attach marked stigma (Kennedy 2003; NAM 2010) and this is increased if sexual practices are deemed as deviant from a cultural or social perspective and issues of morality are often added to the complex mix of views held by individuals (NAM 2010). Blame is often cited which compounds stigma (NAM 2010). If HIV remains undiagnosed, untreated or is not managed effectively, the virus will usually disable the body’s immune function and subsequent ability to fight infection. Individuals with HIV usually become progressively weakened by a variety of illnesses as the immune system fails and ultimately to the development of AIDS. AIDS occurs in patients infected with HIV who then develop an AIDS defining illness. The point of origin remains elusive, but DNA sequencing suggests a Central African origin (NAM 2008).

The HIV virus has two variants, HIV Type 1 and HIV Type 2. HIV 1 is in turn divided into three main groups: M, N and O. Group O is rare and remains mainly in Central Africa. Group M is the most common and has nine sub groups and is the most prevalent in Europe. In 1985 HIV Type 2 was identified but appears to be less virulent and more difficult to transmit (Kanki et al 1994). Genetic testing of the HIV virus is now possible to identify different mutations and strains which can assist in both tracking the virus and it can be used as evidence for criminal cases involving reckless transmission of HIV (Bernard 2005). A positive HIV test requires further investigation to assess immune function and confirm the presence of HIV. This information and transmission is further explored is in the Appendix (see Appendix 5 -further HIV and AIDS information).
2.2.2 SECTION TWO- HIV CHILDBEARING IMPLICATIONS

This section reviews the childbearing implications of HIV once a diagnosis is made.

2.2.2.1 HIV Childbearing for Mother and Infant

Current research demonstrates that a diagnosis of HIV impacts on childbearing and the treatment options available to women (BHIVA 2008, 2010, 2012). This section specifically explores targeted obstetric care and treatment required to maintain optimum health for the mother and her infant. It also explores the difficulties women encounter with the treatment options. Johnstone et al (1990) surveyed 163 women and found some elevation but no significant difference in termination rates with women who were positive. They continued their pregnancies if they were informed of infant transmission rates. This is an early indication of women’s choice with childbearing.

2.2.2.2 Reducing Vertical Transmission

Vertical transmission is the transfer of the HIV virus from an infected childbearing woman to her fetus or infant during pregnancy; labour, at birth or postnatally through breastfeeding (Landesman et al 1996; Kuhn et al 1997; The International Perinatal HIV Group 1999; Lyall et al 2001; BHIVA 2005, 2006, 2008, 2010, 2012). Reducing vertical transmission relies on the pregnant women agreeing to test for HIV and be identified as HIV positive (Ruby & Siney 1997; Kennedy 2003; NAM 2008). This drive to reduce vertical transmission of the HIV virus underpins HIV testing of pregnant women (Ruby & Siney 1997; BHIVA 2001, 2006, 2008). Obstetric interventions, such as the application of cardiotocograph (CTG) scalp clips to the infants head during labour and prolonged rupture of membranes, may increase viral transfer (BHIVA 2012).

2.2.2.3. Breast Feeding Implications

Breast feeding is implicated in HIV infection with transmission rates varying from 15-30 % (Dunn et al 1992, 1995; Nicoll et al 1995) but this figure is now suspect as it
predates effective drug therapy (NAM 2008). To lower HIV transmission rates the positive women need to abstain from breast feeding (Duong et al 1999). However, this issue is more complex, routine antiretroviral drugs are prescribed to the newborn infants of HIV positive mothers for six weeks to further reduce vertical transmission rates (Intercollegiate Working Party 1998; BHIVAs 2001, 2005, 2006, 2008, 2010). This medication may also be protective if the mother has or continues to breastfeed. Preventing or discouraging an HIV positive woman from breast feeding can drive breastfeeding underground as a woman’s failure to breastfeed in her own community may be seen as socially or culturally deviant with a presumption of HIV positive status (NAM 2008). Some women may find the drive to breastfeed powerful in their social or cultural setting (Kennedy 2003; NAM 2008). This is counterbalanced by the protection of the child’s wellbeing. The literature strongly advocates formula feeding (Nicoll et al 1995; DOH 2004; NAM 2008; BHIVA 2012). Theoretically, vertical transmission rates may now be less if drug therapy is used by a women breast feeding her infant but it is not without risk (NAM 2011). Whilst drug therapy may reduce the risk of infant transmission with breastfeeding but often relies on retrospective information with much of the breast feeding data from Africa and in many cases when drug treatment is given, many women are lost to follow up (Geddes et al 2011). This impedes the collection of accurate breast feeding and HIV infection rate data and needs further sensitive exploration. Pasteurised donated milk from a HIV negative donor is a viable option as this process kills HIV, but most centres are unlikely to pasteurise an HIV positive mother’s own milk unless she is insistent as whilst in all probability a safe option, no absolute assurance can be given due to a technical failure with the pasteurisation process.

2.2.2.4 Antiretroviral Drug Therapy to Reduce Viral Load

Antiretroviral therapy or Highly Active Antiretroviral Therapy (HAART) or known as triple therapy or combination therapy, has had a major impact limiting HIV disease progression and has further impacted on the management of pregnant women who are HIV positive (Lallemant et al 2000; Lyall et al 2001; BHIVA 2001, 2005, 2006, 2010, 2012; NAM 2008, 2010, 2012). This drug therapy consist of a combination of three medications from at least two classes of antiviral HIV medication suppressing the virus
replication in the blood and lowering viral load to undetectable levels (NAM 2012). It is not the remit of this review to explore drug therapy or these recommendations in full as this topic is vast and the recommendations are constantly changing to improve outcome and remain the domain of the HIV specialist. What cannot be denied and the evidence is overwhelming, is that this drug therapy has had a major impact not just on treatment but has justified and driven the rationale for antenatal HIV testing. HIV detection and subsequent drug therapy is an effective method of reducing infection in the infant (RCM 2000, 2001; Kennedy 2003; NAM 2008, 2010). The British HIV Association (BHIVA 2012) gives comprehensive current guidelines in the management of HIV and the use of drug therapy during pregnancy. Midwives in the past, questioned the offer of the HIV test but effective drug therapy has altered this view (Kennedy 2003). Drug adherence is an absolute requirement for efficacy, but some women will encounter difficulties with adherence, especially if the medication and HIV diagnosis remain secret (Kennedy 2003; NAM 2011). Giving infants 6 weeks of antiretroviral drug therapy can also be problematic for women as they endeavour to maintain confidentiality (Kennedy 2003; NAM 2011). The overriding issues are that the viral load and exposure to the infant should be as low as possible in pregnancy to reduce vertical transmission and this is the ultimate goal of drug therapy in pregnancy (BHIVA 2010, 2012; NAM 2011).

2.2.2.5 Interventions and Birth Options

HIV positive pregnant women are encouraged to accept additional protective interventions. This included the use of caesarean section delivery as a mode of birth (European Collaboration Study 1992, 1994, 1996). The European Collaboration Study (1994, 1999), Brocklehurst’s (1999) and the International Perinatal HIV Group’s (1999) meta-analysis demonstrated absolute protective benefits of caesarean section; in all three, the methodology was rigorous. However, the role of caesarean delivery remains unclear at the present time, as these studies were undertaken prior to the introduction of effective antiretroviral drug therapy, which theoretically may now have supplanted the benefit of caesarean section. Many obstetric units now support a short duration, non-interventional vaginal birth, if maternal viral load remains undetectable prior to birth (Chelsea & Westminster Obstetric Guidelines Group 2008; Guy’s and St Thomas
Guidelines 2008). It is not the remit of this literature review to discuss this specific issue around birth options, but women must be informed of reduced infective risk so they can make a considered birthing choice when viral load is low or undetectable.

2.2.3 SECTION THREE- HIV TESTING IN PREGNANCY

This important section examines and critiques pre-test information and the implications of antenatal HIV testing during pregnancy in UK. The body of relevant literature is important for this thesis as it explores HIV testing in pregnancy, which, as previously stated, is the major gateway for an antenatal HIV diagnosis in the UK. HIV testing in pregnancy is routine and fully integrated into antenatal care. Midwives are the prime care providers and routinely offer and recommend HIV screening. This was a midwifery focused HIV study and much of the evidence around antenatal HIV testing contained here is pertinent to midwives as they test women and may encounter positive results in pregnancy.

2.2.3.1 Antenatal HIV Testing in the UK

Government health policy is that all pregnant women should be offered universal HIV screening as opposed to selective screening (which examines risk) and preferably offered by midwives (DOH 1994, 1996, 1999, 2003). In 1999, the offer of testing was emphasised and HIV uptake and detection rate targets set (DOH 1999; HPA Report 2011). Midwives are expected to actively recommend and promote HIV testing in pregnancy and healthcare providers monitor maternal uptake rates (DOH 1999). The 2010 recorded uptake rate of 96% is a remarkable achievement (HPA Report 2011).

(Mercey & Nicoll 1998). Risk factors are often overlooked by midwives (Hawken et al 1995; Mercey & Nicoll 1998). However, some women will have a higher risk of a positive result and this should be explored with women but with the recommendation to test (NAM 2008).

2.2.3.2 UK Antenatal HIV Testing Guidelines

The DOH (1994) issued guidelines for the pre-test discussion and antenatal HIV testing. These were reliant on expert opinion and encouraged testing of pregnant women in high prevalence areas. These guidelines were revised (DOH 1996), and were further amended (DOH 1999) with the added provision that midwives actively recommend the HIV test in pregnancy. Midwifery units generally have an HIV testing guideline or a written policy containing the minimum requirement of pre-test information prior to HIV testing in pregnancy and this includes a care pathway for informing women of a positive or negative result. Some London units send negative results in the post, if women agree to reduce the stress of waiting; other units inform women at their next antenatal appointment. HIV positive results are given face-to-face with the woman recalled for an urgent appointment; for many women this raises the first suspicion that something is wrong (Kennedy 2003; NAM 2008).

Historically, many units at the booking interview had an information checklist which acted as an aid-memoir whilst undertaking the pre-test discussion. This enabled audit and linked individual midwives’ uptake rates and recorded the information discussed with the women. The checklist tool was often abandoned because it increased the ritualising process of testing and took time to complete (Blott et al 1999). Abandonment of may have contributed to less pre-test information being discussed, as the information-giving process is no longer specifically audited. However, computer records may allow retrospective audit of the testing process in some units.
2.2.3.3 Maternal Uptake Rates

The maternal uptake rate has increased and it is often cited that the antenatal HIV testing program is performing well (Kennedy 2003; BHIVA 2010). In 1999 the Department of Health issued a target for uptake rates with a final target of 90% in 2002 with a detection rate of HIV of 80%. This target was exceeded in the UK, with an average 96% each month in many units and in the NHS overall (HPA Report 2011).

Giraudon et al (2009) surveyed 30 London maternity units and found a 95.6% uptake rate for HIV but 1% higher for Hep B and syphilis testing. However, this uptake rate data whilst comprehensive is limited, as testing issues for women are not fully explored or recorded. The maternal HIV testing experience is rarely documented in the literature and often only by women who are supportive of testing. The grey literature and spoken testimony from HIV charities often gives poor accounts of the experiences of women who test positive. Any over-reliance on the maternal uptake rate as an indicator of success is of concern; success parameters need to be expanded to include the women’s testing experience.

Temmermam et al (1995) commentary paper propose that women have a right to test and then to decline the test result, but this is problematic in practice as, if the result was positive, this would create an ethical issue for the expectant mother and her unborn infant. Treatments could not then be given and health would be affected. Sherr et al (1998) commented that women from ethnic minorities were often specifically targeted to increase the uptake and detection rate. This may sound selective and perhaps racially motivated, but on the overwhelming evidence, women from black ethnic backgrounds carry the greatest risk of infection (HPA Report 2011) and targeted responses have health benefits and needs to go beyond a simplistic view that midwives are biased in their testing selection. Ruby & Siney (1997) surveyed the maternity units in the UK and found most units offered HIV testing in pregnancy and that testing was embedded in antenatal care but in an opt out program. This survey did not assess maternal uptake rates, but increased levels of testing were reported.
2.2.3.4 Knowledge of HIV and Impacting on the Uptake Rate?

Desmond (1994) large study indicated that poor maternal knowledge of HIV has been implicated in reduced rates of testing. Increasing knowledge produced a higher maternal testing rate if women were informed of effective treatments. This study had a large sample and recommended a pre-pregnancy HIV information health strategy to increase maternal knowledge. This study was undertaken prior to the introduction of active recommendation and op-out testing; these maternal knowledge factors may be less of an issue as pregnant women are now automatically tested for HIV in the UK.

Duffy et al (1998a) survey on 789 women also measured knowledge and uptake rate within one London unit and found a positive correlation between maternal knowledge of HIV and testing. Duffy et al (1998 b) surveyed 843 women and made the same correlation. These two surveys were on the cusp of drug therapy and when women were made aware of treatment and this may have incentivised them to test as beneficial to health.

Baxter & Bennet’s (2000) survey of 12 women and Bruce et al’s (2001b) survey of 18 women found that women accepted testing when fully informed. Questioning was superficial and lacked depth, samples were small and lack power (Hickson 2008). Whilst the survey findings are limited and not generalisable, they are of interest as women reported increased knowledge assisted with the acceptance of the test.

2.2.3.5 Informed Consent and Role of Pre-Test Information

The literature maintains the pregnant women’s right to receive pre-test HIV information but with the added proviso of encouragement to test because of the established health benefits (Massiah 1993; Sherr at al 2000; Raffle 2001). To give informed consent, ascertainment of current level of knowledge is important; a factor often lacking (Sherr et al 2001; Mazur 2003); risks and benefits must be explained and time should be allowed for women to absorb the information (Power 1997). All legislative and regulatory bodies, including Department of Health (DOH 2001), General Medical Council (GMC 1998) and Nursing and Midwifery Council (NMC 2004), require valid
consent; this must be obtained for any screening test, including HIV testing. Failure can legitimately result in practitioners being accountable to the regulatory bodies Fitness to Practice Committee. Patients are central to the health service and must be given information to empower them to make an informed choice in any planned treatment (The NHS plan part 10, 2000). Maternity Matters (DOH 2007) report and the Darzi (2008) report both endorse patients to be at the centre of care and their experiences must shape future care provision. It is reasonable to presume this includes the experience of HIV testing in pregnancy.

Raffle’s (2001) commentary paper states that informed consent is often not fully gained in antenatal HIV testing and suggests an increase in the uptake rate is the driving force for HIV testing but cites minimal evidence. Information is critical as it enables women to make a personal decision. Mercer’s (1998) commentary paper suggests too much information leads to overload and the impetus to test is lost and recommends pre-test information is succinct. This is a personal opinion and importantly fails to give an indication of the level of acceptable information required for women. This suggests women as users of the testing service need to be involved in this important discussion.

Hehir’s (1999) commentary paper seems to suggest that clinical practice endorses selective information or a denial of full information, whilst unethical; is a common occurrence to maintain uptake rates but this paper lacks evidence. Practitioners often fail to gain informed consent prior to antenatal testing. Reasons cited are reduced resources, lack of time, poor motivation and limited knowledge (Massiah 1993; Sherr at al 2000) but both were also lacking evidence.

De Zulueta and Boulton (2007) qualitative cross-sectional survey focused on informed consent and explored pregnant women's perceptions and responses to routine HIV testing. Data collection was by a semi-structured interview of 32 women at their booking of maternity care. To ascertain the validity of consent, responses were assessed against the DOH antenatal screening standards criteria for informed consent (DOH 2003). The study explored women’s rationale and understanding of testing and explored reasons for declining or accepting the HIV test. The study was set in the antenatal booking clinics of one hospital in central London. At clinic attendance they found only 10 women who were prepared for HIV testing, having received and read pre-test
information. The majority (n=23) were unable to recall any prior information; this questions the adequacy of the consent process. Only 9 women had an understanding of the rationale for the HIV test. Women did not view themselves at risk for HIV infection and questioned relevance of testing. The majority of women accepted testing at the booking clinic as routine or a “job lot” with other tests. A professionally recommended test was a powerful motivator, but 3 women felt pressured to accept and several test acceptors thought they had refused. Test acceptors were receptive of infant and health benefits. Six women declined testing and felt that acceptance of the test was an acknowledgement of risk behaviour. Concern was expressed about the potential negative outcomes of being HIV positive and an inability to cope if the result was positive. Decliner’s rationale cited religion and beliefs which included 2 women of African origin. A significant finding was that none of the participants fulfilled the standard criteria for informed consent. The earlier finding of a lack of pre-test information and unpreparedness for testing contributed to the failure to meet the standard criteria consent assessment. The authors suggest that the power of professional recommendation may increase uptake (acknowledged by a number of women in study) but eroded informed consent. However, whilst there is evidence that informed consent criterion was not fulfilled, linking the two issues is questionable; there was no explicit evidence that consent was eroded by professional recommendation to confirm the author’s hypothesis. The study is qualitative in design and the data collection methods add strength to the study; the interviews were interactive and personal. The interview questions were pertinent and specific. Verbatim text is used appropriately to outline presentation of finding; but the narrative is sparse, depth and meaning of women’s perceptions and the testing experience is superficial. Generalisation is correctly stated as not possible within the research approach used. Interestingly, the author’s state that protection of the infant and partner from infection may outweigh the moral duty of respecting women’s consent and autonomy enshrined in bioethical tradition. However, this is the author’s personal commentary of a separate ethical debate and importantly not a finding of the study. This study clearly demonstrates difficulties in obtaining valid consent with antenatal HIV testing for these participants.
It remains health policy to inform and gain consent for any medical treatment with only a small number of exceptions (under the Mental Health Act and other occasional legal measures to protect public health) (DOH 2001). HIV testing in pregnancy is fully supported in the literature but with informed consent (Intercollegiate Working Party 1998; Jones et al 1998; Roth 2001; RCM 2000; RCM 2001; NMC 2004). If legally challenged, HIV testing without informed consent could be viewed as criminal assault (Kennedy 2003; NMC 2004).

Women, support groups, testing agencies and government policy all strongly argue, HIV testing in pregnancy should remain voluntary (Kennedy 2003: NAM 2010). Compulsory testing in pregnancy has its proponents to protect infants health and wellbeing; this is not endorsed by the midwives’ and nurses’ registering bodies due to consent issues (NMC 2004).

2.2.3.6 Midwives’ Crucial Role in HIV Testing

Goldberg and Johnson (1993) and Brierley (1993) were early supporters of HIV testing in pregnancy. Brierley (1993) commentary paper maintained that midwives had an important role in raising the issue of HIV testing in the antenatal period before HIV testing became routine screening, but raised concerns, that women may be coerced into testing and not be given full pre-test information.

Midwives have questioned their ability to undertake the HIV testing role in pregnancy (Chrystie et al 1995a, 1995b). Hehir (1999) was not supportive of midwives offering an HIV test in pregnancy and cites a number of concerns; these included time constraints, extra work load, coercion and the inability to gain meaningful consent but whilst this was a strong personal opinion, the points raised have some resonance. These issues raised may have validity, but the alternatives for antenatal HIV testing are very limited.

Postma et al (1999) cost analysis with evidence argues that midwives are an excellent resource when cost is taken into account as they have maternal access. Other options, such as individual counselling by trained counsellors, are prohibitively expensive and
would need to be additionally arranged (Postma et al. 1999). Davies (2000), Mercey (1998), and Mercey & Nicolls’ (1998) stated opinion is that midwives are able to offer and recommend the HIV test in pregnancy to all women at the booking interview.

Meadows et al’s (1990) small retrospective study compared 12 midwives differing uptake rates and concluded that those with less knowledge of HIV had markedly lower uptakes rates. However, the retrospective assessment of knowledge was questionable as the survey was performed some time after testing and respondents may have had an increase in knowledge. Meadows et al’s (1992) later survey explored the views of 34 midwives around HIV testing in pregnancy which came to a similar conclusion. This later survey was more robust with the depth of questioning and explored knowledge and views, clearly questioning midwives knowledge and linking it to the individual uptake rate. This study concluded midwives with increased knowledge supported HIV testing and encourage women to test. Again these two studies were prior to effective medication and specific for that time period but both give an indication that midwife knowledge was linked with uptake test rates.

Gibb et al’s (1998) multicentre prospective survey of 18,791 women examined factors affecting maternal uptake rates and without meaningful questioning of the topic concluded midwives’ verbal interaction with women was crucial to encourage and increase testing rates. However, results simply showed that women who lacked information or did not support testing had low uptake rates. They further concluded with a possibly correct assumption, that midwives were crucial for the uptake rate by informing women of the health benefits. This study had the benefit of being multi-centred and the recruitment and sampling strategy was robust. However, the questioning was limited, superficial and lacked depth due to the prohibitive sample size. This study simply asked if women supported testing but importantly, if the answer given was negative, it failed to explore why they did not support testing. This study evidenced that HIV uptake rates were affected by maternal knowledge and whilst claimed, the evidence was lacking on the midwives interaction.

Bruce et al’s (2001a) survey of 12 midwives concluded midwives’ personal views and knowledge were important in increasing the testing rate for Hepatitis B and HIV testing. This survey is clear and unambiguous and perhaps simplistic but of interest and is
followed by Bruce et al’s (2001b) user survey of 18 women, which demonstrated women wanted greater HIV pre-test information prior to testing. This study, whilst limited by the survey method, questioned and ascertained what information a woman required prior to testing in a meaningful way and importantly gave different samples of information for women to choose from. This positive step enabled women to grade the information they required and was an important development. These two studies were undertaken with opt-in screening programmes. It could be postulated that with opt-out testing programmes, the midwife may have less impact on the uptake rate as women are now tested automatically.

Roth’s (2001) commentary paper states time constraints; midwives poor knowledge and inadequate training are implicated in poor uptake rates. Antipathy or antagonism to HIV testing is damaging, however this view whilst valid, is only a supportive paper on HIV testing and draws on limited evidence.

I surveyed 19 midwives around attitudes and beliefs to HIV and HIV testing prior to the introduction of effective antiretroviral drug therapy and found that midwives were generally supportive of HIV testing in pregnancy and supported women infected with the HIV (Lingen-Stallard 1996). Midwives stated they were performing an additional role which they had not been trained to do and questioned the rationale for testing women as treatments were limited at this point in time. This study, whilst of interest, is limited to a small sample but gives early indication of midwives’ support for testing in an inner London unit with a rising level of HIV in the population.

Low et al (2001) used major components of my questionnaire (Lingen-Stallard 1996). This larger sample of 162 midwives was undertaken in the entire health district and again questioned midwives, but importantly after the introduction of effective antiretroviral drug therapy, which now gave a rationale for HIV testing as the health benefits had improved substantially. This study surveyed midwives’ attitudes to HIV and HIV testing and explored how midwives integrated HIV testing into routine antenatal care. This was followed by four focus groups of the survey participants which explored the issues further and importantly in-depth. The findings of the survey and focus groups demonstrated that midwives supported antenatal HIV testing and its integration into midwifery care and further demonstrated midwives accepted and
understood the rationale for HIV testing. This study also found that midwives who had recent updating had a positive attitude to HIV testing in pregnancy and the care of HIV infected women. The return rate in this study was difficult to ascertain as one participating unit did not follow the protocol when issuing the survey. However, this methodological weakness with the return rate does not detract from the findings as it gave early insight into improving midwives attitudes and their support for testing.

2.2.3.7 Please Test: The Recommendation of HIV Testing to Pregnant Women

The DOH (1999, 2004a) states midwives should actively recommend antenatal HIV testing to women. Most antenatal screening informs women of any risks and benefits of any investigation in pregnancy and this should include HIV testing.

Roth’s (2001) commentary paper maintains that failure to offer and recommend HIV screening is of concern as women would miss out on significant health benefits. A proportion of pregnant women remain untested and are unable to access effective treatment and infants are infected (Roth 2001). Whilst this paper does not present empirical research, it makes some valid points. It could be proposed, it is better to recommend HIV testing with limited information than not to offer the HIV test at all.

However, with no or little preparation this could have a damaging psychological and social impact if the result is positive. Occasionally women chose not to test or are coerced or expected to test to protect the unborn infant (Kennedy 2003), but Roth (2001) is adamant that failure to offer and recommend testing is unacceptable midwifery practice and open to legal challenge as the evidence on health benefits is overwhelming.

De Zulueta & Boulton’s (2007) qualitative study found women who accepted antenatal HIV testing, a number acknowledged the power of “professional recommendation” with the test, which was persuasive and a powerful motivator and influenced uptake
acceptance for participants. This suggests midwife recommendation is working and a driver for increasing testing uptake.

2.2.3.8 Reduction of Pre-Test Information: Diminished Choice?

Previously, it was argued that women were fully counselled before HIV testing and often by trained counsellors (Kennedy 2003). This was reduced to information giving, a role undertaken by midwives (Blott et al 1999; Kennedy 2003). However, a further noted decrease in pre-test information given to women has its origins in Simpson et al’s (1998a) RCT study (see below in this section). This RCT in turn, informed De Cock & Johnson’s (1998) clinical expert advice that a reduction of pre-test information and normalising the HIV test was permissible.

De Cock & Johnson’s (1998) commentary article argued powerfully for a reappraisal of HIV testing in pregnancy with a move to normalisation of the HIV test and no longer an exceptional event. However, this was a developed personal view and this normalisation advice developed from Simpson et al’s (1998a) RCT study findings, which were questionable as normalisation of testing was not measured. This study also concluded that reduced information was acceptable to women (see below). Simpson et al’s (1998b) later commentary paper also endorsed this normalisation advice.

Simpson et al (1998a) is an important (RCT) study and concerned with the acceptability and satisfaction of HIV testing. The study examined four different methods of offering the HIV test. In pregnancy pre-test information consisted of either; a detailed written leaflet or a short written leaflet and two levels of verbal discussion prior to offering the test. The findings suggested giving women minimal information was acceptable, as they had a similar uptake rates of testing as those given more information. The study concluded women found less information acceptable and maternal uptake rates were similar. Less information saved time and intensive information could be abandoned with little impact on acceptability. Participants were 3024 women from a hospital antenatal clinic and randomly sampled to each group, however it is not clear if this was blind randomisation. They measured women’s knowledge, uptake rate, acceptability, satisfaction and anxiety. The control group received no information and no direct offer
of the test; the rates of uptake were low at 6%. Those given information in any
combination and also directly offered the test had a similar 35% uptake rate. However,
the findings are debatable as the control group should have been offered the test like the
other two experimental groups but not given pre-test information and therefore were not
an effective control group. The effect of just offering an HIV test may have achieved a
similar uptake rate in all three groups. Simply the offer of an HIV test across all groups,
including the control, may have got the same uptake rate of 35%. This is irrespective
of the information, short long or not given at all. This RCT is the only one for HIV testing,
but is less relevant today as most units are achieving over 96% uptake as opposed to
the 35% in the study (NHS London 2008; HPA Report 2011). Women seek more pre-
test information (Sherr & Hedge 1990; Lingen-Stallard 2006), and further evidenced
women like a detailed pre-test information leaflet. This is in direct contrast to Simpson
et al’s (1998a) findings and commentary paper (Simpson et al 1998b). The tool to
measure the acceptability within the RCT, of the differing information methods is
questionable, as women in the experimental groups were questioned specifically “are
you in favour of an HIV test being available to all pregnant women?” Women
responded they were in favour which was to be expected. A limitation was that the
women had not experienced the different methods of imparting information, so were
unable to compare which information method was acceptable or not. Further, on
examination of the midwives’ normal individual uptake rates these were low in the
control group which may have been a confounding variable. Simpson et al (1998a)
concluded, maternal knowledge of the benefits of the test improved the uptake rate and
did not affect maternal anxiety with HIV testing. Minimal information was endorsed as
the study found less information was acceptable as the rates of uptake were the same.
This conclusion that minimal information is acceptable has impacted on policy and also
underpins the practice of normalisation of the test. However, Simpson commented that
he felt the homogeneity in his Scottish sample may have had an effect as women
accepted what was given.

Simpson et al’s (1998a) study was importantly undertaken in an opt-in testing
programme. Simpson then proposed a reduction of pre-test information within an opt-
out approach - a major concern, as this study is not relevant to an opt-out program. De
Cock & Johnson (1998) supported Simpson et al (1998a) and proposed normalisation of
the test would increase uptake if coupled with opt-out screening programme. This
linked expert opinion supported the questionable research results. However, uptake rates have risen and this is used to justify the change.

Simpson et al (1999), in the next year, changed the testing programme to opt-out and undertook a survey measuring the same pre-test information parameters (Simpson et al 1999). Questioning was very superficial around the issue of the acceptability of less information. This was not made explicit to women and a major weakness is that women were denied the knowledge about the reduction in pre-test information. The author’s simply state they failed to find evidence that women found it difficult to decline a test, but this was never asked. Simpson et al (1999) again accepted the homogeneity of the sample and led to the women simply accepting what was provided. This raises the issues of how this study can be generalised to the wider population; a conclusion that Simpson et al (1999) endorses.

Roth et al’s (2003) qualitative study examined HIV pre-test information for non English speaking women in one London unit. They specifically evaluated and importantly observed the bilingual advocacy service at the booking interview in relation to antenatal HIV testing. Focus groups were also used with a subset of woman who had been involved in the HIV testing process. The focus groups were limited to Turkish, French, Somali and Bangladeshi. They found that when advocacy was unavailable, HIV testing was presented to women in English and consent was then threatened. More often close relatives were used as interpreters and it is likely to have had an impact on the offer of a test. This had a major implication on the issues of consent and reduced uptake rates. All the women questioned wanted language support and the advocacy role to be maintained. Some contextual weakness is probable as the same interpreters were used in the focus groups, data gathering and for advocacy role with women. Even with this limitation, this study still found that these women do not receive adequate HIV pre-test information in many instances when offered testing.

Sherr & Hedge (1990) surveyed 24 maternity units’ antenatal HIV testing information leaflets. Each unit’s leaflet was examined for information content and whilst some were clear and contained pertinent information when marked against a checklist, the majority lacked important pre-test information and were therefore limited. The authors concluded that leaflets are an acceptable method of conveying information but arrangements
needed to be in place for women for whom English is not their first language and for those women unable to read. The conclusion on acceptability is debateable as women were not specifically questioned on this aspect but this early study indicates a weakness with written information.

Sherr et al’s (2000) survey study and audit consisted of two parts; Part one, audited 288 clinics in the UK and Eire and had an excellent 91% response rate. They examined antenatal information on blood tests available in pregnancy. They also specifically examined HIV testing and when benchmarked against information standards found units failed to ensure consent during antenatal screening. The maternity units’ written policy was also examined and found deficient in obtaining consent for any antenatal blood test including HIV. Part two of the study; whilst limited to a survey, questioned 882 women in four London units about consent to all antenatal blood tests including HIV testing and 79% \( (n=697) \) women responded, which is a high return rate for a survey and adds power to the findings. The majority of women (80%) believed consent would be requested for an antenatal test, but were often unsure of the consent process. They commented that screening information was deficient and interestingly 18% believed HIV testing to be compulsory. Sherr et al’s (2000) survey was methodologically sound and whilst questioning was simple and at times superficial, it was pertinent and well designed. They concluded pre-test information and consent was noticeably poor in all antenatal screening offers. The majority of the units were, at that time, offering selective risk screening or universal testing but in an opt-in screening programme.

Sherr et al’s (2001) observational study observed 154 antenatal booking interviews in four London units with midwives offering HIV testing in an opt-in screening program. Using a standardised check list, they observed and monitored the minimum amount of information that should be discussed with the woman by the midwife during the pre-test discussion. Whilst the check list was superficial, it assessed if the midwife raised issues of: risk, effective treatments, reducing vertical transmission, advantages, disadvantages and importantly the possibility of a positive result. The full booking interview took a mean of 33 minutes, but only 2 minutes (mean) explored HIV testing. Risk was rarely raised; with only one woman in five informed about interventions to reduce infant transmission. Only one in ten women were informed of the advantages/disadvantages of testing. The possibility of a HIV baby was raised more often. If the midwife did fail to
mention effective interventions to reduce vertical transmission the mother would be less likely to accept testing. Sherr et al (2001) was concerned about the lack of information and links, poor maternal uptake to poor information given during the booking interview and that women are ill prepared for HIV testing. This must impact on a woman receiving a positive HIV test result. The conclusion again states, that information giving may be improved with opt-out testing and this is extremely debatable as not a study finding. Sherr et al (2000, 2001) is correctly concerned about the lack of pre-test information and concludes that opt-out testing if preferred, but this conclusion for both papers are not based on the actual study findings and a personal view.

De Zulueta & Boulton (2007) qualitative cross-sectional survey (previously discussed see 2.2.3.5) explored pregnant women's responses to routine HIV testing and women’s reasons for declining or accepting the HIV test with the focus on consent but a relevant finding was that out of 32 women interviewed; 22 women had limited pre-test information with only a minority of women (n = 9) had a broad understanding of the rationale for the test. Only 10 women were prepared for HIV testing as the remaining participants did not recall if pre-test information and if it was sent to them, recalled receiving or recall ever reading the information. This finding is suggestive that women are not prepared for HIV testing on clinic attendance and questions if the result was positive it is likely to increase distress.

Failure to warn pregnant women in advance that they will be offered HIV testing is poor clinical practice (DOH 2003) and does not allow an individual time to consider the advantages or disadvantages for themselves personally (GMC 1998). Failure to warn that the test could come back positive (DOH 2003) and the social implications generated are of concern, as the experience may be traumatic with the women being ill prepared (NAM 2012). However, Mercy (1998) in commentary paper, citing evidence argues that women who do not test will only delay the inevitable outcome if they are positive; the diagnosis would occur at a later date when symptomatic. However, HIV positive women are often abused, abandoned, stigmatised and ostracised by family friends and partners (NAM 2012). Suicide may be contemplated and is reported (Kennedy 2003; Sherr 1995; NAM 2012) and women may need time to prepare for testing. An open and honest dialogue of this possibility may indeed help in that preparation.
2.2.3.9 Let’s Make Testing Normal

Mercy’s (1998) commentary paper was critical of the low uptake rate and at that time called for a radical review of antenatal HIV testing. Since 1999 there has been a move to normalise the HIV test. In the normalisation strategy the test is viewed as a “normal” blood test, much like any other routine blood test in pregnancy, undertaken along with other antenatal blood tests and importantly no longer regarded as special or exceptional in any way (De Cock & Johnson 1998; Kennedy 2003). Kennedy (2003) maintains HIV tests treated as “special” negatively impacted on the uptake rate, but this is a personal view. This “normalisation” policy was proposed by De Cock & Johnson (1998), and supported by Department of Health (1999), and viewed favourably by Kennedy (2003) and discussed earlier in the review. This impacted on the amount of pre-test information given to women by midwives but with little evidence to support this policy change.

Most non-pregnant women and men who test for HIV identify some personal risk or concern and are self-selecting (Kennedy 2003). Pregnant women are “captured” and receive a very different testing service when compared to other HIV testing programs not linked to pregnancy. Chrystie’s (1995a) pilot study of the implementation of voluntary HIV testing with 6 midwives and 204 women care episodes over a year demonstrated that non-pregnant HIV testing services offered 18 minutes of pre-test information with extended counselling. Contrasting with midwives had a mean of 6 minutes. Chrystie (1995b) further argues in a commentary paper and cites this 18 minutes service is not routinely available to pregnant women, due to cost and time. However, many maternity units can accesses in-depth counselling if the women request it or specific risk is identified and a positive test result expected. However, many results are unexpected as this thesis will further testify. Miller & Lipman’s (1996) commentary paper argued that they supported the substitution of the term “pre-test information giving” in place of counselling and cite counselling as costly, labour intensive, and required the women to be referred, with the impetus lost to test, due to the time delay.

The previous selective approach to HIV testing was reliant on the ability of midwives to identify maternal risk of HIV and was laden with preconceived ideas of who is truly at
risk (Blott et al 1999; Kennedy 2003). Perhaps antenatal pre-test HIV information is diminishing and women are now expected to test. My Masters’ findings support this concern as less information was shared with respondents and many believed they were automatically tested for HIV as a normal screening event (Lingen-Stallard 2006).

Jones et al’s (1998) cross sectional survey of 23 midwives demonstrated women’s rate of uptake was affected by the experience and personal views of the midwife offering HIV testing. They effectively questioned midwives with practice, belief and views using agree or disagree questions with free text and cross referenced this to individual uptake rates. Midwives with a positive belief, valued testing and had a better individual uptake rate. Uptake rates were reduced with midwives who were indifferent. However, midwives who had limited knowledge or midwives, who limited discussion with the woman, also had a higher uptake rate. A degree of coercion was suspected from the midwife, especially if the women were from an ethnic minority. Sherr et al (1998) and Johanson et al (2000) also suspected a degree of coercion with testing but this is counterbalanced by a more benevolent stance with the influence, motivator and power of professional recommendation” to test and testing accepted as a normal event in pregnancy (De Zulueta & Boulton 2007).

2.2.3.10 Opt Out Testing: Improved Rates of Testing

The majority of maternity units have introduced an opt-out service (Blott et al 1999). This replaced the previous opt-in service whereby women actively choosing to accept the offer and the recommendation of HIV testing in pregnancy. This “replacement” is in line with De Cock & Johnson’s (1998) expert conclusion and Simpson et al’s (1998a) study. The majority of women in the opt-out program now test for HIV with an uptake rate of 96% recorded in most centres (HPA Report 2011). However, other issues need to be explored around choice and consent, simply women have little option or choice with the opt-out testing service. Perhaps they feel they must comply or are not empowered to decline (Kennedy 2003). This suggests issues of professional power that is perhaps detrimental to informed choice and consent (Kass et al 2000).
Women may test without valid consent and I discovered five women from my study that had not consented to HIV testing within the opt-out programme (Lingen-Stallard 2006). Normalisation of the HIV test has probably now led to women simply accepting it as another test. Opt-out testing reduces time, explanation and the emotional input for a busy midwife. Perhaps even maternal and midwife’s apathy is now the motivator to test. Opt-out testing allows limited pre-test information as the HIV test becomes a normal event (Lingen-Stallard 2006). This may have negative impact should the test come back positive. This strongly suggests pre-test information is the key to exploring the testing process with all women, but specifically if there is suspicion the test may prove positive.

Written HIV test information is now incorporated in general blood test leaflets with less specific detail than when the HIV test information leaflet was independent and more detailed previously (Kennedy 2003). The denial of information may be health beneficial in the long term as women simply test. A midwife discussing HIV testing issues fully, may empower women to decline testing, but this would reduce the uptake rate which in turn could decrease the health benefits of testing. This would be problematic to targets and public health policy. Childbearing and HIV testing is problematic, pregnant women are a specifically captured group and are treated differently, when compared to non-pregnant individuals testing for HIV, with their own specific needs. What is accepted is that a positive HIV test result is a life changing event for the individual diagnosed in pregnancy (Kennedy 2003; NAM 2008, 2011).

2.2.3.11 Evolution of Antenatal HIV Testing Practice

Antenatal HIV testing practice has evolved without robust evidence. Testing commenced in 1985 with full pre-test counselling and referral to a third party. In 1990, testing was offered by midwives but targeted individuals at risk with pre-test information (selective screening). In 1994, testing was offered to all pregnant women (universal testing) in a managed opt-in antenatal screening program (DOH 1994, 1996), and changed to active recommendation of the test by midwives in 1999 (DOH 1999). In 1998, the HIV test was not seen as special or distinct and became “normalised” (De Cock & Johnson 1998). Therefore women had to actively withdraw from antenatal
screening with an opt-out screening programme and endorsed by clinical experts (De Cock & Johnson 1998; Blott et al 1998; Simpson et al 1999). Antenatal HIV testing rates have increased with each development (Kennedy 2003) and Kennedy (2003) defends these changes and states old practices needed to be abandoned to increase the HIV uptake rate. However, since the introduction of opt-out antenatal testing, research into HIV testing issues has noticeably declined despite more women being tested and diagnosed in pregnancy.

2.2.3.12 Troublesome: Women’s Personal Risk Identification

Personal risk identification is problematic for many women (Mercy et al 1996; Meadows et al 1994a, 1994b) as they do not accurately perceive their personal risk of HIV infection. They often maintain they are monogamous and in a stable relationship which they believe to be protective (Gibb et al 1998). Many new HIV infections are from long term partners (NAM 2011) which may confirm that monogamy and fidelity is often difficult to maintain in a relationship. Sexual fidelity is often tested during pregnancy and in a relationship (Kennedy 2003) with increased risk of infection as the numbers infected with HIV grow and opportunity for illicit sexual liaisons increases especially in urban cities. Condom use effectively reduces transmission, but abandonment is common even in relationships of short duration (NAM 2008). Women may state that they are married or in a long term relationships and therefore decline the offered HIV test (Conaty et al 2005). Personal risk is perceived as small with relevance of the test questioned. Testing was often perceived not for personal risk but “a routine” with other antenatal test or tested accepted as a “Job lot” (De Zulueta & Boulton 2007).

2.2.3.13 Women’s Support for HIV Testing

Larson et al’s (1990) questionnaire survey of 198 Swedish women demonstrates that 99.3% of women support HIV testing in pregnancy. A notable weakness was the overreliance on agree or disagree responses and the questions, at times, seem leading and limited in this aspect. Also the women who were all HIV negative, had high levels
of knowledge and were also encouraged to be tested by the Swedish government, for the health benefits.

Meadows et al’s (1993a) survey explored the views of 318 women in a hospital antenatal clinic. Women were supportive of HIV testing but did not identify themselves at risk of HIV and questioned the relevance. Meadows et al (1993b) later published a commentary article of the survey findings to explore the issues further. Data was then reanalysed from the original 1993 study to predict which women choose HIV testing in pregnancy (Meadows et al 1993c). The findings suggest women supported testing but did not always test as it was not relevant to their personal circumstances or risk. Meadows et al’s (1994a) retrospective study again explored why women choose to test for HIV and the findings were similar. Meadows et al (1994b) wrote a commentary on this later study and concluded that women need to have their personal risk explored at the pre-test discussion to encourage testing. These studies were limited to a survey or a retrospective research method, but the findings gives insight in to how women view personal risk, support and accept or reject the test. Opt-out testing has now probably reduced the opportunity of rejection with the test. Duffy et al (1998a, 1998b) were two prospective surveys, that demonstrated women supported HIV testing in pregnancy. Both were limited with the size of the samples and little depth with questioning and reliant on agree or disagree answers with minimal exploration. Support for testing is not disputed on the evidence but they both fail to fully explore the reason for this support.

Boyd et al’s (1999a) survey of 29 women has greater depth when questioning participant’s, who definitively supported HIV testing in pregnancy, but they also believed their personal risk of HIV was low and questioned whether HIV testing was personally relevant. Boyd et al’s (1999b) second survey examined 10 midwives uptake rate after offering testing to 2727 women; they claim they measured the acceptability of testing, but this is questionable as it did not explore motivation or maternal choice and must be treated with caution.

Stevens et al’s (1989) small survey of 26 negative women, found women supported the test process but noted maternal anxiety was mildly elevated whilst waiting for the HIV result but anxiety subsided if negative. However, all women were negative and this
reduction in anxiety was to be expected. This survey method is limited by the questioning as whilst anxiety is questioned any further exploration is minimal.

Baxter & Bennett’s (2000) qualitative study interviewed 12 women and found that women, whilst supportive of HIV testing, liked to be given information and importantly participants stated when given more information, this encouraged them to test. The interview was limited to a small number of set questions and allowed very little discussion outside of these specific issues; importantly it asked women face-to-face about their support and uptake of testing and linked this support to increase in information. My survey (Lingen-Stallard 2006) questioned 366 women with a return rate of 144 responses ascertained that women supported HIV testing for the health benefits but required in-depth pre-test information. However, women’s support for testing was limited to one question.

2.2.3.14 Ethnic Differences in Support or Uptake Rates

Studies exploring HIV testing uptake with ethnic background have mixed results. For example, Sherr et al (1998) surveyed 6 maternity units in London found no significant difference. Jones (2004) examined 2138 antenatal testing audit forms in one London unit and found 328 (15%) declined HIV testing and found a higher incidence with black women declining the test(20%), citing cultural or religious reasons on the forms. Conaty et al’s (2005) audit of the uptake rates of 2710 women in three London maternity units and of the 15%, who declined, 38% of this group had previously tested. Sub-Saharan women were at no greater risk of declining the test than women from other regions. Southgate et al (2008) retrospectively reviewed antenatal testing data in a unit outside London. Of the 1586 women tested, 8 new infections were identified, 6 were women of black origin. High risk ethnic minority women did not decline screening, and whilst not significant only 8.2% declined testing when compared to 9.8 % white or Asian women who declined. As the number of black women who tested positive rose, this perhaps would have strengthened midwives determination to target this group. These findings suggest that women with the highest level of HIV do test and then go on to make up a significant number of new HIV infections diagnosed in the UK.
2.2.4 SECTION FOUR-THE POSITIVE WOMAN’S EXPERIENCE

This section explores and critiques the literature relating to women’s testing and care experience with a positive result; other relevant testing positive experiences are also drawn from the literature. Due to the study’s findings the African women’s experience of HIV is included in section five of this chapter (see 2.2.5).

2.2.4.1 Women’s Experience of Testing HIV Positive in an Antenatal Screening Program

Simpson and Forsyth (2007) examined women’s experience of an HIV diagnosis in pregnancy after the introduction of state mandated HIV testing in pregnancy in Connecticut, USA. This study is an evaluation of women’s reactions to the Connecticut Public Act 99-2, which established mandatory HIV testing for pregnant women. The women were subjected to an enforced HIV testing regime, however the authors do explore the traumatic effect of a positive result for the participants. Eleven women agreed to an in-depth interview which focussed on issues relating to the law around testing. Women shared their personal perspectives regarding the benefits and adverse outcomes of HIV testing for themselves, their children, and public health. They describe the shock and disbelief, the emotional distress, the fear of stigma and effects on their partner and family. Each woman recalled her initial response to the mandatory law, to her HIV diagnosis, to the challenge to her self-identity and described the adjustments she made as she tried to regain normality after testing positive. There was agreement by all the participants that the law was of overriding and significant benefit. These women were compliant to this testing law in pregnancy and had no choice. Whilst it is presumed to be a good law for health by these women, the freedom to reject testing is removed (Kass 2000) and formal consent is no longer valid; fetal rights supplanting maternal rights. This study demonstrates the distress but also validates enforced testing which is of great concern.
An important **UK paper**: Kelly et al.’s (2012) prospective qualitative study explored antenatal HIV diagnosis from the pregnant woman’s perspective with antenatal testing in Northern Ireland. The study is small with 4 participants drawn from a larger study (Kelly et al 2011) and included diverse backgrounds from Northern Ireland, Eastern European, Asia and one participant black African. Multiple interviews were stated as undertaken during pregnancy and after the infant’s birth. Factually; this was two interviews, one in pregnancy and one post birth. The philosophical framework was informed by interpretive sociology and its concern with social construction of consciousness and how individuals understand and make sense of their lives. Thematic analysis was supported by a computer package after initial coding by the team. This study explored the emotional struggle as women create continuity in their lives. HIV disrupted health, relationships and social identity for the women. The initial contact to return for the result raised suspicion for some women. The diagnosis created chaos, a fear of dying and extra vigilance with health and threatened their significant relationships. Suicide was contemplated but tempered by the pregnancy and women were shocked if their partner tested negative. The women were in another world separated from normal and they tried to represent themselves as “good people” and tried to distance themselves from the associations of HIV. The pregnancy was a focus to live and fight for and the primary concern was the baby and the possibility of a sick baby. The HIV diagnosis was traumatic but the baby became a metaphor for hope and orientation toward the future with motherhood which became their liveable future. The study draws on Becker’s theory of disruption and the core concept of embodied distress. The term *disruption* in the study title is perhaps understated, as women reported traumatic events more akin to a major derailment of their lives but the essence of this testing experience was trauma and chaos. All the participants were newly diagnosed HIV positive in pregnancy and were in a vulnerable position. Consent was obtained and the ethical standards were high. Repeating the interviews can change the narrative as later interviews may be more reflective and evolved over time and the horizon changed (Gadamer 1989). However, the first interview was more a conversation which shaped the later semi-structured questioning. The researchers may have acted as a support mechanism and the women may have found this valuable and interviews cathartic. This study brings clarity to antenatal HIV testing and a positive result and is a valuable addition to the literature. It is not my intention to compare my study with Kelly et al (2012). Many of the findings resonate independently with my study findings. The
differences and similarities are evident but also the perspective and approach and importantly the women are different. A significant difference is that I used a hermeneutic phenomenological approach as I seek the phenomenon of the testing positive experience. This study is relevant but, due to publication timing, did not inform my study.

2.2.4.2 Childbearing and Care Experiences with HIV

Njie-Carr et al’s (2012) qualitative study examined decisions about childbearing and the experiences and decisions about HIV testing, status disclosure, adhering to treatment, and specific experiences in violent intimate relationships. Semi structured interviews were used with 23 HIV-positive African-American and African-Caribbean childbearing women. Positive experiences of care were reported which was helpful as they adjusted to a life with HIV and personal resilience were often gained from faith and prayer. Most important to the women were the perceived benefits of protecting the health of their baby as they had information that empowered and enable them to focus on infant wellbeing. Transference of the finding is probable in a similar setting and the data was rich, with themes drawn from the narrative which are pertinent and eloquently tell of women’s experience living with HIV. The complexities with HIV and a woman of black origin are expertly revealed with the powerful and meaningful narrative. Whilst all were HIV positive, I am unsure if participant were diagnosed in pregnancy or some of childbearing age and diagnosed but planned a pregnancy. However, this study reveals the great difficulties of childbearing and vulnerability whilst of original African decent and living with HIV.

Kelly et al’s (2013) recent study explored HIV positive women’s experience of maternity care in Northern Ireland which focused on midwives interactions with women when accessing maternity care. Participants were drawn from same sample as Kelly et al (2011) study with 10 HIV positive women undertaking 22 interviews. They found women needed to have normalcy in pregnancy and this was best provided by midwives who were knowledgeable and empathetic. The fear of pervasive stigma threatened this experience and a powerful toxic force that was distressing and damaging. This
qualitative paper eloquently explores how women are reliant on midwives for support and understanding. If perception of the interface with the midwife was a good, the experience was meaningful for women. The attainment of normalcy was important focus for women and supportive midwives were vital. The narrative is powerful and expertly gives meaning. Most women had been diagnosed HIV positive before access to the maternity services but were apprehensive when seeking care.

2.2.4.3 Pregnancy and Motherhood with HIV

Sandelowski & Barroso’s (2003) metasummary and metasynthesis of 56 qualitative HIV studies involving HIV positive women explored the specific theme of motherhood with the focus on “HIV positive mothering”. The inclusion of the qualitative papers in the review was any women who was HIV positive and mothering. This metasynthesis included women who were diagnosed in pregnancy but included other HIV testing programs such as HIV drug testing programs. It does not focus or examine antenatal testing and for some women in the included papers they were aware of the diagnosis before contemplating pregnancy, others were tested some time after and for others this is not explicit. The findings from the studies included in the metasynthesis are of interest and found women fought hard to protect their child from HIV and to preserve their own identities. Motherhood was affected with an over protection of the infant. Whilst these finding are not doubted, they only seem the “tip of the iceberg” and much is left unexplored. The author accepts they were 3 times removed from the women’s experience which further justifies a drilling down of the issues raised by exploring the data from the original sources. However, whilst motherhood is of interest due to evident themes, it is not the focus of this study or thesis to explore mothering per se as this is a separate but complimentary issue. The authors produced a previous paper explaining the meta synthesis process titled Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women (2003), however whilst useful in it explanation of the process, the data is not fully explored or available for detailed analysis.

Sanders’ (2008) qualitative phenomenological study explored pregnancy and mothering. All participants were diagnosed HIV positive sometime before pregnancy residing in New York. A purposive sample of 9 women all been diagnosed between 10 and 21
years prior to interview which is likely to have had some effect on recall. Common themes were apparent and were vividly explained by women, so I can reasonably infer that emotional recall was strong. They recalled the immediate emotional distress at the HIV diagnosis; a number had been tested in a previous research study and talked of the devastation they felt at finding this out by this method. Feeling stigmatized by the infection and all the women reported at least one poor experience with care providers and stating feelings of; marginalisation, their privacy being invaded, vulnerability and of being less of a person. Confidentiality was a concern for women with care providers. However, all reported positive care experiences with kind, caring and supportive care. Motherhood was an issue, 8 of the 9 women were mothers and 1 was currently pregnant. Severn of the 9 women had temporarily lost parental rights due to illicit drug use or addiction. This drug use had a detrimental effect on family relationships, with one women reporting she still had difficulties with her son of 21. Drug usage had a major impact on the mothering relationship and is difficult to disentangle this issue from the HIV diagnosis in this study. However, it was reported that motherhood encouraged them to try drug recovery and not the diagnosis of HIV. Drug use and its complications are unlikely to be the main issue in HIV transmission in the UK as African women are infected sexually and rates of drug use are currently low. Levels of transmission of HIV by drug use are generally low in UK (NAM 2010). Motherhood had a positive impact on all their lives. The author concluded that the experience of pregnancy for women with HIV is complex, with isolation, extreme anxiety and distrust. Hope for the women came from the normality of pregnancy and motherhood. Phenomenology was an appropriate tool in this study and the powerful narrative around the women’s experience of pregnancy and HIV diagnosis captures the life experience of mothering and expertly explored themes, emotions, concerns and issues that women with HIV face in pregnancy in the USA.

Ingram & Hutchinson (1999) specifically explored the issue of defensive mothering and stigma and demonstrate how stigma pervades the lives of HIV positive mothers and children and interviewed in-depth 18 mothers following an HIV diagnosis in USA, some after antenatal screening and the psychological aspects of HIV mothering were examined. Information from this grounded theory study on HIV-positive mothers was used to illustrate Goffman's theory of stigma and its effect on mothers. The research
states this study is an example of "emergent fit" where existent theory is discovered by the interpretive researchers to fit much of the data. The concern here is how much more data was discarded with the research process. Defensive mothering was the basic social psychological process that was used in response to their diagnosis and the inherent stigma. Their defensive mothering posture gave a degree of psychological protection but involved tiring mental processes that included three sub-processes: preventing the spread of HIV to the child, preparing the children for a future without her and protecting themselves through maintaining thought control. The mothers put great value on being perceived as normal but acknowledged that normality was now lost for them because of the stigma of HIV infection. They tried to pass as normal by managing information and manipulating their environment. They attempted to cover up their illness by lying and pretending to others. The mother felt disempowered by stigma and the author states health care professionals can provide quality, client-centred care when they truly understand the power that stigma holds over these women as mothers and the strategies used that effectively mitigate stigma. How stigma envelope a mother is powerfully explored as mothers attempt to balance their immediate lives overshadowed by stigma. Whilst some of these women were diagnosed prior to pregnancy a number were diagnosed in pregnancy. This study powerfully explored the issues of stigma and findings demonstrate its destructive power as it pervades women’s mental health and wellbeing. The paper clearly shows the strain of mothering when infected with HIV.

2.2.4.4 Impact of an HIV Diagnosis with Reproductive Intentions

Ingram & Hutchison’s (2000) second qualitative study specifically examined the reproductive choices and also the mothering experiences of women infected with HIV. Again using grounded theory, twenty HIV positive women participated in 31 in-depth interviews in the USA. A communication pattern known in the psychiatric literature as a double bind was discovered to be a basic social psychological problem that affected the women's experiences with subsequent reproduction and mothering. Mothers felt stigmatised, unworthy and this reflected on their choices and ability to reproduce or to mother effectively. An understanding of this power and influence of these double binds permits health care professionals to plan women centred care programmes and to
individualise care specifically for HIV-positive women so they are informed and supported with reproductive choices and mothering skills. The rich storytelling data has a powerful impact in that women were often at the mercy of their own belief systems when trying to be effective mothers with HIV infection which often affects their reproduction choices after diagnosis.

Kirshenbaum et al’s (2004) qualitative study examined pregnancy decision making after an HIV diagnosis among 56 HIV-positive women, in 4 U.S. cities. A number of focus groups examined individual, medical, biological, social and cultural themes and divided the focus groups into past pregnancy experiences and future pregnancy intentions. Regardless of women's pregnancy experiences or intentions, pregnancy decision making themes emerged that included: the perceived risk of vertical transmission (which was overestimated in many groups), the beliefs and views about vertical transmission, reducing risk, the desire for motherhood, the real stigma of infection, their own religious beliefs, attitudes of partners to HIV infection and health care providers attitudes. They explored how long the women could be well and if the child was to become infected, how long the child would live. Most women who already had children did not want further children after diagnosis stating the vertical transmission risk was too great which was again overestimated. Those who desired or later became pregnant after their HIV diagnosis seemed more confident of treatment to reduce vertical transmission. The author concluded that the factors that influence pregnancy decision-making among HIV positive women need to be examined and that HIV positive women of childbearing age may benefit from counselling that is sensitive to women's pregnancy decisions when HIV positive. Whilst these women were already diagnosed HIV positive, those with no children sought to minimise transmission risk and gain motherhood, those with children overestimated transmission risk and the desire for pregnancy was reduced. This study again demonstrates the negative impact of an HIV diagnosis around future pregnancy decisions. It would be of interest to repeat this study in the UK and to compare findings. The method of inquiry enables the reader to conceptualise the experience when exploring this paper. Further it enables the reader to understand the mental anguish of reproduction after diagnosis.

Kelly et al’s (2011) study focused on reproductive decision-making and HIV transmission risk and examined the negotiation of risk in sexual relationships in
sero-discordant couples. Eighteen in-depth interviews were conducted with 10 individuals in Northern Ireland during 2008-2009. They used a sociological methodological approach, and found that physical pleasure, love, commitment and a desire to conceive without medical interventions. A dislike of condoms shaped individuals' sense of biological risk. In addition, if a partner was not infected the added security of an undetectable viral load significantly impacted upon women's and, especially, men's decisions to have unprotected sex in order to conceive. What is of concern is that the women were involved with two studies, but I am unable to ascertain if they occurred consecutive or simultaneously. The presumption is that they occurred simultaneously due to the timing of interviews in the second study. Kelly et al (2012) acknowledges that most women from the first study declined to be involved with the second study.

2.2.4.5 The Psychological Impact of HIV Diagnosis in the UK and Elsewhere

This thesis and the focus of midwifery study remains the exploration of “the phenomenon, essence and meaning of the experiences.” Specifically; the women’s antenatal experience with receiving a positive HIV result in pregnancy within the UK (see 1.1). Psychological issues following an HIV diagnosis, whilst of interest, were not the remit of this study. Whilst the lack of psychological literature may limit the review, consideration of measurements of psychological well-being would have deviated from the study focus. However, consideration is given to the following important systematic review and critique.

Sherr et al (2011) systematically reviewed a large number of papers around the psychological impact of HIV diagnosis and the majority reported shock, anxiety, distress and post traumatic stress disorder. This review focused and specifically examined post trauma growth (PTG) and resilience versus post traumatic shock disorder (PTSD). They retrieved 206 papers with HIV and post traumatic stress disorder. Importantly, the review identified a further 13 papers which examined HIV and post trauma growth. They argued that an HIV diagnosis can cause PTSD and this was prevalent in those diagnosed. This included symptoms of anxiety, palpitations and
flashbacks. Women with HIV as a sub-group were more affected with rates of between 5%-74% in all papers when compared to a 7% background rate of PTSD in the general population. Some of these women would have been diagnosed in pregnancy but this cannot be interpreted from the findings as the review was not focused on positive HIV test results from the perspective of pregnant women. Papers report; shock, anxiety, distress and post traumatic stress disorder were all frequently encountered. This review argued that interventions to reduce PTSD and distress were available but under reported and that only 33 papers did so and only 3 out of the 13 papers showed psychological interventions for growth. These interventions included HIV education, coping techniques and support groups to aid growth and resilience. They argued that the evidence to promote growth showed promise but was inadequate. Concern was apparent as there was no harmonised measuring tool to measure PTSD or PTG in the psychological literature. This review revealed a large number of papers on the psychological impact of HIV. Whilst this was a human experience most psychological papers were of an HIV diagnosis affecting gay men. His critique is of concern that the psychological reporting of trauma and distress was strong but interventions were not utilised to improved or promote psychological growth or resilience. However, I am reliant on Sherr et al (2011) assessment with this critique and synthesis.

