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When Motherhood Beckons: an exploration of the transition to
Motherhood for HIV positive Women

by

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Dedicated to all the HIV positive mothers and babies whom I have cared for
and those I have yet to meet.

ABSTRACT

The aim of the research was to explore the transition to motherhood for women who have been diagnosed with HIV before pregnancy. Pregnancy is a time of adjustments for all women; socially psychologically and physically, the midwife has a fundamental role in supporting the woman to make a successful transition. HIV is increasing in New Zealand's heterosexual population and with the national introduction of antenatal HIV testing midwives the diagnoses made will increase. Communities and health professionals need to hear about women's experiences and recommendations from research about how best to provide individualised care for both mother and baby.

This small research study was undertaken in 2008. Three women living in New Zealand with a positive HIV diagnosis were interviewed about their transition to motherhood. The babies of mothers in this study were aged between 3 and 18 months and the women knew their HIV diagnosis prior to pregnancy. The women spoke candidly about their experience of becoming pregnant, being pregnant and the transition to motherhood over the subsequent months of their babies' lives. Three chapters present the themes from the women's narratives; Chapter Four details the journey to becoming a mother. The themes identified were the desire to become a mother; "*working hard for this baby*"; maternal-infant attachment and "*becoming a mother changes everything.*" The themes in Chapter Five focus on how the women manage stigma and disclosure of their condition. The theme of managing disclosure in their personal world to family, friends and the child is identified. The maintenance of privacy and confidentiality is a theme arising from their step into the health service. In Chapter Six the theme of disempowering behaviours and

perceived lack of evidence based care is discussed. The women describe how knowledge of HIV positive mothers was lacking as some health professionals queried “why aren’t you breastfeeding?” The women identified sources of support and knowledge which used to address the imbalance of power they felt whilst engaging with health professionals and wider society.

In conjunction with midwives and other health professionals, the communities in which the women live are an integral component of supporting women to become mothers.

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CHAPTER ONE

Orientation to the study

Introduction

This research was undertaken to explore the transition to motherhood for women with Human Immunodeficiency Virus. In this study two of the three participants contracted the disease in New Zealand via heterosexual contact, reflecting the predicted increase in HIV among heterosexual New Zealand residents (National Health Committee, 2004).

This first chapter outlines the aim of the study and a background provides context for its inception and development. An outline of the structure of the study is provided.

BACKGROUND TO THE STUDY

Human Immunodeficiency Virus (HIV) is a virus which erodes the immune system over a life long period and can develop into AIDS (Acquired Immune Deficiency Syndrome) which is the name given to a range of debilitating and fatal diseases. HIV infection affects approximately 37.8 million adults and children worldwide and in Oceania there were an estimated 78,000 adults and children living with HIV in 2005, with an estimated 1400 in New Zealand (UNAIDS, 2001).

In 2003, the number of new HIV cases in New Zealand was the highest since the epidemic began in the 1980s. The largest number of children ever diagnosed was five. The trend for heterosexual transmission is rising in New Zealand and therefore women and their babies are at risk of becoming infected. The transmission of HIV amongst the

heterosexual population in New Zealand is increasing. The social and psychological adaptations women make as they become mothers has been well researched (Miller, 2005; Mercer, 1995; Oakley, 1979) but an exploration of the transition for HIV positive women in New Zealand has not been researched.

Motherhood is a cherished status in the majority of societies; it enables women to fulfil a unique role, a sense of purpose and to provide a stable secure base from which the infant develops and begins to explore, safe in the knowledge of the continuity and security of its mother. Society expects the mother to be self sacrificing in the interests of the child's emotional and physical wellbeing. The need to learn about the lived experiences of HIV positive women who became mothers in New Zealand was identified as a gap in the knowledge about the transition to motherhood.

ORIENTATION OF THE RESEARCHER

The decision to explore the transition to motherhood for HIV positive women in New Zealand was borne from a personal philosophical base that pregnancy and birth are normal physiological family focused events during which women should feel empowered to make positive health choices for themselves, their baby and their family/whanau. I wanted to explore the transition to motherhood for HIV positive women to inform midwifery and other health professionals practice.

AIM OF THE STUDY

The aim of the study is to describe the transition to becoming a mother for HIV positive women in New Zealand. The findings will inform recommendations about the knowledge and information needs of midwives and other health professionals to ensure HIV positive women are supported in their transition to motherhood.

REVIEW OF THE CHAPTERS

Chapter One introduces the thesis topic and aims, and provides the background for the current study. An outline of each chapter is provided.

Chapter Two examines the literature concerning the transition to motherhood for HIV positive women. The literature search identified studies based in Europe, the United States of America and Australia. There were no studies based in New Zealand so this study starts to address that gap in the literature. The studies focused on the experience of mothering when HIV positive, living daily life as a woman with HIV and mothers experiencing stigma due to their lifestyle. The themes identified from the literature review were motherhood as a desirable role for women in society, managing stigma and disclosure for HIV positive women and the power imbalance that can be felt through having a stigmatising illness. The literature review discusses findings from nursing theorists and provides a context for the transition to motherhood for HIV positive mothers in this study.

Chapter Three provides an overview of the methodology and methods used for this study. A qualitative approach using narrative interviewing was selected as the most appropriate

method. Thematic analysis using Van Manen's sentientious approach enabled a logical approach to identifying the themes from the interviews. Concluding the chapter is a discussion about the trustworthiness of qualitative research.

Chapter Four presents the theme of becoming a mother and is supported by excerpts from the narratives of the women. It provides an insight into the challenges they faced regarding the decision to become pregnant, managing intimate relationships, the pregnancy, birth and postnatal experience as an HIV positive woman.

In Chapter Five the themes of stigma and disclosure, and how the women manage perceived and experienced stigma are explored. The challenges of disclosing their HIV status to loved ones, friends and to the wider community or public domain are discussed.

Chapter Six focuses on the knowledge-power struggle experienced by the three women in this study as they encountered the staff working in the maternity services. The power struggle is explored in relation to the impact on their transition to motherhood as well as the impact on their children and other family members.

In Chapter Seven, the final chapter, the threads of the transition to motherhood for HIV positive mothers are brought to a conclusion and I evaluate if the aim of the study has been achieved. I identify key recommendations for midwifery practice, health professionals' education and recommendations for further research arising from this study.

SUMMARY

This study sets out to explore the transition to motherhood for HIV positive women in New Zealand. The context for the study is set at a time when an offer of universal Antenatal HIV screening is being implemented in New Zealand. It is therefore pertinent to identify the issues for women becoming mothers diagnosed as HIV positive to enable health professionals to have an understanding of the issues for HIV positive women and mothers. The importance of understanding the needs highlighted in this study could contribute to the development of a strong psychological foundation as the women negotiate the transition to motherhood.

CHAPTER TWO

Literature Review

“We haven’t begun to find out what is going on in the creative, experiential process of being a part of making a baby, making a mother” (Reva Rubin, 1984).

Introduction

In the previous chapter I introduced the aims of the study; to describe the transition to becoming a mother for HIV positive women. The findings will inform the knowledge and information needs of midwives and other health professionals to ensure HIV positive women are supported in their transition to motherhood.

Chapter One provided an overview of the structure of the thesis. In this chapter I review the literature written about HIV positive mothers’ transition to motherhood and the theories of the transition to motherhood from two nursing theorists. The literature review aims to identify the findings from research literature, prior to the commencement of the current study, about HIV positive mothers as they make the transition to motherhood.

THE LITERATURE SEARCH

The literature search used the keywords HIV and motherhood to search databases and Massey University library catalogue. The databases used were the Web of Knowledge, a health and medical science database and Psycinfo, a psychological research. The Web of Knowledge was used as it has broad coverage of health science, nursing journals and journal articles specific to AIDS/HIV research. A database search revealed seventy-five

journal articles which included a number of research studies undertaken in Sub-Saharan Africa; many of the titles pertained to breastfeeding and HIV transmission in those countries. Web of Science was searched to access the literature investigating the sociological aspects of being an HIV positive mother. A search of book titles with Motherhood/HIV or HIV and Motherhood or Transition to Motherhood in the Massey University library catalogue revealed titles on contemporary motherhood (Kent, 2000; Alizade,2006) as well as seminal texts on the theory of the Transition to Motherhood from nursing theorists Reva Rubin (1984) and Ramona Mercer (1995) and sociologist, Ann Oakley (1979). These titles enabled an understanding of the foundation of the theory of the Transition to Motherhood, and the history of the social context of motherhood in the twentieth century which remains relevant today.

AIDS and HIV research has historically been undertaken in countries with a high prevalence such as Sub-Saharan Africa, where HIV infection is at epidemic levels with 22 million adults and children living with HIV (UNAIDS, 2001).

The decision not to use studies from Sub-Saharan Africa are due to the factors which are believed to have influenced the HIV epidemic there; the relationship between sexually transmitted diseases, parasitic infections, tuberculosis and HIV against a background of widespread poverty and inadequate healthcare (Kennedy, 2003). The decision was also informed by the fact that this study was to examine the transition to motherhood in New Zealand. The perceived challenges faced by HIV positive mothers and their families needed to reflect contemporary New Zealand society's values. I thought the social, medical access and economic challenges for mothers in rural Sub- Saharan Africa could

not be transposed to women in New Zealand or vice versa (Lawn, Harris, Angaret, Myer & Wood, 2008). Research undertaken by Jirapaet (2001) in an urban region of Asia was used because it provided an insight into the cultural and social context of family which was rich in similarities to New Zealand and featured the transition to motherhood and HIV as the focus of the research.

THEMES IDENTIFIED FROM THE LITERATURE REVIEW

The literature search enabled the consolidation of information which has been written on HIV and motherhood. Books about HIV and motherhood focused on research that had been undertaken in the United States of America and described research studies dated from the early nineteen nineties. These studies described women who had contracted HIV from illegal intravenous drug use and reflected the demographic of women affected by HIV in America at that time; black or Hispanic ethnicity, low socioeconomic status and low educational achievement. Some studies coincided with the advent of antiretroviral therapy being administered during pregnancy and childbirth to HIV positive women to reduce the risk of HIV transmission. The literature then started to reflect how the subject of motherhood with a positive HIV diagnosis was becoming a choice for women.

The main themes identified from all the literature reviewed with regard to HIV and motherhood centred on the importance of motherhood, the information HIV positive women received from healthcare workers about childbearing, what HIV positive women think healthcare providers ought to say, and the stigmatising effect of being HIV positive. A review of the literature using these themes is provided in the following sections.

The Desire for Motherhood

Becoming a mother in contemporary western society is viewed as a mark of adult status for women and a woman's reproductive status is seen as central to her identity (Kent, 1994; Phoenix, Woollett & Lloyd, 1991). Motherhood as a goal for identity fulfilment and promotion of self esteem within the female HIV positive population was a central theme identified from the literature (McDonald & Hurley, 2002; Ciambone, 2003). This central theme of motherhood providing self esteem could be due to the fact that the participants in these studies were from low socioeconomic backgrounds, or faced social marginalisation due to ethnicity or lifestyle behaviours such as illegal drug abuse.

The diagnosis of HIV/AIDS often leads the woman to contemplate significant losses; motherhood and loss of self describe the "double devastation" felt (McDonald, 2001, p. 35). A survey of 126 people living with HIV/AIDS which followed up with in-depth semi-structured interviews of 24 HIV positive women living in Australia, identified a common theme to many women's narratives when recounting their diagnosis; their desire to become a mother and how their dream was suddenly shattered.

Since the discovery of HIV infection in women the medical and social concern has been the risk of transmission to the fetus, termed mother to child transmission (MTCT) or vertical transmission. There are known contributing factors which can increase the transmission rate such as the level of the virus in the blood, known as viral load. The viral load can be at an increased level if infection and pregnancy occur simultaneously and/or

if there are other opportunistic infections present which would lower the woman's immune system. For a woman with HIV the risk of vertical transmission is 25% and breastfeeding can add another level of transmission. The risk of transmission cannot be calculated accurately as it is thought that breastfeeding exclusively i.e. no other medicines or breastmilk substitutes may coat the intestinal environment with a protective seal of immunoglobulins thus reducing the risk of HIV transmission (Van de Perre, 1995 cited by World Health Organisation, 2007). However, it is thought as the infant becomes introduced to breastmilk substitutes or is weaned onto solid food the protective barrier is eroded and the virus is absorbed (Rollins et al, 2001, cited by WHO,2007). The recommendation from the World Health Organisation (2007) based on the available evidence is HIV positive mothers in countries with clean drinking water sources and safe alternatives to breastmilk such as modified cow milk formula should be advised not to breastfeed or give the baby their breastmilk.

For women living with HIV, pregnancy and motherhood has become an achievable option through the advent, in the early nineteen nineties, of highly active antiretroviral treatments (HAART).The combination of these drugs with protease inhibitors to further 'stunt' the replicating virus reduces the viral load in the maternal blood stream. Further research found elective caesarean section surgery at 38 weeks gestation contributed to a further reduction in the transmission rate by 50%. If mothers withheld breast milk the risk of transmission reduced by a cumulative rate of 16.2%. Therefore the administration of antiretroviral drugs to reduce the risk of vertical transmission during pregnancy, childbirth and the newborn period coupled with elective surgery for birth, and

withholding breastmilk has been shown to reduce the vertical transmission of HIV to <1% (Connor et al, 1994; European Mode of Delivery Collaboration, 1999; Nduati, Richardson, John et al, 2000).

The factors affecting a HIV positive woman to consider pregnancy are varied, with cultural, social and psychological factors all contributing. Siegel and Scrimshaw (2001) aimed to identify the reasons and justification given by HIV positive women for considering a pregnancy. Their research aimed to give HIV positive women a voice at a time when “many might view HIV infected women as selfish or deviant for desiring a child or becoming pregnant” (p.114). Participation in the study gave women an opportunity to verbalise not only their reasons but the justification for those beliefs about having a baby after being diagnosed HIV positive. The multi-ethnic sample of 51 women living in New York City was taken from a sample of women who self referred for inclusion in the study after extensive advertising about the study and its aims. A further screening interview over the telephone enabled the researchers to refine the sample. The purposive sample was chosen if they met the following criteria; were aged between 20 and 45 years, had tested seropositive for HIV antibodies, resided in the New York metropolitan area, if Latina or Puerto Rican and had resided on the mainland for at least four years and were currently pregnant or attempting to become pregnant. The demographics of the sample had a mean age of 32 years; a large proportion of the women were already mothers, 67% (n=34) of the sample with between one and six children and 22% (n=11) of the sample were pregnant. A small number, (n= 3; 6%) reported no religious affiliations. At the time of the interview 45% of the sample had been diagnosed

with an AIDS defining illness. A focused interview was then undertaken and a thematic analysis of the interviews identified ten strong themes.

Participants in their study were noted to actively weigh both the potential risks and benefits of their pregnancy decisions. “The decision to attempt a pregnancy was not made easily or taken lightly by these women” (Siegel & Scrimshaw, 2001, p. 115). Women reported three major reasons for wanting a child; her husband/boyfriend really wants children, having missed out on raising her other children, and believing that a child would make her feel complete, fulfilled, and happy. Women also reported several justifications that they believed offset the risks of pregnancy with HIV, including “other HIV infected women were having healthy babies, feeling optimistic about having a healthy baby due to the prophylactic effects of AZT (Zidovudine), having faith that God will protect the child, being young and "healthy" will prevent transmission, and feeling that she is better able to raise a child now” (p. 118).

The study found women felt increasingly confident about reducing the risk of passing HIV to their baby due to the efficacy of antiretroviral therapies such as AZT. The introduction of AZT (Zidovudine) as a treatment to reduce transmission was viewed by the respondents as a strong justification for considering a pregnancy. The participants in the study raised concerns about the extent of the toxicity of the drug and its potentially unknown interaction with the developing fetus. This apprehension led some women to abstain from treatment quoting a 75% chance the baby would be HIV negative. The study identified the strong influence of peer beliefs and experiences. Women would meet other

HIV positive women at the clinic and see that they were pregnant or had an HIV negative baby. The study found that this social network amongst the women was a factor in antiretroviral drug therapy compliance as the HIV positive women were more likely to listen to another HIV positive woman's advice about drug adherence than to a health professional.

An earlier study in North America researched the values and experiences of HIV positive women to inform public policy (Kass & Faden, 1996). Seven HIV positive women were interviewed and verbalised various reasons or justifications for continuing their pregnancy citing "one too many abortions", "it's up to God's will now" and the desire "to have at least one child" (Kass & Faden, 1996, p. 435). Three women knew their diagnosis and planned to become pregnant. They cited their decisions as wanting to make a new start and to stop using drugs. One woman wanted lots of children to replace the one she had lost to AIDS, and another wanted to have at least one child and as her CD4 count (immunity status) was high she regarded it was an appropriate time.

Aside from spiritual beliefs motherhood was viewed by one respondent as a woman's basic right; "I think for women who never had a child and who have been diagnosed with HIV-positive, we (*sic*) ought to have at least one baby, I mean they're due that. Before I got pregnant with my child, I was feeling like I wasn't a woman" (Kass & Faden, 1996, p.430).