Catalan et al (2000) reviewed mental health referrals from all one centre in London from a cohort of HIV infected patients after a recent diagnosis and the common finding was receiving a HIV diagnosis was traumatic with poor psychological adjustment, denial with feelings of vulnerability, the fear of disclosure to others, isolation and depression which whilst reactive at first become more problematic. These referrals were for the more problematic cases and the author accepts that many cases are probably underreported. Stevens & Hildebrandt (2006) assessed psychological wellbeing and examined simply the words and metaphors of women recently diagnosed HIV positive in an HIV clinic (non pregnant) and they reported similar findings with vulnerability, isolation and depression being the main words used by women.
2.2.4.6 Experience of Testing HIV Positive in Non Pregnant Testing Programs

Schrooten et al’s (2001) questionnaire surveyed 1366 cases of individuals receiving a positive HIV result in Europe. Fifty-four percent of respondents felt that the experience of being informed was poor and the support inadequate. The shock and distress of receiving a positive result threatened confidentiality and increased stigma. Whilst the sample was large and mostly confined to gay men or drug users it failed to explore this experience in detail due to the confinements of the survey method and superficial questioning techniques (Polit et al 2001). Lewis (1999) interviewed 25 gay men’s individual experiences of receiving a positive HIV result and found high levels of distress and poor support. The strength of this study was exploring this distressing experience very well, however whilst this was a human experience, it is confined to men’s experiences.

Anderson et al (2010) explored the initial responses to a positive diagnosis in Caribbean people in London and found that the 25 individuals were shocked and distressed when informed; they lost their past life and their future life was threatened. This in-depth interview study only examined the initial response to the news but this focus was pertinent and powerfully highlights human distress following a positive result and importantly examined a differing ethnicity in London. Male and female participants were included but both sexes reported similar findings.

There are relatively few studies focused on the experience of having tested positive for HIV from the perspective of pregnant women in an antenatal setting. Kelly et al’s (2012) recent paper used a human science approach to explore the lived experience. A significant difference is that I used a hermeneutic phenomenological approach which focused on the phenomena and essence and meaning of testing HIV positive in pregnancy to gain a different perspective with this experience.
2.2.5 SECTION FIVE: THE AFRICAN EXPERIENCE OF HIV AND HIV TESTING

Whilst the original literature search was limited to positive HIV testing in a high resource setting, I became increasingly aware that the women who responded to my study were African in origin and to ignore this aspect would be remiss. Importantly, women respondents reported some strong cultural and beliefs around HIV and stigma with testing positive. These influences were reported as imported from the women’s home countries prior to antenatal testing in the UK. This needed further investigation of the African literature with these aspects and its importance became evident from the findings not only about testing, but cultural beliefs around HIV causing death from the country of origin. Whilst this will be explored in the appropriate findings section, women in this study often equated HIV infection with stigma, sexual deviancy and prostitution. Importantly, they believed the child would be infected and HIV infection was a death sentence both for them and their child. It was new information, given later to the women about HIV in a high resource setting, which challenged these beliefs and concepts. I have not integrated this section into the main body of the literature review as it merits a defined separate section due to all my study participants’ stated African origin and my study findings with imported beliefs from the country of origin around stigma and past experience with HIV. Also this African section followed the true development of this thesis and importantly demonstrates my reflectivity and how the findings impacted and required an additional literature review.

2.2.5.1 The Sub-Saharan HIV Perspective

Sub-Saharan Africa is unique as HIV is highly prevalent and death is a common outcome as symptoms worsen and develop into AIDS in the absence of drug treatment (UNAID Report 2010). This outcome is rare in the UK due to access to effective therapies (NAM 2011). Death from HIV is devastating in African society. Jewkes et al (2009) maintains HIV transmission and access to HIV treatment is linked to poverty, inequality, lack of strategic leadership, failing statehood, poor health, male dominance, role of religion, physical and sexual violence including high levels of rape and sexual practices that risk the young. All these factors individually and collectively have been implicated in the endemic spread of HIV. Women have a lifetime risk of rape of 1 in 3
in South Africa (Jewkes et al 2009). Sex has often been viewed as a commodity and traded to improve social standing (Jewkes et al 2009). Prostitution and sex working are linked to high incidences of HIV (Jewkes et al 2009; UNAID Report 2010). Reluctance (and poor availability) to use condoms to reduce risk exacerbates the high levels of HIV in the population (Kalichman & Simbayi 2003). Little access to effective drug treatment means viral loads in infected individuals remains high and therefore the risk of infection to others also is increased. These factors fuel the belief systems of HIV infection held by sub-Saharan Africans. Care must be taken not to treat all sub-Saharan African states the same: Nigeria and South Africa’s political systems are different and how HIV is tested and managed varies by country. Nigeria is the most populated state in Africa and has greater social taboos with stigma and dominance of religion (Winskell et al 2011). Until recently, South Africa’s government’s policy was to “deny HIV” refusing to acknowledge the presence of HIV as a causation of AIDS (Jewkes et al 2009). This changed with a change of leadership and South Africa now administers medication to pregnant women with HIV and encourages screening. Zimbabwe endorses HIV testing and treatment but due to economic difficulties it is thought to be failing to meet its testing targets in pregnancy, as quality information is currently lacking (UNAID Report 2010).

2.2.5.2 Attitudes and Beliefs with HIV, AIDS and HIV Testing: Stigma

Kalichman & Simbayi (2003) surveyed 224 men and 276 women in a black South African township from multiple venues that ranged from hospitals, taxi ranks and street corners; 98% were of black origin. They examined attitudes to HIV, AIDS, stigma and HIV testing. They divided the group into those that had tested and those that had not. They found 47% had tested previously for HIV and 9% were positive. The positive rate was 10.7% in the general population in the Cape, so the sample represented the population characteristics with the number identified as HIV positive. This previously tested group held far more favourable attitudes and fewer stigmas. However, those that had not tested showed marked negative attitudes describing AIDS shameful and disapproving of infected individuals. They also discriminated against those that contemplated HIV testing which is of concern as it acts as a barrier to test in future. However, this group were less likely to use condoms and took greater personal risk, for
example 10% of all participants had traded sex in both groups. The researchers concluded that education was required to challenge negative attitudes. This study was large and sampled from different townships around the Southern Cape. However, the questions in the survey are direct, simple to understand if perhaps leading, asking “do you think AIDS is shameful” or “people with AIDS cursed”. The response is either yes or no. What may have been helpful if a number of these individuals who held negative views and beliefs had been interviewed in-depth to ascertain why they believed it to be so shameful? However, the study demonstrated that the population in this study did markedly stigmatise and held negative views of HIV. This study strongly confirms the view that HIV was viewed as a stigmatising infection in South African Cape.

De Beer et al (2012) also undertook a two part survey amongst University Students in Namibia. Half (n = 2790/5568) of the university students and 45% (n = 2807/6302) of the Polytechnic students participated in the knowledge and attitudes surveys. HIV/AIDS knowledge was reasonable, except for misperceptions about transmission. Awareness of personal HIV status and personal risks of transmission was low. The second part of the study was to assess HIV prevalence. 55% (n = 3055/5568) of university students and 58% (n = 3680/6302) of the polytechnic students participated in the HIV prevalence survey; 54 (1.8%) university students and 103 (2.8%) polytechnic students tested HIV positive. The attitudes, whilst variable were generally good but one must question if this was in part due to the educational attainments and wealth of the students. The author does not state the survey findings could be generalised across the country as a whole which suggest the finding are specific to this knowledgeable group of students.

Winskell et al (2011) compared stigma which they stated arises from moralistic value judgements attached to people living with HIV. They maintain little is known about cross-national variation in symbolic stigma in Africa. The purpose of the study was to inform stigma reduction strategies and compared social representations of HIV in six African countries with estimated adult HIV prevalence rates ranging from 1 to 33%. The study used a unique data source, namely a stratified random sample (n = 586, 5%) from 11,354 creative ideas contributed from six countries to a continent-wide HIV-related scriptwriting contest held between February and April 2005. Whilst unique, this suggests that the contributors were fairly well educated and may not represent the views
held by the majority of people from these countries and the findings skewed towards the educated elite. The narratives were written by males and females, equal number, aged 10-24 in from urban and rural areas of Swaziland, Namibia, Kenya, South-East Nigeria, Burkina Faso and Senegal. They combined three analytical approaches: descriptive statistics on certain quantifiable characteristics of the narratives such as repetitive or negative terms used, thematic analysis of the narrative as a whole, and a narrative-based approach trying to make sense of the written narrative. The association of HIV with outsiders, such as not of the same nation ("othering") was strongly represented and they noted a preoccupation with the circumstances of HIV infection, such as sexual acts which were more common in lower prevalence countries but vary substantially in moralising tone depending on the socio-cultural context. The highest proportion both of moralising narratives and of narratives with pessimistic outcomes come from South-East Nigeria and, to a lesser extent, from Kenya, countries with prevalence levels of moralising at 3.9% and 6.1% respectively and have a notable evangelical Christian influence. The findings provide a rare cross-cultural overview of symbolic stigma, and they found negative impacts from both public health and human rights perspectives. They identified country specific needs, and point to strategies for future educational programming. Social representations from the highest prevalence countries, Swaziland and Namibia, and from lower prevalence Burkina Faso offer potential models for the positive framing of HIV in ways that serve to increase social proximity to those infected and counteract symbolic stigma. This study confirms that varying degrees of stigma exist even from an educated population with written narrative. The learning and exchange of ideas from one nation to another is of interest in combating the prevalence of stigma. This study gave a Sub-Saharan African overview of the factors influencing stigma, such as the role of religion and positive exposure to others with HIV.

2.2.5.3 Sub-Saharan Antenatal HIV Testing

Antenatal testing is encouraged in South Africa after a change of leadership and Government. Geddes et al’s (2011) study examines follow up from a maternal positive HIV result. Of 5303 women; 4891 (92%) had an HIV test, and 703 (14%) were HIV positive. The HIV positive women were subsequently followed up: 653 (93%) received antiretroviral therapy or prophylaxis, including 424 (60%) who received triple therapy.
Of the 699 live babies delivered, 661 (94%) received prophylaxis. At 6 weeks 571 babies (82%) were brought back for HIV testing and 16 (2.8%) were positive. After 6 months, only 150 women (21%) were receiving follow-up care at the adult HIV clinic. They propose that by testing and giving drug therapy only 2.8% (n=16) infants were vertically infected which corresponds well with findings in Europe (NAM 2011). They acknowledge concern that many women (79%) were later lost to follow up and therefore fell out of treatment which must have impacted on data. They proposed liberal testing and treatment in South Africa. This study confirms that antenatal testing and treatment reduces vertical transmission rates but also demonstrated women are lost to health maintaining measures. These untreated women are likely to go on to breast feed and therefore expose their infants to an increased transmission risk (UNAID Report 2010). Formula feeding is generally not an option economically or due to lack of availability. Whilst systematic reviews have demonstrated the benefits of antenatal testing, the South African government has only recently moved its position to one of testing and treatment and has its own very recent low resource setting research which is pertinent to them as they can prove to their own population the health benefits. What is alarming is that so many women fall out of treatment. Clearly more research is needed into the cause of this. What these African studies demonstrate is that stigma remains a major issue in the African population and that these negative beliefs are probably held by women and later transported to the UK. Antenatal HIV testing and treatment in a low resource setting can work in Africa and is beneficial to infants, but women themselves may not receive the health benefit if lost to follow up.

2.2.5.4 Little Control with Sexual Practice

Orubuloye (1993) noted African women's control over their sexual relations with husbands or other stable partners in situations where there is a high risk of sexually transmitted diseases (STDs) and HIV/ AIDS was limited. Orubuloye (1993) examined other research findings in sub-Saharan Africa, and then reported on a study carried out by survey among the Yoruba people in south western Nigeria. The study focused on limiting STD transmission and subsequently to limit HIV transmission. The mixed methodology and recruitment strategy is unclear and confuses the issues of HIV and other sexual infection. HIV is not explicit but sexual practice are which may have had
some impact as if they knew or suspected their partner was likely to have HIV, Yoruba women were reluctant to engage in sexual practices that risked infection. It is noted that women had an ability to refuse sexual relations for a limited time only; this ability may be even more limited in the case of AIDS because of its longer duration. This study demonstrated women had very little choice with sexual activity even if at risk. Jewkes et al (2009) maintains that little has changed for women in Africa and they are subject to the sexual demands of men with little control.

2.2.5.5 Death and Dying: A Common Outcome

The individual mortality rates demonstrate that AIDS is the common cause of death in sub-Saharan Africa. This is witnessed by a significant proportion of the African population as HIV prevalence rate vary between 4-33% in sub-Saharan Africa (UNAIDS Report 2010). Effective treatment is often unaffordable unless charity or government sourced. Therefore progression to AIDS and death is common (UNAIDS Report 2010). The wasting effects of AIDS are often seen as a sign of HIV infection and can lead to social isolation and stigma (UNAIDS Report 2010).

2.2.5.6 Disclosure to Others in Pregnancy- The South African Experience

Visser et al (2008) maintains that many South African HIV positive pregnant women do not disclose their HIV positive status to their partners, family and friends. This increased sexual transmission to partners and mother-to-child transmission through breastfeeding. This study explored recently diagnosed HIV positive pregnant women's reasons for disclosure and non-disclosure to various members of their social and family networks, as well as the consequences of their disclosure. Data were collected through open-ended questions as part of a short semi-structured interview with 293 recently diagnosed HIV positive pregnant women recruited from antenatal clinics in two townships in Tshwane, South Africa. A simple content analysis of responses showed that women weighed fear of abandonment and discrimination against their desire to raise risk awareness and their need for support. Partners when informed, most often responded to disclosure with disbelief and shock, whereas parents, family and friends
frequently exhibited emotional distress, but were still supportive, as were other relatives and friends. The women subsequently experienced low levels of adverse consequences after final disclosure. The results aid our understanding of the complexity of pregnant women’s decisions to disclose to various members of their social networks and emphasize the need for continued support in this endeavour with disclosure.

This concludes the African experience in this subsection and the possible impact on women who participated in this study. Women in this study were sub-Saharan African women in origin. Many had come to the UK to reside and be with their partner and they came with cultural influences from their own country of origin. This review has explored some of the possible influences and beliefs respondents reported. Women in effect had a life world in Africa and transported this to the UK.

2.3 SUMMARY OF THE LITERATURE

The current literature on HIV issues is substantial, especially with drug regimes, interventions, treatments and care which will also affect pregnant women and their infants. There is a vast amount of literature around HIV standards, treatment and care in pregnancy, delivery and postpartum. Whilst this literature is important and provided context to my study, generally this body of literature is not pertinent to the aims of my study or the midwifery focus of antenatal HIV testing in pregnancy and specifically a women’s experience of a positive HIV result in pregnancy when tested for HIV in an antenatal screening program.

The quality of the existing research is variable and often subject to personal bias and opinion in relation to HIV testing. Antenatal HIV testing research has reduced since the introduction of universal testing and the introduction of opt-out screening. Women routinely test today, the experience does not seem to generate much interest and the impetus to explore this and a positive HIV result for women in pregnancy appears minimal with one small study by Kelly et al (2012). There is some strong qualitative literature around women’s mothering and reproductive choices after an HIV diagnosis, which is powerful in its analysis of women’s individual stories but whilst
complementary is not this thesis focus. The experience of receiving a positive HIV result is somewhat confined to the non-pregnant population which is insightful but fails to tell women’s story of HIV diagnosis in pregnancy.

Kennedy (2003) acknowledges that HIV literature is often focused on expert opinion or comment. Randomised controlled trials (RCTs) are highly valued in research, but RCTs have been mainly used around HIV drug use and treatment intervention strategies and rarely antenatal HIV testing. Even when randomisation with a control group is used in the one study by Simpson et al (1998a) about antenatal HIV testing, this paper makes a questionable conclusion that women are not concerned about receiving reduced information prior to HIV testing in pregnancy. The DOH has made a number of policy decisions on antenatal HIV testing but research evidence is fairly limited in the formulation of antenatal HIV testing policy. If Kennedy (2003) is correct, and this review supports Kennedy’s view, HIV management and HIV policy is often guided by expert opinion with a reliance on survey, observational, cross-sectional and retrospective study data and whilst adequate in many instances this is not the highest level of research evidence when assessed against Sackett et al’s (2000) hierarchy of evidence (Appendix 4). The level of evidence needs to be acknowledged in any testing policy or clinical guidance with the strengths and weaknesses of the evidence made explicit, however this is not seen in most instances when examining the current policies and guidance around antenatal testing. What is also clear from this review is that little research into the issues around antenatal HIV testing has been undertaken since the introduction of opt-out testing. There is often an over reliance on the survey method and this is marked for HIV testing issues and the quality of the testing experience is absent in many cases and this is an important facet. Some of the qualitative methods give an important insight into HIV and how living with HIV is problematic. The psychological literature whilst pertinent around the impact of a positive HIV test result has greater grounding in the gay man’s experience and whilst a human experience, is a different experience to a woman who tests in pregnancy. The African experience was enlightening as it gave an overview of the influences of this “life-world” as women who participated in this study move to the UK from sub-Saharan Africa and were later tested by a UK midwifery antenatal testing service.
2.4. CONCLUSION

Antenatal HIV testing is supported in the literature and with adequate pre-test information given to women. Information needs to be understandable and allow participants to give informed consent. Defining what constitutes an adequate level of information is difficult and relies on women being consulted. The HIV test should not just be offered but actively recommended as it is beneficial for maternal health and reduces vertical transmission. This active recommendation of the HIV test is applied to clinical practice today.

Midwives are appropriate practitioners to offer the test, there are no cost-effective alternatives and the literature suggests they are pivotal in increasing uptake rates; however, whether this is still valid in an opt-out program is questionable. One could argue that with opt-out testing programs, midwives have less of an impact on uptake rates as the onus is now on the women to actively refuse. What evidence is available with opt-out screening programmes is correctly concerned with gaining informed consent. Surveying and questioning the experience of a user of the service is a powerful tool and is in line with the NHS Plan and other developments in the NHS (DOH 2000, 2004b, 2004c) and Darzi’s (2008) vision for the NHS.

Healthcare professionals, to achieve an increase in the HIV testing rate, may use undue power and influence (Johanson et al 2000). Vertical transmission remains problematic and the undiagnosed (HPA Report 2011) must be reduced and aggressive antenatal HIV testing to protect the infant will achieve this (Kass 2000).

Values and behaviours are imposed on women when pregnant with a responsibility to protect the developing infant. This is probably a strong motivator to test. HIV testing may add additional pressure on vulnerable women who may have concerns around fetal health (Massiah 1993) but whilst the evidence is strong that testing protects the infant long-term it is often the mother who received inadequate testing information. The infant often takes precedent and is the focus and needs protection in pregnancy. Kass (2000) and Kass et al (2000) raised valid concerns that this protective focus is very unhelpful and coercive and calls for a more partnership approach with women contemplating HIV
testing, but this view, whilst if heartfelt, is limited to personal commentary. The ethical debate is ongoing about maternal responsibility in pregnancy and testing positive is one aspect that needs further exploration.

Women are under-represented in the UK HIV literature when compared to the gay men’s testing experience; more specifically African women’s valuable UK experience is often missing or inadequately researched and representation is minimal when exploring and reviewing the impact of an antenatal HIV diagnosis in the UK. There is limited awareness of the impact of a positive diagnosis on this specific community. The evidence is strong that stigma is problematic and damaging for positive women and motherhood is threatened and damaged (Sandelowski & Barroso 2003). Confidentiality is at risk and care provision a concern. The individual narrative and experience is often powerful at shaping change (Stein & Roberts 2011). The psychological literature gives insight with the issues that positive diagnosis brings. A traumatic human experience but with women often underrepresented. Sherr et al (2011) is critical of the support on offer and often centre on the damage but failing to explore ways to bring about a resolution.

A midwifery focus study of an antenatal HIV diagnosis was minimal until Kelly et al’s (2012) recent study. The research findings closely matched my study but the paradigm whilst naturalistic was not hermeneutic interpretative phenomenology in its approach. It was also drawn from a larger study that had a different focus on reproduction whilst HIV positive. Importantly, even with a small number of participants the findings added clarity with testing HIV positive in pregnancy. Many themes from the literature had resonance; essentially these studies did not match the aims or focus of my research and thesis. This was a midwifery focused study which explored women’s experience of an antenatal diagnosis of HIV in pregnancy when screening was offered by midwives in UK.
CHAPTER THREE: RESEARCH METHODOLOGY, METHOD & DESIGN

3.0 INTRODUCTION

This chapter is divided into three sections:

SECTION ONE;
I explore the theoretical principles and important influences underpinning the methodology of this study.

SECTION TWO;
I explore the research design and method chosen and its governance.

SECTION THREE;
I discuss the ethical considerations of this study.

I decided that I would use a qualitative design with a naturalistic paradigm that explored and interpreted the meaning of the real life or lived experience of testing HIV positive during pregnancy. This study specifically uses an interpretive approach and follows the Hermeneutic Phenomenological (Interpretative) European school of Martin Heidegger and specifically the later theoretical aspects and analysis developed by Max van Manen (1990). Other recent proponents of interpretive phenomenology will also be drawn upon. This aspect will be discussed in section one, with the theoretical underpinning of the study. Importantly I will also give a rationale as to why I have chosen an interpretive or hermeneutical phenomenological approach to explore the phenomena and discover meaning with the synthesis of the findings.
3.1 SECTION ONE: THE THEORETICAL PERSPECTIVE AND INFLUENCE ON METHODOLOGY

3.1.1 Introduction to Section One

This study required a qualitative approach with a naturalistic paradigm as the research explored the phenomenon of experience. The philosophy underpinning the study needs to be sympathetic to the study and its aims (Kvale 1984; Steen & Robert 2011). Phenomenology was chosen as the most appropriate underlying philosophy associated with the study. This section will explore the theoretical influences and the philosophical approach taken, which underpinned this study. This section is constrained by thesis requirements and cannot fully explore in-depth or analyse all aspects but it attempts to give an outline and flavour of the influences on the methodology chosen for the study.

3.1.2 The Naturalistic Paradigm

Steen & Roberts (2011) state that a paradigm is a belief, view or a school of thought which the researcher attempts to follow in the acquisition of knowledge. The researcher needs to consider the research paradigm with care by determining the type of knowledge that is to be acquired (Parahoo 1997). Essentially the key paradigms used in midwifery research are the positivist paradigm and the naturalistic paradigm (Steen & Roberts 2011). The positivist paradigm traditionally underpins the scientific approach with quantitative research as it assumes and maintains, reality is fixed and orderly which is objectively measured or studied often with experiments (Steen & Roberts 2011). This study used a qualitative approach and a naturalistic paradigm, as this paradigm maintains that there are multiple interpretations of reality. The goal was to understand how the individuals construct reality within their own context (Steen & Roberts 2011). Subjectivity is recognised and importantly is focused on human experience to understand from the perspective of the women, the meaning of her individual experience of testing HIV positive in pregnancy. In summary, the study was qualitative in approach, with a naturalistic paradigm and used the human science discipline of phenomenology to study
the phenomenon of interest, i.e. the experience of receiving a positive HIV result with antenatal testing.

### 3.1.3 Phenomenology

There are competing and complementary definitions of phenomenology. Heidegger (1962) states the term ‘phenomenon’ is derived from a Greek expression which signifies “to show itself” (Heidegger 1962 p 51) and explored the concept further as he states that “phenomenon” signifies “that which shows itself in itself” (Heidegger 1962 p 51). Phenomenology is a human science discipline and van Manen (1990 p185) boldly states “Phenomenology is the science of phenomena.” Van Manen (1990 p6) defines the concept further “hermeneutic phenomenology” as “a human science which studies persons.” And as “persons, we are incomparable, unclassifiable, uncountable, irreplaceable.” Therefore as “persons” we as human beings are unique. When following the interpretative school of phenomenology, it asks what is the nature and meaning of something and fundamentally explores the essence of meaning. This is underwritten by Merleau-Ponty (1962 pvii) who states “Phenomenology is the study of essence”. This study of essence and meaning is an important concept for this thesis and study as it explores the lived experience of women, who undergo a life changing experience but are essentially unique and have differing interpretations of the phenomenon.

Importantly as a philosophy, phenomenology has developed a number of methodological approaches and interpretations to explore phenomena and reveal its meaning. There is ongoing debate about the suitability and the way in which these methods are used, which will be discussed later. Phenomenology is primarily focussed on considering phenomena from the point of view of the person experiencing it. The chosen methodology makes a distinction between first appearance of the narrative and the later interpretative meaning and essence of the phenomenon (van Manen 1990).

Heidegger (1962) fully acknowledges Husserl as the founder of the phenomenological movement and over time a number of other approaches or methods developed (Koch 1995). Husserl was searching for the essential structure of experience, with a description of experience in its purest form (Heidegger 1962; Dowling 2007). His “life-world” is a
key concept and consists of objects of which we are conscious and by being conscious of them, they mean something to us. This is known as the concept of ‘Intentionality’. Intentionality refers to the internal experience of being conscious of an object and directing one’s thought towards it. The “object” does not have to physically exist for this to take place; it may be intangible such as emotional response (Heidegger 1962; Dowling 2007). The life-world is understood as what individuals experience pre-reflectively without resorting to interpretation and Husserl assumes Cartesian duality, a mind-body split (Dowling 2007).

3.1.3.1 Husserl’s Descriptive Phenomenology

Husserl’s transcendental phenomenology does not attempt to interpret experience or phenomena and is descriptive alone (Heidegger 1962; van Manen 1990; Dowling 2007). Husserl maintained descriptive phenomenology would bring us to the essence of that which was being sought and to the essence that constitutes consciousness and perception of the human world. This descriptive phenomenology is a distinctive school from the interpretative school and the later paradigm shift and development from description to interpretation will be explored in the next section.

It is only the “experience” itself that concerns Husserl; the source or success of the experience are irrelevant and not of importance to Husserl. Importantly, he performs the transcendental phenomenological reduction also known as “bracketing.” He maintained that it must be performed by the researcher in order to gain essential understanding with description (Heidegger 1962; Dowling 2007). In doing this, the researcher suspends all previous assumptions and understandings. Once reduction has been attained, the researcher is able to commence answering questions about human experience that phenomenology is ideal to answer (Cerbone 2006). The process of bracketing defends the validity or objectivity of the interpretation against the self-interest of the researcher (Koch 1995) but whilst this may apply to description, Koch’s view is questionable for interpretation. Heidegger (1962) describes bracketing as refraining from all judgement but later developed this further and rejected this approach for interpretation as it is questionable if suspension of known knowledge or understanding is really attained (Heidegger 1962) and this is discussed in the next section.
3.1.3.2 Heidegger’s Interpretative Phenomenology

Heidegger (1962) was a student and follower of Husserl but importantly developed phenomenology. Whilst he accepts the importance of description of the experience, he is more concerned with interpretation and understanding. This development and paradigm shift is important as understanding is a key concept. Husserl takes a transcendental approach; Heidegger adopts an existential ontological approach. Heidegger’s phenomenological view of the person arises from the question “what does it mean to be a person?” (Leonard 1989). Heidegger is concerned with Dasein (“being there”) as a concept, in particular, how the person sees themselves in the world (“being-in-the-world”). To consider the "being" of something is to ask for the nature or meaning of that phenomenon (van Manen 1990). Heidegger (1962) rejects bracketing, believing that such pre-conceptions are in fact important and an essential element to understanding and the interpretation of meaning. This has implications for the school of philosophy that I followed whilst undertaking this research on “real life experience”. The world the person inhabits is immersed with culture, history and language. Hence, he concerns himself with ontology (ontology will be discussed later –see 3.1.9), particularly pre-ontological understanding which is implicit and manifests itself in how we act. Heidegger (1962) sees humans as temporal beings embedded in historical and cultural concepts and with traditions that are shared with others in the community. This is essentially true also for the researcher, who cannot set this aside and as a midwife this observation is essentially correct one. I would additionally argue this is perhaps influenced far wider today by media and the virtual world with the explosion on information available with technology. Media portrayal of HIV is often alarmist and accusatory and often inaccurate and inhibits understanding, (Kennedy 2003; NAM 2008) and as unique individuals, we as humans will have been affected by this portrayal including the study respondents.

Heidegger (1962) proposes understanding and interpretation is grounded in fore-having, fore-sight and fore-conception and talks of the need for the interpretation to conform to the fore-structures of the understanding. Heidegger (1962) is specific about understanding: the fore-having deals with the notion of totality or whole, the fore-sight with the particular or specific task or entity that is before us within the totality and the
fore-conception which is the conceptualization of that specific entity within the totality. In the interpretation of the concept of Dasein (Being-there) there must be (i) Fore-having: Dasein as a whole, (ii) Fore-sight; Dasein as itself and (iii) Fore-conception: Temporality (Heidegger 1962). Heidegger acknowledges that the impact of time plays an important part of understanding. Simply he proposes, Dasein (Being-there) is a “Being” or existence that is essentially a futural being; that is always looking forward. Heidegger orders time as, future (Ahead-of-itself), past (Already-in-the-world) and present (Being-alongside). Heidegger calls future, “understanding” or “projection”.

Dasein is in the future in that it is always ahead-of-itself (Heidegger 1962; Cerbone 2006). What Dasein does is determined by what it is, how it behaves for the future relates to how it sees itself now. The past, already-in-the-world, “befindlichkeit” relates to us finding ourselves already in a situation (in the world) and with a particular orientation to that situation. Our orientation in the world is affected by our mood, disposition, inclination, beliefs and experience. “Befindlichkeit” is the historical or past nature of Dasein. The present is described as being-alongside (entities encountered within the world). Heidegger (1962) calls this aspect “falling” and this relates to absorption in current activity. Dasein is always falling in that it is always caught up in some kind of ongoing activity. Hence, Dasein is temporally situated in the world. This temporarily allows future, past and presents to be experienced in unity. What is experienced by the person is also coherent with what was experienced in the past and what are expected to be experienced in the future (Heidegger 1962; Mackey 2005).

Importantly Heidegger brings an interpretive approach to phenomenology. He sees us as self-interpreting beings not satisfied with description alone; simply humans need to interpret to understand (Heidegger 1962). Interpretation enables us to fully understand our world without it we cannot have a full life at a cultural level except through the acts of interpretation (Koch 1995). Heidegger explores the essence of “being “and “experiences” of a lived life (Heidegger 1962).

The hermeneutic circle, this circle of understanding is an essential concept for Heidegger (1962). In this circle, interpretation is seen as a circular process whereby fore-structures of understanding are made explicit. They are then considered in terms of the whole of the understanding of something and then considered in new ways which results in a circular process (Mackey 2005). As a researcher, I contribute an essential
element to the hermeneutic circle of interpretation and understanding. I have
experiences that I bring and an essential element of the hermeneutic circle as my
interpretations of the experience add further understanding and meaning. Any objective
stance or my removal or absence from the hermeneutic circle would essentially make
this research, a standalone methodology and essentially a descriptive process and not
the interpretative process, which is required for this study’s methodology.

Researchers in education, social welfare and health, and particularly nurses and
midwives, have been drawn to using phenomenology as it allows researchers to
examine the “lived experience” (Crotty 1996, 2003). Wismont’s (2000) study of the
lived experience of women in prison is an example as she explores the lived experience
of women incarcerated and no longer free. The “lived experience” is to see phenomena
from the point of view of the person experiencing it. This is an important concept to
researchers studying patients’ feelings or the emotional effects of treatment or illness.
This is relevant for women who have had the experience of a life changing HIV positive
result in pregnancy.

Researchers often fail to fully understand the underlying philosophy and importantly its
application and much of that criticism has been levelled at its use in nursing research
(Crotty 1996; Paley1997, 1998). This view is endorsed by Hickson (2008), Holloway &
Wheeler (2003) and Hicks (1996). This failure to understand, can subsequently lead to
the adoption of the wrong approach and method. I accept fully that a failure to follow
the legitimate philosophical principles throughout may lead to adverse criticism and
may damage perfectly justifiable research (Hickson 2008; Holloway & Wheeler 2003;
fully acknowledge the philosophy of phenomenology itself or importantly imbed this in
the research. They state it is often used as a stand-alone methodology and are critical
with a failure to relate both the analysis and findings to the underlying principles.

Paley (1997, 1998) criticised researchers for failing to either fully describe or state
which school of “descriptive or interpretive” phenomenology they are following. Paley
(1997, 1998) is also critical of health researchers using the terms hermeneutic and
phenomenology interchangeably (Paley 1997, 1998). However, it must be noted that
original texts by Heidegger (1962) were difficult to read, interpret or understand and for
this reason it took a number of years for the text to be translated into English. This is perhaps ironic as in the quest for “understanding” is a fundamental principle for Heidegger.

Crotty (1996) supports use of bracketing and believes that researchers fail to do so effectively and is adamant that they are not discovering the true essence of the phenomenon under investigation. Crotty (1996, 2003) argues phenomenology is not as simple as looking at things from the perspective of another and has criticised nurses’ apparent reliance on a wholly subjective standpoint. However, a very important and fundamental principle is that bracketing is only relevant for those following the Husserl school of phenomenology. Heidegger’s (1962) hermeneutic stance acknowledges the pre-ontological state and the need for interpretation to understand. Van Manen (1990) argues and firmly believes that trying to “forget” what we “know” we probably allow pre-supposition back into our reflections. I fully accept this view. Koch (1995) notes that Husserlian’s claim to describe the phenomenon as it is, but suggests that one cannot separate description from one’s own interpretation of the experience. This Husserlian method was rejected for this study as on sustained reflection, it is not suitable and strongly questionable, as in reality my extensive past experience cannot be “forgotten”.

3.1.3.3 The Arguments with Analysis and Analytical Frameworks

Arguments also surround analysis and inappropriate analytical frameworks. Todres (2005) Jarman et al (1997) Giorgi (1985), Colaizzi (1978) and van Kamm (1966) describe different methods of analysis. These methods are similar in that they use varying steps in their approach to data analysis. Confusion is apparent with analysis as Giorgi (1985) and van Kamm (1966) have been associated with Husserlian phenomenology but have also been used by researchers claiming to be following Heideggarian philosophy. Also the frameworks have been criticised as ridged and overly structured. Colaizzi (1978) describes his framework as being derived from Heidegger, but Koch (1995) challenges this, stating that such structured approaches are not conducive to Heidegger’s interpretive approach. This is an important rationale as to why I rejected a more formalised analytical approach as confusion is apparent and opted for van Manen (1990) reflective approach as the emphasis is on the women’s narrative
to aid understanding (van Manen 2006). Importantly, hermeneutics looks at the responses of the women with HIV through meaning, importantly by bringing out issues that would not have been considered at “face value”. The written text from the narrative is essential in this reflective analysis (van Manen 2006) as the researcher explores meaning and essence.

The foundation on which the research is based needs to be stated and embedded and it is important to ensure that the researcher has followed the philosophical school (Crotty 1996). Criticism will entail as there is much debate over old and new phenomenology, the original European and American schools (Caelli 2000) as there are differences in methodology. The need to get it right is important and I have been explicit with the philosophy chosen for this study as it is my aim to produce a clear coherent and logical approach with the study. Full consideration and care has been given to the philosophy behind the methodology.

It is my view that phenomenological research is related to the individual’s situatedness, including their temporality in this world. It is fully accepted that as a researcher, I bring my own situatedness to the research (Situatedness is discussed later-see section 3.1.6). In particular, I have cared for HIV positive women and been immersed in a similar culture on a personal and professional level, which is probably similar to some of the respondents and therefore subject to similar influences. Being reflexive is an important tool and I am aware of this specific influence, so it is my view, I do not feel that bracketing could be realistic or achievable for this study and perhaps honesty and integrity could be lost. In summary, Heidegger’s (1962) hermeneutic phenomenology was chosen as it suits the purpose and interpretive philosophical aims of this study. The study itself is exploratory and interprets the phenomenon of the experience.

3.1.4 Analysis: The Influence of Van Manen’s (1990) Hermeneutic Phenomenological Reflection

Researchers use and adapt particular methods in their own individual ways and the difficulties in staying true to one theoretical approach are known as problematic (Mauthner & Doucett 1998) and they often use several methodologies. Heidegger’s (1962) stance is not exclusive; the concepts of both van Manen (1990) and Gadamer
Van Manen (1990) states “The purpose of phenomenological reflection is to try to grasp the essential meaning of something”

Van Manen’s (1990) accessible text concept takes a hermeneutic stance in considering the “lived experience”, and was suitable as a concept for this type of research. Van Manen’s (1990) position regarding hermeneutic phenomenological writing was incorporated in this study, with regard to analysis, as he maintains a lived experience has to be captured in language (the human science text) and that this is an interpretative process. He accepts some descriptions of the experience and text are richer than others but each has something new and individual to offer. This chosen interpretative methodology by van Manen (1990) focused on the individual and sought to find out how their personal history, previous life events, background, education, social support, social class, and psychological makeup influence the way in which they experience the phenomena (Parahoo 2006) (see findings-4.1.1 to 4.1.14 participant demographics).

Van Manen (1990) maintains isolating thematic aspects or statements, uncovers the meaning of the phenomenon with the analysis of the verbatim text. The verbatim text is taken from the lived-experience description.

He details the three ways or approaches of doing this;

1) the wholistic (sic) or sententious approach
2) the selective or highlighting approach
3) the detailed or line by line approach.

The first of which, is to consider the text as a whole for phrases that may capture the fundamental meaning of the written text. Secondly, a selective approach, highlighting statements that appears to be significant or essential in the text. Thirdly, a detailed
approach, considering every sentence or sentence cluster in detail to reveal what is being described in the experience. In order to analyse the texts these three approaches can be used individually or in combination to analyse the text. I used a combination of the three approaches (see Appendix 17). I read the text in a wholistic (sic) way first to get a feeling of the fundamental issues raised in the data, then proceeded to do a selective approach, highlighting the important statements and then a detailed line by line analysis to discover meaning and themes from the described experience. Analysis was approached in this systematic way in order to ensure consistency and to ensure themes were uncovered and the practical steps of analysis are explored further in the thesis (see section 3.2.15 & 3.2.16 and Appendix 17). Thematic development is essentially an art and assists with the interpretative process as text is undergoes analyses (van Manen 2006).

Whilst he gives the principles involved in analysis, it is less formalised or reductionist in approach and is in keeping with the principles of hermeneutic phenomenology whilst it seeks meaning. I personally felt it gave me freedom to be immersed in the narrative. This was essentially for me, walking along side with the women as she told me about her life, journey and experience. I tried to analyse, understand and make sense with its meaning. It was a life adventure of understanding.

Van Manen (1990) accepts that trying to understand the overall meaning in any text is one of subjectivity and judgement. So in essence it was always going to be a personal but subjective process; however reflexivity had an impact by raising my personal self awareness and challenging my bias but he accepts someone else’s interpretation will be unique and different from mine. But this essentially supports my role in the hermeneutic circle of understanding as a necessary one.

Van Manen (1990) proposes that once transcript themes have been identified, participants can (but not required) undertake a reflective second interview to interpret the significance of preliminary themes under member checking, but due to the sensitive nature and confidentiality issues of this HIV experience and contact difficulties, this was not feasible or actively pursued. However, participants were informed that they could do so if they wished (see member checking 3.2.18). I accept that this may have lead to a reliance on my interpretive analysis but I state that the women’s voices on the
digital recordings and the transcribed verbatim text remain a point of reference. I also fully accept that I had an emotional relationship with the research which meant I had a personal impact on the analytic process which is explored later in this section, under truthfulness and credibility (See 3.1.8). To mitigate against any potential excess of subjectivity and bias, I sought assistance with my supervisory teams with further collaborative analysis on the themes generated, to check on my descriptions, interpretations and reflections on the participants “life-world.” Simply, the interpretations need to have resonance and meaning but importantly ring out as truthful.

Gadamer's (1989) views of historical understanding and language at the core of understanding are also important as all too often original meaning can be lost as time passes. The story or experience may be related orally or written but history or events distort the original message. Gadamer (1989) also discussed that the narrative is time situated and expressed from the unique horizon of the participant and that horizon can change as time passes and that it fuses with the researcher interpretation. The influence of Gadamer’s work is important to van Manen (1990) and he stresses the relevance on his own work with isolating thematic statements. In this study’s analysis and thematic development, I considered the language expressed by women and explored its meaning and the context of its use with the narrative. It was important to acknowledge that a term or word used by an African woman may have a different meaning, so verbal checking during the interview process was necessary at times to explore and clarify its meaning.

3.1.5 Reflexivity

Self awareness is key; using a reflexive approach within qualitative research is a method of acknowledging ‘self-awareness’ in the research process (Kingdon 2005). Reflexivity is valued with critical reflection, with the identification of power, power in relationships and its impact on the research process. Political interests and shared values need to be acknowledged and importantly be explicit and explored (Ramazanoglu & Holland 2009).

The researcher acknowledging their values and beliefs is an important facet for self-awareness as how this was gained, may affect the research. This approach demands
awareness and requires appropriate responses between the researcher and participants. This aspect was aided by keeping a reflective diary which recorded not just my progress but importantly my personal feelings as the research progressed and enabled me to continually reflect during the writing up of the study. During this study, I acknowledged my self-awareness and that I have impact and influence on the process being male, a midwife, white and knowledgeable about HIV.

In a patriarchal society males may be regarded as powerful, whereas women in Western and African culture may have diminished status and power (Jewkes et al 2009). I had to take care not to dominate this process but remain open, intuitive and inquisitive. I questioned my motivation and the research process as I believed I should enable women’s voices to be heard but not be their “spokesman” per se but facilitate the narrative process. It is important that women are heard and that they speak for themselves but recognising the women participants required my assistance to achieve this aim. I tried to be open and transparent about my values and beliefs, acknowledging who I am, my past (and present) life; this allows others to see my aim is to reduce any bias within this study. I write about my past experiences within midwifery and HIV so the history I come with is explicit (see appendix 6). In summary, I acknowledge that I have a personal, emotional and subjective relationship the research process and cannot and will not be divorced from it. As a midwife and researcher, I do not believe you can effectively disengage with your past experiences but to acknowledge and embrace it is an important aspect. Kingdon (2005) additionally maintains the “writing style” often demonstrated engagement with reflexivity as it is informative but demonstrates innate self-awareness. This thesis has developed this stylistic approach.

3.1.6 Situatedness

Situatedness is explored and defined by Heidegger (1962) and the actual translation of situated in German is 'befindlich', a term that refers simultaneously to situational circumstances of action and the emotional disposition of the how do you feel. In this context it provides the multiple perspectives needed for understanding that permits all voices to be heard in good faith. In this study women were situated in a real world with unique experiences that had shaped their world and how they are within it. Also, I fully
acknowledged that I was part of the research and not separated from it and this situatedness impacted on me as a human being. The actions I took within this research had an emotional impact which ranged from elation to disappointment and panic. I would awake at night prior to an arranged interview in a cold sweat, feeling panic at the prospect. This was real anxiety and was not pleasant, but it did improve with time. However, it would have made an impact as on reflection the later interviews became more relaxed and lengthened and more “free” when I learned to manage my personal anxiety.

3.1.7 Epistemology

Essentially epistemology endeavours to study the nature of knowledge and justified belief and how we understand our world; it fundamentally questions and tries to understand how we know what we know (Harding 1993; Dowling 2007). How do I know that the majority of women will have a negative reaction or be distressed when informed they are HIV positive? I know because of experience, but it is possible and feasible I may not have had this specific experience, but drawing on other bad news scenarios in most nursing and midwifery situations, distress is often the first reaction. But how do I know and justify this belief if I have never had any experience? We have all had bad news and breaking bad news may have been taught as a theoretical concept before I ever did it. So my justified belief may later be confirmed by actual experience. However, it may be refuted or modified as I undergo additional life experience, when an unexpected reaction to my certain knowledge is tested and this has occurred when a friend said he was expecting his result to be bad news, it was positive and actually it was ok and he did not get distressed. This modified my justified belief, as it confirmed, we as human beings have different reactions even to similar life experiences.

Many individuals hold counter intuitive beliefs and believe them to be a true knowledge, often they are prejudiced to women, ethnic minorities or those that are gay or have HIV or all or some of these combined. This creates a hierarchy of oppression especially with a black, gay HIV positive man (or a woman) classed lowest in the ranking of oppression. Many would perhaps question this once the effects of this oppression were challenged but others would not seek to modify their certain
knowledge. Many black HIV positive women are stigmatised, often in their own communities (Sanders 2008; Sherr et al 2011), due to strong belief systems. I would suggest that when some individuals in those communities are challenged a number would modify this behaviour and gain new enlightenment and knowledge, whilst others would not. I have beliefs and knowledge that may have errors, but it is often modified and shaped by evidence and life experience. I make sense of my world through my senses, such as vision, hearing, touch and developing my intellect by challenging what I believe to be true. I often state that I have been educated out of any belief in a God or afterlife. I firmly believe that to be true, this sets me free to be human. I am no longer dependant on a reward in heaven but I fully except others will challenge me and in all probability, insist I have closed my mind to a loving God. Many communities are bound by a belief in God, this may give genuine comfort to some with this assured belief and knowledge, but it may also add further distress to others especially with HIV and its sexual acquisition.

3.1.8 Trustworthiness and Credibility

An important principle is the concept of trustworthiness and credibility and the reliability of the narrative and the resonance or meaning of the findings for the reader of this study (Dowling 2007). Knowing what is credible or “true” can be difficult at the best of times. I was left to contemplate “how plausible is this story?” On the face of it, quantitative research has perhaps an easier time in that this approach uses rigour and claims of validity. Whilst this positivist approach may be suitable for some quantitative types of research, this approach is simply not suitable for the interpretative approach. Positivist often only accepts one truth and differences are dismissed. Only one way of viewing the world is the accepted paradigm. Objectivity has long been used in connection with Cartesian dualisms and is at the opposite end to subjectivity (Ramazanoglu & Holland 2009). The quantitative researcher aims to ensure neutral knowledge by control of the research process. For the positivist, objectivity is deemed a purer and realist approach. Within a relativist approach, subjectivity is at the opposite end and is viewed as a failure to control the research process and the “truth” is contaminated by introducing bias to the scientific process. Objectivity is not without its problems and can actually be lost as it sees only one truth existing and is no longer
objective but restrictive to the element of “one truth” (Harding 1993). This is also
dependent on the position and finite view from the world of the quantitative researcher
and also subject to personal bias. In essence the researcher is actually limited by seeking
only this one truth and dismissing all others (Harding 1993). This one truth enables data
to be used and interpreted as being applied and generalised to the whole population and
importantly often takes little interest in the individual experience. Ramazanoglu &
Holland (2009) discuss how the supposed objectivity, neutrality and rationality of
scientific method allow the production of patriarchal knowledge. Little countenance is
given to women and this suppresses the human experience for women as their unique
experience is not worthwhile or of merit in a male dominated world. Harding (1993)
maintains that researchers should not to give up on objectivity, but to use it differently
with the use of reflexivity. This includes the researcher fully discussing how the
knowledge production process is included in the research (reflexivity). Also topics for
research questions should be grounded in the experiences of those who are often
ignored through dominant beliefs or activities. I believe this aspect is assisted in the
candidature of women with HIV in this study. Harding (1993) maintains that strong
objectivity can resist relativism with its very own version of events. However, she is of
the view that “real” objectivity means treating the researcher and the subjects of
knowledge as real, visible and embodied in the experiences (Harding 1993).

I do not intend to explore this objective stance further as whilst this is valid for
quantitative research, I argue that in the differing paradigm of human science qualitative
research that a fully hard objective stance is rejected due to the individual and unique
human experience that I explored in this study. I followed a philosophical framework
proposed by Lincoln and Guba (1985) who state;

“Individuals create, negotiate, and interpret meaning for their actions and for the
social situations in which they exist” (Lincoln & Guba 1985 p34)

I fully accept that human narrative can be varied and subjective and I also accept human
science research needs to be credible, dependable, reliable and truthful; however its
strength was that it did not attempt to remove the researcher (me) from the research
process. In fact the opposite, as a researcher I was able to fully engage and I used
reflexivity as an on-going process of self-awareness and this helped provide validity to
their claims. Simply, I did not seek an absolute objective truth and accepted degrees of subjectivity in participant accounts, in the analysis and the writing up of this study. This view is not without criticism, Paley & Lilford (2011) are very critical of this subjective approach and maintain that just accepting what people tell you as truthful is a naive stance as people may recall some aspects of an experience very well but fill in the remaining gaps with half truth. However, if that happened I would strongly argue did it invalidate all narrative and speech? I did not think so; I was firmly of the view and trusted the individual with their personal testimony. I accept there may be some omissions with accounts but a deliberate fabrication if it occurred was probably rare. I accepted subjectivity in the participant’s accounts but I also acknowledged my subjectivity as a researcher by remaining open and reflexive. Additionally, similar themes were apparent in differing accounts and for me further confirmed the trustworthiness of the women’s narrative.

Memory is the capacity to retain knowledge or an experience acquired in the past. However, I fully accept that participant’s memory was not infallible and recalled memory reliable. How can I be sure or justified that what the women related was truthful or reliable? For instance, I fully accept a woman’s account of her HIV transmission as she apportion blame on her partner but who is to say it was truthful or reliable or her belief justified. Perhaps her account may have differed from her partners if he had been questioned. Which story would be truthful or reliable? She believed he was to blame for her infection but was this personal belief justified. Whilst empirical evidence may suggest she is correct, this may or may not be so, as later scientific testing may prove or disprove her belief and that HIV infection was from elsewhere and not her partner. The belief may be rational but in this instance it would not be correct, absolute or fully justified. However, this alone does not mitigate or invalidate her personal experience of HIV. Whilst women may give an account or experience that cannot be tested for accuracy as she draws on her experience, she in all probability believed it to be a true account. Yes it was her subjective account, but the account she gave derives from her perceived personal experience. This may be a disadvantage for relativists in that they are unable to connect different accounts of individual reality, but no account was viewed as being truer than any other and I accepted it to be truthful. I remained of the view that the narrative was drawn from a challenging personal experience and from the participant perspective was truthful and reliable.
I also accepted that the passage of time may have impacted on recall but it may have also allowed for a more reflective account (van Manen 1990). The assumption and my position is that there are multiple truths that are all valid and equal and are produced within different ways of knowing and this provides ways of rationalising the social world. This position rejected the premise that general rules can be applied across all narrative stories. This therefore allowed each individual story to be unique. I accepted fully what may be said may have had some inaccurate recall but I rejected the position that recall was so inaccurate and therefore did not accept the arguments that human experience is not to be trusted which Paley & Lilford (2011) proposed. I strongly suspect they searched for the “one truth” in human experience but for my study participants, recall and narrative were often heartfelt, emotional and strong and deemed an accurate personal account of their experience. Whilst findings cannot be generalised, this was not the aim, commonality of issues and themes were apparent, therefore in a similar setting transferability is possible (Harding 1993). Whilst immersed in the narrative data, I was still able to question and think “Does this sound credible? Is it plausible? Is it dependable? Resonate as true?.” I came to the conclusion that the narrative was given in good faith (van Manen 1990, 2006). Simply, the participants were motivated to come forward and had important issues they wished to discuss and for me it confirmed trustworthiness. These concepts of ensuring the findings represented the truth were important for me as a researcher; I was also truthful, credible and dependable and confirm the trustworthiness of this study. This was an important aspect in this research process.

3.1.9 Ontology: The Ontological Question

Ontology is the philosophical study of the nature or inquiry of “being, existence or reality” (Mason 2002). Ontology is ‘how things are’ within a world (van Manen 1990) and specifically from the vantage point of the women in this study. For women in this study, the ontological question asked; what was the reality of being diagnosed HIV positive in pregnancy and living with HIV? To be able to study this concept from the perspective of the women, it was necessary to investigate their understanding from their personal view of the world. It refers to the subject of their existence and the nature of
that existence or reality within their environment. It has a long history in philosophy, van Manen (1990 p183) states “ontological inquiry is concern with what it means to be, with the being of things or entities”. Heidegger (1962: p28) calls ontology the “Phenomenology of being” and it must adequately clarify the meaning of being as a fundamental task. Mason (2002) discusses how ontological properties can be extracted from data generated by interacting with people:

“To talk to them, to listen to them and to gain access to their accounts and articulations.”(Mason 2002:p40).

Ontology is also often confused with epistemology, which is about knowledge, knowing and belief. This study’s ontological inquiry specifically explored their existence and reality of life with antenatal diagnosis of HIV.

It was my ontological question and objective to discover their real world through the women’s eyes, to gain a true account of their existence and life with HIV in pregnancy. The finding of this study demonstrates my commitment to how I wished to see their existence from the women’s vantage point. Whilst we know women exist with ontological and epistemological certainty as René Descartes in “cogito ergo sum” or "I think, therefore I am", and argued that "the self" is something that we can know exists with certainty. Until recently, I was not convinced if we know with any certainty about women’s reality, or existence with women of African origin, diagnosed in pregnancy and living with HIV in UK. I fervently believe this aspect has further clarity with the findings of this study.

3.1.10 Etymology

Is the study of the history of words and their origins, and how their form and meaning often changed over time. This concerns the roots of words and how the sounds and spellings, as well as the meanings change or evolve. This leads to the question of the concept analysis of HIV. The Human Immune deficiency Virus or HIV is a recent word and its meaning is understood in the scientific community and by experts and the expert patient. What does it mean to women and specifically to women diagnosed in
pregnancy? To me, it may mean a normal pregnancy but complicated by HIV, to an obstetrician or HIV physician it means HIV is a pathological event, to the paediatrician it may mean something more sinister and threatening to the infant that needs to be contained and to the media as a curse on mankind and personal and societal morality. HIV may have a different meaning to different women. Gadamer's (1989) views of historical understanding are of relevance as he seeks to place writing and event in its historical context and discover the meaning at the time the event took place. Some women had a recent diagnosis and were able to recall events in near time but for other women, some time will have elapsed from initial diagnosis and HIV testing procedure and policy will also have developed further. The essence and meaning of this experience may also have evolved with subjective reflection, essentially what it meant at that time has evolved and the horizon changed with reflection. It is important to place women’s narrative in its time and place. It is also possible should HIV be cured, future generations will not have an understanding of the condition or its impact on women; this study will be reference and demonstrate its impact on women by recording their narrative and lived experience. It will give an historical understanding of the effects of an HIV diagnosis for future generations.

3.1.11 Conclusion - Section One

Interpretative phenomenology was appropriate for this original midwifery research as this methodology can bring deep meaning to the needs, wellbeing and experiences of women. These women are encountering a real life childbearing process which importantly includes HIV testing in pregnancy and the specific instance, receiving a positive HIV result and its impact on a lived, living and future life. However, phenomenology attempts to understand the total or holistic nature of the phenomenon rather than focusing on one aspect or concept (van Manen 1990, 2006) and an HIV positive result in not an isolated event but its impact is a life changing one (Kennedy 2003).
3.2 SECTION TWO: RESEARCH DESIGN AND METHOD

3.2.1 Introduction

The second section of the methodology chapter will explain the research design, method and governance of this study. To guide my research design, I used the knowledge gained from the literature review which is briefly summarised in this section (following a full review in chapter one) as this assists with the understanding of the design and the method of data collection chosen. My previous research experience and midwifery background have also contributed greatly with my chosen method and the naturalistic paradigm which aims to understand the individual and how they construct reality. In this section, I will demonstrate the thematic reflective approach taken to analyse the findings of this study and explore further the theoretical components which allowed the findings from this study, to guide me to my later theoretical perspective. The construction and design of this study is now discussed.

3.2.2 HIV Literature and Current Practice Impacts on the Research Journey and Formulation of the Study

The Department of Health (1999) recommends that women are tested for antibodies for the Human Immune deficiency Virus (HIV) in pregnancy; many authors maintain that pregnant women must be offered antenatal HIV testing in a testing program managed by maternity services (Mercy 1998; Mercy & Nichol 1998; Boyd et al 1999a, 1999b; Baxter & Bennett 2000). Pregnant women are routinely tested for HIV antibodies and the maternal uptake has increased steadily since the introduction of universal testing in 1999. Most units achieve over a 96% uptake rate in the United Kingdom, many with an ‘opt out’ testing programme; where the woman is tested unless they actively withdraw from the test (Kennedy 2003). HIV testing is the gateway for a pregnant woman to receive a positive HIV result in pregnancy. HIV testing is beneficial and the health benefits are well known, with a reduction in infant transmission and effective treatment for women after an HIV diagnosis (Simpson et al 1998 & 1999; Kennedy 2003). There are a number of quantitative, qualitative and mixed method studies and opinion papers
around midwives’ support for the testing programme (Kennedy 2003). More importantly and of relevance is women’s rationale for, and motivation to accept, HIV testing in pregnancy. Studies have inquired about women’s views about the acceptability of the antenatal HIV test in pregnancy (Duffy et al 1998, Simpson et al 1998 & 1999) and have demonstrated women’s support for the antenatal HIV testing program (Boyd et al 1999b).

Studies have also explored HIV pre-test information in pregnancy and found that women were often unhappy with pre-test information (Sherr et al 2000, 2001; Roth et al 2003). My Masters of Science (MSc) study survey (Lingen-Stallard 2006), found that women were not satisfied and received insufficient pre-test information prior to HIV testing. My findings (Lingen-Stallard 2006) had an impact on the rationale for the development of this further study. I wanted to inquire about women’s experiences of an antenatal HIV diagnosis in the UK. HIV infections are now commonly diagnosed in pregnancy, with black African women having the greatest burden of infection in pregnancy due to high levels of infection in migrants to Europe and the UK (De Cock & Low 1997; Kennedy 2003; Southgate et al 2008; Giravdon et al 2009). However, women’s experience or voice and any impact following an HIV diagnosis are relatively few worldwide in comparison to gay men testing HIV positive. The human experience of testing positive is explored in psychological literature but is often male specific. Sherr et al (2011) systematically reviewed a large number of papers around the psychological impact of HIV diagnosis and were critical as focused on post traumatic stress and failed to promote psychological growth. There is evidence that an HIV diagnosis increases stress, anxiety and stigma (Schrooten et al 2001). However, HIV and childbearing women has been explored, with a number of relevant qualitative studies focused on HIV and motherhood (Ingram & Hutchinson 1999, 2000). Sandelowski & Barroso (2003) produced a metasummary and metasynthesis of qualitative papers exploring HIV and motherhood. Sanders’ (2008) produced a specific phenomenological study which also explored HIV and motherhood. However, a relevant topic and specific UK focused paper was published but this was after my studies formulation. This small but recent study explored the important focus of receiving a positive HIV result in pregnancy in the UK (Kelly et al 2012).
Obstetric and neonatal risk is well publicised for women with an undiagnosed HIV infection. For mothers, these include risk of preterm delivery, increased risk of maternal morbidity with symptoms of HIV disease, miscarriage, stillbirth and maternal mortality (Kennedy 2003; NAM 2008). For babies, risks include vertical transmission of the HIV virus, low birth weight and increased perinatal morbidity and mortality (Kennedy 2003). Effective treatment programme may include elective caesarean section which is classified as invasive (Kennedy 2003) and importantly access to antiretroviral drug therapy. Improved neonatal outcomes are well known for babies born to women with a diagnosis of HIV, as treatment reduces vertical transmission to the infant with a reduction in care costs and importantly treatments improve maternal health (Kennedy 2003; NAM 2008).

Although clearly there is a wealth of literature surrounding the obstetric and neonatal risks in undiagnosed HIV infection, a rigorous review of the academic literature prior to the research proposal indicated insufficient qualitative research regarding a pregnant women’s experiences of receiving a positive HIV result in the UK with a long running antenatal testing program. Kelly et al (2012) which was not available at my study’s formulation.

Therefore I proposed a study, exploring these issues for women who have been diagnosed HIV positive since 1999. This research journey and “lived experience” study is outlined in Figure 2. I believed this research journey would enable me to identify whether there is a need to provide further supportive care or a clinical care pathway for women diagnosed in an antenatal testing program. Also I proposed the study may identify if pregnancy and pre-conceptual HIV testing public health strategy needs further development or refinement to enable informed decision making for women contemplating HIV testing.
Fig 2 Research Journey- Developing and Exploring the Woman’s Experience of an HIV Diagnosis

This diagram relates current midwifery practice with antenatal HIV testing in pregnancy with a positive result and the development of the research.

1. Antenatal HIV test routinely offered in UK
2. HIV Test Performed- Consent
3. Result HIV Negative
4. Result HIV Positive-Midwife’s Role- Informing result
5. IMPACT OF HIV DIAGNOSIS
6. Current HIV Literature/ Midwifery Testing Policy
7. Medicalisation of Birth
8. Supported by HIV Team and Specialist Midwives
9. Women’s experience of HIV diagnosis
10. Concern with lack of knowledge of this experience and Impact of diagnosis
11. Research Design of Study Exploring the Meaning of Women’s LIVED EXPERIENCE and the PHENOMENON
12. Keeping Mum and Baby Well

Pre-test Information given by Midwife
3.2.3 Aims and Objectives of the Study

Aims and objectives are explored in chapter one (see 1.2), but primarily were to gain understanding of the meaning and essence of the personal experiences of women testing HIV positive in pregnancy within an antenatal testing program in the United Kingdom and explore the testing phenomenon.