Kass & Faden interviewed 159 HIV positive women, seven of whom were pregnant at the time of interview. Of the remaining sample of the women who did not intend to become pregnant 25% cited their diagnosis had not contributed to the decision, and 50% decided against having any children or more children due to their diagnosis.

Women spoke of their reasons for not wanting any more children due to the risk of the child becoming sick or orphaned. This was viewed as unfair to the child. A further 25% of the sample could not rule out not ever having a baby, the majority of this sample framing the decision to become pregnant in religious terms citing it as being in “God’s hands” (p.429). This spiritual belief system of being rewarded or chosen to become a mother was reflected by respondents in Siegal & Scrimshaw’s study (2001) who reported pregnancy was viewed as a gift from God for “doing the right thing and looking after yourself” (p.119). Some respondents said they would forgo the antiretroviral treatment in a belief that God would see that the baby was born HIV negative.

The study was conducted before the publication of the results of the ACTG 076 (AIDS Clinical Trial Group; Connor et al,1994) which heralded a significant reduction in vertical transmission when HIV infected pregnant women were treated with oral antiretroviral drug therapy during pregnancy. Of interest are the respondents’ answers when interviewers asked if there was a ‘magic pill’ which could reduce the risk of the baby being born HIV positive, would you have another pregnancy? Respondents agreed that if the baby “would come out negative” then they would consider another pregnancy (Kass & Faden, 1996, p. 428).

The desire for motherhood among HIV positive women appears strong and the birth of a baby when HIV positive is almost viewed as a spiritual reward for a life lived well. From a psychological perspective the desire for children can be viewed as providing an identity, a source of accomplishment and maybe more importantly will signify a purposeful life.

The Context of Becoming a Mother with HIV

Stigma provides the context for mothering when HIV positive. The stigma can be perceived or actually experienced. HIV is a stigmatising disease due to its historical mode of transmission through deviant behaviour and its devastating physiological and psychological effects on the body, and the concurrent social implications. The paradox of being HIV positive and a mother in western society can attract dissension as identified in Siegal & Scrimshaw's study. In a study of drug addicted HIV positive women, motherhood has been described as both "redeeming and damning" (Hardesty & Black, 1999, p. 601). It is redeeming as it enables the mother to right the wrongs in her life but damning as she can be judged in wider society by her diagnosis not her identity as a mother.

Hardesty & Black (1999) aimed to examine the importance of motherhood in the lives of 20 Latina Puerto Rican women in various stages of recovery from addiction to crack-cocaine or heroin in South America. The method for data collection was the life history method, with the participants' being interviewed on three separate occasions over the period of one month. The participants' responses were then coded and compared with

others in the sample. From these comparisons of descriptive codes an underlying pattern emerged. Hardesty & Black found “motherhood provided an identity and a line of work that grounded them amidst the dislocation of marginalisation, poverty and abuse” (p. 602). The study found that although motherhood in an addict’s lifestyle “may seem contradictory motherhood remains central to Puerto Rican addicts and provides an anchor in an embattled and disruptive life” (p. 602). In conclusion, motherhood for the women in this study was an activity which provided them with a normalising strategy to cope with the chaos and demands of their lifestyle.

Survival strategies used by HIV positive African women living in London, England was the subject of a study by Doyal & Anderson (2005). The decision to study HIV positive African women in London was due to the rising numbers of black African women living in England with an HIV diagnosis in a different country from that of their birth; “of 2473 women newly diagnosed HIV positive in the UK in 2002, 69% were black Africans” (Public Health Laboratory Service Data to December 2003; cited by Doyal & Anderson, 2005, p.1729). The researchers aimed to explore the women’s circumstances and identify their survival strategies.

To be eligible for entry into the study the women were required to have been residing in England for at least six months, diagnosed as HIV positive for six months or more and state their ethnicity as black African. The number of participants was sixty-two with women coming from eleven different countries. Women were selected from attendees at Sexual Health clinics and possible entry to the study was discussed with them by their

regular clinician complete with written information. Eighty percent of women approached agreed to participate with those withdrawing (n=2) or refusing citing fears over lack of confidentiality, reluctance to discuss painful subjects, lack of time or pressure from a male partner not to contribute.

The women were audiotaped during their interview which was transcribed verbatim. Two women declined to have an audiotape so the interview was written as a recording. Although four women out of the sample required acute psychological help due to distress, the women indicated that the interview itself was a “valued opportunity to have their voices heard and all expressed being willing to be contacted again” (p.1730).

The study found the women struggled with settling into a new country as migrants. One third of the sample entered England as asylum seekers; for the women in this category poverty and migrant status co-existed, deepening feelings of displacement. Over half the sample had children and “the burdens of caring for the children were exacerbated by moral anxieties associated with the social construction of motherhood; mothers are traditionally expected to be the moral guardians of society” (p.1732). The need to deflect associated stigma of being an HIV positive mother was reflected in the stories of how the women contracted HIV, blaming the actions of someone else or misfortune.

In conclusion Doyal & Anderson found motherhood raising children and being HIV positive in African cultures, whilst being central to a woman’s identity, brought many burdens. Similar findings have emerged from studies in the United States where socially

marginalised women report the stress of motherhood in the shadow of HIV but motherhood's enduring feature is its "normalising activity" (Ciambrone, 2003, p.110). The HIV positive mothers in studies (Doyal & Anderson, 2005; Ciambrone, 2003; Hardesty & Black, 1999) report the significance of living for the children as a motivating factor in coping with the disruption of a marginalising lifestyle or disease.

Being HIV positive dictates the context for mothering and the women from the above studies managed the integration of their diagnosis with mothering activities. These activities provide an element of normality for the HIV positive women and social acceptance, and identity within their society. Studies also identified motherhood in the context of HIV provides some women with salvation and a feeling of righting the wrongs in their previous life experiences. The subject of mothering in the context of being HIV positive as a coping mechanism is discussed in the next section.

Motherhood as a Coping Mechanism

This theme of children enabling a coping mechanism to manage potential fatality is highlighted by Ciambrone (2003). Her study found mothering helped HIV positive women cope with their illness as it was a source of commitment, affection, and role fulfillment. The heightened importance of motherhood following a HIV diagnosis has been further supported by findings from Kass & Faden (1996) who found that feelings about motherhood are integral to the lives of HIV positive women. One participant reported the fatality of her illness meant motherhood was a valued role, "Now I see that it's the most important thing in my life because now I don't even know how long I would

be able to be a mother...” (p.430). The Australian HIV Futures Surveys (McDonald & Hurley, 2002) are self administered national questionnaires widely distributed to people living with HIV/AIDS (PLWHA) via community organizations and various health and social agencies. The questionnaires cover a range of demographic, social, attitudinal and health status issues. The Futures Surveys 1 & 2 were undertaken in 1997 and 1999, sample sizes in 1997 were 84 women and in 1999, 89 women. From the sample who returned completed questionnaires in 1999, 24 women were requested to participate in semi structured interviews. This sample represented 10% of the estimated number of women living with HIV in Australia (McDonald, 2001). The interviews revealed issues for the positive women which included how their mothering style had been altered by their HIV diagnosis.

Women talked about the difficulty of living with a life threatening illness and balancing the need to provide their children with love and security and making them independent and able to cope should their mother become ill and then die. One participant revealed “...they’re better off if they weren’t close to me-it would be easier for them. I found it very hard to be loving and caring” (McDonald, 2001, p.27). Another participant in the study reported how fulfilled she felt becoming a mother; “...my baby (has) made so much of a difference because I have always wanted to have children...my baby’s really planned and really wanted...you just wake up every morning [and] you just have to pinch yourself” (McDonald & Hurley, 2002, p.29).

The cultural impact of motherhood as a source of acceptance in society was highlighted by Doyal & Anderson (2005). The cultural norms and expectations also shaped the pursuit of motherhood as there were constructed gender differences in duties, responsibilities, rewards and entitlements (p. 1731). The study of sixty two women from eleven different African countries living as migrants in London, England found motherhood was a “source of legitimacy and identity” in their culture which they identified as African. One woman said “if you have no children it means you are less of a woman” (p, 1731).The social and economic consequences of failing to have children for these women was illustrated by a woman who said “my husband left me because I had produced only one daughter” (p. 1731). Although the women were refugees from war torn areas of Africa and arrived in the United Kingdom seeking asylum, their cultural norms and values continued to be a source for coping with their diagnosis.

Studies indicate women infected and affected by HIV are more likely to be women of colour, poverty, and low educational attainment (Hackl, Somlai, Kelly, & Kalichman, 1997; Jirapaet, 2001; Mc Donald, Grierson, De Visser & Bartos, 2000). These demographics have been reflected by studies from the UK, US, Australia and New Zealand (Ciambrone, 2003; McDonald & Hurley, 2002; Doyal & Anderson, 2005;Grierson,Thorpe, Pitts et al,2008). The studies indicating the demographics of women from three continents infected with HIV/AIDS reflect the low socioeconomic position these women occupy. The social position of mothers are of women identified as taking on the role of primary caregiver to children and their character within that role identified as gender-role conformity and seeks to identify women as caring and selfless.

The ideology of motherhood has both a historical and social contingent reflecting the current social mores. In the twenty first century motherhood is set in the context of technological advances enabling motherhood to be achieved in the face of adversity such as medical conditions and unexplained infertility. Women also play a large role in the economic function of the family with women being expected to return to the workforce after birthing children (Kent, 2000; Harsch, 2006). The transition to motherhood has been described as a process which “requires extensive psychological, social and physical work at a time when her vulnerability is heightened” (Mercer, 2006, p.649). In the next section the work of Reva Rubin and Ramona Mercer, two nursing theorists, is discussed and as it provides a theoretical base for the discussion of the transition to motherhood for women with HIV.

The Theory of the Transition to Motherhood

In order to research the transition to motherhood for an HIV positive mother an exploration and identification of the key aspects of maternal role theory needed to be undertaken. Reva Rubin is a nurse-midwife from the United States of America whose research and theory development stemmed from research questions stimulated by role theory and exploration of the development of the maternal role (Bryar, 1995). Maternal role attainment is a process by which the mother achieves competence in the maternal role and it is an area of importance to midwives and health professionals who work with mothers during the first year postpartum as difficulty fulfilling the maternal role has been shown to have consequences for the child (Mercer, 1990, p. 6; Mercer, 1981). Reva

Rubin (1984) studied the processes involved in maternal role attainment and found deviations from normal resulted in profound doubt about competence and self worth. The importance of exploring the transition to motherhood is further illustrated by Rubin's quote "We haven't begun to find out what is going on in the creative, experiential process of being a part of making a baby, making a mother" (Reva Rubin, 1984, p.4).

Rubin identified and described from her twenty-five years of research and analysis on maternal role attainment that achievement of the four tasks of pregnancy signalled a woman with a positive identity as a mother. The four tasks identified are ensuring safe passage of herself and the child, ensuring social acceptance of herself and her child by people who are significant to them both, ensuring attachment to the baby and an understanding of the complexities of mothering (Josten, 1983).

Mercer (1990), in her study entitled 'Parents at Risk' wrote "transitions as major modes of development are turning points in a person's life in which a new direction is taken that requires a change in role behaviours, responsibilities, goals, identity and feelings about one self; when transition departs from social norms parents' challenges are profoundly increased" (p.3). As discussed in the previous section being a mother with an HIV diagnosis is regarded as departing from social norms.

Deviations can be described as the course chronic illness such as HIV/AIDS causes its sufferers to take, where the symptoms and treatments disrupt everyday life. Bury (1982, cited by Green & Sobó, 2000, p. 70) refers to the disruption of one's expected life

trajectory as “biographical disruption”. The course of chronic illness can prevent people from playing their role, marginalizes them and leads to a feeling of loss of identity (Herlich & Pierret, 1987, cited by Green & Sobo, 2000, p. 70). The theme of identifying features which correlated with achieving the transition to the maternal role was identified by Jirapaet (2001). The phenomenological study explored the factors affecting maternal role attainment in 39 HIV affected low income Thai mothers. Jirapaet used a convenience sample that was selected for their “successful adaptation” to motherhood (p.25). However there was no classification of how “successful adaptation” was measured in the study. The low income threshold was not discussed by the author.

Using in depth interviews and a Maternal behavioural questionnaire Jirapaet identified six themes that described successful attainment of the motherhood role which identified the use of internal and external resources; “setting a purpose for life, raising the infant, keeping secrets from others, a feeling of normalization, having good quality support from others, having hope for an HIV cure and receiving accessible, pleasant health care services that protect anonymity regarding HIV status” (p.28).

Route of Woman’s HIV infection

In Jirapaet’s research 74% (n=29) of the participants reported becoming infected via sexual intercourse with their husbands compared to 26% (n=10) who reported prostitution as a mode of contracting the disease. This finding was reflected by Ciambrone’s study (2003) of 37 women between June 1996 and June 1998 in which

nearly 60% (n=22) reported contracting the virus through heterosexual sexual intercourse as opposed to 32% (n=12) who contracted the virus via intravenous drug use.

The mode of transmission of the virus reinforces the fact that women are biologically more vulnerable to HIV than males, they are eight times more likely to become infected (Alexander, 1996). Biologically women's vaginas are vectors for the absorption of HIV. Further to this risk culturally and socially women may not be in an empowered position to negotiate sexual intercourse using a condom.

Having Hope

Continuing the theme of motherhood as a coping mechanism for HIV positive women, spirituality was an identified method of coping for women who were either migrants or as part of their culture. Goggin, Catley, & Brisco et al.(2001) in their study of fifty five HIV positive women in New York City aimed to find out about the psychological gains of a positive diagnosis. Goggin et al., posed questions about two best and worst things that have happened since becoming HIV positive. They found that women identified a "change in self" (p. 82) which led some participants to change their lifestyle-recovering from substance abuse, feeling empowered through taking care of their health and having a different perspective on their lives which encompassed a new sense of spirituality. Participants were also asked what advice they would offer to newly diagnosed women and the recommendations were for "maintaining a positive attitude, creating a support system, educating oneself and taking care of oneself" (p. 87).

The subjects in Jirapaet's study described their faith as Buddhist and referred to Karma as one of the principles governing their future life, with Karma, being their life now as a consequence of their actions in the past or in a previous life. The women in Jirapaet's study (2001, p. 30) sought to cleanse or to flush out the infection by spiritual acts such as freeing animals or consumption of specific foods or holy water. The women in Doyal and Anderson's study described religious faith as a major source of support in coping with their difficulties, "This disease will probably make me lose my life but He will give me my life back in heaven" (Doyal & Anderson, 2005, p. 1737).

HIV and the diagnosis of terminal illness can be the "impetus to renew or strengthen spiritual ties" (Ciambrone, 2003, p. 79). These acts of faith can be viewed as enhancing a sense of control over the management of their illness by sharing the psychological and physical responsibility for their healthcare.

Health Services Environment

The health services environment was highlighted in two studies as an area which could improve to meet the psychological and social needs of HIV positive women (Jirapaet, 2001; Hackl, Somlai, Kelly, & Kalichman, 1997). Hackl et al identified the need for low-cost transport to the clinics and 'on-site child care would eliminate two major access barriers' (p. 61). Jirapaet (2001) found that 98% of the HIV positive mothers in her sample avoided using health services, citing lack of privacy for personal questions, a lack

of stable care provider and information which would have disclosed their status to family members at home (p.30).

HIV and AIDS services were set up in the wake of the disease predominantly affecting homosexual men, “a group often knowledgeable about AIDS care” (Hackl et al, p. 60) which means health care professionals need to adjust their time to offer full explanations of the aspects of HIV to heterosexuals. Women in Jirapaet’s study (2001) reported “impolite talk” and “scolding and acting sarcastic” (p. 30) from the healthcare workers attending them at the clinic as a further reason for non engagement with health services.

Respondents in Kass & Faden’s study (1996) cited favourable comments from practitioners about becoming pregnant with HIV, information was shared with the positive women about the risk of mother to child transmission and healthcare workers respected it was their decision to make. Some women had met with negative comments which reflected the health workers prejudices.

Summary

The literature search aimed to find out what is already known about HIV positive mothers as they make the transition to motherhood and to provide an understanding of the theories of maternal role attainment and the transition to motherhood. The studies reviewed indicate HIV positive women are generally from a vulnerable population or social group that experiences limited resources and a high risk of premature morbidity and mortality (Bott, 2005). The challenges for HIV positive mothers identified in the literature are those of social isolation, stigma and managing disclosure. The constructive aspects of

motherhood in the context of HIV are social role fulfilment, something to live for, and giving positive women a sense of purpose and grounding. The themes from the literature illustrate that motherhood in the context of HIV enables the woman to have an identity and a role which is incongruent with HIV/AIDS (Kass & Faden, 2006, p. 430) but can be a supportive coping mechanism (Hackl, Somlai, Kelly & Kalichman, 1997).

There were no studies in the literature review exploring the transition to motherhood for HIV positive women undertaken in New Zealand. It is an appropriate time to examine the effect of an HIV diagnosis on women during their childbearing years as New Zealand implements a universal offer of antenatal HIV screening as part of routine antenatal care. It is of equal importance to explore what it means to be an HIV positive woman when she is considering becoming a mother at a critical time in her life and those of her children, during their transition to motherhood.

CHAPTER THREE

The Research Methodology and Research Method

Introduction

The aim of this research was to describe the transition to becoming a mother for women who have been diagnosed with HIV prior to pregnancy. In Chapter Two the literature review provided an overview of the research and theory of women's transition to motherhood. In this chapter a presentation of the research process including the methodology and research method is given.

The literature review provided an overview of the different methods and methodologies used in studies whose participants were HIV positive women becoming mothers. The rationale for the methodology and method used is described.

Methodology and Methods

Methodology refers to the theoretical analysis of methods chosen for the process by which the researcher seeks to answer the research question. The use of qualitative methodology in this study enabled the stories of the transition to motherhood for HIV positive mothers to be explored in order to illuminate "... the particulars of human experience in the context of a common phenomenon" (Ayres, Kavanaugh & Knafel 2003, p.871). Qualitative research is concerned with the meanings people attach to

their experiences of the social world and how people make sense of that world (Mays & Pope, 2000).

Methods describe the systems used to gather and analyse data in order to answer the research question. In this study the data collection method used was narrative interviews. Narrative is “derived from the latin word “narrare” which means to report; to tell a story” (Jelovchelovitch & Bauer, 2000, p.59). Narrative interviewing enables the narrator to make sense of the biography they are relaying, “narratives become an important device through which sense can be made of periods of transition that may invoke biographical disruption”. (Miller, 2000, p.315). Narrative interviewing was a technique I was comfortable with; as a midwife I listen to women’s stories on a regular a basis and I too relay information to students of midwifery in storied form. It enables the information being shared to be set in a context. This statement is supported by Jelovchelovitch & Bauer (2000) who write “narrative is not just a listing of events, but an attempt to link them both in time and meaning.....if they are composed as a story the ways in which events are related allow for the meaning-production operation of the plot.” (p.59). Jelovchelovitch & Bauer (2000) identify a plot as a demarcation for the beginning and end of a narrative. An opening statement was made to the women at the start of the interview, “I would like to ask you where it started for you, motherhood with HIV?” The narratives were analysed using a thematic analysis. Van Manen’s (1990) sententious approach was used as it enabled the identification of an underlying meaning of a phenonomen in a study with a small number of participants. Another author of thematic analysis was also read as part of the process of identifying the correct fit of the

interpretation of the data. Boyatzis' (1998) method of thematic analysis was not chosen as it described a method of encoding qualitative information (Boyatzis, 1998, p.4) rather than examining the underlying meaning of the phenomenon and with so few participants coding the information would be too difficult to interpret.

ETHICAL CONSIDERATIONS

Conducting qualitative research involves emotional, value laden, theoretical considerations, preferences and world views (Boyatzis, 1998). Prior to commencing the current study a research proposal was presented to the Massey University Human Ethics Committee and Multiregional Health and Disability Ethics Committee (MEC/07/09125); written approval was received on 25th February 2008 (Appendix A).

Completion of Locality Assessment forms was requested by the Multi-regional Ethics Committee for each geographical area where interviewing would take place. In addition to the forms there was a requirement for consultation and permission to be granted from local Maori health providers or IWI representatives in the locality. In one locality the consultation was held in a face to face meeting with the District Health Board's Head of Maori affairs. He advised that participants identifying as Maori should have provision made to invite a Kaumatua as part of the interview process. As part of the Multi-regional Ethics Committee recommendation an application for my research proposal to be considered by another District Health Board was written. A separate application was made to a Maori Health provider and approval was confirmed by letter in April 2008

(Appendix B), detailing their requirements, which reflected the recommendations of the Head of Maori Affairs.

PARTICIPANT RECRUITMENT

Recruitment for participants started with exploring possible agencies and social networks for HIV positive women on the North Island of New Zealand. This proved difficult as routine antenatal HIV testing had not been implemented nationally and so the numbers of known HIV positive women were low. At the time of recruitment, antenatal HIV screening in New Zealand was beginning to move from a risk assessment based blood test i.e. offering the test to women with a history of intravenous drug use, country of origin where there is a high prevalence of HIV infection, occupation identified as a sex worker to one of a universal offer of testing for HIV to all pregnant women.

The introduction of a National Antenatal HIV screening programme had not yet been fully implemented at the time recruitment for this study started. One District Health Board had implemented the routine discussion and offer of antenatal HIV testing in 2006. After discussing the study and criteria for inclusion, the advice from the District Healthboard was that the number of women eligible for recruitment would be extremely low. This was disappointing as my clinical experience and interest in exploring the transition to motherhood for HIV positive women was borne from clinical midwifery experience gained in the UK, where antenatal HIV screening had been a normal part of antenatal care since 1998 (Kennedy, 2003). Allied to this was the fact that an HIV positive diagnosis remains a stigmatising condition, and confidentiality would be of high

importance to the participants, factors I thought would have implications for the number of women willing to participate. I aimed to recruit four women.

The next step was to advertise for potential participants and circulate details of the proposed study amongst health professionals and social support networks engaged with HIV positive women (Appendix C). A variety of methods of contacting various agencies and District Health Boards about the study was used including e-mail, telephone and personal visits. I contacted Positive Women, a charitable peer support organisation, the Community Aids Resource Team and the High Risk Clinic under a city based District Health Board. A Clinical Nurse Specialist (HIV) and Infectious disease Consultant at another District Health Board were also contacted and informed about the research and the inclusion criteria for potential participants. The District Health Board was in an inner city area.

The Multi-regional Ethics committee had granted permission for the research to commence in this locality. After communicating via email the service providers and support groups confirmed there were potential participants in the area. In order to circulate the details of the study across the North Island of New Zealand to capture potential participants, advertising the details of the study and inclusion criteria were considered. The cost of advertising the research in a professional journal or local newspaper was prohibitively expensive for me so networks with other health professionals were utilised to discuss the research e.g. during refreshment breaks at

professional meetings such as Ministry of Health meetings, which I attended to discuss the implementation of a national universal routine offer of antenatal HIV screening.

Positive Women had approximately 144 members in 2008. The coordinator offered to assist with the recruitment process by placing an advertisement in a Positive Women newsletter and my name was placed on the newsletter mailing list to enable me to gain an insight into the issues facing positive women and a sense of their community. Potential participants were able to read an article in the newsletter which detailed my journey as a midwife with an interest in HIV and motherhood (Appendix D). A photograph of myself was included so potential participants could make a perceptive judgement about whether I was someone they could share their story with. This personal touch was important as it portrayed me as being transparent in my interest.

The advertisement in the newsletter had potential to be a snowball method (Goodman, 1961) of recruitment as women reading the advertisement may have known other women fitting the inclusion criteria and inform them about the study. This “snowball” method of recruitment was successful in recruiting one participant.

One potential participant had been told about the study from the Community AIDS Resource Team and texted me to say she had been informed about the study; we spoke on the telephone to discuss the study and the need for me to organise travel arrangements to her locality for the interview. When I tried to re-contact the woman to confirm my travel

arrangements she failed to return my text messages and telephone messages, so I assumed she no longer wanted to participate in the research.

I viewed my role as a researcher as one that enabled participants to feel safe and secure to disclose their story and the participants felt I would respect the information shared and uphold the boundaries set in the consent process. A participant information sheet (Appendix E) about the research was made available to all potential participants. The participant information sheet outlined the research process including the need for written consent. The information participant sheet was posted or sent via email and a copy given again to each participant prior to commencing the interview. The participant information sheet detailed the interview was to be audio taped with their permission. The interview could have gone ahead if they declined audiotaping although I would need to have written notes of their interview. A copy of the transcript was sent to each participant for review and removal of data or alterations to be made. Each participant was made aware the audiotapes would be kept in a locked filing cabinet separate from the consent forms, and the transcript, audio tapes and consent forms held for a total of five years as required by Massey University Ethics Committee.

Inclusion criteria

Participants were invited to be included in the study if they met the following criteria; residing on the North Island of New Zealand, diagnosed HIV positive during pregnancy with a baby from that pregnancy who was 4-6 months old, and able to speak and understand English.

The participants who initially made contact had babies who were older than the age criterion and the women had been known to be HIV positive before their pregnancies. It was becoming evident that the low numbers of women diagnosed HIV positive who met all the criteria and were willing to come forward to participate was zero. I lodged an application to change the criteria for participation with the Multi-regional Ethics Committee to include participants living on the North Island of New Zealand, diagnosed HIV positive *prior to* or during pregnancy with a baby from that pregnancy who was aged *up to 24 months old*; able to speak and understand English. This enabled me to interview the two participants who had responded to the article in the Positive Women newsletter. The change in criteria was approved by the Multi-regional ethics committee.

Recruitment was slow despite personal visits, regular email contact and telephone calls to the organisations and health professionals who agreed to assist. The reasons behind the slow recruitment could be attributed to a number of factors; namely the numbers of women fitting the criteria were low as predicted, the stigma surrounding a positive HIV diagnosis and the need for women to protect their privacy, and maybe the health professionals did not support the study and so did not discuss it with potential participants or it could have been they did not have anyone in their caseload who met the criteria.

Two participants initially presented in direct response to the advertisement in the Positive Women Newsletter. A third participant came forward after being approached directly by the Positive Women Co-ordinator to ask if she would consider being interviewed for the

study. Once contact had been made with each participant and they had given verbal consent to proceed, a participant information sheet detailing the study's aim and the process for ensuring anonymity of the data was posted or emailed. Each participant advised me about the best method of receiving written information. This enabled the participant to have control over the process of how to manage disclosure to partners, husbands or others who shared their living arrangements, about their participation in the study.

Informed Consent

All potential participants were informed that the study was to meet the requirement for the completion of a Master of Philosophy degree in Midwifery studies. All participants were given an information sheet detailing the aim of the study and the method of enquiry to support the ethical principle of informed consent. All potential participants were made aware that parts of the research may be accepted for publication in healthcare journals and maybe discussed at healthcare forums or conferences. Potential participants were able to ask any questions about the study and their involvement prior to signing their consent to participate. All participants were informed they could withdraw from the study at any time prior to the writing of the thesis.

Accountability of the researcher

The ethical principle of accountability is partially fulfilled by the completion of an application to the Multiregional Ethics Committee. The framework for the application details the supporting literature for the research and the participants to be recruited. An

interview schedule was included with the participant information sheet detailing the academic support for the research. As a practising midwife and student of Massey University, I acknowledged the professional accountability that needed to be maintained through interactions with the participants. The researcher acknowledged the personal accountability of her actions and omissions whilst undertaking the research process.

The protection of privacy, confidentiality and cultural beliefs and practices is acknowledged and supported during the research by the researcher being held accountable for her actions and omissions. The Participants Information sheet (Appendix E) formed a contract of privacy and confidentiality between both researcher and participant. It was understood by both parties that disclosure of the stories was undertaken on the premise of trust and integrity for both participants and researcher. It was acknowledged by the researcher that the participants would be sharing their personal journey and the stories or narratives may have never been verbalised to a stranger; this commanded respect for the participants' values and belief system which may have differed from mine.

In order to support the promotion of a responsive, supportive environment, participants may require differing levels and types of support, so each were given a list of contacts for local support agencies. The interviews were undertaken at a place and time of the participants choosing where they felt physically, psychologically and culturally safe.

Confidentiality

Confidentiality is crucial to enable the participant to feel psychologically and physically safe and therefore comfortable to share their story. Potential participants were informed that data would be recorded on an audio cassette and transcribed by myself, the researcher. Transcriptions of the interview were then mailed out to the participants for their perusal and comments. Two participants' chose to use pseudonyms for themselves and their family members, one participant consented to the use of her actual name and that of her family where mentioned. All three participants received their own transcripts and two returned their transcripts with spelling amendments and paragraphs deleted.

The gravity of the research process and findings is acknowledged. The academic pursuit of knowledge during the research process means I can be placed in a difficult position of seeking truth and enhancing knowledge but need to avoid the appearance of prying into private lives. This sentiment is reflected by Lalor, Begley and Devane (2006, p. 613) who write "Midwifery research from a social perspective seeks to explore the feelings, values and reactions to life-changing events of those experiencing the phenomena and this often includes those who are vulnerable". To support confidentiality and privacy and prevent accidental disclosure the use of pseudonyms and erasure of identifying information in the final transcript was undertaken. All written transcripts were returned to me from the participants. I offered to return the audio tape of the participant's individual interview at the end of the study but all three participants declined. The audio tapes and transcripts of the interviews are clearly labelled and stored in a locked cupboard. The raw data i.e.

audio tapes and written transcripts are being stored separately for five years and then will be shredded at a local facility where certification of their destruction will be issued.

Research as a Partnership

The partnership model of care is the prevailing model of Midwifery care in New Zealand (Guilliland & Pairman, 1995). The cornerstones of partnership can be defined as acting in good faith, working together with an agreed common purpose, interest and co-operation to achieve a positive outcome and ensuring the integrity and wellbeing of both partners is preserved (Wepa, 2005, p. 48). During the life of the research study the partnership was upheld through communication about the purpose and intent of the research, consent to participate, exchanges about the data and the development of the study and absolute recognition of the valuable contribution from the participants. This was fulfilled by regular email contact and the publication of a thank you letter in the Positive Women's newsletter.

Promotion of the interests of HIV positive women and mothers

It was anticipated that the narratives of the participating HIV positive mothers would be heard through the publication of articles in midwifery and nursing practice journals once the thesis had been completed. The publications would further the promotion of understanding of the factors which promote and impede a smooth transition. This understanding would be aimed at health professionals primarily but the findings detailed in Chapter Five would be applicable for circulation in the public arena.

Advocacy

All participants were given a list of advocacy services in their local area with a free phone number. The participants were notified during their consent process that any information disclosed during the interview would not be able to be accessed by an unauthorised third party e.g. Immigration authority, Housing New Zealand, Work and Income New Zealand. I needed to remain impartial to the information shared in the interviews. Advocacy on a personal level would have meant me becoming involved in their personal lives; this could have contaminated the data as I would have gained an extra insight into some aspect of their life and this would not have been able to be replicated for the other participants. I assured the women that I would not be in a position to actively advocate for them or their families as this would bias the research data. If any issues around service provision or support arose then these were to be discussed outside of the interview session.

Avoidance of Harm

There is a risk of psychological harm for participants sharing their life story around their HIV diagnosis and subsequent transition to motherhood as a variety of emotional responses during a period of continued transition could be highlighted. All the participants were offered a follow up phone call the day after the interview and a discussion took place prior to the interview to ensure a support person was aware of the participant's attendance at the interview and would be available if needed. For the

purposes of this study participants were provided with a list of contacts in their local area if they need psychological support as a result of the interview process. The telephone numbers for 24 hour AIDS hotline, Office Hours -Positive Women Inc, and New Zealand AIDS Foundation Centres were given at the time of the first meeting.

There is also the risk of harm to the researcher and according to Lalor, Begley & Devane (2006) a midwife in a research role will need to “develop skills to monitor the possible entanglement of the woman’s suffering in her own life and control her own emotions during the resurgence of women’s feelings whilst re-telling their stories” (p.613).

Suggestions to prevent such harm are to take time out between interviews to become part of the real world, transcriptions could be undertaken by a professional transcriber, the setting of boundaries within the interview so the interviewer does not get drawn into the participants’ agendas (Rowling, 1999). However detachment or boundary setting could be an antithesis towards maintaining and providing a safe environment for the participant.

Conflict of Interest

No conflicts of interest have been identified at the time of writing. I ensured the participants would not be known to me prior to consenting to participating in the study and if I came to be in a position where I was required to provide midwifery care at a later date then I would arrange for another midwife to provide care. I would not place myself or the participant in a position where disclosure could occur or the findings of the study become distorted. The vulnerability of the women was acknowledged and respected through application of the ethical principles discussed above.

METHOD OF DATA COLLECTION

The method of data collection used was narrative interviewing. This method of data collection would enable the participants to narrate their own experience with interview questions directed at eliciting the information needed to answer the research question as described by Hermanns (1995, cited in Flick, 2009). “In the narrative interview, the informant is asked to present the history of an area of interest, in which the interviewee participated, in an extempore narrative...The interviewer’s task is to make the informant tell the story of the area of interest in question as a consistent story of all relevant events from its beginning to its end” (p.177). In the initial ethics application I had proposed to interview the women on one to three occasions but this proved prohibitively expensive both financially and in terms of time due to the distances to be travelled so only one interview was undertaken with each participant. There was email contact with two participants but this was used to thank them for their participation. I did not enter into any further contact after the interviews as not all the participants could be easily contacted and this was not discussed prior to them entering the study.

The interview process

The question posed to participant’s during the interview was an invitation to ‘walk me’ through their experience from being diagnosed with HIV to the current day, incorporating their pregnancy, birth and transition to motherhood. The chronological sequencing of the narrative interview enabled participants to reflect on the progress they had made but also

the reliving of events whilst narrating their story was a powerful force from which the re-emergence of emotions felt at that time surfaced.