3.2.4 Sample

In qualitative research the aim is to seek out experiences of individuals in relation to a phenomenon under investigation (Bowling 2002). A purposive sample was sought by accessing women who have undergone the experience of an HIV diagnosis in a UK antenatal testing program. Purposive sampling allows the researcher to select those people who have experience or knowledge of the area under investigation (Polit, Beck & Hungler 2001; Bowling 2002), as it is essential to identify those likely to experience the phenomenon in order to answer the research questions or inquiry. I would have liked to have obtained the views of women from different races, ethnicity and social groups to be represented who had experienced the phenomenon. However, most women affected by HIV in the UK are Black African in origin with the majority from sub-Saharan Africa (HPA Report 2011). This study’s findings agree with the literature and all participants were from this defined group. Also of vital importance; Black African women’s voices have been insufficient within HIV research and by default this aspect has improved with this study’s participants.

Also the literature review revealed that women often receive limited pre-test HIV information prior to HIV testing and that the topic of HIV testing may be raised or in a number of cases not raised in any meaningful way. The topic of HIV testing can be raised in a different way within different models of antenatal care, led by different midwives or HIV midwife specialist. The literature, does not comment on whether there is a difference in women’s perceptions if they had experienced HIV testing previously, or if this was their first testing experience before testing HIV positive. However, the important issue and phenomena under investigation was that women had to be diagnosed HIV positive in pregnancy. It was speculated that some women will have
tested HIV positive with a first test, others will have tested negative before and later positive with a later test. Purposive sampling is about “seeking out individuals” where the processes and experience studied are likely to occur (Bowling 2002). Whilst the sample was purposive and drawn from a population of HIV positive women, they needed to have tested HIV positive in an antenatal screening programme, so several sampling strategies were used to select the sample. Whilst a national advert encourages participation, convenience sampling was used in that the most readily available women were selected and asked to take part. These were women who attended the HIV clinics and were known to the HIV specialist midwives. Also women who attended HIV support groups were informed of the study and encouraged to participate. Snowballing sampling was also used where women who had participated in this study and who knew of another eligible HIV positive woman, informed her of the study.

3.2.5 Sample size

A small sample size allows in-depth data to be collected and analysed (van Manen 1990, 2006; Cluett & Bluff 2000). This is especially meaningful as the sample was purposive; all the participants in this study had the experience of testing HIV positive in pregnancy. This allowed essential elements to be explored relating to that particular group of individuals. This study explored the meaning of this HIV testing phenomenon as an individual and unique experience. Each story was personal and had individual meaning (van Manen 1990). It was hoped to recruit a sample of a minimum of six women and up to a maximum of twenty women. The final number achieved is in keeping with the phenomenological approach (Bowling 2002) and this sample size was able to provide rich in-depth data portraying individual women’s accounts of the impact of HIV (see findings- 4.1). However, if more women had wished to narrate their experience, I would have endeavoured to facilitate and accommodate women to achieve this outcome. Some common trends in women’s experiences were found and possibly may have been more pronounced if greater sample numbers had been achieved, but this interpretive phenomenological methodology design does not attempt to generalise finding; it sought the individual meaning of the experience, and this individual meaning was apparent in the later findings. There was an expectation that some women will have commonality with the themes generated and this in turn allowed transferability.
Importantly the individual experience did differ from one woman to other women in the sample and “differences” are demonstrated in the finding. It was therefore not expected that ‘saturation’ of data was to be achieved and was not a requirement for this phenomenological study, as the initial attempt to contemplate a phenomenon remained the focus but was not be the only single aspect to drive this study (Crotty 1998).

3.2.6 Eligibility

Women were eligible if, during their reproductive (child-bearing) years, they had an antenatal HIV diagnosis during pregnancy, since the introduction of universal antenatal testing in 1999. Women diagnosed in other HIV testing programmes or not during pregnancy were ineligible. The final birth outcome was not an important factor for inclusion and women who have miscarried or had a poor outcome were not excluded if they wished to participate (one women with a poor outcome did participate).

3.2.6.1 Inclusion Criteria:

- Women diagnosed in an antenatal HIV testing programme, irrespective of parity or pregnancy outcome since the introduction of routine antenatal HIV testing in 1999.

3.2.6.2 Exclusion Criteria:

- Women were ineligible if diagnosed in any other testing program or prior to pregnancy or before the introduction of routine antenatal HIV testing in 1999.
- Women under the age of 18.
- Women with severe mental or psychotic disorder.
- Women who were unable to consent for themselves.
3.2.7 Recruitment and Identification of Participants

Following Ethics and Research and Development approval and University regulation approval; two recruitment routes were used to recruit this purposive sample that had tested HIV positive in pregnancy, one an NHS route, using targeted sites and other NHS sites and other a non NHS route with the national advertisement. It was presumed participants from non NHS route would have been under NHS care for the antenatal HIV diagnosis and remained under the NHS for ongoing HIV care. Ethics and Research and Development and University regulation for this route was clarified and approved.

Also several recruitment methods were used to sample women in the two (NHS and Non NHS) recruitment routes (which are outlined below) and required a minimum number of participants for viability. The study explored commonalities and differences and diversity women’s testing experience was attempted by recruitment from different recruitment routes (NHS and Non NHS) and included NHS sites and HIV support organisation with third party and self referral. It was hoped the participants would be recruited from a diverse group with regard to education, culture, ethnicity and social background but in fact the majority were of the same or similar attainment in many of these aspects such as culture and ethnicity.

3.2.7.1 National and Local Advertisement

A national and local and website advertisement: This was advertised in the HIV and support literature and on their own web sites and included Positive Nation, Positively Women (now Positively Living), National AIDS Manuel (NAM), and Terrence Higgins Trust (THT) (see Appendix 12). Women who were thought eligible were shown the national advert by the specialist midwives or support worker and informed of the study. This advert was used by other NHS sites and non NHS site to aid recruitment. HIV and African support organisations had the same advertisement with an e-mail and phone contact numbers.
3.2.7.2 Poster

A poster was available in NHS participant clinics and HIV support groups, with a tear off slip that could be discretely used by participants with my contact details. Women were left to self refer or if interested had the option of personal introduction by HIV midwife specialist or support worker (see Appendix 11).

3.2.7.3 Convenience and Snowball Sampling

A snowball sampling approach was used in both recruitment routes, in which a study participant would recommend the study to another she may have known in her support group (Cluett & Bluff 2000; Burns 2000; Bowling 2002). This was successful and is apparent in the finding chapter. As part of the convenience sampling strategy, I had professional contacts with a number of specialist HIV midwives in the targeted recruitment sites and other NHS sites in the UK. They were integral to the recruitment of the NHS sample.

3.2.7.4 Workshops and Personal Introduction

When invited, I attended clinics and support group meeting and attended workshops to advertise the study. After the meeting women could approach me directly or meet me later. I did not approach women directly and women were introduced by the HIV support worker with this third party personal introduction.

3.2.8 Route One- NHS Recruitment

It is important to discuss the NHS recruitment route. This consisted of targeted NHS sites and other NHS sites.
3.2.8.1. Targeted NHS Sites (A) and (B)

Two inner London hospital NHS trusts with high levels of HIV diagnosed in the pregnant population (HIV in Pregnancy figures in London, HIV Data SHA 2009) were targeted and chosen as they provide healthcare to the boroughs of Lambeth and Southwark. London site (A) was the host research organisation. London Site (B) was a referral centre to the host site (A). A third site (C) was an urban NHS was in the North West of England and this site was originally planned to refer women to host site (A) but due to the number of women recruited by site (A), and the release of the national advertisement, this was used as the recruitment tool for site (C). Site (C) was originally targeted as it has rising levels of HIV in pregnancy. In the two targeted NHS recruitment sites, all eligible women were approached or contacted by an experienced HIV specialist midwife from the clinical care team (they knew these women well) and had a first discussion and first meeting, where interested women were fully informed of the study. This was often in HIV clinic or during an antenatal clinic appointment. After this first meeting, women were given several options; to be given my contact details, to self refer, for the midwife to pass on the women’s contact details to me to contact or to be introduced directly to me in person prior to interview. Women did self refer but the majority were directly introduced to me by the HIV specialist midwives after this first meeting. No direct contact was made by me directly to any women in the first instance unless she had passed on her contact details via the HIV specialist midwife. This allowed women to engage freely and reduce the pressure to participate as the personal introduction was several days, weeks or months later after the study was first discussed. Due to the support offered by the HIV specialist midwives this was the most successful strategy within the NHS route. Women who self referred were also given an extended period of time to consider if they wished to participate before an initial first meeting and the second interview meeting. The specific response rate from this NHS strategy is in the findings chapter. A delay in access did occur at site (B), whilst I had obstetric RD clearance, an HIV consultant interjected that they were “HIV patients” and not obstetric patients anymore and not assist with recruitment and secondly they were doing an internal review of HIV pregnancy experience. The R&D department were unaware of this review. I had a period of intense negotiation and we agreed that I would extend my R&D access to the consultants HIV department but that I could not do this for two more
months until the internal review was completed. Site (B) R & D department confirmed I had followed process; but they had failed to inform this specific consultant lead of the study. This caused a significant delay with access to site (B). I was disappointed and annoyed, which required advanced negotiation skills and my personal input with meetings. On reflection it was my tenacity that won the day. I have concerns that medical staff “own patients” when they attend a department. Simply they do not “own patients” and this is perhaps patriarchal. Whilst I understand the need to keep women safe through effective gate keeping, to isolate women is not helpful.

3.2.8.2 Targeted NHS Site (C) and Other NHS Site.

Site (C) was originally a targeted recruitment site that would refer to site (A), but due to the number of women recruited from site (A) and the national advert had been released; I decided to use the national advert as the recruitment tool alone to saved time and expense after a discussion with Site (C) R & D department. They agreed this approach was a viable alternative for recruitment. Other NHS sites in London and elsewhere in the UK could and did use the national advert for recruitment alone, with informing eligible women of the study.

3.2.9 Route Two- Non NHS Recruitment

It is now important to examine the Non NHS recruitment route. The non NHS recruitment consisted several recruitment strategies as already discussed but implemented for this route:

a) National and local advertisements (See advert and poster in Appendix 11 & 12) in HIV specific support literature and on HIV websites was undertaken and women were left to self refer.

b) Poster advertisements to national and local HIV support organisations with study information. The poster was displayed at any meetings or premises.
b) I personally visited HIV support organisations; this included Positively Women. Personal contact with the THT and an African HIV support organisation was also maintained. I spoke to support workers and women affected with HIV within these organisations. I undertook a study workshop at Positively UK. The HIV support worker or I would verbally inform women of the study, giving the participation sheet and my contact details to interested women. I offered to meet women any time, but most introduced themselves or were introduced to me via their support worker after a network meeting.

c) A snowball sampling technique was successful as women had friends who were HIV positive in their support groups (Cluett & Bluff 2000; Bowling 2002). They were able to contact me via email and telephone. The response rate from this non NHS recruitment strategy is in the findings chapter but the recruitment participant pathway is in figure 3 (see Fig 3 -next page).

The non NHS sample attempted to recruit from the entire United Kingdom but due to urban HIV prevalence it was expected metropolitan areas such as London, Birmingham, Edinburgh and the Central Manchester area which is ethnically and socially diverse would be represented. It was presumed participants from non NHS route would have been under NHS HIV care. Ethics and Research and Development and University regulation for this route was clarified and approved.

3.2.10 Overriding Principle- Time to Consider

The overriding and general principle was that all women within the purposive sample were given time to consider participation or not. Firstly women received verbal information with written study information by a number of sources which included me, the HIV specialist midwives, and HIV organisation support workers and secondly they later met me. This study information is contained in the appendix (7) and is further discussed under ethical considerations in section three.
Fig 3- Chart Demonstrates Participant Recruitment Pathway.

- Experiences of HIV in Pregnancy Study Proposal

  NHS Ethics and RD Approval Obtained

  National Advert for Study

  Targeted Host Unit (A)
  Targeted Unit (B)
  Targeted Unit (C)

  Unit A Participants
  Unit B Participants
  Unit C Participants
  Other NHS Units Participants
  HIV Support Groups, Self Referral and Snowball Participants
3.2.11 Academic Host and Insurance for the Study

The University of Manchester was the academic host and provided insurance for the research study which was a requirement from NREC.

3.2.12 Method of Data Collection

Steen & Roberts (2011) maintain research must have clarity between the research method which is the procedural steps for data collection and data analysis and the methodology which is the theoretical and philosophical concept underpinning the research. The methodology was explored previously in section one of this chapter. So I will now be explicit and explain the method and procedural steps for data collection and analysis. Interviews were chosen as a method to collect data and provide an opportunity for women to tell their story by personal testimony. However I must explain why I chose not to collect data by any other method. Due to my past experience, I had a strong feeling that women would be hard to reach, vulnerable and would tell their story once, and once only before the opportunity was lost (the ‘pop up and tell effect’). This, after consideration, led me to reject a longitudinal approach using diaries for data generation or repeat or second interviews as I did not think they would be viable for maintaining women’s engagement with this study as the topic is sensitive and confidentiality could be threatened with an ability to cause harm. This strong feeling was confirmed when I asked women would they be happy to be seen again, and this was rejected by the majority with only two women wishing to engage again if required. I felt that further contact by telephone or text would also be problematic. A number of women stated verbally, that it was good to talk and cathartic as they enjoyed speaking with me, but they did not need to repeat this narrative experience.

Semi-structured interviews were the chosen method to collect data. Semi-structured interviews allow for a dynamic operation between researcher and the participant, as they both shape the focus of the enquiry (van Manen 1990, 2006). This approach allowed for some exploration and insights into beliefs, attitudes and behaviour of participants whilst
exploring the phenomena (Bowling 2002). The semi-structured interview approach had flexibility with sensitive issues and emotional distress with the option to stop or suspend the interview if required. This flexibility also protected the participants from disclosing aspects they felt uncomfortable with and I could move the interview on further with different questions if required. A semi-structured interview plan had been agreed by the ethics committee (see Appendix 10) as a requirement. Whilst this allowed for a non-directive approach to be used, it allowed flexibility to explore topics and issues further and allowed me to change direction depending on the discussion unfolding with participants. Interviews and questioning will vary on an individual basis (van Manen 1990, 2006), with each participants responses to initial questions individually explored for relevance and depth. When questioning and exploring the experience, an awareness of time and the duration of the interview were helpful so that questioning and women’s responses were not constrained by a lack of time. Importantly the direction and flow of the interview was led by the participant narrative and the researcher (me) guiding the interview by posing questions and exploring participant responses with sensitive probing to understand the experience or topic. The interviews were audio digitally recorded in agreement with the participants.

Field notes were made during and following the discussions. The field notes included the reactions of the women when discussing certain issues such as laughter, crying, eye contact, facial expression and any discomfort which are used in the findings. Also the working field notes helped me to recap raised issues and their meanings for later exploration as often the African dialect could be difficult to understand in the first instance and recapping of issues was required at times and the field notes allowed me to return to a topic or explore further.

3.2.13 Data Collection Process

After the first initial contact with participants by the specialist midwives or support workers or by self referral, the following two meeting were arranged as outlined in the study protocol and the chart in figure 4 (see Fig 4).
3.2.13.1 First Meeting

This first meeting was either with me or the HIV specialist midwife/HIV support worker and was used to verbally explain the study further, answer any questions, explain rights of withdrawal, obtain consent and provide written information regarding the study (see Appendix 7) and check eligibility for inclusion. Each eligible woman was given as much time as needed to consider whether or not to participate and to consult with significant others prior the second meeting and interview with myself. Each participant was given the opportunity to ask any questions during this first meeting and throughout the study. Women were informed of the right to withdraw from the study at any time without affecting any future care or management.

If the woman chose to participate, she signed a consent form (see Appendix 8) at this first meeting or subsequently prior to interview. A copy of the consent was offered for her to keep and a second kept with the researcher in safe custody. Interestingly, all the women except one declined the offer of a personal copy and this was offered several times to each participant. On individual questioning, a number of women responded that they felt uneasy with having any information that could be found by others. The researchers copy is presently kept in a secure location and retained as an essential document. All other study information will be destroyed after 10 years in line with current research practice. Also eligibility criteria were re-checked at the initial first meeting and again prior to interview. The research and interview process was fully explained and storage of data discussed at both meetings. The use of digital recordings and pseudonyms to protect identity was also explained. An appropriate date, time and place for the second meeting were also arranged for the interview, this could be home, clinic or in the community. If the woman did not to attend for interview at the second meeting and the participant had given permission, contact was made and an alternative date given for interview. If she failed to attend and had not given permission to be contacted, it was presumed she no longer wished to participate and was withdrawn. All women that I had not met at the first meeting were offered to meet me in person prior to interview (2 out 13). However, two women who had not met me personally declined this, both stating it was not necessary and they wished to meet me at the second meeting as they had the first meeting with the team. All women spoke to me on the phone for an
informal chat prior to the interview via the midwife or support worker. I always checked this aspect with the referral midwife or HIV support worker. If I had already met them this was not an issue that needed to be raised. I met most women at the first meeting (11 out 13) before arranging the second meeting. These two women I had not personally met were seen by the HIV team/support worker.

3.2.13.2 Second Meeting-Sensitivity and Preparation of the Interview

At the second meeting, all eligible women met me alone. The minimum time between meetings was one week. I remained sensitive, open and welcoming throughout and recognised that this research was potentially emotional for participant women and me (Dickson-Swift 2009). This sensitivity has developed as a midwife, but also as a male practicing in a female dominated profession; this was affirmed by 360 degree feedback during supervisory evidence, workplace appraisal and my own reflectivity. This core midwifery skill was transferred to the research setting as sensitivity guards against exploitation of the participant when information and data is revealed during exploration of emotional and sensitive topics (Goodrum & Keys 2007; Dickson-Swift 2009) (see 3.2.2. Harm and Distress). I did not commence questioning or commence the tape recording until the women were relaxed, settled and comfortable, and importantly until they gave me explicit permission to do so. To aid conversation, initial topics discussed included, travel, weather, general wellbeing and infant development; this was to gain women’s trust and a period of time to feel at ease and importantly build a rapport. Rapport is vital for a meaningful interview as the woman’s narrative and ability to talk will be enhanced and improve the experience of being interviewed (Lee 1993; van Manen 1990, 2006). The women were encouraged to express any concerns and I answered openly and with honestly (Campbell et al 2009). One participant required clarification with confidentiality and this issue was further explored. When interviews took place at a hospital site, tea and coffee were offered and often accepted. Fresh water remained available during the interview. If interviewed on the hospital site, prior to arrival of the women the room temperature, tidiness and cleanliness were checked. Also comfort with the environment was checked with the women. Absolute privacy was maintained throughout and the door was always closed so that any conversation could not be over heard by others. Interviews were never conducted in busy periods and no
clinics were running if on a hospital site. The women were provided with a comfortable chair; I never sat behind a desk and always faced women directly so eye contact could be maintained. If interviewed at home, many of the same aspects were checked and permission sought, but I acknowledged it was a privilege to be in her home. I made women aware that I would record field notes and that I was happy to share and discuss these with them if they consented.

Written consent was again checked or obtained prior to interview. The majority of women were introduced by the specialist midwife (or support worker), if we had not met before. However, most women had spoken to me on the phone at some point before the interview, via the specialist midwife or support worker; this was helpful to gain rapport (Lee 1993; Campbell et al 2009). After welcome and further discussion about the study, demographic details of name address, telephone number, age, ethnicity, career, education and obstetric history was collected and recorded on a basic information data sheet which included the participant’s unique study number and pseudonym (see Appendix 9). The demographic information sheet took approximately ten minutes to complete. All personal details such as name or contact details were kept separately to maintain confidentiality. The women were again reminded that the interviews were recorded and that their personally chosen pseudonyms were used to protect her identity. The digital tape recorder was not commenced until women gave me permission to record the interview (Campbell et al 2009).

A short interview schedule (see Appendix 10) was used in order to ask key questions, and provide prompts where necessary to ensure relevance of discussion (van Manen 1990). This semi structured interview schedule content had been informed by the findings of a literature review and professional experience (Hickson 2008). However it was flexible to allow exploration of emergent topics or themes in any discussion. The interview schedule was an aid memoir and not followed for every question. The interview was led by the women and as she revealed her unique experiences (Lee 1993; Campbell at al 2009). Later interviews developed from the experience of earlier ones (van Manen 1990). For instance, early interview finding revealed self harm intent and this was explored in the later interviews as it was an important issue. The interview schedule was adaptable but relevant to the research topic to ensure a credible and
sensitive source of data (van Manen 1990). Great care was taken with sensitivity and reflection to minimise the possibility of being an exploitative interview tool (Darra 2008). The interview took place in a situation determined by the participant, with due regard to my own and the participant privacy and safety. I expected that the majority of interviews would be in the participants’ home, a number of women took this option, but most NHS participants opted to be interviewed in a private room within a private purpose built community Antenatal Clinic at the host site to maintain confidentiality. Non NHS participant’s interviews either occurred at home or at NHS host site (A). None were interviewed at the other NHS sites as the RD approval did not allow this and other NHS target sites were participant referral sites alone. The place of interview was agreed by both parties. I wore my identification badge at all times. Travel expenses and child care were reimbursed. The interview was expected to take approximately one to one half hours. The majority lasted one hour but the shortest was 40 minutes and the longest 80 minutes. As soon as possible after the interview, the tape recordings were transcribed verbatim and field notes typed up. This data was analysed and this is discussed later in this section (See 3.1.4 & 3.2.15 & 3.2.16 & also Appendix 17). The following figure 4 illustrates data collection process and meetings.
Fig 4. Chart Demonstrates Data Collection Process and Meetings

The green circle represents the HIV positive women and white boxes represent the research interaction and meetings. The least time between the first and second meeting was one week. Average two weeks and the longest time three months.
3.2.14 Data Security

The host NHS research site (A) provided a locked office and locked separate filing cabinets and I had an honorary contract as a research midwife from the host Trust. The master key was held by specialist midwife at this host site. Consent forms were kept separate from any identifying or ID data, so that no link can be made due to the sensitive nature of the information. Study data and materials remained available throughout the study and can be examined by individuals from the University of Manchester, from regulatory authorities or from the participating trusts, for monitoring purposes and this could include access to personal information. Women were made aware of this in the study information sheet and verbally. Any computers used were password protected but identifiable data was not stored on a computer and digital recordings and transcribed verbatim was in a secure password (Dropbox) programme, which enabled access from a linked computer only by me. This degree of protection enabled sensitive information to be secure.

3.2.15 Method of Data Analysis and Data Management

My methodology and analysis was guided by van Manen (1990) Hermeneutic Phenomenological Reflection in conducting thematic analysis and is discussed further in section two of this chapter (see 3.1.4). Principally, I rejected the formalised analysis tool of Attride-Stirling (2001) and Smith et al (2009) and others for similar reasons, as whilst these tools were developed to assist analysis (Attride-Stirling 2001; Smith et al 2009) and claimed that their use as a structured thematic analysis tool enhances the capturing of the “voices” in the study. I felt their use was not appropriate to the ideology of this study as it was formulaic and reductionist when organising very individual and different “voices” recorded as data. I felt the individual “voices” may become lost with essence and meaning obscured with the potential dominance of these specific analytic process tools. Whilst there are claims that truth and credibility are supported by these tools, as the audit process is strengthened, I decided no one stated ideological position was absolute or perfect, but I chose van Manen (1990) interpretative reflective approach. This reflective approach was less formalised and the most appropriate and in keeping with this specific study and research objectives. I felt
strongly that women’s personal testimony or narrative with meaning and essence must be the focus and dominate the study and this must not be lost in the process of analysis. Simply it felt comfortable but I fully accept this feeling is subjective. I was aware that I needed to organise the qualitative data obtained and using this qualitative method of reflective analysis with a hermeneutic (interpretative) approach was a personal revelation in my understanding of the principles of qualitative analysis, organisation, thematic development and interpretation of the data. Applying the principles of reflective analysis proposed by van Manen for the purposes of thematic organisation (van Manen 1990) was very helpful in achieving interpretation and analysis of the findings. This aspect of analysis was explored in the theoretical concepts earlier in section one (see 3.1.4). In essence, the interviews and transcripts were listened to/read many times. The digital recording and transcribed text being read and listened together assisted greatly in this process. In isolating thematic statements and conducting thematic analysis, each sentence of the transcript was examined for meaning to become familiar with the emerging preliminary basic themes and meanings and from these first themes they were further categorised to summarise more abstract principles or later secondary themes which were in turn reinterpreted in the light of the basic themes, informing the major themes which emerged from the text as a whole. Using this interpretation of the verbatim text and audio recording helped promote personal understanding and meaning for me and hopefully the reader, this is essential for the hermeneutic circle of understanding. My role was key component with the interpretation and re-interpretation of the text and with the writing and re-writing aiding thematic development. This approach was recorded methodically throughout the research process and helped to support the audit/decision trail. This analysis process is detailed further in the appendix (see Appendix 17). As already stated, it is an important principle that women’s voices are not lost and the meaning obscured in the analysed finding. I was vital for the interview and recording of the “voices” and my role could not be divorced from the process. With my reflexivity, I remained very much aware of my personal impact in the process of analysis as a checked and re-checked the narrative. Themes were written and re-written and my supervisory team discussed the developing themes and there meanings.

My task was to isolate these thematic statements in the text with interpretation and analysis of emerging preliminary and secondary (later) themes, which were manually
coded by me and reviewed independently by my supervisory team before major thematic grouping. The manual coding used recurring specific words or topics that arose from transcribed verbatim emerging from the analysis. The supervisory team reviewed the themes and issues arising, minimising my own interpreter bias. After individual analysis, discussion was held with my supervisory team and a discussion and consensus of the main themes was explored. A reasonable amount of quoted responses verbatim is included to substantiate the findings. Reflexivity is used throughout to illustrate the discussion of the findings with the relationship between myself and the participants and I fully acknowledge my influence on the research process, but also the effects of this research on myself. I remain committed and explore any problems and complications that arose and how it was managed during the research process are included in the fabric of this thesis.

3.2.16 Overview of the Process of Analysis of Data

After the interview, I initially sat and listened to the data recordings three or four times, before attempting to transcribe any of the recorded verbatim. This made me familiar with it, so that I could interpret how participants were explaining issues and relate this to my field notes. The African dialect of the majority of the participants made this more challenging but I have had many years experience communicating with this specific client group so had understanding of the finite nuances during conversation. Often the terms “he” and “she” were interchanged when referring to the same person or sex. Sometimes responses and issues raised were not direct or immediately clear, with issues talked in a “round about” way by many of the women. I would clarify my understanding and their meaning during our taped conversation. This required a lot of thinking on my feet during the interview process. However, it also highlighted issues that in hind sight could have been explored further when reviewing the tapes and transcribed verbatim. Also members of my supervisory team listened to the tapes. I transcribed the data myself for the first three interviews and for interviews six and twelve. Once transcribed, I examined the text as a whole and then manually began to break the data down line by line. I decided not to use any computer software, as I thought that this would allow me to become immersed and engaged with the data and absorb real understanding and meaning of the responses. I listened and also read and reread the transcripts, coding
words that were reoccurring line by line. When I had coded the words I grouped them into preliminary themes. From these I identified secondary later themes and then major themes. I did this process one at a time after each interview. I found this experience extremely valuable, and I can state, I knew the data ‘inside out’. At times it was difficult but essentially an enjoyable and rewarding task. I then also collectively analysed the completed transcripts for any commonality, this identified the preliminary, secondary and major themes. The detail and steps of the process of analysis is further explored in the Appendix (see Appendix 17).

3.2.17 Review and Moderation

Members of my supervisory team reviewed my transcriptions before hermeneutic phenomenological reflection and thematic analysis was performed. During reflection and thematic analysis, I discussed the data in relation to generation of the themes, to ensure my own biases were not influencing the generated themes and that they were a fair and considered view that explored essence and meaning in the transcribed text (van Manen 1990).

3.2.18 Rejection of Member Checking by Participants

Carter (2004) discusses how member checking can be used to confirm the interpretation of researchers’ findings following an interview. Transcriptions of the interview can be sent to participants to ascertain if they are a true reflection of what is said. Van Manen (1990) proposes a second interview to check preliminary themes. Gadamer (1989) is sceptical of second interviews as he believes participant’s narrative is time situated and are from a given horizon. Second interviews change that horizon and the narrative may change as the participant narrates what the researcher wants to hear or changes the account or viewpoint with further reflection. I understood both arguments but later rejected member checking on several counts; I was not convinced it would increase the credibility of my study by sending HIV sensitive data to vulnerable women or asking them to return for a second interview, as in this case it was not really a viable option on topic sensitivity, confidentiality and their time. Importantly when participants were
offered this option to be seen again or sent the information all but two participants resolutely rejected this offer outright. This member checking option was therefore not actively pursued any further; it was the women’s choice that took precedence. The interviews were digitally recorded with transcription and remained a point of reference for a time if themes were questionable. Women were informed they could come to see me at any time if they wished to review their personal data and discuss further any themes identified. No participant did so and the two women who did not reject this also did not pursue this option. The participants were fully informed they could have a written copy of the findings if they wish and that the finding would be given to specialist midwives, HIV support groups and by direct contact with me. I also arranged a number of workshops to present findings to the stakeholders and several participant women did attend to view the findings with their anonymised data.

3.2.19 Conclusion

This concludes the research design and governance process and demonstrates “how it was practically achieved” but also the benefits and non malevolence of the study. This will reassure the reader of the steps I have taken to uphold the governance of the study and that the process had rigour. Section three will explore the ethical considerations and how the requirement and principles are ingrained in governance of this study.
3.3 SECTION THREE: ETHICAL CONSIDERATION

3.3.1 Introduction to Section Three

The third part of this methodology chapter presents the important ethical considerations of the study and the specific processes followed to maintain research governance with this important aspect. Women with HIV are a vulnerable client group and measures were taken to support women in the research process. Whilst some aspects may be repeated here from the research design in the first part of the methodology section, it is imperative that specific ethical considerations need to be explored further in this section, as the study must be ethically sound and ethical consideration were paramount. During this section, I will explore the issues of harm and distress, consent, confidentiality and ethics and research and development committees’ experience.

3.3.2 Harm and Distress- Managing Difficult Situations and Strong Emotions

Harm to participants must not occur and recognition is necessary throughout the research process. Whilst this research process did not cause physical harm, it had the potential to cause psychological harm (Polit & Beck 2008). As an experienced midwife I monitored psychological and physical wellbeing by remaining intuitive to any distress and had recourse to additional expert support. This was explored verbally with women and in the participation information sheet. Women were made aware they could stop the recording at any time. After the interview, I feedback any concerns for the participant’s wellbeing to the HIV specialist midwife or HIV support worker, but the interview content was not divulged. I felt one participant had unresolved issues with reliving the experience and would perhaps benefit from intervention but consent to share was forbidden which I respected as she had recently raised this issue with her support group and I gave her information to seek further help. Awareness of distressed women being upset when recalling their HIV testing experiences was an important aspect of this interactive process for me. A number of women did become tearful but whilst aware they could stop the interview, when offered this during a tearful expression of emotion, they did choose not do so but carried on talking with “occasional tears” during the
interview process. Women were reminded that they could terminate the interview at any time (Campbell et al. 2009). No participant took this option when offered. The interview questioning was amended and issues were not further explored if distress became apparent, but often women returned to the issue later and this was evident with stigma or abuse. Simply, the interview and discussion and were led by the women (Lee 1993; Campbell et al. 2009). One woman expressed unresolved anger at her former partner and that he had infected her. However, she refused referral or help at this time when offered, but was made aware of the further help and additional services that were available (Campbell et al. 2009). I asked how I could assist her to help resolve this issue, but she responded that it was her issues and she would, in time, deal with this anger towards her former partner. If distress was evident then the interview was halted and no further questioning was made until the woman felt able to precede further (Campbell et al. 2009). Equally a number of women noticeably laughed on a number of occasions as they reflected on their experience. The women were aware they could say no and not answer any aspect if they wished. The chosen methodology allows the use of a semi-structured interview schedule. However, van Manen (1990) is critical of “idle chit chat” which he states fails to explore the phenomena under exploration. He endorses the use of a semi-structured interview as whilst he endorses a free flowing conversation, he insists it must have some structure to elicit the meaning of the experience. I used this schedule to gently guide the topic but not dominate the discussion and abandon or moderate questioning if distressed. Also as issues with testing became apparent, such as self-harm, these were later incorporated into the interview schedule. Also, the interview schedule allowed women to choose if they wanted or not, to discuss issues that may have the potential to distress them.

If required, I was able to refer participants to other health and support professionals and HIV groups, if I or any of the participants with consent, felt they needed help to deal with their testing and pregnancy experiences. Steen & Roberts (2011) acknowledges referral to others as an important consideration in the research process. I had additional support from my academic supervisory team and as a registered midwife, a supervisor of midwives. A rigid interview schedule was rejected as this may have forced participants into answering questions they felt perhaps exploitative and uncomfortable with answering (Darra 2008). This was previously explored (3.2.13.2 second meeting). I ensured that my approach during the discussion was open, friendly, facilitative and
confidential (Campbell et al 2009); this I believe allowed the participants to build a
degree of trust with me during this very personal interaction. Gentle probing was
practiced but I remained acutely aware if aspect of the discussion were becoming
uncomfortable and not viable for further exploration (Campbell et al 2009). Van Manen
(1990) and Campbell et al (2009) maintain the exercise of talking about an experience
may be therapeutic to participants if sensitively managed. This was confirmed a number
of times as women often said to me that they found it very useful and enjoyed talking to
me about their experience.

3.3.3 Valid Consent

Valid consent is an absolute requirement for research (Polit & Beck 2008). Clear written
and verbal information on the nature and purpose of the study is essential to ensure
participants understand what the study will entail for them personally (Bowling 2002).
The overriding principle was that participants were given adequate time to consider if
they wished to participate. This included time to consider participation which ranged
from first being made aware of the study, being given written information and from the
first meeting and the later interview. The benefits for others (but less for self) were
discussed. It is important that the information is communicated in a form that
participants can understand without undue complexity. Translation services were
available due to the demographics of the sample. The population were Black African in
origin but living within an inner urban city. Due to the vulnerability of the sample it was
essential that information was first easy to read and secondly all written information
was also verbally discussed face to face. This was to ensure participants with perhaps
poor reading and writing skills, understood what participating in the study would
involve or entail. This face to face discussion was undertaken by the HIV specialist
midwife or by me in the first instance and later in-depth always by me.

The research ethical committee and the research and development committee for the
participating units in the study gave written approval for the study. In NHS recruitment
sites, initial verbal consent was gained by the hospital HIV specialist midwives and
again later by me. I met with HIV specialist midwives at each unit to discuss the study
and their role in identifying potential participants for the purposive sample of women
diagnosed HIV positive in pregnancy. The specialist midwives had written information to refer to regarding the study and the sample required. The HIV specialist midwives then selected and gave written information to potential participants about the study and if able to initially give written consent. The women either contacted me, directly and I met them if they decided to participate or a number agreed to be introduced personally by the midwife at a first pre-meeting. The specialist midwives at the NHS sites had an intense and in-depth relationship with the women which were noted to be extremely protective, kind, supportive and caring. This was reassuring in that they had the women’s best interest and wellbeing at heart and would not allow any pressure to participate. However, both I and the specialists noted that women who participated really wanted to tell their story. This was facilitated by this third party referral by the specialist midwives even if the related testing experience findings were poor and perhaps detrimental (see 4.2.3.4 poor care instances). I fully recognised that this gatekeeping role by the specialist midwives may have had a detrimental effect, but it is my opinion it did not and that due to the potential vulnerability of the sample it had a positive protective effect. I, the specialist midwives or support workers fully discussed the study with potential participants and answered any questions that participants may have had on the first pre-meeting interview. A date and time were agreed for a later interview. This ranged from a minimum of one week and sometimes often longer. This gave participants time to consider and withdraw.

What was apparent was that women were very eager and wanted to relate their story at the first meeting if I was present but were dissuaded until the later interview to follow the research protocol and maintain high ethical standards. This restriction perhaps did not cater for their personal need to immediately tell, but I fully accepted the greater good of allowing time for consideration and consent. One woman wished to be interviewed at the first meeting, I arranged to meet her after one week to tell her story but this still gave her time to consider implication of participating. Her expressed view was that;

“I got a lot less information before the test, so can we do it soon please” Anna

The overall effect was that participants had the first meeting with the specialist midwife, third party HIV support worker or me and a second meeting with me alone. One
potential participant did initially withdraw as she felt unhappy that her voice would be digitally recorded and this she felt may identify her to others. Later she contacted the specialist midwife as she wished to “tell her story”. Women were given the opportunity to be interviewed at home or at the host research unit. At Non NHS recruitment sites the same principle applied and women were given time between the first contact, first meeting and the second meeting and interview.

At all the interview locations whether at home or NHS sites the same principles applied, on meeting me all of the women were given a second opportunity and given the same information participation sheet and given time to read it again. I ensured they had read and understood the information in the sheet and answered any further questions. The reinforcing of the content of information at different stages of the process would help to ensure they were comfortable with the implications of taking part in the study. I obtained written consent or if already obtained from the participants by the specialist midwives or me. I checked valid consent before digital recording commenced. Written signed consent was not only signed to participate in the study, but consent was completed for the use of quotations obtained and for use in research reports, as this was specified by the research ethics committee.

3.3.4 Confidentiality

Confidentiality is at risk of being breached and identifying participants and damaging the research process during publication and dissemination of the research findings (Murphy et al 1998). To mitigate and reduce risk, pseudonyms were used throughout this study to protect confidentiality and during the process of analysis (Murphy et al 1998). The participants could choose one (all did) and if they had not would have been allocated one by myself, as the researcher. Due to the small sample of participants, there is an increased risk of women participants being identified, therefore it is important to maintain confidentiality and women’s anonymity. It was important that participants remained confident with both the concept and maintenance of confidentiality and importantly fully trust the research process with this principle. At the beginning of the interview the importance of confidentiality was discussed, all of the participants agreed to keep the discussions confidential and not divulge any identification of others such as
other women known to be HIV positive by name and to use pseudonyms for themselves and others including their own children. The interviews were recorded using password protected digital audiotape. The first three verbatim interviews on the tape were transcribed by me as soon as possible to assist recall. This transcribing whilst useful, took up to 3 weeks for each interview as I was often time constrained arranging first meeting and later interview dates. To ease the time frame and “personal stress” of balancing my work commitments and transcribing the narrative, later verbatim from subsequent interviews was transcribed by my personal assistant (PA). I understand it may have had some negative impacted but this allowed me increased time to analyse data. I did quality assure and check all transcripts for accuracy and complete the 6th and 12th transcripts myself. It was made clear in the information and verbally that they were able to withdraw from the study at any time and that this would not affect the care they were receiving. Data was kept within a locked cabinet on NHS premises or security password protected on data files. Participant identifiable data such as the consent form was kept locked, separate from study data. All data was stored and collected by myself only to protect participant confidentiality. I reimbursed travel and child care expenses to the participants who attended for interview.

3.3.5 Ethics Committee Experience

Ethic committees are essential to the research process and without ethical and research and development approval access to NHS patients or former patients for research will not be viable. Many ethics committees today are now required to show understanding of different types and styles of evolving qualitative research and not fixed on the positivist paradigm (DOH 2001). The process had noticeably changed as my previous Masters study was considerably delayed and objection arose due to the subject of HIV (I persisted, attended in person and with tenacity made no changes with that study before approval granted). I was expecting to valiantly defend my study due to the sensitive nature of the study but on this occasion this was not the case, the committee which I attended in person were very supportive. The committee consisted of ten members, who introduced themselves. I was asked seven questions, which were straightforward; one was asked by a qualitative researcher. I felt that they all understood the relevance of my study and the chair of the committee stated he felt that the study was worthwhile. One
of my supervisors attended the ethics committee for support but took no active part in committee proceeding.

My application to the Ethics Committee was approved after only minor modifications to the participation information sheet in December 2010 (see Appendix 13). I had worked on the fine detail of the NREC application, research protocol and the required appended further information. This included consent forms, letter of sponsor, participation information sheet, demographic sheet and interview schedule. I committed a considerable amount of time in this specific research process before submission which aided the committee. Also attending in person to discuss issues and show my commitment to ethical principles of this study may have assisted with the application and final approval.

3.3.6 Research and Development Experience

I applied via NREC database, to all 3 NHS sites for research and development (R & D) approval, which whilst procedurally slow was forthcoming. Host Site (A) was the research site and required full approval and site B and C were participation identification and referral sites and referred to site (A). The R & D staffs were very helpful in this process and communication was maintained throughout the research process.

3.3.7 Conclusion of Section Three

This concludes the section exploring the ethical considerations and the practical steps taken to protect women during this research process. Women in this study were protected and cared for sensitively and ethically as they informed me about their experience of a HIV diagnosis. The women were paramount and integral to the findings and needed to be honoured, cherished and treated with upmost respect, dignity and kindness.
3.4 CONCLUSION OF METHODOLOGY CHAPTER

This research topic required sensitivity and the methodology chosen was therefore highly suited to this human science research. This interpretative approach also complements the philosophy of the midwife being ‘with woman’ and giving holistic and individualised care based on the women’s physical, social, psychological, emotional, spiritual and educational needs. The research paradigm must also respect these caring attributes as they have the potential to make a difference with the caring experience. Women need to be safe and secure, their privacy and dignity respected, confidently maintained and have time to consider if they wish to participate. The conclusion of this chapter enables the reader to understand the concepts and influences that have impacted on the development and process of this research study. Also how it is explored and imbedded in this thesis but importantly that the women who participated in the study did so freely and safely. The methodology and method chosen was appropriate and importantly respected and sensitively questioned potentially vulnerable women as they gave me sensitive information. The approach optimised my chances of understanding the issues from the participant’s perspective so that essence and meaning could be interpreted. The women were essential to the methodology, method and the research design. Through this approach I was able to respect their contribution and enable women to engage and narrate their experience of testing HIV positive.
CHAPTER FOUR - FINDINGS AND INTERPRETATION OF THE STUDY

4.0 INTRODUCTION

In this chapter I will explore the phenomenon of transition and transformation which emerged from analysis of the data. This phenomenon is important and pivotal for this interpretative hermeneutic phenomenological study. This phenomenon gives meaning to the lived experience after the women received a positive antenatal HIV result and simply the phenomenon remains the focus of this study.

SECTION ONE - PARTICIPANTS gives an introduction to each participant and their life world. The phenomenon of transition and transformation is drawn from the women’s narrative.

SECTION TWO - FINDINGS, THEMES & INTERPRETATION is concerned with individual and common findings which arose from the women’s narratives, their interpretation and thematic development. The interpretative themes emerged from the rich narrative data and provide a greater understanding of testing positive and the emergent phenomenon. Primary and secondary themes are explored and presented individually and also grouped together as a whole under major thematic headings to aid understanding. Each woman was unique and had different experiences. These differences emerged as the women made sense of living with HIV and “being-in-the-world”. These differences are explored and presented in this chapter. The amount of verbatim text used in this section is deliberate, as it is my absolutist view, that the women’s voices should be expressed as near to their original form as possible. It is in this form that they most powerfully convey their meaning. From the narrative analysis, four major paired themes emerged. This led to an understanding of the overarching phenomenon. I have included the transcripts of the women with no corrections of speech or grammar to as closely as possible relay what the women actually said. Some of these transcripts contain harrowing and frank accounts of the women’s experience of
their HIV diagnosis which readers may find distressing. The contextualisation of the findings and discussion will be presented in the following discussion chapter.

4.0.1 THE PHENOMENON OF TRANSITION AND TRANSFORMATION

Each participant is a real, living and breathing woman; a unique individual who received an HIV positive diagnosis during pregnancy. Testing HIV positive was the “lived experience” for women. The essence and meaning of this lived experience was sought. The experience of being informed of the positive result and its later impact on women “being-in-the-world” was explored by an analysis of the narrative; however the important and dominant phenomenon of this study is the one of transition and transformation. This concept will be explored further in the discussion chapter but needs exploration here to help understanding of the findings.

Transition is the passage or moving from one state to another (Oxford Dictionary 2010). In this study, transition related to the developmental stages that the women passed through whilst transformed by their experience of testing HIV positive. This transition process consisted of women moving, developing and changing from one former life world or “being-in-the-world” where HIV did not feature to a transformed “new being” living with HIV. This transformation leads to a new status, to a different and changed life world and a “new being”. The transition and transformation is like a caterpillar turning into a butterfly; magical but explainable. In essence the caterpillar is the same being but in a new form and ultimately changed. This phenomenon of transition (moving) and ultimate transformation (change) consisted of adjusting to this new and different life of living with HIV. The specific experience of an antenatal HIV positive result was the catalyst and ignited this transition and transformation process. This process is one phenomenon, which is linked and is paired as one does not occur without the other, simply transition (moving) has to occur for the transformation (change) of “being”. Other life experiences, such as violence or abuse, impacted on the transformation of the woman’s “being”. Women often appeared unable to move on until they had received the infant’s HIV result and remained in limbo until they knew this outcome. The phenomenon of transition and transformation, as women moved from one
world to another, was with enormous personal loss and pain. The transition and transformation was, and is, an ongoing evolving and adaptive process and is affected by the woman’s resilience. For some women testing positive, issues and themes remained at the time of interview. They all balanced these issues in their lives, often requiring most energy at the time of diagnosis and becoming less as time passed. The transformation was not completed for some women and may never be so while the challenges of living with HIV remain. Importantly this study demonstrated all women have been transformed (changed) in some way by their diagnosis. For the majority of women, the diagnosis was a cataclysmic event. All the positive results were unexpected and women experienced personal shock, even though a small number had a suspicion that something was wrong. All women were informed of the diagnosis in-person except one who read her result which had been left on a desk. Time was crucial to the process and as time progressed, abatement of the acute distress occurred as women began to make sense and have a growing acceptance and understanding of their HIV infection. They developed personal resilience in dealing with their HIV. This growing understanding was in part due to the health benefits of medication for themselves and for their infants. Women made many adjustments to their “being” in this new life world and understood many aspects of their transformation.
4.1 SECTION ONE-PARTICIPANTS

4.1.1 Participants Life-World

At the time of interview each participant gave an outline of their temporal and spiritual existence within their life world. Each participant’s life world was explored with the women participants during the interview. Each woman chose a pseudonym and only I know of their real names. I accept some women were more powerfully positioned than others and this was apparent in the command and expression of the English language. Narrative was more powerfully expressed by some women and van Manen (1990) accepts this. I do not excuse my use of the best expression of narrative to illustrate my findings but all were considered important. Women are referred to by their pseudonyms in the findings as they are all important contributors and this naming helps them stand out as individuals.

4.1.2 “Clara”- Interview 1

Clara was born in Nigeria and lived with her immediate and extended family. Whilst in Nigeria she went to primary and secondary schools. She then went on to complete a Higher National Diploma in Marketing in Uganda. She met and married her former partner in the UK and for the last 8 years has been a support worker for people with learning disabilities. Her antenatal diagnosis was recent in 2010 and at the time of the interview eight months had elapsed. Since her HIV diagnosis she had separated from her partner and she classes herself as single and unsupported. At the time of her diagnosis she had three living children including a pair of twins. Her HIV diagnosis occurred in her fourth pregnancy at the age of thirty nine. She had an emergency caesarean section for ante-partum haemorrhage and not for HIV diagnosis. On the day of the interview she had met me after a six week paediatric clinic appointment receiving a negative HIV result for the baby. This HIV diagnosis, being recent, she described as ‘raw’. She was motivated to tell her story but was adamant that once told she did not wish to be re-interviewed at any point. She maintained “telling this is important for me.” She remains on antiretroviral medication. Clara was referred by Unit A and asked to be interviewed at this Unit.
4.1.3 “Julie” - Interview 2

Julie was born in Nigeria and remained there for her formative years and schooling. She had a primary and secondary education in Nigeria subsequently gaining a higher education award of a BSc honours in economics. She came to the UK marrying her partner here, who she continues to live with. She is a support worker in a day centre for the elderly. She had an antenatal diagnosis of HIV in 2004 at the age of thirty one. At the time of interview she was thirty-eight years old. She reports that she has only had two previous partners, including her husband, and that both are HIV negative. Julie maintains that her HIV infection was due to a previous termination of pregnancy in Nigeria as she required a blood transfusion after the procedure. Julie has three children; her first two girls were normal births and the last child was born by elective caesarean section at thirty weeks for repeated ante partum haemorrhage. All her children are HIV negative. She remains on antiretroviral medication. Julie was referred by and interviewed at Unit A.

4.1.4 “Anna” - Interview 3

Anna was born in Uganda and remained there for her formative years and schooling. She had primary and secondary education in Uganda, achieving a Diploma in Nursing. She lived with her close and extended family. She came to the UK to marry her partner and has since separated from him since her HIV diagnosis. She is currently completing her final year of a BSc honours in Nursing in the UK. She was thirty at the age of her HIV diagnosis in 2008 and was aged thirty-three at interview. She was HIV diagnosed during her second pregnancy. Anna stated that blood was taken during her first pregnancy for HIV testing but this was not carried out. She then went for her “second” routine HIV test to discover she was HIV positive. Unfortunately, as she states in her interview “I knew my first baby boy was positive as I had breast fed him.” Her second baby was born by elective caesarean section at term and is HIV negative. It transpires that she won damages for lack of care in her first pregnancy. She remains on antiretroviral medication. She further reports that her first child is questioning her as he
too is on antiretroviral medication and he states “I do not need this Mummy, I am not poorly.” Anna was referred by and interviewed at Unit A.

4.1.5 “Grace” - Interview 4

Grace was born in Uganda and lived with her close and extended family there. As an older teenager she had the opportunity to come to the UK, believing she was to work in a “big house”. It transpires that she was taken to a “big house” but was trafficked, and in her own terms “was used and was a prostitute.” She refused to use the term ‘sex worker’. She remained in the “big house” living a subsistence existence with no money and no friends or support. She lived in isolation and seclusion whilst being exploited. Her highest educational achievement was reaching the third year of secondary school. She has never worked legally and cannot work whilst she is seeking asylum. She specifically asked to be interviewed at the home she shared with her partner and three year old son. They all live in a multiple occupancy house in one room, sharing all other facilities. Grace maintains that she became pregnant whilst in the “big house” and concealed her pregnancy for a while, but then was expelled from the “big house” once her pregnancy was apparent. She lived on the streets for three to four weeks in total isolation with no means of subsistence. At twenty-seven weeks of pregnancy a street worker noticed that she was pregnant and referred her to the Poppy charity which supports women who have been trafficked into the UK. They immediately referred her to a local maternity unit where an HIV test was performed on the antenatal ward by a specialist midwife. The HIV result came back positive. She immediately commenced medication and three weeks later had an emergency caesarean section at thirty-one weeks for poor fetal growth. She was twenty seven years old at the time of diagnosis and twenty nine at the time of interview. This child was HIV negative. After the birth of her child she met her current partner who is fully aware of her HIV diagnosis. They decided they wanted a child in this relationship and Grace decided that they would opt for a normal birth and trial of scar (vaginal birth after Caesarean - VBAC). Grace maintains that she was told to present early to the hospital when in labour which she did. Issues arose in that she maintains she was not monitored or admitted to the labour ward. She ruptured her scar leading to an emergency caesarean section and fresh stillbirth at term. She remains on antiretroviral medication. She states the following “it’s
not HIV that’s the problem - it’s losing my baby”. Grace was referred by unit A and asked to be interviewed at home.

4.1.6 “Martha”- Interview 5

Martha was born in Nigeria and lived with her close and extended family there. She remained in Nigeria for her formative years and schooling. She came to the UK to marry her present partner. She had a positive antenatal HIV diagnosis at the age of twenty four. She was thirty six at the time of interview. She was diagnosed at the beginning of the antenatal testing programme and twelve years had elapsed at the time of interview. She was diagnosed in her first pregnancy. She works fulltime as a chartered accountant and achieved a BSc (Hons) degree in accounting and financial services since her diagnosis. She reports that after her diagnosis her partner was initially supportive, but then became abusive and violent. They separated for six months but she states he returned once they had completed counselling, which she describes as very successful and they are now reconciled. She then went on to have two miscarriages and finally, at the time of interview, she had had a normal birth of a second baby which she states she would not have done if there were still issues in her relationship. Her first baby was elective caesarean so she opted for VBAC in her last pregnancy. She reports that she is well on antiretroviral medication. Both babies are negative. Martha was referred by and interviewed at unit A. (Full transcript of interview is in Appendix 14).

4.1.7 “Cindy” - Interview 6

Cindy was born in South Africa. She was previously married and had a seven year old son from this relationship. She had an antenatal HIV test in her first pregnancy and was negative. She commenced a 3 year degree programme but did not complete the last year due to her father’s sickness. Cindy came to UK in 2001 and met her present partner four years ago. Cindy works in NHS as a clinical co-ordinator but is not a nurse. She had an antenatal HIV test in 2010 during her second pregnancy and was diagnosed then. At the time of interview she had been diagnosed for 1 year and she was 35 at the time of the interview. Cindy’s present partner is HIV negative. She reports her previous partner and first son’s father “cheated on her” but reported he was HIV negative when he tested
positive for Syphilis a little later after the birth of their son. She thinks she was infected after this time but admits she had “not always taken care”. Cindy reports her present husband as very supportive and kind. She wished to be interviewed at home as this was where she was comfortable and stated she loved her home. Cindy reports her 7 month daughter was a “natural birth” like her son as her viral load was undetectable. Cindy reported a strong faith and optimism and that she had an Aunt and friends who have HIV which was helpful. She stated it was important to know her status “as HIV is not the killer but AIDS.” She reported she was able to support her sister with her recent HIV diagnosis in South Africa where she reported stigma was less and that people were happy to know their HIV status. She says this is down to the South African Government’s health education system. Both children are HIV negative and Cindy remains on medication. Cindy was a self referral as she saw the national advert but previously had had her baby at unit A.

4.1.8 “Jane” - Interview 7

Jane was born in Nigeria. She was educated in Nigeria achieving a BSc in finance and Masters in management and came to the UK to be with her partner. She looked after her much loved uncle who died of AIDS. She discovered this by reading his hospital notes but never told him as she wanted to care for him. She has worked in marketing in Nigeria and health care provision in UK but is presently not working. Jane disclosed she has no leave to remain in UK and this is a constant worry as she cannot work and if returned she would have no resource to medication. She was diagnosed in her first pregnancy in 2009 age 29 and was 32 at the time of interview. Jane had a second baby after her HIV diagnosis which was unplanned as the condom had broken and that this was a “miracle” as sexual relations with her partner were reduced due to his concern about HIV as he was negative. She separated from her partner in January 2011 citing HIV as the cause. Jane did not inform her partner for 6 months after her diagnosis as she felt he would leave her but she felt pressure to inform him. He was initially supportive but this diminished. Both infants were born by emergency caesarean section for failure to progress and not for HIV. She has a boy and girl and her partner has made limited contact with his children. Both children are HIV negative. She blames her infection on a termination in Nigeria. Jane attends a number of HIV support groups and church where
she has made friends. She lives in shared housing and asked to be interviewed at Unit A
for privacy. Jane had met me previously at a workshop at positively UK however her
pregnancy care was in a North London unit. Jane remains on medication.

4.1.9 “Mary” - Interview 8

Mary was born in Nigeria. She achieved a BSc with honours in economics in Nigeria
but did not work after qualification. She met her husband 8 years ago. Mary came to the
UK to marry her husband in February 2010. She booked late in her first pregnancy and
was recently diagnosed in September 2010 at the age of 29 and was 30 at the time of the
interview. She had a planned Elective caesarean section as she booked late with a recent
diagnosis and medication having had only a recent affect. She had a boy who is HIV
negative. Mary reported that her husband was HIV negative and that after her diagnosis
he reported that should he be negative he would leave her. This he did. Mary cried as
she recounted this. Mary disclosed that prior to her marrying her husband she did not
think he would marry her so she had commenced a relationship with another man who
she believes infected her with HIV. Her husband disclosed this information and her HIV
infection to her family who disowned her as shameful and her partner’s family were
hostile and paternity was disputed by her husband and his family and they disowned
Mary having no contact with her or her son. She was left with no support but attends
church sharing her diagnosis only with the pastor and the friends she has made at
Positively UK. She lives in shared accommodation. She stopped medication after her
son’s birth and remains stable. Mary described herself as lonely, however she was
adamant she was much stronger now. Mary had her care in a North London unit and
asked to be interviewed at Unit A. I met Mary previously at a workshop at Positively
UK.

4.1.10 “Beauty”- Interview 9

Beauty was born in Lagos in Nigeria and achieving a first degree in Management. She
later came to UK, undertaking an NVQ level 3 in health and social care and work in
forensic mental health settling vulnerable clients back into the community. She met her
former partner who she described as violent and had mental health and behavioural
issues. Beauty reported him often hitting her around her head until she was unresponsive. She described him as a “bad man”. She became pregnant having an HIV test but decided on a termination due to his poor mental health and wellbeing. When called back in 2003 to discuss her “result” she at first declined, as she had terminated the pregnancy and no longer felt any results were relevant. She returned after the persistence of staff but was already pregnant a second time. She was informed of the result and decided to keep this pregnancy after being made aware of the excellent non-transmission outcomes for infants. However Beauty decided not to tell him as she feared him and had already decided the relationship was damaged and at seven months of pregnancy separated due to his violent behaviour, drug taking and in Beauty’s term “constant womanising”. He returned to see the baby when 3 months old but has had no contact since which Beauty described as a “relief”. She was 32 at diagnosis and was aged 40 at the time of interview. Beauty maintains firmly that “HIV is her business alone” and maintains she controls disclosure, which is rare. She has only recently informed her mother of the diagnosis, but her mother is supportive. Beauty also reported that she had only been recently informed of Positively UK and wished she had been informed of its existence earlier. She recently met a friend at a meeting and both were surprised to see each other at a HIV support meeting. Her baby is HIV negative. She stopped medication following discussion with her HIV team. She has no current partner and described difficulties and issues in telling someone special or new of her infection. Beauty asked to be interviewed at Unit A, but incidentally had her maternity care at Unit B. This was also a confirmed snowballing referral with her friend informing her of this study. Her friend was originally found to be ineligible when I met with her as she was diagnosed some time after the birth of her children but said she would inform her “good friend” Beauty, as she would be interested.

4.1.11 “Justina” - Interview 10

Justina was born in Nigeria, completing her primary and secondary school education with a secondary school certificate. She came over to marry her partner but this did not transpire. She had her HIV diagnosis in 2008 aged 24. Justine was 27 at the times of interview. She reports she had a termination of a twin pregnancy due to partner pressure of her HIV diagnosis. In 2009 she became pregnant again with full support of her
partner who was HIV negative, who then asked her to terminate the pregnancy as he had been informed the baby would be positive. Justina refused and they separated and on his return to Nigeria, she was informed by his family that he had been killed whilst she was 8 months pregnant. This was devastating for Justina, as she maintained “my child will never know his father”. Justina become tearful whilst recounting the story of her loss of her former partner. She planned for a vaginal birth as she was on HIV medication but her blood pressure rose due to her reported stress and distress at being alone and had an emergency caesarean section. She is seeking asylum and lives with her son in a shared house in North London with shared facilities and lack of privacy. Justina reports she is unable to work at present but has helped friends with informal child minding. Justina is well and remains on HIV medication. Justina was a self referral after hearing of the study from her friend and was interviewed at Unit A.

4.1.12 “Fumi” - Interview 11

Fumi was born in Nigeria and completed her primary and secondary education there. She attended Technical College undertaking a skills-based course in weaving and textiles. She had two children aged 20 and 15 at the time of the interview; her 15 year old daughter lives in the UK but does not reside with her. She came to UK in 2007 and planned to marry her new partner in 2009 but this did not happen. She became pregnant with her third child at the age of 37 and had an antenatal HIV diagnosis in April 2010. Fumi was 39 at the time of interview. She had the offer of a vaginal birth but decided on an elective caesarean section as she was concerned about infant transmission. She separated from her partner “not due to HIV” but he was known to social services and she made a choice that she wished “social services to get out of her life”. Whilst Fumi declined to discuss this issue further as she stated she knew the choice she had to make to keep her daughter. He has supervised contact with his daughter. She described how she refused to tell him of the HIV infection despite pressure to do so. She reported she was grateful to the midwives, who helped conceal her medication during pregnancy and whilst in hospital. On returning home with her baby she left out her tablets and he internet searched them. Then she sat him down to tell him when he questioned her. He tested HIV negative. He promptly told all her family however, they were supportive especially her brother. She asked to be interviewed at home in her one bedroom flat in
North London where she lives with her daughter. She remains on medication. She self referred after being informed of the study by her friend.