The face to face context of an interview enabled the discussion of private and sensitive information. Sensitive information is described as any information which poses an intrusive threat, “dealing with areas which are private, stressful or sacred” (Lee & Renzetti, 1993, p.5). HIV is a stigmatising disease and those affected by it can feel marginalised by society. Participants in the study had young children and families, some of whom are unaware of the participant’s diagnosis. It was anticipated participants would feel apprehensive due to the sensitive nature of their information revealed during the interview. Only one child (aged eighteen months) of a participant was present during the interview. The interviews were audiotaped to assist with the recall of large amounts of information and to enable, through repeated listening, the identification of themes from all three interviews.

Location of interviews

The location and time of the interviews were negotiated with the participants via text messaging or email. Two of the interviews were undertaken in the woman’s homes and one was undertaken at the Positive Women Headquarters.

In the words of Van Manen (1990, p. 102) “the home reserves a very special space experience which has something to do with the fundamental sense of our being. Home has been described as that secure inner sanctity where we can feel protected...home is where we can be what we are”. Van Manen refers to the “lived space” (p.102) and as

such enquiring about the lived space a context is provided for us to understand that person and give quality of meaning.

At the interviews I was shown scrapbooks and newspaper articles detailing their personal journey with motherhood and HIV. This felt very special as it enabled me to gain a deeper understanding of their lived experience and added a depth of meaning to the words the women were speaking.

I had negotiated using a consulting/counselling room at a hospital and Positive Women's headquarters in case this was easier for the women to travel or indeed combine an appointment at the hospital. This was based on an assumption that HIV positive women and their babies would prefer the convenience of a site where they were undergoing regular health assessments with their physician or Clinical Nurse Specialist. This was not the case as two interviews took place in the participants' homes and one participant chose to meet with me at the Positive Women Headquarters.

The interviews were approximately two hours in length. An interview schedule was prepared to support me in remaining focused during the interviews and to enable the stories to focus on the subject area. After undertaking two out of three interviews I felt more at ease as an interviewer by inviting the woman to talk about her journey of becoming a mother who was HIV positive.

Data analysis

Thematic analysis was used to analyse the data from the interviews. The participant's narrative describes the experience and thematic analysis using Van Manen's (1990) phenomenological approach interprets the experience. Van Manen's (1990) phenomenological approach of thematic analysis was selected to interpret the narratives as it enabled the lived experience of the three participants to be captured in their own words and the richness of their stories to be maintained.

The audiotape was listened to in its entirety prior to transcribing. This enabled me to reset the scene of the interview in my mind. The audiotape was then transcribed sentence by sentence and typed into a word document. This was a lengthy process as I typed word for word from the audiotape; I required the place where transcribing occurred to be private so the narratives could not be heard by anyone else. The narrative text was listened to and re-read to capture a phrase or phrases which form the meaning or significance of the text as a whole. The fundamental meanings of the text then formed the basis of the 3 findings chapters.

The written transcription of the interview was returned to the participant to check for accuracy and for them to delete any information or sentences they did not consent for me to use in my thesis or publications or presentations arising from the completed work. Two out of the three participants returned a copy of the transcript. On reflection I would now do this process differently and return the written transcript of the interview but also add the analysis of the interviews so participants can engage in validating my interpretation of

their story and to give meaning to what was said, almost offering some closure for them from the process of being interviewed. One copy of each transcript was sent to each of my supervisors with the knowledge and consent of each participant. The names of the participants, their families and identifying features have been changed to respect the privacy of the families.

Thematic analysis

Van Manen's (1990) selective or highlighting approach was utilised to reveal the themes identified from the narratives of the participating women of becoming a mother with HIV. Themes were identified by repeated listening and transcription of the narratives, this enabled me to hear the nuances in the voice and the emphasis on words or phrases which facilitated the meaning and organisation of themes (Van Manen, 1990, p.93).

The sentences and phrases I highlighted from all three transcripts were then written down under headings which I formed to encompass the meaning behind the themes. This was very exciting for me as I could see very clearly the themes emerging and it reinforced my confidence in the chosen method of thematic analysis.

The themes were then written as headings with the participants' phrases underneath so the rich contemporary data was kept in its original form and context and not disturbed by my interpretation. The findings presented in thesis capture a moment in time and may well be interpreted differently with the passage of time or by someone else reading the excerpts from the women's narratives.

The themes identified from the narratives form the findings chapters. Chapter Four entitled “Becoming a Mother” encapsulate the psychological challenges the participants in this study managed as they made their journey toward motherhood. Themes of stigma and disclosure are discussed in Chapter Five. Quotes from the narratives in Chapter five illustrate the issues of managing disclosure due at the risk of being stigmatised. The themes reflect how participant’s manage and control disclosure of their diagnosis amongst their family, friends, children and health professionals.

The theme of knowledge is power form Chapter 6. The chapter identifies how participants sought to use their knowledge of their condition to inform decisions about their care. It illustrates how participants sought to readdress the imbalance of power experienced as they navigated the health professionals in the health service.

All three participants were offered the choice of using a pseudonym whilst participating in the study. Two participants chose to use pseudonyms for themselves and their family.

Rigour of the research

Qualitative research is often criticised for lacking scientific rigour (Mays & Pope, 1995). Rigour or the underlying truth of the research is tested by using certain strategies. The issue of proving the findings correct and truthful is a challenge in qualitative research due to the method of data collection and methodology. Individuals construct identities through story telling or narratives (Riessman, 1993). It was imperative, that I the interviewer identified the person as they perceive themselves as identified from their narratives and not how I might see them, as this would mean a biased finding.

The narrative method of data collection was used for this study and to enable the truthfulness of the findings to be checked the strategies of triangulation and validation were used. The process of investigator triangulation (Denzin & Lincoln, 2003) was undertaken, with my supervisors reviewing the transcripts and cross referencing the identified themes against the themes I identified. On reflection I could have arranged to send the transcripts and a summary of the identified themes back to the participants.

Trustworthiness

Trustworthiness is the term used amongst qualitative researchers to describe the process of ensuring or evaluating 'rightness/correctness' of the results of the qualitative research study. The criteria for judging the trustworthiness of this research is defined using the following criteria; Credibility, Auditability, Fittingness and Confirmability (Schneider, Whitehead, Elliott & Haber, 2007). Trustworthiness also extends to the relationship between the researcher and participants. In line with the upholding of the principles of the Treaty of Waitangi the principle of protection was afforded by ensuring privacy during consultation about arranging an interview date and time, privacy during the interview, privacy of the data collected and privacy in removing identifying features of the participants' narratives.

The term Reflexivity describes understanding the way the researcher and the research process may have shaped the collected data, including the role of prior assumptions and experiences that can strongly influence the research process (Mays & Pope, 2000). As

already stated I came to the research process with extensive clinical midwifery experience of HIV positive women during the childbearing period. I felt comfortable with discussing all aspects of HIV management with women but it became evident very early on that my experience was not going to be easily transferred to the role of a qualitative researcher.

I needed to approach the research process with a perspective of discovering something for the first time; it was a series of new discoveries for me, particularly in the role of researcher and interviewer. I felt my clinical midwife interviewing skills were not congruent with the skills needed for interviewing women about their lived experiences; and the heavy responsibility of analyzing the information so it captured the meanings of what the participants said was demanding. A confidential reflective journal was started separately from the research data to assist me with keeping emotionally grounded during the transcribing process. On reflection I sense I did not knowingly contaminate the findings in the study or lead the women toward discussing the disempowering aspects of their care.

Credibility

The credibility of the research is described as the truth of findings as judged by the participants and others within the discipline (Schneider et al., 2007, p.149). In order to fulfil this criterion the transcripts of the participants' interviews were sent to the individuals for their approval and to omit any details or data. In order to corroborate my findings from the thematic analysis, the transcripts and the subsequent themes identified

were reviewed by my two supervisors who are academics and practitioners in the discipline of midwifery. Triangulation is used in this context as a strategy to promote the quality of the qualitative data, by using investigator triangulation (Denzin & Lincoln, 2003). Investigator triangulation uses different observers to detect bias that the researcher was not aware of and enabled the requirement of credibility of the research to be fulfilled.

Auditability

The method utilized to collect the data is required to be auditable to ensure the same outcomes would be reached if the same process was followed. This criterion pertains to the judgment of the adequacy of information leading the reader from the research question and raw data through various steps of analysis to the interpretation of findings (Schneider et al., 2007). The methods used in this study have been documented in such a way that this criterion can be said to have been achieved by the readers of the thesis.

Fittingness

Fittingness refers to the faithfulness to the everyday reality of the participants. The aim is that the findings are described in enough detail so others in the discipline can evaluate the importance for their own practice, research and theory development. This criterion can be judged by those who have the experience of being HIV positive when becoming mothers. The fittingness of the findings and their importance for theory development, practice and research has been considered by the supervisors of the study.

Confirmability

Confirmability refers to the degree to which the results could be confirmed or corroborated by others (Trochim, 2006). It is a criticism of qualitative research that it is not scientific and therefore results cannot be replicated as the researcher can influence the findings through lack of objectivity and thus the findings can be biased. The strategies for enhancing confirmability in this study have been documented above, and include the reflective journal documentation throughout the research process.

Summary

In this chapter I have presented the methods and methodology chosen to conduct the research to explore the transition to motherhood for HIV positive women. A narrative interviewing method with Van Manen's thematic analysis identified themes that reflected the participants' lived experiences as they recounted their transition to motherhood. The participants' narratives and main themes from the data analysis are discussed in the following three chapters, *Becoming a Mother*, *Stigma and Disclosure* and *Knowledge as Power*.

CHAPTER FOUR

Becoming a mother

“It was a dream come true, miracle, all those things. It’s something that everyone else takes for granted, procreation is such a common thing but its huge when you are HIV positive” (Marama, April 2008).

Introduction

Becoming a mother is an emotional and biosocial journey interspersed with societal and personal expectations (Miller, 2005). In this chapter the narratives of the women provide an insight into the challenges they faced as HIV positive mothers making their transition to motherhood.

Research has shown that women living with a positive diagnosis of HIV face “... a lifetime of physical, psychological and social challenge” (Greene, Derlega, Yep, & Petriono, 2003, p. 32). The three women in this study had all been diagnosed HIV positive prior to their pregnancies and subsequent births, with their babies ranging in age from sixteen weeks to eighteen months old. The interviews and experiences of the participants were set at a time when the universal offer of antenatal HIV testing was not yet available nationwide but antiretroviral therapies, to reduce the risk of mother to baby transmission, were readily available and accessible under the public health maternity service.

The women were asked at the outset of the interview about their emotional, social and psychological journey from the time of their HIV diagnosis and towards the time of giving birth and becoming mothers. This chapter explores the themes identified from the narratives which include the desire for motherhood, negotiating intimate relationships, the psychological work the women undertook to reduce the risk of vertical transmission and how HIV positive women negotiate assimilation of the maternal role.

The Desire for Motherhood

One of the themes identified from the narratives was that of considering motherhood as an option after a positive HIV diagnosis. Motherhood and society's expectations of the associated behaviors of women as mothers is illustrated by the following quote from Daphne de Marneffe, "Desire we've been told is about sex and motherhood is about everything except sex" (de Marneffe, 2004, p.4). In this theme the term "desire" has been used as it illustrates the strength of emotion the HIV positive women portray in their narratives about wanting to become mothers.

Marama speaks about how she felt about the loss of her potential to become a mother when diagnosed with HIV in 1991. When discussing her desire to become a mother the advice she was given was not to consider it as the risk of HIV transmission to the fetus and baby would be high:

"I felt a huge amount of grief, anger and resentment. But the biggest thing for me was that [I thought] I couldn't have a baby. I went to a HIV

specialist in Auckland and he said at the time the risk of infecting a child was 25%, so don't even think about it."

The desire to become a mother was affected by evaluating the risk of transmission to the baby. The three participants in the study were diagnosed at different times in the history of medical, surgical and pharmaceutical advances in the treatment and management of an HIV positive pregnancy. Marama was diagnosed as HIV positive in 1991, prior to the AIDS Clinical Trial Group study (ACTG, 1994) which identified the safety and efficacy of Zidovudine treatment during pregnancy to prevent mother to child transmission. In 1994 the AIDS Clinical Trial Group (ACTG) found a significant reduction in vertical transmission from 25% to 8% when pregnant women commenced the antiretroviral drug, Zidovudine or AZT, during pregnancy and received an infusion during labour and birth (Connor, Sperling, Gelber, et al., 1994). Such was the significance of the finding that the trial was stopped. Zidovudine remains to this day one of the fundamental antiretroviral therapies of choice to reduce the risk of vertical transmission during the childbearing period (Wilkins, 2006 cited by Downing, 2007). The evidence base developed further and the risk of vertical transmission reduced to < 2% if the mother took antiretroviral drugs during pregnancy, had an elective caesarean section at 38 weeks gestation and did not breastfeed her infant (European Collaborative Study, 1998; European Mode of Delivery Collaboration, 1999).

Deborah was diagnosed in 2004 and describes how she thought her diagnosis would prevent her from becoming a mother:

“When I first got diagnosed I didn’t think I would be able to have kids but then I was told I could. I have always wanted kids.”

Motherhood is symbolically important as it confirms some women’s female identity and it is central to their sense of themselves and gives them identifiable social functions (Phoenix, Woollett & Lloyd, 1991). When a person is affected by HIV it can dominate a person’s sense of self. A diagnosis of HIV can have positive or negative effects on a person’s self image thus affecting how people conduct their lives in wider society (Grierson, Thorpe, & Pitts et al., 2008). A survey of people living with HIV/AIDS in New Zealand, found that 48.9% of respondents felt their HIV status was important but not essential to their character (Grierson, et al, 2008, p.37). The survey findings stated that from a sample of 62 HIV positive women, four women were considering having a child in the future and one was attempting to conceive at the time of the report; two women reported they felt it was too risky (Grierson, et al, 2008). Deborah describes how she was made aware through different sources that motherhood was an option:

“I had been on [Positive Women] women’s retreats before my pregnancy where women had been talking about having babies and my HIV specialist had talked to me quite thoroughly about children so I knew I could have him [the pregnancy] and I knew the likelihood would be that he [the baby] would be negative. I had been diagnosed for about a year when I became pregnant and had done a lot of reading. I was more concerned about bringing it [baby] up on my own.”

Barnes and Murphy (2009) explored reproductive choices and decision making for women with HIV from a sample of eighty HIV positive women of childbearing age in America. They concluded that HIV and motherhood is influenced by the sociocultural context in which the women live. The sociocultural context for HIV positive women contemplating motherhood is further overlaid by knowledge or views held by those in the biomedical sciences and by moral judgments. In their qualitative study of fifty six HIV positive women in the United States, Kirshenbaum, Hirky, and Correale, et al (2004) identified a conflict between society's "overarching doctrine of motherhood as a defining aspect of female identity and adverse judgments concerning HIV positive women who choose to become pregnant" (p.112).

In western society motherhood is viewed as a desirable expectation. For a woman, becoming a mother has been linked to enhancing a woman's sexual identity, self image and self esteem. However, HIV positive women are confronted by predominant ideas about social role obligations that "prescribe that most women should be mothers but proscribe motherhood for women with HIV" (Barnes & Murphy, 2009, p. 481). The juxtaposition of women with HIV and motherhood provides a "double bind" (Ingram & Hutchinson, 2000, p.118) in which HIV positive women seek to justify their decision to become mothers against a backdrop of mothering for HIV negative women being a normal societal expectation.

Children can be a source of self esteem for HIV positive women; signifying not only fulfillment of their feminine identity but of social acceptance of herself and the child

(Rubin, 1984, p. 65). In many cultures “motherhood with a diagnosis of HIV still validates her life” (Carovano, 1991, p.131). The link between self esteem and motherhood amongst HIV positive women is confirmed by Wesley, Smeltzer, & Redeker et al., (2000) who compared desire for motherhood among black women with and without HIV infection and found a link between self esteem and having children at home. Wesley concluded that the desire for children was not affected by HIV status, employment, age, education or income but the desire for children for black HIV positive women was a source of self esteem in a society where people affected by HIV are viewed as “promiscuous and dangerous” (p.40). The study found the decision by these women to continue a pregnancy in the light of a “chronic, life threatening disease did not waiver in their desire for children relative to women without HIV infection” (Wesley et al., 2000, p. 41). This is supported by the findings from the current study.

As advances in medical treatment reduce the significant risk of mother to child transmission, motherhood for the three women in the current study continued to be desirable and achievable. Nevertheless being HIV positive and pregnant created significant challenges for the women.

The Effect of HIV on Intimate Relationships

For HIV positive women forming a relationship in which to have a pregnancy and raise a child can be difficult due to the diagnosis. The following statement applies to two of the HIV positive women in the current study. Both women were diagnosed outside of a relationship and subsequently found forming relationships with men, particularly men

who wanted to start a family with them difficult. This is described by Kent (2000, p.104) as she explores the position of women in families, “Becoming a mother implies a new set of social relationships which while traditionally associated with marriage and family are complex and multidimensional.”

For Marama the desire to become a mother was always there, but as she explains it is not that easy to form and maintain relationships with HIV negative heterosexual partners when you are HIV positive. The term serodiscordant is used here to refer to couples where one partner is HIV positive and the other is HIV negative. Marama found that poor quality, serodiscordant relationships can have a detrimental effect on the HIV positive partner’s self esteem:

“I was at a women’s retreat in 2005 and there was a doctor there explaining a project she was involved with piloting IVF treatment for HIV positive women. I had given up all hope of becoming pregnant and all hope of even having a decent relationship. It’s really hard when you have got a positive diagnosis and they are HIV negative as you tend to put up with a lot of crap because you think no-one else will have you.”

Deborah, who was single and living with Dan at the time of the study, explained how a positive HIV diagnosis affected their relationship. Deborah wanted a child with Dan but felt he was not ready due to the psychological and physical obstacles posed by Deborah’s positive HIV diagnosis. Deborah’s child was conceived in a previous relationship which broke down before the birth. Deborah and Dan have no children together:

“He’s sort of in denial and grieving and it’s quite hard.”

Deborah spoke openly about how the HIV diagnosis affects the intimate side of their relationship:

“He’s worried he’s going to catch it. It can put him off when he is sleeping with me, naturally.”

She is very matter of fact about coping with her boyfriend’s reaction and does not admit to it affecting her self esteem:

“He puts up with it; he knows he could leave me and maybe find someone else who didn’t have what I have. I can accept that, but he’s with me now and there’s too much involved. If he broke up with me because of my health condition then he would feel like a real xxxx (expletive).”

Initiating and forming close sexual relationships can be a source of stress and anxiety for both partners as they negotiate disclosure and intimacy issues in their relationship (Van Devanter, Thacker, Bass & Arnold, 1999). Their study of attendees at a support group of serodiscordant couples in the United States of America found stressors for couples in discordant HIV heterosexual relationships are similar to those whose partners are affected by chronic diseases such as cancer or rheumatoid arthritis. Van Devanter, et al (1999) identified the stigma of HIV in society, managing the secrecy of the diagnosis within the relationship and managing the risk of unwanted disclosure to family and friends as the stressors peculiar to serodiscordant HIV couples. Engaging in sexual intimacy was a

stressor as the couples tried to manage or reduce the risk of transmission without sex “feeling like a public health issue” (p.186).

Deborah spoke about how she sought support for her partner from the NZ AIDS Foundation, thinking that he would benefit from speaking to others whose partners are affected by HIV:

“There is no support [for discordant couples]. I asked for someone to come and talk to him from the NZ AIDS Foundation and they sent a gay man. He doesn’t identify with the gay lifestyle; there was no common ground between them.”

Van Devanter et al., (1999) identified that the issue of commitment was not openly discussed between the discordant couples in their study for “fear of causing distress to the other partner and some expressed a need to protect their partner” (p. 186). The research found there were some HIV negative partners who thought that if they too were HIV positive it would improve the communication and enhance the close emotional bond in the relationship.

Marama developed a close relationship with a man she met at an AIDS seminar in Fiji. She explained how she attended a fertility clinic and enquired about sperm donation to become pregnant. During this period she became involved in public speaking as a way of facing her demons and presented on HIV awareness training programmes. Marama was then approached by a TV journalist wanting to make a documentary to raise awareness about HIV. Marama spoke about her desire and action taken in an attempt to have a baby

and the journalist decided to film Marama's journey. Marama narrated how she met her husband and they found they wanted to commit to having a baby together:

“I was invited to attend a Pacific Islands AIDS Foundation seminar in Fiji. I enjoy attending groups with other positive people as you can get close really fast. You have got that common ground, a bond, and all those things you feel when you are around negative people is gone.”

Tony, Marama's husband, formed a relationship after discussing her search for a sperm donor and he responded with an affirmation he was keen to support her. The couple found they both had compatible strains of HIV and their anti-retroviral treatments were congruent with pregnancy. The relationship developed first from a distance then later in New Zealand and Marama became pregnant. Medical management of their HIV diagnosis and in turn their pregnancy added another element to their decision making about actually having a pregnancy as they considered their cultural and social differences and the potential impact this may have on decisions about where to birth and raise the baby.

In contrast, when Susan received her diagnosis in 2004 the thought of having children was in the *“too hard pile.”* Susan felt that the baby's conception would be artificial as her husband was HIV negative and the issue of confidentiality and disclosure during the pregnancy was too onerous. Susan had just been diagnosed with HIV and as a young married woman pregnancy would have been something she and her husband would have been planning for. After a diagnosis of HIV those plans were reconsidered as Susan's

husband thought a pregnancy could aggravate the HIV and cause an advance in the progression of the disease.

Susan needed to come to terms with her diagnosis and during her period of reconciliation to her HIV positive status, she spoke to her husband about her initial thoughts:

“I said to him “do you think it would be OK if we didn’t have children?” He was quite happy with that because his concern was that a pregnancy could affect my health [adversely]. We just pushed the children thing to one side...we knew we wouldn’t be able to conceive naturally.”

For Susan the method of conception was a psychological and physical barrier toward becoming a mother at this point in her life. Susan had not expected having to consider a positive HIV diagnosis in her life plan and the decision regarding children was a means of coping whilst they managed the enormity of the diagnosis.

Strong feelings about the conception not being natural resonates with couples who become pregnant using artificial insemination methods. Psychotherapist Joan Raphael-Leff (1991) purports the spontaneity of love making between couples using artificial insemination to achieve a pregnancy is lost and can undermine the sexual bodily identity for both partners leading to a loss of self esteem.

Becoming Pregnant

A future pregnancy was not something Susan wanted to give up on despite getting her husband to agree that having children was not what they wanted. She chose to keep her options open regarding pregnancy and antiretroviral treatment and commenced a course of antiretroviral therapies that would enable her to continue the drugs if she became pregnant. Susan's life course then changed; as she and John settled into a new home, jobs, and developed a close social network, the desire for a family became strong. This time Susan and her husband sought professional advice about starting a family from an experienced obstetrician:

“The Obstetrician said ‘you try on your own for six months. If you have no luck then come back to me and we will refer you for fertility treatment or assistance’.”

The specialist had spoken to Susan and her husband about trying on their own for six months using a method where John's ejaculate could be inseminated with a syringe in the privacy of their own home, referred to by Susan as the “egg cup and syringe scenario”. Susan spoke about how she felt when she learned conception would be achieved by this means:

“That was a huge hurdle and it was getting around the whole concept of it being different and being artificial.”

Susan and John had sought natural fertility advice so the timing for conception could be as accurate as possible as they would not be conceiving in the “natural way”:

“It was awkward, we were able to laugh about it afterwards and we can now but it was uncomfortable and there was a sense of it wasn’t the normal way and everyone else can do it the natural way and we couldn’t.”

This feeling of not being normal further reinforces the sense of being different due to HIV as it prevented Susan and her husband from conceiving as other couples were able to conceive.

Ensuring Safe Passage; ‘Working hard for this baby’

Rubin (1984) identified in her research on the development of the maternal role that ensuring safe passage for herself and her baby during pregnancy and childbirth was an activity women undertook during their transition to motherhood. The theme “Working hard for this baby” reflects the experience of the three HIV positive women in this study and highlights the psychological, physical and social challenges described by Greene, Derlega, Yep & Petronio, (2003). The “working hard for this baby” quotation reflects how the women felt during their pregnancies in terms of care and management of their pregnancy, regular blood tests to measure viral loads and information and advice about anti-retroviral treatments, modes of delivery and information about the risks of breastfeeding. The narratives of the participants in this study illustrate the emotional journey embarked upon during their pregnancy and birth experience. The participants all became pregnant under different social circumstances eliciting an appreciation of the

different experiences of HIV positive women becoming mothers. Deborah was parenting alone, Susan had been married for eight years and Marama was engaged to her partner whom she had known for about three months before the pregnancy.

For Susan the lack of control over the ability to naturally conceive was an emotional hurdle to tackle on her journey toward motherhood:

“... there was a sense of it wasn’t the normal way and everyone else could do it the natural way and we couldn’t.”

Deborah had an unplanned pregnancy about a year after her HIV positive diagnosis, and she is no longer in contact with the father of the baby. Deborah’s concerns focused around becoming a lone parent:

“I was very educated about pregnancy and HIV. I had only been diagnosed a year when I found out I was pregnant but I was already over that ‘hump’[of coming to terms with the diagnosis] and so I was more concerned about bringing it up on my own. My specialist has spoken to me about children and so I knew I could have him and that the likelihood of him being negative was high.”

For Marama the physical realities of pregnancy were in contrast to her original mental image of pregnancy and a harsh reminder of her age and health status:

“As much I would like to say it was a wonderful experience, because of my age and the HIV complications [kidney stones at 20 weeks gestation] it was hard. Maybe if I had been younger and fitter it wouldn’t have been so rough.”

The pressure of managing to balance physical health and the physical realities of pregnancy created in the women a sense of having worked hard to achieve a healthy baby, especially one that was HIV negative.

“I have gone through so much to get him here healthy”

The theme of working hard for this baby is reflected in the sentence of “going through so much to get the baby here healthy” and continues to highlight the difficulties HIV positive women face when trying to make decisions which affect both their health and that of their unborn baby. The participants were aware of the need for anti-retroviral therapy during pregnancy to reduce the risk of vertical transmission during pregnancy and labour and for some participants it was a time of starting new therapies or changing their current regime. This meant an added psychological pressure as concerns about resistance and side effects were paramount in the minds of two women affected.

The women were also exposed to inconsistencies of information about mode of delivery and at what gestation to start the anti-retroviral therapy during pregnancy. Although two of the women had attended the women’s retreats organized by Positive Women and spoke highly about the social and psychological benefits of attending, for Deborah it led to her to feeling frustrated about the management of her HIV status during pregnancy:

“I went to the retreat when I was thirty weeks pregnant and a Specialist attending there as a speaker had said I should have started my treatment at twenty-eight weeks! I got my viral load back at thirty eight weeks and it was

undetectable but I would have liked that result at thirty six/seven weeks so I could sit back and relax, as the viral load has a direct consequence of risk to the baby.”

The women spoke about their pregnancies and the advice and support they received from their health professionals in answer to my question “Who spoke to you about what to expect during your pregnancy regarding treatment and mode of birth?” The women’s narratives reflect a struggle to assert control over the welfare of their unborn baby or to protect their HIV status from being disclosed to others in the wider organization. For Susan it was important to have control over who attended the birth and procedures post operatively as she was concerned about disclosure and a breach of confidentiality as she was an employee at the DHB where she birthed.

Deborah wanted to have control over the decisions that would affect the health of her unborn baby. She was booked to birth in a secondary level maternity unit, under the care of a GP LMC with Specialist Obstetrician and Infectious diseases consultations at intervals during her pregnancy:

“I was treated just like a normal pregnancy. I got a lot of information from the Woman’s retreat but it was completely different to what they were doing here!”

Deborah spoke about differing views of managing HIV positive pregnant women compared to where she was planning to have her baby. She felt frustrated at the lack of

options and at times felt too disempowered to challenge the decisions around an elective caesarean:

“When I went to the women’s retreats I got information about natural birth and I really wanted to look into it .I probably would have still had a caesarean but I felt I wasn’t given the option. My Obstetrician would say “well if you don’t want to go with the safest option for your child” You tell any Mum that and of course they are going to go for the safest option.”

Susan was planning for a normal vaginal birth and had been attending antenatal classes in preparation:

“We went to about three or four antenatal classes out of seven. It was awful. She [the childbirth educator] implied midwives push medical intervention on patients. I was also extra sensitive at that time as Duncan [the baby] was breech and I was veering toward a caesar and I didn’t have an option and her information wasn’t making it any easier.”

Then the baby was confirmed as breech on a scan at thirty six weeks gestation and a caesarean section was booked for the following week.

The birth of Marama’s baby also deviated from the planned vaginal birth at a tertiary level maternity unit:

“The doctors in charge of the team looking after me recommended I have a natural birth as my viral load was so low but my waters broke five to six weeks early so I had to have a caesarean.”

The women's narrative identified a need for health professionals to be able to meet their need for confidentiality, and for balanced evidenced based information to be provided in a supportive environment.

Maternal-Infant attachment; 'He was the child I thought I would never have'

All the women in the study spoke of the joy at welcoming their baby after the birth. This is natural considering the emotional and social challenges the women faced during their pregnancies. Putting all their stressors and concerns of the previous months behind them and welcoming the safe arrival of a healthy baby were viewed as positive achievements by all three women:

"It was worth it.....worth every minute."

"There was something special about him because of my health; it's his story as well as mine. It's a journey for that child."

"We were both quite emotional because of the fact that he had arrived safely. Just like any parent, it's a big deal!"

The births of all three babies were by caesarean section. The impact of undertaking an operative birth appeared to interrupt the process of attachment to their newborn for the women in this study. Susan explains how she felt when her newborn baby was held by his father first:

"My husband got to hold Duncan first, and that's one thing, I was telling someone the other day, I would have liked to have done differently. I would have

liked to have held him sooner but they took him away and bathed him quite quickly. I didn't get to hold him straight away... which is kind of sad."

The separation of the new mother and baby in theatre featured in the birth stories of all the women in the study:

"She brought him up to me and I touched his cheek and then they whisked him away to wash him. He was about an hour and a half old before I actually saw him and I had missed his first bath and feed."

Marama's daughter was five weeks premature and was taken from theatre in an incubator to the neonatal unit for observation:

"They bathed her really quickly and took her in the incubator. I was taken into recovery and I kept asking when can I see my baby? Why am I here and my baby is out there?"

It is evident from all three women the length of separation from their newborn babies was too long and from the mother's perspective not appropriate. The babies had been removed from the operating environment for bathing to remove all blood and sources of infectious material. The women's narratives reported the bathing led to an unsettled baby which was then artificially fed prior to returning to its mother.

Susan explains tearfully what she would have preferred to happen:

“We fed him in recovery which was nice. Even though you have bathed the baby for women like us or should I say me, still offer that skin to skin, it’s really important.”

The women in the current study reported having skin to skin contact with their babies at varying times and for differing lengths of time after the birth. The benefits of skin to skin contact for breastfed babies has been shown from a review of 30 studies to reduce crying in the infant, improve mother-baby interaction and keeps baby warmer than when placed in a cot (Moore, Anderson, & Bergman, 2007). Skin to skin contact between mother and baby enables the release of oxytocin known as the hormone of love (Odent,2001) ; it engenders feelings of affection and attachment between mother and baby. Oxytocin release is thought to promote a strong foundation for the development of positive mother-infant attachment where the mother is responsive to the cues of the baby and readily attends to the needs of the baby. Mothers who are not breastfeeding need to be informed of the benefits of skin to skin contact with their babies so they can make an informed decision.

The rationale for bathing newborns of mothers with blood borne infections such as HIV is to remove blood and liquor which has been found to contain the virus (Kennedy,2003). Newborn bathing was recommended by the Centers for Disease Control and Prevention in Atlanta (Centers for Disease Control, 1988, cited by Medves & O’Brien, 2001) “to prevent transmission of blood borne infections from newborns to healthcare workers”

(p.162). Medves and O'Brien, (2001) aimed to find out if bathing newborns removed potentially harmful pathogens from the skin. Their study of one hundred and forty newborns used infants born to mothers without blood borne infections. The sample was randomly assigned to two groups; one group bathed in a mild pH neutral soap and water or the other group bathed in water alone. Swabs of the infants' skin were taken before bathing, after bathing and after 24 hours. The study concluded "the findings did not support the efficacy of bathing with soap and water to reduce skin colonization of bacterial pathogens. Although the incidence of potential pathogens colonizing the skin during the first day of life is low and unlikely to pose a risk to healthy newborns, health care professionals may wish to wear gloves until the infant has been bathed" (p.165). The article continues "data is not available to support the hypothesis that HIV can be acquired from the skin of infants. Because of fear and a lack of data, the recommendations for removing blood and blood products have become standard practice and is to remove "potential pathogens viewed as harmful to healthcare professionals" not to remove the risk of infection to the baby." (Medves & O'Brien, 2001, p.163). Hospital protocols which deemed it necessary for the baby to be bathed quickly appear to disrupt those first moments of greeting the baby leaving the women in this study with a feeling of disparity between their expectations and needs as new mothers.

"Becoming a Mother was a huge adjustment for me"

Tina Miller (2005) studied seventeen women over the period of twelve months as they became mothers in the United Kingdom. She writes that for "women in western societies the transition to motherhood is usually experienced against a back drop of professional,

expert management, and self-monitoring” (p.49). She asserts the transition to motherhood challenges our sense of who we are as our identities and experiences shift and our biographical narratives become more difficult to construct as “becoming a mother changes everything” (Miller, 2005, p.49).

During the interviews I asked all the women the question, “How did you feel about becoming a mother?”

Susan describes how it was for her:

“Being a professional woman and becoming a mother was a huge adjustment for me.”