4.1.13 “Bola” - Interview 12

Bola was born in Lagos in Nigeria; she described herself as Muslim. Bola completed her primary and secondary school education and worked in hairdressing. She came to UK to be with her partner and received her antenatal HIV diagnosis in 2002, aged 33, during her first pregnancy. Bola was 40 at the time of interview. Her partner was initially supportive and HIV negative and left 3 months after the birth of her son. On leaving Bola he informed both families of his reason for leaving and doubted the paternity. Later DNA testing proved him to be the father, but she declined to have contact with him. She was desolate with no immediate family and friends she no longer could meet as they knew her “secret” she reported this disclosure as a betrayal. She now lets him have telephone contact with her son who is now eight but remains wary what he may say to him. After her separation Bola claimed asylum and was required to move out of London and was cut off from all her support networks. Bola made friends with another woman from Positively UK and moved back to London with her baby. She was later granted asylum and moved to accommodation in one room. Bola met her second partner who was also HIV positive and had two more planned children all by caesarean section. Bola separated from him, 18 months ago as the incidence of domestic violence increased. Bola stated that “you shouldn’t get together because you have the same virus. Bola was referred by and had all her care at Unit B but also independently self referred from Positively UK. She asked to be interviewed in Unit A. Bola remains on medication.

4.1.14 “Rose” - Interview 13

Rose was born in Nigeria. She completed her primary and secondary school education and achieved an Ordinary National Diploma in insurance but did not work as an only daughter with five brothers. Rose was diagnosed with HIV in her first pregnancy in 2007 after coming to the UK with the intention of marrying her partner. Rose remains with her partner but they have an informal relationship and did not marry after her
diagnosis as planned as he is HIV negative. Rose reported she did not understand what was being raised when she was recalled for the result as she was unaware she had been tested for HIV as this was not implicit. However she accepted on reflection she was better off knowing but reported the impact of her diagnosis as a major life changing event. She said she knew where she had got her infection as her previous partner had died of probable HIV/AIDS. She thought she would be dead within 10 years from the experiences from her own country. It was a revelation to Rose, that on attending an HIV support group she met women with a 20 plus year history of HIV. She was angry this had not been fully explained. Rose was 25 at the time of diagnosis and was 29 at the time of interview. Rose had an elective caesarean section. She informally lives in her partner’s relative’s social housing flat with her daughter and accepts she is vulnerable with this housing arrangement. However she was pregnant for the second time from the same partner at this interview and was referred by and is receiving care from Unit B but was interviewed at Unit A. Her partner is supportive but ambivalent about this pregnancy, but she stated she wanted the baby even if he should go. She is of the view HIV has ruined her chances of marriage for now. She asked to be interviewed at unit A for privacy and was also aware of the study from the HIV support group Body and Soul. Rose has restarted medication during this pregnancy and has become an expert in concealing it from her friends who remain unaware of her diagnosis.
4.2 SECTION TWO- FINDINGS, THEMES & INTERPRETATION

This section presents the findings of the study and the emergent themes that were apparent after completion of the analysis of the verbatim narrative and review of the field notes. The essence and meaning was explored with women during the interview as, due to their African accent, interpretation of meaning often had to be clarified and explored. This was further studied later with analysis of the transcripts. In isolating thematic statements and conducting thematic analysis, each sentence of the transcript was examined for meaning to become familiar with the emerging preliminary basic themes and meanings. These first themes were further categorised to summarise more abstract principles or later secondary themes and meanings which in turn were reinterpreted in the light of the preliminary basic themes, informing the major themes which emerged from the verbatim texts and audio recordings. Although presented separately, overlapping themes were apparent and sometimes difficult to disentangle. A neat thematic fit is not always possible or desirable as the women weaved several themes in the narrative (van Manen 1990).

4.2.0 THE FOUR MAJOR PAIRED THEMES

Four major paired themes emerged from the data, which help capture the meaning and essence of the narrative. The pairing of these major themes is deliberate as they were symbiotic and interwoven in the data. The themes are bound with the phenomenon of transition and transformation.

They include:

- Shock and Disbelief
- Anger and Turmoil: Loss of Old Self
- Stigma and Confidentiality
- Acceptance and Resilience
4.2.1 THEME ONE- Shock and Disbelief

The exact moment of being informed of the diagnosis had profound meaning for women. All but one woman received the result verbally in person. Most women were recalled to clinic for their results; one woman received her result as an inpatient on the antenatal ward. Women were all on their own when they were informed of their diagnosis by the health professional (usually a midwife). The moment the positive test result was given was indelibly imprinted in the women’s memory. This result was distressing and cataclysmic for the majority of the women; its impact immediately life changing for her and her partner and extended family. The shock was described as immediate and its effects long lasting. Women retained strong memories of the intensity of this shock. Being informed instilled a sense of shock and was recalled as ‘shocking’. The effects were variable in duration for women, but whilst vividly recalled, the intensity dissipated over time. Importantly, a number of women did not believe the result to be true.

4.2.1.1 The Exact Moment of Being Informed

The exact moment of being informed of the HIV diagnosis and their initial reaction is vividly reported by women, whilst mixed with the themes of shock and disbelief which will also be examined, it is worthy of exploration as an individual theme. The women often painted a picture of trepidation and anxiety in the moments whilst they awaited the result. Some women were suspicious of there being a “problem” as they had been called back to clinic, others thought the call to return was routine and had no idea of a potential problem. However, the HIV result which was reported by all participants as unexpected and distressing but importantly, the starting point for the phenomenon of transition and transformation. It is this unexpected HIV result that changes everything for the women, HIV is now in the women’s life, simply there is no going back and being informed of the result was vital for the transition and later transformation of “being” and living with HIV.
Julie gives a detailed account and recalls the exact moment clearly and the effect was emotionally painful:

“I went to the station and they said wait there and I waited and the midwife came and took me inside and then they said to me,............. and they explain to me that all the bloods are fine, all the results in the blood test are fine except one, then I said which one? And I looked straight into her eyes, which one? What is wrong with it? she said, sorry about this but you are HIV positive and I screamed and I shouted AIDS, AIDS, AIDS and she said no, no stop it, it’s not AIDS, I need to talk to my husband, stay with me don’t call your husband.” Julie

Julie’s shouting and screaming ‘AIDS’ is profound. The full horror of this news was too much to contain and she could not hold back. Anna also remembers being informed and her initial reaction; she simply stared at the midwife as she tried to comprehend the news. Anna was questioned further about how she was informed:

“She said, I’m sorry, I’m sorry to let you know, I’m sorry to tell you this but that your, that your results, you know that specifically the one for HIV came out positive.” Anna

This was devastating for Anna, her life was about to change and she knew it. Grace reported that the HIV specialist came to her hospital bedside to inform her of the diagnosis and she asked that the news was repeated so she could understand what was being said. Martha reported in detail her experience of being informed. Her initial reaction was to cry. She was concerned for her unborn baby:

“I think there were two people in the room I think one was a midwife. I can’t remember but there were two people in the room and they talked about my tests and they said well, one of the tests was an HIV test and I’m afraid that the results have come back positive and I just started crying from there and err and I asked so what’s going to happen to the baby so they explained that the baby could still go on to have a healthy baby” Martha

Like many of the women, being informed that they were HIV positive manifested itself physically, as well as emotionally. One woman, Fumi, stated that she felt like she was going to die, that death was ‘lurking’ in the room. Cindy remembers the moment with great anticipation and her heart was pounding and she was asked by the midwife not to panic or worry. This offered reassurance but longer term it would not as she did worry for herself and the baby. Women’s recall of the moment and the events and feelings
leading up to the news was strong and was imprinted in the memory of women. They were simply able to recall the exact moment with clarity and recall their reaction and the effect on them. This interpretation for the meaning, suggests that it was seared into the memory, and like many traumatic events replayed time and again. Post traumatic stress is implicated in vivid recall of personal trauma (Sherr et al 2011). The exact moment is replayed and causes repeated distress for some time after the event.

4.2.1.2 Initial Reaction to News: Shock and Distress

The initial reaction to being told they were HIV positive was immediate shock; this was commonly reported as traumatic and caused distress. For some women an extreme reaction occurred on hearing the news. Shock and distress are themes that resonate with that reported by Sherr et al (2011); to be discussed in the following chapter. Clara was not given the diagnosis in person; she read her diagnosis from a report that had been accidently left on the desk by the midwife. The midwife was unaware that the result was positive. On reading her positive result, Clara stated:

“I took it and read it, the blood test” and “I saw it and said what’s this HIV positive and then I started crying and rolling on the floor.” Clara

This indicated the awfulness of the result and the unfortunate way Clara received this result, Clara’s world had collapsed and rolling on the floor was an expression of the hopelessness of the situation, simply there was no escape from this personal nightmare as transition and transformation of her being commenced, transition had begun with real distress. Julie’s final transformation was some way a head in the future but the transition was not without pain. Julie also reported an extreme reaction of shouting on being told of her diagnosis, screaming she had AIDS which was not the case. Again Julie’s comprehension of this bad news can be interpreted that she saw her HIV diagnosis leading to AIDS and her probable death. Shouting was her only way of vocalising her extreme distress. A similar initial reaction is reported by Anna, all she could think about was her death and mortality. This was overpowering for Anna for her HIV had a meaning, of probable death:

“I don’t know how to explain it but at that very moment something just hit me, ok I could just imagine death straight away, as much as I’m educated I know, it’s you
know it’s a killer disease, you can live a longer life if you have medicines and stuff like that but at that moment it didn’t cross my mind that you can live a longer life and, so all I could think of was death, that’s it.” Anna

When questioned further her thoughts were also for her son. This interpretation is that Anna was fully aware of the possible repercussion for her son’s health and immediately saw the implication of her HIV diagnosis and the real impact it would have on her son as he was born before this pregnancy diagnosis. Grace reported her initial reaction with some distress which she felt she needed to control:

“She told me you are like this and you are HIV positive, I said what?... and she said it back to me. So I was like now, what should I do? Should I start crying? Should I start doing what? Fine I had a cry.” Grace

This illustrates the need to control her emotional response. Grace was being the mistress of her own emotions, and this governance is probably very difficult in a period of shock and stress. When questioned further, Grace controlled her reaction due to her concern for the unborn baby’s wellbeing; she needed to keep him from harm even though unborn. Grace reported that she was confused and tried to comprehend what she had been told which suggests she was unable to take in the full meaning of this news and could not understand fully what was being said as it was just too awful to contemplate. Jane reported physical and psychological symptoms as she reacted with shock and distress, her defensive reaction was not to believe it possible that she could have HIV and the thought made her ‘cold’. Mary reported that she was informed the test result was unclear (equivocal) and she had a strange feeling which she demonstrated by putting her hand on her stomach during the interview. Mary was retested and waited a whole week and whilst suspicious, did not believe she would be positive. Mary gives a detailed description of being called into the room but reports a confusing picture of information and you can sense the alarm in her narrative:

“They called me so I went to see the midwife, suddenly then I’m started preaching gospel telling me confusing words and I said please can I have an appointment with my GP, I just came to pick results up, they said we are coming to that, do you want a cup of tea, I said no, no I just want to get the information and go, she didn’t say go straight to the point.” Mary
Mary sensed something was dreadfully wrong but could not ‘put her finger on it’. The midwife did not help as she failed to get to the point and it took some time before Mary was explicitly told she was HIV positive. Her reaction was speechlessness that lasted twenty minutes. This interpretation was as if the ‘wind had been knocked out’ of Mary, simply she lost the power to communicate and no longer was able to vocalise her distress at the news of her positive result. The distress was there but she was no longer able to speak. Justina’s reaction was expressed by prolonged crying. The midwife tried to calm her down but she had this need to cry. Crying was a common outcome for women when told they were positive, it was often all they could do when shocked and distressed. It was the one emotion that allowed them to express their distress as they received the news they dreaded and little did they know they were now in transition as they moved from the old life and shock and distress was the first expression with a transformative journey as simply the old life slipped away and they had little control and demonstrating strong emotion was important as they mourned the old life. Fumi reported a similar initial reaction with screaming and physically rolling on the floor:

“I sat on the floor sat there rolling and screaming and she tried to hold me and tell me this is not the end of your life.” Fumi

Fumi reported the midwife holding her and being informed her child will be fine with available treatment helped Fumi to understand all was not lost. There was hope for a well baby and a long life for Fumi as she could simply see a future with her baby and this vision aided transition and her later transformation when confirmed with a good health outcome for her and the baby. This holding and closeness of another accepting human being, gave comfort in a time of extreme distress. The empathy and sympathy shown to women was an important anchor whilst distressed. Bola ran out of the room screaming as the intensity of the shock and distress was too much to bear. In essence for the majority of women, the reaction to the news was devastating, causing them to react in an extreme way. This reaction was variable but in essence was still one of distress, shock and devastation. The shock and emotional distress remained for some time after being told. Martha elaborated further on her initial reaction in a number of terms and emotions, she felt she could have died, her world had collapsed and she expressed this with real tears as it was very traumatising and emotional time. Martha reported that she lost the will to live and did not want to do anything. What was important was further information that her baby could be healthy:
“It just made me stop thinking of myself and it was just, because initially I was thinking there is no need the child will come out and be sick and probably die before me and things like that but when they said you can have a healthy baby HIV free completely ok that’s a positive side.” Martha

This news of a possible healthy child was new for Martha and liberating for some of her acute distress and probably aided her transition and transformation as simply it was vital and important information that forecast a viable future with her baby. This news is an important facet for making things seem a little better and gave Martha a reason to go on. Grace reported support from her consultant who offered reassurance and she felt she was not alone with her condition. This is a true statement but Grace in reality had no support other than the hospital staff as she had been in effect a virtual prisoner as a trafficked women. Grace reported she was surprised and shocked. This may seem strange as the transmission risk that Grace was exposed to would have been great:

“I was so, so shocked I couldn’t sleep and I was everywhere and I was what am I going to do and I was like am I going to die tomorrow but with time as I went talking to my Consultant and when I go there I find so many people coming there so I felt that I wasn’t alone” Grace

Grace reported shock and denial (denial is reported in next section) as she did not believe it, but was also able to quickly rationalise how she may have become infected. This interpretation is that Grace was probably aware of the risk she had been exposed to as an enforced sex-worker but personal relevance was dismissed as to shocking to contemplate:

“I was shocked, very, very shocked, I could not believe it, but I was like, since I was trafficked to this country, they are being, used me as a prostitute, so I said maybe that’s why, that where it came from.” Grace

It is uncomfortable that she uses the term prostitute, as the term is very emotive and brings a moral stance to this issue which was beyond her control. Cindy, Jane, Mary and Rose also reported their initial reaction as extreme shock with distress, often shouting or in Rose’s account, a quietness and speechlessness occurred; they simply could not understand what had gone wrong but in essence their life world had inexplicily changed forever. Beauty reported that her shock lasted and that she keeps remembering
the day which suggest that she repeats the event in her mind and probably had some degree of post traumatic distress (Bonanno 2009):

“It keeps coming back, I was sitting down, I was staring at the window, it was so it was a bad day.” **Beauty**

She described thinking she was in a dream that she could not believe, a sort of out of body experience. Beauty kept thinking of how she was told and she remained dissatisfied, with how the news was broken:

“I think it's as though I am dreaming, I didn’t believe it, I thought it was a dream, so I keep asking them no and I keep crying, I didn’t cry initially but it didn't sink in properly, and I keep and even after many years now I keep thinking, the way the news was broken to me I think about it.” **Beauty**

Beauty also reported emotional hatred; in essence she was enraged that this terrible event should have happened to her. Justina reported her shock of receiving the result and that she did not see the point of living. Essentially to go on living was now questionable and her life lost its meaning as the intensity of the shock overwhelmed her.

“I was very shocked, I started crying and I was like, I want this life to end. I don’t want to live anymore and lost sense of living.” **Justina**

Bola reported shock and was shouting and the midwife tried to hold her but she ran into the hall way which alerted her partner. This was the point that disclosure was no longer in her domain, she simply lost this as she tried to run away and escape. However, there was no escape for any of the women. In essence women reported that the result was shocking causing great emotional shock and distress and in essence their world changed at this point as they absorbed this difficult news. Transition and the transformation of being were now underway with no return to the former life. The world they knew and inhabited had changed and not into a world they wanted. A number reacted in an extreme and intense way. It was simply too awful to contemplate and women then did not believe it (See next section).

### 4.2.1.3 Initial Denial and Disbelief

Initial denial and disbelief with the positive result was a very common finding for a significant number of women. In essence, women could not believe the result; it was
false and simply not true. They did not want or even wish to contemplate this result as true or accept it. Essentially denial could not last and they were going to be ultimately transformed. Whilst this may sound remarkable, it is in keeping with Kübler-Ross’ model (1969, 2005) about understanding personal loss. It is a coping strategy and most women denied did not believe or accept the news because it was too awful to contemplate:

“I couldn’t believe it, I couldn’t believe it.” And “I just couldn’t believe, I didn’t know if I wanted to cry or whether to you know, but it was quite daunting really.”  
Anna

When asked about her understanding of the result, she understood the result but did not believe it to be true as she believed she had been tested previously (she had not been tested before as the hospital failed to test the sample of blood in that pregnancy) but importantly she did not believe herself to be at risk as she had only one sexual partner, her husband. But ultimately this is not protective. Clara would also not accept it to be true and denied the result as true:

“This was a terrible day for me because, I was like, no it’s not true, no it’s not true. I was having it in the back of my mind it’s not true”  
Clara

Later when the HIV team came to see her and tell her she absolutely refused to accept it was possible and denied it using a protective mechanism that it could not be her result, that some human error had been made. However, she quickly ascertained it may be true and she described dying inside as if the life blood slipped away and her hopes for her children ending as she will leave them. This similarity to death is a powerful narrative:

“When they called in the team, when they came in I said No this is not my result. It’s not true but I’m dying inside me. I’m crying, my mind just went to my children and oh so this is the end I’m leaving my children.”  
Clara

Clara still did not believe her result but could comprehend its potential impact and only really believe it when a confirmatory test was performed. Martha and Cindy reported they were unable to believe it and Jane had tears rolling down her cheeks but also could not believe this news. It was not possible they were simply undeserving and it was as if someone was conspiring against them to ruin their world. Jane later asked to be retested and when later blood testing revealed poor CD4 levels, this confirmed the initial result.
This confirmatory test when asked for was important with reinforcing the news and that their HIV diagnosis was real. Mary and Rose believed HIV was a disease of the promiscuous and not applicable to them. Rose also thought it may be an error in the identification of the sample. Mary had not been wayward so the result could not be true:

“Back home when we discuss a lot I never knew I would find myself in this situation, you understand so you know but when you discuss about, when you see people that are wayward.” Mary

Mary therefore could not accept she was positive, simply she could not be positive as she had done nothing wrong. Mary asked to be retested for a third time and she was retested and that she knew inwardly she was positive but she just wanted to be sure. Beauty also reported that she believed that HIV was a disease for prostitutes and gay men and this contributed to her disbelief of the result and reported:

“You are HIV positive and I said NO, that not true and they should do it again.” Beauty

Justina also did not believe her result and demanded a second test. Bola also did not believe it:

“I was shouting, screaming this is not my result I started banging on the door there, I was crying.” And “I didn’t believe it I said it’s not my result.” Bola

This resort to shouting and screaming was Bola’s only outlet as she did not believe the result. The coping mechanism was that there was an error; simply the result was wrong and therefore untrue. In essence women disbelieved the test result and some needed further testing for confirmation. This denial was displayed by the majority of women. This finding fully endorses the denial stage of Kübler-Ross’ model (1969, 2005). Disbelief and denial with the news was essentially time limited; simply the positive result was correct and transition inevitable for women. However, for a few women transformation did not stop them hoping it was not true or a false result. One difference was that Fumi, whilst shocked, believed the result as the blood test was performed in the UK. This demonstrates her faith in the system of testing.
4.2.1.4 The Unexpected Result and Unpreparedness added to Shock

With further exploration of the cause of this shock, a common and significant finding was that the positive HIV test result was unexpected which worsened the experience of being informed and women linked this aspect to being unprepared for the result. Being unprepared for the possibility of a positive result is a major finding and a real concern for women as simply being unprepared made the situation worse in their view. They were shocked because the news was so unexpected and it struck like a lightning bolt. This interpretation of the unexpected result is likened to a mortal blow. With simply no body armour of preparedness to protect them, women were vulnerable. Women believed if the possibility had been raised that they could have had a poor result it may have made a difference to them. Simply they could have made some personal preparation and donned protective armour and additionally prepared for the transition required with achieving the transformation of their “being”. They were unprepared that life was to be forever changed:

“I was expecting it to be normal because I wasn’t thinking I can have that problem I wasn’t thinking I would be affected by that.” Julie

What is of interest is that Julie uses the terms, “that problem” and “that” for HIV which is interpreted as disassociating herself from HIV and a negative view of the infection. For Anna the result was also reported as unexpected and further stated that the result was a shock as she believed she had a healthy son previously and the result was unexpected for her. The interpretation of a previously healthy child as protective is known by Anna to be erroneous now as she was accidently untested for that previous pregnancy, but this belief was powerful at the time as she really believed she would be negative:

“I had a baby before everything was normal, I had a healthy son, you know, so it was a total shock for me.” Anna

Later Anna would learn her son was not healthy. Grace also reported she did not believe her test would be positive and as Grace was admitted to the antenatal ward she had a one day HIV test and was unprepared for this quick positive result. Martha believed it was going to be negative and the result was unexpected as she previously tested
negative. She was adamant had she been more prepared for a positive result it may have helped:

“I think I would have been more prepared, because what they told me was that it’s just a routine test everything would be alright things like that so I wasn’t prepared for the results.” Martha

When she went for the test result she was not expecting a positive result as she was an optimistic person. What this demonstrates is that optimism is no protection against HIV. What is of interest is that Martha reported that her first thought on her diagnosis was for herself and different as most women thoughts were for their children or unborn baby.

Cindy and Jane reported the result was unexpected. Jane reported she tested as she firmly believed it would be negative and tested for her baby’s wellbeing. This compounded Jane’s shock, that she was wrong. Mary was adamant that her result was unexpected as she believed only wayward people got HIV which implies that HIV infection is perhaps deserved for the lives people lead. Beauty also believed the same thing and her result was therefore unexpected as she did think it could be HIV. Justina also in common with the others reported that her result was unexpected even when called into the room. Bola reported that she was not expecting this result and demanded re-testing. Rose was very critical of not being prepared for the possibility of a positive result:

“If they had told me I would have prepared myself.” Rose

In essence women were unprepared and the result unexpected, which added to the shock. Kennedy’s (2003) view is that poor preparation gives rise to an unexpected result. Most women did not even discuss HIV testing with their partner or any one significant as they saw this as a routine test and simply they were ill prepared for the possibility of a positive result. This lack of preparedness was due to the lack of information with personal risk information; this added to women’s distress. How well women can be prepared is difficult to ascertain and raising the possibility the test may come back positive is problematic as it may cause undue alarm to women whose personal risk is low. But as demonstrated by this interpretation, not preparing women caused shock and harm when the result was positive. However, ‘getting the balance of personal risk probability” is difficult but essentially it may help with accepting this life
change as they may then have foresight of a life possibly with HIV. Importantly the overarching phenomenon of transition and transformation may also be aided with a degree of preparation, as women with elevated risk will be aware and can have supportive strategies in place for a positive result.

4.2.1.5 Suspicion and Anxiety Waiting for the Result

However, for a number of women suspicion and anxiety were raised that something was wrong when contact was made to re-attend the antenatal department. For others this was not a concern and a contrasting difference:

“Yeah when I got the letter, I was a bit worried but I wasn’t thinking, so I was a bit worried the day that I came for the result.” Julie

But for Anna when she was asked if contact had raised any suspicion she reported several times a resounding no. Martha reported her raised anxiety and raised suspicion when recalled to attend to discuss her blood results:

“I kept asking is it the HIV one cause I can’t deal with the results and the lady said no there are more results that we need to discuss not just the HIV one.” Martha

She also reported its effects on her wellbeing and raising feeling of panic which had a physical effect with cold sweats in the night. This was emotional anxiety manifest in physical symptoms. When questioned further, she could visualise what life would be like if she were HIV positive, whilst waiting for the result and this was before her actual diagnosis:

“Waking up having nightmares, I was dying in my dreams, so I was thinking of the child and it was just awful.” Martha

This feeling of dying gives an indication of the dreadfulness of the situation she was facing. Her partner during this waiting period tried to reassure her all would be well but this was not helpful or reassuring but it clearly demonstrates they had discussed the possible result. Cindy was worried about the phone call to return to the hospital to discuss her test and reported that she gained some peace even if it was the news she personally dreaded as God would support her in her hour of need:
“Whatever happens God will not give me anything that I cannot handle.” And “Instead of me sitting here killing myself with worry.” Cindy

Mary was adamant that she thought the phone call routine as she booked late. Even when asked to come back she thought it was normal as she “was not wayward”. So went into the room with no indication there might have been a problem. Beauty ignored the repeated calls to return as she had terminated her pregnancy due to violence. She did finally attend but thought it was for her sexual health like syphilis or perhaps diabetes:

“HIV would be the least of the things.” Beauty

But Beauty became worried when they took her things from her on arrival and had a feeling of panic and sensed something was badly wrong from observing the lack of smiling and body language of staff. Justina also talked of the unexpected result but also sensed something was terribly wrong but still did not envisage HIV:

“I felt that that something’s wrong, I felt something is wrong terribly wrong.” Justina

In essence a number of women were suspicions and had raised anxiety when called back but still did not suspect that HIV would be the issue. HIV was not in the immediate consciousness for the majority of women in this study even if suspicions were aroused. They were not prepared for this terrible news and most were insistent it may have helped. However, if they had been really aware, during the wait for the result perhaps anxiety may have been substantially increased as Martha reported. The following diagram (Figure 5) illustrates of the major paired theme of shock and disbelief and a selection of the primary and secondary themes. The woman is represented and centrally placed with the view looking down on to the top of her head and the major paired themes are encased within her head. The primary and secondary themes are external but radiate in to her head as they are pivotal to major thematic development.
Fig.5. Diagram representing THEME ONE – Shock and Disbelief.

NB. The top of woman’s head is viewed from above and centrally placed and the major paired themes are red and encased within her head, primary and secondary themes are external but radiate in to her head.
4.2.2 THEME TWO– Anger and Turmoil: Loss of Old Self

Anger and turmoil were reported, and this was also coupled with a loss of the old self and things being no longer being the same. They were in transition as their “being” was transformed. This transition with the loss of old self caused anger and turmoil as they reacted against the inevitable transformation. Wanting to self harm or commit suicide was a significant finding and one woman reported she considered harming her child. Also a paralysing belief they and their baby would die from HIV. Isolating self from others but also trying to maintain normality was difficult in this period of turmoil. A desire to terminate the pregnancy was common. All except one woman informed their partner of the infection and a number blamed the partner. If the partner was negative they began seeking out the cause of the infection. Separation from partner was a significant finding and if relationship was maintained ongoing trust issues were apparent.

4.2.2.1 Loss of the Old Self

Loss of old self and not the same person were reported directly and indirectly with sadness as they mourned the loss of their old self. A number reported with sadness a loss of the old self as a primary and secondary finding and an overriding major theme. Loss of old self was spoken or alluded to directly and interwoven as a major theme with anger and turmoil in this findings section. It was the loss of the old self that acknowledged a life change and a transformation. Clara vividly reported no longer being the same person and reported a physical effect akin to out of body experience and that something had left her, something intangible but perceptible, the old self:

“When I left the hospital, I’m not myself, it’s like it felt like floating you know, I don’t know if I’m walking” and “going home I’m not the same person, I was like there’s not any me, it’s just like something like going.” Clara

Julie reported the loss of old self and its effects as she could not sleep, eat and was crying. The effects were real and not imagined they were physical, powerful and the loss of the old self was physically and emotionally wearing:
“I said to her I can’t sleep, I can’t do anything now. I think she actually gave me some very mild sleeping tablets, what happened I couldn’t sleep all of the night I was crying I couldn’t eat anymore.” **Julie**

Anna reports sadness and relates this to giving medication to her son and how it affects her positive child. You sense the sadness as she understands the implications for her positive child. This is not only Anna’s loss of her old self but also the loss of the life she wanted for her son:

“You look at all this, especially the liquid for my son, its normally three months supply, so think this is all, for a child having to take all this, sometimes when I’m giving him medication, my tears, I just cry, I don’t know.” **Anna**

For Grace she had become “one of them” and had journeyed from one side to the other which scared her. This journey is the beginning of the transition and transformation of her being as she was now no longer the same person. Jane had sadness with the loss of old self and its effects. Her dream of a happy married life with her new child had turned sour. She was expecting a pregnancy and birth and the child to be a joyous event. Unfortunately it had given her distress and sadness as the news was not good. In essence this is to be expected as her dreams were dashed. Jane was aware that she was unable to talk about her true self and was saddened at this loss of her old self. She knew that people could not tell outwardly she had HIV but it changed her ability to be able to communicate with people. These were significant people were family and friends. Jane could not help but feel depressed and saddened by this loss:

“I know HIV isn’t written on my face, I am HIV positive.” And “So my life has really changed because I can’t be open with people, to talk about myself and I feel very low when people talk of HIV.” **Jane**

Bola reported the following since her diagnosis. Her life had changed and she saw great personal difficulties in her temporality. Her tangible and intangible existence had changed:

“I don’t have a proper house I was only living in a room so it was difficult for me, how am I going to cope, how am I going to eat.” **Bola**
In essence things were no longer the same for many of the women and they mourned the loss of the old self as there former life slipped away and essentially they had no control over it. They were becoming aware of the transformative power of HIV and the effect on their being. They remained in turmoil and expressed anger by words and deeds.

### 4.2.2.2 Anger and Self Harm- Considering Suicide

A significant finding was that a number of respondents reported that they considered suicide and self harm. Suicide and self harm is reported (Sherr 1995; Kennedy 200; NAM 2008) due in part to the loss of control and the hopelessness experienced with an initial HIV diagnosis. This demonstrated the emotional distress women were under from the impact of the HIV diagnosis. Successful suicide would terminate their being and end the transformation abruptly. Clara reported that she considered suicide and that someone was the cause and perceived them as wicked. The cause of this infection was due to someone else’s wickedness. They had caused emotional pain and thoughts of suicide:

> “I feel like oh I want to commit suicide and oh this is a wicked world how could someone do that to me.” **Clara**

Julie wanted to kill herself but thought that it would trigger a police investigation and importantly it would be reported on the news. In effect whilst it would free her from her pain it would cause further pain to others if she pursued this final act of personal harm. When questioned further what had stopped her, she responded she did not want everyone to know of her HIV even after death. She believed her confidentiality would be broken and this would affect the people she loved. Anna reported she also considered suicide as her world was crumbling and that she imagined death due to her infection. The distress was palpable and real to Anna and considering suicide was a viable alternative to stop the emotional pain. When questioned further about suicide she expressed the feeling as very strong. When prompted further she stated that it was the support from the hospital that helped her overcome these feelings and the information that she would live longer if she took her medication. This and her daughter were pivotal in not going through with it. This was a turning point for Anna:
“One, one thing made me not do it, I think being in this country and obviously I had a lot of support from the medical stuff down here, the (clinic name removed), obviously I started to look at it as a positive point of view knowing that once you take the medication you can, you know, you can live, you are going to die anyway but at least you can stay a bit longer and obviously my other daughter, like ok if I die now what’s going to happen but then I was still pregnant with my daughter (name). I wasn’t going to put my daughter through it, so but it was kind of a mixed feeling, really should I commit suicide both me and my son and we all go and you know”

Anna

When questioned further on the ending of the life of her son, Anna admitted considering this option but she sought professional help with a psychologist and this restored her resilience and her life became liveable which is also supported by Bonanno (2009) (This will be reported in the next chapter). Martha reported she considered suicide because of her husband’s abuse and the disclosure of her HIV status to her family and not because of the diagnosis of HIV itself.

“We live on the sixth floor and I was going to jump basically.” Martha

She decided that she would not give-in to this abuse (see 4.2.2.10 - abuse and violence section of this chapter). Mary reported she did not actively consider suicide but wanted to die because of the shame of HIV the diagnosis. Mary was seen by the health visitor and referred to the mental health team; this intervention was helpful and can be needed to restore natural resilience (Bonanno 2009). Importantly the HIV support group’s intervention helped Mary (see 4.2.4.6 support groups section in this chapter). Justina also wished to die but this was an emotional verbal response at this time. However, self harm later became an issue for Justina, as her partner later left her, was killed and then she seriously considered suicide in her pregnancy. However, the intervention of her HIV specialist helped her immensely. The baby’s birth then gave Justina a reason to live and the focus of the baby was reported as helpful. This is a significant finding as whilst self-harm was contemplated, even whilst not enacted, it demonstrated the women’s vulnerability at the time of the diagnosis and vigilance with further help may be required as suicide and self harm is a common reaction.
4.2.2.3 Turmoil and the Belief that HIV Equated with Death

A significant finding was the turmoil and a belief they would die. This is common in the African countries of origin of the women (UN AIDS Report 2010). This belief is imported from the women’s country of origin as it is not a common outcome in the UK due to effective drug treatment. The impact of the diagnosis was traumatic for many of the women and whilst contributed to the initial shock also contributed to their turmoil as death and dying was believed to be their outcome. Many were unaware at the time of diagnosis that medication could be beneficial and they could continue to be healthy and live with HIV. The belief that death was near would affect and override the transformation of living with HIV as the thoughts of death were distressing for women.

The following are powerful excerpts from the narrative that convey the pain and thoughts of death:

“All I knew is that it was a death sentence and that you could die of it” and “that if you’ve got it, all I knew was that if you got it if you did, you, you are not going to escape it.” Clara

“I said I’m dead, I’m dead, I’m dead.” Julie

“In my home country, once one got diagnosed, obviously it was dependant on your status really if you are in the higher class you could afford the drugs and the medication and then obviously lower class you, obviously you think you are looking at I’m going to die.” Anna

“I cried holding my son and thinking of him, all I could think of was him, we are going to die and I was still pregnant, all I could think of.” Anna

“I only knew that it kills and it has no cure.” Grace

“What I know is that if you were HIV positive that you will definitely will die.” Martha

“dead, dead, dead that’s what I felt.” Rose

When questioned further, all expressed a wish that they had wanted to be informed this was not the case. This is a silent point; they had not been informed of this vital information prior to their diagnosis. HIV is no longer a death sentence if medication is adhered to in the UK (NAM 2010). However women imported the belief from their country of origin as this was their background knowledge, belief and exposure about
HIV. It was their ontology (how things are), situatedness (how they felt) and epistemology (their justified belief). They simply believed from past experience, they would die. Cindy, Jane, Beauty Justina and Rose also felt the HIV diagnosis equated to death at the time of diagnosis. This belief that HIV is a death sentence is powerful, their own and their child’s mortality was on the line. This imported belief was later rectified by post-diagnosis information but it would have helped the women if given prior to the result. Fumi was of the view that whilst she thought HIV was a death sentence being told that medication works was very reassuring. However, Fumi’s view was this information would have helped beforehand. Bola reports this belief of dying was not rectified until she attend a support group several years later and found a number of women who were still alive after being diagnosed for a long time. It is very sad and that she carried this burden of error for such a long time and may have had impact on transition and transformation of her “being” as she believed she could not be long lived with HIV. Once informed and seeing women alive and long-lived, her life view changed and she had proof you could live with HIV and her transformation could proceed:

“I saw people diagnosed ten years ago and they are still alive.” Bola

This was revelatory for Bola, she now tells any women in her support group that they will not die because of this real fear she derived from her testing experience and now knows to be untrue and this has become her personal quest. This belief that HIV equated with death is significant and demonstrates that women were not aware of the facts prior to testing. Had they been more informed before testing their reaction may not have been so severe.

4.2.2.4 Social Isolation

A significant finding was a number of women reported isolating themselves from significant others including children, friends and work, immediately after the diagnosis. This can be reported by the narrative by Clara:

“I got home and I locked myself in the room and started crying” I don’t want to look at my children’s face because their mum seen their face and their mum crying and oh
something bad has happened to me.” And “I couldn’t sleep at night, I wake or cry and can’t eat, I can’t eat, in fact at that time I stopped going to work, yea cause I don’t want to see peoples face” Clara

“Yeah my friends, even when I got back home, my cousins flat, sharing with somebody and because of this I put like a barrier, she didn’t know what was happening to me, she thought maybe I went mad.” And “but they don’t know what I was going through at that time because I go to my room, you have to get out, you need to get out, you get out as normal but you lock yourself inside.” Julie

Interpreting this, strongly suggests, that the need to uphold a degree of normality was strength and also being reclusive was a way of coping with the news. Turmoil was often hidden from others, however sometimes strangers were perceptive that things were not right as Julie explains:

“One day I was in, I went to (name removed) Road, the station there, I went there and this man was calling from the station, and he saw because my head was down like that, with my hands in the pocket and she saw me and she said hello are you depressed but whatever you are going through, it is going to be well, because the way you look now, it is too much.”(Note -he and she are often interchanged in the African language but does not reflect on the truthfulness of the narrative) “Yeah, she doesn’t know me, she doesn’t know me from anywhere but, she just saw the way I was walking.” Julie

Julie must have looked emotionally unwell and this was displayed by her physical demeanour. Anna also reported shutting herself away in her bedroom. She did not want to see anybody including family; it was all too painful and traumatic. She needed to be alone to work things out. For Grace her isolation was imposed, she had no one as she had been trafficked. She was in late pregnancy, giving birth two weeks later and was already isolated but helpfully her support worker from a charity for trafficked women came to see her immediately to offer support. Mary reported isolation but this time self-imposed and she did not want to see anybody. Interestingly, social isolation was imposed on those women whose HIV infection was revealed. It was held that HIV was perhaps a white person’s disease in Africa. In the UK it can sometimes be seen as a disease of the black population. Mary reports:

“To be honest with you, back home the way we look at HIV , it’s really bad, it’s really bad because when you hear this person is HIV you don’t want anything to do with that person because you believe that even when you use eeerr (Condom) what the white person uses, you get infected.” Mary
Mary viewed this isolation to be protective from infection but essentially relies on the person looking unwell. Justina also felt that stigma from others had the potential to isolate her:

“You think people will isolate from you, everybody knows this is what you are, they won’t come close to you, they will be away from you, so you feel that it feels like death.” Justina

Justina’s isolation was likened to an emotional death and is terribly sad. Bola reported social isolation as she simply locked herself away and kept separate from others. Her partner told her to tell no-one. He later did disclose and as a Muslim she felt estranged from her community as Bola reports:

“I don’t have any friends, nobody except the support worker who used to see me.” Bola

This isolation is still felt. Bola then corrected herself and then recognised she had made friends at her support group and smiled. This initial isolation was compounded as Bola was made to move to another town after seeking asylum after her partner left her. She found a woman who was also diagnosed HIV positive and moved back to London and lived with her for a while.

Social isolation was significant short-term as women in their turmoil locked themselves away as they comprehended their HIV diagnosis but also had lasting impact for women as they often remained isolated. This isolation was also linked with stigma (see-stigma with isolation issues in this chapter-see section 4.2.3.3). In essence women were isolated by HIV and some still remained so and this isolation in all probability impacted on the transitional journey and transformation of their “being”. Alone they could not build networks of support from other women in the same situation and this may have inhibited the potential to be the powerful resilient woman. Many were unable to integrate with others, but later learned to do so and often with the help of other women in the same position (see-value of support groups in this chapter-see section 4.2.4.6).
4.2.2.5 Anger and Turmoil: Termination of Pregnancy

A number of women contemplated abortion after being informed of their HIV diagnosis. Kirshenbaum et al (2004) reported that information helps the decision making process and this was evident in the women in this study, however several did terminate their pregnancies based on decisions often linked to the wider impact of the test result and with partner pressure after diagnosis. Further anger and turmoil was apparent for several women with an immediate and strong wish to terminate the pregnancy as the child would be infected:

“I want to abort this baby; they should take this baby out of me.” Clara

“I said to her can you please terminate this pregnancy, she said no you cannot terminate the pregnancy.” And “Because I thought the baby would be, would have that problem as well.” Julie

This belief was based on a falsehood and when explained that the infant would not necessarily be infected, relief and rationalisation developed so that being pregnant was seen as beneficial. Julie maintained she would not have known about her HIV without being pregnant but still took some time to be convinced before changing her mind about her planned termination. Julie attributed a lack of knowledge as a reason for misplaced belief for the need to terminate her pregnancy. Martha also reported turmoil and wanting to terminate her pregnancy whilst waiting for the result of her HIV test:

“I was thinking I’m HIV positive, is it already killing the baby, should I go and find an abortion now to save myself all the hassle, there were all sorts of things going through my mind.” Martha

Martha interestingly reported her husband raised the issues of abortion. Mary was asked after being informed of her HIV diagnosis whether she wanted to keep her baby, but she had other issues on her mind particularly telling her husband and replied that she would keep her baby.

Justina gave a detailed account of her termination after her HIV diagnosis and linked this to pressure from her partner and that he believed the children (twin pregnancy) would be infected. She terminated after he threatened to withdraw support. Justina was devastated but quickly became pregnant again. He again pressured for termination
which she refused and he then left her. Fumi considered an abortion but quickly dismissed it once she had been informed of the likelihood of a negative child. Rose considered keeping quiet and silently having an abortion but then decided it could be her one chance to have a baby and be a mother. The mothering instinct was strong even with a recent diagnosis. This information about the possibility of a negative child was vital for a number of women and made a significant impact on maternal choice around this issue. In essence, termination choices were not explored until diagnosis and perhaps the possibility of a negative child may have helped if this had been raised prior to testing.

4.2.2.6 Telling the Partner and the Implications.

Most of the respondents in a relationship told their partner of the diagnosis, some immediately some with a degree of planning but with varying degree of response from their partner, some partners believed HIV was shameful. Grace was single at the time of her diagnosis and as she was trafficked for sex was not able to ascertain who the father was and had no partner at the time of her diagnosis. Also Beauty did not inform her former partner due to violence and after becoming pregnant for the second time broke-off the relationship without telling him. Shame and secrecy prevailed for some and loss of disclosure became an issue for others as their partner then told others. Some women including Jane took some time to disclose, and felt pressured to do so by staff. Informing partners was important for the women’s transition and transformation of her “being” but this disclosure had some major implications; partnership breakdown, the negative partner, blaming him for the infection, trust issues, abuse and violence and loss of control with disclosure.

Clara reported informing her husband and his ambivalent reaction to the news. This was of concern for Clara as she told him on the phone and latter took the paperwork home to prove her diagnosis in all probability to get some reaction:

“I told him, so he was like Oh, is that why I’m crying” and to reinforce this diagnosis “When he came (Home) I took the paperwork home. I showed him but he wasn’t bothered.” Clara
Clara was amazed that he should be so unaffected which in her view implicated him in transmission. Julie reported informing her husband and his reaction was that his life was finished due to the shame and the connotations of how she may have got HIV:

“Then I called my husband I told him I said this is what they said to me and what he said was like my life is finished, my life is finished tell your family that I have cancer now and I to bed tomorrow, HIV is something that is shameful and everybody thinks that you are a prostitute because that was my home, I’m embarrassed I never have it.” Julie

The sense of horror of diagnosis for Julie and her partner is palpable in this quote. It was shameful for them and this was unbearable. Anna reported she went down to Accident and Emergency department as her son had incidentally been admitted, to meet her husband and tell him in person, she had to tell him as her distress was noticeable and reported his reaction to this news as one of quietness and with little discussion. Anna looked at the floor whilst telling me her story. The urge to tell him was strong but his reaction and lack of sympathy was perplexing. Martha also reported telling her husband and she had the resilience to wait, to tell him in person. And when he was present Martha was able to inform him:

“When he came the counsellor was there and I just told him that the HIV test results had come back and I was positive and the first thing that came up was oh my God we do need to go and find an abortion and I said no, we don’t that’s when the counsellor started explaining about having a healthy baby.” Martha

Martha’s husband was offered HIV testing at this point but he declined and was unable make a rational decision. Cindy reported she had to plan how to inform her partner and kept it secret for a while and showed a lot of strength in doing so. Cindy sat him down after two weeks and calmly told him, giving a detailed account what was she said to him. She was relieved he was so supportive and she cried for the first time.

“I told him, then he looked at me and just came close and he just grab me and hugged me.” Cindy

He told her how much he loved her and how sorry he was and that he was not going to leave her and would stand behind her. This was not the reaction most women got from the disclosure of their result to a partner. Cindy’s partner wanted to be supportive and declined to be tested until after the baby was born so as not to stress her in her
pregnancy. He tested negative later and remains committed and supportive which is unusual for most women. Jane delayed telling her partner and used strategies to avoid sexual contact as this gave her more time:

“For the sake of the baby that I told him not to be having sex again.” And “I couldn’t bring myself to tell him, then the midwife kept advising me to tell him.”

Jane

Jane also started avoiding the midwife as she felt pressured to tell her partner. In the end due to the midwife’s persistence she informed him but around six months into the pregnancy. Jane then gave a detailed account of informing him and his shock, walking out and leaving her alone. He would not speak for 3 three days and this damaged her relationship long-term. Beauty tried several strategies but failed to tell her partner as he was violent, the relationship ended after an argument when she became pregnant after her termination. She gave a detailed account of the devised plans to tell him but he would fail to turn up to appointments - she suspected he knew. They had a very volatile relationship with much sexual distrust (see next section-partnership breakdown) and so she ended it. Justina felt she was pressured to tell her partner on the day of her diagnosis. This was awful for her. She gave a detailed account of how she returned to the hospital and tried to get him in to the hospital to tell him, but due to pressure ended up telling him over the phone. He told her to return home and that he was shocked and felt the HIV was self-inflicted. Fumi waited two weeks and then left her medication out on purpose after taking it in his presence her partner did an internet search and questioned her and she told him. Bola was shouting in the hallway and this alerted her partner and this revealed her news. Rose also told her partner. All the women, except one, told their partner, some straight away, others required time and a strategy to do so. It was understandable as normality could be maintained for a while. However, secrecy with a diagnosis added complexity with daily living, transition occurred but on a torturous path and transformation was overshadowed by the balance of keeping the diagnosis a closely guarded secret often from significant loved one or family member. However, if they did disclose, this disclosure was not without personal loss as we can see in the next themes.
4.2.2.7 Partnership Breakdown

A significant finding was that women reported the permanent breakdown of their relationship after an HIV diagnosis. This added to their anger and distress and they mourned this additional loss. This transformed their “being” as their lived lives had an added vulnerability with partner desertion and for some a vital support mechanism was gone. One woman temporarily separated and was later reconciled which was miraculous for her. Partner separation was socially significant for the women as they were then left alone, often in pregnancy. Clara decided she would not be a victim or be disempowered by her husband’s infidelity and separated from her husband. She believed she had a choice in the UK:

“When I saw him going around (with women) I wouldn’t be a victim, I will not be a victim of this.” Clara

This showed great courage as she was alone. However, even with her past distress and permanent separation, Clara showed understanding of her former husband who has not tested. She keeps in contact with him for her children:

“Sometimes I just look at him and I feel sorry for him because he say he doesn’t want to go for the test, he doesn’t want to be tested and I see him and I feel sorry for him.” Clara

Anna also separated from her partner citing blame (see 4.2.2.9 blaming partner). She blamed him and left him as she no longer trusted him. Martha’s temporary separation from her husband and later reconciliation is reported under abuse and violence on the next page. Jane’s partner also left her and is reported in the next section negative partner. He left her for someone else in her second pregnancy. Mary reported her husband went for testing and informed her if he was negative he would leave her. The result was negative and he left and never returned. This was life changing for Mary, as she was alone in a country with no social or monetary support. Justina’s partner declined to marry her, pressured her for a termination for her twin pregnancy and again later in her subsequent pregnancy. When she refused he threatened to leave and did so, returning to Africa during her pregnancy. Shockingly he was killed when she was eight months pregnant and she lost any chance of reconciliation. This was traumatic and was succinctly portrayed:
“I just cried, felt lost, feel alone” Justina

Fumi also reported the breakdown of her relationship. Whilst HIV was a factor, social services were involved and to keep her child she decided to end her relationship. Beauty’s relationship ended as he walked out and was violent (see 4.2.2.10). Bola’s partner initially stayed with her, then as her pregnancy progressed, refused to marry her and he left her whilst pregnant, returning to Germany. This was difficult for Bola as she was a Muslim and this impacted on her standing in this community. She later had two more children and a new partner who was HIV positive and on effective medication. This relationship broke-down and was in her view HIV related as he was angry with life. The loss of their partner following a positive diagnosis was cataclysmic for women. This finding demonstrates that women faced momentous partnership issues. They were abandoned in significant numbers, often pregnant and alone in a country with little control or support. They were now often transformed alone with no partner for support and a new baby. They were now transformed into a “single” person and no longer part of a couple. This abandonment was often devastating for women in the first instance and later often remarked upon with sadness even if they gained strength and resilience later. However, the baby gave women a focus and the transition proceeded as a mother with a prized and more often negative baby. This infant focus was a very good reason to live a new but changed life but without a partner.
4.2.2.8 The Negative Partner

A common finding was that these women’s partners tested after the woman’s diagnosis and were often not infected. This is perhaps surprising as HIV had been contracted from somewhere and often prior to the marriage or current partner. The women had often come to UK for marriage and brought the infection with them. Having a negative partner was not without problems. The men often had a hold over the women, she being grateful if he stayed, but unable to question him about his sexual behaviour. Often the men abandoned the women when they had a negative result. Martha became hesitant when speaking and did not at first believe him to be negative but later accepted this, but not without some reservation. Martha had questioned him about his HIV status, but could rationalise why a negative partner might be beneficial for her baby:

“I have asked him and he said do you want me to show the result just to prove that I’m not, it’s now becoming like a big, big.” And “I was warning him, reminding him, don’t forget it is almost three months you have to go and have the next test done, because I was really thinking about my child, I said if I die at least there will be a healthy parent to be looking after the child.” Martha

Cindy was happy with the negative result for her partner as her baby would have someone around should she die. This was a reasonable assumption but life expectancy has greatly improved with treatment (NAM 2012). Jane reported that her partner later tested negative. He started avoiding her sexually but got pregnant again by mistake which she thought was a miracle. She reported HIV damaged her relationship and blamed condom use for the failure of her relationship.

“African men will stop there, they don’t like using condom so in some way, he came back one day from work, he tell me that how he’s fed up with the relationship.” Jane

Jane reported he was not good at using a condom, so he avoided her, was no longer interested and that he felt she had let him down and told her he was seeing someone else. They separated. Mary cried as she retold, whilst still pregnant, the following ultimatum:

“I wouldn’t lie to you because but when he was going for the test he told me that if the results came out negative and he was going to leave.” Mary
He expressed a view that he did not want to be negative as he loved her. He stated if negative he would leave her and left when the result was negative. He also disclosed the reason for leaving to Mary’s family. For Julie whilst her initial distrust subsided when her husband’s test was negative it remained in other aspects regarding his sexual fidelity:

“He went for the test and when he came back he saw that the result was negative and at that time I didn’t want to keep myself down, yeah because I was thinking maybe he’s been doing something (bad) but at that time his results came out negative”

Julie

Justina’s partner also tested negative. But quickly withdrew his support and demanded she terminate her twin pregnancy, which she felt compelled to do (see termination section). Fumi’s partner also later tested negative but due to social services’ involvement she ended the relationship to keep her child. Bola’s partner reported he was negative and as her pregnancy progressed, he left her. The experience of a negative man for the women was not good. They often had a hold over the respondents and used it as a powerful weapon. Many of the partners tested later and were reported as negative by the women. This shows that most of the women in the study did not contract HIV from their current partner and they did not infect them either. This finding also challenges their perceived view that their partners were responsible for the transmission. Some women did blame their negative partner initially but women were often surprised by their negative result. This may have disadvantaged them later as their relationships often floundered and impacted on their transformation as support was often absent.

4.2.2.9 Blaming the Partner and Trust in the Relationship

A significant finding was anger and turmoil with blaming their partner for the HIV infection. Simply the phenomenon of transition and transformation was affected by issues such as blame and mistrust, these issues impacted on their relationship with a partner. They could not trust or often blamed their partner and anger got in the way for a while as transition was affected by this powerful emotion and they could not live with perpetual turmoil or persistent anger, but anger would sometimes surface at times when reflective. Some women need to take positive action or learn to live with the issue
which was often suppressed. Clara was adamant who was to blame and his lack of an explanation or apology was damaging and had a terminal effect on her relationship:

“I knew somebody (Husband) doing this to me and the person is not even sorry and not even a sorry that is when I cry more” Clara

Clara felt let down by her husband and felt this to by unfair. Anna also reported she was well aware who had infected her and was angry and blamed her husband:

“Obviously yes, because I knew he was the one who had infected me, so that very first confrontation was him cause, if I came to this country and had to undergo a medical check up it’s one of the processes of getting a visa for coming here.” And “Yes I did blame him a lot.” Anna

And this blame was a contributing factor to her permanent separation from him. Whilst she now had the capacity to forgive, her life had moved on without him. Anna blamed her partner for the cause for her infection and this destroyed her relationship. Cindy blamed her previous partner for her infection as he slept with other women. She reported she had acquired syphilis from him and was in no doubt of the source of her infection. Beauty in no uncertain terms blamed her former partner:

“He was a bastard, he womanises, he sleeps about.” And “No I knew where it comes from.” Beauty

For some women the blame was easy, as their partner was positive or believed them to be so. This enabled them to focus the blame. It became more problematic when a later discovery was that the partner was negative. Women often blamed their partner when they were later abandoned, simply for not standing by them.

In a continuing relationship or prior to failure, turmoil and anger often persisted with issues of mistrusting a partner often vocalised and this issue led to separation for a number of women. Trust was vital and for women this evaporated with the diagnosis. When Clara was asked further about her husband’s surprising response to her diagnosis with his ambivalent attitude, she reported that this made her feel “bad”. She spontaneously raised the following trust issues and her perception of African women’s situation around risk and sexual behaviour. Staring right into my eyes she said:
“I just look at it because most African women say nothing, because in my country you can’t tell your husband to protect himself if he wants to have sex with you and if you deny your husband from coming closer to you then you will suffer from it. They not take care of your children” Clara

Trust issues, sexual fidelity and power in a relationship were then raised by Clara whose husband’s fidelity was questionable and he failed to protect himself, Clara and others, but she felt limited in what she could do:

“You know I know that something is going on and that he’s not protected while out of the country but you can’t say no to him.” Clara

Julie relayed, choosing her words carefully and with some hesitation about her perception of her negative husband’s sexual behaviour and fidelity since her diagnosis. She rationalises why this may be so suggesting the use of condoms as not being a satisfying experience for him and so has sex without a condom with others:

“I think that err it’s not how will I put it now, he’s been cheating on me, so because he’s a negative man, I don’t want to ask him, you know, but why did you do this, because I think to myself maybe he’s not satisfied because we use condom and may be he’s not satisfied with the condom, that’s why he is doing it” Julie

Julie remained suspicious of her partner’s sexual behaviour and raised this directly with him. Julie accepts his behaviour in her relationship because he does not use HIV as a tool or weapon against her. This suggests that Julie is restrained with how far she can explore this issue with her partner:

“Whenever I mention to him about the, that he’s cheating on me or I caught him with something he never mentions anything about this HIV” Julie

When questioned further, Julie further states she found out a lot about him. But her being HIV positive limits further discussion as he is negative. She has to accept the situation as she has in effect lost any rights or power in the relationship due to HIV:

“When I came here I found out a lot of things and then I talk and I talk but after I realise that he is a negative man, I’m positive. I went like I couldn’t ask him anymore” Julie
Beauty reported sexual distrust prior to ending her relationship. With a history of violence lack of fidelity finally broke the relationship:

“I know he’s slept half dozen of the ladies.” And “I say and what about you, you keep sleeping about with every Tom, Dick and Harry and spreading your diseases about and I am telling you up to this moment he didn’t call me” Beauty

She is trying to tell him something about HIV as she is aware of her own infection but felt unable to bring this up directly. Beauty remained angry about this relationship and on further probing she felt HIV stopped her getting someone new after the break up. Even with detailed discussion she remained angry and blamed him. Bola lost trust and control when her partner disclosed her diagnosis to others in her family. Originally he did not want anybody else to know, this caused great emotional pain. Trust was a major issue for some women in the study. Trust leaving their relationship had implications for their future. It was a catalyst for partnership breakdown but also impacted on enduring relationships and the woman’s transformation as the loss of trust impacted on their fundamental “being”. Women were aware of sexual fidelity issues but were often disempowered to pursue them further. Honesty and fidelity were important to the women and this was often lost. These women’s recourse to blame was strong in the findings. Blame for some allowed anger and turmoil to be channelled at the perceived source of HIV in their lives and the partner’s sexual fidelity. It was not of their making and they could transform but assured “others” were at fault. Powerful but not always correct.

4.2.2.10 Abuse and Violence

Anger and turmoil is further apparent and complicated with growing abuse and violence. Dhairyawan et al (2012) reports increased levels of abuse and violence in women with HIV. In an inner London HIV clinic, HIV positive women reported by survey a 50% life time risk of former or current partner abuse and violence (Dhairyawan et al 2012). This was an additional cross to bear for women and its effects cannot be underestimated and was an additional negative factor with the phenomenon of transition and transformation. Violence and abuse was precedent and affected this phenomenon.
Transition was difficult and slowed by abuse. Martha describes this aspect as more difficult to handle and damaging than her HIV diagnosis:

“It was just really bad, to the point that the HIV wasn’t the issue it was now the violence and abuse after that, it was really killing me.” Martha

This resulted in her temporary separation which lasted for 6 months until he completed successful counselling. When Martha was questioned further about the violence she gives a horrific account of its impact:

“Because the violent even got worse after the baby was born and the baby came back negative so you should expect things to improve, it didn’t improve so it broke down to the point I had, the violence was so bad I had two surgeries done to my eye in (name of hospital) and I almost died and the police didn’t believe the injuries I sustained was done by him and hand they are like, maybe you passed out something else was used, I said no nothing else was used.” Martha

Martha relates how this violence was managed with the help of the church and anger management classes. When Martha was asked how things are now, she reported a marvellous and miraculous change in her husband, which felt sincere and heartfelt as she looked me in the eye:

“I have another baby, from the same person (Big smile) (Recent birth), it’s improved drastically, it’s changed and he is more supportive.” Martha

Martha blamed the HIV diagnosis for the violence. Beauty also reported violence but attributed this to her former partner’s mental health as he remained unaware of her HIV diagnosis at the time of separation. They had an argument about his sexual fidelity, he did not return. Fumi also reported abuse and escalating violence from her partner. Violence and abusive behaviour from the women’s partner was damaging to the women affected. Transition became a more tortured path which impacted negatively as they struggled to deal with this abuse.
4.2.2.11 Loss of Control with Disclosure: Partner Telling Others

Both Martha and Mary report their partners telling significant others about their HIV infection. This loss of control over disclosure caused pain. Martha’s husband saw the error of this disclosure and was later sorry. Mary’s husband and his family denied his paternity and left Mary isolated and pregnant. He has never seen his son this has caused pain and further distress to Mary. Fumi also reported her partner telling significant others of her HIV infection, this impacted on Fumi and made things worse when she was at her most vulnerable. This is spontaneous reaction by her partner but unfortunately once disclosure has been made it cannot be retracted:

“I said sit down, yes it’s true I have AIDS and he started screaming and calling people in Nigeria, calling my sister, my brother.” Fumi

Fortunately her family were very supportive and told her they loved her.
Bola reports her partner told her family and friends on leaving her and this contributed to her isolation. Loss of control with partners telling others was a real issue for some women affected. They lost control over important information and this was not only challenging but damaging for most women during transition and an extra burden to carry. This loss of control added complexity and possible rejection with each significant person informed without her consent. The secret of HIV was now lost (see section 4.2.2.13 Keeping Secrets).