Susan’s HIV diagnosis did not appear to impact on her transition to motherhood, it was her identity as a professional woman that required an adjustment. Susan was used to feeling in control of her time; now with the birth of Duncan daily routines were dictated by the physical and emotional needs of the baby.

In her research exploring the development of maternal identity, Rubin (1967) identified grief work or “letting go” of former identities as part of the transition to motherhood for women. Rubin asserts new mothers find some degree of resolution between their previous identity and that of being a mother and the lifestyles that are no longer compatible will need to be stopped (Winson, 2009). Susan’s professional identity differed greatly from that of being a new mother and as Rubin identified if there is no reconciliation between the previous role and the new role, depression may occur. Susan

goes on to explain about the feelings of guilt she experienced after wanting the pregnancy and working so hard to achieve a healthy baby under difficult circumstances:

“I wanted him so badly and then when he was crying so much and unhappy I couldn’t handle it and when I wanted to walk away I felt guilty. We had tried so hard, worked so hard to get him and gone through so much for him and I couldn’t handle it.”

Here Susan describes feelings that are very common in new mothers whatever their childbirth experience. Feeling unable to cope with the demands of a new baby and “wanting to walk away” can all be signs of an internal turmoil as the mother assumes a new identity with changing responsibilities and roles.

For Marama becoming a mother was the culmination of a long held dream:

“It was a dream come true, miracle, all those things. It’s something that everyone else takes for granted. Procreation is such a common thing but it’s huge when you are HIV positive.”

Deborah planned to stay at home with her son:

“Nothing prepares you for motherhood. I knew I wanted to be very involved with him and be a ‘stay at home mum’. I was lucky to have him. I’ve always had that appreciation.”

Health professionals and new mothers seem to hold the notion that mothering behavior is a natural progression for women, and new mothers will instinctively be able to interpret

and respond to their newborn's cries. Miller (2005, p. 97) writes about the early mothering experiences of the women in her study: "the women are now mothers. They were expected to naturally know how to mother and the women shared this expectation." Susan relays her experience of being a newly delivered mother unable to identify the reason for her baby son's distress and her need for kind support:

"One night Duncan was beside himself crying, and I got upset because I couldn't settle him. When the midwife came she asked the HCA (Health Care Assistant) to settle the baby whilst she calmed me down as I was sobbing. The HCA came in first and said "what's the matter?" I explained he was crying uncontrollably and all I was doing was changing his nappy. She replied "well, that's what they do". That's not what you say to a new mother and I got really upset and I urged her to call the midwife. The midwife said "the baby needs to finish his bottle". They then took the baby out of my room to finish his feed! I never gave them permission to take the baby out of the room [crying] and they never asked me did I mind? I was too upset and their attitude implied "that's what we do here and pull yourself together, you'll be alright."

The need for empathy from health care professionals during the postnatal period is paramount for all women who are new mothers. The physical and emotional challenges posed by birth and the postpartum hormonal surges render the new mother in need of support, guidance and understanding of these changes.

The women were asked about how life progressed for them once they returned home and into society with their new baby. As Miller writes “The shift from hospital to home marks both the beginning of a return to “normal” and the gradual disengagement of medical and health professionals” (2005, p. 48).

Susan explains how she knew it was time to leave the hospital with her new baby, Duncan, despite a member of the midwifery staff verbalizing their concerns:

“She made her opinion very clear by saying ‘you are going home very early you know’ and I just said “yes but I’m better off at home and I am very sensible and I think I can manage”. I just wanted to go home. It was easier at home, much easier.”

I asked the women about the support networks which were available to them once they returned home and if they accessed them:

“I have got a support structure but it is not the same as having your family on the doorstep. There are a lot of women in the church group I am involved with who have children and they have been brilliant.”

“My friend supports me a lot; she comes with me and my son to all my blood tests. I went to stay with my mum for a week after the birth, which was a great support as I was struggling on my own.”

Many authors (Oakley, 1979, Miller, 2005) have written on the importance of social networks for mothers and their unborn baby's wellbeing but also in the prevention of postnatal depression. Postnatal depression can be defined as a set of major clinical depression symptoms occurring in the first months after birth and up to one year postpartum (Mothers Matter, 2010).

Both Susan and Deborah reported seeing counselors for on-going personal issues which were not related to their HIV diagnosis. It was Susan's counselor, who detected symptoms of postnatal depression when Duncan was six to eight weeks old:

"It was my counselor who suggested that I had symptoms of postnatal depression and what did I think? I wasn't eating well at the time, I wasn't sleeping very well and I was still quite weepy and there were times when I wanted to close the door on the baby when he was crying too much."

When asked about their experiences of the having their care referred onto the Well Child provider at six weeks postbirth, the women reported having varying concerns related to disclosure of their status. All three mothers were transferred to Plunket for their on-going parental support and well child development checks. Susan requested that her Plunket nurse not be informed about her diagnosis as Duncan was well and all his blood tests to date indicated he was HIV negative:

"She left out my HIV diagnosis [on the discharge summary] because I heard about an experience from another woman who had a baby and it was written all over her child's Plunket book and I just thought "I'm not having that."

Two of the women reported they had midwifery care until the babies were six weeks old, with one woman unable to remember exactly and then the care was transferred to the well child provider. Susan spoke highly of the benefit to her of having the continuity of one midwife through the postnatal period:

“Usually midwives sign you off at four weeks but she kept us on her books until six weeks which was great.”

It is a Ministry of Health requirement women have access to midwifery care and support until their child is six weeks old (Ministry of Health, 2007). It is another time of transition for women as they reach the six week point after the birth. Classified as the end of the puerperium it traditionally signifies a new era for the mother’s journey into motherhood and the social integration of her new role.

Summary

In this chapter the mother’s have described their individual experiences of their transition to motherhood which starts before their baby is born with the formation of expectations and hopes. Those hopes were formed from their expectation that they would become mothers one day. Then after a diagnosis of HIV the hope for a child became a difficult journey. Their understanding about the potential for transmitting HIV to their baby, the formation and negotiation of intimate relationships and then the planning for a pregnancy and the birth were all obstacles that needed careful consideration.

The depth of contemplation may not be unique to this group of women but it must be respected and supported. The journey to motherhood may be challenging for many

women but it is the social and psychological impact of HIV which sets it apart from other illnesses. Then as the baby is born those first moments when the baby is welcomed was the culmination of an emotional, physical and social journey for the women in this study and was disrupted by health care practices which did not facilitate the sanctity of those first minutes after the birth. The women felt they needed longer to assimilate the mothering role than anticipated by the health professionals, as they expected mothering to come naturally for the women in those first few days. The factors which shape health professionals' attitudes towards HIV positive mothers and the relationship between stigma, knowledge and power and how this affects the transition to motherhood for HIV positive mothers are explored in Chapters Five and Six.

Chapter Five

Stigma and Disclosure

“There are family members we purposely haven’t told because of reactions and stigma.” (Susan, November, 2008).

Introduction

Stigma can be defined as “a process by which the reaction of others spoils normal identity” (Goffman, 1967, p. 10). Stigma can be attached to one’s personal attributes such as sex, race or sexual orientation and poses a threat to one’s personal and social identity (Russo & Tartaro, 2008). The psychological impact of concealing a perceived stigma is significant for HIV positive women as they become mothers as it “may undermine mental health by interfering with receiving or obtaining social support from others” (Russo & Tartaro, 2008, p.470). In this chapter the concept of stigma and the women’s decisions regarding disclosure of their HIV status to family and members of the wider community is discussed.

Stigma

In his sociological essay entitled “Stigma; notes on the management of a spoiled identity”, Erving Goffman (1967) writes about how members of society categorize persons and assign a social identity which informs the perceiver about what can be expected from an interaction with this otherwise unknown person. Goffman (1967, p.167) argues that “stigma is intimately associated with stereotype and this is related to unconscious expectations which act as unseen arbiters in all social encounters.” Evidence

can arise from our social interaction that this person possesses an attribute that makes him or her different from others in that category e.g. mother. Goffman defines stigma as an “undesired differentness from what we had anticipated, he is reduced in our minds from a whole and usual person to a tainted, discounted one” (1967, p.15).

Deborah spoke about the effect of stigma after being identified as HIV positive by a member of a local group she had been attending with her baby:

“They didn’t know me well at the group but one of the girls who also attended was the partner of one of my ex-boyfriends. Next thing I know I am getting a telephone call from the group saying ‘you cannot use our cups anymore’ and asking if my baby was infected. I said ‘no’ but I know they didn’t believe me. One of the women, on hearing about my diagnosis, had said ‘I won’t be in her position because I don’t do drugs’. She just assumed I contracted HIV through drug use.”

Deborah’s experience highlights how those affected by HIV can be stigmatized due to the perceived potential threat or danger they pose and this further reinforces the exclusion HIV positive women can feel. “Stigmas label people as different and devalued by others leading to low status, loss of power and discrimination” (Russo & Tartaro, 2008, p.470). Goffman (1967, p.120) asserts “members of society construct an ideology to explain the inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences”. In Deborah’s case it was being HIV positive and assuming she had contracted HIV through intravenous drug use. This experience could have left Deborah feeling disempowered but she took her case to the Human Rights Commission

and through educating other members of the group about HIV she now attends without feeling any discrimination.

Marama describes herself as being very open about her HIV status and regards herself as 'normal' until an event brings her to an abrupt realization that others don't see her as 'normal':

"It's like you can think you are normal and then something will happen to indicate you are not. People don't know enough about the virus, they instantly think you are contagious, everything you touch, every cup, all those sorts of things."

Marama and husband Tony, also HIV positive, have different attitudes towards disclosing their status. Tony is from Papua New Guinea and lost his first wife and two children to AIDS. The discrimination toward those with HIV was graphically described by Marama when she told how her husband finds it difficult to be as open as she about his status for fear of reprisals:

"Tony still gets worried about discrimination. He is worried about the reaction of people at Church. Tony has not been diagnosed for as long as I have; he was diagnosed in 2004. The stigma and discrimination in his culture of being HIV is a huge thing. A few people in Papua New Guinea have been stoned to death for being HIV positive."

Advances in antiretroviral treatment have led to longevity and reproductive choices for HIV positive women who up until the mid ninety nineties were not empowered to consider pregnancy as the risk of mother to baby transmission (vertical transmission) was 30% and chances of the child surviving into adolescence was slim. The safety and efficacy of using anti-retroviral therapy during pregnancy has enabled HIV positive women to make informed and supported choices but for the women in this study their experience was that it did not change the stigma associated with HIV, that it is contracted by people with deviant sexual behavior and or those who use illicit intravenous drugs. HIV remains unique from other potentially life threatening chronic illnesses in that it is associated with behaviors some find immoral or deviant (Greene, Derlega, Yep & Petronio, 2003). The stigmatising effect of HIV and its association with drug use, promiscuity and prostitution means HIV positive mothers have to manage the paradox of normal cultural norms and expectations of motherhood and the abnormal fit of HIV and motherhood. Motherhood with HIV exaggerates the deviancy status of the disease by society, a situation described as the “double bind” by Ingram and Hutchinson (2000, p.117). The purpose of their grounded-theory research was to describe the reproductive and mothering experiences of HIV-positive women. Twenty HIV-positive women participated in 31 in-depth interviews. The grounded-theory method was used for data analysis. 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 reproduction and mothering. An understanding of the power and influence of these double binds permits health care professionals to plan patient-centered

programs and to individualize care specifically for HIV-positive women. The nature of a double bind is that the person cannot confront the inherent dilemma, and therefore can neither comment on the conflict, nor resolve it, nor opt out of the situation.

Disclosing to Loved Ones

In the case of HIV infection a couple has to confront the stigma associated with the disease and the potential social consequences of disclosing to family, friends, work colleagues plus managing sexual behaviors to protect the non- infected partner. This places a great strain on the relationship and calls for clear communication to conquer these issues (Moore, Harrison, Vandevanter, et al., 1998). Disclosure was and remains a significantly individual experience as the women weigh up the circumstances and consequences of disclosing their HIV status. Disclosure may result in social rejection and exclusion, which have powerful negative effects as well as making the management of stigma a highly stressful psychological process. This was reflected in the findings of this study. Each of the women identified their individual reasons for disclosure and non disclosure of their HIV status. In this section the factors affecting disclosure are explored under the theme of loved ones which include parents, partners, siblings and children. The notion of loved ones implies social support and acceptance regardless of behavior or consequences of chosen behavior. The relationships in families are not always based on love but may be based on duty and responsibility.

For one woman the issue of disclosure was not something she had any control over as her diagnosis had been publicized through a court case involving the partner from whom she

had allegedly contracted the virus. In this excerpt Marama describes how her cousins came to her home with the newspaper article detailing the story of the partner who was in court facing charges of knowingly infecting women with HIV:

“It’s really hard to keep a lid on something like that ...and after all these years I kind of understand that they needed to talk about it too as it was huge for them as well.....it did kind of spread like wildfire, I didn’t have any control over that at all.”

The lack of control Marama felt about the disclosure can incite feelings of helplessness and depression. Ciesla and Roberts (2001) meta-analysed ten studies of an HIV positive diagnosis and depression and concluded HIV positive individuals were more at risk of developing depression. Further studies examining whether disclosure can improve or hinder the psychological health of HIV positive individuals are needed as authors Greene et al (2003) found no conclusive evidence in their study about the psychological benefit or adverse outcome experienced for the HIV positive person after disclosing to loved ones and friends. What is known is that HIV positive people come to terms with “living with dying” (Greene et al., 2003, p. 137).

Marama relays her feelings after being diagnosed HIV positive in the story that follows:

“There were quite a lot of years [prior to meeting her current husband]. I spent quite a few years in therapy, I couldn’t shake this feeling that I was going to die anyway, and I stopped working and actually ended up marrying someone else for a little while. We travelled all over New Zealand; it wasn’t a good time.

Thinking I was going to die I lived like I wasn't going to live-didn't put roots down or anything, not making any commitments."

Marama and her husband parted and she found more encouraging company:

"I met some really awesome people-positive strong people-Christians. They pulled me out of a bit of a depressing time."

As demonstrated in Marama's narrative, HIV not only affects the wellbeing of the affected person but also those who are intimately involved with them (Moore, Harrison, Vandevanter, Kennedy, et al., 1998). It has been documented in studies on chronic disease such as cancer, diabetes and arthritis that the spouses have more difficulty adjusting to the illness than the ill person (Moore et al., 1998, p. 166; Manne & Zautra, 1990).

Deborah's partner, who is not the father of her child, spoke about how they decided not to tell her partner's family. She feels part of the reason for this decision rests with the fact her partner is in denial about her diagnosis:

"He's accepted it but he hasn't, he's not where I am, he is in denial and grieving. I think he knows if I wasn't in his life then he wouldn't have to deal with it but there's always other things, like meeting the woman of your dreams and she could have cancer or something"

Deborah spoke about protecting her partner's family members from knowing as it would only make them "worry":

"His family doesn't know because I do not know how to tell them, they would only worry."

Deborah did not elaborate and little is known about disclosure to extended family such as in-laws, and step parents (Greene, Derlega, Yep & Petronio, 2003). Deborah does mention "*not knowing how to tell them*", and research into the area of disclosure and methods of communicating the message identify ways HIV positive individuals use to disclose their status. These methods may include third party, non-verbal strategies such as writing a letter, or wearing a t-shirt indicating support for an AIDS cause. With advances in telecommunications such as email and telephone text messaging other avenues are available that enable the affected person not to face the person's initial reaction and to protect themselves from the initial emotional response.

However research by Greene et al., (2003) has indicated that using non verbal messaging with no face to face contact can have the undesired effect of avoidance by the recipient of the message. For example, a HIV positive man disclosed his HIV result using email to his ex-lover and encouraged him to get tested, "I waited weeks and weeks, and he checks his email all the time, he's obsessive. He never said a word. To this day I have not heard from him. That's two years and counting." (Greene et al., 2003, p. 86).

Susan, spoke about purposely not disclosing to family members because of not wanting to cope with others “*reactions and stigma*”. She perceived that the reaction of her family members would not be “*favorable*”. Susan considered the effect of non-disclosure on her own psychological wellbeing stating fear of rejection as a factor for not disclosing:

“I didn’t want to face the rejection; it’s actually not worth it.”

Susan’s reaction and choice had been an informed one after experiencing her family’s knowledge of and attitudes toward HIV. In their study of 77 HIV positive men and women in the United States; Klitzman & Beyer (2003) sought to explore how decisions about disclosure were made. Their “intent was to explore through narrative accounts how in the extreme cases of HIV and AIDS, people faced questions of secrecy morality and trust” (p.4). In Susan’s case the previous experience of reactions to disclosure about being HIV positive elicited a decision to keep quiet; “the choice of silence resulted not only from the circumstances surrounding AIDS but from prior experience” (p.25).

This has been the experience of Susan, who spoke about the decision not to disclose to one particular family member explaining it was too difficult:

“Due to her 1980s mentality towards her understanding of HIV. It’s just too difficult to bring her up to speed.”