4.2.2.12 Searching for the Cause of Infection

Searching for the cause of the infection was a common finding as this information allowed transition and transformation to progress if the cause was found and the question answered. However the phenomenon was often impacted, if the partner tested negative, with this search becoming more acute. After her husband tested negative, Julie began searching for the cause of the HIV infection, which became a consuming quest as she went on a “hunt for the cause” including questioning her previous partner and his family in a surreptitious way;
“My husband is the second boyfriend that I had before, so I know I know I’m not a prostitute I don’t sleep around and I was taking the other boyfriend I was having sex and sometimes I told myself back home to say I’ve listened to him to, I just want to know if he’s sick or he’s not well.” Julie

When satisfied he was well, after this questioning, Julie maintained her infection was probably due to a previous termination of pregnancy in Africa and that unclean instruments were to blame. No mention is made about any other sexual contacts as Julie has satisfied herself with this aspect. She distanced herself from the cause of her infection and she felt morality was important to uphold and that HIV was linked to prostitution and not applicable to her.

Martha also reported trying to find the cause of her HIV infection and cites that she had remained monogamous and that a blood transfusion was the probable cause. What this fails to ascertain is the question of sexual contact but this may be correct as blood is implicated in African transmission as it is often not screened (UNAIDS Report 2010). This had occupied her thoughts for many years as she tried to comprehend the cause of her infection:

“It’s been a lot on my mind because I have thought of everything I said is it the needles they used in the hospital, did I cut myself, all sorts, I was thinking of every single possible, how and I just came to the conclusion because the other ones the risk are not as significant as having a direct blood transfusions.” Martha

Cindy admitted she had not always been careful and had taken some risks:

“No saint and I could have taken more care but I didn’t think for one minute I would be positive.” Cindy

Cindy made a decision not to search for the cause but as revealed earlier suspected her former partner. She ascertained that it makes no difference to her now as this can be interpreted that simply her transformation was in a settled state with this aspect of her life. Jane reported her first thoughts were where the HIV infection arose from and suspected a previous termination as her husband tested negative. Mary also searched for the cause of her infection once her partner was negative. Mary gave a detailed and somewhat open and honest account of her life and a relationship she had in Africa, whilst she was engaged as she did not believe her future husband would return to marry
her. She blamed herself for this one off relationship and believed it was the cause of her infection and regretted this:

“I do blame myself I said why I (NOT) believed him that he is coming back.” Mary

Mary blamed herself, one of a few that did. Rose also saw her sexual behaviour as contributing to her infection. She was engaged but her diagnosis stopped her planned marriage but she is still supported by him and was currently pregnant for the second time when interviewed. Her former partner who she believed infected her was now dead so she had a cause for infection but blamed herself. Blame may not be a useful response to HIV. HIV is a consequence of behaviour that may transmit the virus but this blame and regret may be detrimental to wellbeing in the longer term. Justina also reported she searched for the cause of her infection and more so when her partner tested negative. She enquired after previous partners’ wellbeing and health but they failed to make contact so did not pursue this further and came to a resolution it did not change the result anyway. Fumi also searched for the cause but gave up as it was wasted energy and as her partner had gone it made no difference for her. Her other children were tested and were negative and this ended her search for the cause of her infection. It is significant that women needed to know were HIV had come from either from their partner or others. They accepted it could not spontaneously appear so someone or something was to blame for the transmission and this had contributed to anger and turmoil as they searched for the actual cause of infection. Once this vital question was answered or settled, then transition and transformation of their “being” could proceed.

4.2.2.13 Keeping Secrets: Disclosure to Others and Importance of Looking Well

Trust issues were reported as an important aspect of living with a positive diagnosis. Telling significant others was important balancing a considered need to control disclosure. For some it was important to keep HIV secret, as HIV was an unwanted guest or interloper. Secrecy maintained confidentiality and importantly control. Looking well was an important facet and hid HIV from view. If they looked well, this would not raise the suspicion that they may have infection. Clara reported she had a friend in the house on her return from hospital after being diagnosed but kept it a secret from her.
You sense this secrecy was an important facet to maintain a degree of control. Clara did inform her mother who was supportive. When questioned further, she could tell her mother but no one else as her mother was essential for support but would also keep her daughter’s secret:

“I told my mum but I never tell my sister or brother cause my mum’s my mum whatever happens to me, she can keep a secret for me, she can not disclose it with anybody and she never tell anybody, she was just praying for me” Clara

Julie also reported the turmoil in telling others and could not even tell her friend. It was important to maintain the secrecy and still did not wish to tell anyone of her diagnosis. Even today she still keeps it very quiet and secret. For Julie she then mentioned a “dark place” which was literal with a darkened room in her house. When questioned further it was also a dark psychological place with thoughts that were dark and included social isolation with a withdrawal from others who may have been able to help her:

“Where I went, I just wanted to be on my own I don’t want to talk to anybody I just want to be in that dark place” Julie

Help and support was offered repeatedly during the pregnancy as Julie’s distress was palpable to staff but she declined all help. Simply she needed to be alone to work it out. This interpretation suggested she needed to build her own resilience.

Martha reported difficulties with the reaction of her disclosure of HIV to her mother and others in her family as they were angry. This saddened her and she felt she had let them down also. She reported with irony the loss of control of disclosure by her husband to others (see 4.2.2.11 Loss of Control with Disclosure: Partner Telling Others) and how she told her mother:

“Well he didn’t keep it to himself (Laughs).” Martha

Martha’s husband repeatedly threatened to disclose to others, which he did:

“He (Husband) kept threatening he was going to call my mother, because my dad is dead and he was going to call everybody and tell them and my uncle came to visit, that’s I think later after I had the baby, he said he was going to tell people, he told his brother, he just started telling people about me.” Martha
When asked how this made her feel, Martha reported that she challenged her husband’s behaviour and his beliefs which show strength and resilience:

“Really bad, it made me feel really, really bad, like these people don’t know about, look at the way you are treating me do you have any little knowledge of what HIV is like, oh I don’t want them coming to the house before you infect them, oh like am I going to start sharing needles with them or am I going to start having sex with them or something like that (laughs).” Martha

It became a battle but she was forced to tell her mother over the phone. Her mother’s reaction to the news was disbelief as she equated HIV with having increased number of sexual partners. Her mother was focused on the unborn baby and the effect of HIV on her potential grandchild. This was probably reassuring for Martha as she was not rejected. Jane reported she could not tell her family back home in Africa as they believed HIV leads to AIDS and death. This in effect enforced secrecy. Sadly, Beauty had told no one of her HIV infection for many years until she attended Positively UK. Then she was for the first time in her life no longer alone with her diagnosis. She was also saddened that only recently she told her mother as she did not want to add to her mother’s burden. Her mother has been very supportive. Beauty rationalised why she did not tell her mother or others and she locked me in a glance as she reported:

“I didn’t know the whole thing upsetting; you know you keep it to yourself, safe.” Beauty

Beauty was adamant it was her business alone and distrusted others with her secrets as it kept her safe. This is for her may have been a true interpretation but it is impossible to ascertain if this secrecy really kept her safe as she would not engage further with this topic. Justina only told her support group network and she kept quiet about HIV to others. Justina also reported she kept HIV secret on her partner’s instructions:

“He told me not to tell anybody, my family, his own family; it was between the two of us.” Justina

Fumi reported she kept HIV to herself as it was her cross to bear. Bola reported she told no one except those at her support group. Rose told only her friends from the HIV support group and felt it best to maintain secrecy. In essence women needed to balance the need to tell significant others and the support they could give verses keeping the
HIV diagnosis a secret as protection of self. This was very difficult and women managed this in their own unique and individual way. When in control of this issue, they balanced who or not to tell. This control was an essential element for women. Effects of apparent ill health were a threat to disclosure for Julie and she isolated herself as she thought if she looked unwell, others may guess she had HIV. Back home in Africa, people were aware sick people may have HIV leading to death (UNI AIDS 2010):

“Why I was keeping it to myself at that time, I think because the impression I had back home is by the time you have it in a few months, you’ll be lost (die) and they are looking at you if you are ill.” Julie

Beauty felt African men used appearance to judge if a women was acceptable to sleep with but she knew of girls “most of them prostitutes” with HIV who look good. This had a slightly sinister tone and edge, in that men would ultimately have revenge served upon them for all they did. Justina succinctly stated:

“If you are never sick, nobody will know, not if you don’t tell them.” Justina

I observed and noted most women attended the interview well dressed and when asked they said it was important to look well and not ill in their community. This observation from the field notes is an important one. It would indicate that the pretence of looking well was a requirement as part of the armoury of women’s coping mechanisms. Simply any noticeable change in appearance due to HIV was a concern for women. The transformation of “being” whilst not apparent in a visual way, the women needed to look well and by dressing well this aided that allusion all was well and good in their life. The following diagram (Figure 6) illustrates the major paired theme of anger and turmoil: loss of old self and a selection of the primary and secondary themes. The woman is represented and centrally placed with the view looking down on to the top of her head and the major paired themes are encased within her head. The primary and secondary themes are external but radiate in to her head as they are pivotal to major thematic development.
Fig. 6. Diagram representing THEME TWO – Anger and Turmoil: Loss of Old Self

NB. The top of woman’s head is viewed from above and centrally placed and the major paired themes are blue and encased within her head, primary and secondary themes are external but radiate in to her head.
4.2.3 THEME THREE- Stigma and Confidentiality

All except Grace and Fumi reported the pervasiveness of stigma and reported how they managed and importantly coped with this aspect in their lives. For some a journey had evolved from stigmatising other to being stigmatised. They gave instances of how confidentiality was upheld but also threatened and one respondent discussed the perceived hidden language of professionals. Stigma was reported from a number of sources including self, partner, family and from professionals and own support communities. Whilst excellent support and care is often reported, poor care instances are also evident. Stigma is a reoccurring theme in the literature (Ingram & Hutchinson 1999, 2000; Kirshenbaum 2004; Sanders 2008; Sherr et al 2011) and its effect is toxic and damaging. Stigma was real, experienced and menacingly overshadowed women and impacted on transition and transformation as women fought a harder battle when stigma was present. They learnt coping mechanisms such as keeping HIV a secret and not being open in many cases as this was protective of her confidentiality.

4.2.3.1 Personal Stigma

Clara with a number of the women respondents saw her infection as a personal stigma that she was aware of HIV within herself. HIV was indeed an interloper and she did not like it but she had to cope within her life:

“You know because there is a stigma, before I put myself together if I’m going to work, I start looking at myself, Oh I’ve got this stigma” Clara

When asked to clarify, Clara said she looked at others on her journey to work and saw them as different from her: “you’ve got this thing.” This thing was HIV and not pleasant or warranted. Clara further sates she has gone on a personal journey from one side to the other with the stigma of HIV: from stigmatising others to feeling stigmatised herself:

“You didn’t want to sit near the person, you’re like oh I’m catching it if I talk to him or her, so I was like, so this is happening to me.” Clara

This is interpreted as one aspect of the transition and ultimate transforming process. Going from one side to the other brought some unpalatable issues for Clara to now
balance in her life. Julie’s own personal misplaced beliefs were acknowledged as a source of stigma and caused isolation for her:

“Like if you are a prostitute that you can have it” Julie

However, this belief was rectified by further assurance from her HIV Specialist midwife who was adamant that this was not correct. This made a difference for Julie as she was now aware this was not the case. Stigma and shame was still attached to the HIV diagnosis. Julie talked of the “innocence” of children and their infection:

“It’s very difficult for those child to be born like that, they have not slept with anybody, they do know anything, may be for me too hard for me” Julie

Fumi talked of her own cross to bear, whilst denying stigma, she kept HIV quiet. Bola also saw that she formally stigmatised as she thought HIV was from prostitution and blamed them for the infection in her country. She later realised this was not the case. Women often stigmatised themselves as they tried to make sense of HIV and were aware of the acute pain that it caused them. They once stigmatised others and now knew others stigmatised them, which was painful as they wanted be seen as morally good.

4.2.3.2 Stigma from Partners

A number of women reported stigma which emulated from there partner. This stigma so close to home was toxic and women were badly let down and were unsupported:

“I kept it to myself ‘cause it’s not something like, there is stigma, because he wasn’t really nice to me after that.” Martha

Martha reported stigma emulating from the home and her partner was the major instigator of stigma:

“I think because of the experience I had the early years, the stigma and the way they treated, you know the bad treatments it was like trying to come in from my within my home all the HIV positive, don’t touch them make sure you wear gloves before you carry the child and all those kind of things, it was told by my partner.” Martha
This was extremely hurtful but she believed was due to his ignorance, however longer term it made her stronger as she faced it. When asked how she challenges this:

“That was really hard and I just ignored him, he kept going on and on and because she was so poorly and premature so we were going in and out of hospital all the time and he kept saying oh she’s infected and things like that and you know he kept going on and on and he wouldn’t call me when she was having her results done he was really, really hurtful and one of the reasons I said I can’t carry on like this, I will not carry on like this, so unhappy and I don’t know being in that kind of relationship so that’s when we went our separate ways for six months I think he was more miserable and he came out with I don’t mind you being HIV so long as I am with you.” Martha

Her partner’s behaviour was of real concern and feels this is in part due to this stigma (This is reported further previously under abuse and violence see 4.2.2.10). The stigma and shame that emulated from home did improve and her husband now has issues with stigma emulating from others. But Martha reminds him he was once like that himself. This probably gave perspective to his former behaviour. Beauty also reported Stigma from her partner. Fumi reported that whilst she did not feel stigma now, her partner was abusive and stigmatised her at first, then he understood the issues and stopped but she ended the relationship for other issues. In essence stigma was damaging from any source but close to home was even more toxic as they no longer had sanctuary or peace and this was devastating, painful and damaging to relationships.

4.2.3.3 Stigma in the African Community: Isolation

The stigma or potential for stigma and its toxic effect was raised as contributing to longer term isolation after an HIV diagnosis by a number of women. The support from the women’s community was threatened. Anna reported stigma causing isolation in her own community:

“And then you sort of get all the stigma around the, people having to isolate themselves from you” Anna

Jane also reports she would not tell others in her community and the stigma was marked and damaging:
“The stigma is very, very hard.” And “the black community, in Nigeria where I come from I know it’s very, very high.” Jane

Beauty was questioned about the effects of stigma within her culture:

“It’s too much.” And “You keep it quiet you can’t open up to tell anybody.” Beauty

However, she has recently attended Positively UK after many years and has made African friends. She also met one of her long term friends at the group who she did not know had HIV. Justina also reported the fear of stigma from others in her community and though less in the UK was still prevalent in her home country. Bola reported that as a Muslim women stigma was strong in her community and that she told no one. Stigma and its role in telling others in the social network or community of a positive result is an interwoven theme and is also reported under telling others such as family, friends, church or faith groups. In essence women understood their communities held stigmatising views of their infection and this caused difficulties often with isolation and the need to keep HIV quiet was important for them. This had a detrimental effect on the phenomenon of transition and transformation. Simply, stigma hindered this transformative process.

4.2.3.4 Poor Care Instances: Confidentiality at Risk

A small but significant number had a poor perception of staff caring for them and poor care instances were revealed not by the specialist HIV teams who were held in a positive light but often the ward or other allied staff. I do not apologise for the amount of narrative in this section as it is pertinent to the midwifery/nursing profession and it often speaks for its self and can be self interpreted. These care experiences had an effect. Julie gave an in-depth account of her perceptions of a “hidden language” by midwives to tell others she was infected with HIV and this included hidden hand signals and whispered terms that she felt damaging to her confidentiality:

“Life is getting better and erm what I want to tell you is the nurses, it’s not like Debbie who works with HIV, I mean the wards, those that works in the ward and some of them they are really bad and when they come to you they are like bad.” Julie
Julie reported that staff were cold and did not touch her but she just reluctantly accepted it and often “thanked” the perpetrators. This made Julie rationalise that it was just how some people are. However, one day she challenged a staff member and reported the incident to her HIV specialist. This demonstrates how staff can impact on the women’s self worth. Julie also strongly suspected a staff member informed a friend of her HIV:

“I was bleeding at the time I couldn’t cope with them and then I met this South African lady and we’re like friends and start talking lots and we started talking and chatting and there was this woman within an health care system, she came and told her that she should stop being friend of mine. Bad. I think the nurses had passed (information) to her” Julie

But Julie also noted an improvement in her last stay. Communication and kindness were more evident as she had built up a relationship with staff. Exposure to kind staff made all the difference to Julie. Anna was a student nurse and gave a detailed account that doctors talked about her condition as if she was not there whilst in the ward and in the presence of other patients. Anna complained to the hospital:

“I had an incident when I was admitted in the ward, myself I felt that my confidentiality was compromised, cause the doctors talked about my condition, I wasn’t there and yet I was there and they were talking about it in front of the patients. So I made a complaint to the hospital for which they apologised for it, so hopefully it doesn’t happen to anybody else.” Anna

Anna also reported social isolation on a longer term due to her “sickness” and had made friends with the “ward sister” as she would understand her HIV. This ally was important to her. She related her isolation to stigma:

“I don’t know I don’t know whether it’s being selfish or not, I am HIV positive, fine but I just find that I don’t fit in really, I wouldn’t fit in, cause everywhere I go I still feel people in one way or another, there is still a stigma, you know.” Anna

She later relates there is a lot of stigma in health care as she is aware of this as a student nurse and then relates how she is tackling this by studying the topic of HIV. This gathering of HIV knowledge helped Anna to deal with stigma and inform others. Her course tutors were supportive which helped Anna.

Stigma was also an issue for Martha who reported a number of specific instances. She was given poor information by her GP when she went for assisted conception and
related this to stigma and ignorance. Referral was refused by her GP as she was told they would not see her due to her HIV status. She knew this was not the case and tackled the GP. Then the GP wrote twice on the form she was HIV positive on a second referral scan. Martha complained

“she just put HIV positive twice and I was so upset I had to call the practice manager and I said this is now becoming personal and I reported the GP to the practice manager and I said look I could take you further, you do need to educate your GPs about these things.” Martha

Her perception of her care from her GP was poor as this was a recent event which made her indignant but also empowered her to do something and challenged her GP directly.

“It was quite recent, it’s not like it was ten years ago and I told her it was the worst treatment I’ve had since I was diagnosed with my HIV, I mean it is the worst treatment from a medical person, she apologised.” Martha

Martha also reported a poor care experience and related this to stigma in special care unit:

“The only bad experience I had was, because my daughter came really early, she was born thirty weeks and three days and she was in a special care unit, I think she was being, being cautious and it was, I could feel the stigma there while she was in special care, oh she’s too young for them to know her diagnosis if she’s positive she still has the antibodies because she came quite early so I noticed there was just extra caution from the nurses when they were handling my baby, put on three gloves.” Martha

Putting on three pairs of gloves was a personal insult, it was stigmatising her baby. This was unacceptable to Martha as she knew it was not clinically required. When questioned how she felt:

“Really bad, I felt awful, I didn’t like it one bit I couldn’t wait to take her home, yeah.” Martha

Jane reported a poor instance of care from her GP surgery where a receptionist separated her from others in the waiting room after reading her file. She felt helpless to challenge. This interpretation demonstrates that health care providers have innate power over a vulnerable patient (Lee 1993). Jane reported difficulties with access to hospital with formula milk but this was less to do with stigma and not understanding her medical
condition. It was still a painful experience. Mary gave a detailed account how a midwife or nurse came in the room to take her temperature and Mary acted out how the midwife did not want to make bodily contact with her:

“I cried and cried; this is the life nobody wants to share with you.” Mary

This has far wider implication than the first narrative, this is the time that Mary comes to the realisation that HIV may hinder future relationships. However, she bravely raised this with another midwife/nurse on the ward:

“I said is this how people treat you with HIV, she said no, she hugged me and said no its just the individual. Mary

This hug was important for acceptance of Marys HIV from the world of midwifery, not all people were going to make life difficult, and some would be kind. Beauty also reported poor care in labour and was forceful in her explanation, she got a feeling it was due to her HIV infection and is very critical of care:

“You know they definitely nasty there was one person that was really nasty, very nasty.” Beauty

Beauty told her to keep her hand off her. However, she did not complain further as it was probably a battle not worth fighting for her:

“I don’t want people to start talking about me I just want to have the baby and get out.” Beauty

Beauty’s recall and perception is very worrying. In essence a significant number of women were unhappy with direct care given and often linked this to the HIV diagnosis. It was sometimes due to ignorance and poor understanding. However, some instances were perceived as intentional and cruel but women often felt powerless to challenge due to their vulnerability (Lee 1993). This is a major concern. These are health professionals and allied workers in health care and it is simply shameful and unacceptable and against professional standards (NMC 2004). Women knew this poor behaviour by health care workers was detrimental to them and this hindered their transition and transformation as the power displayed by health professionals could be damaging to this process. They were supposed to understand and support them and by not doing so, made transition
unnecessarily a more painful process and transformation perhaps damaged or incomplete. The support and facilitation to aid transition and transformation was simply removed by poor health provision and practice.

### 4.2.3.5 Lack of Education: Impact on Stigma

Martha and Cindy believed a lack of knowledge to be the root cause of stigma and must be challenged:

“A little education makes people. You know they say a lack of knowledge is bad…HIV is in your blood not written on your forehead…..In South Africa it’s not a secret….Every person has to know their status for your own life.” Cindy

Cindy was refreshingly open about her HIV, one of the few women that felt able and even encouraged her mother to test and stated awareness and knowledge of HIV was key to challenging poor perceptions of HIV. This was a notable difference as most women remained guarded; the personal risk was too great. Cindy had good care and that there was never a negative judgement of her. Jane reported the damaging effects of stigma and how it gets in the way of knowledge of HIV:

“Because of stigma and the fear, stigma, fear and ignorance, they are highly ignorant of the effects of HIV and the symptoms and the consequence of it.” Jane

Jane trusted staff to know her HIV diagnosis in UK and was less concerned for others to also know now, but not those in her country of origin. She had not told anyone in her home country and keeps HIV a family secret:

“You know there’s something that needs to be a family secret.” Jane

Beauty reported there needs to be more awareness and education and they need to know that HIV is not a punishment for being gay or a prostitute. Justina was also of the view that education was an important concept in tackling stigma but still kept her diagnosis quiet as she has too much to lose.
In essence women believed stigma should be tackled through education but were wary of openness to others, but felt by being open it may challenge it. Importantly the concern women had with possible stigma kept women from disclosing HIV to others, which impeded their ability to form a relationship and build social capital networks. This was damaging. Martha kept her life separate and was able to ‘pigeon hole’ her HIV only letting others with HIV know her diagnosis. But Martha worked around this aspect to assist others, as she was aware of the health benefits of testing:

“A lot of people don’t know, a lot of people don’t know about these things and this lady I met with one of my very close friends, my very close friend cause we have known each other for years now, decades but she still doesn’t know about my diagnosis, the lady was pregnant and she came up and can you imagine one of the midwives said she should have the HIV test, she said what kind of nonsense talk is that and I’m like oh why do you think that is nonsense talk, she’s like I can’t believe you are bringing this up, really people don’t want to talk about it, I said it will be good for you to know.” Martha

Martha was adamant she would not disclose to her employer due to possible stigma and managing her HIV as confidentiality is an issue even in health human resource (HR) management. Her colleague’s reaction to HIV still shocked her and Martha was adamant confidently of clients was often breached in HR health care. Cindy recognised stigma was damaging and existed but gave it little thought as she believed it was wrong to stigmatise or be stigmatised and felt this was due to the openness of HIV in South Africa. But Cindy also recounted good care including the pharmacist at the hospital and her perception and exposure was limited. Beauty felt the only way to maintain confidentiality was to tell no one. This was a winnable war and she used secrecy to achieve it Justina felt she needed to keep HIV quiet as did Bola and Rose. The need to keep quiet and preserve confidentiality is in essence a coping mechanism; it allowed a degree of control over their life with HIV but importantly allowed transformation. The following diagram (Figure 7) illustrates the major paired theme of stigma and confidentiality and a selection of the primary and secondary themes. The woman is represented and centrally placed with the view looking down on to the top of her head and the major paired themes are encased within her head. The primary and secondary themes are external but radiate in to her head as they are pivotal to major thematic development.
Fig. 7. Diagram representing -Theme Three- Stigma and Confidentiality.

NB. The top of woman’s head is viewed from above and centrally placed and the major paired themes are green and encased within her head, primary and secondary themes are external but radiate into her head.
4.2.4 THEME FOUR- Acceptance and Resilience

A significant number of women reported a growing acceptance of their HIV diagnosis and also with the experience of receiving a positive result. A growth in personal resilience and coping with the challenges of a life HIV were reported with a fair degree of optimism and hope as time passed. The growth of acceptance made life with HIV more manageable; simply acceptance reduced the power and dominance that HIV once held. The growth of resilience empowered women and improved their ability to cope with a life with HIV. Hope and optimism made life worthwhile and aided transformation of their “being” as living with HIV became less of an issue for a number of women. Acceptance and resilience were pivotal and contributed to a less arduous process with the phenomenon of transition and transformation. Transition and transformation was a smoother process and less of a battle as acceptance and resilience were positive factors that aided less problematic transition and greatly influenced transformation, with HIV perceived as not as large or troublesome issue as it once was. Living a daily routine existence confirmed that life had a degree of normalcy and children were often the prime focus of their current existence. However, they reported that informing children of maternal or child infection remains an issue to be faced, but one that will be confronted later in life. Women valued and trusted medication and valued support and the HIV specialist teams. Support for antenatal testing was apparent but with the caveat of further pre-test information to explore issues but essentially it was better to know of their HIV infection, than be unaware. However, few women in this study talked of their specific pregnancy other than a wish for a negative child or divulged how HIV affected this aspect of their pregnancy experience of “being pregnant with HIV”. Once diagnosed with HIV, there seemed to be some dislocation from the pregnancy, until the child was tested and the result known. If suicide was contemplated the pregnancy was protective and stopped this consideration of harm. Essentially the pregnancy allowed hope for a future life. The specific information and confirmation of the child’s HIV status then allowed acceptance and resilience to flourish, which was irrespective of final outcome of the child’s HIV status. This also allowed the phenomenon of transition to proceed and later a transformed life, adjustment to living with HIV but with a child’s HIV status known. This gave comfort to women.
Grace only knew of her infection two weeks prior to giving birth, when directly questioned how HIV made her feel about her pregnancy due to the short time reported:

“*That’s what was worrying me, I was just praying I was saying, God I wish my son was ok, I wish he could be fine, at least I know it’s me and I am fighting for my own life but not, fighting for two people.*” Grace

Grace was fighting for her child as well as self. Martha responded that her strong desire was for a negative child, which took a year for confirmation with her first child. This waiting for confirmation was dominant in Martha thoughts:

“The next test they did came back negative so she’s got rid of all my antibodies, then they did another one and they did a final one when she was one year old and it was negative, so the whole year was just waiting and waiting and hoping.”

This understandable wish, desire and hopeful outcome for a negative child was strong. This seemed more important, than how HIV impacted on them personally during the pregnancy, even when major issues were identified such as partner separation, social isolation, turmoil and concerns how this impacted on the pregnancy. This lack of information on the experience of being pregnant with HIV is perhaps a disassociation or a distancing and only after the birth of the child, with a result confirmed, did this seem to allow acceptance and a growing personal resilience. It was noted personal sadness with stoicm if the child was HIV positive, but absolute relief if the infant was negative. The need to live for the child was a strong and lasting reaction as women became more resilient:

“You know it will be a real benefit for me to live.” Julie

Julie saw worth in her life, it was beneficial for her children, without her they would be essentially orphaned and vulnerable. She was able to protect them if alive as were all women.

4.2.4.1 Waiting for the Child’s HIV Result

Waiting for the infant (or other children’s) HIV result was the culmination of the testing experience for women. They needed to know this outcome before they could move on
with life. This halted the transition and transformation process as the information was key to the next stage. Waiting for their child’s result was stressful for women and expressed as fear and trepidation. Grace needed to be strong for her baby and reported:

“I’m not alone in this, I need to be strong and be there for him (pointing at her child).” **Grace**

Clara with trepidation had major worries with testing all her children and as each was diagnosed negative; her relief was palpable as the implications for her would have been too awful to contemplate if they tested positive. She would have blamed herself:

“Oh I felt that she (pointed at her baby) is not involved in this, I was like ah I’m just waiting to have her, to do the test, I had the fear for her.” And “so when I did the first test (For the baby) and they say it’s negative I feel more relief.” **Clara**

Julie reported whilst waiting for the result of her baby, the anticipation is again palpable as she relates her story:

“I was very, very nervous and the medication they gave me and I’m waiting for the time to come, I think it was 10o/Clock, 10o/clock in the morning I found out then.” **Julie**

Fumi felt more confident as she believed in the health message with her adherence of the medication. Bola felt relieved when she had the result for her child. All the women reported degrees of anxiety and stress whilst waiting for the child’s result. In essence women needed to know the outcome for their child or they simply could not move on. This was the focus of HIV testing for women, a well baby even if they were not free. The hope for the child’s wellbeing was strong and mothering evident.

### 4.2.4.2 The Positive Child: Stoicism and Acceptance. The Negative Child: The Ultimate Prize

A positive child was a rare finding but its impact was reported by Anna who had been diagnosed in her second pregnancy. On her diagnosis, her thoughts were for her firstborn son and she believed he would be infected which was later confirmed. Anna
believed he would probably die and also herself. The feelings invoked were traumatic
and devastating:

“I had a baby yes, more on guilt because I know it is transmitted, I breast fed myself, so obviously I knew he would have it even if there was no chance he was going to survive, so I was just thinking of my son at that time, and he is going to die, we are all going to die…. knew it was going to come back positive because I had breast fed him, so there was no way I was expecting a negative result.” Anna

And when asked how she felt about this result for her son, she admitted she coped by
not discussing it, but knew deep down that his infection is a real issue for her as she
knows that transmission was through her:

“I tend not to talk enough about it, I tend to hide it, I try to think it doesn’t exist but it
does.” Anna

This result whilst devastating, Anna remained stoical and accepting, importantly she
had a second baby and also reported on her daughter’s negative result with excitement:

“I was very happy, I was very happy, actually nervous waiting for the result, so the
day that I got the phone call and she is negative I was really excited.” Anna

Grace reported her wait for her infants result was short as he was tested at birth. Grace
was also greatly relieved when the test was negative. This was the news she needed to
hear to make her world seem normal. Martha responded with hope when the first result
for her baby was negative but she would have liked further information at the time to
give her hope as this was a constant worry while she waited. However, she still had
some doubts that the result for her baby may be wrong:

“So I still had that thing in my mind that maybe things, this time it’s negative
because they got the results wrong.” Martha

Cindy, Jane and Mary reported immediate relief and happiness with negative children
but also reported the wait for the result as stressful. Mary reports that she kept calling
for the baby’s result and when she was informed negative:

“I said God thank you at least he’s fine, I didn’t have anything to worry about him.” Mary
Jane reported seeing her child’s negative result on the paper was important for her and requested that it was sent to her by post to confirm that it was true. Beauty reported she was worried waiting for her child’s result as to see him suffer or die would be too much. However, she was aware that women had negative children which gave her reassurance and encouragement:

“I was worried I was thinking I don’t want to bring a child to suffer and a child to die.” And “I see a lot of women who got two or three children, they say they’re fine, they’re fine, so that keep encouraging me.” Beauty

Justina felt very reassured by the child’s result and importantly believed the child would be negative as she believed and trusted the doctors with her medication, care and treatment. Fumi reported the same as she had adhered to the medication. Bola and Rose had the same view. In essence the ultimate prize was the negative baby, it made the experience of testing worthwhile, if not for them personally but for their baby. This news allowed transition to proceed with hope and a positive factor for transformation

4.2.4.3 Children: The Focus for Living and Less Importance of Self

The child was now their prime focus in life and less importance of self was evident. They sacrificed their own future relationship in some cases. The child was now the focus and putting the child first was an important coping strategy; Clara reported that she needed to be optimistic and happy as this made coping easier:

“I make myself happy, like now when I have the baby, I just look at myself and I say look I’m not going to be depressed by anybody, I want to make myself happy, I want to look good and do whatever I can for my children to make them happy.” And “yes they are my priority” Clara

This forcing of self to be happy is remarkable; she did this for her children but was it a mask for her feeling as she saw the danger of self pity and possible depression. Anna reported her growing resilience and focus of the children even thought this meant the end of her relationship:
“It’s done with, I’m not going to get back with him and I don’t think of getting married or getting into a relationship, you know. At the moment I just want to focus on bringing up my two kids and obviously the way it will end, cause at some point we are going to die anyway so.” Anna

What is apparent is that Anna’s end point is death. This is a correct assumption but with medication an unlikely near event. Jane reported the same need to put her child first and additionally that she had taken all interventions for the sake of her child’s health and wellbeing even if it meant facing unpalatable intervention:

“I wanted to be safe, I never liked caesarean in my life.” Jane

Mary reported that she needed focus and to follow all the HIV pregnancy guidelines to get a well child:

“They say if you follow this paper all the instructions that the baby will be clean so I say Ok but within me I’m still worried.” Mary

Interestingly Mary used the term “Clean” on a number of occasions in the quest to be rid of HIV. Justina’s child was the focus of her life after the death of her separated partner and her mothering was strong to protect this precious child:

“I love my baby.” And “I feel emotionally strong, I am the only one he has got, the only one he’s got, so I have to try and give him, try and give him the best.” Justina

Fumi, Bola and Rose reported they wanted the best for their baby. Bola additionally reported she had gained confidence and was happy simply having all her children with her:

“I have my children around me all the time and there’s nothing wrong with them”

In essence the child or children were the future and the reason to live a fuller life. This is an important finding as even in adversity, the children came first. The “mothering” instinct to protect, nurture and love was in abundance (Sanders 2008). The child was the focus for life and had to be nurtured at all cost even if the self was not so important. The strong transformed “being” was an important factor; women recognised they needed to be strong as protective of the child wellbeing. The child’s well being was a focus and central to her strong transformed existence and her strength was also required for the child’s wellbeing with both factors co-dependent as she strove for a liveable life.
4.2.4.4 Telling the Child of Maternal Infection

Concerns were raised with the impact of maternal diagnosis on the child and how will they tell or negotiate behaviour with the child but many of the women had given thought to this future question. This demonstrated that women had thought of a future, a future with their child which is in essence wonderfully reassuring:

“When they grow up I will tell them, yes I will tell them so they will be careful, because they are my blood, they are my children.” And “yes if my children grow up, it’s something up to an age I have to tell them.” Clara

Anna reported she had worries as her son is already questioning the differences between himself and his sister and had strategies in place to mother him:

“That is something that worries me a lot, when my son grows up, he’s now only four but he questions me when I give him medicine, why don’t I give it to his sister, why am I giving him.” Anna

When questioned further how she manages this:

“I just have to play stories around it. Obviously when he grows but it’s a challenge I’ve yet to face, having to tell him this.” Anna

Anna worries that this revelation that both she and her son are positive could be damaging for future life with him:

“I worry that could really erm, It could damage our relationship, me and my son, cause how is he going to react when his sister is negative and he is positive, all those sort of things.” Anna

Anna was in a difficult situation as her child was positive and he would need to know. For Martha letting her child observe her taking medication is a bold way of being open, it will lead in future to further questioning. You sense Martha needs and will eventually develop an open and honest relationship with her daughter:
“She turned eleven in December by September it will make it twelve years since I found out I was positive, I would have told her a long time ago but her dad says she is just too young to tell her and I should wait, she has already seen me taking my medication and she has asked why am I taking my medication I say I just take it to stay alive to look after you, so she knows I’m on medication.” Martha

When asked further her feelings of this issue Martha was worried that her daughter as a sensitive girl would worry for her mother as she was a worrier already. Martha was adamant she would hear this information from her, as it was her mothering duty. This was in essence the one piece of control many women retained. Cindy was adamant she will also inform her children but with an added health message to protect them:

“I will tell them cause I also need them to be cautious, to be more careful, so I want them to hear it from the horse’s mouth not to hear it from someone else” Cindy

Cindy reported she will push condom use and educated her family even her brothers. Jane reported she was adamant would also tell them but when they are a certain age.

Mary reported she will tell her child as she wants him to know the full story as he will want to know about his absent Dad. Mary reported she was lonely at times:

“When I stay alone a lot goes through my mind and so I was thinking maybe when this boy grows up he will like to ask me about his dad.” Mary

Beauty gave a differing detailed account that she may not tell her children and she will always hide her medication. This in essence gave her some control over her HIV:

“They are negative what’s the point.” Beauty

Then reflectively thought she may do so at a later stage when perhaps her child was twenty but this may be Beauty giving an answer what she thinks I may wish to hear. Justina was adamant he would tell her child later as will Fumi and Rose. In essence women had contemplated telling the child at some point often as a warning to protect the child. Protecting the child from harm was important and often linked to maternal disclosure as HIV had transformed women but with many difficulties. Only Beauty had a different and valid view as it was her HIV.
4.2.4.5 Living with HIV: Challenging

When questioned about living with HIV long term, this was expressed very succinctly by women as they speak for themselves and their uniqueness:

“It’s not easy.” Clara

“I try to put it away” Anna

“I’m fine, I’m fine because I’m really fine.” Grace

“I’m living with it, it’s not how would I say it’s not what defines me anymore” And “It’s not me, it’s not, oh I’m HIV positive, so what.” Martha

This strongly suggests some women found living with HIV more difficult than others but had made adjustment with this transition and transformation to a “being with HIV”. For Anna this was related to her positive child and how she was dealing with her child’s HIV infection long term. She reinforces the child is sick but he recants that he is well:

“Sometimes I just tell him you’re not well but he keeps saying, no mummy I’m fine.” Anna

Cindy reported an inner strength, resilience; simply she no longer worried about HIV. Time had passed and she saw HIV for what it really was and that it did not control her:

“It’s funny but I’m just being honest, I don’t, I don’t worry.” And “I have got my inner strength, nothing, if this was going to kill it would have killed me when I had my baby.” And “Being HIV is fine you don’t want to die of AIDS because when it gets to that point it is just so hard to get back to your normal self.” Cindy

Cindy saw herself as normal and living with HIV. Jane reported she managed living with HIV and no longer thought of it or worried, she had simply blocked it out of her life and was adamant she was living with HIV for the sake of her children. Mary wanted to be clear of HIV, start treatment and also expressed a strong wish to see HIV banished from her life:

“I am praying for something that will just come and take it away completely.” And “I am hoping one day hopefully I will be alive to see that this disease is no more.” Mary
Beauty discussed the two sides of balancing and living with HIV. She was adamant she was strong and when she was depressed went to see a doctor, who prescribed medication but did not use it as she understood her depression was caused by her partner abandoning her with no money or entitlement to benefits, and she thought she was going mad. But she overcame this due to her inner strength and resilience. However, she still reports anxiety and longer term effects:

“To be honest it has affected me mentally, I keep worrying.” Beauty

Beauty also recognised that HIV limited her chance of a new relationship. She was scared of breaking this news and any new partner keeping a secret;

“They are not going to like you for what you are or them to keep a secret so to me it has affected me mentally because I can’t tell them, so it makes me single.” Beauty

Justina reported her acceptance of HIV in her life and she had moved on as she was transformed and accepted HIV:

“I have managed to put it away.” And “I don’t worry about HIV anymore.” Justina

Fumi reported the same and that she had her moments but HIV was not the issue now in her life. Bola reported that now she is aware you can live with HIV, she views it as a disease like diabetes and manageable but kept HIV quiet. However, Bola did report she found difficulties with trying on clothes in shops as she worried that she could pass on HIV even though she knew it not to be true, this was a remnant of concern with passing on HIV to her child and others. In essence women lived with HIV, often an unwelcome intrusion or interloper but with time learnt to live with HIV and get on with life. Acceptance and resilience were important factors as it aided transition and transformation with a life now featuring HIV.
4.2.4.6 Making a Difference: Kind and Caring Midwives and the Value of Support Groups- Breaking Social Isolation

The women valued the specialist HIV care team and specifically the specialist midwives, with their care, support, availability and approachability and in all probability this aided acceptance and resilience. Interestingly because of the empathy shown, Julie questioned if the HIV specialist was HIV positive and had this “problem”:

“I said are you positive and she said no because the way she talks to you and the way she handles you I think that maybe she is having maybe she’s one of those having the problem that’s why she is working with it.” Julie

Julie came to the conclusion that the midwife helped her out of kindness and this was important for Julie, the midwife was approachable and understood her difficult journey with her diagnosis. Anna also thanked her HIV team for kindness. Martha reported how the midwives supported her but alarmingly stated she did not feel “diseased”:

“When I had my daughter the midwives were great, it was brilliant, I didn’t feel like somebody that is diseased.” And “The midwives were great.” Martha

Martha was appreciative of the midwives sensitive handling of her medication which ensured her confidentiality. Martha felt things had improved in the 12 years from her first baby and initial diagnosis to the birth of her recent second baby. The midwives and consultant were very supportive with her last birth experience.

Also women valued other professionals with care given to them this included counsellors and paediatricians. Most women reported an excellent rapport with HIV specialist midwives and HIV team but less so with others in the maternity services. Simply the kind and caring team members made a major contribution to women living with HIV and they valued them.

Support groups were important for many women and a life line thought attendance was not a priority for some women;

“I’m not going to any.” Julie
Anna gave a detailed reason for her non-engagement after trying attendance once as she felt very sensitive who should know of her HIV. She lost a degree of disclosure control by attending and that she felt she did not belong:

“I don’t know, I just didn’t fit in, I didn’t feel so free talking about it, where as the other people I met there some had been going fourteen years of coming, they had been coming to that organisation but to me it didn’t.” Anna

Being a nurse, Anna felt she may meet someone she knew, which may in turn have compounded her social isolation. For Clara her isolation encouraged her participation and reliance on the Poppy charity for trafficked women. This was important support for Clara; they understood her condition and importantly did not judge her as a trafficked woman with HIV. For Martha her value of support groups was apparent:

“I had to go to the support groups and I was reading all the flyers that were coming into the hospital and I also joined the news letter for women so they were keeping us updated on the medication and things like that.” Martha

She later stopped attending because she was studying but was very appreciative.

Cindy and Jane also valued the HIV organisations for support. Jane felt that her network was church and she did not have a life of support outside of the HIV organisations at present. Mary gave a detailed account of the support she had received from Positively UK and how this had helped her make friends. Beauty gave a similar account but wished she had been told sooner. Interestingly she only recently discovered that women have been living with HIV for a long period so was a little surprised she could possibly live so long. She also reported she was not so isolated now as before. Fumi felt the same way and got great support. Bola felt similar and she only discovered that women were alive some time after diagnosis by attending a support group, but as time had passed she was busy with her three children so had less time but goes now and again. This was a similar finding for Rose and attended the African HIV support group, Body and Soul. All the women who attended Positively UK and other HIV support organisations were grateful for the support on offer and firm friendships were made reducing isolation. Some recognised that attendance could be problematic as HIV was a feature each time
they attended. But the loneliness experienced by some was dissipated for a while, this was important for resilience to flourish.

4.2.4.7 Acceptance: The Absolute Support for HIV Testing and Best to Know HIV Status

The support for HIV testing in pregnancy was strongly apparent for all women, no one felt otherwise and this gives an indication that women accepted HIV in their transformed lives. The support given was often for the benefit of the child and less for own wellbeing. When asked of her views of the HIV test Clara stated it was much better to know than not as she could access treatment. Interestingly Clara blamed herself for her infection, but stated simply, she had to accept it and all people in life will face the certainty of death:

“It’s like it was your fault, it’s not like people without it will never die, so it is just a matter of accepting it.” Clara

Anna strongly supported testing but to protect the innocent child:

“I would strongly encourage people to test, cause you wouldn’t want to put a child through it, honestly it’s the worst, it’s the worst thing one could do, you know carrying on as if everything is normal and yet it’s not, you know cause children don’t deserve it honestly, they don’t.” Anna

Cindy could do something to aid her recovery which was to access treatment:

“I thank God I got tested and I got the results became positive and I did something about it.” Cindy

Fumi was of the view it was important that everybody tested for HIV due to health benefits and not worry about being positive and that it was not the end of life and that they should count themselves lucky they knew. It was not a good experience for Fumi but was a life experience. Bola was grateful to know as this had allowed her to take medication and her children were negative. What is apparent even though these positive women have had a very difficult experience, they support HIV testing, for them and more often their child’s benefit. All the women spoke of their support for testing.
Women additionally accepted on reflection, it was simply best to know their HIV diagnosis, even after the original personal trauma and shock due to the health benefits:

“It's not nice but if I’m not pregnant I wouldn’t have known.” Clara

“I would rather know than not know.” Grace

Martha reported the benefits of testing and knowing her status and knew what the outcome could have been if not diagnosed. She was empowered to take care of her health and understood the outcome if she had been unaware. This was true reflection for her:

“I think if I hadn’t had the test done I probably well, I would have slowly, slowly my health would have started falling sick and may be it would have been too late for me and I would probably have had HIV positive babies now.” Martha

Mary was adamant it was better to know and would encourage others to test. Beauty thought it was good to know as HIV was harmful otherwise and so supports testing. Interestingly she thought the antenatal test was compulsory and was rather surprised when I informed her otherwise. Fumi was of the same view that it was best to know as she could access treatment. Bola thought it was best to know. In essence women were being pragmatic, they did not like knowing their HIV status, it was damaging but on reflection it was still best to know as they assessed their transformed lives. All women in this study expressed that it was best to know about their HIV whilst experiencing the drawbacks of a diagnosis they knew the health benefits for themselves and their children.
4.2.4.8 Hope, Optimism & Acceptance: Growing Stronger and Resilient as Time Passes

Hope and optimism for the future was apparent in the narrative. Women accepted HIV in their lives, it transformed their being. They grew stronger and resilient. This resilience was important, they learnt to deflect the unpalatable issues with HIV and whilst vulnerable had grown stronger as a person with HIV. Clara also expressed hope and strength with her acceptance:

“I have to be there I have to be strong there is still hope.” Clara

A significant finding was optimism and hope for the future with resilience, but this was tempered by the ability to enjoy some aspects in life as for Clara she had experienced depression which worried her should it return. Julie’s optimism was for more children later.

“I know when I have more children that they are going to be ok.” Julie

Anna’s motivation was her nursing and she had support from her training school. She had faced her HIV and used the term “HIV” instead of “it.” The use of “it” was a common term for some women respondents when referring to HIV but not for Anna. This was her nursing experience having an impact.

“I’ve grown up, I have become more mature, cause I used to rely on my husband to do things a lot but this diagnosis has turned my life upside down, I have learnt to become more independent, more assertive, you know, more organised.” Anna

For Grace her optimism and hope was expressed through her child, with a desire to see him grow up, this reward was enough:

“I have a kid, it’s like I have to move on and I have to be strong for him and the people around me make me, give me hope, that someone can live for years and see your kids grow up.” And” It gives me hope and it gives me, really a smile that he’s fine he’s happy I have to take medication, I am healthy and I can look after him.” Grace
Grace expressed a hope for another baby in the future as treatment is effective; this was after the loss of her second baby with a stillbirth following spontaneous rupture of her uterus in labour:

“**The good things, I’m on treatment, which is responding well and I feel I have life ahead of me and I will have another baby.**” *Grace*

For Martha her optimism was reported as HIV was something that could be controlled long term which she compared to the management of diabetes and she had become stronger and more resilient person:

“**I am a stronger person, after my diagnosis I just studied, I wanted to be the best in everything, I went to University I got a first class degree, it’s just the way forward now, I am just going.**” *Martha*

A sense of purpose was apparent for Martha as she appreciated life and what life had to offer, she saw HIV as a challenge but it gave her a will to succeed in life. Cindy’s resilience is palpable as she was adamant nothing would stop her:

“**The future is bright for me, I mean I’ve got my children, I just want them to be there to see them grow up, you know and nothing is going to stand in my way.**” *Cindy*

Mary reported a viable future with hope. Life was recoverable, the past whilst not pleasant was in essence behind her:

*I will just say the past is behind me now. And “so it’s not about HIV because people have been living with it for years.” And “within me I feel I’m not sick, nothing is wrong with me so just move on, a least who knows get married someday and start a new life again, yeah.”* *Mary*

Mary could envisage a life with a new partner and had hope for a better future. Justina reported she wishes to continue her education and get a degree and gaining asylum has given her a positive outlook on life. Fumi reported she just wanted to get on with her life. Fumi reported her resilience as need for a greater and improved life:

“**The important thing in my life is that I just. I want to be greater than before, I want my life to be greater than before.**” *Fumi*
Bola reported the break up of two relationships but she felt that she had much to give to her children and to possibly find a new partner in future. However she understood that it will entail telling him of her diagnosis but felt she could do so. In essence women were hopeful and optimistic for the future. They made plans and sought out a life, a life for living. HIV was not going to make them a victim; life was recoverable and importantly liveable even with the presence of HIV. Women grew stronger and more resilient as time passed and they accept HIV in their lives. Interestingly for Julie, HIV not always viewed negatively as her resilience had grown:

“The good bit about it, is that I now realise that’s it is not bad being positive.” Julie

This had enabled Julie, with the need to help others and she planned possible future involvement with a charity. See later section. Martha reported her resilience as growing stronger. Martha reported as the years progressed living with HIV became more relaxed with disclosure and whilst loss of control was an issue at the beginning her husband, he later told her of his discomfort with her telling a GP receptionist she was HIV positive, when she was reluctant to arrange a flu Jab. She was becoming brave and no longer afraid used her HIV diagnosis to achieve her aim:

“He was really upset do you have to go about telling people, you know it’s not something you should be happy about, I’m like I’m not happy about it, but now she’s,(receptionist) she’s quiet.” And “Normally I don’t just go blurring out, like I had to say it.” Martha

Jane reported she had become more resilient and drew on her inner strength; she would be strong because she could determine this aspect herself. She had control:

“I decided to be strong no matter what.” Jane

This is ultimately reassuring as destiny was being reclaimed. Whilst Beauty still worried about HIV she reports:

“I’ve accepted it, well I don’t let it control me” Beauty
HIV had the potential to invade and control and Beauty understood this and she still maintained HIV as her secret. Bola was adamant she was stronger and HIV became less of an issue as time had passed, she lived through two relationship break ups and believed she coped well as she had her children. All women when questioned felt more assured and were stronger and resilient. They did not like their HIV and some saw it as an interloper in their lives, but essentially they saw the challenges of HIV and simply got on with it, even when difficult. Most women reported as time passed became more relaxed when HIV mentioned, but it had the capacity to cause alarm or distress with some anxiety for Julie:

“I’m starting to relax about it, even now when watching a film and suddenly they say something.” Julie

Trying to accept the diagnosis still caused heartache for Anna especially as her son was positive:

“I could deal with just me but having a positive son and you know a negative daughter, that is something up to now as much as I am trying to get on with my life but I can’t get over it.” Anna

Picking up the medication for her son and giving him medication triggered a painful response:

“Every time I come to pick up medicines, especially for my son, I mention it to the pharmacist one day, can I just take a little dose, not having a three month supply, cause you look at all this especially the liquid for my son, it’s normally a three month supply, so think this all, for a child having to take all this, sometimes when I’m giving him medication my tears, I just cry, I don’t know.” Anna

In essence most anxiety did lessen for women; it did not mean they did not worry or become anxious any longer but learnt how to manage it with their strength and resilience. They became more optimistic and full of hope with a transformation of “being”.
4.2.4.9 The Value of Medication

A number of women valued medication for their own wellbeing and that of the infant. Simply it allowed them to live as a transformed “being”. This was also linked to optimism for the future and specifically the medication was viewed as of great value:

“It is, it makes a lot of difference. **Julie**

Also trust in the medication and its effectiveness was reported by Julie and Grace:

“They will make sure your baby, your baby, I think its about 90% that your baby will not have it, they will test.” **Julie**

Grace, Cindy and Jane all reported the benefits of medication and is also linked to hope for a long life Jane valued her medication to keep her unborn baby well as she became responsive to effective treatment:

“I started feeling a victory at last in me. I know that it's not the end I know I have not been cured.” **Jane**

Interestingly Jane felt that her working medication allowed her time not to disclose to her partner whilst she sought a strategy to do so. (See 4.2.2.6 section telling partner). By not being very infectious and a low risk to her partner, this allowed her a breathing space to review her options. Justina, Fumi Bola and Rose valued medication as did all women when asked directly. Bola’s eldest child was questioning her more though as he had witnessed her taking her medication. It mattered greatly and they were able to manage their diagnosis. Fumi was grateful for the home delivery service as she did not have to carry boxes of medication home.

4.2.4.10 Strong Faith: Important for Some

A spiritual faith, church or Islamic support if a Muslim, was important for a number of women as they accepted HIV and became resilient and stronger:
“You know sometimes it’s like oh you’re dying you know, I just put my hope in God.”

Clara

Martha reported herself as Christian and that this helped restore her fractured relationship with her husband—(see under Abuse and violence). Cindy reported a strong faith that was important to her and she did not worry about her pregnancy because of her faith. Jane had friends in church who knew. Mary whilst professing a personal faith expressed disappointment at her rejection by her family:

“They are Christian they don’t want anything to do with me.” Mary

No one talked of outright rejection of faith, but suspicious of the church or faith group were raised by Beauty who raised her eye brow and pulled in her lips:

“I haven’t told them anything.” And “They aren’t the sort you can reveal your secret to.” (Smiling and Chuckling). And “You go there to do your business with God then come back. No because when you tell them your business, they use it against you.” And “No I’m not going to tell anybody not even the Pastor.” Beauty

You sense Beauty’s distrust; her business is with God, not other human beings. This demonstrates the resultant isolation. Justina and Rose were also sceptical but valued the support from church as they were sometimes lonely. Fumi told no one in her church. Bola had faith but as a Muslim woman kept her HIV quiet. Many women saw the value of the support on offer but were wary of the human aspect of their faith and were discreet with those in their faith.

4.2.4.11 More Information Please

When asked if the experience could have been improved, the following issues were was raised; Anna felt the need to explain testing issues fully and the lack of pre-test information was of concern for Anna and gave a detailed narrative:

“Well, not really much apart from really encouraging you know, testing for women and obviously midwives to explain more to women, instead of rather than just saying, ok we are going to test this blood as a normal procedure, just you know point it out, it would be nice to point it out to a mother, to an expectant mother, yes, cause you wouldn’t miss out certain things, cause it is bad having a positive child, not good, it’s not good they have got a whole lot of life ahead of them so they shouldn’t be.
feel that’s bad really because when you are taking someone’s blood you should really highlight the key issues really, we do this because of this, we do this because of this. Rather than just telling someone we do bloods as a normal routine, it’s a routine fair enough but it’s just like screening every mother you know, when your child is screened for Down’s Syndrome, you tell them it’s specifically for this, so to me I feel the midwives failed me on that occasion really.” Anna

When asked if the benefits of testing had been explored, she reported they had not.

For Martha when questioned about pre test information and the perceived lack of information and requirement for further information:

“Tell them people are living longer, It would have been really helpful; it would have been really helpful.” And “They just said they were blood testing test and they asked my permission to do the HIV test and I said yes I would like to have it done but no information was given to me about HIV.” Martha

That its emphasis was on the baby benefit and less for her wellbeing was of some concern for Martha. However Martha fully supported HIV testing in pregnancy:

“I would tell any women to have the test done, very important, not just for the sake of the baby, for your own sake.” And “I tell everybody, my sisters before, my other sister is getting married and I just say you and your partner to go and get HIV test done and the blood results came in, she’s had one done before, well you separated and now you are back together again so if you do need to have it done again, she’s like what if it comes back positive and I said well what if it comes back positive, you can start taking medication and you will be healthy and carry on your life and live long.” Martha

Martha reported disappointment she was not fully informed of this shock with an HIV diagnosis, if pre-test assurances had been given with further information, this would have helped her before testing and perhaps lessened the effect. The important message was that medication helps:

“Most mothers when they are pregnant all you are thinking about is the baby and if they can reassure them that the baby will be fine as long as you take the medication your viral load is (low), that reassurance kind of gives them a lot of strength.” And “At the point of testing they said we do have healthy babies even if you are HIV positive but they didn’t stress the fact that if you do this, this and this I just saw it as assurance because they wanted me to have the test done or something like that, so if they had emphasised that look if the result is positive it is not the end and the child will be fine so you wouldn’t worry too much about the results I think.” Martha
Martha stressed that she wishes this baby focused information had been told to her before testing as this would have helped her. Cindy responded and felt improvements could be made in the testing experience:

“Basically they counsel you for the worst, even though they know you might be ok.”
And “More Information would help, especially if it were also offered and I think that it would open up the African population.” Cindy

Cindy reinstated her view that this would break down stigma and allow people to be more open. Jane felt she could have been counselled before testing and that she would have liked to have been told in a more roundabout way as it was such a shock and no warning. But when asked how this could be done recognised the difficulties. Jane simply felt unprepared for the result when asked directly. This she felt contributed to her partner leaving. Beauty was very unhappy with the post diagnosis information; it was reliant on bio-medical care giving her no social support:

“When I was first diagnosed and I went to the hospital they should have given me support groups, I wasn’t given this information, I was told you go back to the hospital, do blood check.” Beauty

She was adamant there was little information and no support which isolated her and she would like this information available as she may have well returned earlier and found out people lived longer with HIV and given her more hope and she would not have been so lonely. She attended a number of support groups and states she has learnt many things. Justina, Fumi, Bola and Rose wanted further information and were critical of the lack of information prior to testing and often immediately post diagnosis. Fumi wishes she been told how to practically tell her partner as leaving her mediation around was the only thing she could think of and practical advice about managing him as he was trying to later cover up her HIV infection (but he had already told her family). In essence women stated they required greater information; they offered ways forward how this may be achieved for others who were to face this future challenge. They had experienced a transformation of “being” which was difficult and were perhaps looking for a less traumatic pathway for others.
4.2.4.12 Helping Others

Most women saw the benefit in helping others even if not empowered to do so. This was ultimately reassuring. Anna was a student nurse and a number of participants had gone into health care support roles since being diagnosed. Julie wanted to work in a related charity. Cindy gave a detailed account of her sister’s recent diagnosis in South Africa and how she was able to comfort her with her distress. Cindy also reported that recently a woman at church had confided her of her HIV diagnosis:

“She just confided in me and said she had HIV.” Cindy

Cindy admitted she had not told her of her own HIV. It was obvious from the discussion that Cindy was an accepting individual who felt stigma was very wrong. Jane wanted to be an HIV activist. Bola told anybody new to her support group that they would live and felt it was her mission to do so. In essence women needed to help others, the experience had widened their empathetic understanding and they saw a role for them in helping others. The need to help others in the same situation was strong, they simply wanted to help. Transition and transformation had changed them and had given direction, often with development of women’s caring attributes. They were mothers and drew on this experience and saw their children as the future. There were resilient and able to help others. The following diagram (Figure 8) illustrates the major paired theme of acceptance and resilience and a selection of primary and secondary themes. The woman is represented and centrally placed with the view looking down on to the top of her head and the major paired themes are encased within her head. The primary and secondary themes are external but radiate in to her head as they are pivotal to major thematic development.
Fig. 8. Diagram representing - THEME FOUR- Acceptance and Resilience.

NB. The top of woman’s head is viewed from above and centrally placed and the major paired themes are purple and encased within her head, primary and secondary themes are external but radiate into her head.
4.3 GRACE’S TRAUMATIC LOSS

Grace reported the loss of her baby following a fresh stillbirth was more distressing than having HIV and gave an in-depth narrative of this traumatic experience in addition to HIV diagnosis. She met her new partner and conceived. Grace was given the option of VBAC after the birth of her first child. She was informed of the need to come in to the hospital for monitoring as soon as labour commenced to monitor her scar and foetal wellbeing. However she was not monitored effectively in her view and the baby was lost as a fresh stillbirth.

Grace reported this experience was worse than being diagnosed HIV positive. This does not mitigate the other women’s experience of testing positive, only that for Grace this stillbirth was catastrophic event. After the recording ended, Grace also reported verbally the recent death of a close friend as more traumatic than being informed of the positive result and living with HIV. This finding suggests for Grace, she had rationalised how HIV impacts on her life in the longer term and in her view that HIV is a lesser problem or issue in comparison to these traumatic events. This would suggest the impact of the stillbirth was more severe for Grace than her HIV diagnosis. The pertinent narrative of this specific experience is recorded in the Appendix (see Appendix 13). It is included as the narrative importantly records personal loss with a stillbirth and personal loss with maternal HIV infection. This narrative recording of this sad and tragic event, affected me personally as a researcher during the interview. But Grace’s natural resilience is also present and she expressed hope and optimism for a new baby.
4.4 CONCLUSION OF THE FINDINGS CHAPTER

What is apparent from the narrative and themes is that testing HIV positive in pregnancy is life changing and extremely challenging. Women are on a journey and there is a transition and transformation from an old life or “former being” to a new life or “new being”. This transition may stall or slow until the child’s HIV result is known. The journey can then recommence and women transform into the new evolved “being-in-the-world”. The primary, secondary and major themes were revealed in the findings but importantly women balance them in their lives as they make sense of their experience as they “tested positive” and understand its essence and meaning as HIV is integrated with in their new life world. Ultimately the themes were generated from these women’s narratives, both superficially and also as the layers are peeled away, to reveal depth and meaning of this testing experience. For a significant number of women this is a life without a partner but ultimately with a child, and for the majority of women, a child without HIV. This child or children is a major achievement and the ultimate prize for women; an unaffected child was a major battle won. However, there were still more skirmishes to face. Simply, a negative child was the reason to test, however the fallout from the testing experience such as stigma, isolation and partner abandonment was a real challenge and this will be discussed in the next chapter. I accept that some of the narrative was short in the findings section but it was powerful and leads me back to the view that in the chorus of singing I did not want to lose the one voice. It was difficult to remove narrative and abridge common themes when required, but this thesis must have a succinct and powerful global overview of the messages.
CHAPTER FIVE- DISCUSSION AND CONCLUSION

5.0 INTRODUCTION

This chapter discusses the findings and the methodological and theoretical influences. It also discusses the emergent phenomenon of transition and transformation and presents a diagram of my Pivotal Balancing Model and how this applies to the women in the study in relation to the identified themes isolated from their narratives. Each identified and interpreted theme is discussed and the conceptual literature explored, where relevant. This will include Kelly et al (2012) as the findings have relevance to my study’s findings and can now be discussed from this point in the thesis as it aids understanding. My intention was to protect my study’s findings from this paper’s influence as they are both studies which were completed and interpreted independently. Also examined is how women balance the major, primary and secondary themes as they are transformed by the experience. Kübler-Ross’s (1969 & 2005) model for grief and personal loss is explored as the major themes advance this theory relating to antenatal HIV diagnosis in the UK. In this chapter, I discuss the strengths and limitations of the study and discuss the implications for further research. I also provide recommendations on how these findings may impact on midwifery practice. Lastly, I draw on my reflective journey whilst undertaking this study and conclude the study and this thesis.
5.1 THE PHENOMENON OF TRANSITION AND TRANSFORMATION, THE PIVOTAL BALANCING MODEL OF THEMES: MEANING AND ESSENCE OF THE EXPERIENCE

The emergent phenomenon of this antenatal testing experience is transition and transformation, which was described in the findings chapter (see 4.0.1). This phenomenon is the focus and with the four major essential paired themes emerged from analysis of the transcripts relating to the experience of receiving a positive antenatal HIV result. Receiving this positive result was the origin for the transformative process to begin and revealed emergent themes. The paired themes of: shock and disbelief, anger and turmoil, loss of old self - stigma and confidentiality and lastly acceptance and resilience were apparent in the findings. The impact and meaning for the women are presented and a number of primary and secondary themes are also analysed and discussed (see section 5.3).

The Pivotal Balancing Model of the four paired major themes – relating this to the phenomenon of transition and transformation of “being” describing the antenatal experience of testing HIV positive in pregnancy for women respondents in the study is illustrated in figure 9.

Wismont’s (2000) pregnancy in prison study presented themes with a similar diagrammatic format to that illustrated in figure 9. I have further adapted their diagram and present evidence for a Pivotal Balancing Model of antenatal HIV diagnosis in pregnancy.
Fig. 9. Diagram of the Antenatal Experience Testing HIV Positive in Pregnancy: Pivotal Balancing Model & Transition and Transformation Model

The four Major themes are represented and adapted from Wismont (2000). Alongside is the diagram of transition and transformation.

This model proposed that women balance the major themes isolated from the antenatal HIV positive testing life experience. These themes were isolated from the narrative and thematic statements made by women. The phenomenon of transition and transformation during this life experience are also placed alongside as this process is enacted. The
balancing of the themes and transition and transformation takes place over time. Time is crucial as it probably allows a more retrospective viewpoint to emerge and the emotional distress curtails and life changing effects with HIV become embedded in women’s lives.

The positive result is the fulcrum in which the themes balance. Time and its effect start from this point, which also takes on a new meaning as she is now a pregnant woman with HIV. However, importantly each woman’s experience is unique and some themes will be more problematic or larger in their life world than others and may require more energy to maintain the balance as they have impact on the women. The size of the box representing each balancing theme will be different for each woman. Each participant women could draw the size of each themed box to show the effect in her life.

For instance, shock and denial and the acute distress often dissipate as women move forward in time. Then anger and turmoil and longer chronic distress becomes more evident, but the effects of shock while less acute may remain. However, as transition occurs, the effects of stigma may become more evident and damaging as women balance this in their lives. There is no one “exact, identical model for all” as the diagram is a unique personal representation of how themes impact and are balanced in her new life. Each woman essentially has her own unique personal model to represent her personal HIV testing experience.

The identified themes impact on the transition and transformation of being. This can be identified by examining stigma. Stigma impacts on the “transformed being”. Stigma and its secondary themes may require more balancing of this issue for some women than others. Simply, stigma is potentially toxic to the women and damages the women’s life-world and being, but its toxicity affects women differently as each woman is unique. Stigma may enhance the need for the woman’s needs for secrecy. Stigma transforms the woman into a secret “being in the World”. She is transformed but cannot be fully honest or open in her dealings with the world, as this stigma may potentially harm her, her family but importantly her important focus, her child.

Time is a crucial element in the transformative process as already stated. As time passes resilience and acceptance are often apparent and are also balanced, but this can be
fragile and only developed by becoming stronger later with greater resilience emerging in a developmental process. The result is transformative to the women’s “being”, but the transition and transformation is not without emotional and psychosocial pain. Time is an essential element, women need time, whilst time unfolds transition and transformation occurs at a rate which is unique for each woman.

For a significant number of women the transition process was interrupted whilst they awaited their child’s HIV result. This child’s result was a necessity for all participants. Women stated they needed to know the infant’s result. Once the result was received and they were no longer ‘in limbo’ they were able to get on with life and ultimately transform. Simply knowing this vital information allowed mothering of the infant to continue fully in a meaningful way. They were often transformed with hope for the future.

Social isolation was often damaging to the transformative process. If they mixed and gained situated knowledge from others, such as an HIV team or a support group, they learnt to balance these aspects more easily with the shared knowledge and emotional support and by direct observation of their peers. Violence and partner abuse also impacted on the transition and transformation of their “being”. If the participants were subjected to these events it slowed their ability with acceptance of self and the transformed self.

What was evident from the findings was that resilience was a key theme to transformation of “being”. Once a degree of resilience was gained, women learnt to cope and live with HIV. This transition and transformation effected real life and managing life events as they accepted and lived with HIV. A transformation of her being often allowed the emergence of a strong resilient woman which enabled them to be a strong presence in the world. The transformation was also abstract. The child was a metaphor for hope for the future but hope grew from the transformative process. Women became stronger as they were transformed; they started to live with HIV and integrate it in to their being. Resistance to the acceptance of HIV impacted on transition and transformation and a further delay in the growth of resilience was apparent. Simply as they transformed, they grew stronger, resilient and hopeful. As they grew stronger, for some, HIV was no longer a dominant force, overpowering them. Women learnt to
cope, despite coming from a period of deep despair. Strong, resilient transformed women were often dismissive of the power of HIV in their lives. Women often became more open and less fearful of life and its challenges. Family members would be alarmed at their frankness with living with HIV.

The transformational process was vital for wellbeing; women could not stay hidden forever, crying and in shock. Women had to become resilient and transformed to simply survive in life and get on with everyday living. It did not mean that they did not revisit issues that were once powerful with testing HIV positive as some issues are and were long lived. Time helped to soften the pain of this testing experience, but doubt and sometimes for some anxiety arose as the burden of HIV could be challenging, but resilience helped them cope with life events. A vivid recall and replay of events and the shock of her HIV diagnosis was imprinted in her memory and still had the power to drive an emotional narrative.

Women led a transformed but often resilient life after diagnosis. This transformation made them stronger and able to cope with what life threw at them. Every participants “being-in the-World” had been transformed in some way, some having overcome major issues, others on a more acceptance and resilient transformation pathway. Victims they were not, transformed resilient being was in abundance as the participants demonstrated how they often lived with the difficulties of being HIV positive.

Transformation may be more dramatic for some women. This is most likely dependent on their life experiences, and this HIV diagnosis may be the first life changing experience. However, most participant women had moved from their country of origin; from the familiar to the unfamiliar, so probably had developed a degree of tenacity and strength. A number of women were affected by the dramatic chaos that occurred with this antenatal HIV positive result. Quickly they recognised that a degree of normalcy had to be maintained. Simply the child had to be cared for. They got on with their lives but with HIV and the worries that brought to their existence and being. If they worried, some kept it to themselves, but this showed resilience in a situation that they had little control. As time passed developing resilience and her transformation allowed her to gain some control and for some HIV and the fear and power it once had started to diminish.
Partners affected the transformed being, some in a damaging way with abuse, but often harmful with neglect and abandonment. The women reported issues of harm in the finding. A few partners were supportive and nurturing; this affected the woman’s transformation in a positive way. Women could accept who they were and what they had, simply a mother and woman with HIV. Women who had informed their mothers, and they were aware of her daughters diagnosis had often great potential influence and support. They participants responded when they shared their burden and were supported, living with HIV and in essence transition and transformation was less traumatic.

The findings strongly suggest the same principle applies for any health care experience or health professional interaction. If negative and unsupportive it had great potential to cause harm. The highest standards were not always achieved. Acts of kindness, holding, caring, non judgemental support was empowering. Transition was often guided by key workers such as the midwifery HIV specialist and support group staff and led to transformation with empowered resilient women. This aspect will be discussed further in the discussion of themes in this Chapter (see 5.2.3-Stigma and Confidentiality).

It is important that the major themes are discussed further in the next section as these themes were meaningful and had impact for women in this study and balanced in their lives.
5.2. DISCUSSION OF IDENTIFIED MAJOR THEMES AND PRIMARY AND SECONDARY THEMES WITH THE METHODOLOGICAL INFLUENCES OF THE STUDY AND CONCEPTUAL LITERATURE

This section will discuss each of the major paired themes and the primary and secondary themes within the methodological perspectives and influences which are relevant to the balancing model previously discussed (fig 9) and study findings. The discussion of the finding and concepts will draw on the conceptual literature and discuss the essence and meaning of the testing positive experience for the women who participated. This study’s focus explored this HIV testing experience and the methodology was *Hermeneutic Phenomenology* and the (Interpretative) school of Martin Heidegger (1962) and further guided by van Manen (1990). It attempted to gain understanding of this experience from the women’s perspective. It does not give definitive answers to this experience but tries to gain an understanding from the women’s narrative and from their unique “horizon” which was time situated (Gadamer 1989). I was and remain an essential element in this circle of understanding as I interpret this study’s findings. Writing and rewriting was essential in thematic development (van Manen 2006) but essentially it was interpreted from their narrative and participants understanding of this experience and is personal and unique for each woman.

5.2.1. THEME ONE –*Shock and Disbelief*

Immediate shock was reported by the women. For some this shock led to an extreme reaction on being told they were HIV positive; this was these women’s reality. Shock is reported in the HIV and psychological literature (Schrooten et al 2001; Sherr et al 2011) after receiving a positive result and more recently in antenatal literature (Kelly et al 2012). Creamer et al (2004) describes shock as an acute stress reaction to traumatic events. This stress reaction is psychological and the stress reaction produces physiological changes with the release of predominately adrenalin from the adrenal glands and has a variety of symptoms ranging from an initial daze, numbing sensation
to agitation and acute anxiety but importantly these symptoms tend to dissipate over time ranging from a few hours to several weeks. Creamer et al (2004) studied 363 patients with an acute stress reaction (shock) and noted very few developed long term problems. However they recalled the traumatic event well and described the effects of shock, replaying the events, or for some, avoiding any reminder of the event.

What was marked were women’s recollections of being informed and the contributory causes that made it worse, which were vividly recalled as a traumatic event causing great distress. This reported distress was manifest in shouting and screaming to complete and utter silence which supports Creamer et al’s (2004) findings. Women identified that this reaction was due in part to a lack of pre-test information and importantly the result was unexpected and they were not prepared for the possibility. Women attributed their shock to this unexpected result which was cataclysmic and traumatic.

Also of great concern, and identified from an epistemological perspective, was that in their own culture African women equated this HIV diagnosis with death. This belief arose as the common outcome in Africa of HIV is death and women drew on this prior experience. They held the belief that the baby would be infected and both would die. This lack of information effected women greatly as this firm belief was reported as contributing to a traumatic and cataclysmic experience. A number reported they were not informed of this possible impact of shock with an HIV diagnosis. A number stated and wished that it had been explained that HIV does not equate with death as it would have made a difference to this experience. This finding is an important one for clinical practice as this specific information helped women greatly but was given too late and only after diagnosis. Women were adamant it may have helped if given before testing.

Shock may still have been apparent but the lack of preparation made it intense and worsened the experience. From an ontological perspective this was their existence for a time living with the effects of the shock. Their situatedness was distress and was traumatic for most.

A personal disbelief and a denial of the result was a common finding and the positive result was unexpected for all women and therefore in all probability elongated the shock
and distress of the diagnosis when they were told. A significant number of the women simply did not believe the result to be true. Disbelief is reported by Sherr et al (2011) and Kelly et al (2012) but importantly would confirm the findings of Kübler-Ross (1969, 2005) with grief and personal loss and was applicable when the women in this study received their positive result. They sought re-testing or needed further assurance the result was correct. From an epistemological perspective this re-testing allowed them to have new knowledge and confirm the test was correct. If there was any ambiguity with the result such as an equivocal result that required re-testing this was reported as contributing further to distress.

What is marked is that no midwife prior to testing had said to any of these women that her result had a higher probability of coming back positive, as the evidence is strong that sub-Saharan Africans have an elevated risk (NAM 2010). This was a major omission for any pre-testing information as it is pertinent to women of sub-Saharan African origin. From an ontological perspective living with the aftermath of an HIV diagnosis, the intensity of shock was strong, but importantly shock and disbelief did subside over time. This suggests women quickly understood HIV was in their life and they needed to use their natural resilience to live with HIV. Recall was strong and longer term anxiety remained for a number of women.

Shock and distress has been reported with HIV diagnosis by Sanders (2008) and others, what this study has revealed were the intensity and profound effect for these women. Some women (like Beauty) in all probability had some post traumatic stress but still declined further intervention as they believed in their own resilience. Beauty believed she could deal with HIV, but it was tiresome and took energy as the events were replayed many times as she attempted to do so. This supports Bonanno’s (2009) assertion that resilience builds over time. It also suggests that building self-resilience may also be problematic for Beauty as she does this alone. Intervention may have helped her but her developing resilience also got in the way as she declined help.
5.2.2 THEME TWO—Anger and Turmoil: Loss of Old Self

Anger is described as an emotional state and psychological in origin often due to provocation and linked to a feeling of injustice, it is normative, acute and quickly dissipates (Videbeck 2006). It can be a troublesome emotion for some individuals and those with an angry personality. The recall of a traumatic event may trigger anger. Anger symptoms can be aggressive and quickly dissipated or anger described as passive and longer lasting. Passive anger may remain following a traumatic event. However, passive anger can be expressed and give rise to secretive behaviour, blame, self sacrifice, evasion and sadness (Videbeck 2006). Turmoil is described as a state of great uncertainty, chaos or disorder and has an unknown etymology (Oxford English Dictionary 2011). Women expressed anger and turmoil with the impact of the HIV result and recognised they had lost something of value. Kelly et al (2012) describes this as chaos and “otherness”. A separation from the life and person that was formally normal.

A significant number of women reported sadness, a loss of the old self as a basic and secondary finding and an overriding major theme. Loss of old self was spoken or alluded to directly and interwoven in this important theme of anger and turmoil. Simply they had lost their old self. They were no longer the same, often referring to HIV as “it”. They were angry and HIV was an interloper or unwelcome infection with a number of women hoping to banish it in future. Kelly et al (2012 describes this further as a disjuncture as the former life was no longer open to them. However, my study revealed, this was also tempered with a small number of women living in relative comfort with HIV. Reflection and time modified its effects. Those women were often diagnosed some time ago and as time had passed were more able to integrate HIV into their lives. Many were often also living a difficult and sometimes lonely life with HIV in the UK. Women reported they lost (were bereaved of) their old way of life, which greatly saddened them.

In their situatedness at the time, anger and turmoil was evident. A significant number of respondents self-reported that they considered suicide and self-harm and one woman reported contemplating ending the life of her child. This has been reported by Sherr (1995), after a review of case notes, with distress of a new diagnosis with an increased
incidence of self harm. This is a worrying concern as most women reported this even if fleetingly; for some it was a serious consideration only ameliorated by support from the HIV team or own concern for the unborn child or other children. This finding was worryingly also reported by Kelly et al (2012) who reports that pregnancy was the saviour and focus for women to live and fight for. Pregnancy in both studies did save participants from harming themselves. It is not known whether non-participant women in both studies have caused themselves harm after being diagnosed. This aspect warrants further investigation with an appropriate research methodology.

A significant finding was that women in their anger and turmoil wanted to terminate their pregnancy as they believed the child would be infected. Kelly et al (2012) also reports this finding. From an epistemological perspective this was what they knew and believed but importantly this anger and turmoil subsided when given further information; the new knowledge superseded the old. Again, what is unknown from this study is how many women went on to terminate on the grounds of their HIV infection. Termination was a common outcome in the early day of the epidemic, before the advent of drug therapy (Johnstone et al 1990; Johnstone 1996; Kennedy 2003). What is reassuring is that the women were quickly advised that the baby could be born well and not infected, which impacted on the decision to maintain the pregnancy. However, this aspect should have been discussed pre-test and not left until after a positive result.

The loss of old self also included isolating self from significant others, they simply could no longer mix with others and retreated into a world of isolation with anxiety and concern for the future with unanswered questions around their own or their infant’s wellbeing. This isolation must have compounded distress and from an ontological perspective, this was their reality. For some it may have allowed a period of reflection as they contemplated HIV. However, isolation longer term was difficult for women and it allowed women to ruminate and dwell on their diagnosis. Beauty’s isolation was marked as she did this.

In answering the ontological question of women’s reality of being diagnosed HIV positive in pregnancy, a major issue was the effect on their partner and their relationship. Telling partners was often problematic and differences were noted. Some women taking time to do so as they sought a strategy, other women told their partner
immediately. Kelly et al (2012) notes three out of her four participants informed their partner immediately and that in her study it threatened their relationships. All but one of the women in my study informed their partner, but most reported telling them was challenging and caused distress. It is reassuring from a health message that women in this study did tell their partners. However, it is plausible that others who did not participate may have taken a different pathway. The one woman (Beauty), who could not tell, gave a detailed account why she could not do so as the relationship had broken down during pregnancy as he had mental health issues which may have affected her safety as he was abusive and violent towards her. This was a legitimate reason to withhold this information in her view and difficult to argue against. The ramifications were great for most women when they told their partner. Most reported the HIV diagnosis had caused a significant impact on their partnerships. The ontological question, ‘what is the reality for women is the breakdown of their relationship with separation/abandonment?’ is a significant finding. In their time of greatest need, they were alone, often pregnant and in their situatedness they felt turmoil and abandonment. Some were supportive, many were shocked, a number indifferent or unsupportive. Some women found their partner very supportive and loving, but this was in the minority. Kelly et al (2012) does not report any breakdown in participant relationships but recognises HIV added problems to the relationship. A number in my study reported anger with blaming the partner for the infection, and in a continuing relationship issues with trusting a partner were often vocalised. Kelly et al (2012) also reports shock when the partner was found to be negative.

In my study if the partner was later identified as negative, searching for the cause of the infection was reported. This searching was important as a number of women needed to know where HIV came from. Knowing was an important issue and when examined from an epistemological perspective, it provided knowledge and it justified their belief how they got their infection. This is not evident in Kelly et al (2012) study. A number of women in my study used investigatory methods often asking friends of former partners if they were well or had died. A number blamed previous terminations procedures. However, other women were forthright and were well aware of their previous sexual history and the risks taken. If the current partner was positive it was easy to identify the cause in the women’s view although this may not have been correct.
From epistemological perspective, searching for the cause became a preoccupation for some women as they needed to know.

Women experienced direct abuse and violence and from the ontological perspective, for a number of women, this was their reality and experience with HIV. This was reported by several respondents after diagnosis, but for one this improved and for another, violence was present before diagnosis and this led to her leaving him. Anger and abuse was also covert and subtle and when women were questioned, this was uncovered for a number of women. Trust issues around sexual behaviour of the partner often remained even if the partner was negative. It was a vital issue and women often blamed an underlying African culture in their men-folk with fidelity not being important for men. The use of condoms was seen as a factor for the man to look elsewhere for sex. However, one could challenge this need to use condoms as the latest research demonstrates that an undetectable viral load is as protective as condom use (NAM 2012), but this aspect is often ignored as other health benefits of condom use are reported. A number of women in my study were unhappy with the impact of condom use as it interfered with intimacy. This is reported in Kelly et al’s (2011) study on negotiating risk. Women were anxious awaiting the partner’s result with a number hoping their partner would be negative so they could care for the child if they themselves became ill. This was also reported as a cause of abandonment as one partner informed his new wife he would leave her if he was negative and promptly did so, informing everyone of her diagnosis. Control of disclosure was lost for some women with an angry partner disclosing to others in the women’s support network and family often with repudiation of the women. This left women socially isolated and angry and in further turmoil. Mary’s partner, on abandonment, denied he was the father and sought no further contact. This level of anger against the women in the study is a major concern and is supported by recent evidence (Dhairyawan et al 2012). This level of abuse is not reported in Kelly et al (2012).

Difficulties in revealing diagnosis to significant others were also reported. Interestingly, even when some women professed a strong faith and had great support, they were often very careful within their churches/faith institutions about who they told. A number of women reported they were lonely and this was expressed vividly at times but also tempered by hope for the future. Discloser was carefully managed by most women in
my study as they were wary of stigma and keeping the infection secret from others was in their view protective and a coping strategy. This belief that secrecy could be protective was common. Secrecy allowed them to control disclosure but its effects were not always healthy as women remained isolated. Essentially this was women’s reality of living with HIV. It was a coping strategy to maintain their life-world.

5.2.3 THEME THREE- Stigma and Confidentiality

The etymology of stigma derives from Latin but arises from ancient Greek from the words “brand” or “mark” and refers to a mark of infamy or disgrace (Trepp 2001). Marks or badges were often used to set people apart and this has included the badge or yellow star which the Jewish community were required to wear as a badge of shame in the Middle Ages and in recent times in Nazi Germany and Axis occupied states (Trepp 2001). Later the Jewish nation reclaimed it and transformed it into a badge of honour (Trepp 2001). The Gay community have also reclaimed the ‘pink triangle’ as a badge of honour, which was similarly used as a badge of shame by the Nazis (Jensen 2002). Ingram & Hutchinson (1999, 2000) and Sanders (2008) reported the toxic effects of stigma with an HIV diagnosis. In this study, stigma and the fear of stigma were pervasive in these women’s lives, and had a major impact. Kelly et al (2012) reports stigma but from participants own beliefs and not directly experienced per see. In her study stigma is referred to others not wanting to mix or be around you as not seen as moral. Kelly et al (2012) refers to women distancing themselves as they are different with HIV and stigma is mentioned as contributory.

In my study the ontological perspective of being diagnosed HIV positive was the effect of stigma and shame. This was the reality for women, they became isolated, unable to freely move or engage fully in their communities. All reported the pervasiveness of stigma and how they managed this aspect. Stigma or the fear of stigma was toxic for many women. Women recognised they had stigmatised others in the past but had crossed the other side and were now fearful of the stigma that they recognised from their past life as it was their justified belief at that time, which was now being challenged. It has been raised that stigma and low self worth is often anaesthetised by drug dependency and ongoing self harm but no women reported this even when asked
directly how they managed their diagnosis. Life was not chaotic or in a downward spiral, they sought strategies to live with HIV. Sanders (2008) found that the majority of women in her American study resorted to drug use, but perhaps drug use is uncommon or not reported in the participants African community in the UK (NAM 2010). The reverse happened; they grew stronger as time passed even when often alone with their child. This resilience is discussed in the next section.

A number of women referred to HIV as ‘it’ or a separate entity. In their situatedness, HIV did not make them feel worthy and contributed to feelings of low self worth and HIV was often something to be got rid of if possible as it had moral connotations around behaviour. This is understandable, as stigma remains for women and HIV is still perceived as self inflicted problem and not fully worthy of sympathy or empathetic understanding (Sanders 2008). The women were critical of the African culture around this issue and a number believed targeted education was needed. A number of women, whilst professing hope for a new partner in the future, felt stigma and disclosure to be the main stumbling block of a new relationship.

Stigma was reported as a personally held belief attached to HIV and the view that HIV was something if not to be rid of, at the least kept quiet and secret as they were aware of its effect. Kelly et al (2012) also reports that women reported themselves as good people and distances themselves from HIV associated behaviours and not worthy of infection. This is a finding in my study with women questioning how they became infected, but later reflection allowed a number of women in my study to understand how it happened and discuss this more openly with sexual behaviours. Stigma and shame are reported from partners, family, friends, and communities and of great concern and its effects were potentially damaging and toxic. One women attributing stigma as starting her domestic violence first vocally, then physically, but after a trial separation and intervention with education, she reported this ceased.

Confidentiality is an ethical principle that is upheld by the NMC (2009). Ingram & Hutchinson (1999, 2000) and Sander’s (2008) studies reported that confidentiality was an issue for women. It was also an issue for women in this study. Concerns were raised with the use of a hidden language and the threat to confidentiality was reported in detail by one woman and alluded to by several others, the whispering, the looks of staff and
concern over written notes. The maintenance of women’s confidentiality by staff was an issue for some women. Whilst good care was reported, a significant number of poor care instances were revealed which is of great concern. One woman firmly believed her diagnosis had been told to her friend in the next bed who ceased immediately to have anything to do with her. This perception if true is worrying. This woman was angry but when asked if she had reported this, felt unable to do so; the power of professionals over women was apparent. In essence a number of professionals failed to cherish or care for these women (Hehir 1999; Johanson et al 2000).

Women were balancing the need to keep things private and keeping things secret, protective of their future choices. A number of women were grateful to midwives for their collaboration in keeping secret from others, for example passing the child’s medication off as antibiotics to others. They valued this specific issue as it made life manageable at a time of distress and pressure. However, good care was reported and valued by all the women, they valued the HIV team and specifically the support given by the specialist midwives, if concerned with other team members or midwives at times. This support by the midwives was immensely important to women, dispelling half truths and misguided beliefs. This improved the challenging experience of being HIV positive. All valued the specialist team and women noted they also reduced stigma with empathy, kindness and touch. Touching and holding women was important for a number of women, it stopped them feeling unclean and stigmatised.
When examining the ontological question, what is the reality of living with HIV, a substantial number of women reported growing acceptance and personal resilience as time passes. Acceptance is an important concept for the Kübler-Ross (1969, 2005) model. Acceptance of how things are and not what you want them to be facilitates transition and transformation and is important for life move forward. Resilience is defined as a psychological process in which an individual has the ability to cope with anxiety and stress after adversity (Bonanno 2009). The growth of acceptance and resilience allows a person to recover a liveable relationship with his or her psycho-physical being (Bonanno 2009).

The need to know the child’s result was very important for women. Personal sadness with stoicism was noted if the child was HIV positive, but absolute relief if the infant was negative. A number of women bartered and prayed for a negative child which supports the Kübler-Ross (1969, 2005) model with this important issue. Women seemed unable to move on until this specific outcome was known to them and this featured large in their thoughts. This was their reality, real anxiety for a time; they knew how they felt but could not take further action to resolve this anxiety until they had this answered. Simply they needed to know the child’s diagnosis to move on and this in all probability had an effect on their pregnancy. Not knowing this result caused anxiety. Relief was immediate at first test of the child and whilst anxiety was still apparent, it subsided as each subsequent test on the child proved negative. However, for some women they were concerned that they could pass on the HIV to the child so took care to minimise infection risk with how they handled the child. This would infer for some women, HIV had a negative effect on mothering (Ingram & Hutchinson 1999, 2000; Sanders 2008). One woman professed this was extreme at first with repetitive hand washing but this later subsided as she understood this was not possible to transmit HIV easily. Simply waiting for their infant’s result was stressful for women and interrupted their transformation and keeping the infant negative was an occupation of motherhood.

A significant finding was that women reported that the child was now their prime focus in life with less importance of self. The child was the essence of their being; it allowed
women a future with optimism as they believed the child would in all probility be negative and most were. This focus was a coping strategy and importantly, it allowed women to mother their infant (Ingram & Hutchinson 1999, 2000; Sanders 2008). Kelly et al (2012) reports the same findings with the child the focus of concern. Concerns were raised about the impact of maternal diagnosis on the child and how will they tell or negotiate behaviour with the child in the future; this was something they would deal with later.

They all valued specialist HIV care by midwives during this transition and importantly with a new baby. This tailored support must not be undervalued in the midwifery profession, it was critical to the transformation of women. Simply their intervention helped. All women supported HIV testing in pregnancy; for the child’s benefit but less for their own wellbeing. If the child benefited it was worthwhile. Women often did not discuss the effect of the HIV diagnosis on their pregnancy when asked directly. This took probing and often they would not discuss this other than to state they had anxiety as they waited birth.

Most women voiced concern with the lack of pre-test information and a number were very critical as this could have improved the experience. Importantly all women accepted on reflection, it was best to know their HIV diagnosis, even with the original personal trauma and shock of the diagnosis. Kelly et al (2012) reports the same finding and this view developed as time passed with my study participants. Time was the great healer as it allowed reflection, the growth of resilience and acceptance (Kübler-Ross 1969, 2005; Bonanno 2009).

Acceptance is marked for the women, very early on even with recent diagnosis, they learnt to accept HIV as part of their lives, they did not like it, but acceptance allowed them to transform further. Kübler-Ross (1969, 2005) and Bonanno (2009) both acknowledge that acceptance allows life to become liveable again. One woman reported for her, the loss of her baby following a fresh stillbirth and the loss of a close friend was more distressing than having an HIV diagnosis or living with HIV however this did not negate other women’s experiences as this was unique to her.
All the women professed hope for the future and could see a future for themselves and their children. Hope was an important concept, without hope, life would be meaningless (Bonanno 2009) and this is reported by Kelly et al (2012). A number were awaiting decisions from the home office about leave to stay but were hopeful that the HIV diagnosis would help them to stay in the UK as they would need treatment. From an ontological perspective, optimism was marked with the child now their prime focus of life. The women’s situatedness they importantly felt, life was recoverable and liveable with HIV. Kelly et al (2012) explores this aspect in her theme of creating continuity with women in her study. Learning to accept and live with HIV was the positive action women took to have a meaningful life.

5.3 THE DIFFERENCES AND SIMILARITIES

Women were unique and each were different but also had commonality with this experience. The common view was that women when asked, all but two participants only wanted to tell their story once only. This once only narrative or “pop up and tell” is not unusual for vulnerable groups or for sensitive topics and whilst it may be cathartic for participants, it is also challenging as the opportunity will occur only once and the researcher must use the once only interaction well (Lee 1993). Their testing positive experience was deeply meaningful, challenging and many had essential elements that made up this testing experience. Essence and meaning was not easy for them to always directly express and required interpretation. Some of the women reported social isolation both after the diagnosis and also with fear of being recognised as having the features of HIV. They needed to look well or they believed this would raise the index of suspicion they were infected. HIV infection can affect appearance for some individuals with noticeable changes in fat distribution and muscle wasting giving a classic “infected” look, however this is less with modern drug therapy (NAM 2011) but from an ontological perspective they all retained their dignity and all presented at interview in immaculate dress and cared for their outward appearance with several women stating this was important factor both culturally and even more so with HIV. Simply they dressed to impress, to show all was right with their life-world. This was a powerful message but for some it may have only been a veneer. Some women were early in the time line of diagnosis and anger was still acute, whilst others had travelled further in the
pathway of acceptance and were more comfortable, with one woman reporting she was no longer afraid to tell others of her HIV. However, from an ontological and epistemological perspective, for many women secrecy remained apparent for women and was a coping strategy, with a number disclosing to no one significant, especially after the breakup of a relationship. Living with HIV in their lives was variable for women.

I wondered if these women were victims, as they were as beholden to society expectations around behaviour and were African, but essentially they were not victims but resilient. They were trying to incorporate HIV in their lives, often as an unwanted intruder. Some women were comfortable and HIV did not worry them, for others anxiety remained but time was an important factor. Women talked of the immediate impact of knowing their status and also its longer term impact on their lives, however the majority were adamant they were stronger as a person when questioned and stated the very experience of being diagnosed in time so they and their child could benefit, made them stronger and it was simply better off to know as they could control their health and wellbeing but more importantly it helped to keep the child free from infection. Whilst some were vulnerable especially with an early diagnosis, they were resilient and strong women.

I strongly suspect but cannot absolutely prove a link that this was in part to the support on offer from the HIV team specialist midwives and for a number of women the support from the support groups was of vital importance. This exposure led to mutual support from others who were infected as a number stated they learnt they could survive from others who had done so. Whist some women did not need supportive groups or intervention; others did so and were grateful. Cindy and Jane both had family members with HIV and reported this helped them and other family members who were affected. Some women were more open with their HIV diagnosis; they learnt to be so and often not to be concerned. However, most remained very careful with disclosure.

Death, dying, grief and personal loss all impact on all of us at some point in life. They are essential components of living. As a registered midwife and nurse, I have been influenced by the work of Elisabeth Kübler-Ross, M.D and her original model of grief (Kübler-Ross 1969) and adapted model for loss (Kübler-Ross 2005). She gives a comprehensive pathway of this dying and personal loss process. The stages include: Denial, Anger, Bargaining, Depression and Acceptance.

Denial as the person does not believe the loss or news to be true. Anger is expressed as the person asks “why me”. They then often bargain, perhaps with a supreme being or their medical doctor that if they do one thing or change, then the loss may be mitigated. Depression is often evident as they come to an understanding that the loss is permanent and for most an acceptance that they cannot change the inevitable outcome or loss.

Originally Kübler-Ross applied these stages to people suffering from terminal illness, but later expanded this model to any form of catastrophic personal loss which may include loss of a job, income, freedom and significant life events such as the death of a loved one, divorce, addictions, and importantly and of relevance for this study, the onset of disease. Kübler-Ross claimed these steps do not necessarily come in the order noted above, nor are all steps experienced with this process, though she states a person will experience at least two. I had a suspicion that women with an HIV diagnosis may follow similar stages with this model. This model is not without criticism as a simplification and neat theory (Brent 1981; Maciejewski et al 2007). Maciejewski et al (2007) is critical of the stages and evidences that people accept death of a loved one straight away. However, this is relation to death, which may be different to an individual who is dying and to other personal loss situations, as this study strongly suggests it takes time for the individuals to accept their HIV diagnosis and this study advances this acceptance theory when related to an antenatal HIV testing diagnosis. I propose that participants as individuals and as a collective did exhibit a number of these stages. Further collectively all of the stages in her model were demonstrated by the study participants, these included strong denial, anger (with turmoil), bargaining (wish for an unaffected child), depression (withdrawal from the world), and acceptance of the diagnosis and living with HIV. The result was often catastrophic leading to many issues for women such as the
breakdown of relationships and the HIV diagnosis was the catalyst in the stages proposed by Kübler-Ross and evident in this study’s findings. Importantly this study also supports the work of Bonanno (2009) who reviewed the scientific findings of grief and trauma following adversity from the peer reviewed literature, which included thousands of subjects who had undergone personal loss. Importantly he identified that personal resilience was strong; simply people had immense capacity to get over trauma and loss and often ultimately thrived in the face of adversity. About 10 to 15% of individuals did not fare so well, and need further help in gaining resilience. He maintains that whilst most individuals demonstrated the stages defined by Kübler-Ross (1969 & 2005), interestingly a small number did not show any stages of the Kübler-Ross models and Bonanno disputed the belief that a least two stages were followed to be psychologically healthy. He found that after review they were often to be just as resilient and healthy and needing no assistance but whilst this was not a common finding, it was a unique one. I fully accept that the finding of resilience that was manifest in this HIV study may only have resilient women and women who did not fare so well, perhaps are not represented. However, this study confirms a number of these finding around acceptance and resilience. In this hermeneutic phenomenological study, this aids further understanding of this experience.

5.5 SYNOPSIS: WHAT WAS KNOWN AND WHAT IS ORIGINAL NEW KNOWLEDGE

This section does not intend to re-examine the findings but highlight what was previously known from research with what is new from this study findings.

We know that shock and distress is a common finding on receiving a positive result (Schrooten et al 2001; Sherr et al 2011; Kelly et al 2012) and is an acute stress reaction to traumatic events (Creamer et al 2004).

- What is original is the extent and intensity of the shock with antenatal testing and specifically the impact for African women on being informed and the extreme reaction for a number of women. We now know from this study’s findings drawn from the narrative, African women equated an HIV diagnosis
with death, dying and infant infection which compounded shock. An unexpected result was cataclysmic and women correlated the unexpected result to their extreme reaction.

- Disbelief and denial of the result were very strong emotions for women in this study. They simply could not believe it.

We know that anger, distress and turmoil are a common finding (Schrooten et al 2001; Sherr et al 2011; Kelly et al 2012).

- What is original is the amount of anger and turmoil. A number of women wished to terminate their pregnancy.
- Partnership trust issues were common after HIV diagnosis.
- Abandonment and breakup of the significant relationship was a common and significant finding.
- Social isolation, both short and long term, were reported and linked with stigma.
- Sadness at the loss of the old self. Simply the old life had gone.

We know stigma and poor care are well documented. Confidentiality is threatened (Ingram & Hutchinson 1999, 2000; Sanders 2008).

- This is confirmed, but additionally antenatal HIV tested African women are extremely vulnerable to the toxic effects from their partner, family and communities. A number noted a hidden language and felt strongly that confidentiality was threatened or perceived as breached.
- Women trusted their HIV team and specialist midwives and were grateful for the care provided.

We know personal growth after a post traumatic event such as an HIV test result is recorded as is psychological trauma (Sherr et al 2011). Resilience is a common outcome recorded following adversity (Bonanno 2009).

- Acceptance and resilience was strongly manifest in the study participants.
• The women valued peer support which assisted in transformation.
• The child is often the focus of life and knowing the child HIV status was key to women’s transformation.
• Hope and optimism was strongly demonstrated by women.

We have new evidence that the findings support and advances Kübler-Ross (2005) model of personal loss and the work of Bonanno (2009). The proposed HIV testing pivotal balancing model informs how women balance the significant phenomenological themes from their lived experience descriptions. The study has revealed the phenomenon of transition and transformation of “being” with this positive HIV result commences at diagnosis as women live with HIV and that this transition and transformation process is an adaptive and challenging one. This new and confirmatory information advances HIV testing theory and practice. However, the evidence is strong that African women are infected in greater numbers in the UK (HPA Report 2011), so I would argue that these women need to be cautioned of the higher risk of a positive result. Whilst it would be questionable to single one group out for selective testing, I would argue, possible or likely finding should be explored for any African women due to current evidence with infection rates. I fully accept you can be a white women or other ethnicity with HIV, but would argue tailored pre-test risk information can be appropriately targeted to individuals or groups. This should not however diminish inclusivity by exploring the health benefits to test and the advances in HIV treatment and transmission risk reduction. If midwives explore testing and get pre-test information right for each woman, this may improve the testing experience, particularly for those found to be positive. This entails exploring the issue with women and checking the level of understanding. I would suggest that some women in this study suspect their partner of commitment issues, but are not empowered to challenge the man’s authority or standing in the relationship and testing for HIV could not reveal this aspect. Testing and a positive result is not an isolated event and had the capacity to inflict great distress and relationship breakdown.
5.6 STRENGTHS AND LIMITATIONS OF THE STUDY

This is an independent and original study and its strength is that women have been asked to give a narration of their experience that have tested HIV positive with an antenatal test in pregnancy. Kelly et al’s (2012) study findings correlates with a number of my study finding which gives it further strength. However, my study explored the phenomenon of testing HIV positive in pregnancy and adds further new knowledge.

5.6.1 The Strengths

The findings add to the growing body of research of women testing HIV positive and specifically testing positive in pregnancy and importantly African women’s testing experience in the UK. The in-depth analysis of this experience is unique for women testing positive in antenatal testing. It gives a unique insight for midwives who offer antenatal HIV testing.

The women’s narrative and their voices were digitally recorded with an in-depth interview, the verbatim narrative was transcribed and was interpreted and analysed for essence and meaning using a reflective model to ensure consistency. Women were able to give their personal testimony of this experience which is an absolute strength of the study. Simply, the focus was that women were for the first time able to recount their antenatal HIV positive testing experience in UK. Whilst the body of women were African, they are greatly affected and the strength is that they are now represented and had a voice with this testing experience.

5.6.2 The Limitations

The findings from this qualitative study are of value as they add to the current body of literature. Elements may only be transferable to similar contexts. The experiences of women in this study may or may not be similar to other women testing positive in pregnancy. Women who chose not to participate may have had a differing experience
and therefore their voices are not represented. The women who participated may have had some recall bias (Holloway & Wheeler 2003) concerning their experience after receiving a positive result and this horizon of the event was time-situated (Gadamer 1989). For some, the time frame was recent for others a longer period since diagnosis had elapsed; this may have aided a more reflective account. Effort was made to recruit women from diverse racial and ethnic backgrounds; Black African women came forward to participate and they are the greatest ethnic group affected by HIV in the UK. The findings gave remarkable insight into Black African women’s testing experience and gave these women a voice. One woman who came forward was South-Asian origin, but her ability to understand and consent was questionable, even with the availability of an interpreter; she was therefore not eligible.

5.7 IMPLICATIONS FOR FURTHER RESEARCH AND STUDY PUBLICATION

Following this study’s findings, further studies are needed to clarify other testing and screening aspects:

- A follow up study to explore and address why relationships fail after an HIV diagnosis.
- A study to explore partner notification, the role of blame and seeking out the cause of HIV infection and its impact.
- A study to investigate if, when or how HIV positive women tell their children of maternal infection.
- A study of partners experience when they receive the news of the positive diagnosis in pregnancy from their pregnant partner.
- A study of self harm for women with HIV.
- A study investigating unpreparedness and preparedness.
- A study to investigate further natural resilience and the antenatal HIV diagnosis.
- A study investigating the HIV Gatekeeper role.
- A study investigating midwives experiences of presenting an HIV diagnosis.
• A renaissance for audit and new research on antenatal HIV testing service provision and specifically a comparison study with generalisable outcomes of different formats pre-test information. Compare and contrast outcomes with other HIV testing programmes that test women for improvements to the testing service.

It is important that the finding of this study are published in a peer reviewed midwifery or HIV journal. A draft paper is presently being formalised for review and consideration.

5.8 IMPLICATIONS FOR MIDWIFERY PRACTICE AND RECOMMENDATIONS

5.8.1 Overview and General Comments

The hermeneutic phenomenological reflection of the narrative identified major themes and the emergent phenomenon. This gave meaning and essence to women’s experience of testing positive and aids understanding of the testing process. Now providers need to develop the service further. Innovation is required, testing needs to be open for easy access and facilitative but also sensitive and remain confidential with every opportunity to test taken (HPA Report 2011). This may help to demystify HIV and reduce stigma. It is better to know the diagnosis than not (NAM 2011). Testing need not be problematic but as a society we perhaps make it a moral one (NAM 2011). HIV is a virus that with modern western treatment can be well controlled. Developments have made it less of a health issue but society needs to catch up. Stigma with testing and a positive result is of great concern and this needs to be reclaimed with a “new badge of honour” with HIV testing. It will take brave individuals to reclaim this, but it is possible for positive individuals to do so if they should choose this.

Whilst the present antenatal testing program is excellent at identifying women with HIV infection, HIV testing programs need to be developed further with the introduction of regular testing opportunities and pre-conception testing developed for those
contemplating pregnancy. Antenatal testing must be maintained but this should not be the only opportunity offering HIV testing to women. Finding out a positive test result in pregnancy is probably not the best time and other testing strategies should be available. Testing should be widened with regular outreach testing opportunities to individuals and communities at a higher risk of HIV (NAM 2011).

This study found women even after testing positive were supportive of testing and this support must be maintained with easy access programs but with tailored support for positive women, her partner, family and community. The women were very grateful for the support they received, this must continue. HIV testing is important to maintain health but it has implications for women. This study indicates that a midwifery led model of care is of benefit in offering HIV testing and that a model ensuring continuity to the positive women can provide advantages for both women and midwives in relation to HIV testing.

Midwives need to be aware of the influence they can have on women’s empowerment and the important decisions around the HIV testing process. This influence needs to be pro-testing (HPA Report 2011) but supportive to the imparting of pre-test information to enable meaningful consent (NMC 2004). Importantly midwives need to prepared and inform women and African women specifically when a higher risk of a positive HIV result is more likely. Preparation for a possible positive result cannot be underestimated as the findings starkly reveal, unprepared women, given a positive result, worsens the catastrophic, turbulent, distressing and extreme reaction for the women in this study. Whilst a positive result is not going to be welcomed, good information prior to testing is likely to soften the effect and subsequent reaction of this news. The antenatal testing and screening service needs to work with its stakeholders, meet the women’s requirements and include service users to shape future provision. Midwives also need to be aware of the cultural influences that women may bring. This has an impact on the news women receive with a positive result and should have been explored pre-testing. Simply; women will not die, their child can be unaffected and strategies with how would they manage stigma if found to be HIV positive.

The level of adequate information is determined locally and only general principles alluded to in an HIV testing policy. This possibly creates ambiguity when defining
adequate levels. The early literature was more definitive with what was expected to be discussed but later literature often talks of general principles. Midwives are perhaps unsure what they need to discuss during a pre-test discussion unless they are regularly updated. But we have not recently questioned midwives. The literature warns of information overload and the failure to set a minimum standard of information may have led to a degree of confusion. I would strongly suggest women themselves need to define the required level of pre-test HIV information that will enable women to choose to test and importantly prepare them for a positive test result.

Women are influenced by what they see portrayed in the media with stigma. The portrayal needs to be empathetic and portrayal not sensationalised. African or women in general, must not be demonised. The health tourist label is not helpful in combating HIV. Simply by treating all positive individuals with HAART drug therapy this lowers the pool of infection, protects the population and unborn children (HPA Report 2011).

This study found peers groups are important for many women, to see them attending their support groups with the potential for empowerment, was simply inspiring. I have met these women in the flesh, they are real women, often marginalised but refusing to be victims. They were fantastic and open with each other as they were allowed to be so.

I would additionally argue that effective treatment in the UK reduces viral load and so reduces HIV infectivity which is better than condom use (NAM 2012). Condom use is an issue for many men (NAM 2010), if we liberalise treatment as in some American states such as New York (NAM 2012), this will reduce HIV infectivity of the population and condom use will be an additional safeguard. Many gay men with HIV have abandoned condoms in a stable relationship as whilst not condoned by health experts, the evidence for transmission is negligible on review (NAM 2011). No women in the study were aware of this information, they were told to use condoms, as this was the only effective risk reduction strategy even when they were on effective treatment and this made their transmission risk to others low. This information may salvage some African HIV discordant relationships that have failed due to HIV infection and specifically the use of condoms. I would strongly suggest we think outside of the box and review the evidence, be factual, explain risk but importantly stop using outdated
evidence to control behaviour. We know sex to be creative and fun but we need to reduce the danger of HIV transmission in a meaningful way.

HIV is damaging when allowed to be so. It is time to foster an enlightened approach that is non-judgemental, health-efficient and has excellent outcomes with increased detection and reduced infection. This study has shown the difficulties women face and they need to be further empowered and not controlled by half truths or simplistic messages that fail to address the real problems women face with a diagnosis of HIV in pregnancy.

Women desire a healthy pregnancy outcome and to achieve this undertake a variety of screening tests in pregnancy. HIV testing is one antenatal screening option available to achieve this outcome (Kennedy 2003). If a woman fails to take the test she is often viewed with suspicion and failing to protect her infant from HIV (Kass 2000). She may be regarded as deviant by health professionals, but also probably by women themselves as they support testing (Boyd et al 1999a, 1999b). Women that identify themselves at risk may not feel empowered or engage with the maternity services, should they disclose sexual practices that are of personal risk.

The values and beliefs held by the African community and by African women are noticeably absent in the HIV literature in UK and this study allowed some collective and individual insight how these values and beliefs affect living with HIV in the UK. The African literature gives a degree of insight into this specific aspect as culturally held beliefs were imported. Women are now tested in great numbers by midwives but the specific experience of African women receiving a positive HIV result was minimal in the literature. This study rectified this deficit and has been explored in this thesis. HIV infection is a disability and individuals now have rights to protect their interest (Disability Act 2004) but unfortunately the obstacle of stigma remains very problematic to those infected and affected (Sanders 2008) and was evident in this study.

The knowledge gained from this study contributed to an area of research about HIV testing in pregnancy that has not been flourishing and has in effect been mostly hidden
until recently. It leaves unanswered other women’s experiences of testing positive in other programmes which is ripe for further research. Larger studies are needed to determine best practice for antenatal HIV testing in the UK. Antenatal HIV testing research has quietened in the last 10 years, more needs to be undertaken and a more open debate developed. Testing needs to be honest and flexible to meet women’s needs and concerns around HIV testing. The antenatal UK testing or screening program tests all women but has not fully explored the impact of a positive result for women, their family and social circle. This study has explored this issue but more needs to be done.

5.8.2 Recommendations from Study Finding

This study found midwives had an important and crucial role as they supported women with the experience of testing HIV positive in pregnancy. Midwives were vital facilitating (or damaging) the growth of natural resilience and the phenomenon of transition and transformation. Transition was often interrupted, slowed, harmed or damaged by complex factors associated with testing HIV positive. This impacted women’s transformation of being as they integrate HIV in the lived world.

The study found women mourned the loss of the old life and displayed grief with this personal loss. It is recommended that midwives are informed of this study finding and informed of the issues that add further complexity with testing HIV positive. Midwives can enable women with supportive strategies that engender acceptance of the diagnosis and foster personal growth as women live with the challenges of HIV.

The study found women were vulnerable with self harm risk including the contemplation of suicide. It is recommended that intensive support is routinely available for the newly diagnosed HIV positive women in the immediate post HIV diagnosis period. Vigilance, practical support and referral may be required (Sherr 1995; Kennedy 2003; NAM 2008) to aid coping and the restoration of resilience (Bonanno 2009). The development of a trusted and regulated buddy system with pair-up support for women by other positive women for those diagnosed within the maternity services
may be an option. This support will enable women to see they are not alone and may assist in managing distress which was evident in this study.

This study found that many African women believed death was the outcome of an HIV diagnosis; a belief imported from their country of origin and was often unaware that HIV is treatable and unlikely to die with a very high probability of a negative baby. The absence of this information made the immediate reaction with testing positive more extreme and distressing. It is recommended all women but specifically African women are explicitly informed of this pertinent information prior to any screening or recommendation of the HIV test.

The study found being unprepared for the possibility of a positive result made the experience traumatic. An unexpected result had great emotional impact; women were often unprepared as the possibility of a positive result had not been discussed. It is recommended that midwives prepare women with this possibility with pre-test information giving.

The study found women had an intense reaction to being informed of a positive result and contributory factors discussed with the above recommendations. It is further recommended that additional support for midwives is available when giving a positive result to meet this challenge. The use of drama and role play may enable midwives to develop the supportive skills further to effectively support those who are distressed when receiving bad news.

This study found that women supported HIV screening and knowledge of HIV status as a health benefit was a factor was contributed to this support. It was reported that it was simply best to know and importantly HIV treatment gave them hope. It is recommended that this excellent treatment outcome information is given before actual testing as it made a difference with a positive result.
This study found a lacks of information and not being informed of the issues with a positive result was a concern for women. It is recommended that written, pertinent, clear, succinct, up to date evidenced HIV care and information guidelines are fit for purpose and available. Information must be regularly reviewed and developed further that meet women’s and partner’s information needs.

This study found women were often isolated and lonely and reported stigma (both real and perceived) contributed to isolation in a time of great need. It added complexity to women living with HIV and empathy and understanding often hidden. It is recommended that midwives fully explore stigma and isolation. The source of stigma and any intervention required will be specific for each woman and with consent early referral to HIV support organisations may be beneficial to reduce isolation and build future social capital.

This study found difficulties with health care provision and stigma was perceived as the cause. Stigma was reported as both overt and covert with poor care experiences Midwives were perceived as unkind or unthinking with a failure to challenge negative stereo typical images or poor practice with HIV infection; specifically double gloving marked them out as different. It is recommended that regular updates of all staff address issues of poor care provision and the malignant influence of stigma.

This study found women were concerned confidential information. Women trusted HIV specialist midwives with personal information. Hidden language and leaked information was suspected, but not proved in the maternity setting. It is recommended that the maternity services maintain confidentiality and all staff are updated regularly. Any breaches of confidentiality should be formally investigated and any action taken recorded. Maternity services should address these concerns and work in partnership with women, HIV/African support agencies; legal and professional organisations to further develop confidentiality standards that inspire trust.
This study found the care and support given by HIV specialist midwives was life enhancing and vital for childbearing women with HIV. It is recommended that maternity units with a high prevalence of HIV that this midwifery focused HIV specialist role is protected and maintained and further promoted to women and developed further as it may be helpful as the first point of contact and referral for women. The role may also have a wider remit for sexual health, blood born infection; however, midwifery competency in HIV care for pregnant women must be maintained.

This study found women had some difficulties with HIV disclosure to significant individuals and supporters were problematic and it is recommended that women are given enabling strategies to achieve this outcome. This may also include role play with this disclosure issue.

This study found women were at risk with an abusive relationship when diagnosed and need to be informed of this added risk after a positive HIV result. It is recommended that midwives discuss and encouraged women to report abuse and the maternity services have a clear reporting policy with supportive measures in place with any reported or suspected partner abuse.
5.9 FINAL OUTCOME FROM THE STUDY

As an outcome of the study I plan to use information technologies to promote the study findings and use it as a vehicle to promote sexual health, HIV screening and testing HIV positive during childbearing. I plan to use various media, DVD, POD cast and the iPod; I will after submission of this thesis submit a proposal for consideration jointly with HIV support organisations to take this forward. I also intend to write a book for women and midwives, of the collective experiences of antenatal HIV testing for women. All women who participated in this study have been extremely positive about this aspect as long as confidentiality is not threatened in any way.

5.9.1 Influencing Change

A DVD/POD cast is planned on completion of this thesis incorporating information about the HIV testing process and how to prepare for testing and the result. The DVD will be piloted by gaining opinions from four focus groups (women and birth partners). The developed DVD will be website hosted, with website links to Acute Hospitals Trust, the Royal College of Midwives, and Local Supervisors Authority (LSA) and HIV charities and support websites. The website will acknowledge that the idea came from the findings from my research and that intellectual property rights belong to me, my supervisors and any other contributors. This DVD and website will be a direct product from the study as women demanded greater information for antenatal HIV testing and possible outcomes.

- Develop the pre testing information pack, highlighting the greater risk of a positive result for black African women.
- Develop the “Positive Pregnancy Pack” an HIV positive pregnancy information pack for all women and specifically African women newly diagnosed. All information to be in written format but also web based and exploring HIV Childbearing and motherhood as described above.
5.9.2 Other Proposed Developments

Midwives need to be confident with HIV testing, with offering, testing and giving the negative and positive results. Non Judgemental, empathetic, supportive, kindness and understanding is required. Information need to be clear, concise but meaningful and whilst pro-health benefits of testing and knowing status, respectful and meeting the requirements of informed consent.

Proposed developments include working with National AIDS Trust and Positively UK;

- Prior to pregnancy - develop HIV and sexual health awareness campaign. I suggest a new “Don't be mean, HIV test and screen” or similar as this study found woman’s first opportunity to test was often in pregnancy which is perhaps not the most optimum time for the woman to receive a positive result.

- Social capital development of positive women with HIV support groups integrating with maternity services as this study found women were often isolated after a positive result.

5.10 MAKING A DIFFERENCE

My aim is to inform others of the findings of this study, which in the future I hope may enhance the experiences of women and midwives that provide care. The findings and knowledge gained from this thesis will be disseminated to the national HIV midwifery networks and charities such THT, National AIDS Trust, Positively UK and local based charities. It is only by disseminating this thesis; I can help to make a difference to maternity care provision by rising awareness of the themes found in this research study. The focus of maternity care needs to move away from the emphasis of testing for the health benefits alone and infant transmission rates, to a partnership working with women. Moves towards “salutogenesis” where childbearing is interpreted through a wellness model rather than an illness model is perhaps the way forward (Downe & McCourt 2004). If this model was embraced for HIV testing this would help push aside
HIV as a fearful illness to one of optimism model which would enable the midwives to practice an essential element of ‘being’ with the women as she receives her positive result and offer support with the transformative journey. This journey whilst difficult would be aided by HIV being viewed as an inconvenient truth but normative with treatment. My hope is that this work will go some way to changing the future of HIV testing in the maternity services to make a real difference to women’s experiences.

5.11 DEVELOPING THOUGHTS AND REFLECTIVE JOURNEYWHILST UNDERTAKING THE STUDY

This thesis is unique in its exploration of antenatal HIV testing and the experience of testing HIV positive and the emergent phenomena. It provides both original knowledge and also builds on what is already known and is supported by the findings of Kelly et al (2012). It provides original narrative data, using interview as data collection method. It gave African women a voice; women’s perceptions and experience were told by themselves by their own testimony. I now offer some reflection on my experience and my final thoughts of the study. I feel absolutely privileged to have had the opportunity to engage with women with HIV. When I started this research journey I commenced a reflective journal which not only recorded the research progress but the emotional journey for me. What started as just wanting to know more about women’s testing experience became an all consuming passionate and emotionally challenging study. It has had a major impact on my life, as I had engaged with predominately African women with an HIV diagnosis, their families and supporters. The main problem was accessing eligible women through the gatekeepers who were understandably protective. To overcome this, multiple recruitment strategies were used. Moreover, as this is a phenomenological study it generated a vast amount of rich data; the sample size whilst good was less important than the data quality (van Manen 2006). These women were wonderful, my questions answered openly. Sometimes questions were answered in a roundabout way, often with laughter and also with crying. Their narrative rang true; recall clear, and the only occasional tentative response was only when we explored how they may have got their HIV infection or the affect on the pregnancy. The shared view often talked about was the cathartic nature of the discussion we had. They allowed me to look into their own life-world and this allowed me to interpret and explore their
situatedness and the epistemological and ontological perspectives. I have had a very special privilege of women letting me into their life and reveal a powerful phenomenon. I cared for these women in a way that went beyond my role as a nurse and a midwife. This study became full of passion for them and their testing experience. I thought they would be victims of HIV testing; they were in many ways, but what was remarkable was that whilst each had their own fragility, this was overshadowed by their tenacity and sheer resilience. They were resilient and strong and intended to remain so. The women, both eligible and ineligible for the study, that I met at the study workshop were strong and supportive of each other, but also had vulnerability as they sought support, often after partnership or significant relationship breakdown.