The complexities of family dynamics contributed to the decision by Susan not to disclose to her family members other than one sibling.

Disclosure to siblings is slightly different to that of parents as they share generational experiences and may have a more contemporary understanding of social and sexual mores. In line with the findings from Klitzman & Beyer (2003) the current study found that Deborah and Susan both identified as being close to a sibling with whom they felt they could disclose their HIV status. This ability to open up to a close sibling ensured a means through which emotional support could be gained from a loved one they could trust. Klitzman & Beyer (2003, p.73) found “the specific family histories filled with love and anger, shattered or fulfilled expectations, support, conflict and competitiveness shaped how much individuals felt safe or needed to reveal themselves.”

The challenges of disclosure for women in this study and those in Klitzman & Beyer’s research were not only family related but included friends, acquaintances and other social situations such as work and contact with the health services.

Disclosing to Friends

In a society where extended families have become increasingly separated either by distance or employment friendships provide a source of support, affection, pleasure and fun. Here an excerpt from Klitzman & Beyer’s study describes how disclosing to friends was more difficult than disclosing to family for the participants in their study, “The bonds of friendship more than those of family are created giving them not only a special value but fragility” (Klitzman & Beyer, 2003, p.97). Susan narrated how disclosing to close friends rather than family members created a source of support for her:

“There are two people who I told about the diagnosis from the beginning and they are very close friend .I am being very selective about who I have told and why. Purely because of the reactions from people and being very aware there is still a large stigma attached to being HIV positive.”

The heightened state of vigilance when outside a trusted circle of friends was palpable from Susan’s narrative and the consequences of the silence can be perceived as an emotional burden. For Deborah disclosure to a friend led to public disclosure:

“I have found a lot of people have found out that I would not have wanted to know. When I first got diagnosed I told one of my close friends and she went and told three or four people in a small town like this.”

In her interview Marama spoke about how she supports Deborah to manage and cope with the parochial attitude she has experienced towards her diagnosis from peers in her community. Marama provides emotional support for Deborah; they met through the Positive Women’s retreats held on an annual basis and funded by the Positive Women organisation. The retreats offer women and their children an opportunity to meet and share common experiences and to provide support and friendship.

Managing Disclosure to their Children

Marama describes how she has been open about her diagnosis with her nieces and nephews. After relaying a story about how her niece had confidently deflected negative

comments about Marama at school she spoke about how she will teach her daughter, Maiinga, about HIV so she and her friends are not afraid of her parents:

“I am going to teach Maiinga to be that kind of person, to have that knowledge. Knowledge is power. If she has the knowledge and people are giving her tick about her father and me she can say “you’re done because you don’t know.”

Deborah spoke about how she does not want her son to be afraid of her and how she plans to manage inviting his friends over to play. She hopes her diagnosis will not affect opportunities for her son to be invited into his friends’ homes:

“I’m a little bit more protective of him I think. I don’t parent him differently, I still bathe with him. I do that because I don’t want him to be afraid of me but I am very vigilant when we are around other people. I am vigilant about him sharing drinking cups but I don’t want other people to have that fear. I don’t want people not wanting to have him around to play because he’s got a cut lip or something.”

Deborah went on to speak about how her diagnosis has impacted on her life and thoughts about her and her son’s future:

“I used to worry about taking him to school camps and I was thinking about doing teaching for a while, but who would want their child taught by an HIV

positive person? It will hurt me more when its affects him rather than how [HIV] affects me.”

Deborah considered how disclosure to her son may occur as he gets older. Her fear was not so much about how she herself may react but how the disclosure to her son will affect him. It has been noted in research that stigma by association is a very real experience for friends or family members of HIV positive persons (Greene & Serovich, 1998; Greene et al.,2003). Deborah felt if her child had seen and experienced her living and undertaking a “normal life” she hopes that it will be those memories which sustain his faith in her ability “*not to die on him*”.

Deborah has created beautiful scrap books and memory boxes for her child, something she said she would have done anyway but their meaning is more poignant in these circumstances for all involved.

Public Disclosure

During the first decade after HIV was identified in 1981 as a disease affecting homosexual men and intravenous drug users, fear of contagion merged with social hostility toward the infected (Klitzman & Beyer, 2003). However with medical advances affording improved prognosis it has been asserted that as the HIV epidemic enters its third decade, a diagnosis of HIV in 2003 has a more positive prognosis than one in 1983 or even 1993 (Vasquez-Pacheco, 2000).

In addition to the issues of self-disclosure of their HIV status the women's narratives told of a lack of control over who has access to personal health records within the public health system. The need for control over confidentiality and public disclosure was described by Susan as a "*big deal for me.*" Susan's first experience of stigma was from a health professional who had inadvertently accessed her health records but then asked Susan inappropriately for details of how she contracted HIV and subsequently became pregnant. After the consultation Susan was left feeling insulted and deceived by those she trusted to support her through her pregnancy. Trust in the system was restored after Susan spoke and relayed the event to her LMC midwife who settled the situation to ensure such incidents would not reoccur. Susan was keen to have as few health professionals as possible involved in her maternity care and advised about the needs of pregnant HIV positive women:

"One midwife contact during your antenatal visits; try to keep the amount of people you come into contact with to an absolute minimum so you don't have to feel like you need to explain yourself over and over, so you don't have to talk about your illness every time. Seeing one midwife made a huge difference and having someone who understands that it is a big deal."

Public disclosure about one's positive HIV diagnosis involves exposing oneself to scrutiny and judgment. In some situations a HIV diagnosis can embolden some individuals to make a public declaration about their status and actively participate in sharing their experience and knowledge of living with HIV to those in their community.

Herek (1990) suggests people who become actively involved in AIDS groups may achieve a level of self esteem higher than that held by the majority of the non stigmatized group. This has been attributed to the amount of social acceptance amongst the stigmatized group who would be grateful for the support and acceptance offered.

Summary

It is evident from the three narratives in this study that stigma and fear of discrimination are an integral part of coping with a positive diagnosis of HIV. The subject of disclosure is negotiated on an individual basis balancing the benefits and risks to the discloser of that which is disclosed. Disclosure to family was affected by negotiating the risks and benefits of disclosure balanced with a consideration of family dynamics. The path from learning about the diagnosis and its associated complexities, of keeping it a secret or making it public is long and convoluted. When thrust into the public world of health services and its layers of bureaucracy there is a balancing act of need versus risk for the women as they negotiate maintaining their privacy at the same time as accessing effective healthcare for themselves and their unborn baby. The children of HIV positive mothers may experience stigma by association. It must be remembered that they have a fundamental psychological right to acceptance and a sense of belonging in the society in which they live. Members of the community/society need to support that right. In the words of the African proverb “it takes a village to raise a child.”

CHAPTER SIX

Knowledge is Power

*“Knowledge is the best thing they can have, the best weapon for all of it”
(Marama, April, 2008)*

Introduction

The above quote is from a woman living with HIV and describes the power she feels when acting from a situation of being knowledgeable about HIV and how that knowledge enables her to challenge commonly held assumptions or stereotypes about HIV positive people. Chapter Six illustrates how the knowledge-power struggle played out when the participants in this study came in contact with the health professionals in the maternity services. The struggle the women experienced had an impact on their transition to motherhood.

The main themes identified from the women’s narratives included; lack of professional knowledge of HIV, limited options for decision making, a moral panic (or judgment) around breast feeding and the need for women to be cared for as any HIV negative women with a newborn baby. All three women in the study had different experiences during their antenatal period; two women were cared for by a specialist team of HIV physicians and obstetricians in a tertiary hospital in New Zealand and one was cared for by a visiting HIV specialist physician and a GP in a regional secondary care unit in New Zealand. Susan had a dedicated midwife assigned to her and Deborah saw her GP for antenatal care and was then assigned a midwife further along in the pregnancy.

Disempowering Behaviors

When disclosing an HIV positive diagnosis to a health professional it is thought it will afford that person better and more co-ordinated healthcare. “People generally expect medical professionals to have more accurate knowledge about transmission and to be less prejudiced in their attitudes about someone with HIV” (Greene, Derlega, Yep & Petronio, 2003, p. 76). The subject of behaviors is discussed here to gain an insight into how a lack of professionalism and knowledge can lead to the disempowerment of HIV positive women. Barbee, Derlega, Sherburne & Grimshaw (1998) asked HIV positive individuals to recall times when someone thought they were being supportive but their actual behavior had been either helpful or unhelpful in the context of coping with HIV.

One helpful behavior identified by participants in their study was showing “understanding and empathy” (p.129). Barbee et al (cited by Greene et al.,2003, p.129) found “someone asking too many personal questions about how the disease was contracted” was an unhelpful behavior; this sentiment was reflected in Susan’s narrative below.

Susan attended a consultation during her pregnancy which left her feeling frustrated and angry. When attending a consultation with a medical practitioner there is an expectation that personal or probing questions not related to the reason for the consultation would be avoided so as not to cause psychological harm or emotional upset. Susan narrates her interaction with a medical officer during her pregnancy:

“I went into the Consultation room, [she wasn’t the usual doctor who I saw but I didn’t question it].She started asking me questions about my HIV and how did I contract it and how had I become pregnant. She then asked me if this was my first pregnancy and [then enquired] about any abortions I might of have had although I had confirmed this was my first ever pregnancy.”

Susan became very upset at the intrusive nature of the probing enquiries and offers suggestions about how an encounter with a health professional should proceed. Susan cited building a rapport with patients and being mindful of how questions should be posed:

“There is a way of asking things and developing a rapport is important when talking to patients.”

A study examining obstetric nurses’ attitudes and nursing care intentions in the United States further highlights the link between how health professionals’ attitudes can be disempowering. Tyer-Viola (2007) found that obstetric nurses’ clinical care intentions are influenced by the characteristics of the patient and states: “If a patient’s characteristics are deemed undesirable or judged as unacceptable then their care may be compromised” (p.405). Hodgson’s (2006) ethnographic study of nurses working in an infectious diseases unit identified curiosity about how the patient contracted HIV and their lifestyle informed or dispelled judgments:

“In the beginning I was a bit nosy reading through the notes trying to find out how they contracted it, a bit about the lifestyle they led. But I soon realized that it’s just all walks of life” (Hodgson, 2006, p. 287).

During her stay on the postnatal ward Susan encountered a midwife whom she felt wanted to learn more about HIV and built a rapport with Susan, her partner and baby following the birth:

“The midwife looking after me during the day had been the same one for three days. She was lovely. She said “We don’t get a lot of women like you very often, we can actually learn a lot from people like you”. She asked lots of questions; she wanted to know how I’d been with it all and having Duncan. She was trying to learn, which was great and I tried to give her as much as I could with the time she had.”

Personally knowing someone affected by HIV is an important determinant of positive attitudes. Tyer-Viola’s (2007) research supported the findings from other authors (Herek & Capatano, 1997; Hodgson, 2007) who reported that when lay people had direct contact with HIV positive people they reported less stigma, less avoidance and less blame than those with no direct contact. When discussing formal pre-qualification and post qualification education for health professionals Marama advocates a multidisciplinary group and the invitation for someone living with HIV diagnosis to come and talk:

“It’s got more impact when you have a person living with it sitting in front of you.”

When faced with someone living with a potentially fatal disease people can feel uncomfortable and threatened. They feel uncertain about what behaviors are helpful or unhelpful to that person so they can exhibit behaviors which are perceived as insensitive and rejecting by the affected person (Wortman & Lehman, 1985). By inviting people living with potentially fatal conditions health professionals can have a tangible experience which can possibly affect their behavior in a positive way.

‘I didn’t have an option’

Information sharing with pregnant women who are subsequently empowered to make decisions affecting their maternity care has been shown to have far reaching psychological benefits (Gatrell, 2005; Sandall, 1995). However the balance of power between those imparting the information and the needs of those receiving the information can be unbalanced. Authoritative knowledge is a term coined by Bridgette Jordan (1997) to explain the identification of knowledge which carries more weight due to the efficacy of the knowledge or its association with a stronger power base, usually both. When considering the application of knowledge “it is understood that there are various ways of knowing and that equally legitimate parallel knowledge systems exist and people move equally between them, using them sequentially or in parallel fashion for particular purposes. But frequently one kind of knowledge gains ascendance and legitimacy” (Jordan, 1997, p.56).

This ascendancy and legitimacy given to one kind of knowledge can lead to a “dismissal of all other kinds of knowing” and “those who espouse alternative knowledge systems then tend to be seen as ignorant, naïve or worse simply as troublemakers” (Jordan,1997,p.56).

Deborah reported feeling a troublemaker when trying to discuss alternatives to an elective caesarean section about which she felt she had no choice:

“I probably would have still gone for a caesarean but I didn’t have an option and I said to my midwife and obstetrician “can you look into this as I really don’t want to have to go down this road?” They got really annoyed with me [laughs]. They thought I was one of those annoying patients who create a real stink.”

Deborah spoke about the disjointed care she received and how she felt a lack of confidence in some of the health professionals caring for her. She felt it was due to her provincial location that prevented medical advances and practices common in larger urban centres reaching her locality. When asked about her care and choices about mode of birth Deborah replied:

“I didn’t have an option really [for a vaginal birth]. All the information I was given was about caesarean birth. They said the risk [of passing the virus to the baby] was less with a caesarean.”

Authoritative knowledge is persuasive because it seems reasonable and “consensually constructed” (Jordan, 1997, p. 56) and those who decide against the advice can be left feeling disempowered as Deborah stated:

“You tell any mum that they [the Obstetrician] are offering you the safest option for your baby then of course you are going to do what they say.”

The disempowerment felt by Deborah is reflected by findings from Lazarus (1994) whose decade of research on birthing women in the United States found “many women feel responsible for the events at birth but they in fact have very limited influence over the medical procedures applied” (p.132).

I understand birth is an event that women prepare for; it is anticipated and planned for from the time of confirming their pregnancy. Deborah reports it was her understanding of HIV during pregnancy and birth that she had gleaned from reading and attending the Women’s Retreats that supported her in making choices which felt right for her and her baby. The importance of the strength of support afforded by the women coming together and sharing their experiences and knowledge at the retreats is highlighted by Irwin & Jordan (1987) who found that women who escaped court ordered caesarean sections in the United States, “had powerful social networks within which their version of reality was upheld and supported. The ones who got the sections were the ones who did battle with the prevailing view alone, or as an isolated couple on alien territory” (p.59).

The decision to go ahead with an elective caesarean section for HIV was not one Deborah made lightly:

“I didn’t like the way I was treated and if I had not gone to the women’s retreat I wouldn’t have known there was an option there [for a natural birth]. I felt I had no choice but to have a caesarean as I thought they wouldn’t know what to do if I had a natural birth.”

Based on her experiences of the health professionals encountered during her pregnancy Deborah was concerned about the HIV knowledge of those health professionals who would attend her if she opted for a vaginal birth. As a result she decided it would not be a safe option:

“I was really angry as there was nothing I could do and I remember the night before I had the baby saying to my Mum that I was going to have the caesarean the following day because I had no choice. Did I really have an option? I felt I would be putting his life at risk because they’re not trained [the health professionals]. They won’t know what to do if I have him naturally.”

Deborah felt she had no-one to advocate for her during her pregnancy and she felt her requests to discuss topics such as mode of birth and infant feeding in detail were denied, with a plan for the birth dictated to her.

Authoritative knowledge (Jordan, 1997) such as a mandated elective caesarean section Human Immunodeficiency Virus positive women, becomes custom and practice amongst health professionals and reinforces its legitimacy. This legitimate view makes women who have different knowledge feel disempowered and threatened leading them to make decisions they feel coerced into because choices do not seem to be available. Not only was choice with regard to type of birth denied these women but they were also concerned about knowledge about breastfeeding and HIV transmission amongst the health professionals they encountered.

“Why aren’t you breastfeeding?”

Current research based evidence on the management of HIV during pregnancy, labour/birth and the postnatal period is focused on reducing the risk of vertical transmission of the virus to the unborn baby. Seminal research by Dunn, Newell & Ades (1992) and Thirry, Sprecher-Goldberger, Jonckheer, (1995) has indicated that HIV can be transmitted via breastmilk from the HIV positive mother to her infant and is only advocated in circumstances where alternatives to breastfeeding would render the baby at risk of gastrointestinal infection, dehydration and death (World Health Organization, 2004). In New Zealand the advice for HIV positive mothers is not to breastfeed as the country has a safe standard of drinking water and modified cows milk formula is viewed as an appropriate alternative (Ministry of Health, 1993). In this section the narratives describe how authoritative knowledge prevails in the absence of any evidence or knowledge of the research evidence, which makes the women feel they are at risk and are challenging the system thus creating a problem for those caring for them.

Deborah explains how a lack of knowledge about infant feeding for HIV positive mothers from a health professional undermines the trust between woman and midwife:

“It was shocking, the first time I saw her, my midwife initially said I had to breastfeed him. I said ‘No!’ I said in Africa they make them breastfeed because the water isn’t hygienic. She didn’t believe me and it really upset me.”