The research processes was long, hard and stretched me by the amount of work required. Whilst aware of the capacity to produce rich data, I did not expect the sheer volume of rich data. I worried if I would do the narrative justice. My skills around questioning and analysis improved and the questioning became more open and influenced by each women I encountered (van Manen 1990). I had to overcome my phobia of digital technology, but it never stopped me worrying that it might fail to record. I became obsessive about the need to back up data as it must not be lost. I could be frustrated at times, especially as recruitment was slow to be approved by RD departments or heads of midwifery. However, this was tempered by the joy of women coming forward to participate once the door was opened. I have been grateful for the support given by my advisors, for without them the problems would have impacted on me much more. The pragmatism in the face of adversity with the threatened withdrawal of one unit site gave me nightmares, but I understand fully from this research experience how support in times of acute crisis can help with these events. I struggled and sometimes had difficulty in understanding methodological matters and theoretical concepts, but van Manen (1990) became my enlightenment, showing me the way. Concepts and model-building and themes became easier as the narrative took centre stage. The past four years have been an enlightening and inspiring journey. I have experienced both joy and sadness as women and midwives have shared their stories with me. I hope to have transferred these insights to the pages of this thesis, while endeavouring to understand the concepts and meanings through my methodology and theoretical perspective.
This thesis is rooted within my own perceptions, my own experiences of HIV testing in pregnancy, my role as a midwife and promoting testing and the legitimate concerns I held. I was surprised that the majority of the partners were negative or claimed to be so. I had held the prejudicial view that the male partner would be positive also. This belief was questioned as the study findings strongly suggest that the majority of women prior to arrival in the UK imported the HIV infection into their relationship. This may have given the men a legitimate rationale to reject the relationship, however they would need to be questioned further to explore this aspect. I am a father and now a grandfather and this has impacted on a future filled with promise and optimism, but my concerns with aspects of testing and the lack of information, questions would I want this experience to be repeated for them as family – simply it needs to be improved! I believe I have been honest and truthful within this thesis and have explored the issues of reflexivity and my own knowledge and situatedness. I believe my experiences assisted my total immersion into this study and assist my understanding of the issues. My colleagues, supervisory team and my partner and family have further assisted me as I have discussed and developed the thesis to its ultimate conclusion. It is my own work but subject to many influences, but the women are the essence and remain centre stage.

The HIV result was cataclysmic for most women and life-changing causing acute emotional distress for the study participants. However, the findings of this study demonstrate new understanding and new original knowledge. The women were eager to share their experiences but as a one-off event with all but two women refusing to meet again. The interviews allowed a meaningful interaction, they were cathartic and all thanked me for the opportunity to tell of their experience. This was personally gratifying and rewarding. The interview process allowed me, as an outsider, to better understand this testing experience and its meaning for the women. I am left with one nagging issue to understand: women attend for the result alone and the only immediate support were the staff, should not black African women be informed to bring someone of their choosing they could trust should the result be positive? Failing that, the maternity services could have someone readily available that had survived the distress of a positive result. Women could choose this option of support if it were available.
5.12 CONCLUSIONS FROM STUDY AND CONCLUSION OF THESIS – CLOSING REMARKS

This research investigated in-depth the phenomenon of an antenatal HIV diagnosis and the meaning and essence of this lived experience. Women were tested in pregnancy by midwives, who were crucial to this testing process and this research examined their impact and role. Further, women absolutely needed midwives caring skills to assist them with this HIV diagnosis. This had not been attempted or completed at the formulation of this study. Simply this study gives greater insight into this hidden experience which affected African childbearing women. This thesis and study is important in opening the debate around testing or screening for the health professional. It is only a start for a process that examines women’s experience of the HIV integrated service that is supplied by midwives and supported by the HIV team. There is a need for a renaissance of understanding, so that the screening service is truly woman centred and meets their needs.

I have been inspired by midwives who were kind and showed human warmth but dismayed and concerned with reported instances of poor care as this was damaging to women when support was vital. I hope this study has highlighted the great difficulties women face with HIV but also how they have sought strategies to overcome and live with HIV. HIV had a major impact on women and their families but the reward of a negative child offered some degree of compensation. This research has been immensely rewarding and a challenging process which increased my knowledge and understanding of this unique experience of testing HIV positive in pregnancy. Importantly my engagement with women was a great privilege and truly inspiring as they sought meaning in a time of great adversity. It was not the result or news they wanted and a traumatic experience with great personal loss was reported. I remain inspired by the resilience of women as they were transformed by this diagnosis. I hope I have been successful and importantly given justice to women who participated and narrated their experiences. This study informs midwives of the challenges newly diagnosed women face when confronted with HIV during pregnancy. The growth of resilience assisted women with transition and transformation and living a meaningful life with HIV. Midwives are crucial by improving the testing experience and supporting childbearing
women with a positive result as they adapt and recover a liveable life. I firmly believe this study independently supports Kelly et al’s (2012) research findings but has additionally contributed new and vital knowledge which will develop future midwifery practice and research.
References


Guy's & St Thomas' Hospital NHS Trust Women's and Neonatal Services (2008) HIV intrapartum guidelines. London:


Hult J, Maurer S, Moskowitz J (2009). ‘I’m sorry, your positive’: a qualitative study of individuals experiences of testing positive for HIV. *AIDS Care*. 21,185-188


Lingen-Stallard A (1996). A study of midwives attitudes and beliefs to HIV and antibody testing.(BSc Hons Dissertation) Kings College University of London. (Questionnaire used by Low et al 2001)

Lingen-Stallard A (2006). A study of women’s views and experiences of HIV test information in Pregnancy in an opt out screening program. (MSc Dissertation). Kings College University of London, (Unpublished but available to view at KCL library or contact author- aplingenstallard@aol.com).


NAM Charitable Trust (2012). NAM: HIV & AIDS treatments directory (On Line updates weekly on AIDSmapnews@nam.org.uk)


APPENDIX TO THESIS

CHAPTER TWO-Literature Review

Appendix 1-Search Process –List of Tables

Appendix 2- Shows Relevant HIV Studies Included In the Comprehensive Literature Review

Appendix 3- Check Box Criteria Used In Review

Appendix 4- Hierarchy of Research Evidence Used with Score

Appendix 5 –Further HIV and AIDS Information

CHAPTER THREE- Methodology

Appendix 6- My Journey within Midwifery and HIV

Appendix 7-Example and Copy of Study Participant Information sheet

Appendix 8- Example and Copy of HIV Study Consent Form

Appendix 9- Example and Copy of Study Demographic Sheet

Appendix 10- Example and Copy of Semi Structured Interview Schedule for NREC

Appendix 11- Example and Copy of Poster

Appendix 12- Copy of Advertisement

Appendix 13- Copy of Favourable NRES Opinion

Appendix 14- Copy of letter from R&D-Recruitment Site

Appendix 15- Copy of Letter re Progress Report to NRES

Appendix 16-Further Details of the Analysis Process
CHAPTER FOUR-Findings

Appendix 17- Copy of Full Transcript from “Interview 5” Martha

Appendix 18- Graces’ Loss
Appendix 1

Search Process- List of Tables
### Table (1) – Specific HIV Search Terms Used From Research Question or Phenomenon

Boolean Logic was used (AND, OR, NOT, WITH).

<table>
<thead>
<tr>
<th>Population/Problem</th>
<th>Intervention</th>
<th>Comparison/Context</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Or Human immune deficiency virus Or AIDS Or Acquired Immune Deficiency Syndrome</td>
<td>Test Or Testing Or Screen Or Screening</td>
<td>AND</td>
<td>AND</td>
</tr>
<tr>
<td>HIV (exploded) AND</td>
<td>Testing (exploded) WITH Antibodies Or Antibody Or Positive AND Diagnosis Or Diagnosed Diagnosis (exploded)</td>
<td>High resource Setting Or</td>
<td>Developed countries Or</td>
</tr>
<tr>
<td>Pregnancy Or Pregnant Or Antenatal Or Prenatal Or Gravid</td>
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<td></td>
<td></td>
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Table (2) - Journals Consulted (Start date 1981 to present)

<table>
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<tr>
<th>Main Journals Consulted and Hand/Computer Searched</th>
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<tbody>
<tr>
<td>AIDS Care</td>
</tr>
<tr>
<td>AIDS Journal</td>
</tr>
<tr>
<td>British Journal of Midwifery</td>
</tr>
<tr>
<td>British Medical Journal</td>
</tr>
<tr>
<td>HIV &amp; AIDS treatments directory</td>
</tr>
<tr>
<td>HIV Medicine</td>
</tr>
<tr>
<td>International Journal of Nursing</td>
</tr>
<tr>
<td>International Journal of Midwifery</td>
</tr>
<tr>
<td>Journal of American Medical Association</td>
</tr>
<tr>
<td>Journal of Acquired Immune Deficiency Syndromes</td>
</tr>
<tr>
<td>Journal of Infectious Diseases</td>
</tr>
<tr>
<td>Lancet</td>
</tr>
<tr>
<td>Midwives (RCM)</td>
</tr>
<tr>
<td>New England Journal of Medicine</td>
</tr>
<tr>
<td>Nursing Times</td>
</tr>
<tr>
<td>National AIDS Manual (NAM)</td>
</tr>
<tr>
<td>Positive Nation</td>
</tr>
<tr>
<td>Psychology, Health &amp; Medicine</td>
</tr>
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</table>

Table (3) - Medical and Nursing Databases Accessed

<table>
<thead>
<tr>
<th>General Medical &amp; Nursing Databases Accessed</th>
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<tbody>
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<td>(Via National Electronic Library for Health Site and Athens portal personal account)</td>
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<td>AIDSline</td>
</tr>
<tr>
<td>Medline</td>
</tr>
<tr>
<td>Embase</td>
</tr>
<tr>
<td>CINAHL</td>
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<tr>
<td>Pubmed</td>
</tr>
<tr>
<td>Cochrane</td>
</tr>
<tr>
<td>PsychLIT</td>
</tr>
<tr>
<td>British Nursing Index</td>
</tr>
<tr>
<td>ASSIA</td>
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<tr>
<td>NAM</td>
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### Table (4)-Specific Midwifery Database

<table>
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<th>Specific Midwifery Database Accessed (Subscription)</th>
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</tr>
</thead>
<tbody>
<tr>
<td>MIDIRS sub section HIV Antenatal Screening</td>
<td></td>
</tr>
</tbody>
</table>

### Table (5)-HIV and AIDS Sites Accessed

<table>
<thead>
<tr>
<th>HIV &amp; AIDS Information Sites Accessed</th>
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<td><a href="http://www.AIDSmap.com">www.AIDSmap.com</a> (NAM)</td>
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<td><a href="http://www.AIDSONline.org">www.AIDSONline.org</a></td>
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<tr>
<td><a href="http://www.nat.org.uk">www.nat.org.uk</a></td>
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<td><a href="http://www.i-base.info">www.i-base.info</a></td>
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<td><a href="http://www.positivenation.co.uk">www.positivenation.co.uk</a></td>
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<td><a href="http://www.positivelyuk.org.uk">www.positivelyuk.org.uk</a></td>
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<td><a href="http://www.positive-negative.org">www.positive-negative.org</a></td>
<td></td>
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<tr>
<td><a href="http://www.avert.org">www.avert.org</a></td>
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<tr>
<td><a href="http://www.bhiva.org">www.bhiva.org</a></td>
<td></td>
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<td><a href="http://www.projinf.org">www.projinf.org</a></td>
<td></td>
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<td><a href="http://www.positivelyuk.org.uk">www.positivelyuk.org.uk</a></td>
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<td><a href="http://www.positive-negative.org">www.positive-negative.org</a></td>
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<tr>
<td><a href="http://www.projinf.org">www.projinf.org</a></td>
<td></td>
</tr>
<tr>
<td><a href="http://www.ama-assn.org">www.ama-assn.org</a> (JAMA)</td>
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### Table (6)-Search Engines Used

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<td><a href="http://www.aol.com">www.aol.com</a></td>
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</tr>
<tr>
<td><a href="http://www.google.com">www.google.com</a></td>
<td></td>
</tr>
<tr>
<td><a href="http://www.yahoo.com">www.yahoo.com</a></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2

Shows HIV Studies included in Comprehensive HIV Literature Review
Table of HIV Studies and own HIV dissertation x 2 (with the hierarchy design scores) included in the comprehensive literature review from the years 1981 to present

### General Search Results on Antenatal HIV Testing

#### Pre-test Information and Antenatal HIV Testing

<table>
<thead>
<tr>
<th>Author Date</th>
<th>Aim</th>
<th>Sample Setting</th>
<th>Design</th>
<th>Findings Result</th>
<th>Design Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sherr &amp; Hedge (1990)</td>
<td>Measured the impact and content with use of HIV pre-test leaflets</td>
<td>24 Maternity Units in UK</td>
<td>Prospective Survey</td>
<td>Content evaluation of leaflets were variable and affected the issues with consent and were an addition to pre-test information</td>
<td>II-2b</td>
</tr>
<tr>
<td>Simpson et al (1998a) (Simpson et al (1998b) is a commentary paper on above)</td>
<td>Measured 4 differing methods both written and verbal of offering HIV testing information in pregnancy and assessing acceptability and women’s satisfaction</td>
<td>3024 Women in opt in screening program in Scotland</td>
<td>RCT of 4 groups of randomised women (Experimental study)</td>
<td>Women were satisfied with less information- Randomised groups of women were given different level of information which and were satisfied with but no comparisons of information were given to make a choice - questionable methodology with comparing information experience leading to questionable conclusions.</td>
<td>I</td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Participants</td>
<td>Data Collection</td>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Simpson et al (1999)</td>
<td>Measured acceptability and satisfaction of antenatal HIV testing after the introduction of a later opt out screening program.</td>
<td>924 Women in an opt out screening program</td>
<td>Prospective Survey</td>
<td>99.1% response rate. Women were satisfied with the HIV testing program but questions simplistic</td>
<td></td>
</tr>
<tr>
<td>Sherr et al (2000)</td>
<td>Measured antenatal information and testing policy with consent and choice</td>
<td>Part 1, 288 maternity clinics UK and Eire (91% response rate) and Part 2, n =697 women surveyed in 4 London units</td>
<td>2 Part Prospective Survey</td>
<td>Good response rate for both surveys. Testing policy and information haphazard and poor with limited maternal consent and choice</td>
<td></td>
</tr>
<tr>
<td>Sherr et al (2001)</td>
<td>Observed pre-test discussion and offer of HIV test in pregnancy</td>
<td>Midwives 154 booking interviews</td>
<td>Observational</td>
<td>Limited discussion, consent or choice with only 1 in 10 women informed of the advantages and disadvantages of testing. Poor uptake noted with poor information levels</td>
<td></td>
</tr>
<tr>
<td>Roth et al (2003)</td>
<td>Observed pre-test discussion with women who first language was not English</td>
<td>Women and midwives in 1 London unit</td>
<td>Observational Focus groups Qualitative</td>
<td>Limited discussion, consent or choice observed</td>
<td></td>
</tr>
<tr>
<td>Lingen-Stallard (2006) (MSc Dissertation)</td>
<td>Measured pre-test information, and satisfaction with testing program</td>
<td>144 Women in an opt out testing program</td>
<td>Postal Survey</td>
<td>Women support testing but critical of limited information</td>
<td></td>
</tr>
</tbody>
</table>

**Search- Antenatal HIV Testing and Midwives or Women’s Views, Opinion, Knowledge, Support, Uptake Rates, Consent and Women’s Experience of Testing in Pregnancy**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Methodology</th>
<th>Participants</th>
<th>Data Collection</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stevens et al (1989)</td>
<td>Experience whilst waiting for the HIV result</td>
<td>26 Negative Women</td>
<td>Survey</td>
<td>Reported Maternal anxiety mildly elevated whilst waiting for the result</td>
</tr>
<tr>
<td>Study (Year)</td>
<td>Research Question</td>
<td>Sample</td>
<td>Study Type</td>
<td>Findings</td>
</tr>
<tr>
<td>-------------</td>
<td>-------------------</td>
<td>--------</td>
<td>------------</td>
<td>----------</td>
</tr>
<tr>
<td>Meadows et al (1990)</td>
<td>Examined midwives individual uptake rates of testing</td>
<td>12 Midwives in 1 London unit</td>
<td>Retrospective Survey</td>
<td>Poor knowledge implicated in low levels of testing-range from 82% to 3%</td>
</tr>
<tr>
<td>Larsson et al (1990)</td>
<td>Opinion and uptake of testing in Sweden</td>
<td>198 negative Women</td>
<td>Prospective Survey</td>
<td>99.3% tested and were supportive of testing for health benefits</td>
</tr>
<tr>
<td>Meadows et al (1992)</td>
<td>Views of HIV testing</td>
<td>34 Midwives in 1 health trust</td>
<td>Prospective Survey</td>
<td>Midwives were supportive of testing but felt it should not be compulsory</td>
</tr>
<tr>
<td>Meadows et al (1993a)</td>
<td>Views of the consumers of HIV testing</td>
<td>318 Women in 1 London antenatal clinic</td>
<td>Survey</td>
<td>Good level of knowledge increases likelihood of testing. 33% felt test should be compulsory</td>
</tr>
<tr>
<td>Meadows et al (1993c)</td>
<td>Prediction of women who chose to test</td>
<td>318 Women in 1 London antenatal clinic</td>
<td>Study data of 1993a study</td>
<td>Strongest predictors were if perceived benefit to self, baby and partner more likely to test and poor knowledge of sexual transmission likely not to test</td>
</tr>
<tr>
<td>Meadows et al (1994a)</td>
<td>Examined which women chose to test</td>
<td>88 Women in 1 London unit</td>
<td>Structured interview</td>
<td>Good level of knowledge increases HIV testing but personal risk identification is problematic and infant transmission knowledge poor</td>
</tr>
<tr>
<td>Desmond (1994)</td>
<td>Measured knowledge of HIV (but results reported in a brief BMJ article)</td>
<td>238 Women</td>
<td>Prospective Survey</td>
<td>Knowledge good and HIV test acceptable to women but poor levels of knowledge implicated in low uptake rates and 155 thought test should be compulsory</td>
</tr>
<tr>
<td>Chrystie et al (1995a) (Chrystie et al (1995b) is a discussion paper)</td>
<td>Implementing HIV testing in a community antenatal clinic in London</td>
<td>6 Midwives and 204 women attendees based in London community antenatal clinic over a one year period</td>
<td>Pilot Study</td>
<td>Increase in level of testing up to 44% uptake and maternal satisfaction increased but time to offer test was an average 21 minutes and incurred costs</td>
</tr>
<tr>
<td>---</td>
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<td>---</td>
</tr>
<tr>
<td>Lingen-Stallard (1996) (BSc Dissertation)</td>
<td>Examined attitudes and belief around HIV testing</td>
<td>19 Midwives in 1 London Unit</td>
<td>Survey</td>
<td>Good attitudes to HIV and midwives supported testing</td>
</tr>
<tr>
<td>Ruby &amp; Siney (1997)</td>
<td>Examined the implementation of antenatal HIV testing</td>
<td>Maternity Units in UK</td>
<td>Survey</td>
<td>Most units offering HIV testing in an opt in program with increased level of testing reported</td>
</tr>
<tr>
<td>Duffy et al (1998a)</td>
<td>Measured uptake rate</td>
<td>789 Women (50% White) in 1 London maternity and 6 community clinics</td>
<td>Prospective Survey</td>
<td>Uptake rate increased when knowledge good but only to 35% and more declined in a community setting. No difference in ethnicity</td>
</tr>
<tr>
<td>Duffy et al (1998b)</td>
<td>Measured knowledge, attitudes and acceptability</td>
<td>843 Women (51% Caucasian) in 1 London unit and 6 community and 1 midwifery practice clinic</td>
<td>Prospective Survey</td>
<td>Knowledge and attitudes good and HIV test acceptable to women but community clinic lower rates and 36% women changed their mind to no after seeing midwife.</td>
</tr>
<tr>
<td>Jones et al (1998)</td>
<td>Examined midwives individual rates of testing and the influencing factors to offer the test</td>
<td>23 Midwives</td>
<td>Cross sectional study</td>
<td>If midwives knowledge is good more likely to offer test. No difference in offer of the test with ethnicity of midwives</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Sample Size/Study Design</td>
<td>Findings</td>
<td></td>
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<tr>
<td>----------------------</td>
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</tr>
<tr>
<td>Gibb et al (1998)</td>
<td>Factors affecting HIV uptake rates</td>
<td>18,791 Women and in multicentre study (6 London Units in 1995-96)</td>
<td>Low uptake rates in all London units with universal offer of test range from 3.4% to 51.2% uptake. Variable uptake with women’s ethnicity. Poor maternal knowledge a factor but higher risk women tested.</td>
<td></td>
</tr>
<tr>
<td>Sherr et al (1998)</td>
<td>Trends of testing and ethnic minority uptake rates</td>
<td>6 Maternity units in London</td>
<td>No difference in rates of uptake</td>
<td></td>
</tr>
<tr>
<td>Postma et al (1999)</td>
<td>Cost analysis of testing in England</td>
<td>HIV Screening program in England</td>
<td>Midwives are cost efficient when compared to others HIV testing programs</td>
<td></td>
</tr>
<tr>
<td>Boyd et al (1999a)</td>
<td>Views of antenatal testing</td>
<td>29 Women in an antenatal clinic in Scotland</td>
<td>Women were supportive of antenatal HIV testing for health benefits but questioned testing for themselves</td>
<td></td>
</tr>
<tr>
<td>Boyd et al (1999b)</td>
<td>Acceptability of testing</td>
<td>10 Midwives who had offered HIV testing to 2727 women</td>
<td>Midwives with the most positive attitude had highest testing rates and caused less maternal anxiety</td>
<td></td>
</tr>
<tr>
<td>Baxter &amp; Bennett (2000)</td>
<td>Measured women’s knowledge and views of testing</td>
<td>12 Women</td>
<td>Supportive of testing but critical of limited information. Women knowledge of HIV was good but questioned relevance of the test</td>
<td></td>
</tr>
<tr>
<td>Bruce et al (2001a)</td>
<td>Views and Knowledge of Hep B and HIV</td>
<td>12 Midwives</td>
<td>Increased knowledge increased testing</td>
<td></td>
</tr>
<tr>
<td>Bruce et al (2001b)</td>
<td>Views and Knowledge of Hep B and HIV</td>
<td>18 Women</td>
<td>Women asked for more information to be informed and were supportive of testing</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Methodology</td>
<td>Sample</td>
<td>Findings</td>
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<tr>
<td>Low et al (2001) (Used major survey component of Lingen-Stallard 1996 study)</td>
<td>Integration of HIV testing in midwifery practice and midwives attitudes to testing</td>
<td>Cross sectional study-Survey and Focus groups</td>
<td>162 Midwives in 4 London Units with an opt in program</td>
<td>Midwives support HIV testing as drugs were available to treat HIV infection and have integrated testing in to antenatal care</td>
</tr>
<tr>
<td>Jones D (2004)</td>
<td>Examined why women decline testing</td>
<td>Retrospective survey and audit</td>
<td>1 London Unit-2138 audit test forms of who 306 declined</td>
<td>Found 20% of black women declined testing for cultural or religious reasons. Most stated not applicable as in a stable relationship</td>
</tr>
<tr>
<td>Conaty et al (2005)</td>
<td>Examined uptake rate of testing and reasons for declining HIV testing</td>
<td>Retrospective Survey and audit</td>
<td>3 London maternity units-uptake rates of 2710 women</td>
<td>High and sustained level of testing but 15% of women declined and of this group 38% had tested before and questioned relevance. Sub-Saharan women were just as likely to test</td>
</tr>
<tr>
<td>De Zulueta &amp; Boulton (2007)</td>
<td>Explored pregnant women's responses to routine HIV testing, reasons for declining or accepting the test</td>
<td>Qualitative cross-sectional survey-Interview</td>
<td>1 London Unit -32 women at booking with routine HIV testing</td>
<td>32 interviewed, only 10 were prepared for HIV testing at the booking interview. None felt at risk. 9 understood rational for test. 6 declined as equates acceptance as admitting risky behaviour. Assesses responses if fulfil standard criteria for informed consent and none found.</td>
</tr>
<tr>
<td>Southgate et al (2008)</td>
<td>Explored ethnic minority uptake rates and if women decline testing</td>
<td>Retrospective Survey</td>
<td>1586 women in 1 maternity unit outside London-</td>
<td>No difference in rates of uptake of testing</td>
</tr>
<tr>
<td>Reference</td>
<td>Title</td>
<td>Sample</td>
<td>Method</td>
<td>Summary</td>
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</tr>
<tr>
<td>Giraudon et al (2009)</td>
<td>Measured rates of antenatal HIV, Hep B and Syphilis testing</td>
<td>30 London Maternity units</td>
<td>Survey</td>
<td>Good rates of testing at 95.6 % for HIV but 1% higher for the other screening tests</td>
</tr>
<tr>
<td>Simpson and Forsyth (2007)</td>
<td>Women’s experience of HIV diagnosis in a state mandated system of compulsory testing in pregnancy in USA</td>
<td>11 HIV positive women (Purposive sample)</td>
<td>In-depth structured interviews</td>
<td>Women share their personal perspectives regarding the benefits and adverse outcomes of HIV testing for themselves, their children, and the public health. Each woman recalled her initial response to the law, to her HIV diagnosis, and to the challenge to her self-identity and described the adjustments made. There was universal agreement by the participants that the law was of overriding and significant benefit.</td>
</tr>
</tbody>
</table>

**Specific Search Results of Antenatal HIV Diagnosis in Pregnancy**

**Women’s experience of antenatal HIV positive diagnosis with a result in pregnancy** - In Early July 2012- whilst undertaking a final review the following published paper was found in June 2012 - Kelly et al (2012)- *Creating continuity out of the disruption of a diagnosis of HIV during pregnancy*  This is pertinent and reinforces my study findings. My Study was analysed and completed at the time of this paper publication. Kelly et al (2013) was also published later in Nov 2012 and is also relevant with HIV pregnancy care experiences.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Sample</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kelly et al (2012) Kelly et al (2013)</td>
<td>Women’s experiences of HIV diagnosis in Pregnancy (UK Study)</td>
<td>4 pregnant HIV positive women were drawn from case studies (Purposive sample). The participants drawn from a larger study on negation of risk in sexual relationships and reproductive decision making</td>
<td>Prospective quality study Multiply (two) interviews</td>
<td>The women were drawn from a larger study of reproductive decision making following a HIV diagnosis. Multiply interviews (In fact two each) were undertaken during pregnancy and after the birth of their infants. Thematic analysis. Drawing on Becker’s theory of disruption and emotional struggle as they create continuity in their lives. HIV disrupted health, relationships and social identity. The diagnosis was traumatic but the baby became a metaphor for hope and orientation toward the future. Explored this lived experience but not the phenomena of testing</td>
</tr>
<tr>
<td>Ingram &amp; Hutchinson (1999)</td>
<td>Explored the theme of Stigma with motherhood</td>
<td>18 HIV positive women who were mothers in USA (Purposive sample)</td>
<td>In-depth semi structured interview</td>
<td>Stigma evident and mothering affected. Mothers often lied to protect their interest and infants wellbeing.</td>
</tr>
<tr>
<td>Ingram &amp; Hutchinson (2000)</td>
<td>Explored reproductive and mothering experiences</td>
<td>20 HIV positive women who were mothers in USA(Purposive sample)</td>
<td>In-depth semi structured interview</td>
<td>Most women did not want further children and HIV affected the mothering experience negatively with bonding issues</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Methodology</td>
<td>Participants</td>
<td>Findings</td>
<td>Reference</td>
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</tr>
<tr>
<td>Sandelowski &amp; Barroso (2003)</td>
<td>Explored the theme of motherhood with HIV positive women</td>
<td>Review of 56 qualitative studies conducted with HIV-positive women exploring the theme of motherhood.</td>
<td>Metasynthesis and metasynthesis of 56 qualitative HIV studies involving women. Women fought hard to protect their child from HIV and to preserve their own identities. Motherhood was affected with an over protection of the infant. Limitations - Author accepts 3 times removed from the women’s experience. The authors produces a previous paper explaining the meta synthesis process - titled - toward a metasynthesis of qualitative findings on motherhood in HIV-positive women (2003)</td>
<td>II-2c</td>
</tr>
<tr>
<td>Kirshenbaum et al (2004)</td>
<td>Examined future pregnancy decisions/intentions after an HIV diagnosis</td>
<td>56 HIV positive women who were mothers in 4 USA cities</td>
<td>Interview and focus group</td>
<td>II-2a</td>
</tr>
<tr>
<td>Sanders (2008)</td>
<td>Later experience of pregnancy and motherhood after a diagnosis with HIV</td>
<td>9 HIV positive women in New York in the USA (Purposive sample)</td>
<td>In-depth Interview</td>
<td>II-2a</td>
</tr>
<tr>
<td>Study</td>
<td>Research Question</td>
<td>Participants</td>
<td>Methodology</td>
<td>Findings</td>
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</tr>
<tr>
<td>Kelly et al (2011)</td>
<td>Reproductive decision making following an HIV diagnosis</td>
<td>10 women and partners in sero-different couples</td>
<td>In-depth Semi structured interviews</td>
<td>18 interviews of the 10 women and their partners. The women were pregnant or trying to conceive or recently given birth. Dislike of condoms and willing to negotiate risk as men were more likely to have unprotected sex if the viral load was undetectable to conceive and for pleasure (Kelly participants in 2012 study is drawn from this sample)</td>
</tr>
<tr>
<td>Njie-Carr et al (2012)</td>
<td>Explored the experiences of HIV-positive African-American and African Caribbean childbearing women</td>
<td>23 HIV Positive childbearing women</td>
<td>In-depth semi structured interviews</td>
<td>This qualitative study examined the experiences of 23 HIV-positive African-American and African Caribbean childbearing women and related to decisions about HIV testing, status disclosure, adhering to treatment, decisions about childbearing, and experiences in violent intimate relationships. Positive experiences and resilience were gained from faith and prayer. Most important to the women were the perceived benefits of protecting the health of their baby.</td>
</tr>
<tr>
<td>Study</td>
<td>Focus</td>
<td>Sample Size</td>
<td>Data Collection Method</td>
<td>Summary</td>
</tr>
<tr>
<td>------------------------------</td>
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<tr>
<td>Kelly et al (2013)</td>
<td>Explored HIV positive women’s experience of maternity care in Northern Ireland</td>
<td>10 HIV positive women</td>
<td>In-depth semi structured interviews</td>
<td>22 interviews of 10 women who were HIV positive when considering or accessing maternity care drawn from same sample as Kelly et al (2011) which focus on midwives interactions with women and found women need to have normalcy in pregnancy and this was best provided by midwives who were knowledgeable and empathetic. The fear of pervasive stigma threatened this experience. Most women had been diagnosed HIV positive before access to the maternity services.</td>
</tr>
<tr>
<td>Johnstone et al (1990)</td>
<td>Knowledge of HIV and possible termination outcomes</td>
<td>163 Women (69 positive v 94 negative)</td>
<td>Survey and audit</td>
<td>Increased knowledge unlikely to terminate pregnancy as choice. But Higher but not significant rates in HIV infected women with 44 positive women and 21 decided on termination when previously known. 25 new infections and 10 terminated. (94 women negative and 33 terminated)</td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Participants</td>
<td>Methodology</td>
<td>Findings</td>
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</tr>
<tr>
<td>Lewis J (1999)</td>
<td>The experience of testing HIV positive (Canada)</td>
<td>25 HIV positive Gay men</td>
<td>Semi structured interview</td>
<td>Qualitative study with poor experience of testing and being informed of the result with high levels of distress</td>
</tr>
<tr>
<td>Schrooten et al (2001)</td>
<td>The experience of testing HIV positive in Europe</td>
<td>1366 HIV positive men and women (Non pregnant)</td>
<td>Survey</td>
<td>Poor experience of testing and being informed with shock, distress, confidentiality and stigma an issue for respondents</td>
</tr>
<tr>
<td>Hult et al (2009)</td>
<td>The experience of testing HIV positive (USA)</td>
<td>50 participants mostly gay men (6 women) in San Francisco</td>
<td>Semi structured interviews</td>
<td>Team based analysis for themes. Shock and distress. The informer made it worse for a minority of participants</td>
</tr>
<tr>
<td>Sherr et al (2011)</td>
<td>Examined post-traumatic stress disorder (PTSD) and post traumatic growth (PTG)</td>
<td>206 psychological papers with HIV diagnosis PTSD and 13 papers with PTG.</td>
<td>Systematic review</td>
<td>Reported of PTSD with HIV- but little to encourage personal growth as resilience noted in many papers- Review was critical of the measurement tools or the absence of them</td>
</tr>
</tbody>
</table>

**African HIV Literature (Stigma, Attitudes, Belief and Prevalence)**
<table>
<thead>
<tr>
<th>Study</th>
<th>Research Question</th>
<th>Sample</th>
<th>Methodology</th>
<th>Findings</th>
<th>Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orubuloye et al (1993)</td>
<td>Examined control over sexual relations in the era of AIDS</td>
<td>189 Yoruba women in Nigeria- Sub-Saharan Africa</td>
<td>Survey by health workers questioning women</td>
<td>Little sexual control for women with high risk of HIV due to prevalence in population</td>
<td>II-2c</td>
</tr>
<tr>
<td>Kalichman and Simbayi (2003)</td>
<td>Attitudes, beliefs, stigma with HIV and AIDS</td>
<td>224 men and 276 women in a black South African township</td>
<td>Venue intercept survey</td>
<td>47% had tested for HIV. Poor attitudes noted and stigmatise those with HIV. Those that had tested before had favourable attitudes and fewer stigmas when compared to those that had never tested</td>
<td>II-2c</td>
</tr>
<tr>
<td>Visser et al (2008)</td>
<td>Discloser of HIV to partners</td>
<td>293 HIV positive Women in South Africa</td>
<td>Semi structured interview</td>
<td>HIV positive women for a time do not disclose their HIV status to partner. Disbelief and shock but low levels of adverse consequences after disclosure</td>
<td>II-2a</td>
</tr>
<tr>
<td>Geddes et al (2011)</td>
<td>Examined follow up after an HIV diagnosis</td>
<td>703 African Women with recent HIV diagnosis</td>
<td>Survey and audit</td>
<td>Most women lost to follow up with only 150 women (21%) returning at 6 months and the rest (79%) were not able to access care and lost this health opportunity.</td>
<td>II-2c</td>
</tr>
<tr>
<td>Winskell et al (2011)</td>
<td>Examine Stigma from a HIV script writing contest</td>
<td>African population in 6 African states, 11,354 script identified and stratified sample 586 (5%) examined</td>
<td>Analysis of script writing for themes</td>
<td>Thematic analysis -Moralistic value judgement are attached to people living with HIV in Christian influenced African states</td>
<td>II-2c</td>
</tr>
<tr>
<td>De Beer et al (2012)</td>
<td>Knowledge, attitudes Stigma and HIV prevalence in second part of survey</td>
<td>University students in Namibia n=2790 and n =2807</td>
<td>2 part survey</td>
<td>Knowledge was reasonable. Stigma a concern and 2nd part of survey HIV prevalence range was 1.8% to 2.8%</td>
<td>II-2c</td>
</tr>
</tbody>
</table>
Appendix 3

Check Box Criteria Used in Review
<table>
<thead>
<tr>
<th>Criteria for Assessing the Relevance &amp; Quality of Each Study or Paper (Adapted from Bowling 2003)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the study ascertain or seek women’s experience of a positive HIV test in pregnancy?</td>
</tr>
<tr>
<td>Does the study inquire women’s antenatal testing experience or inquire about HIV testing?</td>
</tr>
<tr>
<td>Are the aims and objectives of the study or paper clearly stated?</td>
</tr>
<tr>
<td>Is the target population clearly stated and described?</td>
</tr>
<tr>
<td>Is the rationale given for the choice of research design used in the study?</td>
</tr>
<tr>
<td>What is the sample size?</td>
</tr>
<tr>
<td>How was the sample chosen?</td>
</tr>
<tr>
<td>How was access to the sample achieved?</td>
</tr>
<tr>
<td>What was the time span of the study?</td>
</tr>
<tr>
<td>Is any intervention clearly described? (Control versus experimental)</td>
</tr>
<tr>
<td>How the data was collected and is this clearly stated in the study?</td>
</tr>
<tr>
<td>Was the data clearly analysed?</td>
</tr>
<tr>
<td>Was the data evaluated?</td>
</tr>
<tr>
<td>Do the findings of the study relate to the results of the study?</td>
</tr>
<tr>
<td>Were the findings clearly reported?</td>
</tr>
<tr>
<td>Were the limitations of the study expressed?</td>
</tr>
<tr>
<td>Was the literature selected appropriate to the study objectives?</td>
</tr>
<tr>
<td>Was the literature incorporated into the study data?</td>
</tr>
<tr>
<td>Implications for future practice</td>
</tr>
</tbody>
</table>
Appendix 4

Hierarchy of Research Evidence
<table>
<thead>
<tr>
<th>Grade</th>
<th>Study design</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Well–designed randomised controlled trials</td>
</tr>
<tr>
<td>II-1a</td>
<td>Well-designed controlled trial with pseudo randomisation</td>
</tr>
<tr>
<td>II-1b</td>
<td>Well-designed controlled trial with no randomisation</td>
</tr>
<tr>
<td></td>
<td><strong>Cohort Studies</strong></td>
</tr>
<tr>
<td>II-2a</td>
<td>Well-designed prospective study with concurrent controls e.g. Observational studies</td>
</tr>
<tr>
<td>II-2b</td>
<td>Well-designed prospective study with historical controls</td>
</tr>
<tr>
<td>II-2c</td>
<td>Well-designed retrospective study with concurrent controls e.g. questionnaire surveys, comparative studies</td>
</tr>
<tr>
<td>II-3</td>
<td>Well-designed case-control retrospective studies or historical reviews</td>
</tr>
<tr>
<td>III</td>
<td>Comparative studies with no controls, including non-systematic reviews, exploratory studies</td>
</tr>
<tr>
<td>IV</td>
<td>Opinion of respected professionals based on clinical experience, descriptive studies or reports of expert committees</td>
</tr>
</tbody>
</table>
Appendix 5

Further HIV and AIDS Information
Confirming and Monitoring of HIV

A P24 viral antigen test detects circulating HIV viral proteins which confirm the presence of HIV particles in the blood. This is a definitive test that HIV is active and present. A second investigation and important HIV monitoring tool is the viral load test, which quantifies the amount of circulating HIV virus and again is confirmatory that HIV is present. A viral load test is useful to monitor and gauge the activity of the virus and also the effectiveness of therapy. A CD4 white blood cell count measures the numbers of circulating CD4 cells and falling numbers indicate failure of the immune system and is used to determine when treatment should be commenced. These two specific monitoring tests, with others such as HIV resistance testing and CD8 cell levels are important for managing HIV (Adler 2001a Kennedy 2003). High levels of virus, low CD4 numbers and an increase in CD8 cells, are indicative of poor immune function and require drug intervention to prevent acute or chronic immune collapse and the development of AIDS (Adler 2001a, Kovacs et al 2001, NAM 2008).

Transmission of HIV

For HIV to spread, it must pass into a non-infected individual by infected body fluids or blood to blood contact. The virus is present in blood, seminal fluid and cervico-vaginal fluids and whilst present in saliva is not thought potent enough to cause infection (Adler 2001a, 2001b, Kennedy 2003, NAM 2009, 2010). The main route of viral transmission is sexual intercourse with an infected partner (horizontal transmission) (Kovacs et al 2001). Kovacs et al (2001) and Kennedy (2003) suggest 80% infections are due to penetrative sexual intercourse either vaginal or anal - receptive anal intercourse being more likely to transmit the virus due to the delicate lining of the rectum (NAM 2009). Transmission does not occur at every sexual contact. Kennedy (2003) gives a mean rate of 0.3% (3 per 1000) episodes of contact. However caution is required with this figure as the individual transmission rate varies markedly, due to the level of infectivity of the donor and health with susceptibility of the recipient – particularly other sexually transmitted infections aid transmission (Adler 2001a, 2001b).
Viral transfer rates increase with the amount of virus (viral load), viral strength (virulence) and the duration of exposure to the HIV virus. Individuals with newly acquired infection or symptomatic HIV disease, due to increased viral load, have greater capacity to transmit the virus (Adler 2001a, 2001b, NAM 2010).

The HIV virus may be transferred with blood products, if ineffectively screened or treated - this is rare in Europe today (Adler 2001a, NAM 2008). The Department of Health (1999) attributes 8% of UK HIV infection to sharing injecting equipment for illicit drug use and has developed health improvement strategies to support individuals with illicit drug use and HIV (Lowson et al 2000; NAM 2010). Increased HIV transmission rates have been implicated with sharing nasal snorting equipment in some European cities. Illicit drug use is also implicated in transmission of Hepatitis A, B and C (Adler 2001a 2001b; NAM 2008).
Appendix 6

My Journey within Midwifery and HIV
My Journey within Midwifery and HIV

I have been a midwife since 1988 and a registered nurse since 1985. Throughout my midwifery career I have a strong belief that normality must prevail in childbirth as this has untold benefits for women. As a father, my personal experience of witnessing the process of normal birth with my three sons and acting as the attendant midwife for birth of my youngest son. I have a strong belief that being a male midwife; I must facilitate normal birth and not control the physiological process. However, during the early years of being a midwife, I became increasingly concerned with the raising HIV infection rate and its effect on the childbirth process in inner London. I worked as community midwife and later within caseload midwifery practice in inner London that specialised in an HIV caseload. This gave me a personal experience of caring for women with HIV. They often lived in urban, socially and economically deprived areas in the capital city and most, but not all were of African origin. I often felt their voices were noticeably absent with both the process of diagnosis and living with HIV infection with childbearing. I worked with HIV medicine and obstetric teams with the introduction of universal HIV testing in the locality. However, my concerns remained with the lack of pre-test information. I completed a BSc degree in 1996 and found that midwives supported antenatal testing and my study methodology and findings were used to develop a further study at University of Bristol (Low a et al 1997). In 2006, I undertook Master’s study and found that women supported HIV testing but asked for further information. A number of women had not given valid or any consent prior to testing. This finding alarmed me as I contemplated the effects on women whose HIV result should come back positive.

I am now a consultant midwife; I specialise in emergency care and transfer in London, but retain my specific interest in HIV and childbirth. I am moderately dyslexic and have to work hard with my written skills, but I have been able to produce original academic work and author and co author published papers. The women and local HIV support groups have been extremely supportive and they maintained my commitment to achieve this study for women affected, to give women infected with HIV an opportunity to have “a voice”. I feel women are not given the opportunity to relate this HIV diagnosis experience in the literature and this is my opportunity to be a conduit for them. I have
concerns that women and socially disadvantaged individuals and groups do not have a voice.

My Civil partner is a General Practitioner (GP) and has a special interest in HIV and is a trustee of the National AIDS Trust (NAT) and advisor and governance committee member of the Terrance Higgins Trust (THT). He has a defined HIV caseload in the community which is unusual for HIV practice. We have both seen an evolving HIV care pathway from original palliative and terminal care, to now offering testing to all who will engage with this health benefits message. I have personal experience with close friends, family, colleagues and importantly clients who are infected and living with HIV. I fully acknowledge that this personal experience of individuals exposed to HIV is very powerful on an emotional level. I have, and still see today many individual lives impacted by HIV, with a spectrum of effect on wellbeing both physical and importantly psychological and socially. This spectrum ranges from full acceptance of the diagnosis and living life to the full (sometimes with added risk to life and limb) to withdrawing from everyday life and for some, deep despair with on ongoing anxiety and acute and chronic depression with an HIV diagnosis. I have seen the effects in the early 1990s with very poor outcomes, but fully accept that this is much less today with effective treatment. Death is rarer than in the past but it is important to still accept HIV is causing premature death especially in those with late presentation (HPA Report 2011). Developing “Hope” has played a part as progress with treatment has made real improvement in wellbeing. I have moved and shifted from my original personal belief from questioning what the point is or value of testing as only limited treatment was available to now embracing the health benefits of testing and early diagnosis due to effective treatment. However, I also fully accept the major life changing impact an HIV diagnosis can bring. I have an important proviso that still remains when offering testing and that is, if screening is offered it must be with factual information to gain meaningful consent. Whilst this information must be simple, easy to access and the testing process and information must not be complicated, it must be informative. This personal belief upholds the Nursing and Midwifery council (NMC 2010) standards required of registrant midwives and nurses.
I have concerns with some of the limitations of the testing process and aspects in testing women in an antenatal setting as opposes to others that seek testing and recount the following story.

With verbal consent, one personal friend imparted the following on his recent HIV diagnosis;

“Why delay inevitable bad news, it’s probably better to know long term even if I don’t like it.”

This was a truthful statement from him and when I questioned on his meaning further, he felt that he did not like this diagnosis; simply it was bad news for him as it set him apart from others. However, he felt he could at least now access treatment and take care of himself and others he loved. He was hoping not to be infected with HIV, but felt he gave valid consent for testing and knew the consequences of testing. My concern that still remained during this study was that women undergoing antenatal HIV testing in pregnancy may not be aware of the full impact should the test return positive. Some women may not have their “eyes” open and be aware of the impact of this life changing event. This study explored this life changing impact of a HIV diagnosis during pregnancy and is discussed later in the thesis. I understood the need for sensitivity and have worked hard to develop and maintain this core midwifery skill. This skill was transferred to the research setting but a theoretical framework need further study to fully understand the research requirements.

I passionately want to make a difference to women with HIV in the maternity service and want their voices to be heard. Producing this original research study is demonstrating my commitment to women and midwives. It will try to improve the service that women and their families receive from the NHS whilst undergoing antenatal testing. This has had a major impact on the research design, so that women were heard. I have future plans and an exit strategy as I will have more time availability on completion of this thesis. I have disseminated the study finding at a number of regional workshops and conferences. I will be presenting at a major national conference in June 2013. I intend to use this thesis as a catalyst for improvements in practice and research and importantly work with other national bodies such as NAT as a combined approach.
add strength to improvements and change but ensure HIV positive women have a voice and are not forgotten.
Appendix 7

Copy of Study Participant Information Sheet
Testing HIV positive in Pregnancy: A study of women’s experiences and personal testimony, following a positive Human Immune deficiency Virus (HIV) antibody test result during pregnancy

**Short title: Testing HIV positive in Pregnancy: A study of women’s experiences.**

(Version 2, 26/11/10)

**Participant Information Leaflet**

**Introduction**

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why we are doing this research and what is involved. Please take time to read this leaflet, and if you want to, discuss it with your doctor, midwives, family or friends. Please feel free to ask us if anything is not clear, or if you would like more information.

Thank you for taking the time to read this.

**What are we trying to find out?**

Most women are deciding to have an HIV test in pregnancy. Some of the results come back with a positive result. This research wishes to understand the experience of women who have tested positive to HIV in pregnancy and what women like your self have experienced when they got this result. It is your opportunity to discuss the good and difficult things involved in getting this result whilst you were having a baby. We aim to do this by obtaining the experiences of women like you who have received a positive HIV result whilst pregnant.
Why have I been chosen?

You have been chosen because whilst you were pregnant, you received this HIV result.

Do I have to take part?

It is entirely your choice. If you agree to join the study you will be asked to sign a consent form, and you will be given a copy to keep. You are free to change your mind and withdraw from the study at any time, without giving a reason. The care you receive, now or in the future, will not be affected in any way by your decision whether or not to take part.

What will happen to me if I take part?

You will be asked to complete a short background information questionnaire (approximately ten minutes) and take part in one interview of approximately an hour and thirty minutes or possibly longer, at a time and location convenient to you. You can decide where and when the interview will take place and you can choose the appropriate time and venue for the interview. You will be interviewed by the researcher, a Research Midwife, to discuss your views and experiences. There are no right or wrong answers, we just want to try and understand your experience.

What happens to the information we collect?

Any identifiable data such as name & address will be removed to protect your identity. If you agree the interviews will be tape recorded where possible, and the recordings will be transcribed (word for word) into a written format for analysis by the researcher and research team. Following transcription, tape recordings will be destroyed. The data will be analysed by the researcher and the research team. This transcribed data and any other information will be destroyed after 5 years in line with good research practice.

What are the benefits of taking part?

There is no direct benefit to you of taking part; however the study may benefit future generations of pregnant women who undergo HIV testing in pregnancy. The only material benefit of taking part in the study is that you will be reimbursed local travel expenses at bus fare rates if this has occurred.

What are the risks of taking part?

The interview will gain sensitive information which could potentially induce distress. If distress or any emotional trauma arises during the interview or later, professional support is available. I will also be available for your immediate
support and further professional help will be available with referral to the
maternity services, specialist HIV midwife services or HIV clinic and HIV support
services and HIV user support groups.

What if new information becomes available?

Should any relevant new information come to light your Research Midwife will
tell you about it and discuss whether or not you want to continue in the study.

Complaints

If you have a concern about any aspect of this study, you should ask to speak
to the researchers, who will do their best to answer your questions. If they are
unable to resolve your concern or you wish to make a complaint regarding the
study, please contact a University Research Practice and Governance
Coordinator on 0161 275 7583 or 0161 275 8093, or by e-mail to
researchgovernance@manchester.ac.uk

Will my taking part in this study be kept confidential?

All information collected about you during the course of this study will be kept
strictly confidential and locked in a secure setting at (name removed) Hospital
as a collaborative site. Identifiable information will be stored separately from the
research data with only the researcher (myself) having full access, to protect
your identity. The research team will only have access to research data. Any
information about you that we wish to use in publications about the study,
including direct quotations, will be referred to using a pseudonym (false name),
so that you cannot be identified. Any information about you that leaves the
hospital or university will have your name and address deleted, so that you
cannot be recognised by it. This includes data that are transmitted
electronically. All information will remain confidential, unless disclosure is
essential to protect you or others from the risk of significant harm, or disclosure
is required by law or by order of a court. If during the interview information is
disclosed regarding the safety of others, such as children, evidence of abuse or
harm, the researcher would be bound by professional standards to report the
incident to the appropriate authorities. Should further studies be planned related
to you and your involvement in this study, we will contact you to seek your
permission.

What will happen to the results of the research study?

The study results and findings will be written up as an article for publication in a
scientific journal and may be presented at conferences. Your individual results
will not be available. Please contact Andrew.Stallard@manchester.ac.uk or
aplingenstallard@aol.co.uk for a copy of the final study results. The study’s
results with recommendations will be presented as a PhD thesis at University of
Manchester.
Who is organising this research?

This research study is being sponsored by The University of Manchester. NHS Collaborative NHS sites include (name removed) Hospital Foundation Trust, (name removed) Foundation Trust and the (name removed) Hospital Foundation Trust. The hospital and other clinicians/research staff do not receive any payment if you take part in this project. I also have a research contract from (name removed) Hospital Foundation Trust.

Who has reviewed this study?

This study has been reviewed by National Research Ethics Committee (NREC) and meets the standards of research governance. The University of Manchester as sponsor has also reviewed this study.

Thank you for your time

Contact for further information:

Researcher / Research Midwife: Andrew Lingen-Stallard
07703 278952
Andrew.Stallard@manchester.ac.uk or

pregnancyexperiences@gmail.com

Professor of Midwifery: Tina Lavender
0161 306 7744
Tina.Lavender@manchester.ac.uk
Appendix 8

Copy of HIV Study Consent Form
HIV Positive: A study of women’s experiences and personal testimony, following a positive Human Immune Deficiency Virus (HIV) antibody test result during pregnancy. Consent Form (Version 1, 26/01/10)

(NB Hospital Logo will change as required with participating NHS Sites)
Centre Number:
Study Number:
Patient Identification Number for this study:

**CONSENT FORM**

**Testing HIV positive in Pregnancy: A study of women’s experiences.**

Name of Researcher: Andrew Lingen-Stallard

<p>| | | | | | | | |</p>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>I confirm that I have read and understand the information sheet dated 25 January 2010 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</td>
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<td>2.</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.</td>
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<td>3.</td>
<td>I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.</td>
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<td>4.</td>
<td>I agree to the use of tape recording of my conversation during interview</td>
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<td>5.</td>
<td>I agree to having quotations published using a false name (pseudonym).</td>
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<td>6.</td>
<td>I agree to take part in the above study.</td>
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</tbody>
</table>

Name of Patient Date Signature

Researcher Date Signature

When completed, 1 for patient; 1 for researcher site file; store, locked and separate from demographic sheet

330
Appendix 9

Copy of Study Demographic Sheet
Testing HIV positive in Pregnancy: A study of women’s experiences

(Version 1, 25/01/10)

The demographic information sheet

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Address</td>
</tr>
<tr>
<td>Telephone Contact number</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Study number</td>
</tr>
</tbody>
</table>
Chosen Pseudonym (False Name)

Eligibility Checked

Obstetric history

Pregnancy outcome after HIV diagnosis

<table>
<thead>
<tr>
<th>Age at Diagnosis</th>
<th>Age Now</th>
</tr>
</thead>
</table>

Highest Educational Award

Brief Career History

Other info

Support at Home

NB- Eligibility criteria will be re checked at the initial discussion and prior to interview. Store separate locked cabinet from all other study information

Field Notes
Appendix 10

Copy of Semi Structured Interview Schedule for NREC
Testing HIV positive in Pregnancy: A study of women’s experiences and personal testimony, following a positive Human Immune deficiency Virus (HIV) antibody test result during pregnancy.

Interview Schedule Prompt Sheet (Version 1, 25/01/10)

Study Title:
Testing HIV positive in Pregnancy: A study of women’s experiences.

Introduction
The research facilitator will thank the participant for attending and attempt to make them feel as relaxed as possible.

Setting of ground rules

- Explain study
- Explain that matters discussed will not affect future care
- Explain tape recording and transcription
- Explain unique study number (confidentiality)
- Explain use of pseudonyms (anonymity)
- Explain can stop the interview at any time
- Explain that the interview is intended to take no longer than one and half hours
- Explain can refuse to answer a question
- Give opportunity to ask questions
- Check consent
Questions

1. What did you know about HIV or AIDS before testing was raised in your pregnancy?

2. Did you receive any pre test information before the test?

3. Before the test were you able to discuss HIV testing with family, friends or your partner?

4. Did the person taking blood tell you the benefits of testing?

5. Did the person taking blood tell you the test could come back positive?

6. What was it like waiting for the result?

7. Did anybody go with you?

8. Any concerns something may be not right?

9. Who told you that you were HIV positive?

10. Did you understand what was being said?

11. Were you expecting this positive result?

12. What support were you offered or given?

13. Did you tell anyone?

14. After the result, how did you feel about your pregnancy?

15. Waiting for the baby’s HIV results?
16. Explore – your partner reaction to result?

17. Could this experience have been done different or changed?

18. After this experience would you encourage other women to test for HIV in pregnancy?

Prompts to encourage depth

- In what way?
- What was it like?
- How did you feel?
- Can you explain that to me further?
- Why do you think that?
- What does it mean to you?
- Can you say any more about that?

FOLLOWING THE INTERVIEW

The researcher will advise the participant that a summary of the findings will be available to them at the end of the study.

Arrange further support if required

Clarify any outstanding issues

The researcher will thank the participant for their time.
Appendix 11

Copy of Poster
Diagnosed HIV positive during Pregnancy?

Would you like to tell your story of this experience in confidence? If you are interested and would like further information

Contact

Andrew Stallard (Research Midwife) on Mobile/text 07703 278952 or email Andrew.Stallard@manchester.ac.uk or pregnancyexperiences@gmail.com
Appendix 12

Copy of Advertisement
Features

Issue: 143

Volunteers needed in researching the experience of testing HIV+ in pregnancy

Most women are deciding to have an HIV test in pregnancy and the rates of HIV testing have increased since universal antenatal HIV screening was introduced in 1999. As more women test, some results come back positive.

This research wishes to understand this experience of women who have tested positive for HIV in pregnancy. This research gives, for the first time, women the opportunity to discuss the impact of getting this result during pregnancy.

This will be done by an interview lasting about 1-half to 2 hours long, in a suitable location anywhere in UK. The interview will be tape recorded but will remain confidential and volunteers will remain entirely anonymous.

Nance Stollard is a Consultant midwife and studying for a PhD and has many years experience as a midwife with a specific interest in HIV in pregnancy and he will conduct the interviews.

The research has NHS Ethical and Research and Development approval and is sponsored by the University of Manchester under Professor Tina Lavender and hosted by Kings College Foundation Trust in London.

The findings of the research will be available and published in research journals, but it is hoped that if enough women volunteer to tell their powerful story, a book will be published at a later date.

For an informal chat in strict confidence text or ring Andrew on 07763 279853 or contact the following email:

pregnancyexperiences@gmail.com

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Appendix 13

Copy of Favourable National Research Ethics Service (NRES) Opinion
13 December 2010

Mr Andrew Lingen-Stallard
Consultant Midwife
London Ambulance Service NHS Trust
HQ 220 Waterloo Road
London
SE1 8WA

Dear Mr Lingen-Stallard

Full title of study: Testing HIV positive in Pregnancy: A study of women’s experiences and personal testimony, following a positive Human Immune Deficiency Virus (HIV) antibody test result during pregnancy (Protocol. 1 April 2010 Version 1)

REC reference number: 10/H1010/60

Thank you for your letter of 26 November 2010, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair (Professor Ravi Gulati – Consultant Physician) and Professor Caroline Carlisle (Visiting Professor to the Department of General Practice and Primary Care – The University of Glasgow).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
Management permission ("R&D approval") should be sought from all NHS organisation(s) involved in the study in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System (IRAS) or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter: From Professor Tina Lavender, The University of Manchester</td>
<td></td>
<td>13 October 2010</td>
</tr>
<tr>
<td>REC application</td>
<td>3.0</td>
<td>13 October 2010</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>01 April 2010</td>
</tr>
<tr>
<td>Investigator CV: Mr Andrew Philip Lingen-Stallard</td>
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<td></td>
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<tr>
<td>Investigator CV: Professor Tina Lavender</td>
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<tr>
<td>Participant Consent Form</td>
<td>1</td>
<td>26 January 2010</td>
</tr>
<tr>
<td>The demographic information sheet</td>
<td>1</td>
<td>25 January 2010</td>
</tr>
<tr>
<td>Interview Schedule</td>
<td>1</td>
<td>25 January 2010</td>
</tr>
<tr>
<td>Advertisement: Poster, calling card and advert text</td>
<td>1</td>
<td>25 January 2010</td>
</tr>
<tr>
<td>Letter from Sponsor: From Mohammed Zubair, The University of Manchester</td>
<td></td>
<td>14 October 2010</td>
</tr>
<tr>
<td>Response to Request for Further Information: From Mr Andrew Lingen-Stallard</td>
<td></td>
<td>26 November 2010</td>
</tr>
<tr>
<td>Participant Information Sheet: with tracked changes</td>
<td>1</td>
<td>25 January 2010</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>2</td>
<td>26 November 2010</td>
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</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views
known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email:-

referencegroup@nres.npsa.nhs.uk

10/H1010/60 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

[Signature]

P.P. Professor Ravi S Gulati
Chair

Email: noel.graham@northwest.nhs.uk

Enclosures: “After ethical review – guidance for researchers”
Appendix 14

Copy of letter from RD-Recruitment Site
Mr Andrew Lingen-Stallard  
Consultant Midwife  
London Ambulance Service NHS Trust  
HQ 220 Waterloo Road  
London SE1 8WA  

26th April 2011  

Dear Andrew  

**Title:** Testing HIV positive in Pregnancy: A study of women’s experiences and personal testimony, following a positive Human Immune deficiency Virus (HIV) antibody test result during pregnancy  

In accordance with the Department of Health’s Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.  

- **Ethics Number:** 10/H1010/060  
- **Sponsor:** University of Manchester  
- **Funder:** No funding  
- **End Date:** 06/06/2012  
- **Site:** Patient identification site at  
- **R&D Approval Date:** 26th April 2011  

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion letter dated 13th December. I am pleased to inform you that we are approving the work to proceed within HS Foundation Trust and that the study has been allocated the Trust R&D registration number **RJ111/N127**. Please quote the R&D registration number in any communications with the R&D Department regarding your project.  

**Conditions of Approval:**  
- The principal investigator must ensure that the recruitment figures are reported.  
- The principal investigator must notify R&D of the actual end date of the project.  
- R&D must be notified of any changes to the protocol prior to implementation.  
- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.  
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.
Data Protection:
Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:


If appropriate it is recommended that you register with the Current Controlled Trials website; http://isrctn.org/

Amendments:
Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Annual Progress Report:
It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please submit a copy of the progress report on the anniversary of the Ethics favourable opinion (13th December)

Should you require any further information please do not hesitate to contact us.

Thank you for registering your research project.

Yours sincerely

[Signature]

Karen Ignatian
R&D Governance Manager
Appendix 15

Copy of Letter re Progress Report to NRES
20 January 2012

Mr Andrew Lingen-Stallard
36 Romola Road
Tulse Hill
London SE24 9AZ

Dear Mr Lingen-Stallard

Study title: Testing HIV positive in Pregnancy: A study of women’s experiences and personal testimony, following a positive Human Immune Deficiency Virus (HIV) antibody test result during pregnancy (Protocol. 1 April 2010 Version 1)

REC reference: 10/H1010/60

Thank you for sending the progress report for the above study dated 02 January 2012. The report will be reviewed by the Chair of the Research Ethics Committee, and I will let you know if any further information is requested.

The favourable ethical opinion for the study continues to apply for the duration of the research as described in the application and protocol agreed by the REC, taking account of any substantial amendments.