Marama shared a similar experience during her stay on the postnatal ward:

“So when the breastfeeding thing came up it was my personal choice and do I want to take the risk, knowing about the risk? I considered how I would be judged and I decided, I didn’t want to have that. I had a dispute with one of the midwives at the hospital, you know how they change shifts and you get a different one? Well I got one who said to me “aren’t you breastfeeding?” I said no and she persisted so much with her information and videos. I thought initially she obviously hasn’t read my file completely and so I said “I’m HIV positive. She replied ‘doesn’t mean you can’t breastfeed’”. When I explained I did not want to take the risk she could not understand why.”

Marama explained that formula feeding meant Maiinga could bond with her father and they shared the feeding between them particularly overnight so each could get some sleep. Susan also cited not breastfeeding as *“not an issue for me.”*

The lack of tact and empathy health professionals showed regarding the subject of breastfeeding and how difficult it can be for the women to make that decision is narrated by Susan who was one day post caesarean section:

“The day after my section they are washing me and I am completely exposed and the midwife says “Oh it is such a pity you can’t breastfeed; you have such perfect nipples.” I thought I am going to bite my tongue but thought “lady, you are so lucky this is not an issue for me.”

Those involved in the care of the HIV positive mothers did not appear to acknowledge the emotional and physical challenges for these mothers, who had undergone major surgery and who are encouraged not to breastfeed. The frustration the women in this study felt about their experiences was palpable as I listened to their stories.

“Knowledge is Power”

Marama has been living with an HIV diagnosis since 1991 and describes her HIV status as “public”. Marama’s journey towards motherhood has been the subject of a television documentary; she feels her purpose for the documentary and newspaper articles (Personal communication, March 2008) was to educate HIV negative people about safe sexual practices, and to educate health professionals about the psychological, physical and social needs of those affected by HIV. The public acknowledgment of living with a HIV positive diagnosis affords Marama the opportunity to provide hope and support to those

who are newly diagnosed. Marama provides a credible example to illustrate there is a lot of life to be lived after a diagnosis of HIV:

“I think if someone did that when I was diagnosed it would have relieved me.

It’s giving the hope that your life doesn’t end.”

It is evident from the narratives that the women in this study find comfort and strength amongst those who are diagnosed HIV positive. The women felt they belonged when they were in the company of other women, who were HIV positive, as reflected in the following comments:

“Feel less than [inferior] when I am with HIV negative people”

“Women like us, I mean women like me.”

This sense of community and belonging amongst a group affected by a common factor is supported by findings from Hays, Magee & Chauncey (1994). In their study twenty-five HIV positive homosexual men identified helpful and unhelpful behaviors of loved ones. The research found that emotional support, companionship, information and advice significantly enhanced the quality of life of the person living with HIV/AIDS.

Summary

Chapter Six illustrated how a knowledge-power struggle existed between the women in this study and health professionals they encountered during their maternity experience. It is evident from the three narratives that the women’s experiences of care during their

pregnancy were tainted by curiosity and unprofessional attitudes. Staff not only lacked knowledge about HIV transmission but an understanding of those living with HIV which impacted on the woman's experience of their pregnancy and those first formative days with their baby.

CHAPTER SEVEN

Discussion

Introduction

In this chapter the threads of the transition to motherhood for HIV positive mothers are brought to a conclusion. The research aim was to describe the transition to becoming a mother for HIV positive women. The findings would then be used to inform midwives and other health professionals to enable them to support HIV positive women as they made the transition to motherhood. The limitations of the study and recommendations for midwifery practice, health professionals; education and recommendations for further research are discussed.

The Research Question

The research question was borne from the idea that as heterosexual transmission of HIV is rising in New Zealand then midwives and health professionals would need to be informed about the transition to motherhood for HIV positive mothers in New Zealand. The findings of the study would then inform midwifery and other health professionals practice. Through understanding the needs of HIV positive women approaching motherhood it is asserted information from this study would enable professionals to support the women to make positive health choices for themselves and their family/whanau. The transition to motherhood for HIV positive women in New Zealand is a complex interplay of social and psychological factors unique to each woman. Stigma and the management of disclosure about their HIV status provides the context for the transition to motherhood for HIV positive mothers in New Zealand.

The key findings from this study are discussed.

Key Findings

The Timing of Motherhood and HIV Diagnosis

All the participants in this study had been diagnosed with HIV before their pregnancies. As antenatal HIV testing has been introduced nationwide in New Zealand it is estimated the number of women diagnosed during pregnancy will increase. For those women their transition to motherhood may reflect a different experience. As stated earlier the transition to motherhood starts from the time of planning a pregnancy which itself for these women was a predetermined life event they wanted to achieve. Motherhood for the HIV positive women in this study was a fulfillment of their hopes and desires as women which is not different for other women choosing motherhood. The women in this study discussed their very personal journeys toward motherhood; acknowledging motherhood was an option; the challenge of having a HIV negative partner; the loss of being able to conceive naturally and having to use artificial insemination technique.

The Effect of Stigma on the Transition to Motherhood for HIV Positive Women

A review of the literature prior to undertaking this study identified themes reflected in this study's findings; stigma providing the context for mothering with HIV, the desire for motherhood, and managing the stigmatising effect of HIV during their transition to motherhood. The women in this study all experienced the effects of stigma associated with HIV and shared how they managed the stigma through making decisions about who to disclose to. Once disclosure had occurred the women used their knowledge and

understanding of the disease to reinforce social acceptance for themselves and their loved ones.

Implications for Healthcare Practitioners and Midwives

Trust is an ethical principle which underpins our integrity as health professionals. Health professionals' have a duty of care when providing care, support and information to clients and patients. HIV positive women need to be able to trust health professionals providing their maternity care. The women need to know that their privacy is respected and the information they receive is from a professionally trusted source. One solution to building a trustworthy relationship could be the employment of the Lead Maternity Carer model of midwifery care providing continuity of midwifery care liaising within a small team of a physician, obstetrician and pediatrician. The stigma felt by the women in this study was from a variety of sources but the healthcare setting appeared to be the most threatening. Healthcare staff can gain easy access to maternity records and test results which can mean those not necessarily caring for the mother and baby can access private and confidential data. Healthcare settings may need to revisit policies around the privacy and confidentiality of health records. Staff caring for families affected by HIV, needs to be made aware of sensitive information on a need-to-know basis. The majority of healthcare settings have measures to keep computer managed health records safe from curious viewers but the woman needs to be made aware of the measures to protect accidental disclosure.

A further recommendation for healthcare and midwifery practice from this research is that there is regular feedback and contribution made by HIV positive women to their local maternity and well-child services and at a Ministry of Health level. HIV positive women not only need to contribute to services which intend to serve the needs of HIV positive mothers and their families but also to provide an insight to services such as antenatal HIV testing and the emotional, cultural and social support needs of newly diagnosed. If the heterosexual transmission of HIV increases then there will be a need to develop services which meet the needs of this group of mothers in society.

What came through clearly is the women in this study want health care professionals to be knowledgeable about HIV, pregnancy and breastfeeding, using the most up to date research based information.

Improving the Conditions for Mother-Baby Attachment

The love and attachment a mother feels for her baby is vitally important for the mother's mental health and the emotional development of the baby. If women feel supported in their decisions and empowered to make decisions which affect their wellbeing and that of their baby then this will build the foundations for a strong attachment and resilience to postnatal challenges. Research continues to explore the effect of the intrauterine environment and how the effect of maternal stress can impact on the fetus's health later in life (Murphy Paul, 2010). In this study the mothers all feel they worked hard to achieve a healthy outcome; a HIV negative baby and it was a huge psychological effort managing disclosure of their HIV status in the health service.

The women in this study all cited the disappointment and regret they felt about not having those first moments with their baby immediately after the birth. The women felt the hasty removal of the baby from the birthing environment in order to bathe the baby disrupted their attachment to their newborn. This study identified no research to support the bathing of a baby of a HIV positive mother immediately after the birth. The women in this study felt it disturbed those first moments with their baby and felt aggrieved at the length of time before they held their baby. The removal of evident blood and debris from the infant's skin should be performed in a sensitive manner and the baby handed to the mother for skin to skin contact. Skin to skin contact should not just be for breastfeeding babies but the skin contact can aid the release of Oxytocin which enhances the positive feelings of love and attachment to the baby. This in turn could have a protective effect on the mental health of both mother and baby (Odent, 2001).

Implications for Health Professionals' Education

HIV is a condition which affects people from all social, cultural and ethnic backgrounds. Education about HIV should encompass the biology, transmission, social and psychological impact of living with HIV and clinical care and management. HIV education should be compulsory for all healthcare workers and those in allied health such as physiotherapists, social workers and healthcare assistants. It is advisable to include a session delivered by a person living with HIV. This would aid the improvement of knowledge and understanding of HIV and potentially reduce the stigmatizing behaviors and language used. The education should include an exploration of how we form stereotypes and how destructive stereotypes are when forming therapeutic relationships.

HIV education should be integrated into breastfeeding education. A curriculum would need to include the biological structure of the disease, transmission of HIV through breastmilk, and the psychosocial consequences for HIV positive women withholding breastmilk. In a society where breastfeeding is promoted as an optimum method of infant feeding health professionals need to be aware of the current evidence about breastfeeding and HIV so they provide women with information to make informed choices but also support women with their choice.

Limitations

The study was very small with only three participants and therefore the findings cannot be generally accepted as affecting all women with HIV making the transition to motherhood in New Zealand. The three participants were all from different cultural backgrounds to each other but again there cannot be any conclusions drawn about the impact of culture on the transition to motherhood.

Recommendations for Further Research

Further research of the transition to motherhood for HIV positive women in New Zealand could yield a more in depth analysis by performing a prospective, longitudinal study. Another research project could assess the attitudes of health professionals towards HIV positive mothers in New Zealand. A gap in the research was identified during this research process; there was very sparse information about HIV disclosure to extended family such as step-parents and parents through marriage; in-laws. A further study could explore the effect of culture on the transition to motherhood for HIV positive particularly

in the islands of the Pacific Ocean. These would be recommendations for further research related to HIV positive mothers.

Conclusion

This study aimed to explore the transition to motherhood for HIV positive women. To conclude the main finding has been that HIV positive women make the transition to motherhood in the context of stigma. The journey toward motherhood for the women in this study was not easy. Their narratives portrayed the psychological effort undertaken to negotiate those challenges. This study highlighted the importance of empathy and understanding of issues related to living with HIV from those caring for HIV positive women, mothers and their families. There appears to be an urgent need for health professionals to be educated about HIV positive women during the childbirth continuum. The urgency is that as universal Antenatal HIV screening is established the number of diagnoses amongst pregnant women may increase. The final message from this study is that HIV positive women making the transition to motherhood should be nurtured and supported not judged.

APPENDIX A: RESEARCH CONSENT

Multiregional Ethics Committee

**APPENDIX B: LETTER OF RECOMMENDATIONS AND
COMMENTS FROM MAORI HEALTH PROVIDER**

APPENDIX C: ADVERTISEMENT FOR POTENTIAL PARTICIPANTS

[Printed on Massey University departmental letterhead]

'When Motherhood Beckons: an exploration of the transition to motherhood for women with HIV'



Kia Ora my name is Amanda Hinks. I am a registered midwife carrying out a research project to complete my Masters degree with Massey University at Palmerston North.

My area of interest and midwifery practice in the past (in the UK) has been antenatal HIV testing and the subsequent care of positive women and their families. As antenatal HIV screening becomes part of mainstream antenatal care in New Zealand increasing numbers of women will be affected and I am interested in finding out how this diagnosis affects women as they become mothers. You will be required to have a private and confidential interview with me only.

I am interested in hearing from you if you;

- Have had a pregnancy knowing your HIV diagnosis OR diagnosed HIV positive during your pregnancy,
- Have a baby from that pregnancy who is two years old or younger.
- Live on the North Island of New Zealand,
- Speak and understand English easily.

Interested? Please call Amanda (Cell phone number) and leave a message with a contact number and a time it will be convenient for me to call you.

[Photograph attached]

APPENDIX D: ARTICLE FOR POSITIVE WOMEN NEWSLETTER

Hello, my name is Amanda Hinks and I am currently undertaking research for my Masters thesis in Midwifery at Massey University in Palmerston North. My research is focusing on how women with HIV make the transition to motherhood.

I think women enter pregnancy with thoughts, dreams, or ideas about motherhood. I am interested in finding out about how a HIV diagnosis made before or during pregnancy affects those thoughts, dreams, and what, if any is the impact on the woman's social and psychological adjustment to motherhood.

Between 1998 and 2001 in the UK I had the privilege to work as a midwife with women diagnosed with HIV during pregnancy and to care for them and their families until they left hospital with their new baby at 4-5days old. During the three years I worked with positive women I never formally found out about how the diagnosis had impacted on the woman and their adjustment to motherhood once they left hospital.

I am now seeking the opportunity to give something back to positive women and their families. I would like to hear the stories of women who become mothers in the shadow of an HIV diagnosis and to write about these experiences so other midwives can develop an understanding and knowledge of what it is like for you so we can truly walk beside through the whole experience.

I am interested in hearing from you if you;

- Were diagnosed HIV positive before or during your pregnancy,
- Have a baby from that pregnancy who is between 4-24 months old,
- Live on the North Island of New Zealand,
- Speak and understand English easily.

You will be required to have a private and confidential interview with me only.

Interested? Please call Amanda (Cell phone number) and leave a message with a contact number and a time it will be convenient for me to call you.

APPENDIX E: PARTICIPANT INFORMATION SHEET

[Printed on Massey University departmental letterhead]

‘When Motherhood Beckons: an exploration of the transition to motherhood for women with HIV.’

INFORMATION SHEET

Introduction

I am Amanda Hinks, a registered midwife practicing in Taranaki, carrying out supervised research to complete a Masters degree in Midwifery with Massey University at Palmerston North.

My area of interest and clinical practice in the past in the UK has been antenatal HIV testing and the subsequent care of positive women and their families. As antenatal HIV screening becomes part of mainstream antenatal care in New Zealand increasing numbers of women will be affected and I am interested in finding out how this diagnosis affects women as they become mothers.

My Research Supervisors are:

Dr Cheryl Benn; Associate Professor (Midwifery) School of Health Sciences Massey University Palmerston North. Contact details:

Jeanie Douche; Senior Lecturer Women’s Studies at Massey University Wellington. Contact details:

Participant Recruitment and Involvement

I would like to interview 4 – 6 women on 1 to 3 occasions to find out about their experience of motherhood once they had been diagnosed as HIV positive. The first interview will take about 60-90 minutes with the following ones being shorter in length, approximately 20-40 minutes each. I will also ask participants to check typed copies of their interviews and will call them the day after the interviews to check if they have any needs or concerns.

I am interested in hearing your story if you meet the following criteria:

- HIV positive woman diagnosed before or during pregnancy
- Have a baby from the pregnancy when HIV was diagnosed
- The baby should be aged up to two years old
- Reside on the North Island
- Able to consent to full participation i.e. fluent in English.

Project Procedures

- If you agree to participate I will interview you and audiotape the interview with your consent. We will meet for the interview at a mutually agreed venue and time. After the data has been collected the audiotape will be transcribed into words and the completed transcription will be posted to you for corrections or approval to be used for my thesis..
- The audiotapes and transcriptions from the tapes will be kept in a locked area in my home. The transcripts will be kept separate from consent forms and audio tapes in a locked filing cabinet. After 5 years you will be offered to have your audiotapes returned to you. If you decline then the tapes and transcripts will be shredded or destroyed by a company who can issue a certificate of disposal.

- A summary of the research findings will be sent to all participants unless you indicate you do not wish to receive a copy of the summary.
- I will keep your participation in the study confidential and will ask you to choose an alternative name (pseudonym) for the purposes of the research.

Participant's Rights

You are under no obligation to participate in this study. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time until you have agreed for your transcript data to be used for the thesis;
- ask any questions about the study at any time during participation;
- ask for the audiotape to be turned off at any time during the interview.
- provide information on the understanding that neither your name nor any identifying information will be used in the thesis or related documents;
- be given access to a summary of the project findings when it is concluded;

Support Processes

If you agree to participate you may become distressed during the course of the interviews. If this happens you may request to stop the interview or to have a short break. I will also offer you some contact names of people who may be able to support you or provide counselling to resolve some issues that have not been addressed. I will also give you a list of local Health and Disability offices if you need an advocacy service and telephone numbers for Positive Women (9am-5pm) and the AIDS helpline (24 hours). I will contact you by telephone the day after the interview to enquire if you have any needs or concerns that have arisen as a result of the interview.

Project Contacts

If you have any queries or concerns about the research you are invited to contact myself or my research supervisors;

Amanda Hinks; Midwife c/o Taranaki Base Hospital David Street New Plymouth Taranaki.
Contact details: phone or text:

Dr Cheryl Benn; Associate Professor (Midwifery) School of Health Sciences Massey University Palmerston North. Contact details:

Jeanie Douche; Senior Lecturer Women's Studies at Massey University Wellington. Contact details:

This study has received ethical approval from the Multi-region Ethics Committee which reviews National and Multi regional studies and Massey University Human Ethics Committee.

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