10/H1010/60: Please quote this number on all correspondence

Yours sincerely

Noel Graham
Committee Co-ordinator

E-mail: noel.graham@northwest.nhs.uk

A Research Ethics Committee established by the Health Research Authority
Appendix 17

Further Details of Study Analysis Process
Further Detail of Study Analysis Process

It is essential that rigour is embedded throughout the research process and I have attempted to achieve this whilst conducting this research. Morse (1991) maintains it is important to choose a methodology that suits the study aim. It was also essential to consider methods of analysis specifically suited to the hermeneutic Heideggarian philosophy of this study. Hermeneutic phenomenology aims to transform lived experience into a textual expression of its essence (van Manen 1990).

Humans express their experiences in language and consciousness and it is through language that understanding is achieved. Gadamer (1989) believes human thought and human language are inexorably bound together with language a central concept for hermeneutics. Spoken language is translated into verbatim text and the act of reading and importantly understanding the text is interpretive in itself. It was a requirement that the analysis was sympathetic to this important stance. However, very little in guidance is offered relating to analysis by hermeneutic phenomenology. However, this study required a hermeneutic phenomenological approach to data analysis and thematic analysis of the interview data was guided by van Manen (1990).

It is important to explain that van Manen (1990) provides a guide to interpretation, not a step by step method as simply this is in keeping with the very nature of phenomenology. I will explain what I did in following this guidance. I noted that a number of prescriptive methods are ascribed to phenomenological analysis but was open to valid criticism (see 3.1.3.3 & 3.2.15) and in my view, reductionist and inappropriate with the rich data in this study.

Central to van Manen’s (1990) approach to analysis is phenomenological, hermeneutic reflection to gain understanding and an insight and into the essence of a phenomenon. This involves “a process of reflectively appropriating, clarifying and making explicit the structure of meaning of the lived experience” (van Manen 1990: 77). He details three ways or approaches of achieving this:

Firstly, a “wholistic [sic] approach”, considering the text as a whole (van Manen 1990: 92).
**Action Taken**

1) I read the transcribed text as a whole to get a feeling for what was being said and the believability of the text. I undertook this twice, listening to the digital recording, listening to the participant’s voice, the dialect, pronunciation, tone, emotion, and checking the text matched the spoken words ensured accuracy and I reviewed the field notes. This “immersed” me in the spoken narrative and the written text.

2) I read the text whole again but without the tape running to immerse myself in the written text and got a “feel” for the data. This was repeated several times during the analysis process.

**Outcome**

Verbatim transcripts were vital and much of the essence of the data was only observable from reading the whole of the document. Frequently participants returned to an issue or incident, which they discussed earlier and the thread of an idea was sometimes only clear when reading the whole text, but when concentrating on a single sentences or a clusters of sentences this would sometimes be lost.

**Secondly**, a “selective approach”, highlighting statements that appears to be significant or revealing in the text (van Manen 1990: 92).

**Action Taken**

1) On the transcripts I marked and highlighted significant statements within the text from the narrative of each interview.

**Outcome**

Significant or revealing statements were drawn out of the text by following van Manen’s (1990) selective approach. Key concepts were revealed from the significant statements which contributed to the thematic analysis. Certain sentences or clusters of sentences stood out clearly within the text. Differing participants would sometimes use the same phrase or metaphor to describe idea, feeling or a situation, which increased the
significance. Other pertinent phrases in the text revealed themselves or sometimes provided the distillation of an idea into one sentence or phrase.

**Thirdly,** a “detailed approach”, considering every sentence or sentence cluster in detail (van Manen 1990: 92).

**Action Taken**

1) I highlighted each sentence or sentence cluster in detail within the text from the narrative using a yellow pen.

**Outcome**

Reading each line in detail helped to determine and reveal the meaning of what was being said. In isolation and together, significant sentences were read with the whole text in order to discover meaning. This emphasis and the language used was often a focus as some issues had been missed in the overall reading of the transcript. This very detailed approach aided further understanding of the text.

In order to analyse the texts, a combination of the three approaches was utilized. It was important that analysis was approached in this systematic way to ensure consistency. Manual coding used recurring specific words or topics from the data and an example is unpreparedness and shock (see example below). Key themes emerge from the text and need to be ordered, which is a complex, iterative and creative process (Carter 2004). This was a dynamic and cyclical process and for simplicity, I wrote emerging key statement/themes in circles with lines to text on the narrative document (see below) and later transferred the *preliminary basic themes* on yellow postage notes. *Later secondary themes* that emerged with analysis were also written on the document and transferred on pink postage notes. Themes or statements that were thought significant were recorded in red as this aided reflection and thematic development. They were then later grouped under the four (paired) *major themes* that emerged from further cyclical data analysis. This helped with the later formulation of the thematic diagrams for each of the four main paired themes which is exemplified in the main thesis (see Diagrams figures 5-8-Themes 1-4). The focus remained the meaning and essence of the narrative experience and over arching phenomenen. The phenomenon of transition and transformation emerged with the cyclical data analysis of narrative data and thematic development. Field notes were important in the development of the themes as reoccurring information
and key words were often recorded. My reflective journal was also important in this process (see next section).

My supervisory team ensued I followed this process and detailed discussion of the groups and themes took place to ensure I was interpreting the written narrative data in a non biased way and we explored my prejudices as the data sometimes revealed some thought provoking themes.

Van Manen (1990) specifically does not discuss the hermeneutic circle; he does describe the circular process of moving between the parts and the whole. The circle is a key concept to both Heidegger’s and Gadamer’s philosophies with interpretation and the hermeneutic circle was employed in considering the whole and the parts of the data. It was necessary to move from the whole text to parts of the text and back again in order to gain understanding in a cyclical, dynamic process. I also considered other interpretations of the circle, such as moving between culture and context, and between the cultures of the participant and the researcher (Leonard 1989). These additional interpretations were appropriate to analysis as the participants were of African origin. There was in effect more than one circle occurring simultaneously during analysis of the data. Using the approach suggested by van Manen (1990) and the hermeneutic circle, was important in revealing and exploring themes and the overarching phenomenon of transition and transformation as phenomena are multi-dimensional (van Manen 1990).

Van Manen (1990) maintains the act of writing is central to reflection in the analysis process. Writing and re-writing is a circular process in itself, ideas and thoughts around understanding and interpretation begin to be formed. They were returned to, reflected upon and then with subsequent re-formulation gain more depth. This re-writing is referred to by van Manen as a complex process of “re-thinking, re-reflecting and re-recognizing” (1990: 131). Van Manen (1990) maintains writing can create distance and from this distance we can reflect and contemplate the subjectiveness of daily existence, i.e. decontextualise, but this can return us more closely to the phenomena under investigation. Writing and re-writing aided my reflection on the written text and the questions posed within it. Essence and the phenomena were essential to the study. Throughout analysis, writing was used to maintain and gain a depth of understanding.
Reviews of my written reflexive research diary throughout analysis were important. It helped to me return to and further develop my evolving thought processes. Developing themes and emergent questions from this source were recorded. This in turn helped to interrogate the data further and contributed to this cyclical and dynamic process. Meaning and essence, themes with the overarching phenomena of the experience emerged from the data and writing and re-writing helped to develop them from brief notes into a rich text of interpretive understanding (van Manen 1990). Analysis allowed comparison and triangulation of data from all the sources and texts were considered;

A) Individually from participants
B) Jointly with data from the same setting,
   Unit A Participants,
   Unit B Participants
   Other NHS sites Participants
   Non NHS Participants
C) Finally data from all settings.

This allowed me to explore both the differences and commonalities. Discussions with my supervisors enabled a consensus to be reached for the themes, essence and meaning and the emergent phenomena the focus of this study. The final stage was a “critical synthesis” of the findings (Langdridge 2007: 140). This critique and synthesis requires that study findings are related clearly to the narrative, themes and importantly the reflexivity of the researcher. This was explored and discussed in depth on many occasions with my supervisors. The impact of email and electronic face time talking has evolved considerably and was used with the process of data analysis. I have attempted to provide a clear description of the way in which I approached analysis. It is important to note that although analysis may be replicable with the steps I have taken; it is unlikely the findings will be so. This is relevant with any interpretive phenomenological study including this one, firstly; the data collection is both time and contextually situated and secondly, different researchers will undoubtedly bring their own, very different, pre-conceptions, experiences and theoretical stances to the data (Sandelowski 1993). Van Manen (1990) accepts that trying to understand meaning in any text is one of subjectivity and judgement. It was always going to be a personal but subjective process; however reflexivity with self awareness and challenging personal bias had an
impact. However, someone else’s interpretation will be different from mine. Therefore my interpretation and analysis of the study findings is unique (van Manen 1990). To give a flavour of analysis two examples have been selected from the transcript narrative data of Jane and Beauty.

**Line by line Analysis – Jane-Interview 7- first emergent statements and themes**

ALS: Did anybody say to you there are benefits of this test, did they say there are health benefits for you and your baby or did you just know it?

Jane: Nobody told me about the benefits or the side effects of the test or anything. It was when the results came out that I was invited by the midwife to the hospital, so when I went to meet the midwife she told me that all my tests were all good except one

ALS: so this is on the day that you came to have your result

Jane: yes

ALS: so did they ring you, did they ring to say could you come in we need to discuss something with you?

Jane: No, they ring me that I should come for errm an antenatal check

ALS: oh ok. Did that raise any suspicions?

Jane: no, not really no

ALS: you thought it was just a normal….

Jane: yeah

ALS: yeah. So you got the phone call and you come along for the routine antenatal test. And what happened, can you tell me your story what happened about how they told you, can you remember it?

Jane: Yeah, errm I’ve forgotten the midwives name, I used to remember but when I came in she called me, she gave me a cup of tea and she said let’s talk about your pregnancy and the results you went through, so she told me all the results were good except one, I was like which one. Then she scrolled down the computer

ALS: she scrolled down the computer?

Jane: yeah and she showed me all the results and then told me that my HIV results came out positive, I was shocked. I didn’t expect it, she did not counsel me, like tell me, back home then, when I joined the ante HIV group they had to counsel someone they have to tell the person, but you want to hit at something, you want to hit something on the nail but you don’t just go directly to tell the person…. 

**No Suspicion raised by call**

**Benefits not explained /aware after positive result**

**Midwife initial prep to tell**

**Told directly**

**Told directly**

**Result Unexpected**

**Not prepared/not counselling**

**Questioned which test a problem**

**Issues with told directly**
ALS: to tell them in a round about way? you are saying in your home, in Nigeria that’s the programme that you do that?

Jane: yeah

ALS: but she just told you outright?

Jane: yes she told me….

ALS: How did you feel, what was your feeling at that point?

Jane: I was so cold, I was shocked, I didn’t believe it

ALS: yeah, yeah

Jane: Tears rolled down my cheeks, I didn’t believe it and when you’re telling someone something and if you said that maybe there is a solution to it but then I know that was, they said it and it didn’t feel like a nice thing, it’s death

ALS: so you equated the HIV diagnosis with death, is that what you’re saying?

Jane: yeah that is what I believed, back home the medication wasn’t there and not knowing that here it’s a different ball game

ALS: would that have helped if that had been told to you before you had the test?

Jane: it would have helped if she had told me stories about like she has a friend or anybody who is sick, you know for me not to really understand where she is going to, it would have helped, it wouldn’t have been as bad as it was then

ALS: Did the midwife not tell you that the test could come back positive did they say anything to you

Jane: no

ALS: so they didn’t really say to you that you know there is a chance like anybody that you could come back with a positive result

Jane: no
Line by line Analysis – Interview 9- Beauty -first emerging statements and themes

ALS: but then you decided to terminate that pregnancy

BEAUTY: no I didn’t know result then, after I terminated the pregnancy

ALS: tell me a bit more

BEAUTY: the pregnancy was meant to be kept

ALS: oh all right

BEAUTY: the relationship was just a violent one and I was just…

ALS: and that was your reason

BEAUTY: I terminated, so when they told me about it, they keep calling me, I keep ignoring them because they wouldn’t tell me the values over the phone

ALS: aaahh

BEAUTY: I say no way, I’m not coming and they say oh it’s for your own good, it has something to do with it, it has nothing to do with the pregnancy, the pregnancy is aborted but you just have to come we can’t share the news over the phone

ALS: so did that raise any suspicions with you that…..

BEAUTY: it raised suspicions but not that kind of thing, maybe like diabetes, not that

ALS: so you thought it was something else but you never, never…..

BEAUTY: yes so I went to the hospital and I was told by a nurse

ALS: so when you went for the HIV test did anybody tell you the benefits of that test, did anybody say to you, you know, Beauty this is a really good test to have or did they just take your blood

BEAUTY: as I was told you earlier it was a routine test to do with antenatal, the midwife didn’t say anything she just said oh we have to this and I take so it wasn’t like personally went for HIV test

ALS: so no one went with you

BEAUTY: no I just went by myself to see the midwife

ALS: so there you are you got this call and they keep badgering you now saying come back, come back and you know you’re saying well no I don’t really want to come back, what made you decide to come back then

ALS: a wanted baby/Termination

Violence reason for termination not HIV

Ignored calls & refused to come in

Face to face meeting required for HIV result

Routine-takes test –not a proactive choice

Lack of info-
Benefits not explored

“That” =HIV

Suspicions but not HIV

Suspicion but not HIV

[Diagram showing the flow of issues discussed]
BEAUTY: oh well the call was persistent and it was worrying when they keep saying it has something to do with your health and I say health so maybe it’s like other sexual disease, like gonoreha or syphilis or diabetes or something like that, HIV would be the least of the things that comes to my mind so I didn’t, so I just went there and you know.

ALS: so you were quite relaxed?

BEAUTY: yeah but I was a bit worried when I got to the eighth floor and they took my things and they were working to enquire about me I was a bit panicked I said God what the hell are they doing

ALS: so you picked up the little vibes there that something was not quite right

BEAUTY: yeah cause there was no smiling face and you know, you ok, you ok, I know that something is going, something is bad

ALS: how did you feel about that?

BEAUTY: even though I was worried there’s bad news I didn’t think of that, I didn’t know why, I didn’t think about that

ALS: now let’s take you back to the time that they actually told you, there you are in this room, how did they break the new to you, how did they tell you

BEAUTY: to be honest they did it in a professional way because I work with......

ALS: they did it in a professional or unprofessional way

BEAUTY: no it was professional cause I work in, with a lot of different health professionals and I know when to break bad news they did it in a professional way

ALS: yeah tell me more

BEAUTY: they saying you remember you took some ante natal checks things down throughout your pregnancy even though your pregnancy was aborted but this is what we found out in your blood

ALS: yeah

BEAUTY: you are HIV positive and I said no, that’s not true and they should do it again

ALS: so you didn’t believe

BEAUTY: no, I think it’s as though I am dreaming, I didn’t believe it I thought it was a dream, so I keep asking them no and I keep crying later I didn’t cry initially but it didn’t sink in properly, and so shocked I keep, and even after many years now I keep thinking, they way the news was broken to me I think about it
ALS: so it plays on you it keeps coming back

BEAUTY: it keeps coming back, I was sitting down, I was staring at the window, it was so it was a bad day

Field notes = Explored and offered referral but resolutely declined offer- “I deal with it”= coping but? Not sure dealing with issue but she has recently raised with support group and given info

Bad day =a traumatic experience= experience relived
? Post traumatic stress

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Appendix 17

Copy of Full Transcript from “Interview 5”
   Martha
INTERVIEW WITH MARTHA

ALS: How are you today?

MARTHA: I’m fine thank you

ALS: and your health?

MARTHA: very well

ALS: oh good

MARTHA: yes

ALS: and it’s been some time since you’ve diagnosed hasn’t it?

MARTHA: yes

ALS: when was that?

MARTHA: I was diagnosed in 1999 September to be precise

ALS: let’s look back, if you look back before you had the test, what did you know about HIV and AIDS?

MARTHA: not much, errm just what I know is that if you were HIV positive that you will definitely will die (baby crying)

ALS: (baby crying) so, if you’ve got HIV you will die

MARTHA: yes

ALS: so did that scare you?

MARTHA: yes it did (baby crying) …..that’s why I had the test done during my pregnancy

ALS: that information about you know you could die did you get that from your home country?

MARTHA: yes it was from my home country

ALS: yeah, yeah. How did that, where did it come, where did you get the information that you wouldn’t necessarily die from HIV?

MARTHA: here, errm when I got my diagnosis, the first thing that went through my mind was what would happen to me and the baby and errm so it’s quite helpful that things have changed since the HIV was discovered and people do live on medication and you could have a healthy baby
ALS: so re-capping on that, that was the information that you got after you got the results

MARTHA: yes, after I got the results

ALS: would it have been helpful to have got that information before?

MARTHA: before, it would have been really helpful, it would have been really helpful

ALS: yeah, did you receive any, before you actually went for the test did you receive any information about HIV?

MARTHA: No

ALS: Any written, no other information?

MARTHA: no

ALS: did the midwives raised the issue of testing with you

MARTHA: yes they just said they were blood testing tests and they asked for my permission to do the HIV test and I said yes I would like to have it done but no information was given to me about the HIV

ALS: did they raise with you about the benefits of having the test

MARTHA: yes they said erm well it wasn’t just for the HIV one they had other tests I think they did hepatitis and syphilis and all those ones and they said basically it’s for the baby to have a healthy child and things like that

ALS: so they explained

MARTHA: yes

ALS: that it was good for the baby

MARTHA: yes

ALS: did they explain that it was good for you

MARTHA: it was more about having a healthy baby yeah it was more it wasn’t about me I think

ALS: how does it feel, about you?

MARTHA: err not bad because I was thinking more about the baby

ALS: when looking at that, you were thinking that you know this is sort of for having a healthy baby
MARTHA: yes

ALS: did you talk about the HIV test with your partner?

MARTHA: yes I did, he didn’t want me to take it

ALS: he didn’t want you to

MARTHA: no he said oh we’re fine, I said well even if we are fine just to be on the safe side, just to know anyway because I really wanted to know because I had a test done in 97 I had ovarian cysts and I lost a lot of blood so I was given a blood transfusion because the rest of my family had it I had the same blood type as my dad, he’s dead, the rest of my sisters and brothers have my mum’s blood so no one could give me so we had to buy blood

ALS: so was that in your home country

MARTHA: it was in my own country, so I was a bit scared but that was at the back of my mind when I

ALS: you saw that as a risk

MARTHA: yes I did, yes I did

ALS: and could you, did you explain that to your partner?

MARTHA: yes I did, because I had the blood transfusion and the way the testing was done, they were not testing that blood then as they would have been doing now so there was always a small risk involved

ALS: and when you had that, when the issue was raised about testing did they tell you that it could come back positive?

MARTHA: no they didn’t

ALS: no

MARTHA: no

ALS: what do you think about that?

MARTHA: well I think I would have been more prepared, because what they told me was that it’s just a routine test everything would be alright things like that so I wasn’t prepared for the results

ALS: so was that about someone trying to reassure you do you think, let you know that you were going to be alright
MARTHA: probably, yeah maybe that also made me really want to have the test done and everything will be alright just have it done yes

ALS: then you went for the test, did you have any suspicions that it might come back positive or did you just think it was going to be ok

MARTHA: I thought it was going to be ok because I’ve been really well I’m not the kind of person that falls ill, you know when everyone is falling around me things like that I never fall sick. I had a test done before my surgery that was in 97 just to know my blood type and see if I have any kind of blood disorders?

ALS: disorders?

MARTHA: yes but

ALS: but they came back ok

MARTHA: yeah, they came back ok so I didn’t have any doubts about the test coming back positive or negative I just thought oh

ALS: so what was it like waiting for the result?

MARTHA: it was scary, because they said that it would take, two months no four weeks and after the fourth week I had all the results, I think they posted the results to my place but they didn’t say anything about the HIV at all

ALS: oh so you had the blood results posted

MARTHA: yeah, yeah

ALS: but there was nothing about HIV in there?

MARTHA: no, no

ALS: ok, so how did you get, did you get a phone call

MARTHA: yes I got a phone call from I think from one of the midwives or one of the nurses in the hospital that there was a problem with one of my results if I can come in so I can have a discussion with me about the results, so I panicked, I started panicking from there and I kept asking is it the HIV one cause I can’t deal with the results and the lady said no there are more results that we need to discuss not just the HIV one

ALS: so you got this phone call which raised your suspicion, it made you panic

MARTHA: panic, I was panicking

ALS: how long did you have to wait for them?

MARTHA: a week
ALS: you had to wait another week for them
MARTHA: week before I went into to meet with
ALS: and how were you feeling at that point?
MARTHA: I was almost making myself ill with panic
ALS: did you talk to your partner about that?
MARTHA: I did and he said oh everything is fine, it’s just routine
ALS: yeah
MARTHA: yeah
ALS: so he was sure
MARTHA: he was really sure
ALS: not worried
MARTHA: no
ALS: did anybody go with you?
MARTHA: no
ALS: so you went on your own
MARTHA: I went on my own yeah
ALS: would you have liked someone to go with you?
MARTHA: I would have loved my partner to be there but he was working
ALS: so you talk about the concerns that something might not be right
MARTHA: yes
ALS: how did that make you feel at that point when you talk about the panic and the concerns what was the actual feeling like was it just, can you explain that at all
MARTHA: I was waking up in cold sweats during the night
ALS: this is waiting for the results
MARTHA: yes waking up and having nightmares, I was dying in my dreams, so I was thinking of the child and it was just awful
ALS: You were thinking about your pregnancy and the effects it would have?

MARTHA: yes, because I was four to eight weeks into my pregnancy so I was thinking is it because I’m HIV positive, is it already killing the baby, should I go and find an abortion now just to save myself all that hassle there were all sorts of things going through my mind

ALS: so it was it was a real turn off point

MARTHA: it was, it was, it was dreadful and no matter how I raised it with my partner he kept saying oh you worry too much, it’s going to be alright but that’s not what I wanted to hear

ALS: so you had it in your brain something in your head that something wasn’t quite right.

MARTHA: Yeah, yeah

ALS: Going back to the day that you came in you were on your own which you have already said

MARTHA: I did, I came in on my own

ALS: you were all by yourself who told you that you were positive?

MARTHA: I think there were two people in the room I think one was a midwife I can’t remember but there were two people in the room and they talked about my tests and they said well, one of the tests was an HIV test and I’m afraid that the results have come back positive and I just started crying from there and errm and I asked so what’s going to happen to the baby so they explained that the baby could still go on to have a healthy baby and that I do need to go on to medication as soon as possible my blood could be down when the baby comes and the information was so much overload of information and immediately I was moved to the (name removed) Centre, it was just too much.

ALS: so you had a lot of information, you had this result that you might have been suspecting, what was it like, what was it like at that point when they told you?

MARTHA: I could have died I’d been saved, everything just, I lost the will to live basically I didn’t want to continue the only thing that pulled me out it was when they said you can still go on and have a healthy baby, people live longer

ALS: oh so that’s interesting so someone told you it was like a piece of information

MARTHA: yes it just made me stop thinking of myself and it was just, because initially I was thinking there is no need the child will come out and be sick and probably die before me and things like that but when they said you can have a healthy baby HIV free completely ok that’s a positive side

ALS: the question that makes me raise then is would that have helped if that information had been given to you before?
MARTHA: before yes that would have been really helpful although you worry there’s no way you can worry about your health but that information would make you sleep a lot better

ALS: yeah so if you’d been worrying about the test you were told actually this diagnosis is not going to kill you, we can treat you and care for you

MARTHA: at the point of testing they said we do have healthy babies even if you are HIV positive but they didn’t stress the fact that if you do this, this and this I just saw it as assurance because they wanted me to have the test done or something like that, so if they had emphasised that look if the result is positive it is not the end and the child will be fine so you wouldn’t worry too much about the results I think.

ALS: it leads to another question, so did you understand what was being said to you when they told you that you were positive

MARTHA: no I didn’t understand I was like how, why, why I had to like did you know that you were positive, no I didn’t I wouldn’t have had the test done I would have just said how many partners have you had and have you had a test done before, you do need to let your partner know, so it was just too much, everything was just coming round and I was just in tears basically

ALS: cause you know that you said that you had the suspicion that it could come back because the way it was raised before

MARTHA: yeah

ALS: but you weren’t really expecting a positive result

MARTHA: no I wasn’t expecting a positive result. I am an optimistic person so I never see the down side of things I always, although I could, realistically I think it could be positive but when I got to hospital it was positive

ALS: so you got this inkling that something was wrong because of the process of you being informed, called back

MARTHA: yes, yes

ALS: but you still

MARTHA: yeah, the lady it wasn’t the HIV, because they said there were other tests that they had to discuss, yeah so maybe the HIV, because all my partner said was you know the HIV test takes a lot longer than the other ones so I don’t why you worry too much so I just said maybe the HIV ones they wanted to talk about, a different test that sort of thing

ALS: so you talked about you went to the (Centre name removed). What immediate support was given and what support
MARTHA: I met a counsellor that was really nice, just talked more about what’s going to happen from there on I will not be seeing the hospital again, I will be seen there I will have a doctor to check my final blood and try to explain the whole process and asked if I needed to call anybody and I said yes my husband, he would have to know, so I called him that he should come up and I didn’t tell him

ALS: so you didn’t tell him about the result

MARTHA: yes, he would probably need to come or something

ALS: so you had the strength of mind to say I need you to come to the hospital

MARTHA: yes I said, listen can you come to the hospital and he’s like is everything alright and I said yes everything is fine just come and pick me up or something

ALS: did he have any suspicions

MARTHA: no he didn’t, because he can be calming in times of crisis

ALS: understandable so talk to me about telling your partner

MARTHA: when he came the counsellor was there and I just told him that the HIV test results had come back and I was positive and the first thing that came up was oh my God we do need to go and find an abortion and I said no, we don’t that’s when the counsellor started explaining about having a healthy baby and doesn’t have to but I don’t think he heard anything they said, yeah it was just the HIV positive thing and they suggested if he would like to have a test done and he said he would but for now just too confused to think but he will come back later to have the test done

ALS: did he have a test

MARTHA: yes he told me he did, yes he did because I didn’t come back for him and he’s not been with me to the hospital since I told him about, I found out when we found out about the HIV he had a test done and he said it’s negative I’ve not disputed that result

ALS: have you talked to him further about that

MARTHA: I have asked him and he said do you want me to show the result just to prove that I’m not, it’s now becoming like a big, big misunderstanding and all those kind of things and the first test, they said he should come back in three months time then once you have a negative test and you have been with a positive person then they will tell you to come back in three months time just to be on the safe side, I think I was warning him, reminding him, don’t forget it is almost three months you have to go and have the next test done, because I was really thinking about my child, I said if I die at least there will be a healthy parent to be looking after the child

ALS: that’s interesting isn’t it

MARTHA: yeah
ALS: so you were thinking well if you’ve got a negative partner that should you die you will have that

MARTHA: yeah, that’s why I was very keen for him to be negative and that’s when I knew that I probably got infected from when I had the blood transfusion because then I was with him and I’ve not been with any other person and we got married that same year so we have been together since 94 so it’s, it just came down to that, that is the only thing I could think of

ALS: did you do a lot of searching about were you thinking the HIV how you may have become infected, has that been a lot on your mind

MARTHA: it’s been a lot on my mind because I have thought of everything I said is it the needles they used in the hospital, did I cut myself, all sorts, I was thinking of every single possible, how and I just came to the conclusion because the other ones the risk are not as significant as having a direct blood transfusions

ALS: how do you manage now that, to stop thinking or are you still thinking about it

MARTHA: oh no I’m not, I’m not, he was surprisingly my husband was really, really angry he wanted to sue the hospital where I had my surgery done, my mum too was very angry, everybody was very upset, and I just said I’m just unfortunate, I didn’t understand, I didn’t understand why I’m not so upset, angry ??

ALS: so you told your mum

MARTHA: yeah, my mum and my brother, my brother just found out this year

ALS: so you told your brother later

MARTHA: yes

ALS: when did you tell your mum?

MARTHA: my mum I told that same year, that same month

ALS: so you kept to yourself to you and your partner a little while

MARTHA: well he didn’t keep it to himself (laughs) I kept it to myself cause it’s not something like, there was the stigma, because he wasn’t really nice to me after that

ALS: he wasn’t

MARTHA: oh God no, he’s been horrible

ALS: yeah, yeah

MARTHA: it was just really bad, to the point that the HIV wasn’t the issue it was now the violence and abuse that came after that, it was really killing me so
ALS: so you’ve still got the same partner?

MARTHA: well he’s going for counselling now

ALS: oh ok

MARTHA: and the management, he is being educated about the HIV thing and all that, yes

ALS: so now

MARTHA: oh yeah, yeah I was referred to, for the mental health somebody from the Maudsley, I think I was seeing someone called (name), he was coming to the house and talking with me and things like that and I was really, really emotional

ALS: so that was a really testing time

MARTHA: it was traumatising, it was really

ALS: so you’ve got your diagnosis so you’ve now got some domestic issues going on

MARTHA: yeah

ALS: was it physical as well?

MARTHA: yes, yeah

ALS: I mean how did you cope with that?

MARTHA: my mum

ALS: oh ok

MARTHA: yes because when I didn’t want to tell my mum my diagnosis over the phone it’s not something you should tell someone over the phone and he kept threatening he was going to call my mother, because my dad is dead and he was going to call everybody and tell them and my uncle came to visit, that’s I think later after I had the baby, he said he was going to tell people, he told his brother, he just started telling people about me

ALS: so in effect you lost control about who you told

MARTHA: yes I did

ALS: how did you feel?

MARTHA: really bad, it made me feel really, really bad, like these people don’t know about, look at the way you are treating me do you have any little knowledge of what HIV is like, oh I don’t want them coming to the house before you infect them, oh like
am I going to start sharing needles with them or am I going to start having sex with them or something like that (laughs)

ALS: so you had this battle?

MARTHA: it was a big battle, I had to call my mum and I told her over the phone and I could just see her over there and I think she passed out, because somebody else took the phone and is everything alright, did somebody die or something, I said no everything is fine and I said just let her be calm and I will call her back later in the day and I called her and she’s like

ALS: what was her reaction?

MARTHA: she’s like no it’s a lie it cannot be (laughed) she’s like it cannot be, I said it is, she said how, it cannot be you’ve had only two partners all your life (laughed) how can it be

ALS: so she was trying to work it out

MARTHA: yes she was trying to work it out

ALS: yeah, yeah

MARTHA: and she was how is the baby everyone is worrying about the baby

ALS: so you had the baby by then, you had or you hadn’t, no you were still pregnant

MARTHA: no I was still pregnant then, the pregnancy is progressing, she’s like are you keeping it, will the baby be alright, I said yes the baby will be fine. It’s something we will be talking about when you come I want to tell you everything about it, I just wanted to let you know before you come

ALS: and how did you manage with this, you know you were talking about your partner’s massive violence and aggression, how has that improved over time?

MARTHA: well it’s, we were separated

ALS: so you did separate for a while

MARTHA: yes for six months and

ALS: were you pregnant when you separated or was it after

MARTHA: after the violent even got worse after the baby was born and the baby came back negative so you should expect things to improve, it didn’t improve so it broke down to the point I had, the violence was so bad I had two surgeries done to my eye in Kings and I almost died and the police didn’t believe the injuries I sustained was done by him and hand they are like, maybe you passed out something else was used, I said no nothing else was used, so we separated for six months and he went for anger management classes, came back begging me, the whole family and because I told him I
can’t, and my mum was going now you are going to have children from other places (laughs)

ALS: so you separated, how did you get back together did you see an improvement or?

MARTHA: yes I did he, because I am a Christian, he decided to go through the route, possible I’m not going to fault, he went to the priest and the priest said she’s already told me, cause I told the priest basically this is what is happening and its like you have to go for anger management classes, you do need to go for counselling and you do need to go an understand what your wife is suffering for you to be able to, so he went for the classes I was demanding training, he was doing that with the priest and the priest told me if he could see his daughter, cause all the violence that I experienced was in front of my daughter so she was also afraid of him so you know

ALS: so how are things now?

MARTHA: Yeah I think it’s ok

ALS: you have another baby

MARTHA: I have another baby, from the same person (Big smile) (Recent birth)

ALS: from the same person yeah and that improved

MARTHA: it’s improved drastically, it’s changed and he is more supportive, he still has issues with the HIV thing although he understands how it works but he’s still, now it’s a different kind of, the way he behaves it’s different, he kind of blames other people so if I come in to hospital on emergency, cause when I was pregnant in my house I was spotting and things like that so I was ending up in the A&E

ALS: so you thought you were going to lose the baby

MARTHA: oh they are treating you differently because you are HIV positive so he had that thing in his head, it’s in your head I said I don’t care. He was becoming really, really bad, I said don’t come to the hospital with me any more, I also told the midwife, I said there are things that are really, really winding me up, too much when he comes to hospital with me so he’s not going to be coming to hospital with me anymore

ALS: so you had support from the team of midwives here and how’s that been

MARTHA: very good yeah

ALS: you found that useful

MARTHA: well yeah very good even when I had my daughter the midwives were great, it was brilliant, I didn’t feel like somebody that is diseased

ALS: so can we recap on that because you talked about the stigma haven’t you

MARTHA: yeah
ALS: how do you feel about that?

MARTHA: because, my first pregnancy, I was seen by the HIV centre, in the centre and the midwives and I think HIV midwives so I didn’t have anything to do with the other midwives even when I went into hospital, my medication was they were coming to say that have you taken your multivitamins and things like that when I had friends and family arrive

ALS: good experience

MARTHA: yes they did and I wasn’t treated differently

ALS: so the experience, so you found the experience quite a good experience

MARTHA: it was at that time, it was a good experience, the only bad experience I had was, because my daughter came really early, she was born thirty weeks and three days and she was in a special care unit, I think she was being, being cautious and it was, I could feel the stigma there

ALS: while she was in special care

MARTHA: yeah, while she was in special care, oh she’s too young for them to know her diagnosis if she’s positive she still has the antibodies because she came quite early so I noticed there was just extra caution from the nurses when they were handling my baby, put on three gloves

ALS: how did that make you feel?

MARTHA: really bad, I felt awful, I didn’t like it one bit I couldn’t wait to take her home, yeah

ALS: but the midwives

MARTHA: oh the midwives are great

ALS: and this pregnancy

MARTHA: oh this pregnancy’s been brilliant, and it’s full term and everything is going nicely yeah

ALS: it’s been a long time since you’ve been diagnosed, isn’t it, 1999

MARTHA: yes

ALS: it’s a few, what is it twelve, eleven years

MARTHA: yeah

ALS: do you think things have moved on in that time
MARTHA: it’s moved on really, it’s gone, it’s moved on, even when I came in it’s like since the last time you had the last baby, things have changed, it’s

ALS: so you had a caesarean section

MARTHA: I had two caesarean section, I was really looking forward to a natural birth but I couldn’t because I’ve had similar surgeries to the back region and I had microscopic surgery to take out fibroids so the Consultant strongly, he wrote a letter to my doctor, my HIV team I should he would suggests for me to have a caesarean, I shouldn’t have a normal

ALS: you had a caesarean with your son here

MARTHA: yeah

ALS: so you’ve had two caesarens

MARTHA: yes

ALS: good. If you, your pregnancies, your first pregnancy and you had all this going on in your pregnancy, how did you manage, how did you cope what did you draw on

MARTHA: the fact that the child will be healthy

ALS: cause the medication, they had told you about taking the medication

MARTHA: I started immediately, after the blood results came, they were surprised because the viral load was really, really low they said I probably got AIDS, I said well it’s down to two years is it possible for the viral load to be that low, like it’s possible

ALS: yes you can because the antibodies that you make are very effective, I mean, you know you get your antibodies, that’s why you produce your antibodies and the antibodies dampen down the viral load and they are very effective for quite a while, so yes it can be

MARTHA: so yes it was quite low so it was easy for me to start the medication immediately

ALS: yeah

MARTHA: for the viral load to come down really, but the down side was that the baby came earlier than expected yeah and so that was another thing that and they had to come and speak to me because the baby was born quite early so they have more chances of being HIV positive than full term babies, so just prepare me

ALS: so how long you on medication for, for your first pregnancy

MARTHA: I was diagnosed in September and I started medication
ALS: when

MARTHA: right away and I had the baby in December so about three months

ALS: oh that’s good, good amount of time. What’s, when your baby was born and your baby was in special care they must have done a blood result on the baby

MARTHA: yeah, I think the first result came positive, because they said the baby had the antibodies from me that they will not

ALS: they do different test nowadays

MARTHA: so they said they will do another test when how old was she, I think it’s changed

ALS: they did not look at the virus directly in those days, they just used to look at the antibodies but they look at the virus directly now.

MARTHA: so the next test they did came back negative so she’s got rid of all my antibodies, then they did another one and they did a final one when she was one year old and it was negative, so the whole year was just waiting and waiting and hoping

ALS: so each one came back negative did that give you some hope

MARTHA: it gave me some hope but I would have liked them to say because this one is negative there is more chance that the next one will be negative as long as you don’t breast feed her as long as you don’t do this as long as you don’t do that, so I still had that thing in my mind that maybe things, this time it’s negative because they got the results wrong, so I’m like it might be the wrong result, something like so I had it in my head

ALS: what about your second baby, your son, you had the first result

MARTHA: I had the first result yeah I know he’s fine

ALS: you’ve had a negative one haven’t you, you are just waiting for the second one

MARTHA: I have yeah

ALS: you are just waiting for the second, how old is he now?

MARTHA: he’s eight weeks old

ALS: he’s lovely isn’t he, he’s great. A number of women have raised some other issues I just want to see if there is a similarity or not, there may not be. One of the things you talk about is the stigma and that’s been raised by another women, one of the other ones is around self harm, they have raised the issue of self harm, did that come into your head in any way
MARTHA: no, the only time it came into my head was when my partner told his brothers

ALS: ok

MARTHA: I got really offended and I was thinking of just, because we lived on the sixth floor and I was just going to jump basically

ALS: but that because of what he, it wasn’t because of the HIV diagnosis

MARTHA: no it wasn’t no, because I was really upset and I just said what your child

ALS: another thing people have raised, some other women have raised disbelief, they didn’t believe the result, did you believe the result

MARTHA: yeah, I did but my mum doesn’t

ALS: she still doesn’t

MARTHA: she still doesn’t (laughs) she comes with me, when she’s around she comes with me to see the doctors then they discuss my results and things like that but she still doesn’t

ALS: is that because you look well

MARTHA: I think so, yes I think because I

ALS: she has something in her brain you know in your own country people can look very ill can’t they very quickly, you look fit you look well

MARTHA: I look well and

ALS: you’ve had another baby

MARTHA: I’ve had another baby I’ve had two miscarriages, she like then how is it possible, you have a negative partner, and I told her the whole process of how to get pregnant with a negative partner

ALS: yes they went into detail with that did they

MARTHA: yes

ALS: how to manage that, so you reduce the risk, good. If you look now at the whole experience that you’ve been through, there are probably positive bits about it and negative bits about it, could we have done anything differently

MARTHA: yes, if we are given the information prior testing, offering the assurance so you are not left in the dark and you don’t worry too much, cause most mothers when they are pregnant all you are thinking about is the baby and if they can reassure them
that the baby will be fine as long as you take the medication your viral load is, that
reassurance kind of gives them a lot of strength

ALS: so hope for the baby and for you

MARTHA: yes and you tell them now people are living longer and you know how long
you’ve been in the you know, cause my Consultant told me then I been treating HIV
positive people for the past ten years that was 99 and I’ve not lost any patients, so that
gave me a lot of assurance and like don’t worry you know

ALS: so got explained about the changing face of HIV how it was and what it’s like
now

MARTHA: exactly and the medication, cause then apart from them telling me about the
HIV and the medication and they are like oh you could have side effects from your
medication and we would have to change it and you could get resistance on the
medication so I was looking at the options and they were not looking really good, so

ALS: so you think you have become a bit of an expert on HIV?

MARTHA: yes because I had to go to the support groups and I was reading all the
flyers that were coming into the hospital and I also joined the newsletter for women so
they were keeping us updated on the medication and things like that

ALS: so you went out to have your support from outside on other issues

MARTHA: yes I did

ALS: how quickly did you get that

MARTHA: immediately

ALS: ok so you were made aware of them and you

MARTHA: yeah I was made aware and so I called them up, so yeah

ALS: so do you still go

MARTHA: no I haven’t had the time to go, no time cause the day I was studying so I
had to stop studying with the baby

ALS: so you’ve had the diagnosis for eleven years, what’s the impact of it now from say
when you look at the beginning and where you are now, has it changed, has it evolved

MARTHA: yes it has, I’m now comfortable with it, I know I could die any day but it
doesn’t necessarily have to be the HIV that kills me so I’m used to it now

ALS: you are living with it
MARTHA: I’m living with it, it’s not how would I say it’s not what defines me anymore

ALS: that’s interesting, it’s not, HIV isn’t you

MARTHA: it’s not me, it’s not, oh I’m HIV positive, so what

ALS: that’s acceptance

MARTHA: I’m just going over everything now I’m just preparing myself to tell my daughter because she is coming to that age, I’m just waiting to tell her

ALS: she’s ten or eleven now

MARTHA: she’s eleven, she turned eleven in December by September it will make it twelve years since I found out I was positive, I would have told her a long time ago but her dad says she is just too young to tell her and I should wait, she has already seen me taking my medication and she has asked why am I taking my medication I say I just take it to stay alive to look after you, so she knows I’m on medication

ALS: so she getting slightly prepared, she starting to get inquisitive about it

MARTHA: yes she is being inquisitive about it

ALS: so you feel that the question could come any day soon

MARTHA: it is, it is I’m ready to sit her down and tell her

ALS: and how do you feel about you know having to raise that how does that make you feel?

MARTHA: slightly worried because I think she I just fear for the way she’s going to start feeling, she will probably, every time I fall sick she will start panicking that mummy is going to die and something like that, she’s a worrier, she worries too much

ALS: it’s making that balance isn’t it between openness and transparency but also being not to trying

MARTHA: to burden her yeah

ALS: you said she is a worrier

MARTHA: yes she worries too much

ALS: maybe you should leave it for a while

MARTHA: I know she’s a worrier that’s why I’ve left it for a while it will change her life once I tell her so I’ll probably leave it till she is eighteen

ALS: where do you think she would rather hear it from you or someone else?
MARTHA: no she will definitely hear it from me, she wont hear it from my mum or my brother cause my brother still doesn’t believe he’s like what do you mean you are HIV positive, oh they just found traces of it, there is nothing like traces of it, he doesn’t believe also so I don’t know what to do about that

ALS: so talk about you know things that could change, that’s more information is there anything else that could change or improved on?

MARTHA: no I can’t think of any other thing, the way well another thing is the results, I don’t think it’s, it’s good to post the results to patients for them to know what the results are for them to get some of the results and then you tell them to come in to hospital for some of the results you just creating the avenue of worries

ALS: worries

MARTHA: just tell them to come for the results

ALS: not post them

MARTHA: no just so that they can see them, to tell them that the results are that and that

ALS: so much more face to face

MARTHA: yeah

ALS: now looking at this experience which you say you have gone through all the difficulties but also some of the positive outlooks, can you tell me anything positive that has come out of it having this result?

MARTHA: the HIV results, positive, well for me I think if I hadn’t had the test done I probably well I would have slowly, slowly my health would have started falling sick and maybe it would have been too late for me and I would have probably have had HIV positive babies now

ALS: so by finding out you are now in control

MARTHA: I now have control of my health and look after myself

ALS: so again to ask the question do you think it is better that you should know or not to know

MARTHA: it is better to know, it is better to know

ALS: and overall if you look now would you encourage other women to test

MARTHA: oh definitely, definitely I would tell any women to have the test done, very important, not just for the sake of the baby, for your own sake
ALS: you are quite supportive (of testing)

MARTHA: oh yeah I tell everybody, my sisters before, my other sister is getting married and I just say you and your partner to go and get HIV test done and the blood results came in, she’s had one done before, well you separated and now you are back together again so if you do need to have it done again, she’s like what if it comes back positive and I said well what if it comes back positive, you can start taking medication and you will be healthy and carry on your life and live long

ALS: so that actually means something different now

MARTHA: it does, I see it as a it see it as a blood condition something like diabetes you do need to take medication to control that’s how I see HIV it’s when you don’t control the virus in your blood then it gets out of hand and that’s when other things start

ALS: so after this experience, how do you feel

MARTHA: I am a stronger person, after my diagnosis I just studied, I wanted to be the best in everything, I went to University I got a first class degree, it’s just the way forward now, I am just going

ALS: so it’s given you a sense of purpose

MARTHA: yes it is, I think I started appreciating life, after the diagnosis I just saw it as finding out about the HIV has given me the strength you know the will to succeed, I appreciate life more instead of going through life like oh you know like it’s something you’ve earned

ALS: has that grown with time

MARTHA: it has

ALS: that’s good. Is there anything else that you would like to tell me?

MARTHA: like

ALS: anything about HIV or anything else

MARTHA: oh right. The thing is with the stigma thing a lot of people are still clueless about HIV and how it works with it being there for so long and there being so much information on the internet, with so much information a lot of people still don’t know a lot about it

ALS: so you think there is not a lot of education

MARTHA: cause none of my friends, I’ve not told any of my friends

ALS: so your friends don’t know
MARTHA: not my direct friends, I do have some HIV positive friends and they are the only ones that know about

ALS: cause that’s the support group

MARTHA: exactly that’s the support group and sometimes we meet in hospital so, they are saying the same thing that, oh there was one of my friends, oh do you know that your next door neighbour doesn’t know about my status, I’m like she doesn’t know about mine! It’s like ok just let me know not to mention anything about the HIV

ALS: so you disclose when you think it’s appropriate

MARTHA: yes I’ve only disclosed to my family, that’s it, I’ve not told any of my friends cause I’ve hear the conversations, we’ve had conversations about HIV and what they’ve been saying is bad, you don’t know anything about it

ALS: is that the friends in the community that you mix with that have that view or is that generally the people you meet

MARTHA: generally the people I meet

ALS: so they are not educated

MARTHA: no they don’t know, a lot of people don’t know, a lot of people don’t know about these things and this lady I met with one of my very close friends, my very close friend cause we have known each other for years now, decades but she still doesn’t know about my diagnosis, the lady was pregnant and she came up and can you imagine one of the midwives said she should have the HIV test, she said what kind of nonsense talk is that and I’m like oh why do you think that is nonsense talk, she’s like I can’t believe you are bringing this up, really people don’t want to talk about it, I said it will be good for you to know

ALS: and that’s the message isn’t it

MARTHA: and she’s like did you have your HIV test done and I said yes I did and she said how did you feel I said well I’m a happier person for knowing now

ALS: but you didn’t tell her

MARTHA: no I didn’t say well it came back positive (laughs and flicks head back)

ALS: well that’s fine it’s all about disclosure

MARTHA: I told her I am a happier person for knowing this now so yeah, people don’t know about these things

ALS: and does that create difficulty do you think

MARTHA: yes it does, it does it does create some cause when I have appointments in the hospital
ALS: cause you are working aren’t you full time

MARTHA: I am working full time

ALS: and do they notice it

MARTHA: yeah but the good thing is that my appointment is once every six months so it’s, the thing is I have to come in for my bloods and also come in to see the doctors so I tend to have my appointment quite early in the morning so I take flexi time so I work longer that day

ALS: so you are managing your HIV in way that doesn’t impact on your work

MARTHA: it shouldn’t be that difficult we expect you know employers to know these things but even where I work they still, the HR I notice because I work closely to HR, I work in Finance so I work closely to HR and they discuss these things you know they discuss this person is going for chemo or this

ALS: so you are not sure about the confidentiality

MARTHA: there is no confidentiality

ALS: really

MARTHA: oh God

ALS: but is there a reason why for work it doesn’t impact on it does it

MARTHA: no, no it doesn’t I don’t take my medication at work I take it once a day at night at home so nobody knows I’m on medication

ALS: and you are aware as well you know that HIV is covered by disability act anyway so, if push came to shove you’ve got a strong weapon haven’t you

MARTHA: yes

ALS: so how do you think about the future now, how do you feel about it?

MARTHA: great I’m thinking I need to wait another year and have another baby

ALS: oh you going to have another one

MARTHA: yes, I think it will the final one

ALS: a final baby

MARTHA: hopefully it will be twins

ALS: twins!!
MARTHA: yes it’s going to be twins, my first miscarriage was twins, I was eight weeks pregnant

ALS: so you’ve got hope for the future again, has that evolved as times gone on

MARTHA: yes it has, it has I just really, the HIV thing is not an ongoing issue for me I think people around me still struggle with it, my partner, my mother she says I don’t believe it

ALS: so she is still in denial

MARTHA: she is still in denial after having years from the time of my diagnosis to now but I’m still telling her because every time I bring up the issue I want to tell my sisters but she doesn’t want me to tell them

ALS: so you want to tell your sisters

MARTHA: yeah I want to tell the whole family, my brother but he still doesn’t believe the way my mum just says oh she’s just making things up don’t listen to her that’s how she made it sound

ALS: oh ok like you were attention seeking

MARTHA: because we sat down my partner was there, my brother and my mum and I was telling my brother because he’s kind of like having relationships here and there and I wanted to tell him the risks involved and things like that, just to keep him healthy and my mum just said oh they have just found traces, it’s nothing there and I wanted to go on and my partner just said calm down, leave it alone and now he’s the one that doesn’t want anyone to know

ALS: so from his initial anger wanting to not tell, wants to keep in

MARTHA: yes he doesn’t want anybody to know and things like that, it’s like you don’t want to tell them that you are HIV positive cause I want to go to the surgery and I wanted the flu jab and they are like I didn’t want the flu jab because I was invited to take the flu jab at the GP and the receptionist there like why would the GP invite you to come and have the flu jab and things like that and I said because I’m HIV positive

ALS: oh so you told her

MARTHA: so I told her and she was like oh really and he was really upset do you have to about telling people, you know it’s not something you should be happy about I’m like I’m not happy about it but you know you know shut up, now she’s quiet and running around, normally I don’t just go blerting out like that well I had to say it, so yeah

ALS: because you are more comfortable with it
MARTHA: yes I am more comfortable with it and I will have told my very close friend a long time ago but he doesn’t want me to say anything

ALS: you want to respect your partner but also your control of who you want to tell

MARTHA: I think he is more worried how it’s going to look regarding him, nobody will believe when you tell them that you are positive that I’m not positive and I’m like well I’ll tell them your not, no one will believe, why is he still with her if she is HIV positive and I say I really don’t care, so

ALS: so really you’ve faced the stigma face on really haven’t you

MARTHA: I have really yes I have and I think because of the experience I had the early years, the stigma and the way they treated, you know the bad treatments it was like trying to come in from my within my home all the HIV positive, don’t touch them make sure you wear gloves before you carry the child and all those kind of things, it was told by my partner

ALS: do you have control at home now

MARTHA: yes, yes the most hurtful one is the one coming from home, yeah you can manage everyone else you say they are ignorant and or things like that but the one within the home so that made me really, really strong

ALS: how did you manage about when he was saying to you, you need to wear gloves to hold the baby how did you challenge that?

MARTHA: that was really hard and I just ignored him, he kept going on and on and because she was so poorly and premature so we were going in and out of hospital all the time and he kept saying oh she’s infected and things like that and you know he kept going on and on and he wouldn’t call me when she was having her results done he was really, really hurtful and one of the reasons I said I can’t carry on like this, I will not carry on like this, so unhappy and I don’t know being in that kind of relationship so that’s when we went our separate ways for six months I think he was more miserable and he came out with I don’t mind you being HIV so long as I am with you

ALS: really

MARTHA: that’s what he said

ALS: well that shows that sometimes that separation does put things into reality

MARTHA: it does put things into reality

ALS: you know the choice becomes stark he either has a life with you or without you and the baby, so in some ways it is quite empowering isn’t it

MARTHA: it is and it’s worked really well he’s come back
ALS: he’s changed, so if you look at your relationship now do you think it’s stronger now.

MARTHA: it is stronger now, he’s the one that is finding it difficult to deal with outside people when people are talking about HIV he’s like they wouldn’t know anything about it they should shut up and I like you don’t just say that don’t forget that you were in that position where they are now you were like that before so

ALS: it’s a journey, it’s been a journey.

MARTHA: another thing recently that happened, just before I became pregnant with my son, the GP my GP one of the GPs in my surgery, because I wasn’t conceiving and we tried for so long and I had a miscarriage, we tried for so long and the doctor here suggested I should ring my GP for them to refer me assisted conception unit and they do help out with things like I said fine, so I went to the GP and I told her and she said ok she would refer me and I left, I got a phone call telling me to come back in and she said oh I’m sorry cause you’re HIV positive they won’t be able to see you at the assisted conception unit and I knew that wasn’t true because (name) has told me they see HIV positive people so the GPs don’t even know and another time again she was referring me to have a scan done just to have a look at my womb just see what is going on in there, to see that the tubes are fine and the ovaries are fine and the whole thing and on the referral note she just put HIV positive twice and I was so upset I had to call the practice manager and I said this is now becoming personal and I reported the GP to the practice manager and I said look I could take you further, you do need to educate your GPs about these things.

ALS: so also what you are telling me there is ignorance.

MARTHA: exactly the medical profession you expect people in the medical profession to be aware of these things but surprisingly a lot of them are not.

ALS: so your treatment.

MARTHA: no I was a bit stunned when I saw that.

ALS: that written.

MARTHA: yeah I just couldn’t believe it and I said look from the point of going into the Kings Hospital downstairs I don’t know where I’m going to I will go down to the person and I’m like please can you tell me where I will go for this test so right there and then the people in the reception will know I’m HIV positive then I go upstairs whoever handles the paper will see I’m HIV positive I mean it’s just, I don’t have issues with my status it’s just.

ALS: it’s about disclosure, confidentiality and sensitivity.

MARTHA: yes, yes.

ALS: and that’s not been displayed.
MARTHA: no, no it’s not I’m going for a procedure that is put in, whoever is doing the procedure at risk, it’s just a scan they do they put something into me and just have a look at what’s going on, so it was quite upsetting and that was two days ago so it was quite recent it’s not like it was ten years ago and I told her that this is the worst treatment I’ve had since I was diagnosed with my HIV I mean it is the worst treatment from a medical person, she apologies and she is a lot nicer

ALS: now you have another baby and you have plans for the future

MARTHA: yes I do

ALS: it’s really good, ok well thank you very much

MARTHA: thank you, it’s been good to talk
Appendix 18

Graces’ Loss
GRACE’S TRAUMATIC LOSS

Grace reported the loss of her baby following a fresh stillbirth was more distressing than having HIV and gave an in-depth narrative of this traumatic experience which requires no interpretation as the original narrative conveys meaning. This powerful narrative is included as this is Graces account of a stillbirth with her diagnosis of HIV (I will not use Grace after every section of this detailed descriptive narrative and it is has not been fully analysed as the description alone is powerful).

After her HIV diagnosis in her first pregnancy after being trafficked to UK and used as a sex worker against her will. Grace later met her new partner and conceived. Grace was given the option of VBAC after the birth of her first child. She was informed of the need to come in to the hospital for monitoring as soon as labour commenced to monitor her scar and foetal wellbeing.

“My doctor was very happy so at the last minute when I started my labour it was weekend, Saturday night I started my labour, so in the morning I called the hospital to let them know, so when I called them the person who was on call said no don’t come over I said yes it’s started and it’s coming like 30 minutes, ok that’s fine. Then at night on Saturday, on Sunday night it was worse, so I called the person again, I said please it’s like this and this and this and this. They said if you haven’t seen anything don’t come because if you come to the hospital they will take you back, I kept quiet and for some time the contractions were coming, they were strong, so I had to call an ambulance, my partner wasn’t around, I had to call an ambulance. The ambulance came, I said look I’ve seen blood, I’m heavily pregnant.”

And

“Cause I thought cause I’d never seen it so it was like blood. So the ambulance said no you call the hospital and let them know cause we may take you and they will bring you back. I called this lady again who was on duty then she told me you know what put some water in the bath, make a cup of tea, I said no I have a scar which needs monitoring so I need to come over to the hospital, I’m in pain and when the pain comes I feel like pushing. She said ok tell the ambulance people to bring you over to the hospital I am going to let the hospital know about it so when they took me to the hospital they handed me to the reception over to the receptionist, so they told me that somebody was going to come and take me inside. I said to the receptionist I’m in pain after one hour, I was like what’s happening, I’m in pain. I go to the reception, I said look I have a scar I have been brought here by ambulance, I’m in pain, I’m in a lot of pain, she told me you see those two ladies there, they came before you so they have to go in first, because I said look, I’m overdue I have gone for 41 weeks and two days.”
And

“So she said no you can’t go in I had to go back and sit I was on the floor everybody was staring at me, I said what’s happening, I was there almost two hours and half.”

When asked if she was assessed in anyway- Grace answered “no”

“So after it was two hours and a half a midwife came and picked me up and I said ok, I’ve been waiting for longer but at least she has come to help me and take me inside and she took me in a room, is it a prep-room? Then she told me ok we need to monitor the baby.”

And

The baby, the baby’s heart then she told me to hold the monitor and she was going to look for the belt to hold the monitor. She stayed there for ages, I was in pain, I couldn’t hold it anymore, I said no this is enough I just had to throw it away. So after some time she came back and said I have to examine you then she examined and said oh you are eight inches, then she gave me a sheet to wrap around myself then she told me you know, I am going to take you to another room, let me come back, she didn’t come back. I was in the room on my own, I am screaming with the pain, I’m on the floor, I’m pulling this, nobody’s coming, I’m screaming I’m trying to push until I got exhausted. So after some time some two midwives came one was a student and one was a midwife. So they came and they said oh we are coming to help you and have your baby I said but I am dying baby wanted to come long time ago but I have been on my own, I’m dying, I’m dying now it wasn’t contractions any more it was something else.”

Grace recognised the pain as something sinister. When asked if she was worried about you being positive during this time;

“Now it had gone out of my head.”

And

“Yeah because I was in pain.”

And

“So they came in and said we are going to help you we are going to take you to the bath tub and you have your baby, I tell you people I’m dying, help me I’m dying. I was on the floor and I started vomiting so they helped me they tried to, the only thing I could give them was I’m dying, I felt I was exhausted and I was in pain the pain I was getting wasn’t contractions anymore. So when they are trying to put me on the commode I felt, I became weak and they are telling me ok put your leg, I couldn’t even put my leg up, so when they put me on the commode I just felt that my life was getting out of me, so I collapsed. They didn’t even know what was going on, they did nothing, I don’t know.”

When asked if anyone listen to the baby’s heart? Grace reported;

“At this stage NO. So they are trying to take me to the bath tub, they didn’t know what this one who was helping me, didn’t tell them anything oh this lady she needs this and this, nothing. So they came knowing maybe the contraction (?pain) I don’t know what she wrote there. So only when they saw me falling down, they rushed calling whoever was around, I had the Consultant coming in, I could hear but I couldn’t talk I couldn’t do anything.”
And further added
“So when she touched my pulse oh this lady was supposed to have gone she is in
danger, that is what I could hear, I could hear them moving this and this and this and
this. I think then that’s the time I last knew what was going on.”
Grace was in a collapsed state and when asked at what point did you know that you’d
lost her baby;
“So they rushed me to the theatre ,they removed the baby and they tried resus him,
but it was late already and the baby had come out of the uterus and it was in the
tummy.”
And
“What had happened is that the scar had opened up and the baby had gone into
abdominal cavity, which is a recognised risk , when I was taken to the theatre at 9
ish from my midwife, I found out that the baby is dead but I was still in coma, so until
at 5 in the evening, that’s when I came back. I want my baby to come tonight, your
baby passed away.”

The HIV specialist informed Grace of her baby’s death.

When questioned of her feelings;
“It was so, so horrible really.”
When asked about her partners feeling about this event, Grace reported his disbelief;

“He couldn’t believe it because it was not somebody who was sick, you understand. I
didn’t have any complications nothing.”

Grace reported this experience was worse than being diagnosed HIV positive. This is
Graces unique narrative and does not lessen the effects of HIV for other women or
mitigate the other women’s experience of testing positive, only that for Grace this still
birth was catastrophic event when compared to HIV.

After the tape ended, Grace also reported verbally the recent death of a close friend as
more traumatic than being informed of the positive result and living with HIV. This
finding suggest for Grace, she had rationalised how HIV impacts on her life in the
longer term and in her view that HIV is a lesser problem or issue in comparison to these
traumatic events. This strongly suggests the impact of the still birth was more severe for
Grace than her HIV diagnosis.